Notice of a public meeting of

Health and Wellbeing Board

To: Councillors Coles (Chair), Ayre, Runciman, Webb, Balsom, Broughton, Campbell, Coltman-Lovell, Hussain, Jones, Kelly, Morritt, Padgham, Semmence, Stoltz and Winward
Siân Balsom – Manager, Healthwatch York
Dr Emma Broughton – Joint Chair of York Health & Care Collaborative
Zoe Campbell – Managing Director, Yorkshire, York & Selby - Tees, Esk & Wear Valleys NHS Foundation Trust
Sarah Coltman-Lovell - York Place Director
Jamaila Hussain - Director of Prevention & Commissioning, City of York Council
Shaun Jones – Interim Director, Humber and North Yorkshire Locality, NHS England and Improvement
Martin Kelly - Corporate Director of Children's and Education, City of York Council
Simon Morritt - Chief Executive, York & Scarborough Teaching Hospitals NHS Foundation Trust
Mike Padgham – Chair, Independent Care Group
Alison Semmence - Chief Executive, York CVS
Sharon Stoltz - Director of Public Health, City of York Council
Lisa Winward - Chief Constable, North Yorkshire Police

Date: Wednesday, 20 September 2023

Time: 4.30 pm

Venue: The George Hudson Board Room - 1st Floor West Offices (F045)

A G E N D A

1. Declarations of Interest (Pages 1 - 2)

At this point in the meeting, Members and co-opted 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].

2. 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 have changed to 2 working days before the meeting. The deadline for registering at this meeting has been extended at the discretion of the Chair and will now be at **5.00pm** on **Tuesday, 19 September 2023**.

To register to speak please visit www.york.gov.uk/AttendCouncilMeetings to fill out an online registration form. If you have any questions about the registration form or the meeting please contact the Democracy Officer for the meeting whose details can be found at the foot of the agenda.

Webcasting of Public Meetings

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

During coronavirus, we've made some changes to how we're running council meetings. See our coronavirus updates (www.york.gov.uk/COVIDDemocracy) for more information on meetings and decisions.

3. Report of the Chair of the York Health and Wellbeing Board (Pages 3 - 8)

This paper is designed to summarise key issues and progress which has happened in between meetings of the Health and Wellbeing Board, giving board members a concise update on a broad range of relevant topics which would otherwise entail separate papers.

4. Update on the Implementation of the Dementia Strategy (Pages 9 - 34)

A presentation on the implementation of the Dementia strategy.

5. Report of the Health and Care Partnership (Pages 35 - 46)

This report provides an update to the Health and Wellbeing Board regarding the work of the York Health and Care Partnership, progress to date, and next steps.

6. York Health and Wellbeing Strategy 2022-2032: Report of the Acting Director of Public Health (Pages 47 - 56)

This paper is intended to present to the Board the current data on inequalities in life expectancy and healthy life expectancy in York.

7. Healthwatch York Report (Pages 57 - 114)

This report shares local experiences of adults seeking an Autism and/or ADHD diagnosis in adulthood during the piloting of a new pathway.

8. Presentation: Adult Social Care CQC Readiness (Pages 115 - 128)

A presentation introducing members of the Board to the Care Quality Commission's (CQC) Operating Model, and the CQC's New Single Assessment Framework.

9. Urgent Business

Any other business which the Chair considers urgent under the Local Government Act 1972.

Democracy Officer:

Reece Williams
Telephone No – 01904 551088
Email – reece.williams@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
- Any special arrangements
- Copies of reports and
- For receiving reports in other formats

Contact details are set out above.

This information can be provided in your own language.

我們也用您們的語言提供這個信息 **(Cantonese)**

এই তথ্য আপনার নিজের ভাষায় দেয়া যেতে পারে। **(Bengali)**

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)**

☎ **(01904) 551550**

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.

Health and Wellbeing Board **20 September 2023**

Report of the Chair of the York Health and Wellbeing Board

Chair's report and updates – September 2023

Summary

1. This paper is designed to summarise key issues and progress which has happened in between meetings of the Health and Wellbeing Board (HWB), giving board members a concise update on a broad range of relevant topics which would otherwise entail separate papers.

2. It will consider:

- Board business.
- Local updates for the board.
- National updates for the board.
- Actions on recommendations from recent Healthwatch reports.

Board Business

1. Following discussions at the last HWB meeting, the new Health and Wellbeing Board Terms of Reference (ToRs) are being drafted in conjunction with colleagues from Democratic Services and will be shared with board members for comment during the autumn.

2. Progress against the Joint Health and Wellbeing Strategy (JHWS) action plan will also be brought back to the Board at the November 2023 meeting.

Key local updates for the board

(Web links to key documents mentioned included at the end of the paper.)

3. City of York Council has published its four-year **Council Plan**, with four core commitments at the centre: Equalities, Affordability, Climate and Health. The plan is due to be discussed at the council's executive meeting in September.

4. An **All-Age Commissioning Strategy** for the city has been produced and is currently being approved by the council's executive. The vision is for the council to provide person-centred and outcome-focused care through a sustainable market that is inclusive and well-led, and the Strategy sets out a number of priorities the council will have in its adults and children's commissioning, including for some key upcoming contracts such as the **reablement service**.

5. I have had the pleasure of meeting with a number of **carers and carer-supporting organisations** in the city recently. Only a third of adult carers in York have as much social contact as they like (ASCOF), and 71% of carers have poor physical or mental health (MHF). We are lucky to have a fantastic Carers Centre in York, working in partnership with carers, statutory and voluntary organisations to ensure unpaid carers throughout York have access to confidential information, advice, and support for carers of all ages.

6. Amongst a number of key projects funded by the Health Inequalities Fund this year, the first **York Health Mela**, a multi-cultural health festival, is being held on 24 September 10am-5pm in the gardens of York art gallery and will be a fantastic mix of diverse music and culture, food, and health promotion.

Key national updates for the board

(Web links to key documents mentioned included at the end of the paper)

7. The Department of Health and Social Care (DHSC) have announced that this year's **autumn flu and COVID-19 vaccine programmes** will start earlier than planned in England as a precautionary measure following the identification of a new COVID-19 variant, which according to the latest risk assessment by UKHSA (the UK Health Security Agency) has a high number of mutations and has appeared in several countries in individuals without travel history. Eligibility for the vaccine (over 65s, those at risk, care home residents, health and care staff) has not changed. Vaccinations started on 11 September 2023, with adult care home residents and those most at risk to receive vaccines first, and flu and COVID-19 vaccines delivered at the same time where possible.

8. A new **national suicide prevention strategy** 2023-2028 has been published, with the aim to reduce the national suicide rate over the next five years. The Strategy sets out a roadmap for providing tailored, targeted support to priority groups, including children and young people, middle-aged men, people who have self-harmed, people in contact with mental health services, people in contact with the justice system, autistic people, pregnant women, and new mothers. It also sets out to address common risk factors linked to

suicide at a population level by providing early intervention and tailored support. These are physical illness, financial difficulty and economic adversity, gambling, alcohol and drug misuse, social isolation and loneliness, and domestic abuse.

9. National **smoking prevalence** data has been published, which shows that the proportion of people smoking in York has fallen to 8.7%, the 17th lowest rate in the country, and a larger drop than that seen nationally.

10. The **UK Health Security Agency** replaced Public Health England last year as the national body overseeing the response to infectious disease and hazards to health. Their new 3-year strategy sets out their priorities including responding to health hazards, improving health outcomes through vaccines, reducing the impact of infectious diseases and antimicrobial resistance, protecting health from threats in the environment, improving action on health security through data and insight and developing UKHSA as a high-performing agency.

11. £25m has been announced by the DHSC to create **Women's Health Hubs**, bringing together local services from local gynaecology through to menopause clinics, contraception services and sexual health clinics.

12. The NHS has released its **winter planning** letter, setting out operational planning requirements for systems to cope with winter pressures this year. People will remember that last year, high levels of flu and COVID-19, the rise in cases of scarlet fever/strep A, together with NHS backlogs and pressures, meant a very difficult winter for the NHS which to some extent still feeds through into current high levels of activity, and potentially lay behind a rise in excess deaths seen nationally and in York.

Recommendations from recent Healthwatch reports

13. In July 2023 the HWB received two York Healthwatch reports:

- Health and the Cost of Living in York
- Breaking Point, A Recent History of Mental Health Crisis Care in York

14. The recommendations from these reports are included as an annexe to this paper, and the Chair will be asking relevant board members for an update on progress at today's meeting.

Author:

Peter Roderick
Acting Director of Public Health

Co-Author:
Cllr Jo Coles
Executive Member for Health, Wellbeing and Adult Social Care

Chief Officer Responsible for the report:
Peter Roderick
Acting Director of Public Health

Report Approved ✔ **Date** 20.09.2023

Specialist Implications Officers
Not applicable

Wards Affected: **All** ✔

For further information please contact the author of the report

Background Papers

Suicide Prevention Strategy
https://www.gov.uk/government/publications/suicide-prevention-strategy-for-england-2023-to-2028/suicide-prevention-in-england-5-year-cross-sector-strategy#executive-summary

Major Conditions Strategy
https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2

UKSHA 3-year plan
https://www.gov.uk/government/publications/ukhsa-strategic-plan-2023-to-2026

Women's Health hubs
https://www.gov.uk/government/news/25-million-for-womens-health-hub-expansion

NHS England Winter Pressures letter
https://www.england.nhs.uk/long-read/delivering-operational-resilience-across-the-nhs-this-winter/

Annexes

Annexe A – Recommendations from Healthwatch Reports in July 2023

Annexe A

Recommendations from Healthwatch York report: Health and the Cost of Living in York

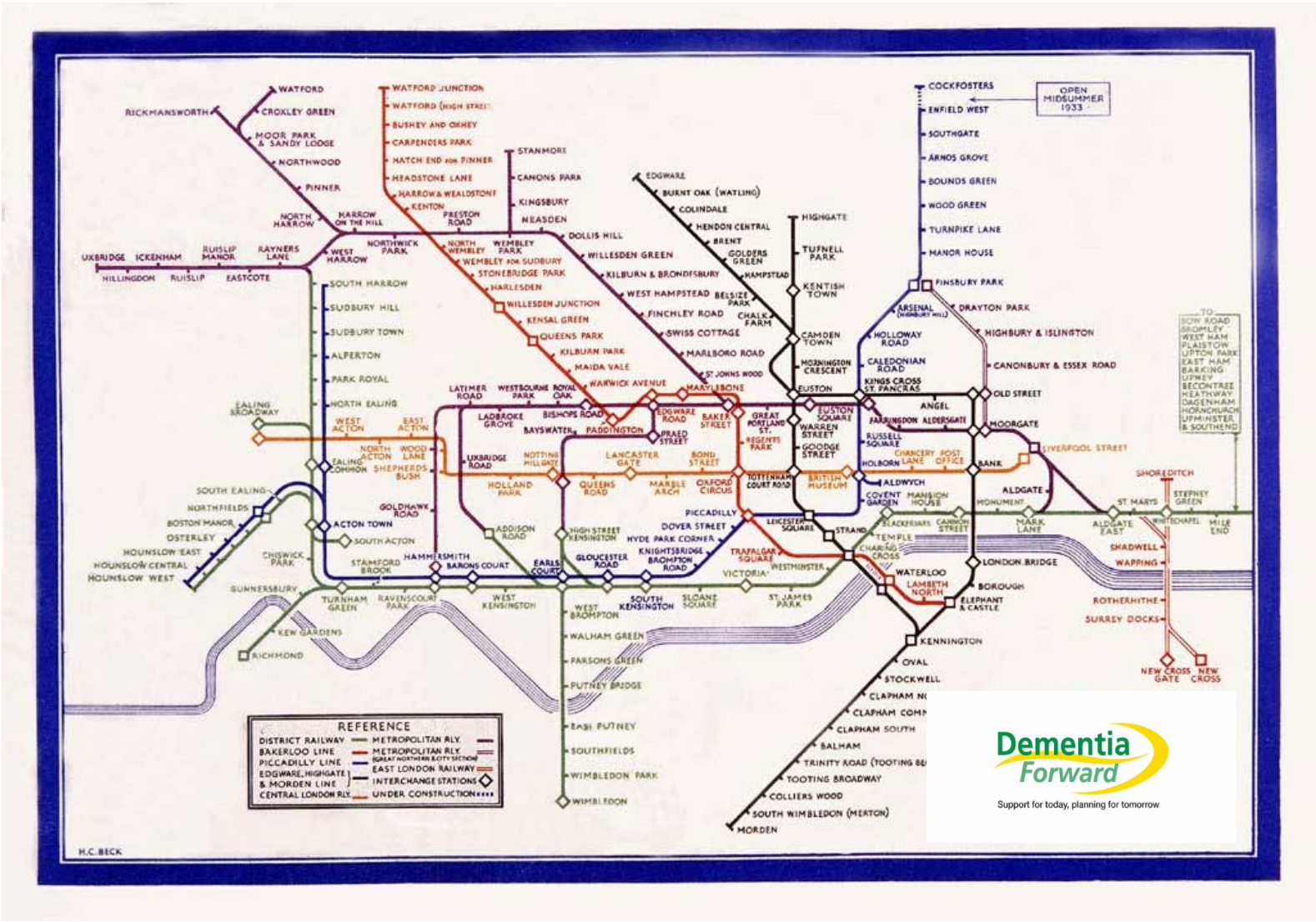
Recommendation	Made to:
Consider ways of measuring and monitoring the health impacts of cost of living rises across the York population, for example monitoring over time the levels of people admitted to hospital who are malnourished	York Population Health Hub
Consider ways of making sure everyone has access to advice and information, not just those living in known areas of deprivation in the city. This must include access for those in the outer villages and those experiencing digital exclusion	City of York Council, Advice York
Consider the findings from the pilot of heating help for those with long term health conditions in Gloucester, and whether opportunity exists locally to support those most at risk through winter pressures funding	York Health and Care Partnership
Continue to make strong representations to challenge the perceptions of York as an affluent city and speak out for our residents who are currently struggling. This must include making sure colleagues across the wider Integrated Care System are fully sighted on the particular issues York residents are experiencing	York Health and Care Partnership
Collectively recommit to the council motion to recognise socio economic status	City of York Council, York Health and Wellbeing Board, York Health and Care Partnership

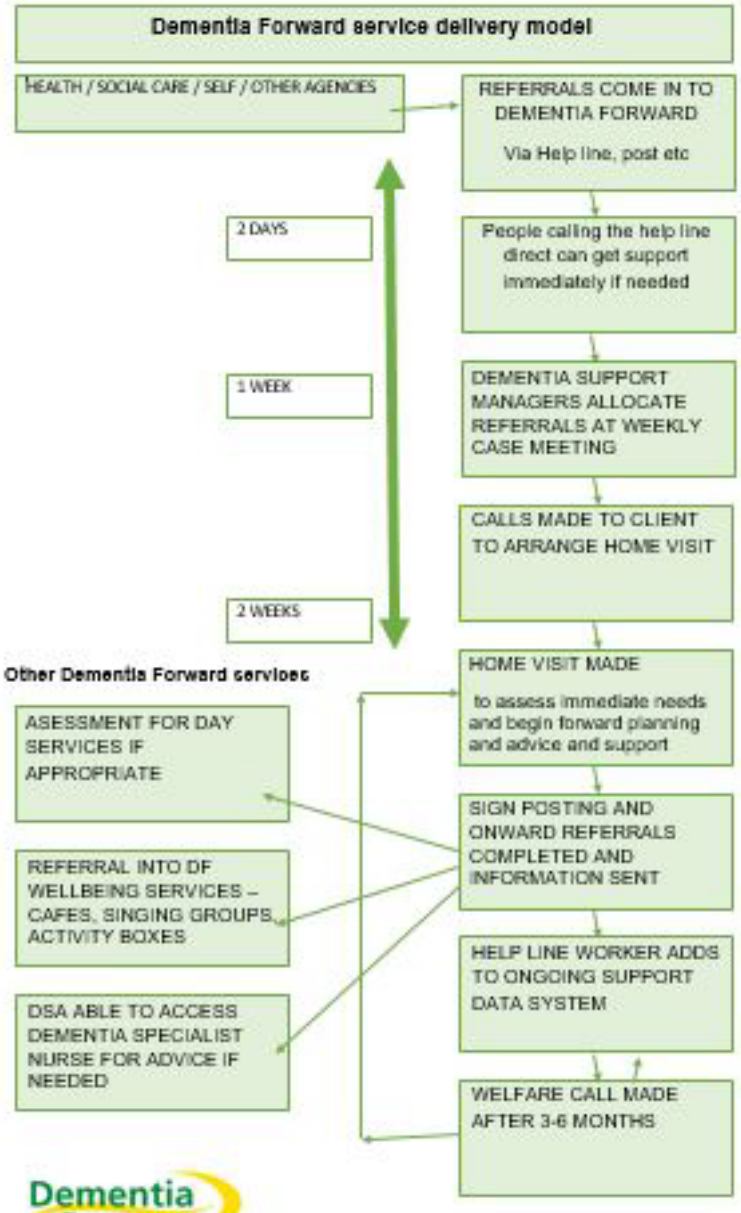
Annexe A

Recommendations from Healthwatch York report: Breaking Point, A Recent History of Mental Health Crisis Care in York

Recommendation	Made to:
Reinstate and strengthen the Mental Health Crisis Care Concordat to clarify care pathways, provide clear minimum performance standards for all those working in services, and make sure members of the public can access the right help and support at the right time delivered by appropriately trained professionals.	NYP, TEWV, CYC, Y&SHNHSFT, Voluntary sector partners, YAS
Review existing resources, support services and gaps in the pathway and identify the most effective ways to deliver support and fill gaps, including those best provided by the VCSE sector.	YHC, TEWV, CYC
Restructure approaches to coproduction to make sure everyone's views and experiences are heard and influence service design and delivery. This must include working with external partners to facilitate involvement for those who cannot engage directly. Consideration must be made of the resource implications for VCSE organisations to make this possible	TEWV
Learn from schemes improving people's experiences of crisis response / changing the system to identify ways to invest in and maintain those that work (for example, the positive feedback about police street support)	YHCPEC / MHCC
Make sure workforce plans reflect the specific challenges for attracting health and care staff to York (including lack of affordable housing, transport). Work together locally to learn from historical examples such as the Rowntree Housing model and how this fits with Local Plans.	HNY ICB
Embed a compassionate culture towards all people experiencing mental ill health.	YHCPEC / YHWB

Mind the gap!


OPEN MIDSUMMER 1933
REFERENCE
DISTRICT RAILWAY
BAKERLOO LINE
PICCADILLY LINE
EDGWARE, HIGHGATE & MORDEN LINE
CENTRAL LONDON RLY
METROPOLITAN RLY
METROPOLITAN RLY (GREAT NORTHERN & CITY SECTION)
EAST LONDON RAILWAY
INTERCHANGE STATIONS
UNDER CONSTRUCTION
H.C. BECK
Dementia Forward
Support for today, planning for tomorrow


Dementia Forward service delivery model
HEALTH / SOCIAL CARE / SELF / OTHER AGENCIES
REFERRALS COME IN TO DEMENTIA FORWARD
Via Help line, post etc
2 DAYS
People calling the help line direct can get support immediately if needed
1 WEEK
DEMENTIA SUPPORT MANAGERS ALLOCATE REFERRALS AT WEEKLY CASE MEETING
CALLS MADE TO CLIENT TO ARRANGE HOME VISIT
2 WEEKS
HOME VISIT MADE
to assess immediate needs and begin forward planning and advice and support
Other Dementia Forward services
ASESSMENT FOR DAY SERVICES IF APPROPRIATE
SIGN POSTING AND ONWARD REFERRALS COMPLETED AND INFORMATION SENT
REFERRAL INTO DF WELLBEING SERVICES – CAFES, SINGING GROUPS, ACTIVITY BOXES
HELP LINE WORKER ADDS TO ONGOING SUPPORT DATA SYSTEM
DSA ABLE TO ACCESS DEMENTIA SPECIALIST NURSE FOR ADVICE IF NEEDED
WELFARE CALL MADE AFTER 3-6 MONTHS
Dementia Forward
Care and Support for Life

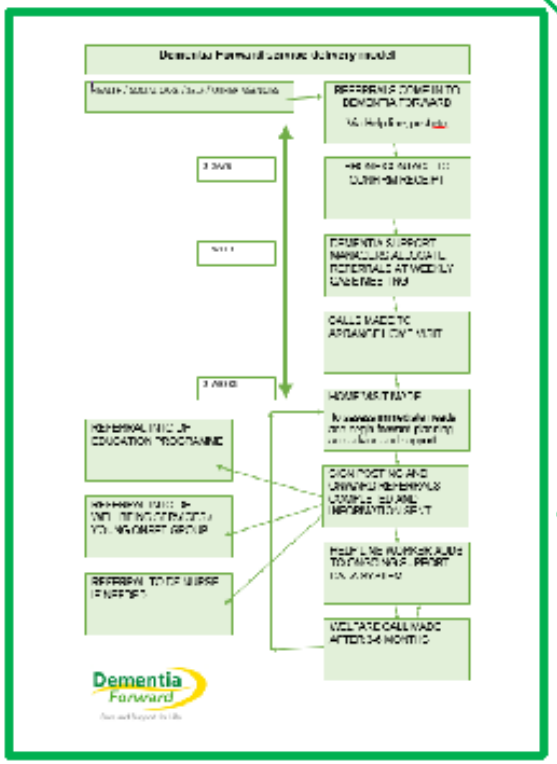
Dementia Stronger Care Pathway

How potential patients are found

System searches (see notes)

Revealed at routine GP or Nurse appointment

Alert from Social Prescribers or Frailty Coordinators



Options

If immediate support is needed refer to Dementia Care Coordinator (DCC) / Dementia Forward for ongoing support, in addition to proceeding with diagnosis

Use Diadem tool to diagnose

Who?

