



Norfolk County Council

Norfolk Health Overview and Scrutiny Committee

Date: **Thursday 15 July 2021**

Time: **10.00am**

Venue: **Council Chamber, County Hall**

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, Tim Shaw (contact details below) by **no later than 5.00pm on Monday 12 July 2021**. 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 Michael Chenery
of Horsburgh

Cllr Barry Duffin

Cllr Brenda Jones

Cllr Alexandra Kemp

Cllr Robert Kybird

Cllr Nigel Legg

Cllr Cate Oliver

Cllr Richard Price

SUBSTITUTE MEMBER

Vacancy

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

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

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

Cllr Emma Corlett
Cllr Anthony Bubb

Cllr Helen Crane

Cllr David Bills

Cllr Adam Giles

Cllr Carl Annison / Cllr Michael
Dalby / Cllr Chris Dawson /

REPRESENTING

Great Yarmouth Borough
Council

Norfolk County Council

Norfolk County Council

Norfolk County Council

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

Breckland District Council

South Norfolk District Council

Norwich City Council

Norfolk County Council

Cllr Sue Prutton Cllr Robert Savage	Cllr Lana Hemsall / Cllr Jane James / Cllr Julian Kirk Cllr Peter Bulman Cllr Carl Annison / Cllr Michael Dalby / Cllr Chris Dawson / Cllr Lana Hemsall / Cllr Jane James / Cllr Julian Kirk	Broadland District Council Norfolk County Council
Cllr Lucy Shires Cllr Emma Spagnola Cllr Alison Thomas	Cllr Tim Adams Cllr Adam Varley Cllr Carl Annison / Cllr Michael Dalby / Cllr Chris Dawson / Cllr Lana Hemsall / Cllr Jane James / Cllr Julian Kirk	Norfolk County Council North Norfolk District Council Norfolk County Council
CO-OPTED MEMBER (non voting) Cllr Colin Hedgley	CO-OPTED SUBSTITUTE MEMBER (non voting) <i>TBC</i>	REPRESENTING Suffolk Health Scrutiny Committee Suffolk Health Scrutiny Committee
Cllr Keith Robinson	<i>TBC</i>	

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

Tim Shaw on 01603 222948
or email committees@norfolk.gov.uk

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It will be live streamed on YouTube and, in view of Covid-19 guidelines, we would encourage members of the public to watch remotely by clicking on the following link:

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Councillors and Officers attending the meeting will be taking a lateral flow test in advance. They will also be required to wear face masks when they are moving around the room but may remove them once seated. We would like to request that anyone attending the meeting does the same to help make the event safe for all those attending. Information about symptom-free testing is available [here](#).

A g e n d a

1. Election of Chairman

The Chairman to be elected from the Norfolk County Councillors on the Committee.

2. Election of Vice-Chairman

The Vice-Chairman to be elected from the Norfolk district councillors on the Committee.

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

4. Minutes

To confirm the minutes of the meeting of the Norfolk Health Overview and Scrutiny Committee held on 18 March 2021.

(Page 5)

5. 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.

6. **To receive any items of business which the Chair decides should be considered as a matter of urgency**
7. **Chair's announcements**
8. **10:10 – Cancer services** (Page 11)
11:10
9. **11:10 – Access to local NHS services for patients with** (Page 47)
12:10 sensory impairments

12:10 – BREAK
12:20
10. **12:20 – Children's neurodevelopmental disorders – waiting** (Page 110)
13:20 times for assessment and diagnosis
11. **13:20 – Norfolk Health Overview and Scrutiny Committee** (Page 172)
13:25 appointments
12. **13:25 – Forward work programme** (Page 174)
13:30
- Glossary of Terms and Abbreviations** (Page 177)

Tom McCabe
Head of Paid Service

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NORFOLK HEALTH OVERVIEW AND SCRUTINY COMMITTEE
Minutes of the meeting held on Microsoft Teams (virtual meeting)
at 10am on 18 March 2021

Members Present:

Cllr Penny Carpenter (Chair)	Norfolk County Council
Cllr Nigel Legg (Vice-Chair)	South Norfolk District Council
Cllr Michael Chenery of Horsburgh	Norfolk County Council
Cllr David Harrison	Norfolk County Council
Cllr Brenda Jones	Norfolk County Council
Cllr Chris Jones	Norfolk County Council
Cllr Alexandra Kemp	Borough Council of King's Lynn and West Norfolk
Cllr Robert Kybird	Breckland District Council
Cllr Laura McCartney-Gray	Norwich City Council
Cllr Richard Price	Norfolk County Council
Cllr Sue Prutton	Broadland District Council
Cllr Sheila Young	Norfolk County Council

Substitute Members Present:

Cllr Wendy Fredericks for Cllr Emma Spagnola North Norfolk District Council

Also Present:

Hollie Adams	Committee Officer, Norfolk County Council
Cath Byford	Chief Nurse, Norfolk and Waveney Clinical Commissioning Group (CCG)
Anna Morgan	Director of Workforce, Norfolk and Waveney Health and Care Partnership
Maureen Orr	Democratic Support and Scrutiny Team Manager, Norfolk County Council
Caroline Shaw	Chief Executive, Queen Elizabeth Hospital NHS Foundation Trust
Dr Frankie Swords	Medical Director, Queen Elizabeth Hospital NHS Foundation Trust
Emma Wakelin	Head of Workforce Transformation, Norfolk and Waveney Health and Care Partnership

1. Apologies for Absence

- 1.1 Apologies were received from Cllr Emma Flaxman-Taylor, Cllr Keith Robinson and Cllr Emma Spagnola (Cllr Wendy Fredericks substituting). Cllr Fabian Eagle and Cllr Judy Cloke were also absent.

2. Minutes

- 2.1 The minutes of the meeting on 4 February 2021 were agreed as an accurate record.

3. Declarations of Interest

- 3.1 Cllr Alexandra Kemp declared an "other" interest as she had been working with the NHS to help set up a system to help care leavers find work in the NHS.

4. Urgent Business

- 4.1 There were no items of urgent business.

5. Chair's Announcements

- 5.1 The Chair acknowledged that the meeting was being held at a time of great pressure for the NHS, during the pandemic, and thanked representatives who were present at the meeting. One item had been postponed due to pressures on commissioners and would be rescheduled for later in the year.

6. The Queen Elizabeth Hospital NHS Foundation Trust

- 6.1.1 The Committee received the report examining the Queen Elizabeth Hospital NHS Foundation Trust's (QEH) progress following the Care Quality Commission (CQC) full inspection in 2019 and the hospital's last report to the Norfolk Health Overview and Scrutiny Committee in February 2020.

- 6.1.2 The Chief Executive, Queen Elizabeth Hospital NHS Foundation Trust, introduced the report:

- Staff survey results placed the QEH as the twelfth most improved Trust in the country for every key indicator.
- A clear strategy had been approved for the hospital around quality, engagement and healthy lives.
- The Trust had set up and were running two vaccination hubs, one on the hospital site and one in Downham Market.
- A key stakeholder review and medical staff engagement review had been carried out with positive feedback.
- There had been improvements in the operational performance for ambulance offloads and this was on course to achieve the target by March 2021.

- 6.2.1 The following points were discussed and noted:

- The Chief Executive, Queen Elizabeth Hospital NHS Foundation Trust, updated the Committee about the issues with the roof; because of this, 71 props had been placed throughout the hospital. A positive meeting had been held with the Health Minister and money would be awarded through the STP to help with stabilisation of the roof and decamp patients into other ward areas. In the 2021 spending review there would be a push to for the QEH to be included in the 8 hospitals to receive funding for a new build or partial new build.
- Members praised the Trust on the improvements they had made since the last report.
- Work on the nurse training centre had begun and was on track. The Trust was working closely with the local college and work was underway to link the centre to a university to accredit the training.
- Overall recruitment at the hospital was good with a low vacancy rate among nurses and nurse assistants. There was recruitment drive for more midwives, and an international recruitment campaign had been carried out.
- The inclusivity of recruitment was queried; QEH representatives reported that work was being done to attract candidates from all backgrounds, including a piece of work being carried out to value equality and diversity.
- There was a legacy programme offering staff the opportunity to remain in the NHS in a more advisory role at a later stage in their career.
- Coordination across the 12 hospitals affected by the Reinforced Autoclaved Aerated Concrete (RAAC) planks was queried. The Chief Executive, Queen Elizabeth Hospital NHS Foundation Trust, reported that a network was in place between the 12 hospitals to review which were most at need of replenishing their planks. There

was funding for only 8 hospitals at that time, and it was noted that the QEH was at a greater need regarding this issue than some of the other hospitals.

- Clinical services in Norfolk were working more closely with one another and across the three acute hospitals with an aim to improve quality and access to care across the county.
- QEH representatives reported that staff turnover rates had improved, in part due to the pandemic, as some staff had joined on temporary contracts and chosen to stay on a full-time basis.
- Recruitment days carried out each month had helped address issues around recruitment of healthcare assistants. Recruitment in physiotherapy, occupational therapy and radiography was challenging across the country, and the workforce model was being reviewed to see what could be done.
- The Nursing vacancy rate had reduced and was now 7% and 5% on wards.
- The inspection in September was a partial inspection due to the pandemic but QEH representatives hoped that the area of “well led” would improve on reinspection.
- Twenty members of staff had been trained across the hospital to provide mental health first aid. Discussions were ongoing on how to introduce regular mental health support for staff.
- The Vice-Chair asked how much the work to review and maintain safety of the roof would cost; the Chief Executive, Queen Elizabeth Hospital NHS Foundation Trust, **agreed** to find out and circulate details to Committee Members after the meeting.
- The Chair noted the high instance of pressure ulcers reported. The Chief Executive, Queen Elizabeth Hospital NHS Foundation Trust, confirmed that there had been a spike in pressure ulcers nationally caused by Covid-19 patients on ventilators being placed in the prone position, as it was found this was beneficial to their recovery. Learning from the first wave had prevented proning related pressure ulcers during the second wave of Covid-19.
- QEH representatives discussed that the performance in the emergency department in February 2021 indicated that a bigger hospital was needed.
- The ability of staff to speak out about issues was queried. QEH representatives reported that staff could now use “speak up guardians” and there was a proactive “speak up group” in place helping the Trust to learn and change practice.
- The Medical Director, Queen Elizabeth Hospital NHS Foundation Trust, confirmed that the Trust was on track to achieve the 3 “must-dos” placed on it by the CQC around staff training for anaesthetic staff by April 2021. The 2 “must-dos” around diagnostic imaging staff were underway including succession planning and a dedicated culture programme to improve engagement and happiness in the team to retain existing staff and attract new staff.
- QEH representatives confirmed that the Trust was now resuming its elective service. The focus under national guidance was to assess and clinically prioritise patients on waiting lists to ensure those in most need received treatment first and everyone on waiting lists had been contacted. There were 15000 people on the Trust’s waiting list in total, and 10000 were within the 18 week referral to treatment national target.
- Clinics, such as diabetes and renal clinics, had continued throughout the pandemic focusing on the most urgent patients and those who needed regular surveillance. Most appointments had been virtual or by phone. Some appointments were difficult to carry out in this way and therefore the Trust was prioritising which patients most urgently required face to face appointments.
- The Chair and Committee were unhappy that hospital staff had to manage around ceiling props and wished to offer their support by writing to MPs.

1. AGREED to:

- Write to Norfolk MPs and the Secretary of State for Health and Social Care about the condition of the QEH building and the need for funding for a new hospital. Details of the risks to the local population and the cost of mitigation measures to be included.
 - Letter to be drafted & circulated to committee member for comment before final sign off by the Chairman.
- Recommend that Norfolk and Suffolk NHS Foundation Trust liaises with the QEH to provide joined up community mental health services to support staff.

2. ASKED:

- QEH representatives to return to NHOSC with a progress update before the end of 2021.

7. Local actions to address health and care workforce shortages

7.1 The Norfolk Health Overview and Scrutiny Committee received the report examining the Norfolk and Waveney Health and Care Partnership's workforce workstream's local action to address and mitigate the effects of national workforce shortages affecting health and care services.

7.2 The following points were discussed and noted:

- The Director of Workforce, Norfolk and Waveney Health and Care Partnership, reported that the launch of the adult social care strategy helped in the work to encourage people to work in Norfolk by spotlighting people working in social care and highlighting the benefits of living and working in Norfolk.
- The announcement in the budget about freezing lifetime allowances for NHS staff for 5 years was noted as likely to encourage workers to retire earlier. Representatives were asked how this would be mitigated. The Health and Care Partnership were working with unions to look at the impact of this issue. Because 45% of the Norfolk workforce were over 45, officers were looking at ways for staff to work more flexibly such as with a portfolio-based career, with different organisations, part time and carrying out other roles to encourage older workers to stay on. The legacy programme would support experienced staff to be re-engaged following retirement by supporting development of new staff.
- The Director of Workforce, Norfolk and Waveney Health and Care Partnership, reported that work was ongoing to join up with the Local Enterprise Partnership to identify roles that could be advanced jointly. Officers were working with local job centres to encourage people looking for a job change to apply for roles, such as the apprenticeship programmes which were available for people of all ages.
- Some of the £2m social care grant was used to help people achieve the level of English and Maths training they needed to go on to social care training pathways.
- A workshop was carried out in October looking at issues for Black, Asian and Minority Ethnic staff which identified recruitment as a barrier to inclusion. An action plan was developed to address the issues identified and help Norfolk and Waveney Health and Care Partnership be a more inclusive employer.
- Representatives were asked about the issue of low paid and zero hours contracts in care, particularly in North Norfolk. The Director of Workforce, Norfolk and Waveney Health and Care Partnership, replied that a project was underway in Wells to support with recruiting younger people to health and social care.
- The high number of requirements for retired staff to re-join the NHS was noted as a barrier. Representatives agreed the recruitment processes could be bureaucratic and this was something the Health and Care Partnership wanted to look at. A

reservist scheme was in place so that less training was required for retired staff wishing to return to help with the vaccination scheme.

- The Norfolk and Waveney strategy had been delayed slightly but launched in August 2020; bringing in apprenticeships of all ages had continued during the pandemic.
- In the second Covid-19 peak in December 2020 there were 2000 staff absent from NHS organisation in Norfolk and support from the armed forces, District Councils and fire service was brought in. Sickness had reduced significantly over the last few months reducing the need for this support.
- The Health and Care Partnership were satisfied that there was planning for future staffing in GP, dental, pharmacy and optician practices. Funding was available for new roles in Primary Care Networks and therefore Health and Care Partnership officers were working with Primary Care colleagues to identify new roles.
- The health and care ambassador programme had set up webinars and support for interviews on a 1:1 basis for care leavers seeking health and care careers. The programme had also visited young carers groups to offer support on this topic.
- The number of students at UEA medical school had increased from September 2020, and the Health and Care Partnership was working with them to look at increasing the number of clinical placements that could be offered each year.
- Support for staff suffering from “long Covid” was queried. The Director of Workforce, Norfolk and Waveney Health and Care Partnership, replied that funding had been received to provide services for people with long Covid, including staff.

7.3 Norfolk Health Overview and Scrutiny Committee

- **AGREED** to write to Norfolk MPs highlighting concerns affecting recruitment and retention of health and care staff including:
 - Impact of recent changes to pension and tax rules on retention of senior staff
 - Overly bureaucratic recruitment procedures for people wishing to help in the response to Covid 19
 - Impact of the issue of low pay in care careers.
 - Letter to be drafted & circulated to committee members for comment before final sign off by the Chairman.
- **RECOMMENDED** that the Health and Care Partnership provides careers advice on new health care roles, liaising with Children’s Services to make schools aware of the emerging new roles.
- **AGREED** that the Health and Care Partnership provide a written update on progress in 12 months’ time.

9. Forward work programme

- 9.1 The Norfolk Health Overview and Scrutiny Committee received and reviewed the forward work programme.
- 9.2 The report on access to local NHS services for patients with sensory impairments had been rescheduled for 15 July 2021.
- 9.3 The Norfolk Health Overview and Scrutiny Committee
- **AGREED** the forward plan with the addition of:
 - A progress report from the QEH before the end of 2021 (agenda item)
 - A written update from the HCP on progress in addressing health and care workforce shortages in 12 months’ time (in the NHOSC Briefing)

- **AGREED** that service providers would be invited to attend the item “Access to local NHS services for patients with sensory impairments” on 15 July 2021

Chairman

The meeting ended at 12:04



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Cancer services

Suggested approach from Maureen Orr Democratic Support and Scrutiny Manager

Examination of the situation regarding provision of cancer services in Norfolk and Waveney in light of Covid 19, including cancer screening, diagnostic and treatment services.

1.0 Purpose of today's meeting

1.1 The focus of the meeting is to examine:-

- (a) The impact of Covid 19 on backlogs and waiting times within screening, diagnosis and treatment services
- (b) The impact on cancer patient outcomes in Norfolk and Waveney
- (c) Measures to encourage people to come forward for screening, particularly those who are vulnerable and need support
- (d) Effectiveness of the measures to encourage people to come forward for screening.

1.2 The Norfolk and Waveney Clinical Commissioning Group (CCG) has been asked to provide a report on the current situation in respect of (a) & (b) above, including statistical information which is attached at **Appendix A. CCG representatives will attend to answer Members' questions.**

NHS England and NHS Improvement (NHSE&I) has been asked to report on the current situation in respect of (c) and (d) above, including the breast, cervical and bowel cancer screening services. NHSE&I's report is attached at **Appendix B**. Representatives of NHSE&I will attend to answer Members' questions.

2.0 Background information

2.1 National cancer waiting time standards

2.1.1 The national standards are:-

- 2 week wait from GP urgent referral to first consultant appointment (for all cancers (target 1) and a separate target for patients with breast cancer (target 2).
- 1 month wait from decision to treat to a first treatment for cancer (for all treatments (3) and separate targets for radiotherapy(4) and surgery (5) and anti cancer drug regimens (6).
- 2 month wait from GP urgent referral to a first treatment for cancer (7) (and a separate target (8) when referral is from a national screening service).
- 28-day wait from GP urgent referral to a diagnosis or ruling out of cancer (9).

2.2 Previous report to NHOSC

2.2.1 Norfolk Health Overview and Scrutiny Committee (NHOSC) examined cancer services on 8 October 2020 amid concerns about the effects of the Covid 19 pandemic on outcomes for people with cancer, in terms of reduced numbers presenting for initial diagnosis and longer waiting times for those who were in the system.

The reports and minutes of the meeting are available via the following link; [NHOSC 8 October 2020](#) (agenda item 6).

2.2.2 At that stage, before the second wave of the pandemic fully took hold, the Norfolk and Waveney system was working to national NHS instructions issued on 31 July 2020 to:-

- Reduce unmet need and tackle health inequalities, work with GPs and the public locally to restore the number of people coming forward and appropriately being referred with suspected cancer to at least pre-pandemic levels.
- Manage the immediate growth in people requiring cancer diagnosis and/or treatment returning to the service by ensuring that sufficient diagnostic capacity is in place in Covid-19-secure environments
- Increase endoscopy capacity to normal levels
- Expand the capacity of surgical hubs to meet demand and ensuring other treatment modalities are also delivered in Covid-19-secure environments.
- Putting in place specific actions to support any groups of patients who might have unequal access to diagnostics and/or treatment.

- Thereby reducing the number of patients waiting for diagnostics and/or treatment longer than 62 days on an urgent pathway, or over 31 days on a treatment pathway, to pre-pandemic levels, with an immediate plan for managing those waiting longer than 104 days.

In Norfolk and Waveney the acute hospital Chief Executive Officers were aware of every person waiting more than 104 days for cancer diagnostics or treatment, reason for the wait and that there was a clear individual plan for each patient. All Trusts were seeking to have no patients waiting over 104 days by December 2020.

Activity in elective surgery for cancer was expected to rise to above 90% of baseline (pre pandemic) levels by October 2020, and outpatients and diagnostics to above 90% by November 2020. The system was also planning for the increased use of independent sector capacity, where NHS clinicians and operational managers collectively agree this was appropriate.

93% of cancer patients were being seen within 2 weeks of GP referral.

3.0 Suggested approach

- 3.1 Members may wish to explore the following the NHSE&I and local NHS representatives:-

Capacity of services in light of Covid 19

- (a) What is the current reduction in capacity of local cancer screening, diagnostic and treatment services because of the necessary restrictions to minimise spread of Covid 19 compared to pre-Covid capacity?
- (b) Do the local services have capacity to reduce current waiting times?
- (c) To what extent have local hospitals increased their capacity for face-to-face diagnosis, treatment and monitoring of cancer patients since the height of the second wave of the pandemic?
- (d) When will local providers have a shared patient tracking list to make best use of capacity?

Mitigation in place while diagnostic and treatment capacity is reduced

- (e) How are 'harm reviews' of cancer patients currently carried out?
- (f) To what extent are commissioners and providers confident that patients can be appropriately prioritised in this way?

Process of restoration of services


- (g) Are the national cancer waiting time standards realistically achievable in the foreseeable future? What is the timescale for achieving them?

Communication with the public

- (h) What is done to ensure that vulnerable people understand that screening is available for them and are encouraged to take up the offer?
- (i) What is done to inform patients of the current likely waiting times for diagnosis and treatment?

4.0 Action

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

 The logo for IN TRAN features the words 'IN' and 'TRAN' in a bold, sans-serif font. To the left of 'TRAN' is a stylized graphic of two triangles pointing towards each other. Below the main text, the phrase 'communication for all' is written in a smaller, lowercase font.	<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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Update on Cancer Services in Norfolk and Waveney Health Overview and Scrutiny Committee 15th July 2021

Background and Purpose of Paper

Members received a briefing and presentation in relation to cancer services, at the October 2020 meeting. An update has been requested, particularly in relation to the impact of Covid-19 on backlogs and waiting times within screening, diagnosis and treatment services and the impact on cancer patient outcomes in Norfolk and Waveney.

1. Background to cancer care in Norfolk and Waveney

Cancer services in Norfolk and Waveney are commissioned by Norfolk and Waveney Clinical Commissioning Group (CCG) and are provided by the Queen Elizabeth Hospital (QEH), the Norfolk and Norwich University Hospital (NNUH) and the James Paget University Hospital (JPUH), Norfolk Community Health and Care (NCHC) East Coast Community Health (ECCH) and local GP practices in the Norfolk and Waveney Primary Care Networks. There are also some patient flows to Addenbrookes Hospital in Cambridge.

2. Impact of the pandemic on cancer care in Norfolk and Waveney

The pandemic has impacted in various ways. In the first and second waves there were significant reductions in patients presenting to Primary Care with symptoms which could be due to cancer, a reduction in diagnostic capacity due to Covid-19 infection, prevention and control measures, the initial suspension of Aerosol Generating Procedures except in emergency situations, staffing issues related to Covid-19, suspension of cancer screening programmes and significant patient concerns around attending healthcare settings. These factors led to a reduction in diagnostic and treatment capacity, altered clinical pathways to reduce risk, patients electing not to proceed with diagnostics or treatment and significant backlogs for diagnostics and screening programmes. Some patients and carers are now also wishing to delay their diagnostics/treatment appointments until they are fully vaccinated. (see Appendix 1. N&W Cancer Activity & Performance Covid-19 Recovery June 2021).

At a system level, this impact has been monitored and mitigated via the Norfolk and Waveney Cancer Programme Board. The programme board has worked in partnership with local providers to address the challenges of cancer restoration and recovery in order to:

- Prioritise cancer care provision on the basis of clinical need as per national guidance.
- Monitor and mitigate clinical harm as robustly as possible during the pandemic.
- Work in partnership with the Cancer Alliance to establish a system of mutual aid for cancer services due to the reduction in access to HDU/ITU beds for complex cancer surgery due to the Covid-19 response.
- Maximise use of local independent sector (IS) capacity in line with national guidance.
- Support diagnostic and cancer services to maintain Covid-19 adapted cancer pathways as per national guidance given the reduction in diagnostic and cancer specialist team capacity due to infection, prevention and control (IPC), staffing issues related to Covid-19 self-isolation/Covid-19 illness and redeployment to support inpatient care.
- Monitor the impact of pauses in screening programmes which could worsen current backlogs in partnership with the regional NHS E/I screening team
- Monitor urgent cancer referral pathway (2 Week waits) recovery and the associated risks of reduced referrals due to national restrictions and patient anxieties.
- Support Primary Care during the pandemic re the cancer-Covid-19 impact.
- Maintain a dialogue with cancer patients/ carers to support them through the pandemic and to reinforce national and local messaging re the pandemic.

3. The impact of Covid-19 19 on backlogs and waiting times within screening, diagnosis and treatment services:

3.1 Covid-19 impact on backlogs and waiting times within cancer screening:

There are three national cancer screening programmes for breast, bowel and cervical screening. Cancer screening is commissioned by the regional NHSE/I screening team and they are members of the Norfolk and Waveney Cancer Programme Board. They are attending the HOSC meeting to provide a separate update on backlogs and waiting times for cancer screening. The breast and bowel screening programmes were paused during the pandemic. Delivery of the cervical screening programme in Primary Care has continued during pandemic and Covid-19 vaccination programme.

3.2 Backlogs and waiting times within cancer diagnostics:

Work is underway to minimise diagnostic delays and Independent Sector (IS) capacity has been used wherever possible to support this. Robust processes have been put in place to establish “green” (Covid-19 secure) pathways through all three local hospitals to protect diagnostic capacity as much as possible. Additional cancer transformation resource has been used to support the trusts to streamline their diagnostic pathways (e.g. through the establishment of one stop clinics), use of IS capacity, weekend working and extended hours to clear backlogs and reduce waiting times.

There is also an enhanced communications and engagement plan to encourage patients to attend their GP practice with any worrying symptoms. This has led to a surge in urgent cancer referrals and pressure on local diagnostic services in particular imaging and endoscopy. This is being closely monitored at Trust level and via the Cancer Programme Board.

The three trusts have plans in place to address cancer diagnostic backlogs and reduce waiting times:

3.3 Backlogs and waiting times within cancer surgery, radiotherapy and chemotherapy:

The surge in urgent cancer referrals is now having an impact on cancer treatment capacity. This is being closely monitored at Trust level and via the Cancer Programme Board. Work is underway to minimise treatment delays.

1. Cancer Surgery:

National guidance continues to be followed to prioritise cancer patients for their treatment according to their clinical need. This approach¹ is based upon tumour site **specific cancer Multi-Disciplinary Teams (MDTs) agreeing a treatment/management** plan for each individual patient and then

¹ <https://www.rcseng.ac.uk/coronavirus/surgical-prioritisation-guidance/> Clinical guide for the management of essential cancer surgery for adults during the coronavirus pandemic – 07 April 2020

considering the urgency of this treatment. For example, Priority level 1a (P1a) would indicate that an emergency operation is needed within 24 hours, P1b, within 72 hours, P2 that elective treatment with the expectation of cure is needed within 4 weeks to save life/stop progression of the disease, (taking into account symptoms and complications from lack of treatment). P3 relates to elective surgery that can be delayed for 10-12 weeks and will have no predicted negative outcome.

At the QEH, NNUH and JPUH, ITU/HDU capacity was affected by the first and second waves of Covid-19 but the majority of P2 surgery has been maintained. QEH and JPUH patients requiring complex surgery (mainly from head and neck, gynaecological, thoracic and urology cancer pathways) are normally referred to NNUH and Addenbrookes as local Cancer Centres.

Some P2 tertiary referral patients were delayed due to ITU/HDU capacity at these tertiary centres during the first and second Covid-19 waves as both Addenbrookes and the NNUH were Covid-19 Surge Centres. P2 patients are all included in the regional and local mutual aid processes, co-ordinated by the EOE Alliance and the local hospitals respectively. P3 patients are now being reviewed. Robust processes have been put in place to establish “green” (Covid-19 secure) pathways through all three local hospitals to protect surgical capacity as much as possible. Additional cancer transformation resource has been used to support the trusts through weekend working and extended hours to clear backlogs and reduce waiting times. The independent sector has been used for surgical patients during the pandemic, e.g. Some JPUH patients received their breast cancer surgery at the Spire Hospital in Norwich during the first wave.

2. Chemotherapy: is provided at all three local hospitals.

There has been a recent increase in demand on chemotherapy provision due to the increased level of chemotherapy referrals now coming through the pathway. This is currently most effecting service provision at the NNUH and so additional cancer transformation resource is being used to support the dept. to meet the demand through weekend working and extended hours.

3. Radiotherapy:

Radiotherapy is accessed at the NNUH (and Addenbrookes for some QEH patients). Radiotherapy has also just started to experience increased demand due to the increased levels of radiotherapy referrals now coming through the pathway. Additional cancer transformation resource is being used to support the NNUH radiotherapy dept. to meet the demand through weekend working and extended hours.

3.4 The impact on cancer patient outcomes in Norfolk and Waveney

As outlined above, the pandemic has impacted in various ways. As a result, there is potential for a widening of existing health inequalities and increased clinical harm. There is national cancer restoration guidance and processes in place to oversee the restoration of cancer services, which is focused on local systems taking the following actions to:

- Restore urgent cancer referrals to pre-pandemic levels
- Take immediate action to reduce number of longer waiters, starting with those waiting over 104 days
- Ensure that we have sufficient diagnostic and treatment capacity in place to meet demand through the autumn
- Restore cancer services in an inclusive manner.

The Norfolk and Waveney Cancer Programme Board has operated within this framework to agree a local plan for the inclusive restoration of cancer services in Norfolk and Waveney. This will ensure that there are robust and consistent processes in place to minimise and monitor clinical harm for people affected by cancer so that:

- We understand our local data re healthcare access for particular patient groups or demographics to identify any unwarranted variation and address inequalities – *we have reviewed our system cancer data collection, in alignment with the regional and national cancer “sitrep” and 104 day waits data submissions for cancer.*
- Any changes in cancer care/transformation to have appropriate Equality and Health Inequality Impact Assessments carried out – *A methodology has been agreed and this work is underway to inform our communications and engagement.*
- We identify and implement strategies to minimise digital exclusion for people affected by cancer from particular patient groups or demographics – *we are working in partnership with Healthwatch Norfolk and Suffolk to have better insight into digital exclusion experienced by people living in Norfolk and Waveney who are affected by cancer. We are also working in partnership with Norfolk Libraries Service to provide access to equipment and digital training for people affected by cancer who do not have access to the Internet and or are not confident in their digital skills.*
- We support system work towards a shared cancer patient tracking list (PTL) to make best use of system capacity – *this work is in progress across the three local hospitals.*
- We ensure robust governance processes are in place for clinical harm reviews – *local cancer clinical harm policies have been reviewed and where necessary amended vs the regional “shared principles cancer quality approach”.*

- We achieve a better understanding of which local groups are slow to return and to target engagement approaches to enable their return to GP surgeries – *see above re system cancer data pack – urology and dermatology cancer pathways have been most affected by the pandemic, with urology and lung cancer pathways slowest to recover.*
- We progress specific projects focused on reducing health inequalities – *the population health management project to improve uptake of cervical screening and pilot of a lung cancer biomarker test in Primary care have been completed and are now being evaluated.*

The scope of this work covers cancer services provided for people affected by cancer who live in Norfolk and Waveney. This includes all tumour site cancer pathways across all care settings for both adults and children. It also needs to include all stages of the cancer care pathway; from referral, diagnostics, treatment and supportive/palliative care.

Data has been collated to assess impact of Covid-19 on cancer referrals for discussion at the system Cancer Programme Board. The data re cancer referrals in Primary Care has been collated by the CCG BI team in partnership with Norfolk County Council Analytics team. (see Appendix 1. N&W Cancer Activity & Performance Covid-19 Recovery June 2021). This is cross referenced with the Cancer Alliance Informatics which shows regional comparisons. Key indicators include:

Local providers all have robust quality assurance processes in place for patients waiting more than 104 days. These have been reviewed and where necessary revised in the light of regional work to establish a set of shared principles re cancer quality. The processes ensure that all acute Chief Executives are aware of every person waiting more than 104 days for cancer diagnostics or treatment, that the reason for the wait is understood and that there is a clear individual plan including escalation if necessary for each patient. There is regular and proactive patient contact by clinical nurse specialists, which is documented appropriately, with additional support from Consultants if needed to encourage patient attendance. Weekly reports are in place and provided to executive and operational teams for oversight of all patients waiting over 104 days. Clinical harm reviews are undertaken, and learning shared in line with local trust clinical harm policies. There is system oversight via the Cancer Programme Board, fortnightly cancer assurance meetings with the EOE North Cancer Alliance and via Acute Trust Board Quality Committees.

The system risks and issues log for cancer transformation currently includes system risks and issues associated with clinical harm. It has been updated to include risks/issues associated with health inequalities in access to cancer care once the Primary Care cancer referral data has been analysed.

As always it is difficult to establish causal links between changes to pathways and outcomes, especially in the current situation, survival from cancer is often measured over 1, 5 and 10 years. At a system level we monitor early indicators of other changes which can be plausibly linked to potential future outcome. In

particular, diagnosing cancers at a later stage would be a potential warning sign, along with routes to diagnosis (to monitor if there has been an increase in emergency presentations for people with cancer).

From the time of diagnosis to treatment, a joint British and Canadian review of all studies in the British Medical Journal determined that based on over 30 studies, the links between delays in treatment was most consistent for surgery, with risk of death being increased by a factor 1.06 for every 4 weeks of delay. Less consistent links were found for radiotherapy and chemotherapy, although are similar in magnitude. Applied to the Norfolk and Waveney context, the number of patients receiving surgery within 31 days was 96 out of 110 in 19/20 and was a lower proportion, 80 out of 101, in 20/21. If 20/21 performance had matched pre-pandemic levels, 8 patients more would have been seen within 31 days. It is not possible to calculate from this an exact expected additional mortality, as some patients may have been on the wrong side of the target but not delayed by a full 28 days.

4. Summary:

In conclusion the Covid-19 pandemic has impacted upon local cancer services in Norfolk and Waveney in various ways. The emerging impact on patient outcomes will be fully realised in future years. The local system Cancer Programme Board maintains close monitoring of the situation and emerging impact. It also co-ordinates a system wide response to issues and challenges that arise.

Dr Mark Lim MRCPCH MFPH

Interim Director of Clinical Services and Clinical Transformation, Norfolk and Waveney CCG, July 2021

N&W Cancer Activity & Performance – Covid-19 Recovery *April 2021*



Introduction

Background

The purpose of these slides is to help understand the impact that Covid may have had on the N&W cancer activity and performance and help track the progress of the N&W Cancer restoration programme.

Sources of Data *(N&WCCG only)*

- **Local acute referral data:** 2WW GP referrals into NNUH, JPUH and QEH
- **SUS outpatient data:** First outpatient attendances referred by GPs for 2WW into all Acute providers.
- **Performance data:** NHSE Validated Monthly data from Cancer Waiting Times and DM01: Diagnostics Waiting times. Total organisation values shown where available, if N&CCG not available the total of NNUH, JPUH and QEH is used.

Reporting Period:

April Validated Data (Month 1). 1920, 2021 and 2122 values are YTD totals i.e. April

N&W Cancer Summary

Key Performance and Activity Metrics



Norfolk and Waveney
Clinical Commissioning Group

N&WCCG performance and activity.

Group	Indicator	Target	Value	Last 3 Months			Trend
				Feb	Mar	Apr	
Performance	2WW Suspected	93%	% Performance	87.2%	89.4%	75.1%	
	2WW Breast	93%	% Performance	49.7%	59.3%	39.7%	
	31Day First Treatment	96%	% Performance	92.8%	91.5%	87.1%	
	31Day Subsequent Surgery	94%	% Performance	75.7%	79.3%	69.9%	
	31Day Subsequent Drug	98%	% Performance	99.5%	94.9%	99.5%	
	31Day Subsequent Radio	94%	% Performance	98.1%	96.0%	93.7%	
	62Day First Treatment	85%	% Performance	63.3%	62.8%	66.5%	
	62Day NHS Screening	90%	% Performance	73.3%	75.5%	77.1%	
	62Day Upgrade		% Performance	77.5%	77.3%	71.1%	
	104 Day Waiters (Provider Only)	0	Total patients	24	38	32	
Activity	Diagnostics completed <6 weeks (All patients, not just Cancer)	99%	% Performance	56.7%	59.9%	62.3%	

Performance RAG: Green - Target Achieved, Amber - Within 10%, Red - Outside 10%

Activity	2WW GP Referrals	19/20	Activity	3,355	4,499	4,423	
	2WW 1st OP Attendance - GP referred	19/20	Activity	2,583	3,639	3,169	

Activity RAG: Green - Equal or greater than baseline, Amber - Within 10% of baseline, Red - Outside 10% of baseline

19/20 YTD	20/21 YTD	20/22 YTD	Var to 1920	Var to 1920 (%)
92.2%	84.6%	75.1%	-17.1%	-18.6%
85.6%	91.4%	39.7%	-45.9%	-53.6%
97.2%	96.3%	87.1%	-10.2%	-10.5%
87.3%	79.2%	69.9%	-17.4%	-19.9%
99.4%	99.4%	99.5%	0.1%	0.1%
97.1%	93.7%	93.7%	-3.5%	-3.6%
78.6%	62.8%	66.5%	-12.0%	-15.3%
90.5%	70.8%	77.1%	-13.4%	-14.8%
80.6%	83.7%	71.1%	-9.5%	-11.8%
0	25	32	32	
97.9%	44.6%	62.3%	-35.6%	-36.4%

3,685	1,555	4,423	738	20.0%
3,173	1,307	3,169	-4	-0.1%

Executive Summary

After the general improvement in Cancer performance in March, April has seen a decrease in performance for N&W, most noticeably in 2 weeks, 2 weeks breast and 31 day surgery. In April, only 31 day drugs has achieved target. This reduction in performance is not being driven by an increase in activity, with patient numbers lower in April than March.

NNUHFT 2 Week and 2 Week Breast has seen a significant reduction in April, with 2 Weeks falling to 62% and 2 Week breast to 7.8%. 31 days radio and now 31 days drugs are the only metrics achieving target in April.

QEHKLFT continues to perform well on cancer indicators, now achieving the 62 day standard in April. 2 Week Breast is the only metric under target, achieving 90.6% against the 93% target in April.

The JPHFT continues to achieve the majority of cancer indicators in April, with the exception of 62 Days and now 31 days, which has slipped to 93.2% against the 96% target.

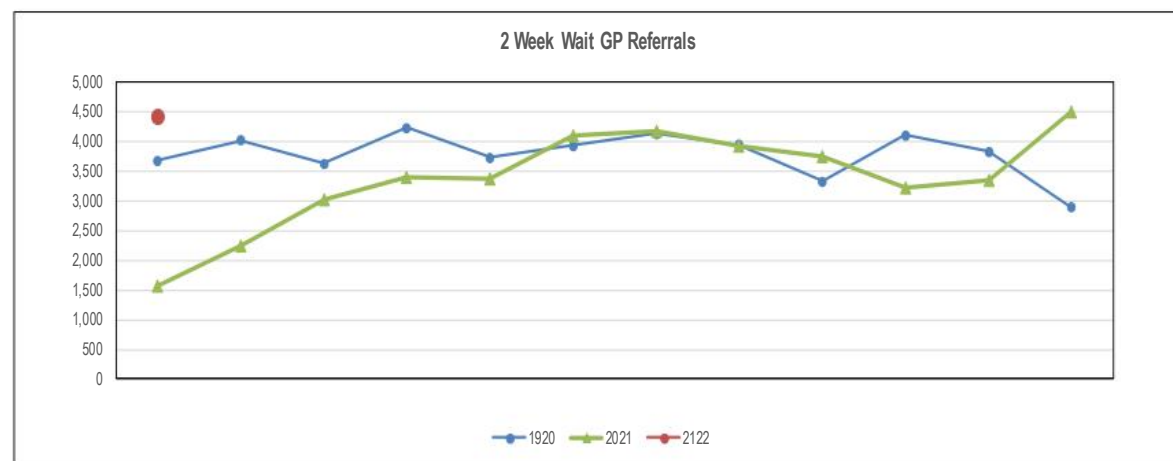
2WW GP Referrals

Trend and Specialty



Norfolk and Waveney
Clinical Commissioning Group

	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	YTD
1920	3,685	4,022	3,628	4,229	3,726	3,926	4,125	3,942	3,324	4,108	3,835	2,891	3,685
2021	1,555	2,242	3,016	3,394	3,377	4,108	4,169	3,914	3,751	3,216	3,355	4,499	1,555
2122	4,423												4,423
Var to 1920 (#)	738												738
Var to 1920 (%)	20.0%												20.0%



Top Specialty	1920 YTD	2021 YTD	2122 YTD	Var (#) to 1920	Var (%) to 1920	Monthly Activity Trend
100: General surgery	742	499	974	232	31.3%	
330: Dermatology	754	271	929	175	23.2%	
301: Gastroenterology	483	65	569	86	17.8%	
101: Urology	452	192	451	-1	-0.2%	
502: Gynaecology	393	127	396	3	0.8%	
103: Breast surgery	305	121	413	108	35.4%	
120: Ent	198	60	230	32	16.2%	
104: Colorectal surgery	106	44	117	11	10.4%	
140: Oral surgery	78	40	82	4	5.1%	
Other	252	176	262	10	4.0%	
Total	3,685	1,555	4,423	738	20.0%	

N&W observed an 11% drop in 2WW GP referrals in 20/21, following the Covid outbreak. March's high volumes of referrals continue into April, with April 21, 20% above that of April 19.

