



Norfolk County Council

Norfolk Health Overview and Scrutiny Committee

Date: **Thursday 14 July 2022**

Time: **10.00am**

Venue: **Council Chamber, County Hall, Martineau Lane,
Norwich**

Persons attending the meeting are requested to turn off mobile phones.

Members of the public or interested parties may, at the discretion of the Chair, speak for up to five minutes on a matter relating to the following agenda. A speaker will need to give written notice of their wish to speak to Committee Officer, Jonathan Hall (contact details below) by **no later than 5.00pm on Monday 11th July 2022**. Speaking will be for the purpose of providing the committee with additional information or a different perspective on an item on the agenda, not for the purposes of seeking information from NHS or other organisations that should more properly be pursued through other channels. Relevant NHS or other organisations represented at the meeting will be given an opportunity to respond but will be under no obligation to do so.

Membership

MAIN MEMBER

Cllr Daniel Candon

Cllr Penny Carpenter

Cllr Barry Duffin

Cllr Brenda Jones

Cllr Alexandra Kemp

Cllr Julian Kirk

Cllr Robert Kybird

Cllr Nigel Legg

Cllr Julie Brociek-Coulton

SUBSTITUTE MEMBER

Vacancy

Cllr Carl Annison / Cllr Michael Dalby / Cllr Chris Dawson / Cllr Lana Hemsall / Cllr Jane James

Cllr Carl Annison / Cllr Michael Dalby / Cllr Chris Dawson / Cllr Lana Hemsall / Cllr Jane James

Cllr Emma Corlett
Cllr Michael de Whalley

Cllr Carl Annison / Cllr Michael Dalby / Cllr Chris Dawson / Cllr Lana Hemsall / Cllr Jane James

Cllr Fabian Eagle
Cllr David Bills
Cllr Ian Stutely

REPRESENTING

Great Yarmouth Borough Council

Norfolk County Council

Norfolk County Council

Norfolk County Council
Borough Council of King's Lynn and West Norfolk

Norfolk County Council

Breckland District Council
South Norfolk District Council
Norwich City Council

Cllr Richard Price	Cllr Carl Annison / Cllr Michael Dalby / Cllr Chris Dawson / Cllr Lana Hemsall / Cllr Jane James	Norfolk County Council
Cllr Sue Prutton	Cllr Peter Bulman	Broadland District Council
Cllr Robert Savage	Cllr Carl Annison / Cllr Michael Dalby / Cllr Chris Dawson / Cllr Lana Hemsall / Cllr Jane James	Norfolk County Council
Cllr Lucy Shires	Cllr Robert Colwell	Norfolk County Council
Cllr Emma Spagnola	Cllr Victoria Holliday	North Norfolk District Council
Cllr Alison Thomas	Cllr Carl Annison / Cllr Michael Dalby / Cllr Chris Dawson / Cllr Lana Hemsall / Cllr Jane James	Norfolk County Council
CO-OPTED MEMBER (non voting)	CO-OPTED SUBSTITUTE MEMBER (non voting)	REPRESENTING
Cllr Edward Back	Cllr Colin Hedgley / Cllr Jessica Fleming	Suffolk Health Scrutiny Committee
Cllr Keith Robinson	Cllr Jessica Fleming	Suffolk Health Scrutiny Committee

**For further details and general enquiries about this Agenda
please contact the Committee Officer:**

Jonathan Hall on 01603 679437
or email committees@norfolk.gov.uk

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However, if you wish to attend in person it would be helpful if you could indicate in advance that it is your intention to do so as public seating will be limited. This can be done by emailing committees@norfolk.gov.uk

The Government has removed all COVID 19 restrictions and moved towards living with COVID-19, just as we live with other respiratory infections. However, to ensure that the meeting is safe we are asking everyone attending to practise good public health and safety behaviours (practising good hand and respiratory hygiene, including wearing face coverings in busy areas at times of high prevalence) and to stay at home when they need to (if they have tested positive for COVID 19; if they have symptoms of a respiratory infection; if they are a close contact of a positive COVID 19 case). This will help make the event safe for all those attending and limit the transmission of respiratory infections including COVID-19.

A g e n d a

1. To receive apologies and details of any substitute members attending

4. Minutes

To confirm the minutes of the following meetings of the Norfolk Health Overview and Scrutiny Committee:

- 12 May 2022
- 28 June 2022

(Page 5)
(To follow)

3. Members to declare any Interests

If you have a **Disclosable Pecuniary Interest** in a matter to be considered at the meeting and that interest is on your Register of Interests you must not speak or vote on the matter.

If you have a **Disclosable Pecuniary Interest** in a matter to be considered at the meeting and that interest is not on your Register of Interests you must declare that interest at the meeting and not speak or vote on the matter

In either case you may remain in the room where the meeting is taking place. If you consider that it would be inappropriate in the circumstances to remain in the room, you may leave the room while the matter is dealt with.

If you do not have a Disclosable Pecuniary Interest you may nevertheless have an **Other Interest** in a matter to be discussed if it affects, to a greater extent than others in your division

- Your wellbeing or financial position, or
- that of your family or close friends
- Any body -
 - Exercising functions of a public nature.
 - Directed to charitable purposes; or
 - One of whose principal purposes includes the influence of public opinion or policy (including any political party or trade union);
Of which you are in a position of general control or management.

If that is the case then you must declare such an interest but can speak and vote on the matter.

4. To receive any items of business which the Chair decides should be considered as a matter of urgency

5. Chair's announcements

- 6. 10:10 – 11:00 Annual health checks for: people aged over 14 with learning disabilities, Looked After Children and adults with Severe Mental Illness in Norfolk and Waveney** (Page 12)
- Health Checks: Learning Disabilities** (Page 15)
- Health Checks: Looked after Children** (Page 22)
- Health Checks: Severe Mental Illness** (Page 25)
- 7. 11:10 – 11:55 Children's neurodevelopmental disorders - waiting times for assessment & diagnosis** (Page 36)
- 8. 11:55 – 12:00 Forward Work Programme** (Page 84)

Tom McCabe
Head of Paid Service
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Date Agenda Published: 6 July 2022



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**NORFOLK HEALTH OVERVIEW AND SCRUTINY COMMITTEE
MINUTES OF THE MEETING HELD AT COUNTY HALL, NORWICH
on Thursday 12 May 2022**

Present:

Cllr Alison Thomas(Chair)	Norfolk County Council
Cllr Daniel Candon	Great Yarmouth Borough Council
Cllr Penny Carpenter	Norfolk County Council
Cllr Barry Duffin	Norfolk County Council
Cllr Brenda Jones	Norfolk County Council
Cllr Alexandra Kemp	Borough Council of King's Lynn and West Norfolk
Cllr Julian Kirk	Norfolk County Council
Cllr Robert Kybird	Breckland District Council
Cllr Nigel Legg	South Norfolk District Council
Cllr Lana Hemsall substitute for	Norfolk County Council
Cllr Richard Price	
Cllr Sue Prutton	Broadland District Council
Cllr Robert Savage	Norfolk County Council
Cllr Lucy Shires	Norfolk County Council
Cllr Adam Giles substitute for Cllr	Norwich City Council
Ian Stutely	

Co-Opted Members

Cllr Edward Back	Suffolk Health Scrutiny Committee
Cllr Keith Robinson	Suffolk Health Scrutiny Committee

Also Present in person:

Rebecca Hulme	Associate Director of Children, Young People and Maternity, Norfolk and Waveney CCG (All items)
Laura Skaife-Knight	Deputy Chief Executive Officer, Queen Elizabeth Hospital NHS Trust (Item 8)
Denise Smith	Chief Operating Officer, Queen Elizabeth Hospital NHS Trust (Item 8)
Alex Stewart	Chief Executive Healthwatch Norfolk (Item 8)
Kevin Clark	Deputy Governor HMP Norwich (Item 9)
Peter Randall	Democratic Support and Scrutiny Team Manager
Maureen Orr	Democratic Support and Scrutiny Team Manager
Jonathan Hall	Committee Officer

Present via video link

Claire Weston	Regional Head of Health and Justice East of England (Item 9)
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1. Election of Chair

The committee officer Jonathan Hall opened the meeting and invited nominations for the election of the Chair. Cllr Alison Thomas was nominated by Cllr Carpenter and seconded by Cllr Barry Duffin. All in agreement. Cllr Alison Thomas was elected Chair for the forthcoming year.

2. Election of Vice Chair

Cllr Thomas thanked members for electing her as Chair for the forthcoming year and invited nominations for the election of Vice Chair. Cllr Daniel Candon was nominated by Cllr Kybird and seconded by Cllr Prutton. All in agreement. Cllr Daniel Candon was elected Vice Chair for the forthcoming year.

3. Apologies for Absence and details of substitutes

- 3.1 Apologies for absence were received from Cllr Richard Price (substitute Cllr Lana Hemsall), Cllr Ian Stutely (substitute Cllr Adam Giles) and Cllr Emma Spagnola.

4. Minutes

- 4.1 The minutes of the previous meeting held on 10 March 2022 were agreed by the Committee and signed by the Chair as an accurate record of the meeting.

5. Declarations of Interest

- 5.1 Cllr Penny Carpenter disclosed an other interest as a board member of the Norfolk Safeguarding Board (Item 11).

6. Urgent Business

- 6.1 There were no items of urgent business.

7. Chair's Announcements

- 7.1 The Chair had no announcements.

8. The Queen Elizabeth Hospital NHS Foundation Trust – progress report

- 8.1 The Committee received the annexed report (8) from Maureen Orr, Democratic Support and Scrutiny Manager, which provided an update on progress in addressing the issues raised by the 2019 CQC full inspection report. The Queen Elizabeth Hospital (QEH) had provided detailed information on their actions which had met the CQC requirements together with current performance and the on going situation regarding building safety and bids for funding for a rebuild. The committee had last considered the item in March 2021 where representatives of the hospital and the CCG provided a response to the CQC inspection. The hospital at that stage remained in special measures.

- 8.2 The Committee received evidence in person from representatives of QEH: Laura Skaife-Knight, Deputy Chief Executive and Denise Smith, Chief Operating Officer, Norfolk and Waveney CCG: Rebecca Hulme Associate Director of Children, Young People and Maternity, Healthwatch Norfolk: Alex Stewart Chief Executive.

Laura Skaife-Knight and Denise Smith gave a presentation which is available on the [committee's website pages](#). The presentation reflected the hard work that had been undertaken in the past three years and documented the enormous progress that had

been made. Following CQC inspections in December 2021 and January 2022 their findings had seen Medicine, Urgent and Emergency Care and Critical Care all rated as 'Good' alongside the Trust's rating for Well Led. The Trusts overall rating had improved from Inadequate to Requires Improvement. The Trust also received its first rating of 'Outstanding' for Well Led for Critical Care. This overall rating reflects that only three core services were inspected during the last inspection which was due to the Covid 19 Pandemic and therefore reflected what was technically possible for this inspection. The improvements had all been achieved against a backdrop of a building that was being held up by over 1500 props which was affecting patient experience.

Alex Stewart, Chief Executive of Healthcare Norfolk commented that the transformation of the hospital was phenomenal. Engagement with patients was excellent and there was a willingness and openness from all staff to help improve services and patient experience. The mix of approach to provide all types of appointments from telephone, virtual and face to face was welcomed and was helping patients receive treatment and services faster and more effectively. He concluded by saying that he hoped good news would be forth coming soon with a positive announcement of funding of a new hospital.

8.3 The reports submitted were taken as read and during the ensuing discussion the following points were noted:

- The committee congratulated the QEH staff and management in their achievements and echoed the hope that funding for a new hospital is announced soon.
- In March 2021 the committee learnt that due to the poor state of the building 40 operations had to be cancelled however since then no further selective surgery has had to be cancelled, but the hospital facing significant challenges to operating on a day to day basis.
- The School of Nursing was now operational and had 20 nurse associates already recruited. This was a good example of a partnership working well with the Borough Council and West Anglia College. The School should bring through dozens of "home grown" nurses to the hospital in the future.
- In February 2022 the CQC had removed 18 of the 22, section 31 conditions from the Trust's Certificate of Registration. In July, the hospital will apply to have 3 of the remaining 4 to be lifted.
- Regular audits and robust monitoring were in place to ensure that resuscitation equipment was always operational in the hospital. This area had been highlighted as an area of concern in the latest inspection.
- The expected life of the hospital building was for a further eight years to 2030. The situation if no funding is found to build a new hospital is bleak with the possibility of whole areas of the hospital would need to be shut down.
- Fail safe funding to ensure the continuation of services stood at £90m but this only secured the ground floor of the hospital. This would ensure the status quo and no improvements would be made.
- Cancer wait times did not meet the national standards overall, however times for initial consultation and treatment once diagnosed were good, diagnostic waits were longer, meaning overall wait times did not meet the national standard. Plans were in place to address this. Referrals had also increased towards the back end of the pandemic, although additional MRI and CT scanners being installed this year will help reduce waiting times.
- After having completed a Duty of Candour exercise the hospital published a Learning from Covid report which demonstrated their commitment to openness and transparency. Laura Skaife- Knight said she would return to the

committee with precise numbers, but she believed that around 200 patients had contacted Covid whilst in the care of the hospital.

- The hospital ensures that progress is sustained against its 21/22 Integrated Quality Improvement Plan (IQIP) by closely monitoring changes to ensure these are sustained and embedded over several quarters before approving closure of the action.
- Once the hospital had been lifted out of special measures the monitoring of the 'must and should do' actions moved to a compliance plan. Laura Skaife-Knight said she was happy to share the plan with members of the committee but the types of issues still outstanding, of which there was 35, includes items such as mandatory training which accounted for about a third.
- Rebecca Hulme, Associate Director of Children, Young People and Maternity for Norfolk & Waveney CCG thanked the committee for the acknowledgement of progress QEH had made. In addition, she added that throughout the process of improvement the QEH had been good system partners offering advice and help and sharing openly their experiences with other health providers both locally and nationally.

The Chairman concluded the discussion by acknowledging this had been a very pleasing report and the good progress had been noted. There was still some work to do and the determination of the QEH staff to complete the job and to sustain improvements was clearly in evidence. It is hoped that the hospital will be included on the list of funding for new hospitals to be built as the current state of the building is of great concern but despite those challenges vast improvements had been made.

The Committee undertook a short break and reconvened at 11.12am

9. Prison Healthcare – access to physical and mental health services

- 9.1** The Committee received a briefing report by Maureen Orr, Democratic Support and Scrutiny Manager updating members on Prison healthcare services following a report from commissioners, NHS England and NHS Improvement (NHESI) which the committee received in February 2021.

Norfolk has three prisons, HMP Wayland, HMP Bure and HMP Norwich. Norwich also has the only Young Offenders Institute (YOI) in Norfolk. NHESI commissions all health services for the prisons, including drug and alcohol services but it excludes emergency and out of hours services which are provided by the CCG for the whole community, not just the prison service.

- 9.2** The Committee received evidence online from representatives of NHESI; Claire Weston Regional Head of Health and Justice East of England, and in person from HMP Norwich; Kevin Clark, Deputy Governor.

- 9.3** The following points were noted during the discussion:
- Covid measures had only just been lifted and there was a gradual return to business as normal for prisoners. Any denial of wellbeing and health services to prisoners should be reported as incidents and follow the appropriate complaint procedures.
 - NHS standard contracts terms apply to all health care providers who have services commissioned from NHESI and processes are followed if contractual failures happen. Monitoring of services takes place by inspection, quality care visits, observation by prison staff and feedback from prisoners.
 - HMP Norwich has 24 hour healthcare beds available and because of this these beds were in high demand, including requests received from out of

area. These beds are managed by the healthcare provider although the prison is included in bed management meetings.

- Dental care data seemed to indicate that treatment was received quickly but it was established that through the triage of cases, prisoners often had telephone consultations and treatment for pain management or infection control rather than receive dental services.
- Mental Health training was available for all staff through module 5 of the ACCT (assessment, care in custody and teamwork) training (this was mandatory) and by NSFT who run a programme that could also be accessed online. 45 members of staff were undertaking the NSFT training.
- During inspection HMP Bure had been commended for notable positive practice for identification and addressing mental health needs of prisoners.
- The GP-to-GP programme meant that the transfer of medical records, with the patients consent, was much easier once a prisoner had left prison and was moved back into primary care.
- The Government introduced a new programme to help drug and alcohol misuse called from Harm to Hope and the prison service was actively engaging with partners to roll out this programme in the service.
- Claire Weston committed to providing the committee with links to metrics and data concerning substance misuse. Any further clarification could be followed up.
- There has been a move away from a medical model to support prisoners with a learning disability to a more community based model. The emphasis was on assessment and diagnosing. This move was based to help support prisoners to fulfil their potential. Neuro Diversity Support managers were currently being recruited to in 2 of the 3 prisons in Norfolk to provide support for this area.
- There were several programmes and processes to assess a prisoner's educational needs on admission and relevant support and help was provided by a variety of sources to address those needs whilst someone was in prison.
- The data provided indicated that prisoners at HMP Norwich were twice as likely to suffer depression above the national average. A medical day care centre had just been opened in Norwich to address the concern of which prisoners can either self refer or be referred by any staff member. This takes those referred out of the main stream prison routines to work with health, educational and wellbeing professionals.
- The diversion process should take place before individuals get to prison. Those individuals who agreed to intervention and assessment did receive different sentencing to help and support their needs. Claire Weston committed to providing further details on the diversion schemes running.
- Those prisoners who were assessed for Tier 4 beds and were sectioned needed to be done so quickly and concerns of the speed of the process had been raised nationally recently. Sectioning of a prisoner had to be carefully considered as it reduced a prisoner's freedoms whilst in prison.

The Chair concluded the discussion by acknowledging that a large number of issues had been discussed including how services were returning to normal coming out of the pandemic, how contracts were managed, training for staff for identifying and helping prisoners with mental health issues, transfer of patient records and details on the diversion schemes.

It was agreed that an update via a HOSC briefing would be appropriate in 9 months time.

Cllr Jones asked whether she could supply written questions she was unable to ask. Claire Weston agreed to the request.

A open invitation to the committee was made by Kevin Clark to visit HMP Norwich and assess the healthcare services in situ.

- 9.5** The Chair thanked all those who had taken part in the discussion both online and in person.

10. Norfolk Health Overview and Scrutiny Committee appointments

- 10.1 The committee **agreed** to the following appointments:

CCG / Provider Trust	Governing Body / Board meeting schedule	Current NHOSC link
Norfolk and Waveney CCG (& subsequently Norfolk and Waveney integrated Care Board from 1 July 2022, pending legislation)	Every other month, usually on the last Tuesday, 1.30 – 4.00pm (online)	Chair of NHOSC (substitute – Vice Chair of NHOSC)
Queen Elizabeth Hospital NHS Foundation Trust	Monthly, on the first Tuesday, 10.00am (online)	Julian Kirk (substitute - Alexandra Kemp)
Norfolk & Suffolk NHS Foundation Trust	Every other month, usually on the fourth Thursday, 12.30pm (online)	Brenda Jones (substitute - Lucy Shires)
Norfolk & Norwich University Hospitals NHS Foundation Trust	Usually every other month, on the first Wednesday, 9.30am (online)	Dr Nigel Legg
James Paget University Hospitals NHS Foundation Trust	Every other month, usually on the last Friday, 10.00am (online)	Daniel Candon (substitute – Vacant)
Norfolk Community Health and Care NHS Trust	First Wednesday of every month except Jan & Sept, 9.30am (online)	Emma Spagnola

11. Forward Work Programme

- 11.1 The Committee received a report from Maureen Orr, Democratic Support and Scrutiny Manager which set out the current forward work programme and briefing details that was agreed subject to the following:
- 11.2 The Committee **agreed** additionally for the NHOSC Member Briefing:
- June 2022 – Menopause services. What is available and how is access gained?
- 11.3 The committee agreed to the forward work programme and in addition:
- 8 Sept 2022
Norfolk and Suffolk NHS Foundation Trust – action plan for improvement.

Meeting concluded at 12:22

Cllr Alison Thomas, Chair



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**Annual health checks for: people aged over 14 with learning disabilities,
Looked After Children and adults with Severe Mental Illness (SMI)
in Norfolk and Waveney**

Suggested approach from Liz Chandler, Scrutiny and Research Officer

Examination of three reports from the CCG into annual health checks in Norfolk and Waveney for:

- People aged 14 and over with learning disabilities
- Looked After Children
- Adults with Serious Mental Illness

The commissioners previously provided a briefing to NHOSC concerning annual health checks for people aged over 14 with learning disabilities and autism in March 2021.

1.0 Background

- 1.1 ***People with learning disabilities:*** all people aged 14 years and over with a learning disability are eligible to receive an annual health check and there is a nationally negotiated enhanced service contract available to GP practices to fund this work.
- 1.2 ***Looked After Children:*** when a child is first placed into local authority care, the relevant clinical commissioning group has a statutory responsibility to ensure that a full health assessment takes place and that a health plan is drawn up and implemented within 20 working days from when the child started to be looked after. The review of the child's health plan must happen at least once every 12 months.
- 1.3 ***Adults with SMI:*** NHS England set out the ambition for annual physical health checks for those living with an SMI in the NHS Long Term Plan.

1.4 Previous Report to NHOSC

- 1.4.1 NHOSC previously looked at the level of take-up and quality of health checks for people aged 14 and over with learning disabilities and autism (LD&A) in September 2019. The report and minutes of the meeting are available through the following link: [NHOSC 5 September 2019](#).

Following the September meeting, an update was provided to Committee members in a briefing in March 2021. This briefing reported that general practices had been asked to achieve an annual rate of 67% of completing annual health checks for people aged 14 and over with LD&A by 31st March 2021. Figures supplied in this briefing showed that Norfolk and Waveney had not managed to reach this target: NHS England and NHS Improvement (NHSE&I) data showed there was an overall achievement of 33% across Norfolk and Waveney for the first three-quarters of 2020/21; the CCG's business intelligence data reported an overall achievement of 49% up until 24th February 2021.

The briefing included a number of measures that had been implemented to improve this performance including a project to support access to LD&A health checks amongst BAME, Traveller, Roma and Gypsy, asylum seeker and refugee community groups in particular.

2.0 Purpose

- 2.1 The purpose of today's meeting is to review progress on annual health checks for people aged 14 and over with learning disabilities since the previous briefing in March 2021. The attached briefing report at **Appendix A** also highlights the review of annual health assessments for Looked After Children in Norfolk and Waveney and provides a review of the Severe Mental Illness (SMI) annual health check programme work.


