Notice of a public meeting of
Health and Wellbeing Board

To: Councillors Runciman (Chair), Brooks, Cannon and Craghill

Keith Ramsay (Vice Chair)	Lay Chair NHS Vale of York Clinical Commissioning Group (CCG)
Sharon Stoltz	Director of Public Health, City of York Council
Martin Farran	Corporate Director-Health, Housing and Adult Social Care, City of York Council
Jon Stonehouse	Corporate Director Children, Education and Communities
Lisa Winward	Deputy Chief Constable- North Yorkshire Police
Sarah Armstrong	Chief Executive, York CVS
Siân Balsom	Manager, Healthwatch York
Julie Warren	Locality Manager (North), NHS England
Colin Martin	Chief Executive, Tees, Esk and Wear Valleys NHS Foundation Trust
Patrick Crowley	Chief Executive, York Hospital NHS Foundation Trust
Phil Mettam	Accountable Officer, NHS Vale of York Clinical Commissioning Group (CCG)
Rachel Potts	Chief Operating Officer, NHS Vale of York Clinical Commissioning Group (CCG)
Mike Padgham	Chair, Independent Care Group

Date: Wednesday, 8 March 2017
Time: 4.30 pm
Venue: The George Hudson Board Room - 1st Floor West Offices (F045)

AGENDA

1. Declarations of Interest (Pages 3 - 4)

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. A list of general personal interests previously declared is attached.

2. Minutes (Pages 5 - 16)

To approve and sign the minutes of the last meeting of the Health and Wellbeing Board held on 18 January 2017.

3. Public Participation

It is at this point in the meeting that members of the public who have registered their wish to speak can do so. The deadline for registering is **Tuesday 7 March 2017** at **5.00 pm**

To register please contact the Democracy Officer for the meeting, on the details at the foot of this agenda.

Filming, Recording or Webcasting Meetings

Please note this meeting will be filmed and webcast and that includes any registered public speakers, who have given their permission. This broadcast can be viewed at http://www.york.gov.uk/webcasts.

Residents are welcome to photograph, film or record Councillors and Officers at all meetings open to the press and public. This includes the use of social media reporting, i.e. tweeting. Anyone wishing to film, record or take photos at any public meeting should contact the Democracy Officer (whose contact details are at the foot of this agenda) in advance of the meeting.

The Council's protocol on Webcasting, Filming & Recording of Meetings ensures that these practices are carried out in a manner both respectful to the conduct of the meeting and all those present. It can be viewed at:
http://www.york.gov.uk/download/downloads/id/11406/protocol_for_webcasting_filming_and_recording_of_council_meetings_20160809.pdf

4. **Appointment to York's Health and Wellbeing Board** (Pages 17 - 20)
   This report asks the Board to confirm a new appointment to its membership.

5. **Governance Arrangements for the Health and Wellbeing Board** (Pages 21 - 34)
   During the course of 2016 and early 2017 Health and Wellbeing Board members attended a number of development sessions facilitated by the Local Government Association.

   These sessions included discussion relating to the governance of the Health and Wellbeing Board. This report sets out the outcomes from those discussions and asks HWBB members to formally approve the recommendations at paragraph 35 of this report.

6. **Update on the work of the Joint Strategic Needs Assessment/Joint Health and Wellbeing Strategy Steering Group** (Pages 35 - 104)
   This report provides the Board with an update on the work that has been undertaken by the Joint Strategic Needs Assessment/Joint Health and Wellbeing Strategy Steering Group since it last reported to the Board in September 2016.

7. **Monitoring the Performance of the Joint Health & Wellbeing Strategy** (Pages 105 - 114)
   This report sets out options by which the Health & Wellbeing Board (HWBB) can maintain oversight of progress and performance against York’s Joint Health and Wellbeing Strategy 2017-2022 (JHWBS).

8. **NHS Vale of York Clinical Commissioning Group's Operational Plan 2017/18 - 2018/19** (Pages 115 - 216)
   This report presents the NHS Vale of York Clinical Commissioning Group (CCG) two year Operational Plan for information to the York Health & Wellbeing Board.

9. **Status Report on the Better Care Fund (BCF) Programme** (Pages 217 - 228)
   This report updates the Health and Wellbeing Board on progress in relation to the Better Care Fund (BCF) programme for 2016/17 and 2017/19.

10. Healthwatch York Reports (Pages 229 - 378)
This report asks Health and Wellbeing Board (HWBB) members to receive three new reports from Healthwatch York namely:

a. Continuing Healthcare (Annex A)

b. Support for Adults with Attention Deficit Hyperactivity Disorder (ADHD) (Annex B)

c. Making York Work for People Living with Dementia (Annex C)

11. Meeting Work Programme (Pages 379 - 382)
To consider the Board's Meeting Work Programme.

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

Democracy Officer:

Name- Judith Betts
Telephone No. – 01904 551078
E-mail- judith.betts@york.gov.uk

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

- Registering to speak
- Business of the meeting
- Any special arrangements
- Copies of reports and
- For receiving reports in other formats

Contact details are set out above.

This information can be provided in your own language.

我們也用您們的語言提供這個信息 **(Cantonese)**

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

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

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

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

☎ (01904) 551550

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Extract from the
Terms of Reference of the Health and Wellbeing Board

Remit

York Health and Wellbeing Board will:

- Provide joint leadership across the city to create a more effective and efficient health and wellbeing system through integrated working and joint commissioning;
- Take responsibility for the quality of all commissioning arrangements;
- Work effectively with and through partnership bodies, with clear lines of accountability and communication;
- Share expertise and intelligence and use this synergy to provide creative solutions to complex issues;
- Agree the strategic health and wellbeing priorities for the city, as a Board and with NHS Vale of York Clinical Commissioning Group, respecting the fact that this Group covers a wider geographic area;
- Collaborate as appropriate with the Health and Wellbeing Boards for North Yorkshire and the East Riding;
- Make a positive difference, improving the outcomes for all our communities and those who use our services.

York Health and Wellbeing Board will not:

- Manage work programmes or oversee specific pieces of work – acknowledging that operational management needs to be given the freedom to manage.
- Be focused on the delivery of specific health and wellbeing services – the Board will concentrate on the “big picture”.
- Scrutinise the detailed performance of services or working groups – respecting the distinct role of the Health and Adult Social Care Policy and Scrutiny Committee.
- Take responsibility for the outputs and outcomes of specific services – these are best monitored at the level of the specific organisations responsible for them.
- Be the main vehicle for patient voice – this will be the responsibility of Healthwatch. The Board will however regularly listen to and respect the views of residents, both individuals and communities.

Health & Wellbeing Board
Declarations of Interest

Patrick Crowley, Chief Executive of York Hospital
None to declare

Rachel Potts, Chief Operating Officer, Vale of York Clinical Commissioning Group)
None to declare

Mike Padgham, Chair Council of Independent Care Group

- Managing Director of St Cecilia's Care Services Ltd.
- Chair of Independent Care Group
- Chair of United Kingdom Home Care Association
- Commercial Director of Spirit Care Ltd.
- Director of Care Comm LLP

Keren Wilson, Chief Executive Independent Care Group

- Independent Care Group receives funding from City of York Council

Siân Balsom, Manager Healthwatch York

- Chair of Scarborough and Ryedale Carer's Resource
- Shareholder in the Golden Ball Community Co-operative Pub

Councillor Brooks

- Member of Mental Health and Learning Disabilities Partnership Board
- Governor of Leeds and York Partnership NHS Foundation Trust

Councillor Douglas

- Governor of Tees, Esk and Wear Valleys NHS Foundation Trust

Agenda Item 2

City of York Council — Committee Minutes

Meeting	Health and Wellbeing Board
Date	18 January 2017
Present	Councillors Runciman (Chair), Brooks, Cannon and Craghill Keith Ramsay (Lay Chair of NHS Vale of York Clinical Commissioning Group) (Vice Chair) (apart from Minute Items 49 & 50) Sharon Stoltz (Director of Public Health, City of York Council), Martin Farran (Corporate Director-Health, Housing and Adult Social Services, City of York Council), Jon Stonehouse (Corporate Director-Children, Education and Communities) , Phil Mettam (Accountable Officer, NHS Vale of York Clinical Commissioning Group) Sarah Armstrong (Chief Executive, York CVS) Tim Madgwick (Deputy Chief Constable, North Yorkshire Police), Siân Balsom, (Manager, Healthwatch York), Mike Proctor, (Deputy Chief Executive, York Teaching Hospital NHS Foundation Trust) (Substitute for Patrick Crowley), Ruth Hill (Director of Operations (York and Selby) (Tees, Esk and Wear Valleys NHS Foundation Trust)) (Substitute for Colin Martin) Keren Wilson (Chief Executive, Independent Care Group) (Substitute for Mike Padgham)

Apologies	Patrick Crowley, Colin Martin, Rachel Potts, Julie Warren and Mike Padgham

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Chairs Comments

The Chair announced to the Board that it was Tim Madgwick's last meeting. She thanked him on behalf of all Board Members for his valuable contributions and wished him well.

40. 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.

Councillor Brooks declared two personal interests in the remit of the Board in that; she was a member of the Mental Health and Learning Disabilities Partnership Board and a governor of Leeds and York Partnership NHS Foundation Trust.

Councillor Cannon declared a personal interest in the remit of the Board as her husband was a current outpatient at York Hospital.

41. Minutes

Resolved: That the minutes of the last meeting of the Health and Wellbeing Board held on 23 November 2016 be approved as a correct record and then be signed by the Chair.

42. Public Participation

It was reported that there had been two registrations to speak under the Council's Public Participation Scheme in relation to issues within the remit of the Board.

Sheena Foxwell from Defend our NHS York spoke about how black, red and OPEL alerts were now being triggered in Accident and Emergency (A & E) departments and hospitals.

This situation meant that hospitals were unable to deliver care and patient safety could be compromised due to overwhelming demand. She also commented that the Care Quality Commission (CQC) had identified that York Hospital had breached its 4 hour waiting time in A&E for the past two years. In addition, inpatient beds across the country were being cut without facilities in the community to replace them. She highlighted the loss of 22 inpatient beds from the closure of Archways and cuts to the adult social care budget and delayed discharges which she felt had compounded bed losses. She questioned what proposals had been put forward to resolve the situation.

Anne Leonard also from Defend our NHS York spoke about obesity and the rationing of medical care for those who were obese or overweight. She informed the Board that obesity was largely a social issue. She felt that obesity would not be lessened by the rationing of services and neither would blaming obese people themselves. In her opinion, this masked the real problem which was that services were not capable of being stretched any further. She urged the Board to investigate the issue further.

In response to the speakers a number of Board Members commented;

The Deputy Chief Executive of York Hospital NHS Foundation Trust informed the Board that there had been unforeseeable increases in admissions to the hospital over the Christmas period. For example there had been an 11% rise in ambulance arrivals and a 22% rise in attendance at A&E. There was spare care capacity in the community which had been made available from the removal of inpatient beds.

The Director of Public Health informed the Board that the causes of obesity were complex and it was a societal issue. She intended to develop a Healthy Weight and Active Lives Strategy along with partners this year.

Two Members of Council spoke, one was concerned with the cuts to NHS budgets and services and how comments raised about how there was not sufficient money within the wider system for transformation in the NHS seemed to not be taken on board. The other referred to a recent motion approved by Council which objected to NHS Vale of York CCG's decision to ration access to services to those who smoked or were obese. The Accountable Officer from NHS Vale of York CCG noted that demand for services were often outstripping financial resources and therefore in order to meet the challenge a better joined up system was needed.

The Chair also noted that, in reference to an item later on the agenda, Community Pharmacies might help to keep patients out of A&E. In regards to the obesity issues raised by the speaker, she suggested that the Health and Adult Social Care Policy and Scrutiny Committee might wish to investigate this further. She thanked the speakers for their comments.

43. Appointments to York's Health and Wellbeing Board

Board Members received a report which asked them to consider updating two appointments to its membership.

Resolved: That;

(i) Sue Collins, Director of Development at York CVS be appointed as a substitute to replace Catherine Surtees.

(ii) Lisa Winward replace Tim Madgwick as the North Yorkshire Police representative on the Board.

Reason: In order to ensure proper representation on the Health and Wellbeing Board.

44. Future in Mind

Board Members received a report which updated them on the progress of the Future in Mind local transformation plan, and the plan's refresh and update.

The Senior Commissioner from the NHS Partnership Commissioning Unit presented the report and underlined how the Future in Mind local transformation plan was a living document with a focus on the continuous improvement of children's mental health.

It was noted that the School Wellbeing Service which had been partly funded by Future In Mind (FIM) had been a success in that it had been a genuine collaboration between partners. The main concerns from headteachers had been the ability to respond to emotional health of children in school. Even though the Government had mentioned that FIM funding had reached its intended places, remaining areas still needed funding. These remaining areas would not be funded through FIM, but through a partnership of Schools Forum and council funding.

A new strategic partnership led by CYC and the CCG was developing following a realignment in Child and Adolescent Mental Health Services (CAMHS) through FIM, in that the single point of access (SPA) would align with the Local Area Team (LAT) arrangements.

Board Members questioned if school changes would have implications on the delivery of the service. In addition, it was questioned if all schools, including Multi Academy Trusts would engage with the agenda. It was felt that all schools regardless of their type would engage with the FIM agenda.

Concerns over additional pressures such as the small amount of spending on CAMHS (Children and Adolescent Mental Health Services) in relation to other areas were raised. It was felt that this would be the marker to the success of the Future in Mind plan.

Resolved: (i) That the report and work to date be noted.

(ii) That the Future in Mind Transformation Plan at the time of writing be received and noted.

Reason: To keep the Health and Wellbeing Board up to date with the Future in Mind workstream.

45. The Role of Community Pharmacy in Health and Wellbeing

The Board received a report and PowerPoint presentation on the role of Community Pharmacy in Health and Wellbeing. Jack

Davies, Chief Executive Officer and Tracey Chambers (Committee Member) from Community Pharmacy North Yorkshire presented the report.

The main points arising from the presentation were;

- Most people lived within 10 minutes of a community pharmacy
- 100 hour pharmacies (those that opened seven days a week) were now in operation, Sunday was the most popular day of use.
- That community pharmacies could offer personal care- case studies were given; how medication was ordered for a patient who had forgotten to reorder, a patient's blood pressure checked due to medication change and attending a social event following a bereavement.

Questions from Board Members related to;

- Cross Charging- where the costs of the services used were used by non York residents, but were not charged back to the area where the user was normally resident. Could data be recorded to the areas in which the charges needed to be made to?
- Minor illness and ailments- would the business attracted from a service offered for these two particular issues sustain a business model?
- What were the consequences for pharmacies if they did not achieve Healthy Living Pharmacy Status?

It was reported that postcodes had previously been used when collating data on cross charging. However, it was a challenging issue as budgets were stretched and the council did not have the facilities to cross charge.

Minor ailments were often self referred to pharmacies, but it was felt that there would be advantages of having a minor ailments service. Healthwatch York, had been informed that people had been interested in a minor ailments scheme and had referred to it online.
However, those people who needed it the most could not access it. It was the hope that all pharmacies would achieve Level 1 of the Healthy Living Pharmacy Status.

Resolved: That the report and presentation be noted.

Reason: To update the Board on the role of Community Pharmacy in Health and Wellbeing in the city.

46. York Pathways

Board Members received an update report from York Pathways, a partnership who were committed to improving the response to individuals experiencing ‘complex distress’ placing a high demand or at risk of placing high demand on services. These individuals were often those who had mental health challenges and suffered with alcohol and drug problems.

Tim Madgwick introduced the presenters and informed the Board that the Pathways project had been nationally recognised. However, it could no longer rely on unsustainable funding resources.

Sarah Owen Rafferty and Samantha Durrant from Together York presented the report and informed the Board using sound clips that it was often difficult to actively listen to service users because of the way that they presented themselves to services. They carried out an exercise amongst Board Members which asked them to think of vulnerable people in York and write down their priorities.

Following the exercise, it was noted that break down in relationships and reliance on alcohol were some of the issues faced by service users in York. However, it was felt, that attention needed to paid to those groups who did not currently use services.

Some further areas that were important to service users identified were;

- Resilience
- Wellbeing
- Motivation
- Change
- Interpersonal Trust
- Hope

Prior to Pathways, service users showed negative responses across all of these areas, and seemed worse than other groups surveyed such as prisoners. Therefore it was felt that a more holistic intervention approach was needed.

Sarah and Samantha shared a service user’s story with the Board.

The Chair informed the presenters that although the Board supported the work and aims of Pathways, they did not have a budget.

The issue of social prescribing was raised and it was felt further discussion was needed, in regards to positive outcomes from further individual interventions, it was noted that there were those who felt their needs were not addressed by any services and work to bring services together, could only be a positive thing.