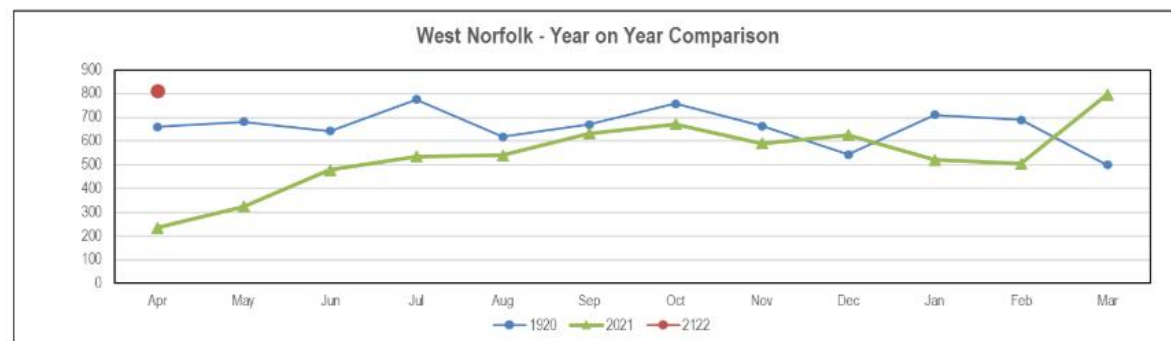
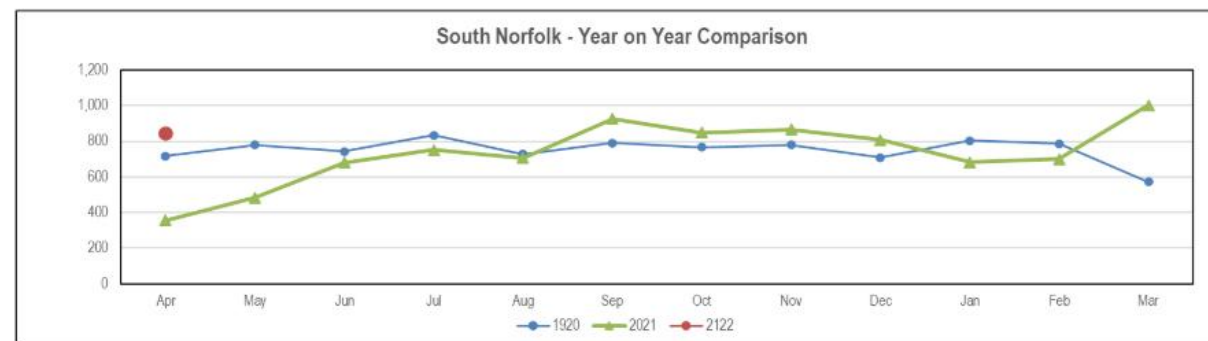
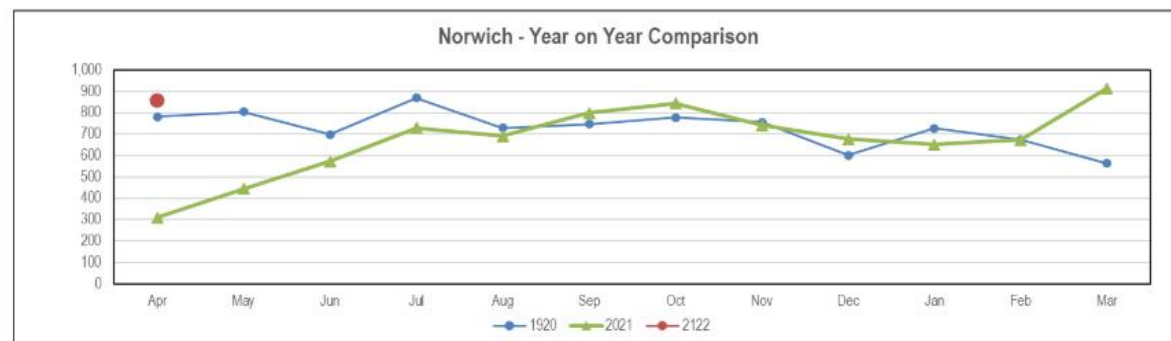
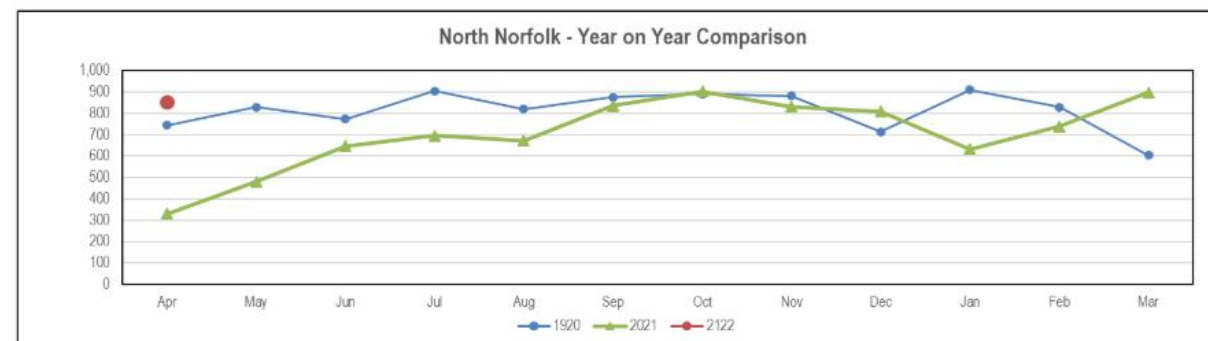
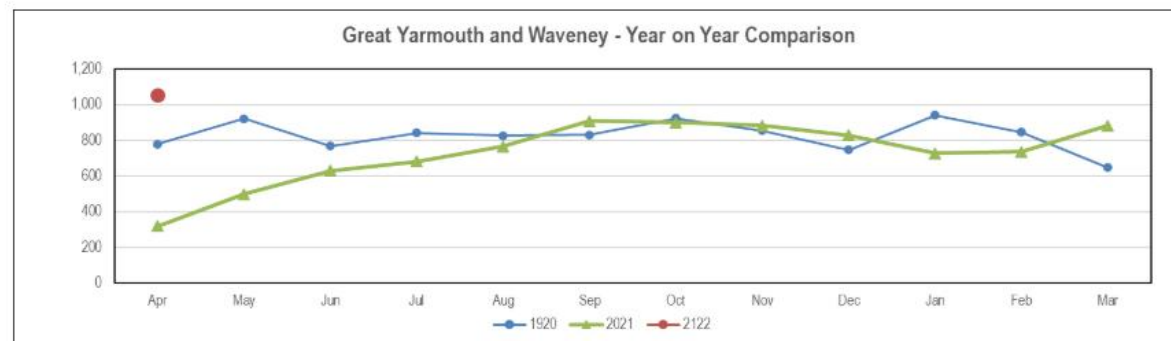
The majority of specialties have seen an increase on 19/20, most noticeably in General Surgery, Dermatology, Gastro and Breast Surgery. Urology however remains inline with 19/20 levels.

2WW GP Referrals

Locality



Norfolk and Waveney
Clinical Commissioning Group



All localities have seen an increase in referrals in April 21 compared to April 19.

Work is still underway with the localities and PCNs to understand these trends further and what can be done to improve referral rates and appropriateness.

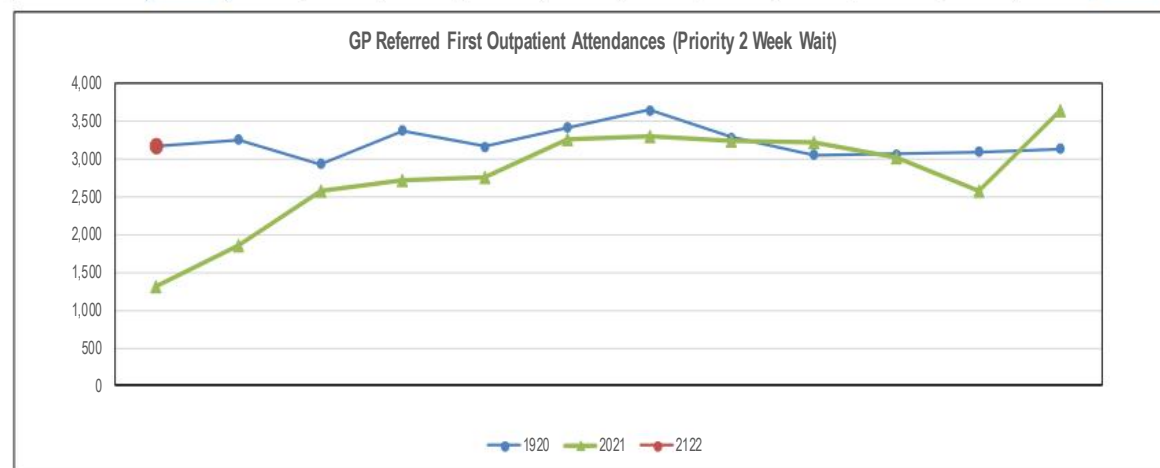
2WW 1st OP Attendances (GP Referred)

Trend and Specialty



Norfolk and Waveney
Clinical Commissioning Group

	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	YTD
1920	3,173	3,254	2,929	3,370	3,164	3,412	3,641	3,282	3,054	3,066	3,097	3,131	3,173
2021	1,307	1,851	2,568	2,727	2,753	3,250	3,295	3,248	3,214	3,018	2,583	3,639	1,307
2122	3,169												3,169
Var to 1920 (#)	-4												-4
Var to 1920 (%)	-0.1%												-0.1%



Top Specialty	1920 YTD	2021 YTD	2122 YTD	Var (#) to 1920	Var (%) to 1920	Monthly Activity Trend
330: Dermatology	726	257	733	7	1.0%	
100: General surgery	633	389	815	182	28.8%	
101: Urology	555	180	403	-152	-27.4%	
502: Gynaecology	372	156	391	19	5.1%	
103: Breast surgery	362	109	360	-2	-0.6%	
120: Ent	227	61	192	-35	-15.4%	
104: Colorectal surgery	116	33	58	-58	-50.0%	
503: Gynaecological oncology	22	35	35	13	59.1%	
340: Respiratory medicine	50	25	27	-23	-46.0%	
Other	160	87	155	-5	-3.1%	
Total	3,173	1,307	3,169	-4	-0.1%	

N&W observed an 13% drop in 2WW 1st OP attendances in 20/21, following the Covid outbreak. March's exceptionally high volumes of attendances have reduced in April, but remain consistent with 19/20.

As per 2WW GP referrals, Urology remains the main area of concern, with activity still considerably under that of 19/20, -27% in April. Activity for ENT, Colorectal Surgery and Respiratory medicine all remain under 19/20 levels. General Surgery continues to perform consistently above 19/20.

Diagnostics Waiting Times

In Month Performance by Diagnostic Test and Weeks Waited



Norfolk and Waveney
Clinical Commissioning Group

*Diagnostics completed within
6 weeks - NNUH*

Diagnostic	Performance			Wait Breakdown (Provider Breakdown Only)						
	Within target	Total patients	Performance %	0-2	2-4	4-6	6-8	8-10	10-12	12-14
Total	9080	15357	59.1%	5397	2192	1491	1166	895	658	3558
AUDIOLOGY_ASSESSMENTS	246	253	97.2%	141	82	23	2	1	0	4
BARIUM_ENEMA	23	25	92.0%	16	7	0	0	0	0	2
COLONOSCOPY	458	636	72.0%	312	91	55	41	46	39	52
CT	1730	4159	41.6%	1123	333	274	179	132	72	2046
CYSTOSCOPY	155	368	42.1%	57	68	30	35	21	8	149
DEXA_SCAN	495	568	87.1%	254	131	110	31	12	4	26
ECHOCARDIOGRAPHY	395	1105	35.7%	148	103	144	161	178	133	238
ELECTROPHYSIOLOGY	0	0		0	0	0	0	0	0	0
FLEXI_SIGMOIDOSCOPY	130	215	60.5%	72	37	21	22	24	12	27
GASTROSCOPY	508	838	60.6%	296	102	110	71	77	62	120
MRI	1646	1786	92.2%	1253	309	84	41	15	8	76
NON Obstetric Ultrasound	3006	4979	60.4%	1546	844	616	548	369	295	761
PERIPHERAL_NEUROPHYS	81	85	95.3%	64	16	1	2	1	0	1
SLEEP_STUDIES	118	132	89.4%	97	15	6	2	2	1	9
URODYNAMICS	89	208	42.8%	18	54	17	31	17	24	47

Performance RAG: Green - Target Achieved, Amber - Within 10%, Red - Outside 10%

*Diagnostics completed within
6 weeks - JPUH*

Diagnostic	Performance			Wait Breakdown (Provider Breakdown Only)						
	Within target	Total patients	Performance %	0-2	2-4	4-6	6-8	8-10	10-12	12-14
Total	4368	5779	75.6%	1946	1505	917	304	181	173	753
AUDIOLOGY_ASSESSMENTS	110	111	99.1%	72	29	9	0	0	0	1
BARIUM_ENEMA	3	3	100.0%	3	0	0	0	0	0	0
COLONOSCOPY	220	412	53.4%	118	90	12	25	16	17	134
CT	900	1249	72.1%	369	318	213	83	65	90	111
CYSTOSCOPY	124	293	42.3%	104	8	12	27	31	9	102
DEXA_SCAN	101	101	100.0%	60	36	5	0	0	0	0
ECHOCARDIOGRAPHY	315	323	97.5%	122	131	62	3	2	1	2
ELECTROPHYSIOLOGY	0	0		0	0	0	0	0	0	0
FLEXI_SIGMOIDOSCOPY	123	330	37.3%	69	41	13	12	8	16	171
GASTROSCOPY	124	263	47.1%	83	33	8	17	9	15	98
MRI	1219	1492	81.7%	431	423	365	109	42	18	104
NON Obstetric Ultrasound	1128	1178	95.8%	514	396	218	28	7	7	8
PERIPHERAL_NEUROPHYS	0	0		0	0	0	0	0	0	0
SLEEP_STUDIES	0	0		0	0	0	0	0	0	0
URODYNAMICS	1	24	4.2%	1	0	0	0	1	0	22

Performance RAG: Green - Target Achieved, Amber - Within 10%, Red - Outside 10%

*Diagnostics completed within
6 weeks - QEH*

Diagnostic	Performance			Wait Breakdown (Provider Breakdown Only)						
	Within target	Total patients	Performance %	0-2	2-4	4-6	6-8	8-10	10-12	12-14
Total	3461	6956	49.8%	1520	1046	895	570	393	265	2267
AUDIOLOGY_ASSESSMENTS	219	261	83.9%	112	75	32	18	8	2	14
BARIUM_ENEMA	0	0		0	0	0	0	0	0	0
COLONOSCOPY	128	194	66.0%	73	31	24	25	14	8	19
CT	653	1539	42.4%	337	180	136	100	77	48	661
CYSTOSCOPY	11	42	26.2%	1	5	5	2	0	0	29
DEXA_SCAN	121	288	42.0%	57	12	52	39	33	38	57
ECHOCARDIOGRAPHY	475	1537	30.9%	162	164	149	133	103	75	751
ELECTROPHYSIOLOGY	0	0		0	0	0	0	0	0	0
FLEXI_SIGMOIDOSCOPY	51	67	76.1%	31	11	9	10	4	0	2
GASTROSCOPY	137	176	77.8%	70	41	26	16	15	4	4
MRI	610	1450	42.1%	291	168	151	128	84	58	570
NON Obstetric Ultrasound	873	959	91.0%	332	279	262	57	18	0	11
PERIPHERAL_NEUROPHYS	167	264	63.3%	52	75	40	34	30	22	11
SLEEP_STUDIES	0	0		0	0	0	0	0	0	0
URODYNAMICS	16	179	8.9%	2	5	9	8	7	10	138

Performance RAG: Green - Target Achieved, Amber - Within 10%, Red - Outside 10%



Cancer Screening Report for the Norfolk HOSC

July 2021

This report was produced by the Screening and Immunisation Team, July 2021

NHS England and NHS Improvement

Cancer Screening Report for the Norfolk HOSC

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1. Cancer Screening Summary

Cancer screening programmes are commissioned regionally by NHS England's Screening and Immunisation Teams (SITs) as part of the Section 7a agreement. The screening services in Norfolk and Waveney are generally well run and achieve higher levels of coverage than the national mean. Despite this there are varying levels of coverage in certain areas within Norfolk and Waveney.

2. Breast Cancer Screening

Programme Overview

The NHS Breast Screening service offers breast screening to women between the ages of 50 and 70 years of age. It also offers screening at an earlier age to those women who are identified as having a higher risk of breast screening due to genetic reasons. Eligible women are identified through GP registration systems based on their year of birth. All women should be invited by their 53rd birthday and then recalled every 36 months after their last normal mammogram. Most units operate vans which will screen women at the nearest location to their home address using digital mammography.

Women whose mammograms are abnormal are recalled for further assessment. They are usually seen in a trust's breast screening unit where they may need further mammograms, ultrasound or a biopsy. The interval between abnormal mammography and further assessment should be no longer than three weeks. Women who are found to have breast cancer are referred to a specialist cancer team for treatment. Further information can be found on the NHS Breast screening services [website](#).

Norfolk and Waveney Breast Screening Services

There are three breast screening programmes in Norfolk and Waveney, based in each of the three acute hospital trusts: James Paget (JPUH), Norfolk and Norwich (NNUH), and Queen Elizabeth Kings Lynn (QEHKL).

NNUH is the largest service, serving a population of 1 million, while QEHKL and JPUH both serve smaller populations of approximately 250,000. There are recognised national shortages of radiologists and radiographers, and while smaller services are often more vulnerable at times of annual leave, sick leave or retirement of senior staff, all three trusts are experiencing challenges in recruitment and retention across their breast screening programmes. However, due to the rural geography and varying demographics, it is felt vital to maintain the delivery of assessment clinics in each trust, to minimise barriers to access for patients.

The Screening and Immunisation Team has reviewed the recovery of the three trusts by arranging monthly review meetings in addition to the screening programme boards. Uptake and round length data has been regularly tracked and the providers were asked to give regular updates on the estimated time by which the round length will be recovered. Breast screening uptake has also been monitored at different sites where possible. The national reporting collections for KPI data is planned to re-start later this year, which will mean the SIT will be able to monitor the quality of the programmes using accurate data at programme boards, as was the case before the pandemic. The two smaller services have actually recovered faster from impact of COVID-19, returning to the 36 month round length standard in December 2020 at QEHKL and January 2021 at JPUH, whereas NNUH is not expected to recover until the end of August 2021. However, all three trusts recognise the risks that staffing shortages pose, and are supportive of a plan to develop a collaborative network to increase the future resilience of breast screening services across Norfolk and Waveney. The purpose of the network will be to use technology to improve virtual liaison within and between the three services, so that staffing capacity can be shared and used flexibly, while offering education and training opportunities to support staff recruitment and retention. NHS England is working closely with Norfolk & Waveney CCG and ICS (Integrated Care System) to set up a project group to oversee the development of the network, which is anticipated to include both breast screening and symptomatic breast services.

Breast Screening Coverage

Coverage is defined as the percentage of women in the population who are eligible for screening at a particular point in time, who have had a test with a recorded result within the last three years. Uptake refers to the proportion of women accepting invites. As seen in Chart 1, the coverage of breast screening has generally been higher than the England mean, but replicates the pattern seen in England with regards to the decrease in uptake since 2010. This pattern is also repeated within the five historical CCG populations in Norfolk and Waveney, as seen in Chart 2 (from 20/21 data will only be available by Norfolk & Waveney CCG). Interim quarterly PHE data for 2020/2021 is unavailable because of known inaccuracies due to the impact of the COVID-19 pandemic on screening services in this period.

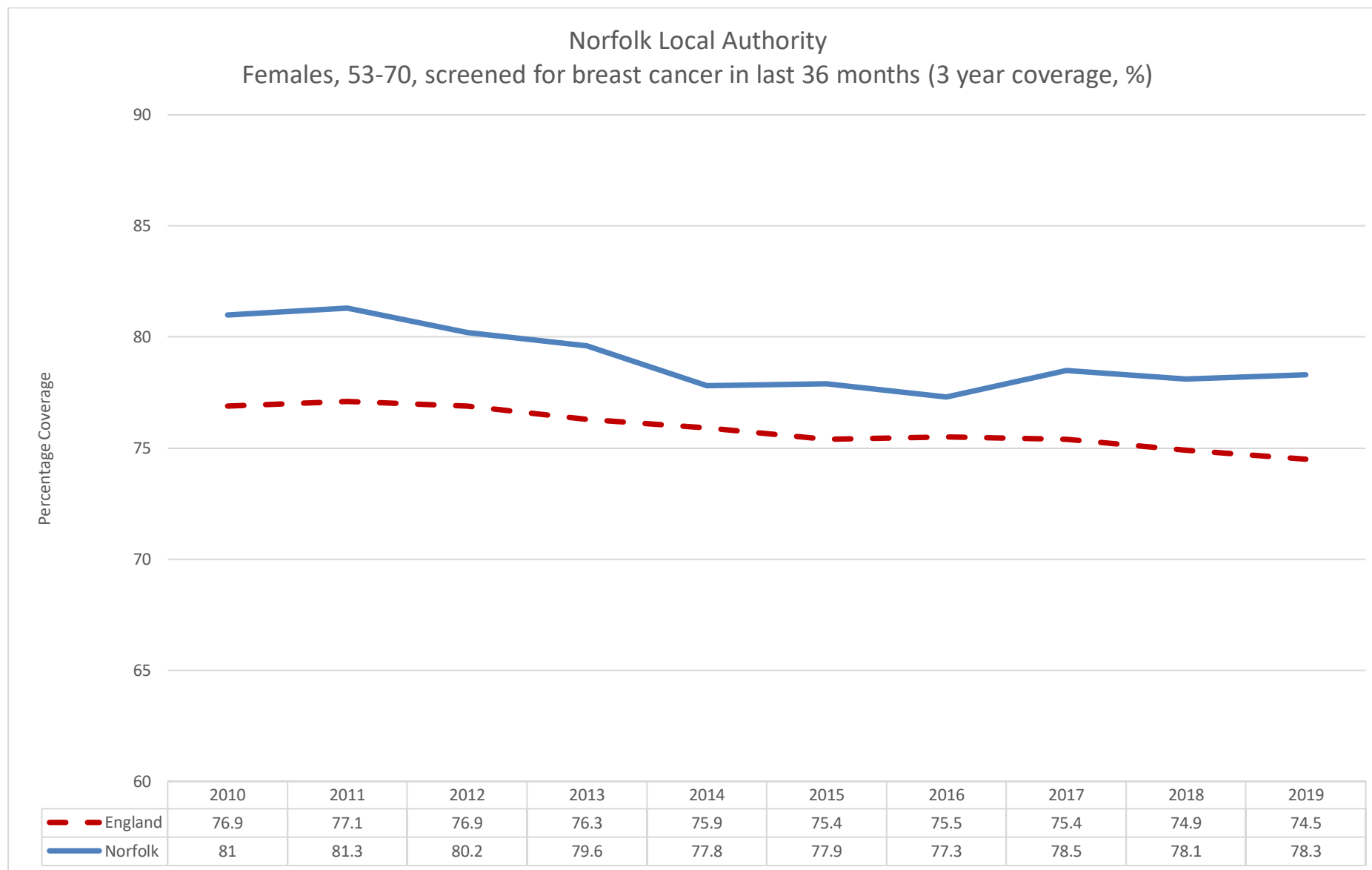


Chart 1. Annual breast screening 36 month round length coverage for women aged 53-70 in the Norfolk local authority region (Source: PHE Public Health profiles)

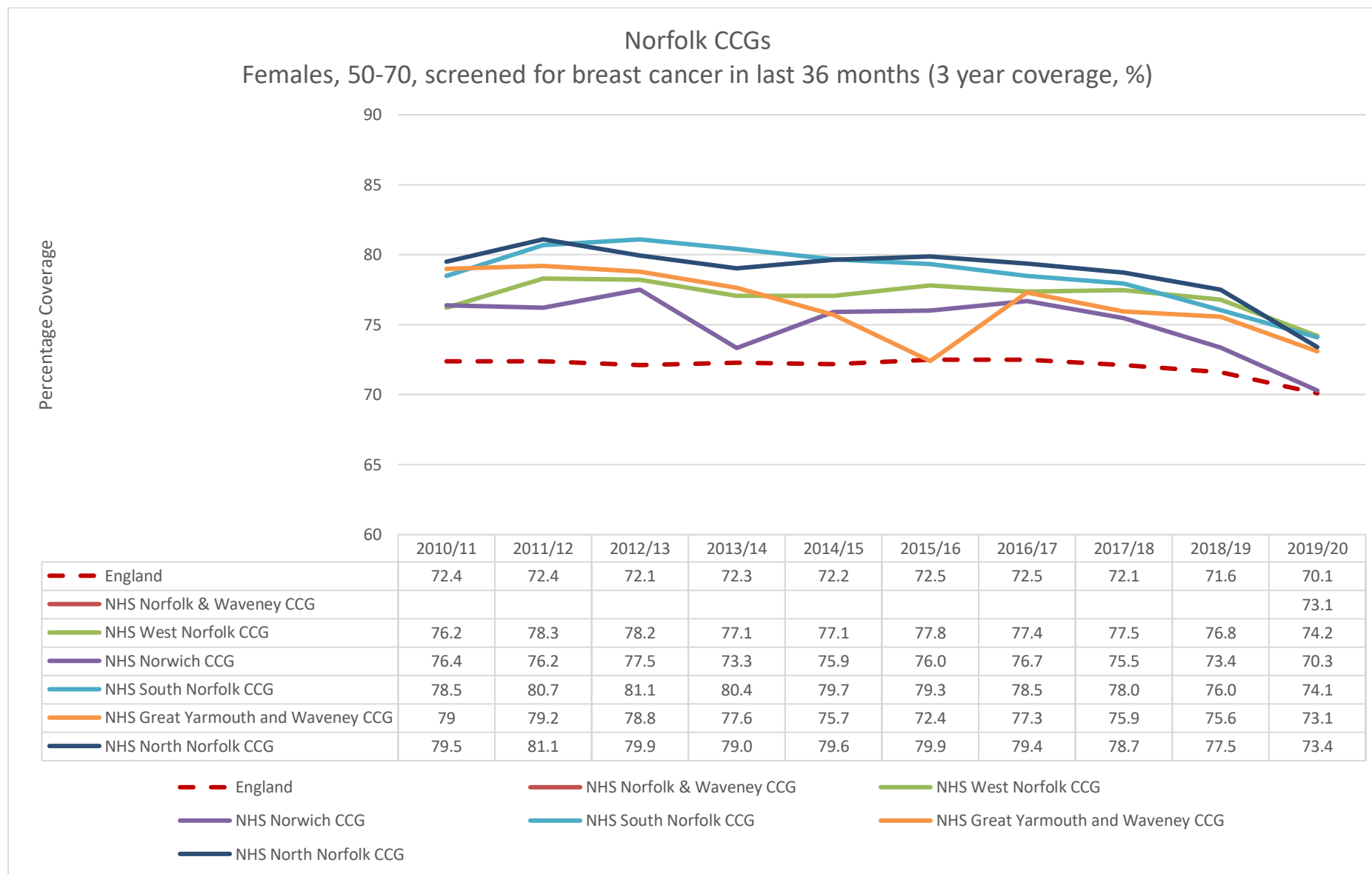


Chart 2. Annual breast screening 36-month round length coverage for women aged 50-70 within the Norfolk & Waveney CCG region (Source: PHE Public Health profiles)

3. Cervical Screening

Cervical Screening Programme Overview

Cervical screening is offered to women aged 25 to 64 (every three years to women aged 25 to 49 and every five years from the ages of 50 to 64). A sample is taken using Liquid based cytology (LBC) and is tested for the presence of strains of HPV responsible for most cervical cancers. This is the first test used for women's samples and those women found to be negative for HPV require no further testing and are sent back to normal recall of 3 or 5 years. Those samples which are positive for HPV are sent to cytology to undergo a full cytological examination. Those women found to be HPV positive and have an abnormal cytology result are referred to Colposcopy for further examination and further treatment if necessary. A full flowchart of the cervical screening protocol can be found at the following [link](#).

Norfolk and Waveney Cervical Screening services

Screening samples are taken at primary care services (usually GP practices) and are sent to a lab for processing. The screening test in Norfolk and Waveney is the primary HPV test which is provided by the Pathology services at the Norfolk and Norwich Hospital. This lab is situated at the Cotman centre and provides primary HPV services for the East of England as a whole. It has historically performed well and regularly meets the key performance standard for results being processed within 2 weeks of receipt (>98%). There are three Colposcopy units in Norfolk and Waveney which are situated in the three hospital trusts. All three regularly meet their KPI targets and are well run but do sometimes struggle with staffing capacity.

Cervical Screening Coverage

As can be seen in Chart 3, the pattern of coverage for the younger cohort (defined as the percentage of women aged 25-49 eligible for screening at a given point in time who were screened adequately within 3.5 years of their previous screening test). Similar to breast screening, coverage in Norfolk is higher than the England mean, but has shown a comparable slow decline between 2010-2018. However, there was an increase during 2019 and 2020, thought to be because of greater awareness, due to national and regional campaigns. The coverage for older women, as seen in Chart 4, is generally higher. It follows a similar pattern to the younger cohort but is nearer to the national mean figures overall. Tables 1 and 2 show coverage for the first 3 quarters of 2020/21 and is the most up to date published data.

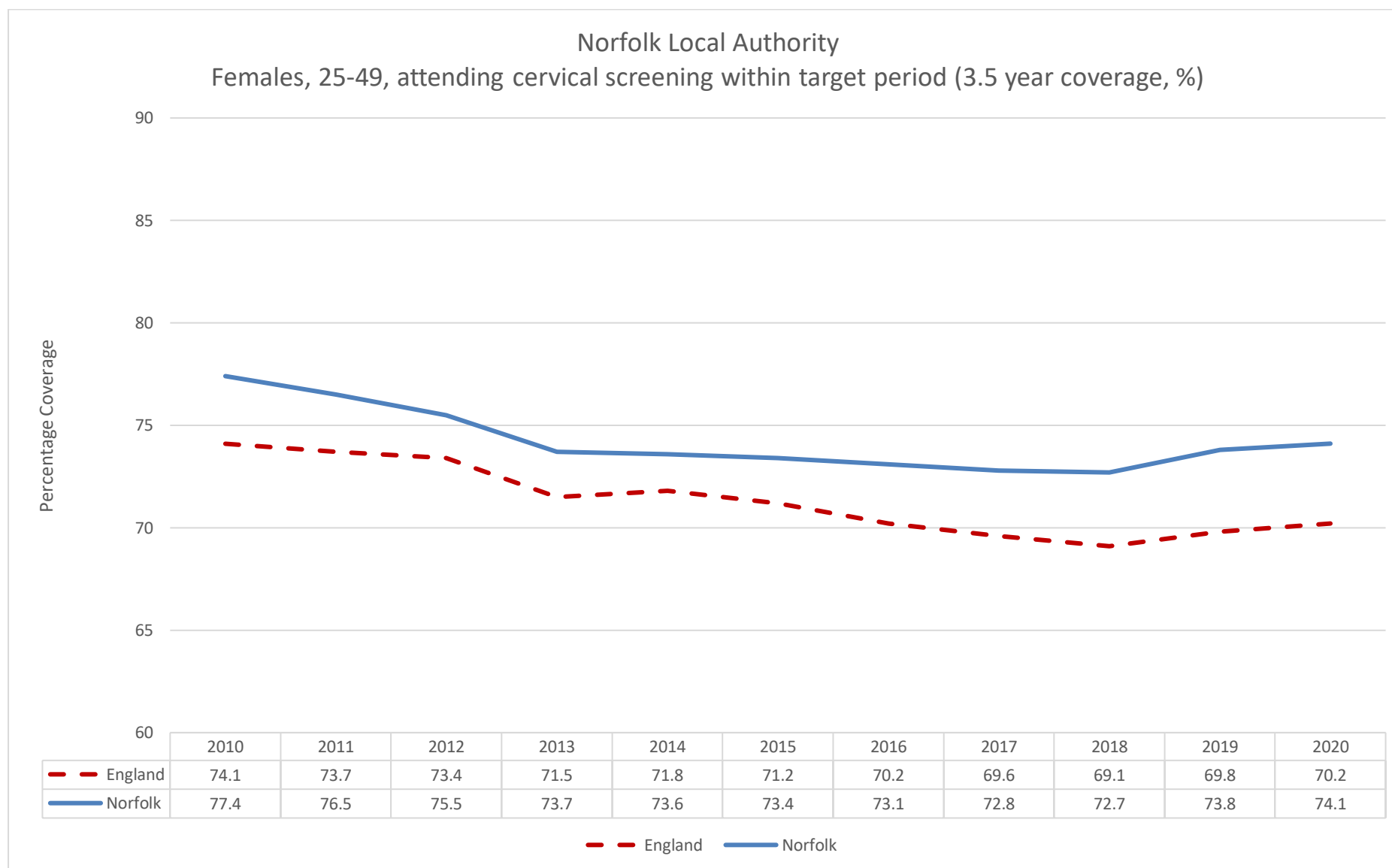


Chart 3. Annual Cervical Screening coverage for the younger Cohort of women (25-49) within the Norfolk Local Authority region who have been screened within the 3.5 year target period (Source: PHE Public Health profiles)

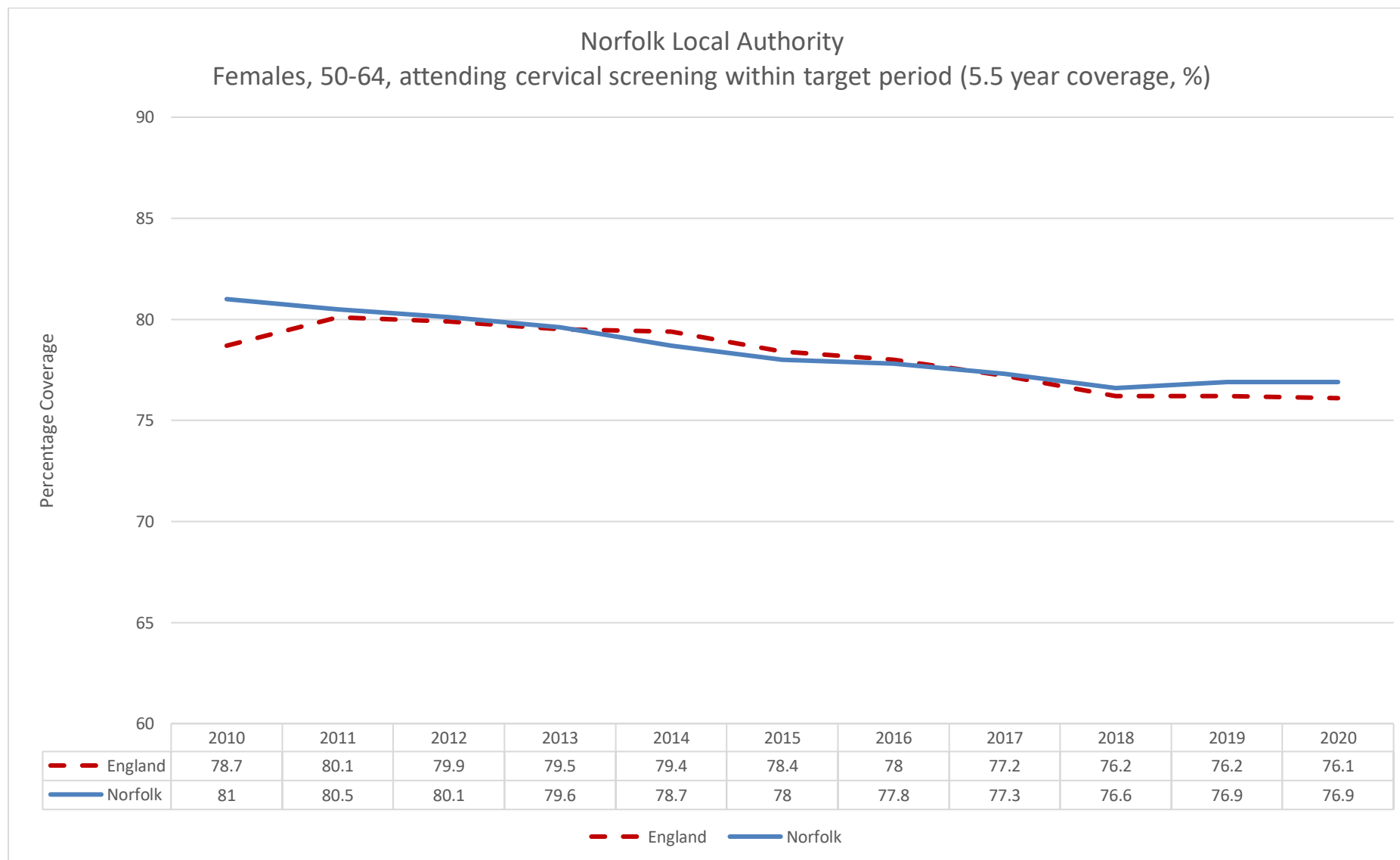


Chart 4. Annual Cervical Screening coverage for the older Cohort of women (50-64) within the Norfolk Local Authority region who have been screened within the 5.5 year target period (Source: PHE Public Health profiles)

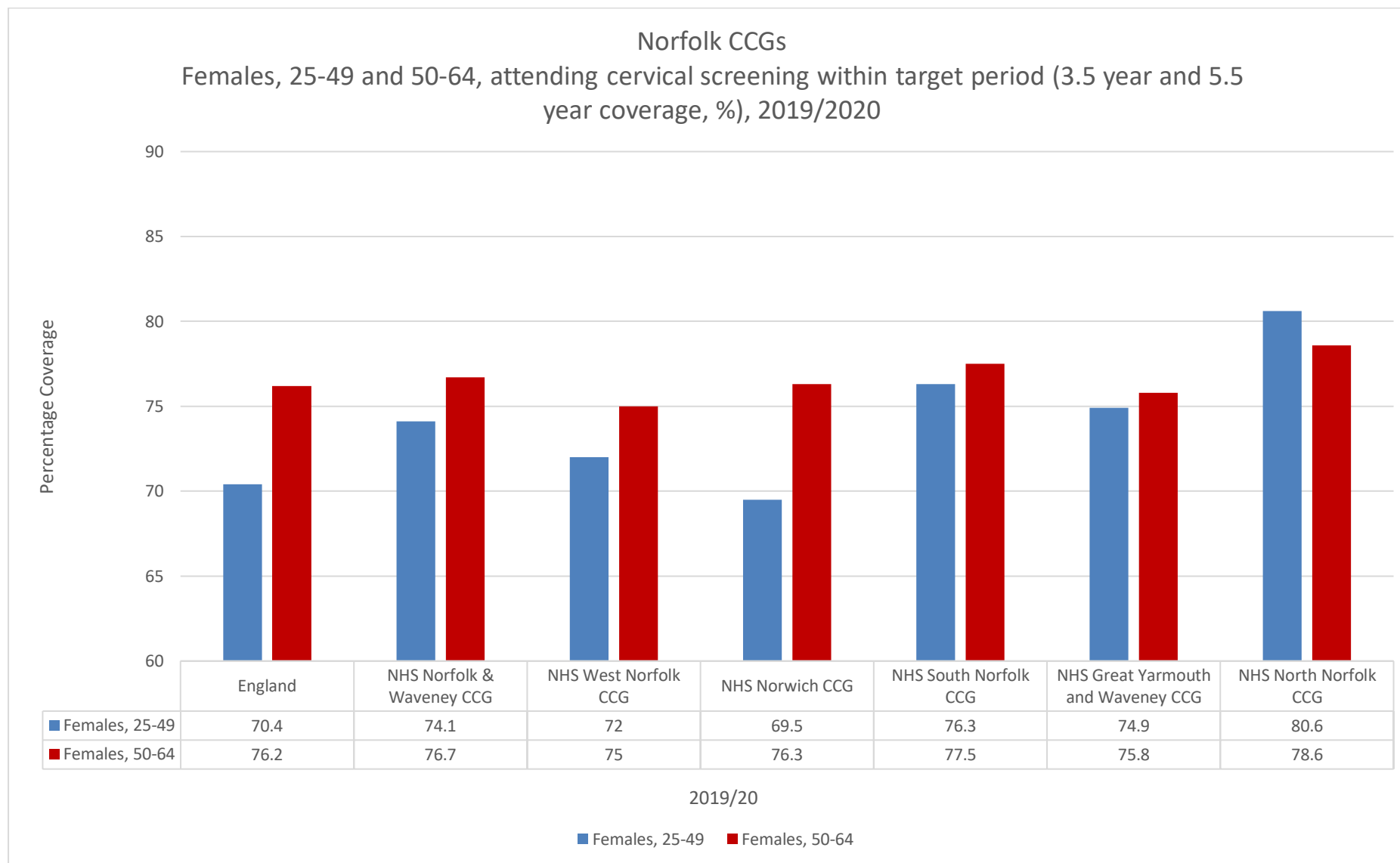


Chart 5. Annual Cervical Screening coverage for women aged 25-49 and 50-64 within the Norfolk & Waveney CCG region who have been screened within the 3.5 or 5.5 year target period respectively (Source: PHE Fingertips/PHOF)

Females, 25-49, attending cervical screening within target period (3.5 year coverage, %), 2020/21 quarterly data

	20/21 Q1	20/21 Q2	20/21 Q3
Norfolk Local Authority	72.7%	71.9%	72.1%
England	69.4%	68.3%	68.1%

Table 1. Quarterly Cervical screening coverage (females, 25-49) for the Norfolk & Waveney CCG eligible population (Source: NHS Digital Cervical Screening Programme - Coverage Statistics)

Females, 50-64, attending cervical screening within target period (5.5 year coverage, %), 2020/21 quarterly data

	20/21 Q1	20/21 Q2	20/21 Q3
Norfolk Local Authority	76.5%	76.1%	75.8%
England	75.8%	75.3%	75%

Table 2. Quarterly Cervical screening coverage (females, 50-64) for the Norfolk & Waveney CCG eligible population (Source: NHS Digital Cervical Screening Programme - Coverage Statistics)

4. Bowel Cancer Screening

Bowel Cancer Screening Overview

Bowel cancer screening is currently offered to men and women aged 60 to 74, but is being extended to 50-59-year olds over the next 4 years, starting with 56-year-olds during 2021. The test used is the faecal immunochemical test (FIT). Individuals are sent an information leaflet and invitation letter from the bowel screening Hub, followed one week later by a FIT kit. This test requires a single stool sample only (compared to the older FoBT test which required 4 samples), which is then returned by post to the hub. Samples are quantitatively analysed in the laboratory, with samples recorded as having 120 micrograms of haemoglobin per gram of stool being recorded as positive. Patients should receive their result (positive or negative) within two weeks of the laboratory receiving the kit. The test is repeated at two-yearly intervals. Around 2% of patients can be expected to have a positive result and these individuals are referred to the local Bowel Screening Centre where they are seen by a specialist screening practitioner who goes through varying options and offers the individual a colonoscopy if it is suitable. Those deemed unfit may be referred for CT colonography (a radiological examination). Colonoscopy allows an endoscopist to visualise the lining of the entire large bowel. Around 10% of patients undergoing screening colonoscopy can be expected to have a cancer and a larger number (around 30%) will have polyps detected. Polyps can generally be removed during the colonoscopy. If a cancer is detected, the patient is placed on the cancer referral pathway and may require surgery.

