Notice of a public meeting of

Health, Housing and Adult Social Care Scrutiny Committee

To: Councillors J Burton (Chair), Vassie (Vice-Chair), Hook, Moroney, D Myers, Rose, Runciman, Smalley, Wann and Wilson

Date: Wednesday, 6 November 2024

Time: 5.30 pm

Venue: West Offices - Station Rise, York YO1 6GA

AGENDA

1. Apologies for Absence
To receive and note apologies for absence.

2. Declarations of Interest (Pages 1 - 2)
At this point in the meeting, Members are asked to declare any disclosable pecuniary interest or other registerable interest they might have in respect of business on this agenda, if they have not already done so in advance on the Register of Interests. The disclosure must include the nature of the interest.

An interest must also be disclosed in the meeting when it becomes apparent to the member during the meeting.

[Please see attached sheet for further guidance for Members]

3. Minutes (Pages 3 - 10)

i. To approve and sign the minutes of the meeting held on 9 October 2024.

ii. To amend the minutes of the meeting held on 11 September 2024, item 15 (Community Pharmacy Provision in York), to replace:

- 'Several members drew attention to access issues for those living in rural wards who further than a 15-minute walk from a pharmacy and often not on a direct public transport route, including those in Skelton and Poppleton who had to travel to Tower Court.'

with:

- 'Several members drew attention to access issues for those living in rural wards who lived further than a 15-minute walk from a pharmacy and often not on a direct public transport route, including those in Skelton who had to travel to Tower Court.'

4. Public Participation

At this point in the meeting members of the public who have registered to speak can do so. Members of the public may speak on agenda items or on matters within the remit of the committee.

Please note that our registration deadlines are set as 2 working days before the meeting, in order to facilitate the management of public participation at our meetings. The deadline for registering at this meeting is **5:00pm on Monday 4 November 2024.**

To register to speak please visit www.york.gov.uk/AttendCouncilMeetings to fill in an online registration form. If you have any questions about the registration form or the meeting, please contact Democratic Services. Contact details can be found at the foot of this agenda.

Webcasting of Public Meetings

Please note that, subject to available resources, this meeting will be webcast including any registered public speakers who have given their permission. The meeting can be viewed live and on demand at www.york.gov.uk/webcasts.

During coronavirus, we made some changes to how we ran council meetings, including facilitating remote participation by

public speakers. See our updates (www.york.gov.uk/COVIDDemocracy) for more information on meetings and decisions.

5. **Urgent Care Delivery**
   To consider a report from the Humber and North Yorkshire Integrated Care Board (ICB) providing a review of Urgent Care delivery. [To follow]

6. **Update on the York Autism and ADHD Health Needs Assessment, and progress towards a York Autism and ADHD strategy** (Pages 11 - 60)
   To consider a paper introducing the draft Autism and ADHD health needs assessment (HNA) and setting out a proposed three phase plan for developing a strategy on the same topic.

7. **Winter Planning and Pandemic Preparedness in York** (Pages 61 - 72)
   To consider a report providing an update on winter planning in 2024/25, and pandemic preparedness in York following the report of the COVID-19 Enquiry Module 1 (Resilience and Preparedness).

8. **Work Plan** (Pages 73 - 74)
   Members are asked to consider the Committee's work plan for the 2024/25 municipal year.

9. **Urgent Business**
   Any other business which the Chair considers urgent under the Local Government Act 1972.

Democracy Officer: James Parker
Contact details:

- Telephone – (01904) 553659
- Email – james.parker@york.gov.uk

For more information about any of the following please contact the Democracy Officer responsible for servicing this meeting:

- Registering to speak
- Business of the meeting

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Ta informacja może być dostarczona w twoim własnym języku. **(Polish)**

Bu bilgiyi kendi dilinizde almanız mümkündür. **(Turkish)**

یہ معلومات آپ کی اپنی زبان (بولی) میں بھی مہیا کی جاسکتی ہیں۔ **(Urdu)**

Agenda Item 2

Agenda Item 1

Declarations of Interest – guidance for Members

(1) Members must consider their interests, and act according to the following:

Type of Interest	**You must**
Disclosable Pecuniary Interests	Disclose the interest, not participate in the discussion or vote, and leave the meeting unless you have a dispensation.
Other Registrable Interests (Directly Related) **OR** Non-Registrable Interests (Directly Related)	Disclose the interest; speak on the item only if the public are also allowed to speak, but otherwise not participate in the discussion or vote, and leave the meeting unless you have a dispensation.
Other Registrable Interests (Affects) **OR** Non-Registrable Interests (Affects)	Disclose the interest; remain in the meeting, participate and vote unless the matter affects the financial interest or well-being: (a) to a greater extent than it affects the financial interest or well-being of a majority of inhabitants of the affected ward; and (b) a reasonable member of the public knowing all the facts would believe that it would affect your view of the wider public interest. In which case, speak on the item only if the public are also allowed to speak, but otherwise do not participate in the discussion or vote, and leave the meeting unless you have a dispensation.

(2) Disclosable pecuniary interests relate to the Member concerned or their spouse/partner.

(3) Members in arrears of Council Tax by more than two months must not vote in decisions on, or which might affect, budget calculations, and must disclose at the meeting that this restriction applies to them. A failure to comply with these requirements is a criminal offence under section 106 of the Local Government Finance Act 1992.

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City of York Council	Committee Minutes
Meeting	Health, Housing and Adult Social Care Scrutiny Committee
Date	9 October 2024
Present	Councillors J Burton (Chair), Vassie (Vice-Chair), Hook, Rose, Runciman, Smalley [to 7:08 pm], Wilson [to 7:54 pm], K Taylor (Substitute) [to 7:31 pm] and Whitcroft (Substitute)
Apologies	Councillors Moroney and D Myers
In Attendance	Councillor Pavlovic (Executive Member for Housing, Planning and Safer Communities) Councillor Steels-Walshaw (Executive Member for Health, Wellbeing and Adult Social Care)
Officers Present	Sara Storey, Corporate Director of Adult Social Care and Integration Patrick Looker, Head of Service Finance Steve Tait, Finance Manager Denis Southall, Head of Housing Management and Housing Options Michael Melvin, Director of Adults Safeguarding
External Visitors	Professor Nicholas Pleace, Centre for Housing Studies, University of York

18. Declarations of Interest (5:32 pm)

Members were asked to declare at this point in the meeting any disclosable pecuniary interests or other registerable interests they might have in respect of the business on the agenda, if they had not already done so in advance on the Register of Interests.

None were declared, although with reference to agenda item 4 (2024/25 Finance and Performance Monitor 1), the chair Cllr J Burton noted in the interests of transparency that she used the Be Independent service mentioned in the report.

19. Minutes (5:32 pm)

Resolved: That the minutes of the meeting held on 11 September 2024 be agreed as correct record and signed by the Chair.

20. Public Participation (5:33 pm)

It was reported that there had been no registrations to speak at the meeting under the Council's Public Participation Scheme.

21. 2024/25 Finance and Performance Monitor 1 (5:34 pm)

Members considered a report setting out the projected 2024/25 financial position, the performance position for the period covering 1 April 2024 to 30 June 2024, and outturn information for 2023/24.

Officers provided an overview and responded to questions from the committee. It was noted that:

- The overall forecast overspend for 2024/25 of £3.4m was a significant improvement on the £11.4m forecast overspend at this stage last year, but there was a continuing need to deliver savings to safeguard the Council's financial position. No Public Health finance information was included in the report as there were no significant variations for the first quarter.
- Any further pressures on the budget that might be incurred due to requests received from care providers for higher rates of inflation than currently agreed had to be balanced against the risk of provider failure, as the Council had a statutory responsibility to ensure people's needs continued to be met regardless of eligibility. The evidence base would be closely examined in considering any such requests.
- With reference to the table at paragraph 13 of the report, the largest projected overspends were for Direct Payments and Supported Living. The position of the former had improved from the outturn as there was more ability to recover unused funds, and pressures on the latter were partly due to the full-year effect of a mid-year inflationary uplift for providers during 2023/24; 'Other' referred to the Adult Social Care grant received by the Council.
- Housing rent arrears had been broadly flat over the last year and work was being done through the housing team to ensure tenants were not getting into further debt. By the end of the last financial year arrears had increased by around £100,000; this was manageable

given a total rent roll of around £30m. Officers would provide members with more detail on unpaid debts and uncollected charges in domiciliary care, and the approach taken to collecting these.

- The hospital discharge team was funded through the Better Care Fund. Integration and joint commissioning with health partners offered opportunities to reduce duplication, make efficiencies and improve outcomes; the benefits of this would likely be felt in future years. The Corporate Director for Adult Social Care and Integration was leading a project for the Integrated Care Board (ICB) on multidisciplinary integrated discharge hubs.
- Opportunities to work with the York and North Yorkshire Combined Authority were being explored, including around housing accessibility and workforce education and skills.
- Of the £7m growth received by Adult Social Care in 2024/25, beyond the allocations detailed in paragraph 15 of the report the remaining £3.8m had been used to relieve pressures on home and day support and residential care budgets.
- An overspend on Be Independent was due to financial problems inherited when the service was brought in-house which were still in the process of being addressed.
- Concerns were raised over the impact of the expiry of the Council's contract for the provision of day clubs for older people with Age UK. The challenge faced by elderly people who had used the clubs was acknowledged, and it was noted that when savings had to be found from social care budgets there were few good options but that statutory services had to be prioritised. Those who had eligible needs would be supported and others could be signposted to alternative community services, including through Local Area Coordinators, although it was noted that not all wards were currently covered by the latter. It was anticipated that from November places would be available at half-day clubs, in addition to services the Council funded in partnership with the ICB, while the Dementia Day Clubs commissioned from Age UK were continuing.
- Given the extent of savings that were still required, it was noted that scrutiny could play a productive role in contributing to conversations around how this could be done while protecting services for the most vulnerable.
- The housing stock condition survey was nearly complete, and while emergency repairs had been carried out, it was anticipated that the percentage of dwellings failing to meet the decent homes standard was likely to rise due to historic problems not addressed in previous years. The survey results would be made available for consideration by the committee, and an action plan with resource implications would follow, with a goal of bringing the percentage down to as close to zero as possible.

- National and regional benchmarking data had been included where available in the indicators scorecard in the annex to the report.

Resolved:

i. To note the finance and performance information.
ii. To note that work will continue on identifying savings needed to fully mitigate the forecast overspend.

Reason: To ensure expenditure is kept within the approved budget.

22. Draft Homelessness and Rough Sleeping Strategy 2024-29 (6:25 pm)

Members considered the new draft Homelessness and Rough Sleeping Strategy 2024-29, ahead of it being presented to the Council Executive.

Officers were joined by the Executive Member for Housing, Planning and Safer Communities and Professor Nicholas Pleace of the University of York's Centre for Housing Studies in introducing the report and responding to questions from the committee. It was noted that:

- The strategy built on existing successes and partnerships to offer pathways to suitable housing, sustained by high-quality and person-centred support, and giving focus and structure to the range of homelessness and rough sleeping services and initiatives across York. The strategy had been developed with a range of organisations and individuals and feedback from recent consultation work had been positive.
- A Housing First-led approach would focus on ending homelessness amongst those with high and complex needs. This population was relatively small but tended to incur the highest human and financial costs, including acute mental health problems and addiction issues, and accounted for the highest cost to local authorities, the NHS, and criminal justice.
- This approach would focusing on making specific interventions based on individual needs, including mental health support and support with managing money, to support people to live independently. There was cross-party support for Housing First and international evidence suggested that it was highly effective at ending homelessness among its target population, as well as being cost-effective.
- Rapid rehousing within 7-10 days would be utilised alongside Housing First. Research showed that 70% of those able to live in a tenancy with a lesser extent of floating support were in expensive tier 1 hostel accommodation; the longer people remained in a high and

complex needs environment, the more likely they were to develop those needs; as such the focus was on getting people onto the right pathway as quickly as possible as a routine part of homelessness services.