3.0 Suggested approach

- 3.1 The committee may wish to discuss the following areas with the CCG representatives:
- (a) How many individuals are registered within these cohorts and eligible to receive the relevant annual check?
 - (b) How many actually received it in 2021-22?
 - (c) An update on the data cleansing work, bringing NHS records and County Council records of these cohorts into line.
 - (d) An update on work to encourage GP practices to offer the checks and to encourage / help individuals to take up the offer.
 - (e) To what extent are health checks carried out virtually / in person within the three cohorts?
 - (f) What progress has there been with education and support to GP practices for outreach to BAME/Traveller/transient populations within the three cohorts?

- (g) What percentage of GP practices currently offer health checks for each of the three cohorts?
- (h) What are the current targets for delivery of health checks in the three categories?
- (i) What specific interventions are offered to GP practices who are struggling to meet the targets?
- (j) What is included in the annual health checks offered to each of the three cohorts and to what age range are they offered?

4.0 Action

- 4.1 The committee may wish to consider whether to make comments or recommendations as a result of today's discussion.

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Briefing for Health Overview and Scrutiny Committee

Annual health checks for people over the age of 14 with learning disabilities in Norfolk and Waveney

1. Introduction

This paper is to provide an update to members of the Health Overview and Scrutiny Committee (HOSC) on the learning disability (LD) annual health check programme for people aged 14 and over with a learning disability in Norfolk and Waveney.

This follows on from the previous update in the March 2021 HOSC Briefing.

2. Background

All people aged 14 years and over with a learning disability are eligible to receive an annual health check and there is a nationally negotiated enhanced service contract available to GP practices to fund this work. As of March 2022, this represents a population of just over 6,800 people across 105 GP practices in Norfolk and Waveney. There is a national requirement for clinical commissioning groups to ensure they commission for a 75% uptake among the eligible population.

Throughout 2021-22, Covid-19 continued to place significant pressure on healthcare providers across Norfolk and Waveney. The competing challenges of high levels of staff sickness and absence across general practice, along with people with a learning disability being worried about coming into general practices, had a significant impact on the planned delivery and uptake of learning disability health checks.

In addition, December's national prioritisation of the Covid-19 booster programme in response to the new Omicron variant and subsequent diversion of clinical staff also affected practices' ability to deliver health checks at a time when the majority of health checks are usually scheduled.

Despite the considerable challenges presented by Covid-19, colleagues in general practice, supported by the CCG team, continued to work hard to support the health and care needs of their patients with a learning disability. All GP practices signed up to provide LD health checks in 2021-22 and all appointments reverted to face-to-face after having moved online during the previous year.

3. Overview of 2021-22

Achievements

In 2021-22 the Norfolk and Waveney system completed annual health checks for 4,799 people with a learning disability, which is the equivalent of 70.4% of people on a learning disability register.

Reviewed in the context of the significant ongoing pressures placed on GP practices and the wider health and care system by Covid-19, this serves to demonstrate the

drive and determination of our health and care colleagues to continue to support people with a learning disability.

This success was supported by a number of innovative workstreams aiming to improve both the quality and uptake of learning disability health checks across the system.

- **Peripatetic Team pilot**

Having secured Transformation funding, a new team was established to support the provision of learning disability health checks within general practice. The pilot focused on the Norwich locality, which had historically poor performance with LD health checks. The pilot involved offering targeted training and guidance for GP practice teams, support with identifying and focusing on patients who had not had a health check in the last 12-18 months, LD register data cleansing and developing more personalised communications tools and reasonable adjustments. 18 out of 22 practices took up the offer of support and the uptake increased 17% in 2021-22 and was 5% higher than before the pandemic.

Cumulative and comparative performance data – Norwich Locality					
Year	LD register	Q1	Q2	Q3	Q4
19/20	1325	109 (8.2%)	290 (21.8%)	509 (38.4%)	842 (63.5%)
20/21	1511	37 (2.4%)	135 (8.9%)	349 (23.1%)	789 (51.5%)
21/22	1488	166 (11.0%)	450 (30.0%)	683 (45.2%)	1017 (68.3%)

- **Exemplar project**

As a result of an innovative bid, Norfolk & Waveney CCG was selected to be the exemplar site for the eastern region by NHS England. Outreach learning disability workers were recruited to promote the importance of a learning disability annual health check and provide appropriate support access particularly amongst ethnic minority groups, Traveller, Roma and Gypsy families, Asylum Seekers and Refugees community groups.

- **Additional resource – West and South Norfolk**

Further to NHS England's request to all systems nationally to increase support to improve the uptake of health checks, in February 2022 a short-term externally staffed model was commissioned to provide additional resource that could be rapidly mobilised to carry out annual health checks by a registered learning disability nurse. This resource was initially focused on the CCG's West Norfolk locality where the lowest uptake of health checks was reported.

The provision of dedicated specialist resource has allowed for more than 150 additional and high-quality health checks, with nurses able to undertake a full and holistic patient consultation and onward referral to additional services where necessary. This service has typically targeted harder to reach cohorts requiring additional time and input to facilitate engagement within the health check process.

Positive feedback has been received, both from people with a learning disability in terms of experience and quality of care, and practice teams in terms of provision of specialist guidance and support

The success of the initiative triggered an interest among practices in the CCG's South Norfolk locality and further resource has been secured to support the delivery of annual health checks into Quarter 1 and 2. This also supports our ambition to move away from delivery of health checks in Quarter 4 to a more balanced distribution across all four quarters.

Opening Doors peer-led workshops

Norfolk and Waveney CCG commissioned Opening Doors, a user-led organisation run by people with learning disabilities, to develop a workshop to support people with a learning disability, their families and carers to gain a better awareness and understanding of the benefits of annual health checks.

A mixture of virtual and face-to-face workshops ran through January and February 2022. During this time, Opening Doors engaged with 47 people with a learning disability as well as paid and family carers. Feedback was overwhelmingly positive, with the majority of respondents confirming they found the training useful in increasing knowledge and confidence about annual health checks. The workshops also proved helpful in collecting information on potential barriers to people attending a health check, the types of reasonable adjustments people would find useful and how best to share invitations to health checks.

Learnings and outcomes will be shared with GP practices and learning disability champions.

Challenges

There are several key challenges that continue to be addressed:

- **Complex needs:**
Whilst the system as a whole delivered health checks to almost 5,000 people with a learning disability, this means there remained around 2,000 people who did not receive a health check in the last year. It is recognised that this cohort of people may be amongst the hardest to reach and therefore, more difficult to engage using traditional methods of contact. Plans are progressing to secure additional capacity to support practices to engage with this cohort within the health check programme.
- **Quality:**
It is recognised that the quality of health checks is inconsistent across the system, which may have been further exacerbated through the move to remote service provision during the pandemic. Evidence shows us that good quality annual health checks are important in early identification and treatment of unmet health needs. We have identified a need for additional training to support GP practice teams – from administrative to clinical staff – and we have plans through our in-house training hub to make this available.
- **Data:**
The CCG's Business Intelligence team developed a report in 2021-22 extracting available monthly performance data from the national reporting system much earlier than the release of nationally validated data to give a monthly snapshot of LD register numbers and uptake broken down by practice, Primary Care Networks and the five CCG localities. Whilst the aim was to enable identification of potential

discrepancies between practice data and what was reported via the national portal to be reviewed much more quickly, anecdotal evidence suggests that historical coding anomalies remain an issue for many practices and that actual uptake figures at practice-level are much higher than the nationally extracted data reporting. Whilst data continues to improve, further work is underway with the CCG's Business Intelligence team and other stakeholders to align different coding and systems and achieve one version of the truth.

Workforce:

Recruitment for additional workforce to support with LD health checks has been a challenge for many PCNs and practices. PCNs are working closely with the CCG to explore other ways to support workforce-related issues.

- **14–17-year-olds:**
An initial review of uptake of 14–17-year-olds in 2021-22 indicates low participation in the annual health check programme. The CCG's Children's and Young People team is working with schools, families and carers and GP practices to raise awareness and understanding of the benefits of annual health checks and to improve participation within the programme.

4. Delivery and uptake

In 2021-22 NHS England asked CCGs to ensure 75% of all people with a learning disability aged 14 and over had an annual health check.

The table below shows 2021-22 performance across Norfolk and Waveney based on data received from NHSE&I with an overall achievement of 70.4%%.

All practices within Norfolk & Waveney CCG signed up to deliver learning disability health checks and confirmed their aim to deliver a minimum of 75% of health checks in 2021-22. However, as previously noted, the unplanned diversion of staff to deliver the Covid-19 booster programme in December 2021/ January 2022 and the increased prevalence of Covid-19 in the community in January – March 2022 had a significant impact on planned delivery. However, despite this the system delivered an increase of 2.7% on 2020-21 performance.

Uptake of learning disability annual health checks 2021-22						
	Total uptake 2021-22			Previous year comparison 2020-21		
Locality	Register (Mar 22)	Total AHC	% AHC	Register (Mar 21)	Total AHC	% AHC
Norfolk & Waveney	6812	4,799	70.4%	6,810	4,607	67.7%
East of England	33,255	23,292	70.0%	31,921	22,224	69.6%
England	300,818	214,622	71.3%	284,755	209,433	73.5%

Uptake of learning disability annual health checks NWCCG 2021-22						
Locality	Register (Mar 22)	Q1	Q2	Q3	Q4	Total checks
GYW	1778	171 (9.6%)	257 (14.5%)	348 (19.6%)	420 (23.6%)	1196 (67.3%)
N Norfolk	1197	72 (6.0%)	149 (12.4%)	242 (20.2%)	419 (35.0%)	882 (73.7%)
Norwich	1488	166 (11.2%)	284 (19.1%)	233 (15.7%)	334 (22.4%)	1017 (68.3%)
S Norfolk	1360	109 (8.0%)	103 (7.6%)	217 (16.0%)	474 (34.9%)	903 (66.4%)
W Norfolk	989	71 (244.8%)	93 (320.7%)	176 (17.8%)	362 (36.6%)	702 (71%)
N&W	6812	589 (8.6%)	886 (13.0%)	1216 (17.9%)	2009 (29.5%)	4700 (69.0%)

5. Patient stories

A piece of work is underway to collate patient stories and feedback from the CCG's Peripatetic team and additional LD nursing initiative in West Norfolk to share vital learning with the wider system. Some examples of the Peripatetic team's work are highlighted below:

Patient 1 – male, late-forties 48-years old, had never had an annual health check before. The team at the patient's GP practice explained that, despite many attempts, they had never been able to get in touch with him to arrange an annual health check appointment. The Peripatetic team decided to try a different approach and sent the patient a letter explaining the health check process, followed up with a visit to his home. The patient agreed to talk to the team about health checks and, upon running through the process and what to expect, it was discovered that the patient didn't like to visit his doctor's surgery. The team explained the purpose and benefits of the health check and showed the patient what would happen by completing basic observations such as blood pressure, oxygen saturation and pulse rate. This helped the patient to better understand the process and he agreed to book an appointment for his health check which he attended as planned. The appointment went well and it is hoped that this intervention will enable the patient's continued engagement in the annual health check programme.

Patient 2 – male, mid-twenties. Whilst happy to book annual health checks with his GP surgery, the patient had failed to attend any of his previously booked appointments. The Peripatetic Team got in touch with the patient's mum on the morning of his next scheduled appointment to make sure they were still planning to come along for the health check. It turned out the patient was feeling really anxious about his health check and the family was having a really stressful morning trying to get him to the surgery on time. The Peripatetic team offered to visit the family at home to provide some additional support to the patient's mum and accompany them to the

surgery. With some more reassurance, the patient was able to get to his health check appointment on time, where routine checks identified high blood sugars and a likely diagnosis of diabetes. the patient was referred to the local hospital's diabetic centre and the Peripatetic Team again accompanied him to the appointment and helped the patient and his family to understand his new diagnosis.

Patient 3 – female, early-fifties, had no record of ever attending her GP practice. It was noted that her parents had routinely declined a health check on her behalf due to her significant anxieties that had prevented her from leaving her home for many years. The Peripatetic Team wrote to the patient and her family again, following up with a telephone call to her mother who agreed to work with the team. The team is in the process of slowly building up a relationship with the patient with the aim of helping her to complete the first step in the health check progress – a pre-health check questionnaire. Progress so far is positive, and the patient's mother has commented that this is the first time she's seen her daughter communicate with anyone outside of the family for many years. Work continues to support the patient to overcome her anxiety and take the first steps towards her health check.

Patients 4 and 5 – male, early-twenties. These brothers were contacted by the Peripatetic Team and given further information about the purpose and benefits of the annual health check. As a result, one brother successfully went on to attend his annual health check appointment whilst the second brother was removed from the practice's learning disability register further to clinical review.

6. Plans for 2022-23

Improving the health and wellbeing of people with a learning disability is a priority for the CCG and – increasingly – to the Care Quality Commission (CQC) as they begin to roll out their practice inspection programme once again.

NHS England has confirmed a national target of 75% delivery of annual health checks for people with a learning disability in 2022-23, with a commitment that health checks for people with a learning disability that were not completed during 2021/22 should be prioritised for the first two quarters of 2022-23.

Plans have been submitted as part of the CCG's operational planning setting out the aim to deliver health checks to 85% of the eligible population in Norfolk & Waveney in 2022-23 (with the aim that 100% of people will be invited). Planned delivery is based on the assumption that there will be fewer checks completed in Quarter 1 due to recovery work and the Spring Covid booster programme. There is also a need to account for widespread annual leave during Quarter 2.

Work is planned over the longer-term to encourage practices to increase activity in the first two quarters of the year. However, this year – in line with NHS England's request to prioritise health checks for all those who didn't receive one in 2021-22, the CCG will focus on supporting practices with this initiative in Quarters 1 and 2.

Whilst increasing uptake is key, improving the accuracy of the data held by practices and the quality of physical health checks are also priorities.

As such, this year the CCG has plans in place to progress the following initiatives:

- developing a programme of learning for practice staff to support the increased quality of health checks in partnership with the Training Hub.
- providing support to practices to improve the accuracy of their coding and cleansing of learning disability registers
- exploring other, innovative, ways in which to support the delivery annual health checks and engage with people with learning disabilities
- undertaking a system-wide peer review - *Building the right support* – looking at transforming care for people with learning disabilities and autism, led by Norfolk County Council
- supporting practices to engage with more complex, harder to reach people on their learning disability registers
- targeting awareness and uptake of health checks amongst 14–17-year-olds

Briefing for Health Overview and Scrutiny Committee

Annual health checks for Looked After Children in Norfolk and Waveney

1. Introduction

This paper is to provide an update to members of the Health Overview and Scrutiny Committee (HOSC) on the Review Annual Health Assessments for Looked after Children in Norfolk and Waveney.

2. Background

The NHS Mandate states that, 'the NHS has a major role in ensuring the timely and effective delivery of health services to looked-after children'. When a child is first placed into local authority care, the relevant clinical commissioning group has a statutory responsibility to ensure that a full health assessment takes place and that a health plan is drawn up and implemented within 20 working days from when the child started to be looked after. The review of the child's health plan must happen at least once every 12 months.

Most children become looked after because of abuse and neglect. Although they have many of the same health issues as their peers, the extent of these is often greater because of their past experiences. For example, almost half of children in care have a diagnosable mental health disorder and two-thirds have special educational needs. Delays in identifying and meeting their emotional well-being and mental health needs can have far reaching effects on all aspects of their lives, including their chances of reaching their potential and leading happy and healthy lives as adults.

Provision of Initial Health Assessments (IHA) and subsequent Review Health Assessments (RHA) is delivered across Norfolk and Waveney, for children over age five, between two providers: Norfolk Community Health and Care (NCHC) and East Coast Community Healthcare (ECCH). Children under age five years are seen by Cambridgeshire Community Services.

ECCH work in partnership with the Paediatric Team at the James Paget University Hospital NHS Foundation Trust for IHAs. The initial health assessment must be done by a registered medical practitioner. Review health assessments may be carried out by a registered nurse or registered midwife.

Both Initial and review health assessments that are produced by the providers are at a consistently high quality.

Despite the considerable challenges presented by Covid-19, the looked after children providers teams continued to work hard to ensure that the health assessments for looked after children continued as per national guidance, these were undertaken virtually rather than face to face during the height of the pandemic.

As of 31 May 2022, there were 1314 looked after children with Norfolk and Waveney, this figure changes daily as new children become looked after and others cease to be looked after. Young people cease to be looked after for a number of reasons including turning 18, return home to family, become adopted or entering custody system.

3. Current issues

The current issues across Norfolk and Waveney are:

- Neither of the providers for the over 5's are undertaking the review health assessments within the statutory timeframes. There is a backlog of children who are overdue a review health assessment and this number is increasing per month. Currently across Norfolk and Waveney 128 children are overdue their RHA.

Overdue RHAs as of 31st May:

ECCH :15

NCHC :113

- The current staffing resource within both providers does not support the demand for the service
- An increasing number of unaccompanied asylum-seeking children are arriving in Norfolk; these cases are particularly complex due to a range of factors including language barriers, the trauma resulting in the young person presenting in the UK and previous limited access to health services. There are currently 92 unaccompanied asylum-seeking children in Norfolk.
- There is limited capacity to contribute to other looked-after children work e.g., attendance at strategy meetings about a child
- Norfolk and Suffolk Corporate Parenting Boards are seeking assurance that robust plans are in place to meet the statutory requirement of RHAs and IHAs

4. Actions to address deficits in RHA performance

- Both providers have submitted a business case to request funding to increase staffing capacity. It is proposed that this increase will enable the services to address the backlog of children in need of a review health assessment and meet the ongoing demand for the service.
- NCHC have recruited one part time substantive specialist looked after children nurse post and one part time fixed term nurse (to cover maternity leave) both due to commence posts in August
- ECCH have one full time substantive specialist looked after children nurse post out to advert currently
- Both providers have risk assessments in place to prioritise unaccompanied asylum-seeking children, children with complex health needs, children where they have been strategy meetings and children in residential care or frequent moves of placement

- There will be continued oversight by Corporate Parenting Boards for both Norfolk and Suffolk
- A full review of the Norfolk and Waveney Looked After Children (LAC) model has commenced. The review will consider the performance of the current providers and determine any operational, performance or service model changes required to ensure the service can meet future local health needs and be delivered in the most efficient and sustainable way possible. The review will inform future commissioning intentions for the service.

Briefing for Norfolk Health Overview and Scrutiny Committee

Annual health checks for adults with Severe Mental Illness in Norfolk & Waveney (Update and Assurance plan)

1. Executive summary:

This briefing paper has been prepared for the members of the Norfolk Health Overview and Scrutiny Committee (NHOSC) to provide an overview of the Severe Mental Illness (SMI) annual health check programme work.

Recognising the health inequalities for people living with an SMI, NHS England has made a commitment to improve the quality of care and treatment of people living with a severe mental illness and has set national performance targets for all Clinical Commissioning Group (CCGs) in England. There are currently 9,126 adults living in Norfolk and Waveney (N&W) with SMI and a total of 3,548 people received a physical health check in 2021/22.

Delivery was significantly impacted by the restrictions associated with COVID-19, particularly in primary care where there was a national focus on the vaccination programme. This paper will provide background information, local routes of delivery, progress on delivery against the national targets and our plan to improve the uptake and quality of annual health checks.

2. Introduction and Background:

NHS England set out the ambition for annual physical health checks for those living with an SMI in the NHS Long Term Plan. The CCG data collection for people with SMI receiving a full physical health check data contains information on the number of people on the General Practice SMI register at the end of each quarter, and of these how many received a comprehensive physical health check in the 12-months to the end of the reporting period.

The national metric for CCG performance is set by NHSE/I, and was previously given as a percentage of the SMI population, given in table 1:

Table 1: SMI PHC ambition for Norfolk and Waveney	2021/22	2022/23	2023/24
NHSE/I set minimum number of people with SMI receiving APHC	5,184	5,939	6,695
% of the SMI population (based on 21/22 Q4 QOF register size (9,134) (note QOF register size varies each quarter)	57%	65%	73%

Note: QOF is the Quality and Outcomes Framework, which is a voluntary framework that incentivises practices to deliver care according to nationally negotiated indicators.

Severe Mental Illness (SMI) is defined in this instance as all individuals who have received a diagnosis of schizophrenia or bipolar affective disorder, or who have experienced an episode of non-organic psychosis.

To achieve the full completion of a SMI annual check, table 2 outlines the elements that need to be completed and accurately recorded by the patient's GP practice.

Table 2 – elements of the annual physical health check for SMI	
Core Physical Health Checks	Additional elements, screening, and interventions
<ol style="list-style-type: none"> 1. BMI or Waist Circumference. 2. BP recorded. 3. QRISK or Cholesterol. 4. Blood Glucose or HbA1c recorded. 5. Alcohol Consumption recorded. 6. Smoking status recorded. 	<ol style="list-style-type: none"> 7. An assessment of nutritional status, diet and level of physical activity. 8. An assessment of use of illicit substance/non prescribed drugs. 9. Medicine's reconciliation or review. 10. Follow-up interventions for: weight management; blood pressure; blood glucose; alcohol consumption; smoking; substance misuse; blood lipids. 11. Access to national cancer screening for: cervical cancer; breast cancer; bowel cancer.

For monitoring, NHSE measures the system against delivery of the core 6 physical checks; however, all 11 elements need to be recorded as part of the complete annual health check.

3. Health Inequality and Impact:

3.1 Health Inequalities

People living with SMI face stark health inequalities and are less likely to have their physical health needs met, both in terms of identification of physical health concerns and delivery of the appropriate, timely screening and treatment.

Compared to the general population, people living with SMI:

- Face a shorter life expectancy by an average of 15 – 20 years, however this life expectancy gap is worse in Norfolk and Waveney with a life expectancy gap of 16.5-20.5 years.
- Are three times more likely to smoke.
- Are at double the risk of obesity and diabetes, three times the risk of hypertension and metabolic syndrome, and five times the risk of dyslipidaemia (imbalance of lipids in the bloodstream).
- Research have also shown this cohort of patients have been disproportionately adversely impacted by COVID-19.

The SMI physical health check was introduced to reduce this inequality and enable people with SMI to have their physical health needs met by increasing early detection and expanding access to evidence based physical care assessment and interventions.

3.2 National Policy:

The Five Year Forward View for Mental Health started the focus on SMI physical health checks, growing the delivery of health checks for this group from 30% (or 140,000 people) in 2017/18, to 60% (or 280,000 people) from 2018/19.

The more recent NHS Long Term Plan (LTP) and associated [NHS Mental Health Implementation Plan 2019/20-2023/24](#), have identified that NHS England should ensure that SMI physical health checks are received by 280,000 people in 2020/21, 280,000, building to 390,000 people in 2023/24.

Additionally, the Core20PLUS5 NHSE/I programme to support the reduction of health inequalities at both national and system level identified the SMI cohort of patients as 1 of 5 focus clinical areas that requires accelerated improvement. Best practice evidence indicates that where primary care teams deliver care collaboratively with secondary care services outcomes are improved.