It was noted that that City of York Council and NHS Vale of York Clinical Commissioning Group had developed a way forwards in regards to a Mental Health Strategy for the city and the work of the Pathways project should link into this. Early low level intervention it was felt should be brought back within an action plan.

Tim Madgwick underlined the significance of the Pathways work in that it worked with groups who were often regular presenters at A&E. It was about making use of the two years worth of work, and about working in an interagency way, particularly given that there was not an infinite amount of money.

Sarah Armstrong volunteered to meet with the representatives from Pathways and report back to the Chair regarding this.

Resolved: (i) That the report and presentation be noted.

(ii) That the learning from the meeting be followed up and future discussions take place in an additional informal meeting between the Pathways presenters and the Chief Executive of York CVS, on behalf of all Health and Wellbeing Board Members.

Reason: The learning from the evaluation in process and strategic board partners informs us that we need to focus on addressing system wide issues if York’s ambitions are to be achieved. Embedding system change at all levels, including those who are directly supporting service users and their managers. We will do this by seeking permission from agency CEO's (for example health, housing, police, substance misuse, third sector) for Pathways to engage with their staff on a regular basis over the year.

It is imperative that we reach relevant Boards and forums to articulate parts of the system that we know are not working and help prevent the potential misalignment of resources. As a result we want to see a shift in a system focused on budgets and outcomes to a system that has the service user at the heart and is fully accountable for individual journeys.

47. Progress Report from the Integration and Transformation Board

Board Members received a progress report into work undertaken by the Integration and Transformation Board (ITB).

The Corporate Director for Health, Housing and Adult Social Care introduced the report.

Board Members were informed that governance issues had now been agreed such as the Terms of Reference. The Vale of York ITB would become one of two or three locality area boards reporting to an Accountable Care Partnership Board for the Vale of York footprint.

Questions from Members included;

- Who would be the independent sector providers mentioned within the Joint Commissioning Strategy?
- Were Accountable Care Systems (which were modelled on US systems) allowing private healthcare providers into the public healthcare sphere?

It was suggested that Board Members receive a Membership list of who was on the Accountable Care Partnership Board.

Resolved: (i) That the Joint Commissioning Strategy be endorsed.

(ii) That the progress in relation to creating an Accountable Care System for the Vale of York be noted.

Reason: To keep the HWBB updated on progress being made by the Integration and Transformation Board.

48. Progress report on the 2016/17 Better Care Fund (BCF) programme: risks and issues

Board Members received a progress report on the Better Care Fund.

The Interim Director of Joint Commissioning and Accountable Officer from NHS Vale of York Clinical Commissioning Group presented the report.

Board Members were informed that;

- The contribution to the delivery of the BCF last year had not been effective as at present. There would be named leadership going forward.
- The plan for 2016/17 was not made until late into the year.
- The BCF for 2017/18 was expected to be a two year plan, but guidance was awaited from NHS England and the Government. This had still not been released.
- The two measures doing less well amongst all the schemes within the BCF were Non Elective Admissions (NEA) and Delayed Transfers of Care (DTOC).

Discussion ensued during which the following points were raised;

- The metrics or names used for the schemes were not helpful. In regards to DTOC it was better to refer to patients as being stranded in hospital. This focused more on the action rather than on the definition.
- Although national guidance was still awaited, there was the opportunity to create a local measure, and to carry out predictive work.

- What was the implication with the £1m risk for the Council? Would it involve releasing staff?
- With £1.2m below the line, the alternative was to find money elsewhere or to cease funding services.
- Members could not factor in the amount of risk share to the Council into their budget discussions, and needed to know the details as soon as possible as the Council were due to set its budget.
- In regards to DTOC, public messages needed to be got across that there was often not a choice as to where you went. There were not enough spaces in care homes, and people might have to take a place in an alternative care home whilst they awaited a bed in the home of their choice. This needed to be communicated, especially if it saved lives in the process.

Resolved: That the report be noted.

Reason: So that the Health and Wellbeing Board has oversight of the Better Care Fund.

49. York Information and Advice Strategy

The Board received a report and presentation on the review of Information and Advice services in York and the development of a new Information and Advice Strategy, informed by the ‘Just Works’ consultants’ report.

The Council’s Head of Commissioning (Early Intervention, Prevention & Community Development) and Jeanette Thompson from Just Works were in attendance to present the report and answer Board Members’ questions.

They highlighted that there were 87 groups who provided information on health and social care to a website in the city and some organisations were happy to provide leaflets for free. Others needed financial assistance to inform the public.
It was felt that a digital inclusion strategy was needed as websites were static, they had so much information for example it was difficult to know what was valid. In addition, they had not been adapting to change.

It was suggested that a task and finish group be convened to carry out an action plan as suggested in the report. It was noted that advocacy groups would not get involved with the action plan unless the partnership governance arrangements were packaged into smaller groups.

Resolved: (i) That the prioritised action plan and how it might be effectively delivered, reflecting partnership governance arrangements and organisational resources be considered.

(ii) That an operational task and finish group, reporting to the Integration and Transformation Board, is convened to progress the delivery of the action plan.

Reason: To keep the Health and Wellbeing Board up to date on progress against this work stream.

50. Meeting Work Programme

Board Members were asked to consider the Board's meeting work programme.

Resolved: That the meeting work programme be approved.

Reason: To ensure that the Board has a planned programme of work.

Councillor C Runciman, Chair
[The meeting started at 4.35 pm and finished at 7.15 pm].

CITY OF YORK COUNCIL

Health and Wellbeing Board **8 March 2017**

Report of the Assistant Director, Legal and Governance

Appointment to York's Health and Wellbeing Board

Summary

1. This report asks the Board to confirm a new appointment to its membership.

Background

2. The Council makes appointments at its Annual Meeting, to Committees for the coming year. However, the Health and Wellbeing Board is able to appoint to or update its membership separate of Full Council. Therefore the following change is put forward for the Board's endorsement:

3. To appoint Gillian Laurence, Head of Clinical Strategy, NHS England as a second substitute for Julie Warren, Locality Director (North), NHS England.

   This appointment has been brought to the Board to allow for its confirmation.

Consultation

4. As this is a substitute appointment to the existing Health and Wellbeing Board membership no consultation has been necessary.

Options

5. There is no alternative nomination for the appointment.

Council Plan 2015-19

6. Maintaining an appropriate decision making structure, together with appropriate nominees to that, contributes to the Council delivering its core priorities set out in the current Council Plan, effectively. In particular, appointments to the Health and Wellbeing Board ensure that partnership working is central to the Council working to improve the overall wellbeing of the city.

Implications

7. There are no known implications in relation to the following in terms of dealing with the specific matters before Board Members:

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

Legal Implications

8. The Council is statutorily obliged to make appointments to Committees, Advisory Committees, Sub-Committees and certain other prescribed bodies. The Board’s terms of reference also make provision for substitutes.

Risk Management

9. In compliance with the Council’s risk management strategy, the only risk associated with the recommendation in this report is that an appropriate replacement would fail to be made should the Board not agree to this appointment.

Recommendations

10. The Health and Wellbeing Board are asked to endorse the appointment as set out in Paragraph 3.

Reason: In order to make this appointment to the Health and Wellbeing Board.

Author:	**Chief Officer Responsible for the report:**
Judith Betts Democracy Officer Telephone: 01904 551078	Andy Docherty Assistant Director, Legal and Governance
	Report Approved ☑ **Date** 21 February 2017

Specialist Implications Officers
Not applicable

Wards Affected: **All** ☑

For further information please contact the author of the report

Background Papers
None

Annexes
None

Health and Wellbeing Board 8th March 2017

Report of the Health and Wellbeing Partnerships Co-ordinator

Governance Arrangements for the Health and Wellbeing Board

Summary

1. During the course of 2016 and early 2017 Health and Wellbeing Board members attended a number of development sessions facilitated by the Local Government Association.

2. These sessions included discussion relating to the governance of the Health and Wellbeing Board. This report sets out the outcomes from those discussions and asks Health and Wellbeing Board (HWBB) members to formally approve the recommendations at paragraph 35 of this report.

Background

3. It is good practice for any Committee and/or Board to review its governance arrangements on a regular basis. The HWBB has been a formal Board of the Council since 2013 and with the development of a new Joint Health and Wellbeing Strategy for York it is timely to review the governance of the Board.

4. This report focuses on the following three areas of HWBB governance:

- Membership;
- Terms of Reference;
- Mechanisms for delivering against the new Joint Health and Wellbeing Strategy.

Main/Key Issues to be Considered

Membership

5. HWBB have a number of statutory members as follows:

- At least one elected representative (nominated by the Leader)
- A representative from each Clinical Commissioning Group (CCG) whose area falls within or coincides with the local authority area
- The local authority directors of adult social services, children's services and public health
- A representative from the local Healthwatch organisation
- NHS England must appoint a representative for the purpose of participating in the preparation of Joint Strategic Needs Assessments (JSNA) and the Joint Health and Wellbeing Strategy (JHWBS) and join the Health and Wellbeing Board when it is considering a matter relating to the exercise, or proposed exercise, of NHS England's commissioning functions in relation to the area and it is requested to do so by the Board. *[In York, NHS England have a permanent place on the Health and Wellbeing Board]*

6. In addition to this local authorities or Health and Wellbeing Boards can add members to the Board beyond those set out in legislation.

7. During discussions HWBB members considered what, if any, changes should be made to their membership. As a result of those discussions the following changes are suggested:

   - The HWBB should have a Vice-Chair and this should be the Chair of NHS Vale of York Clinical Commissioning Group *[this has already been put in place and the Chair of Vale of York Clinical Commissioning Group has joined the Board and has been appointed as the Vice -Chair]*;
   - The HWBB should have clinical representation;
   - The elected member Portfolio Holder for Education, Children and Young People should be a member of the Health and Wellbeing Board.

8. In light of this the following membership of the Health and Wellbeing Board is proposed:

   i. Portfolio Holder for Adult Social Care and Health (Chair)
   ii. Portfolio Holder for Education, Children and Young People

- iii. Elected member opposition representative
- iv. Elected member opposition representative
- v. Chair of the Vale of York Clinical Commissioning Group (Vice-Chair)
- vi. Accountable Officer of the Vale of York Clinical Commissioning Group
- vii. A clinical representative of the Vale of York Clinical Commissioning Group
- viii. The Director of Public Health
- ix. The Corporate Director of Health, Housing and Adult Social Care at City of York Council
- x. The Corporate Director of Children, Education and Communities at the City of York Council
- xi. The Chief Executive of York Teaching Hospital NHS Foundation Trust
- xii. The Chief Executive of Tees, Esk and Wear Valleys NHS Foundation Trust
- xiii. The Deputy Chief Constable of North Yorkshire Police
- xiv. The Chief Executive of York CVS
- xv. A representative of NHS England
- xvi. The Chair of the Independent Care Group
- xvii. The Director of Healthwatch York

9. Consideration was given to inviting other representatives to join the HWBB (for example Yorkshire Ambulance Service, pharmacy representative and fire service representative). However, as the HWBB is already a large Board with a wide range of representation from different organisations it was suggested that organisations not represented on the HWBB could be invited to attend and present to the Board as and when needed.

10. Additionally and where relevant organisations not represented on the HWBB could be invited to be involved in the delivery of the new Joint Health and Wellbeing Strategy and take part in future Health and Wellbeing Board meetings where relevant.

Terms of Reference

11. The HWBB has the power to agree the JSNA, Pharmaceutical Needs Assessment (PNA) and Joint Health and Wellbeing Strategy. Currently the HWBB does not have any responsibilities for budgets and/or commissioning delegated to it by Council, Executive or any partner organisations.

The role of the HWBB as it currently stands is therefore, to influence the vision and strategic direction for the health and wellbeing system within the city of York and effectively act as the system leader. It has a strategic rather than an operational function which is distinct from the role of scrutiny. There are currently no proposals to change this focus.

12. Accordingly the Board have reviewed their Terms of Reference and the draft new Terms of Reference are attached at **Annex A** to this report.

Sub-Structure

13. With the development of a new Joint Health and Wellbeing Strategy HWBB have reviewed the delivery structure (or sub-structure) that sits beneath it. This is to ensure it can effectively deliver against its new Strategy. The key points considered in this discussion have been:

- delivering within existing resources;
- focusing on the statutory functions of the HWBB (including delivery against the new Joint Health and Wellbeing Strategy);
- providing the best support to deliver against the outcomes the Board is trying to achieve;
- agility, responsiveness and flexibility in relation to the local health and social care system;

14. Going forward the key focus for the HWBB will be around its statutory functions:

- Pharmaceutical Needs Assessment (PNA) *[this is due for renewal by March 2018]*;
- Joint Strategic Needs Assessment *[refresh and maintenance of]*
- Joint Health and Wellbeing Strategy *[delivery against and monitoring of].*

15. Resources to support the HWBB, its statutory functions and its current sub-groups are limited and it should be acknowledged that since the HWBB was first established in shadow form, later moving to a permanent form, staffing levels have decreased.

16. Another significant change influencing how the Strategy can be delivered is the introduction of named HWBB members who will take responsibility for each of the themes within the new Strategy; each of these members will be the named responsible person for their identified theme and will be the HWBB's point of contact and assurance in terms of delivery. These are as follows:

    - Mental Health – Martin Farran (Director of Adult Social Care, City of York Council) and Phil Mettam (Chief Accountable Officer, NHS Vale of York Clinical Commissioning Group)
    - Starting and Growing Well – Jon Stonehouse (Director of Children's Services, Education and Skills, City of York Council)
    - Living and Working Well – Sharon Stoltz (Director of Public Health)
    - Ageing Well – Sarah Armstrong (Chief Executive at York CVS)

17. To allow for this to work well the delivery mechanism beneath the HWBB will need to be agile, flexible and focused on the outcomes the Board wants to achieve with delivery and responsibility not restricted to one specific group per theme. The Board will therefore use existing groups where possible (for example: YorOK leading on the Starting or Growing Well theme). They will also continue to look at alternative ways of assuring themselves the Strategy is being delivered and that all voices are being heard. An example of how this might work could be aligning the lead board member for Ageing Well with the York Older People's Assembly and/or the VCS Forum for Ageing Well rather than creating a new group around this theme.

18. An informal delivery mechanism is therefore the preference of the HWBB; this would mean that all existing groups and any new groups that are set up would have to be self supporting in terms of resources required, in particular administrative support and would report 'in' rather than 'to' the HWBB.

19. Only one group *[see paragraph 22]* would have a ‘solid line’ to the Board; all other groups would have a dotted line (i.e. they would have a relationship with the Board but would not be owned by the Board). There would be freedom for groups to set their own agendas around their own areas of expertise but with the expectation that they would contribute towards the delivery of the new Joint Health and Wellbeing Strategy 2017-2022. However they would not be required to be solely focused on this.

20. This model also provides flexibility for any group to be part of the Health and Wellbeing Board ‘family’ and acknowledges that health and wellbeing is wide ranging. It is envisaged that the Board members leading on the individual themes within the Strategy would be involved and/or have contact with a variety of groups whether directly or through close colleagues.

21. With a new Joint Health and Wellbeing Strategy in place the HWBB will be holding themed meetings from July 2017 onwards focused around the priorities and themes within the Strategy. The HWBB will ask groups to contribute to these themed meetings either by way of a report, attendance at the Board or through the lead Board member for the theme.

22. The current JSNA/JHWBS Steering Group will continue but will take on a HWBB business management role. It will keep its existing functions and will review its Terms of Reference to add in any further responsibilities required *[these will be brought to a future HWBB meeting]*. The Steering Group will also change its name to reflect its amended role and give consideration to establishing task and finish groups for some of its key work streams, for example refreshing the JSNA.

23. Equalities and Inequalities will also be monitored through this Steering Group. There will also be an expectation that the lead members for each of the themes in the new Strategy address inequalities and the same expectation will apply to those groups delivering against the Strategy.

24. Additionally this Steering Group will undertake some mapping of existing groups and consider further ways that these could help with delivering against the themes and priorities within the new Joint Health and Wellbeing Strategy.

25. It should also be acknowledged that the sub-structure put in place is only one tool/mechanism for strategy delivery and achieving the Board's collective goals.

26. To complete the picture of this new model of working HWBB has started to develop an Engagement and Communications Plan. This will include the production of a seasonal newsletter (the first of which will hopefully be launched in March 2017 to coincide with the launch of the new Joint Health and Wellbeing Strategy); organising an Annual General Meeting (AGM) for the HWBB and holding one or two engagement and/or listening sessions each year. These mechanisms will provide the HWBB with an arguably more engaging alternative and/or additional way to both listen to the public voice and to let the public know what the Board has been doing throughout the year.

Consultation

27. All organisations represented around the Health and Wellbeing Board table have been involved in the discussions about Board governance. In addition and where they related to Board governance, comments received as part of the feedback and consultation process on the new Joint Health and Wellbeing Strategy have been taken into consideration.

Options

28. There are no specific options for the HWBB to consider. The Board are asked to approve the proposed changes to their membership, Terms of Reference and Joint Health and Wellbeing Strategy delivery mechanisms.