- Research demonstrated that Housing First could be done in ways which were not cost-intensive; the focus was on an ethos and operational framework which cost no more, and over time should cost less, than existing services.
- Delivery could not happen overnight, but the emphasis was on a tailored, individual approach where triaging and rapid rehousing made homelessness rare, brief, and non-recurring. The potential of multiagency working with partners facing the same challenges and a boarder shift towards a community model of support were also highlighted.
- It was an ambition to work with partners in better identifying hidden homelessness, and there was a need to expand the supply of affordable housing. Spending on temporary accommodation was relatively contained in York in comparison to some areas, while the success of a Housing First approach could potentially free more resources for prevention, which should be a focus across Council services.
- In relation to young people, evidence suggested a challenge existed around managing the transition from being a looked-after child. A strategy was already in place for those aged 16-25, supported by Childrens' Services and with specific protocols for care leavers, with the creation of a dedicated Ofsted-registered building included in the action plan.
- Community enterprise models had been successful elsewhere and there was potential in exploring in exploring partnerships with local businesses including tourism. Successive administrations had found the ownership of city centre real estate by overseas pension funds a barrier to making fuller use of city centre buildings for housing. Options such as modular housebuilding and conversion of garage stock were under consideration and there were companies looking to invest.
- The importance of building relationships of trust with people experiencing long-term homelessness was emphasised; medical provision at hostels was highlighted and it was noted that Housing First offered more intensive one-to-one support with dedicated key workers than other approaches aimed at building confidence.
- With reference to ongoing funding, it was confirmed that ending homelessness was an administration priority, and while this work would take time, improvements should be seen year-on-year. The success of the strategy could open opportunities to reprofile elements of current spending on homelessness services.

Resolved: To support the Homelessness and Rough Sleeping Strategy 2024-29 as proposed.

Reason: To support the Council's statutory obligation to have a homelessness strategy in place and the ambition to make homelessness rare, brief and non-recurring.

23. Adult Social Care Strategy Update (7:55 pm)

Members considered a report providing an update on work towards the codesign of the Adult Social Care Strategy.

Officers provided an overview and responded to questions from the committee. It was noted that:

- A 'strategy on a page' document had now been developed incorporating departmental priorities and reinforcing co-production. Engagement and feedback collection with key stakeholders and the public was underway, and officers were working alongside the National Development Team for Improvement (NDTi) in developing the codesign process.
- Members were invited to input into the codesign process, which was due to run until mid-November. This could include email correspondence between formal meetings of the committee, and suggestions from members around other ways to engage effectively were welcomed.
- Access challenges for those with lived experience of social care were acknowledged, and it was noted that a variety of methods including focus groups and targeted interviews were being used to gather feedback from a range of groups. Online questionnaires had been designed to be as accessible as possible with easy-read versions and BSL videos available.
- To ensure feedback was meaningful, the importance of finding people where they were was emphasised. Poppleton Luncheon Club was also suggested as a suitable place to gather feedback.
- Feedback was already gathered from social work staff, and officers would consider the feasibility of incorporating specific questions around the strategy in the feedback staff gathered on visits to people using social care services.
- The committee would receive a further update following completion of the strategy. The strategy was closely linked to the following agenda item (Adult Social Care Peer Review), and there would be opportunities to return to a discussion around assurance for CQC inspection.

Resolved: That members of the committee are included in the codesign process and receive an update following the completion of the codesign exercise prior to the final completion of the strategy.

Reason: To enable the committee to continue to contribute to the strategy through the process and enable a further discussion based on the analysis of a wide range of contributing stakeholders prior to the completion of the strategy.

24. Adult Social Care Peer Review (8:08 pm)

Members considered an update on preparation for CQC (Care Quality Commission) assessment following the peer review of Adult Social Care led by ADASS (Association of Directors of Adult Social Services).

It was noted that:

- The points suggested by the peer challenge team 'for consideration' were not necessarily weaknesses; several referred to strengthening or further embedding existing practices.
- Challenges around self-funding were common in many local authorities.
- The peer challenge team had noted that focusing on the fundamentals did not entail delaying impact on outcomes and finances; this was applicable more broadly across council services.

Resolved: To note the report.

Reason: To keep the committee updated on CQC preparation.

25. Work Plan (8:10 pm)

The committee considered its work plan for the 2024/25 municipal year.

Following earlier discussion of the Adult Social Care Strategy, it was suggested that the committee might receive a further update at its scheduled meeting in January. It was also noted that the work plan items which referred to the Autism and Neurodivergence Strategy should instead refer to the Autism and Neurodiversity Strategy.

Resolved: To note the work plan and request that a further update on the Adult Social Care Strategy be brought to the committee's scheduled meeting in January.

Reason: To keep the committee's work plan updated.

Cllr J Burton, Chair
[The meeting started at 5.31 pm and finished at 8.11 pm].

Health, Housing, and Adult Social Care Scrutiny Committee. **6 November 2024**

Report of the Director of Public Health

Update on the York Autism and ADHD Health Needs Assessment, and progress towards a York Autism and ADHD strategy.

Summary

1. This paper introduces the draft Autism and ADHD health needs assessment (HNA) and sets out a proposed three phase plan for developing a strategy on the same topic.

2. The HNA has been drafted by the public health team. It is not the final published version of the HNA and is supplied to scrutiny members at this meeting for comment and for shaping the final output. It is a provisional full draft being circulated now to support planning of future strategy.

3. Following the HNA being finalised, the CYC Public Health team will also be coordinating the development of a new Autism and ADHD strategy for York, in conjunction with many partners and with public involvement. Publishing an autism strategy is a statutory duty which falls on both health and council partners, and falls across children's and adults services. Public health is leading the strategy development approach and are holding oversight of the engagement and coproduction, but will not be the sole authors; for the strategy to be impactful and robust it is essential that it must be jointly authored by all key stakeholders, and be coproduced by those whose lives are affected by this key issue.

Background

Developing the health needs assessment

4. The provisional full draft of the health needs assessment is attached as an annex. The purpose of this needs assessment is to consider the current and emerging Autism and ADHD needs of residents who live in York.

5. The HNA looks at people of all ages who live in York who have a diagnosis of Autism or ADHD, who believe they have Autism or ADHD, or who would like to receive a diagnostic assessment for these conditions.

6. This HNA looks at many local data sources to understand the local autism and ADHD population.

    - Local authority services: SEND team, adult social care

    - Health services: neurodiversity diagnostic and support services, GP data, hospital data, addiction recovery services, mental health services, children's social care data

    - Other sources: Employment data, criminal justice and police data, large scale research studies

7. This HNA also looks at national and international research for a wider understanding of the health and wellbeing needs of people with autism and ADHD. This can be particularly helpful when local data is incomplete, out of date, hard to access, or does not clearly contain information about Autism/ADHD.

8. The HNA also includes a what works guide. This is a selection of guidance and best practice documents which describe ways of working that can be helpful and inclusive to people with Autism and ADHD.

9. This needs assessment does not make specific recommendations. It identifies topics and needs that should be considered for inclusion in the development of the York Autism and ADHD strategy.

Developing the strategy

10. The all age autism strategy (2017-2021) has now lapsed. The council alongside the ICB have a joint strategy duty to have an Autism Strategy. It has been agreed that this should be, for York, an all-age Autism and ADHD strategy.

11. Subsequent to the production of a need assessment, there is a three-phase plan to developing the Autism and ADHD strategy.

    Phase One: Conversation and Consultation (2-3 months)

12. Using the provisional health needs assessment as a basis, we have developed three 'conversation starters' which we will ask our statutory and voluntary sector partners to capture feedback on:

    a. Enabling society: what needs to change in wider society to make York a better place to be autistic or have ADHD?

    b. Assessment and diagnosis: What can we do to improve the assessment and diagnosis journey for autism and ADHD?

    c. Support and wellbeing: What should support for health and wellbeing look like for those who are neurodiverse, whether with a diagnosis or not?

13. Members of the strategy partnership group are asked to host these conversations with existing public groups and networks.

    Phase Two: Codesigning the strategy (3-4 months)

14. Using learning from the conversations we will co-write the strategy. There will be opportunity to continue to feedback through public groups and networks as well opportunity for individuals to share comments.

    Phase Three: Formal consultation on the draft strategy (1-2 months)

15. A full final draft of the strategy and HNA will be published for formal consultation.

Timeframes

16. It is important to allow sufficient time to engage on, reflect, and coproduce this strategy. We intend to publish the final strategy within 2025.

Consultation

17. The three-phase approach outlines the emphasis on engagement and conversation as well as formal consultation that will be employed in developing the Autism and ADHD strategy.

Analysis

18. Approximately 1% of the population are Autistic and approximately 3-4% of the population have ADHD. Autism and ADHD are associated with an increased risk of physical and mental ill health, of economic disadvantage, and of social exclusion. It is important that we recognise and respond to the different needs of people who are neurodiverse who live in York.

Council Plan

19. Health is one of the four commitments of the council plan. The council is committed “to improving health and wellbeing and reducing health inequalities’ and ‘taking a health in all policies approach’. It also commits to ‘co-produce and publish our approach to supporting people with Learning difficulties, mental health, autism and delivery of adult social care’

20. Additionally the joint health and wellbeing strategy states that; “We take a strengths-based approach which sees people as valuable, not vulnerable, and recognises that everyone has gifts, talents and skills…” We will be taking this same approach of using peoples experience, knowledge and talents to help build our strategy.

Implications

Implications are discussed in relation to the work done so far in development the health needs assessment and in the proposed three phase plan for the Autism and ADHD strategy. Further implications may be identified as the strategy is developed.

- **Financial** *There is no budget allocated to the development of the health needs assessment or the strategy.*

- **Human Resources (HR)** *There are no HR implications of this report, however autistic people and people with ADHD often face barriers within the workplace, including within local government, as the HNA demonstrates, and there are likely to be recommendations for employers and workp[laces emerging through the strategy development*

- **Equalities** *Autistic people and people with ADHD experience poorer health and wellbeing outcomes, including physical health, mental health, social stigma, and economic wellbeing. This is explored in the health needs assessment. In addition, many autistic people and people with ADHD should be considered within policy as having a protected characteristic, and equalities act 2010 should be borne in mind.*

- **Legal** *The development of an Autism and ADHD strategy will support the fulfilment of the duties on local authorities and NHS bodies set out in the Autism Act 2009.*

- **Crime and Disorder** *There are no crime and disorder implications identified at this time.*

- **Information Technology (IT)** *There are no IT implications.*

- **Property** *There are no property implications.*

Risk Management

21. The current Autism strategy has lapsed. The council has a duty to have an Autism Strategy under the Autism Act 2009.

Recommendations

Health Scrutiny are asked to:

- provide comment on the provisional health needs assessment presented in the annex. Members are welcomed to meet with public health separately to this meeting if they would value the opportunity to provide detailed feedback.

- comment on and approve the three phase approach to developing the Autism and ADHD strategy for York.

- comment on and approve the proposed timeframes for developing the Autism and ADHD strategy for York.

Contact Details

Author:	**Chief Officer Responsible for the report:**
Jennifer Irving Public Health Specialist Practitioner	**Peter Roderick** Director of Public Health
	Report Approved √ **Date** *24/10/2024*

Wards Affected: *List wards or tick box to indicate all* **All** √

For further information please contact the author of the report

Background Papers:

Annexes

Annex A: Autism and ADHD in York - A Health Needs Assessment 2024 (Provisional Draft)

Abbreviations

ADHD Attention Deficit Hyperactivity Disorder

ICB Integrated Care Board

HWBB	Health and Wellbeing Board
HHASC	Health, Housing, and Adult Social Care Scrutiny Committee
HNA	Health Need Assessment
SEND	Special Educational Needs and Disabilities

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ANNEX A **This version is a provisional full draft made available to Health, Housing and Adult Social Care scrutiny in November 2024.**

Autism and ADHD in York

A Health Needs Assessment 2024

Francesca Speck- Public Health Improvement Officer

Jen Irving- Public Health Specialist Practitioner (Advanced)

ANNEX A **This version is a provisional full draft made available to Health, Housing and Adult Social Care scrutiny in November 2024.**

Contents

Executive Summary

This is a Health Needs Assessment into people of all ages who live in York who have a diagnosis of Autism or ADHD, who believe they have Autism or ADHD, or who would like to receive a diagnostic assessment for these conditions.

This HNA looks at many local data sources to understand the local autism and ADHD population.

- Local authority services: SEND team, adult social care
- Health services: neurodiversity diagnostic and support services, GP data, hospital data, addiction recovery services, mental health services, children's social care data
- Other sources: Employment data, criminal justice and police data, large scale research studies

This HNA also looks at national and international research for a wider understanding of the health and wellbeing needs of people with autism and ADHD. This can be particularly helpful when local data is incomplete, out of date, hard to access, or does not clearly contain information about Autism/ADHD.

This health needs assessment also includes a 'What Works Guide'. This is a selection guidance or best practice documents which describe ways of working that can be helpful and inclusive to people with Autism and ADHD. In various ways and to various levels, these guidance documents have been developed with input from neurodiverse people.

Findings Summary

To be written

Project Scope

The purpose of this needs assessment is to consider the current and emerging Autism and ADHD needs of residents who live in York.

This Health Needs Assessment is led by the City of York Council Public Health Team. It considers the health and wellbeing needs of people of all ages who live in York who have autism and or ADHD. This includes people with a diagnosis, people waiting for a diagnosis, and people who recognise traits of Autism and or ADHD in themselves.

