

Notice of a public meeting of Health and Wellbeing Board

To: Councillors Runciman (Chair), Craghill, Cuthbertson, Looker,

Dr Nigel Wells (Vice Chair) – Chair, NHS Vale of York Clinical Commissioning Group

Dr Emma Broughton – Chair of the York Health and Care Collaborative & a PCN Clinical Director

Sharon Stoltz – Director of Public Health, City of York Council

Lisa Winward – Chief Constable, North Yorkshire Police

Alison Semmence – Chief Executive, York CVS

Siân Balsom – Manager, Healthwatch York

Shaun Jones – Deputy Locality Director, NHS England and Improvement

Naomi Lonergan – Director of Operations, North Yorkshire & York – Tees, Esk & Wear Valleys NHS Foundation Trust

Simon Morritt – Chief Executive, York Teaching Hospitals NHS Foundation Trust

Stephanie Porter – Director for Primary Care, NHS Vale of York Clinical Commissioning Group

Mike Padgham – Chair, Independent Care Group

Michael Melvin (Substitute for Corporate Director of People) – Director of Safeguarding



Anne Coyle (Substitute for Corporate Director of People) – Interim Director of Children's Services

Date: Wednesday, 16 March 2022

Time: 4.30 pm

Venue: Remote meeting

<u>A G E N D A</u>

In the event that the Health and Wellbeing Board are required to make decisions, physical attendance meetings will be arranged.

1. Declarations of Interest

At this point in the meeting, Board Members are asked to declare:

- any personal interests not included on the Register of Interests
- any prejudicial interests or
- any disclosable pecuniary interests

which they may have in respect of business on this agenda.

2. Minutes

(Pages 1 - 12)

To approve and sign the minutes of the last meeting of the Health and Wellbeing Board held on 19 January 2022.

3. 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 is **5:00pm on Monday 14 March 2021.**

To register to speak please visit <u>www.york.gov.uk/AttendCouncilMeetings</u> to fill out an online registration form. If you have any questions about the registration form or the meeting, please contact the relevant Democracy Officer, on the details at the foot of the agenda.

Webcasting of Remote Public Meetings

Please note that, subject to available resources, this remote public meeting will be webcast including any registered public speakers who have given their permission. The public meeting can be viewed live and 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 (<u>www.york.gov.uk/COVIDDemocracy</u>) for more information on meetings and decisions.

4. Presentation on the Day: Better Care Fund Update

The Director of Prevention & Commissioning will give a presentation to provide the Board with an update on the Better Care Fund.

5. Healthwatch York Report: Dentistry in York: (Pages 13 - 76) Gaps in Provision

Board members will consider a report from Healthwatch York looking at people's experiences of dentistry in the city.

- 6. Healthwatch York Report: Dementia Support (Pages 77 132) This report aims to help shape the dementia strategy in York, sharing Healthwatch York's work looking at the experiences of people caring for those living with dementia in the city.
- 7. Annual Update from the HWBB's Mental Health (Pages 133 166) Partnership

This report presents the Health and Wellbeing Board with an update on the work the partnership has undertaken since last reporting to the board in January 2021.

- 8. Update on the Integrated Care System (Pages 167 180) This report updates board members on the national reforms to the NHS, health and care, and developments locally to plan for the changes which are due to come into force in July 2022.
- 9. Report of the Chair of the York Health and Care (Pages 181 188) Collaborative

The Health and Wellbeing Board is asked to consider a report on the work of the York Health and Care Collaborative which is attached at Annex A.

- **10. Presentation: The Poverty Truth Commission** (Pages 189 196) The Chief Executive of York CVS will give a presentation to board members on the Poverty Truth Commission.
- 11. Presentation on the Day: Update on the Current Situation re: Covid-19

The Joint Consultant in Public Health will give a presentation on the current situation in relation to Covid-19 including recovery plans. This item will be in presentation format to ensure that the most up to date information can be presented to the Health and Wellbeing Board.

12. Urgent Business

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

Democracy Officer:

Joseph Kennally Telephone No – 01904 551573 Email – joseph.kennally@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.

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Agenda Item 2

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City of York Council	Committee Minutes		
Meeting	Health and Wellbeing Board		
Date	19 January 2022		
Present	Councillors Runciman (Chair), Cuthbertson and Looker		
	Dr Nigel Wells (Vice Chair) – Chair, NHS Vale of York Clinical Commissioning Group		
	Dr Emma Broughton – Chair of the York Health and Care Collaborative & a PCN Clinical Director		
	Lisa Winward – Chief Constable, North Yorkshire Police		
	Siân Balsom – Manager, Healthwatch York		
	Naomi Lonergan – Director of Operations, North Yorkshire & York – Tees, Esk & Wear Valleys NHS Foundation Trust		
	Simon Morritt – Chief Executive, York Teaching Hospitals NHS Foundation Trust		
	Stephanie Porter – Director for Primary Care, NHS Vale of York Clinical Commissioning Group		
	Michael Melvin – Director of Safeguarding		
	Anne Coyle – Interim Director of Children's Services		
	Peter Roderick - Joint Consultant in Public Health (Substitute for Sharon Stoltz, Director of Public Health)		
	David Harbourne - Chair of York CVS (Substitute for Alison Semmence - Chief Executive of York CVS)		

Councillor Craghill,

Shaun Jones - Deputy Locality Director, NHS England and Improvement,

Mike Padgham - Chair, Independent Care Group,

Stephanie Porter - Director for Primary Care, NHS Vale of York Clinical Commissioning Group

Alison Semmence - Chief Executive, York CVS

Sharon Stoltz, Director of Public Health, City of York Council

71. Declarations of Interest

Board Members were invited to declare any personal, prejudicial or disclosable pecuniary interests, other than their standing interests, that they had in relation to the business on the agenda. None were declared.

72. Minutes

Apologies

Resolved: That the minutes of the last meeting of the Health and Wellbeing Board held on 17 November 2021 be approved.

73. Public Participation

It was reported that there were no registered speakers under the Council's Public Participation Scheme.

74. Annual Summary: JSNA

Board members considered a report which provided them with an update on the Joint Strategic Needs Assessment (JSNA), including work undertaken in the last year, the refreshed JSNA working group and planned work for the coming year. The Consultant in Public Health and the Public Health Specialist Practitioner Advanced were in attendance to present the report and respond to questions.

Key points raised during the presentation of the report included:

- That the JSNA working group now sat as part of the newly formed Population Health Hub (PHH) steering group.
- Population Health Management improved population health by data driven planning and delivery of care to achieve maximum impact, then stratifying and segmenting the data to identify local at risk population groups.
- Population Health Management in York was split into Enabling, Analysing and Doing sections, as outlined in the presentation.
- The JSNA was an integral part of the PHH as an important component of future service planning, commissioning and improvement.
- The request form for topic specific needs assessments had been simplified and could be found on the JSNA website.
- Topic specific needs assessment outputs of the JSNA in 2021 included on bereavement, as requested by the Mental Health Partnership and a Phase I assessment on Special Educational Needs and Disability (SEND), with a focus on those aged 0-16.
- Planned outputs for 2022 included a Pharmaceutical Needs Assessment, a topic specific needs assessment on Early Years and the SEND Phase II, which was to focus on those aged 17-25.
- A regular, quarterly newsletter was planned with a targeted audience of interested professionals and members of the public.
- A 'sounding board' was planned, where JSNA updates would be discussed and presented to members of the public.
- It was proposed that progress on the Population Health Hub and JSNA outputs be reported annually to the Health and Wellbeing Board.

Comments and questions from board members included:

 It was requested that updates to the JSNA be shared more widely, especially with those involved in primary care. It was important that the Population Health Hub fed into the Provider Collaborative to try and 'join things up'.

- The Early Years Improvement Board did not have a clear timetable for the collection and analysis of its contribution on the JSNA, however it was to be completed before the annual report to the Health and Wellbeing Board in September 2022.
- North Yorkshire Police dealt with issues identified in a reactive way, but were keen to support prevention and early intervention work through the Population Health Hub.
- Board members suggested that Healthwatch York should be invited to 'sense check' the JSNA in terms of readability and accessibility.

Resolved:

- i. That the contents of the report be noted with comments from the board on how the JSNA and work of the Population Health Hub can shape the next York Health and Wellbeing Strategy.
- ii. That comments of board members on the mechanism for keeping the board informed about JSNA progress be noted.
- iii. That comments of board members on the use of the JSNA within their own organisations, and how this use could be increased be noted.

Reason: To keep Board members updated on JSNA progress.

75. Renewal of the Joint Health and Wellbeing Strategy 2017-2022

Board members considered a report which set out a proposal to renew the Health and Wellbeing Board's Joint Health and Wellbeing Strategy 2017-2022. The Joint Consultant in Public Health and the Health and Wellbeing Partnerships Co-ordinator were in attendance to present the report and respond to questions.

Key points raised during the presentation of the report included:

- That there had been great changes since the last Health and Wellbeing Board strategy was approved, including the creation of new Integrated Care Systems (ICS).
- The new strategy needed to be taken into consideration by the ICS when it builds its own strategy.

- The strategy was due to be completed in the first half of 2022, with a view to bringing a draft strategy to the HWBB's meeting in July 2022.
- A 10 year strategic framework for York was also being written, which the Health and Wellbeing Strategy needed to align to.
- There was ongoing work with York residents to engage them in co-producing health services.
- Members were asked to provide comments to shape the creation of the strategy. A draft version would be presented to members in the summer for further comment, before going to a public consultation and being published in late 2022.

Questions/comments from board members included:

- A workshop for members to give ideas and contribute to the crafting of the strategy was to be organised.
- York had significant problems of inequality, which the strategy should seek to address. It was suggested that other organisations such as the Financial Inclusion Steering Group could provide information and participate in this process.
- A focus on the causes of poverty was needed, rather than only alleviating the symptoms of poverty. York CVS was creating a Poverty Truth Commission to bring together those with lived experience of poverty and those in positions to make local decisions to help to address issues of poverty. It was suggested that this commission could link effectively with the development of a new Joint Health and Wellbeing Strategy.
- Loneliness and social exclusion were significant issues in York. Social prescribing had been a success in combating this, but it was felt that more needed to be done. It was emphasised that although loneliness was often spoken about in the context of elderly people, anyone at any stage in life could experience it. The connection between loneliness and mental/physical ill-health was also discussed.
- It was noted that data had shown that some of the greatest sections of the population reporting feelings of loneliness were young people.
- Once approved, the strategy was to be reviewed annually by the Health and Wellbeing Board along with progress made against delivery

Resolved:

i. That the proposal to renew the Join Health and Wellbeing Strategy be approved.

Reason: To ensure that the Health and Wellbeing Board fulfils its statutory duty to produce a Joint Health and Wellbeing Strategy.

76. Establishment of a Children's and Young People's Health and Wellbeing Programme Board

Board members received a report asking it to approve the establishment of a Children's and Young People's Health and Wellbeing Programme Board as a sub-committee of the Health and Wellbeing Board. The Assistant Director - Consultant in Public Health and the Interim Director of Children's Services were in attendance to present the report and respond to questions.

Key points raised during the presentation of the report included:

- The Children's and Young People's Health and Wellbeing Programme Board would be the successor to the YorOK Board, which had a role in delivering priorities of the Health and Wellbeing Strategy, although it had not met since 2019.
- The purpose of the new programme board was to take forward local strategic priorities and to link into new structures of the Integrated Care System.
- There had been a number of conversations and meetings with local stakeholders around setting up the programme board, as well as a workshop. The result was the draft terms of reference attached to the report.
- The main objectives of the new board were to have oversight of delivery of improvements to maternity, children's and young people's health and care in York and over transformation programmes; to set the strategic direction to improve health and wellbeing outcomes for children and young people in York; to influence the wider things that impact on health and wellbeing such as housing and poverty.
- The principles by which the board was to work included reducing duplication of work, reducing inequalities and taking an asset based approach.

• The suggested membership of the board was also included in the draft terms of reference.

Comments/questions from members included:

- It was suggested that the Terms of Reference include mention of the Starting Well and Growing Well themes from the current Joint Health and Wellbeing Strategy and that Director of Operations, North Yorkshire & York – Tees, Esk & Wear Valleys NHS Foundation Trust be included on the new board.
- Concerns were raised that the only councillors who were members of the proposed board were to be executive members, and that opposition councillors would have no representation unlike the former YorOK Board.
- The manager of Healthwatch requested that her organisation be allowed to send a representative to the new programme board, due to concerns around representation of volunteer groups.
- It was suggested that colleges in York be involved in the new board due to their role in supporting Child and Adolescent Mental Health Services and their links with universities in continuing to support the mental health of young people.
- The first report from the new programme board to the HWBB was expected in September 2022 and thereafter on an annual basis.

Resolved:

- i. That the establishment of a Children and Young People's Health and Wellbeing Programme Board as a sub-committee of the Health and Wellbeing Board be approved.
- ii. That the suggestions made by HWBB members in terms of membership of the programme board be further explored
- iii. That the Terms of Reference for the new programme board be approved subject to annual review.

Reason: To support the health and wellbeing of young people in York.

77. Preventing Harm and Supporting Recovery for those using Drugs and Alcohol in York

This report provided Board members with information on the impact of drug and alcohol use in York and work being done to prevent harm to and support recovery for users. Members are asked to provide comments and feedback and consider signing the North Yorkshire and York 'Dual Diagnosis Pledge'. The Joint Consultant in Public Health was in attendance to present the report and respond to questions.

Key points raised during the presentation of the report included:

- That although York was relatively affluent and had overall good health outcomes, this was not the case when looking at consumption of alcohol.
- Issues around the availability of alcohol, levels of harm of self-reported levels of alcohol consumption (especially during lockdowns), GP referrals and hospital admissions had been explored.
- Health conditions known to be attributable to overconsumption of alcohol included several types of cancer, cardio-vascular disease, dementia, diabetes and poor mental health.
- In York, hospital admissions for both directly and indirectly alcohol caused health conditions were higher than other areas, with multiple deaths each year.
- There was a cohort of people in York with varying levels of addiction, and it was noted that the numbers of people receiving treatment for addiction was likely vastly lower than those using addictive substances.
- The number of people dependent on heroin and crack cocaine, which were the largest two cohorts of drug users both in York and nationally was rising.
- Use of novel psychoactive substances was increasing, especially among children and young people.
- Drug related deaths in the UK had risen year on year for over a decade. The number in York was usually around the low 10s each year.
- School services report that the use of drugs by children and young people was increasing and that parental alcohol and drug abuse was also increasing.
- A new national 10 year drug strategy had been announced by the government, which mentioned alcohol, but focused on substance use.

- The national strategy's aims were breaking drug supply chains, delivering a world class treatment and recovery system and achieving a generational shift in demand for drugs.
- Funding attached to the strategy would increase spending around drugs and alcohol treatment and recovery in York by around 40%, which would place funding at similar levels to the early 2010s. This would enable the thresholds for treatment of individuals for misuse to lower.
- Evidence showed that people who have both addiction and mental health issues (dual diagnosis), often have very poor outcomes and regularly do not receive the highest quality, joined-up service. There were often barriers to getting the right mental health treatment for a patient with addictions and vice-versa.
- A Dual Diagnosis Pledge had been written by all treatment and prevention services in the area with the involvement of primary care and others in York and North Yorkshire was attached at Annex A of the report. This sought to engender a number of cultural changes to do with these services, including not asking whether the patient's mental health issues or addiction manifested first, improved communication and training on addiction and mental health issues.

Comments/questions from members included:

- It was important not to let the criminal implications of drug abuse overshadow the importance and impact of alcohol misuse.
- A local community approach to the wider determinants of substance misuse was needed, considering accommodation, employment opportunities etc.
- Excessive alcohol use remains much more socially acceptable than similar levels of substance use.
- People were often asked to choose between their mental health or their addiction problems, which made more work on dual diagnosis important.
- It was important to embed concerns about drugs, alcohol and dual diagnosis into the new Joint Health and Wellbeing Strategy.
- Limitations of the Trieste model of mental health care were discussed which did not acknowledge dual diagnosis or the potential for neuro-divergent people to selfmedicate with drugs and alcohol to 'normalise' their behaviour.

- Ring-fencing of funding for drug and alcohol abuse was needed because users were amongst the least likely to advocate for their health needs, since very often people who turn to drugs come from difficult and disadvantaged backgrounds.
- There were calls for separate drug and alcohol strategies, because of the differing social attitudes towards them.
- More consideration for the role of drugs and alcohol in the exploitation of children was requested. Child exploitation involving drugs and alcohol was at a higher rate in York than the national average.

Resolved:

- i. That the trends and needs around drugs and alcohol in the City of York be noted with members' comments.
- ii. That the new ten year national drugs and alcohol strategy and its implications for partners in York be noted with members' comments.
- iii. That the proposals to work more closely in partnership with North Yorkshire area, including towards a combined North Yorkshire and York Drugs and Alcohol Strategy be noted with members' comments.
- iv. That the Chair sign the Dual Diagnosis Pledge on behalf of the City of York Health and Wellbeing Board.
- v. That the Chair will write to HM Government indicating the Board's support for 50p per unit as a minimum for alcohol pricing.

Reason: To support the work done on alcohol and drug use in York

78. Verbal Update: Current Situation re: Covid 19

The Assistant Director – Consultant in Public Health gave a presentation on the current situation in relation to Covid-19 including recovery plans. This item was in presentation format to ensure that the most up to date information could be presented to the Health and Wellbeing Board.

Key points raised during the presentation of the report included:

• The case rate in York had been dropping rapidly, and were lower than the England and regional averages, with the lowest case rate in the Yorkshire and Humber Region.

- There had been an increase in the number of cases in younger sections of the population, especially those aged 5-9.
- The number of people admitted to hospital and the Intensive Treatment Unit with Covid-19 was considerably lower than the winter 2020/21 peak.
- There had been 172 excess deaths in York since the start of 2020. Overall the number of deaths were around normal per-pandemic levels.
- There were 13 care homes in York with confirmed cases of Covid-19 and 515 school-aged children who had tested positive in the 7 days leading up to 17/01/2022.
- The vaccination programme had continued, with the greatest focus on those recently eligible for their first or second doses, especially those aged 12-15 or younger.
- Overall, vaccine take-up was lower in younger age groups and more economically deprived wards of the city. Work was underway to reach those who had not been vaccinated, for example targeted pop-up clinics were being held in areas of low take-up.

Comments from the Chief Executive, York Teaching Hospitals NHS Foundation Trust on the situation in York Hospitals included:

- That admissions to the hospital had plateaued in recent weeks, but he was anticipating admissions to begin reducing as the number of infections lowered.
- The largest challenge was staffing, with absence rates among hospital workers sometimes going above 10%. There were some absences were decreasing, but it remained high.

In response to questions and comments from Board members, it was noted:

- Data was available for the number of patients admitted to hospital who caught Covid-19 during the course of their treatment there. It was confirmed that all patients were tested on admissions and subsequently at regular intervals, however some infections were inevitable due to the highly transmissible nature of the Omicron variant.
- It was suggested that members of the Public Health team speak to colleagues in Nimbus Care and the Clinical Commissioning Group to explore briefing ward councillors on levels of vaccine take up and intelligence around the reasons people may not be choosing to be vaccinated.

- There were challenges around transport to vaccination sites for some residents, especially in the city centre where car ownership is relatively low. Pop-up vaccination centres helped with this, it was felt more could be done to encourage people to attend pop-up clinics and spread awareness of them.
- Any residents having difficulties booking their booster vaccines, especially those with compromised immune system who have already had three primary injections, should present themselves to their GP who will be able to provide proof that they require another vaccination.

Resolved:

i. That the contents of the update be noted.

Reason: To keep Board members up to date on the Covid-19 pandemic.

Cllr C Runciman, Chair [The meeting started at 4.30 pm and finished at 6.30 pm].



Health and Wellbeing Board

16 March 2022

Report of the Manager, Healthwatch York

Healthwatch York Reports: Dentistry in York: Gaps in Provision

Summary

1. This report is for information, sharing a report from Healthwatch York looking at people's experiences of dentistry in the city.

Background

2. Healthwatch York provides a signposting, information and advice service, helping people navigate health and care. A significant proportion of this work currently is around access to NHS dentistry. As a result we previously published a report about how many NHS dentists were taking on patients in York. This report now looks at people's experiences of dentistry in the city, following a public survey. The survey was very similar to one we conducted in 2018, with the addition of one question about the wider impacts of dential pain.

Main/Key Issues to be considered

- 3. Our previous work looking at dentistry showed things were very challenging. However, it is clear the position has worsened.
- 4. Since the report has been published, the situation has deteriorated further, with both York Dental and Perfect Smile contacting patients to let them know they will no longer be seen as NHS patients. This affects around 10,000 patients in York. Healthwatch York has received a high volume of calls and emails from people affected by this change.

Consultation

5. This report provides the results of a survey, alongside further issues reported to Healthwatch staff at engagement activities.

Options

- 6. Health and Wellbeing Board are asked to note the report, and the 4 areas for action we have identified on pages 57-58 of our report. Namely:
 - a. Rapid and radical reform of the way dentistry is commissioned and provided
 - b. Tackling the twin crises of access and affordability, with particular emphasis on addressing health inequalities
 - c. Improving the clarity of information about NHS dentistry
 - d. Consideration of the role of dentistry to support people's overall health, harnessing opportunities such as the integration of health and care through Integrated Care Systems arrangements, to link oral health to other key issues such as weight management, smoking cessation, cancer awareness and detection, and mental wellbeing.

Strategic/Operational Plans

- 7. The workplan for 2021/22 has been developed to support Healthwatch York continue to explore issues affecting people when accessing or trying to access health and care services in York, and to connect to key initiatives driving change forward. Problems with accessing NHS dentistry remain one of the key challenges people talk to us about.
- 8. All partners have identified the need to understand the barriers to accessing care and removing them as essential to the transformation of local health and care through the work of the ICS at place.
- 9. This report has already been considered by the Health and Adult Social Care Policy and Scrutiny Committee at their January meeting. They have written to the Secretary of State to flag their concerns.

Implications

- 10. 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

11. There are no risks associated with this report.

Recommendations

- 12. The Health and Wellbeing Board are asked to:
 - i. Receive Healthwatch York's report, Dentistry in York: Gaps in provision

Reason: To keep up to date with the work of Healthwatch York and consider what can be done to improve access to dentistry in the city.

Contact Details

Author:	Chief Officer Responsible for the report:	
Siân Balsom Manager Healthwatch York 01904 621133	Report Approved	x Date 08/03/2022
Wards Affected: All		

For further information please contact the author of the report

Background Papers:

Annexes Annex A – Dentistry in York: Gaps in Provision Dentistry in York - Gaps in Provision - January 2022.docx (healthwatchyork.co.uk)

ANNEX A



Dentistry in York -Gaps in Provision January 2022





Acknowledgments

Thank you to everyone who took time out to fill in our survey.

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Summary of Key Points

We acknowledge the huge impact of the COVID-19 pandemic and the additional pressures that enhanced infection and prevention control measures will have imposed on dental practices. However, we believe that the pandemic is not the only cause of the problems outlined below. Access to NHS dental care has been a problem in York for many years and continues to be at crisis point. This is creating additional pressures in other parts of the health system particularly the emergency department and primary care. We need rapid and radical reform of the way dentistry is commissioned and provided.

- In our 2018 survey we asked 'do you have a dentist'? 84% of those who answered this question said they had a dentist. In 2021 this 59% said they had a dentist. This represents a decline over 3 years of 30%.
- Those respondents who did not have an NHS dentist were asked why this was so. In 2018 46% of people replied that they 'couldn't find a dentist taking on NHS patients'. In 2021 this had risen to 71%, an increase of 54%.



- There was a large increase in the percentage of respondents who had not seen their dentist for 1-2 years (a 200% increase), 2-3 years (a 633% increase), 'only in emergencies' (a 200% increase) and 'I don't' (a 100% increase).
- In 2018 the percentage of respondents replying that cost had stopped them getting dental treatment was 28%, in 2021 it was 40% (an increase of 43%).
- In 2018 8% strongly disagreed with the statement 'I can get appointments with my dentist when I need them'. In 2021 41% of respondents strongly disagreed with this statement (an increase of 413%).
- In 2018 7% of respondents strongly disagreed with the statement 'my dentist is in a convenient location for me.' In 2021 this percentage had risen to 26% (an increase of 271%). The percentage of respondents agreeing with the statement in 2018 was 40% and in 2021 this had reduced to 17% (a reduction of 57%).
- In 2018 45% of respondents rated their experience as 'excellent', in 2021 this had fallen to 27% (a reduction of 40%). In 2018 3% rated their experience as 'very poor', in 2021 this had increased to 14% (an increase of 367%).
- 27% of the respondents to the question 'Do you all go to the same dentist?' reported that 'none of us has a dentist'. Of those who answered yes or no to this question, in 2018 36% of respondents said that 'not everyone in the household had the same dentist'. In 2021 this was 68%.

ANNEX A

- healthwatch
- In 2018 the majority of respondents went to the same dentist (74%). In 2021 this had reduced to 46%.
- In 2018 69% of respondents said that they were happy with their family's arrangements for visiting a dentist. In 2021 this had reduced to 27%.
- In 2018 6% of respondents reported that their dental practice was 'not at all accessible'. In 2021 this had risen to 32% (an increase of 433%).
- Out of 153 respondents 79 (52%) reported having one or more of the problems associated with dental pain or poor oral health listed in our survey. Of those that listed at least one symptom 43% reported not being able to sleep properly, 40% reported feeling self conscious about their appearance, 25% unable to eat healthy food, 10% unable to work, 6% unable to undertake physical exercise, 3% unable to care for someone else and 21% listed 'other'.