Analysis

29. There are no specific options within this report. Rationale behind the proposed changes is set out within the body of this report.

Strategic/Operational Plans

30. This report is directly linked with the Joint Health and Wellbeing Strategy. It seeks to strengthen the HWBB's governance arrangements including establishing a fit for purpose delivery mechanism for the Joint Health and Wellbeing Strategy.

Implications

31. **Financial:** Delivery of the Strategy will take place within existing resources.

32. **Legal and Governance** - The Health and Well Being Board is a Committee of the Council with specific statutory functions and with the capacity to perform other functions delegated to it by the Council. The Board has a statutory membership but the Board can appoint additional Members. The Council can also appoint additional Members but must consult the Board before doing so. The Board can establish sub Committees. Members of sub committees have voting rights unless the Council directs otherwise.

33. There are no other known implications associated with this report bar those identified in the paragraphs above.

Risk Management

34. No risks have been identified at this stage.

Recommendations

35. HWBB are asked to approve:

- The amendments to their membership
- The amendments to their Terms of Reference
- The delivery mechanism for the Joint Health and Wellbeing Strategy

Reason: To complete the review of HWBB governance arrangements

Contact Details

Author:	**Chief Officer Responsible for the report:**
Tracy Wallis Health and Wellbeing Partnerships Co-ordinator Tel: 01904 551714	Sharon Stoltz Director of Public Health
	Report Approved ☑ **Date** 27.02.2017

Specialist Implications Officer
Legal – Andy Docherty, Assistant Director, Legal and Governance

Wards Affected: **All** ☑

For further information please contact the author of the report

Background Papers
None

Annexes
Annex A – Amended Terms of Reference

Glossary
CCG – Clinical Commissioning Group
HWBB – Health and Wellbeing Board
JHWBS – Joint Health and Wellbeing Strategy
JSNA – Joint Strategic Needs Assessment
NHS – National Health Service
PNA - Pharmaceutical Needs Assessment

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Annex A

York Health and Wellbeing Board Terms of Reference

The York Health and Wellbeing Board has a key strategic role in carrying out assessments of the health and wellbeing needs of the people of York and in developing strategies to meet those needs. It also has a role in encouraging health and social care providers to work together to meet those needs.

1. Name

1.1 The Board will be known as the York Health and Wellbeing Board (‘the Board’)

2. Membership

2.1 Board members will be required to represent their organisation with sufficient seniority and influence for decision making. The membership of the Board will consist of:

- i. The Leader of City of York Council (“the Council) or his/her nominee, together with a further 3 elected representatives nominated by the Council (to include the Portfolio Holder for Adult Social Care and Health and the Portfolio Holder for Education, Children and Young People)
- ii. The Chair of NHS Vale of York Clinical Commissioning Group
- iii. The Accountable Officer of NHS Vale of York Clinical Commissioning Group
- iv. A clinical representative of NHS Vale of York Clinical Commissioning Group
- v. The Director of Healthwatch York
- vi. The Director of Public Health
- vii. The CorporateDirector of Children, Education and Communities of City of York Council
- viii. The Corporate Director of Health, Housing and Adult Social Care of City of York Council
- ix. The Chief Executive of York CVS
- x. The Chief Executive York Teaching Hospital NHS Foundation Trust
- xi. The Chief Executive of Tees, Esk and Wear Valleys NHS Foundation Trust
- xii. The Chair of the Independent Care Group

xiii. A representative of NHS England
xiv. The deputy Chief Constable of North Yorkshire Police
xv. Other members appointed by the Board or the Leader of the Council after consultation with the Board.

3. Legal Status

3.1 The Health and Wellbeing Board is a committee of the Council and will adhere to the Constitutional requirements of the Council affecting committees unless alternative provision is made within these terms of reference or the law.

4. Disqualification from Membership

4.1 The following are disqualified from being a Board Member

a. Any person who is the subject of a bankruptcy restrictions order or interim order.

b. Any person who has within five years before the day of being appointed or since his or her appointment been convicted in the United Kingdom, the Channel Islands or the Isle of Man of any offence and has had passed on him a sentence of imprisonment (whether suspended or not) for a period of not less than three months without the option of a fine.

5. Quorum

5.1 The quorum shall be 7 members including as a minimum a representative of the City of York Council and a representative of NHS Vale of York Clinical Commissioning Group.

6. Chair and Vice-Chair

6.1 The Chair of the Board shall be the Leader of the Council or his or her nominated representative. The Vice-Chair of the Board shall be the Chair of NHS Vale of York Clinical Commissioning Group

6.2 The Chair of the Health and Wellbeing Board will be required to hold a named delegate list for board representatives including deputies.

7. Frequency of Meetings

7.1 The Board shall schedule meetings at least four times a year.

8. Delegation of Powers

8.1 The Board may establish sub-committees to discharge any function of the Board or to advise the Board in respect of its functions.

8.2 If the Council delegates any of its public health functions to the Board in accordance with section 196(2) of the Health and Social Care Act 2012 then the Board may arrange for those functions to be discharged by an officer. Other functions of the Board may not be delegated to officers.

9. Functions of the Board

9.1 In order to advance the health and wellbeing of the patients and residents in York, encourage persons who arrange for the provision of any health or social care services to work in an integrated manner.

9.2 To provide such assistance or other support as it thinks appropriate for the purpose of encouraging the making of arrangements under section 75 of the National Health Service Act 2006 between the Council and NHS bodies in relation to the exercise of NHS functions or health related functions of the Council.

9.3 To exercise the functions of a local authority and its partner clinical commissioning groups under sections 116 and 116A of the Local Government and Public Involvement in Health Act 2007 relating to joint strategic needs assessments, and the joint health and wellbeing strategy.

9.4 To exercise the statutory functions of a Health and Wellbeing Board in relation to the carrying out and publication of pharmaceutical needs assessments.

9.5 To exercise any other functions of the Council which the Council has determined should be exercised by the Board on its behalf in accordance with section 196(2) of the Health and Social Care Act 2012 including:

- Overseeing the development of local commissioning plans and, where necessary, initiating discussions with the NHS Commissioning Board (NHS England) if an agreed concern exists

- Leading cultural and behavioural change to support a joint approach to meeting local need

- Holding all partners to account for their role in the delivery of joint commissioning and overall stewardship of the health and wellbeing outcomes for patients and residents

- Working alongside local and regional strategic partnership arrangements to ensure the coordination of city wide ambitions, all of which impact on the health and wellbeing of patients and residents.

9.6 Where it considers it appropriate to do so, or when so requested by the Council, to give the Council its opinion on whether the Council is discharging its duty under section 116B of the 2007 Act to have regard to the joint strategic needs assessment and joint health and wellbeing strategy.

9.7 To periodically review the York Health and Wellbeing Board constitution.

9.8 Board members will be bound by the same rules as Councillors

Agenda Item 6

Health and Wellbeing Board 8 March 2017

Report of the Chair of the Joint Strategic Needs Assessment/Joint Health and Wellbeing Strategy Steering Group

Update on the work of the Joint Strategic Needs Assessment/Joint Health and Wellbeing Strategy Steering Group

Summary

1. This report provides the Board with an update on the work that has been undertaken by the Joint Strategic Needs Assessment/Joint Health and Wellbeing Strategy Steering Group since it last reported to the Board in September 2016.

2. The Board are asked to note the update and agree the recommendations at paragraph 37 of this report.

Background

3. Under the Health and Social Care Act 2012, all Health and Wellbeing Boards are under a duty to prepare a Joint Strategic Needs Assessment and from this a Joint Health and Wellbeing Strategy.

4. Under their Terms of Reference the Steering Group is responsible for developing the Joint Strategic Needs Assessment (JSNA) and the Joint Health and Wellbeing Strategy (JHWBS). The Steering Group are also responsible for assuring the Health and Wellbeing Board that the JHWBS is being implemented and delivering improvements in the health and wellbeing of the residents of York.

5. The Steering Group is accountable for the management of the JHWBS and JSNA process ensuring that both these products meet the needs of the Health and Wellbeing Board (HWBB) and that their use is embedded in strategic commissioning for health and social care.

6. Since the Steering Group last reported to the HWBB they have developed a work programme covering their varied work streams.

The work programme is a fluid and responsive document and is regularly updated. A copy of the work programme is at **Annex A** to this report. This report gives more detail in the paragraphs below on those work streams the Steering Group have been most focused on.

Main/Key Issues to be Considered

Joint Health and Wellbeing Strategy 2017-2022

7. Producing a Joint Health and Wellbeing Strategy is a statutory responsibility of Health and Wellbeing Boards. The JHWBS should set out the health and wellbeing priorities for the city based on the evidence in the local JSNA, other local intelligence and data and on engagement with stakeholders and the public.

8. As reported in the last report to the HWBB a period of engagement and consultation has taken place and the initial draft of the JHWBS amended in response to this. The final draft of the new JHWBS, for sign off by the HWBB, is attached at **Annex B** to this report.

9. The new Strategy will run for 5 years from March 2017 until March 2022. It is a high level strategy and will be underpinned by targeted action plans and existing strategies (e.g. alcohol strategy and children and young people’s plan). It is based around the following four themes

   - Mental Health
   - Starting and Growing Well
   - Living and Working Well
   - Ageing Well

10. A named Board member has been identified as the lead for each of the areas above as follows for the first year of the JHWBS (these will be reviewed annually):

    - Mental Health – Martin Farran (Director of Adult Social Care, City of York Council) and Phil Mettam (Chief Accountable Officer, NHS Vale of York Clinical Commissioning Group)
    - Starting and Growing Well – Jon Stonehouse (Director of Children's Services, Education and Skills, City of York Council)

- Living and Working Well – Sharon Stoltz (Director of Public Health)
- Ageing Well – Sarah Armstrong (Chief Executive at York CVS)

11. This should allow for clear accountability in terms of delivery against the new JHWBS and will create a visible contact point and HWBB spokesperson for each of the priority areas. The lead Board members will shortly be identifying their key priorities for year 1 of the Strategy.

12. Governance arrangements for the Board have also been recently reconsidered as has the performance management framework for the Board. Each of these has links to the effective delivery and progress monitoring of the Joint Health and Wellbeing Strategy. These are discussed in more detail in separate reports on this agenda.

13. The Steering Group will also be completing a Community Impact Assessment in relation to the Joint Health and Wellbeing Strategy as part of their programme of work.

The Joint Strategic Needs Assessment (JSNA)

14. The current York JSNA is a web based document that contains a wealth of information covering a wide range of health and wellbeing areas. Discussion about the JSNA takes place at every Steering Group meeting.

15. A JSNA project has recently been initiated by the Steering Group with the aim being to produce an effective and user friendly JSNA. The key objectives are the delivery of:

- A revised website to hold the information (that complements the new Joint Health and Wellbeing Strategy)
- A new set of easily understandable content
- A sustainable resourcing model
- Business processed to control the ongoing prioritisation of work

16. The project will be in two phases as follows:

Phase 1

- Website

    - Development of a simple set of pages, either as part of the City of York Council website or separate *[February to May 2017]*
- Content
    - Capture of existing analytical content from the current JSNA to use for chapters in the new JSNA *[February to May 2017]*
    - Development of summaries for each of demographics (Starting and Growing Well; Living and Working Well; Ageing Well and Mental Health) *[February to May 2017]*
- Ongoing resourcing
    - Identification of resources for ongoing support of the website and the analysis of data to feed the content *[February to May 2017]*
- Prioritisation Process
    - Embedding the prioritisation approach for detailed analysis and the development of chapters *[February to May 2017]*

Phase 2 *(resource dependent)*

- Content
    - Greater analytical development to produce locality based summaries (including at ward level) *[ongoing]*
    - Adding individual chapters as they are developed on a priority basis *[ongoing]*
- Maintenance
    - Develop and embed the processes for maintaining the website and content over the medium term, including the resources required to do so *[May to September 2017]*

Topic specific needs assessments

17. The Steering Group have recently input into and signed off a needs assessment for All Age Autism.

18. Between 1% and 1.5% of the population are estimated to have autism which means there are over 2,000 people living in York with autism. Autism is a lifelong condition which can be diagnosed at different points in a person’s life depending on how it is affecting their daily lives.

19. The needs assessment identifies a number of key issues and gaps and these are detailed in the document at **Annex C** to this report. They have led to the following recommendations which will be taken forward through the All Age Autism Strategy Group:

    i. Review diagnostic pathways and waiting lists

    ii. Improve the quality of primary care data including the improvement of recording those with autism.

    iii. Review uptake of Health and Social Care autism training within York.

    iv. Review pre and post diagnostic advice, support and information.

    v. Ensure Health and Social Services work with people who use their services in a way which looks at peoples strengths and the capacity of the community.

    vi. Engage with mental health services to work towards timely and appropriate access to services for people with autism.

    vii. Increase public awareness in the community and work with mainstream services and employers to ensure they are as inclusive as possible.

    viii. Increase autism awareness across the City.

    ix. Create a specialist training package for employers, police and others in the criminal justice system.

    x. Consult and engage with people with autism, and their families and carers, to understand their particular needs and experiences.

    xi. Scope information available and gaps and how to make accessible and keep up to date.

    xii. Aging well with autism – scope information available on those who are aging with autism.

20. Two key challenges have also been identified and these are achieving the recommendations without any new investment and the development of sufficient local expertise for the needs of the population.

Further Needs Assessments

21. The Student Health Needs Assessment is ongoing and is likely to be considered by the Steering Group at their May meeting with a view to presenting this to the HWBB in July 2017.

Healthwatch York Reports

22. The Steering Group have also given consideration to a report about the recommendations arising from Healthwatch York reports.

23. Currently completed Healthwatch York reports are submitted to the HWBB for consideration but due to agenda pressures are not always discussed in detail. There is currently no mechanism to monitor which recommendations have been implemented and which not. One suggestion was that the HWBB could delegate this responsibility to the JSNA/JHWBS Steering Group; however it has become apparent that the workload for this group is growing and it might not be the most appropriate way forward.

24. After discussion at the Steering group the following was suggested as the way forward for the management of future Healthwatch York reports.

- **Step 1:** Completed Healthwatch reports to be sent to the HWBB in the first instance
- **Step 2:** Chair of the HWBB to send a formal letter to all organisations who need to respond to the recommendations asking that a named representative feedback to Healthwatch York within 20 working days
- **Step 3:** Healthwatch York reports to the Health and Adult Social Care Policy and Scrutiny Committee twice a year already. Updates on recommendations and the responses received should be included within this report (including any concerns).
- **Step 4:** (only if required) – escalation back to the JSNA/JHWBS Steering Group for further consideration.

25. A stock take has taken place in relation to the recommendations arising from previous Healthwatch reports and a list of those where it is not clear whether any action has been taken drawn up. Healthwatch York will shortly be writing out to partners to ask for an update on these.

Other

26. The Steering Group has been in existence for just over one year and will shortly be reviewing its Terms of Reference (ToR); particularly in light of its changing role detailed in the HWBB governance report on this agenda. A copy of the revised ToR will be presented to the HWBB when the Steering Group next reports.

Consultation

27. Engagement sessions and a formal consultation process have been held as part of renewing the JHWBS. Feedback from these has been taken into consideration when producing the new Strategy document.

28. Consultation and engagement has taken place as part of the All Age Strategy Needs Assessment and this is detailed within the document at **Annex C**.

Options

29. The Board are asked to note the contents of this report and its annexes. They are also asked to consider the following options:

    i. Approve the final draft of the new Joint Health and Wellbeing Strategy for York without amendment;

    ii. Note and approve the project timeline for refreshing the JSNA;

    iii. Approve the All Age Autism Needs Assessment and its associated recommendations;

    iv. Note the process for responding to Healthwatch York reports

Analysis

30. **JHWBS -** The Board are recommended to sign off the final draft of the new Joint Health and Wellbeing Strategy for York without further amendment. This will allow for the new Strategy to be launched and for work to begin on delivering against the priorities within it.

31. **JSNA** – the Board are asked to note and approve the project timeline for refreshing the JSNA. Further amendment to the timetable would have a negative impact on delivering the project within the timescales set out.

32. **<u>All Age Autism Needs Assessment</u>** – the Board are recommended to approve the All Age Autism Needs Assessment without further amendment. The document is comprehensive and it is important that this work is approved by the Board so that work on the Autism Strategy can start and the All Age Strategy Steering group can start to implement the recommendations.

33. **<u>Healthwatch York Reports</u>** – the Steering Group had a comprehensive discussion about how best to manage the recommendations arising from Healthwatch York reports and this included a stock take of how many of the recommendations from previous reports had been implemented. Given the high volume of work for both the HWBB and the Steering Group the proposal but forward in the paragraphs above was felt to be the most appropriate way forward. HWBB are asked to approve this. If the process is found not to work the Steering Group will review this again.