Norfolk and Waveney Bowel Screening services

The bowel screening Hub that covers the East of England area is located at the Queens Medical Centre in Nottingham. This is a well-run service which is commissioned by the Nottinghamshire Screening and Immunisation Team. The Bowel Screening Centre is located at the NNUH and is a very well run service. It regularly meets its key performance standards and takes part in efforts to increase uptake. It reached the Hub's target of being within 6 weeks of clearing their backlog by April 2021, and is now within 4 weeks. Age extension is planned to start in July 2021, and will be one of the first services to go live in the region.

Bowel Screening Coverage

The Norfolk bowel screening programme has one of the highest levels of coverage in the country. Charts 5 and 6 show that the levels of coverage have remained relatively stable, before increasing over the last 2 years. It is thought that this is due to the introduction of FIT. Table 3 shows coverage for the first 2 quarters of 2020/21 and is the most up to date published data.

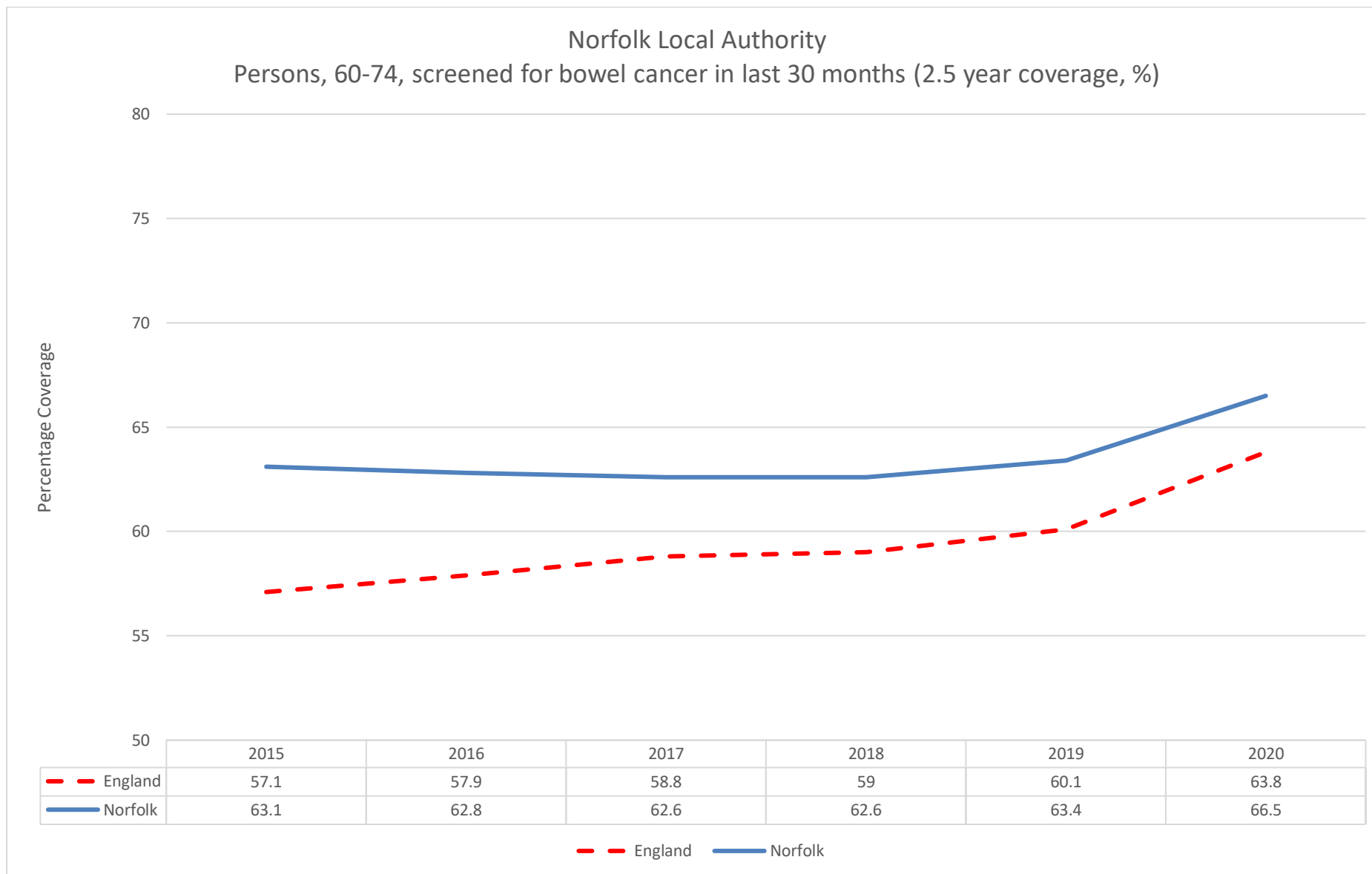


Chart 5. Annual Bowel screening coverage for the Norfolk Local Authority eligible population (Source Fingertips/PHOF)

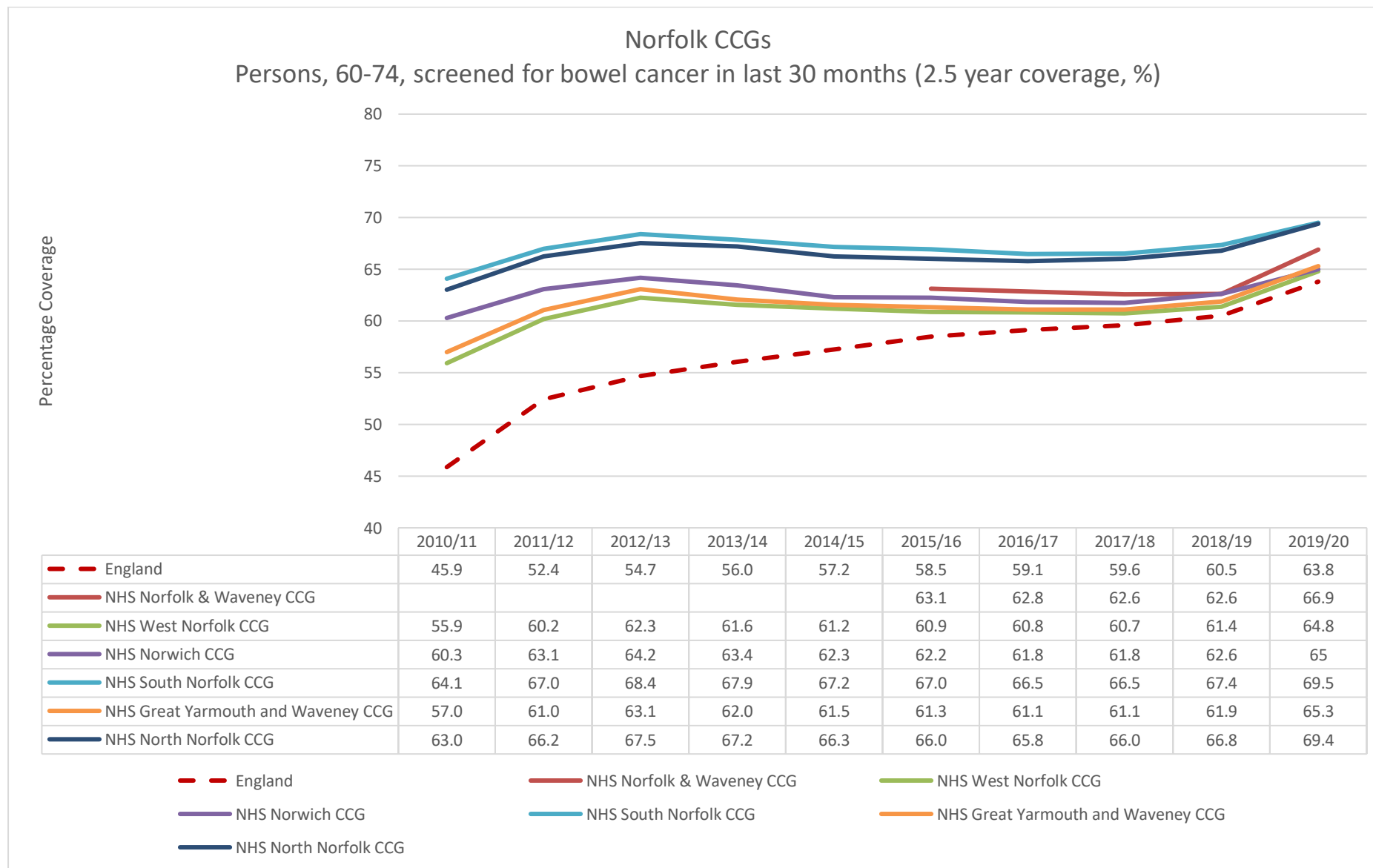


Chart 6. Annual Bowel screening coverage for the Norfolk & Waveney CCG eligible population (Source PHE Fingertips/PHOF)

Persons, 60-74, screened for bowel cancer in last 30 months (2.5 year coverage, %), 2020/21 quarterly data

	20/21 Q1	20/21 Q2
Norfolk Local Authority	64.7%	64.4%
England	62.0%	61%

Table 3. Quarterly Bowel screening coverage for the Norfolk Local Authority eligible population (Source: PHE KPI data, published on GOV.UK)

5. Increasing uptake of cancer screening services

Measures to encourage people to come forward for screening, particularly those who are vulnerable and need support

Inevitably, over the last 12 months the focus has primarily been on supporting services as they recover from the impact of the COVID-19 pandemic and ensuring that patients receive the screening services for which they are eligible. However, there is now a resumed collective focus on improving uptake, and on reducing health inequalities in particular. While overall coverage of cancer screening in Norfolk is higher than the national average, there is still variation, and a clear need to continue to target hard to reach groups, who are often vulnerable and need additional support to access screening. NHS England is working collaboratively with key system stakeholders, including patient representatives, to improve uptake across the East of England region, and in Norfolk & Waveney specifically.

Within the East of England, the NHS England team has developed a new cervical screening strategy, which aims to increase uptake, improve access and reduce inequalities within cervical screening. The strategy includes a number of workstreams, including: a regional text messaging reminder service, which is due to launch in Norfolk & Waveney by the end of July 2021. There are plans to increase choice and access through procurement of iCASH services, and collaboration with GP practices. Work is being conducted with PCNs to make further use of primary care hubs, extended access clinics and flexible appointment times; and work with specific vulnerable and harder to reach communities. This includes the rollout of the Beacon House Colchester model for homeless communities.

Norfolk & Waveney CCG is leading a Cancer Transformation Programme. One of the aims of the programme is to improve the uptake and coverage of national screening programmes and to support reduction in health inequalities for their populations. It includes a specific cervical screening project, which is using a population health management approach to identify and prioritise groups of patients who are at most risk of having undetected disease. The project will then engage with these patients to promote awareness of and improve access to cervical screening, gathering information on any barriers and arranging an appointment at the patient's GP practice if the patient wishes to take up the offer of screening. A separate cervical screening patient engagement project is also running in the Great Yarmouth and Northern Villages PCN, and will be run similarly in Kings Lynn PCN.

During the COVID-19 pandemic, screening services have worked to try and ensure that inequalities did not widen. There has been additional communication with patients to explain how they will be kept safe at hospital appointments, and SSP (specialist screening practitioner) appointments have been conducted virtually to reduce the need for patients to attend clinics at the bowel screening units. Within breast screening, NHS England has funded additional support for providers to ring patients that had not responded to their invitation letter, to encourage them to book an appointment, and some services such as the JPUH have put on out of hours clinics to improve access for women.

Both the Screening and Immunisation team and the NNUH bowel screening programme have produced inequality assessments and have plans to work with the ICS to address inequalities within the Norfolk and Waveney region. These assessments have made it clear that to have an effective plan to deal with inequalities requires a multi system approach. Following a regional health equity audit on the impact of COVID-19 on bowel screening, and a public health registrar within the Screening & Immunisation team is also running a project on inequalities within the programme. This includes facilitating a stakeholder forum with screening providers across the region to share learning and good practice. As the breast screening service has been primarily focused on recovery over the last year, there has only recently been a renewed effort to look at inequalities. However, as with bowel screening, there are plans to conduct an inequalities assessment for breast screening services. Work on inequalities will align with the work being done with regards to bowel and cervical screening on an ICS footprint.

Across the region NHS England is seeking to improve the availability of data to enable prompt identification of eligible individuals, in particular those with projected characteristics and those requiring reasonable adjustments. Access to the Eclipse platform is currently being explored, as this has the potential to provide real-time access to detailed demographic data, collated from GP systems, in relation to screening uptake (and is already being used for cervical screening in the CCG's population health management project as described below). The insights gained from this data could then be used to plan and implement more targeted work to improve uptake among under-served groups.

A pilot project is currently underway in Suffolk to improve screening access and uptake amongst people with learning disabilities, and to ensure they have necessary support required to complete the screening pathway. Following evaluation, it is hoped that this project can be replicated in Norfolk. Separately, the Norfolk & Waveney CCG Learning Disability Quality Improvement team are working to improve uptake of annual health checks for people with learning disabilities, which includes a discussion about screening uptake. This work is initially concentrating on GP practices within the OneNorwich area, with the intention of expanding to other GP practices in due course.

Effectiveness of the measures to encourage people to come forward for screening

Uptake of screening, and the effectiveness of initiatives to improve this, is monitored regularly at Programme Management Board meetings (commissioner-chaired oversight meetings for each screening service). Regionally, NHS England holds meetings for each of the three cancer screening services, where performance is monitored, and any learning or good practice is shared, while the delivery of projects is monitored at a dedicated regional public health group. In addition, a public health assurance report is shared and discussed at the regional Primary Care & Public Health Oversight Group. As part of increased collaborative working with systems, the Screening & Immunisation team now provides quarterly reports on screening uptake to the Norfolk & Waveney ICS Cancer Programme Board.

Nationally, there is a strong evidence base for public health initiatives, and mechanisms are in place to share research and best practice with teams across the country. Initiatives adopted in the East of England to improve uptake are informed by existing evidence of effectiveness, although they may be adapted to meet local needs, and evaluation is a key part of all projects. For example, the cervical screening text messaging reminder service was informed by an extensive pilot and subsequent roll-out of a similar service in London. Data will be shared with the team on a bi-weekly basis to enable ongoing monitoring, before a more detailed evaluation is carried out by CSAS (Cervical Screening Administration Service) to inform the expansion of text message reminders to other screening programmes.

National measures to increase uptake are also routinely evaluated before and after implementation. For example, the national introduction of FIT for bowel screening followed positively evaluated pilots, and it is hoped that pilots of self-sampling for cervical screening will yield a similarly positive impact on uptake, and lead to a national roll-out. In response to the COVID-19 pandemic, a decision was taken nationally to switch from timed appointments on breast screening invite letters, to 'open invitations', where women are invited to call and book an appointment. The intention was to reduce the number of DNAs and maximise the number of appointment slots being filled, to help mitigate against the reduced capacity of screening services and to reduce their backlog. The national PHE team is currently undertaking a review of the impact of this change on uptake. It will also consider whether there has been any negative impact on health inequalities. In Norfolk, QEH have continued to use timed appointments as they were able to clear their backlog quickly, whereas JPUH and NNUH are using open invitations in line with the majority of providers across the country. Decisions on future invitations will be informed by PHE's evaluation once published.

The CCG's Research and Evaluation Team will be evaluating the impact of the CCG's Cancer Transformation Programme. This is being undertaken via analysis of quantitative cancer screening coverage/uptake data and primary care awareness of strategies to achieve an earlier cancer diagnosis. This data is drawn from a system wide primary care cancer data set for cancer screening coverage and uptake and earlier cancer diagnosis.

Access to local NHS services for patients with sensory impairments

Suggested approach from Maureen Orr
Democratic Support and Scrutiny Manager

The committee will follow up on its initial examination of the experiences of people with hearing impairments and sight impairments when accessing local NHS services, which took place on 26 November 2020.

1.0 Purpose of today's meeting

- 1.1 Today's meeting is a follow-up to the Norfolk Health Overview and Scrutiny Committee meeting on 26 November 2021 when the committee heard about negative experiences of Deaf¹ people and those with sight impairments² when accessing services in Norfolk and Waveney.

The committee will focus on:-

- (a) NHS England and NHS Improvement's (NHSE&I) progress toward re-procurement of interpreting services for primary care. This affects British Sign Language (BSL) users whose access to all primary care services relies on the effectiveness of the interpreting service.
- (b) Steps taken to mitigate the difficulties with the current BSL interpreting service, which were brought to NHOSC's attention on 26 November 2020 via Healthwatch Norfolk.
- (c) NHSE&I and Norfolk and Waveney Clinical Commissioning Group's work to embed the Accessible Information Standard (AIS) with service

¹ **Deaf** - A person who identifies as being Deaf with an uppercase D is indicating that they are culturally Deaf and belong to the Deaf community. Most Deaf people are sign language users who have been deaf all of their lives. For most Deaf people, English is a second language and as such they may have a limited ability to read, write or speak English. A person who identifies as being deaf with a lowercase d is indicating that they have a significant hearing impairment. Many deaf people have lost their hearing later in life and as such may be able to speak and / or read English to the same extent as a hearing person.

² **Sight impairment** – depending on the severity of vision loss a person may be registered as sight impaired (previously “partially sighted”) or severely sight impaired (previously “blind”). The category of registration depends on measurements of visual acuity (ability to see detail at a distance) and field of vision (how much can be seen from the side of the eye when looking straight ahead).

providers across primary and secondary care and enable easier access for all patients with hearing and sight impairments.

1.2 In relation to (a) & (b) above, which concern the BSL interpreting contract in primary care, NHSE&I has been asked to provide a report on:-

- The extent of its consultation with service users in Norfolk and Waveney before re-procurement of the BSL interpreting service.
- A summary of the feedback received in response to the consultation.
- Decisions regarding the service to be procured and how it will differ from the current offer.
- The programme for the re-procurement.
- Steps taken to mitigate users' difficulties with the current BSL interpreting service, as highlighted to NHOSC on 26 November 2020.
- Any other relevant information.

NHSE&I has provided the report attached at **Appendix A**. Representatives from NHSE&I and the provider DA Languages have been invited to attend the meeting to answer councillors' questions.

In relation to (c) above, Norfolk and Waveney Clinical Commissioning Group (N&W CCG) has provided the paper at **Appendix B** on the embedding of the Accessible Information Standard (AIS) with service providers across primary and secondary care to enable easier access for all patients with hearing and sight impairments. Representatives from the CCG and some of the local service providers will be available to answer councillors' questions.

2.0 Background information

2.1 Previous NHOSC meeting – 26 November 2020

2.1.1 NHOSC examined 'Access to local NHS services for patient with sensory impairments' because of councillors concerns about:-

- (a) Difficulties faced by Deaf people (BSL users) in accessing GP, dental and pharmacy services since a change to the primary care interpreting contract in 2019. Healthwatch Norfolk also presented further evidence of this concern on 26 November.
- (b) Specific difficulties faced by the small number of Deaf people who require access to psychological therapists with a suitable level of BSL interpreter expertise.
- (c) Inconsistent implementation of the AIS in Norfolk and Waveney and consequent access difficulties for sight impaired patients.

The report to NHOSC (agenda item 6) and minutes of meeting are available via the following link [NHOSC 26 Nov 2020](#).

NHSE&I commissioners and primary care interpreting services providers DA Languages were in attendance to answer the committee's questions on (a).

Due to rising Covid pressures at the time, N&W CCG was unable to attend the meeting for this item.

In respect of (b), access to psychological therapies for BSL users, the CCG was asked to contact Norfolk County Council Sensory Support Team directly, when work pressures allowed, as it was felt discussion between them and Norfolk and Suffolk NHS Foundation Trust (NSFT - the provider of psychological therapies) could lead to a suitable solution for the very small number of vulnerable BSL users who required this service. The matter was not discussed at the NHOSC meeting on 26 November 2020. It is understood that discussion between the NHS and the County Council Sensory Support Team has not yet taken place, however the team is aware of one person who was recently offered an alternative service to the standard NSFT service. Due to low incidence of people needing a psychological therapist with BSL expertise this might have been the only person in need.

In respect of (c) above, inconsistent implementation of the AIS, the committee heard from the Royal National Institute of Blind People (RNIB) and from a district councillor, which confirmed councillors concerns.

- 2.1.2 During discussions at the meeting on 26 November 2020 the Head of Commissioning, NHSE&I agreed to discuss with N&W CCG what could be done to ensure a joined-up approach to assist patients with sensory impairments at hospitals in Norfolk. He also agreed to look at what adjustments could be put in place in the current primary care interpreting contract to support people in the short term.

The committee made five recommendations to NHSE&I on 26 November 2020. The recommendations and responses are set out in the report from NHSE&I and the CCG at Appendix A & Appendix B.

2.2 Implementation of AIS

- 2.2.1 The full AIS and Implementation Guidance is available on NHS England's website:-

<https://www.england.nhs.uk/ourwork/accessibleinfo/>

The Standard applies to service providers across the NHS and adult social care system, and it specifically aims to improve the quality and safety of care received by individuals with information and communication needs, and their

ability to be involved in autonomous decision-making about their health, care and wellbeing.

There are five basic steps in the AIS:-

1. Ask: identify / find out if an individual has any communication / information needs relating to a disability or sensory loss and if so what they are.
2. Record: record those needs in a clear, unambiguous and standardised way in electronic and / or paper based record / administrative systems / documents.
3. Alert / flag / highlight: ensure that recorded needs are 'highly visible' whenever the individual's record is accessed, and prompt for action.
4. Share: include information about individuals' information / communication needs as part of existing data sharing processes (and in line with existing information governance frameworks).
5. Act: take steps to ensure that individuals receive information which they can access and understand, and receive communication support if they need it.

On 26 November the RNIB suggested that more needed to be done to implement the AIS and asked for:-

- NHSE&I and N&W CCG (the commissioners) to monitor the extent to which healthcare providers are consistently implementing the AIS in Norfolk & Waveney
- The commissioners to ensure all frontline staff receive training in the requirements and implementation of the standard; i.e. mandatory training that is regularly refreshed.
- The commissioners to share their experience of implementing the standard with as part of the current year's review of the AIS by NHS England.

3.0 Suggested approach

3.1 At the meeting on 26 November 2020 NHOSC heard from Healthwatch Norfolk, the RNIB and others who represented Deaf and sight impaired service users. The problems they were experiencing were clearly communicated. On this occasion NHOSC may wish to focus on the action the NHS commissioners and service providers have taken in the interim and their plans for improvements in the future.

3.2 Members may wish to explore the following areas with the NHS representatives:-

BSL interpreting service for primary care

(commissioned by NHSE&I; provided by DA Languages)

- (a) Did DA Languages undertake a review of training of its interpreters and report their findings and any subsequent actions to NHSE&I by end April 2021 as requested by NHS E&I following NHOSC's

recommendation on 26 Nov 2020? What action was taken following the review?

- (b) Considering the level of dissatisfaction with the quality of the current BSL interpreting service, as expressed in NHSE&I's survey, are the commissioners confident that D A Languages can introduce a good quality service to enable Deaf patients to use BSL interpreters to make primary care appointments for them (i.e. the pilot Deaf Enhanced Support Service, 19 July 2021 – March 2022)?
- (c) How is the Deaf Enhanced Support Service pilot scheme being publicised to potential users?
- (d) Given that BSL users raised concerns about the interpreting service in 2019 but action to address those concerns has only recently started (slowed by the pandemic), what will the commissioners do to ensure that any BSL user who is having difficulty accessing services in a timely manner from this point onwards is given rapid advice and support?

Implementation of AIS

- (e) How have the commissioners monitored implementation of the AIS across Norfolk & Waveney? What are the results?
- (f) Do the commissioners know to what extent frontline staff have received AIS training and how often it is refreshed?
- (g) Have the commissioners shared experiences of implementing the AIS with NHS England as part of the current year's review?
- (h) Has the new training for frontline staff in GP practices been launched as part of the CCG's Training Hub plans for April 2021? How will take-up be encouraged?

4.0 Action

4.1 The committee is asked to consider:-

- (a) Whether to make comments or recommendations as a result of today's discussions.



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Translation and Interpreting Services in Primary Care in the East of England Update to Norfolk Health Overview & Scrutiny Committee

Introduction

1. At the Norfolk HOSC meeting in November 2020, the NHS England and NHS Improvement(NHEI) Direct Commissioning (Primary Care) team presented an overview of the translation and interpreting services commissioned in the Norfolk area; and heard the difficulties faced in accessing British Sign Language (BSL) support for residents in the local area. A further update has since been provided (see Appendix One) in March 2021.
2. We agreed to move as quickly as possible to help resolve some of these issues. To note is that since this meeting there has been another wave of COVID which meant that from January 2021 many staff in the primary care team were deployed with no notice to support the vaccination programme and other COVID related cells. This has meant that there has been a delay in programmes of work, however we recognised and appreciated the comments from stakeholders in Norfolk and have integrated these into our commissioning of these services.
3. This report provides a further update on progress and future plans and is split into three sections to reflect the:
 - (1) extension to the current contract to include opticians in the Norfolk area;
 - (2) progress with the pilot enhanced service;
 - (3) long term future service, currently out to tender for all four contractor groups (GPs, Pharmacy, Opticians and Dentists).

Section One - Extension to the Current Contract to Include Opticians

4. It was acknowledged that there was a gap in the services commissioned by NHSEI and provided by DA Language, in that patients were unable to access translation and interpreting services when visiting an optician for NHS eye care in the Norfolk, Suffolk and Cambridge areas.
5. Extensive work was undertaken as swiftly as possible to rectify this, involving the identification and agreement of funding resources, liaising with the national commercial team, and negotiating a contract variation with DA Languages. This was challenging given the redeployment of many members of the regional and national teams who would normally undertake this work. Communications were sent to optometry contractors as well as the relevant stakeholders on this new service and how to access the service.
6. This additional service commenced on the 19 April 2021, and as of 2 July there have been 5 face to face request made by 3 different optometrists and a total of 2 hours and 3 minutes for telephone interpretation. This will now be included in the



long-term service (see Section Three). The East of England Local Ophthalmic Regional Forum has thanked NHSEI for putting this service in place.

Section Two – Pilot Deaf Enhanced Support Service

7. There was also a gap across the whole of the East of England, including Norfolk, for patients who may face greater barriers in accessing primary care and are unable to use existing arrangements. As a result of this feedback, NHSE has developed a pilot for a new service to provide enhanced support to deaf patients. The objective of the pilot is to reduce barriers deaf patients currently face when booking appointments with GPs, dentists, opticians and pharmacists, by enabling them to access an interpreter to book their primary care appointment for them. As there was little data available it was decided to pilot a region-wide service, and during the pilot collect data to inform future provision.
8. The aims of this service are to:
 - provide an enhanced level of support to patients with a sensory impairment;
 - enable patients to communicate when they wish to use Primary Care services in a way that is safe and appropriate
 - deliver equity of access for a vulnerable group; and
 - meet the NHSEI requirements to meet the NHSE's Accessible Information Standards.
9. To implement the pilot there has been non-recurrent funding secured; and an Expressions of Interest (Eoi) process has taken place. From the Eoi stage, four potential providers were identified. There was then an assessment of the responses and from this it was agreed to award the contract to DA Languages as they were best placed to deliver the service on a regional footprint (see Appendix Four for Key Performance Indicators (KPIs)).
10. The service is currently being mobilised with the aim to go-live to start on 19 July 2021 and run until March 2022, with an assessment in early December 2021 to inform next steps.

Section Three - Long Term Future Service

11. A review of Translation and Interpreting services across the East of England showed a patchwork approach to the commissioning and to the breadth and depth of services available. In each local area primary care contractors had different methods of accessing services; and the level of services also differed.
12. Agreement was reached with all Clinical Commissioning Groups (CCGs) in the East of England in January 2021 that NHSEI would commission and lead a procurement on their behalf to secure an East of England Translation and Interpreting Service for all four primary care contractor groups. There is one exception in that Bedfordshire, Luton and Milton Keynes CCG will continue to commission services for GPs separately for Luton as this has recently been procured as a joint appointment with the local council.

13. The aim is to have an interpreting and translation service in place by November 2021 which will cover all four contractor groups¹ and the East of England geography for patients attending for NHS care and will ensure consistency of service and reduce confusion across system boundaries within this geography.
14. To note is that Clinical Commissioning Groups are responsible for commissioning services for general practice (GPs), and NHSEI the remaining groups. This is expected to change over the coming years as proposals are being discussed in Parliament that could potentially enable the delegation of NHSEI's direct commissioning functions (including optometry, dentistry and community pharmacy) to Integrated Care Systems
15. To help inform the service development an engagement exercise was undertaken in 2020 (see Appendix Two). Based on East Anglia data, non-speaking services such as British Sign Language accounts for approximately 15% of all face to face language requests. The responses indicated that this group of patients were most likely to find it harder to access services.
16. The most requested language is Lithuanian; other frequently requested languages include Polish, Romanian, Portuguese, Russian, Arabic, Kurdish Sorani, Chinese Mandarin, Cantonese, Bulgarian, Hungarian, Bengali and Urdu. The intention is to commission telephone services, online virtual access to services and face to face where a clinical need is identified (subject to approval of each request). Written translations of medical records will also be available.
17. The Guidance for Commissioners² published by NHS England was updated in March 2019, and this guidance, together with NHSEI's guidance - Accessible Information Standard has informed commissioning plans. We will work with the appointed provider(s) and CCGs during mobilisation of services to ensure these standards are met.
18. It was agreed with CCGs that the procurement would be based on one of the national Frameworks with local requirements built in. Working with NHSEI's Commercial Team it was agreed to adopt the Crown Commercial Services Framework (CCSF)³. The future contractual arrangements will be based on a Call Off arrangement with key performance indicators (see Appendix Three) and robust performance management measures, including escalation. The procurement will be based on two lots:
 - Non spoken languages; and
 - Spoken languages.
19. It is hoped that splitting the lots in this way will encourage a more targeted approach for individuals who use non-spoken languages with appointment of an expert supplier.
20. The services include:

¹ Excludes GP practices in the Luton area.

² <https://www.england.nhs.uk/wp-content/uploads/2018/09/guidance-for-commissioners-interpreting-and-translation-services-in-primary-care.pdf>

³ <https://www.crowncommercial.gov.uk/agreements/rm1092>

- telephone and online video interpreting;
- Face to Face Interpreting (where clinically required) for non-English speaking patients;
- Face to Face for all non-spoken languages and written translations of medical records.

21. Due to restrictions because of COVID the intention is for telephone interpreting or online services to become the preferred default option for all primary care contractors. We will introduce assessment criteria for face to face interpreting services for non-English speaking languages. This is a change in way services have been historically provided in Norfolk and Waveney and formed part of the engagement exercise. This may revert back to pre-COVID ways of working and we will monitor this.

22. There was a delay in the publication of the updated CCSF to mid-May (from early April), which has in turn resulted in a one-month delay to the procurement. Existing contractual arrangements have been extended to accommodate the delay and will terminate on the 31 October 2021.

23. Approval has been granted by Commercial Executive Group for a contract term of at least five years with a break clause at 3 years. A longer-term contract will provide stability and enable NHSEI to put in place longer term measures to ensure equitable access for all patient groups, including regular training and awareness sessions.

24. The current milestone plan is as follows

Milestone	Initial Timescale	Revised Timescale
i. National service specifications updated to reflect local requirements	Beginning of April	31/05/21
ii. Publish ITT	01/05/21	01/06/21
iii. End of Tender Period	31/05/21	30/06/21
iv. Moderation Panel	21/06/21	15/07/21
v. Due Diligence	21/06/21	15/07/21
vi. Award	22/06/21	16/07/21
vii. Contract Start	01/10/21	01/11/21

25. The timeline provides a three-month mobilisation period which is the minimum required to mobilise services. During this period there will be extensive engagement with patients, contractors, and other key stakeholders to raise awareness, ensure there is a representation of the patients' voice and to carry out any necessary training of primary care staff.

26. The continuing involvement of patients and patient forums, such as Healthwatch, will also be critical throughout the mobilisation of services as well as robust communications and engagement processes.

END

APPENDIX ONE - HOSC update – 25 March 2021

Access to local NHS services for patients with sensory impairments

Thank you for the time afforded to NHSEI in November 2020 to outline the proposals for access to primary care services for individuals with a sensory impairment. Please find below the requested update on the actions raised.

HOSC action	Response
To ensure the 'tell us once' policy is in place and adhered to so that there is improved access for patients with sensory impairments.	<p>For clarify the NHS does not have a policy call "tell us once". However, the NHS recognises the need to ensure that patients care records are shared, where appropriate and with consent, to minimise the need for patients to repeat certain information. This is reflected in the NHS Long Term Plan which sets out the ambition to "set standards that keep information secure and make sure NHS IT systems talk to each other to provide health and care staff with complete access to joined up patient records."</p> <p>The NHS digital vision for a connected health and care records is being progressed with several workstreams in place across the country and regionally. There are many different applications currently used across multiple organisations, which is making progress slower than anticipated.</p> <p>Primary care, however, is doing better in terms of sharing information across the relevant care organisations as there are only a small number of different clinical systems used in primary care. And therefore, most clinicians are accessing the same record, regardless of whether they are a GP or community nurse.</p>
To ensure that all frontline staff receive training in the requirements and implementation of the accessibility standards.	<p>Specific training for frontline staff in GP practices is being developed for Norfolk practices as part of the CCG's Training Hub plans commencing in April 2021.</p> <p>Training and education of all staff within primary care services will also form a key component of the mobilisation plans for the new interpreting contract working in collaboration with the new supplier(s) once appointed. Mobilisation will take place during June – end Sept 2021 and there will be an ongoing requirement under the new contract terms for the new supplier to undertake a rolling programme of training in conjunction with the CCG.</p> <p>NHSEI sent out a reminder in December 2020 to all primary care services across the region about their obligations under the Equality Act and the NHS Accessible Information Standard to make reasonable adjustments where appropriate and necessary to ensure equitable access for all patients.</p> <p>When a concern is raised, this is followed up with the individual contractor to ensure remedial action is taken and any training needs addressed.</p>
	The current Call Off Contract with DA Languages and Crown Commercial Services Framework document

HOSC action	Response
To review training of BSL interpreters to ensure suitable skill for local needs.	<p>stipulate the level of qualification and standards required of all interpreters delivering services under the contract.</p> <p>Contractors are requested to evaluate individual interpreter performance and report any concerns after each appointment.</p> <p>The commissioners regularly review all concerns raised with DA Languages that relate to the service they provide to ensure that if the concern is found to relate to an individual interpreter performance, remedial action is taken to address any training issues or gaps.</p> <p>We have asked DA Languages to undertake a review of training and to report their findings and any subsequent actions to NHSEI by end April 2021.</p>
To make a contract variation to enable patients to ask a BSL interpreter to make an appointment for them, to protect their privacy and dignity.	<p>The existing contract does not allow patient access to directly contact interpreters. NHSEI has discussed this option with the current provider and are unable to vary the contract at this stage. We are however planning to pilot a scheme from May 2021 to offer BLS to those patients that need it.</p> <p>This will include making and attending appointments and follow up afterwards to ensure they receive the care, guidance and treatment they need. This will be evaluated with an aim to contracting a service from April 2022.</p>
To ensure a rapid response to members of the public who are currently having difficulty accessing services.	<p>Different models for interpreting services are in place to support patient choice, including face to face interpreting services and online virtual access.</p> <p>The commissioners will ensure that any member of the public having difficulty accessing services who contacts them will be given appropriate advice and support to access services in a timely manner. Individuals are recommended to contact their local CCG PALS service in the first instance.</p> <p>The contract with DA Languages requires the supplier to respond to a routine booking request within 6 hours and an urgent request within 2 hours.</p>

APPENDIX TWO: Engagement Report

East of England NHS Interpreting Service Survey Non-Spoken Languages

Engagement Conducted by Cambridgeshire Deaf Association
Report written by NHS England and NHS Improvement
Translation and Interpreting Project Team

December 2020

Introduction

Within the East of England, there are multiple arrangements in place for interpreting and translation services for patients accessing primary care services. A patient and key stakeholder engagement exercise commenced in July 2020, with a view to procuring a new contract commencing April 2021. Including learning from previous experiences, the engagement sought to identify the different arrangements currently in place that restrict or enhance equitable access to services for both spoken and non-spoken languages. The outcome of the engagement would inform the specification and aspirations for services when tendering for a new contract.

By commissioning the service across the region, the CCGs will benefit from economies of scale as well as the adoption of a consistent approach to reducing health inequalities for these patient cohorts. Subject to final approval, the procured service will cover all Primary Care disciplines; Medical, Dental, Community Pharmacy and Optometry.

This report specially looks at the engagement exercise conducted for non-spoken languages, including what platform was used, why and the results.

Pre-Consultation Engagement Phase

In the pre-consultation engagement phase, insights from local Deaf charities and organisations across the East of England were sought. The exercise gathered general feedback on the best way to engage with individuals in the East of England who are Deaf, hard of hearing or who are Deafblind.

After several discussions with Deaf organisations and charities, an online survey in written English, Sign Supported English (SSE) and British Sign Language (BSL) where respondent could take part using any of those was determined to be the best course of action considering the Covid restrictions. A paper survey was also available on request and was communicated to organisations along with the link to the online survey.

Engagement Exercise

An online survey and a written survey were used to conduct the patient engagement, using the same questions as far as was practicable as those used in the interpreting service telephone surveys conducted by Arden and Greater East Midlands Commissioning Support Unit for spoken languages other than English. These questions were adapted to be applicable to those who are Deaf, Deafblind or hard of hearing. The online survey was live from Friday 23rd October at 17:00 to Thursday 26th November at 17:00, at which point the results were taken for this report. The survey remains open during the procurement and results will be checked regularly.