GP

HCA

Dementia Specialist Nurse (DSN)

Refer to Memory Clinic

During wait for appointment Dementia Forward can support

Where complexities mean there will be a delay in diagnosing refer to DCC and / or DSN

Diagnosis confirmed

DCC contacts patient for care planning and signposting, ACP, referral to DF

CODING

Not a dementia diagnosis – refer or signpost if needed

(Dementia Forward do support people with MCI)

What we do

A Local Help line

Answered by trained staff Mon - Fri

Advice and Information

Delivered by Dementia Support Advisors, supported by our Specialist Dementia Nurse. Through home visits, Education sessions, and a variety of services

Support throughout the journey

Support to people with concerns, through a diagnosis and ongoing including support to those in residential care and beyond

Emphasis on well being

Specialist Young Onset service

Weekly Wellbeing cafes

Hub Clubs (AKA Day services!)

Education and training

Social activities and outings

The numbers!

Area in North Yorkshire	Number of active cases held by Dementia Forward	Number of people with young onset dementia held	Young Onset as a % of caseload		Date young onset service started
Craven	257	15	5.84		Coming soon!
Richmond and Hambleton	812	40	4.93		Coming soon!
Harrogate District	991	72	7.27		1st service - 2013
Scarborough	518	32	6.18		4th service - 2020
Vale of York	513	47	9.16		2nd service - 2019
City of York	921	68	7.38		3rd service - 2020
TOTAL	**4233**	**274**	**6.47**		

Hub Clubs

Hub Clubs are the Dementia Forward way of delivering day services. They are centered around the person diagnosed with meaningful, tailored activity but also give the family carer a full day of respite.

We run them in 8 locations across North Yorkshire and York.
The ones accessible to York are Poppleton, Acomb and Barmby Moor near Pocklington.

Wellbeing cafes also run in 14 locations every week and the ones accessible to York are in Clements Hall York, Acomb and Barmby Moor near Pocklington.

Young Onset dementia services

Young Onset Specialist service

We run a dedicated Support and advice service.

We also run outward bound day services every week.

We are trialling place based day services for people who are a higher risk or more impaired.

24 October every year is **Y**oung **O**nset **D**ementia **A**wareness day

Please put it in your diaries and use it to spread the word

We do a awareness raising sessions and education programmes every week, delivering to care homes, general public, sports and leisure facilities, businesses, transport etc!

We have over 250 trained volunteers who support all of our work including adding 1:1 support into our hub clubs and cafes

We support the strategic work of our partners in health and social care and we are able to bring the voice of the people we support and to highlight where there are patterns of un-met need.

To sum up – our service is from pre diagnosis to end of life and if anything is about dementia we are interested!

Help line number 03300 578 592
info@dementiaforward.org.uk
www.dementiaforward.org.uk

Dementia Together

Steering Group Meeting 20 February 2023

Positive Progress Updates

- DDR 55.6% September 2022
- Average 85 referrals per month – far exceeding pre-pandemic levels
- The ICB has secured funding for 1 ANP to undertake additional training in Dementia Diagnosis in 22/23 to help increase capacity and reduce waiting times for assessment.
- ICB developing dementia dashboard
- Proposed CT scan waiting list initiative
- Successful bid to ICS for Brain Health Café - this will include targeted support for people awaiting memory assessment
- Acomb Garth Dementia Hub – an integrated health and social care offer at the new community care centre

Positive Progress Updates

- New dementia club at The Gateway Centre, York
- Young onset dementia hub club in York
- Dedicated space for information and advice about Dementia on Live Well York
- York Learning activities
- £5k winter pressures funding to DF to support people with dementia who live alone. Welfare calls and visits from 17/12 for 12 weeks
- DiaDEM pilot at Jorvik Gillygate practice and The Chocolate Works Care Village

Issues and blockages

- New referrals to the memory service are exceeding pre-pandemic levels but with no corresponding increases in DDR
- Resource capacity is a key issue
- Barriers relate to recruitment, access to CT scans and being unable to clear the current backlog of patients waiting for assessment
- Reduction in register sizes due to deaths or people moving out of area is impacting on recovery rates
- Stigma – people declining automatic opt-in to pre-diagnostic support

KPIs

Preventing Well

The risk of people developing dementia is minimised

- **Outcomes**
- People over 40 years of age lead a healthier lifestyle.

Indicators

- Percentage of adults that smoke
- Physical activity in adults
- Rate of alcohol related admissions to hospital
- Excess weight in adults
- Prevalence of depression

- Increase in number of people accessing NHS Health Checks and behaviour change interventions and programmes
- Greater awareness among both the public and practitioners that the risk of developing some types of dementia can be reduced, or the onset or progression delayed, through lifestyle changes.
- People feel confident to seek help early, know where to go for help People know to approach their GP if they have concerns about their cognitive health

Diagnosing Well:

Timely, accurate diagnosis, care plan and review within the first year

Outcomes

- Sustained achievement of the dementia diagnosis rate of 67% of estimated prevalence
- There is good quality support and information available to people from the pre diagnosis stage and throughout the diagnosis journey and people know where to access this

Indicators

- New dementia diagnosis recorded on to Primary Care registers including development of annual care plan
- People newly diagnosed with dementia and their carers receive written and verbal information about their condition, treatment, research opportunities and the support options in their local area including referral to Dementia Forward

- A redesigned dementia assessment pathway providing support to plan, live with and manage the condition with effective end of life care pathways
- Diagnosis is timely and accurate and people can access support and treatment sooner so they and their family and carers know what to expect so that they can consider future mental capacity and make plans early
- Memory assessment services, and primary and community/ social care systems to work in partnership to enhance working practices to support recovery of the dementia diagnosis rate and access to pre and post-diagnostic support.

Supporting Well:

Safe high-quality health & social care for people with dementia and carers

Outcomes

- Those living with and affected by dementia are able to lead fulfilling lives and live independently for longer
- People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing
- People with dementia receive care from staff appropriately trained in dementia care
- People with dementia and their carers get the correct assessments and entitlements

Indicators

- Evidence of local arrangements to ensure services are tailored to an individual's needs
- Proportion of people with dementia whose individual needs are assessed and whose care plan states how these will be addressed
- Proportion of carers who are satisfied with the services they and the person they care for have received from Adult Social Care in the last 12 months

Living Well: I can live normally in a safe and accepting community with post diagnostic support available when I need it

Outcomes

- York is a dementia- friendly and inclusive city

Indicators

- People with dementia are enabled, with the involvement of their carers, to take part in activities based on individual interest and choice
- Proportion of adult carers who have as much social contact as they would like
- Carer- reported quality of life score
- Number of community activities for people with dementia
- Number of services for people with dementia
- Providers of activities and services that are available for people with dementia commit to reviewing their information every 6 months
- 100% of activities and services for people with dementia have been reviewed at least within 12 months
- Uptake of activities/courses offered in the community
- Referrals to community providers and SPLWs

Dying Well: To die with dignity in the place of your choosing

Outcomes

- People with dementia supported to live and die well in the place of their choosing
- People with dementia are supported to put legal, financial and end-of-life plans in place

Indicators

- Evidence of local protocols on the discussion of advance decision- making
- Proportion of people with dementia, while they have capacity, and their carer/s, who are given the opportunity to discuss with health and social care professionals about the use of ‘Advance Statements’

Performance framework for the strategy

Dashboard/data

Key statistical data monitored regularly

Exception reporting

- Escalated to the Steering Group if requiring review or action
- Updates to the Ageing Well Partnership

- Themed monthly meetings of the Dementia Together Delivery Group focusing key issues of the Dementia Well Pathway - generates challenge and actions – for example the hospital pathway
- **Peer review:** We seek to enhance the performance of the strategy and share learning – 4 planned events throughout the year
- Ensure that the voices of people with dementia, their families and carers are heard through the development of a network

Dementia Together

Steering Group Meeting

Monday 22 May 2023

MS Teams

Dementia Action Week 15 – 19 May

Nationally

- Improving Access to Timely Diagnosis - latest report from The Alzheimer's Society published

Barriers include

- A lack of multi-disciplinary and innovative approaches to dementia diagnosis
- Workforce capacity, training and development
- Report recommends a multi-disciplinary approach to diagnosis along with innovative ways of working to ease workforce pressure, including remote appointments and upskilling staff
- It recognises the advent of new, disease-modifying treatments as a driver for immediate system change to increase diagnosis rates
- Asks for guidance on MCI so that people living with dementia are diagnosed at the earliest opportunity and can take advantage of revolutionary new treatments as soon as they are available

The People's Postcode Lottery has awarded £5 million to Alzheimer's Society and Alzheimer's Research UK for a project that aims to revolutionise early dementia diagnosis in the UK

Locally

- We've been promoting our strategy in and around York!

Where?

✓ Acomb Explore

✓ York Explore

✓ York Hospital

✓ Wheldrake Shared Lives

Successful bid to National lottery and £8k awarded to deliver a small cognitive rehabilitation pilot in York – approx. 18 CR interventions

- CR improves functional ability and enables people to develop coping strategies that will help with everyday life - self-management of physical and mental health and wellbeing
- Referrals will come from the Memory Service and Dementia Forward
- A diagnosis of dementia with a mild to moderate cognitive impairment
- People must have 'engaged' and supportive family member/s who can ensure practice between sessions.

Updates

- The dementia diagnosis rate for York is 55.3%
- There are an estimated 2,874 people over 65 living with dementia in York
- Of those 2,874, only 1,588 people have received a diagnosis
- It is estimated that 2/3 of people with dementia in York are living in the community, whilst 1/3 are living in care

- 80 referrals per month to memory service (April)
- No Dementia Coordinator roles in York since early April
- Funding risk to DC role – exploring options to fund and recruit within PCNs
- DiADEM pilot
- Jorvik Gillygate/Chocolate Works

Issues and blockages

- New referrals to the memory service are exceeding pre-pandemic levels but with no corresponding increases in diagnosis rates
- Resource capacity is a key issue
- Barriers related to recruitment
- Reduction in register sizes due to deaths or people moving out of area is impacting on recovery rates
- Stigma – people declining automatic opt-in to pre-diagnostic support

- Public awareness and understanding of dementia and when/how to seek help
- Difficulties in navigating/accessing primary care; Accessibility of GP practices and availability of appointments
- Physical investigations/routine screening not being action or undertaken correctly resulting in referral back to the GP from memory service
- Limited/delayed access to CT scanning and reporting – some improvement in April/May

Positive Progress Updates

- 921 active cases held by Dementia Forward and receiving DSW support
- 68 people with Young Onset Dementia
- Hospital pathway workshop 15 June
- Dementia module being developed on Live Well York website to provide information, advice and resources across dementia pathway
- Brain Health Café – average attendance 12 people - includes targeted support for people awaiting memory assessment
- Acomb Garth Dementia Hub – an integrated health and social care offer at the new community care centre – Talking Point staff attending weekly
- Dedicated space for information and advice about Dementia on Live Well York

BHC ACTIVITIES

May/June 2023

- Memory Service
- CYC Intensive support and Be Independent
- Falls and frailty Team
- Conversation on Mindfulness
- Fun social session
- CYC Older person housing specialist
- Occupational therapist
- CYC Local Area Co-ordinator
- Advice on cold calling and scams
- Keep Moving! inclusive fun dance and exercise class
- Primary Care in-reach – speak to a GP/health professional

Hub Clubs

Hub Clubs are the Dementia Forward way of delivering day services. They are centered around the person diagnosed with meaningful, tailored activity but also give the family carer a full day of respite.

We run them in 8 locations across North Yorkshire and York.
The ones accessible to York are Poppleton, Acomb and Barmby Moor near Pocklington.

Wellbeing cafes also run in 14 locations every week and the ones accessible to York are in Clements Hall York, Acomb and Barmby Moor near Pocklington.

Preventing Well

- **Keep moving** - seated dance and stretch class run in conjunction with our city collaborative and York Learning, Marjorie Waite Court.
- Wide range of older people attend – dementia, Parkinson's, frail
- The fitness instructor is supported to run the class by a volunteer so that we can ensure that all participants are supported to engage as much as possible.
- The group is gaining popularity, up to 15 people at any one time
- The majority of group participants are residents who live in the independent living with extra care centre
- Raising awareness in the community through the Local Area Co-ordinator and social prescriber, and more local people are joining

Many of the group, report practicing some on the exercises after the class so they are building on the strength and stamina movements they engage with each week

Here's what they told us:

"I'm definitely learning how to move my body better and it keeps your brain active. Otherwise we'd just sit at home not doing anything"

"This is keeping me mobile! If I didn't come here I would just sit in a chair & wither away. It keeps me busy and fit…It keeps me moving, this makes me come out"

"This brings people together socialising"

Funding needed to pay for venue hire next term

Health and Wellbeing Board **20 September 2023**

Report of the York Health and Care Partnership

Summary

1. This report provides an update to the Health and Wellbeing Board (HWB) regarding the work of the York Health and Care Partnership (YHCP), progress to date, and next steps.

Background

2. Partners across York Place continue to work closely together to commission and deliver integrated services for our population. The YHCP shares the vision of the York Health and Wellbeing Strategy that in 2032, York will be healthier, and that health will be fairer.

The YHCP has an Executive Committee (shadow) which is the forum through which senior partnership leaders collaborate to oversee the delivery of the partnership priorities. The Executive Committee meets monthly, and minutes from meetings held in 2023 are available in Annex A.

This report provides an update to the York Health and Wellbeing Board on the YHCP's progress since the last report provided in July 2023.

Recommendations

3. The Board are asked to note the report of the YHCP.

Reason: To ensure the Board is up to date with the work of the YHCP, their progress to date, and next steps.

Update on the work of the YHCP.

4. In the August YHCP Executive Committee meeting the focus was on our Integrated Community Offer priority, with a discussion centred around Dementia care. This priority focusses on greater access to personalised support and integrated care outside of hospital, with tailored support that helps people live well and independently at home for longer. Dementia Forward provided an update on their delivery model and how this provides personalised care, supporting people in their communities and reducing pressure on other services.

The YHCP also heard an update on the York Dementia Strategy, covering:

- Dementia Diagnosis rates.
- Proposals to renew the offer of a dementia coordinator service located in Primary Care.
- Proposals for an integrated community-based offer of dementia care and support that shifts the focus of delivery to early help and prevention, with personalised care at the center of the approach and which also builds on the existing work of the York Integrated Care and Frailty Team.

The YHCP agreed to collectively think about sustainable, recurrent funding options and resources for Dementia Care.

Winter planning

5. In July 2023 NHS England outlined their expectations[1] for ICBs to deliver operational resilience across the NHS this winter, setting out four areas of focus for systems to help prepare for winter:

I. Continue to deliver on the UEC Recovery Plan by ensuring high-impact interventions are in place.
II. Completing operational and surge planning to prepare for different winter scenarios.
III. ICBs should ensure effective system working across all parts of the system, including acute trusts and community care, elective care, children and young people, mental health,

[1] NHS England » Winter Plan – 2023/24

primary, community, intermediate and social care and the VCSE sector.

IV. Supporting our workforce to deliver over winter.

The Department of Health and Social Care has also set out[2] the key steps needed so that adult social care systems are resilient and able to provide people and their carers with the support they need this winter.

Work is underway across the whole York system to prepare for winter, and the YHCP Executive Committee will receive the whole system winter plan at the September meeting. Recognising that resilience plans are often focussed on health and care services, in May 2023 the YHCP agreed to produce a whole system resilience plan summarising the prevention work underway across the partnership to keep people well and supported throughout the year.

The purpose of the whole system plan is to:

- Ensure the partnership is sighted on each organisation's plans from prevention services to hospital admission and discharge, to ensure that opportunities for integration are utilised.
- Understand if there are gaps in service provision.
- Learn from what worked last year and build on system resilience as we move through winter and beyond.
- Provide opportunity for our system teams to be sighted on the plan by disseminating through the partnership.
- Ensure our plans are in line with our values 'We are in it together' and 'We will connect clinicians and professionals'.

Health Inequalities Projects

6. As outlined in the July 2023 HWB report the YHCP Executive Committee has agreed a series of Health Inequalities projects following a process to identify schemes that reduce unwarranted variation in access to care, quality of care, or health outcomes, and that focus on York's Core20PLUS5 populations. These schemes are funded by the ICB's health inequalities Programme. The schemes are in the initiation stage and an update will be provided to the HWB on progress in Q4 2023/24.

[2] Adult social care winter letter 2023 to 2024 - GOV.UK (www.gov.uk)

Joint Workforce Recruitment Event

7. As part of the YHCP's 'Drive Social and Economic Development' priority a joint workforce event is being held between Health and Social Care services in York. The event will be held on 4th November at West Offices. The event will bring partners across York Health and Care Partnership to seek to recruit to existing job opportunities, engage with people who are interested in careers in health and care whether that is through college or university programmes, apprenticeships, paid employment or, through volunteering opportunities.

IERUK (Inclusion, Equality, and Race Equality UK) Anti-Racist city

8. At the August YHCP Executive Committee meeting the Partnership also heard from CYC colleagues about the Anti-Racism and Inclusion Strategy. Partners were encouraged to offer pledges of support to the strategy and to support the city-wide summit that is being planned.

Work of the York Population Health Hub

9. As a key enabler of the YHCP, the York Population Health Hub continues to bring together partners to enable, analyse and undertake population health management approaches to provide a clearer picture of the health of the population and the inequalities people face across York place.

Cost of Living data pack

As part of work to understand our population and inform service delivery the Hub is updating the Cost of Living data pack produced in 2022 (Cost-of-Living Crisis in York: Understanding and Reducing the Health Impacts data pack). This update aims to demonstrate the impact of the Cost-of-Living crisis on York's communities during 2023. We will provide an update on the pack at the November HWB meeting.

Population projections to inform CYC's Local Development Plan

Informed by discussions at the Executive Committee around the New Local Plan, the York Population Health Hub has undertaken

analysis on population projections to understand the impact of population growth on the utilisation of health and care services. This work is being used to support estates conversations between the Local Authority, health and care services and the New Local Plan developers to ensure that future developments include plans around increasing health and care infrastructure to support population increases. A working group has been set up with system partners to progress this work.