Strategic/Operational Plans

34. The Health and Wellbeing Board have a statutory duty to produce both a Joint Strategic Needs Assessment and a Joint Health and Wellbeing Strategy.

Implications

35. There are resource implications associated with delivering complex projects. Discussions are ongoing in relation to resourcing the JSNA project.

Risk Management

36. The production of a JSNA and a Joint Health and Wellbeing Strategy are statutory responsibilities for the HWBB. Delivering against both is resource intensive and needs to be managed to ensure a fit for purpose JSNA and Joint Health and Wellbeing Strategy are produced.

Recommendations

37. The Health and Wellbeing Board are asked to note this update and are recommended to:

    i. Approve the Joint Health and Wellbeing Strategy 2017- 2022

ii. Note the project timeline for refreshing the JSNA

iii. Agree the recommendations arising from the All Age Autism Needs Assessment

iv. Note the process for Healthwatch York reports

Reason: To update the Board in relation to the work of the JSNA/JHWBS Steering Group

Contact Details

Author:	**Chief Officer Responsible for the report:**
Tracy Wallis Health and Wellbeing Partnerships Co-ordinator City of York Council/NHS Vale of York Clinical Commissioning Group	Sharon Stoltz Director of Public Health City of York Council
	Report Approved ☑ **Date** 22.02.2017

Tel: 01904 551714

Specialist Implications Officer(s) None

Wards Affected: **All** ☑

For further information please contact the author of the report

Background Papers:
Joint Strategic Needs Assessment

Annexes
Annex A – JSNA/JHWBS Steering Group Work Programme
Annex B – Joint Health and Wellbeing Strategy 2017-2022
Annex C – All Age Autism Needs Assessment

Glossary
HWBB – Health and Wellbeing Board
JHWBS – Joint Health and Wellbeing Strategy
JSNA – Joint Strategic Needs Assessment
NHS – National Health Service
PNA – Pharmaceutical Needs Assessment
ToR – Terms of Reference

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Work Programme for the JSNA/JHWBS Group – 2017/2018 Annex A

Red – The objective is very much behind target and requires corrective action and/or the objective cannot be resolved by the Steering Group and requires escalation

Amber - One or more aspects of the objective is delayed, however, the deviation from plan is within tolerances and completion can still be met by the Steering Group

Green –Delivery against the key objective is on target

Purple - complete

Work Stream: Joint Health and Wellbeing Strategy (JHWBS)

	Priority	Key Objectives	Work to be done	Owner/Lead	Timescale	Status	Rating
1	High	Renew JHWBS	Produce draft for formal consultation	SFS	W/C 14 Nov 2016	Complete	🟪
2	High	Produce Consultation Materials	• finalise consultation questions • send draft strategy to designer • draft survey monkey • finalise summary of engagement feedback • write introductory paragraph for consultation	FP/TW	W/C 14 Nov 2016	Complete	🟪
3	High	Start Consultation	• upload and initiate consultation process online (CYC consultation pages) • e-mail consultation to interested parties/distribution lists • ask partners to add link to consultation on their websites • ensure consultation considered by all relevant meetings and organisations (OSC, CMT, VCS Forums for example)	SFS/TW	W/C 14 Nov 2016	Complete	🟪
4	High	Post Consultation	• consider consultation responses • amend draft JHWBS • arrange Comms for launch of JHWBS • launch JHWBS at March 2017 meeting of HWBB	FP/SFS/TW	Jan – March 2017	Complete	🟪
5	High	Community Impact Assessment	• To complete a Community Impact Assessment in relation to the JHWBS	TW/FP/WB	March – April 2017		🟩

Work Programme for the JSNA/JHWBS Group – 2017/2018 **Annex A**

Work Stream: Joint Strategic Needs Assessment (JSNA)							
	Priority	**Key Objectives**	**Work to be done**	**Owner/Lead**	**Timescale**	**Status**	**Rating**
1	Phase 1	Renewing the JSNA Project	• Agree scope of project and produce Project initiation Document (PID)	WB	Beginning Feb 2017	Complete	🟪
2	Phase 1	JSNA website	• Agree platform (CYC or external) • Development of simple set of pages	NS	By April 2017	In progress	🟩
3	Phase 1	Content	• Capture of existing analytical content from the current JSNA to use for chapters in the new JSNA • Development of summaries for demographics and life courses	WB	Feb to March 2017	In progress	🟩
4	Phase 1	Ongoing resourcing	• Identification of resources for ongoing support of the website and the analysis of data to feed the content	FP	By March 2017	In progress	🟩
5	Phase 1	Prioritisation Process	• Embed the JSNA prioritisation process within CYC and partner organisations	WB	Ongoing		🟩
6	Phase 1	Stage Completion	• Completion of Phase 1	FP/WB/NS	End of July 2017		🟩
7	Phase 2	JSNA Content	• Analytical development to produce locality based summaries • Adding individual chapters as they are developed on a priority basis		May to Sept 2017		🟩
8	Phase 2	Maintenance	• Develop and embed the process for maintaining the website and content		May to Sept 2017		🟩
9	Medium	Communicating the JSNA	• Look at ways of communicating the JSNA (e.g. via road shows, newsletters) • Embed this into the Engagement and Communications Plan for the HWBB	TW	By end of 2017 (or to tie in with any launch of the renewed JSNA	In progress	🟩
10		Topic Specific Needs Assessments	• establish a 'template' for needs assessments for consistency		Ongoing		🟩

Work Programme for the JSNA/JHWBS Group – 2017/2018 **Annex A**

			• Monitor progress of ongoing needs assessments and sign off draft needs assessments				🟩

Work Stream: Performance Management

	Priority	Key Objectives	Work to be done	Owner/Lead	Timescale	Status	Rating
1		Performance Management Framework	• develop a performance management framework for the HWBB that effectively monitors delivery against the new JHWBS	TC	By Late Feb 2017 (to be ready for the March HWBB Meeting)	In progress	🟩
2		Topic specific needs assessments	• Monitor delivery against signed off needs assessments		Ongoing		🟩

Work Stream: Healthwatch York Reports

	Priority	Key Objectives	Work to be done	Owner/Lead	Timescale	Status	Rating
1		Establish process for how the Steering Group will manage Healthwatch York Reports	• Arrange meeting Siân/Tracy/Sharon/Fiona for initial discussions	SB/TW	Dec 2016 meeting	Slipped to January but now in progress	🟨
2		Take proposals to the Steering Group	• Add to Steering Group agenda	TW	Dec 2016 meeting	Slipped	🟨 Considered in January 2017
3		Add to work programme	• Once above has been established add into the Steering Group's work programme	TW	Dec 2016 meeting	Ongoing	🟨
4		Report to HWBB	• Include update on process and work to date in Steering Group's updates to HWBB	SFS/TW	Ongoing	Report to HWBB March 2017	🟩

Work Programme for the JSNA/JHWBS Group – 2017/2018 **Annex A**

Work Stream: Pharmaceutical Needs Assessment (PNA)							
1		Refresh/renew the current PNA	- current PNA runs March 2015 to 2018	FP/SFS	By March 2018	Not started	
2		Renew the current PNA	- start planning process for renewing the PNA/consider doing this jointly with North Yorkshire County Council	FP/SFS	March 2017	Not started	
Work Stream: Miscellaneous							
1		Governance	- annual review of ToR and membership for the Steering Group	SFS/TW	Dec 2016 Meeting	Not started	Slipped to January but impacted by the overall governance review of HWBB
2		HWBB Annual Report	- preparation of the annual report of the HWBB	SFS/TW	Jan- Feb 2017	Not started	Needs to be ready for the March meeting of Health and Adult Social Care Policy and Scrutiny Committee

York's Joint Health and Wellbeing Strategy 2017-2022

CITY OF
YORK
COUNCIL

Contents

Glossary

Advanced Directive – a legal document in which a person specifies what actions should be taken for their health if they are no longer able to make decisions for themselves because of illness or incapacity

Health and Wellbeing Board – Health and Wellbeing Boards are a statutory forum where key leaders from the health and social care system work together to improve the health and wellbeing of their local population

Joint Strategic Needs Assessment – a systematic method for reviewing the health and wellbeing needs of a population, leading to agreed commissioning priorities that will improve health and wellbeing outcomes and reduce health inequalities

Local Area Teams – multi agency teams, covering the entire city and delivering early intervention services to families with children aged 0-19 years (up to 25 years for those with a learning or physical disability)

Social prescribing – a means by which primary care services can refer patients with social, emotional or practical needs to a range of local, non-clinical services, often provided by the voluntary and community sector

Workplace Wellbeing Charter – a statement of intent showing an employer's commitment to the health and wellbeing of their workforce

Foreword

On behalf of City of York's Heath and Wellbeing Board, we are delighted to present our new Joint Health and Wellbeing Strategy for the five years to 2022.

There is much to be proud of in York. We all love living here, and appreciate what the city and its community have to offer. On almost every indicator, health, wellbeing and happiness in York is well above the national average. We must make sure we keep it that way.

However, these benefits do not extend to everybody. There are communities within our city for whom health and wellbeing outcomes fall well short of those enjoyed by the majority. The difference in life expectancy between the most and least deprived wards is 7.7 years for women and 5 years for men. In particular, people who experience mental ill health are still not consistently getting the services they need. The Health and Wellbeing Board is determined to make sure this changes.

At the same time, we need to reduce pressure on our services by supporting people to better manage their own health and wellbeing, and by intervening at the earliest sign of problems. This was a consistent theme in the engagement exercises we conducted as part of the preparation for this Strategy. You also asked us to place more emphasis on the things to do with health and wellbeing that are not about doctors or hospitals - wider issues such as poverty, household income, housing, crime, loneliness, transport and the environment. We have taken this into account, whilst at the same time being open about the extent and the limitations of what the partners on the board can do.

We have therefore decided to concentrate on just four themes: **mental health and wellbeing**, and three **life stages**. Within each theme we have set out our top priority, plus five or six other things we want to achieve. We hope that this approach will help everybody to focus their efforts over the next five years. By everybody we mean not just those who commission or provide health and social care, but also communities and individuals, who are just as significant. We want everyone in York to have the confidence to play their part.

This Strategy is important. It is a shared agreement between each partner organisation in the Health and Wellbeing Board with, and for, people of all ages living in York. It is about what we can and want to change. We hope the new Strategy inspires you to be part of that change.

Cllr Carol Runciman
Chair, York Health and Wellbeing Board

Sharon Stoltz
Director of Public Health, City of York

How we put this Strategy together

In putting this Strategy together we have taken account of:

- the latest evidence about what is needed in York, drawing on information from a wide range of sources. You can see the most recent analysis in our Joint Strategic Needs Assessment, which is available at **www.healthyork.org**. There are key facts and figures in the individual chapters of this Strategy;
- an honest assessment of how far we have achieved the objectives we set out in our previous Strategy, published in 2013. Some of the priorities in that document have continued into this one;
- your views about what's important for your long term health and wellbeing, expressed individually and collectively through a large number of consultation and engagement events, plus an online survey. We received over 1200 comments; a summary of these is available at **https://www.york.gov.uk/info/20139/health_and_wellbeing_partnerships/973/health_and_wellbeing_board**, and key points are summarised in the individual chapters;
- the wider things - beyond the state of someone's physical health - which can affect a person's wellbeing. You told us this was particularly important;
- groups or communities who have particular needs;
- the latest relevant national guidance, and links to other local plans, strategies and reports.

We will also need to be continually mindful of the budgets available to us and likely further reductions in these over the next five years.

York in a nutshell

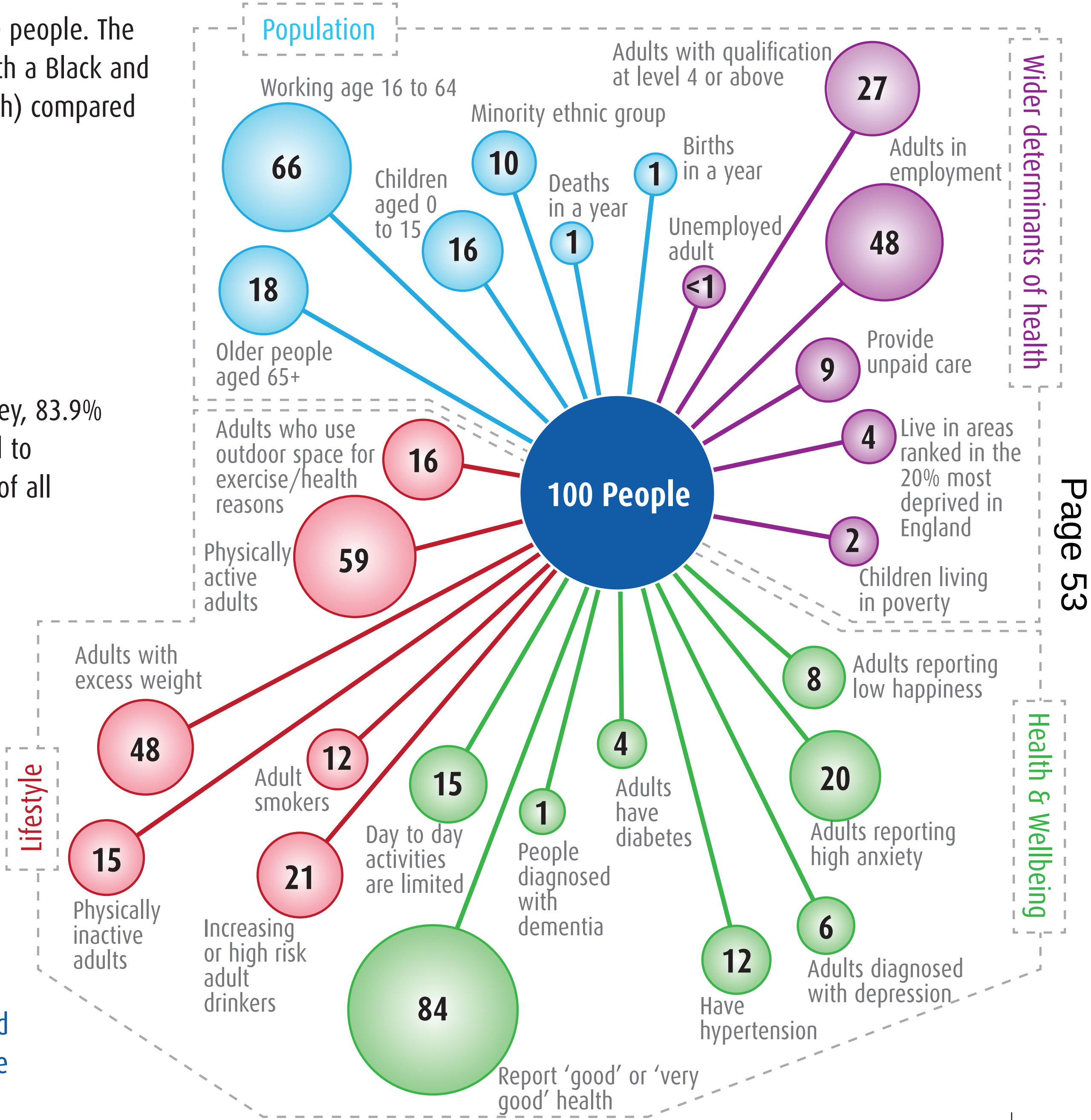
York's population is now estimated to be just over 200,000 people. The city has become more culturally and religiously diverse with a Black and Minority Ethnic (BME) population of 9.8% (non White British) compared to 4.9% in 2001. By 2025, it is estimated that

- the 65+ population in York will have increased by 16%;
- the 85+ population in York will have increased by 32%;
- the 0-19 population will have risen by about 9%.

York's population is on the whole healthy (in a recent survey, 83.9% stated that they are in very good or good health compared to 80% regionally and 81.2% nationally). But this is not true of all communities and groups.

This graphic illustrates what the composition of york would be like if it was a village of 100 people based on available data. (October 2016)

If York was a village of 100 people



The new Strategy on a Page

What we want to achieve is simple to say: our ambition is for every single resident of York to enjoy the best possible health and wellbeing throughout the course of their life:

- by promoting greater independence, choice and control,
- building up community based support;
- by supporting self care and management;
- with greater use of early help though targeted/short term interventions;
- by imaginative use of new technology;
- with fewer people using statutory services.

This document sets out how we will do this. It doesn't attempt to describe every trend or cover every issue. Instead, it seeks to focus on the key priorities. These are illustrated in the diagram below and explained in more detail in the following chapters.