There are two main aims of this project:

1) To build collective understanding of the Autism and ADHD population of York. This includes information about the population size and demographics, current use of health, care, and other key service areas.
2) To make recommendations and support preparation for a city-wide Autism and ADHD strategy that is intended for 2025.

This needs assessment is not making specific recommendations. It identifies topics and needs that should be considered for inclusion in the development of the York Autism and ADHD strategy.

What does neurodivergent mean?

A neurodivergent person is someone who's brain processes information in a different way. The opposite of this is a neurotypical person - a person who's brain processes information in a typical way.

There are lots of different ways a person can be neurodivergent. Neurodiversity is a collective term to describe people who have conditions such as autism, ADHD, dyslexia, dyscalculia, dyspraxia, stammering, or Tourette's syndrome.

In most cases a person is neurodivergent for their whole life. Some forms of brain injury can create a neurodivergence, but this is quite rare.

Specific learning disabilities such as dyslexia are a form of neurodiversity. However general learning disabilities are not a form of neurodiversity. Some neurodivergent people also have a learning disability, and some do not.

Some neurodivergent people also have other conditions such as a mental illness. This a separate condition that can come and go over a person's life.

This needs assessment is only looking at two neurodivergent groups – people with autism and people with ADHD. This is because York in planning an autism and ADHD strategy in 2025 and we want this needs assessment to support the strategy planning process.

Diagnosing neurodiversity in York and England

Overview

In this section we will talk about how autism and ADHD are diagnosed in children and adults in York. This includes:

- information on which organisations fund and provide diagnosis services
- information on recent waiting times
- information on recent changes to diagnosis services for adults
- the process of making a diagnosis

Diagnosing autism in children and young people

Autism is diagnosed through a detailed assessment by a team of health professionals with expertise in developmental disorders.

The National Institute for Health and Care Excellence (NICE) recommends that individuals referred for an autism assessment should be seen within three months. However, the actual waiting time across

the UK ranged from 218 to 306 days (approximately seven to ten months) between April and December 2023.[1]

In York, children under 5 are assessed at the child development centre at York hospital. The assessment process can take around a year, as paediatricians need to rule out other health or developmental issues before conducting a full autism assessment.

Children aged 5-18 are assessed by Child and Adolescent Mental Health Services (CAMHS). Referrals can be made by the GP or School Special Educational Needs Coordinator. Due to a significant increase in referral numbers, there is currently a long wait for these assessments within CAMHS.[2] As of March 2024 there were 450 children and young people aged 5-18 waiting for an assessment for autism diagnosis. In March 2024, just over a quarter of children and young people had been on the waiting list for more than a year. Compared to 2021, the service has seen a 50% rise in the number of referral requests each month.

Diagnosing autism and ADHD in adults

Requests for autism assessments in adults are growing rapidly across England. In England, 80% of adults now wait more than 3 months for an initial assessment, with half waiting more than 9 months[3]. The typical waiting time for a completed assessment is close to two years in England. For ADHD there is no central waiting list record, ADHD UK have made freedom of information requests to each ICB individually[4]. Only 15% of ICB boards were able to report their ADHD waiting times, so its not possible to describe the average national wait time for assessment.

The NHS adult autism and ADHD diagnosis service is delivered by The Retreat in York. The service completes diagnostic assessments for both autism and ADHD but currently there are separate diagnostic pathways for each. In January 2023 there were 1,560 people awaiting autism and ADHD assessment and a further 2,000 referrals that had not yet been triaged. These figures are for York and North Yorkshire, between April 2018 and July 2023 54% of these referrals came from the Vale of York area. It was estimated that the waiting list would be five

[1] Abreu, L., Parkin, E., Foster, D et al. Autism: Overview of policy and services.
[2] York SEND
[3] The rapidly growing waiting lists for autism and ADHD assessments | Nuffield Trust
[4] https://adhduk.co.uk/nhs-adhd-assessments-waiting-lists-report/

years. In response, the ICB developed a two-tier pathway in order to prioritise resources to those most at risk of harm, the proposal was that this would be used as an acceptance criteria for the current waiting list and not as an expedite criteria. People would be referred for assessment only if they were at immediate risk of harm to themselves or others, at risk of being unable to have planned life-saving hospital treatment or care, or were at imminent risk of a family court decision determined on diagnosis; dependent on the outcome of the referral being triaged.

A three month pilot (later extended to a year and is now still ongoing) was implemented by the ICB. This pilot directed everyone else to an online tool known as the 'do-it profiler'. The profiler was intended as a self-help resource and not a diagnosis tool.

In response to these changes and the lack of consultation, the York Disability Rights Forum[5] begun a legal challenge against the ICB, and HealthWatch published a report collating and describing the public concern[6]. There were also two presentations to the Health and Wellbeing Board.

In June, an amendment to the referral and acceptance criteria was launched. Referrals can be made by GPs and by community mental health teams. The backlog of 2000 referrals from January 2023 have now been triaged, but only a limited number of referrals since March 2023 have been triaged. This is partly due to lack of information to enable triage from the Do It Profiler platform. The time for assessments in September 2024 was: ADHD - 3.7 years (average); autism – 3.4 years (average) [7]. Currently both autism and ADHD services are assessing referrals from mid 2021 to the end of November 2021.

Going forward, people who do not meet the updated acceptance criteria will be added to a holding list. They may use the do-it profiler, but this is not a requirement. The Retreat have also published their post diagnostic support packs for both Autism and ADHD, meaning that anyone who self-identifies as autistic able to make use of them[8]. The packs are a directory of recommended books, websites, videos, and local support groups.

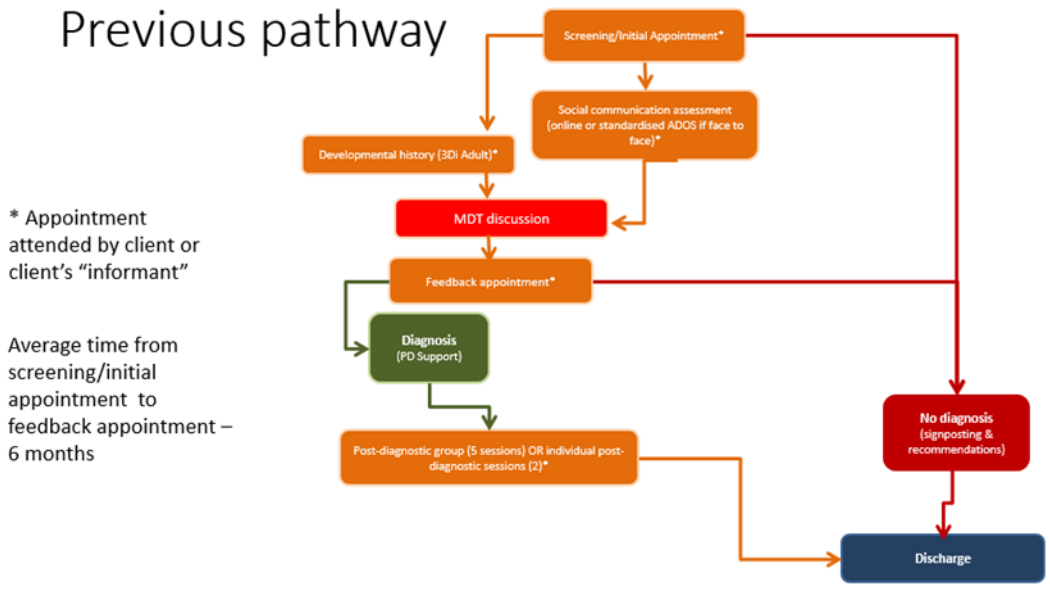
The Process of Making a Diagnosis

[5] Autism and ADHD Assessment Access - York Disability Rights Forum (ydrf.org.uk)
[6] Guidance (healthwatchyork.co.uk)
[7] https://theretreatclinics.org.uk/waiting-times/ (correct September 2024)
[8] Autism Post-Diagnostic Pack (theretreatclinics.org.uk)

Autism

Autism diagnostic assessments at The Retreat are completed in line with the National Institute for Health and Clinical Excellence (NICE) guidelines (Autism spectrum disorder in adults: diagnosis and management – CG142 – June 2012). Assessments are completed by a specialist multidisciplinary team that includes psychologists, nurses and occupational therapists. All members of the multidisciplinary team are trained in the use of standardised autism diagnostic tools, including the Autism Diagnostic Observation Schedule (ADOS-2), The Developmental Diagnostic Dimensional Interview (3Di) and Autism Diagnostic Interview – Revised (ADI-R).

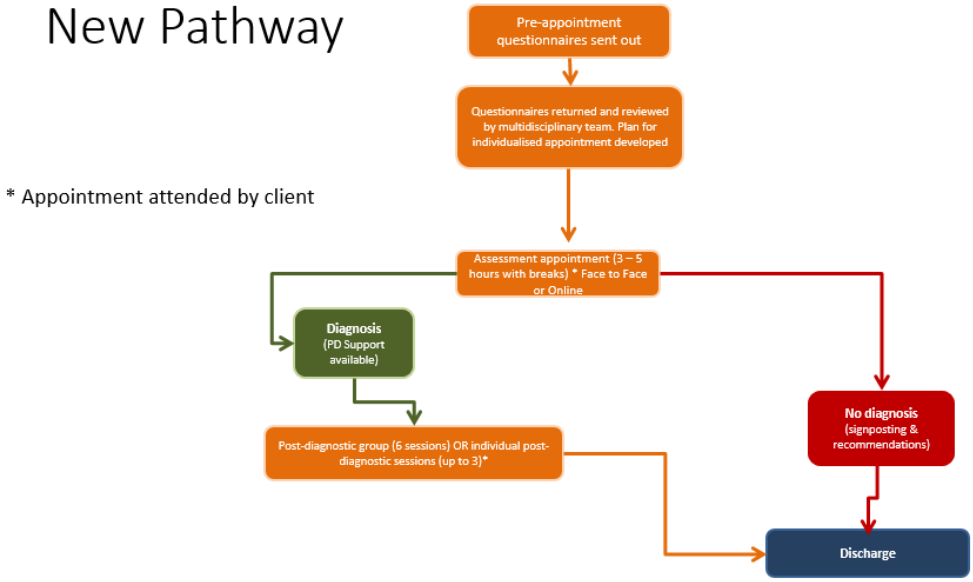
In February 2024, The Retreat updated its diagnostic assessment pathway. Previously the assessment had included three diagnostic assessment appointments, a multi-disciplinary discussion and feedback appointment. The time taken to complete this whole process, could vary but the average time between attending the screening/initial appointment to receiving feedback on the outcome of assessment was 6 months.



Between May and December 2023, a project was trialed by The Retreat using an alternative method of completing autism diagnostic assessments. This process utilised "front loading", the gathering of extensive information in advance of an individual attending to complete an appointment. This process aims for individuals to then be able to attend for one extended individualised appointment, where the aim would be to provide an outcome for their diagnostic assessment within this one

appointment. The questionnaires you completed prior your appointment included: Information Questionnaire, Sensory Questionnaire, Repetitive Behaviour Questionnaire, Informant Information, and Well-Being Update Questionnaire. The appointment includes interview, observations, multi-disciplinary discussion, and feedback.

A service evaluation followed this trial and detailed feedback was gathered on this assessment process from those who participated in the trial. The overwhelming positive feedback from this trial led to the implementation for this to be the standard pathway for autism diagnostic assessments at The Retreat from February 2024.



For those cases where there are additional complexities and it is not possible to complete the assessment within the individual appointment, further appointments can be arranged in order to ensure an accurate outcome to the assessment.

The outcome for approximately 80% of assessments completed is a diagnosis of autism (sometimes referred to as conversation rate). This has remained consistent for the service for a number of years and continues to be the case within the new diagnostic assessment pathway.

ADHD

ADHD diagnostic assessments at The Retreat are completed are in line with the National Institute for Health and Clinical Excellence (NICE) guidelines (Attention deficit hyperactivity disorder: diagnosis and

management – NG87 – March 2018). Assessments are currently completed by specialist psychiatrists.

Similar to the autism diagnostic pathway, the ADHD assessment process includes the completion of forms in advance of the individual attending for their assessment appointment. The forms completed include information from an informant, someone who knows the individual well and ideally knew them during childhood. Most ADHD assessments are completed in an individual appointment which will include a detailed review of current and historic mental health and exploration of examples of the ADHD diagnostic criteria, both during childhood and currently. Assessments are individualised and if required will include the completion of standardised ADHD diagnostic assessment tools, including the Diagnostic Interview for ADHD in adults (DIVA), Conners' Adult ADHD Rating Scales (CAARS) and Nuerocogntive screening tests.

In most cases an assessment outcome can be confirmed within a single appointment, but in case where there are additional complexities further appointments can be arranged in order to ensure an accurate outcome to the assessment.

The outcome from approximately 79% of ADHD assessments is a diagnosis.