Background

Healthwatch York has been hearing from the public about issues regarding dentistry since we started in 2013.

In 2018 Healthwatch York published 'Filled to Capacity: NHS Dentistry in York a Report Based on Local People's Experience', which found that it was difficult to access NHS dentistry in the city. At that time 46% of people that responded to our survey reported that they couldn't find an NHS dentist that was taking patients and 45% of people who had been looking for an NHS dentist said they had been trying for over 2 years.

https://www.healthwatchyork.co.uk/wp-content/uploads/2014/06/Healthwatch-Y ork-Access-to-NHS-Dentistry-Report-2018.pdf

Healthwatch England continued to hear concerns about dentistry which were highlighted at the end of 2020 in the 'Dentistry and the Impact of COVID-19 Report'.

https://www.healthwatch.co.uk/news/2020-12-09/dentistry-and-impact-covid-19

Their report shows a 452% rise in calls and complaints throughout the summer of 2020. In a follow-up review, Healthwatch England looked at 1,129 people's experiences of accessing dental care received between October and December 2020 and found that access to dentistry was difficult for more than 7 in 10 people (72%), with some people actively seeking dental treatment being told they would have to wait anywhere between a few months to, in one case, two years for an appointment.

Healthwatch England's research continued to show many people continue to struggle to access or afford NHS dental treatment. Feedback on NHS dental care between January and March 2021 found that 80% of people found it difficult to access timely care. Other data sources mirror these findings:

• When the National GP Patient Survey asked if people if they had successfully got an NHS dental appointment in the last two years, in



2020, 6% of the respondents had said no. In contrast, in 2021, this figure was nearly four times higher at 23%.

- In 2020-21, the NHS delivered 69% fewer courses of treatment compared with the previous year, NHS Dental Statistics for England Annual Report.
- The difference in the number of appointments for children in 2021 is particularly stark. An analysis of NHS Digital Data for 2019 and 2021 found that the number of child patients seen has nearly halved, 44% down in 2021 compared to two years earlier.
- NHS Digital's figures also suggest that dental access issues are now acute in many areas. Our analysis of the latest data* found that seven of the NHS's 42 new sub-regions, known as Integrated Care Systems, report that they have no practices taking on new adult NHS patients. And less than one in five (17%) of practices say they are taking on new child NHS patients at the moment.

<*Data supplied by NHS Digital on 7 December 2021>

Healthwatch England previously called for more emphasis to be placed on solving structural issues within NHS dental services and warned that dental care was facing an immediate crisis. The Chair of Healthwatch England, Sir Robert Francis QC, said:

"The big worry about the shortage of NHS appointments leading people to private care is that it further deepens the health inequalities that COVID-19 has starkly highlighted. We won't build back a fairer service until access to NHS dentistry is equal and inclusive for everyone. Today, dentistry remains the only part of the NHS that receives a lower budget in cash terms than in 2010. The ongoing neglect of NHS dentistry will have repercussions for the life-long health of current and future generations. Lack of access to dental care,



particularly for children, is a hugely worrying issue that the NHS must tackle immediately."

In July 2021 we published 'NHS Dentistry - A Service in Decay?' which exposed a continuing decline in access to NHS dentistry in the city.

Volunteers and staff at Healthwatch York contacted all 39 practices in the city. At the time of the research in May and June 2021 we found that no practice in York was currently accepting new NHS adult patients. We called for urgent and rapid reform of NHS dentistry.

The full report can be viewed at:

https://www.healthwatchyork.co.uk/wp-content/uploads/2021/07/NHS-Dentistry -A-Service-in-Decay-July-2021-2.pdf

Healthwatch York Manager, Siân Balsom said;

"NHS dentistry in the city has reached a new low and is in need of urgent and radical reform. If we fail to act soon we'll be putting further pressure on an already severely stressed health system."

In November 2021 Director of Public Health in York wrote to the Chief Dental Officer on behalf of the City of York Health and Wellbeing Board to inform her of the *"concerns we have about poor access to NHS dental care for adults and children living in York."*

The letter detailed some of the findings from our report and added; "reports from the health visiting service (are) that parents are unable to access routine dental care for their children. This is of particular concern given the rise in hospital admissions of children requiring dental treatment under anaesthetic."

"The Health and Wellbeing Board understand that the deteriorating situation will, in part, be caused by the impact of the COVID-19 pandemic and the additional pressures that enhanced infection and prevention control measures will have imposed on dental practices. However the pandemic is not the primary cause of the problem. Access to NHS dental care has been a problem in York for many years but is now at crisis point. The Board also heard that the



lack of dental care is creating additional pressures in other parts of the health system particularly the emergency department and primary care."

The letter concluded; *"it is clear that a significant reform of the national dental contract is required to address the increasing problems of access to NHS dental care in the longer term. The Health and Wellbeing Board look forward to receiving your response to the issues raised in this letter together with an update on the work that is going on nationally to address our concerns."*

A high level of feedback from patients concerning dentistry has continued throughout the Autumn of 2021. Some examples are detailed below:

"Person has a serious issue with gums and has been trying to get NHS treatment. Only offered private treatment at a cost of £4,000."

"Person has been trying to get an NHS dentist due to an urgent issue with his teeth. Has called NHS 111 and contacted all the dentists they suggested, but none of those was accepting emergency cases."

"Man trying to find a dentist for himself, his wife and family. Looked up dentists, called 10. None taking people on, waiting lists of 2-4 years for treatment. So called NHS England. They told him they can't help, and that they know the information on the website isn't up to date so he'd have to call all of them as that's the only way. They also said patients are expected to be able to travel up to 30 miles to access a dentist so he should look at places like Leeds as they might be better."

"I'm looking for an NHS dentist for myself and for my family in York. As far as I can tell such a thing doesn't exist, and the whole industry has been privatised by stealth. I have contacted many practises and got nowhere. There is one 1 place I've found that's taking new people on and they have a 3 year waiting period."

"Partner had a broken tooth, trying to get urgent care. Was eventually given an appointment in Scarborough, which she was worried she'd struggle to get to. She called to find out what they would do, and they told her she would just get a temporary filling as urgent care. So she had to pay for a private appointment for a permanent fix, but saved the train fare to Scarborough."



"I am an NHS patient with this dental practice which has always been excellent. However I recently received a letter from them stating that my planned appointment with a dentist has been cancelled. I have not seen a dentist for 2 years. Apparently they are unable to deal with routine appointments due to the backlog as a result of Covid, and are asking patients to only contact them if they need emergency treatment."

"Unable to find an NHS Dentist that's taking on new patients."

"Child has Hypomineralisation. Needs 3 month check ups as teeth can cause severe pain. Child is on waiting list with London hospital to have teeth removed but huge delays mean this can take a long time. Parents are unable to find a dentist in york that will take on a new patient. Escalated to NHS England and received a generic response stating that it was their responsibility to find a dentist. Parents would like info on anywhere that is taking appointments and also on how to escalate the issue further. Shocked as feels this is the responsibility of the Government to ensure that children are able to receive regular checkups as part of general health."

"It is rather alarming that, 7 months on from my original email, I am still unable to find an NHS dentist anywhere within a sensible distance of York! I have just rung the only practices listed as accepting new NHS patients, only to be told that they have a 3 year waiting list. I am now not only thinking of myself (still entitled to free dental care, supposedly, and with rapidly deteriorating teeth I can't afford the hundreds of pounds to fix!) I am also thinking of my baby son, who should start having dentist appointments as soon as his teeth come through."

"We have been residents of York for a year now and I have contacted every local NHS registered dentist but none have places. We are now on a waiting list of people over 2,000 long. Please can you advise what options are available to us - private care is incredibly expensive for a family of 4."

A parliamentary question in January 2022 revealed that in the year up to March 31, 2019, there were 239 dentists working in the Vale of York CCG area, by March of 2020 that had fallen to 218 and by March last year, it was down to 209; lower than at any time since 2015.

ANNEX A



In January 2022 The British Dental Association (BDA) said that 'from this month, NHS dentists have been required by government to treat at least 85 per cent of the number of patients they treated before the Covid pandemic, but almost two thirds of practices say they are 'incapable' of doing that;

"Treating large numbers of patients is 'entirely at odds' with efforts to prevent the spread of Covid, and would 'put both patients and staff at unnecessary risk', the organisation says. As a result, more than 40 per cent of NHS dentists say they are now likely to change career or seek early retirement."

The BDA's North Yorkshire representative Mark Green said:

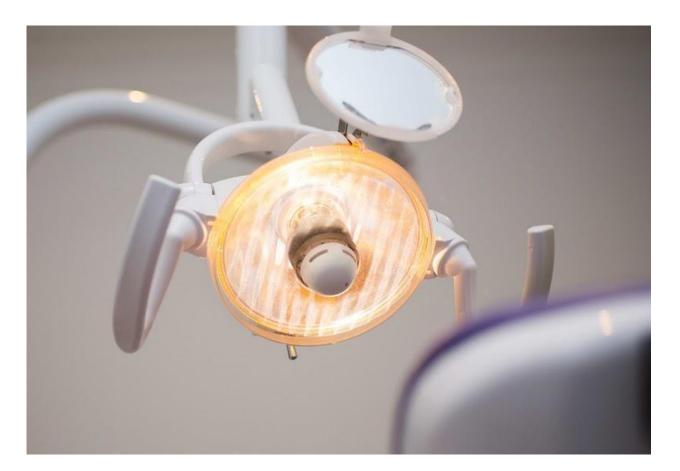
"Last year nearly a thousand dentists left the NHS in England. For years we've worked to a broken system that's failed to recognise and reward commitment to the NHS. Now, to add insult to injury, Ministers have imposed ludicrous targets during the Omicron wave. Colleagues who have worked their whole professional lives in the NHS are now looking for the exit."

<York Press, 11th January 2022>

In the Autumn of 2021 we launched an online survey for people in York about their experiences of accessing NHS dentistry in the city and complemented this with outreach sessions at a variety of locations. The following section details our findings.

ANNEX A





Our Findings

Question 1. Do you have a dentist? (173 respondents)

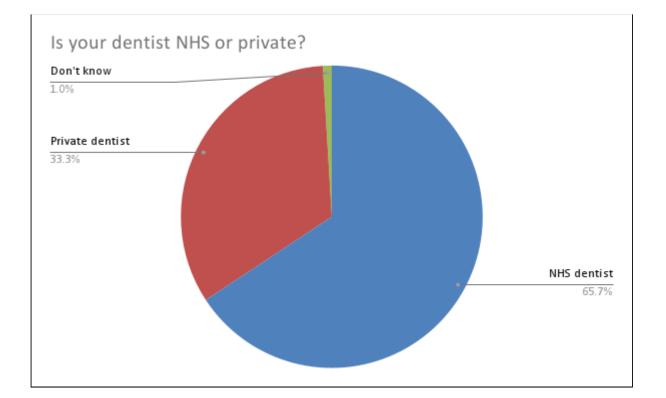
In our 2018 survey 84% of those who answered this question said they had a dentist. In 2021 this 59% said they had a dentist. This represents a decline over 3 years of 30%.

Q2. Is your dentist NHS or private? (100 respondents)

In our 2018 survey 62% of respondents had an NHS dentist, 23% had a private dentist. In 2021 66% of respondents had an NHS dentist and 33% had a private dentist. There has been a notable 43% increase in the number of respondents accessing private dentistry since 2018.

ANNEX A

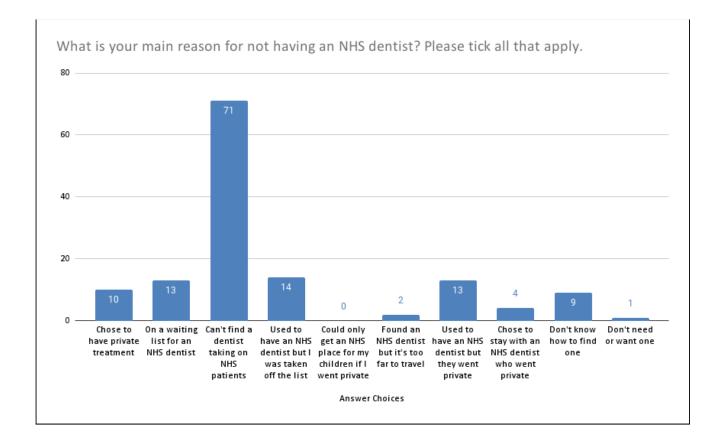






Question 3. What is your main reason for not having an NHS dentist? (100 respondents and options to give more than one reason)

Those respondents who did not have an NHS dentist were asked why this was so. In 2018 46% of people replied that they 'couldn't find a dentist taking on NHS patients'. In 2021 this had risen to 71%, an increase of 54%.

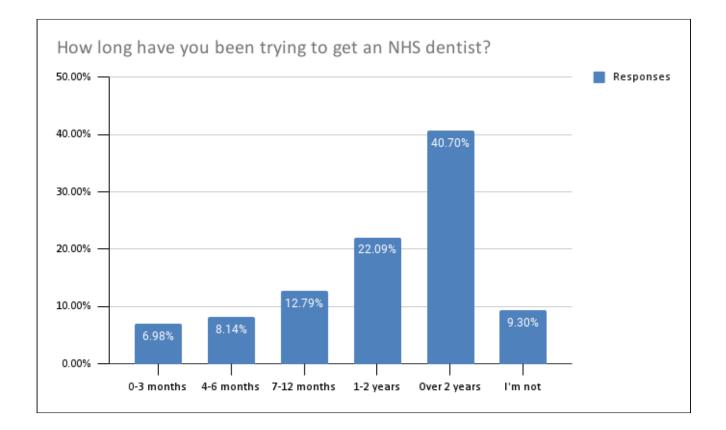






Q4. How long have you been trying to get an NHS dentist? (86 responses)

In 2018 45% of respondents reported that they had been looking for over 2 years. In 2021 this had fallen slightly to 41% and 1-2 years had fallen very slightly from 24 to 22%.



Q.5 Which of the following have you tried to find an NHS dentist? (82 responses and able to give more than one answer)

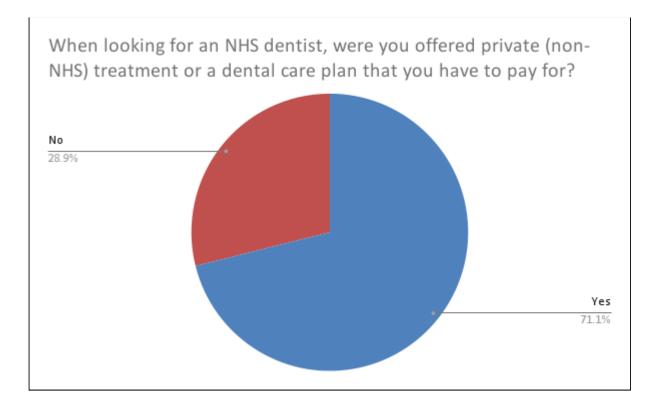
This question was asked to those who did not have an NHS dentist. In 2018 69% or respondents 'contacted dentists directly', in 2021 this had increased to 84. In 2018 'NHS choices' had been contacted by 59% of respondents in 2021 this had risen to 73%. An 'internet search' was performed by 39% of respondents in 2018, in 2021 it was 68%.



Q.6 When looking for an NHS dentist, were you offered private (non

NHS) treatment or a dental care plan that you have to pay for? (83 Respondents)

In 2018 56% of respondents who were looking for an NHS dentist were offered private (non NHS) treatment or a private dental care plan. In 2021 this increased to 71%.

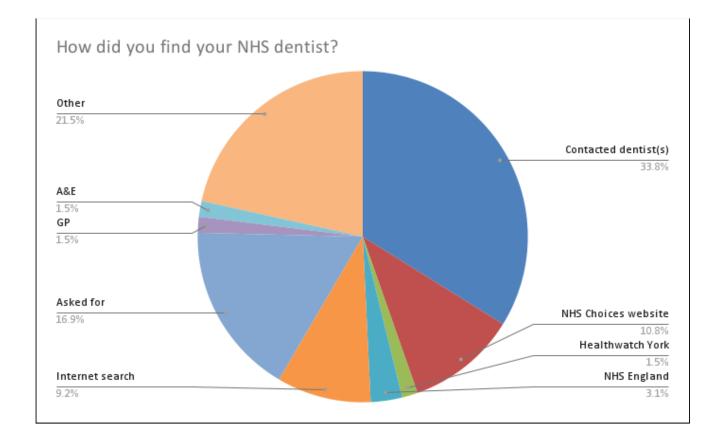






Q.7 How did you find your NHS dentist? (48 responses from respondents with an NHS dentist and options to give more than one answer)

Direct contact with dental practises remained the primary method of respondents in 2021 (34%). The profile of responses remained broadly similar to 2018, although A&E, Healthwatch York and GPs were specifically mentioned in 2021.

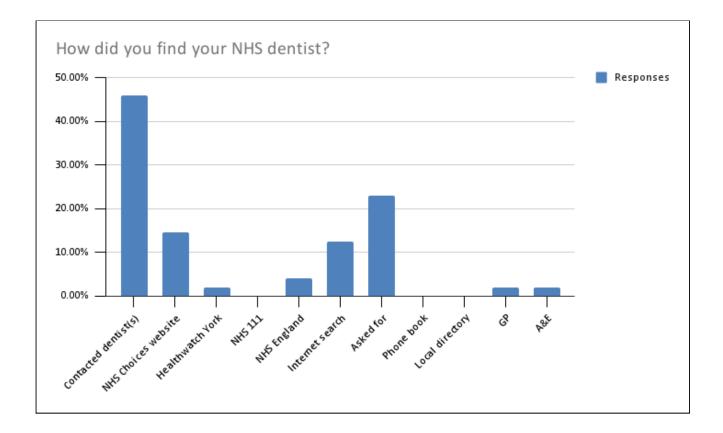




Q.8 How long did you wait to get your NHS dentist? (60 respondents)

The waiting times for participants who already had an NHS dentist were similar in both the 2018 and 2021 surveys, however, the percentage of respondents waiting over 2 years fell from 10% to 5% in 2021.

	2018	2021
0-3 months	59%	62%
4-6 months	16%	15%
7-12 months	10%	10%
1-2 years	6%	8%
Over 2 years	10%	5%



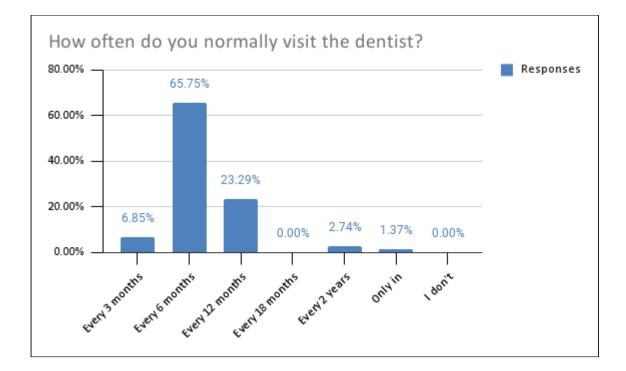


Q.9 Which dentist do you go to? (76 respondents)

It was interesting to note that alongside local York practices respondents listed dentists as far afield as Stokesley, Great Ayton, Whitby, Selby, Easingwold, Bradford and London.

Q.10 How often do you normally visit the dentist? (73 respondents)

66% of respondents normally visit the dentist every 6 months and 24% annually. This was broadly in line with the previous survey in 2018 (69% six-monthly and 19% annually).





Q.11 When did you last see a dentist? (156 respondents)

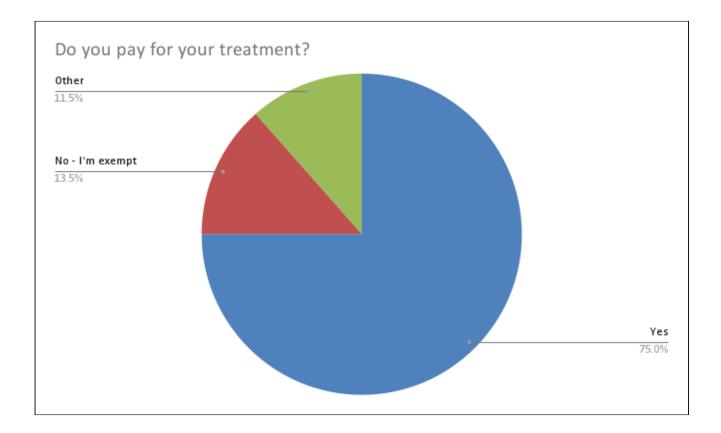
There was a large increase in the percentage of respondents who had not seen their dentist for 1-2 years (a 200% increase), 2-3 years (a 633% increase), 'only in emergencies' (a 200% increase) and 'I don't' (a 100% increase).

	2018	2021
Within the last 2 weeks	13%	7%
3 weeks to 1 month	14%	11%
2-3 months	23%	10%
4-6 months	25%	9 %
7-12 month	10%	10%
1-2 years	5%	15%
2-3 years	3%	22%
Only in emergencies	3%	9 %
l don't	3%	6%



Q.12 Do you pay for your NHS treatment? (156 respondents)

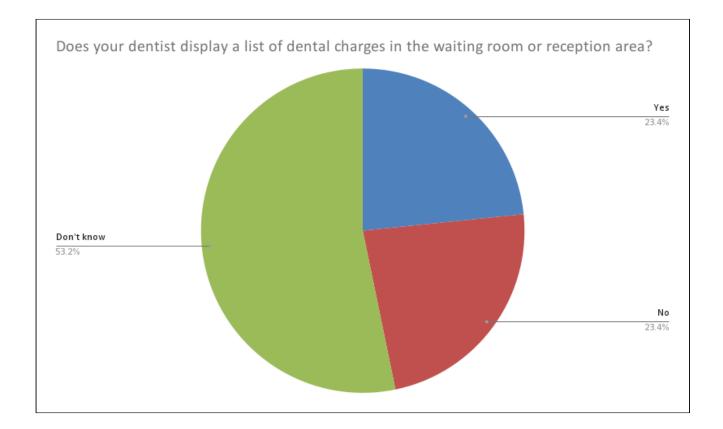
75% of respondents paid for their treatment in 2021, 13.5% were exempt and 11.5% replied 'other'. This is a broadly similar profile to the 2018 results.





Q.13 Does your dentist display a list of dental charges in the waiting room or reception area? (156 respondents)

In 2018 44% of respondents reported that their dentist did display a list of dental charges, but in 2021 this had fallen to 23%.

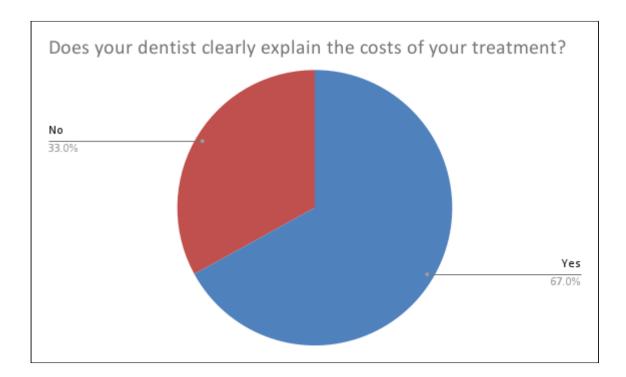






Q.14 Does your dentist clearly explain the costs of your treatment? (156 respondents)

In 2018 65% reported that their dentist clearly explained the costs of their treatment, in 2021 this remained broadly similar (67%).

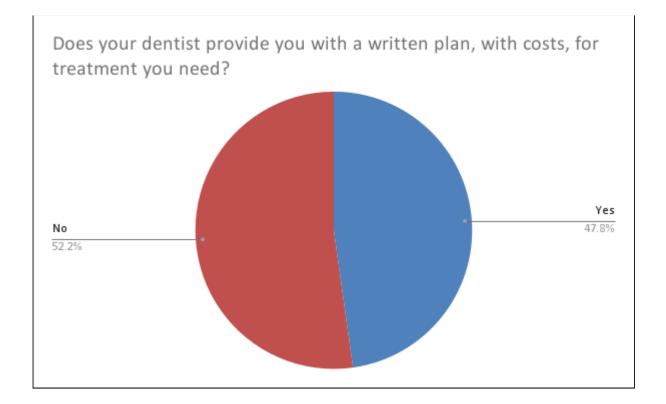






Q.15 Does your dentist provide you with a written plan, with costs, for treatment you need? (155 respondents)

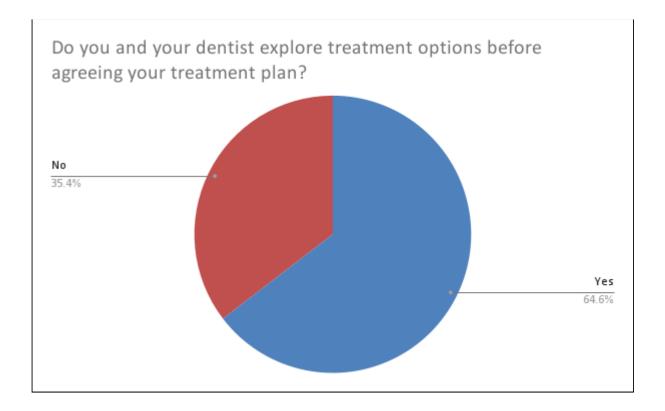
48% of respondents reported that their dentist did provide them with a written plan, with costs, for treatment they needed. This is broadly similar to the 2018 survey (45%).





Q.16 Do you and your dentist explore treatment options before agreeing your treatment plan? (154 respondents)

40% of respondents reported that they explored their treatment options with their dentist before agreeing their treatment plan. This is a reduction since the 2018 survey (73%).