Four themes for Health and Wellbeing in York 2017-2022

Theme	**Mental Health and Wellbeing**	**Starting and Growing Well**	**Living and Working Well**	**Ageing Well**
Top Priorities	Get better at spotting the early signs of mental ill health and intervening early	Support for the first 1001 days, especially for vulnerable communities	Promote workplace health and remove barriers to employment	Reduce loneliness and isolation for older people
Additional things we want to achieve	Focus on recovery and rehabilitation Improve services for young mothers, children and young people Improve the services for those with learning disabilities Ensure that York becomes a Suicide Safer city Ensure that York is both a mental health and dementia friendly environment	Reduce inequalities in outcomes for particular groups of children Ensure children and young people are free from all forms of neglect and abuse Improve services for students Improve services for vulnerable mothers Ensure that York becomes a breastfeeding-friendly city Make sustained progress towards a smoke-free generation in York	Reduce inequalities for those living in the poorer wards and for vulnerable groups Help residents make good choices Support people to maintain a healthy weight Help people to help themselves including management of long-term conditions Work with the Safer York Partnership to implement the city's new alcohol strategy	Continue work on delayed discharges from hospital Celebrate the role that older people play and use their talents Enable people to recover faster Support the vital contribution of York's carers Increase the use of social prescribing Enable people to die well in their place of choice

Directed by dedicated groups, and measured through both hard data and what people tell us

Mental Health and Wellbeing

What this covers: anyone who experiences mental ill health or who is affected by its impact on others. Over the course of a lifetime, this is pretty much everyone.

We know that:

- 25% of adults experiences at least one diagnosable mental health problem in any given year;
- 50% of those with poor mental health had symptoms before the age of 14;
- Between 2006 - 2014 there were 154 suicides in York; 84% of those were men;
- York has a higher rate of emergency hospital admissions for intentional self-harm than the national average;
- York has an estimated 2,717 people with dementia and this is expected to rise to 3,503 by 2025.

You told us that mental health services in York are still not good enough; that more support needs to be given in particular to families and carers; and that intervening earlier would be far more effective. You were particularly concerned about support for young people, for students, and for those with dementia. You said that mental health needs should be treated with equal importance to physical health needs.

We want to see people in York enjoying good mental health throughout their lives, with the confidence to promote their own wellbeing, supported by excellent, integrated services should they need it.

Our top priority is to get better at spotting the early signs of mental ill health so that we can provide support sooner and prevent problems from escalating.

We also want to:

- focus our efforts on recovery and rehabilitation wherever this is possible, recognising people's need for ongoing support and the importance of housing, education and employment;
- improve services for young mothers, recognising that this group can be particularly at risk;
- improve mental health and wellbeing services for children and young people;
- improve the services we offer to those with learning disabilities;
- ensure that York becomes a Suicide Safer City and a mental health friendly environment;
- continue the work to ensure that York is a dementia-friendly environment.

The board will:

- promote the **five steps** to **wellbeing** approach to help people to improve their own mental health;
- use its influence to press for greater parity between mental and physical health services;
- tackle stigma, ensuring there are safe places to talk to friendly people, and that everyone is treated with respect and dignity;
- develop a better understanding of mental health needs in York so that we can ensure our services are fit for purpose, redesigning them if necessary;
- work in particular to improve mental health services for children and young people so that emerging issues are quickly identified and supported within universal settings, and that timely specialist help is available when it is needed;
- ensure that the actions arising from this Strategy also take account of the guidance and specific targets within the national **Five Year Forward View for Mental Health**.

We will monitor our progress on:

- access to, and take-up of, talking therapies;
- dementia diagnosis within primary care;
- a sustained reduction in premature deaths among people with severe mental illness;
- a sustained reduction in the number of people admitted to hospital for self-harm;
- regular sharing of information between GPs and CYC about people with learning disabilities;
- more people telling us that they and their families feel well supported through a crisis and afterwards.

Starting and Growing Well

What this covers: pregnancy, birth, early years, childhood, schooldays and young adulthood - roughly up to age 21.

We know that:

- 16% of York's population are children aged 0-15;
- 10.9% of York's population is a Higher Education student;
- 11.7% of children in York were living in poverty in 2015;
- Childhood obesity affects more children in our most deprived wards;
- During the first two years of life the foundations of a baby's mind are being put in place; when a baby's development falls behind during the first years of life, it is likely to fall even further behind in subsequent years.

You told us that you value services provided by children centres and school nurses, but that there should be more support for young mums, including parenting skills and healthy eating. You wanted more play spaces and were concerned about air pollution. You felt schools should provide education on a wider range of life skills. You were concerned about the impact of domestic abuse. Young people said they wanted to be able to talk privately to GPs and specialist staff.

We want to see every young resident of York getting the best possible start in life, with excellent opportunities to grow up healthy and happy

Our top priority is to provide excellent, coordinated support through pregnancy and the first two years - the first 1001 days - especially for our most vulnerable communities.

We also want to:

- reduce inequalities in outcomes for particular groups, including children eligible for free school meals/ the pupil premium, children who are looked after, young carers and refugees;
- improve services for vulnerable mothers, including very young mothers, single parents, parents with learning disabilities, or those whose children have learning disabilities;
- improve services for our large student population;
- make sustained progress towards a smoke-free generation in York;
- ensure that York becomes a breastfeeding-friendly city;
- ensure children and young people are free from all forms of neglect and abuse.

The board will:

- promote healthy choices including healthy eating and locally-sourced food;
- ensure the successful establishment of York's Local Area Teams;
- further develop the parenting offer for all families, especially those with children under five;
- ensure that the ambitions outlined in the **Children and Young People's Plan 2016-2020** are delivered;
- ensure that the particular needs of students are understood and reflected in all relevant local plans.

We will monitor our progress on:

- the increase in the percentage of mothers in York who are breastfeeding;
- improvements in the timeliness of visits and reviews in the first year of life to at least the national average;
- reducing the variation in obesity levels between different wards in York;
- improved school readiness for the most vulnerable groups, e.g. those on free school meals;
- reducing hospital admissions for tooth decay in children (working with the Safeguarding Board);
- more young people in York telling us they feel safe, happy and able to cope with things.

Living and Working Well

What this covers: adulthood - roughly from 21 to 66 - including working life.

We know that:

- 60% people in York are of working age (16-64);
- 3.8% of York's population live in areas that are among the most deprived in the country;
- poverty is associated with much poorer health and wellbeing outcomes;
- there are also poorer outcomes for certain vulnerable groups, e.g. the gypsy and Roma community and the lesbian, gay, bisexual and trans (LGBT) population.

You told us you wanted to see the living wage across the board in York and more affordable housing; better advice; and more job opportunities, especially for those who may face difficulties in the market, e.g. those with learning or physical disabilities or long term conditions. You wanted us to promote the importance of a good work/life balance and to engage early with those who need to change their lifestyles. You told us that LGBT people experience significant health inequalities which need to be addressed. You asked for a comprehensive strategy to address alcohol use in the city.

We want to see everyone in York having the maximum opportunity to live their lives to the full, including employment for everyone capable of it, with employers taking seriously the health and wellbeing of their staff.

Our top priority is to work with York's employers to promote health and wellbeing in the workplace, and to help remove any barriers to the employment of vulnerable groups.

We also want to:

- reduce inequalities in outcomes for particular groups, including those living in the poorer wards, and vulnerable groups such as the LGBT community and the Gypsy and Roma community;
- offer a range of support to help residents make good choices about their own health and wellbeing;
- support people to lose weight and maintain a healthy weight, including promoting the benefits of walking and eating healthily;
- help people to access the services to help them to help themselves, including the management of long-term conditions;
- work with the Safer York Partnership to implement the city's new Alcohol Strategy.

The board will:

- promote greater awareness of, and referral to, services that support people to live healthily by all frontline staff;
- oversee the establishment of an integrated wellness service in York, providing advice on a wide range of health and wellbeing issues;
- promote the Workplace Wellbeing Charter amongst the city's employers, ensuring board members lead by example;
- lead by example in the employment of people with learning disabilities, and other vulnerable groups;
- scrutinise and challenge the development and delivery of local health and care services to ensure a focus on physical activity and healthy weight is embedded in the management of long term conditions;
- increase the visibility of alcohol-related harm as a key public health issue, supporting an approach to alcohol licensing that ensures alcohol is sold and consumed in a responsible way.

We will monitor our progress on:

- improving uptake of all screening programmes;
- the number of major employers signed up to the Workplace Wellbeing Charter;
- reducing the number of adults classed as overweight or obese;
- sustaining a reduction in the rate of admissions involving an alcohol-related primary diagnosis or an alcohol-related external cause;
- York being nationally recognised as a more equal city, with a measurable reduction in the gap in outcomes between different wards;
- increasing the number of people with a learning disability or mental health condition in employment;
- more people, particularly from vulnerable groups, telling us they are happy with their health and wellbeing.

Ageing Well

What this covers: the so-called third age, roughly from 66 onwards, including the end of life.

We know that:

- over the next 15 years the number of people over 65 in York will increase from 36,000 to 46,000 and those aged 75 and over from 17,000 to 26,000;
- nationally, 10% of older people are suffering from chronic loneliness;
- in 2014 there were 1,771 deaths of York residents;
- In 2014, 9.2% of households in York were living in fuel poverty;
- the number of delayed discharges from hospital beds in York is higher than the national average.

You told us you wanted to feel included in your community, and that your age and experience is valued. You wanted more support and advice for people to manage long term conditions away from GP services and a wider range of housing options for older people. You asked for more resources for care agencies and better services. You wanted better public transport. You particularly wanted us to tackle isolation and loneliness and to ensure that in York, no one ever dies alone.

We want to see York as a fantastic place to grow old, with our increasingly ageing population able to stay fit, healthy and independent for longer, and (though it is a sensitive topic) also a good place in which to die.

Our top priority is to reduce loneliness and isolation for older people.

We also want to:

- ensure that there is sufficient community-based support to tackle the problem of delayed discharges from hospital;
- celebrate the role that older people play in making York such a special place;
- enable people to recover faster and remain independent for longer;
- recognise and support the vital contribution of York's carers;
- increase the use of social prescribing, ie, linking patients in primary care with sources of support within the community;
- enable people to die well in a place of their choosing and encourage people to prepare advanced directives.

The board will:

- promote volunteering, befriending and other opportunities to share knowledge, skills and experience;
- promote local social opportunities such as health walks;
- press for improvements in the accessibility and availability of community transport;
- press for improvements in the range and choice of accommodation available for older people;
- ensure that the needs of carers feature prominently in all policy making and service delivery;
- offer practical support and advice to those preparing for the end of life;
- champion the issues of older people, ensuring they have a voice in all local debates.

We will monitor our progress on:

- more older people telling us they have as much social contact as they would like;
- reducing the number of unnecessary acute and mental health admissions to hospital for older people;
- reducing the number of delayed discharges from hospital beds;
- more older people still being at home 91 days after reablement or rehabilitation;
- more volunteering opportunities for older people;
- more older people telling us they are happy with the care they receive, and have done the groundwork to prepare for their end of life.

How we will deliver the Strategy

In order to deliver this Strategy we will need to transform the way in which we work - with individuals, with communities, and with each other. Each of these has three components.

Transforming how we work with individuals

- continuing the process of **transferring responsibility**, decision-making and (where possible) budgets to individuals so that they can better understand the choices available to them, and take full ownership of the outcomes. Some call this way of working co-production;

- seeing the **whole person**. This means ensuring that we can (for example) recognise the physical health needs of someone presenting with mental illness, and vice versa. Our staff need to be trained to have the confidence to think beyond their professional specialism, while also being clear about when a referral to another service may be needed;

- acknowledging the **wider determinants** of people's health and wellbeing, especially housing, employment and environmental health impacts. These may not be directly under our board's control, but we can use our influence to ensure that policy-makers always take this dimension into account; and at an individual level, ensure we are equipped to point people in the right direction for advice and support. The board recognises that economic growth is not always inclusive and some people can get left behind. The board endorses the use of tools such as the Joseph Rowntree Foundation's Inclusive Growth monitor, which assesses inclusivity within regions.

Transforming how we work with communities

- helping to build friendly, **resilient communities** in York through targeted interventions and support. Such communities need the encouragement and resources to help themselves, for example through building networks of peer support;

- ensuring that when we commission services, we do so taking full account of the individual circumstances - and, in particular the **assets** - of the community;

- reducing the use of traditional medical prescribing and increasing the use of **community-based solutions**, - such as joining a club or engaging in volunteering - where this may be the best approach to an individual's problems.

Transforming how we work with each other

- further work to pool our budgets and commission services on a **joint basis** where this makes sense, as part of a strategic process to transform the way that health and social care services (in particular) accept joint responsibility for issues such as delayed discharges;
- ensuring that organisational boundaries never stand in the way of the best solution to an individual's issues, and that the principle of **no wrong door** runs through all of our services. Our workforce may need additional training to deliver this;
- focusing in particular on **transitions** between institutions and services. Experience - and your feedback - suggests that this is the point at which problems occur, and that we could transform people's experiences if we could get this right.

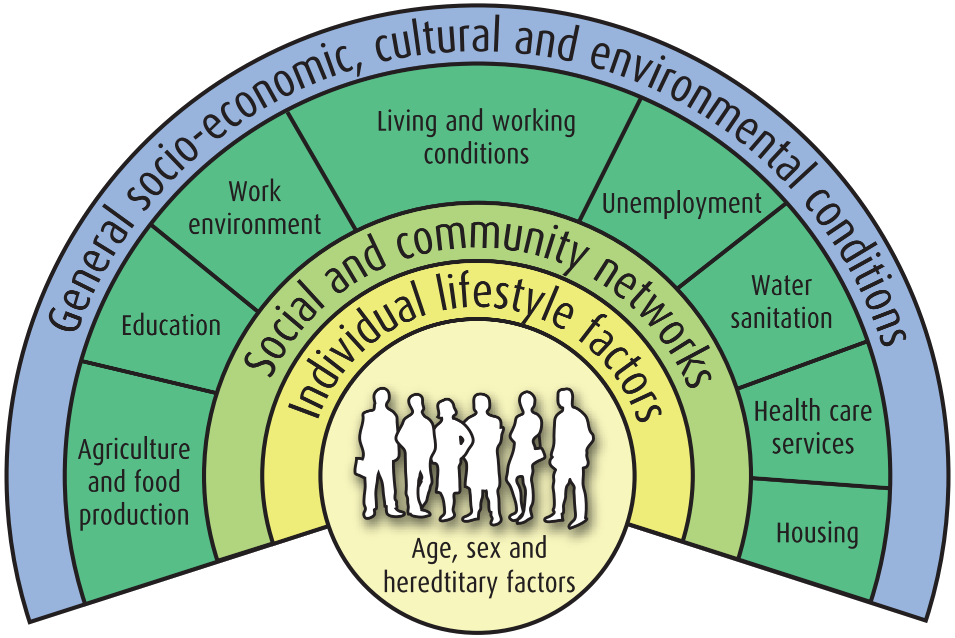
The role of the **Health and Wellbeing Board** will be to champion the ambition and priorities of this Strategy, maintaining a clear focus on outcomes. This will require us to support and challenge organisations to align their work to the strategic direction we have set out and to show action-focused leadership if barriers exist and are preventing progress. This may include board members working to drive change in their own organisations, or looking together at how resources are used across different agencies and partners for maximum impact.

How we will measure outcomes

The board will make use of a range of groups and action focused task groups, to develop action plans to take forward the initiatives outlined in this Strategy. Each will be the personal responsibility of an individual board Member. The board will monitor a range of indicators, some of which were set out in the previous chapters, to ensure that the Strategy is on track and - if not - to make adjustments based on clear evidence. At the same time, the board will establish new mechanisms to ensure it is constantly in touch with what residents think and feel, and has access to relevant case studies, because we accept that some aspects of health and wellbeing can't be measured by numbers alone. The board has also agreed some key principles that will underpin this work.

Wider determinants of people's health and wellbeing

The health and wellbeing of individuals and communities in York is affected by a wide range of fators. Some of these, such as gender and genetic makeup are outside our control. Other factors which might be beyond an individual's control can be improved with support from organisations such as the NHS, local authority or voluntary sector. These factors include things like the environment, the economy and housing.



Factors that affect people's health and wellebing are generally connected.

Plans and strategies

The board will take into account the relevant national and local plans and strategies.

Some of the groups in York where there is evidence of poorer outcomes

- Those living in the **poorer parts of the city**, where there are higher rates of childhood obesity, greater prevalence of chronic health conditions, and lower life expectancy;
- **single parents** - to ensure their children get the best possible start in life, and that their own health needs are not neglected;
- **children on free school meals**/eligible for the pupil premium, or in the care of the local authority;
- **students** - there is concern at the apparent increase in students of all ages experiencing mental and emotional health issues;
- people with **long term conditions**, who may find it difficult to get employment;
- people with a **learning disability**;
- people from **minority ethnic groups**, such as the traveller community;
- those from the **LGBT** community, where there is evidence of poorer health outcomes;
- **frail elderly** people living on their own;
- **carers** - people who deserve more support, and who have their own health and wellbeing needs.