4. Overview of 2021-2022

All people with SMI are eligible to receive an annual health check inclusive of all ages. As of March 2022, this represents a population in Norfolk & Waveney of 9,134 people. Responsibility for the delivery of SMI checks is shared amongst 2 main groups (Primary care and Secondary Care) and is supported by voluntary sector. This is demonstrated further by **Appendix A**.

Throughout 2021-22, Covid-19 as well as the subsequent vaccination booster programme continued to place significant pressure on healthcare providers across N&W. The competing challenges of high levels of staff sickness and absence across general practice and people worried about attending general practices have had a significant impact on the planned delivery and uptake of SMI health checks.

Despite the considerable challenges presented by Covid-19, colleagues in general practice, supported by the CCG team and in conjunction with secondary care mental health teams, continued to work hard to support the health and care needs of people living with SMI. However, despite the sustained hard work and efforts, the national target has not been met.

5. Delivery position in N&W and nationally:

As a system, at the end of Quarter 4 21/22, N&W had completed 3,548 SMI checks, against an ambition (nationally set) of 5,184 – this is 38.9% delivery compared against the national target previously expressed as 60%.

The number of SMI annual health checks carried out historically from 2019/20 to 2021/22 across Norfolk and Waveney is shown in figure 1, with the national ambition and local trajectory outlined for comparative purposes. **Appendix B** also provides further detail into the quarterly activity figures.

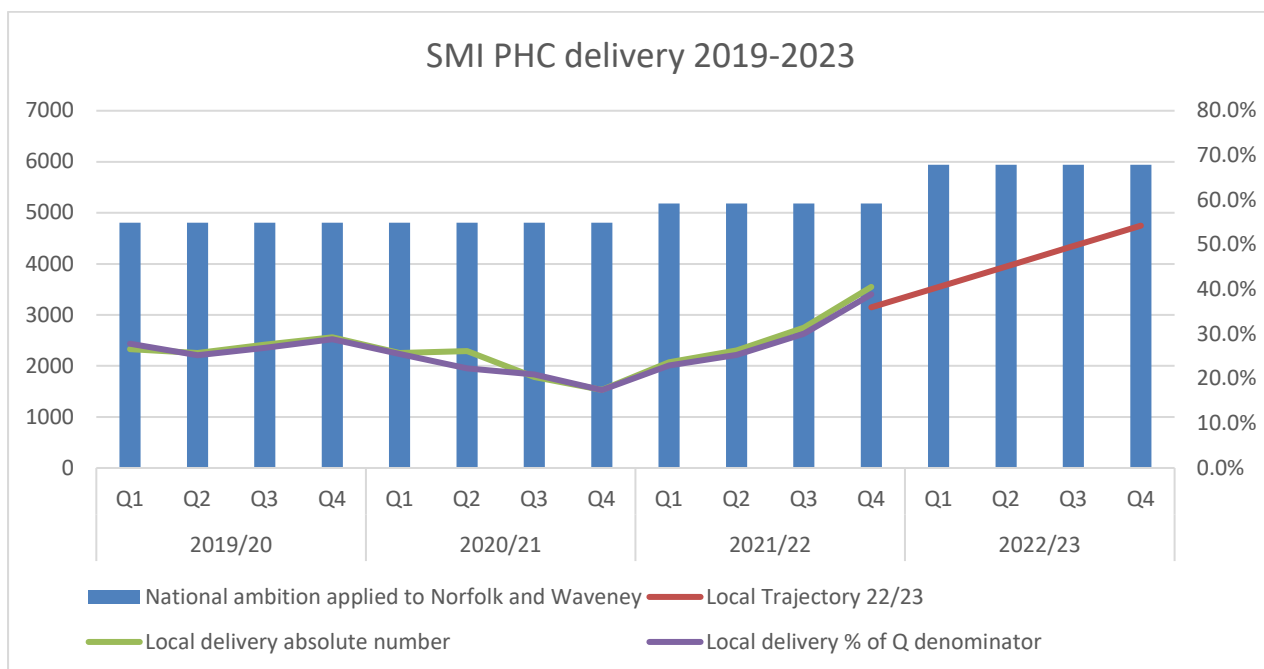


Figure 1

Source: [Statistics » Physical Health Checks for people with Severe Mental Illness \(england.nhs.uk\)](#)

For further context and benchmarking, the regional and national delivery are mapped below (percentages have been used to provide comparative data):

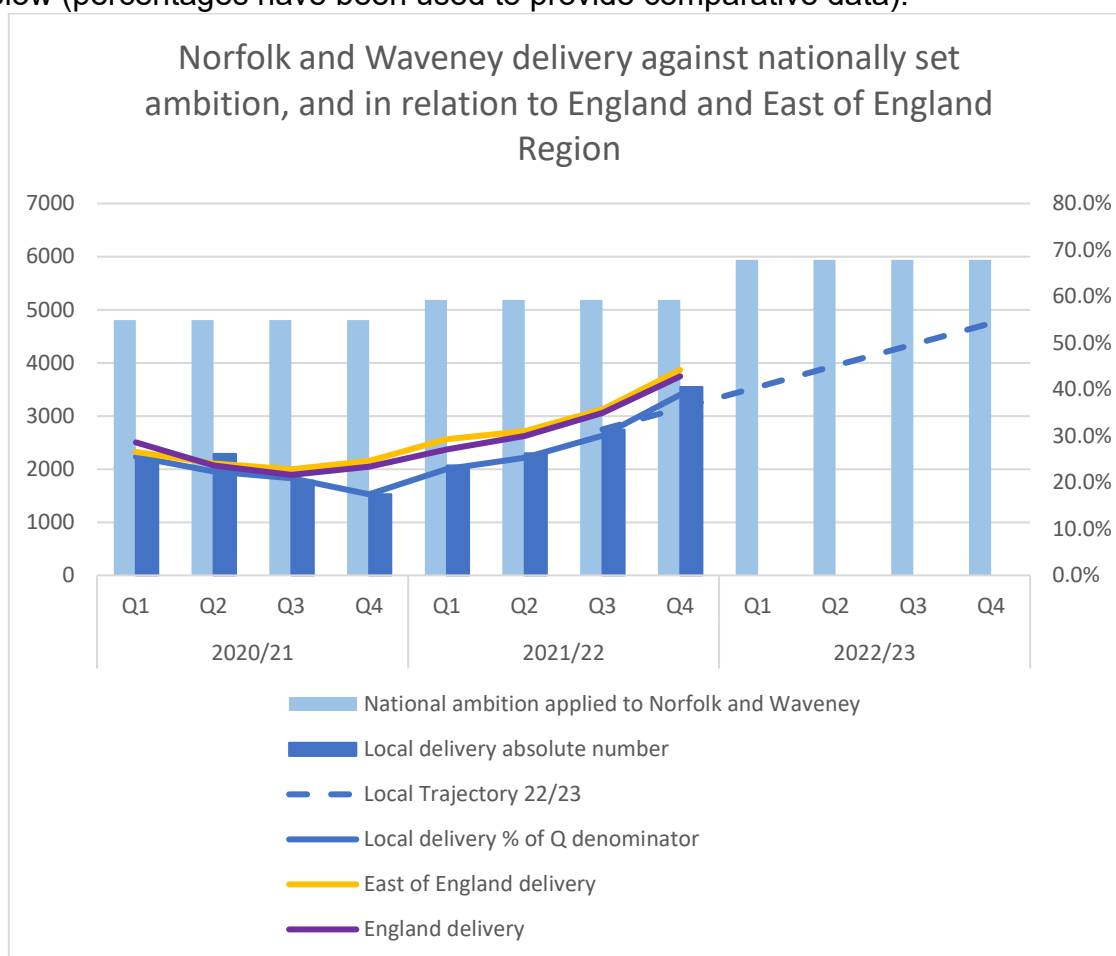


Figure 2

From the above, the following observations can be drawn out:

- The pattern of delivery follow regional and national metrics, with a downturn through 20/21 and upturn through 21/22.
- N&W has recovered to the pre-Covid19 delivery position.
- On average using 2019-20 activity figures, the system carried out 2,389 checks per year. The impact of COVID-19 is highlighted when reviewing the figures for 2020/21; where 1,985 checks were done, a reduction of 404 SMI checks. This showed the impact patient access, relocation of resource to support the booster programme etc.
- The system shows good signs of recovery post COVID-19, carrying out 3,548 checks in 2021-22; however, the national target has not been met.
- The local trajectory across 2022-2023 follows the uptake seen in checks performed at the end of 2021-22.
- Compared against the East of England and National delivery, the N&W are underdelivering in terms of health checks provided.
- The project group is working with colleagues to understand the reasons for this performance; however, it appears to be multi-faceted including:
- Prioritising patients who have not had their health checks; sufficient allocation of resource, booking and coding practices and finally focusing on those patients who are missing individual checks.

Utilising the end point baseline performance position for 2021-22; the table 3 shows the delivery of annual health checks across the 5 localities in Norfolk and Waveney:

Table 3

Locality	Number of checks carried out:	Local Delivery Percentage:
Great Yarmouth and Waveney	871	33.9%
North Norfolk	557	37.5%
Norwich	960	36%
South Norfolk	577	36%
West Norfolk	413	35%
Year-end Position	3,548 (including NSFT)	38.9%

Figure 3 shows the delivery of each of the individual 'core 6' elements of the health check (referenced in table 2). This demonstrates that many people living with an SMI do access healthcare services but are having only some of the health check elements completed. With further engagement, both with system providers and our SMI population, we are confident that completion of full health checks will continue to improve through approaches such as *Making Every Contact Count*.

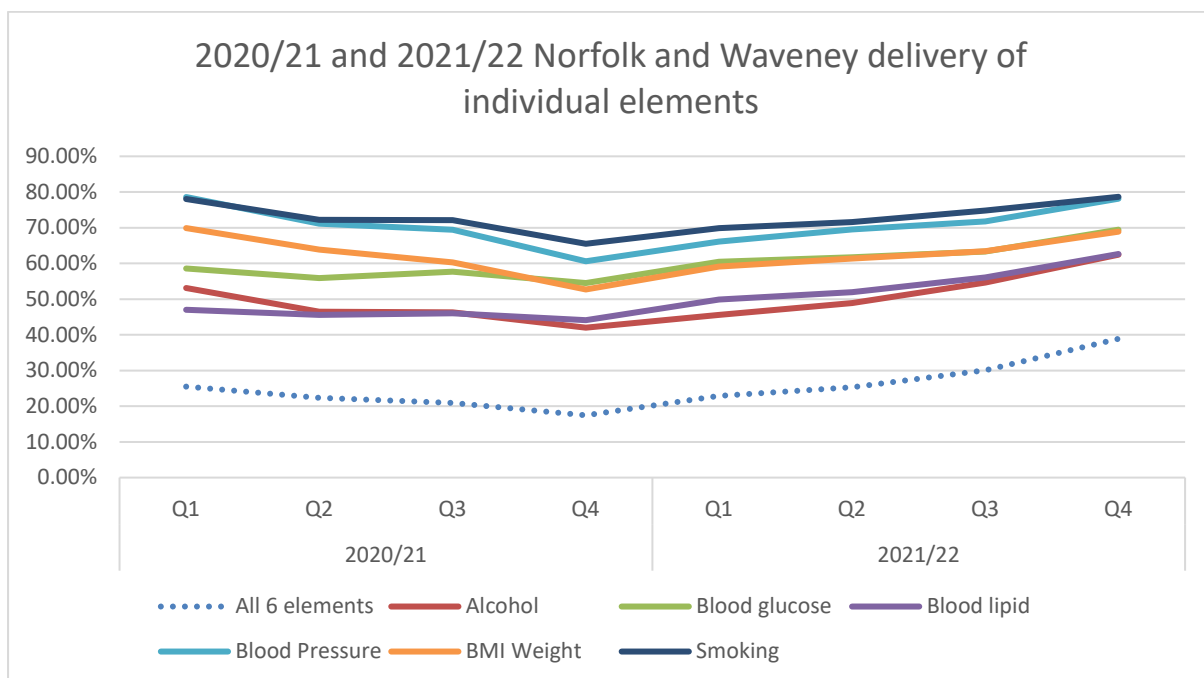


Figure 3

6. Governance and escalation

The system provides assurance to NHSE/I through the Mental Health Commissioning team within the CCG, including a recovery action plan submitted to NHES/I as part of planning for 2022/23. The mental health team provide assurance to the Norfolk and Waveney system through the Mental Health Partnership Board, and SMI PHC is viewed monthly.

Simultaneously, the uptake and quality of SMI annual health checks has been identified as a risk and will be monitored by the Primary Care Commissioning Committee's (PCCC) risk register during the monthly meetings which are held in public. Mitigation has been supplied in the risk assessment for oversight and assurance with progress update reports to be submitted to PCCC on a quarterly basis.

7. Opportunities & Translation of good practice:

Opportunity	Action being taken:
a) System wide recognition of inequalities, raised through Covid19 and Core20Plus5 This heightened awareness provides an 'open door'	<ul style="list-style-type: none"> Monthly meetings re-established to monitor progress and support delivery. Regular agenda item in our meetings with locality teams NSFT will be focusing on the quality of checks; specifically, what happens once the checks are done (smoking cessation, dietary management etc.)
b) In year funding to support new approaches and capacity	<ul style="list-style-type: none"> Proof of concept to test out a dedicated resource to deliver SMI checks within a Primary Care Network.

	<ul style="list-style-type: none"> This will be to trial a peripatetic team approach for the hardest to reach individuals following the model of a successful scheme for Learning Disability health checks.
c) Ensuring the full SMI PHC is completed Ensuring all core elements of health checks are completed when the patient attends the practice will result in a higher completion rate and help to make every patient visit count.	<ul style="list-style-type: none"> Liaise with GP practices, understand the data streams and how these searches can be access on SYSTM-One Point of Care testing pilot

The SMI working group engages with experts by experience, to inform improvement work. Work is underway to collate patient stories and feedback from SMI service users across N&W.

8. Risk and Challenges:

Risk	Mitigation / action
a) Workforce Workforce training in some areas remain unclear on training and upskilling opportunities; with not all staff being trained to the required level.	<ul style="list-style-type: none"> Workforce capacity and recruitment is being reviewed We are using multiple channels to share SMI PHC training and upskilling resources e.g. practice letters, online channels.
b) Engagement Work to drive up engagement in this patient cohort; targeting the hardest to reach patients.	<ul style="list-style-type: none"> Empowering people to ask for their health check through education and drive up patient self care. Continuation of the Outreach service in 2022/23 Close work with experts by experience. The new SMI locally commissioned service incentivises practices to dedicate increased resource to engagement with this patient group and the nomination of a SMI champion.
c) Quality The health checks will only have impact on people that are supported to alter their lifestyle as a result. Not all intervention services currently have offers that suit those living with SMI	<ul style="list-style-type: none"> A pilot of dedicated weight loss support for people with an SMI National early implementor status (one identified per region nationally) of tobacco cessation for people living with an SMI Work with the Health Intervention Transformation Group to meet the 'so what' aspect once the health check is carried out. Work with experts by experience.

<p>d) Data</p> <p>There are ongoing challenges to ensure all activity is correctly coded and able to be shared across the system.</p>	<ul style="list-style-type: none"> • Use of multiple channels to share guidance to enable operational colleagues to pinpoint and find data to then carry out checks. • NSFT internal capacity resource for leadership • Digital colleagues are working with us to scope potential solutions – this will improve clinical care, future data reporting and efficiencies.
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9. Delivery and Improvement Plans for 2022-2023

A key focus for 2022-23 is to assist practices by undertaking proof of concepts that will lead to increases in patients accessing their SMI check. Several initiatives are planned to boost performance through 2022/23 are outlined as follows:

9.1 NSFT clinical / operational manager new role:

- The creation of a post to strengthen the links between NSFT and primary care teams and provide leadership to support system solutions from within.

9.2 Continue Outreach project through 22/23:

- The charity 'Together' has been commissioned support the uptake of checks for people with SMI through 2021/22 and 2022/23. The team supports practices by organizing and scheduling the SMI checks. Communications are ongoing to promote this service.

9.3 Dedicated SMI & Eating Disorder nursing Proof of Concept:

- Discussions have taken place about testing the above dedicated resource via funding from the Mental health commissioning teams for 1 year.
- The proposed concept of nursing/HCAs will work closely with a PCN to deliver SMI checks as well as advise on eating disorders.
- Modelling outlines that this would result in circa 420 additional SMI checks per year. If successful, these posts could be scaled up across PCNs / localities.

In addition, the team are still developing the below 2 interventions which will serve to further improve the current position for SMI in Norfolk & Waveney:

9.4 Resiliency Primary Care Liaison and Learning post:

- The initial scoping work done has exposed the potential need for a primary care liaison and learning post to be piloted.
- This post could provide practices with expert advice on clinical systems, how to ensure their SMI registers are up to date, scheduling and coding and translation of good practices across primary care networks

9.5 Dedicated SMI resource web resource:

- We are also scoping plans to develop a purpose-built web resource that the system can utilise to help support in the uptake and delivery of SMI checks.

Recognising the importance of learning across programmes and maximising the opportunities to engage with people in our communities, we have brought together teams which are working on supporting the physical health of those living with an SMI, Learning Disabilities, Neurodiversity and Autism to share good practice and address challenges collectively.

10. Conclusion

This report acknowledges the hard work done to recover from the impact of COVID-19 on the delivery of SMI health checks. However, there still remains work to do to improve the uptake and the impact of the SMI health checks and ensure this is sustainable over time.

Learning taken from across our own system and through networks across the Region have helped inform the current plan for improvement. The uptake and quality of SMI annual health checks has been identified as a risk and will be monitored by the Primary Care Commissioning Committee's (PCCC) risk register during the monthly meetings held in public, to ensure patients with SMI have access to their annual health checks.

Appendices:

Appendix A- Roles and responsibilities in delivering SMI Health Checks:

Primary Care:

General Practice colleagues carry out annual physical health assessments and follow-up care for: patients with SMI who are not in contact with secondary mental health services and patients with SMI who have been in contact with secondary care mental health teams (with shared care arrangements in place) for more than 12 months and / or whose condition has stabilised. In Norfolk and Waveney this is commissioned as a Locally Commissioned Service (LCS) which complements the quality and outcomes framework and was revised for 2022/23 to support practices in being able to invest more time to build relationships with individuals.

Secondary Care

Mental Health teams are responsible for carrying out physical health assessments and checks for patients with SMI under the care of a mental health team for less than 12 months and/or whose condition has not yet stabilised. In Norfolk and Waveney our secondary care mental health provider, Norfolk and Suffolk Foundation Trust (NSFT) has been commissioned to provide additional support staff to enable the health checks to be undertaken.

Voluntary Sector

The VCSE provider Together have been commissioned to provide an outreach service in conjunction with Primary Care. Together are very experienced in working with people with an SMI and have robust networks to support people living in the community. The service supports GP practices to contact people on their quality and outcomes framework register who have not had a complete SMI physical health

check and enables conversations and practical help to support uptake of assessments and interventions.

Appendix B- Quarterly Activity figures for SMI checks delivered, 2019/20-2021/22:

	2019/20				2020/21				2021/22			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
National ambition applied to Norfolk and Waveney	4806	4806	4806	4806	4806	4806	4806	4806	5184	5184	5184	5184
National ambition applied as % to Norfolk and Waveney	-	-	-	-	54%	47%	56%	55%	57%	57%	57%	57%
Local Trajectory 22/23	-	-	-	-	-	-	-	-	-	-	-	3148
Local trajectory for 22/23 as %	-	-	-	-	-	-	-	-	-	-	-	34.5%
Local delivery absolute number	2326	2254	2414	2562	2254	2288	1785	1530	2069	2302	2748	3548
Local delivery % of Q denominator	27.8%	25.3%	26.9%	28.8%	25.5%	22.3%	20.9%	17.4%	22.9%	25.3%	30.1%	38.9%
East of England delivery	26.90%	28.70%	29.60%	35.80%	26.6%	24.0%	22.8%	24.6%	29.3%	31.0%	35.7%	44.2%
England delivery	29.50%	30.00%	32.30%	33%	28.6%	23.7%	21.6%	23.4%	27.1%	30.0%	34.9%	42.8%

Children's neurodevelopmental disorders: waiting times for assessment and diagnosis

Suggested approach from Liz Chandler, Scrutiny and Research Officer

Examination of CCG report into waiting times for assessment and diagnosis for children's neurodevelopment disorders since the commissioners last report to NHOSC in July 2021.

1.0 Background

- 1.1 Clinical pathways to assess children and young people for neurodevelopmental disorders (NDD) are provided across Norfolk and Waveney through two main providers: Norfolk Community Health and Care Trust (NCH&C) for Central and West localities and the Newberry Child Development Centre (hosted by James Paget University Hospital) for Great Yarmouth and Waveney. The exception is Thetford, where children registered to GP surgeries will be referred to Suffolk based assessment services.

1.2 Previous Report to NHOSC

- 1.2.2 NHOSC previously looked at the process and waiting times for assessment and diagnosis of children experiencing neurodevelopmental difficulties at the two main NHS providers of this service in Norfolk and Waveney. The report and minutes of the meeting are available through the following link: [NHOSC 15 July 2021](#).

The July 2021 report was requested following an initial report concerning children's autism spectrum disorder (ASD) diagnosis within the NCH&C Central and West Norfolk service which was presented to NHOSC on 11th January 2018. The report and minutes of the meeting are available through the following link: [NHOSC 11 January 2018](#). Following a subsequent briefing in February 2019, and further enquiries in February 2020, it became apparent that there was a disparity between the waiting times for children to be accepted onto the ASD assessment pathway and those for children to be accepted onto the neurodevelopment disorders assessment pathway.

While NCH&C Central and West Norfolk service had successfully reduced the waiting time for ASD assessment to 18 weeks or less from the point of referral, children accepted onto the neurodevelopment disorders assessment pathway were waiting around 40 weeks for the start of assessment.

- 1.2.2 The disparity in waiting times for children being accepted on the ASD and neurodevelopment disorders assessment pathways, prompted NHOSC to request a report on the wider subject of assessment and diagnosis of general neurological disorders at the meeting on 11th July 2021.

2.0 Purpose

- 2.1 The purpose of today's meeting is to examine the report from the CCG (attached at **Appendix A**) in response to the committee's request at the previous NHOSC meeting in July 2021 for further information to:

- Clarify demand and capacity in the service and the consequent funding gap.
- Set out the top priorities for action in the short to medium term.
- Identified opportunities to improve processes within the pathways (potentially by sharing good practice across the two services).