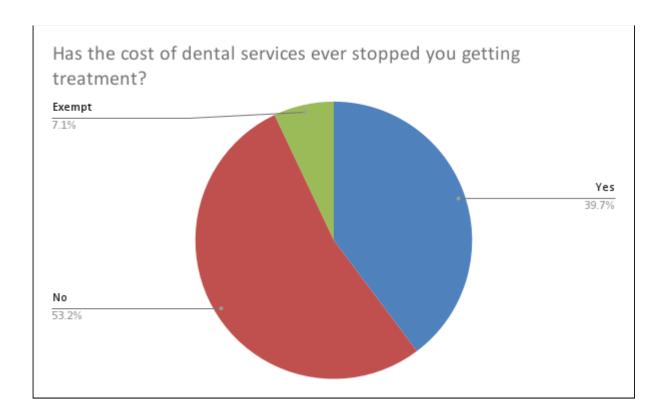




Q.17 Has the cost of dental services ever stopped you getting treatment?

(156 respondents)

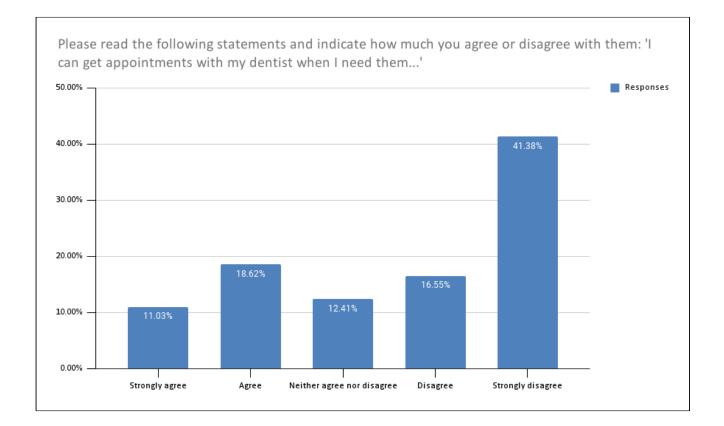
In 2018 the percentage of respondents replying that cost had stopped them getting dental treatment was 28%, in 2021 it was 40% (an increase of 43%).





Q.18 I can get appointments with my dentist when I need them (145 respondents)

In 2018 8% strongly disagreed with the statement 'I can get appointments with my dentist when I need them'. In 2021 41% of respondents strongly disagreed with this statement (an increase of 413%).

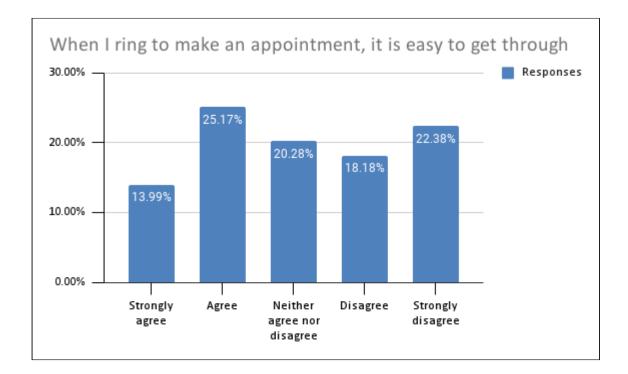






Q.19 When I ring to make an appointment, it is easy to get through (143 respondents)

In 2018 50% of respondents agreed with the statement 'when I ring to make an appointment, it is easy to get through.' In 2021 25% of respondents agreed (a reduction of 100%). In 2018 6% of respondents 'strongly disagreed' with the statement. In 2021 22% of respondents 'strongly disagreed' with the statement (an increase of 267%).

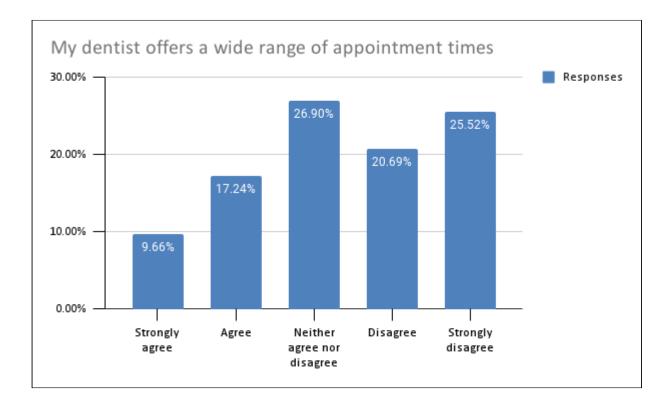






Q.20 My dentist offers a wide range of appointment times (145 respondents)

In 2018 50% of respondents agreed with the statement 'my dentist offers a wide range of appointment times.' In 2021 25% of respondents agreed (a reduction of 100%). In 2018 6% strongly disagreed. In 2021 22% strongly disagreed (a reduction of 276%).

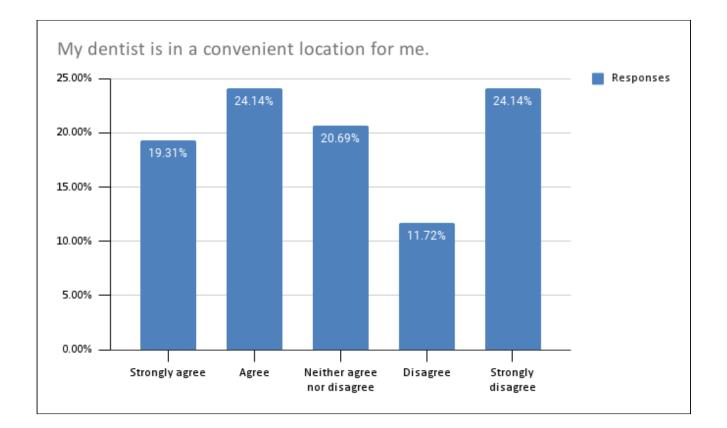






Q.21 My dentist is in a convenient location for me

In 2018 7% of respondents strongly disagreed with the statement 'my dentist is in a convenient location for me.' In 2021 this percentage had risen to 26% (an increase of 271%). The percentage of respondents agreeing with the statement in 2018 was 40% and in 2021 this had reduced to 17% (a reduction of 57%).

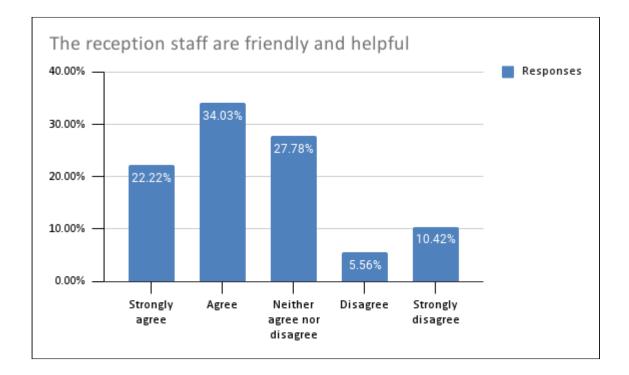






Q.22 The reception staff are friendly and helpful (144 responses)

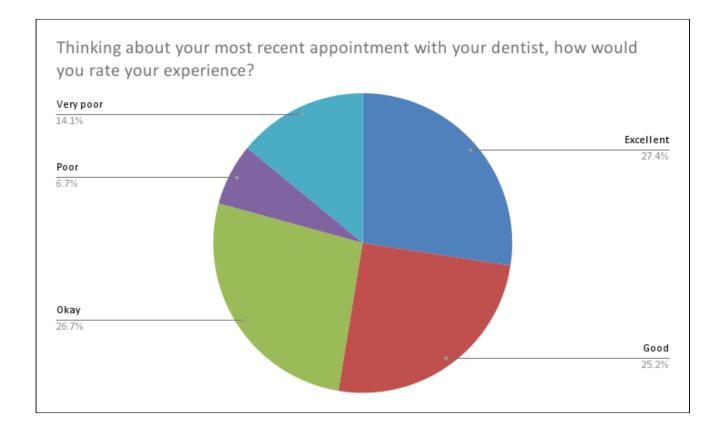
In 2018 52% of respondents 'agreed' with the phrase 'the reception staff are friendly and helpful.' In 2021 the percentage of respondents agreeing had reduced to 34% (a reduction of 35%). In 2018 3% of respondents strongly disagreed with the statement, in 2021 10% strongly disagreed (an increase of 233%).





Q.23 Thinking about your most recent appointment with your dentist, how would you rate your experience (135 responses)

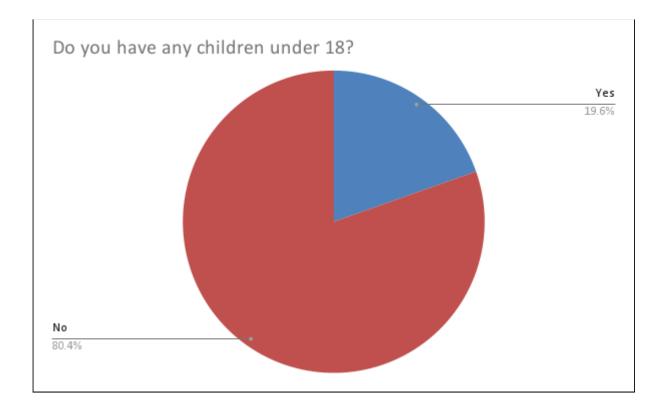
In 2018 45% of respondents rated their experience as 'excellent', in 2021 this had fallen to 27% (a reduction of 40%). In 2018 3% rated their experience as 'very poor', in 2021 this had increased to 14% (an increase of 367%).





Q.24 Do you have any children under 18? (153 respondents)

20% of respondents stated that they had children under 18.

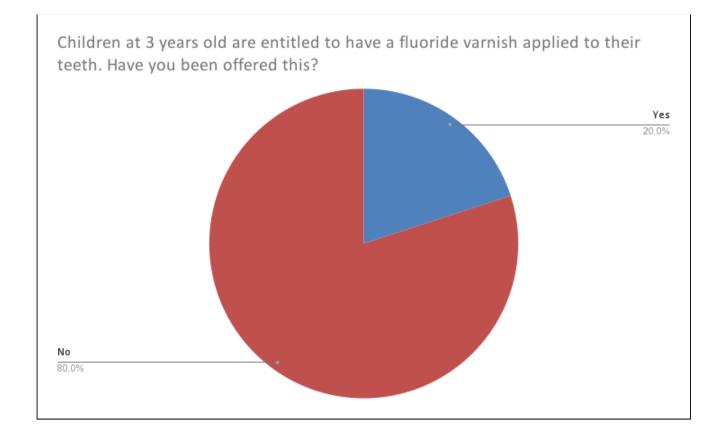






Q.25 Children at 3 years old are entitled to have a fluoride varnish applied to their teeth. Have you been offered this? (30 respondents)

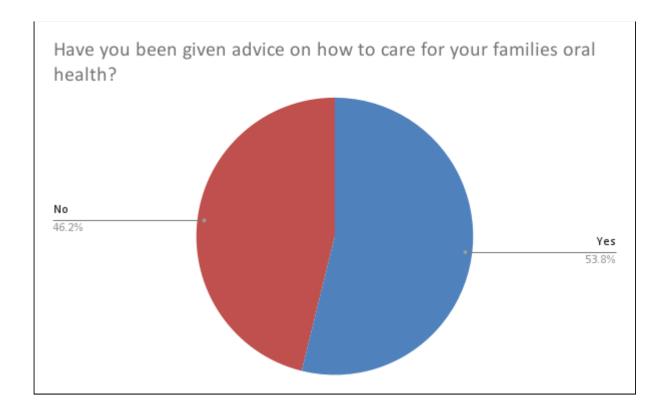
In 2018 52% of respondents replied that they had been offered a fluoride varnish for their children. In 2021 this percentage was 20% (a reduction of 62%).





Q.26 Have you been given advice on how to care for your family's oral health? (30 respondents)

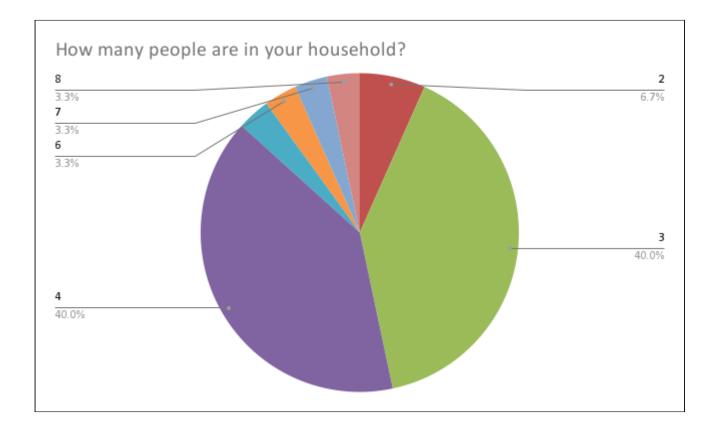
In 2018 once removing those who stated it was not applicable, 81% of respondents had been offered advice on how to care for their family's oral health. In 2021 this percentage was 54% of respondents.





Q.27 How many people are in your household? (30 respondents)

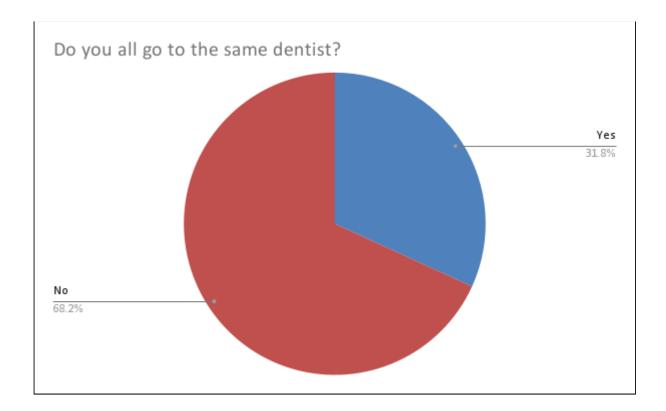
87% of respondents said that they had a household of 4 people or fewer.





Q.28 Do you all go to the same dentist? (30 respondents)

27% of the people who answered this question reported that 'none of us has a dentist'. Of those who answered yes or no to this question, in 2018 36% of respondents said that 'not everyone in the household had the same dentist'. In 2021 this was 68%.

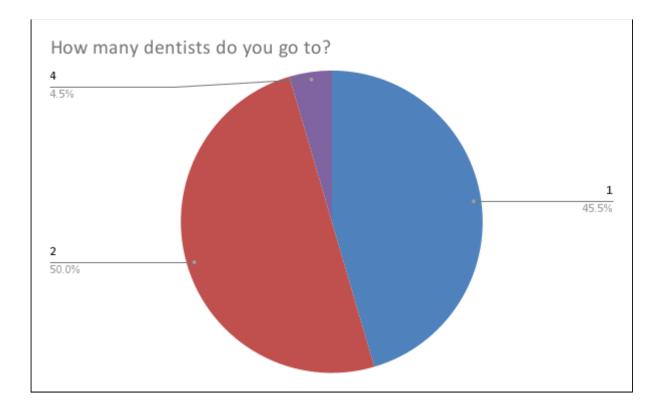






Q.29 How many dentists do you go to? (30 respondents)

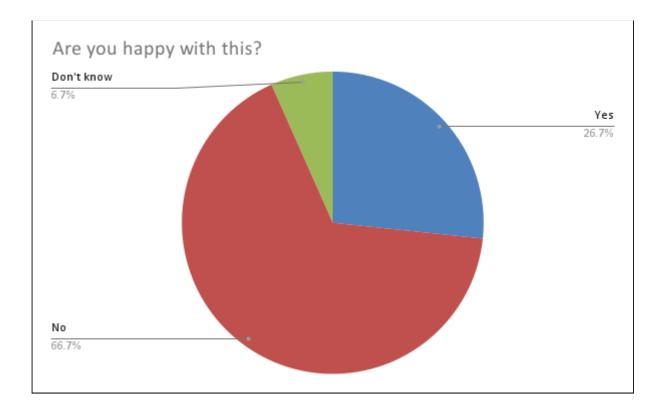
In 2018 the majority of respondents went to the same dentist (74%). In 2021 this had reduced to 46%.





Q.30 Are you happy with this? (30 respondents)

In 2018 69% of respondents said that they were happy with their family's arrangements for visiting a dentist. In 2021 this had reduced to 27%.



Q.32 Do you have any comments about dental access for families? (30 respondents)

Comments included:

"Most dentists in York won't even put us on a waiting list for NHS places. We have to drive so far to get to our NHS dentist it's inconvenient and makes us miss work."

"I think there needs to be some prioritisation - to make sure families with young children get to establish healthy habits now. It's been really tough during the pandemic but we need to make things like dental check ups routine for





children. That's impossible with so many families unable to find an NHS dentist."

"When did dentistry become something only for the wealthy?"

"Me and my sons have been trying to get a dentist in York for over two years,my teeth are loose, I have permanent toothache, my 26 year old son has exposed nerves and crumbling teeth he's in permanent agony where he is crying, my 16 year old has tooth ache all the time."

"I rang 22 dentists in and around York and most had no space with a few who had 3 year waiting lists."

"I have registered for an NHS dentist in xxx which is a 40 minute drive for me but they can't get me an appointment until 2022."

"I have booked into xxx and am paying privately a one off fee to ensure we all get seen this year. I have a tooth that needs attention so I could not wait."

"My son who is 3 has only been to the dentist once in his life and my daughter who is nearly 2 hasn't been seen yet."

"Every child should be able to access dental care where they live."

"It's appalling. I don't buy that it's all down to the pandemic. Our original xxx dentist left at least a year before it started and we were already struggling."

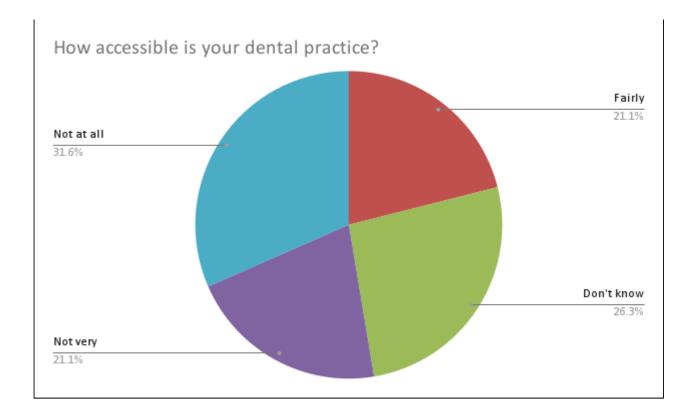


32. Do you consider yourself a disabled person or have any access issues? (151 Respondents)

13% of respondents said that they 'considered themselves to be a disabled person or have access issues.'

Q.33 How accessible is your dental practice e.g. automatic doors, lifts, ramps, hearing loops? (19 Respondents)

In 2018 6% of respondents reported that their dental practice was 'not at all accessible'. In 2021 this had risen to 32% (an increase of 433%).







Q.34 Are there any things your dental practice does really well that you think other dental practices could learn from? (60 respondents)

Negative comments:

"No, they've gone massively downhill even prior to covid and seem more interested in private work and implants."

"No, I think they are very commercial and constantly try to sell extra treatments."

"Keeps us hanging on phone listening to stupid music."

"As someone who is nervous about dentists, faints when having blood tests, etc, I would hope that they are all kind and compassionate with someone like me. It is partly my fear that is keeping me away from the dentist, in addition to the challenges of being able to pay."

Positive comments:

"Always checks jaw etc. and recommends the best inter-dental product and can supply them but suggests where I could get them at a cheaper rate."

"Good availability of appointment times."

"Dental hygiene is prioritised."

"Cheerful."



"They explain everything very fully."

"I have been with my dentist for 30 years and wouldn't choose to go anywhere else. Very customer-service focused, reliable and proficient. Worth travelling to London for!"

"Have no complaints....always had excellent service.....it's private practice."

"They are wonderful. They listen, they care, they are efficient and helpful."

"The professionalism of the dentist when you actually get to see him is very high!"

"They usually send text or call reminders about appointments."

"The new contact system by email is an improvement and gets a response."

"They are aware of my extra physical issues and take extra care to ensure my comfort as much as possible."

"Empathy."

"Very friendly and an advocate of the NHS dental services."

"My last dentist was super efficient and skilled at her job. I understand the delay to my appointment is due to her leaving."

"Reasonable prices if taking up the private option."



"Private dentists are ok, providing that they are more available and prices do not ruin the average household budget."

"They stayed open through the pandemic. Some of my friends' dentists still are not open and must be hiding away like the GPs."

"The reception teams are good at all places...other than that I'm all round upset with the whole thing."

"Friendly reception staff."

Suggestions for improvement:

"TV above the dental chair to distract nervous patients."

"Having clear pay-as-you-go prices online. As someone with relatively healthy teeth, I've never really needed to pay for a plan and so having annual checkups and hygiene appointments is all I'm ever looking for. If I do need any further dental work, I know I can always refer back to the website to keep an eye on my costs."

Q.35 Is there anything else you want to tell us about your dentist? (70 respondents)

Reduced service

"This practice used to pride itself on being an NHS centre of excellence but no more. They've recently lost staff, their reputation - and lost their way!"

"As it has grown over the years the service is not as good."



"Turnover of dentists seems to be high. Rarely see the same person more than twice."

Effect of Covid-19

"I'm glad I have them given the appalling situation re: dental access in York."

"I have been impressed by the way they have adapted to new procedures in the light of Covid-19."

"Dealt with the difficulties arising from the pandemic in an extremely professional manner."

"I do like my practice and do understand that they have struggled to maintain service levels as the building is old and hard to make Covid secure. There seems to be high staff turnover though."

Tensions with private treatment

"There is a clear divide between NHS and paying patients in terms of waiting areas, etc."

"Some reception staff treat private patients more favourably than NHS patients."

"Would not see people all last year even though other dentists would. May have seen me if I was private but no access for NHS patients."

"We have had adverts for private dental appointments while still being told we cannot have a routine NHS appointment."



"They take more care and have more time for the private or cosmetic dentistry patients than the NHS patients and this is not fair. We can't all afford a private dentist but don't make us feel like we have a lesser right to seek treatment like we are a burden on them."

Quality of care

"Dental treatment now seems very rushed with little consultation. Have had to return several times for the same filling to be done, as it keeps breaking up. Inferior materials? Now faced with cost of a crown, but will it last?"

"I do not believe he was efficiently up to date with his qualifications, training, I wonder as with GP's, Consultants, and other health care professionals are they subject to assessments about their ability and whether the practice is suitable/adequate and patient led?"

"I believe XXX are trying to make money out of their customers and don't care much for good customer outcomes. I have reported them to the commissioner and I'm currently looking for a new dentist."

"They are focussed purely on profit and don't care about dental health, I have tried to go to a different dentist but can't get an appointment anywhere for a basic check-up, even if I pay full price for it."

"I had forgotten that before the pandemic I turned up to xxx for treatment (filling) and was told it wasn't actually going to be a dentist doing the treatment & was this OK. I really wasn't sure, but proceeded (mainly as I felt pressured to). The untrained dentist did a temporary filling that was never replaced. This is now the tooth that has to be extracted. I worry that there is real professional negligence at this practice."





"Our dentist - XXX - is wonderful."

"Very kind and informal with excellent people skills and clinical care."

Cost of treatment

"My dentist is great but treatment is very expensive and although I earn a good salary the cost is very difficult to meet. I would love an NHS dentist but just can't find one."

"I would love to tell you about 'my dentist' - but I do not have one to tell you about...that's the point! Too many of your questions assume we have a dentist when many people on low incomes cannot access one at all. York is an absolute disgrace for this and has been for many years now."

"I wish I could get one, my teeth hurt and I'm too poor for private :("

"Dentist of 15 years changed to all private work now. No NHS provision even for children. Costs very expensive, over £100 for a dental hygienist appointment. Poor availability of appointments."

"I am so desperate for treatment that I have now paid £235 for a check up and a filling and signed up for a payment plan for £14 a month and they have not treated the tooth which is infected. I could cry as I am not working and the costs for the tooth which has a chronic infection. I have been quoted £2,000 to £3,000 or I can have the tooth extracted for around £300. It is scary that I am using my burial savings to sort out one tooth. I have looked for two years for an NHS dentist without success and am at my wits end."



"They seem to take liberties in assuming people can afford over inflated treatment costs, even as a full time student which I am."

"I was at this dentist for years paying private prices until I heard someone asking at reception if they could go on the NHS list so I asked and heard I had been successful in about 3 months, very happy."

"I have the feeling they suggest work to bring money into the private practice. I am worried about the future as I get older and need more dental work - the prices are thousands which I just can't afford. We need more NHS dentists taking on new patients in York."

"They should provide all treatments at NHS charges."

Continuity of care

"Whilst I have seen a variety of dentists over the years. The one member of staff who has remained constant ensures that new dentists are aware of how they need to alter their normal procedures to take care of me."

"I feel let down by this practice, previously I had been at the same practice for over 40 years. Since moving I've had poor care."

"There is no consistency with the dentist. Not guaranteed to see the same dentist on each visit."

"Had a very poor experience with them in terms of cancelling appointments and not being able to rebook them promptly. This means I've missed over 2 years of check ups. I also dislike seeing a different dentist each time, consistency is very poor. I am considering going private with a different dentist as I can now afford to, but it's not a reasonable solution for many."





Communication

"The dentist used to book appointments automatically (pre-lockdown) and not inform you of the date/time until a text reminder the day before. If the appointment was on a Monday the reminder comes through a Saturday (when the practice is closed) so if you can't make it you have to cancel on Monday morning and incur the NHS late cancellation first strike."

"The dentist I had claimed I'd missed an appointment but there was recourse to complain despite being unaware of the appointment. I suspect they saw me as an easy case to get off their books as a carer."