Key Principles for the Health and Wellbeing Board

Ensure that we work together in true partnership for the good of the people of York;

Involve local people in identifying the challenges and redesigning services;

Promote equality of opportunity and access for all communities, and challenge discrimination if it arises;

Treat everyone with dignity and respect at all times;

Recognise and promote the vital role of unpaid carers who contribute so much to health and wellbeing in York;

Champion the role of the voluntary sector and the value its strength, diversity and knowledge brings in improving the health and wellbeing of our residents;

Work with the Adults' and Children's Safeguarding Boards to ensure that everyone always feels safe, and that the ways to report concerns are clear.

This Strategy does not stand alone, and the board is not the only body with an influence over the outcomes.

The board will strive to ensure that all these strategies and plans are aligned, so as to maximise their impact. This is especially important given the pressures on our budgets. The board will keep an overview of certain additional indicators that are not its direct responsibility in order to achieve this alignment and in case there is a need to challenge partners.

There will also need to be actions at a community level and by families and individuals. The board will not seek to micro-manage, but will instead maintain a strategic overview. We hope this Strategy will encourage individuals to take more responsibility for their own health and wellbeing, and to look out for others in their local community.

People should, of course, not hesitate to ask for help if they need it. For our part, we undertake to continue to listen to residents to ensure we are getting things right, and to make rapid changes if we are not. If we can nurture and sustain a spirit of true partnership throughout York, we really will be able to make it the best City in England in which to grow up, live, and grow old.

Annex B

If you require further information then please contact the Public Health Team:

Tel: 01904 551714

E-mail: healthandwellbeing@york.gov.uk

Public Health Team
City of York Council
West Offices
Station Rise
York YO1 6GA

Partners who sit on the York Health and Wellbeing Board

Independent Care Group

Tees, Esk and Wear Valleys NHS
NHS Foundation Trust

York Teaching Hospital NHS
NHS Foundation Trust

NHS
Vale of York
Clinical Commissioning Group

yorkcvs

healthwatch
York

NHS
England

CITY OF
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COUNCIL

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ANNEX C

City of York

Needs Assessment for All Age Autism

December 2016

Contents

Ronnie’s Story

As a child I was never invited to birthday parties. I wasn’t even aware that this was a ‘thing’ until I had children of my own. I was the child who felt somehow different, who found social situations confusing and who would stim and make strange noises. The signs were there but were dismissed by family as something I would grow out of and by teachers as eccentricities. I was of a generation where the autism spectrum was still in the early days of being fully understood and all but the severest of cases were overlooked or, in some cases, misdiagnosed. I managed to get through childhood and early adulthood with a mixture of copying my peers and the fact that I was completely unaware that not everybody experienced the world in the way that I do.

By chance, I found myself reading about autism in my early 40’s and quickly realised that many of the signs applied to me, both as a child and now. Not only the main signs of autism but also many of the common co-morbid conditions. Throughout my life I’d baffled doctors with my constant stomach problems and severe vertigo and light sensitivity. I’d had decades of tests, medications and even psychiatric counselling but nothing seemed to help and nobody could find a root cause. How obvious it now seemed, researching autism and finding all the pieces suddenly fitting together.

After a couple of years of researching autism on a daily basis I finally decided to visit my GP. My doctor looked through my medical history in light of my findings and agreed that it warranted investigation. At the time there were no facilities locally for adult assessments and I was placed on a waiting list in West Yorkshire. I remained on the waiting list for a couple of years before the opening of an autism assessment centre for adults at The Tuke Centre in York, part of The Retreat. I arranged myself to transfer the referral and funding. From there the process was very quick including the approval of funding. The staff at The Tuke Centre were excellent and after a series of appointments and tests with both myself and a family member, a diagnosis of Autism Spectrum Disorder was confirmed. I had just turned 45 and it really feels that it was then that my life truly began. The sense of relief was enormous. A huge weight was lifted off my shoulders and I really had a sense of who I was. Everything finally made sense and I was slowly able to forgive myself for a lifetime of my own perceived failings. Yes, I had been happily married for many years with happy, successful children but I had always struggled with everyday life when others didn’t seem to. Social situations, theory of mind, sensory differences and many other challenges were all something I’d just lived with without explanation. Now I knew that I was autistic. For me this revelation was huge and certainly nothing to be embarrassed or ashamed about. I’ve discovered many times that autism only seems to be seen as this terrible condition that can be a devastating diagnosis by neurotypicals, usually parents or peers. For myself, as an autistic person, it is no such thing. It is rather the lack of understanding from others that is the real cause of problems. I am not neurotypical and so I see, feel, hear and experience everything differently in a world that is not built for me. However, armed with my diagnosis and this knowledge I can accept and understand these differences.

Since my diagnosis the world has opened up for me. I am now doing things I wouldn’t have even considered attempting before I was diagnosed. I know my limitations but I also now know my strengths. It would be so easy to be bitter about my late diagnosis. Would I rather I’d been diagnosed as a child? Of course. I spent a lot of time wondering what my life would have been like with that knowledge. However, I will be forever grateful for my diagnosis, no matter how late in life it came. I finally know who I am. Autism is part and parcel of who I am. I am autistic but I wouldn’t change a thing even if it were possible. I’m a Mac in a PC world. I’m wired a little differently with a different operating system but I can still reach the same goals when allowed to do things the way that I’m designed to.

Definitions

ADHD	Attention deficit hyperactivity disorder (ADHD) is a group of behavioural symptoms that include inattentiveness, hyperactivity and impulsiveness.
ASCEND	Autism Spectrum Condition Enhancing And Nurturing Development is a course for adults with children who have recently received a diagnosis.
ASD	Autism Spectrum Disorder
CAAT	The Customer Access and Assessment Team (CAAT) is the first point of contact for any adult with social care enquiries for new customers who reside in the City Of York Area.
CAMHS	Stands for Child and Adolescent Mental Health Service
CDC	Child Development Centre
City of York Council	is the local authority in York which manages social care and other Public Services.
Clinical Commissioning Group (CCG)	is a group of doctors and other health professionals who decide what local health services to spend money on.
CYP	Children and Young People
Diagnosis	is when the symptoms or problems you are having are recognised as being caused by a known illness or condition.
EHCP	An Education, Health and Care (EHC) Plan is for children and young people aged up to 25 who need more support than is available through special educational needs support. EHC plans identify educational, health and social needs and set out the additional support to meet those needs.
ERP	is an enhanced resource provision within a mainstream school for young people with autism
ESC	Early Support Coordinator works in the Early Support is a programme designed to deliver better coordinated service for parents/carers of disabled children aged 0-5, as soon as the child is identified as needing additional support.
GP	General Practitioner (doctor)
IQ	intelligence quotient - an intelligence test score that is obtained by dividing mental age by chronological age and multiplying by 100: a score of 100 therefore indicates a performance at exactly the normal level for that age group

LAC	Looked After Children – a child is ‘looked after’ if they are in the care of the local authority for more than 24 hours.
LTT	Long Term Team (adults) is one of the Local Authority’s adult social care teams.
PA	Personal Assistant
Personal budget	is an agreed amount of money that is allocated to a person by the local council (and other funding streams) following an assessment of their care and support needs
Portage	is a home visiting education service for pre-school children with disabilities and/or additional needs. The aim of Portage is to help parents help children develop and learn.
Priorities	are the things that you must do first because they are the most important.
Public Services	are services provided for local people by the council. This includes things like buses, bin collection and traffic wardens.
SAF	Self Assessment Framework – is primarily for adults and is a return by Local Authorities for Central Government to identify progress in the implementation of Think Autism (2014)
SALT	Speech and Language Therapy
SEND	Special Educational Needs and Disabilities
SEYT	Specialist Early Years Teachers
Transition	a word used to describe when something changes, like when a child grows up into an adult.
Autism	Includes those with a diagnosis of autism, Asperger’s syndrome, ASC/ASD

Summary

Between 1% and 1.5% of the population are estimated to have autism. About 206,000 people live in York which means there are over 2,000 people living in York with autism, either diagnosed or undiagnosed. Autism is a lifelong condition which can be diagnosed at different points in a person's life depending on how it is affecting their daily lives.

The local picture in York – demographic information:

- **Diagnosis for children** - the diagnosis service for children in York is not currently performing well. As at September 2016 there was a waiting list of 107 children with an average waiting time of 35 weeks from referral to first appointment. Once the diagnostic process has been completed only 50% will have a positive diagnosis which is low in comparison to surrounding CCG areas.
- **Diagnosis for adults** - there is a diagnosis service for adults with autism York but this service does not assess those with complex learning disabilities and autism. The service in York started in January 2016 and has a limited budget. From August 2016 it started to hold a waiting list. Of those who have been assessed there is a 96% positive diagnosis for autism.
- **Education** – there are currently 250 students (including year 14) in York who have a diagnosis of autism which is a 70% increase in autism diagnosis for students in York schools. 65% of those 250 students are supported in mainstream settings compared to 35% in more specialised settings.
- **Student female / male diagnosis** – Although male student diagnosis remains higher than female diagnosis, it is to be noted that from 2012-16 there was a 63% increase in male diagnosis but a 115% increase in female diagnosis. This trend is likely to continue.
- **Adults known to social care** – collation of data for the SAF has become more robust and there is a significant increase from 23 to 38 adults who are known to social care who have autism but no learning disability from 2014 to 2016.

The local picture in York – services available

- **Post diagnostic support –** post diagnostic support is limited and further work is being undertaken with regards to the pathway for support.
- **Education –** the support provided is dependent on the needs of the individual student.
- **Adults with a learning disability and autism –** if support is required it will be through the Community Learning Disability Team which is a multi-disciplinary and multi-agency team.
- **Adults with autism and no learning disability –** if an individual requires support and is in agreement to an assessment this will be delivered through the adult social care teams.

- ⇨ **Parent / carers of someone with autism –** if someone wishes to receive support in their role as a carer, an assessment of need can be undertaken and ongoing support or a carers grant are available, where appropriate.
- ⇨ **Voluntary sector / local support groups –** there is a vibrant voluntary sector in York and a few proactive groups have been started at a grass roots level.

Projected Service Use in York:

- ⇨ **Education –** if the trend of increased diagnosis continues there could be an increase of approximately 97 students with an autism diagnosis in schools by 2021.
- ⇨ **Adult population –** as the increase in diagnosis continues in childhood this means there will be an increased population of adults with autism who have a formal diagnosis. This will need to be recognised and adjustments made in higher education and into work environment. As the general population live longer into old age so too with adults with autism.

Residents in York views:

- ⇨ An all age autism joint strategic needs assessment survey was undertaken which was responded to by 39 people, there was also a focus group and information from the Inclusive Communities survey (152 responses) were also reviewed. Key points were with regards:-
    - waiting times for an assessment although there were no issues with the process of the actual diagnosis;
    - over 40%of those who responded have not been able to access mental health services when they needed them;
    - more easily accessible and available information and advice;
    - parent training courses at different times in a persons life; and
    - more employment support.

Key issues / Gaps

- Robustness and consistency of data collection and recording of people with a diagnosis of autism.
- Disparity in prevalence as between males and females, arising from inbuilt bias in diagnostic tests
- Some adults with high functioning autism continue to be excluded from accessing health and social care services because they do not fit the perceived remit of learning disability or mental health services.
- There may be some gaps in training / knowledge amongst frontline staff in the Local Authority and Health Services with regard to how to work effectively and efficiently with people with autism.

Introduction

Autism is defined as:

> “a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all autistic people share certain difficulties, their condition will affect them in different ways. Some autistic people are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People on the autism spectrum may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.”[1]

Asperger syndrome is a condition on the autistic spectrum most commonly used to describe people with autism with average to above-average intellectual ability. Therefore individuals with Asperger syndrome generally will not be classified as having a learning disability. In the UK adults with Asperger syndrome are often excluded from accessing statutory health and social care services because they do not fit the perceived remit of having learning disability or need for mental health services.

The term autism in this needs assessment includes those with Asperger syndrome.

It is currently estimated that approximately 1% of the population has autism with the prevalence rate being higher in men than it is in women (1.8% versus 0.2%)[2]. Current thinking, however, is beginning to question this perceived gender split and querying whether there is a potential under diagnosis of autism in females. **The Adult Psychiatric Morbidity Survey (2014)** [3] states “It has been suggested that assessments for autism may draw more on how the condition manifests in men, and this may lead to under identification of autism in women (Trubanova et al. 2014)”

The gender split is being researched more and a summary of current theories can be found in a National Autistic Society (NAS) article, **Gender and Autism** [4]

It is estimated that 60-70% of people who have autism will also have a learning disability.[5]

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[1] National Autistic Society, website definition, March 2016, http://www.autism.org.uk/about/what-is/asd.aspx

[2] NHS Information Centre, *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey*, 2012

[3] *Adult Psychiatric Morbidity Survey of Mental Health and Wellbeing*, England 2014, NHS Digital

[4] How does autism present differently in women and girls, NAS article, November 2016, http://www.autism.org.uk/about/what-is/gender.aspx

[5] NHS Information Centre, *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey*, 2012

There are estimated to be 388 children[6] (0-18) and 1,635[7] adults (18+) with autism in York, either diagnosed or undiagnosed.

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[6] Estimate based on 2012 ONS census 0-17 population, York, assumed 1% prevalence.

[7] Projecting Adult Needs and Service Information website (18-65) and Projecting Older People Population Information System website (65+), February 2016

The bigger picture – national policy

The Autism Act (2009) identifies the collective commitment to improve the lives of all people with autism and their families. It was the first legislation which focussed on autism and ensured the government made a commitment to improving service provision and support for those with autism. The Act made two key provisions; that the Government produce an adult autism strategy by 1 April 2010, and that the Secretary of State for Health issue statutory guidance for local authorities and local health bodies on supporting the needs of adults with autism by 31 December 2010.

It is important to note that all adults with autism are now formally recognised as having a disability by the Autism Act (2009). This is a slightly stronger position than that of the Guidance published in 2006 to accompany the Disability Discrimination Act which makes it clear that the definition of disability can cover people with all forms of autism, including Aspergers Syndrome. This is especially relevant given the difficulties people with autism report in accessing mainstream services in Health and Social Care. It gives added weight to the legal duties on the NHS bodies and local authorities, for example to ensure access to diagnosis, assessment, information and advice.

In 2010 **Fulfilling and rewarding lives. The strategy for adults with autism in England**[8] was published with the key aim of improving the lives of people with autism and their families. Following on from this the first year delivery plan was published in April 2010, **Towards fulfilling and rewarding lives: the first-year delivery plan** [9] This set out the governance structure and the actions, with timescales and responsibilities, to be taken in the first year to support the implementation of the adult autism strategy.

In December 2010, the Department of Health published **Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy**[10] This provided guidance to local authorities, NHS bodies and NHS Trusts on the following key areas; training of staff who provide services to adults with autism, identification and diagnosis of autism in adults, leading to assessment of needs for relevant services, planning in relation to the provision of services to people with autism as they move from being children to adults; and local planning and leadership in relation to the provision of services for adults with autism.

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[8] *"Fulfilling and rewarding lives" The strategy for adults with autism in England*, Department of Health, 2010

[9] *Towards "Fulfilling and rewarding lives" The first year delivery plan for adults with autism in England,* Department of Health 2010

[10] *Implementing Fulfilling and rewarding lives: statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*, Department of Health, 2010

Children and Families Act (2014) amends existing legislation and services for children and young people, and provides a new special educational needs and disability support system, covering education, health and social care.

In January 2015, the Government published a new **Special Educational needs and disability code of practice**[11] for children and young people between 0 – 25 which provides statutory guidance for organisations which work and support children and young people who have special educational needs or disabilities.

The Care Act (2014) builds on recent reviews and reforms, replacing numerous previous laws, to provide a coherent approach to adult social care in England. It states clearly that all staff who undertake autism assessments must have appropriate training.

In 2014 **Think Autism strategy**[12] was published. This builds on rather than replaces the themes in *Fulfilling and Rewarding Lives* (2010). *Think Autism* sets out fifteen priority challenges for action from the perspective of people with autism and carers. There are three new key proposals in the *Think Autism* strategy (building communities that are more aware of and accessible to the needs of people with autism, which have autism champions for change; promoting innovative local ideas, services or projects which can help people in their communities through new models of care, and focusing on how advice and information on services can be joined up better for people.) which are in addition to the existing duties of the 2010 strategy.

In 2015 The Government published a new statutory guidance, which replaced the existing statutory guidance. **Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy**[13]. This guidance tells local authorities, NHS bodies and NHS Foundation Trusts what actions should be taken to meet the needs of people with autism living in their area. The guidance was revised to take account of responses to a related consultation[14]. It also takes into account progress made since the 2010 guidance, and recent legislation including the *Health and Social Care Act 2012*, the *Care Act 2014* and the *Children and Families Act 2014* which provided new duties for people with autism.