What is autism?

Overview
In this section we will talk about

- How common autism is
- The signs of autism
- Research on the causes of autism
- GP data on autism in York
- Education data on autism in York
- Autism and gender/sex
- Make sure these bullet points are in the right order

How common is autism?
Autism is a lifelong condition which affects how people communicate and interact with the world. It is thought that just over 1% of the

population are autistic. This means there are around 700,000 autistic people in the UK.[9]

Autism is a complex neurodevelopmental condition that affects social interaction, communication, interests, and behaviour[10].

Autism and ADHD

It is quite common for a person to have both Autism and ADHD, although estimates vary. Roughly 50-70% of people with Autism also have ADHD. Equally, roughly 30-60% of people with ADHD will have autism. These studies are usually based on observed signs and symptoms of autism and ADHD in people, not on diagnosed rates.

Signs of Autism

The signs of autism in younger children include:

- not responding to their name
- avoiding eye contact
- not smiling when you smile at them
- getting very upset if they do not like a certain taste, smell or sound.
- repetitive movements, such as flapping their hands, flicking their fingers, or rocking their body
- not talking as much as other children
- not doing as much pretend play
- repeating the same phrases

The signs of autism in older children include:

- not seeming to understand what others are thinking or feeling
- unusual speech, such as repeating phrases and talking ‘at’ others
- liking a strict daily routine and getting very upset if it changes
- having a very keen interest in certain subjects or activities
- getting very upset if you ask them to do something
- finding it hard to make friends or preferring to be on their own
- taking things very literally – for example, they may not understand phrases like "break a leg"
- finding it hard to say how they feel

[9] National Autistic society
[10] NHS Autism guide

The signs of autism in adults include:

- finding it hard to understand what others are thinking or feeling
- getting very anxious about social situations
- finding it hard to make friends or preferring to be on your own
- seeming blunt, rude, or not interested in others without meaning to
- finding it hard to say how you feel
- taking things very literally – for example, you may not understand sarcasm or phrases like "break a leg"
- having the same routine every day and getting very anxious if it changes

Other signs of autism include:

- not understanding social "rules", such as not talking over people
- avoiding eye contact
- getting too close to other people, or getting very upset if someone touches or gets too close
- noticing small details, patterns, smells or sounds that others do not
- having a very keen interest in certain subjects or activities
- liking to plan things carefully before doing them

This report will mainly use ‘autism’, but may also use ‘autism spectrum disorder’ and ‘ASD’ where this terminology is used in other sources.

What causes autism?

The cause of autism is unknown, and it is unlikely that there is a single cause for autism. Most likely there are a mix of genetic factors and environmental factors that work together to produce autism. This is known as epigenetics.

We know that siblings of individuals with autism had a significantly higher chance of also having autism themselves, compared to the general population. One study revealed that if an older sibling had autism, the younger siblings had a 30% chance of also having autism.[11]

[11] Miller, M., Musser, E. D., Young, G. S., Olson, B., Steiner, R. D., & Nigg, J. T. (n.d.). Sibling recurrence risk and cross-aggregation of attention-deficit/hyperactivity disorder and autism spectrum disorder.

This can rise to 60% for twins[12]. There are similar links between a parent having autism and their child having autism. Because of this, people say that autism can 'run in families'.

A review of all published literature also found that some pregnancy and birth factors are also linked to autism, for example, a child with a low birth weight or who needed support to breath after birth (perinatal hypoxia)[13]. Additionally, a range of environmental influences during pregnancy, including exposure to air pollution and pesticides, have been associated with an increased risk of autism.

GP data on autism in York

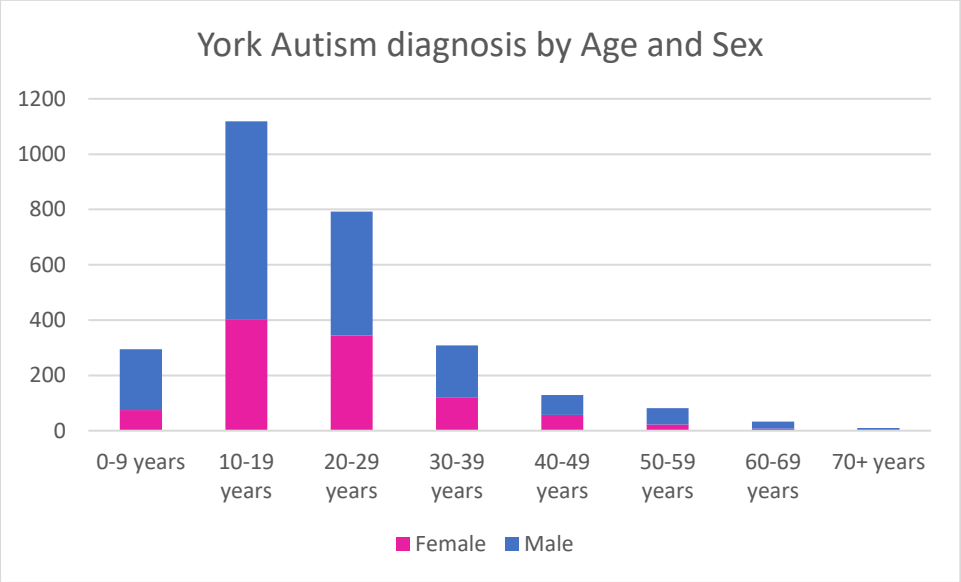
Primary care data can tell us about the number of people who are registered with a GP in York and who have a diagnosis for autism. It is well recognised that not everyone with autism will have a diagnosis recorded.

In total there are 2,786 people who are registered with a York GP and who have a diagnosis of autism on their health record. This information was collected in summer 2024.

The data is separated by sex and shows that there is roughly a 3:1 ratio of men to women with autism diagnosis. This follows the expected national pattern.

[12] Genetics and epigenetics of autism: A Review - Waye - 2018 - Psychiatry and Clinical Neurosciences - Wiley Online Library

[13] Early environmental risk factors for neurodevelopmental disorders – a systematic review of twin and sibling studies - PMC (nih.gov)



The data is also separated by age band. It shows that very few older adults have an autism diagnosis (0.2% of the population). This also follows the national pattern. It is because in previous decades autism was less recognised and less diagnosed.

The majority of autism diagnosis are in people aged 0-9 (approximately 300 people), 10-19 (approximately 1100 people), and 20-29 (approximately 800 people).

Education data on autism in York

There is also data on the numbers of people with autism in the education records. This is held by the special educational needs team.

A child has special educational needs if they need additional or augmented support to access the school or the curriculum. This can come in the form of a SEN-support plan (additional support coordinated by the school) or an Education, Health, and Care Plan (a plan made jointly by these three teams of professionals).

In total, just over 700 children and young people have SEND with autism as their primary need. This is a fifth of all pupils with SEND.

Children and young people living in deprivation in York were no more or less likely to have a SEND record for Autism or ADHD as children living in other areas of York.

Autism and gender/sex

It is thought that autism is more common in males than females. There are different estimates, but most likely the prevalence is one female to every 3 or 4 males has autism[14].

It is also though that autism in females is sometimes missed or misunderstood. This happens because the signs of autism in females can be different and may look like other conditions. For example, girls with autism may be able to 'mask', meaning they can copy others behaviour and behave like a neurotypical person in some social settings. This can be very stressful and is known to increase feelings of anxiety in females with autism[15].

The estimates of how many women and girls with autism may be undiagnosed vary considerably and there is no consensus at this time. The Autistic Girls Network have summarised the current understanding and impact of autism on women and girls[16].

Autism and gender diversity

There is a correlation between autism and trans people, gender diverse people, or people experiencing gender dysphoria. A UK project looking at 600,000 adults found that transgender and gender-diverse adult individuals were between three and six times more likely to say that they were diagnosed autistic compared to the general adult population of the UK[17].

Data from GP practices in York, says that there are 48 people with a medical diagnosis of Autism and a record that they are 'trans or non-binary'. This is 1.6% of everyone with a diagnosis of Autism on their GP record, about 3 times the prevalence in the general population[18]. This data would not include people who do not currently have an autism diagnosis.

[14] https://www.autism.org.uk/advice-and-guidance/what-is-autism/autistic-women-and-girls
[15] The National Autistic Society
[16] https://autisticgirlsnetwork.org/keeping-it-all-inside.pdf
[17] Transgender and gender-diverse individuals are more likely to be autistic and report higher autistic traits | University of Cambridge
[18] Gender identity, England and Wales - Office for National Statistics (ons.gov.uk)

Autism and health and wellbeing

Overview

This section looks at health and wellbeing topics and how they relate to autism. We summarise national research and include local information where it is available.

Topics are discussed alphabetically:

- Adult social care
- Criminal justice
- Downs syndrome
- Ehlers-Danlos Syndrome
- Epilepsy
- Employment
- Gastrointestinal issues
- Homelessness
- Learning disabilities
- Life expectancy
- Mental health (including anxiety, depression, OCD, and bipolar disorder)
- Obesity
- Sensory sensitivity
- Sleep
- Smoking
- Substance misuse (drugs and alcohol)
- Topics may be added to or deleted as we engage with the community through out the strategy development process

Learning disability and adult social care

Lots of people will need help with personal care and day-to-day tasks in older age. Some people also need help as a younger adult, usually this would be because of a learning disability, a physical disability, or a serious mental health condition.

There is a known link between autism and learning disability. The NHS estimate that 60-70% of adults with autism also have a learning disability[19]. As a result, people with autism are more likely to receive help with daily activities as younger adults.

In York, CYC holds a record of 3,900 adults who receive care to help with daily activities. In theory it is possible to know how many people receiving care have autism. In practice the local authority care records list just over 100 adults with autism that are known to it, nearly all of whom also have a learning disability. It is widely acknowledged that the true number of people with autism known to the local authority is higher, but that due to nationally defined criteria we recognise that many people with a primary need of learning disability have not yet had their autism diagnosis included on their individual care record.

Record keeping is slowly improving as the team are now taking greater steps to record known autism diagnosis for new and existing customers.

The York GP data can also help us to understand about autism, learning disability, and care need. Compared to other local authorities nationally, York has a statistically significantly lower prevalence of people diagnosed with a learning disability. This might suggest that there is an element of under-diagnosis amongst the population.

In total there are 222 people in York who have both Autism and a learning disability coded on their GP health record. This equates to around 7% of all people with an autism diagnosis. Evidence suggests that around 1 in 3 (33%) of autistic people also have a learning disability, although this varies by age group. The ICB has piloted various initiatives to improve learning disability recording in GP practices. This is important because people with learning disabilities are eligible for routine Annual health checks throughout their adult lives, and are also eligible for free flu vaccinations.

Criminal Justice system

[19] Estimating the prevalence of autism spectrum conditions in adults - GOV.UK (www.gov.uk)

There are no clear records of the number of Autistic or neurodivergent people in criminal justice system.

Some characteristics of autism might make young people more at risk of offending. This might include a having smaller social support network and social naivety, meaning others can 'take advantage' of Autistic people in some circumstances. In a publication for The Children's Commissioner the prevalence of Autism among young offenders is estimated to be 15%.[20]

In July 2021, a national review on neurodiversity within the criminal justice system highlighted insufficient efforts to address the needs of neurodivergent individuals. Responding to this, the Ministry of Justice released a neurodiversity action plan in June 2022, with updates in January 2023. The revised plan outlines the introduction of neurodiversity support managers in prisons, with a goal to have one in each facility across England and Wales by 2024.[21]

In York the youth outcome panel, which aims to divert people form criminal justice is able to know about any young person with diagnosed neurodiversity or who is awaiting assessment. This means that the actions of the rehabilitation orders can be tailored to suit the young people. The youth justice service also follow up young people with SEND to understand their longer term outcomes.

North Yorkshire police have annual training that includes responding to neurodiversity and have 'trigger plans' in place for meeting alternative communication or sensory needs for individuals who they routinely support through mental health crisis.

North Yorkshire police have also scoped their custody suits for reasonable adjustments that could be made to support sensory sensitivity. This includes sensory toys, adjustable lighting, ear defenders, and backboard paint walls. The age and layout of some of the buildings create limitations, but refresh of the lighting was completed in 2024.

Ehlers Danlos syndromes and hypermobility syndromes

[20] https://www.childrenscommissioner.gov.uk/resource/nobody-made-the-connection/

[21] Abreu. L et al., (2024) Autism: Overview of Policy and Services, Research Briefing, UK Parliament

Ehlers-Danlos Syndromes are a group off rare inherited conditions that affect connective tissue[22]. This can lead to hypermobility and stretchy skin. People with these syndromes can be at more risk of physical injury from things like heavy lifting or contact sports. It is thought these conditions run in families and overlap with autism. Around 8% of autistic people also have an Ehlers-danlos syndrome themselves[23].