Family Voice Norfolk (FVN) has also provided an update on parent carers' experience of the Neurodevelopmental Service providing the results of their recent experience of accessing pathways and services supporting diagnosis of some neurodevelopmental disorders. This is attached at **Appendix B**.

3.0 Suggested approach


- 3.1 The committee may wish to discuss the following areas with the CCG representatives:
- (a) Clarity around demand and capacity in the service and the consequent funding gap.
 - (b) Setting out the top priorities for action in the short to medium term.
 - (c) Identifying opportunities to improve processes within the pathways (potentially by sharing good practice across the two services).
 - (d) Benchmarking of Norfolk and Waveney's services against other services regionally / nationally.
 - (e) Figures / graphs showing current waiting times in the two services (NHC&C and The Newberry at JPUH) in the same format as last time:
 - a. Current waiting times from referral to start of assessment in each element of each pathway (i.e. the average time already waited by those who are currently waiting for start of assessment and the longest time waited amongst those who are currently waiting), and for different age groups where pathways differ depending on age of the child. Comparison with waiting times a year ago.

- b. Average time from start of assessment to diagnosis in each of the pathways and longest time experienced by a child who completed the journey from start of assessment to diagnosis on each of the pathways in the past year (clearly defining the basis on which the calculations are done).
- c. Details of the standards / performance indicators that are in place for different elements within each of the various pathways; current performance against those standards; any benchmarking available between local services and services regionally or nationally.

(f) Any change to the structure of the services / contracts.

4.0 Action

- 4.1 The committee may wish to consider whether to make comments or recommendations as a result of today's discussion.

	<p>If you need this report in large print, audio, Braille, alternative format or in a different language please contact Customer Services on 0344 800 8020 or Text Relay on 18001 0344 800 8020 (textphone) and we will do our best to help.</p>
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Health Overview and Scrutiny Panel - Report for 14th July 2022

The commissioners have provided the following information: -

Children's neurodevelopmental disorders – waiting times for assessment and diagnosis.

Presented by:

Rebecca Hulme – Associate Director for Children, Young People and Maternity Services - Norfolk and Waveney Integrated Care Board (ICB)

Clare Angell – Deputy Head of Children, Young People and Maternity (CYPM) Services – Norfolk and Waveney Integrated Care Board

Dr Richard Allen – Designated Doctor for Safeguarding - Norfolk and Waveney Integrated Care Board

Amie Swithenbank – Interim Head of Children, Young People and Administrative Services – Norfolk Community Health and Care Trust (NCHC)

Mark Walker - Operations Director - Specialist, System Operations and Children's Services (SSOCS) - NCHC

Jo Scott – Matron, Community Paediatrics Services, CYP Services, James Paget University Hospital Trust (JPUH)

The purpose of this paper is to.

1. Provide an updated detailed overview of current waiting times for providers in Norfolk and Waveney and benchmarking against other service regionally and/or nationally
2. Clarify demand and capacity in the services and any consequent funding gaps
3. Identify opportunities to improve processes within the pathways (potentially by sharing good practice)
4. Set out the top priorities for action in the short to medium term
5. Any other relevant information from the CCG and service providers.

Author/s:

Clare Angell

Amie Swithenbank

Joanne Scott

1 Introduction

This report follows a previous one submitted in July 2021 regarding pathway waits across Norfolk and Waveney and work underway to improve these. Both core providers are working closely with commissioning representatives from the Integrated Care Board and continue to implement innovative changes to improve the experiences for children, young people, and families. There remains more to do, in response to worsening mental health during the pandemic, reduced resilience in families and pressures across the children's workforce. The backlogs generated

and/or exacerbated during 2020 and 2021 continue to disadvantage neuro developmental assessment teams to meet the current demand as is seen across all elective waits within the system.

Since last year, monthly referrals for assessments have steadily increased in number. Aside from term start and end peak activity, there is an overall an increasing trend in referrals for most of Norfolk and Waveney. For Norfolk Community Health and Care Trust (NCHC), the number of referrals received and accepted is increasing with a monthly average of 119 during 2021/22. James Paget University Hospital observed a fall in monthly referrals, more in line with pre-pandemic levels. The peak in activity for March 2022 is likely due to Autism Awareness week and Neurodiversity celebration week.

Detailed descriptions of assessment pathways are included in Appendix one: Health Overview and Scrutiny Panel - Report for 15th July 2021

1.1 Overview of any changes to waiting times since July 2021

James Paget Hospital – Newberry centre

- Average waits to first assessment are 52 weeks – an increase since 2021
- Average waits from assessment to discharge have increased by 52 weeks from 26.5 to 82.7
- Maximum waits to discharge have increased by 42 weeks from 87.6 to 130.2

Norfolk Community Health & Care Trust

- Average waits to first assessment are 42 weeks – no change since 2021
- Average waits from assessment to discharge have increased by 15 weeks from 84 to 98
- Maximum waits to discharge have increased by 8 weeks from 144 to 152
- Incomplete waits to assessment, between 10 and 52 weeks, have decreased since this time last year

During 2021/22, a set of locally defined performance indicators was agreed with JPUH. These will be manually collated and shared automatically to the ICB on a monthly basis. While work continues to refine this process, this is a significant and positive change from last year.

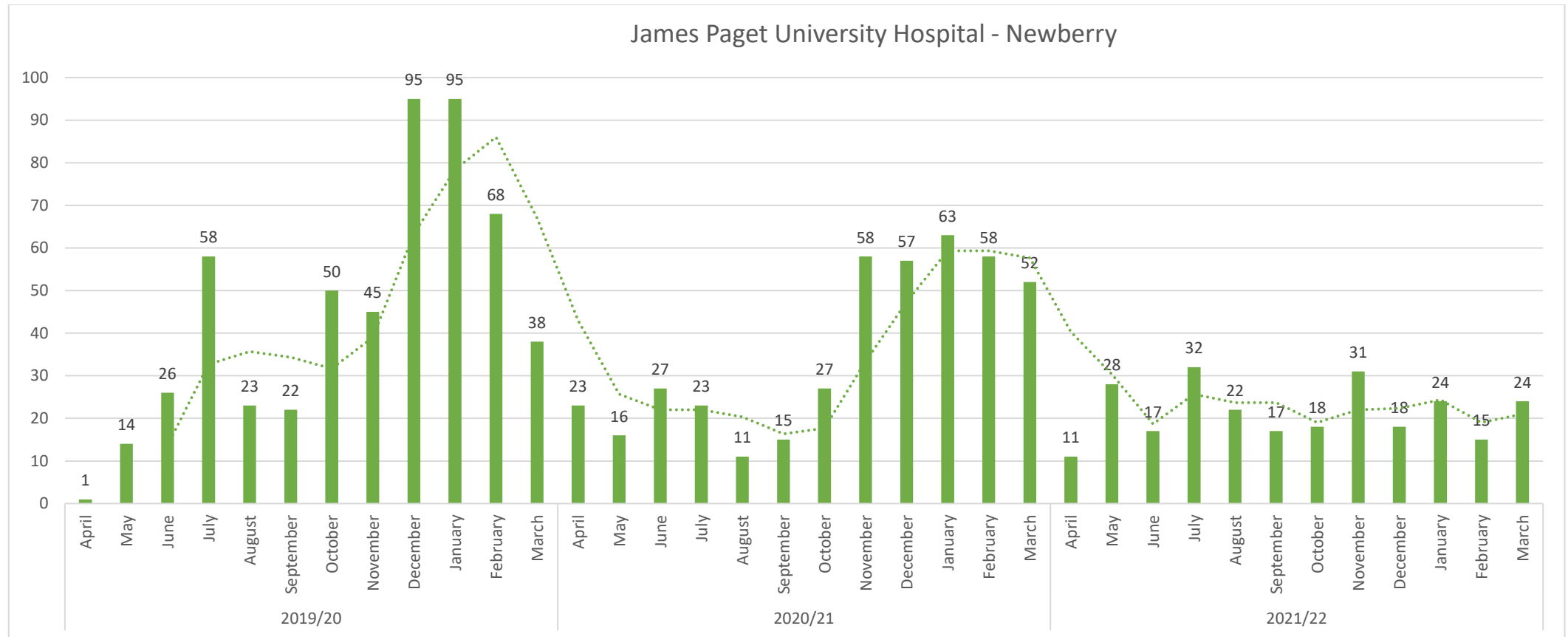
Table 1. Local list of indicators agreed

Metric agreed
Total number on waiting list
Total number discharged with no diagnosis
Total number diagnosed (using ICD10 codes F900 ADHD F840 ASD)
Wait for 1 st assessment in pathway
Average wait from referral to pathway to discharge
Number waiting for each assessment

There has been no change to the existing contracts.

Overleaf are graphs, enlarged for ease of understanding, showing the overview of current waiting times for providers.

1.2 Demand for assessments (accepted referrals only) with a trend line based on a 3-month rolling average

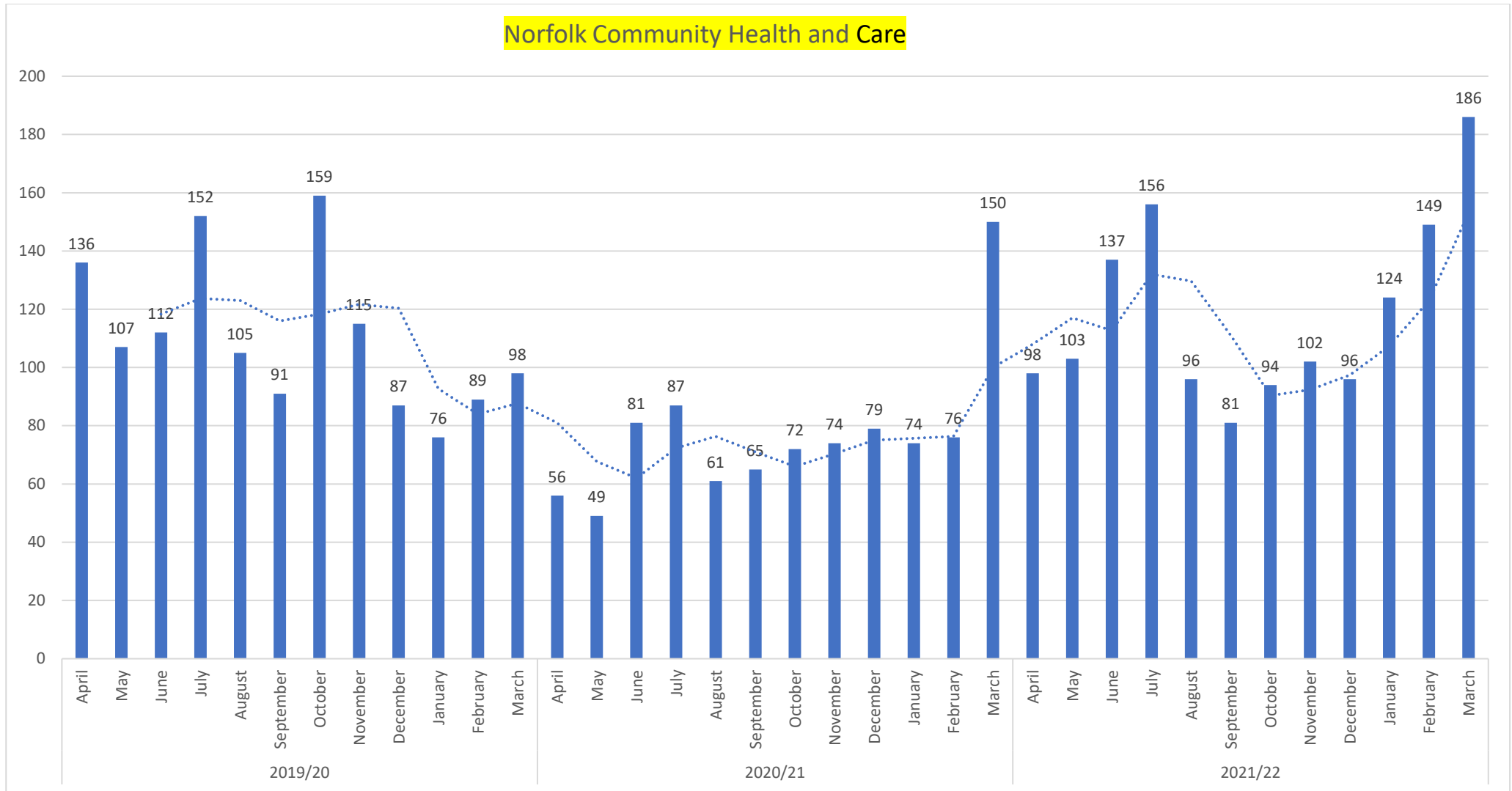


Business Intelligence analysis: 2021/22 demand showed a decrease of 40.2% on 20/21 levels and a decrease of 52.0% on 19/20 (i.e., pre-pandemic) levels.

Total referrals for 2019/20 = 535, 2020/21 = 430, 2021/22 = 257

Due to a change in Paediatric Consultant, the number of available triage clinics per week reduced from nine to three. The triage outcome determines the level of demand for neurodevelopmental assessments. As the numbers being triaged have reduced, it suggests the demand is decreasing. This is not the case. Increased waits reflect the reduction in clinics and impact of the pandemic.

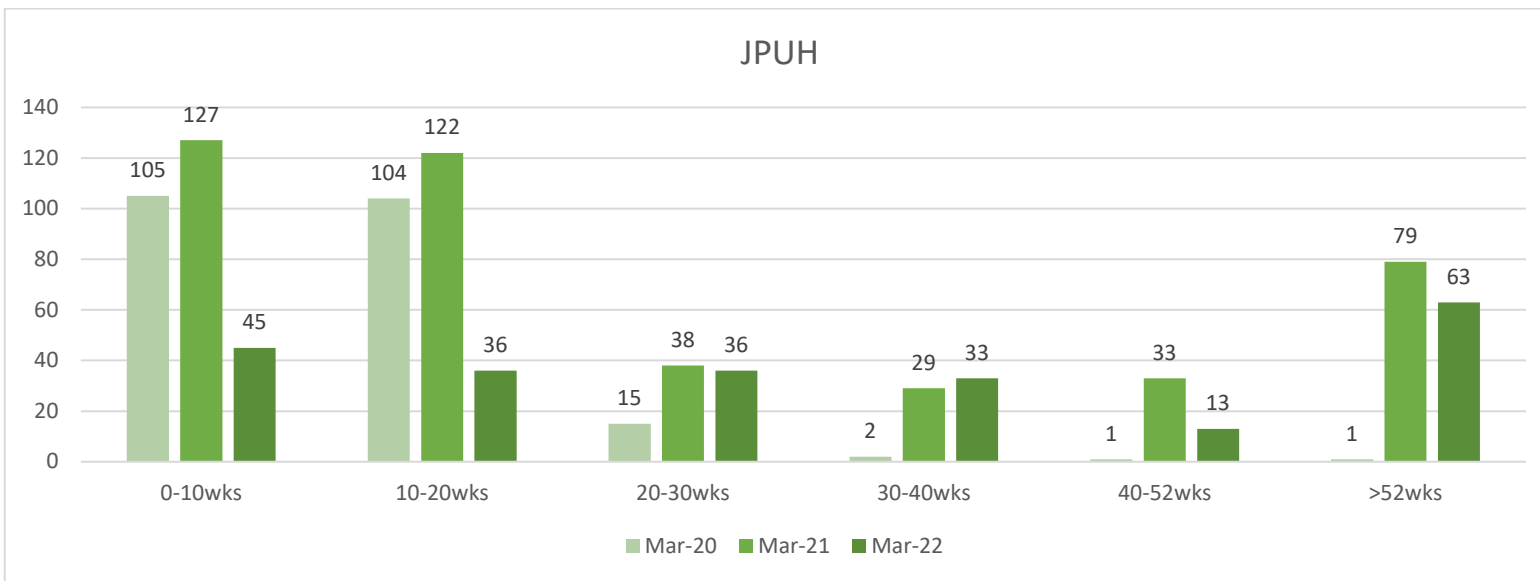
Norfolk Community Health and Care



Business Intelligence analysis:

*2021/22 demand showed an increase of 53.9% on 2020/21 levels and an increase of 7.2% on 19/20 (i.e. pre-pandemic) levels. 2019/20 = **1327**, 2020/21 = **924**, 2021/22 = **1422***

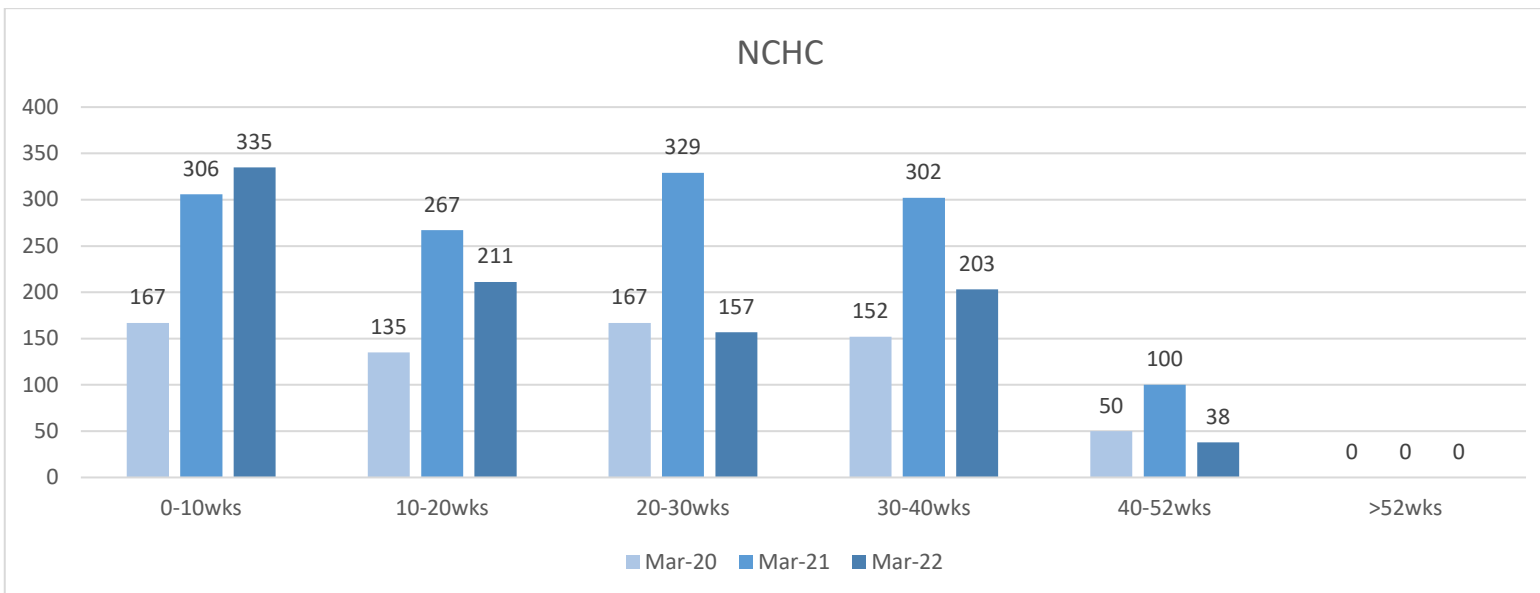
Graphs 3 & 4. Incomplete Waits – Waiting for Assessment as at end of March '20, March '21 and March '22



Business Intelligence analysis:

*Total number waiting for assessment has decreased back to pre-pandemic levels: Mar 2020 = **228**, Mar 2021 = **428**, Mar 22 = **226***

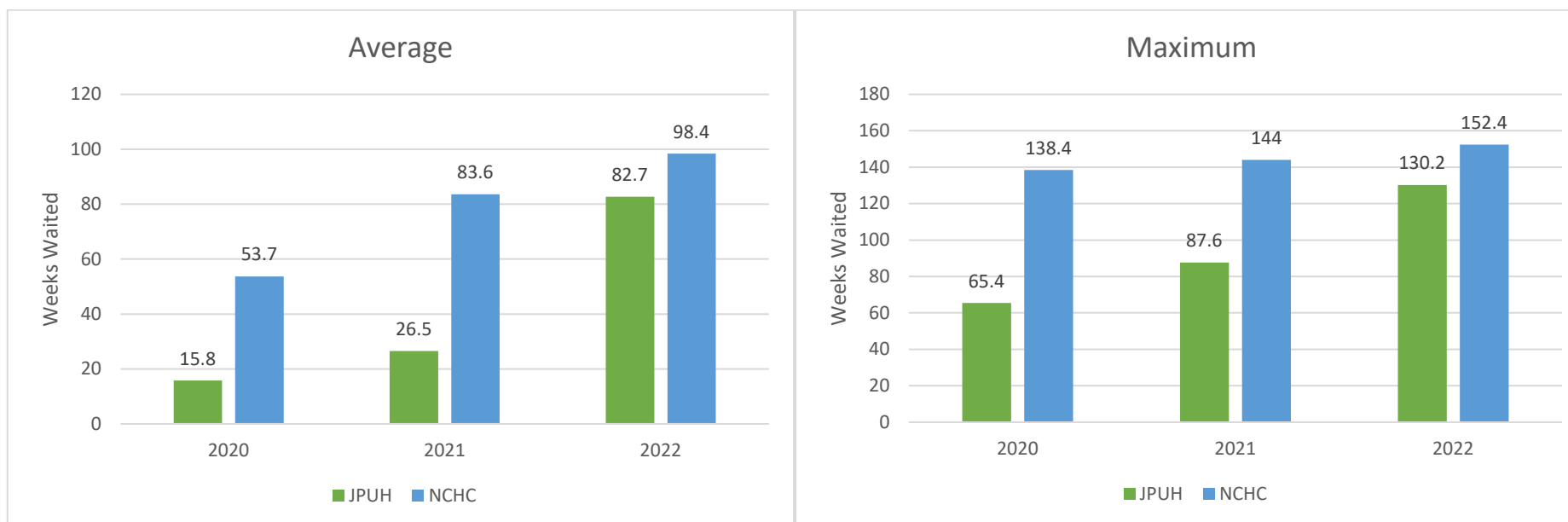
Longest waiters are the key area of focus for both providers. The graph below is a positive example of progress



Business Intelligence analysis:

*Total number waiting for assessment has decreased compared to last year (decrease of 27.6%) but is still **40.7% higher** than pre-covid: Mar 2020 = **671**, Mar 2021 = **1304**, Mar 2022 = **944***

Graphs 5 & 6 Assessment to Discharge based on patients discharged in March '20, March '21 and March '22



Business Intelligence analysis:

JPUH increase of 212.0% on 20/21 – increase of 423.4% on 19/20 (Pre-pandemic)

NCHC increase of 17.7% on 20/21 – increase of 83.2% on 19/20 (Pre-pandemic)

Business Intelligence analysis:

JPUH increase of 48.6% on 20/21 – increase of 99.1% on 19/20 (Pre-pandemic)

NCHC increase of 5.8% on 20/21 – increase of 10.1% on 19/20 (Pre-pandemic)

1.3 Benchmarking of performance

National autism data is available via the Mental Health Services Dataset (MHSDS) but the quality and accuracy are unreliable. It is managed by NHS Digital with the aim of benchmarking provider performance across England. MHSDS is a patient level, output based, data set and people who receive autism spectrum disorder services or who are thought to have an autism spectrum disorder or other neurodevelopmental conditions are within the scope of the MHSDS.