Cambridgeshire Deaf Association focused on contacting the Deaf organisations across the region and were available to support individuals to complete the survey. Cambridgeshire Deaf Association contacted the following organisations;

- | | |
|---|---|
| - PCCDCS | - My Sign Tuition |
| - Sense Peterborough | - Deafblind UK |
| - Access Bedford | - Deaf Connexions |
| - Sense Norfolk, Cambridge, Bedford and Suffolk | |
| - Norfolk Deaf Association | - Ipswich Deaf Society |
| - Peterborough Deaf Club | - Royal national Institute for the Deaf |
| - Luton Deaf Club | - Essex Deaf Ramble Group |

- Colchester Deaf Club
- West Norfolk Deaf Association
- Hearing Advisory of Hertfordshire
- Hertford Deaf Club
- Cambs Deaf Church
- Essex Deaf Child's Society
- Bury Deaf Association
- Heathlands BSL Centre
- Jack Hunt School
- Royal Association for Deaf people
- Cambridgeshire Hearing Help
- Hearing Advisory Suffolk
- Phoenix Group for Deaf People Hertfordshire
- Welwyn Hatfield Deaf Club
- Forest Deaf Club
- Norwich and Norfolk Deaf Social
- Heathlands School
- Oaklands College
- Middleton Primary School

The NHS England and NHS Improvement Translation and Interpreting project team also reached out to Deaf organisations, charities and patient forums in the East of England. The following additional organisations were contacted;

- Ipswich Deaf Association
- Healthwatch Cambridgeshire & Peterborough
- Royal Association for Deaf People, Deaf Parents Deaf Children
- Phoenix Group for Deaf Children and Young Adults
- Stevenage Deaf Club
- Come and be heard
- Deafblind UK
- Bury St Edmunds Deaf and Hard of Hearing Association
- Ipswich Deaf Children's Society
- Hand in Hand
- Lowestoft & District Deaf Society
- Healthwatch Essex
- Healthwatch Thurrock
- Healthwatch Norfolk
- Cambridge Hard of Hearing Club
- Sensing Change
- Hemel Morning Deaf Group
- Action on Hearing Loss

Cambridgeshire Deaf Association have reported that the online survey reached 13,000 people, with the video being viewed 6,000 times. In total, the survey was completed by 136 individuals from within the East of England region.

Survey Results

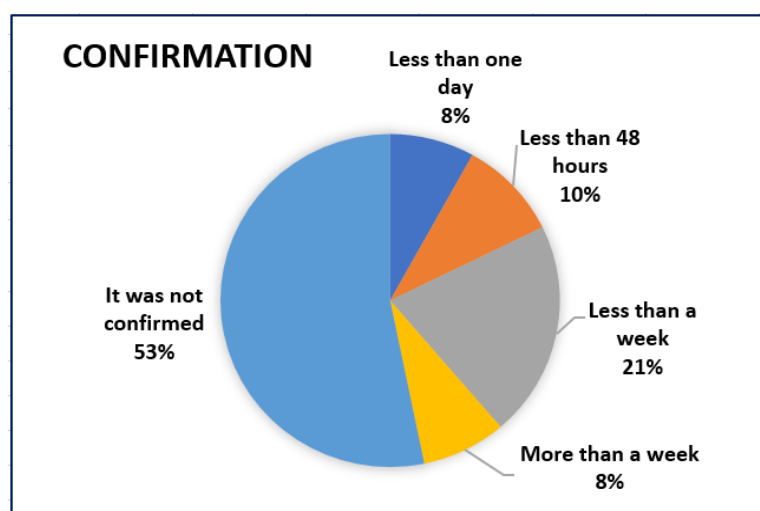
Due to the way the survey was conducted and that respondents could respond either using the set multiple choice or by uploading a BSL or SSE video, some individuals provided several answers to one question. Owing to confidentiality and the vast amounts of data received, responses to the open questions have been categorised to assist with the analysis. Direct quotes have been used where it is not immediately clear what the respondent meant in order to prevent the data being misconstrued. All responses received have been included in the results and presented in the clearest way possible, found at Annex 1. A summary has been provided below.

Participation

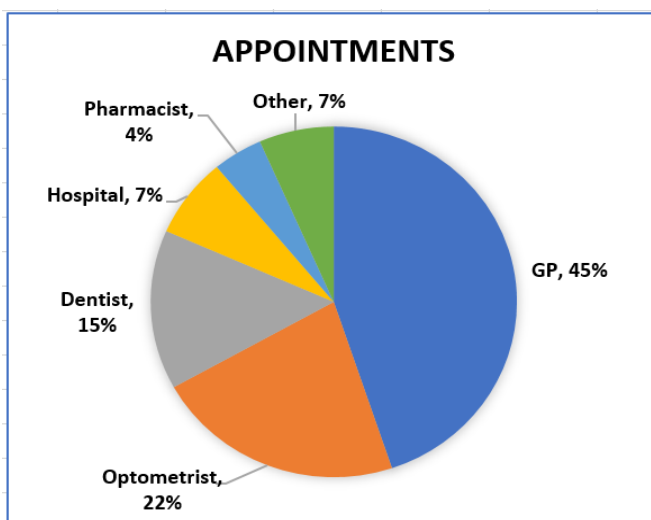
A total of 136 individuals completed the online interpreting survey with a good geographical split, with more responses from individuals living within Norfolk and Cambridgeshire & Peterborough. A section of equalities monitoring questions were added in order to understand the demographic characteristics of the respondents.

Historical use of the service

The results show that 83 (61%) of the respondents had **used the NHS Interpreting service**, compared with 47 (35%) who had not. By far the most common **language respondents required the interpreter to speak** was BSL with 91%. When asked if they **took somebody along to their appointment** to help with the interpreting in addition to the interpreting service, 29% had done so. In addition, 40% of service users reporting that they had at least one experience of **a booked interpreter not attending** their appointment. Although not asked directly, it is possible to infer from this that one third of service users may not trust the level of interpreting available or not trusted that the interpreter will show up.

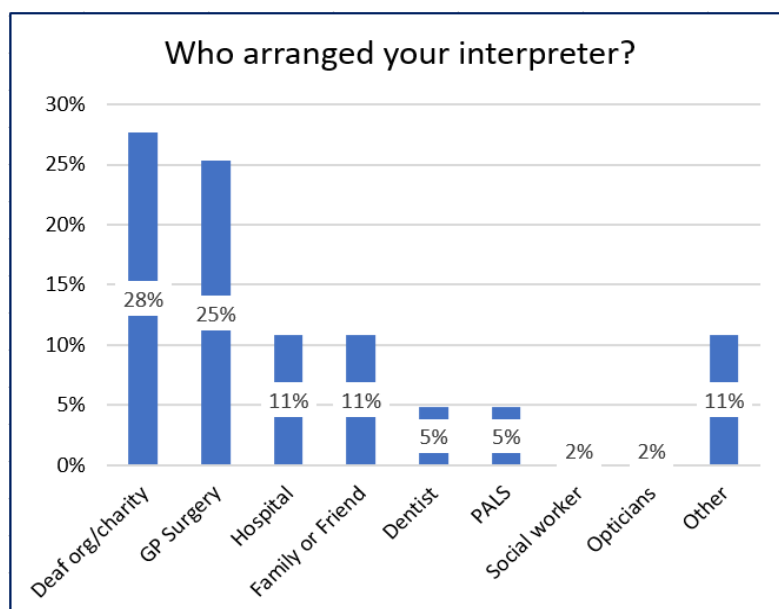


When service users were asked how long it took to receive **confirmation that an interpreter was available**, 53% reported that it was not confirmed and thus the individuals could have taken someone along with them to translate as they did not receive confirmation that an interpreter would be present for their appointment.



The service users needed the NHS Interpreting Services for a broad **range of appointments**, with 45% of individuals using the service for GP appointments, 22% for Optician appointments and 15% for Dentist appointments.

However, **when asked who arranged the interpreter** for them, the results differ suggesting that patients are making appointments and booking an interpreter separately. Possible reasons for this may include that individuals are not aware of the NHS Interpreting service ahead of the appointment or may find the process of requesting or booking an interpreter via the provider too complex or unreliable. Only 13% of service users were unaware that a free translation service was available.



Although some individuals may be **aware of the NHS Interpreting service**, they may find it hard to find the information on the service. The results show that 59% of service users found **information on the interpreting service** difficult to find, 30% found it available on request and only 11% found it easily available.

When asked **how this could be improved** the top results were -

- 17% for the interpreting service to be better advertised
- 17% for staff to be Deaf aware and communicate to them in their language
- 16% for professionals to know how to book interpreters
- 13% for the patients to have access to a booking system so they do not have to rely on others

Some of the responses are shown below -

"There should be an option sent to everyone when an appointment is made and, in the options listed out, it should ask if we need an interpreter...."

“There should be access for Deaf people, why should I have to ask my Mum? I am a grown man, and she is getting old.”

“They should automatically show up on the Drs computer database that I need an interpreter...”

“There is no information on how to book an interpreter. There is no way I can book an interpreter myself.”

Experience of booking an Interpreter

When service users were asked if they had experienced any **barriers when booking an interpreter**, 71% reported that they had, 29% reported that they had not-which shows that two thirds of service users state they are facing barriers to accessing healthcare.

When asked to list these barriers, there was a significant range of responses -

- 27% was that they were unable to ask for an interpreter
- 20% felt the barrier was the interpreter not showing up
- 17% that it was an interpreter not being available
- 14% that providers are unable to provide an interpreter for short notice appointments

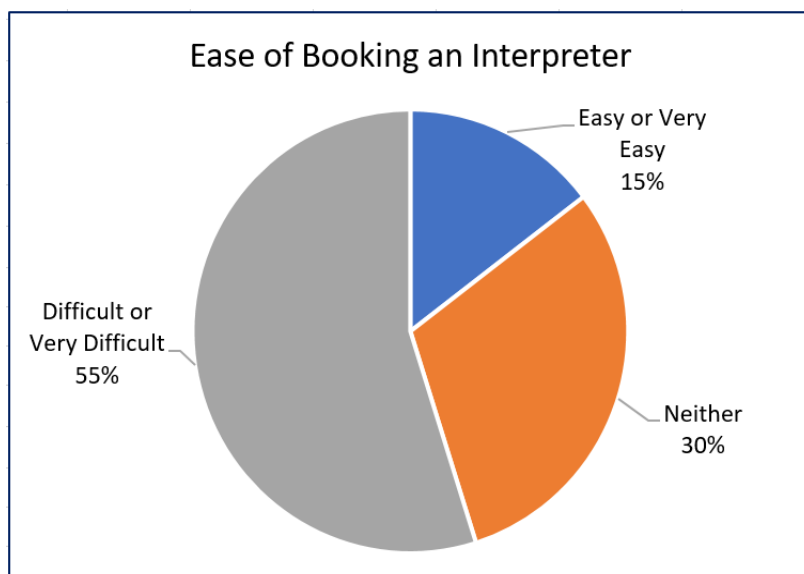
Some of the responses shown below provides further insight into the barriers Deaf people face -

“We do not know who the interpreter is. We do not know if they will turn up.”

“We can’t request a health appointment so Deaf people are entirely excluded from primary care.”

“Advocate asked surgery and dentist to get an interpreter, but they said they couldn’t get one. How am I supposed to talk to them? I don’t understand what doctors say, he write things down but I don’t read English. My language is BSL.”

“Reception at doctors, dentist don’t sign. So how can I ask for an appointment and interpreter? I have to ask a friend. It’s embarrassing. I want to be private.”



When asked **how easy it was to book an interpreter**, only 2% found it very easy, whereas 25% found it very difficult. Further emphasising the barriers to equable service access.

Some of the responses shown below provides further insight into the issues the service users face -

"The service needs to ensure primary health is Deaf accessible from requesting an appointment to the actual consultation."

"I would like my preferences for the interpreter being used to be taken into account. NHS appointments are personal, and it is important to feel comfortable with the particular interpreter in attendance and confident in the information being transferred."

"I cannot book. There is no contact for the Interpreter service. I cannot ask my GP to book, they do not have fax or text. If I go see them, they do not sign. It is not accessible."

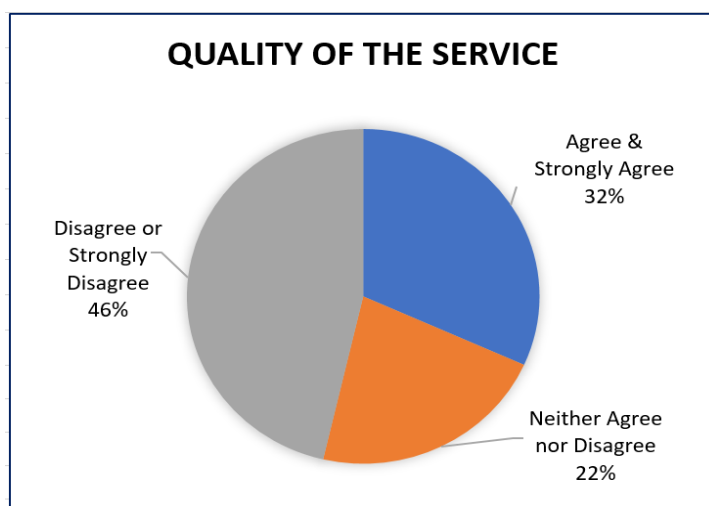
"When my children have an appointment, I do feel left out as they are hearing and they can consult with the GP. I can't catch what is happening in the appointments. When I know hearing parents can be there and support, I feel my responsibility as a mother is not fair and I do feel sad about that. I like to know what is going on, what the medication is for, how to take it and how to support my children through their appointment."

Experience of the current NHS Interpreting Service

When asked if there was ever a time when they **needed an interpreter and one was not available**, 85% of service users responded with yes, and only 15% had never experienced it.

For those who answered yes, they were asked to provide the reason an interpreter was not provided. The most popular responses were -

- 37% stated an interpreter was not available for the language required
- 14% stated the interpreter not showing up to the appointment
- 9% that an interpreter was available for short notice appointments



When asked to consider the **quality of the service** by being asked to what extent they agreed with the statement 'The interpreting service was efficient, professional and gave me the confidence when attending my NHS appointment', 40% strongly disagreed with that statement.

The main reasons for this reported by the service users was the poor quality of interpreters (16%) and that the interpreters cancel, rearrange or do not show up to appointments (12%). Some of the responses have been included below which show the issues the respondents have faced.

"Sometimes there has been an interpreter, but they are not qualified enough for their role. BSL Level 6 and interpreter qualifications are really important..."

I never know who it will be or if they will turn up. I don't know what they look like, man or woman."

"Because I didn't get interpreters to my appointment. It's hard to get appointments at all because receptionists can't sign and I can't use English. Who can I ask to book an appointment?"

When asked **what was good about the interpreting service** provided –

- 26% stated the quality of translation
- 26% thought it commendable that the interpreter turned up
- 11% said that nothing was good about their experiences

When asked **what would improve the service** -

- 11% wanted to be able to book their own appointments
- 10% would like a local interpreter
- 10% would like confirmation that an interpreter has been booked
- 10% wanted providers to know how to book an interpreter with no issues

Some of the responses have been included below -

“Having the NHS systems recognise that I am Deaf and need a BSL interpreter would be very useful. Currently I have to request an interpreter each time.”

“Would be good to have an appointment with a doctor within 48 hours rather than waiting a week to allow time for an interpreter to be booked. Sometimes urgent health issues cannot wait for a week.”

“Interpreters should be booked to start 15 minutes before the actual appointment time. This would allow me time to brief the interpreter on the background of the appointment and give them any contextual information they need in order to be able to fully understand the appointment...”

“In the GP waiting rooms, please advertise this and make it clear how to book an interpreter...”

“Would like more time with the interpreter, possibility after the appointment to clarify things.”

“It would be improved if it was a strictly enforced requirement that all interpreters are BSL Level 6, interpreter qualification and continued professional experience and development.”

Requirements of a new NHS Interpreting Service

When asked what would be most important when using the interpreting service –

- 13% wanted a reliable service
- 13% wanted a local interpreter
- 13% wanted confirmation that an interpreter had been booked and who they are
- 12% wanted qualified and registered interpreters.

Other areas highlighted have been included below.

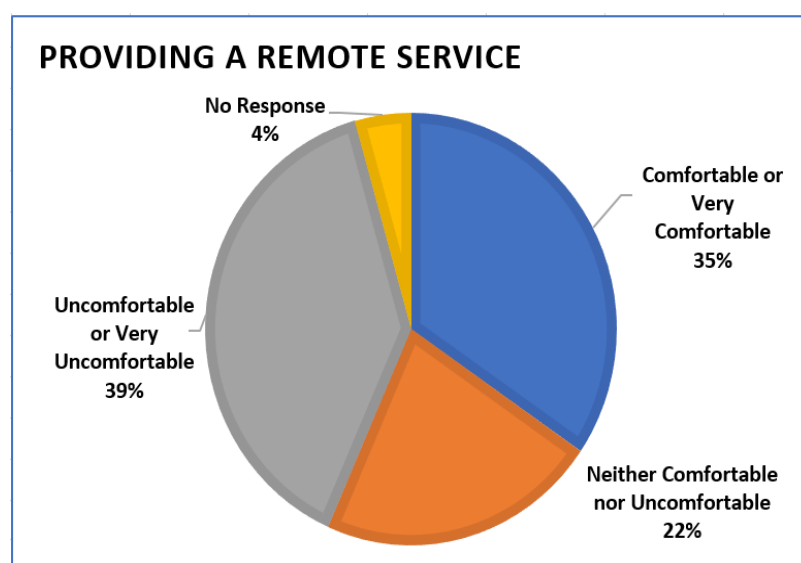
“The interpreter is available 15 minutes before the appointment so that they can be briefed about the background and context of the appointment.”

“We appreciate it when the BSL Interpreter can adapt and adjust if we sign SSE and translate back to us in SSE.”

“A trusted local interpreter, with a yellow badge. I want to know who it is so I know who I am looking for.”

“I can get an interpreter for an emergency appointment... I don't have to wait 2 weeks for an urgent health problem.”

Virtual Interpreting



There were mixed results when respondents were asked **how they felt about a virtual interpreting service**, with only 13% feeling “very comfortable” compared to 31% who would feel “very uncomfortable”

When asked what the **advantages of a virtual interpreting service** would be;

- 19% felt that it would be quicker, smoother, easier and offer more flexibility
- 15% felt it would help with having short notice appointments
- 11% felt there would be no advantage

When asked what the **disadvantages of a virtual interpreting service** would be –

- 26% were concerned about IT issues
- 9% were concerned about the quality of interpretation
- 9% were concerned about the lack of privacy

Summary of Recommendations

The survey results have highlighted several barriers that Deaf, Deafblind or hard of hearing people in the East of England have faced with the existing service and has highlighted several areas of improvement. These areas of improvement have been categorised and listed below.

Provider requirements

- Primary Care Services to have full knowledge of the service and how to book an interpreter
- Primary Care Services to advertise the NHS interpreting service
- Primary Care Services to receive Deaf awareness training, understanding the barriers Deaf people face and the importance of an interpreter
- Primary Care Services to offer video interpreting as a choice

Booking an interpreter

- For NHS systems to record that the individual needs an interpreter to ensure they have access to one for appointments
- For an interpreter to be booked at the same time as an appointment
- Explore the possibility of patients being able to book an interpreter themselves
- For the patient to receive prompt confirmation that an interpreter has been booked
- To receive information about the interpreter so they know who to look for and whether there might be Conflict of Interest concerns

Interpreter requirements

- Interpreters to have a set level of qualification i.e. Level 6
- Interpreters to have significant medical interpreting experience
- Interpreter to be adaptable to the patient to support their understanding
- Interpreters to wear their National Register of Communication Professionals (NCPD) badge so there can be easily identifiable
- Interpreters that know local sign

Service requirements

- Deaf patients to have the option of same day appointments
- Deaf patients to be informed in a timely fashion if the interpreter is unable to make the appointment

- The time slot with an interpreter to be extended, so they get time before the appointment to provide context and after the appointment to clarify areas. This would also ensure the interpreter is available in case the appointment is pushed back
- Deaf patients to have their letters interpreted
- To be offered a choice of interpreter if possible, or the same interpreter be allocated, in the hope of achieving some continuity of care
- Deaf patients to be asked for feedback in a confidential manner
- The option of video conferencing to be considered for a minority of appointments based on patient choice

NHSE/I

- To ensure that any interpreting service change is communicated to Deaf patients effectively
- To ensure that Deaf organisations/charities are aware of any provider change to help with sign posting
- To commit to an ongoing campaign of awareness of the service, including providers
- To have access to an interpreter in all four primary health groups
- To routinely monitor service user feedback to ensure the barriers identified in accessing healthcare are being tackled and mitigated

Future Engagement

The pre-consultation engagement phase was successful in identifying the preferred option of engagement considering the Covid restrictions. However, whilst the survey results have highlighted the several areas Deaf people in the region would like from an interpreting service, some areas need greater exploration and the possibility of holding focus groups will be explored.

Annex 1: Full Survey Results

1. Would you like the questions in BSL?

	Number	Percentage
Yes	51	37%
No	77	57%
Did not provide a response	8	6%

2. Would you like to reply in BSL?

	Number	Percentage
Yes	47	34%
No	77	57%
Did not provide a response	12	9%

Historical Use of NHS Interpreting Service

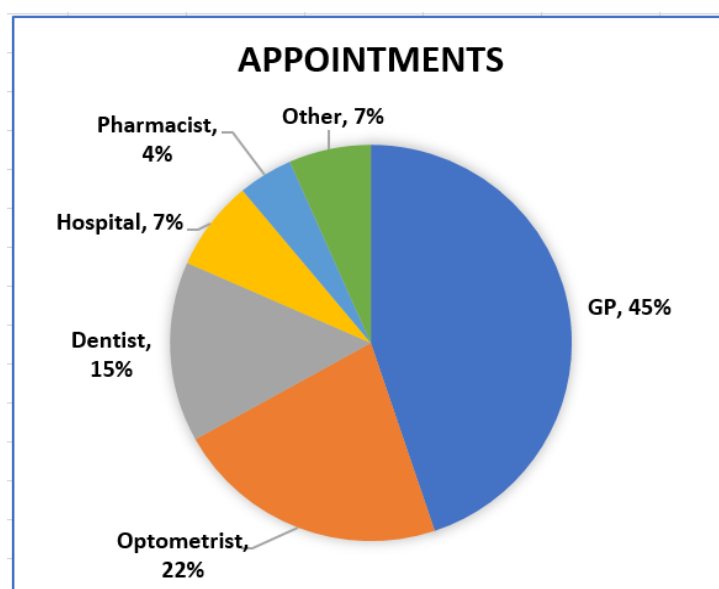
3. Have you ever used the NHS Interpreting service?

	Number	Percentage
Yes	83	61%
No	47	35%
Did not provide a response	6	4%

Those who had used the NHS Interpreting Service were then asked the following questions –

4. For which appointment(s) did you use an interpreting service?

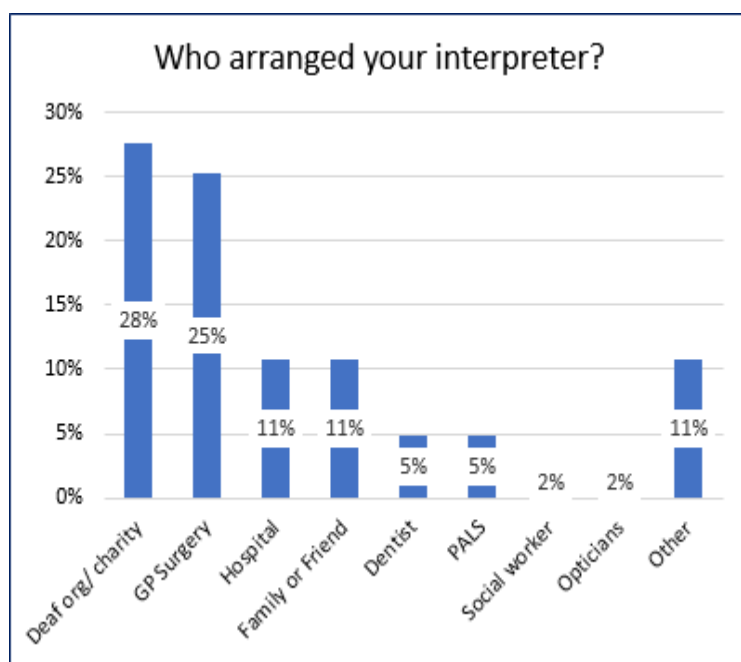
	Number	%
GP	61	45%
Optometrist	30	22%
Dentist	20	15%
Hospital	10	7%
Pharmacist	6	4%
Hearing test	1	1%
Physio	1	1%
Midwife	1	1%
Audiology	1	1%
Radiotherapy	1	1%
Other	1	1%
Oral maxillofacial dept	1	1%
Psychotherapy	1	1%
NHS	1	1%



5. Were you aware that a free interpreting service was available before your appointment?

	Number	Percentage
Yes	71	87%
No	11	13%

6. Who arranged the interpreter for you?

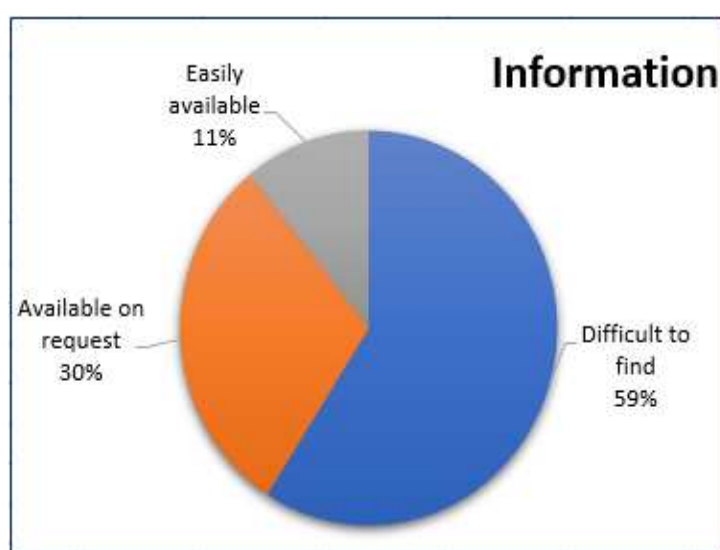


	Number	Percentage
Deaf org/charity	23	28%
GP Surgery	21	25%
Hospital	9	11%
Family or Friend	9	11%
Dentist	4	5%
PALS	4	5%
Social worker	2	2%
Opticians	2	2%
Unsure	2	2%
Physiotherapist admin	1	1%
Interpreter at work	1	1%
Advocate service	1	1%
Themselves	1	1%
NHS	1	1%
'am happy'	1	1%
'I asked them to book'	1	1%

7. Did you take somebody to your appointment to help with the interpreting in addition to the NHS interpreting service?

	Number	Percentage
Yes	24	29%
No	58	71%

8. Was the information on the interpreting service you needed:



	Number	Percentage
Difficult to find	49	59%
Available on request	25	30%
Easily available	9	11%

9. How could this information be improved?

Responses extrapolated from video and written comments, the 83 respondents may have mentioned more than one mitigation. Percentage is that of respondents so total is >100%

	Number	Percentage
For the interpreting service to be advertised/communicated, including posters in GP surgeries, leaflets, instructions, letters, text messages, social media, newsletters, GP websites, email signature and appointment letters	14	17%
Staff need to be Deaf aware/ Communication to them in their language (BSL)	14	17%
Help professionals know how to book an interpreter	13	16%
Deaf patients to have access to a booking system so they do not have to rely on others	11	13%
Getting confirmation and information on the interpreter booked, with contact details	9	11%
Be able to contact the interpreting provider to arrange appointments	6	7%
Be able to get same day appointments with an interpreter/ have on-call interpreters	3	4%

Required level of interpreter	3	4%
BSL video showing information on the service	2	2%
Not to cancel an appointment when an interpreter cancels/ cannot find an interpreter	2	2%
Reliable interpreter	2	2%
Change from the current provider	2	2%
BSL video explaining if there is a change in provider	2	2%
Interpreter to have the confidence to challenge the health professional if the patient requires it	1	1%
Interpreter to get to know the patient	1	1%
Providers to be aware that the service exists	1	1%
The GP database to tell the surgery that I need an interpreter	1	1%
An interpreter to be booked when an appointment is made	1	1%
'Delivered in BSL'	1	1%
Have a Deaf charity/organisation as a signpost/point of contact	1	1%
To have the option of face to face appointments	1	1%
Interpreting provider to translate letters	1	1%

10. Which language did you require the interpreter to speak?

	Number	Percentage
BSL	69	91%
SSE	4	5%
Interpreter	1	1%
BSL or SSE	1	1%
English	1	1%

11. Did the booked interpreter attend the appointment?

	Number	Percentage
Yes	50	60%
No	33	40%

Experience of Booking an Interpreter

12. Have you experienced any barriers when booking an interpreter?

	Number	Percentage
Yes	59	71%
No	24	29%

13. Please list the barriers you faced and any comments.

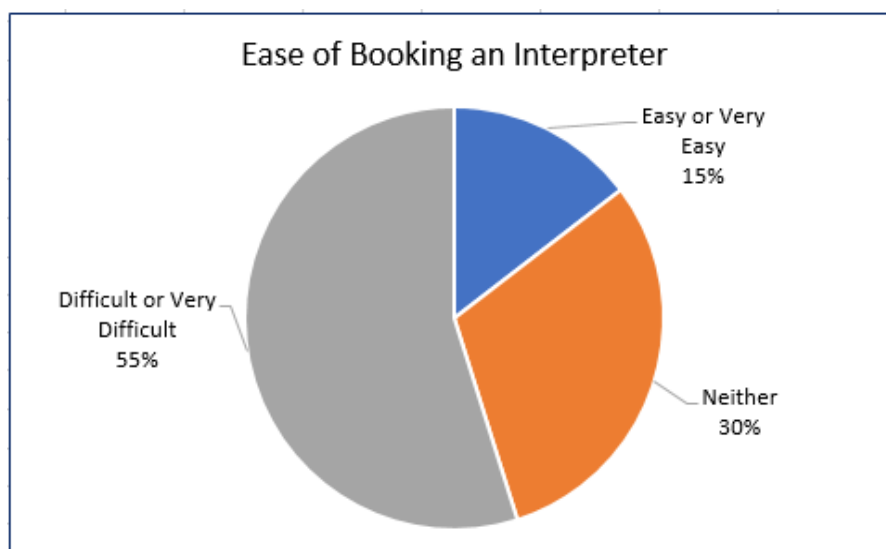
Responses extrapolated from video and written comments, the 83 respondents may have mentioned more than one mitigation. Percentage is that of respondents so total is >100%

	Number	Percentage
Unable to ask for an interpreter	22	27%
Interpreter did not show up to the appointment	17	20%

An interpreter was not available	14	17%
Unable to provide an interpreter for short notice appointments / long wait times for interpreters	12	14%
No communication that an interpreter was booked	9	11%
Refused to book an interpreter (3 Opticians, 1 Hospital, 1 Dentist, 2 Unknown)	7	8%
Staff writing things down for Deaf people in English, but they do not speak/read English	7	8%
Quality of interpreter was poor, resulting in incorrect translation	6	7%
Interpreter arrived late	4	5%
No communication when an interpreter was not available	4	5%
GP practice would not book an interpreter	3	4%
Require information on the service/how to book an interpreter	2	2%
An interpreter was not booked for their appointment	2	2%
Not having a consistent interpreter	2	2%
The interpreter was hostile	2	2%
Appointment was cancelled	1	1%
Only offered a telephone appointment	1	1%
Wrong type of interpreter present for the appointment	1	1%
Not offered a written interpreting service	1	1%
Not offered a local interpreter	1	1%
Not offered an online interpreter	1	1%
Unable to get the interpreter they wanted	1	1%
Cannot confirm the name of the interpreter booked	1	1%
'maybe you can text me? Or give letter'	1	1%

14. On a scale of 1-5, how easy was it to book an interpreter?

	Number	Percentage
1 Very easy	2	2%
2 Easy	10	7%
3 Neither easy nor difficult	25	18%
4 Difficult	11	8%
5 Very difficult	34	25%



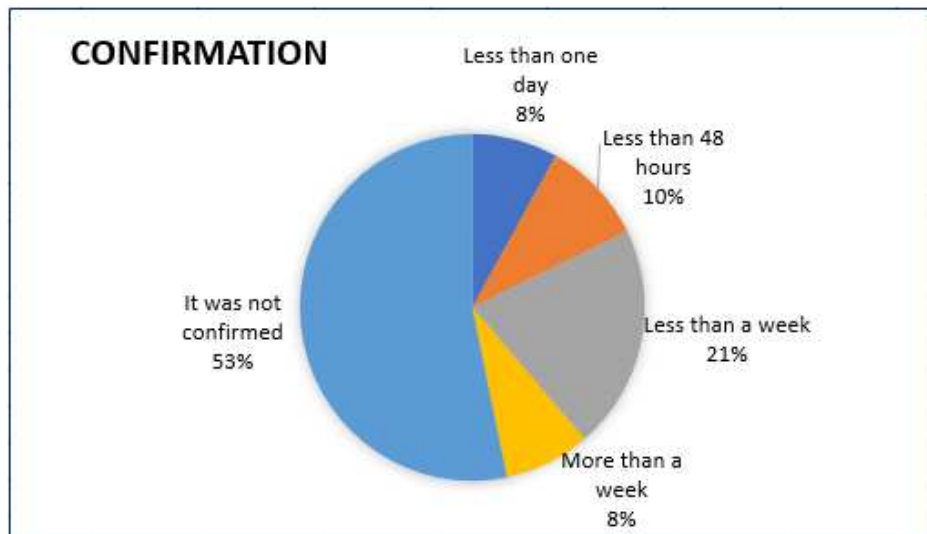
15. Do you have any other comments on how easy it was to book an interpreter?

Responses extrapolated from video and written comments, the 83 respondents may have mentioned more than one mitigation. Percentage is that of respondents so total is >100%

	Number	Percentage
Impossible/ not easy to book an interpreter	25	30%
Had to ask a friend/family member/colleague, Deaf charity to book for them	7	8%
Staff did not book an interpreter for the appointment	5	6%
Want to know who the interpreter will be	4	5%
Easy to book an interpreter	4	5%
Unable to book an interpreter as unable to ask for one	4	5%
Would like to book an interpreter themselves	4	5%
Unable to get an interpreter for short notice appointments	3	4%
No confirmation that an interpreter has been booked	2	2%
Do not know how to book an interpreter	2	2%
Do not have confidence in the interpreter showing up	2	2%
They do not know or understand the interpreter	1	1%
They have had to call the provider to arrange the interpreter themselves	1	1%
The interpreter does not show up to the appointment	1	1%
Was easier to book an interpreter when they could fax	1	1%
Would like a local interpreter	1	1%
Would like appointment letters to be interpreted	1	1%
Primary Health Care needs to be Deaf accessible, from requesting the appointment to the actual consultation	1	1%
Be able to contact the provider to ensure an interpreter had been booked	1	1%
Would like to be able to request a specific interpreter	1	1%
Want an interpreter to be booked at the same time as the appointment	1	1%
Staff are not Deaf aware	1	1%
Face to face appointments are required	1	1%
Would like an interpreter to be booked when attending their children's appointments	1	1%
No Comment made	28	34%

16. How long did it take to receive confirmation that an interpreter would be available for you?

	Number	Percentage
Less than one day	7	5%
Less than 48 hours	8	6%
Less than a week	18	13%
More than a week	7	5%
It was not confirmed	45	33%



17. Was there ever a time when you needed an interpreter and one was not available?

	Number	Percentage
Yes	70	85%
No	12	15%

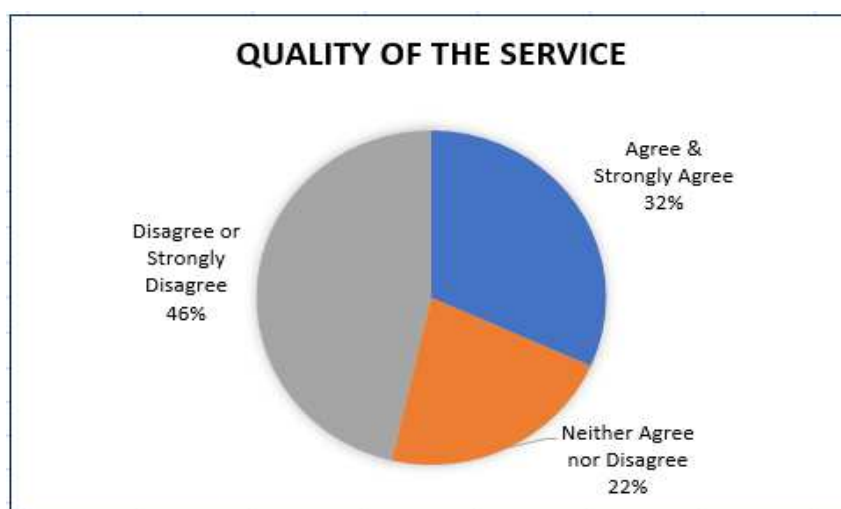
18. If you answered Yes, please describe the language you needed interpreting and the reason an interpreter was not provided.

	Number	Percentage
BSL: An interpreter was not available	21	26%
BSL: An Interpreter did not show up to the appointment	11	14%
An interpreter was not available	9	11%
BSL: An interpreter was not available for short notice appointments	7	9%
BSL: An interpreter was not booked	4	5%
BSL	4	5%
Although my medical records show I am Deaf, an interpreter was not booked	3	4%
BSL: Opticians would not book an interpreter	3	4%
BSL: Dentist would not book an interpreter	3	4%

BSL: The interpreter cancelled on the day	2	3%
BSL: Staff did not know how to book an interpreter	2	3%
SSE: Staff did not know how to book an interpreter	2	3%
Opticians would not book an interpreter	2	3%
GP surgery would not provide an interpreter	1	1%
Dentist would not provide an interpreter	1	1%
Provider unwilling to pay for an interpreter	1	1%
BSL: Did not get the interpreter they wanted	1	1%
BSL: Cannot remember	1	1%
Interpreter did not turn up	1	1%
'And a confirmation of rebook date'	1	1%

**19. To what extent do you agree or disagree with the following statement:
'The interpreting service was efficient, professional and gave me confidence when attending my NHS appointment'**

	Number	Percentage
Strongly agree	11	13%
Agree	15	18%
Neither agree nor disagree	18	22%
Disagree	5	6%
Strongly disagree	33	40%



20. Please tell us the reasons for your answer.

Responses extrapolated from video and written comments, the 68 respondents may have mentioned more than one reason. Percentage is that of respondents so total is >100%

	Number	Percentage
Poor quality of interpreter lead to incorrect translation	13	16%
The interpreter cancelled / rearranged / did not show up	10	12%
Never been provided with an interpreter	6	7%
Staff are not Deaf aware	6	7%
Would prefer a local interpreter	4	5%

The interpreter was not confirmed	4	5%
Received no information on who the interpreter was	4	5%
No problems	3	4%
Not able to get a short notice appointment	3	4%
Unable to book an appointment by themselves	3	4%
'ok' service	2	2%
Interpreters can be patronising	2	2%
Would like to choose between a male or female interpreter	2	2%
The service is unclear	2	2%
No interpreter was booked	2	2%
poor' service	2	2%
The wrong type of interpreter was booked	2	2%
Inconsistency of interpreter	2	2%
Interpreter books appointments for them	2	2%
An interpreter is unavailable	1	1%
Not informed of the provider change	1	1%
The interpreter was late	1	1%
Not comfortable with some of the interpreters	1	1%
Do not want a family member to interpret due to privacy	1	1%
Have not experienced the service	1	1%
Want to be treated with equality	1	1%
Always able to get an interpreter	1	1%
Unable to choose their interpreter	1	1%
Cannot understand the interpreter	1	1%
Would like to be able to book an interpreter themselves	1	1%
Various experience, some good and some bad	1	1%
Interpreter has little medical interpreting experience	1	1%
It is difficult to access the service	1	1%
'There is no interpreting service'	1	1%
Interpreting is essential so they understand what is going on	1	1%
'Will explain on call chat is possible'	1	1%
Bad previous experience	1	1%

21. What was good about the interpreting service providing for you?

Responses extrapolated from video and written comments, the 62 respondents may have mentioned more than one reason. Percentage is that of respondents so total is >100%

	Number	Percentage
Quality of the translation	16	26%
The interpreter turned up	16	26%
Nothing	13	21%
Helpfulness of interpreter	9	15%
Good communication	2	3%
Professional	2	3%
The interpreter understood them	2	3%
Continuity of interpreter	1	2%

Friendly	1	2%
The service books the appointment for them	1	2%
Received confirmation	1	2%
Interpreter was available at short notice	2	2%
Full access and information	1	2%
'it is ok'	1	2%
'it is free'	1	2%
Happy with the service provided	1	2%
Not good, but better than nothing	1	2%
Assistants sent when the interpreter is not available	1	2%

22. What would improve the interpreting service provided for you?

Responses extrapolated from video and written comments, the 62 respondents may have mentioned more than one reason. Percentage is that of respondents so total is >100%

	Number	Percentage
To be able to book their own appointments	11	11%
Would like a local interpreter	10	10%
Services know how to book interpreters with no issues	10	10%
Would like confirmation that an interpreter has been booked and who they are	10	10%
To be able to book short notice appointments	8	8%
Using 'Deaf Connexions'	8	8%
The interpreter will show up	6	6%
A set qualification level for the interpreters	4	4%
To be able to book an interpreter themselves	5	5%
For medical records to inform staff that they require an interpreter	3	3%
Staff to be Deaf aware	3	3%
Right type of interpreter to be booked	2	2%
Interpreter before, during and after the appointment to clarify areas	2	2%
Staff who can sign	1	1%
Continuity of interpreter	1	1%
'Happier' interpreter	1	1%
An interpreter to be booked at the same time as the appointment	1	1%
Interpreter to wear their NCPPD badge	1	1%
Reinstate fax machines	1	1%
Have a designated person at each hospital/GP surgery	1	1%
GPs to understand their legal duty to book an interpreter	1	1%
The option of a video call interpreter	1	1%
Help with talking to services to book an appointment	1	1%
Be able to ask for a specific interpreter	1	1%
An interpreter is booked in good time	1	1%
The service is advertised more	1	1%
Simple/clearer process	1	1%
To be an NHS/nurse discipline	1	1%

Requirements of a new NHS Interpreting Service

23. Please describe what would be most important to you if you needed the interpreting service?

Responses extrapolated from video and written comments, the 68 respondents may have mentioned more than one reason. Percentage is that of respondents so total is >100%

	Number	Percentage
Reliable service (interpreter to show up / not cancel / show up on time)	15	13%
Local interpreter	15	13%
Confirmation that an interpreter has been booked and who they are	14	13%
Qualified and registered interpreter	13	12%
Have access to an interpreter	8	7%
Interpreter to be available short notice	7	6%
To access services independently	6	5%
Continuity of interpreter	5	4%
Be able to choose an interpreter (by name or gender)	4	4%
Access to the right information	3	3%
Interpreter to be available before, during and after the appointment	3	3%
Simpler, more accessible service	3	3%
Adaptable interpreter to meet the patients' needs	3	3%
Help with getting their prescription after the appointment	2	2%
An interpreter to be booked at the same time as the appointment	2	2%
Experienced interpreter	1	1%
Information on what to do if the interpreter fails to attend	1	1%
Friendly interpreter	1	1%
The right type of interpreter to be booked	1	1%
Deaf Connexions	1	1%
Clear communication, without barriers	1	1%
Be able to understand the interpreter	1	1%
The interpreter to access my health records	1	1%
'If I lost my implant, I would have no idea if for example I was in RTC'	1	1%

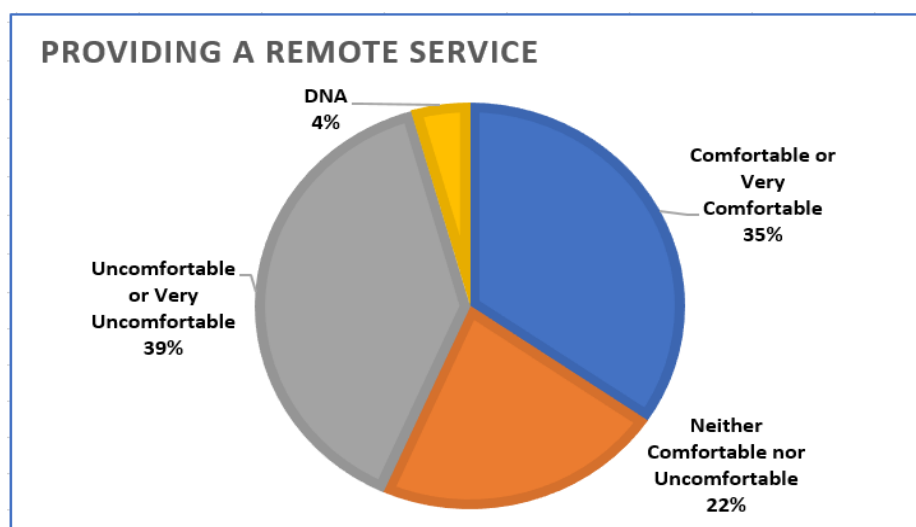
Virtual Interpreting

24. Have you ever experienced the interpreting service on video call?

	Number	Percentage
Yes	28	21%
No	102	75%
Did not provide a response	6	4%

25. In the future how do you feel about having an interpreting service virtually e.g. over the phone or via a video call?