Gastrointestinal issues

People with autism are more likely to have Gastro-intestinal health issues. This causes constipation, diarrhoea, acid reflux, difficulty absorbing nutrition from food leading to vitamin deficiency, stomach pain, and intolerance to lactose or gluten. Estimates vary considerably, and there are only a few big studies, but it is thought that at least a third of people with Autism are impacted by GI issues[24].

In some cases, gastro-intestinal health issues can be made worse by restrictive eating (when a person eats only a small number of foods), however this is not usually the primary cause.

Employment

People with autism are over twice as likely to experience unemployment. The national Labour Force Survey tells us that 30% of working-age autistic adults are employed, compared with 50% of disabled adults, and 80% of non-disabled adults[25]. Data from the Association of Graduate Careers Advisory Services indicates that autistic graduates also face challenges with only 36% working full-time employment a year after graduating.

Employment is associated with better mental and physical health and is important for the wider economy. The Retreat post-diagnosis resources do include some information on employment, but people are not directed towards any schemes operating locally.

[22] Ehlers-Danlos syndromes - NHS (www.nhs.uk)
[23] Ehlers-Danlos Syndrome and Its Comorbidities as a Co-Occurring Health Issue in Autistic People - Autism Spectrum News
[24] Prevalence of gastrointestinal symptoms in autism spectrum disorder: A meta-analysis - ScienceDirect
[25] Abreu. L et al., (2024) Autism: Overview of Policy and Services, Research Briefing, UK Parliament

We are not aware of any York specific data that could indicate the employment rates for neurodiverse people living in York.

Homelessness

The current research suggests that people with autism are more likely to experience homelessness. In 2017 in the UK a sample homelessness key workers were asked to consider their clients against the diagnostic criteria for autism[26]. The researchers found that 12% of the group were described as showing 'strong signs' of autism, and another 10% showing some autistic traits. Although this was not a diagnosis, this research suggests that autistic traits are much more common in homeless people than in the general adult population.

Homeless Link say that "Personal social challenges, a lack of community understanding and support, and employment disadvantage and discrimination are likely to be key reasons why autistic adults may be more at risk of homelessness." In addition, autistic people who are homeless are more vulnerable to further harms from violence or abuse.

Homeless Link have produced a toolkit[27] which provides resources to help key workers to identify people with traits of autism in their clients and to consider suggests in reasonable adjustments to working practices which can help people with autism to fully access the support on offer. Homeless Link recognise that in many cases neurodiverse people experiencing homelessness have not received a diagnosis, and levels of self-identification vary.

Currently, the homelessness support services in York don't specifically ask whether a person has Autism as a standard question, but do seek to understand the health and wellbeing needs of their clients, and recognise autistic characteristics in many of their client group.

GP data is not a particularly good source of information on homelessness. GP data shows there are currently 19 people with a diagnosis of Autism who also have current homelessness recorded on the GP record.

[26] https://homelesslink-1b54.kxcdn.com/media/documents/Autism_and_Homelessness_Toolkit_Edition_2.pdf
[27] https://homelesslink-1b54.kxcdn.com/media/documents/Autism_and_Homelessness_Toolkit_Edition_2.pdf

Life expectancy

The average life expectancy in the UK is 80 years for men, and 83 for women. The life expectancy for people with autism is about 5 years shorter, and about 10 years for people with autism and a learning disability[28].

	Men	Women
General population	80	83
Autism	75 (-5 years)	77 (-6 years)
Autism and Learning Disability	72 (- 8 years)	70 (-13 years)

The reasons for this are likely to be complex. This health needs assessment identifies may factors which can impact life expectancy. Additionally, the report into life expectancy describes that autistic people may find it more difficult to explain their symptoms to others and this can complicate access to healthcare services.

Substance misuse

Autistic individuals are less likely to report regularly consuming alcohol or binge-drinking compared to non-autistic individuals. However, survey data[29], [30] shows they are almost nine times more likely to use alcohol or drugs to 'self-medicate' i.e. to use substances to help manage the symptoms of stress and anxiety. Autistic adults were also more likely to report using drugs at a young age, or being coerced into using drugs by others. This is important for people working to support people with addiction and/or mental illness and safeguarding.

The GP data for York records 40 people with autism who also have 'drug or alcohol abuse' on their health record. This is 1.3% of everyone with autism.

[28] Premature death of autistic people in the UK investigated for the first time | UCL News - UCL – University College London

[29] Weir, E., Allison, C., & Baron-Cohen, S. (n.d.). Understanding the substance use of autistic adolescents and adults: A mixed-methods approach

[30] Understanding the substance use of autistic adolescents and adults: a mixed-methods approach Elizabeth Weir, BA Carrie Allison, PhD, Prof Simon Baron-Cohen, PhD

Mental health

There is no central data set looking at autism and mental health in England so the best information comes from big research studies that collect information from medical records. This type of research shows that Autistic people are about twice as likely to experience anxiety and also depression as people who do not have Autism[31][32][33]. The research showed that anxiety symptoms rise in teenage and 20s. This is also true of the general population, but the rates of anxiety are higher. The research also shows that Autistic people are particularly likely to have social anxiety or OCD symptoms.

York GP data shows that in total 40% of people with diagnosed autism also have a mental health condition in York.

- 33% have an anxiety condition,
- 21% have depression
- 3% have a serious mental illness.

In line with national data, this is considerably higher than the expected values for adults without Autism.

Epilepsy

Epilepsy is more common in people with autism, especially if the autistic person also has a learning disability.

A review suggests that 12% of people with autism also have epilepsy[34], possibly rising to has high as 26% in autistic teenagers[35]. Epilepsy is also most common in autistic people who also have a learning disability, 22% compared to 8% without a learning disability[36].

The NHS page on 'living with epilepsy' says that people who have epilepsy should avoid excess stress or becoming too tired, as these

[31] Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis | Psychological Medicine | Cambridge Core

[32] Anxiety Disorders in Adults with Autism Spectrum Disorder: A Population-Based Study - PMC (nih.gov)

[33] Association of Comorbid Mood and Anxiety Disorders With Autism Spectrum Disorder | Anxiety Disorders | JAMA Pediatrics | JAMA Network

[34] NHS England » National bundle of care for children and young people with epilepsy: annex 2

[35] Clinical characteristics of children with autism spectrum disorder and co-occurring epilepsy - PubMed (nih.gov)

[36] Epilepsy in autism is associated with intellectual disability and gender: evidence from a meta-analysis - PubMed (nih.gov)

things can trigger epilepsy episodes. People are also advised to cut down on alcohol. There are also considerations for reasonable adjustments at work, driving a car, doing sports, pregnancy and looking after young children.

The York GP data does not agree with these national findings. In York only 1% of the people with a diagnosis of autism also had epilepsy on their health record. This may need further exploration.

What is ADHD

Overview

This section looks at:

- The symptoms of ADHD in children
- The estimated prevalence of ADHD in England
- Data on the diagnosed prevalence of ADHD in York
- Data on diagnosed ADHD in York by age
- National and international trends on age of diagnosis
- The symptoms of ADHD in adults
- Research on ADHD and sex or gender
- Research on Gender dysphoria and ADHD
- Review bullet points when sections are finalised
- Possibly add something about sleep?

How common is ADHD?

The true prevalence of ADHD is thought to be 3%-4%[37], this figure includes both people with and without a diagnosis.

The signs of ADHD

The symptoms of Attention Deficit Hyperactivity Disorder (ADHD) can be described by two broad categories: “inattentiveness” and “hyperactivity and impulsiveness”.

The main signs of inattentiveness are:

- having a short attention span and being easily distracted
- making careless mistakes – for example, in schoolwork

[37] Prevalence | Background information | Attention deficit hyperactivity disorder | CKS | NICE

- appearing forgetful or losing things
- being unable to stick to tasks that are tedious or time-consuming
- appearing to be unable to listen to or carry out instructions
- constantly changing activity or task
- having difficulty organising tasks

The main signs of hyperactivity and impulsiveness are:

- being unable to sit still, especially in calm or quiet surroundings
- constantly fidgeting or excessive physical movement
- being unable to concentrate on tasks
- excessive talking
- being unable to wait their turn or interrupting conversations
- acting without thinking
- little or no sense of danger

It is thought that 50%-75% of people with ADHD have both inattentive and hyperactive-impulsive symptoms with the remainder mainly have one type of symptoms[38].

The way in which ADHD affect adults can be different from the way it affects children. Typically, adults have fewer symptoms of hyperactivity, but retain the symptoms of inattentiveness. This means that adults with ADHD may continue to find things like organising, prioritising, finishing tasks, or dealing with stress challenging.

The Scottish charity 'ADHD Foundation' are keen to emphasize the strengths of many adults with ADHD in a publication for employers.[39]

"Many adults with ADHD are noted for strengths such as:

- Ability to 'hyperfocus' on things they are interested in
- Willingness to take risks
- Spontaneous and flexible
- Good in a crisis
- Creative ideas – thinking outside the box
- Relentless energy
- Often optimistic

[38] Prevalence | Background information | Attention deficit hyperactivity disorder | CKS | NICE
[39] An Employer's Guide to ADHD in the Workplace - Scottish ADHD Coalition (adhdfoundation.org.uk)

- Being motivated by short term deadlines – working in sprints rather than marathons
- Often an eye for detail."

What causes ADHD?

The cause of ADHD is unknown and it is unlikely to be caused by one single thing.

There is a strong between-sibling link for ADHD, and also a strong parent-child link. The link is especially strong for twins, if one twin has autism there is a 74% chance that the other twin will also have ADHD[40].

There are also factors in pregnancy and early childhood linked to ADHD. There is convincing evidence of the link to, maternal obesity before pregnancy, childhood eczema, maternal high blood pressure during pregnancy, and maternal pre-eclampsia[41].

None of this evidence can say what causes ADHD, just that these things are likely to be present where ADHD is present. This may have an impact on the care plans for a pregnant lady with ADHD.

Some researchers have looked at pollutants and ADHD, in particular lead and heavy metals exposure in childhood[42]. However, in the UK exposure to high levels of lead is very rare (7 cases in 1 million children)[43], and so this cannot be a major cause of ADHD.

There are various news stories about a link between ADHD and air pollution. One review of all available studies found credible evidence that various air-borne pollutants are linked to higher rates of symptoms ADHD, the authors were cautious in their findings, as there was not agreement between the studies on the amount of air pollution that was

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40 https://idp.nature.com/transit?redirect_uri=https%3A%2F%2Fwww.nature.com%2Farticles%2Fs41380%E2%80%90018%E2%80%900070%E2%80%900&code=233eb717-46d0-4955-9812-62cbc1965bd9

41 Vitamin D Status and Attention Deficit Hyperactivity Disorder: A Systematic Review and Meta-Analysis of Observational Studies - PubMed (nih.gov)

42 Environmental pollution and attention deficit hyperactivity disorder: A meta-analysis of cohort studies - ScienceDirect

43 Lead Exposure in Children Surveillance System (LEICSS) annual report, 2021 (publishing.service.gov.uk)

harmful, and also that most individual studies looked at parent identified symptoms rather than a clinician led diagnosis[44].

There is a link between a child having ADHD and the family experiencing poverty, but it is not straightforward to explain why. Data from the Millennium Cohort Study also links ADHD to living in social housing, to having a younger mother, and to living in a single parent household, and to having a parent with few qualifications[45]. Many of these factors, together or separately, can link to low income. As with the previous section on pregnancy factors, these studies simply describe a connection, but do not explain if one thing is causing another.

There is a lot of discussion in the news about the influence of social media on childhood development, and specifically in ADHD. A publication in 2022 looked at all available research on the connection between 'digital media use' and ADHD symptoms in children and teenagers. They found that there was a two-way relationship between social media use and severity of ADHD symptoms. They say that 'Children with ADHD symptoms appear more vulnerable to developing high or problematic use of digital media and that digital media also have effects on later ADHD symptom levels, either because of specific characteristics of digital media or because of indirect effects on for example sleep and social relationships."

A related publication in 2022 promotes the idea that support for young people with ADHD should specifically include support and guidance on social media use[46].