From 1 April 2018 providers of mental health, learning disabilities and autism spectrum disorder services were expected to start submitting data related to autism patients.

These statistics are classified as 'experimental' and should be used with caution. Experimental statistics are new official statistics undergoing evaluation. They are published to involve users and stakeholders in their development and to build in quality at an early stage. Changes to reporting have been made year on year with little impact. Current data reflects performance in Q3 2020/21.

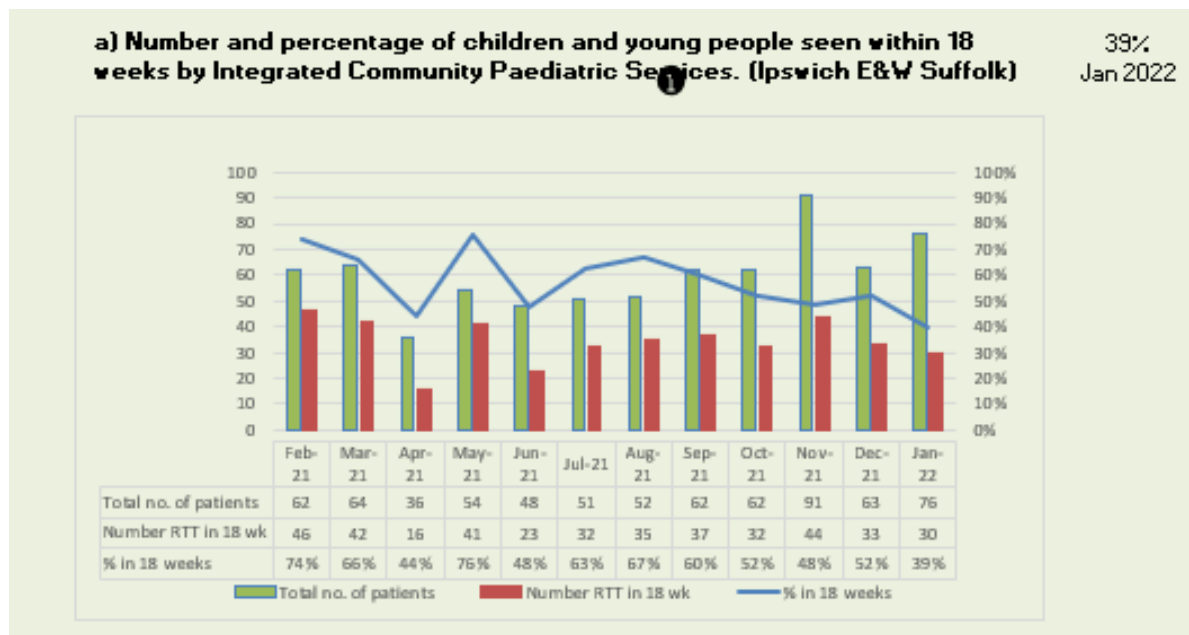
Most referrals and assessments for autism are undertaken in child development services e.g., community paediatrics. These services were out of scope of the dataset and therefore not included in the statistics available. Work to improve this nationally is ongoing.

Latest Department of Health and Social Care figures show that only one in seven people with suspected autism receives any care contact within 13 weeks of referral – with many waiting up to two years to be assessed.

For the report, the ICB CYPM team contacted commissioning representatives across the region. From this contact, it was established that performance indicators across the footprint differ, and in some areas, such as Hertfordshire, pathway waits from referral to discharge are unknown.

In Cambridgeshire and Peterborough, waits for assessments can be between three and five years.

In Suffolk, 39% of children are seen within 18 weeks. Average waits to discharge are likely to be in line with Norfolk and Waveney.



2.0 Demand and capacity and funding gaps:

Due to additional investment over the last twelve months enabling recruitment to assessment teams, more time is required to determine if the additional capacity can meet ongoing and future demand. While there has been positive progress on wait to first assessment for NCHC, the overall open caseload has observed a significant increase.

2.1 Recurrent Investment for Neuro developmental services

In September 2021, the CYPM team successfully secured £375k in additional recurrent funding for Norfolk Community Health and Care Trust. This has permitted the trust to recruit additional clinicians to support the assessment of children on the pathway.

Transforming Care funding created a role to scope the design of a pathway for children with Avoidant Restrictive Food Intake Disorders (ARFID). We look forward to testing the lessons learnt.

This was further supported by a successful three-year funding bid of £1.6m to create and expand a keyworker team whose role is to assist families in navigating the health and care system where a child with a learning disability and/or autism is at risk of an inpatient admission.

We are also very proud to have been selected to be a nationally funded Integration Test Site for an NHS programme, implementing recommendations following a review into occupational therapy services. Key aspects of the four-year programme include delivering sensory support for children who are neuro diverse and upskilling families and professionals (particularly schools) to support children with sensory needs.

2.2 Non-recurrent investment for neuro developmental services

The report last year referenced opportunities to apply for funding through the government spending review. Through various expressions of interest, Norfolk and Waveney received £219k to implement new care models. This enabled NCHC to implement a proof of concept sub team model, detailed in section 3, and funding for the Sunbeams charity to provide creative alternative therapies to improve mental health and for a project lead to review our mental health response within neurodiversity services.

2022/23 includes additional funding of £39k for post diagnostic support and £36k to support training in schools. A dedicated working group of SENCOs will support the ICB CYPM team and Norfolk County Council to design an accessible training programme.

3.0 Opportunities to improve processes

Norfolk Community Health and Care:

A sub team pilot was operational from 2021 for twelve months with continual points for review and change for improvement.

Key improvements include:

- Improved staff morale to support recruitment and retention. This is a direct result of improved opportunities for holistic assessment and multi-disciplinary team (MDT) working.
- Children not “bouncing around the service” – once a child is picked up by the sub team they are actively in assessment until conclusion of the process, and they are discharged. Previous working models meant that they were held on various waiting lists for various assessments. Assessments would be undertaken and then the individual would be subject to long waiting times between steps, causing frustration for families.
- Unnecessary delays and appointments are avoided as the time frame is smaller.

- Improved experience for CYP and their families as the key clinician follows the assessment journey and provides increased communication throughout the pathway.
- Improved safety netting processes.

In 2020, NCHC implemented the use of a QB test. The QB test is a diagnostic screening tool which provides objective information to aid assessments for ADHD. Using age and gender matched comparisons, the test assesses the child's ability to concentrate, their movement and impulsivity. Following a successful trial, additional QB equipment has been purchased so that efficiency can be maximised across the county and all new starters have been trained in the use of QB.

Licences have been funded for online questionnaires to improve turnaround time for returns. This will alleviate delays where questionnaires are not returned in a timely way. Additional assessment tools such as Wechsler Intelligence Scale for Children WISC have also been purchased to increase the number of children who can be assessed.

In 2018/19, a pilot triage scheme was tested with a cluster of schools to determine if telephone consultation with school SENCO's and duty coordinators within Neuro developmental services would reduce the number of inappropriate referrals. Following its success, NCHC launched the Education Triage Scheme ETS in October 2020. CYP are discussed anonymously regarding appropriateness of referral or sign posting. The Scheme has been evaluated and changes from September 2022 will reflect further efficiencies to include full access to patient records in some cases. Patient records, we will gain parental consent for the consultation and record the outcome on the patient record. Schools have welcomed this change.

3.1 ICB neurodiversity waiting list initiative

The neuro diversity diagnostic service waiting list initiative is an interim service response to address long current waits for assessment and diagnosis. This procurement aims to assist in reducing waiting lists, restoring provision to the expected NHS standard 18-week RTT within two years and has a value of £1,000,000. A market engagement event took place on April 12 2022, attracting strong interest and introducing the potential to develop innovative models in the assessment and diagnosis of neurodiverse conditions. The full procurement went live June 9 2022, and it is anticipated the service will be mobilised by autumn 2022. It is expected that children and young people experiencing the longest waits will be offered the option of a transfer of care for assessment and diagnosis with an independent provider. The offer will be inclusive of all children and young people (up to 18 years) with specialist provision identified for those presenting with complexity and for those aged 6 or under.

4.0 Top priorities for action

- Monitor impact of additional pathway funding and use learning to expand across the system
- Monitor effectiveness of neuro diversity diagnostic procurement exercise to reduce waits and use learning to expand beyond 2023
- Design a training programme for schools
- Provide support for families where sensory needs are unmet either through training or specialist advice
- Expand the sub-team model within NCHC from September 2022 achievable because of the additional funding received and the recruitment of eight full time clinicians to the team.
- Improve collaborative systemwide response to meeting need during the diagnostic process.
- With the Norfolk and Waveney Transition Network, implement a transition protocol with adult services and improve surveillance and prescribing for ADHD medication

5.0 Any other relevant information from the ICB and service providers

Over the last year the neuro diversity transformation programme has worked with system stakeholders to.

- Publish family friendly information packs in response to the 2020 SEND inspection
- Publish professional friendly information packs to help schools and universal services support and signpost families effectively
- Align the work across Children's and adults commissioning
- Raise the profile of challenges and barriers for our neuro diverse community
- Launch the first all-age stakeholder group for neuro diversity

In March, the neurodiversity lead for the ICB worked with colleagues in the Communications Directorate to coordinate a series of posts for neurodiversity celebration week. By raising the profile both internally and externally, ICB teams hope to engage with all providers and commissioners and highlight the importance of understanding and accommodating neuro diversity.

A helpline for 18-25-year olds launched in June 2022 and through collaboration, the autism training offer, available through the local authority, now includes other neurodiverse conditions

School for Parents is a service for families of children aged 0 – 5 years who have a neuro diversity or exhibit some form of developmental delay. Children attending School for Parents sessions present with a range of needs associated with disturbed, restricted, or limited mobility and motor skills, speech language and communication and sensory processing. Norfolk and Waveney CCG currently funds NANSAs (Norwich) and Little Discoverers (King's Lynn) who provide a child-centred programme of learning and support through weekly sessions delivered by practitioners trained in Conductive Education. Conductive Education is a multi-sensory approach through which children learn and develop new physical, social and communication skills whilst having fun with their peers. Parents develop confidence to continue these activities at home and consistently report progress in positive outcomes for their child. The Children and Young People's team is undertaking a light-touch review of the School for Parents service. The findings of the review will inform future commissioning arrangements.

The quality and duration of sleep experienced by children and young people is variable and vulnerable to many influences. Neurodiverse children and young people may have irregular and disturbed sleeping patterns, associated with their condition, physical mobility, sensory processing or medical interventions or medications. For those with sleep difficulties that persist, the impact upon the health and wellbeing of the child and the family can be significant and pervasive. Sleep Services provide support for families whose children have additional needs and are experiencing ongoing sleep difficulties. Existing sleep routines and behaviours are explored, and families supported to develop a range of effective strategies. The service is effective; few families need to return to the service for further sleep support. NANSAs (Norwich) are commissioned to provide a Sleep Service for children, young people and families. Demand for the Sleep Service continues to rise.

Continued challenges across the system:

- Access to mental health services is not consistent and is affected by a genuine skills gap across the workforce
- Increasing waits to diagnoses impact on school placements which are determined by diagnosis
- Services to support neurodiverse individuals continue to experience overwhelming levels of demand that have worsened because of the pandemic

6.0 Conclusion

Diagnostic waiting times are only part of the story. If children and young people had access to flexible and adaptive services regardless of a diagnosis, demand on assessment pathways would reduce. Parallel to any focus on reducing the waits is the availability of accessible and needs led support services.

The softer bench marking data from other ICB's shows that other areas are facing similar challenges.

The services described in the report help to raise the importance of needs led services in Norfolk and Waveney. Further work is required to develop mental health related services for children and young people and upskill our workforce. This is planned for 2022/23.

The neurodiversity programme remains a key priority for the ICB and local authorities and there is genuine enthusiasm and motivation to maintain the pace of the transformation. The impact for children and young people will not be fully realised for some time, largely owing to the impact of the pandemic but there is confidence that it is achievable. Regional and National scrutiny of provision for those with learning disabilities and autism is increasing and the ICB remains hopeful that this will result in continued additional investment and support for our population.

END.

Appendix one: Health Overview and Scrutiny Panel - Report for 15th July 2021

The commissioners have provided the following information: -

Children's neurodevelopmental disorders – waiting times for assessment and diagnosis.

Presented by:

Cath Byford – Chief Nurse Norfolk and Waveney Clinical Commissioning Group

Rebecca Hulme – Associate Director for Children, Young People and Maternity Services

Dr Richard Allen – Designated Doctor for Safeguarding Norfolk and Waveney Clinical Commissioning Group

Alan Hunter – Head of Children, Young People and Admin Services – Norfolk Community Health and Care Trust

Justine Goodwin - Head of Neonatal, CYP Services, James Paget University Hospital Trust

The purpose of this paper is to;

6. Provide a detailed overview of the different Neuro Developmental Disorders (NDD) pathways across Norfolk and Waveney, including current waiting times and pre-requisites for referral
7. Provide details of the standards / performance indicators that are in place for different elements within each of the various pathways; current performance against those standards (locally and nationally); and information of the impact of the Covid 19 pandemic
8. Provide information of what support and resources are available to families awaiting assessment including any Positive Behaviour Support Programmes (PBSP)
9. Any other relevant information from the CCG and service providers.

Author:

Clare Angell Senior Manager for Children, Young People & Maternity
Norfolk and Waveney Clinical Commissioning Group

2 Introduction

1.1 Overview of clinical pathways

Neuro Developmental Disorders (NDD) covers a range of conditions that tend to share some or all the following characteristics:

- Delay in expected features of development
- Impairments in reciprocal, social and communication skills
- Behavioural issues
- Gaps between attainment and underlying ability

Conditions that are sit within the NDD umbrella include.

- ASD – Autistic Spectrum Disorders
- ADHD – Attention Deficit Hyperactive Disorder
- Communication Disorders e.g., Tourette's
- Dyslexia, Dysgraphia, Dyscalculia
- Sensory Impairments

Clinical pathways to assess children and young people for neurodevelopmental disorders (NDD) are provided across Norfolk and Waveney through two main providers; Norfolk Community Health and Care Trust for Central and West localities and the Newberry Child Development Centre (hosted by James Paget University Hospital) for Great Yarmouth and Waveney. The exception is Thetford, where children registered to GP surgeries will be referred to Suffolk based assessment services.

All providers work towards achieving the 18week referral to start of assessment standard and this includes the ASD assessment pathway.

Services are delivered at clinics, but home/ school appointments may also be offered. In central and West Norfolk, children under six years old must be seen by a Community Paediatrician prior to a referral although in the East (Newberry), the paediatrician is involved in the initial triage discussions

All children need to be referred in using a provider specific referral form. All children must have an accompanying supporting assessment report ideally from either an Educational Psychologist, Specialist Learning Support Teacher (SLST) or Specialist Behaviour Support Teacher (based at one of the Short Stay School's for Norfolk). Reports will usually contain the following.

- Detailed observations of behaviours which are suggestive of underlying neuro-developmental difficulties, to include examples of the child's social communication, interaction, and behaviour during structured and unstructured times.
- Details of the child's expressive language and comprehension ability
- Details of the child's overall level of cognitive functioning and potential in comparison to their peers.

When children and young people are referred to providers, a triage is undertaken to determine whether the individual meets the criteria for assessment. Information about the child is gathered, usually in the form of questionnaires completed by both parents or carers and the child's nursery or school. Education settings will be asked to submit information to describe how the child compares to peers of a similar age and this will include peer to peer relationships and academic achievement.

If the child does meet criteria for assessment, the child and their parents/carers are usually invited to attend a clinic appointment. This is where an initial consultation of the child takes place and a detailed developmental, medical, and family history is taken from parents or carers.

Following this, assuming ongoing assessment is still required, the clinician will arrange the most appropriate assessment. The child may see several professionals throughout the process of their assessment including Paediatricians, Psychologists, Specialist Nurses, Occupational Therapists and Speech and Language Therapists. This is a specialist area of practice and clinicians in the team will usually have undertaken additional training and have extensive expertise in the field.

There is not one clear assessment path for neurodevelopmental conditions; each child's assessment will be based on the clinical assessment of the child's needs at each stage. There are some essential elements though and for both ASD and ADHD, as well as the detailed history, observations of the child are required. For many, this will take the form of an observation in school completed by a member of the Neurodevelopmental Assessment team. This is best practice as it allows clinicians to observe the child in a real-life context and compare it to observations in clinic.

When assessing for ASD, other standardised assessments such as the Autism Diagnostic Observation Schedule 2 (ADOS 2) may also be used but not all children will require this, and the NICE guidelines suggest this may be needed but is not essential. The guidelines are also clear that a diagnosis cannot be made based on a standardised assessment such as an ADOS 2 alone. Other clinic based observational or standardised assessments may be required.

Assessment for neurodevelopmental conditions is complex, to be able to define a condition as 'pervasive,' the team must be able to evidence that it has been present across the lifespan and affects the child across at least two important areas of their life e.g., social, familial, educational and/or occupational settings. Many children who meet criteria for ASD or ADHD may also have co-morbid conditions (additional conditions that occur alongside the primary diagnosis). A key element of the diagnostic process, as stated in the NICE guidelines, is to rule out other 'differential diagnoses,' these include but are not limited to learning disability, developmental coordination disorder, mood disorder, conduct disorder, sensory impairment, selective mutism, and developmental trauma. The assessment process therefore can take longer for children with complex needs who present differently in different contexts or who have evidence of a differential diagnosis or co-morbid condition.

Once assessments are completed, multidisciplinary discussion takes place for each child where all the evidence is reviewed, and the outcome of the assessment is determined. This is then shared with the child or young person (when appropriate) and their family, best practice is that this is completed by a clinician. Full assessment reports are then sent out and the child is discharged from the pathway.

1.2 Demand for assessment:

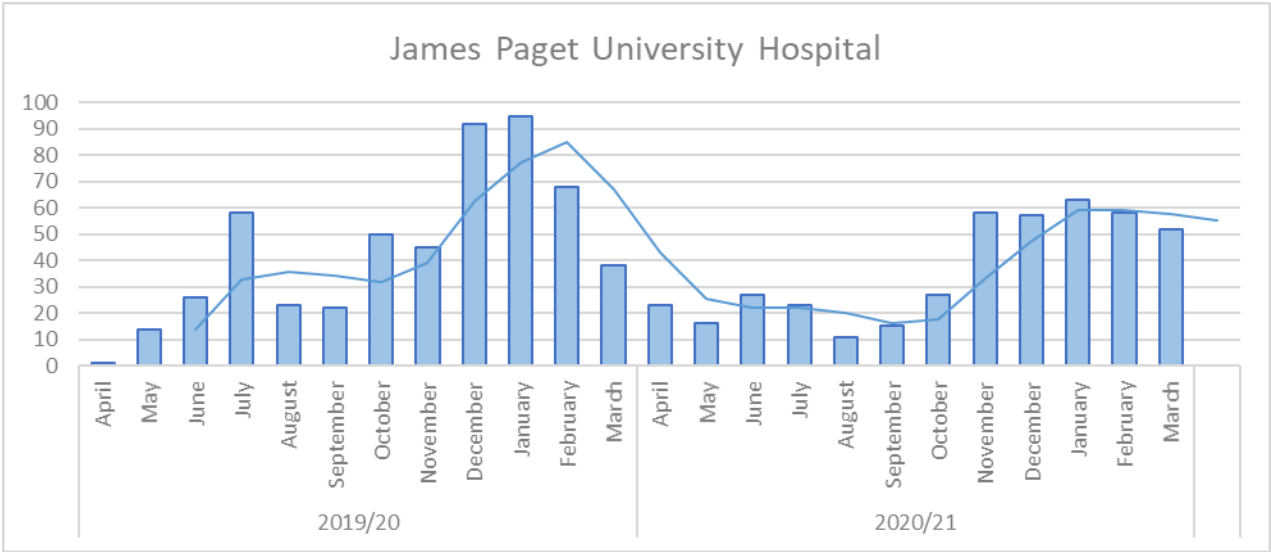
Prior to the Pandemic in March 2020, waiting times for NDD pathways were not consistent. In the East of the county, children would be seen for their first appointment within two weeks and would usually complete the pathway by twenty-nine weeks. By comparison, children referred to NCHC might wait for up to forty-two weeks for their first appointment with pathway completion to diagnoses being more than 104 weeks.

A business case, developed to increase clinical capacity on the pathway, was approved in November 2020 by the Clinical Commissioning Group but unfortunately, funding is not available at this time to implement it.

Members are asked to note that pathway data for NCHC is recorded and shared electronically with the clinical commissioning group but not the James Paget University Hospital.

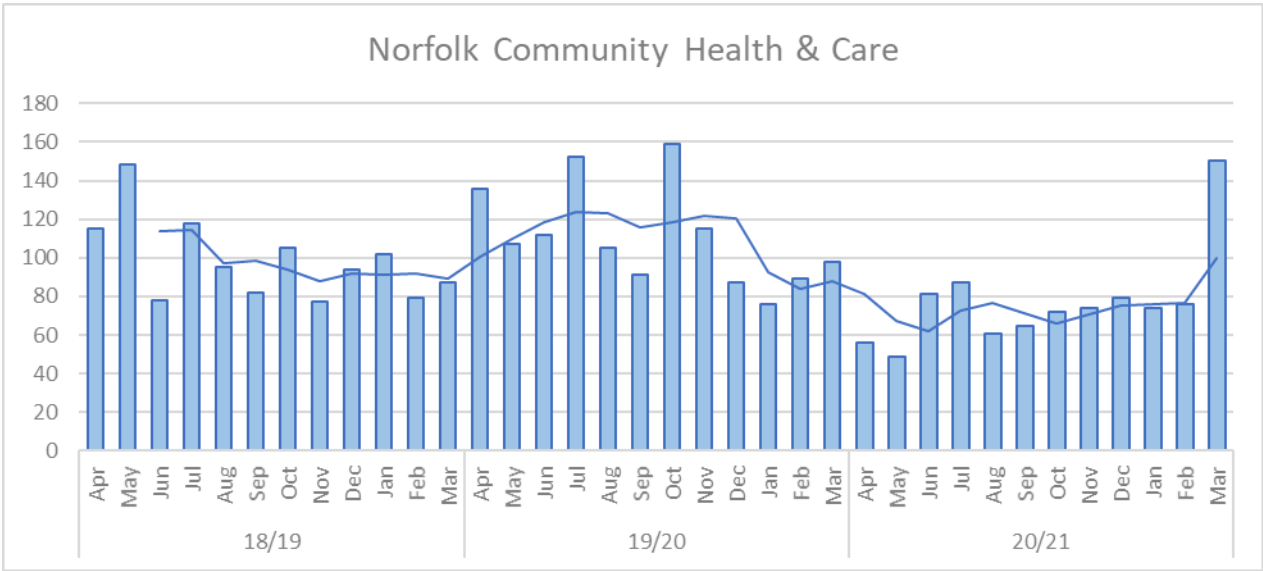
Demand is accepted referrals only with a trend line on each graph is based on a 3-month rolling average. Data is displayed by provider.