"One of the receptionists can be quite rude and make it difficult to give an appointment."

"My dentist/practice is still listed as a NHS dentist on the NHS website - it is misleading."

Access to service

"I wish I had one!"

"As of today I have tried to join 3 waiting lists closest to me and out of those only one has allowed me to give full details to join them, two have point blank said they are not currently accepting new patients in their NHS waiting lists."

"I am currently pregnant and concerned that I will not be able to find a dentist for my child as well as being unable to access a dentist myself."

"I understand he's left but the dental practice say we will get a call, when they've recruited a replacement. Fingers crossed as otherwise we can join the





massive queue of people desperately seeking a dentist."

"They are short of dentists."

"The location is beneficial due to my age. Both hips replaced and when necessary I use a stick."

"Seems absolutely daft that we pay our taxes for a free national healthcare service which covers everything except our teeth and gums. Dentists show what goes wrong when you outsource NHS services to private companies and start privatising the healthcare service. I can only assume politicians have dentist friends."

"I can't get an NHS dentist so if I have a dental emergency I will go to A&E and if not an immediate emergency I will go to my GP; perhaps they'll be able to get me an NHS dentist spot?"

"I worked with someone who moved from York to Wales and hadn't given up their spot at a York dentist because it was equally hard to find spots elsewhere in the UK and so now travels hours back to York for appointments, taking up spaces for locals."

"I really hope to find one in York where I have lived for the past 8 years!"

"I have been in pain for almost a year. No NHS dentist in this area. Even 111 couldn't help. Very poor service over the phone."

"Just desperate to find one."



"Can't really say much as I dont have one been trying to get one for over a year was with xxx in York but they can be quite rude."

"I felt trapped with my previous dentist even after a bad experience they wouldn't let me change to another partner - I felt the only option was to drop off the register and try and find another dentist."

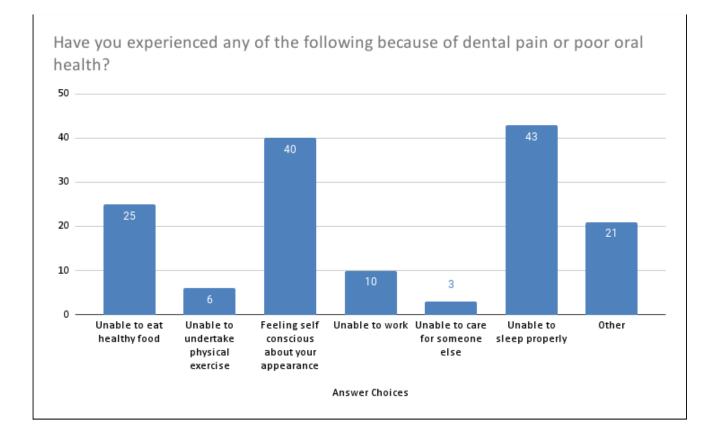
"Have concern that if my dentist leaves or goes private, I would have difficulty getting another NHS dentist."

"I just wish we could get an appointment again."



Q.36 Have you experienced any of the following because of dental pain or poor oral health? (153 respondents)

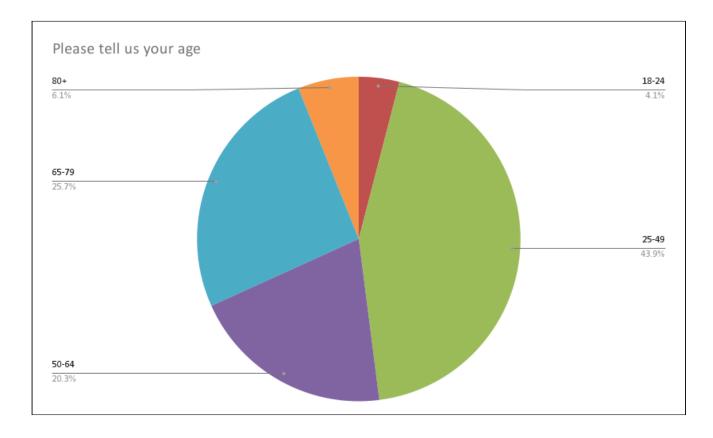
Out of 153 respondents 79 (52%) reported having one or more of the problems associated with dental pain or poor oral health listed in our survey. Of those that listed at least one symptom 43% reported not being able to sleep properly, 40% reported feeling self conscious about their appearance, 25% unable to eat healthy food, 10% unable to work, 6% unable to undertake physical exercise, 3% unable to care for someone else and 21% listed 'other'.



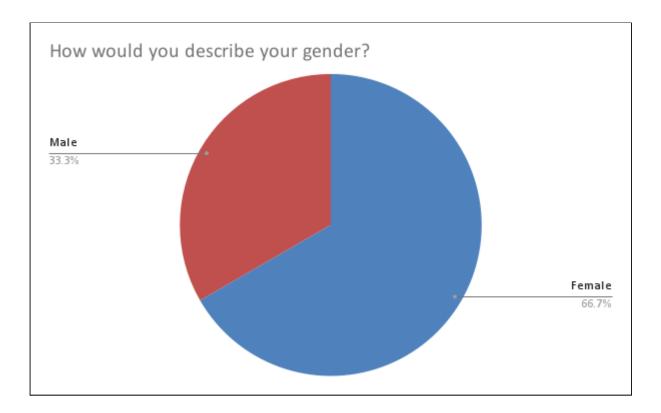




Demographics of our survey respondents



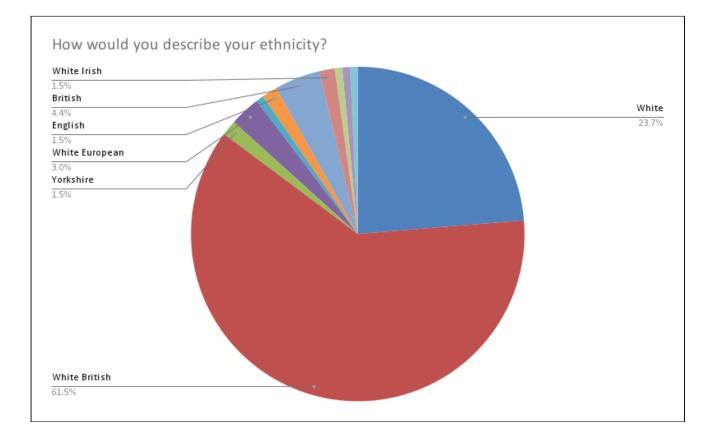
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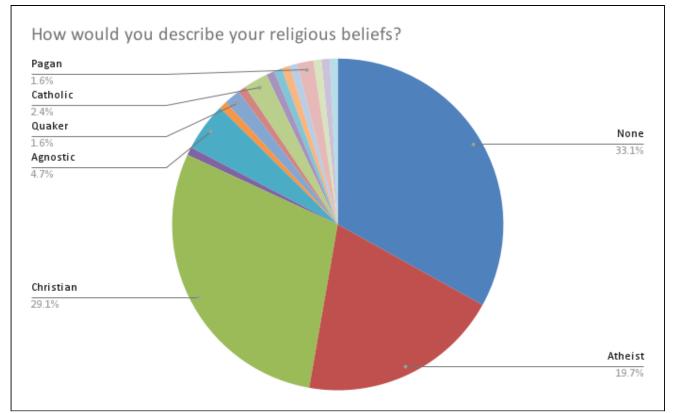


Healthwatch York | Dentistry - Gaps in Provision









Healthwatch York | Dentistry - Gaps in Provision



Feedback from Outreach Work

We recognise that online surveys have little use in capturing the lived experience of people who have limited access to the internet and suffer multiple deprivations. We targeted some key locations in the city including Carecent and Red Tower and began focused conversations about dentistry from September to November 2021. Snapshots from some of these conversations are listed below.

<Male 60+>

"I've tried 20 dentists, but got nowhere. Over the last 12 years my teeth have been falling out and it's now difficult to eat properly. The lady downstairs from me, we rang and the dentists together. Most of them said 'we are a private surgery'; I can't afford to go private. I do have pain. My neighbour below me is struggling too; she had a lot of pain and had to go to Harrogate to have a procedure done. She went on the train and she's alright now, but there was nothing available in York when she rang for urgent treatment. We've got railcards but it's still difficult to get to Harrogate. I'm an ex-servicemen and I was thinking of trying to contact the army doctor but I don't know if they're still there. I could try Catterick. She rang the urgent care number and ended up in Harrogate! There is no one in York. Is there a service for ex-servicemen?"

<Male 50+>

"I have an NHS dentist, I go to XXX. I normally have a check up somewhere between six months and annually. I am not eligible for free treatment. I pay for cleaning but I do not pay for the check up. When covid came it stopped the service."





<Volunteer Female 60+>

"Is there a retired dentist who might offer advice or a real one!?"

<Male 60 +>

"My dentist is super groovy and is based in XXX. They don't want to do a root canal because it's too expensive. I just take antibiotics. My old dentist 'Tory boy' was rubbish! I'll have to pay now."

<Male 60+>

"I have an NHS dentist at the moment and I last saw them in February 2021. I had pain and got treatment by being persistent. I had to exaggerate the truth to get treatment; I went to XXX at XXX. The reception staff dealt with it and the support staff were well trained. The tooth was extracted; they have been rebuilding the tooth for 20-years. I don't think there was any other real option; either this or nothing. I asked them if they could do a crown, but they said no. The treatment took about 30-minutes. The pain stopped me sleeping but was controlled with painkillers, but I found out I shouldn't be using ibuprofen. My pharmacist bothered to tell me what was on record, they don't usually tell you the results unless you go to find out."

"The larger the body the bigger the reform needed, small organisations are better. The unit of government is too big; if Labour said 'more accessible and smaller units' they might do better. There are too few medical practices in York; XXX have a reputation but are useless. There are only 3 or 4 practices in York, so if you have a history you're in trouble. They are too big. The level of treatment of care is not good. We need small friendly personable units. Discredited economies of scale don't work. For example, merge 6 accountants into one at the hospital and this accountant has no idea about the true costs.



We have a monopoly buyer which is as bad as having a monopoly seller. Underfunded support and managing by emotion is not practical. Gigantism is leading to maladministration."

<Male 60+>

"I went to Lawrence Street dentist, I was with them for years but I lived abroad for 10 years and when I came back I had no continuity and they said 'we are not accepting new patients'. The nearest was in Market Weighton which took two buses."

<Volunteer Male 60+>

"What about mobile dentists? We could pay if they came here and can promote the service. We could let people in the flats know about it."

"People come here on a Monday then they go to the Folk Hall on a Tuesday Lidgett Grove on a Wednesday Southlands on Thursday and Foxwood Community Centre on Friday. The design of the dentistry system needs review."

<Male 60+>

"I had a dental appointment at the XXX surgery. I got treated with two new crowns last week!"





<Male 30+>

"I am in a lot of pain with my teeth that haven't been to the dentist for over 8 years. I've tried to get an appointment but I can't. I will need to ring 111 very soon. I'm scared about going and would like someone else to come with me."

<Volunteer Female 60+>

"Is there one central point where a patient could be notified if there are any NHS places or one central number for any vacancies that come up?"

<Male 50+>

"I was in a lot of pain and couldn't get to see a dentist last year, I tried and tried, but got nowhere, so I thought 'xxx it I'll pull it out'. I used salt water and it healed up eventually." Page 74

ANNEX A





What needs to happen...

We believe that action in four areas needs to be taken to address the issues that people have shared with Healthwatch.

- Rapid and radical reform of the way dentistry is commissioned and provided - recognising that the current arrangements do not meet the needs of many people who cannot access NHS dental care in a timely way and acknowledge issues faced by the dental profession.
- Reform commissioning to tackle the twin crises of access and affordability - ensuring that people are not excluded from dental services because of lack of provision locally or difficulty in meeting charges. Currently, there are significant inequalities that must be removed. New arrangements should be based on maximising access to NHS dental services, with particular emphasis on reducing inequalities.
- Improve the clarity of the information about NHS dentistry improving information, including online, so that people have a clear picture of where







and how they can access services, and the charges they will need to pay.

 Use dental practices to support people's general health - harnessing opportunities, such as the development of Integrated Care Systems (ICS), to link oral health to other key issues such as weight management and smoking cessation.





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York CVS

Healthwatch York is a project at York CVS. York CVS works with voluntary, community and social enterprise organisations in York.

York CVS aims to help these groups do their best for their communities, and people who take part in their activities or use their services.

This report

This report is available to download from the Healthwatch York website:

www.healthwatchyork.co.uk

Paper copies are available from the Healthwatch York office, if you would like this report in any other format, please contact the Healthwatch York office.

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Health and Wellbeing Board Report of the Manager, Healthwatch York

16 March 2022

Healthwatch York Reports: Dementia Support – Listening to Carers of People Living with Dementia in York

Summary

1. This report aims to help shape the dementia strategy in York, sharing Healthwatch York's work looking at the experiences of people caring for those living with dementia in the city.

Background

2. Healthwatch York works with partners to explore the challenges people are experiencing in the city. The pandemic has been a particularly challenging time for people with dementia and their carers. With funding from Joseph Rowntree Foundation, this report provides the results of a survey conducted during the pandemic, asking what is needed to improve dementia support in York.

Main/Key Issues to be considered

3. There are some key themes and recommendations from those caring for people with dementia, which are useful in helping shape the dementia strategy for the city.

Consultation

4. This report and the survey used has been developed working alongside organisations working with people with dementia and their carers. This work was conducted at a time where face to face consultation was difficult, and as such there was a higher level of feedback from carers than people with dementia. The feedback from people with dementia will be the subject of a further short report in Spring 2022.

Options

- 5. The report outlines some key aspirations for improving dementia support in York. Health and Wellbeing Board are asked to note the report, and these key aspirations, outlined from page 42 onwards. Namely:
 - a. A key person with knowledge of support available and connections to the person's GP practice
 - b. A hub, with a wide range of activities, and able to provide care so carers also get a break
 - c. Improved emotional, practical and financial support for carers
 - d. Improved medical and social care for people with dementia with regular checks
 - e. Improved dementia training for all frontline health and care staff

Strategic/Operational Plans

6. A Dementia Strategy for York is currently being developed. This report identifies some key areas where people in York believe services and support can be improved.

Implications

7. 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

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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

8. There are no risks associated with this report.

Recommendations

- 9. The Health and Wellbeing Board are asked to:
 - i. Receive Healthwatch York's report, Dementia Support: Listening to Carers of People Living with Dementia in York

Reason: To keep up to date with the work of Healthwatch York

Contact Details

Author:	Chief Officer report:	r Responsible for the
Siân Balsom Manager Healthwatch York 01904 621133	Report Approved	x Date 08/03/2022
Wards Affected: All		

For further information please contact the author of the report

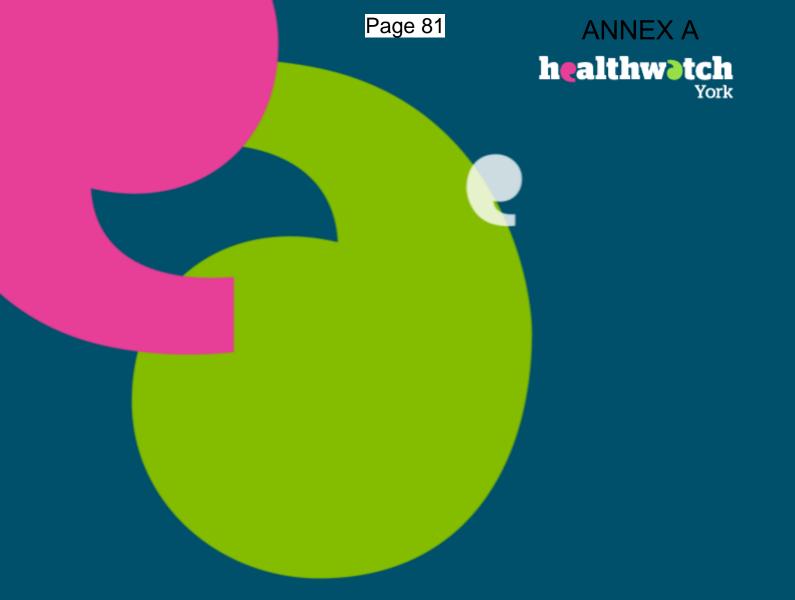
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Background Papers:

None

Annexes

Annex A – Dementia Support: Listening to carers of people with dementia in York



Dementia Support

Listening to carers of people living with dementia in York

Healthwatch York Report February 2022



Acknowledgments

Thank you to everyone who took time out to respond to our survey and to all the organisations that have helped to develop this report, including Joseph Rowntree Foundation, Joseph Rowntree Housing Trust, NHS Vale of York CCG, Minds and Voices, York Dementia Action Alliance, City of York Council, Age UK and The Alzheimer's Society.

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Summary of Key Themes

1 in every 14 people aged 65 years and over has dementia. This number is set to increase as our population ages and lives longer. In 2020, it was estimated that there were 2,511 people with dementia aged 65 and over and 79 people with dementia aged under 65 years, living in York. Our survey of carers of people with dementia in the city has identified the following key themes:

Diagnosis

Some people had waited a very long time for a diagnosis without information or advice and some felt the diagnosis had been delivered poorly. Additionally, people reported little or no follow up support or contact after diagnosis leading to many feeling abandoned and alone. Carers talked about the challenges faced when the person they supported did not acknowledge a diagnosis. There appeared to be a lack of ability in services



to offer support which responded to this either for the carer or person they supported. An inconsistency with GPs, both in their approach and ability to respond effectively to carers concerns was raised. The felt lack of knowledge from doctors around early onset dementia was also a concern.

Access to services/support after diagnosis

Access to support after diagnosis was a mixed picture and shows an inconsistent approach to support across dementia care in York. Follow up care had already been highlighted as limited in many instances. Some carers spoke about having a very good, accessible GP who had been supportive, able to access the right services and able to set in motion the right support. However, it was also reported by many that GP access was very difficult. Often carers felt unable to get through or that it took weeks to make contact. Many carers felt that their GPs were not able to offer the support needed for dementia related problems. They spoke about concerns when more specialist teams discharged them back to GP care due to the lack of support they then experienced. Carers also spoke about the difficulties caused by fragmented services, being passed between services and the difficulties grasping the number of services involved. Some carers had faced challenges trying to co-ordinate and 'untangle' all these services who often didn't communicate well with each other. People talked about not knowing what to ask for or who to contact.

Longer term support

Kinds of support received varied across the public and voluntary sector either for themselves or for the person they support. However, some reported not receiving any support at all and others gave many examples where the support offered had not met their emotional or practical needs. People spoke about the 'standard' kinds of support they'd received such as phone calls or being given leaflets. Some people had benefited from these but there were many experiences where this support had not met the needs of individuals and families. This kind of support was often associated with feelings of being abandoned and 'left to get on with it'. The inflexibility of



services creates difficulties especially for carers currently in employment and increasing numbers of people are struggling to juggle work and caring commitments.

How services work together

Where services had worked well together carers felt better informed and had an improved understanding about the condition. In some cases, carers reported that the happiness of the person with dementia had increased. Carers had also been able to receive the needed practical support such as additional carers, or necessary equipment. Carers told us about experiences where services had not worked well together. These included poor communication between organisations and a lack of expertise in dementia.

Planning for the future

A large number of people felt they had not discussed planning for the future with professionals in health and social care but felt this would be useful. When asked about their concerns for the future carers spoke about wanting to understand dementia more including learning about what they could do to help. They wanted to know more about what help was out there and how/if they could access respite and day centres for support with care enabling them to return to work. People had concerns around housing and finances and understanding what to do and how to manage things as the disease progresses.

Activities and socialising

Many carers spoke about the difficulties of leaving the person they care for, which meant they were unable to do activities of interest to them. It made socialising particularly difficult. Some carers felt they didn't know much about what was available to them or felt there were no activities of interest to them. Carers told us about the effects of loneliness and the lack of support they experienced. This often caused them to feel as though they are on their





own and unable to give the support they would want for their loved one. Carers also described the frustration and the lack of support and opportunity for stimulation/meaningful activity for the person they supported. Carers told us about the impact the pandemic had had on people they supported. They felt the consequences of the pandemic such as lock downs and closures of services had accelerated symptoms, decimated people's routines and self-confidence, increased isolation, anxiety, and dependency on certain family members. Alongside coping with the impact on the person they support, carers told us about the immense challenges that came with not being able to get support from other family members or getting support from or being able to socialise with other carers. Some carers felt they were so familiar with isolation and a lack of any external input that they didn't feel much of an impact from the pandemic.

Being listened to

Some carers were able to tell us positive experiences where they had felt listened to by health professionals. However, many told us about feeling ignored and having to fight to be heard. Some carers felt they had only been listened to when things had reached crisis point. Some carers told us their experiences of feeling as though they were listened to, but the outcome had been ineffective due to the lack of follow up or any real help.



Towards a New Service

Carers imagined:

- Reduced waiting times for diagnosis and improved communication and support following diagnosis
- A consistent approach to dementia care across the city with improved GP access and support from specialists, where care was integrated across a network of closely allied organisations
- A new service which included an allocated person to seek support from in the longer term
- A key physical place/centre to provide social and physical support for people
- Improved opportunities for activities and socialising for people with dementia and their carers across the city
- A network of respite and day centres for support
- Advice on housing and finances and understanding what to do and how to manage things as the disease progresses
- Being listened to by health and social care services, both as a person with dementia and as a carer.



Background Information

Dementia facts and figures

Research in 2019 showed that there were over 850,000 people with dementia in the UK (Alzheimer's Society 2019).

This means that 1 in every 14 people aged 65 years and over has dementia. This number is set to increase as our population ages and lives longer.

Dementia is not a single illness but a set of symptoms affecting areas such as memory or thinking caused by damage to the brain. Different types of dementia include:

- Alzheimer's disease
- Vascular dementia
- Dementia with Lewy bodies
- Frontotemporal dementia

Data from 2013, shows that there were 42,325 people in the UK with early-onset dementia (onset before the age of 65).

The National Picture

As the number of people living with dementia steadily increases, the government and NHS England have pledged to make improvements to dementia care a key priority. Some key publications which outline current and future plans include:

- The National Dementia Strategy for England 2009
- The Challenge on Dementia 2015-2020
- The NHS well pathway
- The Dementia Care Pathway: Full Implementation Guidance
- <u>NICE pathways: Dementia overview</u>

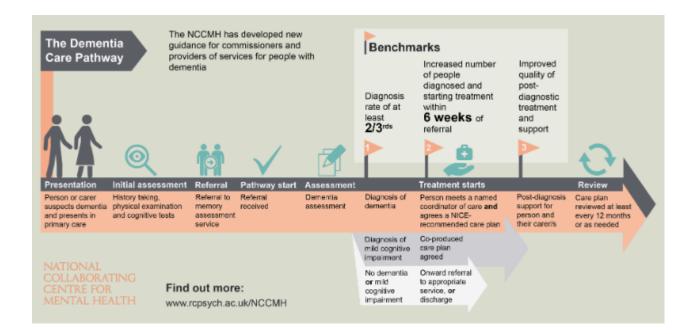


National policy discusses improving care for people with dementia through several initiatives. For example:

- Improving public awareness and understanding of factors which increase the risk of developing dementia
- Increasing and maintaining the rate of diagnosis of dementia.
- Improving the quality of treatment and support after diagnosis
- Reducing health inequality and ensuring equal access to quality care and support
- All NHS staff receiving training on dementia appropriate to their role
- Increasing investment in dementia research

Good dementia care is seen as needing to be delivered across the 'Well Pathway', from prevention through to supporting people at the end of life.

So what should good support look like?





Receiving a timely diagnosis is seen as giving people the best opportunity to get the right support from the beginning, plan for the future and prevent crises as well as receive any treatments which could slow progression of the disease. The aim is to increase the amount of people being diagnosed with dementia and starting treatment within 6 weeks of referral.

Following diagnosis each person with dementia alongside any family or carers should be offered consistent support in line with NICE-recommended care. It should involve having a named co-ordinator of care who would support with creating a flexible and up-to-date care plan which is reviewed at least every 12 months, but updated regularly to reflect the person's current needs and wishes.

The co-ordinator of care would be the point of contact for the person with dementia and their family and/or carer when they need information, advice or help. The co-ordinator should be suited to the individual needs of the person with dementia and could come from a variety of settings including primary care, the voluntary sector or memory assessment services.

"Good dementia care should be personalised and life-long, taking into account the individual needs and preferences of the person living with dementia and, where applicable, their family or carer."

The Local Picture

In 2020, it was estimated that there were 2,511 people with dementia aged 65 and over and 79 people with dementia aged under 65 years, living in York (PHE).

Public Health England publishes data which allows CCGs across England to compare performance across different local areas.

The data suggests that compared to England, York has a significantly lower dementia diagnosis rate for people aged 65 and over. The amount of people with a dementia diagnosis having their care plans reviewed every 12 months has also decreased between 2019 to 2020 and is also currently lower than the average in England.

This means that some people living in York are not receiving a dementia diagnosis in a timely way and that some people's care plans are not being reviewed regularly and kept up to date.



More positively, figures show that York has less emergency hospital admissions and a lower rate of mortality for people with dementia aged 65 and over, compared to the average in England.

Our Project

Why are we looking at dementia?

At Healthwatch York we frequently hear from people with dementia and those who support them about the difficulties finding or getting the right support.

In 2020, Healthwatch York received funding from the JRF to develop a project with people living with dementia.

Whilst planning this project it was announced that the City of York were developing a Dementia Strategy for the Autumn 2021. This has not existed in the city previously.

We felt it was vital that the voices of people living with dementia are at the very heart of this strategy and shape its development and creation.