GP data in York about ADHD

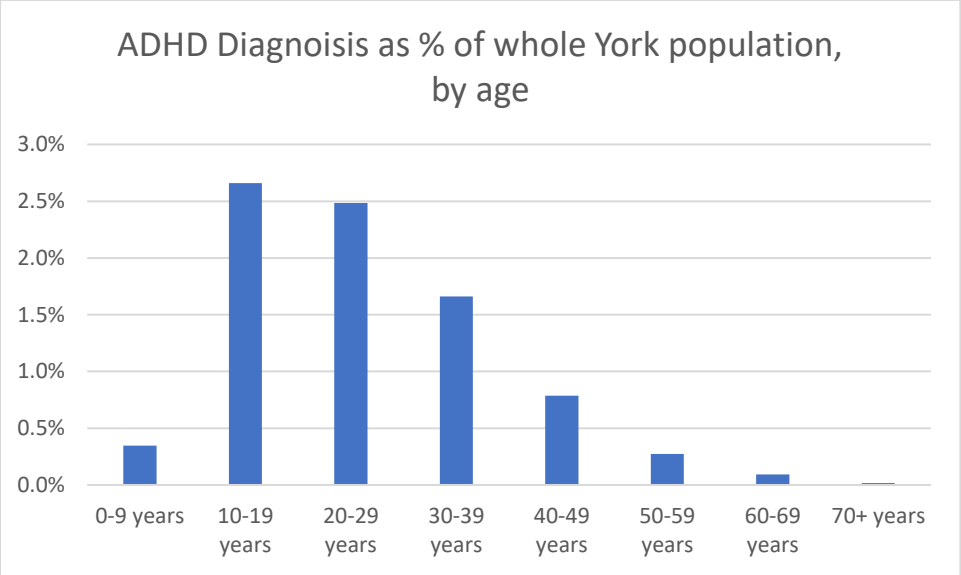
Not everyone with ADHD has a diagnosis, but GP data is still a valuable source of information about ADHD in York.

[44] Exposure to environmental pollutants and attention-deficit/hyperactivity disorder: an overview of systematic reviews and meta-analyses | Environmental Science and Pollution Research (springer.com)
[45] Featured news - ADHD linked to social and economic disadvantage - University of Exeter
[46] Understanding Problematic Social Media Use in Adolescents with Attention-Deficit/Hyperactivity Disorder (ADHD): A Narrative Review and Clinical Recommendations - PMC (nih.gov)

GP records show that 2,311 people in York have a diagnosis of ADHD. This is 1.1% of the York population. For the whole of England the diagnosed prevalence of ADHD is 0.8%[47].

The table below shows the spread of ADHD diagnosis by age. It shows that most people with an ADHD diagnosis are in their teens and 20s. It is expected that only a small number of young children have an ADHD diagnosis it is rarely confirmed in early childhood.

Additionally, few older adults have a diagnosis of ADHD. This is also expected as the modern understanding of ADHD is relatively new[48], and ADHD was less identified in previous decades.



ADHD and Gender or Sex

The prevalence of diagnosed ADHD in the UK is approximately three boys to every one girl. It is generally accepted that ADHD is more common in boys. It is also thought that boys are more thoroughly diagnosed as they have more ‘classic’ symptoms.

ADHD is usually first suspected because of behaviours that are visible to other people (i.e. difficulty sitting still or impulsivity). Often these visible behaviours are more common in boys than girls. By contrast, females with ADHD are more likely to have difficulty organising their thoughts or anxiety-like symptoms. This has led some people to think that female

[47] Attention deficit hyperactivity disorder (ADHD) and epilepsy - NHS England Digital
[48] The history of attention deficit hyperactivity disorder - PMC (nih.gov)

ADHD is sometimes missed or diagnosed late[49]. This remains an under researched area, although there is a recent commentary on the impact of heritability, diagnostic criteria, societal expectation and more factors which outlines the subject of gender and ADHD in greater detail[50].

Gender diversity and ADHD

There is little academic research on the topic of ADHD and gender diversity or trans. Two systematic reviews, one from 2019[51] and another from 2022[52] both looked at all the available studies on the topic. Both found a lack of research, and in particular a lack of good quality research, and both were unable to draw any firm conclusions.

ADHD and Health and Wellbeing

Overview

This section looks at what we know about the health and wellbeing of people with ADHD. We combine information from national surveys or research, and local data where it is available.

In this section we look at alphabetically.

- Diabetes
- Sleep
- Smoking
- Criminal justice
- Life expectancy
- Mental health (including depression and anxiety)
- Obesity
- Epilepsy
- Substance misuse (drug and alcohol addiction)
- Employment

[49] Gender differences in adult ADHD: Cognitive function assessed by the test of attentional performance - PMC (nih.gov)

[50] Why are females less likely to be diagnosed with ADHD in childhood than males? - The Lancet Psychiatry

[51] Prevalence of Autism Spectrum Disorder and Attention-Deficit Hyperactivity Disorder Amongst Individuals with Gender Dysphoria: A Systematic Review | Journal of Autism and Developmental Disorders (springer.com)

[52] A PRISMA systematic review of adolescent gender dysphoria literature: 2) mental health | PLOS Global Public Health

- These may change, as the strategy develops. Additionally, need ordering

Diabetes

A review of all available evidence found that children with ADHD were twice as likely to also have type 2 diabetes than children without ADHD[53]. Additionally children with ADHD and diabetes were more likely to have high blood sugar and high ketone, both suggesting that the diabetes is not well controlled. It is thought that children with ADHD may need additional support to keep on top of the daily monitoring and management of diabetes.

Need to look at local data - pending

Smoking:
People with ADHD are more likely to smoke and start smoking at a young age[54]. There was no difference in eventual successful quit rates, but people with ADHD were more likely to make a quit attempt.

GP data records 351 people with ADHD who are current smokers, this is 14% of everyone with ADHD, and is higher than you would expect to find in the general adult population of York.

The York stop smoking service does not currently collect information neurodiversity when people are referred to stop smoking.

Obesity

People with ADHD are more likely to be overweight or obese. Research looking at lots of individual studies found that as many as 70% of adults with ADHD also experience overweight obesity[55]. There are many reasons for this. For example, the ADHD medications are known to

[53] Association of ADHD symptoms with type 2 diabetes and cardiovascular comorbidities in adults receiving outpatient diabetes care - PMC (nih.gov)
[54] Cigarette Smoking Progression Among Young Adults Diagnosed With ADHD in Childhood: A 16-year Longitudinal Study of Children With and Without ADHD - PMC (nih.gov)
[55] The Association between ADHD and Obesity: Intriguing, Progressively More Investigated, but Still Puzzling - PMC (nih.gov)

cause weight gain as a side effect, and people with ADHD can be drawn to high carbohydrate and high sugar foods which can cause weight gain.

In York, the data does not agree with the national studies; 37% of people with an ADHD diagnosis are overweight or obese according to their GP record, this is less than the rates of overweight and obesity in the general adult population.

It is possible, though not explored, that this finding is because the overwhelming majority of people with diagnosed ADHD in York are young people and young adults and that people with a younger age also typically have a lower BMI.

Criminal justice

ADHD includes symptoms such as 'acting without thinking' and 'little or no sense of danger', in some circumstances this can lead to offending behaviour. The Children's Commissioner estimates the prevalence of ADHD among young offenders is 12%[56]. The ADHD foundation suggest that 25% of adults in prison have ADHD, and that 96% have a further need such as addiction or personality disorder[57].

In York the youth outcome panel, which aims to divert people form criminal justice is able to know about any young person with diagnosed neurodiversity or who is awaiting assessment. This means that the actions of the rehabilitation orders can be tailored to suit the young people. Since 2023 the youth justice service also follow up young people with SEND to understand their longer term outcomes such as education, employment or training. This is early data and it describes very small numbers of young people, but it is positive at this stage.

North Yorkshire police have annual training that includes responding to neurodiversity and have 'trigger plans' in place for meeting alternative communication or sensory needs for individuals who they routinely support through mental health crisis.

North Yorkshire police have also scoped their custody suits for reasonable adjustments that could be made to support sensory

[56] Nobody Made the Connection | Children's Commissioner for England (childrenscommissioner.gov.uk)

[57] Takeda_ADHD-in-the-CJS-Roundtable-Report_Final.pdf (adhdfoundation.org.uk)

sensitivity. This includes sensory toys, adjustable lighting, ear defenders, and backboard paint walls. The age and layout of some of the buildings create limitations, but refresh of the lighting was completed in 2024.

Mental health

People with ADHD are more likely to develop depression as teenagers and adults, compared with people who do not have ADHD. One large study of nearly a million people estimates people with ADHD are six times more likely to develop depression[58]. One explanation is that people with ADHD are more likely to experience chronic stress linked to social relationships, school, or work, and this can increase the risk of depression. Related to this, a large Swedish study shows people taking ADHD medication are at 20% lower risk of depression than those not taking medication[59].

The York GP data shows that 1096 people with ADHD diagnosis also have a mental health condition, this is 44%.

- 34% have an anxiety disorder
- 29% have depression
- 3% have a serious mental illness

These figures are far higher than prevalence in the neurotypical population of York.

Drugs and alcohol

The UK Addiction Treatment Centre says that of all people with ADHD, 12% will develop an alcohol addiction and 28% develop a drug addiction at some point in their lives[60]. In the general adult population, around 1% of people will develop these conditions. It is suggested that ADHD can lead to greater difficulty maintain relationships, achieving academic or

[58] Longitudinal association between mental disorders in childhood and subsequent depression – A nationwide prospective cohort study - ScienceDirect

[59] Medication for Attention-Deficit/Hyperactivity Disorder and Risk for Depression: A Nationwide Longitudinal Cohort Study - ScienceDirect

[60] https://www.ukat.co.uk/mental-health/adhd-and-addiction/

career goals, and increase chronic stress and impulsivity, all of which are factors that increase the vulnerability to addiction.

The addiction recovery service askes all clients a set of standard questions about disability or health conditions. In response, 0.8% of clients said they had 'autism or an other health condition'.

However, the addiction recovery service estimate that more than half of people in addiction recovery show characteristics of neurodiversity, mainly these are ADHD type characteristics, and predominantly individuals do not have a diagnosis.

GP data shows that 2% of all people with ADHD also have drug and alcohol abuse or dependency included on their health record. This is 58 individuals.

Early death and causes of deaths:

Unlike with autism, there is no national review of early deaths of people with ADHD. Death certificates would not ordinarily include reference to ADHD. As discussed through this health needs assessment, people with ADHD are more likely to experience obesity, smoking, mental ill health, unemployment, and a range of other chronic physical health conditions. One small study, not from the UK, tried to model the impact on projected life expectancy and found a reduced life expectancy[61].

Additionally, several systematic reviews have found convincing evidence that people with ADHD are at greater risk of early death from 'unnatural causes' such as accidents[62]. However, the way that the studies were presented means the researchers could not look at other important factors, for example other health conditions or social deprivation.

There is no local data on this topic.

[61] Hyperactive Child Syndrome and Estimated Life Expectancy at Young Adult Follow-Up: The Role of ADHD Persistence and Other Potential Predictors - Russell A. Barkley, Mariellen Fischer, 2019 (sagepub.com)

[62] Mortality in Persons With Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder: A Systematic Review and Meta-analysis | Attention Deficit/Hyperactivity Disorders | JAMA Pediatrics | JAMA Network

Employment:
It's not easy to get UK data on employment and ADHD but data from other countries suggests people are less likely to be in work and are more likely to be fired from a job.

The Scottish ADHD coalition highlights that many people with ADHD have particular strengths which can be very useful in the workplace[63]. For example, creative thinking, an eye for detail, and being good with short deadlines.

Heart health:
Some people with ADHD take an amphetamine medication to help manage symptoms. In the long term, this medication is linked to weight gain and some chronic heart conditions.

A Swedish study[64] followed over 5,390,000 adults without cardiovascular disease and found that 38% of ADHD individuals went on to develop CVD, compared with 24% of non-ADHD individuals. People with ADHD were also becoming ill at a young age. The risk was higher again if the person also had a mental illness.

Good practice: A what works guide

This chapter of the health needs assessment gives some examples of 'what works' or 'good practice' for neurodiverse people. This includes making adaptations or designing services or places for neurodiverse people. They are examples, not all evidence and research are included.

Example topics:

- Education
- Mental health
- Criminal justice
- Workplaces
- Communication adaptations
- Buildings and public spaces adaptations

[63] An Employer's Guide to ADHD in the Workplace - Scottish ADHD Coalition (adhdfoundation.org.uk)
[64] Attention-deficit/hyperactivity disorder as a risk factor for cardiovascular diseases: a nationwide population-based cohort study - Li - 2022 - World Psychiatry - Wiley Online Library

Title	Autism: A guide for GPs
Source	https://autismwales.org/resource/Autism_-A-Guide-for-GPs-English.pdf
Summary	This short guide provides practical advice for GPs that can be impliemnted in their daily practice. It includes: - Identifying signs of autism - Appointments - Communication style - Pain and physical sensory processing - Assessment and treatment

Title	Autism and education
Source	Good Autism Practice Guidance | Autism Education Trust
Summary	This set of guidelines is written by members of the Autism Centre for Education and Research (ACER) at the University of Birmingham. The guidelines have been generated from a review of the research evidence, current policy documents, expert opinion, statutory guidance and from the accounts of autistic individuals. They identify eight key principles of good autism practice in education, from early years through to post-16 education. 1. Understanding the strengths, interests and challenges of the autistic child and young person. 2. Enabling the voice of the autistic child and young person to contribute to and influence decisions. 3. Collaboration with parents and carers of autistic children and young people 4. Workforce development to support children and young people on the autistic spectrum. 5. Leadership and management that promotes and embed good autism practice. 6. An ethos and environment that fosters social inclusion for children and young people in the autism spectrum. 7. Targeted support and measuring process of children and young people on the autism spectrum. 8. Adapting the curriculum, teaching, and learning to promote wellbeing and success for autistic children and young people.