Graph 1: Demand for assessments, including comparison between current level and previous years at James Paget University Hospital (JPUH).



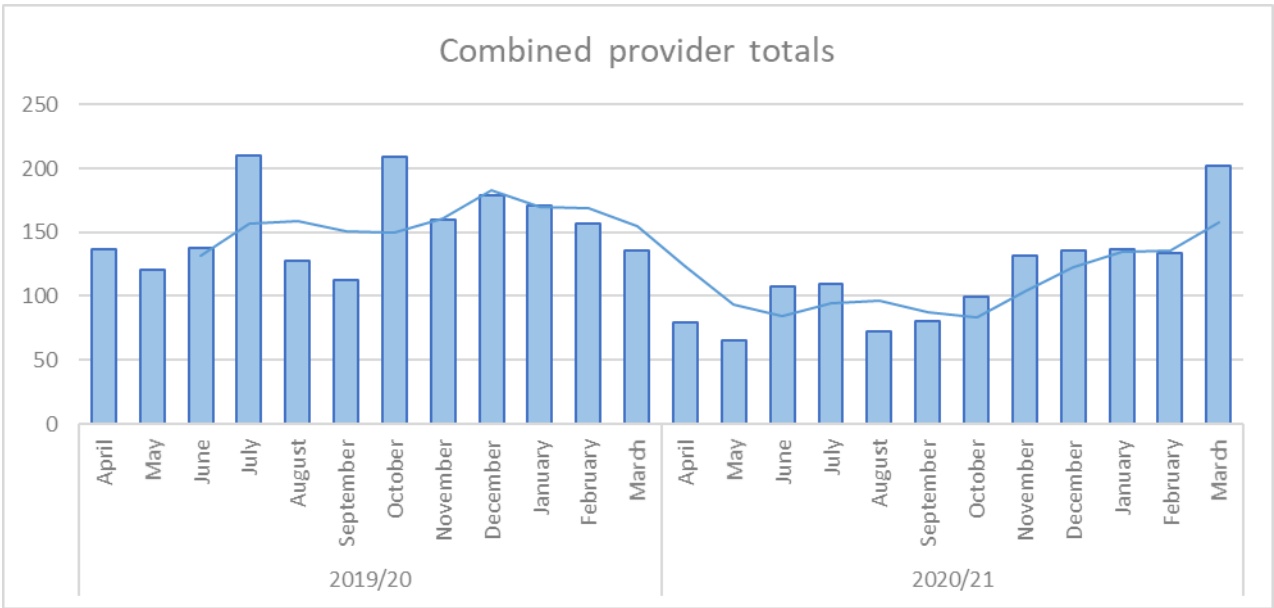
Data for James Paget University Hospital relies on a manual trawl of case records. For this reason, data form 2018/19 could not be submitted. Soft intelligence suggests referrals are increasing.

Graph 2: Demand for assessments, including comparison between current level and previous years at Norfolk Community Health and Care Trust (NCHC).

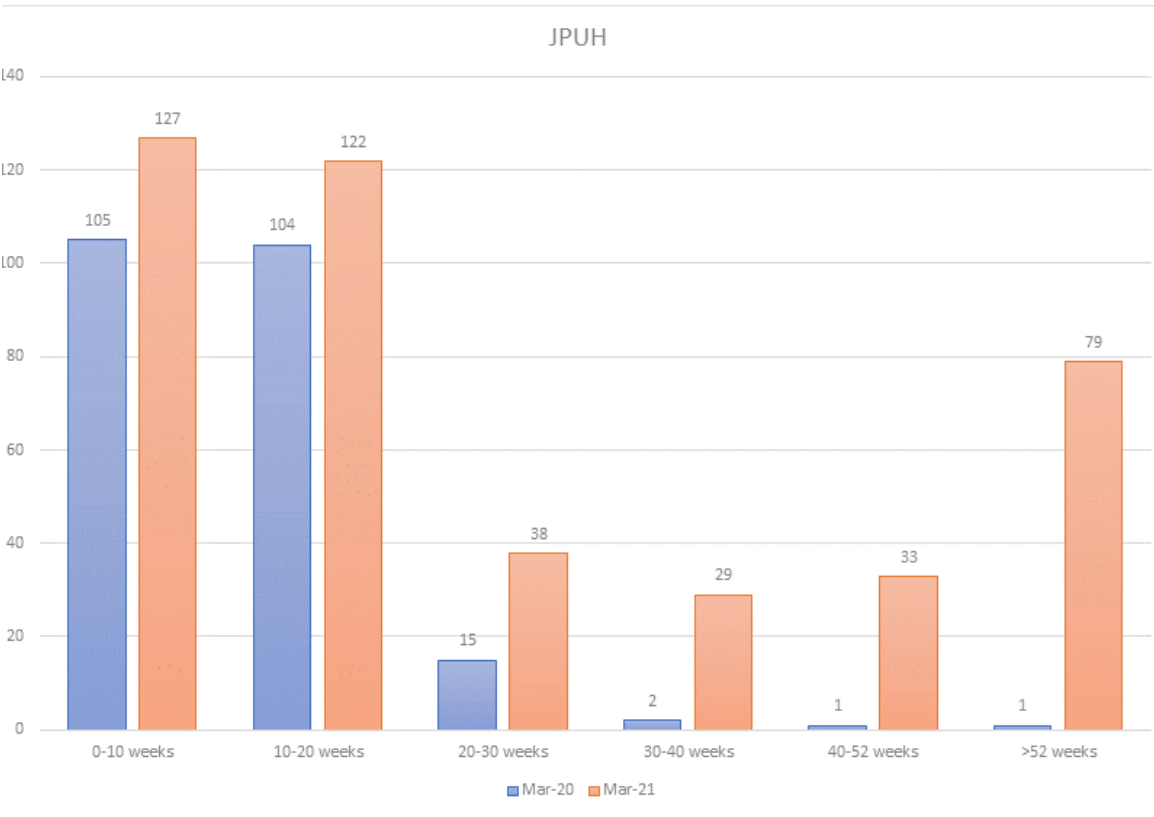


In May 2020 and in response to COVID, the provider observed a significant drop in demand. Social distancing measures and digital capability at that time prevented the clinical team from taking advantage of this. The peaks in demand correlate with schools re-opening to all or most pupils.

Graph 3: System wide view of demand for assessments, including comparison between current level and previous years(both providers).

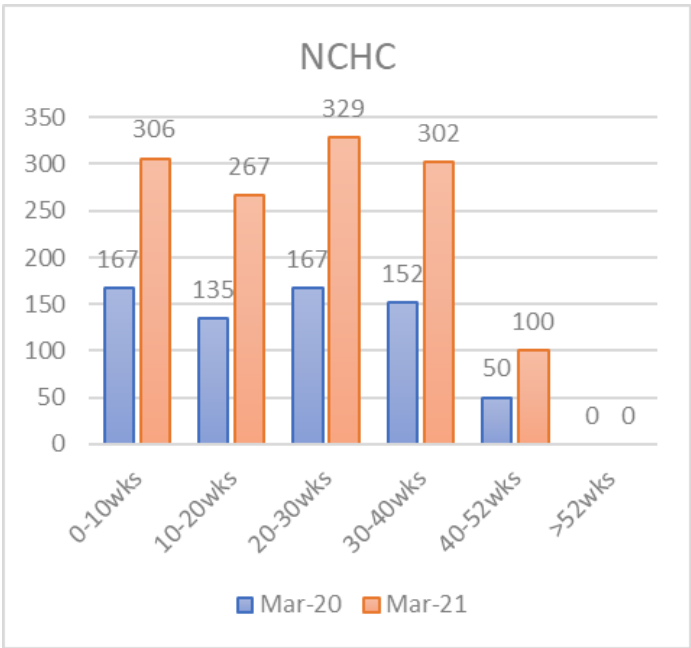


Graph 4: Current incomplete waits for those awaiting start of assessment as of March 2021 compared to March 2020 at James Paget University Hospital (Newberry)



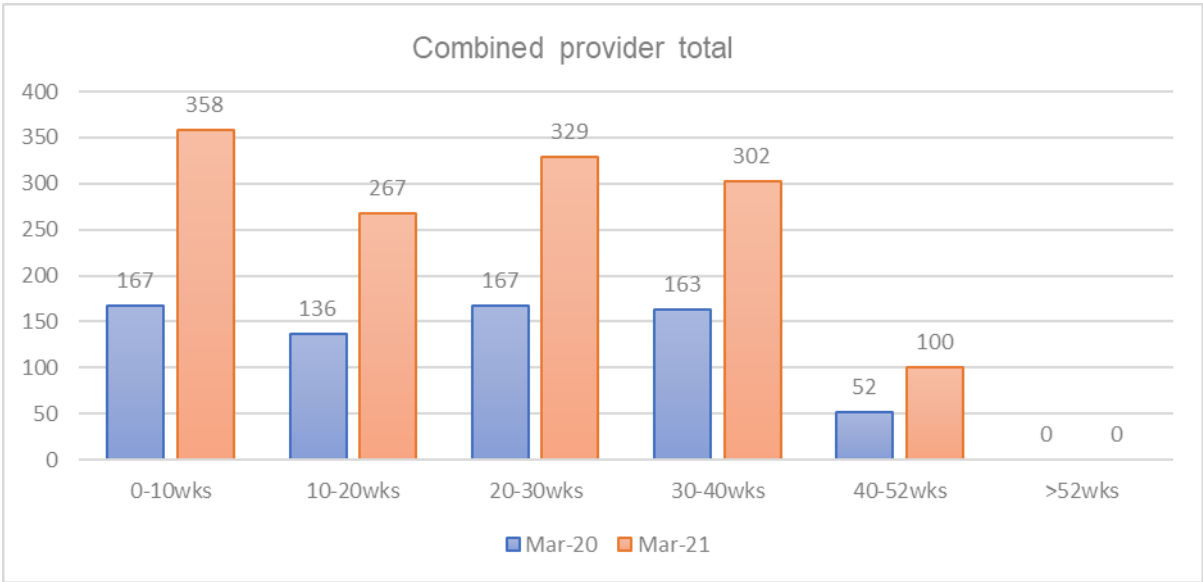
The maximum wait as at 31st March 2020 was 72.6 weeks
The maximum wait as at 31st March 2021 was 91.3 weeks
These waits were due to appointments not being attended.

Graph 5: Current incomplete waits for those awaiting start of assessment as of March 2021 compared to March 2020 at Norfolk Community Health and Care Trust



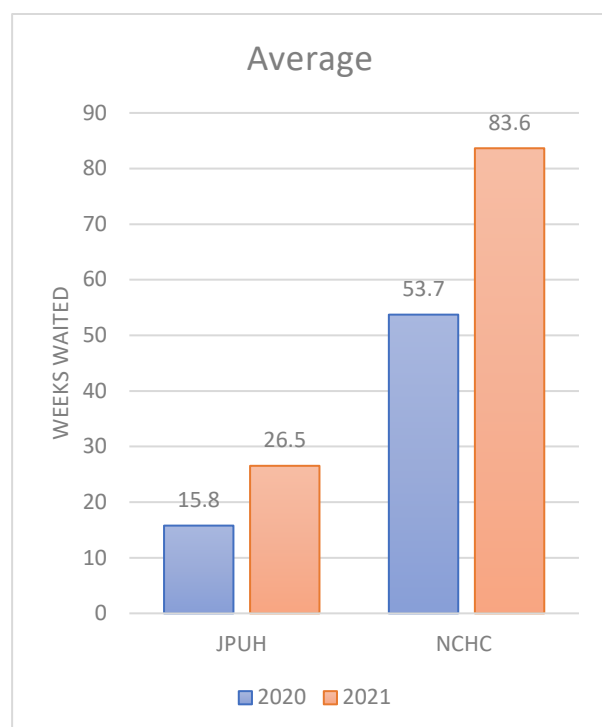
The maximum wait as at 31st March 2020 was 43 weeks
The maximum wait as at 31st March 2021 was 42.3 weeks

Graph 6: System wide incomplete waits for those awaiting start of assessment as of March 2021 compared to March 2020

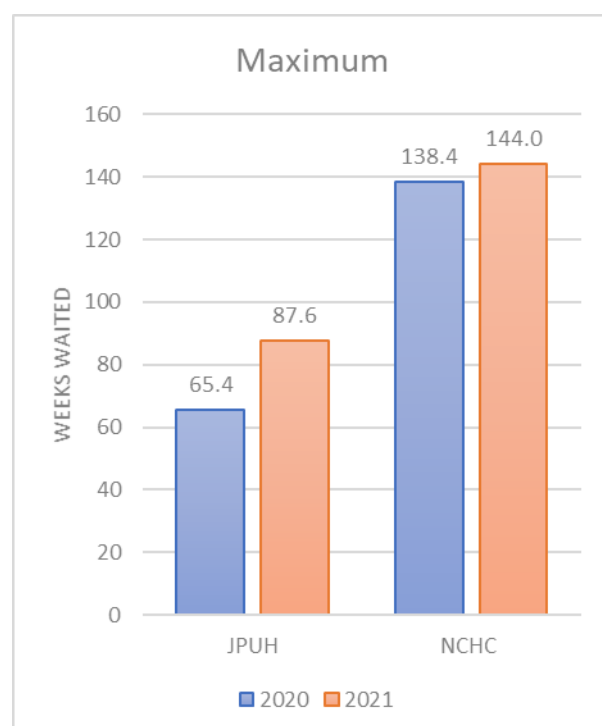


Children waiting between 40-52 weeks will each have or have had a scheduled appointment with the clinical team

Graph 7: Average time from start of Assessment to Discharge based on patients discharged in March '20 and March '21 (both providers)



Graph 8: Maximum waits from start of Assessment to Discharge based on patients discharged in March '20 and March '21 (both providers)



For NCHC, Discharge is usually up to two weeks after diagnosis whereas children attending the Newberry Clinic (JPUH) will be discharged during their 'Feedback' meeting.

1.3 Key Performance Indicators

How we measure the effectiveness of the assessment pathways and the impact for children and families is one of the recommendations of the RETHINK review, commissioned in 2017/18 to review mental health services across the system. During 2020, we attempted to source benchmarking data for Autism and Neuro developmental Disorders across the region and/or other parts of the UK, not currently available from NHS England. Through discussions with commissioners in the East and Southeast of England, we learned that lengthy pathway waits are a shared problem and data collected is inconsistent. There is a national focus to improve consistency of KPI's.

Currently, providers across Norfolk and Waveney report on different key performance indicators which creates a challenge when comparing patient experiences. The Newberry Clinic is still unable to flow data automatically to the Commissioning Support Unit business intelligence teams. Any data collected is reliant on a manual trawl. We are working with system data leads to resolve this.

Norfolk Community Health & Care Trust provide detailed monthly reports to the CCG. This includes,

- Breakdown of the number of children waiting at each stage of the pathway
- Number of patients waiting within 18 weeks
- Number of patients waiting over 18 weeks
- % Patients waiting within 18 Weeks
- Total number of patients waiting
- Total number of patients waiting over 40 weeks

1.4 Impact of COVID19:

COVID19 has impacted all assessment and treatment pathways across Children's and Adult's services. All NHS services are now proactively managing a 'COVID backlog' in referrals which has placed additional pressure on financial planning for 2021/22 and beyond.

1.4.1 NCHC

In March 2020 all face-to-face appointments were suspended. At this point the system observed a reduction in referrals into services. Initial appointments continued as they have always been via telephone. NCHC quickly adopted the Attend Anywhere telehealth system and set up virtual appointments where this was appropriate such as for Early Developmental History and ADHD assessments. Other assessments such as ADOS assessments were put on hold, as these required attendance in person.

During the Summer of 2020 face-to-face appointments resumed albeit in much lower volumes and referrals began to pick up again particularly after the schools returned to education on site. The impact of this was that children and young people whose waiting time had been exacerbated by COVID 19 restrictions became priority cases as things started to "switch back on". This has resulted in increased waiting times for those CYP referred during 2020.

1.4.2 JPUH

At the Newberry clinic, face to face appointments were suspended and staff were redeployed to support front line COVID support activity. Unfortunately, ICT capability restricted the adoption of virtual appointment software. Clinical case reviews for children on the pathway continued and the clinical team who remained in situ used the time to move children forward to 'Feedback' (where applicable). School observations resumed in October 2020 and Doorstep drop-offs for families were arranged to provide additional support.

1.4.3 Service restoration

Children awaiting school observations and ADOS assessments were worst hit through the cessation of face-to-face consultations, PPE requirements and restricted access to education. Additional factors such as managing staff sickness with COVID, remote working capabilities and a growing anxiety in young people and their families has only added to the pressure. In the East, an unexpected consequence of remote GP consultations resulted in a significant increase in referrals with insufficient information, owing to the inability of the GP to meet with the family. This meant that fewer referrals have been rejected and an additional information gathering exercise is required prior to triage by the neuro developmental team.

A further impact of COVID 19 on this demographic is that many more families report a lack of resilience and risk of family breakdown. Services are receiving a growing number of calls from families requesting their child is prioritised for urgent assessment.

1.5 Strategies to reduce waits.

In response to an increase in inappropriate referrals (where the behaviour is not considered to be due to an underlying neuro developmental condition), the Newberry clinic is offering support and expertise in strategies to support the mental wellbeing of children and young people directly affected by COVID19. Families where the child does not meet the criteria for assessment will receive good advice and guidance. The intention is that families receive support and inappropriate re-referrals will be managed more effectively. This should have a positive impact on the waiting times following triage.

Norfolk Community Health and Care Trust NDS teams are adopting new ways of working. They are trialling the efficacy of the QB assessment tool for ADHD which nationally has been shown to be effective at reducing the number of clinic assessments needed for a diagnosis and are looking at how a lead clinician model supports a more positive patient experience. This model allows for a single point of contact for parents and should ensure that caseload management is more effective.

Both locally and nationally, pathway waits for children awaiting NDD assessment is a priority for 2021/22. The government led spending review has created opportunities to apply to national and regional COVID recovery funding schemes, to specifically target waiting time backlogs for NDD pathways. Immediate work for commissioners includes submitting bids for national funding and progressing the business case that was approved in 2020 but remains unfunded. It is a critical aspect of service improvement and is highly likely to be a feature of the next Norfolk SEND inspection.

2.0 Support and resources available to families awaiting assessment:

In April 2020, the Clinical Commissioning Group formally commissioned a pilot support service for children and families awaiting assessment on NDD pathways. Family Action are the provider of this service. Due to the volume of young people on the NCHC pathway, those families who had received their first appointment, but would experience long waits before the next step in the pathway, were the focus of referrals. The number of families identified was 1400.

Families and professionals can request support. Each family is contacted by phone where the support worker will look at the needs of the whole family and suggest options for support. This might include 1-1 interventions, peer group workshops and meetings, social networking opportunities and signposting to other agencies such as SENDIASS to support school discussions.

The pandemic forced the support service to operate virtually throughout the twelve-month period but the impact on families was reflected in quarterly reporting to the CCG.

By Q2 of 2020/21, Family Action had contacted over 627 families.

Feedback from parents, carers and families was as follows;

- 84.4% feel more confident as a parent.
- 90.9% feel better able to support their child.
- 87.5% have a better understanding of the assessment pathway.
- 100% were able to access the information and support they needed.
- 100% know where to go for help in the future.

Family Action also worked with Cambridge Community Services and Psychologists for the Starfish + team to develop online positive behaviour videos for parents with helpful strategies to use at home. This was an innovative and swift response to the cessation of face-to-face group work and was well received.

This contract has now been extended for a further three years, following a light touch procurement exercise.

3.0 Any other relevant information from the CCG and service providers:

From February 2020, the NDD transformation programme formally commenced following a restructure and merger of the CCGs across Norfolk. In March 2020, a stakeholder group was established to assist with co-designing and implementing the recommendations of the RETHINK review (2018) and work began to review the communication and information needs of families before, during and after referral. This has resulted in the development of information packs for parents and professionals which will be available across all provider websites and the local offer. These are due to be completed in June 2021.

Throughout 2020, commissioners attended school SENCO forums to inform professionals about the NDD pathway and transformation work and explain why the needs of children should be met regardless of a diagnosis. Feedback by SENCOs was particularly positive.

We continue to finalise work developing consistent service specifications across system and increasing support for families. This includes commissioning sleep support services across Norfolk and Waveney and developing video resources for young people. The CYPM team also diverted NHSE funding targeting respite support for children and young people with Learning Disability and/or Autism through Norfolk Community Foundation. This is having a positive impact for voluntary and community organisations supporting families.

NDD now sits within the Norfolk Joint Commissioning Framework and a new post holder will start in September to align the work across Children and Adults commissioning. In the meantime, a task and finish group has been set up to start mapping how support with neuro-divergent conditions needs to be more consistent for all ages. This was a recommendation from the RETHINK report.

The national government spending review has resulted in opportunities to apply for funding, either on a regional fair share basis or through individual bidding exercises. We have already submitted two applications for consideration. We expect to be informed of the outcome by the end of July 2021.

3.1 System Challenges

One of the challenges for children and families across the education system is myths around school funding decisions based on diagnoses. Regardless of any forthcoming diagnosis, the needs of that child will remain the same. The collective goal for health and education is to shift towards a needs-

led system; a strategy supported by senior local authority colleagues. While it is important to reduce waiting times to diagnosis, we must ensure that children have the best chance of thriving in education while they are assessed for neurodevelopmental conditions.

When children develop needs and require appropriate support which costs a mainstream education setting over £6,000 per annum, schools can apply to Norfolk County Council for High Needs funding. Despite this, families continue to report challenges with receiving additional support for their child during the school day.

Additionally, there is a skills gap across the workforce. Teachers, health, and care workers do not have access to the range of training required to build confidence and competencies when teaching and supporting children with neuro developmental disorders. This leads to a greater emphasis on referral to assessment, in the hope that a medical diagnosis will lead to a package of support for the family.