In March 2015 the Government published the consultation paper, **No voice unheard, no right ignored** which was for people with learning disabilities, autism and mental health conditions. The consultation examined how people's rights and

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[11] *Special educational needs and disability code of practice: 0 to 25 years; Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities*, Department of Education, 2015

[12] *Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update,* Department of Health 2014

[13] *Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy,* Department of Health 2015

[14] *The Government response to the consultation on revised statutory guidance to implement the Strategy for Adults with Autism in England*, Department of Health, March 2015

choices can be strengthened. The Government provided a response to this consultation in November 2015**. Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions.**[15] The Government set a series of proposals grouped into three implementation phases, early actions that seek to sustain momentum generated, chiefly through the use of existing powers and building on work currently underway, further changes, including proposed legislative changes that cannot be achieved via existing powers (and which relate principally to the Mental Health Act 1983), and, a third phase, which explores more radical solutions to longer-term issues, as well as ongoing monitoring and review, and a commitment that the Government will intervene further, including through legislation if necessary, if the improvements sought continue not to be realised in practice.

In 2016 the **Progress report on Think Autism: the updated strategy for adults with autism in England**[16] was published. This report details what has been achieved since the publication of *Think Autism*. It also sets 31 new actions to continue to help local areas implement the autism strategy and focuses on education, employment, the criminal justice system and better data reporting.

In 2011 the Winterbourne View Hospital scandal occurred when a BBC Panorama programme revealed widespread abuse by staff of people with learning disabilities. . The Department of Health undertook a review and In response to this **Transforming care: A national response to Winterbourne View Hospital**[17] was published which committed to producing a report 2 years later setting out the progress that had been made to ensure what happened at Winterbourne View is not repeated.

The subsequent report, **Winterbourne View: Transforming Care Two Years On**[18], set out what had been achieved but recognised that there was still progress to be made. The national plan, **Building the Right Support**[19], 2015, has been developed jointly by NHS England, the LGA and ADASS, and is the next key milestone in the cross-system Transforming Care programme. This programme includes those with more severe autism who are in residential care.

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[15] *Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions*, Department of Health, November 2015

[16] *Progress report on Think Autism: the updated strategy for adults with autism in England,* Department of Health, 2016

[17] *Transforming care: A national response to Winterbourne* View Hospital, Department of Health Review, 2012

[18] *Winterbourne View: Transforming Care Two Years On,* Department of Health Review, 2015

[19] *Building the Right support, A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition*, NHS England, the LGA and ADASS, 2015

NICE guidance

The National Institute for Health and Clinical Excellence (NICE) has published the following clinical guidelines on autism:

- *Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum;*[20]
- *Autism: The management and support of children and young people on the autism spectrum);*[21]
- *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum.*[22]

The NICE guidance states that the local services (including health, mental health, learning disability, education and social care services) for children and young people with autism, should be coordinated by a local autism multi-agency strategy group and that the coordination of care should be provided through local specialist community-based multidisciplinary teams ('local autism teams') which should include professionals from health, mental health, learning disability, education and social care services. A recent self-assessment exercise to map progress locally and nationally with delivery of the adult autism strategy showed that structures are in place in many areas, including the creation of diagnostic leads.

NICE has also published a Quality Standard (QS51, January 2014) to help inform the commissioning of autism services for children, young people and adults, focusing on the key areas for improving the quality of existing services.

NICE guidelines describe best practice to help reduce variations in service provision for people with autism, but they are not mandatory. However, the Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality.

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[20] *Autism spectrum disorder in under 19s: recognition, referral and diagnosis*, Clinical guideline [CG128] Published date: September 2011

[21] *Autism spectrum disorder in under 19s: support and management* Clinical guideline [CG170] Published date: August 2013

[22] *Autism spectrum disorder in adults: diagnosis and management* Clinical guideline [CG142] Published date: June 2012, updated: August 2016

The local picture – demographic information

Diagnosis for children

In York there is a diagnostic service for children and a separate service for adults. The service for children is delivered by the National Health Service. The assessment is undertaken by York Hospital for those aged 0-5 and at Lime Trees for those aged 5-18.

Under five years old diagnostic process

Children under the age of five are referred into the paediatric service in York for assessment.

- ✓ The child is seen by a paediatrician, and also by a specialist speech and language therapist, and sometimes other therapists (for example occupational therapists).
- ✓ Clinical observation and information gathering takes place. As young children often have a rapidly changing presentation and develop different skills at different rates, the timing of the process is not fixed.
- ✓ Once sufficient information has been gathered, and the child’s overall developmental profile considered, the child is discussed at the multi-agency autism forum (convened in conjunction with CAMHS) and a decision as to whether the child meets the ICD 10 criteria[23] for a diagnosis of autism is reached.
- ✓ Sometimes a further period of observation or further assessments are recommended as a result of discussion at the autism forum, and the child is then taken back for further discussion at the autism forum once these are completed.

Five to 18 years old diagnostic process

Children aged 5 to 18 are assessed by trained staff (including Clinical Psychologists and Clinical Nurse Specialists) at Limetrees Clinic in York. All children and young people referred have an initial screening by a trained health worker, this includes gathering information from school and parents. Following screening if indicated the family are offered a full assessment for Autism Spectrum Disorder by the multi-disciplinary team. . This will include an autism specific diagnostic interview with the parents and an Autism Diagnostic Observation Schedule (ADOS) with the child. Where needed an observation of the child/young person will be completed in school. A multi-disciplinary discussion then takes place in order to determine whether the

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[23] http://www.autism.org.uk/about/diagnosis/criteria-changes.aspx

child/young person meets the ICD-10 criteria for a diagnosis of an Autism Spectrum Disorder.

At the moment the whole pathway from 0-18 is being reviewed in order to make the process meet the standards set out in NICE Guidance 128 for the referral, assessment and diagnosis of children and young people with suspected autism. In particular in the pathway for 5-18 year olds this would include a reduction in waiting times and the inclusion of Speech and Language Therapy in the diagnostic process. To make the pathway fully compliant a number of developments are being undertaken.

Diagnosis data for children (5-18 years old)

Referrals for autism are increasing in York. As at September 2016 there was a waiting list of 107 children with an average waiting time of 35 weeks from referral to the first appointment.

	Numbers of individuals (5-18 year old)		**Weeks**		
	Total no. referrals	**Waiting list – NOT had apt by end of reporting period**	**Average wait time from referral to 1st Apt.**	**Longest wait time to 1st Apt.**	**Average wait time from 1st Apt to diagnosis**
April 2014 to March 2015	88	31	22	26	18
April 2015 to March 2016	130	66	16	39	17
April 2016 to Sept. 2016 **HALF YEAR**	70	107	35	51	15

Professionals working in this area are sensitive to the emotional impact of the diagnostic process as it can be complex and challenging for families and individuals. The assessment process and the confirmation of diagnosis through a multi disciplinary panel can take up to 15 weeks or longer in some cases. This means currently individuals and their families / carers can wait for up to a year from referral to diagnosis.

	No. completed diagnosis process (age 5-18)	**Outcome**		**Percentage (%) Positive autism diagnosis**
		Yes	**No**	
April 2014 to March 2015	89	49	40	55%
April 2015 to	89	54	35	61%

March 2016				
April 2016 to Sept. 2016 HALF YEAR	22	11	11	50%

From April 2016 to September 2016 there were 22 assessments with a conversion rate of 50%. This is low in comparison to other surrounding areas where there is a conversion rate of about 75-80% which is the expected level if inappropriate referrals are screened out at an early stage.

CCG Area	Percentage (%) Positive autism diagnosis April 2016 – September 2016 (age 5-18)
HaRD (Harrogate & Rural District)	77%
HRW (Hambleton, Richmondshire & Whitby)	78%
SR (Scarborough & Ryedale)	75%
VoY (Vale of York)	54%

The low conversion rate in York needs to be explored as there may be a number of contributing factors.

If there is no diagnosis of Autism Spectrum Disorder then the multi-disciplinary team will consider if further assessment or intervention is necessary

Diagnosis for adults

Diagnosis process for adults with autism

The adult service is commissioned and delivered by the Tuke Centre at the Retreat in York. The service assesses for autism and ADHD, but does not assess those with complex learning disabilities.

This is a new local diagnosis and assessment service which started in January 2016. The service has a limited budget and as of August 2016 started to hold a waiting list. Up to that date there was a 96% conversion rate from referral to a positive diagnosis. This is to be expected in an adult diagnostic service.

Data from the Tuke Centre for the period January to September 2016 for the whole of the Vale of York CCG area shows:

- 47 screenings for ASD
- 41 assessments for ASD
- 57 waiting for screening or assessment
- 7 discharged without screening or assessment

It has not been possible to disaggregate the screenings and assessments for those people referred from the City of York.

These figures are significantly higher than for other North Yorkshire CCG areas, but the commensurately larger population will explain the disparity in figures.

Recording for adults receiving a diagnosis up to the new service starting in January 2016 wasn't recorded specifically for York. Historic data in the Vale of York in 2014 indicates an average of 2 to 3 referrals a month for autism and ADHD.[24]. The conversion rate of these referrals is unknown.

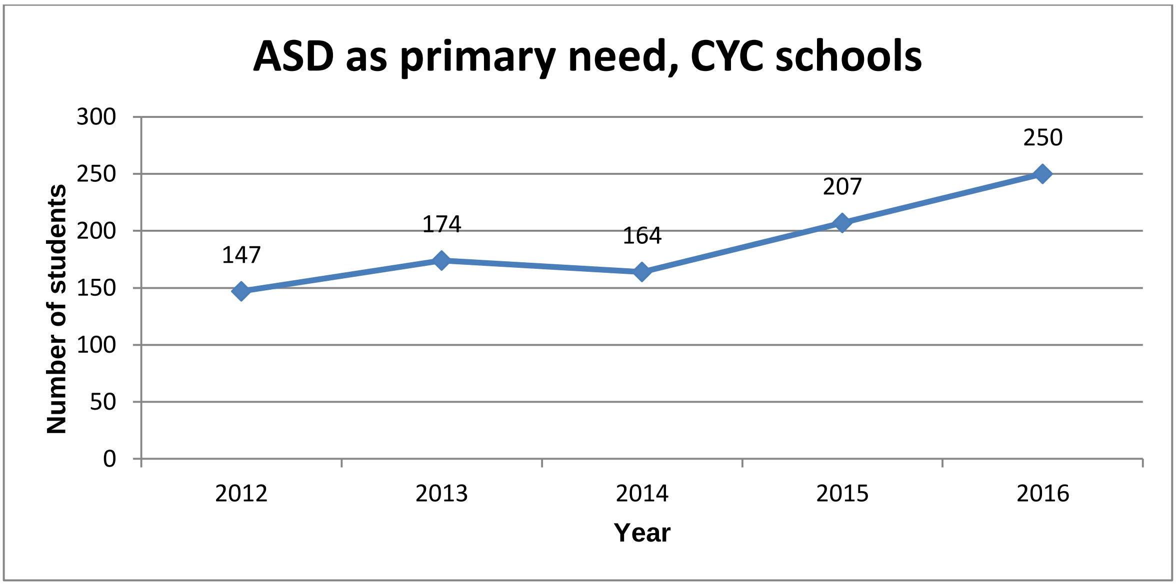
Diagnosis process for adults with autism and a learning disability

For adults who have a learning disability and are known to mental health services, the assessment will be undertaken by the adults' service. The small number not known to services would need to be referred by their GP to a specialist out of area service.

Education and autism (age three to 19 years)

Within the general school population there has been a growth from 0.62% students diagnosed with autism in 2012 to 1% of students being diagnosed with autism in 2016 (1.1% in primary and 0.8% in secondary)[25].

There are currently 250 students (including year 14) in York schools who have a diagnosis of autism. In addition to these 250 there are also 6 students who are currently not attending school who have autism. In January 2012 there were 147 students (including year 14) in York schools with autism - a 70% increase in autism diagnosis for students in York schools from 2012 to 2016.



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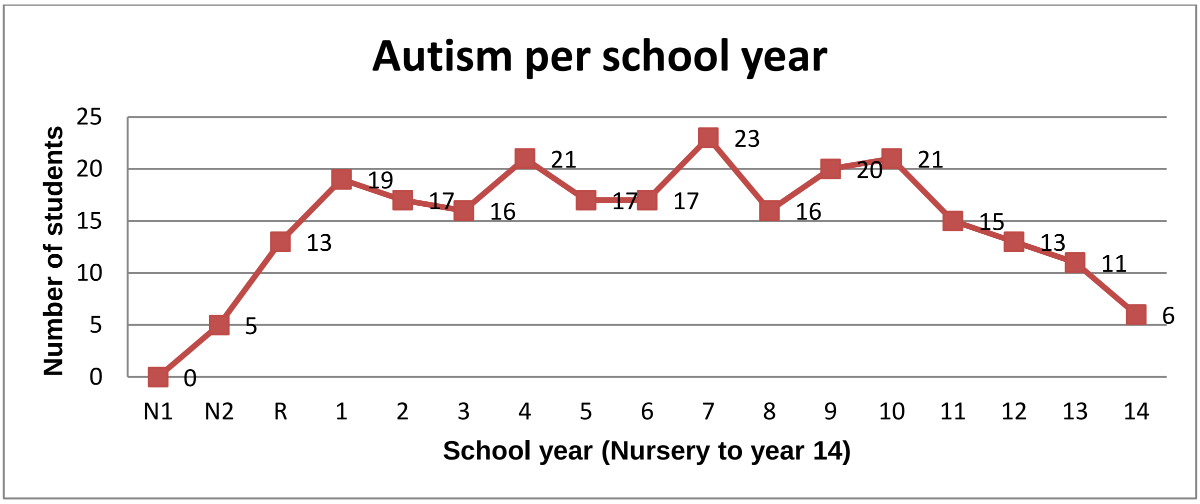
[24] Attention deficit hyperactivity disorder
[25] School Census, January 2016

There are more students with autism being supported in mainstream schools (65%) as compared to those in more specialised settings (35%).

Diagnosis before age five will continue to remain low because of the difficulties giving a firm diagnosis in this age group. Autism diagnosis rises from age five when children enter formal education where there are over ten students a year with autism, peaking at 23 in year 7.



Student female / male diagnosis

As detailed above, from 2012 there has been a 0.4% growth in students with autism in the general school population to 1% in 2016. The diagnosis for male students remains far higher than for female students with a 63% increase in diagnosis from 2012 to 2016. However, in that same period there has been a 115% increase in female diagnosis. Anecdotal evidence suggests that the increase in female diagnosis will continue as a trend.

Year	Male	% Male	Female	% Female	Total
2012	127	86%	20	14%	147
2013	146	84%	28	16%	174
2014	140	85%	24	15%	164
2015	175	85%	32	15%	207
2016	207	83%	43	17%	250

If autism were compared to other disabilities, for example, learning disabilities, where the gender split is approximately 60/40 (male/female)[26] the disparity in diagnosis further demonstrates that female presentation and diagnosis is an area which needs to be explored.

Adults and autism - Self Assessment Framework, 2016

The purpose of the self-assessment is to enable local strategy groups to review their progress and to assist in future planning with partners including people with autism and their families. The self-assessment is primarily for adults and sets out and expands on the priorities set out in **Think Autism** (2014) and updated in the **Progress Report on Think Autism: the updated strategy for adults with autism in England** (2016). The process is the key means of identifying progress in the implementation of the strategy at a local level.

The process has just been completed and returned to the Department of Health for York. This will analysed and published in early 2017. Results from the 2014 Self Assessment Framework (SAF) are available online.[27]

From 2014 to the 2016 SAF some of the questions changed to enable more meaningful data analysis. Where there is comparable data progress can be evidenced. Transitions data is much more robust across all children services with a diagnosis being included whereas previously this was mainly for children with autism and a learning disability. Therefore the figures have increased substantially from 26 in 2014 to 71 children aged 15-18 years in 2015-2016.

Adult Social Care – Care & Support

As part of the SAF return the following data was submitted with regards to adult social care.

1	What is the number of adults assessed as being eligible for adults social care services who have a diagnosis of autism and in receipt of a personal budget?	87
2	What is the number of those in question 1, who have a diagnosis of autism but not a learning disability	38
3	What is the number of those in question 1, who have a diagnosis of autism AND a learning disability	49

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[26] *People with Learning Disabilities in England 2010, Services and Support*, E Emerson, C Hatton, J Robertson, H Roberts, S Baines & G Glover, Improving Health and Lives : Learning Disabilities Observatory and DH, 2010

[27] http://www.improvinghealthandlives.org.uk/projects/autsaf2014results

The questions with regards to autism and adult social care have been modified but where it is comparable it shows there has been an increase of those with diagnosis of autism but no learning disability from 23 to 38 which is a significant increase.

The local picture – services available

Post Diagnostic support

Post diagnostic support for parent / carers of children 0-18 years old

For the parents of children / young people who have received a diagnosis there is a course called ASCEND (Autism Spectrum Condition Enhancing and Nurturing Development). The programme aims to share theoretical and practical strategies with parents and carers of children on the autism spectrum and to give opportunity for parents to meet with and gain support from each other as well as from the course facilitators. This is currently managed by CAMHS and co-delivered with the Specialist Teaching Team for Autism.