Contact Details

Author:
Anna Basilico,
Head of Population Health and Partnerships, Humber, and North Yorkshire ICB (York Place)

Chief Officer Responsible for the report:
Sarah Coltman-Lovell,
NHS Place Director (York),
Humber and North Yorkshire ICB

Ian Floyd,
Chief Operating Officer CYC and York Place Lead

Report Approved ✔ **Date** 1/9/23

Wards Affected: List wards affected or tick box to indicate all [most reports presented to the Health and Wellbeing Board will affect all wards in the city – however there may be times that only a specific area is affected, and this should be made clear] **All** ✔

For further information please contact the author of the report

Background Papers:

NHS England Winter Plan
NHS England » Winter Plan – 2023/24

Adult Social Care Winter Letter 2023 to 2024

Adult social care winter letter 2023 to 2024 - GOV.UK (www.gov.uk)

Annexes

Annexe A - YHCP minutes, August 2023

Annexe A

York Health and Care Partnership

Monday 21st August 2023, 12:30 - 15:00
Severus Meeting Room; First Floor, West Offices
Chair: Ian Floyd

Present		
Ian Floyd (Chair)	Chief Operating Officer	City of York Council (CYC)
Sarah Coltman- Lovell	York Place Director	York Place, H&NY ICB
Rebecca Field	Joint Chair of York Health and Care Collaborative	York Medical Group
Emma Johnson	Chief Executive	St. Leonards Hospice
Zoe Campbell	Managing Director, NYY&S	TEWV
Prof Mike Holmes	Chair	Nimbuscare
Alison Semmence	Chief Executive	York Centre for Voluntary Services (CVS)
Simon Morritt	Chief Executive	YSTHFT
Professor Karen Bryan	Vice Chancellor	York St John University (representing higher education)
Martin Kelly	Corporate Director of Children and Education	CYC
Jamaila Hussain	Corporate Director of Adult Service and Integration	CYC
Debbie Mitchell	Chief Finance Officer	CYC
Cllr Claire Douglas (on behalf of Cllr Coles)	Leader of Labour Group	CYC
In Attendance		
Anna Basilico	Head of Population Health	York Place, H&NY ICB
Hannah Taylor	Team Administrator	York Place, H&NY ICB
Kerry Carroll	Deputy Director of Strategic Development	North Lincolnshire and Goole Hospital
Lynette Smith	Deputy Managing Director, Humber and North Yorkshire Collaboration of Acute Providers	H&NY ICB
Joy Dodson	Governance	H&NY ICB
Andy Growns	Governance	H&NYICB
Sheila Fletcher	Commissioning Manager; Mental Health and Vulnerable Adults	York Place, H&NY ICB
Jill Quinn	CEO	Dementia Forward
Pauline Stuchfield	Director, Customer, and Communities	CYC
Laura Williams	Assistant Director, Customer, and Communities and Inclusion	CYC
Anita Dobson (on behalf of Peter Roderick)	Consultant in Public Health	CYC

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Dan Moynihan	Contract Commercial Senior Lawyer	CYC
Shaun Macey	AD Primary Care Transformation and Pathways	York Place, H&NY ICB
Apologies		
Helena Ebbs	Director Clinical & Professional Services	York Place, H&NY ICB
Cllr Jo Coles	Executive Member for Health, Wellbeing and Adult Social Care	CYC
Peter Roderick	Acting Director of Public Health/ Deputy Director of Population Health	CYC/York Place, H&NY ICB
Gail Brown	CEO	York Schools & Academies Board
Sian Balsom	Manager	York Healthwatch
Brian Cranna	Care Group Director of Operations & Transformation, North Yorkshire, York and Selby Care Group	TEWV

Minutes – draft

Item	Title	Led by
1	**Welcome and apologies for absence** The Chair welcomed everyone to the meeting. The minutes of the meeting held on 17.07.2023 were approved. There were no declarations of interest in the business of the meeting. Alison Semmence highlighted the roll out of the York Ending Stigma Suicide Prevention film is starting in the autumn. The YHCP is asked to support roll out of the film through showings in each organisation. 9th September, Alison would send out in an email following the meeting.	Chair
Extra Item	**Integrated Care Offer (Intermediate Care)** Sharing Slides Jamaila gave an update on the integrated care offer sharing the highlights from the task and finish groups that had been set up in the 3 programme areas. Jamaila shared information on the Frailty Hub plans, future model and the timelines, Single point of Access plans, outcomes and vision and Specification development, timeline and the next steps updating the board will continue to get highlights and when the 3 phases will be implemented.	Jamaila Hussain
2	**Citizen Story** Jill shared a story of an individual with Young Onset Dementia who has received ongoing support from Dementia Forward. Jill outlined how the Dementia Forward helpline supported the individual and their family throughout receiving the diagnosis and shared how Dementia Forward offered wrap around support to the individual	Jill Quinn

Annexe A

	when they were unable to engage with the service. Dementia Forward have also offered support and education to the individual, people around them and places they frequently visit to support the individual to live a well and fulfilled life. Jill ended with some positive feedback they had received from the individual and family members around how Dementia Forward have continuously helped the individual to maintain routines and stay well in their community.	
3	**Update on the Dementia Strategy** Jill informed the Committee about Dementia Forward and their purpose, outlining how their delivery model helps to divert people from calling GP's and Social Workers, the aspirations for the future model and the numbers of people they offer support to within the York area. Sheila highlighted some areas from the circulated paper including: • A funding gap which resulted in the loss of Dementia Co-Ordinators within Primary Care • Non recurrent funding for the Brain Health Café, Dementia Wellbeing Café, and the Dementia Nurse via Dementia forward • Estimated 53% growth in Dementia by 2030 with a timely diagnosis crucial for the new medication that is being rolled out. • 28.5 week to get a diagnosis • Data on the amount of people who are waiting a diagnosis and how much the cost of Dementia will be by 2030 • Patient Story of a Lady who attends the Brain Health Café. Discussion from the Committee took place on: • Number of Young Onset Dementia being unique in York and queries as to why this may be. • Collectively thinking about Dementia and sustainable, recurrent funding options. • Number of people who get a diagnosis after support from Dementia Forward pre-diagnosis. • Reablement. • Improvement of coding health records with pre-dementia diagnosis and the possibility of using the 'working diagnosis' code prior to confirmed diagnosis. **Action** Sarah Coltman-Lovell will have a conversation with Nigel Wells and Helena Ebbs about improving the use of the 'working diagnosis' code. Further Paper to come to the Committee to look at resource and innovated funding – Sheila Fletcher.	Jill Quinn Sheila Fletcher
4	**Conflicts of Interest** Andy shared a presentation informing the board of how the ICB manage Declarations of interest, purpose of the Conflict of Interest Policy, where to find the ICB Declaration of Interest register and the roles/responsibilities/duties.	Andy Growns Dan Moynihan Joy Dodson

Annexe A

	Joy added that it is best people declare an interest if they are unsure and it is important to declare so that decisions are made right. Dan updated on how the council manage declarations of Interest. **Action** Hannah Taylor to compile and circulate a Declaration of Interest Register	
5	**Collaborative of Acute Providers development of the H&NY Planned Care Strategy/Framework** Lynette and Kerry updated on the planned care strategy approach sharing the collaborative of acute providers is reflected in the NHS Long Term Plan. Sharing the next steps and collate outputs from the 4 trusts within the ICB data driven from the 4 trusts on where they are in elective care, engagement, and continuation. Discussion ensued on: • Future items on how the collaboratives fit into Place would be helpful for the Committee • Where providers come together, what place is doing to support • Primary/Secondary Care Interface group which has recently met. **Action** Simon Morritt to bring an item to a future meeting on what CAP do, what they are trying to achieve both ICB and Nationally, what they focus on and the Future. Anna to explore performance reporting at ICB level linked to our place priorities and bring back recommendations to this meeting.	Lynette Smith Kerry Carroll
6	**IERUK Anti-Racist city** Pauline started by giving some background, adding that the intention for the circulated supporting document is to promote equality and diversity. Pauline informed that City of York Council approved and funded the work but even with York being a City of Sanctuary there is still a way to go to tackle casual racism in York, the next step is for a paper to go back to the Council CMT in November with a detailed action plan for the Council and they have been asked to make a pledge against racism which has now been signed by the Leader of the Council, Cllr Douglas. Pauline asked how do partners wish to contribute and would they support a city-wide summit. Topics covered in discussions were • The pledge link is on the council website • Where the document has been circulated • Some information not accurate in the paper reported by TEWV • Discrimination from patients to Medical Staff • Partners to contact Pauline with names of People for the Summit **Action** Board to receive further updates from Pauline Stuchfield/Laura Williams All partners to contact Pauline Stuchfield with names of people for the Summit.	Pauline Stuchfield Laura Williams

Annexe A

	AOB Sarah informed that she would be emailing partners following the meeting about the NHS Winter Plan and the focus of the September Board meeting be on Winter Planning with a strong element in the NHS and Local Authority Plan to consider and submit. Sarah informed the Committee of a Health and Care Recruitment, Careers and Volunteering Event that is taking place at West Offices on the 4th November and encouraged partners to sign up for a stall. **Action** Sarah Coltman-Lovell to email the YHCP members with information about winter planning in preparation.	Chair

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Health and Wellbeing Board **20 September 2023**

Report of the Acting Director of Public Health

Goal #1 in the York Health and Wellbeing Strategy 2022-2032: 'Reduce the gap in healthy life expectancy between the richest and poorest communities in York'.

Summary

1. Over the next ten years, the York Health and Wellbeing Strategy sets out our ambition to reduce the gap in healthy life expectancy between the richest and poorest communities in our city.

2. The Strategy made clear that this was an 'overarching goal', one that can't be approached through single actions but will instead be the result of a whole-system shift to greater health equity and to a health-generating city.

3. This paper is intended to present to the Board the current data on inequalities in life expectancy and healthy life expectancy in York, and thus to set out the scale of the challenge, with some guidance on where and how the inequalities arise and 'where to look' for solutions, in order to guide discussion.

Recommendations

4. The Board are asked to:

   - Note and comment on the current data on inequalities in life expectancy and healthy life expectancy in York.

   - Discuss where and how the inequalities arise, and 'where to look' for solutions.

     Reason: So that the Board is aware of the current data on inequalities in life expectancy and healthy life expectancy in York.

What is Life Expectancy and Healthy Life Expectancy?

5. The life expectancy of any given area is:

   ‘The average number of years a person would expect to live based on contemporary mortality rates, if he or she experienced the age specific mortality rates for that area and time period throughout his or her life’ (Office for Health Improvement and Disparities; OHID, 2023).

6. Life expectancy can be measured at birth, and at age 65. The first measurement will reflect the impact of infant mortality on life expectancy, to a higher degree than the second. Both will reflect the determinants of health across the life course.

7. The healthy life expectancy of any given area is:

   ‘A measure of the average number of years a person would expect to live in good health based on contemporary mortality rates and prevalence of self-reported good health.’ (OHID, 2023)

8. This essentially means that healthy life expectancy (HLE) is a composite measure, combining a local area’s life expectancy (LE) with the proportion of people reporting ‘good’ or ‘very good health’ from the Annual Population Survey (Office for National Statistics; ONS).

Measuring and understanding the gap

9. Whilst the definitions of LE and HLE are clear, measuring the gap in these statistics (i.e., the inequalities) between local areas is more complex. This may explain why there are sometimes several ‘versions of the truth’ for York’s health inequality gaps.

10. Firstly, because of the sample size of the Annual Population Survey, data on HLE is actually not available for small areas, such as council wards. The only comparisons which can be made are between York and another local authority (or with regional/national data).

11. Secondly, LE data is available at a small area level (down to areas with populations of a few thousand people). This presents another challenge: whether to highlight the LE difference between one council ward and another council ward, or between the most deprived small areas in a local authority (which could be located across a number of different council wards) and the least deprived.

12. Thirdly, sometimes data on inequalities in HLE / LE is presented as the difference between the lowest and highest areas, but also sometimes as the gradient of the line between them.

13. Locally, we have decided that as part of the Health and Wellbeing Strategy Population Health Monitor which will come regularly to the board, we will take this last approach and measure the Slope index of inequality in life expectancy at birth (3-year average). The Slope Index is:

'A measure of the social gradient in life expectancy, i.e., how much life expectancy varies with deprivation. It takes account of health inequalities across the whole range of deprivation within each area and summarises this in a single number' (OHID, 2023).

Trends in York's Life Expectancy and Healthy Life Expectancy

14. The table below presents the current LE and HLE data for York, comparing it with national / regional data and breaking down LE into ward and deprivation decile:

HEALTHY LIFE EXPECTANCY			
	Male Healthy Life Expectancy at birth (years)	**Female Healthy Life Expectancy at birth (years)**	**Time period**
York	65.3	64.6	2018-20
Y+H	61.1	62.1	2018-20
England	63.1	63.9	2018-20

LIFE EXPECTANCY			
	Male Life Expectancy at birth (years)	**Female Life Expectancy at birth (years)**	**Time period**
York	79.9	83.6	2018-20
Y+H	78.4	82.2	2018-20
England	79.4	83.1	2018-20

GAP IN LIFE EXPECTANCY			
	Male Life Expectancy at birth (years)	**Female Life Expectancy at birth (years)**	**Time period**
Lowest Ward in York (Westfield)	76.1	80.6	2016-20
Highest Ward in York (Copmanthorpe)	87.1	91.8	2016-20
Gap between wards	11.0	11.2	2016-20

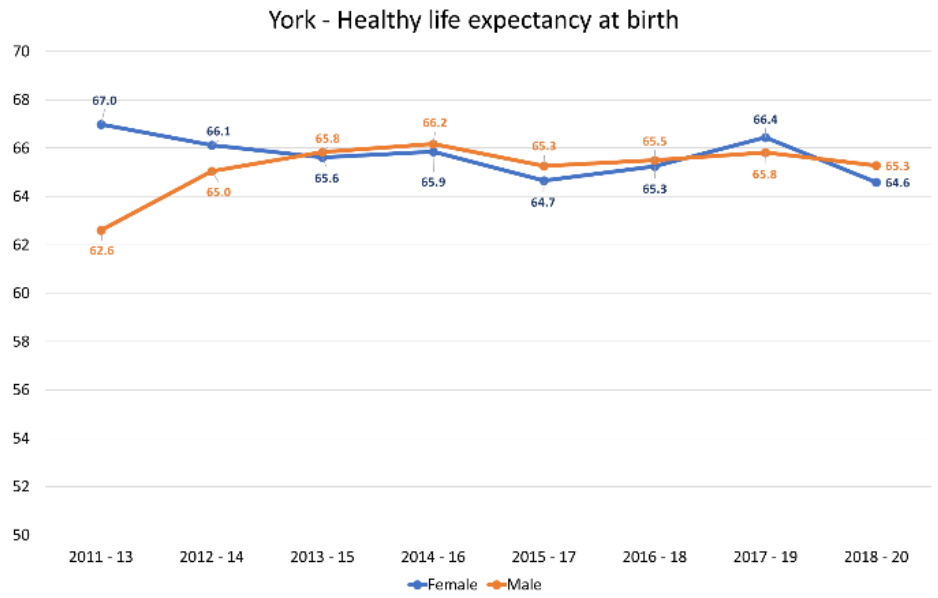
SLOPE INDEX OF INEQUALITY IN LIFE EXPECTANCY			
	Slope index of inequality in Male LE at birth (years)	**Slope index of inequality in Female LE at birth (years)**	**Time period**
York	8.4	5.7	2018-20
Y+H	10.7	8.8	2018-20
England	9.7	7.9	2018-20

Source: OHID fingertips tool

15. This table also illustrates that men can expect to live on average 14.6 years and women 19 years in 'bad or very bad' health.

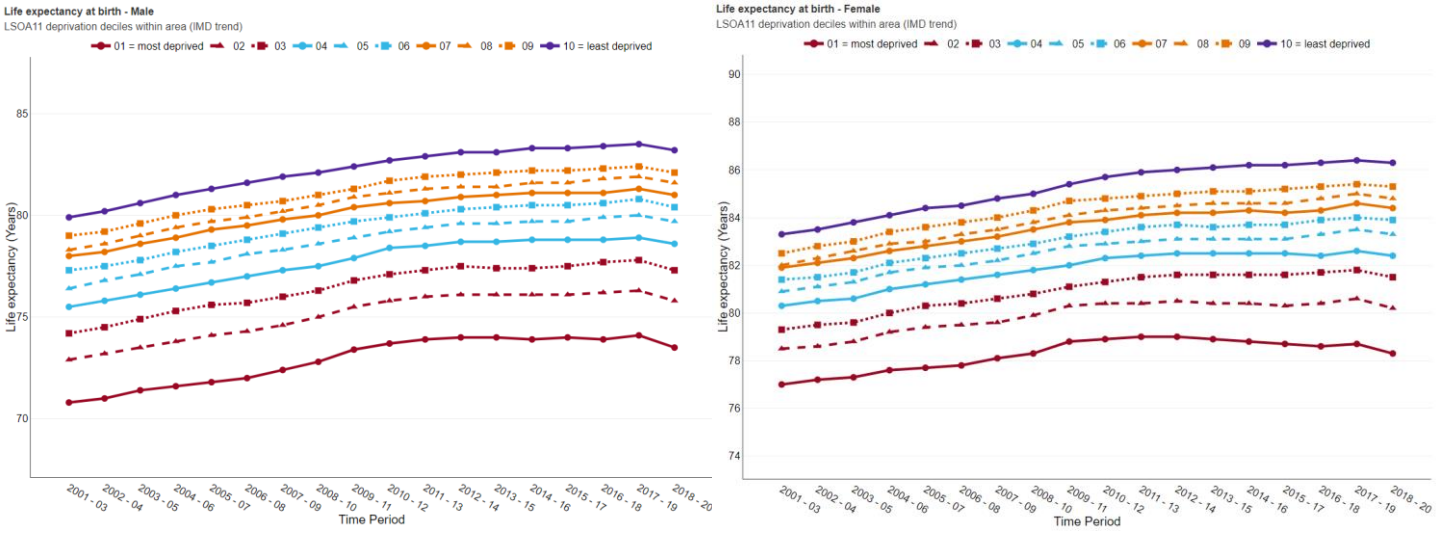
16. It should be noted that the most recent data ends in 2020 and is therefore slightly out of date and will not reflect the impact of the COVID-19 pandemic to its fullest extent.

17. York's trends in HLE over the last decade are shown in the graph below. Fluctuations between years are to be expected, and the general trend over time should be where attention is focussed. HLE in females started the decade higher than males, but had declined to be lower by 2018-20, whilst male HLE improved at the start of the decade but remained broadly static since 2013-15.



Source: OHID Health Inequalities tool

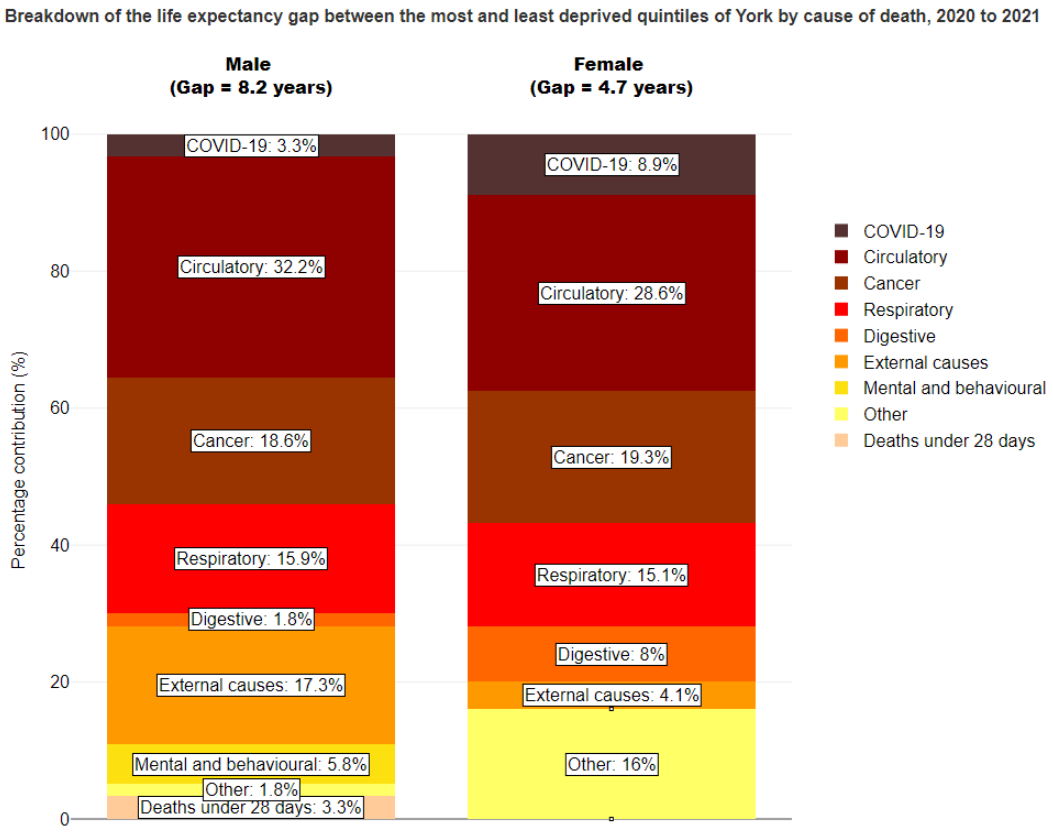
18. Trends in LE over two decades in our city are shown below, with each line of the graph representing 10% of York's population according to deprivation levels. Three long-term shifts can be seen: first the gap in LE has grown between the most and least deprived deciles, from 9.1 to 9.7 years in males, and from 6.3 to 8 years in females. Secondly, improvements in LE were made in the first decade of the century and stalled in the second. Thirdly, the gap between the most deprived decile and second most deprived decile is large that all other decile gaps (the 'cliff edge' effect).