	Number	Percentage
Very comfortable	17	13%
Comfortable	30	22%
Neither comfortable nor uncomfortable	30	22%
Uncomfortable	11	8%
Very uncomfortable	42	31%
Did not provide a response	6	4%



26. Please tell us what the advantages of a virtual interpreting service would be for you.

Responses extrapolated from video and written comments, the 102 respondents may have mentioned more than one advantage or disadvantage. Percentage is that of respondents so total is >100%

	Number	Percentage
Flexible, quicker, smoother, easier	19	19%
Be able to have short notice appointments	15	15%
Better/clearer communication	10	10%
Better privacy	4	4%
Did not know it existed	4	4%
Good previous experience	3	3%
Would need a BSL interpreter present	2	2%
Could not use it as they do not have a computer/ would not know how to use it	2	2%
Would offer more independence	2	2%
Would ensure Covid safety	2	2%
Would boost equality	2	2%
Can lipread if there is a video	2	2%

Would like the choice	1	1%
Would use it	1	1%
Would have more confidence in the interpreter showing up	1	1%
Would help with the accent problem	1	1%
Would release the reliance of their family member for translation	1	1%
A live transcription or captioning service would be helpful	1	1%
Would mean an interpreter and appointment is booked at the same time	1	1%
A better service for Deaf people that BSL interpreting should be provided	1	1%
DISADVANTAGES EXPRESSED FOR THIS QUESTION		
No advantage	15	15%
Would not use it	12	12%
Do not know	6	6%
Bad previous experience, "it was awful"	5	5%
Could not use it as they do not have internet	3	3%
Would not be able to hear on virtual devices	2	2%
Would not be suitable for Deaf children	1	1%
Lip reading would be an issue without subtitles	1	1%
BSL must be face to face	1	1%
Hearing difficulties virtually	1	1%
'I don't sign'	1	1%
Would not work due to limited sight	1	1%

27. Please tell us what the disadvantages of a virtual service would be for you.

Responses extrapolated from video and written comments, the 94 respondents may have mentioned more than one disadvantage. Percentage is that of respondents so total is >100%

	Number	Percentage
Concerned about IT issues	30	26%
Concerned about the quality of interpretation	11	9%
Lack of privacy	11	9%
BSL needs to be face-to-face	10	9%
Would not work	8	7%
Would prefer human contact / face to face	7	6%
Would not know how to use it	7	6%
Would not feel comfortable using it	4	3%
Do not have IT access	3	3%
Would feel impersonal/disconnected	3	3%
Unlikely to have the same interpreter twice	2	2%
Not sure how it would work	2	2%
Would find it harder to build a rapport	2	2%
GPs may not feel comfortable using it	2	2%
Would not be able to use it due to visual impairment	1	1%
Concerned that the interpreter would not understand them	1	1%

Not comfortable using technology	1	1%
Would have issues with the background noise	1	1%
Would be unable to show or demonstrate their symptoms, issues or problems	1	1%
Concerned that the interpreter would not attend	1	1%
My requests would be ignored	1	1%
Good previous experience	1	1%
'I do not use BSL'	1	1%
Would not work due to limited sight	1	1%
Would like a messaging service	1	1%
Would need captions	1	1%
'going through a third party'	1	1%
'timing and availability'	1	1%

28. Please let us know anything else you would like us to consider when providing a virtual interpreting service.

Responses extrapolated from video and written comments, the 66 respondents may have mentioned more than one disadvantage. Percentage is that of respondents so total is >100%

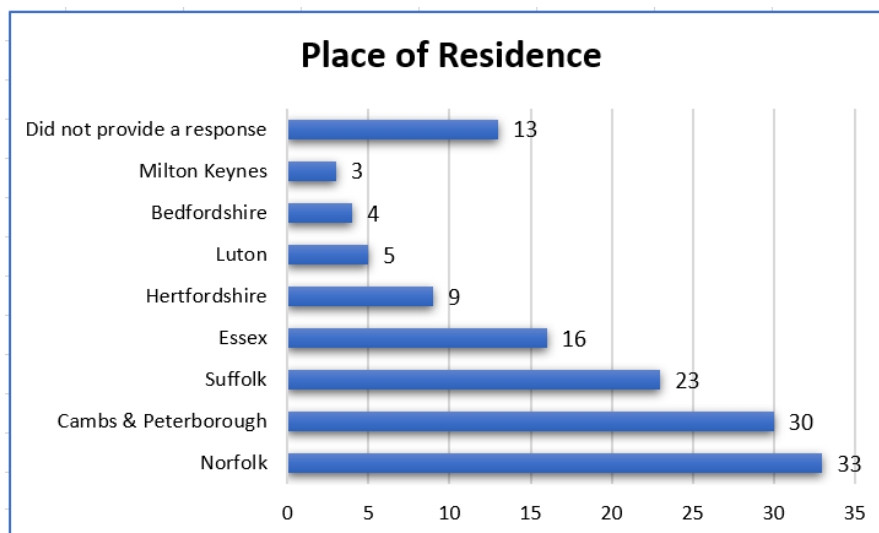
	Number	Percentage
Would not be appropriate for health matters	10	15%
Staff must be Deaf aware / have full knowledge of the service	5	8%
Would need to be easy to use	4	6%
Would require help to use the service	4	6%
Would want a face to face appointment	4	6%
Would need a texting service	3	5%
Subtitles would be required	3	5%
Voice to text would be beneficial	3	5%
Need a lip-reading service	3	5%
Would not use it	3	5%
Concerned about the internet connection	3	5%
Patients should be given the choice	2	3%
Staff would need to be patient with them	2	3%
Would only use if a face to face appointment was not available	2	3%
The service would need to be advertised	2	3%
A 24/7 service	2	3%
Captioning and audio description	2	3%
Looking forward to trying it	1	2%
Confidentiality agreement	1	2%
Concerned about the quality of interpreters	1	2%
Test runs would be needed	1	2%
Would like contact information for the service	1	2%
Must be instantly available	1	2%
Unsure how it would work	1	2%
Should be used in emergencies	1	2%

Do not have the equipment to try this	1	2%
Go back to the old providers	1	2%
Would not be able to use it due to sight problems	1	2%
There GP Practice does not offer it	1	2%
'Having enough interpreters'	1	2%
'Normal video chat'	1	2%
'Stand by remote interpreter'	1	2%
Good relationship between the NHS and the interpreting service	1	2%

Equalities Monitoring Questions

29. What town/county do you live in?

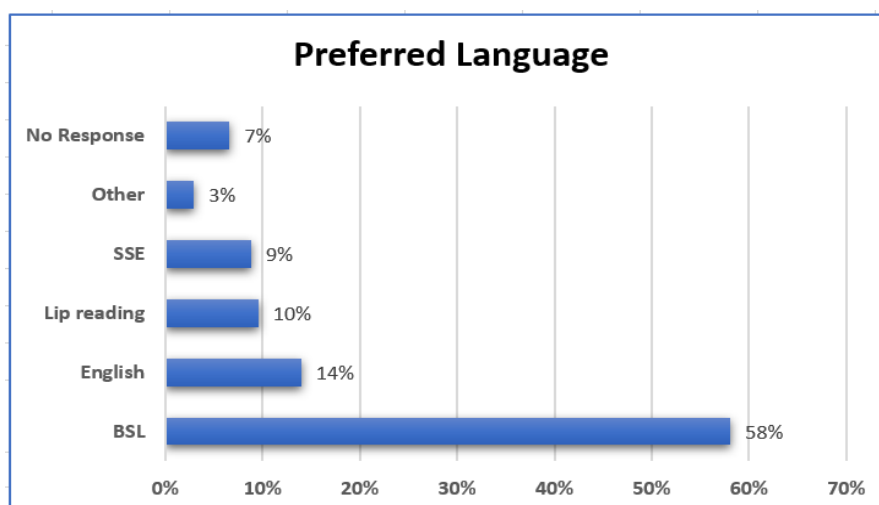
	Number	Percentage
Norfolk	33	24%
Cambs & Peterborough	30	22%
Suffolk	23	17%
Essex	16	12%
Hertfordshire	9	6%
Luton	5	4%
Bedfordshire	4	3%
Milton Keynes	3	2%
Did not provide a response	13	9%



30. What is your preferred language?

	Number	Percentage
BSL	79	58%
English	19	14%
Lip reading	13	9%
SSE	12	9%
Polish	1	1%
Deafblind manual	1	1%

Hand on signing	1	1%
Mix of BSL and English	1	1%
Did not provide a response	9	6%



31. What is your gender?

	Number	Percentage
Female	86	63%
Male	41	30%
Prefer not to say	2	1%
Did not provide a response	7	5%

32. If female, are you currently pregnant or have you given birth within the last 12 months?

	Number	Percentage
Yes	8	6%
No	95	70%
Did not provide a response	33	24%

33. What is your age?

	Number	Percentage
Under 16	1	1%
16-24	5	4%
25-34	22	16%
35-44	24	17%
45-54	31	23%
55-64	20	15%
65-74	15	11%
Over 75	13	9%
Did not provide a response	5	4%

34. What is your ethnic group?

	Number	Percentage
White or White British	116	85%
Mixed dual heritage	8	6%

Asian or Asian British	4	3%
Chinese	1	1%
European	1	1%
Did not provide a response	6	4%

35. Do you look after, or give any help or support to family members, friends, neighbours or others? *Please note this is not referring to the person you care for if you are a specified carer or if you are completing this survey on behalf of someone else.*

	Number	Percentage
Yes	40	29%
No	88	65%
Did not provide a response	8	6%

36. Are your day-to-day activities limited because of a health condition or illness which has lasted, or is expected to last, at least 12 months?

(Please select all that apply or if other leave a comment or video)

The 126 respondents may have mentioned more than one condition. Percentage is that of respondents so total is >100%

	Number	Percentage
No	8	6%
Prefer not to say	5	4%
Hearing (such as due to Deafness or partial hearing)	110	87%
Mental ill health	16	13%
Mobility (such as difficulty walking short distances, climbing stairs)	14	11%
Social or behavioural issues	5	4%
Dexterity (such as lifting and carrying objective, using a keyboard)	5	4%
Vision (such as due to blindness or partial sight)	5	4%
Ability to concentrate, learn or understand (Learning Disability/ Difficulty)	4	3%
Stamina, breathing difficulty or fatigue	4	3%
Memory	4	3%
Bowel disease	1	1%
Kidney disease	1	1%
Breast cancer	1	1%
Did not provide a response	11	9%

37. What is your sexual orientation?

	Number	Percentage
Heterosexual (straight)	95	70%
Prefer not to say	25	18%
Bisexual	2	1%
Gay	1	1%
Lesbian	1	1%
Did not provide a response	12	8%

38. What is your marital status?

	Number	Percentage
Married/civil partnership co-habiting	57	42%
Single	27	20%
living in a couple	22	16%
Separated (still married or in a civil partnership) divorced/dissolved civil partnership	8	6%
Prefer not to say	6	5%
Widowed/Surviving partner/civil partner	4	3%
Married (but not living with husband/wife/civil partner)	2	1%
Never married or partnered	1	1%
Did not provide a response	7	5%

39. What is your religion or belief?

	Number	Percentage
Christian	54	39%
No religion	53	39%
Prefer not to say	9	6%
Buddhist	4	3%
Spiritualist	2	1%
Quaker	2	1%
Muslim	1	1%
Did not provide a response	11	8%

APPENDIX THREE: Key Performance Indicators

Key Performance Indicators – Non-Spoken Languages					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
KPI 1	Capacity	Fill Rates (excluding face to face on demand bookings)	<p>The Supplier shall fulfil 100% of NHS England and NHS Improvement's requirements to meet the following minimum Fill Rates for Non-spoken Interpreting for face-to-face interpreting:</p> <p style="text-align: center;">BSL ≥ 97%</p>	<p>Minimum Dataset (MDS)</p> <p>Numerator The total number of bookings provided by the service in any one month, calculated using the 'booking outcome' column, filtered by booking type and by non-critical requests only.</p> <p>Denominator The total number of bookings, calculated using the booking accepted column, filtered by booking type and by non-critical requests only.</p>	<p>Subject to clause 13 (Service Levels and Service Credits) of the Framework Call Off Terms and the following methodology:</p> <p>If the provider breaches the tolerance permitted by the threshold, they will incur a single penalty sanction which is calculated by taking:</p> <p>The average of the actual costs of the breached cases as isolated in the MDS</p> <p style="text-align: center;">and multiplying it by</p> <p>the number of percentage points the provider has breached the tolerance by.</p> <p>For the avoidance of doubt, if the average costs for the cases in excess of the tolerance were £100 and the provider achieved 91% performance, the penalty value would be 4 x £100 = £400. This is because the permitted tolerance has been breached by 4%.</p> <p>NB. Whilst data will be collected by the provider on a monthly basis, reporting and penalty calculations will be on a quarterly basis as per the contractual reporting cycle.</p>
KPI 2	Interpreter Quality / Service Provision	Non-spoken Language Interpreters	The supplier will ensure all interpreters used for non-spoken languages supplied on behalf of the Commissioners shall have the relevant qualification as well as a contingency plan in place to	<p>Minimum Dataset (MDS)</p> <p>Numerator The number of 'PASS' tags in the 'Interpreter Qualifications Level' filtered by each 'Urgency of Request' category.</p>	<p>Framework Call Off Terms and consequence below:</p> <p>NHS England and NHS Improvement shall require an exception report detailing the action being taken by the Supplier to remedy the situation, and the associated timescale for the remedy, in the event that the Supplier falls below the stated minimum non-core language fill rate in any one quarter.</p>

Key Performance Indicators – Non-Spoken Languages					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
			<p>demonstrate any non-spoken language resource issues.</p> <p>The supplier must have in place arrangements to ensure interpreters are available for face to face appointments and online consultations to respond to requests for appointments at short notice, i.e. 97% of appointments can be attended within 72 hours. Where this is not possible, the Supplier will contact the Commissioner to agree alternative arrangements.</p>	<p>Denominator The total number of requests per 'Booking Type' category in the reporting period.</p>	<p>For the avoidance of doubt, the Supplier's continued status as a provider of the Services to NHS England and NHS Improvement under the Call-off Contract shall be dependent upon the Supplier meeting NHS England and NHS Improvement's minimum non-core language fill rate as set out in the threshold column.</p> <p>If the Supplier fails to remedy the non-core language fill rates, notwithstanding the implementation of such Remedial Proposal in accordance with the agreed timescales for implementation, then this shall be deemed a material breach of the Call-off Contract not remedied in accordance with the agreed Remedial Proposal and NHS England and NHS Improvement may terminate the Call-off Contract forthwith by notice in writing.</p>
KPI 3	Service Provision	Difficult to Source Languages	The supplier shall ensure a contingency plan is in place for difficult to source languages.	<p>Minimum Dataset (MDS)</p> <p>Numerator The number of 'N' tags in the 'Booking Accepted' category.</p> <p>Denominator The total number of requests per 'Core Language' category in the reporting period.</p>	<p>Framework Call Off Terms and consequence below:</p> <p>NHS England and NHS Improvement shall require an exception report detailing the action being taken by the Supplier to remedy the situation, and the associated timescale for the remedy, in the event that the Supplier falls below the stated minimum fill rate for face to face on demand bookings in any one quarter.</p> <p>For the avoidance of doubt, the Supplier's continued status as a provider of the Services to NHS England and NHS Improvement under the Call-off Contract shall be dependent upon the Supplier meeting NHS England and NHS Improvement's minimum fill rate for face to face on demand bookings as set out in the threshold column.</p> <p>If the Supplier fails to remedy the face to face on demand fill rates, notwithstanding the implementation</p>

Key Performance Indicators – Non-Spoken Languages					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
					of such Remedial Proposal in accordance with the agreed timescales for implementation, then this shall be deemed a material breach of the Call-off Contract not remedied in accordance with the agreed Remedial Proposal and NHS England and NHS Improvement may terminate the Call-off Contract forthwith by notice in writing.
KPI 4	Requestor Experience	Booking Confirmation Times	<p>The Supplier shall ensure that bookings are acknowledged in a timely fashion and in line with the following criteria:</p> <p>Critical Requests (Defined as an assignment within 2 hours) ≤ 1 Hour</p> <p>Urgent Requests (Defined as an assignment within 24 hours, but not within 2 hours) ≤ 2 Hours</p> <p>Routine Requests (Defined as an assignment occurring between 24-48 hours from the time the booking was received) ≤ 6 Hours</p> <p>Longer Term Requests (Defined as an assignment occurring over 48 hours from the time the booking was received) ≤ 24 Hours</p>	<p>Minimum Dataset (MDS)</p> <p>Numerator The number of 'PASS' tags in the 'Booking Confirmation Performance' column, filtered by each 'Urgency of Request' category.</p> <p>Denominator The total number of requests per 'Urgency of Request' category in the reporting period.</p>	<p>Framework Call Off Terms and consequence below:</p> <p>NHS England and NHS Improvement shall require an exception report detailing the action being taken by the Supplier to remedy the situation, and the associated timescale for the remedy, in the event that the Supplier falls below the stated minimum fill rate for face to face on demand bookings in any one quarter.</p> <p>For the avoidance of doubt, the Supplier's continued status as a provider of the Services to NHS England and NHS Improvement under the Call-off Contract shall be dependent upon the Supplier meeting NHS England and NHS Improvement's minimum fill rate for face to face on demand bookings as set out in the threshold column.</p> <p>If the Supplier fails to remedy the face to face on demand fill rates, notwithstanding the implementation of such Remedial Proposal in accordance with the agreed timescales for implementation, then this shall be deemed a material breach of the Call-off Contract not remedied in accordance with the agreed Remedial Proposal and NHS England and NHS Improvement may terminate the Call-off Contract forthwith by notice in writing.</p>

Key Performance Indicators – Non-Spoken Languages					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
			Non-spoken language Interpreters to be confirmed within 24 hours and to be available to attend an appointment within 72 hours of the request from the primary care organisation either face to face or by video services.		
KPI 5	Interpreter Punctuality	The provider shall ensure that interpreters supplied on behalf of the Commissioners arrive at their assignments in a timely fashion.	<p>97% of interpreters should arrive at their assignment prior to the requested booking time.</p> <p>NB. In cases where the booking is non-face to face, the punctuality is recorded as the time the interpreter joins the relevant phone call or video call.</p> <p>For written translations, the punctuality is recorded as the point at which the written product was provided to the requester.</p>	<p>Minimum Dataset (MDS)</p> <p>Numerator The number of 'PASS' tags in the 'Punctuality Performance' column.</p> <p>Denominator The total number of tags in the 'Punctuality Performance' column.</p>	<p>Framework Call Off Terms and consequence below and the following methodology:</p> <p>If the provider breaches the tolerance permitted by the threshold, they will incur a single penalty sanction which is calculated by taking: The average of the actual costs of the breached cases as isolated in the MDS and multiplying it by the number of percentage points the provider has breached the tolerance by.</p> <p>For the avoidance of doubt, if the average costs for the cases in excess of the tolerance were £100 and the provider achieved 91% performance, the penalty value would be 4 x £100 = £400. This is because the permitted tolerance has been breached by 4%.</p> <p>NB. Whilst data will be collected by the provider on a monthly basis, reporting and penalty calculations will be on a quarterly basis as per the contractual reporting cycle.</p>
KPI 6	Service Quality	User experience	The provider shall have a system in place whereby patients can submit	Provider reports to be submitted to the Commissioner on a monthly basis.	Framework Call Off Terms and consequence below:

Key Performance Indicators – Non-Spoken Languages					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
			<p>confidential feedback on services received.</p> <p>Information to be gathered and common themes identified. Findings to be shared at review meetings.</p>		<p>NHS England and NHS Improvement shall require an exception report detailing the action being taken by the Supplier to remedy the situation, and the associated timescale for the remedy, in the event that the Supplier falls below the stated minimum fill rate for face to face on demand bookings in any one quarter. For the avoidance of doubt, the Supplier's continued status as a provider of the Services to NHS England and NHS Improvement under the Call-off Contract shall be dependent upon the Supplier meeting NHS England and NHS Improvement's minimum fill rate for face to face on demand bookings as set out in the threshold column.</p> <p>If the Supplier fails to remedy the face to face on demand fill rates, notwithstanding the implementation of such Remedial Proposal in accordance with the agreed timescales for implementation, then this shall be deemed a material breach of the Call-off Contract not remedied in accordance with the agreed Remedial Proposal and NHS England and NHS Improvement may terminate the Call-off Contract forthwith by notice in writing.</p>
KPI 7	Service Quality	User experience	<p>The provider shall have a system in place whereby Primary Care Organisations can submit feedback on services received.</p> <p>Information to be gathered and common themes identified. Findings to be shared at review meetings.</p>	Provider reports to be submitted to the Commissioner on a monthly basis.	<p>Framework Call Off Terms and consequence below:</p> <p>NHS England and NHS Improvement shall require an exception report detailing the action being taken by the Supplier to remedy the situation, and the associated timescale for the remedy, in the event that the Supplier falls below the stated minimum fill rate for face to face on demand bookings in any one quarter. For the avoidance of doubt, the Supplier's continued status as a provider of the Services to NHS England and NHS Improvement under the Call-off Contract shall be dependent upon the Supplier meeting NHS England and NHS Improvement's minimum fill rate for</p>

Key Performance Indicators – Non-Spoken Languages					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
					<p>face to face on demand bookings as set out in the threshold column.</p> <p>If the Supplier fails to remedy the face to face on demand fill rates, notwithstanding the implementation of such Remedial Proposal in accordance with the agreed timescales for implementation, then this shall be deemed a material breach of the Call-off Contract not remedied in accordance with the agreed Remedial Proposal and NHS England and NHS Improvement may terminate the Call-off Contract forthwith by notice in writing.</p>

Key Performance Indicators – Spoken Languages					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
KPI 1	Capacity	Fill Rates (excluding face to face on demand bookings)	<p>The Supplier shall fulfil 100% of NHS England and NHS Improvement's requirements but is required to meet the following minimum Fill Rates for Spoken Interpreting - Core Languages (As defined by Language Groups A-D) for telephone and face-to-face interpreting:</p> <p>telephone interpreting ≥ 95%</p>	<p>Minimum Dataset (MDS)</p> <p>Numerator The total number of bookings provided by the service in any one month, calculated using the 'booking outcome' column, filtered by core languages, booking type and by non-critical requests only.</p> <p>Denominator The total number of bookings, calculated using the booking accepted column, filtered by core</p>	<p>Subject to clause 13 (Service Levels and Service Credits) of the Framework Call Off Terms and the following methodology:</p> <p>If the provider breaches the tolerance permitted by the threshold, they will incur a single penalty sanction which is calculated by taking:</p> <p>The average of the actual costs of the breached cases as isolated in the MDS</p> <p>and multiplying it by</p>

Key Performance Indicators – Spoken Languages					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
			<p>face-to-face interpreting ≥ 95%</p> <p>written translation 99%</p>	languages, booking type and by non-critical requests only.	<p>the number of percentage points the provider has breached the tolerance by.</p> <p>For the avoidance of doubt, if the average costs for the cases in excess of the tolerance were £100 and the provider achieved 91% performance, the penalty value would be 4 x £100 = £400. This is because the permitted tolerance has been breached by 4%.</p> <p>NB. Whilst data will be collected by the provider on a monthly basis, reporting and penalty calculations will be on a quarterly basis as per the contractual reporting cycle.</p>
KPI 2	Capacity	Fill Rates (excluding face to face on demand bookings)	<p>The Supplier shall aim to fulfil 100% of NHS England and NHS Improvements requirements but is required to meet the following minimum Fill Rate for Spoken Interpreting - Non-Core Languages (As defined by Language Group E):</p> <p>telephone interpreting ≥ 90%</p> <p>face-to-face interpreting ≥ 90%</p> <p>written translation ≥ 95%</p>	<p>Minimum Dataset (MDS)</p> <p>Numerator The total number of bookings provided by the service in any one month, calculated using the 'booking outcome' column, filtered by non-core languages, booking type and by non-critical requests only.</p> <p>Denominator The total number of bookings, calculated using booking accepted column, filtered by non-core languages, booking type and by non-critical requests only.</p>	<p>Framework Call Off Terms and consequence below:</p> <p>NHS England and NHS Improvement shall require an exception report detailing the action being taken by the Supplier to remedy the situation, and the associated timescale for the remedy, in the event that the Supplier falls below the stated minimum non-core language fill rate in any one quarter.</p> <p>For the avoidance of doubt, the Supplier's continued status as a provider of the Services to NHS England and NHS Improvement under the Call-off Contract shall be dependent upon the Supplier meeting NHS England and NHS Improvement's minimum non-core language fill rate as set out in the threshold column.</p> <p>If the Supplier fails to remedy the non-core language fill rates, notwithstanding the implementation of such Remedial Proposal in accordance with the agreed timescales for implementation, then this shall be deemed a material breach of the Call-off Contract not remedied in accordance with the agreed Remedial Proposal and NHS England and NHS Improvement</p>

Key Performance Indicators – Spoken Languages					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
					may terminate the Call-off Contract forthwith by notice in writing.
KPI 3	Service Provision	Difficult to Source Languages	The supplier shall ensure a contingency plan is in place for difficult to source languages.	Minimum Dataset (MDS) Numerator The number of 'N' tags in the 'Booking Accepted' category. Denominator The total number of requests per 'Core Language' category in the reporting period.	Framework Call Off Terms and consequence below: NHS England and NHS Improvement shall require an exception report detailing the action being taken by the Supplier to remedy the situation, and the associated timescale for the remedy, in the event that the Supplier falls below the stated minimum fill rate for face to face on demand bookings in any one quarter. For the avoidance of doubt, the Supplier's continued status as a provider of the Services to NHS England and NHS Improvement under the Call-off Contract shall be dependent upon the Supplier meeting NHS England and NHS Improvement's minimum fill rate for face to face on demand bookings as set out in the threshold column. If the Supplier fails to remedy the face to face on demand fill rates, notwithstanding the implementation of such Remedial Proposal in accordance with the agreed timescales for implementation, then this shall be deemed a material breach of the Call-off Contract not remedied in accordance with the agreed Remedial Proposal and NHS England and NHS Improvement may terminate the Call-off Contract forthwith by notice in writing.
KPI 4	Requestor Experience	Booking Confirmation Times	The Supplier shall ensure that bookings are acknowledged in a timely fashion and in line with the following criteria: Critical Requests (Defined as an assignment	Minimum Dataset (MDS) Numerator The number of 'PASS' tags in the 'Booking Confirmation Performance' column, filtered by each 'Urgency of Request' category.	Framework Call Off Terms and consequence below: NHS England and NHS Improvement shall require an exception report detailing the action being taken by the Supplier to remedy the situation, and the associated timescale for the remedy, in the event that the Supplier falls below the stated minimum fill rate for

Key Performance Indicators – Spoken Languages					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
			<p>within 2 hours) ≤ 1 Hour</p> <p>Urgent Requests (Defined as an assignment within 24 hours, but not within 2 hours) ≤ 2 Hours</p> <p>Routine Requests (Defined as an assignment occurring between 24-48 hours from the time the booking was received) ≤ 6 Hours</p> <p>Longer Term Requests (Defined as an assignment occurring over 48 hours from the time the booking was received) ≤ 24 Hours</p>	<p>Denominator The total number of requests per 'Urgency of Request' category in the reporting period.</p>	<p>face to face on demand bookings in any one quarter.</p> <p>For the avoidance of doubt, the Supplier's continued status as a provider of the Services to NHS England and NHS Improvement under the Call-off Contract shall be dependent upon the Supplier meeting NHS England and NHS Improvement's minimum fill rate for face to face on demand bookings as set out in the threshold column.</p> <p>If the Supplier fails to remedy the face to face on demand fill rates, notwithstanding the implementation of such Remedial Proposal in accordance with the agreed timescales for implementation, then this shall be deemed a material breach of the Call-off Contract not remedied in accordance with the agreed Remedial Proposal and NHS England and NHS Improvement may terminate the Call-off Contract forthwith by notice in writing.</p>
KPI 5	Interpreter Punctuality	The provider shall ensure that interpreters supplied on behalf of the Commissioners arrive at their assignments in a timely fashion.	<p>97% of interpreters should arrive at their assignment prior to the requested booking time.</p> <p>NB. In cases where the booking is non-face to face, the punctuality is recorded as the time the interpreter joins the relevant phone call or video call.</p> <p>For written translations, the punctuality is recorded as the point at which the written</p>	<p>Minimum Dataset (MDS)</p> <p>Numerator The number of 'PASS' tags in the 'Punctuality Performance' column.</p> <p>Denominator The total number of tags in the 'Punctuality Performance' column.</p>	<p>Framework Call Off Terms and consequence below and the following methodology:</p> <p>If the provider breaches the tolerance permitted by the threshold, they will incur a single penalty sanction which is calculated by taking:</p> <p>The average of the actual costs of the breached cases as isolated in the MDS</p> <p>and multiplying it by</p> <p>the number of percentage points the provider has breached the tolerance by.</p>

Key Performance Indicators – Spoken Languages					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
			product was provided to the requester.		<p>For the avoidance of doubt, if the average costs for the cases in excess of the tolerance were £100 and the provider achieved 91% performance, the penalty value would be $4 \times £100 = £400$. This is because the permitted tolerance has been breached by 4%.</p> <p>NB. Whilst data will be collected by the provider on a monthly basis, reporting and penalty calculations will be on a quarterly basis as per the contractual reporting cycle.</p>
KPI 6	Service Quality	User Experience	<p>The provider shall have a system in place whereby patients can submit confidential feedback on services received.</p> <p>Information to be gathered and common themes identified. Findings to be shared at review meetings.</p>	Provider reports to be submitted to the Commissioner on a monthly basis.	<p>Framework Call Off Terms and consequence below:</p> <p>NHS England and NHS Improvement shall require an exception report detailing the action being taken by the Supplier to remedy the situation, and the associated timescale for the remedy, in the event that the Supplier falls below the stated minimum fill rate for face to face on demand bookings in any one quarter.</p> <p>For the avoidance of doubt, the Supplier's continued status as a provider of the Services to NHS England and NHS Improvement under the Call-off Contract shall be dependent upon the Supplier meeting NHS England and NHS Improvement's minimum fill rate for face to face on demand bookings as set out in the threshold column.</p> <p>If the Supplier fails to remedy the face to face on demand fill rates, notwithstanding the implementation of such Remedial Proposal in accordance with the agreed timescales for implementation, then this shall be deemed a material breach of the Call-off Contract not remedied in accordance with the agreed Remedial Proposal and NHS England and NHS Improvement</p>

Key Performance Indicators – Spoken Languages					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
					may terminate the Call-off Contract forthwith by notice in writing.
KPI7	Service Quality	User Experience	<p>The provider shall have a system in place whereby Primary Care Organisations can submit feedback on services received.</p> <p>Information to be gathered and common themes identified. Findings to be shared at review meetings.</p>	Provider reports to be submitted to the Commissioner on a monthly basis.	<p>Subject to the Management Information of the Framework Call Off Terms and consequence below:</p> <p>NHS England and NHS Improvement shall require an exception report detailing the action being taken by the Supplier to remedy the situation, and the associated timescale for the remedy, in the event that the Supplier falls below the stated minimum fill rate for face to face on demand bookings in any one quarter.</p> <p>For the avoidance of doubt, the Supplier's continued status as a provider of the Services to NHS England and NHS Improvement under the Call-off Contract shall be dependent upon the Supplier meeting NHS England and NHS Improvement's minimum fill rate for face to face on demand bookings as set out in the threshold column.</p> <p>If the Supplier fails to remedy the face to face on demand fill rates, notwithstanding the implementation of such Remedial Proposal in accordance with the agreed timescales for implementation, then this shall be deemed a material breach of the Call-off Contract not remedied in accordance with the agreed Remedial Proposal and NHS England and NHS Improvement may terminate the Call-off Contract forthwith by notice in writing.</p>

APPENDIX FOUR - Key Performance Indicators for Enhanced Pilot Scheme

Key Performance Indicators - Non-Spoken Enhanced Service					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
KPI 1	Capacity	Fill Rates	The Supplier shall fulfil 100% of NHS England and NHS Improvement's requirements to meet the following minimum Fill Rates: The service is expected to support up to 600 patients across the region.	Minimum Dataset (MDS) Numerator The total number of bookings provided by the service in any one month, calculated using the 'booking outcome' column, filtered by booking type and by non-critical requests only. Denominator The total number of bookings, calculated using the booking accepted column, filtered by booking type and by non-critical requests only.	If the provider breaches the tolerance permitted by the threshold, they will incur a single penalty sanction which is calculated by taking: The average of the actual costs of the breached cases as isolated in the MDS and multiplying it by the number of percentage points the provider has breached the tolerance by.
KPI 2	Interpreter Quality / Service Provision	Non-spoken Language Interpreters	The supplier will ensure all interpreters used for non-spoken languages supplied on behalf of the Commissioners shall have the relevant qualification as well as a contingency plan in place to demonstrate any non-spoken language resource issues. The supplier must have in place arrangements to ensure interpreters are available to respond to requests at short notice, i.e. 97% of requests are met with Where this is not possible, the Supplier will contact the	Minimum Dataset (MDS) Numerator The number of 'PASS' tags in the 'Interpreter Qualifications Level' filtered by each 'Urgency of Request' category. Denominator The total number of requests per 'Booking Type' category in the reporting period.	NHS England and NHS Improvement shall require an exception report detailing the action being taken by the Supplier to remedy the situation, and the associated timescale for the remedy, in the event that the Supplier falls below the stated minimum fill rate in any one quarter. For the avoidance of doubt, the Supplier's continued status as a provider of the Services to NHS England and NHS Improvement shall be dependent upon the Supplier meeting NHS England and NHS Improvement's minimum non-core language fill rate as set out in the threshold column.

Key Performance Indicators - Non-Spoken Enhanced Service					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
			Commissioner to agree alternative arrangements.		
KPI 4	Requestor Experience	Booking Confirmation Times	<p>The Supplier shall ensure that bookings are acknowledged in a timely fashion and in line with the following criteria:</p> <p>Critical Requests (Defined as an assignment within 2 hours) ≤ 1 Hour</p> <p>Urgent Requests (Defined as an assignment within 24 hours, but not within 2 hours) ≤ 2 Hours</p> <p>Routine Requests (Defined as an assignment occurring between 24-48 hours from the time the booking was received) ≤ 6 Hours</p> <p>Longer Term Requests (Defined as an assignment occurring over 48 hours from the time the booking was received) ≤ 24 Hours</p> <p>Non-spoken language Interpreters to be confirmed within 24 hours and to be available to attend within 72 hours of the request from the primary care organisation.</p>	<p>Minimum Dataset (MDS)</p> <p>Numerator The number of 'PASS' tags in the 'Booking Confirmation Performance' column, filtered by each 'Urgency of Request' category.</p> <p>Denominator The total number of requests per 'Urgency of Request' category in the reporting period.</p>	<p>NHS England and NHS Improvement shall require an exception report detailing the action being taken by the Supplier to remedy the situation, and the associated timescale for the remedy, in the event that the Supplier falls below the stated minimum fill rate in any one quarter.</p> <p>For the avoidance of doubt, the Supplier's continued status as a provider of the Services to NHS England and NHS Improvement Contract shall be dependent upon the Supplier meeting NHS England and NHS Improvement's minimum fill rate for face to face on demand bookings as set out in the threshold column.</p>

Key Performance Indicators - Non-Spoken Enhanced Service					
Ref	Technical Guidance Reference	Quality Requirement	Threshold	Method of Measurement	Consequence of breach
KPI 6	Service Quality	User experience	<p>The provider shall have a system in place whereby patients can submit confidential feedback on services received.</p> <p>Information to be gathered and common themes identified. Findings to be shared at review meetings.</p>	Provider reports to be submitted to the Commissioner on a monthly basis.	
KPI 7	Service Quality	User experience	<p>The provider shall have a system in place whereby Primary Care Organisations can submit feedback on services received.</p> <p>Information to be gathered and common themes identified. Findings to be shared at review meetings.</p>	Provider reports to be submitted to the Commissioner on a monthly basis.	

Subject:	Access to local NHS services for patients with sensory impairments
Presented by:	
Prepared by:	Fiona Theadom, Interim Head of Primary Care Strategic Planning
Submitted to:	Norfolk County Council - Health Overview & Scrutiny Committee
Date:	15 July 2021

Purpose of paper:

To inform Norfolk County Council's Health Overview and Scrutiny Committee (HOSC) of Norfolk and Waveney Clinical Commissioning Group's work to embed the Accessible Information Standard (AIS) with service providers across primary and secondary care and enable easier access for all patients with hearing and sight impairments.

1 Introduction

Interpreting and translation services are commissioned in a variety of ways across NHS organisations in the Norfolk and Waveney CCG area depending on the service arrangements.

As indicated, the NHS's Accessible Information Standard (AIS) was established in 2016. Communications have been shared widely with all staff across primary, secondary and community care settings regarding the requirement to ask patients, and where applicable carers, about their specific communication needs and to raise awareness of the AIS.