We worked alongside people with dementia, carers and organisations across York who support people living with dementia to plan, develop and deliver this project.

Previous work at Healthwatch York

Since Healthwatch York formed in 2015 we have had the opportunity to hear the views and experiences of people living with dementia through various engagement work.

In 2017, Healthwatch York worked alongside Minds and Voices to run focus groups to understand how York City could be made more dementia friendly.

In 2019, as part of the NHS Long term plan project, we ran a focus group for people with dementia and carers to listen to their views on priorities.

Between 2018 and 2021, we had contact with 38 members of the public who raised concerns around support for dementia. Many people told us about their difficulties of getting the right support when dementia needs had become more complex.



During the Covid lockdown in March 2020 we undertook welfare calls in collaboration with York CVS. We spoke to people living with dementia both via a hotline number and through lists provided to us by GPs.

This project aims to build upon what has been learned so far and to continue the conversation with York residents who have dementia, and their loved ones.

Challenges and limitations

We were keen in this project to have the voice of people with dementia alongside the carers voice to achieve a balance of this.

This project was developed and delivered during a time of uncertainty during the Covid-19 pandemic. Though we had hoped that face-to-face engagement would become increasingly accessible during the later months of the project, it continued to be problematic. Many groups for people living with dementia had not yet re-started and keeping people safe and not exposing them to any unnecessary risk was paramount. As such, we had to work creatively and flexibly in order to spread the word and reach out to people living with dementia and their carers.

However, we are acutely aware that due to these challenges and restraints we were unable to reach as many people living with dementia as we would have wanted and were unable to provide the face-to-face engagement so necessary for many individuals to be able to take part.

What did we do?

Planning and pilot phase

When the York Dementia Action Alliance spoke to people directly affected by dementia and professionals working to support them, they found five key areas needing improvement. These were:

- Improved accurate and early diagnosis
- To have a post diagnostic pathway of support
- For services to work together better
- The development of carers' support

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ANNEX A



• A positive campaign for living with dementia

The questions in this survey ask for people's experiences as well as what could be improved in these five areas.

Healthwatch York and these organisations have worked together to produce a draft survey. This survey is now going through a pilot phase whereby carers of people with dementia can test it and give their feedback. Healthwatch will produce the final draft. It has gone out to a sample of Dementia Forward's clients and the Minds and Voices. In collaboration with organisations across York, we developed a survey for carers of people living with dementia. We then asked carers to give us feedback about the survey and what they thought worked or didn't work. We used their feedback to make changes before releasing it more widely.

We were aware that online surveys were not going to be accessible to a large number of people we wanted to reach and so used the survey as just one tool to get feedback. We worked closely with different services and organisations to produce and disseminate multiple tools to get feedback. This included working with:

- Age UK and Alzheimer's Society who supported with dissemination of paper survey packs to their members and support workers
- Social prescribers to develop a "one sheet feedback" form to capture experiences or comments
- York Hospital to create a short survey so that staff could support people to answer questions
- New Earswick Folk Hall to provide surveys and support from staff plus a collection box
- Attendance at a local support group for people with dementia.



Findings

Responses

We heard from 84 people in total.

There were 74 responses to the carers survey, 67 of these were from carers and 6 stated they were writing it together with the person they support. 1 person did not answer the question. One carer emailed us their experience.

We visited a group run for people living with dementia and received feedback from 5 people. We also heard from 4 people living with dementia who completed the online survey. This will be covered in a separate report.

Diagnosis: Summary

Some carers talked positively about diagnosis. For them it had been timely and delivered in a kind and professional way. Carers spoke positively when they felt they had been well informed during the process and staff had been approachable and understanding towards all the people involved.

However, many carers talked about their experiences of diagnosis negatively. Some had waited a very long time for a diagnosis without information or advice. The inconsistency with GPs, both in their approach and ability to respond effectively to carers concerns was raised. Some felt the diagnosis had been delivered poorly. Additionally, people reported little or no follow up support or contact after diagnosis leading to many feeling abandoned and alone.

Carers talked about the challenges faced when the person they supported did not acknowledge a diagnosis. There appeared to be a lack of ability in services to offer support which responded to this either to the carer or person they supported. The felt lack of knowledge from doctors around early onset dementia was also raised.





Diagnosis: Themes

Waiting times

"My mum went to the GP due to memory problems and got a diagnosis a year later."

"Process reasonably quick."

"I feel three years was too long to wait and perhaps taking medication three years earlier may have held it at bay for a while longer, who knows?"

"From the initial appointment to diagnosis was far too long"

"It took several years to diagnose"

"It took a long time to get a diagnosis and there was no/limited support until we did receive the diagnosis. We were lucky in that the Memory Clinic was just being phased out so we were able to get a diagnosis with relative speed but I cannot imagine how difficult it must be without a central service and being reliant on overstretched GPs to make a diagnosis, etc."



Poor recognition of early onset

"My husband stopped work because he was no longer able to do his job but was not diagnosed with dementia until 6/7 years later thus losing many opportunities for treatment. His dementia was quite advanced at this time. I feel that GP's could be better trained to spot possible symptoms especially in younger patients."

"My wife, aged 62, was showing signs of dementia. We booked to see the GP and he said there is nothing wrong. I passed him a note saying that she has a short-term memory problem. He asked questions mainly about politicians which she answered mostly correctly. She was unable to recall the postal address he gave her two minutes previously. The GP said there is no memory problem. We had to go back again 4 years later. A different GP referred her to the memory clinic."

Follow up care

"We were quite shocked and went away not understanding the normal procedure. I expected annual reviews and assessments ...but there are none."

"We were handed a pile of leaflets and a booklet and told to read it and call dementia forward who would help with any questions. It was brutal to say the least."

"The diagnosis did not come as a surprise, but what I did expect and didn't get was some sort of follow up...I felt rather abandoned."



"I felt we were dealt with sympathetically but needed much more information as to what the future could or would be like."

"Support for helping people to understand challenges of accepting diagnosis I would like to know how we could get my mum to understand and accept her condition in order that she would allow help from outside to step in."

"My main social contact is with a person (s) who has limited understanding of the current world and is isolated . The person I care for is not the person I have known from the past . The person does not comprehend the situation and support I give them and is resistant to my help . I find myself doing things behind their back which puts a strain on my mental situation as I am constantly hiding my actions and their consequences . I would like someone experienced in Dementia care to actually visit my parent and chat with them about the need to accept help and understand their position and how they can agree to prepare for possible future challenges . I don't think most GP's could do this."

"As a registered carer the carers assessment team have been helpful in trying to give me a break i.e. respite care for mum while i take a break. But mum won't agree to any of this so it is left to me to carry on with no break for 6 years in total. They have signposted us to Alzheimer's society and dementia forward etc but as my Dad has not accepted my Mum's condition and she is unaware it is difficult."

Poor delivery

"Was given in an uncaring and quite blunt way"

"Diagnosis was very blunt and to the point"

"The diagnosis was given after a memory test...whilst she was in bed!"





Challenges for carers around diagnosis

"We felt very awkward. Felt unable to ask questions."

"As the accompanying relative/carer I would have appreciated an additional face to face session with the consultant after diagnosis, I did have power of attorney for health at the time."

"It's very difficult taking a family member to the doctors or dementia clinic and having to talk to them about their problems in front of them. Also, the clinic would ring the patient to make appointments and the patient would refuse the appointment making it very difficult all round."

"It is a challenging situation when someone with dementia living on their own refuses to acknowledge any problem, I think through fear of diagnosis"

"His diagnosis was only achieved when it was needed to advance care packages. Should we or the professionals have pushed for earlier diagnosis? I don't know."

Access to services/support after diagnosis: Summary

Access to support after diagnosis was a mixed picture and shows an inconsistent approach to support across dementia care in York. Follow up care had already been highlighted as limited in many instances. Some carers spoke about having a very good, accessible GP who had been supportive, able to access the right services and able to set in motion the right support.

However, it was also reported by many that GP access was very difficult. Often carers felt unable to get through or that it took weeks to make contact. A large number of carers felt that their GPs were not able to offer the support needed for dementia related problems. They spoke about concerns





when more specialist teams discharged them back to GP care due to the lack of support they then experienced.

Carers spoke about the difficulties caused by fragmented services, being passed between services and the difficulties grasping the amount of services involved. Some carers had faced challenges trying to co-ordinate and "untangle" all these services who often didn't communicate well with each other. People talked about not knowing what to ask for or who to contact.

Access to services/support after diagnosis: Themes

The "GP Lottery" – Access to primary care

When access was poor

"It took us some weeks before we could get an appointment to discuss our concerns with a GP. It is very much a lottery getting access to a GP who shares our concerns."

"The GP surgery have not even recognized the diagnosis or referred to it or made it have any impact on care provided."

"Ringing the GP surgery isn't successful as it takes weeks to get an appointment."

"The GP was reluctant to prescribe medication to enable us both to get a good night's sleep. Fortunately, I received help from the York crisis team."

"I discussed my husband's memory problem with a GP. A blood test was done but nothing else until some considerable time later when I told a different GP."





When access was good

"When I have been to our GP they have been very good to talk to and advise me what to do."

"Nothing happened for some years but during the covid pandemic I was desperate. At that time I saw the GP and she was excellent and set in motion the mental health assessment."

"The GP was very supportive but I struggled to know who to contact. As the illness progressed my husband became incontinent we managed to get an assessment but never heard of any information or contact."

"My husband had an appointment a year after diagnosis. Then that ceased to exist and we were referred back to our GP. The only contact we have had with the surgery is a once or twice yearly check of his blood pressure. The only good thing is when we had to see our GP about another issue and I mentioned how much worse the dementia was, and his balance was now poor so I was looking for a wheelchair. She sent an application to the wheelchair Service who acted quickly and delivered one within a week."

Fragmentation of services

"It's difficult to grasp why so many agencies get involved, hospital care workers, dementia forward, integrated care team, Alzheimer's Society, Age Concern, York Council..."

"I found the experience of being given support initially from secondary services good but the experience…but then was told to revert to access only by GP. Very disturbing and unfair as his illness was acute and ongoing but all support was withdrawn."



"It has been difficult as he has moved Authorities, so York had to hand-over to them."

Kinds of support: Summary

Kinds of support received varied across the public and voluntary sector either for themselves or for the person they support. However, some reported not receiving any support at all and others gave many examples where the support offered had not met their emotional or practical needs.

People spoke about the "standard" kinds of support they'd received such as phone calls or being given leaflets. Some people had benefited from these but there were many experiences where this support had not met the needs of individuals and families. This kind of support was often associated with feelings of being abandoned and left to get on with it. The inflexibility of services creates difficulties especially for carers currently in employment and increasing numbers of people are struggling to juggle work and caring commitments.

Ideas about what should be available and what would help included:

Having a support worker who is someone to talk to about feelings and also someone to turn to ask for advice over time.

More support with the challenges of being a carer whilst trying to work and services being able to understand and be flexible for this, and the importance of needing a break.

The support that works for some didn't work for others; there needs to be a more questioning attitude from services; 'are we meeting your needs?' or 'do we need to be thinking about something else?' Most people had suggestions for improved support.

There was evidence of a need for more appropriate and engaging activities to meet the needs of people living with dementia.



Experiences of kinds of support: Themes

Telephone calls

"I get a telephone call from a lady (carers support I think) every 3 or 4 months but that is of no help when you are with him 24/7 and so he is in the room and is not unaware that he is the subject of the conversation. I just want to cry and say how bad I feel but I can't as it would upset him so the stock answer of 'I'm ok' trots out. I was upset to see that these phone calls are logged on my medical notes as social prescribing. The only concession I feel we have is that I am allowed to come into consultations with him now."

"When help was requested, it was always forthcoming as long as you were patient but the feeling that you had been abandoned was very strong. A spontaneous phone call even at infrequent intervals would have made a huge difference."

"I haven't had any support, I've had the occasional phone call from Dementia Forward, nothing from the GP."

Signposting and leaflets

"There has not been any support really. Beyond being supplied with leaflets we have been left to our own devices. I do not know what could have been better. Perhaps a support worker to talk through feelings and where to turn for support if needed."

Respite and care services

"To be able to rely on carers service would have been so beneficial, everyone else has been great, especially the Be Independent Service."



"I have been able to discuss problems but unpaid carers need some breaks and respite. It's very unfair that having a much needed break should be so expensive."

"When my husband was in hospital I spoke with someone from Social Services regarding some respite for a couple of weeks. Nowhere suitable was available and I couldn't leave my husband in hospital until there was a suitable place for him to go to. As a family we decided to bring my husband home as he was deteriorating, he stopped trying to feed himself and the incontinence was getting worse."

Flexibility in services for carers

"I travel over 60 miles to care for my relative in York. Health professionals make it a battle all the time to get access. They want all sorts of paperwork including LPA (Lasting Power of Attorney) documentation sending. Appointments are made without taking into account the distance I have to travel. They do not always appreciate that it takes a long time to get people dressed, etc to get to the appointment. Parking is also a major issue when you have a person with dementia whose mobility is very weak. Obtaining a blue badge is impossible in York."

"In the early stages the health, social care system seemed to conspire to make life more difficult. [You have to act as a] go between for different services when you don't understand the system or speak their language. Always having to take parents to appointments and take time off work when the district nurse could easily have taken blood, or doctors and pharmacies arranged to send each other prescriptions or information directly. Picking up incontinence pads when they could have been delivered. There was a difficult period in the community when there were so many appointments with various services that my sister and I had to take them to when many could have been done more easily in home visits. The impact was severe on



me. I couldn't juggle work and all the needs of my parents. One example is when flu jabs were required but carers for a whole block of elderly people were expected to take people taking time off work, when a couple of district nurses could have done it in an hour in the block."

"The most help we got was from Dementia Forward which I'm so glad we attended....Any problems I had they could help me solve, and it was so helpful as a carer to talk to other carers. At the end my husband was sectioned under mental health but twice I called the crisis team out and they were very good. Nothing but praise for them. They acted very quick."

"We don't feel we have received much support from health professionals. They do not seem to have any understanding of what it is like trying to look after 2 people with dementia and trying to work."

How services worked together: Summary

Carers told us about their experiences where services **had** worked together. These included:

- When discharges from hospital had been coordinated well
- When hospital wards liaising well with specialists e.g. neurologists
- Good communication between different professionals e.g. mental health nurse and care home, occupational therapists and consultants.

Where services had worked well together carers felt better informed and had an improved understanding about the condition. In some cases carers reported that the happiness of the person with dementia had increased. Carers had also been able to receive the needed practical support such as additional carers, or necessary equipment.

Carers told us about experiences where services **had not** worked well together. These included:

• When numerous agencies were involved but not communicating with each other

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ANNEX A



- When there was a lack of expertise of dementia and dementia specialists within certain services
- When there was no correspondence between different GPs
- When different services blamed each other
- GPs not having appropriate knowledge to access appropriate pathways of support
- Having to repeat history and issues to multiple professionals
- Problems claiming benefits as health professionals had not responded to forms
- Pharmacies and GPs not talking
- Not aware of agencies working together

"The result of a blood test was given by a receptionist, followed up by a disinterested nurse. It left my wife in bits, with me having to pick up the mess."

Concerns for the future: Summary

A large number of people felt they had not discussed planning for the future with professionals in health and social care, but felt this would be useful.

When asked about their concerns for the future carers spoke about wanting to understand dementia more including learning about what they could do to help. They wanted to know more about what help was out there and how/if they could access respite and day centres for support with care enabling them to return to work. People had concerns around housing and finances and understanding what to do and how to manage things as the disease progresses.

Concerns for the future: Theme

To have more understanding

"Not really sure what will happen as the disease progresses."



"Needed to understand what the route cause was and tests haven't been done to understand this."

"Just understanding [the] illness."

"As the dementia progresses. What to expect and what to do to help?"

To know what help there is

"I may need more help and I would like to know what there is."

"Lack of contact. When I feel I need support I am not always in the best situation to ask for it."

"At the moment I know how to access help if necessary but if/when my situation deteriorates this will likely change."

"I'm trying to find some day care so I can have some respite myself. I have managed to get my husband on a waiting list but due to the Covid situation there is no telling how long it may take to get a place. I also think a step-by-step guide to care homes and how to access them would be helpful."

"What we currently need is a day care centre to drop Dad off at so we can go to work."

"Next stage of care as the illness worsens and how we can proactively put in place Plan Bs for when Plan A no longer works. Finding out about different options, what are the best possible options/solutions, what level of support



is available/funding and how much we might need to self-fund."

"I'm concerned for my own health and would appreciate being able to talk about my situation."

"We just have no idea how to proceed and are just keeping our fingers crossed, hopeful for the best. It's outrageous."

What will happen when I'm not around?

"Nobody has discussed anything with us. My main worry is if I become ill and he has no one here to look after him. I also worry if he should have to go into care if I became ill or predeceased him."

"I am concerned about care should I not be available for any reason."

"We have no idea what options will be available to us when our mother can no longer be cared for by family."

Finances

"We struggled to get financial help. Citizens Advice helped us, no-one else mentioned the fact we are 60 so how do we pay bills, get benefits, which benefits etc. I was always worried how and when/if he went into care, how much it would cost, and all the things involved with that we only had a small amount of savings."

"Lack of financial support."





"Finances regarding my Mum's care on a permanent basis in her current residential setting."

"My partner has young onset. I have to work. He needs a large package of care to enable me to do this, and to keep him active. This I feel needs to be taken into consideration for younger people."

Loneliness

"When are dementia sufferers going to be allowed to meet together, as people can in cafes and pubs, etc."

"My main concern currently is how lonely mum is, especially with Covid, people have got out of the habit of visiting."

Housing, Care Homes

"I am concerned about housing and support at a later date."

"Information about finding a care home for respite care for my husband to give me a break. It has been inferred that if you have savings there is no point in contacting social care and that I have to contact care homes and make arrangements."



Activities: Summary

Some carers told us about activities they were involved in. These included: walking, cycling, gardening, swimming, live sport and outdoor bowls. Carers also mentioned meeting with friends and family as well as going to groups such as Musical Connections, York Carers, Alzheimer's Society, Singing for all, Age Concern and Healthwatch.

However, many carers faced barriers to participating in activities. The majority of carers spoke about the difficulties of leaving the person they care for, which meant they were unable to do activities of interest to them. It made socialising particularly difficult. Some carers felt they didn't know much about what was available to them or felt there were no activities of interest to them.

Activities: Themes

Difficulties engaging in activities due to leaving person behind

".... he goes for his sleep and I can join the class while he sleeps."

"Unfortunately, I can't take part in any activities as this would mean leaving mum for long periods of time and she would become agitated and confused because I wasn't with her."

"My walking group and art group are important but I need help otherwise I can't leave my husband alone."

"Age UK offer me a few hours respite but I would very much like more to see friends, go to the cinema, socialise, walk, etc. I cannot be away from home long enough to pursue these interests."

"I have engaged a private carer for 4 hours a week…so I can have a walk, meet a friend, or do some shopping. It's expensive but something I've had to



do for my sanity. I would still love to hop on a bus and go to the coast for a day though!"

"As a carer I no longer feel as if I have a life of my own. If I need to go to the hospital for myself I have to get my son to come and look after his father and work from our home. I'm lucky in that but as for a social life, forget it."

"The only way to continue with activities that are important to me would be to have more care for my husband but that costs money. Financial support is the real key to helping carers maintain some independent life."

"I am unable to do anything as I can't leave my husband."

"...we also used to go out for coffee or lunch a couple of times a week but that is becoming difficult as toilet access is difficult. I can wait outside the toilet for him but if I want to go he forgets where I am and on one occasion he was walking out of the garden centre looking for me."

No knowledge of what's there

"Didn't know much about any activities open to us. We already belonged to a walking group so we carried on with these..."

"We have no access to services for Dementia activities for my relatives. However, York Carers Trust regularly keeps me updated with their activities but they are the only professionals that send me details of activities."



"No activities which the state or voluntary sector deliver were appropriate to my interests."

Feeling listened to: Summary

Some carers were able to tell us positive experiences where they had felt listened to by health professionals. However many told us about feeling ignored and having to fight to be heard. Some carers felt they had only been listened to when things had reached crisis point. Some carers told us their experiences of feeling as though they were listened to but the outcome had been ineffective due to the lack of follow up or any real help.

Feeling listened to:

"After seeing the GP in November 2020 everyone was very supportive."

"The genuine interest which is shown when they contact me."

"They have always listened to us and given us advice."

"The quality of the staff and their listening skills was always excellent but it was always at my request and never from them."

"Always take time to listen and offer sympathetic support, a listening/caring ear not just a cold/clinical response."

"Now we feel listened to. At first when we got social services involved it took them a while to see the situation how we saw it."





Not feeling listened to:

"Feel it is unrealistic to expect to be listened to and so only ask for factual information which I obtain. No one has time to consider the stresses of caring or listen to my particular situation, so I try to sort difficulties out myself."

"There has been no advice given as when you seek information you are sidelined or can't even get through on a phone."

"The initial diagnosis by the mental health doctor could have been handled a lot better I felt as if I was talking to myself. The impression I had was he wanted us out of his office. When we were re-referred back to the mental health team it was a new doctor and it was all change. I was listened to and given time to explain what was going on without the person I care for in the room. It's very difficult to tell a doctor how a person is behaving when they are in the room with you even if they don't understand what you are saying or will forget it straight away."

"The hospital nursing staff seemed to think my mum was capable of living alone despite my informing them about my mum's deteriorating condition. I felt I was battling against them whenever my mum was admitted to Hospital. Very stressful to say the least."

"GPs ignored me, largely. Hospital did not explain the nature of the medications used, or their impact. Nobody ever discussed alternatives with me."



"Some health professionals are better than others at listening to my concerns. Some GPs are very good and supportive, whilst others... are appalling at listening to my concerns. The Memory Clinic could be better at providing support and listening to concerns."

"I have had to go through complaints procedures to get anything remotely useful considered by care providers."

Listened to but ineffective:

"They have listened but with resources as they are there is very little they can do."

"GP's may have listened but not taken effective action."

"There has been a lot of sympathy but no real help."

"Beyond the diagnosis appointment there have been no contacts with health professionals. At the diagnosis appointment mum was asked if she had considered suicide. Mum said she had but that she would not act on this as she did not want to upset her grandchildren. To have this question asked and answered and then no action taken or support suggested felt brutal. I understand the need to collect data but there was no positive outcome for mum as a consequence of having answered this question. It felt like a tick box exercise for the collation of information not to assess Mum's needs. This has understandably made me feel cynical about the service provided."



Feeling positive

What made people feel positive?

Carers spoke about their self-determination and trust in themselves. Carers felt positive when the person was receiving good and "the right" support for them and when they knew where to go if they needed more help.

"I am a determined person who is comfortable researching information; chasing down the right professionals/services to use etc. I am not afraid to pick up the phone and badger. I am a very positive/proactive person who believes in solutions not that there are only problems. It is my inner strength that helps me feel positive, not necessarily what is available out there. I fear there are many who are not like this and probably fall through the net/do not get the support they need i.e. fly under the radar."

"I am happy he is being cared for and that I am able to visit him."

"I feel I can support my husband well at the moment."

"I feel I do something that is demanding regardless of it's poor recognition. I have kept one diagnosed (and one probable) dementia sufferer safe and out of hospital during the pandemic."

"Just trust in myself and what I do."

"My wife looked after me for almost 50 years through my working life."

"Aware of help if/when needed."



Why did people not feel positive?

Carers told us about the effects of loneliness and the lack of support they experienced. This often caused them to feel as though they are on their own and unable to give the support they would want for their loved one.

Carers also described the frustration and the lack of support and opportunity for stimulation/meaningful activity for the person they supported.

Loneliness and no support

"More help at the first instance on how to cope with such a devastating diagnosis. No one asked me how I was ok. How I was coping I just had to be strong or I would have collapsed. Had to have anti-depressants at first to help me sleep."

"Very lonely. No support."

"Shouldn't have to get to a crisis point before help is offered. Assessments should be carried out if promised."

"Looking after someone with dementia 24/7 is really hard. Carers need a break."

"More support for my mental health."

"My husband requires full time support because of his wandering; therefore it has been difficult to make sure he is looked after if I go out at all."

"I need help with understanding benefits."



"There have been no offers of help from health care professionals other than the GP advising that she is available to speak to with concerns, which is so difficult in the present climate."

"Once you get the dementia diagnosis, we are very on our own."

"Meeting with someone to tell me where we are with my wife's illness. More communication."

"Condemn both the patient and carer to humiliations that are never understood. So feeling positive about the situation is not one that springs to mind"

Lack of stimulating opportunities for a person being supported

"We have no family nearby so reliable, experienced companions to stimulate my husband would enhance his life and give me time to myself."

"My husband is no longer the man I married. I obviously still care for him and do my utmost to give him some sort of meaningful life, but I get nothing from him. Much of the time he doesn't know who I am. I feel cut off from life and constantly frustrated that I can't do things. Even going on holiday is not possible now. The only support I have had over the last 18 months is from Age UK. They have phoned regularly and run a zoom session once a week instead of the day club my husband used to go to."

"I am the support for Mum and Dad and I do not feel that there has been any support beyond the diagnosis of dementia and the initial session at Selby Hospital that Mum attended and was not positive."



"Better diagnosis and correct drugs at the correct time. Part of dementia is feeling like urinating frequently but short term memory stops individuals remembering they have just urinated. Given right royal run around trying to sort either bladder sensitivity or enlarged prostate. In the end no firm diagnosis still so no real treatment so still has problems. This makes it impossible for trips out and has a massive impact on day to day living."