Source: OHID Health Inequalities tool

Explaining the gap

19. It is important to understand the drivers of these gaps so that action can be targeted to tackle them. One way of doing so is by breaking down the clinical reasons for the LE gap between richest and poorest areas:



Source: OHID Segment tool

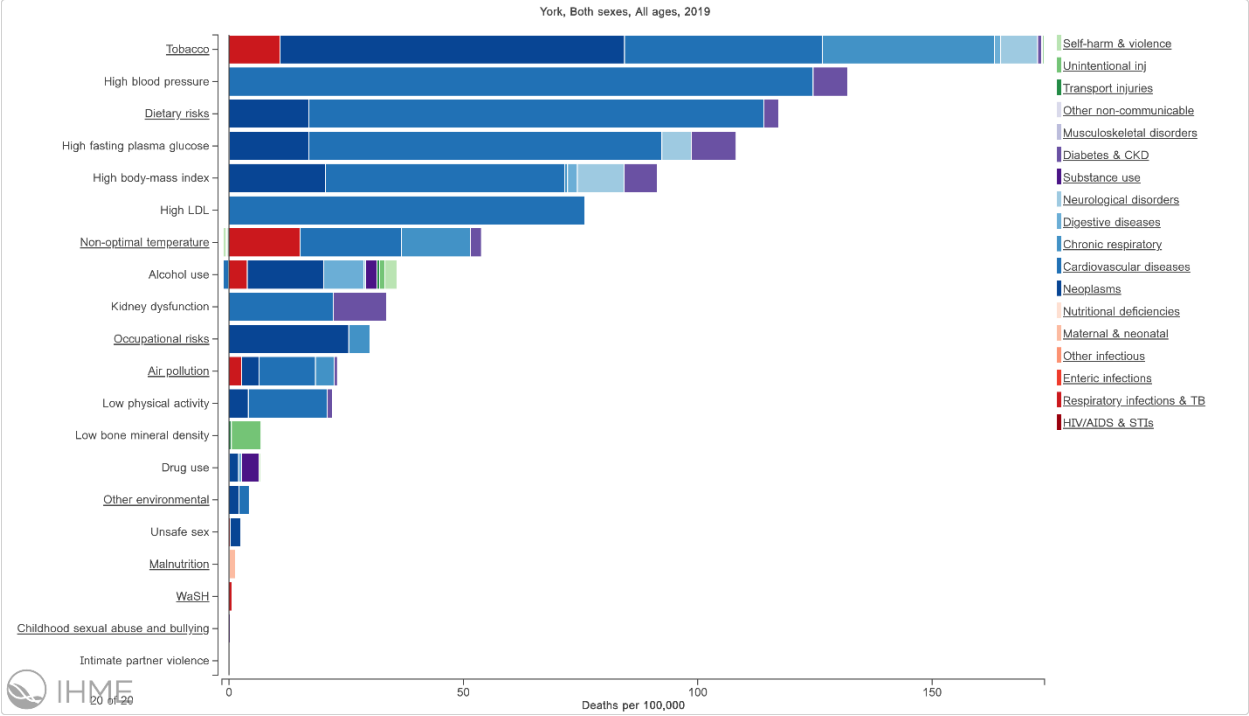
20. As the chart shows COVID-19 contributed within this year, following a pattern seen in other areas where higher death rates were seen in poorer communities from the virus. But in keeping with other years

where COVID was not a factor, around two thirds of the LE gap in both females and males comes from three areas: cardiovascular diseases (CVDs), cancer, and respiratory diseases.

21. An estimated 80% of CVDs are considered preventable (World Health Federation; WHF), 30% of cancers are considered preventable (World Health Organization; WHO) and around 60% of respiratory diseases are considered preventable (ONS).

22. Preventing these three diseases is, therefore, highly achievable, and likely to be the highest impact thing we can do to reduce health inequalities.

23. Lying behind these diseases areas there is a set of ‘risk factors’, as the following chart from the Global Burden of Disease study shows:



24. Unsurprisingly, the trio of tobacco use (20%), high blood pressure (15%) and poor diet (14%) are responsible for a large proportion of the diseases noted above which contribute the most to the LE gap.

25. In addition, 23.9% of York residents in the most deprived quintile live with more than one health condition, versus 21.3% living in the least deprived. The small area of York with the highest proportion of primary care patients in York with more than one long term condition happens to be the most deprived small area of York (York 018B, within the Westfield ward) (source: RAIDR). Living with multiple conditions makes its far more likely someone will report their health as ‘bad or fairly bad’ in the APS survey, the source of HLE data.

26. Underlying the clinical areas and their risk factors are, of course, the wider determinants of health, and again significant variation is seen in these:

	Variation between wards in York	
Households in fuel poverty	16.9% (Westfield)	8.1% (Copmanthorpe)
Child Poverty (IDAC)	19.8% (Hull Road)	2.2% (Bishopthorpe)
Older people in poverty (IDAOP)	16.6% (Clifton)	4.0% (Heworth)
Unemployment	5% (Westfield)	1.3% (Wheldrake)
Overcrowded housing	21.3% (Guildhall)	0.9% (Copmanthorpe)
Prevalence of overweight and obesity in Reception	28.6% (Heworth)	14.7% (Rural West York)

Source: Local Health (OHID)

Key conclusions to inform work on tackling the gap.

27. This data leads us to conclude that:

- Trends in our key Health and Wellbeing Strategy indicator are hearing in the wrong direction, and the direction of travel will need to be reversed first before a reduction in the inequalities gap is seen.
- Female HLE is worsening in York, and females are living longer in poorer health. Male LE, both for the city as a whole and in terms of an inequality gap, is worse in absolute terms.
- The number of people living with multiple long terms conditions is a large driver in the downward trend in HLE in York.
- There is variation across the city in the distribution of the physiological factors which lead to early disease and death, for instance high blood pressure, which could be tackled fairly swiftly (within a 3–5-year window)
- There is variation across in the distribution of the risk factors which lead to early disease and death, for instance poor diet, which could be tackled within a reasonable time frame (within a 5–10-year window)
- Ward based outcomes in LE largely follow the pattern of the wider determinants of health in each ward. These will take longer to shift (within a 10–15-year window)

- Amongst the many wider determinants of health which need ‘levelling up’ in the city, Michael Marmot’s six priorities from his seminal report ‘Fairer Lives, Health Society’ (2010) are still the most evidence-based way to reduce health inequalities in the long term:

    - Good early child development.
    - Education and lifelong learning.
    - Employment and working conditions.
    - Having enough income to lead a healthy life.
    - Healthy and sustainable places to live and work.
    - Taking a social determinants approach to prevention.

- Given the challenge to public sector finances, universal approaches to the distribution of health, council and third sector support are unlikely to address the gaps highlighted in this paper and should be reinforced by targeting to those in greatest need. This will include area-based targeting, but also the increased use of personalised approaches given that at any geography, the average masks variation (for instance Heworth ward contains small areas which are the 12th least and the 108th most deprived out of York's 120 small areas).

- There are significant co-benefits in reducing health inequalities. There is evidence that for each of eleven different health and social problems (physical health, mental health, drug abuse, education, imprisonment, obesity, social mobility, trust and community life, violence, teenage pregnancies, and child well-being) outcomes are significantly worse in more unequal rich countries (Wilkinson and Pickett 2007). The 10-year Health and Wellbeing, Climate Change and Economic Strategies for our city all emphasise how these issues inter-relate.

Consultation

28. This is a discussion document and thus the HWB are being consulted on a variety of issues related to the Board's work.

Council Plan and other strategic plans

29. This paper reinforces some of the key aspirations of the Council Plan 2023-27 and the

Implications

30. The HWB has no decision-making responsibilities for service provision or finance. There are no known implications in this report in relation to the following:

    - Financial
    - Human Resources (HR)
    - Equalities
    - Crime and Disorder
    - Property
    - Other
    - Legal Implications

Recommendations

31. The Board are asked to:

- Note and comment on the current data on inequalities in life expectancy and healthy life expectancy in York.
- Discuss where and how the inequalities arise, and 'where to look' for solutions.

Author:	**Chief Officer Responsible for the report:**
Peter Roderick Acting Director of Public Health	Peter Roderick Acting Director of Public Health

Report Approved ✔ **Date** 20.09.2023

Specialist Implications Officers
Not applicable

Wards Affected: **All** ✔

For further information please contact the author of the report

Background Papers

Joint Local Health and Wellbeing Strategy
https://democracy.york.gov.uk/documents/s163774/Annex%20Di%20Health%20and%20Wellbeing%20Strategy%202022-32.pdf

Health and Wellbeing Board 20 September 2023
Report of the Manager, Healthwatch York

Healthwatch York Report: "I want to know, I want a diagnosis, I want help" - Pilot Pathway for Autism and ADHD: Independent evaluation August 2023

Summary

1. This report is for the attention and action of Board members, sharing a report from Healthwatch York which shares local experiences of adults seeking an Autism and / or ADHD diagnosis in adulthood during the piloting of a new pathway.

Background

2. Healthwatch York provides information and advice about health and care services, signposts people to support, and listens to their experiences when accessing health and care services. Through Connecting our City, we have been involved with work to explore support available to those with a diagnosis of ADHD and Autism. As part of this, we heard about the plans for piloting a new pathway for diagnosis. We agreed, in response to public concern, to complete an independent review of the pilot.

3. We also worked with partner organisation York Disability Rights Forum and encouraged those working in health and care to share their view.

Consultation

4. In producing this report, we shared a survey for people who were going through the pilot pathway, we co-hosted two drop-in focus groups with York Disability Rights Forum, one online and one in person, and we recorded the experiences and concerns of those who contacted our information and advice service.

Options

5. There are two sets of recommendations within this report set out on pages 10.

Implications

6. There are no specialist implications from this report.

- **Financial**

  There are no financial implications in this report.

- **Human Resources (HR)**

  There are no HR implications in this report.

- **Equalities**

  There are no equalities implications in this report.

- **Legal**

  There are no legal implications in this report.

- **Crime and Disorder**

  There are no crime and disorder implications in this report.

- **Information Technology (IT)**

  There are no IT implications in this report.

- **Property**

  There are no property implications in this report.

- **Other**

  There are no other implications in this report.

Risk Management

7. There are no risks associated with this report.

Recommendations

8. The Health and Wellbeing Board are asked to:

   i. Receive Healthwatch York's report, "I want to know, I want a diagnosis, I want help" - Pilot Pathway for Autism and ADHD: Independent evaluation August 2023.

   ii. Confirm the best avenue for further consideration of this matter.

Reason: To keep up to date with the work of Healthwatch York and be aware of what members of the public are telling us.

Contact Details

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Chief Officer Responsible for the report:
N/A

Report Approved ☐ **Date**

Wards Affected: All **All** ☑

For further information please contact the author of the report

Annexes:

Annexe A – "I want to know, I want a diagnosis, I want to help", Pilot Pathway for Autism and ADHD; Independent evaluation August 2023.

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ANNEXE A

“I want to know, I want a diagnosis, I want help”

Pilot pathway for Autism and ADHD:
Independent evaluation August 2023

healthwatch York

Contents

Content warning: contains reference to suicide and suicidal ideation, self-harm, sex work, distress, anxiety, struggles with daily living, family breakdown

Acknowledgements: Cover photo by Andrew Neel (@andrewtneel) on unsplash (woman seated woman at a desk, using a laptop with connected phone, in front of an open window, handbag and empty cups also in shot)

Introduction

From 27 March 2023 to 27 June 2023 a pilot for a new ADHD and autism assessment pathway for adults was trialled. This trial was implemented by Humber and North Yorkshire Health and Care Partnership (HNYHCP) and took place in York and North Yorkshire.

In response to public concern, Healthwatch York undertook an independent review of this pilot. Via a HWY survey, GP survey and conversations with York residents and health professionals, we have gathered the views of those who have completed the profiler, and those involved in supporting people through the pathway.

We also hosted two drop-in focus groups with York Disability Rights Forum (YDRF), one online and one in person.

Fifteen primary care workers, including GPs, shared their views.

YDRF also conducted a survey and HNYHCP has provided us with some of the anonymous data collected via its own survey of user experience. All of which has been included here as part of our assessment.

We also heard from an additional 41 people who shared their experiences via other means including social media and community-led focus groups. These quotes are included towards the end of this report.

In total we heard from 1144 people; 936 via HNYHCP, 30 via our HWY survey, 16 via our information and signposting service, 147 via our work with YDRF, 12 via a GP survey and 3 healthcare professionals.

Thank you to the neurodiverse community for supporting us with our understanding and definitions of autism and ADHD.
Thank you to everyone who took the time to share their personal experiences with us – your voices count.

Summary of Key Findings

From everything we heard, this is what people told us:

- The pathway did not meet their hoped outcomes.
- The DHT (Do-It Profiler) was inaccessible for some.
- Output from the DHT was informative and useful, but it told people what they already knew. Some found it condescending.
- Many are reluctant to apply or share the output from the DHT as they don't feel it would be of benefit.
- The pathway lacked clarity for both patients and professionals.
- Professionals welcomed an efficient and direct pathway to diagnosis and support for neurodivergent individuals.
- People have concerns around whether equality legislation was followed.

There is concern regarding:

- What engagement took place prior to the pilot being implemented.
- The narrow referral criteria which only consider elements of mental health crisis.
- Whether HNYHCP considered the patient's right to choose.
- Whether the DHT used within the pathway meets the scientific rigour required for its use within a diagnostic pathway.
- Whether the DHT used within the pathway meets the requirements for clinical risk management.
- Consideration for wider NICE guidelines for the use of DHT to assist and inform patients.
- Consideration of NICE guidelines on the use of DHT to direct treatment and collect data to make service delivery decisions.
- Consideration made to the Public Sector Equality Duty.
- Consideration of data protection principles and legislation.
- Consideration made to legal requirements of the 2016 Accessible Information Standard.

The pilot pathway

The pilot introduced the following criteria for referral for assessment:

1. Immediate self-harm or harm to others. A mental health assessment must have been undertaken and a crisis management plan put in place.
2. Risk of being unable to have planned life-saving hospital treatment, operations, or care placement.
3. Imminent risk of family court decisions determined on diagnosis e.g. family breakdown, custody hearing.

Only those who met one or more criteria would receive an assessment.

The pilot also introduced a web-based system as entry to the pathway. HNYHCP states: "Patients seeking an assessment can be given access to the Do-it Profiler from their GP via a code and URL address. The Do-it Profiler does not provide a diagnosis, but it will identify characteristics and provide a unique profile describing strengths, challenges, and the skills to develop at home, socially and in the workplace. The profile will also identify where reasonable adjustments should be made which should start as a basis for discussion with occupational health, employers, and educational environments.

"The profiler will determine whether the patient meets one or more of the criteria as listed above. It will then refer these patients on to The Retreat for assessment. Those who are not deemed eligible based on the above criteria, will not be referred for assessment.

"All patients who complete the profiler will receive immediate functional guidance and signposting to support networks. "

Background

What are autism and ADHD?

Neurodiversity is a term used to describe the fact that everyone's brain works differently. It is a biological fact that we are diverse in our minds. Autism and ADHD are both examples of neurodivergence. [1]

Autism is lifelong and shapes how people communicate and interact with the world. Autism is not a learning disability. Whilst autistic people share certain characteristics, they do not all present in the same way. Common ways of experiencing the world that many autistic people share include: enhanced sensory perception, a preference for honesty and clarity in communication, a preference for agency, predictability and control, self-expressive body language and a passionate enjoyment of interests and hobbies (Hartman et al, 2023). [2]

There are an estimated 700,000 autistic adults and children in the UK[3].

ADHD is a neurological condition that affects people's concentration, activity levels and impulses. The impact this has on people's lives is significant with symptoms varying for each individual. "Many patients and clinicians describe ADHD as an iceberg, where most symptoms lay hiding under the surface — out of sight but ever present."[4] The UK NICE guidelines[5] report the adult ADHD incidence rate as between 3% and 4%. In the UK, a research survey of 10,438 children between the ages of five and 15 years found 3.62% of boys and 0.85% of girls had ADHD[6]. ADHD is not a mental health condition although it often occurs alongside or is mistaken for other conditions.[7]

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[1] https://www.humber.nhs.uk/downloads/Adult%20Autism%20Services/Humber%20Autism%20Strategic%20Framework.pdf

[2] Hartman, D., O'Donnell-Killen, T., Doyle, J.K., Kavanagh, M., Day, A., Azevedo, J. (2023) *The Adult Autism Assessment Handbook: A Neurodiversity Affirmative Approach*, Jessica Kingsley Publishers
https://www.autism.org.uk/what-we-do/who-we-are/our-mission-vision-and-values

[3] https://www.autism.org.uk/what-we-do/who-we-are/our-mission-vision-and-values

[4] https://www.additudemag.com/what-is-adhd-symptoms-causes-treatments/

[5] https://cks.nice.org.uk/topics/attention-deficit-hyperactivity-disorder/background-information/prevalence/

[6] https://journals.sagepub.com/doi/abs/10.1177/1087054715613441

[7] https://www.additudemag.com/when-its-not-just-adhd/

There are significant barriers for women and girls to be identified and diagnosed.[8] There is an active discussion about whether female ADHD and female autism is under-diagnosed.[9]

What are the benefits of a diagnosis?

Getting a diagnosis of ADHD in adulthood is important because: "**many adults have lived with feelings of failure, anxiety, poor self-esteem, depression and other negative emotions for years, never understanding that there is a reason for the challenges they have faced.** For those adults who have always felt 'off' or like they just didn't fit in easily with others, discovering that they have ADHD can be life changing."[10]

Mortality rates

"Suicide rates are unacceptably high in autistic people and suicide prevention has to be the number one goal to reduce the worrying increased mortality in autistic people" Simon Baron–Cohen.[11]

Reporting on recent research, Cambridge University stated: "10% of those who died by suicide had evidence of elevated autistic traits, indicating likely undiagnosed autism. This was 11 times higher than the rate of autism in the UK." They also reported on previous research findings - 66% of autistic adults had thought about taking their own life, and 35% had attempted suicide. Despite only 1% of people in the UK diagnosed as autistic, up to 15% of people hospitalised after attempting suicide had a diagnosis of autism. In summary: "both diagnosed autistic people and those with elevated autistic traits are more vulnerable to mental health problems, suicidal thoughts and behaviours."

"Many adults in the UK find it very difficult to obtain an autism diagnosis and appropriate support post-diagnosis. Our study shows that undiagnosed autistic people could be at increased risk of dying by suicide." - Dr Sarah Cassidy

[8] Connolly, M. (2019) "ADHD in Girls: The Symptoms That Are Ignored in Females" https://www.additudemag.com/adhd-in-girls-women/.
[9] https://www.kaleidoscopesociety.com/adhd-in-women-101/
[10] https://www.adhdawarenessmonth.org/adhd-in-adulthood/
[11] https://cks.nice.org.uk/topics/attention-deficit-hyperactivity-disorder/background-information/prognosis/

The researchers concluded: "It is urgent that access to an autism diagnosis and appropriate support post diagnosis is improved. This is the top autism community priority for suicide prevention and needs to be addressed immediately by commissioners of services and policy makers."