Title	Delivering talking therapies to autistic children and adults
Source	Good practice guide (autism.org.uk)
Summary	Our Mental Health Project, in collaboration with Mind, aims to establish how to make mental health talking therapies better for autistic people. This guide incorporates the views of over 1,500 autistic people and almost 1,000 family members who responded to our mental health survey in October and November 2020. It is also based on our in-depth discussions with 17 autistic people, eight family members and 15 mental health professionals The key points for service design: 1) Improve autism understanding for all staff through training 2) Make the physical environment in both waiting rooms and therapy rooms less overwhelming 3) Think about ways you can all change the way therapy is delivered in your service to make it more autism-friendly 4) provide additional support to autistic clients 5) ask for and use feedback from your autistic clients 6) make sure the information about your service is autism-friendly, clear, concise and specific 7) explain the different therapy delivery types you can offer and give your client a choice about what works best for them. Key points for therapy sessions: 1) make sure the therapy room isn't overwhelming 2) Use simple, plain language 3) Give time for autistic people to process information and answer questions 4) Ask them if they would like someone close to them to be involved in sessions 5) Support them to be able to label their own feelings and emotions 6) Try to integrate autistic people's interests if that will help them

	7) Note down what you have covered and share this with the autistic person

	Guidance on criminal justice for Autistic people
	NAS_Police_Guide_2020_17092020.pdf (thirdlight.com)
	This guide provides background information about autism and aims to help all police officers and staff who may come into contact with autistic people meet their responsibilities under the Equality Act 2010 (Disability Discrimination Act 1995, Northern Ireland), Police and Criminal Evidence Act 1984 (Northern Ireland Order 1989) and the Mental Health Act 1983 (Mental Health Northern Ireland Order 1986) It includes help in identifying someone who may be autistic or have different communication needs. It also includes dos and don'ts for arrest, custody and interviewing, strip searching, being in a cell, and the use of appropriate adults for vulnerable adults.

	Statutory guidance for Local Authorities and NHS organisations
	Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (publishing.service.gov.uk)
	Statutory guidance for Local Authorities and NHS organisations to support implementation of the adult autism strategy. The report covers: 1. Training of staff who provide services to adults with autism

	2. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services 3. Planning in relation to the provision of services for people with autism as they move from being children to adults 4. Local planning and leadership in relation to the provision of services for adults with autism 5. Preventative support and safeguarding in line with the Care Act 2014 from April 2015 6. Reasonable Adjustments and Equality 7. Supporting people with complex needs, whose behaviour may challenge or who may lack capacity 8. Employment for adults with autism 9. Working with the criminal justice system

Title	The workplace: wellbeing and retention for neurodiverse people
Source	Neurodiversity at Work 2023 (berkshirehealthcare.nhs.uk)
Summary	Birbeck University of London in collaboration with major employers including McDonalds, Roles Royce, and Sage developed a questionnaire on the experience of being a neurodivergent in the workplace. The research outcomes focus on strategies to retain employees and strategies to improve employee wellbeing.

Title	The workplace: Recruiting autistic people
Source	Employing autistic people (autism.org.uk) and Advertising a role - Employment Autism
Summary	The recruitment process can inadvertently create barriers for autistic individuals. Organisations can implement minor adjustments to make it easier for autistic candidates to apply and showcase their skills, ultimately benefiting all candidates and improving recruitment efficiency.

	The resources above list adjustments to: • Job descriptons and adverts • Application forms • The interview process and alternatives to interviewing

Title	Designing work places for people with ADHD
Source	ADHD Reasonable Adjustments (adhduk.co.uk) ADHD in the workplace (berkshirehealthcare.nhs.uk)
Summary	These publications by ADHD UK and Berkshire Healthcare NHS foundation trust describe how some aspects of the work place can be additionally challenging to people with ADHD and potential adjustments that can support. These adjustments include: - Modifications to the working environment: protected quiet spaces, working from home, permanent desk spaces - Flexibility in working practices: flexible working (where possible), protected time for hyperfocus tasks - Working practices: communicating deadline and work task expectations, - Using feedback: agile working practices, utilising ADHD traits to the benefits of the job role - Useful technology: headphones, diary management tools - HR policies: training for managers, antidiscrimination policies overtly mention neurodiversity, coaching for employees

Title	
Source	
Summary	

Title	Designing public buildings to accommodate neurodiverse people

Source	Environmental checklist for people (southwestyorkshire.nhs.uk) Guide-for-cognitively-inclusive-design-in-primary-care-environments-FINAL.pdf (dimensions-uk.org) Building-Better-Together-Dimensions-Assura-report-web-final.pdf (dimensions-uk.org)
Summary	In 2015 Kirlees Council and the South West Yorkshire Partnership NHS Foundation Trust created an Autism-Friendly Environments Checklist. The Checklist was designed for organisations providing NHS and Local Authority services. The checklist is organised by sensory category (i.e. smell, sight…), with opportunity to make notes about solutions and discussion. Service providers are suggested to start with the smallest spaces and then expand out to larger areas. The 'Designing for Everyone' guide and toolkit brings together current research, evaluation and best practice in design for cognitive impairment and neurodiversity together with reports commissioned by Assura from the Patients Association and Dimensions which focus on the patient experience of health centre buildings. The report is structured around four themes; - Independence and choice: signage and getting around - Dignity: privacy, reception, and toilet facilities - Feeling relaxed: sensory environment and decor - Customer service and patient care: flexibility and involvement

Title	Designing buildings sympathetic to neurodiversity
Source	Designing buildings sympathetic to neurodiversity: a new guide (theconstructionindex.co.uk)
Summary	BSI, the British Standards Institution, has published guidance on designing the built environment to include the

	needs of people who experience sensory or neurological processing differences. These are detailed in PAS-6463

Title	How to design spaces to better meet the needs of neurodivergent groups
Source	How to design spaces to better meet the needs of neurodivergent groups (hdsunflower.com)
Summary	This publication considers - The acoustic environment - Reducing visual noise - An easy entrance - Creating welcoming sanitary facilities - Recalibration and sating

Title	Meeting the needs of Autistic adults in mental health services
Source	https://www.england.nhs.uk/long-read/meeting-the-needs-of-autistic-adults-in-mental-health-services/
Summary	A guide for ICS and other health organisations that recognises that the NHS has seen a 50% rise in in patient mental health care over 5 years. The guidance is about preventing escellating need, and the importance of ensuring services are accessible and acceptable to autistic adults.

Title	Making meetings accessible
Source	https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-meetings-accessible/#accessible-meeting
Summary	This best practice describes making meeting accessible to Autistic people and people with a learning disability. It describes a range of adjustments, for example - Before the meeting tell people who will be in the meeting and what their role is

	- Choose a meeting room with lots of natural light and let people choose where they sit in the room. - During the meeting, keep to the timings on the agenda and make sure only one person talks at a time There is also advice on giving accessible presentations, this includes information about the layout of slides, using handouts, and using the right language.

Title	Tips for communicating with an autistic person
Source	https://www.autism.org.uk/advice-and-guidance/topics/communication/tips
Summary	This guide includes information on topics like: - Getting and keeping attention - Processing information and information overload - Avoiding open questions - Asking for help - Being clear and saying what you really mean - Understanding distressing behaviour - Saying no and keeping a boundary

We will continue to develop and explore this section as we engage, coproduce, and consult on the autism strategy.

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6 November 2024

Health, Housing and Adult Social Care Scrutiny Committee

Report of the Director of Public Health

Winter Planning and Pandemic Preparedness in York

Summary

1. This report provides an update about winter planning in 2024/25, and about our pandemic preparedness in York following the report of the COVID-19 Enquiry Module 1 (Resilience and Preparedness).

Background

2. This report has been written at the request of members for an update and information on winter planning this year, and on the local pandemic preparedness arrangements.

3. Members should be aware that Executive receive the Annual Health Protection Board Assurance Report every year, as a mechanism for ensuring that the local health protection system is robust in line with statutory duties on the Director of Public Health. This report provides a fuller picture of activity around health protection in York.

Key issues

Winter Planning

4. Winter planning is a necessary and critical part of service planning within health and care, to ensure business continuity and to manage risks during what is typically a pressured time of the year. In addition, measures to protect population health from effects of cold weather and increased levels of infection during winter will also help avert healthcare pressures.

5. Winter has the benefit of being predictable, and so prevention to avoid these pressures takes place all year round, through partnership working with primary and secondary care, the ICB, voluntary services and other Local Authorities.

6. A winter planning meeting, led by public health, feeds into the Health Protection Board, although it should be noted that during the winter period specifically, other multi-agency meetings also existing in both healthcare sectors and within communities to prepare and protect citizens. For instance, winter pressures will be discussed daily at system escalation meetings including staff from the hospital, social care alongside other partners. These meetings provide an integrated system response to help relieve pressures and provide ongoing support in the community.

7. Infectious disease levels across any winter can vary quite dramatically. This can be due to the emergence of a new pathogen or significant genetic change of an existing one (e.g. ‘antigenic shift’ in influenza, which might cause a pandemic). However more typically, it is due to rates of disease often coming in waves with variable peaks and troughs depending on transmission dynamic in the population, and the amount of ‘antigenic drift’ seen in the genetics of pathogens that year.

8. For example, in a ‘bad flu year’ like 2017-18, there were 22,500 excess deaths associated with flu in the UK. Latest UK Health Security Agency (UKHSA) data shows that over the past 2 winters (October to May, 2022 to 2023 and 2023 to 2024) at least 18,000 deaths were associated with flu, despite last winter being a relatively mild flu season. In the same two-year winter period the estimated number of deaths associated with COVID-19 was just over 19,500. This suggests that one lasting legacy of the pandemic is an increased bured on Acute Respiratory Illness (ARI) in the population each winter

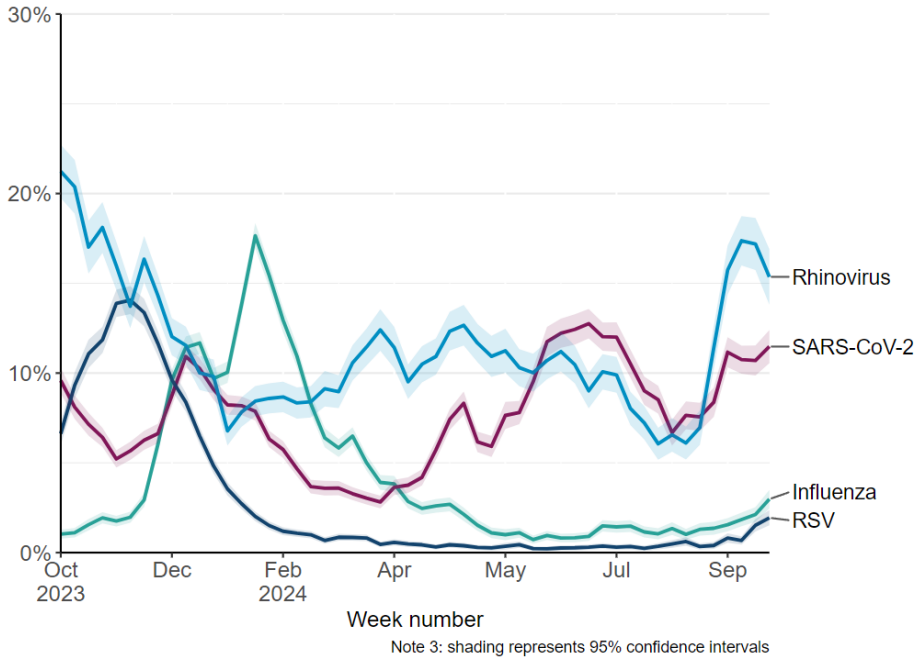
9. Bearing in mind this variability, some principles and predictions which can put forward for winter this year include:

    - A rise in respiratory illness through September relating to ‘back-to school’ mixing of children
    - A rise in Covid cases through autumn, with peak demand at some point in winter
    - A rise in flu in early January 2025

- A peak in Respiratory Syncytial Virus (RSV) in November / December 2024
- Norovirus cases and outbreaks spread across the winter, particularly concerning in sett8ngs with vulnerable residents e.g. care homes.