The effect of the pandemic: Summary

Carers told us about the impact the pandemic had had on people they supported. They felt the consequences of the pandemic such as lock downs and closures of services had accelerated symptoms, decimated people's routines and self-confidence, increased isolation, anxiety and dependency on certain family members.

Alongside coping with the impact on the person they support, carers told us about the immense challenges that came with not being able to get support from other family members or getting support from or being able to socialise with other carers.

Some carers felt they were so familiar with isolation and a lack of any external input that they didn't feel much of an impact from the pandemic.

"As mum is not recognising or refusing to access help we are left waiting until she is very ill. Not sure what can be done apart from lifting stigmas from ageing."

"I love my husband and loved aspects of caring for him, but all the institutional systems have been appalling to non-existent."





The effect of the pandemic: Themes

Impact on person with dementia

"He is very sociable and loves to be with others but because he is classed as extremely vulnerable he has not been out much."

"At the start of the Pandemic my husband was told to shield (no reason given and it did not happen in the second lockdown). We were given a reference number on the letter and went on the government site but the health reasons on there did not apply to him and we were told we could not get help. It took me 6 weeks to find a supermarket slot to get a food delivery and many many tears...6 months later I got the first phone call from the carer support worker and she said if she had known she could have got me help. However, as I did not know of her existence at the time, how could I have asked for help? The main impact I can see is I think his Alzheimer's has progressed much faster and he has become like a lap dog frightened if I leave him alone (which I have never done). All our little trips out each day to keep him engaged we stopped and as he was shielded we could not even go out for a daily walk and our children could not come and visit."

"Routine is everything and day club stoppages really had an effect that would be too difficult to restart."



"The pandemic isolating has coincided with my parents' (sufferers) ageing. They have had little or no opportunity to interact with others outside their home. I have become literally their only face to face contact with the world. This has not helped them to be stimulated mentally or even physically. They are now fully housebound and cut off from neighbours and few friends /relatives. Support could be some face to face visits from a skilled /experienced dementia professional to talk through the support they really need and should accept. When dealing with medical services it has been hard for me to be fully involved with consultations due to restrictions on access."

"Lack of personal contact with family friends and social contacts has increased the decline in my wife's mental health."

"The Age UK day club my husband attended for 5 hours once a week obviously closed - and still has not opened. I was with him all the time with no break as no-one was able to come in. He became a lot less fit and his dementia got worse. There was nowhere to go to mentally stimulate him. I had support from my family over video calls which kept me in touch with other people. Nobody had any idea of the strain I was under looking after him though. The Age UK calls and zoom meetings were a lifesaver though, and I had a useful call from Dementia Forward."

"It's been a nightmare and my husband has gone downhill rapidly. It's extremely difficult to explain to someone with dementia why they can't go out as they just don't understand that you go over the same discussion all the time."

"Lockdown placed entire dependence upon me which has continued to an extent and that causes distress to sufferer if left with a third party."



"Our parents with dementia have only had us to support them throughout. They must have felt abandoned and so alone."

"The pandemic has really affected someone with dementia, their whole situation/daily schedule has been turned on its head, not being able to get out etc., having to tell the patient on a daily basis why things were difficult/different just adds to the stress of trying to live with some kind of normality during this stressful time. I consider myself lucky that my husband is relatively calm, otherwise things would have been harder. Maybe a weekly phone call would have helped, at least we wouldn't feel so alone."

"It had been challenging being restricted as my husband cannot amuse himself and had become more anxious."

"Isolation has worsened short-term memory."

"I think for mum having had a recent diagnosis of dementia and the pandemic then occurring mum has lost a lot of the skills that she previously had. Mum had worked for many years with Age UK and we had planned on trying to keep this going as it would have benefited both mum and Age UK however this interruption that the pandemic caused means that I fear mum may never get these skills back. Apart from a walk around her village (with dad checking on her whereabouts by phone) mum does not do anything on her own now. I feel that this has been accelerated because of the pandemic."



No support and isolation of carer (loss of family members, other carers/knowledge

"Having no support apart from my son has been difficult as when I go up town to the bank and shopping my husband gets very agitated."

"The patient has not really understood what is happening but has not wanted to go out anyway. When other family members have appointments it can be a struggle as the patient cannot be left on their own. Also being the only other female in the house I have to deal with the personal bits."

"Totally left to caring throughout the pandemic. If we had been able to access day clubs maybe we would be better informed (by talking to others, sharing experiences) Did not know that a rapid decline was a possibility so when we got to crisis point we were in shock and felt we were failing in caring for our loved one."

"Getting in touch with the GP/Local Authority. Hours waiting on the phone, impossible whilst working."

"No access to any day clubs. No meeting face to face with other carers who may be able to pass on advice /share experiences."

"It was really hard. My husband was getting worse and I could do nothing for my own wellbeing. Only later did I get a 2 hours a week break thanks to Age UK."



"Being unable to socialise and having my husband totally reliant on me for company has been very draining. Government information leaflets have been of help in sourcing food deliveries and providing emergency phone numbers although they haven't been needed. Last winter was very hard because of not being able to take him out for short walks and not being able to talk face to face to friends"

"Hugely isolating and lack of support as no home visits from GPs or community nurses. Only time any support was forthcoming was too late and when my family was in crisis. Further assessment was needed and nothing happened; now he is in a home and this has been requested but they are still waiting!"

"There has been little or no response or access to virtually any support either physical or moral."

"My dad as main carer has been isolated with my mum so much of the time he is beyond stressed. My mum is not really comfortable going anywhere anymore other than with me and as I am their only child it is a huge burden."

"Everything normal shut down so we couldn't access dementia clubs/activities. I phoned charities to talk over any pointers to help in dealing with issues rather than GP, as a family we felt left to deal with the situation. My own life was on hold and my well being suffered as a result; feeling down and exhausted."

"We were a couple quite happy in our own company and I went to the gym 3 times a week which I now cannot do as he won't stay on his own and I can't leave him in the car as he would forget where I was and go looking for me. We are Christians and the lockdown decimated our routines as the Church was closed. We used to go to the cinema every week, if nothing else it gave me two hours peace. Still not feeling safe enough to return."



No visits and experience of care home

"My husband was in the care home when the pandemic came along. I used to visit him but suddenly I wasn't allowed to. It's agony knowing no visits are allowed but I understood why of course. Even now it's difficult to visit because of rules for entering the care home."

"I have been able to be tested and visit my sister on a regular basis either in a pod or later in the building. They have done as much as possible to keep them entertained and active, giving them a ride out in their minibus, musical entertainment, cheese and wine tasting and art activities etc."

"I was unable to see my husband for many months and he no longer recognises me."

"It has just been horrific. Knowing my dad was in hospital on his own with no way we could contact him or see him was heartbreaking. I was terrified he would die on his own in hospital."

What helped?

"Certainly our local coordinator has been a huge help."

"Initially I had to cope. It was difficult to ask for help when everyone was so stretched. It felt necessary to manage. This continued until my husband's behaviour became too difficult for me to manage. Once this was acknowledged everyone helped but particularly [the] social worker who was excellent."



"For the first time ever we did a few shops online. Although not as good as being in person we were able to do most of our pre-pandemic activities on Zoom."

"I feel the support I have received during the pandemic has stepped up to be as good as it could be under the circumstances. In general it has been good and I am hugely grateful."

"During the pandemic and subsequent lockdowns my relative with Dementia received no support at all apart from myself. I received regular support from York Carers Trust throughout the lockdowns for which I am very grateful because without their support, I would not have been able to manage and cope during this very difficult time. If there were any support services available, they all seemed to disappear overnight. We were truly forgotten in York. Social Care are still not doing face to face visits. We have had an assessment and two reviews of care needs without one professional meeting us. None from City of York Council have ever contacted us to ask if we needed any help/support during this pandemic or subsequent lockdowns. Neither has any other professional apart from York Carers Trust."

"My mum lived in independent living (extra care) so had care without the restrictions of a care home. We are very thankful for the staff and the approach they took."

Inventing something new: Themes

A New Service

Carers described different elements of a service which they felt would be able to provide the support needed to themselves and those they support.



The key elements of this services include there being an allocated person to seek support from and a key physical place/centre to provide social and physical support.

The key person:

- Would have knowledge of the whole person (physical health/social situation) and would be able to monitor change
- Would have knowledge of the care sector and the ability to monitor it and make change or highlight problems with care services
- Would provide face to face contact and a one stop shop for any help and support
- Would have close connections to the GP surgery
- Would have knowledge about local organisations, equipment services and benefit advice to provide the needed support

The physical space (dementia hub):

- Would provide an accessible social space for carers and people living with dementia
- Would provide a space for multi-agency working and joined up services
- Would offer activities and interest groups and opportunities for people to spend the day
- Would provide a communication hub where all relevant services would be available and accessible
- A place where people can listen to you
- Regular face to face contact with the same people



"An allocated 'goto' person who has all medical record access and can see the whole picture who can co-ordinate specialist services when needed and monitor the decline of someone with a diagnosis of dementia. Someone who knows the current state of care available."

"A specialist team based at the local surgery to visit / support dementia patients cared for by that surgery. This person or people could have an understanding of the whole situation of each sufferer including physical conditions and their social situation. They could help with connecting with support organisations. If such providers are there, they could start to monitor or evaluate local private providers as I have not been impressed with the private provision options."

"A dementia village as other countries have done."

"A local hub or one stop shop for multi-agency working and support for family members."

"A support service that genuinely offers support and clear advice and information about options (of any kind)."

"A single point of contact like an umbrella across all service providers, support groups/charities, health care and social care professionals to access services/professionals/support/equipment/what we are entitled to etc."

"Something that joined the services together and funding for services."

"A centre that provided not only a social space but had activities that could be accessed from the beginning of the diagnosis and where clients could



spend the whole day."

"It would help to have regular face to face contact with a professional so that the person with dementia could get to know them as a friend."

"Communication hub where we could access all relevant services available to us. To have an active listening device. We know our relatives and their care needs better than anyone else and we need our concerns to be taken seriously. Contact Hub where we could access all the professionals both statutory and voluntary services. To see professionals face to face."

"Once people are diagnosed it would be nice for the agencies to work under an umbrella and provide support which continues. Support should be offered and once in the system should be reviewed. People should not have to feel unsure about asking for help, or where to go. Wouldn't it be more sensible if you continued with the same social worker as well as they would have more insight into needs and circumstances and any changes."

Improved emotional and practical support for carers

"More support for carers mental health."

"Someone to visit regularly and listen to our problems would be good."

"Obtaining the Blue Badge needs to be more accessible without the need to take our relatives with dementia for an assessment. If we fail to meet the criteria for the Blue Badge, the £40 needs to be refundable. GPs need to form better relationships with their patients and carers in order to understand their situation and get to know their needs. GPs will then be able to complete the questionnaire correctly based on the needs of the patient that



they have to come to know. Professionals need to build up relationships with both carers and the patient with care needs. We need to access Admiral Nurses for specific medical support, especially as Older People's Mental Health Services discharge upon diagnosis. Getting a GP appointment is almost impossible. We do not have access to a named GP anymore who knows their patient and carers well."

"Group support locally would be good for more help for people with early onset."

"We eventually got disability allowance. A lot of forms to fill in which the women at Citizens Advice filled in for us. I can see why others don't bother to apply even then when he had to be interviewed to see if he could follow simple instructions to see if he could do things. He couldn't, of course, so getting disability allowance helped us. No-one but a friend told us we could get a bus pass for him which we did as we were only 60 when diagnosed. The bus pass helped a lot. No-one but another friend told us. We could get our rates cheaper from the council. When we applied for the first time to York City Council we were turned down and told we couldn't have a reduction in our rates. Eventually through Dementia Forward telling me they were wrong I applied a second time and was told 'yes' we could have a reduction in our rates so the Council gave us the wrong information the first time."

"[We need]...more places locally like Dementia Forward, more helpline information. Anything along those lines to help people like carers to get help with practical and financial and future plans as things progress. By more information I mean printed leaflets as a lot of older people don't go online so they are useless to people who don't own computers."

"Monthly telephone calls to provide the feeling that you had not been abandoned."



"Unpaid carers are saving the country a fortune. They should be appreciated much more."

"Not an invention, but a plea for information about support a carer should have available to them, instead of getting a diagnosis and being shown the door. Virtually no information given, everything I've learned I've had to research myself. I've just remembered that I attended a course on caring for people with dementia run by the Alzheimer's Association and that was very useful, informative and good for a small group of carers to get together and share experiences."

Financial Support

"Why don't 'the powers that be' accept that when a diagnosis of dementia is made there should be no obstacle applied that stops you getting help in any form. Automatic attendance allowance for example."

"More financial help for services to carers. Nothing new and this would solve many problems."

"Easier access to monies/allowances."

Improved medical and social care for people with dementia

"Regular health/mental checks with patient, regular reviews/updates with family. And more dementia care. How to help the patient day to day?"

"More help. I was left to look after mam for 3 and a half years until the crisis team was called. No-one phoned to see how she was, the surgery was not





interested and we were just left to get on with it. However, when I phoned 999 (police) they were fantastic but it was very sad as that night my mam was sectioned and is now in [hospital] where the care is fantastic and they let me know everything that goes on."

"Dementia is a disease that is not recognized as a terminal illness. The government keeps putting off their 'oven ready social care plan' and families are left to fend for themselves, leaving the vulnerable to their unlucky 'lottery' fate."

"I understand about hidden disabilities and have purchased a sunflower lanyard for my husband so if we were to be separated while out my contact details are on it. However I do feel it has been abused by folk using it to not wear masks when it was a requirement. In fact a relative who is an occupational therapist actually said it was for exemption from wearing a mask and did not know it was available long before the pandemic. We first heard of it at an airport. Maybe a new symbol such as the 'forget me not' would be an idea for the lanyard so people do not just think it's about masks. My husband wore his when we were out but also wore the mask as we just need it in case he loses me."

"A reliable service of affordable carers who employed ladies / men of a certain age! And paid them a good enough wage that the older generation of workers would be happy to work for. This said I mean all ages/ sexes paid well. People with dementia do not always want a young person helping them."



Improving expertise and knowledge of staff

"If someone could pop in now and again who I could ask questions on how to do things in the best way, [he] cannot talk now and I have to help with feeding and with the toilet, he can hardly do anything himself. But he smiles all the time to me and others so that is good."

"When the young social worker came to assess mum she had no experience of dementia patients. I was shocked when she told me to just leave mum. Mum is not capable of doing anything for herself, when I asked what if mum starts to wander off outside the girl had to ring her boss for the answer. Each time I asked her a question she had to ring her boss for the answer. The questions I asked were as follows. What if mum leaves the hot water on and scolds herself? - after asking her boss - we will turn the hot water off (would that not confuse mum even more?) - what if mum starts wandering outside? put a lock on the garden gate - what if mum fell downstairs put a gate on the stairs there were many more shocking replies to my guestions coming from her boss. At the end of the assessment the girl mentioned that it was all to do with finding. That was my first encounter with social workers and my last. I now understand why social workers get such a bad press. They are the most unhelpful people I have come across so far. It beggars belief that they tell people to just leave a person with dementia to look after themselves. I have spoken to another person in the same position as me, who also asked social workers for help and they were told they were being abusive?? (for asking for help). I did write a letter of complaint to the social services and unsurprisingly never received a reply."

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York CVS

Healthwatch York is a project at York CVS. York CVS works with voluntary, community and social enterprise organisations in York.

York CVS aims to help these groups do their best for their communities, and people who take part in their activities or use their services.

This report

This report is available to download from the Healthwatch York website:

<u>www.healthwatchyork.co.uk</u> Paper copies are available from the Healthwatch York office, if you would like this report in any other format, please contact the Healthwatch York office.





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Health and Wellbeing Board

16th March 2022

Report of the Independent Chair of the Mental Health Partnership

Report of the Independent Chair of the York Health and Wellbeing Board's Mental Health Partnership

Summary

- 1. This report presents the Health and Wellbeing Board with an update on the work the partnership has undertaken since last reporting to the board in January 2021
- 2. The Independent chair of the partnership will be in attendance at the meeting to present this report.

Background

- 3. The joint health and wellbeing strategy for 2017-22 identifies four principal themes to be addressed. One of these themes is mental health and wellbeing with the key priority for that theme being 'to get better at spotting the early signs of mental ill health and intervening early'. Other aims in the joint health and wellbeing strategy in relation to mental health are:
 - Focus on recovery and rehabilitation
 - > Improve services for young mothers, children and young people
 - Ensure that York becomes a Suicide Safer city
 - Ensure that York is both a mental health and dementia-friendly environment
 - Improve the services for those with learning disabilities (to be addressed in its own strategy)
- 4. These are expanded and explored in more detail in the Health and Wellbeing Board's <u>all age mental health strategy 2018-2023</u>.
- 5. Additionally in 2019 the Health and Wellbeing Board undertook a mid-way review of the joint health and wellbeing strategy and

identified that the following priority should be their focus for mental health for the rest of the strategy's lifetime:

The board will promote awareness and understanding of the protective factors that support good mental wellbeing and ensure that compassionate, strength-based approaches in communities are developed.

6. As reported in the partnership's report to the HWBB in 2021 this was communicated to the Mental Health Partnership who were heartened to see that it was a perfect fit to the holistic approach to the delivery of the mental health priorities they had been taking.

Independent Chair's Update

- 7. This annual progress update aims to illustrate how the partnership is continuing to work in an all-inclusive way to shift the focus from hospital based services to a more community focused model of service provision. It gives a flavour of the transformational change needed to achieve our long term vision of embedding a Trieste style model of mental health care in York.
- 8. As chair of the partnership I would like to recognise the phenomenal efforts and achievements of colleagues on the Mental Health Partnership. At the same time as working through a pandemic they have come together to look to the future of how systems and delivery need to change across the city to improve the lives of individuals. The person receiving the mental health services and support is now the starting point for all our planning for the future. This will also include the voice of carers and families.
- 9. As our work progresses we are mindful of ensuring there is an integrated all age approach to mental health services. York has an opportunity to deliver fundamental change over the next five to ten years. It will need a focus on long term community programmes with a system that comes together at 'Place' to create positive opportunities for everyone involved. This will require strategic involvement and drive to deliver.
- 10. The Mental Health Partnership is a vibrant and fast paced group with a myriad of work happening outside of our quarterly meeting cycle. As part of this annual progress report partnership members have provided a number of summary updates on some of the areas of work we have focused on since our last report to HWBB. These are:

- Suicide Prevention (Annex A refers)
- York Against Stigma (Annex B refers)
- Connecting our City (Annex C refers)
- Multiple Complex Needs (Annex D refers)
- Developing a Dementia Strategy for York (Annex E refers)
- Mental Health Housing and Support (Annex F refers)
- 11. These annexes provide summaries focused on the main areas of work that the partnership have progressed but by no means all that we have been involved in. Some partnership members were also involved in the mental health summit held in March 2021. One outcome of this was to produce an in-depth piece of work on bereavement support and this was completed by the JSNA group and presented to the partnership as the 'bereavement support needs assessment' at our September 2021 meeting. As chair of the partnership I have also encouraged all organisations represented at the Mental Health Partnership to sign up to the Dual Diagnosis Pledge, which the HWBB received at their meeting in January 2022.
- 12. Over the coming year we will continue to progress all of our current areas of work and hope the Health and Wellbeing Board will support us in this. At this point I should also mention that with the establishment of the new Children and Young People's Health and Wellbeing Programme Board the responsibility for children's mental health will sit with them. I think some clarification needs to be provided on where student mental health sits and an acknowledgement that there may be areas of cross-over between the Mental Health Partnership and the newly established programme board.
- 13. As detailed in the Connecting our City update at Annex C, the agreed priorities of the partnership have been taken forward this year using York's allocation of the national community mental health transformation fund. These priorities are being delivered through CYC commissioning with significant support and contribution from Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) and the wider system. The partnership will seek to build on the success of this approach in future years. As part of this we will take the opportunity to review the terms of reference of the

mental health partnership as the health and social care integration arrangements in York progress, ensuring a continued focus on delivery of support informed by co-production and strong partnerships.

- 14. I would like to end my annual update with a few heartening quotes from colleagues about their experiences of being a partnership member and some quotes from members of our co-production network:
 - From The Director of Converge: The partnership and its development of the 'Connecting our City' vision has been very important in guiding our strategic vision at Converge.
 - From the carer representative on the partnership: As a carer and thus not part of any particular organisation, I feel that the partnership provides me with a "home", somewhere where likeminded people tackle some very large issues with humour and persistence. I feel part of a team which is built on good relationships and always feel listened to and valued. I am helping make important decisions, it is a place where things get done.

This is an exciting time as we are beginning to see our vision of a Trieste type model of mental health support is coming off the paper and becoming a reality in York. This can only happen because of the breadth of experience and commitment of those involved.

From members of the co-production network: 'Actually, involving the service user who can contribute to make change'; 'This network has a real influence on money and decision that is genuine'; 'York Co-Production Network is a priority to all my meetings, it's the one I want to go to'.

Consultation

- 15. Consultation with a wide audience took place when developing both the joint health and wellbeing strategy and the mental health strategy.
- 16. As referenced in Annex C a co-production network has been established and meets monthly, feeding into the partnership around

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a number of work areas. The partnership have a standing item on their agenda to receive feedback from this network.

Options

17. There are no specific options for the Health and Wellbeing Board but they are asked to note the report and indicate their continuing support for the Mental Health partnership and its chosen direction of travel.

Implications

18. It is important that the priorities around mental health and wellbeing in both the joint health and wellbeing strategy and the all age mental health strategy are delivered. The establishment of the Mental Health Partnership has enabled this to be achieved. There is a recognition that demand on services will significantly increase across all age groups and major change will be required to ensure that all agencies and partners work together in all sectors to meet this challenge; particularly in response to Covid 19.

Recommendations

19. The Health and Wellbeing Board are asked to note the report and their continued support for the Mental Health Partnership

Reason: To give the Health and Wellbeing Board oversight of the work of the Mental Health Partnership and assurance in relation to strategy delivery.

Contact Details

Author:	Chief Officer report:	Responsible for the
Tim Madgwick Independent Chair of the Mental Health Partnership	Tim Madgwick Independent Chair of the Mental Health Partnership	
	Report Approved	x Date 08/03/2022
Specialist Implications Offi None	cer(s)	
Wards Affected:		All

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For further information please contact the author of the report

Background Papers:

None

Annexes

Annex A: Progress update on suicide prevention

Annex B: Progress update on York against Stigma

Annex C: Progress update in relation to Connecting our City

Annex D: progress Update in relation to Multiple Complex Needs

Annex E: Progress Update in relation to developing a Dementia Strategy for York

Annex F: Mental Health Housing and Support

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ANNEX A

Suicide Prevention in York

Jen Irving, public health specialist practitioner

Current picture and impact of covid.

The most recent data that can be compared to national figures covers the years 2018-2020. This data shows that the rates of suicide in York were not significantly different to the national average at this time; however the suicide rates for York men is slightly above the national average. This includes deaths that were inquest informed suicide, and also deaths of undetermined intent.

Nationally, there is no visible trend of additional suicides linked to the dates of covid lockdowns or the years 2020-2021 compared with previous years. However, we do acknowledge that the mental health harms of covid measures are may take longer to be develop and become fully apparent.

Through 2021, there were 16 inquest confirmed suicide deaths in York.

York suicide safer community strategy 2018-2023

The five year York Suicide Safer Community Strategy was launched in 2018, and has two years remaining. The aim of the strategy is to reduce suicide risk and increase support for people affected by suicide, with the vision of Suicide Safer Community designation as set out in the HWBB strategy.

The strategy includes a series of action areas:

- 1. Reducing the risk of suicide in high risk groups
- 2. Tailored approaches to improve mental health in specific groups
- 3. Reducing access to the means of suicide
- 4. Providing better information and support to those bereaved or affected by suicide
- 5. Supporting the media in delivering sensitive approaches to suicide and suicidal behaviour
- 6. Supporting research, data collection and monitoring
- 7. Reducing rates of self-harm
- 8. Training and awareness raising
- 9. Preparedness and post incident management

Going into 2021 significant progress has been made on several areas of the strategy; most notably work with the river safety team on reducing access to

the means of suicide (action area 3), and work with local media and in developing event response protocols within organisations (action area 5). There have also been a pattern of annual conferences which were successful at building a conversation about York's ambition to be a suicide safer community.

York delivery group, leadership, and regional working

To deliver the strategy the suicide prevention delivery group has met regularly throughout 2021. The membership of this group has also been recently refreshed, to strengthen the multi-disciplinary approach.

The previous suicide prevention lead Andy Chapman left CYC in the summer of 2021. The group is now chaired by Fiona Phillips, consultant in public health, and coordinated by Jen Irving, public health specialist practitioner.

Regionally there is an ICS suicide prevention alliance, as well as several subgroups and peer support structures for public health professionals working on the topic. The York delivery group is well linked into these meting structures and this provides opportunity for discussing the application of national guidance, and exploring regional best practice and opportunities for collaboration.

Improved information flow

Real time surveillance

Real time reporting and monitoring is a cornerstone of delivering this strategy: as well as being central to identifying and responding to clusters, it provides a local understanding of high risk groups or locations which is needed to prioritise other work.

Since summer 2021 suspected suicide data is now provided weekly directly from the coroner's office to public health. This includes information about the person who has died, the location of the death, and an initial assessment of the means and cause of death. This information is not perfect, it is a snapshot of information and is often incomplete, but it is vital in early identification of local clusters or high risk locations.

The real time surveillance days from July 2021-December 2021 shows there were 13 suspected suicides in York (some of these will not be found to be a

ANNEX A

suicide at inquest). These people had an average age of 55 (the youngest was 36, the eldest 89). From the information available in the days after the death, there was no apparent connection between the people, and no common location.