The overall prognosis for those with ADHD depends on how severe their symptoms are and how well they can manage other co-morbidities associated with the condition. ADHD is associated with an increased risk of mental health issues including substance abuse and depression. Autism, dyslexia, dyscalculia, and dyspraxia are also common in those with ADHD. All of which can have a significant impact on an individual's quality of life, including their ability to remain in education, work and to form healthy relationships.[12]

In practice, it is only after a diagnosis of ADHD that a person will be offered options of medication and/or therapy.

Therapies have been shown to be useful in helping people manage their ADHD. This is most effective when combined with taking medication. Therapy is also effective in treating the additional mental health issues that often occur in those with ADHD. For an effective pathway of support to be implemented, it is important the individual and the practitioner can express and fully understand what challenges the individual is experiencing.[13]

NICE guidance[14] states that formal intervention and guidance should only come following a formal diagnosis.

"If you think you may be autistic, you might want to get a diagnosis. There are many online 'autism tests' available, but none of these can guarantee accuracy."[15]

[12] Attention-deficit hyperactivity disorder traits are a more important predictor of internalising problems than autistic traits | Scientific Reports (nature.com)

[13] https://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/treatment/#:~:text=If%20you%20were%20not%20diagnosed,may%20then%20be%20gradually%20increased.

[14] https://www.nice.org.uk/guidance/ng87/chapter/recommendations#diagnosis

[15] https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/pre-diagnosis/adults

People who have undiagnosed autism or ADHD can appear to manage well day-to-day and this can create barriers to identification and diagnosis. However, those who do not manage are often misdiagnosed with borderline personality disorder. Women and LGBTQ+ populations are especially at risk of this misdiagnosis.[16] If challenges are left unmanaged, there is an increasing risk of misdiagnosis within the mental health system. This can have devastating effects including medical trauma, inappropriate hospitalisations and medications, and further challenges with accessing mental health support in the community.[17]

Accessing financial support

According to the Office for National Statistics, 29.9% of people on the autism spectrum were in employment in 2021/22, compared to 54.3% of all disabled people and 81.1% of non-disabled people. The National Autistic Society states that 77% of unemployed autistic people want to work.

Depending on how an individual is shown to be impacted by their autism and/or ADHD, they may be entitled to benefits intended to help with the extra costs associated with being disabled.[18]

February 2023 statistics on success rates for Personal Independence Payment (PIP) show that success rates vary wildly between recognised conditions. With ADHD and 'Aspergers' falling below the average success rate, whilst autism falls above. The statistics don't show us whether these applicants had received a diagnosis.[19]

Challenges with getting a diagnosis

BBC Panorama: Private ADHD Clinics Exposed[20] explored concerns around the quality of ADHD diagnoses within the private sector, including assessments funded by the NHS. In response, the ADHD Foundation[21] raised concerns around the report's failure to:

[16] https://link.springer.com/article/10.1007/s00406-020-01189-w
[17] https://www.healthwatchyork.co.uk/wp-content/uploads/2023/06/Breaking-Point-Mental-Health-Crisis-Care-June-2023-updated.pdf
[18] https://commonslibrary.parliament.uk/research-briefings/cbp-7172/
[19] https://www.benefitsandwork.co.uk/personal-independence-payment-pip/success-rates

[20] https://www.bbc.co.uk/iplayer/episode/m001m0f9/panorama-private-adhd-clinics-exposed
[21] https://www.adhdfoundation.org.uk/2023/05/15/response-to-bbc-panorama-private-adhd-clinics-exposed/

- fully explore the context of why so many people cannot access NHS healthcare and feel compelled to explore private help
- fully examine the historic inequality of access to health services for people with ADHD and the lack of priority given to patients with ADHD
- explore the challenges patients experience in trying to access shared care arrangements following a private diagnosis

The programme fuelled national press interest in ADHD assessment waiting times[22]. Another story highlighted the number of people being denied assessments.[23] The coverage also brought attention to the lack of central data collection for ADHD referrals, making it harder to obtain a clear national picture of those coming forward for an ADHD assessment.

A debate in Parliament on February 6 2023[24] recommended: "the government should create an emergency fund to deal with the massive waiting lists for autism and ADHD assessments for children and adults. This would provide resources for local health services to deal with current waiting lists and new patients.

"The government should commission a review of how Attention Deficit and Hyperactivity Disorder (ADHD) assessments are managed by the NHS, including through Shared Care Agreements, and increase funding to reduce waiting times."

During Neurodiversity Month there was a public call to improve diagnosis of ADHD, Autism and dyslexia to prevent people 'falling through the gaps'.[25]

BBC news: Decision reversed to restrict autism assessments in Bristol[26]
On 28 April 2023, Bristol parents and carers publicly challenged changes made to autism assessments for children. They argued that by focusing only on the most severe cases, more children, whose needs could otherwise have

[22] https://inews.co.uk/news/adhd-diagnosis-patients-assessment-specialist-waiting-uk-data-2344513 16 May 2023
[23] https://inews.co.uk/news/adhd-diagnosis-patients-denied-nhs-assessment-gp-referral-2348580 18 May 2023
[24] https://hansard.parliament.uk/commons/2023-02-06/debates/183A24F1-C943-4D2E-8238-4B03AF11D715/AutismAndADHDAssessments
[25] https://inews.co.uk/news/politics/adhd-autism-dyslexia-slow-diagnosis-government-2207011?ico=in-line_link 14 March 2023
[26] Decision reversed to restrict autism assessments in Bristol - BBC News

been managed effectively, would reach crisis point. Following the initial steps of legal proceedings to try to overturn the decision, the changes to the pathway were reversed by the ICB.

Local picture

In 2017[27], Healthwatch York looked at the challenges experienced by people in York living with ADHD. The report highlighted concerns including:

- a lack of understanding of ADHD,
- the absence of support and services in the city,
- challenges with getting a diagnosis,
- the challenges of finding good information, advice and support at every stage of life.

The report made several recommendations to TEWV, Vale of York CCG, City of York Council, The Retreat, SOAAC (Solution Orientated Adult ADHD Carers' Group) and York Health and Wellbeing Board.

In 2022 Healthwatch York released a snapshot report on child and adolescent mental health services[28] which highlighted concerns regarding access to autism and ADHD diagnosis.

"A girl I referred in year 9 is now in year 11 and still hasn't had a full assessment, only the initial one. I am concerned she will age out of the system before we can get her a diagnosis."

Local statistics

There are an estimated 6,000 autistic people living in North Yorkshire[29].

From a Freedom of Information (FOI) request dated March 2022, Leeds and York NHS Partnership Trust reported that 67.8% of people who receive a full assessment for autism, go on to receive a diagnosis[30]. Although this neighbouring trust no

[27] https://democracy.york.gov.uk/documents/s113238/Annex%20B%20-%20Support%20for%20Adults%20with%20ADHD.pdf

[28] https://www.healthwatchyork.co.uk/wp-content/uploads/2022/11/Nov-22-Childrens-mental-health-a-snapshot-report-FINAL-2.pdf

[29] https://www.humber.nhs.uk/downloads/Adult%20Autism%20Services/Humber%20Autism%20Strategic%20Framework.pdf

[30] https://www.whatdotheyknow.com/request/autism_asssessments?unfold=1#incoming-1993543

longer provides services in York. The Retreat has provided the service since 2015 and at time of publication the rate remains high at 67.7%.

Another FOI response showed the increase in people waiting for an assessment. From 1 April 2019 – 1 March 2022, the number of people with suspected autism, who have been waiting for more than 13 weeks, increased from 85 to 225[31].

A recently published FOI request[32] presented to the ICB on 8 November 2022 included an account of local pressures. The information provided to the ICB included: ".....The Retreat is currently receiving an average of 180 referrals per month, with the biggest increase being in ADHD as opposed to autism. This means that as well as the cost impact for the assessments, there is a significant increase in the costs needed for the medication reviews for those individuals who receive a confirmed diagnosis.....

".....[The Retreat] update said that, based on the current number of referrals they have on the waiting list and waiting to be triaged, they will have already used 90% of the contracted value for five years and will need the remaining four and a half years of the contract to complete the activity including all of the associated medication reviews for those on the ADHD pathway.....

".....It is important to note that the diagnosis rate has remained consistent at around 85%, suggesting these are appropriate referrals.....

".....Prior to the end of the three-month trial period, a paper will be brought back to this meeting to update on the position and make further recommendations for a more sustainable long-term solution."

Health and care related guidance and legislation

NICE is there to provide public health and social care bodies with best practice guidance and necessary legislation to deliver the best care for people "fast whilst ensuring value for the taxpayer."[33]

[31] https://www.examinerlive.co.uk/news/local-news/people-yorkshire-waiting-longer-autism-24568234
[32] https://ydrf.org.uk/2023/06/24/the-sound-of-silence/
[33] https://www.nice.org.uk/about/what-we-do

NHS England leads the NHS in England. It supports the ICS "to improve health of the population, improve the quality of care, tackle inequalities and deliver care more efficiently." [34]

One of the five ICS principles is to: "Nurture a culture that systematically embraces shared learning, supporting clinical and care professional leaders to collaborate and innovate with a wide range of partners, including patients and local communities."

We have listed the relevant legislation and guidance associated with this pathway below in Appendix 1. These include (but are not exclusive): Equality Act 2010, 2016 Accessible Information Standard, Digital Health Technology Requirements, General Data Protection Regime, Health and Care Act 2022, Public involvement legal duties.

[34] https://www.gov.uk/government/organisations/nhs-england#:~:text=NHS%20England%20leads%20the%20National,and%20provide%20value%20for%20taxpayers.

Our Findings

To make sense of the qualitative data gathered within the HWY survey, we identified and analysed repeated patterns within the feedback. From this, we established the following themes:

Accessibility – equality and inclusion OR users' ability to use the tool independently.
Appropriateness – the suitability of the pathway for its intended purpose.
Effectiveness – the pathway meeting the intended outcomes for individuals on it OR for those implementing the pathway.
Clarity – public and professional confidence navigating the pilot pathway.
Risk management – associated potential risks of the pilot pathway.
Public trust – impact of the pilot pathway on public perception of health and care.
Patient Choice – the perceived and real impact of the pilot pathway on the patient's right to choose.

What people told us

Everyone's feedback has contributed to the findings of this report. Please take the time to read everybody's comments. To read our data in full, see Appendix 6.

Accessibility
More than a third of our respondents reported that the Do-It Profiler was either difficult or very difficult to complete.

"I struggled with many of the questions. I felt I needed help in understanding them, I didn't have anyone to help me."

"I have concentration and focus issues and I've been left with a ton of things to read through and 'work on'. If it was that easy, do you honestly think I would have put myself through the hell of contacting the doctors for help?!"

"Clunky system ..... I got very confused trying to use the system from my laptop after receiving the information by SMS on my phone. It's not made

clear that the link is one time use only, so you have to use it on the same device that you open it on."

"Struggled to understand some of it due to the way it was laid out."

"I hope this pilot scheme, that amounts to a denial of access to a proper assessment as was highlighted in the Autism Act 2008 for people like myself, can be overturned. It is damaging. I believe it to be discriminatory."

Appropriateness

The time it took for people to complete the profiler ranged between 10 minutes to several attempts over several days. For those who could specify, the average completion time was 1.34 hours.

"It was very upsetting, patronising and dehumanising. I'm not sure what I was supposed to get out of it. It just took my answers to the questions and replayed them back to me with all the nuance removed. It listed some of my difficulties as strengths because I answered that I 'can' do something. It is possible for me to be 'able' to do something, and also have debilitating and impacting anxiety and avoidance behaviours associated with it - but the report does not consider that at all. The resources provided were useless. The reason I came to the GP is because I need more help than tips like 'why not start a new hobby'. I need personalised support from a specialist. Incredibly, a lot of the suggestions in the resources are to 'talk to your GP' which is galling, since that's what I did."

"I can't imagine even sharing it with the mental health practitioner will be helpful because she doesn't have time to read it or help me through it, and she doesn't have the ability to refer me for an assessment or to specialist support. As I mentioned previously, my partner is aware I have been exploring the possibility of ADHD (his comments initially prompted me to look into it) but he has not yet read the report and I worry that he will soon lose patience with me. He is also not trained or equipped to support me on his own."

"It took many attempts over several days."

"I had to listen to music in order to be able to focus on the questions. Of which there were far too many. I didn't have anyone to help me fill out the form so I did the best I could. I know I messed up the workplace section because the questions were related to the last six to 12 months at work but I

am currently on family leave so I couldn't relate to the questions properly and started getting muddled."

Effectiveness

Only three out of 28 people told us that the profiler had either fully or partly given them what they needed.

Over half of respondents told us that the report from the Do-It Profiler was either not very useful or not useful at all.

"I want to know, I want a diagnosis, I want help."

".....the advice available wasn't helpful. Telling people with ADHD to 'be more organised'?!? Would you tell a person with no arm to try to grow an arm back to use?!?....."

"The report was very useful for identifying ADHD and dyspraxia as things I should definitely look into, as well as questions about dyslexia and dyscalculia. However, it did not tell me anything new in terms of coping mechanisms, strategies or techniques....."

"I know these things already, completely useless to me. I need a diagnosis."

"I do not feel comfortable sharing my report with people in my life because it is not a diagnosis and therefore unlikely to be taken seriously. I will share the main results (that the profiler found I have many ADHD traits) with the mental health practitioner on our allocated five-minute follow-up call in about a month's time. I would share the report with a GP if I could get access to an appointment with one..."

"It's not official - it doesn't count according to my employer."

"....my employer requires a diagnosis to make more than very, very basic adjustments."

Clarity

"Your profiler is not clear on whether you have been referred and I cannot get back into it although it clearly said I need support for ADHD and autism."

"..... it wasn't clear what was going to happen next etc."

"I'm looking for a pathway to diagnosis. It doesn't even tell me if there is a next step or if this is everything."

"I didn't get a single piece of feedback to say whether I was even being considered for a referral. Finished the profile and... nothing..."

"It was confusing what it was at first as it is poorly explained and I had asked for a referral for a diagnosis. Even now, when I try to get my report it occasionally tries to make me start from scratch. When in, though, it's good."

"I've been to the GP about it three times. After the first visit, I was given forms in my second visit, and another set to complete in my third. When I spoke to a mental health practitioner, I was then given the Do–It Profiler. I don't understand."

"My GP is unaware of how the profiler works and what the report looks like. She assumed I would qualify for an assessment, as she was unaware that the waiting list is closed to new patients. I have now been advised by the GP's receptionist that I need to find an organisation that will do an assessment through Right to Choose, and request my GP to refer me to them. I am struggling to find such an organisation, as the ones who've come back to me say they only offer private healthcare."

Risk Management

"... It has been a few weeks since I completed it, and my mental health has been awful since then. I've been struggling to sleep and to focus on my work. All because I feel that the hope I had from being put on the waiting list has been taken away from me, and I'm back to the beginning again."

"... I spent around four years building up the courage to contact my GP about an autism assessment. I have been struggling with mental health issues stepping from social anxiety, social isolation, and loneliness... Being put on the waiting list gave me hope that I would get help. ... I am sure you can understand how upsetting it was for the Do-It Profiler to coldly and impersonally remove me from the waiting list. I cried for around an hour after I went through the Do-It Profiler and was unable to focus on my work for the

rest of the day. I am now completely at a loss for what to do with my mental health as I'm back at square one."
"Being rejected from an assessment because I'm not currently a risk to myself... really, really made me want to be a risk to myself. It was rather triggering because I've previously had very volatile mental health (history of self-harm, suicide attempts, etc)."

"I feel worthless as a human being due to this denial of a pathway to assessment."

"The profiler could be a useful support tool either in conjunction with a professional assessment, diagnosis and treatment or as a screening tool that then leads to further assessment of identified condition(s), but it is not an appropriate or acceptable replacement. ... It is incredibly daunting to find out I am likely to have a condition that has caused me immense difficulty and distress throughout my life, and yet I have no viable or credible avenue open to me to access appropriate support to navigate this or access specialist treatment. I understand that those in urgent crisis need to be prioritised but I don't accept that the rest of us should be left by the wayside without access to explore a diagnosis and then specialist support or medication. This could lead to other mental health problems and people seeking help through dangerous means e.g. self medicating..."

Public Trust
"I don't know who to ask for help and I don't particularly feel I can trust my GP practice either after they referred me on to the Do-It Profiler without even telling me it was undergoing a pilot trial."

"I think the system that you're running is shocking and a complete disgrace. My partner has reached out for help and begged for some support to be turned away at the first hurdle. He is now feeling completely lost as to where to go ..."

"Please stop doing this stupid profiler. If you don't have enough staff to carry out the assessments you have on the waiting list already then clearly more money needs to be invested and more staff employed!"

Patient Choice

"...nothing available for adults in desperate need of a diagnosis, unless they can pay to go privately, which we can't afford."

York Disability Rights Forum (YDRF) Findings

Led by disabled people, YDRF works to promote equal access to human rights for all disabled people who live or work in York. YDRF invited the public to share their thoughts and/or experiences regarding the pilot change to the diagnostic pathway.

YDRF's survey findings include:

Accessibility
"Two words: **digital exclusion**..."

"I was sent the profiler. I can't do it. It is too long. Too hard. Don't understand how to do it. So now what? I asked for help filling it in and was told there isn't any... The profiler is too hard."

"How is it legal to remove rights to access to treatment for a known medical condition?"

Appropriateness
"Honestly, I cannot get my head around this. What does criteria two even mean? And surely it's better to get people access to support **before** they are about to lose their kids or kill themselves? Ok, yes there is some support out there without a diagnosis, but there isn't much, and without access to the ND (neurodiverse) community it is almost impossible to find."

"I don't think the decision makers appreciate just how vulnerable people are when they go to a GP to ask for an assessment. You basically have to go to another human being: "hi, I appear to be a failure as an adult and can't fit in anywhere, help?" and that is a really hard conversation to have, to then be told that you may be struggling but you're not struggling enough, or not struggling in the right way, to get an assessment is utterly invalidating."

“As an autistic adult working in autism research, and as someone who previously worked in autism/ADHD diagnosis, I am deeply concerned by the changes to the pathway for a number of reasons:

1) Access to diagnosis and self-understanding is extremely important. This can lead to workplace or educational adjustments, and if people are not formally diagnosed they will not be covered under the Mental Health Act, and workplaces will not have to provide support. This is also true for university level support and DSA (Disabled Students Allowance), which require a formal diagnosis.

2) I am aware that waiting lists are extremely long. However, for autistic people who struggle with uncertainty, being on a waiting list and knowing that an assessment will eventually happen is infinitely better than being told that referrals are not currently being accepted. I'm concerned that many people will become lost and will never seek diagnosis following this.

3) I am also concerned about the threshold for needing an assessment and how this will be assessed. It's a known fact that a high proportion of neurodivergent adults struggle with mental health difficulties and suicidal thoughts, largely internally. These will likely be exacerbated by the lack of access to referral. I am concerned that by the time these mental health concerns are recognised and taken seriously, it will be at an inpatient level, rather than a level at which referral for autism/ADHD assessment is most beneficial.

4) Many relationships are affected by neurodiversity and communication differences. Diagnosis can aid in understanding and communication. A lack of understanding and access to assessment and support may lead to family break-downs.
5) Adults with ADHD will presumably not be able to access medication without a formal diagnosis. This is a huge deprivation of a right to treatment. It may also lead to dangerous self-medication or risky behaviours.”

Effectiveness

“I wouldn't have gotten an assessment under these new criteria. I wasn't under mental health services, I wasn't seen as being in danger of harm, but I was.”

“I was so desperate to fit in and hated myself so much that I let myself be manipulated and used by multiple people. I was vulnerable, but not in any way that the NHS saw or noticed...”

“I am really worried about not only how this will affect individuals but also the impact this will have on GPs, mental health services, and the health service at large. Simply moving or stalling the problem isn't the answer.”

Clarity

“This has all been communicated terribly, neither my GP nor CPN seem to be able to tell me the process, neither seem to know what happens after I do the profiler. I'm getting conflicting information from everyone I speak to. Honestly this is stressing me out and pushing me towards crisis more than not knowing why I am this way ever did. If it wasn't for the fact that the (Community Mental Health Team) CMHT is insisting that I go through the process (they feel that I need an assessment before they can help me any further) I just wouldn't bother with all this.”

“...I live in York and have heard **nothing** about this. It's obviously not been communicated well. My son is on the waiting list for an ADHD assessment and I am autistic myself, we know many ND (neurodiverse) people and yet have heard nothing. ...I find the lack of transparency and communication very concerning.”