Providers often highlighted the challenges with how the NDD commissioned pathways interact with Mental health services. Joint care planning is not standard practice and many children with Autism are unable to access the type of mental health support they need. The two system wide redesign programmes in place should resolve this, but the scale of change is significant and will require involvement from all sectors.

Neuro developmental services are experiencing overwhelming levels of demand that have worsened as a result of the pandemic. Achieving a diagnosis is important for children and families but pathway waits should not determine how soon children and families receive support. From the point of referral, if not before, professionals supporting children and parents can access resources to ensure the needs of that child and family are met. There is strong engagement by stakeholders but the shift to a needs-led system will take time. This does not negate the need to improve pathway waits and patient experience, but a co-ordinated health and care system would allow services and support to be in place while families await an outcome.

4.0 What families will want you to know:

A representative from the Children, Young People and Maternity services team was invited to meet with parents and ensure their voices were heard in this report. The experiences of families reflect the system challenges outlined above yet the report may not adequately describe the adverse impact on families. Some of the rich feedback received is quoted below.

“Mental health is not a consequence of Autism” This was spoken by a parent of two children who have both received a diagnosis from NHS NDS teams. Her son, through access to private therapy funded by his parents, is now able to describe the challenges he faced as a young child. He was face blind which affected his confidence and as a result of bullying during his primary years, he experienced early trauma. Without access to mental health services and therapeutic intervention, he would not be able to adequately describe the trauma and receive the support to manage it.

“We have to do everything ourselves”. Child X received a private diagnosis funded by his parents but to date that diagnosis has not been ratified. A draft Education, Health and Care Plan is now in place, because mum has fought for it. Mum has also experienced two mental health breakdowns due to the lack of support for her child and family, and the guilt associated with not giving equal care to her other child.

Parents also described how their children were not referred for help because of funding issues with sourcing assessments from Educational Psychologists and how referrals were ‘blocked’ as the presenting needs were not observed in school, and therefore not considered necessary.

Across education, we need to assure ourselves that funding isn’t a barrier to health services. For commissioners across health and care, we need to do much more with our post diagnostic offer;

families report feeling abandoned with no access to specialist advice about how best to support their child.

END.



Family Voice Norfolk update on parent carers' experience of the Neurodevelopmental Diagnostic Service

for Norfolk County Council Health Overview Scrutiny Committee

14 July 2022

Consultation

Parent carers of children and young people with special educational needs and/or disabilities (SEND) were consulted via an online survey in June 2022. They were asked to consider their experience of the Neurodevelopmental Diagnostic Service (NDS) during the previous 12 months to update survey results that Family Voice Norfolk presented to the HOSC of 15 July 2021.

Background

Family Voice Norfolk is a collective of parent carers from 1230 families across Norfolk, representing almost 1600 children and young people with SEND. Family Voice Norfolk is the strategic voice of parent carers, working in partnership with Norfolk County Council (NCC), the Norfolk and Waveney Clinical Commissioning Group (NWCCG) and voluntary organisations since 2006. It is funded by a direct grant from the Department for Education, by NCC and by the NWCCG.

Parent carers were invited to complete an online survey to give their experiences of accessing the pathways and services supporting diagnosis of neurodevelopmental conditions, such as autistic spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD).

Family Voice Norfolk received 56 responses to the survey, a third of the responses received to the 2021 survey. Reasons for this may be:

- a) 'survey fatigue' from an intense period of weekly surveys on other topics just before this one;
- b) a sense among some parents that their views are powerless to improve a system so fraught with difficulty and delay;
- c) a sense among some parents that the situation is improving in some ways – if not in the length of time on the diagnostic pathway then at least in the quality of communication with the NDS. Of course, without their responses, we cannot know if this is the reason.

What did the 2022 survey tell us?

In some ways the information parent carers gave was all too familiar, but there were changes in emphasis and some aspects that had a clearer focus than in 2021. There are seven key points that emerge from the 2022 survey responses. These are listed below and detailed more fully in the next section. Finally, narrative information from parent carers given in open text boxes in the survey is included as appendices. These give a powerful sense of the effects of the current system on individuals and their families.

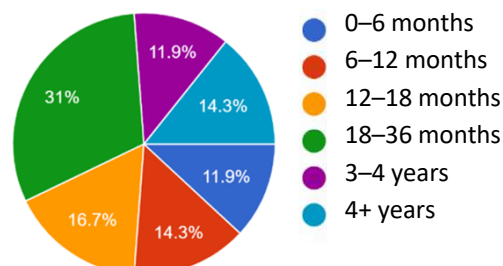
Key issues raised are:

1. LONG WAITING TIMES
2. CONCERN ABOUT YOUNG PEOPLE'S WELLBEING
3. CONCERN ABOUT TRANSITIONS AND EDUCATION
4. PARENTS FEEL DISEMPOWERED AND WHOLE FAMILIES ARE AFFECTED
5. COMMUNICATION AND SUPPORT HAS IMPROVED BUT IS STILL A SOURCE OF ANXIETY FOR FAMILIES
6. DELAYS ON THE DIAGNOSIS PATHWAY AFFECT DISADVANTAGED FAMILIES DISPROPORTIONATELY
7. LACK OF ACCURATE INFORMATION INCREASES STRESS AND LEADS TO FURTHER DELAYS

Key findings

1. LONG WAITING TIMES

It is not possible to compare all statistics from last year's survey, but the length of wait is still parent carers' biggest concern. Our respondents included those who have only just begun their journey towards diagnosis, but nevertheless 26% of our respondents had been waiting over 3 years with almost 12% over 4 years. Those already on the pathway are anxious that there are still years ahead without a diagnosis and many are critical of the information they have been given about this.



How long has your child or young person been on the NDD Pathway?

It is not surprising that when asked how they would rate their experience of the Neurodevelopmental Service overall, parent carers' response was resoundingly negative. On a scale of 1–5, where 1 is Poor and 5 is Good, no one at all replied with a 4 or a 5.

Asked whether the Neurodevelopmental Service and NDD Pathway had been explained by a health professional, 76% of respondents said 'No' compared with 62.4% in 2021.

There are in fact two pathways – pre-6 years and post-6 years – but 62% of respondents did not know which pathway their child was on. This compares to 36.7% of respondents in 2021.

For both of these questions, results were significantly poorer than shown in our survey in 2021.

The long wait for support basically destroyed my child's education

to make parents of pre school children feel like they have to sit at home and wait for years for explanations and understandings is cruel

My child wont have completed their NDD until 16...and they wonder why so many young children suffer with mental health. We all want answers so we can educate ourselves and grow as a family.

2. CONCERN ABOUT YOUNG PEOPLE'S WELLBEING

We know that the pandemic has negatively impacted the mental health of children and young people. Those on the NDD pathway have an additional stress. Parent carers tell us that their child is anxious to understand themselves better and that diagnosis is part of this. As children get older their sense of being 'different' from their peers increases. It is upsetting for parents to have to tell children who are already anxious that 'one day' they will know more about why they feel as they do – but not when that 'one day' is.

My child is anxious that they will not get their diagnosis and often asks what will happen if they don't get officially diagnosed. It's causing them anxiety.

High anxiety for child.

Its affected my child's mental health a lot as they don't understand why they feel so different from peers and I have no explanation as no diagnosis yet.

3. CONCERN ABOUT TRANSITIONS AND EDUCATION

Respondents showed a particular concern about diagnosis not being available in time to facilitate transition from one educational setting to another or to access an appropriate school. In addition, although they know that schools can support without a diagnosis, neurodivergent conditions are themselves diverse and parents are concerned that provision cannot be properly targeted without a clear understanding of their child's condition.

My child is due to start school and a diagnosis is important as it needs to be in their EHCP

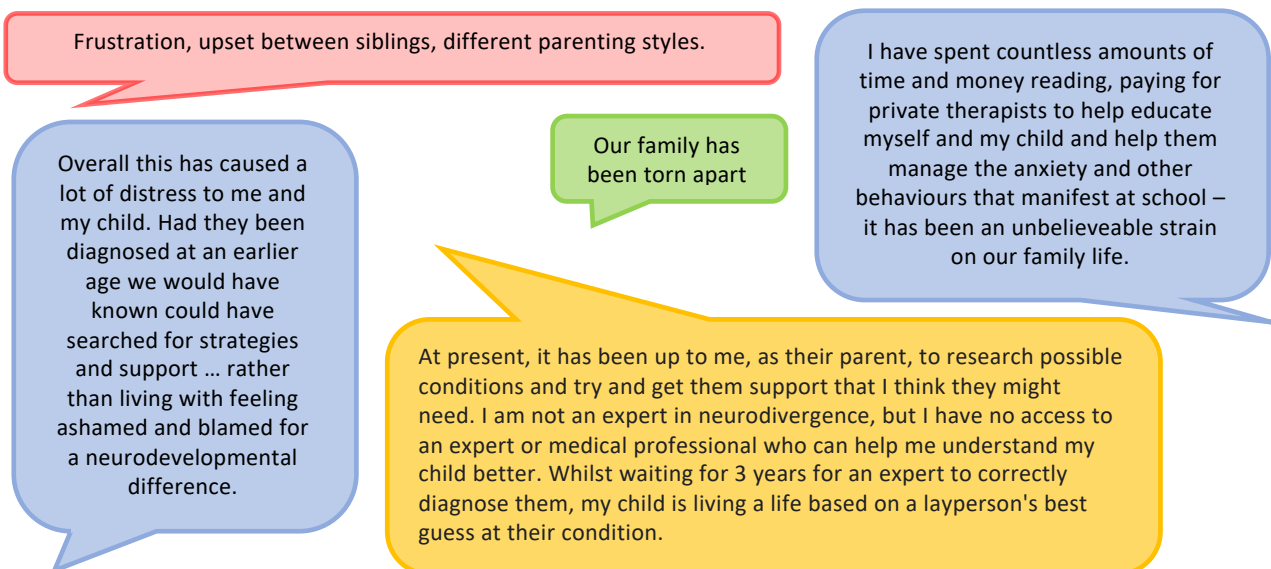
School had advised us at the beginning that our child needed this in place to help them move onto college or education after high school. At this rate they will have left school before assessment is finished.

School currently supportive, but we are aware specialist placement may be needed soon, which is difficult without diagnosis.

Ok for now but high school is coming and we need a diagnosis

4. PARENTS FEEL DISEMPOWERED AND WHOLE FAMILIES ARE AFFECTED

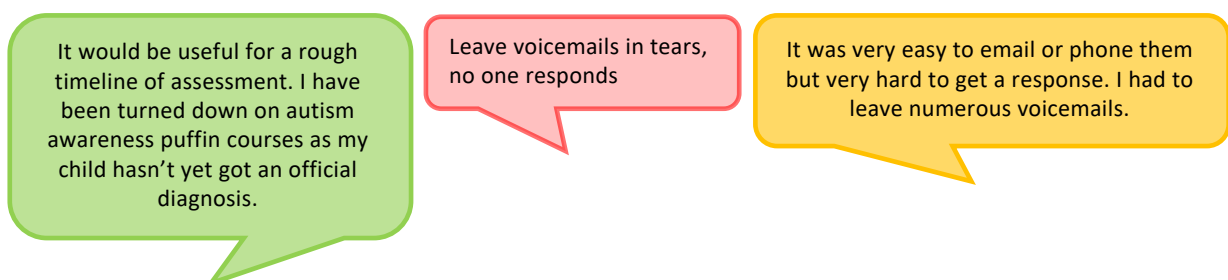
Throughout the survey, parents are strongly focused on the needs of their child who is awaiting diagnosis. Fear for them and the effect that delays are having are paramount. However, in passing they mention significant impacts on themselves and on other members of the family. Among the impacts are parents having to give up work, other siblings being affected, and the whole family feeling uncertainty about whether what they are trying to do for the child awaiting diagnosis is helpful. Parents feel guilt and desperation about not being able to access what their child needs.



5. COMMUNICATION AND SUPPORT HAS IMPROVED BUT IS STILL A SOURCE OF ANXIETY FOR FAMILIES

Communication with families whose children are on the pathway appears to be very varied. Some have had sufficient contact from the Neurodevelopmental Service and have found ways of getting in touch with NDS when they need to, while others have had no or unhelpful contact. The same is true of contact with organisations such as Family Action. NDS appears to use a variety of means – email, face-to-face meeting, phone calls and letters – to contact families, which is good to see.

When asked if they had been offered or given any help and/or advice while waiting on the NDD Pathway, almost 63% of parents said they had, which is an improvement on the 'almost half' of parents who said this in 2021, but the recent figure is still less than two-thirds and leaves a significant proportion who feel that they have received no help or support at all.



Appendix A gives more information about parents' experiences of attempting to contact NDS.

6. DELAYS ON THE DIAGNOSIS PATHWAY AFFECT DISADVANTAGED FAMILIES DISPROPORTIONATELY

The current system led 81.5% of all the parents who responded to consider seeking private diagnosis. Those who could afford it had gone ahead and achieved a much speedier resolution. But many could not afford it. Financial status should not be a barrier to diagnosis. Some parents spend time and resources researching conditions that their child *might* be diagnosed with, in order to be able to advocate for them more effectively in the meantime. It is parents with sufficient time, capacity and ability who can undertake research and educate themselves. Those who are not able to do this – and their children – are also potentially disadvantaged.

Lots of advice says that early intervention is best but it took months to even get to the referral stage. We have since gone private to get our child's diagnosis.

I can't think of anything more soul destroying than having a solution one cannot afford! As a parent this is beyond cruel.

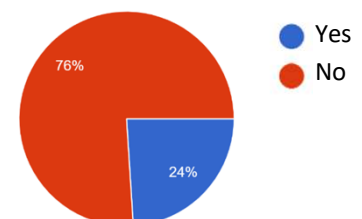
Expected to wait another 6 months on top of the already 3 years. Long waits make us want to get bank loan to help fund our child's needs for better health service and in turn future.

7. LACK OF ACCURATE INFORMATION INCREASES STRESS AND LEADS TO FURTHER DELAYS

This begins at the very start of seeking a diagnosis. In answer to the question, 'Is it clear to you what supporting information is needed for a referral to NDS?' 80% of respondents said 'No'. Information is in fact available on the SEND Local Offer website and in other places, but parents who are already worried and looking for support because their child is displaying signs of needing additional help, should not have to become experts in systems to access that help. Both GPs and schools need to be able to give parents clear and accurate information about what is involved in a referral. To parents it feels as if responsibility is passed backwards and forwards, causing further delays. Families need a sense of professionals working together for the benefit of their child. Difficulties in contact, the involvement of unconnected professionals, and the delays of the pathway itself all communicate to parents that no one cares about their child. This is profoundly worrying for parents who now have questions about the life their child will be able to live in the future and how to prepare for it.

The personnel dealing with our referral changed and it is difficult to keep up with the different services and their representatives because there are so many agencies that are

Pre diagnosis support for families is needed and this service (seemingly supplied by family action) should be integrated with NDS. More cross working between NDS, CAMHS, point one and JustOne emotional/behavioural support is needed, these services do not seem to interact with each other.



Has the Neurodevelopmental Service (NDS) and Neurodevelopmental Disorder Pathway (NDD) been explained to you by a health professional?

Appendix A

Parent carer responses to the request:

Tell us more about how easy it was to contact the NDS team.

Note: these responses have been anonymised by removing names and other identifying details. Nothing has been added to the responses and the writer's message has always been preserved.

Never answer the phone but answer emails

Leave voicemails in tears, no one responds

Never any answer on the phone lines and a long wait for an email response and even then the response was very vague.

Very difficult to speak with someone

I have generally been able to speak to someone on the phone - if I ring early or later in the afternoon.

I spent two years just raising my concerns and try to get help from a health professional, finally the health visitor referred my child for assessment, 7 months later they got an assessment with a health practitioner and 3 months later their referral was accepted since then its been 5 months and we've heard nothing, we don't know what happens next.

I used Email and contacted via mobile numbers

I rang the number on the letter but nobody answered

I contacted them about the correct procedure to refer my child for sleep issues. I was told the GP had to do it, but not that I also had to contact an organisation that dealt with sleep issues to even get them referred by the GP. This was later discovered by a member of the charity, Family Action so contacted them on my behalf.

The communication has been very poor and there has been miscommunication too. I've chased on several occasions. My child has numerous reports which they said they could use and have had a school assessment done about 2 months ago but still no further forward. We already have an ASD diagnosis. The only contact I have had in the last 12 months plus has been after I've contacted them.

Email is the best way of getting a reply. However they will not give details of progress on waiting times when I ask.

I have a named contact

Not helpful and get told different info

I have emailed.

My child's referral was rejected for being too young (you are born with neurodevelopmental disorders so how is it possible to be too young?) - instead of waiting I got a Private diagnosis at the cost of £100 and it got ratified by the NDS 6 months after they received it. If they can't even say they agree with a clinician's report within 6 months there is no hope for anyone getting seen and diagnosed within a reasonable time. They clearly rejected my child's referral to save their own waiting times.

No one ever answers and it can be weeks before a call back and in some cases just a letter is sent.

The personnel dealing with our referral changed and it is difficult to keep up with the different services and their representatives because there are so many agencies that are involved with our child's education and welfare.

Process took so long that fell behind more at school

It was very easy to email or phone them but very hard to get a response. I had to leave numerous voicemails.

Repeatedly contacted to inform of incidents, exclusions, school refusal, mental health, sleep Child was diagnosed with ADHD on almost the information we shared above and beyond the questionnaires and video call

Struggled to ever get the right support for my child who is 23 years of age no one wants to help them because they have always slipped through every net. They have mixed neuro developmental delays hearing loss, and other issues and their learning difficulties are always borderline meaning they never fitted any criteria. As a family we have all suffered and our faith of trusting professionals is nil as other than GP they have all let them and us down. I know I'm not alone but to get the right help for them would be good, wellbeing isn't specialised in their needs and getting referrals to a psychiatrist is not impossible.

I emailed NDS on 04/04/2022, heard nothing so rang and left numerous messages, I finally spoke to someone on 19 April, I then emailed again on 05/05/2022 with a complaint, I received an email on 12/5/2022 saying my complaint had been forwarded to the complaints team - to date (11/06/2022) I have still heard NOTHING - compiling a complaint letter to my MP today - my child has been waiting 3 YEARS for diagnosis

I actually emailed the other day to ensure they'd received everything. They had but I was told not to expect to hear from them for up to 40 weeks! And that's just for the initial information. Assessment is a 3 year wait. Per the email I received.

Appendix B

Parent carer responses to the request:

How has time waiting on the NDD Pathway affected your child or young person, their family and/or their place of learning?

Note: these responses have been anonymised by removing names and other identifying details. Nothing has been added to the responses and the writer's message has always been preserved.

My child has not had to wait. Their needs for their dyslexia are met by their school. Their school are fantastic.

More at school

My child wont have completed their NDD until 16...and they wonder why so many young children suffer with mental health. We all want answers so we can educate ourselves and grow as a family.

Paid for a private diagnosis of ASC to get an EHCP and get a place in a special school. Struggling to get anywhere else though as most other professionals want to wait for ADHD diagnosis to be done by NDS before doing anything else. Child is making no progress at school and cannot afford private diagnosis of ADHD. Behaviour is very challenging and deteriorating and child is very depressed but need NDS to diagnose before CAMHS will intervene.

Can't get support

I have no idea how they can justify their wait times. My child was in year 1 when we applied, they are now year 6. Their last assessment was last October which we got the report from two weeks ago. I wish I had gone private years ago but I do not know who to trust privately. I have had enough now, there is no communication, no support, I have no idea what they are doing. I have not been able to access support from multiple channels as we have no diagnosis.

My child has been passed from teacher to teacher with no real consistency or help.

Child is unable to attend school due to high level of need and does distance learning from home provided by the school. Awaiting ehcp to decide how best to proceed.

Stressful, families need to move the process forward

Affected their ehcp reviews as there has been delays in their diagnosis thus affecting the support they are entitled to.

Ok for now but high school is coming and we need a diagnosis to get them into an autism specific school (already has an EHCP)

My child is anxious that they will not get their diagnosis and often asks what will happen if they don't get officially diagnosed. It's causing them anxiety.

We home educate and are able to differentiate learning experiences to meet the individual needs of our child. It is extremely frustrating to have been waiting three and a half years with minimal communication from the neurodevelopmental service.

Not knowing exactly where their struggles come from have meant both myself and school have to guess at how best to help and support my child.

I didn't know 90% of people with Autism have sensory disorder... for this reason these people don't offer support in this area. So besides a 3 year wait for space, more doors to go through and dealing with the here and now. It's a nightmare. Why can't these things just get done and all be under one umbrella. My child is really trying to hold it together in school, they are what I have learnt the 'fizz pop' affect and I explained this to them in one of their melt downs, so they could stop feeling so guilty. They hold it in all day (if they make school), hates school, even the paper and pencil make them feel funny and this is just the start. Any change and they can't cope with it! Also talking about it they struggle to get their words out, explodes, needs one to one but then Senco isn't supportive and assume they are fine. So when they see me they then explode and the circle starts again. Luckily there are the odd staff member who are really caring, don't shout (my child hates shouting and certain tones of voice) I have them an ILP and a review this week but what leg do I have to stand on with no professional assessment or diagnosis. I am not a professional and I am knackered. I don't have all the answers. My child has always struggled but I never knew about ADHD, Autism etc Until Covid lockdown... then it all made sense but I am still stuck and so is my child and our family. There is only so much one can do, fight for and mentally cope with. These pathways are the key to our future generations with SEN and the waiting times are not good enough, damaging.

This is a rereferral as after 6yrs under a paediatrician they discharged my child. I asked for them to be referred again a year ago as the older they've gotten the more their difficulties are evident. They are 16 and very worried about the future after leaving school.

They have deteriorated a lot. Been in 4 different schools. On medication for sleep issues. Needed social services involvement Police involved Mental health team involvement Lost friends and family members due to severity of their needs

We have had no correspondence for almost a year. Over the last three years they have had part 1 of the assessment twice and then it hasn't gone any further even though I'm told it will! It was very difficult to find appropriate strategies for managing my child's behaviour without a diagnosis. Also we had no support at school for their additional needs.

It is effecting their learning, they are working several years behind

Negatively

High anxiety for child. School currently supportive, but we are aware specialist placement may be needed soon, which is difficult without diagnosis. As a family we are supporting this child as we already have 1 autistic child, and are knowledgeable about the best ways to support our children individually

Worsening of behaviour

They were expelled for behaviour arising from ADHD while waiting for medication.