This paper describes the arrangements in place in primary and secondary care and community services to support patients who are deaf and how services comply with the AIS.

We would encourage any individual to come forward to raise concerns about the AIS so they can be investigated and the cause of the problem identified and addressed. They can do this by contacting the CCG or NHS England and Improvement complaints teams and they will make appropriate arrangements to communicate with the individual.

Secondary Care and Community Services

For the purpose of this paper, the CCG has sought confirmation of individual arrangements from the secondary care and community providers. They have confirmed that policies are in place and that there is a wide range of measures in place to support patients from the deaf community. Interpreting and translation services are provided through contracting arrangements with Intran, including British Sign Language and other non-spoken services such as Braille.

Specific responses from secondary care and community services to each of the key lines of enquiry from HOSC are set out below.

Primary Care Services

Access to both non-spoken languages and spoken languages interpreting services is available to any patient wishing to access GP and dental services in Norfolk. It has also recently been extended to include optometry services.

All primary care services are reminded on a regular basis about their duty to comply with AIS obligations and to take account of individual patient needs. This includes ensuring patient records are kept up to date in this regard so any member of staff authorised to access patient records can easily identify individual patient communication needs.

In January 2021, Norfolk and Waveney CCG's Primary Care Commissioning Committee approved the recommendation for the CCG to participate in the East of England region-wide approach to new contracting arrangements currently being procured for both non-spoken languages and spoken languages interpreting services for patients wishing to access any primary care services. The new contracting arrangements will go live on 1 November 2021.

CCG staff will be working very closely with NHSEI throughout the mobilisation phase from mid July to the end of October to ensure patients, primary care service providers and key stakeholders in Norfolk are all aware of the availability of the individual services that will be available and how to access them. This will be undertaken in conjunction with the new suppliers and with specific reference to the outcomes from the engagement exercise undertaken in 2020 by NHSEI.

The CCG's Training Hub training programme for 2021/2022 will include training and education for reception and admin staff within GP practices to be carried out in conjunction with the new suppliers for interpreting and translation services. This will focus on how they access these services on behalf of patients, compliance with the AIS and the importance of making reasonable adjustments for individual patients where appropriate.

In addition, the CCG's Digital Team is working with Healthwatch Norfolk to look at digital methods of enabling people with a hearing impairment to

access primary care without the need for an interpreter or family member to be present.

This project is part funded by NHSX and match funded from the CCG's Digital First Primary Care funds. This was inspired by a review of access conducted by Deaf Connexions last year. A range of solutions is being explored, from the simple such as face masks with a clear panel so lips can be viewed, and vibrating pagers to indicate it's time to go into the consultation, to transcription software. There is also an excellent short programme of deaf awareness training for practice staff designed by a GP.

The project is progressing well despite the impact of the pandemic, and the CCG is looking forward to it picking up pace in the coming weeks. Healthwatch had engaged with groups representing the deaf community in advance of a stakeholder engagement meeting on 10th June and they provided attendance. Two sign language interpreters were present throughout the session.. A representative from RNID attended to talk about the GP and Practice education toolset for working with people with a hearing impairment.

The CCG has explored captions software, vibrating pagers and AI for sign language interpretation, and solutions such as facemasks with clear panels for lip readers; further investigation of these is ongoing

The CCG has asked Healthwatch to extend their engagement to GP Practices and general social media as it's possible that some people who have hearing loss may not be involved with groups that represent profoundly deaf people. At the engagement event, some people did not identify as digital users so there is scope to widen the engagement further. In addition, at the CCG's digital interest group for primary care, many GP practices expressed an interest in the initiative and this is being followed up.

This paper highlights a variety of projects illustrating the CCG's commitment to ensuring that all patients have equitable access to NHS services within the Norfolk and Waveney area.

HOSC action	Secondary Care and Community Services
<p>To ensure the 'tell us once' policy is in place and adhered to so that there is improved access for patients with sensory impairments.</p>	<p>There is a responsibility on the referring organisation to highlight in a patient referral if any reasonable adjustments and special communication needs are necessary to support individual patients in line with the AIS, for example, if an interpreter is needed or there are literacy problems.</p> <p>Community services use SystmOne digital templates designed to capture the requirements of the AIS at the first contact with the patient, e.g. sensory impairment; this is an electronic clinical record which has been in use since December 2019 in community nursing teams and in therapy settings. It continues to be embedded into referral to discharge processes.</p> <p>This record can be shared with Primary Care teams with the patient's consent, allowing details about the patient to be shared within the patient's clinical records.</p> <p>This information also flows through the service alongside the Service User so any clinician providing support and care will have access to and be aware of any specific needs.</p> <p>Plans were put in place to roll out data collection to inpatient units in spring 2020 and design work for this is complete. However, the rollout was delayed due to the pandemic and the redeployment of the project lead to support frontline services and therefore this project work was stood down. Plans are in place for the rollout to inpatient units to be completed by July 2021. The rollout into Children's services will begin in May and will require some SystmOne re-design work initially.</p>
<p>To ensure that all frontline staff receive training in the requirements and</p>	<p>There are various mechanisms in place to ensure staff, regardless of role, are aware of Accessible Information Standards, for example, through eLearning as</p>

HOSC action	Secondary Care and Community Services
implementation of the accessibility standards.	<p>part of mandatory new starter training or monitored via annual audits and followed up as part of local quality improvement plans.</p> <p>In line with national guidance for healthcare providers to ask all questions relating to protected characteristics at the same time in the patient consultation process, data is captured to meet the Sexual Orientation Standard and information to support Fair Access to Services within the same SystmOne template as AIS data capture. Staff guidance has been issued alongside the rollout to support all staff.</p> <p>Providers have Standard Operating Procedures in place drafted by a wide multi-disciplinary group to support staff in practice.</p> <p>Bespoke reporting on levels of template completion is used to help embed the new process into practice.</p>
To review training of BSL interpreters to ensure suitable skill for local needs.	The training of interpreters and ensuring they meet the required national standards and qualifications is the responsibility of the organisation providing interpreting and translation services. During the procurement process for new services or contracts, compliance by proposed suppliers with these standards will form part of the tender evaluation.
To make a contract variation to enable patients to ask a BSL interpreter to make an appointment for them, to protect their privacy and dignity.	Service providers would ask consent of the service user to use an external provider where a need for a BSL interpreter is identified.
To ensure a rapid response to members of the public who are currently having difficulty accessing services.	Through the contract with INTRAN, secondary and community services can access seamless, quality-assured interpreting and translation services for people who are deaf or hard of hearing, or whose first language is not English and are

HOSC action	Secondary Care and Community Services
	<p>unable to communicate effectively including Deaf ConneXions (British Sign Language & Lip Speaking).</p> <p>Websites have been developed in accordance with accessibility standards and guidelines and endeavours to conform to the World Wide Web Consortium (W3C) Web Content Accessibility Guidelines 1.0. Website accessibility audits have been completed and where improvements have been identified, this work will be carried out.</p> <p>Patient Experience Teams are working closely with community groups to increase involvement with the Trust in the co-design of services.</p> <p>New Service Information leaflets to support patients and carers during the pandemic are available in Easy read versions and overarching patient/ carer information such as Complaints leaflet and 'Friends and Family Test' feedback forms are also available in Easy Read. When service users require information in braille, staff will contact INTRAN translation service in line with service protocols or alternatively, there is a telephone number for patients to request.</p> <p>ReciteMe Accessibility Software or Access Able app is installed on Trust websites. The assistive toolbar enables website visitors to customise the website's content in a way that works for them e.g. text to be read aloud, to be translated into different languages; formatting changes to support readers with some visual and processing impairments.</p> <p>Hearing loop systems in operation and available from Audiology Departments. Ward staff may use pictures/pads/pens to support language barriers/sensory impairments supported by with specialist advice available from the Learning Disability Team and other teams such as Audiology and Speech and Language Therapists.</p>

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

Suggested approach by Maureen Orr Democratic Support and Scrutiny Manager

Scrutiny of the current position regarding waiting times for assessment and diagnosis of children in Norfolk and Waveney experiencing neurodevelopmental difficulties.

1. Purpose of today's meeting

- 1.1 To examine 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.
- 1.2 The service commissioners, Norfolk and Waveney Clinical Commissioning Group (CCG), have been asked to provide a report in conjunction with the service providers setting out:-
 - Description of the different pathways to assessment and diagnoses for various neurodevelopmental conditions within each of the services.
 - Demand for assessments, including comparison between current level and previous years.
 - 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.
 - 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).
 - 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.
 - The effect of the Covid 19 pandemic on the assessment and diagnosis services and details of any catch-up planning.
 - Positive Behaviour Support Programme (PBSP) places are offered to families whose child is waiting for an ASD assessment. Details of any equivalent offers for families of children waiting for general

neurodevelopmental assessment and percentages of families who take up PBSP or any equivalent offers.

- Any other relevant information from the CCG and service providers.

The CCG's report is attached at **Appendix A**. Representatives from the CCG and the two main service providers, Norfolk Community Health and Care NHS Trust (NCH&C) and Newberry Child Development Centre (hosted by James Paget University Hospital) will be in attendance to answer councillors' questions.

- 1.3 Family Voice Norfolk (FVN) has provided the results of a recent survey on experiences of accessing the pathways and services supporting diagnosis of some neurological developmental disorders. Their paper is attached at **Appendix B** and a representative will attend.

FVN is a collective of parent carers from 1150 families across Norfolk and represents over 1440 children and young people with Special Educational Needs and Disabilities (SEND). FVN works in partnership with Norfolk County Council (NCC) and with the CCG. It is funded through a direct Department for Education grant administered by NCC and the CCG. Their paper also includes some information collated by the West Norfolk Branch of the National Autistic Society about their members' experiences.

2. Background information

- 2.1 The World Health Organisation's International Classification of Diseases (revision 11) defines neurodevelopmental disorders as

"Behavioural and cognitive disorders that arise during the developmental period that involve significant difficulties in the acquisition and execution of specific intellectual, motor, language, or social functions".

This is a broad range and it is important to note that people who have been diagnosed with some kinds of neurodevelopmental conditions in childhood or later may not consider them to be 'disorders' at all. Some may be seen simply as non-typical but equally valid ways of being.

- 2.2 NHOSC has previously looked at waiting times for assessment and diagnosis of autism in children but has never before looked at the situation for the full range of neurodevelopmental disorders in children.
- 2.3 The pathways to diagnosis of these disorders are complex and differ depending on the age of the child, the initial presentation of their condition(s) and where they live. Different health professionals are involved along the pathways and there is potential for delay at each stage, as well as potential for delay in obtaining necessary prerequisites to the pathway. Also, a child may need to be assessed for two, three or more different disorders, which can take more time.
- 2.4 The last report to NHOSC, which concerned children's autism diagnosis only, is available on our website via the following link: [NHOSC 11 January 2018](#) (item number 7).

The report focussed on the service in central and west Norfolk, which is provided by Norfolk Community Health and Care NHS Trust (NCH&C). It was followed by a series of updates in the NHOSC Briefing regarding the central & west Norfolk service's progress in reducing waiting times for assessment and diagnosis of autism in children following additional investment by the Norfolk CCGs in September 2017.

The last update was received in the February 2019 NHOSC Briefing. The aim had been to bring down the waiting times for the start of an autism assessment to 18 weeks or less from the point of referral. This had not been achieved in Feb 2019 but further enquiries in Feb 2020 confirmed that it was being achieved by then within the NCH&C central and west Norfolk service.

However, it also became clear in Feb 2020 that the 18 week standard appeared to be met only for children being accepted onto the ASD assessment pathway. Children accepted onto the general neurological disorders assessment pathway were waiting around 40 weeks for the start of assessment.

It was this disparity that prompted NHOSC Members to ask for today's report on the wider subject of assessment and diagnosis of general neurological disorders.

3. Suggested approach


3.1 Members may wish to discuss the following areas with the CCG and providers:-

- (a) It is noted that data from the service in the east of Norfolk & Waveney (Newberry Clinic at JPUH) is reliant on manual search. Are the commissioners clear on the reasons why, prior to the pandemic, waiting times appeared to be much shorter in the east than in central and west Norfolk? Is there potential to share best practice between providers or were there other reasons for the disparity?
- (b) The average time from start of assessment to discharge from the service is much longer in central and west Norfolk than in the east. Do the commissioners understand the reasons for this? Is there potential to share best practice between providers or are there other reasons for the disparity?
- (c) The CCG's report mentions that investments in services which form part of the children's neurodevelopmental disorders assessment process are being considered for a small allocation of additional funding. When will the decision be made and how much difference would the allocation make to waiting times?
- (d) The CCG's report also mentions opportunities to apply to national and regional COVID recovery funding schemes, to specifically target waiting time backlogs for NDD pathways. What are the timescales in relation to these bids and Norfolk & Waveney's level of need in comparison to other areas across England?

- (e) Digital capability restricted the adoption of virtual appointment software at the Newberry Clinic during the pandemic. Has this been addressed to provide future resilience?
- (f) Given that waiting times are already long and demand for services is very high and worsened due to the pandemic, do the commissioners consider it will be possible to meet the 18 week referral to start of assessment target in the foreseeable future?
- (g) The CCG says that pathway waits for diagnosis should not affect how long children and families wait for support to meet needs, but the evidence from Family Voice appears to suggest that it does. What more can be done to hasten the shift to a system that is responsive to needs?
- (h) Family Voice's findings suggest that neither the pathways to diagnosis nor the support available to families to meet needs during that process are well explained to or well understood by families. What more can be done to improve communication with families?
- (i) Around 30 respondents to Family Voice said that their child had been on the NDD pathway for more than 3 years but the commissioners' report says the maximum times spent on the pathway are around 2.5 years. Does this suggest long waiting times for pre-requisites to the pathway and confusion about when formal assessment starts?

4. 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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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;

1. 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
2. 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
3. Provide information of what support and resources are available to families awaiting assessment including any Positive Behaviour Support Programmes (PBSP)
4. 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

1 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

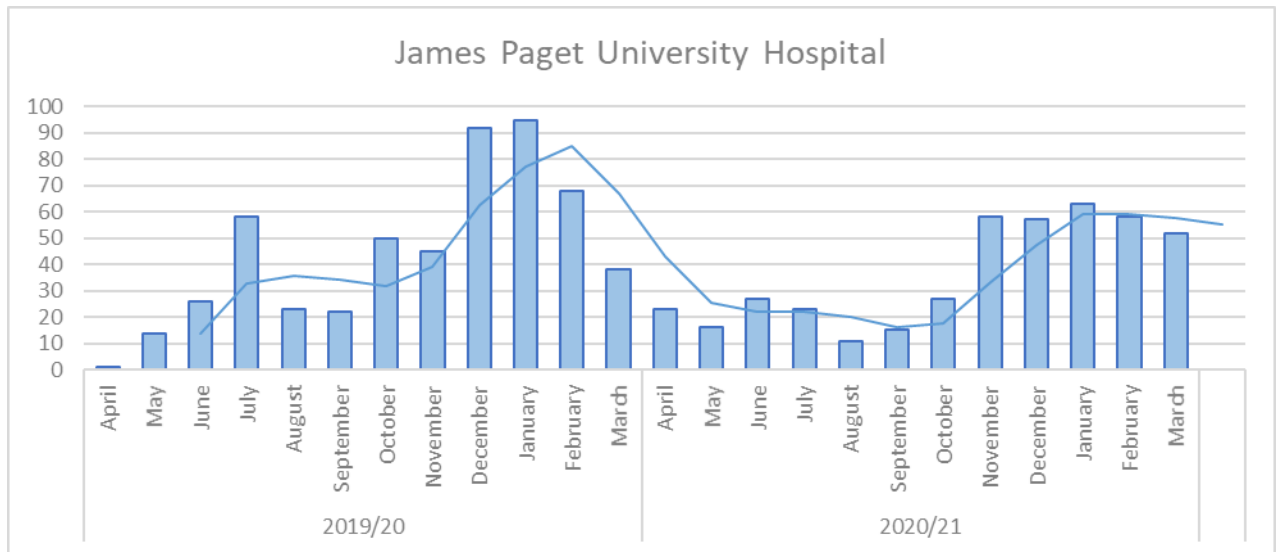
Prior to the Pandemic in March 2020, waiting times for NDD pathways were not consistent. In the east of the county, children would be seen for their first appointment within two weeks and would usually complete the pathway by twenty-nine weeks. By comparison, children referred to NCHC might wait for 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. The CCG has not received the financial allocation for the second half of this year but has identified and agreed with system partners a small allocation to prioritise high priority projects. Investments in services as described in this paper is being considered for this.

Members are asked to note that pathway data for NCHC is recorded and shared electronically with the clinical commissioning group, but this is not the case for James Paget University Hospital. Data from JPUH is obtained via a manual search

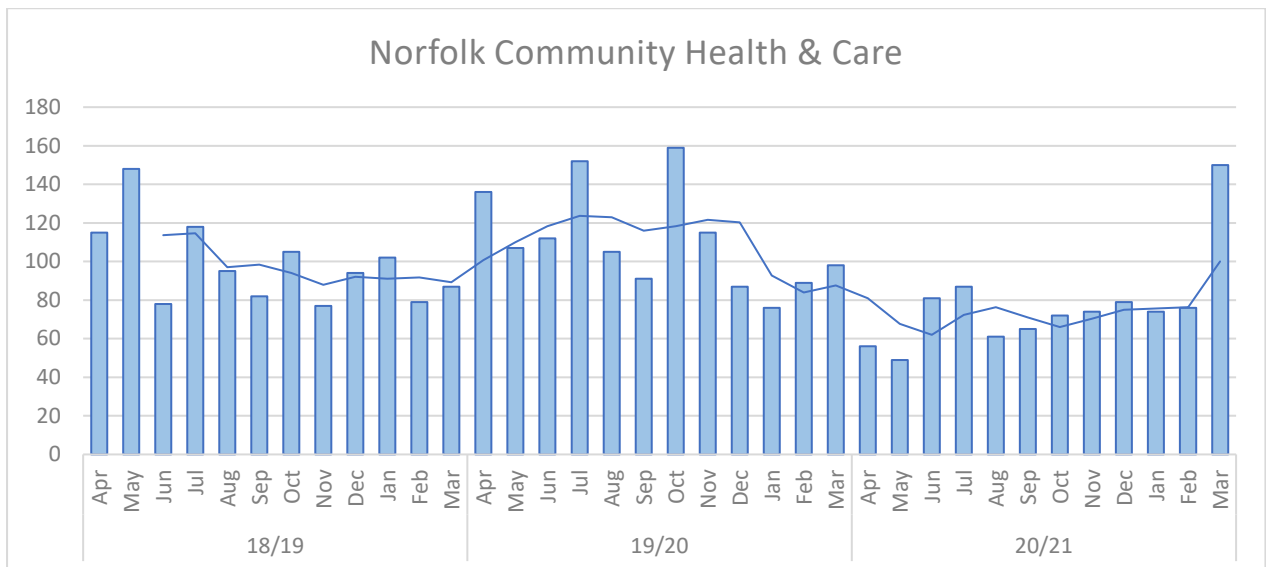
Demand is accepted referrals only, with a trend line on each graph based on a three-month rolling average. Data is displayed by provider.

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



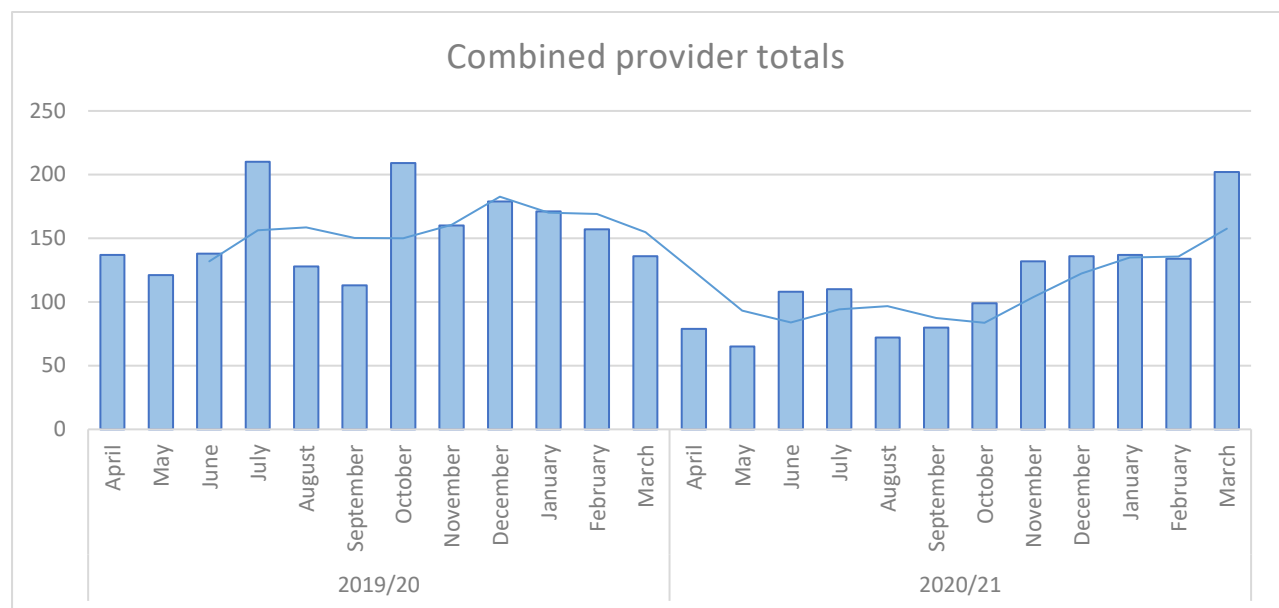
Data for James Paget University Hospital relies on a manual search of case records. For this reason, data from 2018/19 could not be submitted. Soft intelligence suggests referrals are increasing.

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

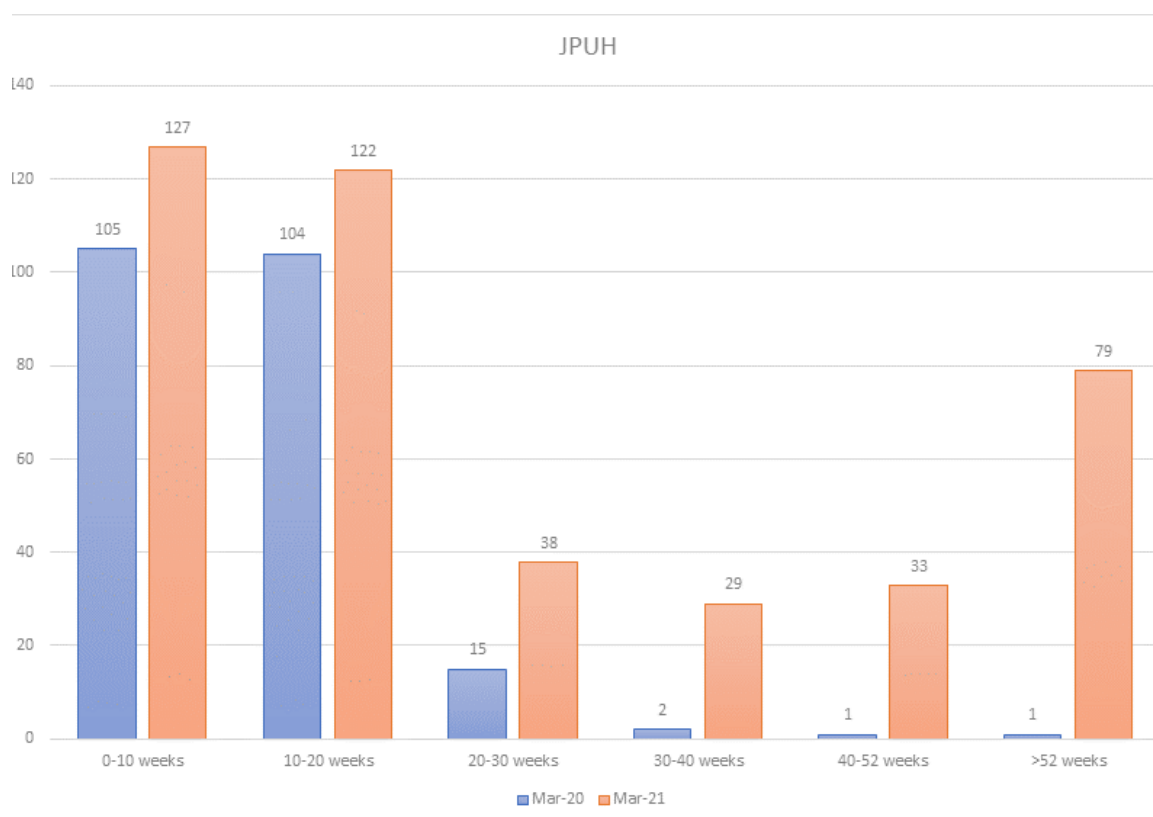


In May 2020 and in response to COVID, the provider observed a significant drop in demand. Social distancing measures and digital capability at that time prevented the clinical team from taking advantage of this in clearing referrals already in the system. The peaks in demand correlate with schools re-opening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

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

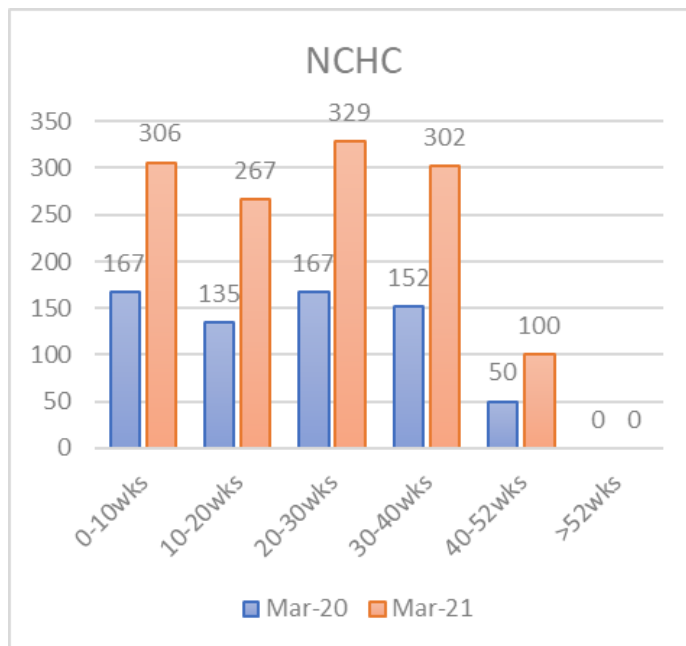


Graph 4: Current incomplete waits for those awaiting start of assessment as of March 2021 compared to March 2020 at James Paget University Hospital (Newberry)



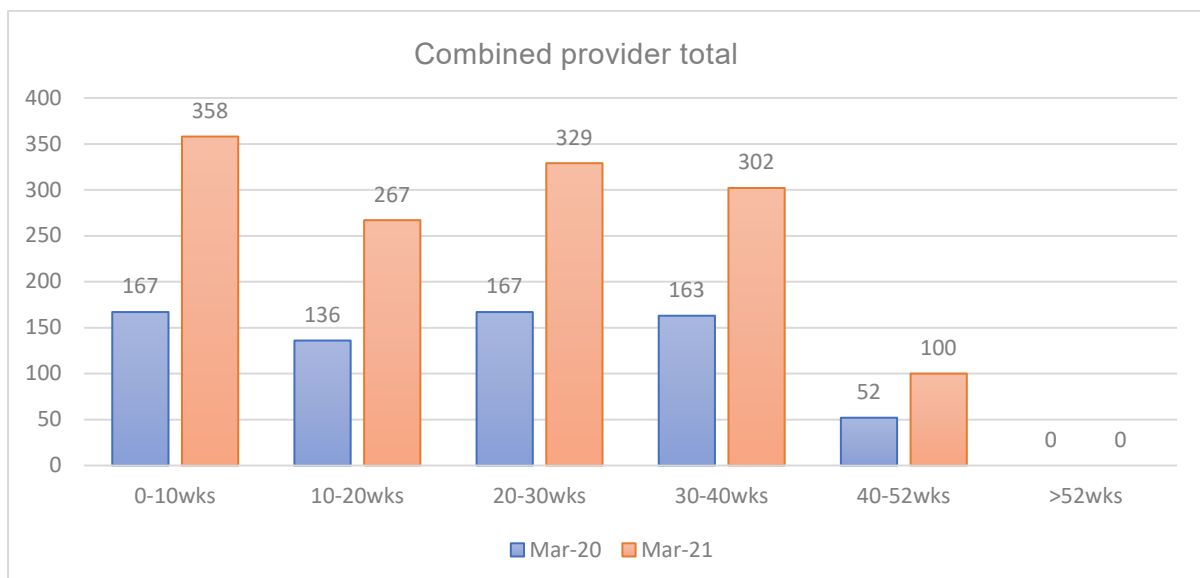
The maximum wait as at 31st March 2020 was 72.6 weeks
 The maximum wait as at 31st March 2021 was 91.3 weeks
 These waits were due to appointments not being attended.

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



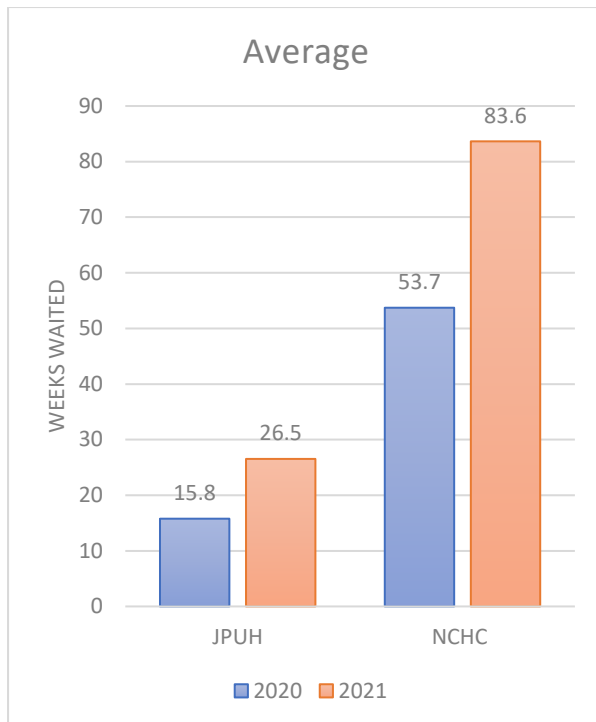
The maximum wait as at 31st March 2020 was 43 weeks
The maximum wait as at 31st March 2021 was 42.3 weeks

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

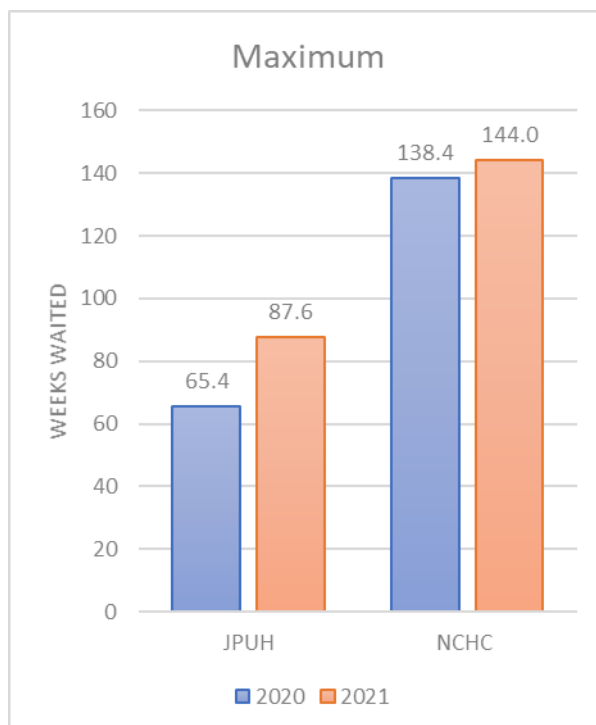


Children waiting between 40-52 weeks will each have or have had a scheduled appointment with the clinical team

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



Graph 8: Maximum waits from start of Assessment to Discharge based on CYP 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 (KPIs)

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 NDD services across the system. During 2020, we attempted to source benchmarking data for Autism and NDD 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 CYP and family 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 search. 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 CYP waiting within 18 weeks
- Number of CYP waiting over 18 weeks
- % CYP waiting within 18 Weeks
- Total number of CYP waiting
- Total number of CYP waiting over 40 weeks

1.4 Impact of COVID19

COVID19 has impacted all assessment and treatment pathways across children 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, digital 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. Collecting information for referrals has proved to be more challenging during the pandemic where face to face consultations have been minimised hence 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 unsuitable 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 unsuitable 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 NDD teams are adopting new ways of working. They are trialling the efficacy of the QB assessment tool, a computer-based test that combines a test of attention ability with a movement analysis based on an infrared measurement system 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 CYP and family 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 has been developed and is awaiting the funding decision from the system. 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 and Waveney. 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 CCG Children Young People and Maternity 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 the 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.

Families continue to report challenges with receiving additional support for their child during the school day, there is Higher Needs funding available and we continue to work with education to ensure appropriate access to this.

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. Two system redesign programmes in place should improve access for mental health support for CYP with autism, but the scale of change is significant and will require involvement from all sectors.

Neuro developmental services are experiencing very high 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 CYP and family 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 NDD 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.

Summary

Norfolk and Waveney CCG acknowledge that the current waiting times are long and we have mitigated this to an extent with a pre and post diagnostic offer of support whilst working closely with health and education colleagues. We are working with system partners to secure of additional resources. Whilst we recognise that the service could be more comprehensive, staff and leaders are working to secure funding, bring about change and deliver the NDD service that the children, young people and families of Norfolk and Waveney deserve.

END.

Family Voice Norfolk Consultation on the Neurodevelopmental Diagnostic Service for Norfolk County Council Health Overview Scrutiny Committee

15th July 2021

Consultation

Parent carers of children and young people with Special Educational Needs and/or Disabilities (SEND) with specific were consulted via an online survey to inform this report. This report will be presented to the Health Overview Scrutiny Committee (HOSC) on 15th July 2021.

Background

Family Voice Norfolk (FVN) is a collective of parent carers from 1150 families across Norfolk and represents over 1440 children and young people with SEND. FVN has been the strategic voice of parent carers working in partnership with Norfolk County Council (NCC) and with the Norfolk and Waveney Clinical Commissioning Group (NWCCG) since 2006. It is funded through a direct Department for Education grant (administered through Contact), by NCC and by the NWCCG.

Parent Carers were invited to complete a survey online and had the opportunity to write comments on their experiences of accessing the pathways and services supporting diagnosis of Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD) and Attention Deficit Disorder (ADD). The survey ran from 23rd June to 28th June 2021. FVN received 178 responses from families living within all 7 district council areas: King's Lynn and West Norfolk, Breckland, North Norfolk, Broadland, Norwich, South Norfolk and Great Yarmouth.

The West Norfolk Branch of the National Autistic Society has collated experiences of the NDS from some of its members and shared with Family Voice Norfolk. We would like to thank them for this and have included transcripts of those experiences shared, as an addition, after the end of our survey results.

Key messages

Family Voice Norfolk consultation on NDS for Norfolk County Council HOSC

1. LONG WAITING TIMES

Waiting times for the different Neuro Developmental Disorder (NDD) pathways are too long.

2. POOR COMMUNICATION

Communication with families is often poor or lacking.

3. IMPACT ON FAMILIES

The detrimental impact of the previous two factors is significant.

Key findings

1. LONG WAITING TIMES

Over 57% of the 178 respondents first requested help over 3 years ago, and a further 24.2% have been waiting between 18 and 36 months. In effect, this shows an alarming 75%+ of families waiting in the service for more than 18 months.

For those who have received confirmation of referral acceptance, over 13% have been on the pathway to diagnosis in excess of 3 years and a total of just over 51% have been on the pathway for over 18 months.

50% of those families who had the referral refused intend to repeat the process.

Based on the lengthy wait times on the pathway, 176 responses were received to the question 'Have you ever considered a private diagnosis route?' Almost 73% of those responses indicated yes, they have considered private diagnosis because of wait times.

Families are looking at private diagnosis out of 'desperation for answers and help'.

As one parent explained "my son needs help now and it's been nearly 3 years and they still can't tell me how much longer it will be, just he's still a way down the list".

Another parent who has experienced two very different systems told us “Although my son was diagnosed with ASD in a different county, he was diagnosed with ADHD through this service. The waiting times are appalling, this service has been reorganised a few times since on the waiting list and in that process a referral was lost in the system, departments do not communicate with each other, due to waiting lists parents are opting to pay privately as the reports are usually more in depth, a considerable amount of time is spent with the child as opposed to the NHS service and your concerns are actually taken on board rather than parent blaming. Too much parent blaming happens when a child’s behaviour is being scrutinised. With private diagnosis you get much more support post diagnosis over what the NDD offers.

2. POOR COMMUNICATION

To the question ‘are you aware of which pathway your CYP is on?’, 36.7% of respondents said they did not know.

Only 37.6% said that the Neurodevelopmental Service (NDS) and the Neurodevelopmental Disorder (NDD) pathway had been explained to them by a health professional. This means an overwhelming 62.4% of respondents had received no help in understanding the pathways and services.

Encouragingly, 69.7% of families had been made aware of their CYP’s referral acceptance. 11.8% of families had been advised of declined referral. This leaves 18.5% of families, however, who have received no notification.

When asked if they have been kept informed of the CYP’s progress on the NDD pathway, 75% of all respondents said that they have not been informed or updated at all and 78.7% had taken action to contact the NDS themselves to get information on progress.

Almost half (48%) of the families responding stated that they had not been offered or given any help and/or advice whilst waiting on the NDD pathway.

An overwhelming 86.9% of those families who knew their CYP’s referral had been accepted had since received no communication from the NDS to explain any delays affecting them.

Being able to contact a service with ease is important to families with over 56.6% of respondents telling us they had needed to contact the NDS team but that just over 50% found that contact difficult to make.

Although there is an NDS website, over 65% of the families who replied to the question 'have you visited the NDS website?' said no, they had not.

3. IMPACT ON FAMILIES

There were 124 responses received to the question 'Has the time waiting on the NDD pathway had any impact on your child or young person, your family or on the educational setting?' 87% of responses indicated yes, there has been impact. This is also reflected in the responses around consideration for private diagnoses. Families have shared some of these impacts with Family Voice Norfolk and all can be seen in the appendix.

To illustrate the impact felt, three cases are listed here:

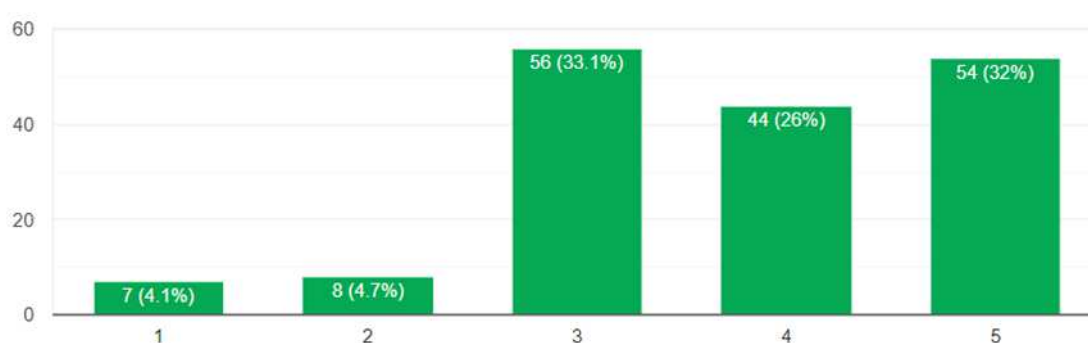
- a) " ...haven't been in mainstream education, due to her phobias, school been supportive but it has taken about 3 years. She can't be left alone die to her self-harm, suicide thoughts, she don't go outside in the sun, she slept on sofa for 2 years, she can't cope with car journeys, she's tried to jump out the car, she sees no danger, she don't stay away from home due to phobias, no days out or holidays due to phobias. She sees CAMHS, but a trainee, only because I cried and broke down begging for support, she's depressed, not motivated, I'm disabled, we have a family support worker and we are all screaming out for help but never get anywhere."
- b) "It has made it difficult for school to accept what we are saying as parents, without formal diagnosis and the GP surgery won't put him on the learning disability register yet. Other services won't help without a diagnosis. Too much importance is put on formal diagnoses."
- c) "Permanent exclusion from school, mum developed anxiety disorder, reduced hours at work, child developed anxiety and school based trauma, child missed 1 year of education."

Overall

Of 169 responses, only 8.8 percent of families rated their whole experience of NDS as excellent or good. 33.1 % rated it as average and a total of 58% said their family's experience was bad or very bad.

Overall, how would you rate your experience of the NDS service?