“Not only is this a ridiculous and harmful idea it is been communicated so badly...”

Risk Management

“So, if I want to get diagnosed with autism or ADHD (both of which I score highly for on self diagnosis tests) and I've been procrastinating on doing for years, the best option for me is to give up not self-harming?”

“My diagnosis literally saved my life. I didn't have a crisis plan, I was not under mental health services, but feeling like I was broken and like I was somehow a bad person because I couldn't do things and couldn't fit in - it was destroying me. I am certain that had I not been diagnosed I would no longer be here.”

“Because my autism wasn't known about, I suffered misdiagnosis after misdiagnosis, was put through unnecessary treatments, therapies, medications, and have medical related Post Traumatic Stress Disorder (PTSD). When we worked out that I was autistic, when I got diagnosed and got to speak to other autistic people, everything just clicked into place. I essentially lost six years of my life and have ongoing trauma symptoms from unnecessary, and incorrect, mental health treatment. I don't want others to go through the same.”

“I am three months free from self-harm, but now thinking I may need to start again in order to be taken seriously.”

Public Trust

“I am upset to know that my city sees people like me as essentially disposable, as collateral damage. I am very upset to think of people within my community being potentially harmed by this.”

“Well, this got snuck through didn't it? A message for the commissioning bodies - if you are going to do stuff like this at least tell people, all this secrecy and half-truths make you look suspicious.”
“I'm disgusted that this pilot has even been considered let alone implemented and it makes me ashamed of the NHS - something I never thought I'd say as I've always been so proud of our NHS.”

Patient Choice

“I can't believe what I'm hearing. Outrageous. The potential consequences of this are really scary. Waiting two years for assessment is bad enough, but this removes patient choice altogether.”

“I'll be honest, I do believe that the assessment process is outdated and has huge issues, same with the mental health service, it did need a total overhaul. However, just removing the assessment option from the majority of people is not the answer. The process is deeply flawed, but something is often better than nothing and people deserve to have a choice.”

“I can't afford to go private and there's no way my GP will be willing to refer me now. I asked them about right to choose but apparently even that is affected - something about funding? I really just don't know what to do, self-diagnosis isn't enough to get any help.”

YDRF statement

YDRF is speaking out against this plan of action which will deprive people of their access to assessment and diagnosis. We are very concerned that there has been no risk assessment, no engagement with the people who will be effected, and no consideration of the potential deadly impact of this decision. This decision appears to have been made purely for financial and systemic reasons, without due regard for patient wellbeing.

We also heard

Through our information and signposting service, we've received an additional 16 calls and emails regarding the pilot approach.

'ADHD campaigner asking for information around the new pilot to ADHD and autism diagnostic services. Concerned about the approach being taken in York and wanting to understand how they can help. '

'Husband approached GP for autism assessment. GP was unsure of the referral pathway. He was asked to complete a short paper questionnaire and the GP put a referral in to The Retreat stating that it was doubtful he'd be given an assessment. The individual wasn't informed of the new pathway or of any changes to the pathway.'

"I have been in tears for the last four hours. My GP sent me the link to the Do-It Profiler which I completed today which shows I have many traits of autism. However, I now understand that's it, I can't have a full assessment so can't get a diagnosis under your new system as you only select certain people for further assessment."

"I would be really interested how the criteria for further assessment is decided. I am 48 years old, have a child with autism, another on an ADHD assessment pathway and my traits are seriously impacting my life on a daily basis. I was quite prepared to go on a waiting list and expected it to be at least a two year wait (it took five years for my son to get his diagnosis), but to be told I can't even go on a waiting list is devastating and I feel a waste of resources (my GP has spent time sending me the link, I spent time completing it and I'm not on a waiting list so will no doubt have to go through all this again at some point to get onto a waiting list)."

"I'd like an explanation as to why this can't be pursued further. There is no other part of the NHS where you are not allowed to at least be put on a waiting list if you are displaying symptoms of a condition. I have worked for the last 30 years and contributed fully to tax and National Insurance so why am I being told I can't access the NHS for further investigation. I am prepared that I may have to wait a considerable amount of time and consent to you looking at my report."

'Telephone call about experience of seeking an autism assessment and being referred to the Do-It Profiler. Very unhappy about the outcome and lack of further assessment or support. Called GP a few weeks ago to request assessment, had been thinking about it a long time due to feedback from colleagues, and has received long term therapy for depression and anxiety. Waited a few weeks to be told they needed to use the Do-It Profiler, they found it very difficult because it was so long and so many questions, also found the questions tricky because they weren't always clear. Also, the explainer video at the beginning was 'weird', as there seemed to be some disconnect between the man speaking and the sound. They received a big list of things to think about at the end, but the suggestions were things that they had already tried or were aware of, nothing new, no help on how to get a diagnosis. Feel abandoned, particularly as they can't even get on a waiting list.'

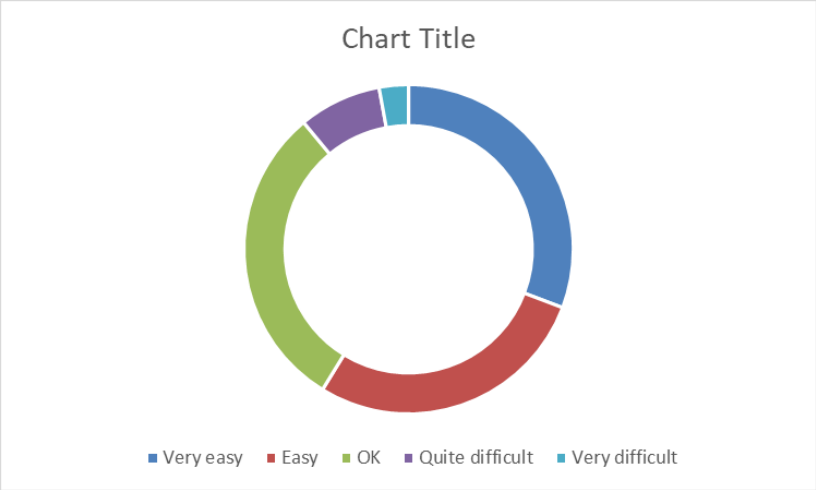
"I've completed all questions on the Do-It Profiler and have downloaded all my reports. How do I know what the next steps are or if I have been referred?"

"I have currently been sent the Do-It Profiler for ADHD by my GP which I have successfully filled out. I'm just struggling to see where it says if you are going to be referred or not? Is this information included as it isn't very clear on the report at all I'm afraid... I can see there are helpful tips on how to cope or change behaviours but nothing on the next step..."

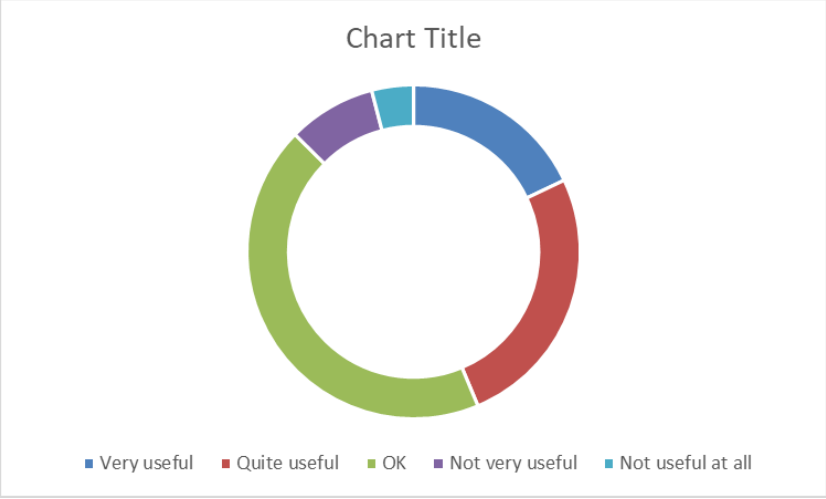
Data provided by HNYHCP

Once people complete the Do-It Profiler they are directed to a feedback form (Appendix 5). This information is collected on completion of the profiler modules. From the experiences gathered, we understand that many believed at this point that completing all the modules within the profiler was the first step to accessing a diagnosis. HNYHCP has provided us with the responses to three of the questions asked within the survey. Answers to open questions were not shared with us and so have not been included in our review. Nine hundred and thirty-six people completed the Do-It Profiler feedback.

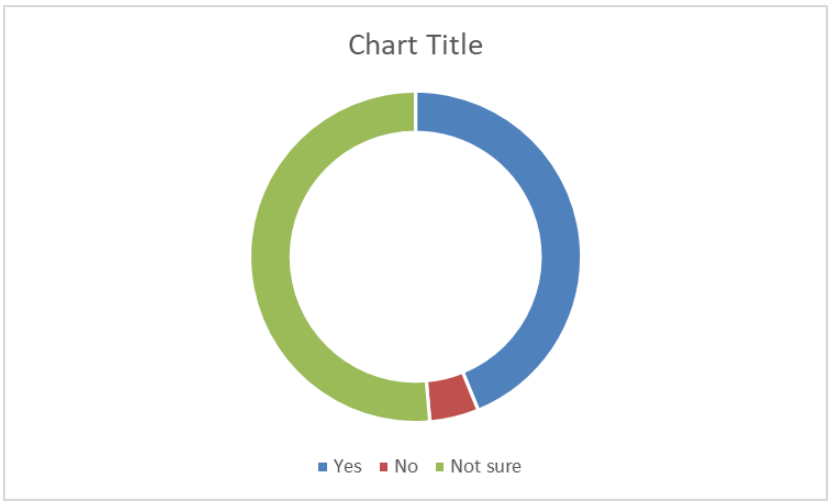
How easy was it to use the do-it profiler? **Total responses: 936**



How useful was the report and practical guidance? **Total responses: 936**



Did you share the report with anyone else? **Total responses: 146**



Feedback from people working in health and care

Outside of the survey, we also received responses from people working within the health and care system. Feedback included:

"I would just like to give some feedback with regards to the Do-It Profiler for ADHD. Firstly, I do feel that this puts people who may have a disability, unable to read/write or have little or no access to IT, at a disadvantage. From the people that I have given this out to, they have come back saying that they have scored high for certain areas, mostly ADHD. But then the Do-It Profiler does not explain that this is all that they are getting and that they have not been given a full assessment and therefore they are assuming that they are now sat waiting on a list.

I am sure that this can be made much clearer. What does happen to those people that do really struggle due to the potential diagnosis and do not meet the four criteria and so are left to just manage. Clarity for patients on if they will receive an assessment or not."

"I've just received some feedback from one of my patients who recently completed the Do-It Profiler. He struggles with forms etc and became very overwhelmed when The Tuke Centre emailed him requesting he fill in more forms. He said he would find it much better if there was someone who could go through the forms with him."

"So some of the feedback that some people are giving back to me regarding this profiler is that they are not sure what happens at the end of completing this link – they tell me that they are given access to resources but then are not aware what happens next in the sense of if they will be accepted for an assessment or not.

I also fear a backlash of people wanting to seek medication for ADHD and coming back to GP surgeries stating that they would like to go down the 'right to choose' option instead so that they can be considered for medication, especially when there is a lot of information around stating that medication is the main route to treat ADHD."

I find this really worrying. Potentially we could miss out those most needing help as they will be the ones who find it most difficult to complete unaided. People need to

be signposted to the support available. But there are also huge challenges with providing that support. I already have a waiting list of around six weeks for my service. If I had just two or three people in a week needing help to complete the profiler, that's going to have a significant impact."

GP Survey

As part of a quick 'snapshot' survey emailed to GP staff, we heard from 12 professionals. Of the 12 respondents, 11 were aware of the changes and two could provide feedback from the patient's perspective. Overall, they welcome an easy and direct referral system for patients. Responses included:

"The only feedback I have had from patients is that when they complete the referral and all the programmes/videos in the process they don't feel it is very clear what happens next and aren't really sure whether it has resulted in a referral being accepted or not, this results in them calling us for advice and we don't really have a clear message to tell them."

"Really good that it is direct access, some headache on what patients are asked to fill out. Overall, I'm really supportive."

"Easy for us [GP] to use as just send a link. Patient feedback is that it isn't obvious what the outcome of the assessment is. Not sure where it directs patients if they don't meet the criteria? Overall, I'd really like it to continue."

"I [GP] was aware of this and the secretaries have been sending out the letter to the patients when I have done a referral. I've not had any feedback regarding this."

"Very easy to use from GP perspective. No feedback from patients."

"Yes, use it every day but just text information to the requesting patient. No issues, but would be good if parents could use it for their children also."

"Very easy to refer those who are eligible and explain to patients what it's about and what to do."

"Just ask secretaries to send a link so don't directly use it. One patient was very disappointed that was no support offered at the end of assessment."

Conclusion

Our findings show a disconnect between the experiences of those going through the pathway and the healthcare professionals involved in delivering the pathway. Healthcare professionals welcome a straightforward and direct referral pathway for people seeking an autism and/or ADHD diagnosis. However, they acknowledge people's want to be referred onto a waiting list (regardless of the wait times); be provided with practical and meaningful support; be able to utilise their legal right to choose - all of which were denied to people as a result of this pilot.

There is a shared desire from healthcare professionals and patients to move to a needs-led model of support, but this is at odds with the current health and social care systems in place, and with the existing stigmas that those with autism and ADHD traits experience. NICE guidance, NHS England guidance, and legislation exists to help commissioners and providers navigate these challenges.

Although the limited quantitative data provided by HNYHCP reports that the Do-It Profiler was 'easy to use' and 'useful', our qualitative data shows that too many people were under the assumption that the Do-It Profiler was the assessment of their possible neurodivergence, and the next stage would be a referral for diagnosis. Many reported that they weren't sure if they had been referred for a diagnosis, and what the purpose of the profiler was.

Communication of the pathway has been poor throughout its design and implementation both to people seeking diagnosis and those working in the health and care system. As a result, use of the profiler doesn't seem to have been consistent across primary care.

Many have approached Healthwatch York, YDRF, local and national campaign groups to express their frustrations around the pathway's failure to address health inequalities. Women told us the pathway prevented them from accessing a diagnosis in later life for traits that weren't recognised as they grew up. Another told us that, without a diagnosis, they were being challenged when applying for disability benefits. This raises concerns that the pathway could increase the risk of poverty for disabled people.

We also heard from those who were unable to access the pathway, with many reporting that they were waiting for the pilot to end before approaching their GP for

help. When asked, we were told by HNYHCP that no additional resources would be given to support individuals unable to access the pathway.

In addition, the pathway doesn't appear to meet the needs of individuals or achieve the intended outcomes expressed by HNYHCP. People reported to us that they wanted a referral for: diagnosis, improved understanding and validation, access to meaningful support, guidance and information, access to therapies, access to occupational support. HNYHCP said that the pathway would outline "strengths, challenges, and skills to develop at home, socially and in the workplace" and identify "where reasonable adjustments should be made which should start as a basis for discussion with occupational health, employers, and educational environments. "

People told us that they felt uncomfortable with the idea of providing employers, and sometimes close relations, with a report that contains their personal information. Even more so when the tool used to identify these traits has little clinical backing.

HWY has not been provided with information about the reliability and validity testing of the digital health technology (DHT) used within the pathway. The tool has been designed to inform an individual around challenges they face within their employment/education. We are not aware of any scientific evidence to support its use for identifying, advising, or informing on traits of autism or ADHD. To add to the confusion, language such as "assessment" and "screening" are used throughout the DHT. There are many readily available free tools that have been scientifically tested to identify ADHD/autism traits (such as the Q10 for autism). Users of the Q10[35] also benefit from only having to complete a short number of easy to understand and less prying questions.

It's important that HNYHCP improves its communications and engagement, shares the rest of its data and prioritises the analysis of this.
The community has questioned whether HNYHCP followed necessary legislation and best practice alongside poor communication and a lack of transparency. People have reported losing faith in NHS services because of this pilot. The pilot appears to have reinforced feelings of marginalisation for those already diagnosed and those seeking a diagnosis for ADHD/autism, contradictory to the aims of the ICS. Given the stated expectation that ICS's will be rooted in the needs of people, communities and places, this is a disappointing start.

[35] https://embrace-autism.com/aq-10/

Failure to follow legislation and guidance contributes to a lack of regard for prevention and failure to meaningfully promote 'waiting well'. At best the pilot provides some people with general guidance around what they can do to improve their functioning within educational and/or occupational settings (assuming they have digital and literacy capabilities). At worst, the pathway fails to meet legislation, NICE and NHSE guidance, resulting in questions around risk management, data management, discrimination, misdiagnosis/inappropriate treatment pathways and disregard for the patient's legal right to choose.

This process has caused considerable distress. Our findings have highlighted risk to the wellbeing of individuals involved, including suicidal ideation and self-harming behaviours. The pilot places significant reliance on considerations that appear irrelevant, the conditions a person must meet to get a full assessment are mostly unrelated to the need for an autism or ADHD assessment and are not based on the need for therapeutic support for autism or ADHD. It is unclear whether the pathway has been assessed for clinical safety.

Had the pathway been co-produced with those diagnosed/and or seeking a diagnosis, the issues raised within this report could have been avoided. Communication between primary care providers and the community would have been significantly better, contributing to better prevention and better-quality outcomes for people.

We acknowledge the challenges providers currently face with the increase in demand for diagnostic services, paired with a reduction in available funding. We also understand that those involved in the decision making of this pilot pathway care deeply about those they serve. The staff are experiencing very real pressures around contractual obligations. However, failure to engage with the affected communities has resulted in the concerns highlighted here.

We call on HNYHCP to review our findings and its own as a matter of urgency. We also call on HNYHCP to immediately amend the pilot in accordance with legislation and best practice, and to embed the views of those most affected by this change into decision making.

On 29 June we were made aware that the pilot is continuing for another nine months with an adjustment to the restrictive criteria currently in place. We believe that this means everyone seeking a diagnosis will now be accepted onto a waiting list, although communication around this was not clear at time of publication.

We invite HNYHCP to work with local Healthwatch to bridge the gap between community voice and the pressures and contractual obligations HNYHCP is working within; so we can achieve better outcomes for the community and successfully meet the aims of the ICB.

ICBs should look to this commissioning decision as an example of why engaging people is so necessary in the design and delivery of services.

We encourage people who receive the profiler to continue to share their experiences of the pilot with us. We also welcome feedback from health and care professionals. We would appreciate feedback via our short surveys:

- For people trying to access a referral:
https://www.smartsurvey.co.uk/s/YorkAADHDPathway/

- For health and social care professionals:
https://www.smartsurvey.co.uk/s/VY0L8Y/

We also understand some people will not want or be able to fill in a further form. Please contact us by any of the other means listed on the back cover of this report if you would prefer.

Recommendations

Action	For
Review the referral criteria, working with leading academics within neurodiversity.	HNYHCP
Review all the feedback available, involving from relevant and appropriate partners.	HNYHCP
Commit to investing in meaningful community engagement throughout the commissioning cycle.	HNYHCP
Commit to providing the resources necessary to support those not able to access the pathway in its current form, communicating how this will be provided.	HNYHCP
Investigate the use of the Do-It Profiler as a digital health technology in accordance with guidance and legislation. This should include the completion of a clinical risk assessment and equality/discrimination assessment.	HNYHCP
Provide effective 'waiting well' initiatives that are accessible to all, working in partnership with others to understand what would produce the best outcomes for people for the best price.	MHP
Implement a strategy for neurodiverse service market growth, ensuring a preventative approach to commissioning and delivering.	HNYHCP / MHP
Immediately amend the pilot in accordance with legislation and best practice.	HNYHCP
Conduct an audit of commissioning to ensure full legislative compliance and learn from mistakes made.	HNYICB

Initial response from HNYHCP

July 2023

We acknowledge receipt of the report and thank Healthwatch York for sharing this insight from users with us. The experience of our patients is our priority, and we actively review our approach based on the feedback we receive.

This report will become part of the body of evidence that helps us improve our approach to adult autism and ADHD assessment, and continue conversions with people with lived experience, clinicians and partners in the months ahead.

We would also like to acknowledge that the pilot aims to identify those most at risk and channel them towards a face-to-face intervention with the specialist provider while allowing others, who might have had to wait years for a diagnosis, to access help online at a much earlier stage. Previously, all referrals were assessed in chronological date order and there was no system for identifying those people who needed help more urgently. The changes are in the context of growing demand for adult autism and ADHD assessments resulting in unacceptable wait times and the need to prioritise resources towards most at-risk adults.