My child's school now say they can't meet their needs and nowhere else has places and also on wait for CASHMS

In addition to the time on the pathway we spent 4 years trying to get accepted onto the pathway. It has been very distressing not to be able to tell people the cause of my child's difficulties. I have repeatedly been blamed for my child's behaviour. I am now at the stage that my child needs to have an explanation of why they have the difficulties that they have. It is a difficult journey to navigate dealing with distressed behaviour and difficulties at school when you don't know the cause. Overall this has caused a lot of distress to me and my child. Had they been diagnosed at an earlier age we would have known and could have searched for strategies and support at a much earlier stage rather than living with feeling ashamed and blamed for a neurodevelopmental difference.

They are becoming more distressed because as they are getting older they are noticing that and will regularly say they are not the same as other people and people/ peers don't understand them. They are becoming more withdrawn and emotional. The masking strategies they used when younger are no longer working which is adding to their anxiety.

Not received the correct support required for my young person to thrive

My child is STILL out of school nearly 18 months after their needs were unable to be met by their school. My partner and I have had to take off time from work to support them and speak to professionals and those we have had contact with have been overwhelmed and sometimes unhelpful. We have struggled as a family with little regard from the services that we have been put in contact with.

Frustration, upset between siblings, different parenting styles.

Learning as within weeks of medication they moved on but over 3 years is disappointing as now my child has to catch up so it's frustrating you know your child and when I knew there was something delaying treatment causing more problems

Thankfully I have been supported by their nursery I'm also a Social Worker by profession so I felt confident in self-referring them for an EHCP and it was accepted this has helped a great deal

We have felt 'stuck'. Lots of advice says that early intervention is best but it took months to even get to the referral stage. We have since gone private to get our child's diagnosis.

Our family has been torn apart, one child become a young carer, another not been in school for nearly a whole school year come September, that's just the start of it, partner unable to work so financially struggling badly one wage pressure on me, damage to property, multiple school exclusion, injuries

Its affected my child's mental health a lot as they don't understand why they feel so different from peers and I have no explanation as no diagnosis as yet.

Had to remove from mainstream and home ed.loss of self esteem.loss of self understanding

Very worried and let down

I have spent countless amounts of time and money reading, paying for private therapists to help educate myself and my child and help them manage the anxiety and other behaviours that manifest at school- it has been an unbelievable strain on our family life (their sibling is ASD/ADHD and SPD took just under 3 years to diagnose pre COVID). Despite school accepting they are SEN every year we have the same struggles with the new teacher NOT understanding their needs. They are a VERY bright child but struggles with attention, impulsivity and anxiety and the teachers tell them off for not concentrating, for their hand writing, etc which then impacts on their sense of worth (they have HUGE rejection sensitivity dysmorphia) and has self harmed because of the pressure school puts on them (been through all the NHS point one referrals etc which were so long or useless that we have seen private therapists)....my marriage has been pushed to breaking point, both my husband and I are on antidepressants ...and if I hear one more time from the school " they don't show any signs of anxiety at school, they just need to buckle down!!!!!!!!!!!!!!one more time it may be the straw that broke the camels back. My child goes to High school in September and i am desperately worried about that HUGE step but NDS dont seem to care, all I need is confirmation they are ADHD so that I then have a diagnosed "stick" to wave at schools to get them to listen to me, as them just being on the SEN register is NOT enough

Horrendous. No diagnosis - absolutely no support. More battles. More judgement. More ignorance. Currently battling for an EHCP.

Appendix C

Parent carer responses to the question:

Where has help and/or advice come from while you have been waiting on the NDS Pathway?

Note: these responses have been anonymised by removing names and other identifying details. Nothing has been added to the responses and the writer's message has always been preserved.

No due to my child having ASD already no one helps

Nothing from GP, School, Senco etc All been my own research!

I had to find it myself. I have received two useless and patronising leaflets from NDS in the last 12 months.

Just one Norfolk

Family action emails have been good for advice however I have been unable to make any coffee morning etc due to work commitments.

Norfolk Community nurse was able to offer advice on services to contact

Family Action/ children centre

Family action

Leaflets with referral letters

We have a lot of experience of asd and adhd in our family so we haven't needed to ask for support.

Family Action

Only through support groups etc but they are not the answer, just a plaster that keeps falling off.

Leaflets and a phonecall.

NDS.CAHMS.ISS.school.Action for children. Suppose groups.Social media.

Family voice, support groups

Family Action, ASD Helping Hands

I think when we got a letter telling us the wait was approximately 3 years we got a list of contacts.

Family action - who sent us some links to resources (including suggesting looking into PDA for our youngest, which we agreed is a likely profile for them, and had already been putting in place PDA strategies such as using declarative language and lowering demands) all of which we knew about

anyway. We have had no support apart from that - to be honest, it feels pointless asking for anything as we have already accessed most things they can point to us.

GP and school

Asd helping hands, family action. Newbold hope, bild - it took me 4 years to accidentally find my way to these services.

In the way of offering advice I mean I was sent a sheet with a list of phone numbers and websites on. We were referred to family action over 4 years ago and were told that at that time they wasn't much else they could help us with and that my child needed to be assessed by NDD, because of this i didn't bother contacting them again.

Family voices, Point One, ASD helping hands. All remotely or by post and not in a useable form of support.

School

Nursery, complex case nurse, salt, sen coordinator at school where my child will start reception in September.

Family action in first year

Swaffam family action, was advised in letter to call then which I did they have been amazing support.

GP

GP, school but have to push for it all the time, private dyslexia testing

We were sent some charity links.

Appendix D

Parent carer responses to the question:

Have you ever considered a private diagnosis route?

Note: these responses have been anonymised by removing names and other identifying details. Nothing has been added to the responses and the writer's message has always been preserved.

My child has been screened for dyslexia and received what they need through their mainstream school. They do not need a Neuro Developmental Service.

Can't afford private

I cant think of anything more soul destroying than having a solution one can not afford! As a parent this is beyond cruel. The waiting time should not be so long in the first place, nor should my childs needs have been missed throughout their education settings all this time! The professionals are to blame in these settings. If it wasn't for my research during 1st lockdown my child would not have what little understanding and support I am able to give them now but there is years and years of their life that they haven't had any support or understanding (due to my lack of knowledge.. I had never even heard of Extreme social anxiety / Autism or ADHD) and it has effected them, our family, their education and probably done more harm to their mental health than if this would of been picked up in their schools etc (You need a de code book for all the abbreviations used.) What is NDS .. for example.

Have got a private diagnosis of ASC but cannot afford private ADHD diagnosis and ongoing support.

Can't afford it and no where nearby

I would love to have a meeting with you guys as I need advise what to do :)

I can't afford it.

I have considered private diagnosis due to length of wait just being referred and then wait within the service and child's level of need/ being unable to attend school. Currently awaiting ehcp outcome to decide on next steps to take to support my child.

Current finances will not allow this

I have so far been waiting for an appointment for 3.5 years.

We have been on the NHS list for 3.5 years. After this long we are determined to stick it out. We have no doubt that our child is Autistic and also has ADHD and have considered a private assessment, but the cost is prohibiting.

After 3 years on the waiting list and my child significantly struggling. I decided to go private as I felt we wouldn't wait another year or 2 as they would be going to secondary school. I wanted to make sure as much was in place before then.

Again (I have done one of these for my child) Offering the answer for your child with something you can not afford is soul destroying and wrong. I also need a de code.. what is NDS?

Unfortunately we had moved from another county to Norfolk and both rely on school reports these haven't always supported the child so considered going private but can't afford that option at the moment and have to be careful where I go because some people I know so could be classed as conflict of interest.

I can't afford it though

Expected to wait another 6 months on top of the already 3 years. Long waits make us want to get bank loan to help fund our child's needs for better health service and in turn future

Because of the horrendous waiting times in Norfolk. But too expensive and we hear private diagnoses are often not accepted by publicly funded agencies (NHS,, LA etc)

We paid around £400 for a private diagnosis for sensory processing disorder as this is not available on the NHS in Norfolk. This was taken into account when they were diagnosed with ASD.

We did consider going private and got so far as to speaking to a doctor but unfortunately I was diagnosed with a serious illness so put it on hold.

Expensive

Ended up going private and NDS referral was rejected due to lack of evidence from school We looked into it, but are already going to be paying for sensory integration therapy and don't think we can stretch to a private diagnosis too!

We have sort additional help via the Adoption Support Fund

We had to get the assessment done privately.

Ccg will pay for private adhd assessment if wait is more than 18 weeks but because so many parents have done this there is now a massive wait to go private

I have now booked private assessment which I am paying for with my childs DLA money which it took me years to realise they were entitled to. It has taken 7 years in total of waiting for me to reach this point. I have made this decision due to increasing difficulties at school and complete lack of support from school in terms of waiting over 18 months for educational psychologist and still counting.

I have explained above how after my child's referral was rejected instead of waiting for a new referral then being on NDS waiting list for up to 3 years I went and got my own diagnoses for my child who is severely autistic

We have bumped around the system for years now. I first asked NSFT to consider whether my child had autism in 2015 . That seemed to get lost in their systems literally, when they changed over to a new operating system or Lorrezzo. (my child and I did subject access requests to try and understand what was recorded and happening) Since then I raised my concern several times with health professionals and schools /college . My child was referred to Children's NDD pathway unfortunately only a few weeks before their 18th birthday . All seemed to minimise my concern . My child believes they have Asperger's . (they are not bothered by the history behind the name re the Nazi connection) I looked into a private diagnosis but it was very expensive and impossible for me to fund it and at the same time my child's education (they are above average IQ) has suffered greatly and I have not received any extra funding that would have come with a diagnosis.

Couldn't afford it!

Both my children have private reports and they were referred and accepted by the paediatric consultant team.

We went privately in January as the wait was almost years!

Have considered a private diagnosis due to the 18month to 2 years plus waiting list, however costs are too high.

It is overwhelming and eye watering expensive.

Going round in circles no one gets back to me. Being ignored, was told 18 weeks from letter which was a year ago. Private is so expensive.

Thought about it but can not afford it

We have gone private and this has been ratified by the NDS. This was for my mental health and well-being as I was so worried about not knowing how to support my child.

Only reason can't afford it as one wage due to not being in school and price

If we could afford it I would have gone down the private route , we was refused twice the 3rd time accepted so it feels like it's been going on such a long time and I feel private may have been a lot quicker.

But can't afford it.

Beyond financial means but would have if had money

We have been told it's not possible to have a private NDD assessment and the wait is 3 yrs
Can't afford the £2500 for private right now. But it will certainly be an option after Christmas.

Appendix E

Parent carer responses to the question:

Is there anything else you would like to tell us of the Neurodevelopmental Service in the past 12 months?

Note: these responses have been anonymised by removing names and other identifying details. Nothing has been added to the responses and the writer's message has always been preserved.

I think this survey may need to be headed differently NDD covers a lot of conditions and not all if these require a medical diagnostic route. Lots of children will have a neuro-developmental disorder but will not health expertise as their main barriers will arise in accessing education.

Its a phone call with then a waiting list of about 3 years and an email for other doors to try and get your answers/ help/ support...

I emailed them and told them I had been really patient but that My child will be drawing their pension before they diagnosed them. The email back with an apology saying we were on the list for assessment and it would be done ASAP. I have been a busy mum/work last few years but I am now on the case. I am currently studying level 2 Certificate in Understanding Autism. I have learned a lot so far. I am looking at places to get private help but do not know which places are trusted. We have had out EHCP approved and is with the commity for finance. I am now applying for DLA (40 page form!) as access card / CEA / blue badge / etc do not take us seriously without DLA, we have not needed to apply for it so didn't. I also thought we could not apply until diagnosis. The kids with ASD are being failed by the NHS. They should have 18 months max to help diagnose these children with drop in centres and people to explain in plain english what is going on. All the acronyms and terms are a nightmare. They are also putting all the kids a one bucket. None of us these children receive blood tests to look at levels and variations. I only last week found about AFRID. a food/eating disorder. This has never been mentioned by NHS yet they were accessed to ensure nothing physically stopped them eating. I feel the NHS have really let us down, without a diagnosis how do you know what to action in order to best help. I could rant on all day! We are lucky and have a great school. x

I have no idea when to expect the next stage of my child's referral. They have 2 years left of primary school. They missed nearly 2 years of learning due to no understanding of their needs in school then 2 years up and down due to covid. I am highly concerned for their education. They are very bright and can become obsessed with certain subject but struggles with their reading writing, spelling and concentration.

They clearly need more staff!

We are 18 months into the expected 3 year wait for diagnoses. In the meantime, it feels like I have had to diagnose my child with ASD in order to get them into the school they need to be in. This is absurd. Perhaps they don't have ASD or maybe they have additional disorders which are not being addressed? They are currently failing in their current school as it cannot support them. Perhaps if they had been assessed by an expert in the NDS, we would fully understand

their condition and be able to meet their needs. At present, it has been up to me, as their parent, to research possible conditions and try and get them support that I think they might need. I am not an expert in neurodivergence, but I have no access to an expert or medical professional who can help me understand my child better. Whilst waiting for 3 years for an expert to correctly diagnose them, my child is living a life based on a layperson's best guess at their condition. Three years is a huge proportion of their childhood and I have to wonder, is my child getting the support they really need? I do not know, because their condition has not been fully assessed and diagnosed. Therefore their needs cannot be fully met until we fully understand what their needs are. My child is being failed and I see the impact that this is having on them every day. They are not thriving or even meeting their potential and until we get a diagnoses I am unsure how their needs can be truly met.

Having had very little contact from the NDS over the past few years, we wrote to our local MP about the state of the service in this area. The MP then contacted the NDS. I then received a phone call from [a senior person who] offered lots of apologies and excuses. They said that the current waiting time until discharge from the service was at that time (Feb 2022) 3 years and 6 months. They also said that although they couldn't say exactly when our child would reach the 'top of the waiting list', they would be quite concerned if it wasn't at some point this year. They then wrote to our local MP saying that they had personally spoken to me about my child's case. I haven't heard another word from them since that call in February. They provide a very poor service.

It would be really useful if parents were given a realistic time scale for waiting times. More support in place whilst we are waiting (I had one call from family voice - lady I spoke to was lovely, but ongoing support would have been nice). *[NB Family Voice does not offer support or advice. The writer may have been thinking of Family Action.]*

Sort the waiting times out. From the phone call there should be an appointment to get things going. Not more plasters!

I think its ridiculous the pathway and the criteria for it we've been waiting a year since moved back to norfolk. Just because a school doesn't see traits or they do but communicate different it's crazy and the fact my child's crisis team worker and the eating disorder team trying to liase with them I call it a "ping pong ball effect"

Wait is too long. Very disappointed with the lack of service. I feel I as a parent have made most of the contact to get answers. Complained to CCG regarding the poor service. No face to face help./Support

No, we are still waiting to be called for an assessment.

My child is due to start school and a diagnosis is important as it needs to be in their EHCP

I'm still waiting for my child's referral (4 years)

Pre diagnosis support for families is needed and this service (seemingly supplied by family action) should be integrated with NDS. More cross working between NDS, CAMHS, point one and JustOne emotional/behavioural support is needed, these services do not seem to interact with each other. In general where a family is dealing with emotional/behavioural difficulties integrated support including mental health support and support for parents/siblings (as needed) is needed. Right now these services are fragmented and very hard to access. Unfortunately in Norfolk we are used to services being rubbish and just accept the situation but this should not be the case.

It took intervention from West Norfolk NAS to get my child on the NDS diagnostic pathway in 2018. They were finally diagnosed with ASD earlier this year.

Absolute shambles

I think it's disappointing that if the school report doesn't show anything the referral is rejected, many children like my child mask extremely well at school and these children are slipping through on that basis, we recently went private and received a diagnosis of Autism and PDA. The wait and lack of contact is awful. Any contact we have had has been purely down to me repeatedly emailing, but they have failed to answer questions about waiting times. Emails take on average a week to be replied to, which is frustrating. There is no point in ringing I have found as no one ever answers the phone. Apart from being sent the questionnaires at the beginning of the process we have had nothing else from them. We are fortunate that my child was added to the pathway when under 6, so is still on the pre-6 list as apparently that is a bit shorter a waiting time, but at almost 2 years with 0 meaningful contact, no phonecalls or emails to see how we are as a family, no further contact from the community paediatrician who initially put in the referral or anything else, we are becoming very disillusioned with the entire process, and feel that we have been left to struggle by ourselves. I have been left to find my own support groups and resources (Newbold Hope has been the most helpful and I would recommend that that was added to resources suggested to families while they're left waiting for years!!), pay for my own learning/training and support for my children. Right now I have very little to say about the NDS that is even slightly positive.

Covid probably hasn't helped the service but we have had very little contact from them

The long wait for support basically destroyed my child's education.

There needs to be change newspaper article needs to shame the service and highlight the failings

We decided to stop seeing a paediatrician when my child was around 9 years of age. This was due to my being convinced that there was abuse of power, untrained staff and poor use of restraint going on. This was not in Norfolk where we now live. However we suffer from national issues.

I am sure that they are very good at what they do (I wouldn't know as I haven't seen them) it is a typical case of under funding to meet the demand and lack of training of the number of appropriate professionals to complete assessments

The NDS in our county is a complete and utter failure. They are failing children. Children who don't get diagnosed young struggle to get their children an appropriate education - how can the EHCP outline a child's needs if they don't have a diagnoses? How can early intervention be applied if you don't have a diagnoses? How can families expect to live their lives and meet their childrens needs without a diagnoses? Imagine If your child had Down's syndrome but you had to spend the first 6 years knocking on doors trying to get a diagnoses? You had no language or OT or physio - or way to explain your child to doctors and friends and school - because you had no diagnoses. The system is honestly a disgrace - if they are underfunded and have unacceptable waiting lists they should just say that - to make parents of pre school children feel like they have to sit at home and wait for years for explanations and understandings is cruel.

Most recently I phoned them in desperation . They got back to me withing a few days . They have been helpful but the previous information I had ie within the last twelve months had been confusing especially around how to achieve a priority assessment The Gp and college were also really unhelpful. My childs education and health and Wellbeing has deteriorated and our relationship has too The lack of knowledge and understanding of ASC is very concerning especially amounts they VSCE wider so called support services eg For parent carers of young adults /adolescents . To many people still saying " we're all have some autistic traits ". And or "they may have some but I don't think it is Autism " " they look me in the eye so I don't think they have " (SenCo) They didn't look the SenCo in the eye and she only met them for about 15 minutes ! They present well (for a short time but really struggled with their executive functioning. They are then judged negatively without a diagnosis.

Just wish they would finish my child's assessments that they started in January/February 2020 when they came to the top of the waiting list and not blame the pandemic as to why they haven't been seen since! Surely if they were being assessed then, they should have been one of the first to continue with their assessments once things got going again. Your not telling me that over the whole pandemic no consultations or assessments were carried out!!

There is a severe lack of communication from the NDS during referral. It feels like you are just left to wait without any reassurance or communication that things are being done.

Worst service I have ever experienced

It would be useful for a rough timeline of assessment. I have been turned down on autism awareness puffin courses as my child hasn't got an official diagnosis

My child has been let down massively throughout the entire process...

My child was referred to the NDS in November 2021 by a paediatrician. I heard nothing from the referral and eventually contacted them in March 2022 to query whether the referral had

been accepted. I was told that due to an 'oversight' my child wasn't even on the list and the referral had been misplaced. At this point I gave up and pursued a private diagnosis which was completed within four weeks.

Feel sorry for the lovely ladies that answer the phone they are so nice but constantly delivering bad news. Have put complaint in in the pa

The system is broken. Far too difficult to get help for clearly struggling young people. Was told no longer than 3 years in system took nearly 5 years to get a diagnosis. Shockingly bad form start to finish

Like everything it's a fight. After years of pushing my child was moved to the 'special' class in high school who quickly said they would like them to have an NDD referral for autistic tendencies. They referred them Oct 2021, school got an appointment for Dec 2021 but this was cancelled due to NDD team staff sickness. School got another appointment for late Jan 2022, they expected this to be an assessment but it turned out just to be a phone call from NDD telling them they are not accepting referrals from schools due to the backlog caused by Covid. We lost 3 months waiting for them to tell us that, not good enough!!!! School advised us to go to our GP as GP referrals cant be ignored, we did this straight away and we got a letter in March 2022 telling us our child joined the waiting list on 09.03.22 and to expect the process to take 3 years. School had advised us at the beginning that our child needed this in place to help them move onto college or education after high school. At this rate they will have left school before assessment is finished. I understand how hard all our professionals, medical and education have worked during covid but this back log is not acceptable. Extra staff need to be employed to meet the needs of our young people. Struggling all their school career and repeatedly being let down by the system has already taken a great toll on our child.

It needs better communication with families, check in with parents, updates on progress etc.

Norfolk Health Overview and Scrutiny Committee

Proposed Forward Work Programme 2022

ACTION REQUIRED

Members are asked to consider the current forward work programme:-

- whether there are topics to be added or deleted, postponed or brought forward;
- to agree the agenda items, briefing items and dates below.

NOTE: These items are provisional only. The OSC reserves the right to reschedule this draft timetable.

<i>Meeting dates</i>	<i>Main agenda items</i>	<i>Notes</i>
14 July 2022	<p><u>Children's neurodevelopmental disorders -waiting times for assessment & diagnosis</u> – follow up to 15 July 2021 NHOSC</p> <p><u>Annual physical health checks for people with learning disabilities, Looked After Children and people with severe mental illness</u> – to examine progress.</p>	
8 Sept 2022	<p><u>Health and care for adults with learning disabilities / autism</u> - local health and social care partners' joint action following the recommendations of the Cawston Park Hospital Safeguarding Adults Review.</p> <p><u>Norfolk and Suffolk NHS Foundation Trust</u> – action plan for improvement</p>	

Information to be provided in the NHOSC Briefing 2022

- Aug 2022
- **Cawston Park Hospital Safeguarding Adults Review** – update from Norfolk Safeguarding Adults Board on action underway to address the recommendations.
 - **Overview of people's health in Norfolk** – annual update from Norfolk County Council Public Health

- **Menopause services** – A broad overview of available services, how these are accessed, and the agencies that are involved. An outline of how services are advertised or communicated to residents, and available data on service uptake.

Date TBC (Feb 23?) - **Prisoner healthcare services** -update on recovery of services from the pandemic.

NHOSC Committee Members have a formal link with the following local healthcare commissioners and providers:-

Norfolk and Waveney CCG	- Chair of NHOSC (substitute Vice Chair of NHOSC)
Queen Elizabeth Hospital, King's Lynn NHS Foundation Trust	- Julian Kirk (substitute Alexandra Kemp)
Norfolk and Suffolk NHS Foundation Trust (mental health trust)	- Brenda Jones (substitute Lucy Shires)
Norfolk and Norwich University Hospitals NHS Foundation Trust	- Dr Nigel Legg
James Paget University Hospitals NHS Foundation Trust	- Daniel Candon
Norfolk Community Health and Care NHS Trust	- Emma Spagnola



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