Post inquest summary

The public health team now also receive a post inquest report from the coroner's office. This provides a much more complete view of the person in the weeks and months before their death. In particular we receive information about their mental and physical health conditions, and recent care or service use, previous suicide attempts, and family circumstances. This level of information is only available once the inquest has been completed, often several months after the death. This is a new line of information for the delivery group and will provide good insight into local priorities for the remainder of this strategy period.

MIRT offer and SOBS role in leading annual service of remembrance

Introductions to MIRT

MIRT have provided emotional and practical support to families who have been bereaved by a suspected suicide for many years. Over the last six months there have been strengthening links between the coroner's office and the major incident response team (MIRT).

The coroner's office now makes a personal phone call to every family to offer an introduction to MIRT. Through 2021 MIRT offered suicide bereavement support to 20 York families. Snapshot data from the coroner's office indicates that 57% of eligible families accepted an introduction to MIRT first time, with another 15% were unsure but accepted the offer of another call in three months. The service is continuing to listen to feedback to improve this figure.

Unfortunately 11 families were not able to access the service because they live outside of the area; these families were directed to national services. MIRT and the coroner's office are working to improve relationships with other postvention teams to ensure a good offer to all families. Additionally, in 2022 the coroner's office has committed to further enhancing the links to MIRT by extending the offer of an introduction to more close contacts of the deceased, not just the primary next of kin. We hope this will increase the numbers of people successfully introduced to MIRT.

SOBS service of reflection

The 2021 Service of Reflection Conference was run and delivered by the peer support group Survivors of Bereavement by Suicide and was well attended both in person and through video call. York SOBS has grown considerably over the last few years, and it was excellent to see this years' service of reflection delivered as a community led event.

Clarifying approach to training in 2022

Towards the end of 2021, the delivery group put a renewed focus on developing a strategic approach on suicide prevention training for York. We are developing a view on the priority workforce groups and their training needs. In particular we are considering where we can influence the training specified within contracts for commissioned services and also our role in influencing compliance competency standards where they exist for professional workforces.

The next strategy

Towards the end of 2022 we will also develop a project plan to develop the next suicide prevention strategy that we will develop through consultation and engagement in 2023.



York Ending Stigma - Health and Wellbeing Board March 2022

York Ending **S**tigma (YES), previously known as Time to Change York, works to end mental health stigma. YES is funded by City of York Council until March 2025, and is hosted by York CVS.

YES Champions share their experiences in a variety of ways (openly or anonymously) including through blogs, radio interviews, videos, and via public events, both in person and online. Last year (2021), champions were very active, this report includes a few highlights and plans for 2022.

Mental health awareness week 2021 with St Nicks – an online panel discussion event on the theme of nature connectedness and mental health, in collaboration with St Nicks nature reserve.





World Mental Health Day on Parliament Street with The Retreat – an in person stand in Parliament Street with Champions talking to passersby to help break down stigmas of talking about mental illness and what people with mental illness 'look like'.





Image 2: Champion Rhys with his Pets as Therapy dog Lucy, and her companion Enya

Open Mic night with York Mind at York Theatre Royal – a 75 ticket sell out event with performances on the theme of personal experiences of mental ill-health.



Image 3: Champion Lauren performing her poetry at the open mic night

Social Media Campaigning – throughout the year we share our lived experience via our many social media channels and the full details can be found on our website: <u>www.yorkcvs.org.uk/york-ending-stigma/</u>

3

Plans for 2022

In 2022, YES marked time to talk day with an event in York railway station with York Samaritans. Further into 2022 YES have plans for a podcast series, a yearlong focus on mental health stigma in the workplace, and specific workshops on stigma linked to self-harm and suicide.

HWBB Update March 2022

Connecting Our City – Update

- Since our last written update the Connecting our City working group has continued to meet every 8 weeks and the connecting our city steering group meets monthly to work on the detail of the York Community Mental Health Transformation Funding. Due to the well-established mental health partnership in York and the extent of the work that had been undertaken to define a vision and priorities for the City, York received a significant amount of pump prime moneys to enable us to start work early last year.
- 2. Progress on the pump priming moneys and year one allocations of the community mental health transformation moneys has been continuing at pace and details of this are included below.
- 3. York continues to be represented on the York and North Yorkshire Leadership Alliance which is leading on the Community Mental Health Transformation Moneys at a sub-regional level. York was allocated £430,000 in year one. Allocations for year 2 will be £940,059 (in addition to 15% cumulative contribution to programme costs which will cover the project management costs for City of York) and £1,161,771 (in addition to 15% contribution to programme costs) for year 3.

4. City of York Year 1 Priorities

Throughout a series of workshops and over a three year period, consistent themes have been identified as priorities for the City of York which have formed the basis of our community mental health transformation year 1 funding priorities:

• Development of mental health hubs

- Investment in the voluntary and community sector
- Culture Change
- Coproduction
- More link worker roles
- Whole system, whole person, whole life

5. Achievements since February 2021

a) Coproduction

The co-production network has grown in numbers, confidence and sense of purpose this year. Having a direct influence on the decision making of the Partnership helps drive it, as does the wide range of life experiences of the members. Anyone is welcome to drop in and out, it reaches those in primary care, secondary care, no care at all and of course those who work with them or just have an interest.

Difficult discussions are had in a supportive, understanding arena, such as how to move away from diagnosis centred conversations and think broadly about what can help everyone to lead their best possible life. The January discussion on how to best spend the money allocated to cultural change was far reaching and settled on finding a way to change attitudes and reduce barriers when trying to access primary care.

• From February 2021 monthly coproduction network meetings established. 11 meetings, regularly attended by 12-15 people (growing each time). 40% Lived Experience (and carers) establishing purpose/aims and ground rules. Establishing speaker briefs and ground rules to support people with Lived experience.

- Safety policy and Guide Top/Top Tip of Co-Production being created by Co-Production Network.
- March 2021 Expression of interest for a voluntary organisation to host a coproduction champion
- September 2021 Coproduction champion in post at York CVS 20 one to one meets and multiple team/zoom meetings
- December 2021 Weekly coproduction drop ins at Priory Street
- January 2022 Weekly drop in at Clarence Street added
- Lived experience involvement across workstreams and working groups
- Partnerships being developed across the City. Including City of York Council, York MIND, CAMHS, YSJ Converge, Carers Centre, York Cares, CAMHS, The Retreat, York Ending Stigma(Previously TIME TO CHANGE) and Multiple Complex Needs Network.

b) Investment in the voluntary and community sector

- Investment in social prescriber roles at Foss Park and as part of hub developments
- Coproduction champion based in the VCS
- Peer Support Project York Mind
- Peer Carer Support York Carers Centre
- VCSE Alliance Development Lead role to be recruited shortly by York Mind
- Initial investment of £125,000 into local VCSE activities grant fund to be established by York CVS over the next few months (recurring over 3 years)
- Financial recovery coach based with Peasholme Charity working out of 30 Clarence Street

c) Pathway to Recovery Project

- Team of social workers, social prescriber based at Foss Park since June 2021
- Peer support and peer carer support established and linked to the project
- Provide placed based early help (to reduce admission length, and/or risk of re-admission).

- Connect people with their communities as part of a strength based community asset model to maximise wellbeing and recovery to those most in need.
- Team has worked with 77 people to December 2021
- Financial Capability Coach to be recruited by Peasholme Charity to support the team and link with 30 Clarence Street interim provision of one day per week in place from February 2022
- Developing links to 30 Clarence Street to encourage a 'step down' approach from Foss Park. Activities and resources available within 30 Clarence Street are being developed including a series of Converge taster sessions.

d) Eating Disorder Provision

- NY&Y Eating Disorder Workshop November 2021 38 attendees.
- Beat (national eating disorder charity) commissioned to provide:
 - 35 waiting list support for adults
 - 35 early intervention support for adults
 - 40 one to one support for parents/carers
 - 64 training/workshop for parents/carers
 - Additional provision for 18-25 year olds across Vale of York with a focus on ARFID
- Successful City of York working group held January 2022 to consider whole system plan for future provision. Evolve Community Eating Disorder Service attended to talk about the provision in Hull.

e) Mental Health Hub Development

- City of York hub development workshop held October 2021
- Discussions with Innovation Unit to support the prototyping of a hub model for York, develop system leadership and integrate secondary care.
- Work to begin the design phase of a hub model in York to begin April 2022

- Re-commissioning of the Haven in progress and has been linked to the connecting our city developments
- Reimagining 30 Clarence Street underway to increase the support and activities available at Clarence Street
- Additional investment and development of crisis support

6. Year one Allocation Detail

Year One Allocations: Description	Year 1 Transformation Funding	Additional Funding
1.1 Whole system approach/programme coordination		
Project management roles – recruitment of Project Manager and Project Assistant	£0	£100,000
1.2 Co-production Infrastructure		
Coproduction champion role employed by York CVS	£0	£40,000
Budget to support involvement with meetings/forums/panels etc	£0	£10,000
1.3 Development of 'Trieste' style mental health hubs		
Hub development support – Commissioning the Innovation Unit to support on three strands of work: system leadership; prototyping and growing a new mental health hub for York and integrating secondary care into the new model.	£49,900	£120,000

Year One Allocations: Description	Year 1 Transformation Funding	Additional Funding
Year 1 Eating Disorder Provision - commissioning a range of packages from Beat (national eating disorder charity) to support families and carers, people awaiting a specialist service and those not currently eligible for specialist support. TBC YSJ DBT group work programme.	£70,000	£85,000
Hub multi agency staffing base to support prototype model including social prescribing and peer support	£90,000	
1.4 Pathway to Recovery Project – team of social workers, social prescriber, peer support and peer carer support. Based at Foss Park hospital working with people on admission to ensure a planned and supported discharge linking to community based support.		
Social work and social prescriber roles	£0	£201,000
Peer Support	£0	£50,000
Peer Carer Support	£0	£50,000
1.5 Investment in VCSE to build capacity and enhance and develop community resources and support.		
Funding for VCSE sector – grant fund for local VCSE orgs to meet the sector's ability to co-produce the support and activities people want in their communities and provide continuation funding for support that works. Focus on inequalities.	£125,000	

Year One Allocations: Description	Year 1 Transformation Funding	Additional Funding
VCSE Alliance Lead post (inc admin support) to provide development support and to capacity build within the sector and to work to evolve this into a VCSE alliance model with a view to mainstreaming into commissioning processes after year 3.	£55,000	
1.5 Community Conversations		
Skilling up local community leaders, community roles such as local shops, hairdressers, pharmacies in MECC, MHFA, and ASSIST. To promote positive conversations about mental health within communities.	£4,000	£4000
1.6 Culture change programme		
Working collaboratively with the coproduction network, the MCN network cultural values project and the people on the ground network. Planning a range of approaches to develop shared culture across the workforce.	£5,000	£10,000
1.7 Evaluation - Application has been submitted to host a PhD student to support the evaluation of the programme. This will be match funded by York St John. We are also working alongside Converge to support in depth evaluation of the pathway to recovery pilot.	£14,000	
Total	£412,990	£400,000

7. What's Next

- Focus on services for people with complex needs associated with the diagnosis of a 'personality disorder'
- Detailed development work on eating disorder provision across the Vale of York
- Prototyping a hub model for York design phase to begin shortly alongside the Innovation Unit

- Grant fund to go live for the VCSE
- Refine priorities for years 2 and 3
- Evaluation how will we know if we have made a difference?

8. Challenges

Whilst the Connecting our City partnership has made huge progress in a short space of time, there still remain some significant challenges for which we request support from the Board:

- The commitment for this project from the outset has been for sustainable funding of at least 3 years, particularly for the VCSE. We urgently require confirmation of the continuation of all existing investments in order to allow contracts to be issued/extended. Lack of this confirmation poses a significant risk to the project and to posts and projects.
- The progress made, has been as a result of having project management capacity to drive it forward. The result of this progress is that we now have a significant and highly complex programme of work which cuts across commissioning, partnership working, service design, coproduction and culture/system change. In order for this to be sustained, additional programme support is required on a sustainable basis.
- City of York have taken a different approach to the transformation work from the rest of North Yorkshire that has widespread support from across the system. However true system change takes time and takes courage. This project requires strategic leadership support from across the system and for this to translate down to senior and middle managers across partner organisations. We would request the establishment of a strategic leadership group for York to

facilitate a way for barriers and challenges to be addressed. The establishment of this group will be supported by the Innovation Unit.

Kate Helme Community Mental Health Project Manager, City of York Council

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York MCN Update: 2021 – 2022

York MCN involves various projects, organisations and people coming together to create change, with the aim of improve the lives of people experiencing multiple complex needs across the city. Information about all of the activities below can be found on our website:

www.yorkmcn.org

Next Network Meeting: Tuesday 5th April 2022, 9.30am to 12.30pm, at Priory Street Centre. To receive an invite to this or any of the meetings mentioned below, please email: <u>info@yorkmcn.org</u>

Current Activity

Cultural Values

Following the Cultural Values Survey in 2020, We began a collaborative sense-making process at the end of April 2021 to explore the results together, help us understand the health of the system, and ultimately make changes that will improve people's experience. We have been through various stages of learning and have now produced a Meetings That Matter toolkit (find this online) to help people plan and facilitate meetings that really make a difference. We are holding a **Cultural Value Community of Practice** meeting on **Tuesday 8th March, 1pm – to 2.30pm.**

Co-location Experiment

In 2021 one working group created a co-location space with the aim of exploring how we can work better together. Individuals from across the city were then invited to use a large space at York CVS Priory Street for work and meetings which was successful. This experiment will be coming to an end on **March 25th 2022** and we hope learning can be shared to help influence the design of the mental health hub.

Creative Action

This group is currently working on two projects which aim to increase wellbeing and develop relationships with lived experiences, creating opportunities for engagement to be an ongoing relationship.

The Mail Art Project hopes to reach those who may be isolated and create a sense of community. The Art Bank Project hopes to provide free art supplies and encourage creativity, and will be located at

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Spark:York on Saturday's between 10am-12pm. These two projects will be launched in April 2022.

Payment for Involvement

This is a new stream of activity in which we'll be exploring how we can co-design and implement a Payment for Involvement policy for all York MCN activity. We've just begun, but will be coming together to begin work soon.

Co-commissioning for system change

Current discussions and work-streams of the Co-commissioning group, which look at those services which are commissioned using public money, include:

- Strengths-based approaches, including a 5-week programme looked at Commissioning and Service Transformation through an ABCD Lens (Asset Based Community Development).
- Staff wellbeing/supervision and support across the system
- Data and definitions of multiple complex needs to inform commissioning
- Whole-system review of resettlement pathway and related services/support, with a multi-agency Project Board supporting an intensive review, with conclusions/recommendations needing to go to CYC Executive by late June 2022.

Future 2022 Meeting dates: 2nd March, 27th April and 8th June. Each starts at 2pm.

Deciding Together – Participatory Grant Making

Through a donation from Lankelly Chase Foundation, and supported by Two Ridings Community Foundation and York MCN, there has been an 11-month participatory grant making process called Deciding Together. It aimed to push the boundaries, encourage big ideas and change how things are normally done, putting people from across York in control of how money is allocated. £218,000 has now been gifted to 20 groups across York, and Two Ridings Community Foundation continues to support those who've been awarded grants from the Deciding Together Fund.

System Changers

We ran a third **Systems Changers Programme** over summer 2021. The Programme gave participants the tools to apply systems thinking to their job roles, projects they may be working on and also across other areas of their lives, encouraging experimentation, collaboration and deep conversation about how we can create change.

In 2022 we will be offering **taster sessions** on topics of interest such as systems thinking, looking at building capacity through ongoing availability of Deep Democracy training, and exploring other facilitation techniques that can support people working in the city.

Together with Young People - Children and Young People Inquiry

The Together with Young People inquiry launched in October 2020, with a passionate and committed group of people coming together to explore the question: "How do we change the systems that perpetuate multiple disadvantage for children and young people in York?"

The group have created a positive, meaningful and open environment that seeks to understand the experiences, feelings and needs of children and young people in York from multiple perspectives, asking what's important to children and young people and how we might go about changing the current way things work.

Over last year the group has been developing relationships and exploring areas of activity to undertake together.

<u>Connections to people and groups with direct and personal</u> <u>experience of multiple complex needs</u>

We continue to have strong connections with the independent lived experience network, **LIFE** and the peer led recover group, **York in Recovery**. Individuals across both groups are integral to various activity across the York MCN Network, and we continue to developed relationships with any individuals with direct and personal experience of multiple complex needs who want to get involved in York MCN. This page is intentionally left blank

Vale of York Clinical Commissioning Group

ANNEX E

Developing a dementia strategy for York

1. Introduction

A key theme of the York mental health strategy is to ensure that York is both a mental health and dementia friendly city, including a priority to develop a joint strategy for improving dementia diagnosis and support services. Discussions at the Ageing Well Partnership in May 2019 indicated that the dementia strategy sits with the work being undertaken on Age Friendly Communities.

2. Completing the strategy

The appointment of a new director in City of York Council with the role of dementia lead means we are now at stage where the Council can make its contribution to ensure the completion of a fully- rounded strategy.

- 3. The draft strategy uses the themes of the National Dementia Pathway as a framework for reviewing and redesigning health and social care services for those people with dementia who require specialist services.
 - Preventing Well: Risk of dementia is minimised
 - Diagnosing Well: Timely, accurate diagnosis, care plan and review within first year
 - Supporting Well: Safe high-quality health & social care for people with dementia and carers
 - Living Well: To live normally in safe and accepting communities
 - Dying Well: To die with dignity in the place of your choosing.
- 4. The themes that have mainly concentrated the minds of health partners so far in developing the strategy is Diagnosing Well and Supporting Well. The work on dementia-friendly communities is designed to complement the national strategy; creating dementia-friendly communities that support and sustain people in their homes, neighbourhoods, and social networks.

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NHS Vale of York Clinical Commissioning Group

5. What has happened in the last 12 months?

• Early identification, diagnosis, and support

Progress has been made including early identification, raising awareness in primary care, addressing low diagnosis rates and the provision of pre and post diagnostic support, achieved through the recruitment of four dementia care coordinators and a specialist dementia nurse located in GP practices. Diagnosis rates remain low however and reflect a national trend largely due to the pandemic, with many older people told to shield and remain at home choosing to delay their memory assessment. Managing the backlog of appointments and staff absences due to covid, has had an impact on the capacity of the Memory Service resulting in long waits from referral to diagnosis. The CCG are working with TEWV and primary care to look at alternative pathways to diagnosis and are currently undertaking an audit with TEWV and tracking ten patient referrals to identify bottlenecks.

• Post-diagnostic support

Improving diagnosis alone is not sufficient and people living with dementia and their carers need appropriate post diagnostic support throughout the rest of their life. The CCG commissions Dementia Forward to be the first point of contact for postdiagnostic support from the Memory Service and work is ongoing to establish this as an 'opt-in' service. To support people on their 'diagnostic journey,' referrals can now be made to Dementia Forward for pre-diagnostic support. The 'core' dementia support service provided by Dementia Forward includes a Helpline, Dementia Support Advisors, wellbeing activities and young onset dementia support. This is funded by the CCG as part of a North Yorkshire wide contract. Demand for these services in York has grown significantly and discussions are currently underway with City of York Council to consider their contribution to a sustainable service model.

In addition, the CCG is funding a pilot 'Good Life with Dementia' post- diagnostic programme created by people living with dementia. It offers an opportunity to talk about the implications of a diagnosis; about the future; about close relationships, about dying; about what's happening and what can help – all done amongst peers.

• Workforce training and learning:

A proposal for a York Learning Network has been developed. This is a facilitated network where all stakeholders can share learning ideas; identify and put in place learning needs through a combination of face to face and virtual meetings, webinars, and facilitated virtual action learning sets. The proposal is being shared with the Humber Coast and Vale dementia steering group and is currently seeking funding.

• Strategy drafting event

An initial series of 'We Will' statements were developed last July . This is very much 'work in progress' as partners respond to the feedback from what people with dementia and their carers have told us from the engagement carried out, outlined below.

• Engagement

In addition to the engagement undertaken by Healthwatch York, the CCG carried out face-face engagement with people at local dementia cafes and carers groups throughout December and January. The findings are currently being collated into a joint report with Healthwatch along with key themes and recommendations. In summary, the feedback reinforces the view that services are fragmented, uncoordinated and with complex pathways across the health and social care system. A lack of accessible, personalised advice and support was highlighted by many. Along with a call for reduced waiting times and improved communication and support following diagnosis, is the idea for a 'physical hub,' providing information and advice along with social and physical wellbeing support, and potentially respite and day centre support.

Personalised care takes a whole-system approach; integrating services around the person including health, social care, public health, and wider services; reinforcing the need for a coherent dementia strategy developed across this wider system.

6. The Humber Coast and Vale Health and Care Partnership Integrated Care System (HCV ICS)

NHS Vale of York Clinical Commissioning Group

HCV ICS has established a dementia steering group to lead on the development and delivery of a dementia work programme, including understanding dementia care pathway quality issues and associated costs across HCV; from timely diagnosis to dying well and including staffing and workforce issues, non-essential hospital admissions and appropriateness of current residential care provision for people with complex needs relating to dementia. The core membership of this group provides a cross representation of health, local authority, community, and provider organisations. It has been proposed that an ICS dementia strategy is developed, bringing a commitment to consistency of support services across the HCV footprint. It is suggested that such a strategy will dovetail with the dementia strategy for York.

Mental Health Housing and Support – Project Update

Introduction

- 1. The Mental Health Housing and Support project has been one of the Mental Health Partnership's priority areas of focus since the Partnership formed in 2018.
- In August 2020 the Council Executive agreed proposals that will see the Council and Vale of York CCG jointly commission much needed new specialist mental health housing and support provision in the city – 55 places as follows:
 - 22 places across 2 two specialist mental health supported housing schemes (11 places at each site)
 - 12 places in satellite flats (6 apiece within a 1-2 mile radius of each supported housing scheme)
 - 21 Mental Health Housing First places.
- 3. As lead commissioner, the Council undertook a market engagement exercise between Dec 2020 March 2021, seeking feedback from both Housing Providers and Support Providers in developing its approach to the procurement exercise.
- 4. A S.75 joint commissioning agreement was signed and sealed by CYC and Vale of York CCG in July 2021 and a two-stage tender process was launched in July 2021.

Abandoned procurement exercise

- 5. Unfortunately, the procurement exercise to find a Housing Provider and Support Provider partnership to develop and deliver Specialist Mental Health Housing and Support provision was unsuccessful. The deadline for final tenders had been 15th December, but we closed the procurement exercise down on 8th December.
- 6. We have collected feedback, both through meetings and written responses, from providers who (a) participated in the tendering process but who dropped out before the final tenders could be submitted in the second stage of the process, and (b) providers who participated in the market engagement exercise, but did not ultimately follow up their interest with a bid.

- 7. The Project Board has reflected on providers' feedback and is considering its options for how to take the project forward. CYC's Housing Delivery Board considered an options paper in Feb 2022 and a small sub-group is exploring whether it would be financially viable for CYC to develop the two supported housing schemes rather than an external Registered Housing Provider. It is not yet clear whether this is a feasible option worth exploring further with Elected Members.
- 8. We are hoping we can crystallise a new plan and timeline for taking the project forward in the coming weeks. The relationship between the Council and its NHS partners remains very strong, and the pressing need for this specialist mental health housing and support provision in York undoubtedly remains. At present, our revised estimated timeline for the two specialist mental health supported housing schemes becoming operational is late 2024.

Other project developments

- 9. In the meantime, in the past year further decoration and maintenance work at 22 The Avenue has been commissioned using the project budget to help keep the property in good order for residents and staff until such time as the new specialist mental health supported housing schemes have been developed and become operational.
- 10. The first Mental Health Housing First Worker started in post (with Changing Lives) in Feb 2021 and had a full caseload of cases (7) by the end of the year. Changing Lives are now out to recruitment for a second Mental Health Housing First Worker. There is funding in the project ultimately for three such workers.
- 11. A Mental Health Housing First steering group with representatives from CYC Commissioning, CYC Housing, TEWV and Changing Lives – meets bi-monthly and continues to build on the learning from the first 12 months of the programme, developing clearer MH Housing First referral criteria; a clearer role and training profile for the MH Housing First Worker role; a clear check-list of joint working protocols; and a plan for evaluating the MH Housing First approach, with support from Nicholas Pleace at University of York.

12. The Mental Health Housing and Support project also remains intrinsically linked with the ongoing work of the Multiple Complex Needs Network, the current review of the resettlement pathway and related services and support, and the 'Connecting Our City' programme of work including Community Mental Health Transformation.

Chris Weeks

Commissioning Manager, People Directorate – City of York Council

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Health and Wellbeing Board

16th March 2022

Report of the Consultant in Public Health, Vale of York CCG and City of York Council

Update on the Integrated Care System

Summary

- 1. This report updates board members on the national reforms to the NHS, health and care, and developments locally to plan for the changes which are due to come into force in July 2022.
- 2. It also updates board members on the progress of establishing a placebased partnership as a joint committee of the North Yorkshire and Humber Integrated Care Board ('The York Health and Care Alliance') together with presenting minutes of the November Alliance meeting for the Board to note.