169 responses



1 = Very good

5 = Very bad

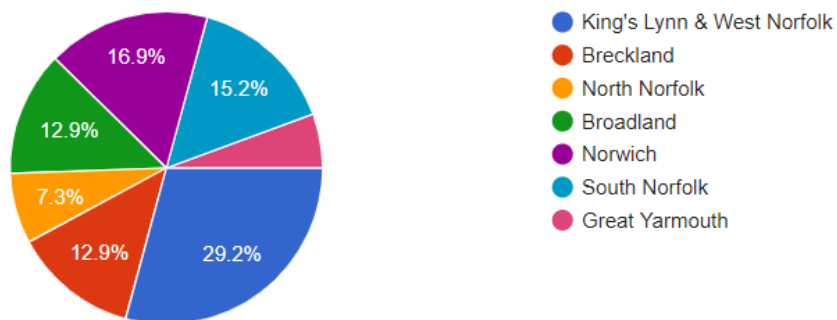
Appendix A: Family Voice Norfolk Survey Results

(NB: Names and locations recorded in response have been redacted to protect anonymity, all other details recorded in full)

178 responses from parent carers of children or young people aged between 25 months and 26 years.

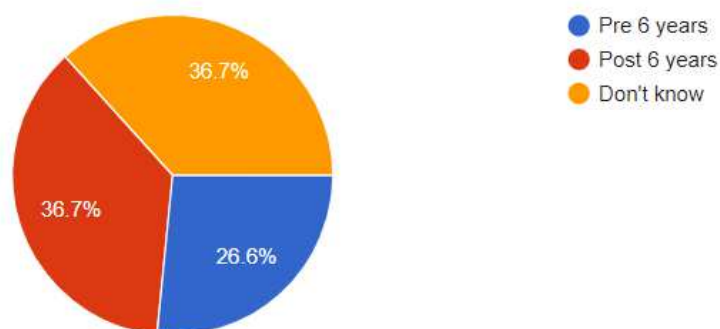
Your location

178 responses



NDD Pathway Route

177 responses



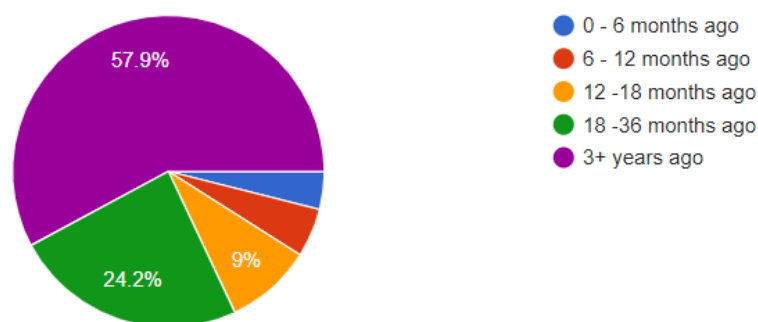
Areas of concern:

85.4%	ASD
47.8%	ADHD
12.4%	ADD

Also mentioned: PTSD, Dyspraxia, Separation Anxiety, ODD, Learning Difficulties, Sensory Processing Difficulties, Trauma and Anxiety, Kleptomania, Hoarding, Meres Irelim, Dyslexia, PDA, Developmental Delay, Hypermobility, Selective Mutism, Social Communication Disorder, PICA, Self Harm, Suicidal Thoughts, Emotophobia, Tourettes, Awaiting Diagnosis.

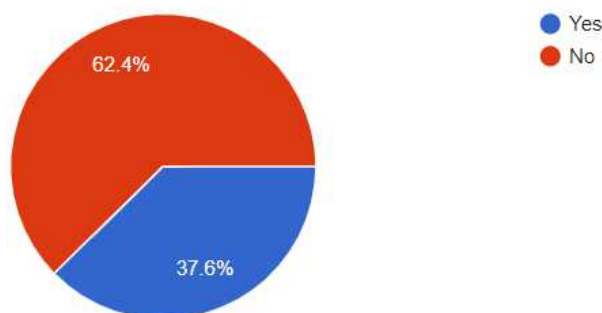
How long ago did you first ask for help from a Health Professional about your child or young person's neurodevelopmental concerns?

178 responses



Has the Neurodevelopment Service (NDS) and Neurodevelopmental Disorder (NDD) Pathway been explained to you by a Health Professional?

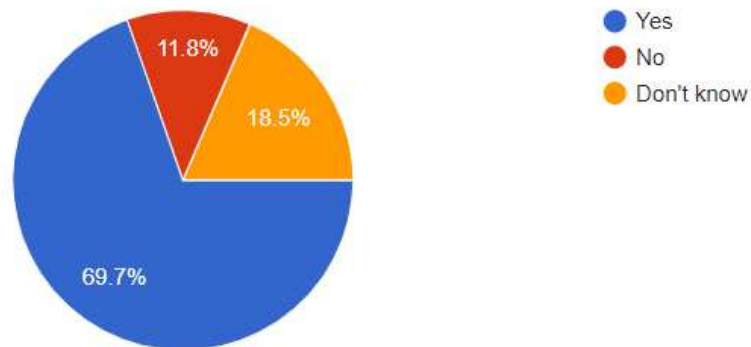
178 responses



Of those who said yes, 55.4% had explanation from NDS Team, 18.5% from GP, other sources mentioned were SENCO, Health Visitor, Paediatrician, Portage, School, Hospital and Teacher.

Has your child or young person's referral been accepted?

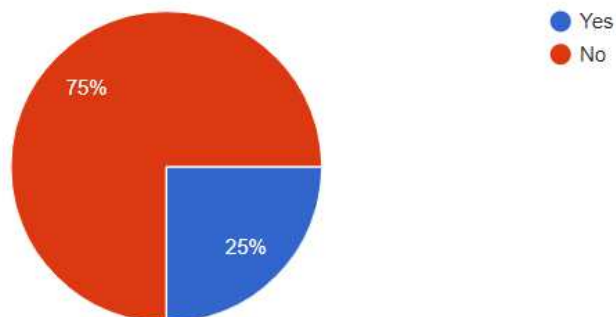
178 responses



When asked when parent carers were told their CYP's referral had been accepted, dates varied between 2016–present day.

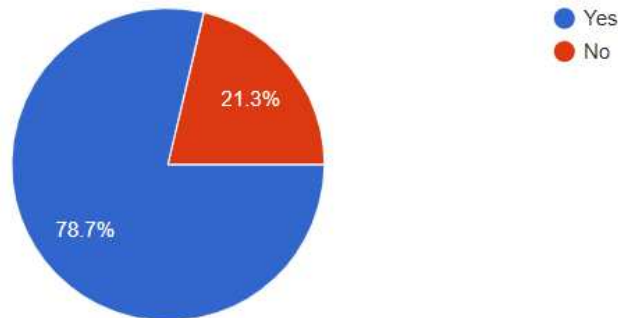
Have you been kept informed of your child or young person's progress on the NDD pathway?

124 responses



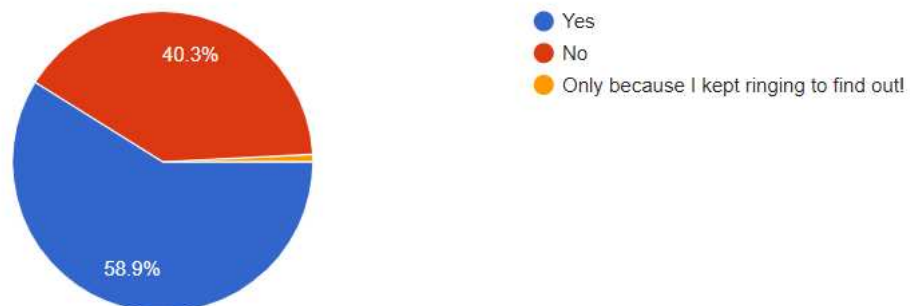
Have you made contact with NDS to find out about your child or young person's progress on the NDD pathway?

122 responses



Do you know what stage of the NDD pathway your child or young person is currently at?

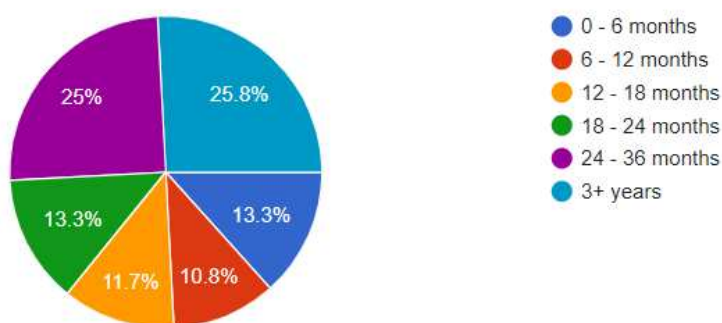
124 responses



Those parent carers aware of the stage that their CYP is on the NDD Pathway were informed by letter, their own contact with NDS (telephone and email), their SENCO, email from NDS, through contacting their MP, telephone call from NDS, multidisciplinary clinic and their social worker.

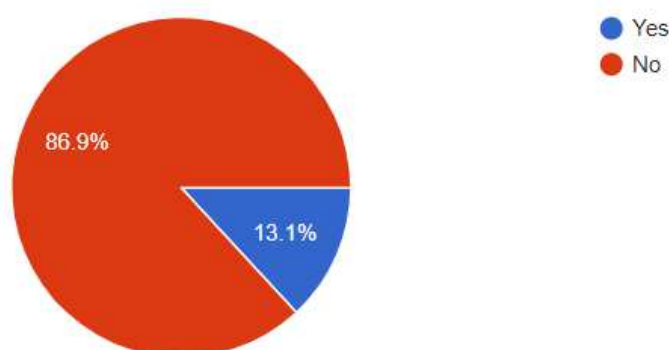
How long has your child or young person been on the NDD pathway?

120 responses



Have you received any communication to explain delays to the service?

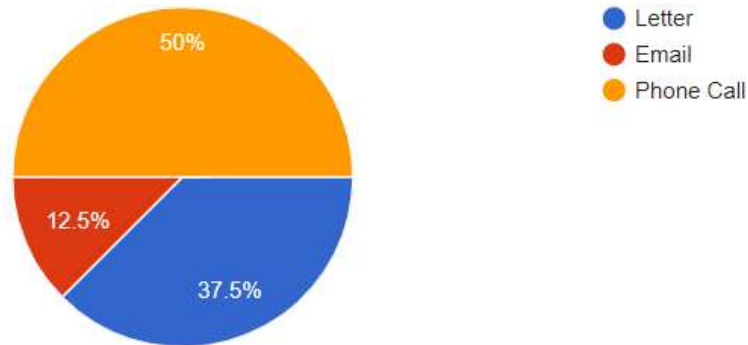
122 responses



Those parent carers who *did* receive communication to explain delays were contacted by NDS, their paediatrician, or only received communication through direct enquiry to NDS.

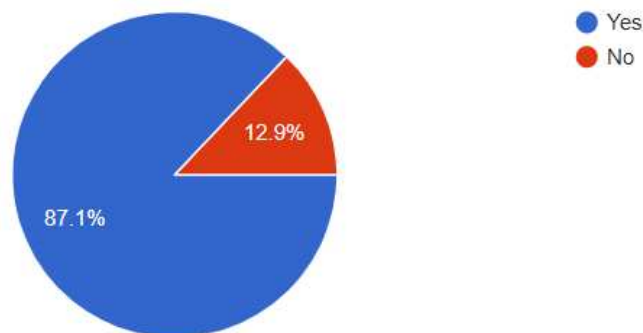
How did they make contact?

16 responses



Has the time waiting on the NDD pathway had any impact on your child or young person, family or educational setting?

124 responses



Parent carers were asked to give details of that impact:

I have been advise current mainstream setting is not appropriate for my child but until know if will gain ASD diagnosis or not can't have alternative school named on EHCP. This has hugely negative impact on child's mental, emotional and academic well being

It had a detrimental effect on his mental health.

It has made it harder for school to gain an EHCP

School refusal, pressure and meetings from school about attendance. Very stressful time.

Worse behaviour

In my last phonecall to ndd, I asked how long we would need to wait. The person couldn't tell me - I asked if it could be months and they said they couldn't say. I asked if it could be years and the person went quiet in a way that suggested this was likely. My daughter is 17 and is looking at options after A levels - she is paralyzed by the lack of diagnosis and doesn't feel ready to take next steps. With this in mind, my family have provided some of the cost of private diagnosis which we are now starting. I am very angry about this - there are a million other ways we could spend the money but my daughter is priority. She deserves better.

Impacted on trying to get him the help he needed.

Keep refusing to diagnosis, traits getting worse

People, namely daughters school have have said there wasn't much they could do as she had no diagnosis

Just want clearer answers to LO behaviour and how to support them. We feel we have been left in limbo.

Child is school refusing, still awaiting a diagnosis, impacts sibling at home, anxiety has increased.

Haven't been in mainstream education, due to her phobias,school been supportive but it's taken about 3years, She can't be left alone due to her self harm, suicide thoughts, she don't go outside in the sun, she slept on sofa for 2years ,she can't cope with car journeys,she's tried to jump out the car,she sees no danger,she don't stay away from home due to phobias,no days out or holidays due to phobias. She see CAMHS,but a trainee,only because I cried and broke down begging for support.shes depressed, not motivated,im disabled we have a family support worker and we are all screaming out for help, but never get anywhere

My child needs support in school

Not getting the support he needs

Struggles with daily living tasks, anger issues, severe anxiety, self harm, biting, hitting himself, expressing to take his own life, troubling with any transitions, sensory overload, unable to regulate emotions and express what his worrying him. Problems getting him to school. Mood swings extreme. Lacks any safety awareness. Previously assessed by Psychology 4 You with diagnosis of Autism. Referral accepted for ADHD and on waiting list to see Clinician and school observation by Clinician, but long waiting list due to Covid Pandemic.

Trying to get extra support and funding at school, ehcp delays due to needing more assessments

the delays have meant his needs were never fully understood and this impacted on his education

Have now paid for a private assessment and awaiting this diagnosis to be ratified by the NHS

We feel like we are fighting the school to be heard. Our hope is that a diagnosis would help make the school take better note of our concerns. To them just being in the system is not enough.

It's hard to understand how best to support the young person without the correct diagnosis and detrimental to their own personal identity waiting for year's to understand themselves better

her behavior and development is getting a lot worse. The impact it is having on the family is not good, it causes a lot of stress for all the family. Her birth mum can no longer cope with her so visits are very short and sweet with her mum rather than sleep overs that were previously taking place. Concerned about her anger and the fact that she would go off with anyone without hesitation is a huge concern. her relationship with food is getting worse.

My son needs an urgent assessment due to withdrawing from school due to PTSD and school "refusal". He wants to go back into the classroom but needs a diagnosis to access support.

My son's mental health and wellbeing hasn't drastically deteriorated as he is getting older and becoming more aware of his differences and difficulties, this is causing a high level of anxiety and is affecting every aspect of his life. Through not having a diagnosis he cannot access services or resources that could massively help him and us as a family to support him.

Delayed support due to no diagnosis

Mental health and support issues

We struggle with X on a daily basis, in particular with his repetitive behaviours and lack of speech which are becoming more of a problem each day. We have had to go private for speech & language therapy, occupational therapy and a diagnosis in order to try to help X's development as much as possible and this has impacted on our finances.

We as a family are struggling with our eldest son, with his behaviour not only does it affect us daily but it's also affecting him in school, his education is more important to me and I feel like he's just been forgot about. We no longer can take our son out in public due to his outbursts and behaviour. His sleep is massively effected also

Moved out of county in August 2020 (for a temporary period) returned in March 2021. Told would have to go back on waiting list and start whole process again. Child was in urgent need of assessment to identify support and behaviour management. End up paying for private assessment.

Unsure of how transition to high school will go

Been excluded from school because of behaviour

It has made it difficult for school to accept what we're saying as parents, without formal diagnosis and the GP surgery won't put him on the learning disability register yet. Other services won't help without diagnosis. Too much importance is put on formal diagnoses.

My daughter has had an awful couple of years and we have no help. We don't have the knowledge of a diagnosis to help us help her.. we are 100% sure she has ADHD and an early diagnosis would have enabled us to get the medication that would help her cope in school!

We had huge issues while he was younger and treated like he was a badly behaved child by school and bullied by a teacher he had a year in secondary school where they lost his diagnosis letter and he received detention constantly every day sometimes 3 x a day

We had the diagnosis for ADHD first as that was a quicker assessment that was available. We are still waiting for an ASD assessment to be completed but are some way through that at the moment. It's the ASD part that is taking so long.

My child had no school place. No school could meet needs due to his ASD but he didn't have a diagnosis. A diagnosis was required for him to have a place at a school able to meet need. This was the situation for 18 months.

No longer able to attend school, can't get right school as no diagnosis

Has been at crisis point with school & home twice in the last 6 months

We needed to know a diagnosis so we would know how best to support him

Without knowing exactly what support my daughter needs we are left to guess what her needs are, what might help. She is now masking a lot at school and she is becoming increasingly physical at home. Needs not being met?!!!

Struggling with anxiety and lack of support - stuck in a limbo

Struggling with behaviour & aggression. Masking at school.

It delayed everything and allowed difficult behaviours to develop in my daughter. Also School didn't understand her needs so impacted school attendance. It delayed EHCP assessment. Just everything. Was so difficult.

He's in mainstream school and doesn't talk

It affects the support you can access

missing out on vital support. School have an LSP in place but don't follow it, using covid and curriculum constraints as excuses. An EHCP has now been applied for (parent) but SENCO wasn't very supportive

Even though this team is busy, I was chasing them up to do their job to get my daughters assessments. She had one home visit. That school visit. Left me for months for no information.

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Permanent exclusion from school, mum developed anxiety disorder, reduced hours at work, child developed anxiety and school based trauma, child missed 1 year of education

Behavioural issues which have had a lasting effect upon our younger children, marital strain, issues coping at school, challenging behaviour at home

High risk of exclusion – we are expecting it to take up to 2 years before he is seen, but we fear he does not have that much time to spare.

Waiting for a diagnosis was stressful

Escalating behaviour and difficulties

Their behaviour is getting worse at times, school are not helping due to no diagnosis and are trying to get rid of his EHCP

With no diagnosis no help was offered as the school couldn't give a written documentation of why extra help maybe needed.

EP assessment and EHCP evidence

Not enough support at school

Struggling to cope in school

The teachers in school are unsure of what my son needs and with no diagnosis or EHCP I do not feel I can question them

She became a full school refuser and is now in tutoring 6hours a week as she couldn't cope in main stream high school

School were slow to accept X has additional needs. Family support worker got involved and problem was resolved.

As my son didn't have a 'formal' diagnosis struggled to get school to agree to put on SEN reg, put support in place

Our child is struggling to self regulate. It means that it is guess work for the school to know how best to support. It has also made transition to high school daunting as we were hoping to be able to have a plan on place before this. We are coping but this is only because we are in the fortunate position to be able to pay for resources such as sensory toys, blankets etc and that school and that we are both school teachers with experience of teaching children with SEN. Our son is desperate to know what he has, to be able to explain it and get the support he needs. School is challenging for him and he has days where he comes home distressed. If we knew what he had, if we had a plan to help him life for him would be so much better and for all of our family. He also has an eating disorder which adds it's challenges. It is such a shame that the waiting lists are so long and that he can't get the help he needs.

Years without a diagnosis meant less support and understanding available at school and from other health services.

Specialist provision can not manage him and he struggles in school environment, impacting on his mental health

My son was repeatedly excluded from school or only allowed in to school for an hour a day for several years

My son's behaviour has effected our whole family and has since been diagnosed privately with severe ADHD

Not believed by school and without an assessment I can't explain to him why he is different to his peers

My son's mental health has deteriorated, he is unhappy at school and struggles with social interaction.

My sons behaviour has gotten worse, his education has suffered badly as he is not getting the help he needs – he has gotten more sensitive, developed ticks and relationships have been affected both at school and at home.

School was failing. Adhd diagnosis wasn't made correctly which had implications for years until I took her private and paid for it to be done again. This is despite nds stating she had ADHD no written diagnosis given.

Constant stress of waiting and no one listening to you so you keep backwards and forwards

He no longer believes that any health professionals will help him or are even bothered

We would like to discuss with our child but without a diagnosis, we are best guessing

It's not affected but delay in completion is delay in receiving support available

Not able to get plans into place as Nursery/School like to have a diagnosis first

My child has anxiety and is self harming. We have been told to hide medications

On medication for depression

exculsions from school

Disaster

Lack of support, treatment, and access to services to make my child cope better

Still waiting for assessment , child struggles to keep up on school

Ended up getting a private ASD diagnosis to secure EHCP ready for transition to high school. Still waiting for ADHD diagnosis.

Its causing family rifts with stress and extra pressure put on sibling. The whole process is unclear and stressful no support

Family Voice Norfolk consultation on NDS for Norfolk County Council HOSC

Now struggling to get him into a suitable school space.

It's the not knowing, he knows something isn't right

No diagnosis no further supporting evidence for ehcp

At the time of going for an autistic diagnosis my child was at the start of key stage 2, we got the diagnosis in year 7 which we really wanted before starting high school, the process took so long and there was so much chasing up to do. A very stressful time

School saw his Behaviour as negative & rude. He would get in trouble for fidgeting and calling out answers. He became very unhappy in school. This created upset at home and his frustrations would come out in meltdowns and lows self esteem.

He's struggling with school, and falling behind.

He could have had more support with his learning

Too late to put in place help at her school

Not been giving a diagnosis makes it difficult to know what you are dealing with. Stuck in limbo.

If my son was given his diagnosis earlier then he could have had more support put in place earlier

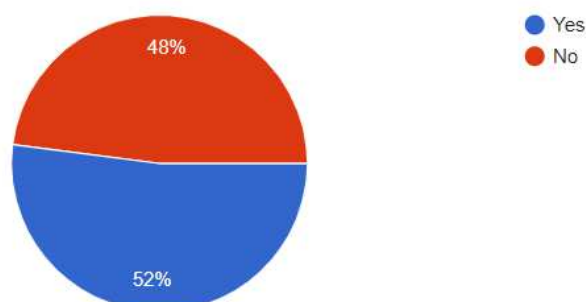
I've been asking for help and assistance for years. We finally get started and Ive only had to fill in a consent for this month in June eithen thou they except the referral in march. My son is due to go to high school in September I'm concerned on how he's going to cope and as he doesn't have a diagnosis on where the school will help with what he needs as we have not proof as such.

His condition worsened in the time and we could not access relevant support without a diagnosis

Lack of support when needed it the most. Although I am aware post diagnosis nothing happens!

Have you been offered or given any help and/or advice whilst waiting on the NDD pathway?
For example, from Family Action, GP, educational setting, or support groups?

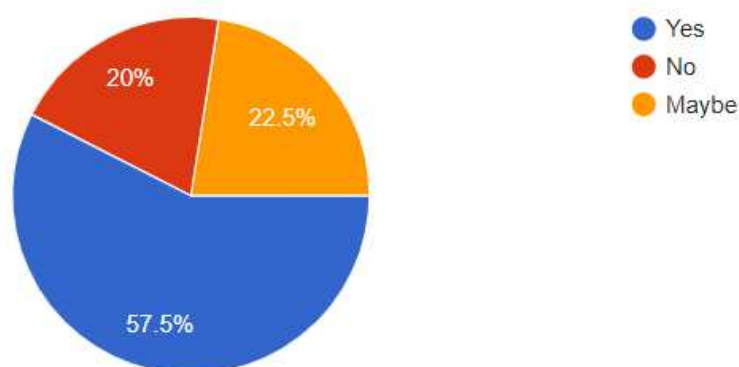
123 responses



Of those that *had* received help and/or advice the following sources were mentioned: Family Action, School, Occupational Therapist, NANSA, SENCO, SEND Norfolk, Portage, Social Services, Family Services, Educational Psychologist, SureStart Centre, SENDsational Families, Family Voice Norfolk, GP, Early Help, Health Visitor, Action for Children, SEND Norwich, SENDIAS, Swan Youth Project, FamilyLine and Point1.

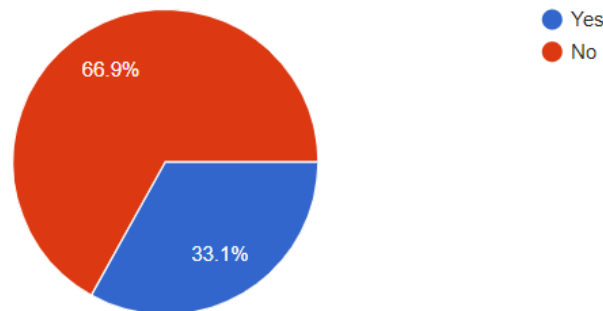
Do you feel COVID 19 has affected your journey on the NDD Pathway?

120 responses



Have you received any communication from the NDS team during the COVID 19 pandemic?

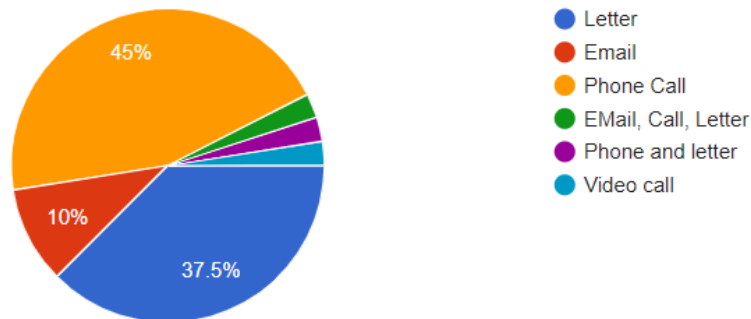
121 responses



Those parent carers who *did* receive communication were contacted by NDS, SENCO, Occupational Therapist, Paediatrician, EHCP co-ordinator, CAMHS, Family Action and SaLT.

How did they make contact?

40 responses



When asked if reasons for delay and what to do next were explained, parent carers responded:

We were told the reason he couldn't be referred for an ASD assessment was because he already had a diagnosis of a deletion on one of his chromosomes and that it wasn't possible to have a second diagnosis. We weren't told what to do next.

The letter only stated that she didn't meet the criteria but didn't explain what that was.

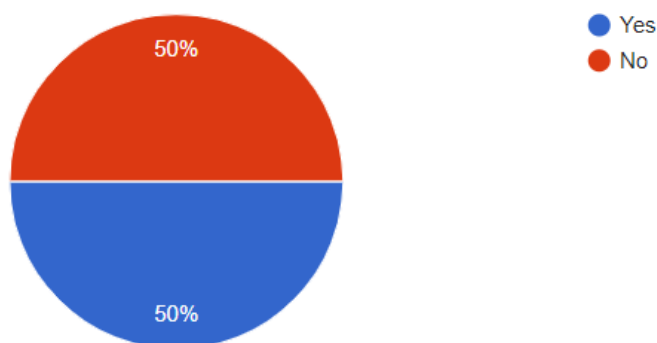
Reasons yes but not specifically what to do next

Told why (no difficulties at school) but not what to do next. We went private instead

I was told any referral had to come from school by my GP

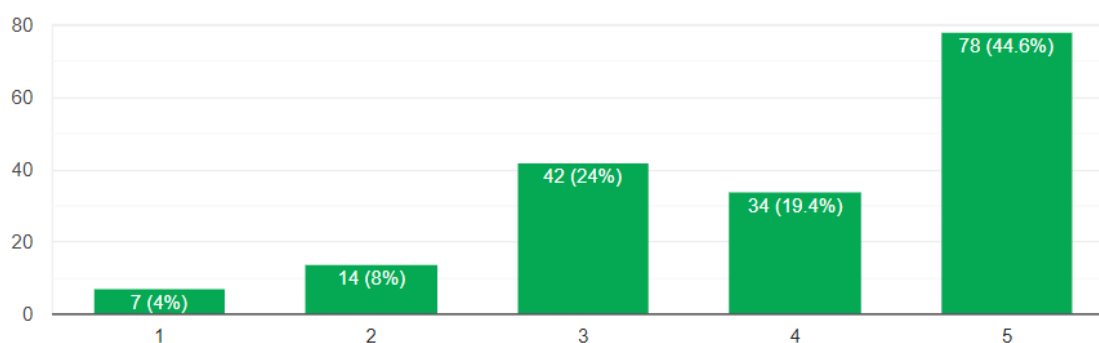
Are you intending to repeat the referral process?

20 responses



Can you rate the referral process?

175 responses



1 = Very easy

5 = Very difficult

When asked to explain their rating parent carers responded:

Nursery advised GP referral to seek diagnosis so they can apply for additional funding but provided no supporting evidence . GP made referral but this was declined on basis of insufficient supporting evidence from nursery

As always the onus is on the parent to keep ringing up to keep updated, send in relevant reports and extremely stressful To be waiting over two years whilst child is suffering

Unfortunately with the cuts there is a long waiting time to be seen

Had to get a private diagnosis, then get the NHS to accept it !

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Still waiting to be seen by someone

I am at the very early stages

My son masks at school so it's very difficult to get a report from school supporting a referral. We had numerous reports from over the years but a referral always seems to hinge on school support. Thankfully we managed to persuade school to write a letter during lockdown stating a report from them would be so delayed that it wouldn't be appropriate to wait that long, which helped, and we sent in a long, detailed report of everything we witness with our son. Not every child displays at school. Parents should be believed. Nobody would make this up!

Because my son was also in the process of having an EHCP, the NDD team were able to use the needs assessment reports; EP, SaLT & OT, to inform their assessments and give him a diagnosis of ADHD. I asked for this to be considered though, but they were very responsive and saw the merits of sharing current assessments across all services.

Not enough information given

A long wait for a diagnosis

The process is absolutely fine and it's obvious the team work hard and are doing all they can for families, but it's the time scale that is the problem. My son was first referred by the GP in May 2018 and I received a phone call from NDS in January 2021 to say his last assessment is likely to be another 2 years. That is not acceptable.

Our first referral was rejected as we didn't have the right type of evidence- There wasn't enough evidence from school, even though at school there are no issues and the majority of the challenges we face are at home. It felt like our experiences weren't valid (something that has happened continuously throughout this process.)

A the start of the referral everything was explained to me

No support for parents and slow process for child

The wait wasn't terrible like others have had

It's awful! The length of time you have to wait is ridiculous! My son had an ADHD diagnosis within weeks when it was done through CAMHS.. I don't understand what takes so long with the NDD team! Having to wait years for a diagnosis is ridiculous especially when years can have such an impact on a child's future

It seems like no professional listens to your concerns and just find more hoops for you to jump through. No one clearly explains what is required and it's always a fight and this should not be the case. I have decided to go private for a diagnosis because the process is so unclear, unhelpful and stressful.

Long waiting list of 3 years I was advised.

It's hard unless someone agrees with you

I havent heard from since September 2020

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The first time round we finally saw someone after nearly two year who then lied on his report about what was said and pretended there are no problems. This left us with the school insisting we try again as there is so clearly a strong problem. Now having the stress of waiting all over again.

It was a lengthy process with no support while it was ongoing. We paid for private speech therapy (and still do) to plug the gap. Our son was non-verbal but with speech therapy support now has age-appropriate speech. We would not have received any support via the NDS or other NHS services.

It takes far too long to get a diagnosis and the children are the ones that are suffering

It was easy to get the referral accepted but the waiting with no explanation was not easy

My child was initially discharged by Community Paediatrician without diagnosis in 2017. With help from the school and Ed Psych and Clinical Psych reports the school arranged privately the referral was accepted and moved on to the NDS multi disciplinary team in early 2018.

No communication at all

ASD referral declined by health, so I went privately and they diagnosed him very swiftly and was shocked that Health declined referral and so was my GP. ADHD referral has been accepted but still waiting to be seen have been told its a long wait

Just absolutely disgusted

blocked from all avenues

I ended up going private as wasn't willing to wait years and see my child miss crucial early years support. We got as far as a NHS triage phonecall and I think we are now on a 'post diagnosis pathway' since our private diagnosis.

Not much info or contact, lack of guidance or knowing whats going to be put into place. We still done no Looking at home schooling as he's been kept back a year in reception and there thinking of doing the same again

It's the length of time that it take to get seen. Even once one person has been out to observe, the wait for the next person is another 18 weeks at least if not longer. With no help, and no recommendations or support

When we started down a diagnosis route there seemed some confusion from the school as to whi should refer and what was needed, and since being referred we have been waiting over 2 years with absolutely no progress.

After asking for referral, we needed to fill in a few forms and then we received a reply that our son is being accepted for ASD assessment, but we haven't been given any date or expected waiting time.

It was easy but I believe things are more tricky now in that you need an ep report already etc it is sitting on the waiting list for years for a single assessment appointment which is difficult.

I've been waiting for 5 years to get someone to listen to me. Even now I'm being listened to it's taking an age and it's not helping my child who has 2 years left in primary.

We were initially turned down, but we were given an appointment anyway where he had a quick assessment, and history was taken, but not all info was recorded.

Actual initial appointment with paediatrician at the hospital was quick and he agreed a referral was needed but rest of it very slow and lack of information

it seems to take so long to get to a point where child is seen and helped unless you work in the hospital and then the process is moved so much quicker.

A lot of standardised questions, doesn't give a rounded picture of the child. Had to go through several other professionals before a referral was made.

Too long, little to no communication, no support suggested during that time, lots of places refusing to accept child is Sen with out formal diagnosis

It was difficult enough to convince the GP to put in the referral I then had to gather a whole heap of evidence to send to the Neurodevelopment team

Was rejected three times before accepting. No contact since then and when I phone I am just told she is not anywhere near the top of the list.

The referral process is appalling, especially as my son's referral got lost then we had to start the process and waiting list again.

I can't even remember how I initially referred it was that long ago now but there has been lack of communication, I've had to do all the chasing and have only received answers through frequent phone calls and emails to them. I feel like I have to keep them on task, there are always different case holders for each part and no one has the overall responsibility of supporting my son to receive a diagnosis or keeping me in the loop. It is a slow, form filled exercise and hasn't even completed after going on almost 4 years now

Takes a very long time from seeing a professional to getting a referral to NDS

to get to this stage can have huge consequences on child given the time frame

It takes time to convince school and GP that there is an underlying problem

Never happened!

It's not until you get rejected to then find out what evidence is required

No body is interested

I have a younger child and I'm trying to avoid the nds pathway at all costs. Given he has 3 siblings who both have dual diagnosis he needs assessing but honestly I don't rate it. A particular issue is it doesn't pick up children who mask, it will only accept information where school identify a problem. However if a child is not disruptive the setting don't overly pick up on it. They have no separate process for these children that I'm aware of (maybe this has changed) and so it makes everything delayed.

My Son was referred but nothing happened so consultant had to re refer as his information got lost on the system by the sounds of it

Very complicated process. Needed evidence from school but unable to attend school. Didn't offer any other pathway to get OT support

My daughter has suspected add however because she masks at school and sendco havent seen her difficults a referral can't be made

I was told to wait by many health professionals as my child was so young (under 1), but once it was accepted then it was smooth

The doctor put the wrong focus of the referral first time round then I had to get them to correct the main focus and resubmit.

no one really seems to know what to do and it seems like it's a battle to even get on. Yet alone get to see or talk to anyone

No help no explanation family GP didn't really understand the process either. There was no follow up from the GP we just got the refusal letter via them and that was it, there wasn't a next steps or an alternative procedure to follow or that I was made aware of at the time. School and school Senco were also of no help or support.

It took years to even get a referral, the sit and wait process is detrimental to the outcomes for children and young people

Such a long wait

The process takes far too long, too much damage is done in that time. Too many years this system has been too slow

No one knew how so Cahms referred us across after realising they were the wrong team. Wasted their time and ours.

Although it took a while the GP made sure she had as much evidence as possible before sending the referral in

GP did the refer

No communication

Was referred to child services after a delay just befor 18th Birthday having first raised concerns I 2015

My son was diagnosed in 2012 we were lucky to receive a diagnosis and get support in place very quickly.

2 year wait for diagnosis appointment

Lack of explanation of process

Long, drawn out, little explanation or support, not being kept up to date, covid being used as an excuse

Simple process for our son and the referral accepted quickly—delays predominately from that point though

Child masks so appears to cope in school so they would not support my claim through lack of evidence

Health visitor suggested drop in SALT went to one they referred got a diagnosis 11 months later

I feel absolutely disgusted with the whole thing. The waiting time is an absolute joke, and when ringing up to find out what's happening you just get told, yes his on the waiting list. Can't give no time frame what so ever, although his teacher was told we was looking at March yet still not heard nothing.

Child been referred multiple times by multiple settings since age of 2 & always been turned down until daughter's psychiatrist got involved through fsp & supported the referral. Been told process could take 2 years so would have been helpful to have been accepted on waiting list before now so gets DX

Lack of communication & wait is far too long

It's a difficult process unless you are knowledgeable about the service and neurodiversity.

It is a stressful time.

The constant refusal to see my child and having to go back and get referred over and over

We seem to be on endless waiting lists for everything. No communication in the meantime.

Made to put off throughout the referral process— barriers constantly put in our way etc

I believe there is a discrimination towards hidden disability which are not taken as seriously as physical disabilities by health professionals. Lack of understanding & awareness is obvious. There seems to be no urgency in supporting & helping a family. Many are forced to raise the funds themselves for a private diagnosis leading me to believe that this part of The NHS went private years ago.

My GP didn't want to know when I approached them. My son's school was also very difficult to give help as they were not seeing the same behaviours in school. We

eventually were referred to Just one Norfolk but was going to be discharged without any further help from the school nurse even though it had been agreed there were some concerns.

No one explains anything, no one offers help or support, especially in health services.

My child has issues and I have been told because of Covid he doesn't meet the criteria

Too slow

As long as you communicate well with school and gp, it seemed quite straight forward.

Time consuming to get all of the views but the primary school and GP were both great.

Took 5 years

Took until he was over 6 to get a diagnosis, and a year from that to get medical help

My son was never accepted and was diagnosed via CAMHS when he was in complete crisis

At nursery's request, the Health Visitor referred X to the community paediatrician in June 2020 who, subsequent to our online video appointment on 3 November 2020, further referred X to the NDS who accepted him on 25 November. The process was straightforward enough – however even in those early stages it took 6 months just for this to be achieved – and since then (another 7 months down the line) we've heard nothing from the NDS.

Because of the old head teacher it was always denied even though it was really lies

To actually get referred took 10 years and now we are on the waiting list

Too slow for children who need their diagnoses in black and white

Nothing is easy

It's such a long process and takes ages for them to contact you

I am answering this questionnaire both as a parent of a child awaiting diagnosis and also as the SENDCo of a school where children have been waiting for over a year with little to no contact. Also referrals in Great Yarmouth can only be made through the GP, not school.

The whole process is unclear and stressful as well as too long

Going to the GP and sending referral in was straightforward

We didn't really have any issues from referral to diagnose

Very confusing

Nothing was made clear. The first referral was rejected.

Getting support and just getting referred was difficult

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Referral accepted easily, but waiting time is terrible

School or GP didn't know the referral criteria and assessments/reports needed. I eventually found it by searching online.

This is our third attempt to get onto the process and without the family worker support I think we'd still be trying.

It takes too long for the children who need it most

The school wouldn't refer so I had to go through GP

Its a nightmare

They don't keep you informed you just left hanging

Both daughters have been waiting for over 4 years

Can never get an update to know what's going on.

It's hard to get support I had to fight for yrs

No communication and the process takes to long

I have been trying to get help for near 5 years now and it seems nobody is listening to me. I have had starfish on board now for about 6 month and they have not told me anything new.... still waiting on a diagnosis after all this time

First spoke to gp when he was 2 and asked for a referral but was told that as a first time mum I was over reacting! I finally got a referral when he was about 4.5 but only because his teacher at the time backed me up in my concern.

I was constantly having to call to be updated

We started the referral at 7 and he's now 10

Never had any luck until now getting support

It wasn't difficult for us to be accepted as we have evidence. However the lack of communication, updates, and long waiting times to hear whether you have been accepted or not are frustrating

It takes so long and is so complicated unless you get a really helpful professional who guides you through, we were lucky to have a fantastic speech therapist who initially got things started

it was too late and no support offered

First referral was rejected

Our GP made it very easy to refer us, it was everything else that delayed things after that

Long winded, no updates

I didn't have no input

It's all confusing and nothing is explained I was told at one point my daughter didn't have Adhd and then in a meeting with my daughters school and NSFT alot of her behavior was blamed on Adhd which they have now decided that my daughter does have. But I have nothing to explain if she has her diagnosis or not.

We were never referred re: ASD. For ADHD it was an incredibly difficult process with the Paediatrician not wanting to recognise ADHD. It took work and evidence from Starfish to be presented to him for him to consider that this was a diagnosis and that medication was required.

No one wants to know

referral made via GP

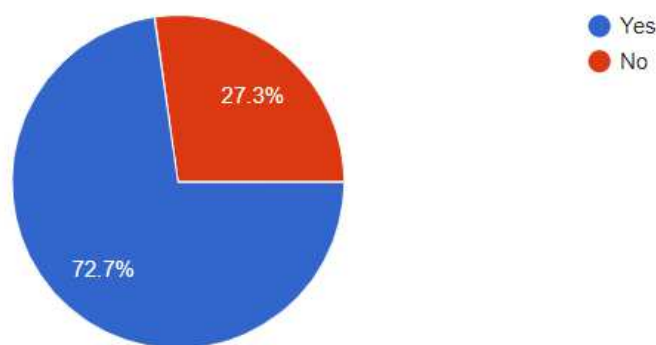
The delay in his diagnosis is effectively delaying better choices of schools

As a parent it feels complicated and criteria for assessment is too narrow.

terrible delays

Have you ever considered a private diagnosis route?