10. So far, as of 17th October (week 42) a COVID-19 and rhinovirus (common cold) peak in September is abating, and there have been some early rises in flu and RSV:

Figure 5a. Respiratory DataMart weekly percentage of tests positive for influenza, SARS-CoV-2, RSV and rhinovirus, England [note 3]



11. One key tool we have to protect the population during winter is vaccination.

12. National Immunisation programmes are delivered through primary and secondary care, pharmacies and the School Aged Vaccination Service (Vaccination UK). Vaccines relevant to our winter planning efforts include:

- The introduction of RSV vaccination programme for older adults (75, plus 76-79 catch up) and pregnant women, which started in September 2024. Infants will be protected by maternal vaccination at around 28 weeks year round, and through direct vaccination for infants and young children at high risk of severe RSV disease

- Flu and COVID vaccination programmes, including eligibility for all frontline health and social care workers.
- Year round MMR and pertussis programmes, due to higher levels of Measles and Whooping Cough (Pertussis) during winter and pressure on services.

13. Local operational groups are held in conjunction with NHSE to monitor uptake of immunisation programmes and identify and address any inequalities to improve uptake and access to programmes.
14. This year, there is real concern from UKHSA around the drop in the flu vaccine uptake rates last winter across all eligibility groups in England compared with the previous year
15. While uptake in older people last year remained high, only 4 in 10 (41%) people with long-term health conditions, just over 4 in 10 (44%) 2- and 3-year-olds, and just 1 in 3 pregnant women received the flu vaccine.
16. Evidence shows the significant impact from last year's flu vaccine with a 30% reduction in the number of those aged 65 and over being hospitalised and a 74% reduction in those between 2 and 17 years of age.
17. The public health team are leading a significant communications campaign this year on vaccination, as well as providing staff vaccination for non-eligible CYC staff.
18. During the winter months the Health Protection Team sees an increase in notifications of outbreaks in settings such as Care Homes, schools and nurseries, including outbreaks of Diarrhoea and Vomiting and Acute Respiratory Illnesses (ARIs) e.g. Influenza and COVID. Locally, the public health team and social care work together with UKHSA in managing these situations and supporting settings.
19. UKSHA provide good surveillance of infectious diseases. They have recently provided an "influenza pack" for all care/residential homes to help care homes detect outbreaks of influenza-like illness quickly, and enable prompt notification and implementation of infection control measures. They are also providing training webinars for care homes in early identification and notification of influenza outbreaks in Care Homes.

20. Together with North Yorkshire Council, the public health team commissions a Community Infection, Prevention and Control (IPC) team, who provide onsite support in outbreaks and training for care homes and domiciliary care staff around PPE, prevention and also produce resources for outbreak management. Within NHS trust settings, for instance the hospital, IPC arrangements are part of the organisation's mandatory duties.

21. As well as infectious organisms, winter brings with it health risks due to extreme cold. The End Fuel Poverty Coalition estimates that in 2022/3 4,950 excess winter deaths were caused by cold homes.

22. The relationship between warm homes, fuel poverty, and health is a significant and multifaceted issue. Fuel poverty occurs when households struggle to afford the energy needed to maintain a warm, comfortable living environment.

23. This can lead to several health-related challenges. One of the outcomes of poorly heated homes can be increased ill-health and therefore an increased demand on primary and secondary care for the treatment of preventable illnesses.

24. There are certain factors that increase an individual's risk during cold weather, and CYC have a communication plan which is based on the national UKSHA Adverse Weather and Health Plan which we use to target communications at times when health harm is likely to be greatest.

25. A significant amount of work happens outside of public health within communities and revenue / benefits teams in the city around fuel poverty, uptake of the Household Support Fund, and advice / support around home insulation and fuel bills.

26. In addition to this, this year CYC Public Health have funded a Winter Warmth Grant, which the council's Healthy and Sustainable Homes team will use in work related to winter warmth and the reduction of hospital admissions relating to poor housing / fuel poverty. It will include the recruitment of a damp and mould expert to identify residents most in need, assess homes, create a ventilation and quick-wins strategy for each resident, and retrofitting properties with items such as draught proofing, radiator bleeding, installation of trickle vents, and referral to other support systems such York Energy Advice.

Pandemic preparedness in York

27. The impacts of COVID-19 on health and wellbeing were not felt uniformly across society. As the British Academy of Sciences have demonstrated, COVID-19 has exacerbated existing structural and social inequalities, with particularly negative health outcomes for those already disadvantaged in society.[1]

28. The 2022 Director of Public Health Annual Report 'York: the pandemic years' tells the full story of the pandemic in York and the city's response.[2]

29. The findings from Module 1 of the national COVID-19 Inquiry, led by Dame Heather Hallett, were published on 18th July 2024. Full and summary versions are available online.[3]

30. Module 1 focuses on the state of the UK's central structures and procedures for pandemic emergency preparedness, resilience and response (EPRR). Other aspects of the Inquiry (e.g. care sector, test & trace, economic response) will be covered in future modules, many of which will have more direct recommendations beyond the national level.

31. The report identifies several concerns about the UK's pandemic preparedness. These include a narrow focus on the risk from pandemic influenza only; an overly complex set of institutions and structures for emergency planning; an outdated pandemic strategy; lack of consideration of health and social inequalities; failure to fully learn from past exercises and outbreaks; and a lack of focus on prevention.

32. There is also recognition that local authorities and volunteers/VCSE were not adequately engaged in the national emergency planning process.

33. The report provides key recommendations to improve the UK's central structures and procedures for Emergency Planning, Preparedness and Response (EPPR). The majority of these recommendations and the action which follows is targeted at national and regional level. However there are some general principles within them that can be applied locally too, and ensuring appropriate EPPR structures relating to

[1] https://www.thebritishacademy.ac.uk/publications/covid-decade-understanding-the-long-term-societal-impacts-of-covid-19/
[2] York: Pandemic Years Annual Report of the Director of Public Health 2020-2022
[3] UK Covid-19 Inquiry: Resilience and preparedness (Module 1) Report - GOV.UK (www.gov.uk)

pandemic preparedness forms part of the health protection duties placed on councils through the Health and Social Care Act 2013.

34. City of York Council Public Health, in collaboration with North Yorkshire Public Health, the North Yorkshire and York Local Resilience Forum (NYLRF) and the joint Resilience and Emergencies Team (RET), have been working through the recommendations and implications from the report. Many findings are not unexpected and have already been acted upon; however, work to embed recommendations from this and future Modules will continue as future reports are released.

35. The recommendations from Module 1 are:

- A radical simplification of the civil emergency preparedness and resilience systems. This includes rationalising and streamlining the current bureaucracy and providing better and simpler ministerial and official structures and leadership.

- A new approach to risk assessment that provides for a better and more comprehensive evaluation of a wider range of actual risks.

- A new UK-wide approach to the development of strategy, which learns lessons from the past and from regular civil emergency exercises, and takes proper account of existing inequalities and vulnerabilities.

- Better systems of data collection and sharing in advance of future pandemics, and the commissioning of a wider range of research projects.

- Holding a UK-wide pandemic response exercise at least every three years and publishing the outcome.

- Bringing in external expertise from outside government and the Civil Service to challenge and guard against the known problem of groupthink.

- Publication of regular reports on the system of civil emergency preparedness and resilience.

- Lastly and most importantly, the creation of a single, independent statutory body responsible for whole system preparedness and response. It will consult widely, for example with experts in the field of preparedness and resilience, and the voluntary, community and social sector, and provide strategic advice to government and make recommendations.

36. A number of the lessons identified have sizable implications on how Government could plan for future UK-wide emergencies. These will impact national, regional and local civil contingencies processes and the RET will utilise existing groups and structures to ensure the recommendations are discussed effectively and efficiently with partner organisations.

37. Local partners are also supporting work being undertaken at a regional level by UKHSA on planning for the next pandemic, as well as supporting capabilities development within the NHS through Humber & North Yorkshire Integrated Care Board (ICB) to respond to future health protection issues.

38. An NYLRF mass treatment plan for North Yorkshire and York was developed pre-COVID, but since the pandemic, am Infectious Diseases Plan has been prepared by public health teams and is now approved. In February 2024, a large multi-agency group came together to exercise the plan (Exercise Tussio), with lessons learned from the exercise used to update the plan prior to recent approval.

39. A lot of learning has already been undertaken within NYLRF on how partners plan for the future pandemics, and a number of points made within the inquiry report have already been implemented. For example, the new Infectious Diseases Plan moves away from single-risk pandemic flu and emerging infectious disease approaches, into a single plan covering multiple transmission routes (as recommended in the Inquiry report) that also considers impacts beyond the direct health response.

40. Together with North Yorkshire, we have continued to advocate for closer links between Directors of Public Health and national emergency planning, preparedness and response structures, most recently as part of lessons learned feedback from the H1N2(v) incident in North Yorkshire in November 2023 which also affected York through a suspected case working in the city.

41. Other findings arising from the report that we will need to consider include:

    - the potential change to national risk assessment processes (that will have knock-on implications for local risk assessment processes);

    - how health protection capabilities (including surge capacity) are expected to be split over local/regional/national levels, with a number of gaps in the health protection system identified locally by Humber and North Yorkshire Directors of Public Health including:

        - out of hours swabbing/testing capability
        - prescribing of prophylactic medication e.g. antibiotics or vaccination
        - contact tracing capacity, particularly in the community.

    - recommendation of external assessment of EPRR processes; and alignment of local structures (particularly LRF and LHRPs)

Council Plan

42. The CYC Council Plan and Health and Wellbeing strategy sets out a vision where the current trend of widening health inequalities is reversed, and people are supported to manage their health and wellbeing, with additional support available for those that need it.

Implications

- **Financial** There are no financial implications of this report.
- **Human Resources** There are no direct Human resource implications of this report. CYC encourages all staff in eligible cohorts to accept the offer of vaccinations and provides an occupational scheme to offer all staff a free flu vaccination who are outside the eligible cohort.
- **Equalities** The overall aim of the national immunisation programme is to protect the population from vaccine preventable diseases and

reduce the associated morbidity and mortality. In the context of health outcomes the national immunisation programme aims to protect the health of individuals and the wider population.

- **Legal** There are no direct legal implications of this report.
- **Crime and Disorder** There are no crime and disorder implication of this report.
- **Information Technology (IT)** There are direct IT implications of this report .
- **Property** There are no property implication of this report.

Risk Management

43. There are no direct risks associated with this report.

Recommendations

44. Members are asked to consider and note the report.

Reason: To keep the committee updated.

Contact Details

Author:	**Chief Officer Responsible for the report:**
Wendy Watson Specialist Public Health Practitioner Advanced	Peter Roderick Director of Public Health

Report Approved	✓	**Date**	23/10/24

Wards Affected: *List wards or tick box to indicate all* **All** ✓

For further information please contact the author of the report

Background Papers:
UK Covid-19 Inquiry: Resilience and preparedness (Module 1) Report, https://www.gov.uk/government/publications/uk-covid-19-inquiry-resilience-and-preparedness-module-1-report

UK Health Security Agency, Adverse Weather and Health Plan - Protecting health from weather related harm, 2024 to 2025 – second edition, https://assets.publishing.service.gov.uk/media/6603fee3f9ab41001aeea372/Adverse_Weather_Health_Plan_2024.pdf

York: the Pandemic Years - Annual Report of the Director of Public Health 2020-2022, https://www.york.gov.uk/downloads/file/1158/director-of-public-health-s-annual-report-2020-to-2022

Annexes
None

Abbreviations

ARIs	Acute Respiratory Illnesses
EPRR	Emergency preparedness, resilience and response
ICB	Humber & North Yorkshire Integrated Care Board
NYLRF	North Yorkshire and York Local Resilience Forum
RET	Joint Resilience and Emergencies Team
RSV	Respiratory Syncytial Virus
UKHSA	United Kingdom Health Security Agency

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Health, Housing and Adult Social Care Scrutiny Committee Work Plan 2024/25

Meeting Date	Item
4 December 2024 Housing	• Finance and Performance Monitor 2 • Revised Housing Repairs Policy – final draft • Update on Void Properties
15 January 2025 Adult Social Care	• Adult Social Care Strategy Update
12 March 2025 Public Health	• Finance and Performance Monitor 3
2 April 2025 Housing	• Asset Management Investment Plan (including a breakdown of budget forecast spending on contractors, apprenticeships, and an update on training to up-skill and cross-skill existing staff). • Housing Estate Management – review of the pilot

<u>Unallocated items</u>

- Autism and Neurodiversity Strategy (early 2025)
- LD Provision – The Glen and Lowfields
- Relevant outputs from LGA Peer Review
- Reablement technology (Practical)
- **Task and Finish Group Review** of Home Care Commissioning
- **Joint Committee with Children, Culture and Communities Scrutiny Committee** on healthy weight/weight management.

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