Recommendations

- 3. Health and Wellbeing Board is asked to:
 - a) Note and comment on the developments, including the proposed structure and arrangements for the NHS and care within our region from next financial year
 - b) Note the minutes of the November 2021 York Health and Care Alliance meeting

Background

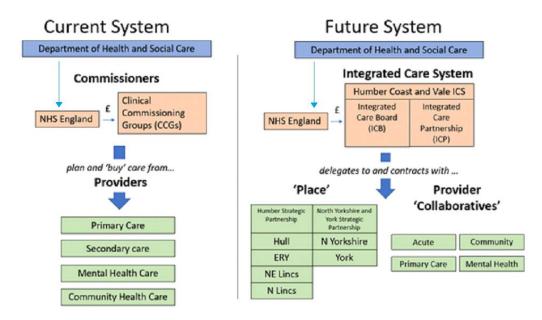
Update on current plans and governance of Integrated Care Systems

4. The NHS White Paper 'Integration and Innovation' was published in February 2021; this led to the Health and Care Bill, published July 2021

which set out key legislative proposals for the NHS reforms. In summary, if the Bill is approved and subsequent legislation comes into force, this will lead to Integrated Care Systems (ICSs) being established on a statutory footing and taking on the statutory and allocative duties of Clinical Commissioning Groups (CCGs) in July 2022; from this point NHS Vale of York Clinical Commissioning Group will cease to exist.

- 5. Humber Coast and Vale Partnership has operated as a non-statutory organisation for several years now, and in 2020 was designated an Integrated Care System (ICS). Once it is formally established in July 2022, the proposal is that it will be renamed, with the two arms of the ICS being known as 'NHS Humber and North Yorkshire Integrated Care Board' and 'Humber and North Yorkshire Health and Care Partnership'.
- 6. Plans for the Humber Coast and Vale Integrated Care System have been emerging over the last nine months, and in October the existing Humber, Coast and Vale Health and Care Partnership consulted on a draft constitution of the ICS.
- 7. This sets out the proposed arrangements for the commissioning and planning of health and social care in our region based on:
 - Six places East Riding of Yorkshire, Hull, North East Lincolnshire, North Lincolnshire, North Yorkshire and City of York;
 - Four sector-based provider collaboratives Mental Health, Learning Disabilities and Autism, Acute, Community Health & Care and Primary Care;
 - a Humber, Coast and Vale wide Integrated Care Board operating through 2 strategic partnerships of the Humber and North Yorkshire & York and a number of committees and forums
 - a Humber, Coast and Vale-wide Integrated Care Partnership
- 8. An overview of the changes showing the current structures of the NHS locally and a simplified version of the new structures is shown below:

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- 9. The Integrated Care Board (ICB) will be directly accountable for NHS spend and performance within the system. The proposed outline membership for the ICB for the HCV region is:
 - Independent lay members (Chair and 2 non-executive directors)
 - Place perspective (one local authority member)
 - Provider perspective (one member each from acute trust, mental health trust and primary medical services (general practice)
 - System executive, including the chief executive, chief operating officer, director of finance, director of nursing, director of clinical and professional services, both strategic partnership directors, the people director, the director of transformation,)
 - Subject matter experts (Voluntary Sector, Public health, communities representative)
- 10. The Integrated Care Partnership (ICP) is part of the ICS tasked with setting strategic direction and including a wide range of partners. The proposal is that HCV ICP base membership should be the six Health and Wellbeing Board chairs or other local government member, six place leaders, the ICB chair and chief executive, and other members of the ICS Executive in attendance as required.
- 11. HCV Partnership has recently announced that it has appointed Sue Symington as its designate Chair, and therefore designate Chair of the anticipated ICB and ICP. In addition, the HCV Partnership (ICS) has recently announced that it has appointed Professor Stephen Eames as

its designate Chief Executive, and therefore designate Chief Executive of the anticipated ICB and ICP. Final appointment to the role of Chair and Chief Executive of the ICB and ICP is dependent on the passage of the Health and Care Bill through Parliament, and any potential amendments made to the Bill and the subsequent legislation.

Place-based partnership: implications for York

- 12. A key part of the reforms aims to reflect that planning of health and care service best works at three geographic levels:
 - Neighbourhood (population between 30,000 and 50,000 people)
 - Place (population between 200,000 and 500,000 people)
 - System (population between 1m and 2m people)
- 13. The national guidance and legislation makes clear that 'place' in the new structure should be coterminous with a local authority area, and that the development of place-based arrangements between local authorities, the NHS and providers of health and care will be left to local areas to arrange.
- 14. At place level, each area will be encourage to established a place-based partnership, which will be a 'joint committee' established between partner organisations, such as the ICB, local authorities, statutory NHS partners or NHS England and NHS Improvement. The relevant statutory bodies can agree to delegate defined decision-making functions to the joint committee in accordance with their respective schemes of delegation. A budget may be defined by the bodies delegating statutory functions to the joint committee, to provide visibility of the resources available to deliver the committees remit.
- 15. As this governance develops at York 'place' it will need to:
 - Use existing mechanisms to embed collaboration, including joint commissioning and joint working (subject to CYC's decision making framework and legislative/statutory framework).
 - Support the NHS to determine the most appropriate governance arrangements for the Integrated Care System by facilitating the emerging environment in York e.g. the Alliance Board
 - Ensure a clear line of sight between CYC health and wellbeing budget and joint arrangements, to ensure exit arrangements are in

place, with CYC remaining accountable for its own delegated spend and cost controls.

- Provide corporate assurance through officer-led engagement in the place based ICS partnership and member-led engagement in HWBB.
- Broaden the functions and role of HWBB to support the place-based ICS partnership, providing opportunity for the Health and Wellbeing Board to play its full part within the Integrated Care System
- 16. The York Health and Care Alliance was established in April 2021 as York's response to these national health and care changes, and to start the work which will be needed if York is to have a place-based partnership able to take on significant responsibility.
- 17. The Alliance Board was established as a sub-group of the Health and Wellbeing Board through consultation with the Health and Wellbeing Board. Papers relating to the establishment of the Alliance board, including a description of its purpose and its terms of reference, can be found in Council Executive papers from their meeting on 18th March 2021 (see background papers).
- 18. As the Alliance Board transitions into a fully-fledged place-based partnership, its governance may need further refinement, and currently discussions are being held between York partners and the ICB on how best to establish the partnership formally.
- 19. It is anticipated that Humber Coast and Vale are soon to announce the process for identifying managerial and clinical leadership at 'place' level, including the process for appointing an 'NHS Place Director' in each area (a senior NHS employee) and a 'Place Lead' (a senior officer or member of a statutory organisation e.g. Local Authority).

Roles of Health and Wellbeing Boards in the future system

- 20. The new legislation includes several references to the role of Health and Wellbeing Boards.
- 21. Before the start of each financial year, an integrated care board (ICB) and its partner NHS trusts and NHS foundation trusts must prepare a plan setting out how they propose to exercise their functions in the next five years. The integrated care board and its partner NHS trusts and NHS foundation trusts must, in particular:

- give each relevant Health and Wellbeing Board a draft of the plan or (as the case may be) the plan as revised, and
- consult each relevant Health and Wellbeing Board on whether the draft takes proper account of each joint local health and wellbeing strategy published by it which relates to the period (or any part of the period) to which the plan relates
- 22. In addition, HWBBs are asked to give an opinion on ICB / Trust forward plans, Joint capital resource use plans, Annual reports (which must reflect local Joint Health and Wellbeing Strategies), and performance assessment of integrated care boards carried out by NHS England.
- 23. A relevant ICB must appoint a person to represent it on each local HWBB. Functions of a local authority under sections 116 and 116A of the Local Government and Public Involvement in Health Act 2007 are to be exercised by the Health and Wellbeing Board and the Integrated Care Board jointly.
- 24. Given this, it is imperative that we develop a strong role for the HWBB in the new system, both through the voice the Chair will have as a member of the HCV ICP, and as the body which sets the strategic direction for health and wellbeing which the York Alliance will work to.

Consultation

25. This paper sets out an update on the progress of national and local reforms, and summarises a policy position taken by partners in York. Therefore most consultation has taken place within health partners in York, including with elected members. Currently, a broad public and third sector consultation is taking place led by the Alliance as part of their Prospectus work, around the type of things which characterise good health and wellbeing in the city, under the banner 'York's Health and Care Big Question'. As the development of a York place-based partnership proceeds, it is anticipated that much more public involvement, consultation and indeed co-production where possible is incorporated into this work.

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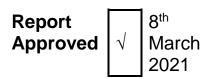
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Peter Roderick Consultant in Public Health City of York Council / Vale of York CCG



Wards Affected: List wards or tick box to indicate all]

All ×

For further information please contact the author of the report

Background Papers:

Health and Care Bill 2021 https://bills.parliament.uk/bills/3022

Executive report March 2021 https://democracy.york.gov.uk/ieListDocuments.aspx?CId=733&MId=12509& Ver=4

Annexes

Annex A: Minutes of the Alliance meeting held November 2021

List of Abbreviations Used in this Report

ICS – Integrated Care System CCG – Clinical Commissioning Group HWBB – Health and Wellbeing Board ICB – Integrated Care Board ICP – Integrated Care Partnership This page is intentionally left blank

ANNEX A



York Health and Care Alliance Board

Minutes of the meeting of the York Health and Care Alliance Board held on 29 November 2021 conducted via Microsoft Teams

Leader City of York Council
Chief Operating Officer, City of York Council
Chair, Nimbuscare York
Vice Chancellor and President, University of York
Accountable Officer, Vale of York CCG
Chief Executive, York and Scarborough Hospital NHS Foundation Trust
Chief Executive, York CVS
Executive Director for Quality & Nursing Vale of York CCG / Director of Nursing & Quality Lead, HCV ICS
Head of Legal and Governance, Vale of York CCG
DH Leadership Alliance, NECS Associate
Legal, City of York Council
Director of Prevention, Commissioning and Education, City of York Council
Consultant in Public Health, City of York Council / Vale of York CCG
York CVS
Health and Wellbeing Partnerships Co-ordinator, City of York Council
Executive Assistant, Vale of York CCG

AGENDA

The agenda was discussed in the following order.

1. Welcome and apologies for absence

The chair welcomed everyone to the meeting and gave special mention to Ian Floyd, Chief Operating Officer, City of York Council (CYC) who had now joined the Board to replace the departing Corporate Director of People.

Apologies were noted from Sharon Stoltz and Brent Kilmurray.

The minutes of the meeting on 27 September 2021 were approved by the Board.

The one item on matters arising remained as the Section 75 Agreement training previously suggested for Board members; this would be deferred to Quarter 4 and synchronised with future governance requirements of the Board as they developed.

2. Update on Developments

Phil referred back to the Alliance Time Out in October where a small number of Board members and Alliance Leadership Team (ALT) members had met and agreed the development of a Prospectus. The ambition of the group was to have a draft Prospectus ready for early in 2022 which could describe the future healthcare offer.

Since then, Phil advised that work had taken place and the Prospectus was firming up with 3 chapters; these were:

- Chapter 1 a provider led outline of recovery from the pandemic
- Chapter 2 a ten year forward view
- Chapter 3 the governance and leadership to be proposed to enable York to take forward the delegated functions and responsibility required to deliver on the above.

In respect of Chapter 2 to describe the vision, arrangements were now coming together for two workshops in January/February to involve and engage local communities in the shaping of the narrative; partners would be asked to help organise and run these workshops.

The Board:

- Welcomed the progress on the Prospectus.

3. Cultural Values Proposal

In introducing Catherine, David alluded to a presentation from Catherine given at the Time Out session in October on the York Cultural Values programme supporting the Multiple Complex Needs Network and surrounding activity. The positive impact the work had had on participants in understanding people's perspectives and developing shared purpose had been emphasised with support given to exploring a cultural values process for the Board and ALT.

Catherine had now joined to elaborate on how a cultural values process for the Alliance could work with suggested timeframes and indicative costings. Additionally, Catherine highlighted consideration of undertaking the programme jointly with the Health and Wellbeing Board (H&WBB).

ANNEX A

David gave appreciation to Catherine for the work so far and sought ratification from the wider Board members to proceed as proposed, including the suggestion on the joint H&WBB proposal.

Board members remained supportive and agreed the joint programme with the H&WBB was a sensible suggestion; David would therefore pull together the next stage on behalf of the Board including the establishment of a steering group.

The Board:

- Supported in principle the joint Cultural Values proposition with the H&WBB
- Noted that nominees for the steering group would be gathered by David
- Noted that a future discussion on costs would be required

4. Update on Alliance area of focus: Diabetes and Healthy Weight

Peter introduced the paper to update the Board on one of its three areas of focus during 21/22, working together to increase the number of people with a healthy weight and to improve outcomes for those with diabetes in York. He highlighted some of the success stories outlined in the paper and the many programmes of work already underway across the system.

Peter referred back to the collaboration on diabetes and healthy weight being chosen as an area of focus by the Alliance, identified as a population health need which crossed multiple sectors and partners around the table. The progress shown in the paper validated the benefit in working together in this way and he welcomed a discussion on how the work on diabetes and healthy weight in York could evolve into the future.

Mike led a discussion and reiterated the thoughts of Peter referring to current system pressures and the need to work together and identify the challenges. There would be opportunities to build on current knowledge, using a population health based approach, empowering people and understanding the finances and resources available could also create opportunities. A radical shift in diabetes was needed which would need strong leadership with learnings taken from other systems. The importance of dedicated resource and time to progress this work including coproduction was emphasised.

The Board acknowledged the need for change and supported the direction of travel; further work would now take place outside of the meeting and be brought back to a future meeting.

The Board:

- Supported the suggested strategy on diabetes and healthy weight and requested that updates be brought back to future meetings.

CJ left the meeting

5. Latest news from the Alliance Leadership Team

The ALT had met twice since the last Board meeting and David provided a brief update from the discussions; he spoke about the meetings being an opportunity to check in with ALT members on how people and the system were feeling, which at the moment was challenging and pressured in all areas with people feeling very stretched. Members had acknowledged the need to discuss the behaviours in the system that were both enabling encouraging collaboration and those that were not, referring back to the behaviours in the peak of the pandemic which had seen everyone really 'pulling together'.

David advised that some debate still remained around the purpose of the ALT versus the York Health and Care Collaborative; the role of ALT had been discussed as the engine room for the Alliance Board, connecting the board to the front line, providing challenge and leading the behaviour change required. A further discussion was suggested about the future of the two groups to confirm their separate purposes.

To help with the understanding of the role of each group alongside the Board, Phil suggested this was articulated in slide form and circulated to members ahead of the next meeting.

The Board:

- Noted the update from the ALT
- Noted that the roles of the ALT and YHCC would be concluded

CS left the meeting

6. Outline of Functional Responsibilities to be carried out in Place

Prior to introducing this item, the Chair highlighted the concerns from Local Authorities, including CYC, around the importance of Place on the proposed Constitution for the Integrated Care System, in particular the desire for each Place Director to have a place on the Integrated Care Board.

Phil referred to the ICS governance which continued to emerge and the HR framework which was still awaited. In the absence of the HR framework, Phil advised that the CCG had been considering the functions that might take place in Place, whilst remaining sensitive to the circumstances. Michelle would shortly be presenting the work so far which had already been shared with CYC colleagues and he gave further assurance to Board members of their involvement as the work progressed.

Michelle presented the slides which described the CCG functions and aimed to raise an initial awareness of opportunities; these also included early comments from CYC. She sought the ambition of the Board on maximising and prioritising the opportunities for Place.

Ian welcomed the aspiration for Place, it was important not to get hampered with the governance and continue working together for the citizens of York. The North Yorkshire and York Partnership between Place and the ICS on the Constitution remained the

biggest concern and would need to be clarified; CYC had already formally fed back their concerns.

Jamaila agreed there were many opportunities to deliver in Place but the decision making proposed for Place did not align.

Michelle referred to the unease regarding the North Yorkshire and York Partnership; whilst the slides, which were similar to other Places, demonstrated fewer opportunities within the Partnership, there would be areas where some business might be better in that space and a substantive post for a Programme Manager was now in train who once appointed would help establish all of this.

The conversation moved on to how the interaction between Place and the Partnership would take place and the Board agreed the Director for the North Yorkshire and York Partnership would be invited to a future meeting or a proposed Alliance Time Out in January.

Simon also highlighted that the Collaboratives were missing from slides and reiterated the national expectation that collaboratives would have responsibilities like Places.

In bringing the conversation to a close, Phil summarised the discussion and suggested the following actions:

- To use the date for the next Board meeting on 24 January as a Time Out to take stock and review the earlier discussion.
- To invite the Humber, Coast and Vale ICS designate Chair and Chief Executive, and the North Yorkshire & York Partnership Director to the proposed time out via letter summarising the earlier concerns and highlighting the progress of York Place so far.
- Establish an 'Alliancing brand' sub-group to create impetus around awareness and marketing of the work to date, and the plans for the next phase. Communications and Media Leads from partners would be invited to take this work forward.

The Board:

- Sought clarity to differentiate the roles of York Place and the North Yorkshire and York Partnership
- Welcomed the work so far on the functions in Place
- Supported a letter to the ICS designate Chair and Chief Executive as proposed

7. Time Out Proposal January 2022

The Board agreed the meeting in January 2022 would be utilised for an Alliance Time Out; a decision on whether this could be a face to face meeting would be made in early January.

8. Any Other Business

Board members agreed to stand down the next meeting on Friday 17 December due to a number of apologies .

The Chair closed the meeting.

Agenda Item 9





Health and Wellbeing Board

16th March 2022

Report of the Chair of The York Health and Care Collaborative.

Summary

- 1. The Health and Wellbeing Board is asked to consider a report on the work of the York Health and Care Collaborative which is attached at Annex A.
- 2. The Collaborative is chaired jointly by Dr Emma Broughton and Dr Rebecca Field, who will present the report at the meeting.

Background

3. The York Health and Care Collaborative is a multi-agency group that brings together a range of organisations involved in health and care in the city. As such it contributes to the delivery of the Joint Health and Wellbeing Strategy and is instrumental in the implementation of the NHS Long Term Plan in York.

Consultation

4. York Health and Care Collaberative includes representation from the Voluntary Sector, who have been engaged right from the start and throughout.

Options

5. There are no specific options for the Health and Wellbeing Board to consider.

Strategic/Operational Plans

6. The work of the York Health and Care Collaborative contributes to the implementation of the NHS Long Term Plan (2019) which is a strategic objective for all NHS Organisations

7. York Health and Care Collaborative priorities for 2021/2022 cover, prevention, ageing well/frailty, mental health and children and young people, all of which align with the Joint Health and Wellbeing Strategy.

Implications

8. It is important that the priorities of the Joint Health and Wellbeing Strategy and the objectives of the Long-Term Plan in relation to integration are delivered.

Recommendations

- 9. The Health and Wellbeing Board are asked to;
 - a. note the report of the Chair of the York Health and Care Collaborative

Reason; there is a shared objective of improving the health and wellbeing of the population. The York Health and Care Collaborative is unique in bringing together; providers and commissioners of health and social care services (from the NHS and City of York Council), colleagues from City of York Public Health together with the voluntary sector as a means of working on joint priorities to achieve this objective. The York Health and Care Collaberative agreed to provide regular updates on its work and progress.

Contact Details	
Author:	Chief Officer Responsible for the report:
Dr Emma Broughton Dr Rebecca Field	Dr Emma Broughton Chair of York Health and Care Collaborative
	ReportXDate08/03/2022Approved
Wards Affected:	All X

For further information please contact the author of the report

Background Papers: None

none

Annexes

All annexes to the report must be listed here. Annex A – Report of the Chair of the York Health and Care Collaborative March 2022 This page is intentionally left blank



Report of York Health and Care Collaborative; Update March 2022

1. Introduction

This report provides update on the work of the York Health and Care Collaborative (YHCC); briefly outlining the scope of each priority workstream.

2. Progress on Priorities;

2.1 Prevention

The responsibility for leading health promotion and prevention activities across the city is with City of York. YHCC provides a forum to share population health intelligence and identify where a collaborative approach can increase the impact and effectives of interventions.

a) Smoking; prevalence in York is below the regional and national average. However, smoking in pregnancy has not decreased locally as much as nationally. Maternity services can refer into CYC, but engagement is low. CYC are in the process of procuring a provider of e-cigarettes and work is being done with the Trading Standards team to look at smoke free parks and school gate initiatives.

CYC have increased the size of the health trainer team and work needs to be done between CYC and primary care to make sure that those with the greatest need, and highest chance of success, are seen.

b) **Substance misuse**; drugs and alcohol; in February, YHCC focused on alcohol misuse, an area where overall York performs poorly on most indicators.

Two alcohol link workers have been recruited by Changing Lives to support people in the community that require an intervention to reduce their alcohol consumption. The pilot was originally set up to be aimed at GPs, but this has now been extended to include health trainers and social prescribers. There is an opportunity for health trainers to work in GP practices to identify those with harmful alcohol consumption. Target health checks can then be



done via text. It was agreed that additional comms was required so that providers know the service is available for referrals.

An action was taken from the February YHCC meeting to understand whether it was possible to link the alcohol reduction programme with IAPT.

c) Weight management, obesity and diabetes; The Healthy Weight Steering Group continues to meet and deliver work on the wider determinants of healthy weight and weight management pathways.

In children at reception age, York benchmarks slightly higher than the national average for weight. Therefore, the weight management offer for children in York focuses on 0-5 year olds. HENRY invites families to meet in group sessions to encourage healthy food behaviours, the service has been commissioned for six months.

For adults, two contracts have been commissioned for people who are obese and meet the eligibility criteria. The contracts are with GLL and Slimming World.

In the February YHCC meeting the group discussed how to increase referrals into weight management programmes. Slides from Public Health were shared to the group alongside a video to help people to have confidence in starting conversations around weight. It was agreed that there could be one offer to all York patients through social prescribers. This will be progressed by the Clinical Directors for York PCNs.

2.2 Ageing Well, Frailty and Multimorbidity

a) Ageing Well and Frailty

The YHCC Frailty Steering Group continues to meet monthly, the aim of the group is to understand how to code frailty and ensure that the coding is readily accessible to all health care professionals supporting frail people. The group have identified and are working towards the following next steps:



- Share training to all health care providers that come across frail patients
- Confirm whether all patients are consented to the ESCR
- To build a practice information pack with the Vale Frailty Group to ensure a consistent approach across primary care, community teams and social prescribers.
- Collate and share survey results from Central and Vale practices
- Schedule a meeting with all relevant stakeholders to understand what services are available in York for frail patients and produce a map that can be shared to providers in the city.

Representatives from York Trust attended the YHCC meeting in January to provide an update around the national guidance that was released in summer 2021 in relation the 2 hour Urgent Community Response, which will come into effect at the end of March 2022. It is recognised that when the clinical models are finalised, they will vary between different geographies. Multiple agencies will need to help to design the model and YHCC will support any necessary conversations between providers in York.

2.3Mental Health

The responsibility for leading mental health transformation is with the Mental Health Partnership. YHCC supports two main aspects of this work; the aim to achieve better integration of mental health into the broader provision of community and primary care services and addressing the need to improve the physical health of people with severe mental health illness (SMI).

A workshop was held in October with the Innovation Unit who proposed three different models for mental health hubs in York. The chosen model will be prototyped through temporary MDT teams in a virtual hub. It was agreed that the hubs would need to be co-produced, and that primary care was central in their development.

Covid Support Hub – The Covid hub was set up in the first wave of the pandemic to offer welfare calls to those that were moderately unwell with Covid and at risk of rapid decline. This service is still in place, but the work of the hub has expanded to include additional services.

The most recent piece of work the hub has started looking at is offering calls to patients on hospital waiting lists to try and ensure they are fit for



surgery when it is offered. York is the first place in HCV to try and tackle the long waiting lists in this way. Long waiting lists are creating an unmet health need in York and it could be up to 5 years before the lists recover from the impact of Covid. Those receiving the calls will all be on P4 waiting lists and therefore, likely to face the longest waits. The cohort will be risk stratified based on health and social factors to make sure those that are most vulnerable are contacted first.

The hub is an example of successful collaborative working between City of York Council, York CVS, Nimbuscare and Vale of York CCG. Relationships formed through the hub have been unique and only made possible due to the foundation that was in place before the pandemic.

3. Future work and further development of York Health and Care Collaborative in 2022/2023

3.1Priority Setting

Priorities for the group in 2022/2023 will be discussed and agreed at the March YHCC meeting.



York Poverty Truth Commission

'Nothing about us, without us, is for us'

Alison Semmence, Chief Executive York CVS

March 2022

What is a Poverty Truth Commission

- A Poverty Truth Commission puts those with direct experience of poverty first
- It asks them to share their knowledge about what's truly needed to make change
- They set the agenda
- It links them with decision makers in the area, building real relationships and real trust
- It humanises the system which is currently in place to tackle poverty
- It is a power-dynamic equaliser, all people within the PTC should be heard, and everyone's opinions are valued

orkcvs

Poverty and York

York is a great place to live for many, however it is a tale of two cities...

- There is a 13 year difference in life expectancy from the least to the most deprived parts of the city
- York has a higher number of part time, insecure and low paid jobs than average
- 1 in 3 people live in social or rented property
- The ratio of rent to earnings is comparable to London
- In May 2021, 12,746 York residents were on Universal Credit (7159 in work). 5541 residents received Council Tax support
- Over 2020 and 2021, over £3.5m has been distributed to local people in financial support





What excites people about a PTC?



- The mechanism of the commission will allow for voices to be truly heard
- An opportunity for real change
- Bursting the bubble of complacency
- Becoming 'more human' to one another

yorkcvs

What concerns people

- Can we persuade enough local decision makers to give this their energy?
- That no power is really given to those who should be equal
- The need to achieve beyond a few tweaks which should be changed anyway
- Lots of noise with no result

Next Steps

yorkcvs

- First two co-production events held more to follow
- Funds for year 1 raised
- Two new 2 co-ordinators employed from 1 March 22
- Community Commissioners are being identified
- Civic Commissioners will then be identified
- Community & Civic Commissioners brought together to work together to bring about change
- Poverty is reduced!





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