176 responses



When asked to explain this answer, parent carers responded:

Concerns around the wait as my son is already at High School

So we know as whether my son has adhd, but have decided to not go down private route as school has assured us we will be supported by them.

Because of the wait and my child was suffering

I've thought about it, however the reality is I don't have £1200+ and even if I did NCC and the NHS refuse to accept private diagnoses.

But it costs too much for private and if you do get one the local gp etc won't accept it

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I feel the delay in diagnosis has delayed my sons learning

Desperation of getting help

I heard no good news about getting a diagnosis . I have supported a friend that took 4years to get diagnosis and then ECHP . A further 4Years to get a place in specialist school.

I met poeple that gave been trying years including one mother still trying to get help with a son of 27 .

I feel lost. A system that seems broken . And difficult to navigate .

I looked up Anglia autism to find the private diagnosis waiting list close . My son was rejected for an EHCP as has no diagnosis . His school didn't take any notice of him asking for help and okayed dorm the idea he had autism . His best friend has a diagnosis (not this area . But manchester before moving to norfolk . They are very similar but my son has gone from being grade as Nine and in too 2% in cCAT test aged 13 to not being able to attend school for the last six months and essentially will now fail his Al Levels .

It's so much faster and they seem to be more honest about the problems that are present. They are not trying to make the government figures look better then they are. The cost is the only problem

Very slow process. Didn't feel they took parents view into consideration at all

I would have preferred to go privately so he could have been assessed and diagnosed quickly, unfortunately it was far too much money.

To get it done faster

Because we are truly suffering without the support us as a family are finding it very difficult to cope being unknowingly how to help deal and support my daughter she is suffering chronic sleep apnea due to lack of support when we ask for it.

Because the NHS had done a micro array test, and then ruled out ASD as well

It seems the only way to ensure a diagnosis is attained in a timely manner

Long waiting times – but is too expensive

Over 4 years to get to a diagnosis

Because the private route seems to be the only way to get a diagnosis for my child quickly rather than have to fight and wait for years. The repeatedly going back to GP and then referrals is an impossible and stressful process for me and my child

I did go private because the wait of 3 yrs+ is obscene. All the while my child was in school fully unsupported and that was not fair!

Because nobody is telling me anything.

The lack of communication, the timescale, not having any idea how much longer it would be before my son was seen. Rumours of the process taking 3 + years

I paid for ASD assessment privately but can't afford to do adhd one

My son needs help now and it's been nearly 3 years and they still can't tell me how much longer it will be just hes still a way down the list

I honestly do not think that the nds will believe parents if school say different. Therefore they won't assess and it just reinforces the view that your child has no difficulty. A private assessment is quicker and would give a professional opinion as to other options for us if our child wasn't fitting criteria rather than writing it off as a behavioural issue or poor parenting. A private diagnosis would be a lot quicker and help us get help quicker - which in terms of my child's development and early intervention is really important.

Because it seems that nothing has happened or changed anything. That they just throw meds at him and the nds pretty much said he didn't tick enough boxes

Because EVERY child matters!

Because my son is due to go to high school it's took me years to get to wear I am and the fact is if I had money and could afford to go private I would have had answer by now and be getting my son the support he needs.

As NHS services are so scarce

To get a definitive answer

NDS take far too long

length of time waiting and then informed child would be placed at back of long waiting list !!! following a tempary stay outside of county.

Camhs and psychologists are not interested and CS are useless

Only way to get an answer

In order to receive a diagnosis and acceptance from school

To get appropriate diagnosis, help, advise, spoke to a private company and with info i provided they agree diagnosis is needed and to go straight for final assessment

Sick of waiting

Early years is crucial for neurodevelopment. As a primary teacher I knew what my son needed and wasn't willing to wait and miss the under 5's years. Felt incredibly guilty that I can afford it and others can't but my hope was by us going private it opened up a space for another family.

Speed of diagnosis

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Waiting too long – felt i had no other choice

My son is suffering mentally and struggling to understand who he is and why things affect him differently, I can't tell him it's because he is autistic as I don't 'officially' know that! If I could afford £2000 for a private assessment I would do it in a heartbeat.

I got ADOS and assessment done private to try and speed up referral diagnosis time

Because it's taking years and as the years go by my daughters are struggling more and more as we all our.

Private seems to be the only way to get help quickly! But the cost and the fact that a private diagnosis isn't always accepted by the NHS means it could be pointless.. plus we shouldn't have to go private!

To get my son seen sooner

because it would help the whole family and her I don't want her to be feeling the way she does for longer then needed.

only reason we haven't is the cost of it.

Because so many people told me early intervention is key. The fact is he was on the pathway from 18 months – finally diagnosed at 6 privately. This in my opinion is far too late to start the interventions & subsequently his Autism became a lot more challenging & obvious when it didn't need to.

My son is 14 and we didn't want to wait until college before he was assessed. He needs the support now. We've been fighting for assessment since he was 3. We saw a doctor at CATS (a few months after our son was accepted for NDS) who referred my son for a private ADOS, which showed scoring for ASD. We didn't take it any further because we felt the doctor was the wrong fit for our family and our son really didn't like her

Want to get help for my son, but we can't afford it

X has been waiting since 2018 and the process is painfully slow. 1+ year between each part of the process, made worse by covid means he is missing out on support and the transition to high school is going to be made more difficult

Private would be quicker

It's a lot quicker, the only problem is the NHS will not always pick your child back up again if you get a private diagnosis

Although my son was diagnosed with ASD in a different county, he was diagnosed with ADHD through this service. The waiting times are appalling, this service has been re-organised a few times since on the waiting list and in that process a referral was lost in the system, departments do not communicate with each other due to waiting lists parents are opting to pay privately as the reports are usually more in depth, a considerable amount of time is spent with the child as opposed to the NHS service and

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your concerns are actually taken on board rather than parent blaming. Too much parent blaming happens when a child's behaviour is being scrutinised. With a private diagnosis you get much more support post diagnosis over what the NDD offers.

Because child's mental health was suffering

Speed of diagnosis

My concerns were around the length of time it took from first our GP agreeing to refer to the paediatrician and the diagnosis process. Now, I'm concerned at the lack of support, understanding and services for my child and family.

Can't get any supportive help for my young person since he left high school

It seems the only way to ensure a diagnosis is attained in a timely manner

If cost wasn't an issue, I just want the best help and support to give my child a happy and fulfilling life.

Costs too much money

Because it would be faster

Because it would be easier to be heard and taken seriously.

The wait for assessments is too long and the referral process is impossible

Such long waiting times

Had to go private to get help needed before high school

Insufficient NHS funding and priority for young children needing this support. Concerns about finding the right high school and whether a diagnosis will be in place in time

Because I don't think anyone understands how hard it is. And as I say the amount of time we have waited already is an absolute joke

To speed the process up.

Out of desperation for answers and help

We are desperate for X to receive the support he needs and we are very concerned about the next stage - which is applying for a school place for him for September 2022. He is non-verbal and still in nappies and he needs 1:1 support which we think would only be achieved if he has an EHCP in place by then. That is also a long process and we could be turned down at any stage. So we thought that a diagnosis would help us in receiving the support that X will most definitely need when he goes to school.

We did go down the private route. The NHS took far too long, we desperately needed an EHCP to get my daughter some help in school. It was so mentally draining not knowing where we stood with the NHS and we as parents wanted to ensure that she got the help she needed and the earlier the help the less she would struggle.

Speed. Told waiting list (once on it) was three years long

I felt I wasn't being listened to

From seeing the Gp several years ago, to being referred to the hospital, we then moved and had to go through the referral process again

No help or support.

I want things in place before my son starts high school.

The waiting times are outrageous. There is no other free help or support available.

I needed to get diagnosis in place before she started High School so she could have allowances in place for issues with uniform, eating and anxieties.

To get a diagnosis without waiting for years.

Because it took a long time to get medication

Because it's taken so long. He has been given spd diagnosis but we believe it's more complex! Feel it's a tick box exercise

Because 8-12 weeks wait is better than 2 years

At the time it was suggested to me by a family member, but I could not afford it, and had to have faith in the public sector

ASD referral declined by health, so I went privately and they diagnosed him very swiftly and was shocked that Health declined referral and so was my GP. I went privately to get my son the correct support he needs

The waiting times and the support is ridiculous

Waiting times were too long, child was unsupported with deterioration of mental health

Because the autism was diagnosed but the adhd diagnosis was messed up and no written diagnosis given so despite every letter saying adhd we couldn't get support or medication. Had to pay private years later to get it. This had an awful effect on my child and family as a whole.

He has been turned down for help although everyone seems to know there is issues

Quicker and essential for evidence to meet sons current needs

I have heard that the whole process can take 3 years + and as our daughter is getting older she needs the support sooner rather than later, we need the diagnosis for school to take us seriously and if it takes this long it will be too late to help her, and also too late to help support us as a family.

To get the diagnosis we need to move forward. It was not affordable though and concerns that the NHS may not accept the private diagnosis anyway

Because had multiple referral turned down & was negatively impacting child

Over two years is such a long time to wait and until has assessment can't name alternative school. So I am currently homeschooling two half days a week and bringing child home for lunch everyday.. this is only way he can survive a week on mainstream education

Because of the timescale

I feel it's my only choice to get my son the help and support he needs at school

Although I am at the early stages, I feel that the road ahead will be a long and stressful one.

For quicker results

I felt I was given no choice but to seek a private diagnosis as I couldn't bare to watch my daughter struggle any longer both her physical and mental, emotional health was in tatters being in a mainstream school with no help no understanding and no support and academically 5 years behind her peers. No friends not able to read social Q's in order to assist her to help make friends but also being used as an escape goat by others for doing things in school for example stealing and then blaming her and my daughter excepting the blame as she was unable to defend herself as she didn't know what was actually going on.

I took my daughter for a private diagnosis in March 2019 and she was given a full diagnosis in the July which I believed helped us to secure the correct outcomes in section B,F & I in her EHCP and securing the correct education establishment for her in January 2020.

have considered but cannot afford

To speed up the process, but it's too expensive

I've been waiting 4 years now for a diagnosis appointment cancelled or moved 6 months behind

To get help sooner but can't afford it

The process takes too long, however we cannot afford a private diagnosis

Because it's just busy and too much for them to handle. Not an experience I ever want to go through again just to get my daughter the help she needs

I have had to book a private SLT ax because my self referral was declined. Despite my daughter being 2 and completely nonverbal.

The NDS route was very lengthy and involved so many assessments, sometimes years apart. We wanted a diagnosis ASAP for our child so they could start to receive more support and understanding from others and for their own personal understanding.

Due to delays.

NHS /LA referrals take a very long time to come to fruition so need to speed up the process if we can.

Waiting times. Non beneficial help for my child so what is the actual point in the services?

Because its quicker

We desperately wanted answers but we decided to wait in the end as it was a lot of money that we then decided could be used for other purposes such as music lessons, forest school and the other activities that our child deserves.

The waiting list is ridiculous. My child needs help now not in 3 years time! I am very concerned about the knock on effect on his mental health and education without appropriate professional support.

To avoid the long delay! Almost two years at school before we have a diagnosis despite being flagged by nursery at the age of 3

If one pays privately I feel there would be a complete and full assessment and all family information would be listened to and not dismissed. The young person would be listened to also. Sadly all disciplines seem to work hand in glove and just agree with each other. They really have no interest in the individual it is just a box ticking exercise. No one has the foresight to look beyond what has been written before. So sadly any chance of a true investigation and outcome is blighted as is the young person's future.

It saddens me beyond belief and that is why my daughter will become a statistic.

The assessment my daughter had was incomplete only one part of the speech and language section was carried out.

I should have followed the official complaints procedure but our experience over the years has put me off doing this as sadly our experience has been that one professional will not speak out against another.

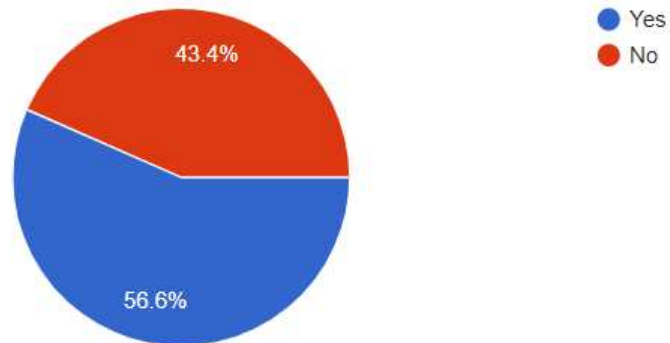
Sadly I think I have now run out of time to make a complaint.

I've been waiting 4 years now for a diagnosis appointment canceled or moved 6 months behind

The wait is to long

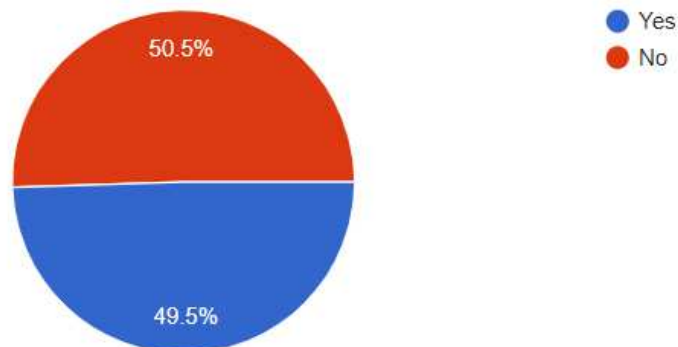
Have you needed to contact the NDS team?

175 responses



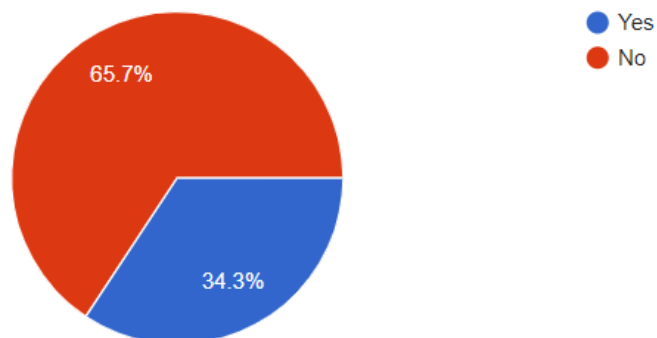
Did you find the NDS team easy to contact?

95 responses



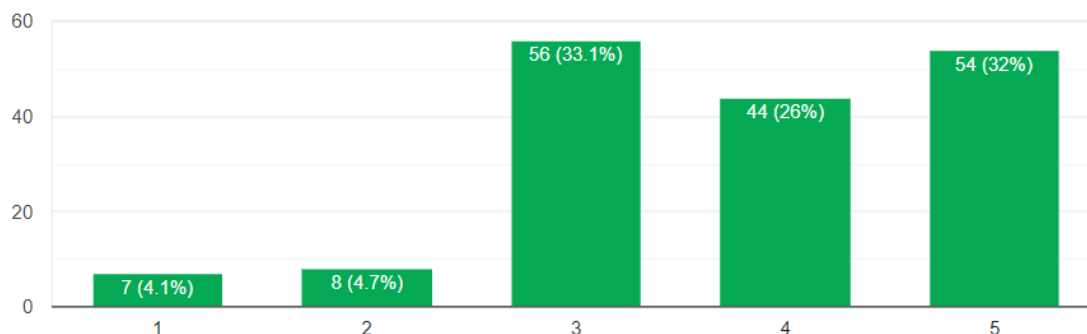
Have you visited the NDS website?

172 responses



Overall, how would you rate your experience of the NDS service?

169 responses



1 = Very Good

5 = Very Bad

Parent carers were then asked if there was anything further they would like to share about their NDS experience. They responded:

Poor communication. Waiting list is far too long

I was lucky to speed up my sons journey by having other ongoing needs assessments. If this hasn't of been the case, I know my son would probably still be waiting, as COVID hit and waiting time for face to face engagements had to stop. Luckily for us my son now has the support he needs from health and his new school. The wait times for referral and first appointments was extremely long and caused anxiety all round. More communication to keep families updated would at least help you feel that you haven't been forgotten! I feel for families now starting their journey with the current wait times in Norfolk.

I was left floundering looking for help my son was rejected twice despite as no assessments being done in thetford he only saw a paediatrician for assessment

I've just discovered that the wait to be seems is over 3 YEARS. By this time my son would have aged out and have to restate the wait in the adult service. This means it's likely he won't get a diagnosis until he hits his MID TWENTIES!!!

The waiting list is ridiculously long

Just long waits. incredibly hard if you are struggling with your child .it's really affected My health.

It has just been confusing as my son is now suffering with his mental health too. If health professional can't distinguish which is which how on Earth am I expected or acted too. At present he has not recieved help with either other than being put on anti Depressants. It has now been over a year since he was referred for support with his mental health and mealy 2year since discussing possible ASD with his GP who

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encouraged him not to worry about getting a diagnosis as this could help him with struggling with A levels and poor health at the time ... November 19 .

The back log feels intentional to hide the true scale of the problem and to put people off getting the support they need

The service is underfunded and understaffed for the volume of referrals but the quality is excellent

My son clearly has ass but because of his complex Id they said they couldn't diagnose asd. We went private and he was diagnosed straight away

Recently asked for son to be tested for SPD got told they don't test for that anymore
I don't even know what they offer fully.

They kept telling me they were short staffed and were recruiting new practitioners to support the service I haven't really seen any evidence of this, I provide any information they require instantly but it doesn't seem to help anything go faster we just pale into the background as my son is only 'low-level disruption' status at school

I would think that their actual practice around diagnosis is pretty good – my daughter has a clear plan of what should happen. Unfortunately the time it takes is destructive and leaves children/families struggling without diagnosis or appropriate help for years.

Rubbish, they wanted to rule out his other diagnosis as being his only one ?

It has been incredibly frustrating. It doesn't help that no one can give me any idea whatsoever about how much longer we are going to have to wait. The only time we have had 'updates' or communication is when I have chased. I feel as though I am letting my daughter down because I cannot afford a private assessment.

While the diagnosis itself was fine to get, there's no support and very little signposting on where to find support. We have no idea on what to do next or whether we should be in contact with the health services and feel we've been left to it on our own – I'm sure the pandemic has exacerbated this, but even with a pandemic some level of support should have been surely offered. We are still paying for private speech therapy as that's the only help our son gets. This is making a huge difference to him, but it's stretching us financially.

Lack of communication is very poor and wait times are horrific

Seems like you wait for eternity then you get diagnosed and are discharged straight away. Like a factory conveyor belt.

Just that parent need to be informed more.

The original referral was rejected as it coincided with myself and my husband separating. Whilst on the pathway the only contact received was to take some very basic demographic information and tell us they didn't know how long till the next stage but it would be a long time. Professionals working with us including SENCO, social

worker, crisis support workers tried to get information on timescales and nothing was available. After having the private diagnosis ratified by the NHS (all within 8 weeks of seeking it). We eventually received information about post diagnosis support for parents. On trying to book into these we were told there was no availability. Far too little much too late. Professionals involved with us didn't really know if it was possible to have a private diagnosis accepted by schools or services. Although my son now has a place at a specialist ASD school he is struggling to attend. Not surprising after so much time out of school. I have been unable to work (as an SEN teacher) since January 2018

It takes too long, damage is done in that time

There is a particular issue about identifying girls who need assessment. They treat girls and boys the same and yet their presentation is very different.

They put all children in a box

I KNOW it's about lack of funding from central government; I KNOW it's about inadequate staffing levels; I KNOW it's not County's "fault". But how does ANY of that help our children?

Why is the process such a long and complicated process?

very limited very unhelpful

The assessment process of the computer based work for parents is very hard going and emotionally draining

The wait is unacceptable. Children's lives are being damaged.

They seem lovely in the small communication I've had. Just so frustrating they're so overstretched!

No guidance, questions not answered, future isn't clear

I think my overall experience once we got to diagnosis stage was good, as I had gone in to say I thought my son had ADHD and SPD, so I think they were pointed in that direction so it was more straightforward. I know a number of families who are struggling getting full diagnoses with multiple issues.

The time scales are ridiculous and children are suffering because of them! The NDS team obviously need more funding and more resources to help resolve this problem!

Lack of communication

A late diagnosis for a child can have a detrimental impact on their future especially ASD children! Early intervention is essential but can't happen when the waiting time is so ridiculous

It took 2 years to get a diagnosis and when we got that, we were thrown out the door with a good luck in the future and no further support!

it seems as if there is not enough staff to cope with the work load.

I really don't see the point of a service that doesn't appear to be helping anyone? You can of course see most of these NDS Doctors privately for around £2000. It is a disgrace that they take the NHS money on top of this as well. Very wealthy Doctors & Very poor, desperate parents with declining children. An absolute SHAMBLES of a service. Where IS the care? Who really DOES care when there is so much £££££ to be made out of children's complex neurological conditions & heartbroken parents, eh?

Waiting list is unbelievable

unacceptable delays. no formal report from a feb 2020 school visit. children's' well being massively impacted. unaware of any other nhs service which is so slow.

You shouldn't have to constantly fight to get what your SEN child needs, there is no support for parents and very little support for the children involved!

Give parents more credit they know their children much better than someone that has only spent 15 minutes with them in an appointment where they can seem "normal".

The NDS service could improve by having better communication between different professionals, having open communication with parents, a suggestion is offering those children with ASD/ADHD yearly health check ups. Offering more support than just sign posting to charities/different organisations. Cutting the waiting times for referral/diagnosis and ensuring the parent is kept in the loop with decision making processes. And this system where the child's behaviour is blamed on parents need to stop.

Diagnosis was spot on, all the professionals and staff we spoke to/ had appts with could not have been more passionate/professional/helpful/caring just too overwhelmed and under funded/staffed

I don't like the way once you have the diagnosis you are pretty much left with just a few leaflets. No further help no further investigations into other comorbidities.

Still waiting with no correspondence

Minimum amount of contact so based on the phone call and 2 letters was ok given information at that time

I understand the back log due to Covid but my Son was referred long before Covid and nothing has seemed to have happened until his Consultant contacted them

Once you get through the process has been OK so far. However getting accepted onto the referral has been a challenge. It feels like it's a challenge for people to take us seriously

Previous experience with eldest child was positive - 3 years ago but we did not wait long, had contact throughout and felt listened to. It's hard to say whether our experience this time is good or bad really due to the complete lack of communication and having failed to have our child seen, spoken to or assessed by anyone since referral

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was made by community paediatrician. Child was under 6 at time of referral – it was never explained to us that he would remain on the same list even after he turned 6 and when we were trying to contact the nds team to find out if that was the case it was very difficult to get hold of anyone, and the information we were given was vague. I understand that covid 19 has made everything more stretched and increased waiting times, but they were appalling before the pandemic too. I understand that it is not the fault of those who are part of the NDS team, and that underfunding and understaffing for the level of need is at fault, but for families who are left waiting without any answers this isn't much comfort.

While those professionals we have had contact with have been helpful and supportive, the time it takes to access this time is horrendously long

Communication is terrible. Not kept up to date what's happening

I understand from various forums I am a member of that the waiting list for a diagnosis with the NDS is currently around 3 years' long which is ridiculous. How are our children supposed to be receiving the support they so badly need with a 3 year' waiting list? Even more worryingly, I also understand that once a diagnosis is given, there is no support to follow (except maybe a training course for the parents). There is no OT available on the NHS in Norfolk and the NHS SALT currently has a 1-year waiting list. We have been using our savings to access SALT and OT privately, but obviously our resources are limited and there are so many families who can't access this at all. There should be so much more help available for SEN children and their families than there currently is and we feel completely let down by the system.

Too long waits, little to no information on help

Speed Up. There are part of the country who can diagnose a child in 8 to 10 weeks, just increase the quantity of clinicians to get the job done and get children the help they need.

Follow ups would be nice to know what is happening. I have had a telephone appointment and filled in questionnaires to be told I am on another waiting list

Slow

The staff are dedicated and helpful when you see/speak to them but the length of time the process takes is shameful.

Waiting times poor and other children getting seen before just because they are severe it should be first come first serve

The waiting time for diagnosis is way too long. Children are struggling in school, and with it taking so long to get help and a diagnosis many children are missing out on an education. Families are also struggling to cope, without answers for their child's difficulties and support with this.

Every step is a battle to get support. If they don't see what I see then it can't be happening. But it is and it does. We were FORCED to go down private route. I knew he

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was autistic but MY evidence is not good enough!!! He was diagnosed ASD and most probably SPD but we couldn't afford for the formal diagnosis.

The NDS staff have always been very pleasant and helpful, although I never really got to use their services. The waiting time though is just abysmal and shocking that children are missing out on vital support. 3 years in the life of a child is a huge amount of missed opportunities.

It seems impossible to speak to anyone from the service and certainly not the same person more than once.

I'm still waiting for someone to get back to me.. I know we've been in lockdown but some acknowledgement that he is still on the system would be appreciated.. Year 4 is looming.. Back and fourth since nursery..

still waiting on assessments

Our paediatric doctor is amazing and has done everything she can to speed things up. She's an absolute rock!

We used this service 9 years ago. The mistakes made have rippled out until I took my daughter private. 7 years of heart ache and stress could've been avoided had the correct paperwork been done.

Expect to wait 2 years plus

Now we are on the pathway we have been pleased with the service. The professionals we have spoken to have been helpful and listened to us. Getting onto the Pathway took time, although not necessarily their fault. We have been informed our daughter will be getting an observation at school by an OT but I feel that we could do with one at home too to help us provide the right environment here for her.

The admin team have always been extremely efficient, supportive and helpful whenever I have contacted them.

It needs to speed up, hard enough trying to cope with the demands and needs of children with additional needs without the hassle of waiting and having to keep chasing things

It's difficult to add additional information to support a referral. The doctors posted some evidence via internal mail which did not arrive. Had to be sent via direct email after speaking with the service. Doctors also did not have an up to date list of items needed for referral eg they said we needed to have a CAF. This was checked and out of date. Doctors need to be a bit more aware of the process to support families in understanding the steps that will/could be taken.

The waiting times are ridiculous. I phoned up to see when my daughter would be seen and I was given a two and half year wait time.

We have had no involvement with NDS and had no idea they existed until this survey.

too late and no support

It wasn't difficult to get the referral, but waiting for the assessment takes really a long time.

Didn't know it existed

I'm just glad I never have to go through this system again

I was never even signposted to the service at all!

I understand it takes a while but 4 plus years isn't good especially when the only person suffering is my child

I don't understand why the face to face school visits are happening now

Sensory Processing Difficulties need to be recognised and children and families need to be supported by OTs specialising in Sensory Integration. Ultimately there needs to be much more funding to support children with additional needs.

N. D. S should deal with the assessments themselves instead of passing it onto starfish plus to deal with who really have no interest and just read a few pieces of paperwork and carry out a cursory assessment then a year later produce a woefully inadequate report.

more information is needed to be given

The wait is miles to long

Appendix B: Email to Family Voice Norfolk

"I wanted to give feedback on the NDS but the questionnaire isn't really appropriate. But I had amazing service from NDS a couple of years ago 2018-2019. I can't comment now, but we were referred to Silverwood centre by a paediatrician. They identified ASD behaviour in my daughter and wrote a report and requested a referral to the NDS, she explained it was a diagnose and discharge service and made it clear what we should expect. We were seen by a doctor within a couple of months and he agreed. It was then only approx 4 months after that she had the observation in school and then a further 3 months roughly to have the results/feedback appointment. I believe we got the diagnosis early in 2019 less than a year since our first appointment. I can't fault any of the professionals we saw. All the reports were detailed, clear and accurate and the staff were polite, empathetic and friendly."

Appendix C: Quotes from members of the West Norfolk Branch of the National Autistic Society

- They desperately need more resources. Expecting the current NDS to be able to cater for the amount of children who actually need their services is like expecting a whale to live in a goldfish bowl. I know this is probably beyond their control though. Honestly I think the bigger issue is with the community paed who refer into the service in the first place, although I believe they're part of the service too. It concerns me that information from the paediatrician who wasn't even going to refer my child is apparently going to be used instead of a proper ADI-R taken by a clinical psychologist.
- All I can say about the neurodevelopmental service is that they need to learn to communicate between the departments, right hand does not know what left hand is doing. Service is poor, they lost my child's ADHD referral a few years back even though they knew my child was home educated they called up asking when they could assess my son in school! No support post diagnosis, no support if there is also severe anxiety present with the ASD unless they are suicidal which how many of us want our children to get to that point before they are seen. I can't comment about waiting times for ASD in Norfolk as my son was diagnosed in Hampshire but that was over 2 years waiting. Services for ASD etc. is atrocious here in Norfolk. Sign posting you to just Puffins Parenting course post diagnosis is laughable using outdated footage from years ago the content I myself would have easily researched via the internet. I know it will never happen because of budget constraints but I would like to see 6 monthly/yearly health check-ups/developmental check-ups etc. a phone call maybe from an assigned ASD/ADHD nurse to see how things are, if there are any concerns etc. like you would have if you were diabetic for example, if that makes sense.
- Took me a year to get a referral accepted for my child because school or GP were not aware of the criteria. It was only because I found a document online that I realised we needed a report from an Educational Psychologist. Referral accepted around March 2019. Received telephone call in December 2019 and spoke with person who was very understanding and informed. Received forms/questionnaires to complete in Jan 2020 and then told next step would be for someone to come and observe child at school (which they said was a long wait – and then Covid hit). I needed a diagnosis for child before they started high school this September so ended up going for a private assessment Dec 2021 and got child ASD diagnosis. I passed on the private diagnosis report to NDS and they sent a letter accepting the diagnosis along with a lot of photocopied leaflets of organisations who can offer help.

- My god where do I start? NDS service has been absolutely ridiculous for us. Finally referred onto them 3 years after constant fights. They then did my child's assessment through Zoom chat with a speech and language therapist which was utterly ridiculous and child did not want to have anything to do with it. They claimed due to Covid they couldn't see her but we still managed to go for a pointless standard hearing test at the hospital 2 meters away from the people conducting it. Anyway we had the pointless assessment and the pointless outcome where they said my child will be discussed at the next meeting. This was January 2021, they then delayed the meeting month after month. I rang every single month to be told sorry it didn't go ahead but I promise child is top of the list and will be discussed. I rang again April for the 4th month to be told the meeting went ahead but my child was not discussed. I made a formal complaint that I didn't hear back from for weeks, when they did call they profusely apologised and said child would be discussed at a priority in May's meeting and will call me straight after. Well we haven't heard a word from them since this day. We've been fighting for 4 years now for a diagnosis but nobody cares. We are now going down the private route because we are struggling too much and we feel that the NHS has failed our child too many times now.
- Absolutely crazy wait times! I went private in the end. I was lucky enough to just about be able to afford it.
- It took 4 years for one child and 5 for another to get a formal diagnosis relying on me constantly harassing NDS as they are incapable of keeping you abreast of updates. Having been thrown the diagnosis of asd with one and moderate adhd with asd with the other the only after support I have is a list of websites I can refer to. Meanwhile I have 2 children I have had to de-register from school as they weren't coping. 2 children that don't want to mix with others. Power struggles. One that chews their fingernails off and one that can't focus on anything etc. etc. No support at all and NDS just say we are only a diagnostic team and we have finished with you now. Shameful service that clearly does not do what it says on the tin. Quite frankly I'm unsure as to how they are allowed to continue whilst offering the useless services they do.
- I felt my child might have ASD when they were 7. They are now 12 and we got an assessment with the help of the NAS this year. Unfortunately my child had a meltdown and they couldn't do it. I was told they would come to the school to do it. I heard nothing, but then a couple of weeks ago my child said a lady from the NHS had come to see them at school. No-one had told me! So we are still awaiting the outcome. Sounds like it will be many months....
- Four and a half years for diagnosis...Puffin course not available till after diagnosis...and I am still on the waiting list for the course...we as carers need the courses to educate ourselves at the start not at the end of the process.

- 5 years to get a diagnosis for 1 child, 4 for the other and after getting asd and adhd moderate to severe, all the help I've had is a list of websites to refer to. Wish I hadn't bothered – achieved nothing in the end.
- Not fit for purpose pretty much covers it.
- Well the lady I spoke to was lovely and very supportive but it's 3 and a half year wait for the ASD assessment and when I asked if I could ask the NHS to fund a private assessment, it was a no.
- Child was in Year 1 when the service accepted the referral for assessment from the GP. All I have had is the initial parent phone assessment and I would call and chase monthly throughout child's time in year 2. Eventually when child started year 3 I decided to go private and child was diagnosed in December last year. I have sent my reports in to be NHS ratified and still waiting. I understand the resources are right etc. but communication would help. I would've made the decision to go private a lot sooner which isn't really OK as not everyone has the financial ability to do so.

Norfolk Health Overview and Scrutiny Committee appointments

Report by Maureen Orr, Democratic Support and Scrutiny Manager

The Committee is asked to appoint Members to act as links with the CCG and local NHS provider organisations.

1. Link roles

- 1.1 Norfolk Health Overview and Scrutiny Committee (NHOSC) appoints link members to attend local NHS meetings held in public in the same way as a member of the public might attend. Their role is to observe the meetings, keep abreast of developments in the organisation for which they are the link and alert NHOSC to any issues that they think may require the committee's attention.
- 1.2 In the past this has involved attending local NHS meetings in person but many organisations now have arrangements for live streaming of meetings or publish recordings of the meetings, so Members may fulfil the role on a virtual basis in these cases.
- 1.3 A nominated Member or a nominated substitute may attend in the capacity of NHOSC link member. Other Members of NHOSC may attend CCG or local NHS provider trust meetings as members of the public if they wish.
- 1.4 The link roles and the Members who currently hold them are listed below:-


CCG / Provider Trust	Governing Body / Board meeting schedule	Current NHOSC link
Norfolk and Waveney CCG	Every other month, on the last Tuesday, 1.30 – 6.00pm (online)	Chairman of NHOSC (substitute – Vice Chairman of NHOSC)
James Paget University Hospitals NHS Foundation Trust	Every other month, on the last Friday, 10.00am (online)	VACANCY
Norfolk Community Health and Care NHS Trust	First Wednesday of every month except Jan & Sept, 9.30am (online)	Emma Spagnola

Norfolk & Norwich University Hospitals NHS Foundation Trust	Usually every other month, on the first Wednesday, 9.30am (online)	Dr Nigel Legg (substitute – VACANCY)
Norfolk & Suffolk NHS Foundation Trust	Every other month on the 3 rd Thursday, 11.30am (online)	VACANCY (substitute - Michael Chenery of Horsbrugh)
Queen Elizabeth Hospital NHS Foundation Trust	Monthly, on the first Tuesday, 10.00am (online)	VACANCY (substitute - Michael Chenery of Horsbrugh)

3. Action

3.1 The Committee is asked to:-

- (a) Confirm the continuation of named link councillors in their roles or appoint different councillors and appoint substitutes as the committee wishes.

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Norfolk Health Overview and Scrutiny Committee

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.

Proposed Forward Work Programme 2021-22

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>
02 Sep 2021	<p><u>Ambulance Service</u> (follow-up to NHOSC 8/10/20) To include</p> <p>i. An update on what has been done to address the CQC concerns about EEAST (i.e. in the September 2020 CQC report, including safeguarding of patients and staff). To include an explanation of the concerns in relation to Norfolk and Waveney, why the concerns persisted for so long, what EEAST has learned from the situation and its changes to policies and practices.</p> <p>A progress report on the measures being put in place to improve the emergency response to patients with mental health requirements, including data on the effect of those measures and an explanation of why the past concerns about the service for patients with mental health emergencies have persisted for so long and what has been learned.</p> <p><u>Vulnerable adults primary care service Norwich</u> (replacing City Reach) – progress report</p>	<p><i>Rescheduled from 10 June 2021</i></p> <p><i>Rescheduled from 10 June 2021</i></p>
04 Nov 2021	<u>Queen Elizabeth Hospital NHS Foundation Trust</u> – progress report	
20 Jan 2022		
10 Mar 2022	<u>Prison healthcare</u> – access to physical and mental health services	

Information to be provided in the NHOSC Briefing 2021-22

- Jun 2021 - **Primary care developments in King's Lynn:-**
- Update on relocation of St James's Medical Practice
 - Progress with development of a new facility for the town using Wave 4b funding
- **Long Covid** – services commissioned for people with this condition
- **Phlebotomy service in Lowestoft** (in response to issues raised at 26 November 2020 NHOSC)
- Aug 2021
- Oct 2021 - **Integrated Care System** – progress briefing on developments:-
- Development of local, place-based health and social care planning and commissioning.
 - Extent to which various healthcare statistics etc will be available on a district or locality basis to enable understanding of local issues.
- Dec 2021 - **Childhood immunisation** - update on take-up rates (follow-up from NHOSC 8/10/20 meeting)
- **ME / CFS** service – steps taken by the CCG and service provider to comply with new NICE Guidance
Depending on publication of new NICE Guidance. Expected publication date 18 August 2021.
- Feb 2022 - **Health and care workforce shortages** – update on local action to address shortages (follow-up from NHOSC 18/3/21 meeting)

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

- | | |
|--|---|
| Norfolk and Waveney CCG | - Chairman of NHOSC
(substitute Vice Chairman of NHOSC) |
| Queen Elizabeth Hospital, King's Lynn NHS Foundation Trust | - <i>Vacancy</i>
(substitute Michael Chenery of Horsbrugh) |
| Norfolk and Suffolk NHS Foundation Trust (mental health trust) | - <i>Vacancy</i>
(substitute Michael Chenery of Horsbrugh) |
| Norfolk and Norwich University Hospitals NHS Foundation Trust | - Dr Nigel Legg
(substitute <i>Vacancy</i>) |
| James Paget University Hospitals NHS Foundation Trust | - Emma Flaxman-Taylor |



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Norfolk Health Overview and Scrutiny Committee 15 July 2021

Glossary of Terms and Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
ADOS	Autism Diagnostic Observation Schedule
AIS	Accessible Information Standard
AI	Artificial intelligence
ASD	Autistic Spectrum Disorders
BI	Business intelligence
British Sign Language (BSL)	BSL is a visual-gestural language that is the first or preferred language of many d/Deaf people and some deafblind people; it has its own grammar and principles, which differ from English.
CAF	Common Assessment Framework
CCG	Clinical Commissioning Group
CYP	Children and young people
DM01	Diagnostics waiting times & activity statistics collection
DNA	Did not attend
ECCH	East Coast Community Healthcare
ECHP	Education health and care plan
ENT	Ear nose and throat
EOE	East of England
FIT	Faecal immunochemical test
FOBT	Fecal occult blood test
GDD	Global developmental delay
HDU	High dependency unit
iCaSH	Integrated contraception and sexual health
ICU	Intensive care unit
IPC	Infection prevention and control
IS	Independent sector
JPUH	James Paget University Hospital
NCH&C	Norfolk Community Health and Care NHS Trust
NDD	<p>Neuro Developmental Disorders - a range of conditions that tend to share some or all the following characteristics:</p> <ul style="list-style-type: none"> • Delay in expected features of development • Impairments in reciprocal, social and communication skills • Behavioural issues • Gaps between attainment and underlying ability <p>Conditions that sit within the NDD umbrella include.</p> <ul style="list-style-type: none"> • ASD – Autistic Spectrum Disorders • ADHD – Attention Deficit Hyperactive Disorder • Communication Disorders e.g. Tourette's

	<ul style="list-style-type: none"> • Dyslexia, Dysgraphia, Dyscalculia • Sensory Impairments
NHOSC	Norfolk Health Overview and Scrutiny Committee
NHSE&I EoE	<p>NHS England and NHS Improvement, East of England. One of seven regional teams that support the commissioning services and directly commission some primary care services and specialised services.</p> <p>Formerly two separate organisations, NHS E and NHS I merged in April 2019 with the NHS England Chief Executive taking the helm for both organisations.</p> <p>NHS Improvement, which itself was created in 2015 by the merger of two former organisations, Monitor and the Trust Development Authority, was formerly the regulator of NHS Foundation Trust, other NHS Trusts and independent providers that provided NHS funded care.</p>
NNUH	Norfolk & Norwich University Hospitals NHS Foundation Trust
N&W CCG	Norfolk & Waveney Clinical Commissioning Group
OP	Out patient
OT	Occupational therapy
PBSP	Positive Behaviour Support Programme
PCN	Primary Care Network
P	Priority
PHE	Public Health England
PPE	Personal protective equipment
PTL	Patient tracking list
QB	Quantitative behaviour
QEH	Queen Elizabeth Hospital NHS Foundation Trust
RNIB	Royal National Institute of the Blind
SALT	Speech and language therapy
SENCo	Special Educational Needs Coordinator
SENDIASS	Special Educational Needs and Disabilities Information, Advice and Support Service
SITs	Screening & immunisation teams
SLST	Specialist Learning Support Teacher
SPD	Sensory processing disorder
SUS	Secondary Uses Service – provides anonymous patient-based data for purposes other than direct clinical care (e.g. healthcare planning)
WW	Week waits