Since the start of the pilot in March 2023 we have identified a number of adjustments based on user and clinical feedback including expanding the triage criteria. Everyone registered with the platform will be offered the opportunity to remain on a triage waiting list and, based on their needs, will be referred for an assessment or offered/signposted to appropriate relevant support.

Data from the Profiler can help us understand where the greatest need is to develop the most relevant programmes and workshops for people needing support. This enables us to provide targeted information about functional skills such as time management, organisation, dealing with anxiety and low mood and understanding local pathways to services.

Appendices

Appendix 1: Health and care related legislation and guidance

Equality Act 2010

The Act sets out when someone is considered to have a disability and is protected from disability discrimination. If you can show significant and long-term adverse effects on your ability to carry out day–to–day activities, you do not need to have a medical diagnosis to be protected under the Act. This makes it challenging however if the other person (i.e. professional/employer) doesn't agree that someone has a disability. In this instance, they should seek medical advice, for example an occupational health report or a medical report from the person's doctor.

A requirement of a diagnosis of ADHD to access support differs across settings despite the Equality Act. For example, although needing a diagnosis to access education support has relaxed recently, traditionally and in practice, this is not a universal approach across all academic settings from primary school to further education.[36]

2016 Accessible Information Standard

All organisations that provide NHS care are legally required to follow the Accessible Information Standard. This also applies to services commissioned by HNYHCP. "Everyone has the right to receive information in a format they can access and understand. "[37]

NICE guidance

NICE states that adults who present with symptoms of ADHD should be referred for assessment by a specialist with training and expertise in the diagnosis of ADHD.[13]

And, if a person scores six or above on the AQ-10, or autism is suspected based on clinical judgement, they should offer a comprehensive assessment for autism[14].

[36] https://www.acas.org.uk/what-disability-means-by-law/considering-whether-someone-has-a-disability

[37] https://www.healthwatchyork.co.uk/wp-content/uploads/2022/06/Accessible-Information-Report-June-2022_0.pdf

NHS England (NHSE) guidance

The 2023 NHS framework for autism assessments[31] states that:

- ICBs should not withhold access to an autism diagnosis because of a local decision to make assessments needs-based.
- Clear, accurate, current and accessible information about the extent to which each service providing autism assessments complies with NICE guidance should be available to inform people's choices.
- It is the responsibility of individual clinicians, their respective professional bodies and people in commissioning roles to ensure public resources are spent on well evidenced services and not on un-evidenced or under-evidenced alternatives.
- There is a statutory duty for ICBs to involve people and communities in developing plans for continual improvement of services.
- Decisions to delay referral for an autism assessment must be underpinned by a clinical rationale.
- Clarity about autism diagnosis can be validating for many people in their day-to-day lives. For example, this can help with the development of a positive autistic self-identity and foster connections with the autistic community.

Digital health technology (DHT) requirements

Health organisations have an obligation to ensure that digital health technologies are compliant with the DCB 0160 clinical risk management standard. This is a mandatory requirement under the Health and Social Care Act 2012. This should be carried out and approved by a Clinical Safety Officer before the technology goes live, and then regularly reviewed.

Suppliers of digital health technologies must comply with the DCB 0129 standard[32]. This standard ensures that a full assessment is in place for the use of the technology in a clinical setting and extends to the use of digital technology in pilots.

NICE Evidence Standards Framework for digital technology

Additionally, NICE guidelines for digital health technologies (DHT) recommend that there is "evidence to show that the DHT has been successfully piloted in the UK health and social care sector" before its use.

NICE provides guidance for the use of DHT in aiding diagnosis, triage and/or when informing next diagnostic or treatment services[33]. This includes DHTs used to:

- take an immediate or near-term action to diagnose, screen or detect a disease or condition

- take an immediate or near-term action to treat, prevent or mitigate by means of providing therapy to a human body.

The guidance is split across five areas of DHT:

- design factors (safety and reliability)
- describing value (value of the technology)
- demonstrating performance (meeting performance expectations)
- delivering value (demonstrating value for money)
- deployment considerations (claimed benefits realised in practice).

For design factors the guidance states that:

- DHT companies should demonstrate that all safety and quality standards relevant to their DHT have been met.
- Companies should describe how representatives from intended user groups were involved in the design, development or testing of the DHT.
- Health inequalities considerations should be factored into the design and evidenced.
- Datasets used to train, validate or develop the DHT should be done and be of a high quality.
- Health information provided is valid, accurate, reviewed and sufficiently comprehensive.
- Relevant health or care professional(s) working in the UK health and social care system have either been involved in designing, developing or testing the DHT, or given their support to the UK deployment of the DHT.
- The DHT is viewed as useful and relevant by professional experts or expert groups in the relevant field.
- Appropriate safeguarding measures are in place including consideration of who has access and why these people/groups are suitable.

Under the category 'demonstrating performance' the guidance states "the DHT should show real-world evidence that the claimed benefits can be realised in practice." The company should have evidence to show that the DHT has been successfully piloted in the UK health and social care system, showing that it is relevant to current best practice in the UK (for tier B and tier C DHTs – see below reference for further information).

Testing should show that:

- the DHT was acceptable to users
- performed its intended purpose to the expected level

- successfully integrated into current service provision or current best practice
- caused no unintended negative impacts on service users or services
- showed improvements in outcomes (costs saved, efficiencies achieved, health and care improvements)
- was used in line with expectation (who, how, for how long).

General Data Protection Regime (GDPR)

Article five of the UK GDPR sets out seven key principles[34]:

- Lawfulness.
- Fairness and transparency.
- Purpose limitation.
- Data minimisation.
- Accuracy.
- Storage limitation.
- Integrity and confidentiality (security).
- Accountability.

Under 'lawfulness, fairness and transparency', personal data must be used "in a way that is fair. This means [providers] must not process the data in a way that is unduly detrimental, unexpected or misleading to the individuals concerned. You must be clear, open and honest with people from the start about how you will use their personal data."

ICO Right to Be Informed guidance

NHS England holds the responsibility for IT systems which support health and social care, as well as the collection, analysis, publication, and dissemination of data generated by health and social care services, to improve outcomes for patients.

One of the five promises NHS England makes[35] is "people can have confidence that their choices will be honoured and that their data is respected, secure, protected and used appropriately."

The ICO GDPR guidance[36] outlines 'rights related to automated decision-making including profiling', stating that individuals have the right to be informed about the collection and use of their personal data. This is a key transparency requirement under the UK GDPR.

Article 22 of the UK GDPR has additional rules to protect individuals if a provider is carrying out solely automated decision-making that has legal or similarly significant effects on them.

Providers must identify whether any of their processing falls under Article 22 and, if so, make sure that they:

- give individuals information about the processing
- introduce simple ways to request human intervention or challenge a decision
- carry out regular checks to make sure that systems are working as intended.

Health and Care Act 2022

Patient choice is the legal right of a patient to choose where they receive their treatment. If you need to be referred due to a mental or physical health condition, you have the legal right to choose which hospital or service you'd like to attend.

"Each integrated care board must, in the exercise of its functions, act with a view to enabling patients to make choices with respect to aspects of health services provided to them." This includes pilot projects.[37]

Public Sector Equality Duty - Equality Act 2010[38]

Public bodies are required by the Equality Act 2010 to comply with the Public Sector Equality Duty. This means that providers need to carry out an equality analysis of their services and any proposals for change. They need to ensure that all strategies, policies, services and functions, both current and proposed, give proper consideration and due regard to the needs of diverse groups to:

- eliminate discrimination
- advance equality of opportunity and access
- foster good relations between different groups in the community.

Public involvement legal duties

The legal duties on public involvement require people to be appropriately 'involved' in planning, proposals, and decisions regarding NHS services.

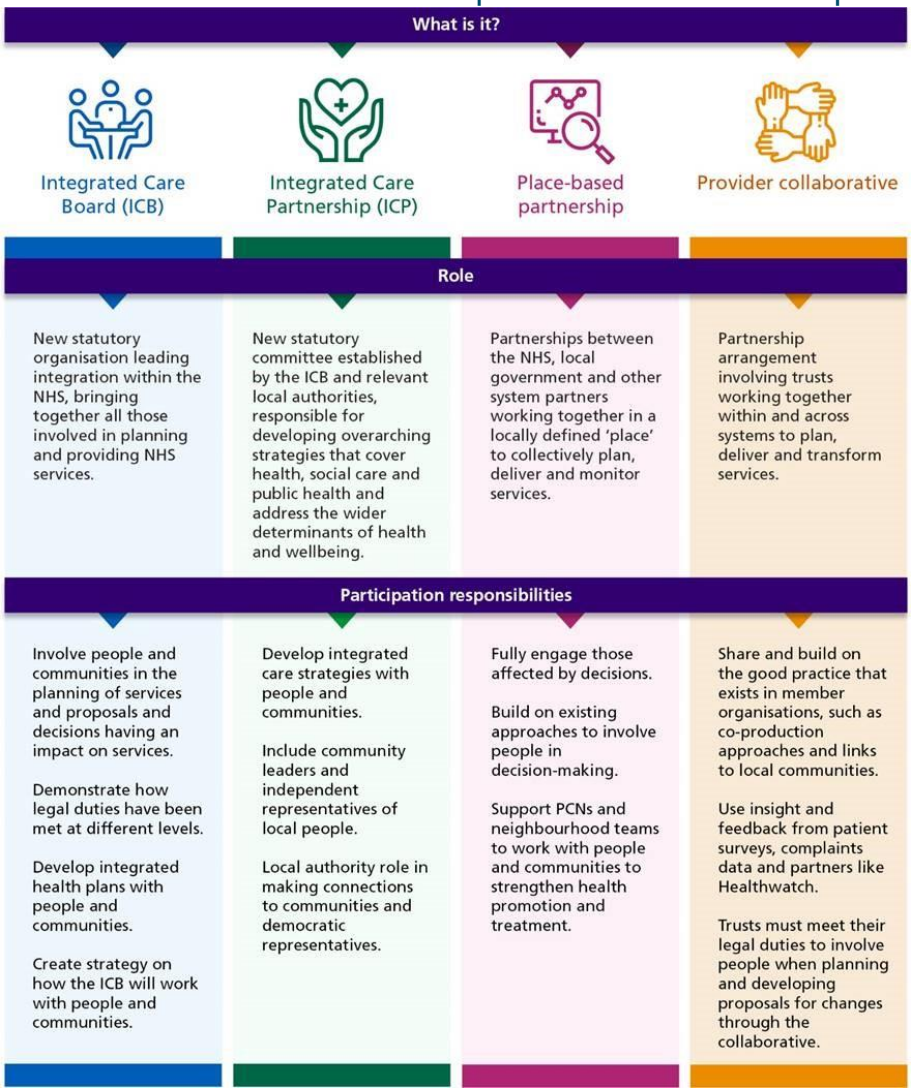
Key requirements of ICBs, trusts and NHS England include that they:

- assess the need for public involvement and plan and carry out involvement activity

- clearly document at all stages how involvement activity has informed decision-making and the rationale for decisions
- have systems to assure themselves that they are meeting their legal duty to involve

ICPs also have specific responsibilities towards participation, summarised below[39]. There are statutory requirements for ICBs and ICPs to produce strategies and plans for health and social care, each with minimum requirements for how people and communities should be involved.

Building strong integrated care systems everywhere: ICS implementation guidance on effective clinical and care professional leadership 2021



Autism Act 2009

The Act requires government to introduce and continuously review its adult autism strategy. The strategy was published in 2010 and includes statutory guidance for NHS organisations and local authorities. This was updated in 2015. [38]

Information for local authorities and NHS organisations on how to support the implementation of the Autism Strategy can be found in this footnote. [39]

Appendix 2: The Healthwatch York survey

Adult autism and ADHD referral pathway pilot survey
Thank you for taking part in our survey. We want to understand more about the adult autism and ADHD assessment process in York and North Yorkshire, particularly whilst the pilot of the Do-It Profiler is running. Healthwatch York and Healthwatch North Yorkshire are independent, and aim to make sure what matters to people in York and North Yorkshire shapes our health and care services.

We know not everyone can give feedback online. For people living in York, you can call us on 01904 621133 (choose the option for Healthwatch York), or email healthwatch@yorkcvs.org.uk if you prefer. For people in North Yorkshire, you can call us on 01423 788128 or email admin@HWNY.co.uk.

The survey is anonymous. It takes about 10-15 minutes to fill it in.

Thank you in advance for your time and help. We really appreciate it.

1) Please tell us what has led you to seek a diagnosis at this time.
   (This might include things you have experienced, who you discuss them with, any support you receive, the length of time you have considered seeking a diagnosis, resources you have used)
2) Do you self-identify as someone with autism, ADHD, or otherwise neurodiverse?

- Yes - autism
- Yes - ADHD
- Yes - neurodiverse
- No
- Not sure
- Other (please specify):

[38] https://commonslibrary.parliament.uk/research-briefings/cbp-7172/#:~:text=The%20Autism%20Act%202009%20requires,authorities%20(updated%20in%202015).
[39] https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance

- Comments:

3) Are you already in contact with any autism, ADHD, neurodiversity or disability groups?
- Yes
- No
- Not sure
- Comments:

4) How long have you been trying to get a diagnosis?
- Less than 3 months
- 4-6 months
- 7-12 months
- 1-2 years
- 2-3 years
- More than 3 years
- Comments:

5) How easy was it to use the Do-It Profiler?
- Very easy
- Easy
- Neither easy nor difficult
- Difficult
- Very difficult
- Comments:

6) How long did it take you to complete the Do-It Profiler?

7) How useful was the report?
- Very useful
- Quite useful
- OK
- Not very useful
- Not useful at all
- Comments:

8) Has the profiler given you what you need?
- Yes, fully
- Yes, partly
- No

- Not sure
- Please tell us more:

9) Have you shared the report with anyone? For example, family, friends, your employer, colleagues, support workers

10) If you have, did you find sharing your report helpful?

- Yes
- No
- Not sure
- Not applicable
- Comments:

11) Has your report helped you with getting reasonable adjustments from other organisations?

- Yes
- No
- Not yet
- Not sure
- Not applicable
- Comments:

12) Has any person or organisation refused to help you without a diagnosis in place? If yes, please provide details

- Yes
- No
- Don't know
- Not applicable
- Details

13) Whilst you have been looking for help, have you come across any resources, organisations, people or places that you think others would find helpful?

14) Is there anything else you want to tell us about your experiences?

15) Can Healthwatch York or Healthwatch North Yorkshire contact you in 3-6 months' time to ask how you are getting on? If yes, please provide your preferred contact details, for example email address or telephone number.

- Yes
- No
- Email address, telephone number or other contact info

The next few questions ask about you. You do not need to answer any of these. But it helps us if you do.

16) Please tell us your age

- 18-24
- 25-49
- 50-64
- 65-79
- 80+

16) How would you describe your gender?

17) How would you describe your ethnicity?

18) Do you consider yourself to be

- A disabled person
- A carer
- A person with experience of mental ill health
- A person with a long-term health condition
- None of the above
- Other (please specify):
- Comments:

Appendix 3: YDRF Survey

Please tell us your thoughts and/or experiences regarding the current change in the autism/ADHD assessment pathway

(if you have been sent/done the do-it profiler please complete this HealthWatch survey as they are doing the independent evaluation - https://www.smartsurvey.co.uk/s/YorkAADHDPathway/)

We would like to share some experiences and statements publicly on our website to help highlight this issue. If you agree to have your statements shared on our social media, blog, or in potential future campaigns please tick below.

Anything else you would like to add?

Appendix 4: Quick GP survey

1. Are you aware of the pilot pathway?
2. Have you used it?
3. Was it easy to use?
4. Any specific issues with it?
5. Any patient feedback?

Appendix 5: Do–It Profiler survey

The Do–It Profiler in North Yorkshire and York is new and we value your feedback so we can learn from your experiences. This will help us make improvements and changes where necessary.
Please complete this module/provide us with feedback after completing the neurodiversity screener.

1) How easy was it to use the Do-It Profiler?

- Very Easy
- Easy
- OK
- Quite Difficult
- Very Difficult

2) How useful was the report and practical guidance?

- Very Useful
- Quite Useful
- OK
- Not Very
- Not useful at all

3) What do you feel are the limitations of the Do–It Profiler?

4) Did you share the report with anyone else?

- Yes

- No

5) Are there other resources/people or places you have found helpful you could share with us so we can add these into help others?

6) Are there any other comments you think would be helpful to further improve this? You can select more than one.

7) What prompted you to seek a potential diagnosis at this point in time?

Appendix 6: HWY Full Survey Findings

You can request a copy of the full survey data by contacting healthwatch@yorkcvs.org.UK
You can also access the data via this temporary link.
https://padlet.com/Healthwatch_York/neurodiversity-gm7ezwos08v90lw2

Appendix 7: Glossary

Term	Definition
Accessible Information Standard	The Accessible Information Standard is a legal obligation introduced in 2016. It applies to all organisations that provide NHS care or publicly funded adult social care. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.
Attention deficit hyperactivity disorder (ADHD)	ADHD is a condition that affects people's behaviour. People with ADHD can seem restless, may have trouble concentrating and may act on impulse. In this report, we include three different types of ADHD including inattentive, hyperactive and impulsive and combined when we talk about ADHD.
Aspergers	A form of autism used to describe people at the higher functioning end of the autistic spectrum. It

	is a life-long condition and is more commonly diagnosed in males than females.
Autism	The NHS defines autism as a lifelong condition that affects how a person communicates with, and relates to, other people.
AQ – Autism Spectrum Quotient	The Autism Spectrum Quotient (AQ) is a 50 item self-report measure used to assess traits of autism in adults and adolescents aged 16 years and over.
Borderline personality disorder	Borderline personality disorder is a mental illness that severely impacts a person's ability to manage their emotions. This loss of emotional control can increase impulsivity, affect how a person feels about themselves, and negatively impact their relationships with others.
Community Mental Health Team (CMHT)	A CMHT can support people to recover from mental health issues. They provide short or long-term care and treatment in the community. Health professionals from different backgrounds work in the CMHT.
Community Psychiatric Nurse (CPN)	A CPN is a mental health nurse who works in the community.
Digital Health Technology (DHT)	DHTs are intended to empower patients to manage their own health and get rapid access to peer support and clinical advice. They also help frontline staff to provide high quality care and make best use of their time.
Do-It Profiler	This is a web-based screening and assessment system for ADHD and autism being used in York, Selby, Tadcaster, Easingwold and Pocklington.
Dyscalculia	Dyscalculia is a specific and persistent difficulty in understanding numbers which can lead to a diverse range of difficulties with mathematics.
Dyslexia	Dyslexia is a common learning difficulty that mainly causes problems with reading, writing and spelling.
Dyspraxia	Dyspraxia (also known as developmental coordination disorder) is a condition affecting movement and

	coordination in children and adults. Dyspraxia affects all areas of life, making it difficult for people to carry out activities that others can take for granted.
Freedom of Information Request (FOI)	An FOI is a request for information held by public authorities, including the NHS and local authorities. They must provide the information unless there are good reasons to keep it confidential.
General Data Protection Regulations (GDPR)	The way organisations use people's personal information is covered by GDPR, which is a law. Personal information means anything that can be used to find out who you are and how to contact you.
Humber and North Yorkshire Health and Care Partnership (HNYHCP)	This is an integrated care system working in partnership with NHS organisations, councils, local Healthwatch, hospices, charities and the community voluntary and social enterprise sector to improve the health and wellbeing of local people.
Healthwatch York (HWY)	Healthwatch York is one of more than 150 Healthwatch across England. It is an independent health and care champion, representing people's experiences and ideas to help improve local health and social care.
Integrated Care Board (ICB)	An ICB is a statutory NHS organisation which is responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in a geographical area.
Information Commissioner's Office (ICO)	The ICO is the UK's independent regulator for data protection and information rights law, upholding information rights in the public interest, promoting openness by public bodies and data privacy for individuals.
Integrated Care Partnership (ICP)	An ICP is a statutory committee jointly convened by local councils and the NHS, comprised of a broad alliance of organisations and other representatives. These work as equal partners to

	improve the health, public health and social care services provided in a geographical area.
Integrated Care System (ICS)	ICS is another name for ICP and is a partnership between organisations that meet health and care needs across a geographical area.
NHSE (NHS England)	NHS England leads the National Health Service (NHS) in England.
National Institute for Health and Care Excellence (NICE)	NICE provides national guidance and advice to improve health and social care.
National Autistic Society	The UKs main charity for autistic people and their families.
Neurodiversity	Neurodiversity suggests that there is not a 'normal' or 'right' way for the brain to develop, in much the same way that there is no 'normal' or 'right' gender, race or culture. Neurodiversity rejects the idea that autism and other neurological differences can be cured.
Office for National Statistics (ONS)	The ONS is the executive office of the UK Statistics Authority, a non-ministerial department which reports directly to Parliament.
Personal Independence Payment (PIP)	PIP is extra money to help people with everyday life if they have an illness, disability or mental health condition. You can get PIP on top of Employment and Support Allowance or other benefits. A person's income, savings, and whether they are working or not does not affect their eligibility.
Post Traumatic Stress Disorder (PTSD)	PTSD is an anxiety disorder caused by very stressful, frightening or distressing events.
Q-10	The Q-10 is a quick questionnaire that primary care practitioners can use to see if a person should be referred for an autism assessment. It provides 10 statements and asks people to agree or disagree with them.
The Retreat	The Retreat is a clinic in York which offers bespoke therapy services to support mental health and

	wellbeing. This includes doing assessments for ADHD and autism for those who meet the criteria.
Right to choose	The NHS provides patients with the right to choose their GP surgery to make choices about their health and care. Patients can also choose the organisation that provides other aspects of their care including hospital treatment.
Shared care agreements	Shared care agreements put the interests and safety of the patient first. They assume communication between the specialist, primary care prescriber (GP or other) and the patient. It is important that patients are consulted about treatment and are in agreement with it.
Solution Orientated Adult ADHD Carers' Group (SOAAC)	The group aimed to raise awareness of ADHD and called for more resources. They were active in 2017.
Tees Esk Wear Valleys NHS Foundation Trust (TEWV)	TEWV is the mental health service provider covering York and North Yorkshire.
Vale of York Clinical Commissioning Group (VoYCCG)	This was the precursor to the Integrated Care Partnership (ICP) and commissioned services for the Vale of York area until 30 June 2022.
York Disability Rights Forum (YDRF)	YDRF is led by disabled people and works to promote equal access to human rights for all disabled people who live or work in York.

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Facebook.com/HealthwatchYork

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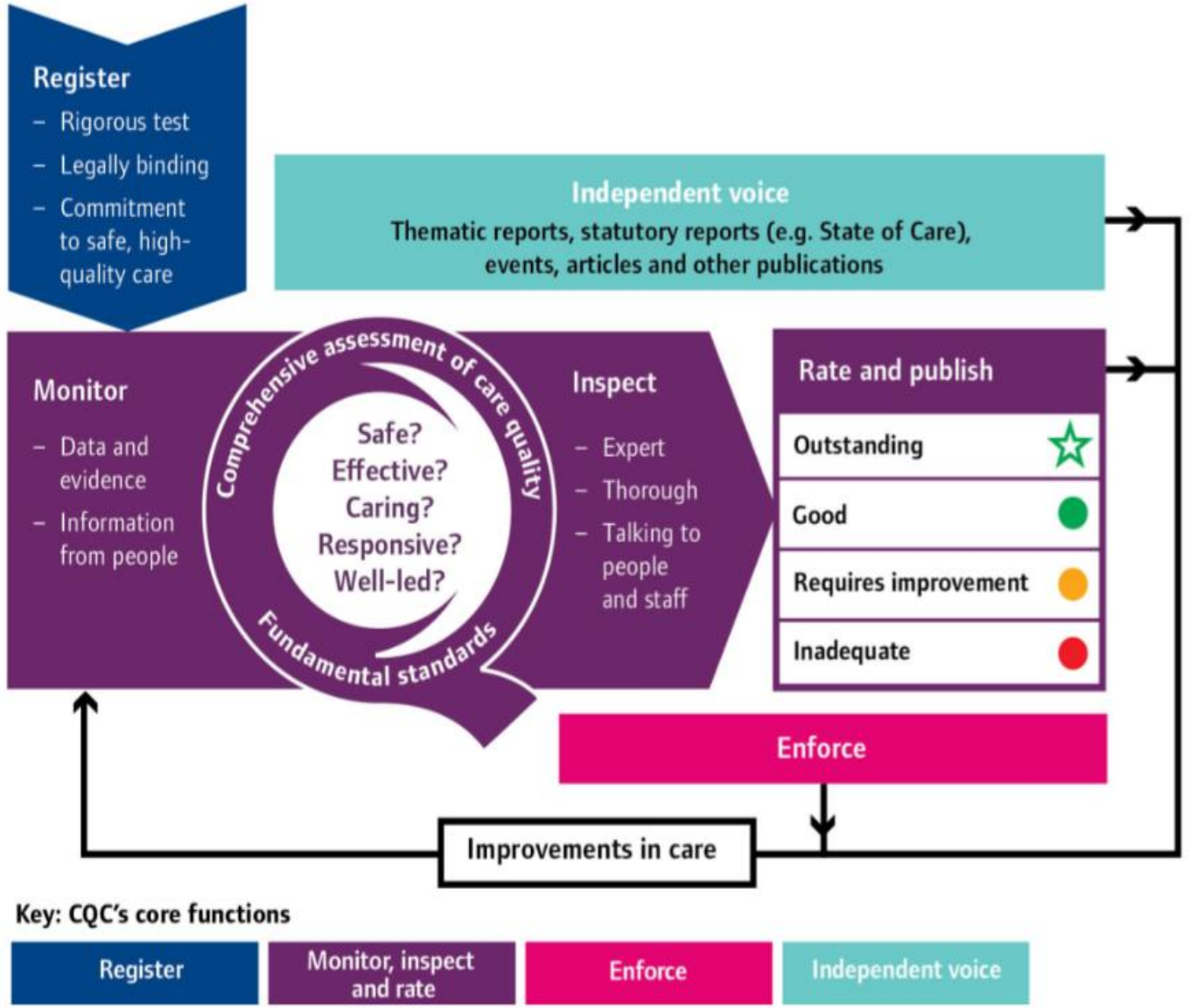
City of York Council

Adult Social Care and Integration Directorate

CQC Assurance – Understanding the New Single Assessment Framework

An Introduction to the CQC

Operating Model



An Introduction to the CQC

The New Single Assessment Framework

- The New Single Assessment Framework allows the CQC to assess **all types of services in all health and care sectors at all levels.** It will apply when **registering new providers through to how we look at local authorities.**
- The **Health and Care Act 2022** gives us new regulatory powers that allow us to offer a meaningful and independent assessment of care at a local authority level.
- Assessing **Local Systems** is a core ambition in our current strategy. It will enable us to provide independent assurance to the public of the quality of care in their area. Our aim is to understand how the care provided in a **local area is improving outcomes for people and reducing / tackling inequalities** in their access to care, their experiences and outcomes from care. This means looking at how services are working together within an integrated system, as well as how systems are performing overall.
- We are also committed to protecting **human rights** through our regulation.
- The assessment framework:
- Sets out clearly **what people should expect a good service to look like**
- Places **people's experiences of care at the heart** of our judgements
- Ensures that **gathering and responding to feedback is central** to our expectations of providers, local authorities and integrated acre systems.

Running through each of the four ambitions are two core ambitions:

THE CQC AMBITIONS under **FOUR KEY AREAS**

Assessing local systems: Providing independent assurance to the public of the quality of care in their area

Tackling inequalities in health and care: Pushing for equality of access, experiences and outcomes from health and social care services

Underpinned by - Legislation

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 (Part 3)

Regulation 4: Requirements where the service provider is an individual or partnership

Regulation 5: Fit and proper persons: directors

Regulation 6: Requirement where the service provider is a body other than a partnership

Regulation 7: Requirements relating to registered managers

Regulation 8: General

Regulation 9: Person-centred care

Regulation 10: Dignity and respect

Regulation 11: Need for consent

Regulation 12: Safe care and treatment

Regulation 13: Safeguarding service users from abuse and improper treatment

Regulation 14: Meeting nutritional and hydration needs

Regulation 15: Premises and equipment

Regulation 16: Receiving and acting on complaints

Regulation 17: Good governance

Regulation 18: Staffing

Regulation 19: Fit and proper persons employed

Regulation 20: Duty of candour

Regulation 20A: Requirement as to display of performance assessments

Care Quality Commission (Registration) Regulations 2009 (Part 4)

Regulation 12: Statement of purpose

Regulation 13: Financial position

Regulation 14: Notice of absence

Regulation 15: Notice of changes

Regulation 16: Notification of death of service user

Regulation 17: Notification of death or unauthorised absence of a service user who is detained or liable to be detained under the Mental Health Act 1983

Regulation 18: Notification of other incidents

Regulation 19: Fees

Regulation 20: Requirements relating to termination of pregnancies

Regulation 22A: Form of notifications to the Commission

Underpinned by – Legislation

Care Act 2014

Section 1: Wellbeing principle

Section 2: Preventing needs for care and support

Section 3: Promoting integration of care and support with health services

Section 4: Providing information and advice

Section 5: Promoting diversity and quality in provision of services

Sections 6-7: Co-operation generally and in specific cases

Sections 9-13: Assessment of an adult or Carers needs for care and support; eligibility criteria

Section 14(1) and (3) to (8); **Section 17**(1) and (3) to (13): Charging and financial resources

Section 18(1)(a), (c); (2) to (4), (6) and (7); **Section 19-20:** Duty to meet needs

Section 19(3): Power to meet needs for care and support

Sections 24(1), (2) and 25, sections 26(1) and (3) and 27: Next steps after assessment plans

Section 30: Next steps after assessment; care and/or support

Sections 31-33: Direct Payments

Section 37(1), (3), (4), (5)(a), (e), (f), and (6) to (15); Section 38(1)(a) and (2) to (8): Continuity of care and support when adult moves

Sections 42-43: Safeguarding enquiries and Safeguarding Adults Board

Section 48: Provider failure (temporary duty to provide services)

Sections 58 - 65: Children and young people's assessments and Transition from childhood

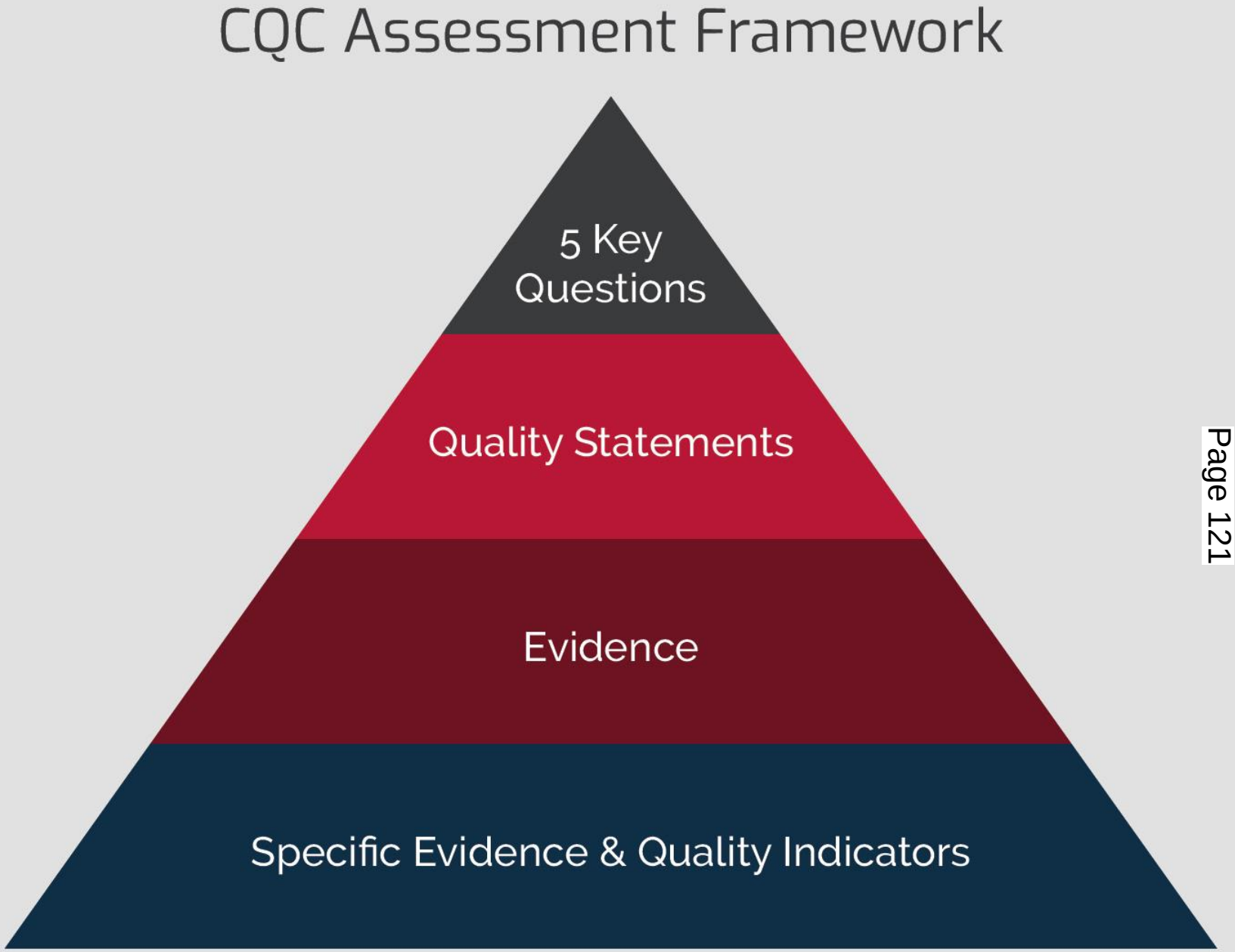
Sections 67: Independent advocacy support

Section 77: Register of Sight Impaired Adults

Section 79: Delegation of functions

Sections 68: Independent advocacy support

The New Single Assessment Framework



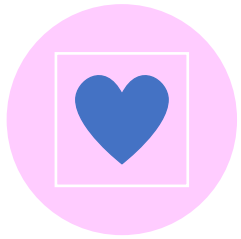
5 Key Questions

staff involve and treat you with compassion, kindness, dignity and respect.

CARING

your care, treatment and support achieves good outcomes, helps you to maintain quality of life and is based on the best available evidence.

EFFECTIVE



SAFE

you are protected from abuse and avoidable harm.

RESPONSIVE

services are organised so that they meet your needs.

WELL-LED

the leadership, management and governance of the organisation make sure it's providing high-quality care that's based around your individual needs, that it encourages learning and innovation, and that it promotes an open and fair culture.

The CQC will use a **subset of the quality statements from the overall assessment framework to assess how well local authorities are performing against their duties under Part 1 of the Care Act 2014.**

We will be assessed under the following 9 quality statements across the 4 themes:

Theme 1: Working with People	Theme 2: Providing Support	Theme 3: Ensuring Safety	Theme 4: Leadership
• Assessing needs • Supporting people to live healthier lives • Equity in experience and outcomes	• Care provision, integration and continuity • Partnerships and communities	• Safe systems, pathways and transitions • Safeguarding	• Governance, management and sustainability • Learning, improvement and innovation

We will…

I and We Quality Statements

I expect…

Quality statements are written in the style of ‘We’ statements from a provider, local authority and integrated care system perspective, to help them understand what we expect of them. They are the commitments that providers, commissioners and system leaders should live up to in order to deliver truly person-centred care and support. They also help to provide a benchmark of what good care looks like by linking to the relevant best practice standards and guidance.

To develop the quality statements, we reviewed our existing assessment frameworks as well as using aspects of the Making It Real framework. Making It Real was co-produced by Think Local Act Personal (TLAP) with a range of partners and people with lived experience of using health and care services. It is a framework for how to provide personalised care and support aimed at people working in health, care, housing, and people who use services. It contains a jargon-free set of personalised principles that focus on what matters to people.

We statements are what Local Authorities must commit to.

I statements are what People expect.

6 Evidence Categories

- **People's Experience** as set out in our experience principles and framework. This category covers all types of evidence where the source is from people who have experience relating to a specific health or care service, or a pathway across services. It also includes evidence from families, carers and advocates for people who use services. Examples include interviews with people, Give Feedback on care forms, survey results, feedback from representative groups and case tracking.

- **Feedback from Staff and Leaders** including for example, from direct interviews, compliments and concerns raised with us, and surveys. Evidence from self-assessments.

- **Feedback from Partners** including for example, commissioners, providers, professional regulators, accreditation bodies, royal colleges, multi-agency bodies. This will include partners involved in the wider determinants of health and wellbeing such as housing, licensing, or environment services.

- **Processes** are the series of steps, or activities that are carried out to deliver care and support that is safe and meets people's needs. We will focus on the effectiveness of the processes rather than simply the fact they exist. This category includes metrics such as waiting times, audits, policies and strategies.

- **Outcomes** are focused on the impact of processes on individuals and communities, and cover how care has affected people's physical, functional or psychological status. Evidence includes information on the quality of a provider, clinically relevant measures, quality of life assessments and population data. Not all Themes / Quality statements will be looked at from an Outcomes perspective.

- ~~**Observations** will not be used as part of a local authority assessment~~

Ratings and Scoring

The CQC have advised us that they will award ratings for all local authorities after the initial baselining period.

They intend to introduce scoring into their assessment process for local authorities. This approach will be consistent with their assessments of registered providers and so ratings will be produced on a similar basis to providers – building up scores from quality statements to a rating.

When the CQC assess evidence, they will assign a score to the relevant quality statement. The scores for the each of the quality statements will be totaled to ultimately produce the ratings, and an overall score. All evidence categories and quality statements are weighted equally.

So, rather than rate all 5 key questions, for each quality statement in the assessment framework, they will assess the 'required evidence' in the evidence categories and assign a score to that quality statement. The score will indicate a more detailed position within the rating scale.

The overall rating will use our four-point rating scale. The scoring framework to support decisions is:

1 = Evidence shows significant shortfalls in the standard of care.

2 = Evidence shows some shortfalls in the standard of care.

3 = Evidence shows a good standard of care.

4 = Evidence shows an exceptional standard of care

When they publish ratings, they will publish the following information:

- the overall rating
- the score for each quality statement.

What the CQC are doing to prepare

Pilots - the five local authorities that will participate in the pilot assessments are:

- Birmingham City Council
- Lincolnshire County Council
- North Lincolnshire Council
- Nottingham City Council
- Suffolk County Council.

The pilots began in May and are still underway – they are a key activity to ensure that our approach to local authority assessments is as meaningful and effective as possible. For each of these local authorities, we will provide:

- a report
- indicative scores for all the quality statements and an overall indicative rating.

- They will use their new single assessment framework when assessing the five local authority sites during the pilots, following our draft local authority assessment framework.

- They will also be undertaking **case tracking** as part of the pilots. This involves retrospectively followin the pathway of a small number of people's cases to gather evidence for the assessment.

- For each local authority in the pilot, we will provide a report and indicative scores for all the quality statements and an overall rating. These are not formal ratings – they are indicative ratings that are determined through piloting. We will work with the LGA, ADASS and the pilot sites to agree the best way of making this clear.

- We will incorporate any learnings into our **formal assessments which will start later in 2023.**

- The CQC have committed to completing all initial formal assessments and award ratings for all local authorities in this phase within 2 years.

What City of York Council Are doing To prepare

- Drop-In Surgeries for Operational Staff.
- Face to Face Workshops exploring each theme and quality statements – 1 / 4 complete to date.
- Head of Transformation to attend Regional Workshops and feedback any recommendations re best practice.
- CYC Senior Leaders will continue to develop and evaluate our self-assessment, with support from ADASS and peer review sessions.
- Senior Leaders will continue to attend Monthly CQC Readiness Meetings with our Health and Community Partners to discuss progress.
- Head of Transformation and Project Manager - Social Care and Integration to work closely with relevant stakeholders to create evidence list.
- Heads of Service to prepare potential questions to support operational staff readiness and circulate as appropriate, as well as explore during drop-ins.
- T&F Group to be established with our ICS colleagues to support us, and them with their CQC readiness.
- Annual Conversation – held
- Mock Inspection – TBC for early 2024