Post diagnostic support for adults who have received a recent diagnosis

When an adult is diagnosed they are offered either 2 one to one follow up sessions or 5 group sessions to help to understand the diagnosis.

As autism is not a medical condition, once the diagnostic process has been undertaken and a diagnosis of autism has been given support from Health is limited and this is the reason further work on joint pathways is being undertaken.

Education (Early years to 19)

Early Support is a way of working that aims to improve the delivery of services for disabled children, young people and their families. It enables services to coordinate their activity better and provide families with a single point of contact and continuity through key working. It ensures that service delivery is child, young person and family-centred. It focuses on enabling services and practitioners to work in partnership with children, young people and their families.

Portage is a home visiting education service for pre-school children with disabilities and special educational needs. Visits are made on a weekly or fortnightly basis. It helps parents and carers to support their child's learning by breaking skills down into small steps. The service is available to families who have a child under five years old with difficulties or delays in more than one area of development. The service was expanded in 2004 to also include children at risk of developmental difficulties through low birth weight and/or premature birth or those who are 'looked after' (LAC) by the local authority.

Educational Psychologists for Early Years, alongside the Specialist Early Years Teachers (SEN) and Portage Home Visitors, play a major role in supporting transitions to nursery or school and provides advice toward statutory assessment when required. They also provide advice on children's development to practitioners, staff and parents/carers through direct casework, training and consultation

The Specialist Early Years Teachers (SEN) provide support and advice for children from 2-5 years with additional needs. They have expertise and training in child development, early learning and teaching children with additional needs. They work directly with pre-school children as well as providing information and advice to others: parents and carers, staff in early years settings, medical practitioners and therapists in the community and at the Child Development Centre (CDC), York Hospital and any other professionals involved with a child

The post of Early Support Coordinator (ESC) within the Specialist Early Years Specialist Teachers (EYST) was developed in 2007 as part of the original Early Support Programme for young disabled children age 0-5 years and their families. The Early Support Key Worker Coordinator (ESC) works closely support services and practitioners from education, health and children’s social care, and particularly the health and disabilities team.

City of York Council also has a Specialist Teaching Team for Autism. This team consists of two specialist teachers and two specialist teaching assistants who work in mainstream nurseries, schools and York College with children, young people, teachers and support staff in these settings. A referral to the team is usually made by clinicians, after a diagnosis has been made at the Autism Forum. Specialist Teacher’s (SPT) make an initial assessment and then make recommendations for each child or young person using a variety of methods including school observation, parent consultation, discussion with school staff, attending reviews etc. Their involvement will vary according to the needs of the child or young person. A specialist teaching assistant may then visit to support the setting implement the advice, for example to establish a social communication group, write a Social Story or set up an individual structured teaching activity. The team will assess and review progress of each child to make sure children are benefiting from the team’s interventions. Specialist teachers are involved in contributing to My Support Plans (MSP) and Education Health Care Plans (EHCP)

In York there are two Enhanced Resourced Provisions (ERPs) at secondary school; these are Joseph Rowntree and Fulford School. These both support ten students with a diagnosis of autism in the mainstream school. The nature of the support depends up the individual needs of each student. Inclusion is a priority and the students spend most of their time in mainstream lessons with their peers. To enable this to happen there is liaison between Subject Teachers, Form Tutors, Directors of Learning, the Senior Leadership Team and Student Support. Additional help and support is given with communication, social interaction and organisational skills and personal development lessons are planned to meet the individual needs of each student in the context of a busy secondary school environment.

Small Step Transition programmes are designed for students moving from Year 6 to Year 7, from KS3 to KS4 and then finally from Year 11 to post-16 provision. The ERPs work closely with families and many other agencies (EPS, Lime Trees, SALT, Occupational Therapists, Social Services etc.) to provide a holistic approach giving each student the opportunity to thrive and succeed.

In addition to this there is a new Enhanced Resourced Provision (ERP) for primary aged pupils opening at Haxby Road School at Easter 2017 which will offer specialist provision for up to 8 children. There is also an inclusion class at Hob Moor Oaks offering specialist provision to children who can access some mainstream learning.

Hob Moor Oaks Special school is federated with Hob Moor Primary and offers specialist autism provision, as does Applefields Secondary special school, for those pupils who have autism and significant special needs.

St. Paul's Nursery School is also classed and funded by the Local Authority (LA) as an Enhanced Resource Centre (ERC), offering 12 additional part-time places for children with a range of special needs and disabilities (SEN), including social communication difficulties/autism.

Further/Higher Education and options Post 16

Young people with autism can study further at York College and Askham Bryan College. Support is available, including mentoring, for young people with an EHCP. Both York University and York St John University offer a range of support to students with autism according to their needs.

There are a number of alternative Post 16 options for young people with autism; including apprenticeships, supported internships and personalised packages.

14-25 year olds with autism, the Transitions Team

The Transitions team is a multi-agency co-located team that works primarily with young people with a learning disability who are aged 14-25. The team is comprised of social care from the children's health and disability team and adult social workers from the Adult Learning Disability Team. Connexions advisors are also part of the team as are independent travel trainers. Young people with Autism can make a referral via adult or children's social care or via your school or college. We work with local education and social care providers to be as creative as possible in order for young people to reach their goal and achieve their full potential.

Adults with a Learning Disability and autism

If an individual has a learning disability and autism, and requires support, this will be delivered through The Community Learning Disability Team. This is a multi-disciplinary and multi-agency team that includes a range of professionals (including Consultant Psychiatrist, Community Learning Disability Nurse, Social Worker, Physiotherapist, Occupational Therapist, Speech and Language Therapist, Clinical Psychologist and Administrative support). It acts as the gate-keeper to services for adults with a learning disability and / or autism living in the community.

Services in the community range from day activities, hydrotherapy, supported living opportunities to short breaks if the individual still lives at home with their parents /

carers. There are different referral routes for the health and social care parts of the team.

Adults with complex autism

An Autism Hub was opened in October 2016 which provides support for adults with more complex autism. The Autism Hub provides a safe, predictable, comfortable and autism friendly environment for people to spend time accessing support. Individuals receive training and life skills development and increased confidence leading to an improved quality of life.

> “An individual’s special interests are nurtured and used as the base for learning and skills can be built around these that can be used in different situations. For example; one person who comes to The Hub has a special interest in The X-Factor. We are supporting him to ‘be a judge’, he watches clips of the show and decides who he is going to vote to stay in or vote out of the show. We then spend time with him looking at how the decision he has made might make the contestant feel, exploring empathy and consequence.
>
> This gentleman recently had his annual review and the feedback we received at that review was amazing. His support team told of how attending The Hub had actually ‘changed his life’. He now has reason to get out of bed in a morning and has more meaningful conversations when at home, talking about the things he has done whilst at The Hub. He has also started doing more things for the person he lives with such as setting the table for tea for both of them rather than just for himself and buying his housemate a birthday card. These are things which he wouldn’t have thought about doing previously.”
>
> The Autism Hub, November 2016

Adults with autism and no learning disability

If an individual, who has autism and no learning disability, requires support and is in agreement to an assessment, this is delivered through the adult social care teams.

Customers who are transitioning from children’s services who have a diagnosis and have an IQ of over 70 are routed either through the Long Term Team (Adults) or Mental Health Team depending on their main presenting need.

Customers who are not known to the children’s team and are not known to adult social care already come via CAAT (Customer Access and Assessment Team) for an assessment.

The Long Term (Adults) Team (LTT) currently supports a number of customers who have had an assessment of their needs and require assistance with maintaining their personal care or home environment, maintaining their nutritional needs, and / or family and personal relationships. The Long Term Team can also assist customers in accessing work, education, volunteering or training opportunities and give advice as to options within the wider community for recreational opportunities. The team work alongside individuals to meet their identified outcomes whether this is via a commissioned service, a direct payment to employ a PA or support to access voluntary services.

Parents / carers of someone with autism

City of York Council's Carers Support Workers work alongside York Carers Centre to provide ongoing support to carers of adults with Autism who wish to receive support in their role as a carer. York Carers Centre also work with parent carers and also support parents of young people with autism.

An assessment of needs is carried out and ongoing support or carers grants are available, where appropriate, to sustain this caring role.

Employment

There is no robust data with regards to employment and autism. Research undertaken by the National Autistic Society, in 2009,[28] indicated that the number of people with autism in employment is very low, indicating that just 15% of adults with autism in the UK are in full-time paid work. The research also found that many of those not in work were also excluded from the benefits system with one third currently without a job or benefits.

Sustainable employment is still difficult to achieve with no evidence that the findings from 2009 have improved. The Department for Work and Pensions have recently published **Improving Lives, the work, health and disability green paper**[29], which highlights the inequalities faced by those with disabilities, for example, 52% of disabled people are not in employment and 54% of those people will experience mental health conditions.

Criminal Justice System

Recording autism as a condition is not required by the criminal justice system (CJS) which means there is no reliable data and therefore there has been only limited analysis regarding prevalence of individuals within the CJS. An individual with autism may enter the CJS as a victim, witness or as a suspect/offender.

It is unclear how many adults with autism are within the CJS but limited research studies indicate that they are over represented within the whole system, both as victim and perpetrator.

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[28] *Don't write me off, make the system fair for people with autism*, National Autistic Society, 2009

[29] *Improving Lives, the Work, Health and Disability, Green Paper,* Department for Work and Pensions, October 2016

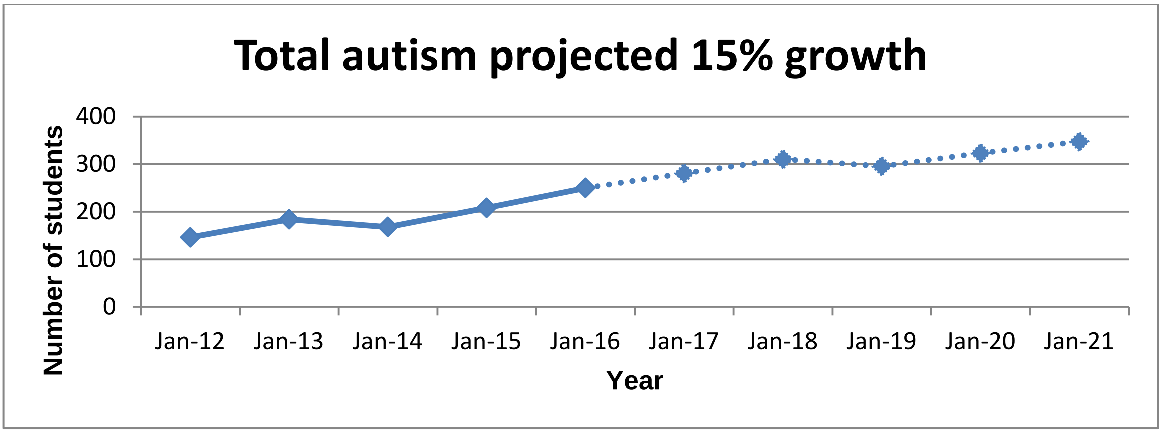
Voluntary sector / local support groups

York has a vibrant voluntary sector and proactive groups which have started at grass roots level. A comprehensive mapping of opportunities and groups needs to be undertaken and information made accessible and kept up to date.

Projected service use

Education (Early years to 19)

From 2012 to 2016 there has been a 70% increase of students diagnosed with autism. If this trend is averaged out over this period it means an approximate 15% increase year on year during this period. If this is projected forward this would mean that there would be 347[30] students with a diagnosis of autism by 2021 in both mainstream and specialist school settings, a growth of approximately 97 students which is a 39% overall growth in students with autism.



It must be noted that this also means that approximately 66 students will become adults and this may impact on adult services depending on presenting need.

To note – due to the long waiting times for an assessment (at September 2016 there was a waiting list of 107), taking into account current conversion rates of 50% this would mean that the actual figures in 2017 could potentially be low but the projection should still be accurate as assessments are completed.

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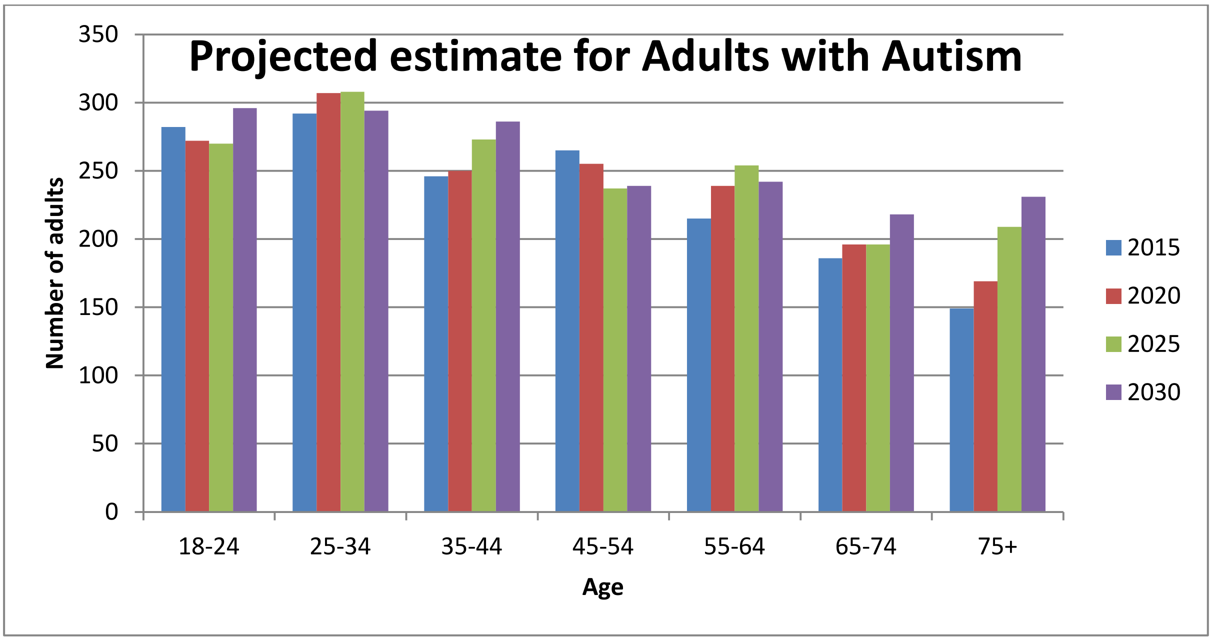
[30] Based on current yearly intake minus students leaving school (total 66 estimated school leavers)

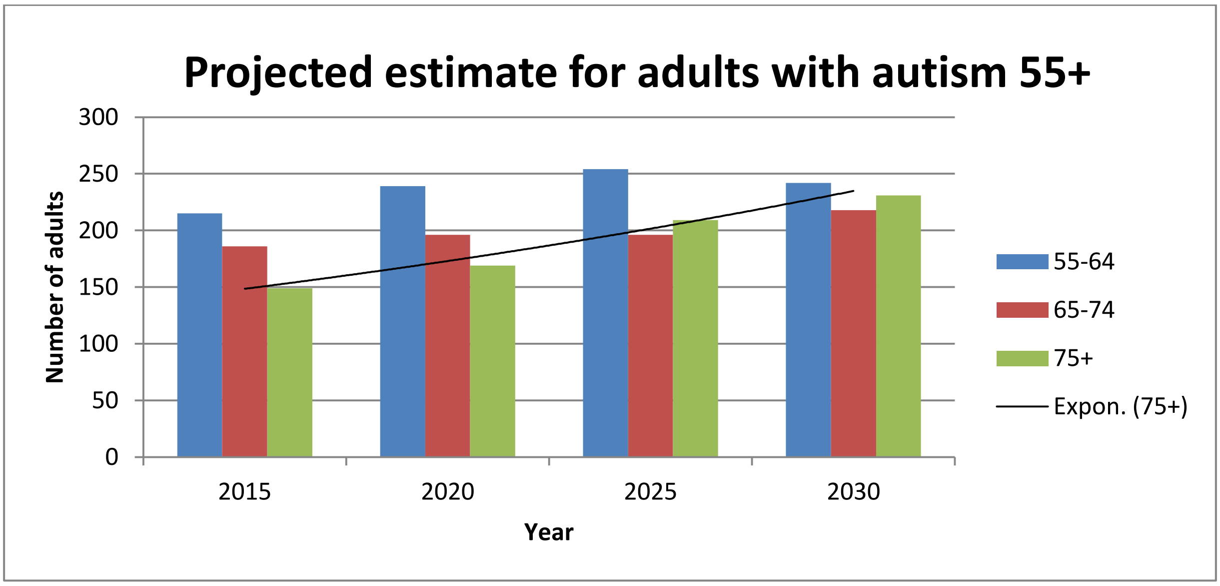
Adult population (18+)

General population estimates[31] show an increase in line with overall population. Data is projected using a 1% growth assumption.



POPPI/PANSI data, November 2016

As with the general population, people are living longer into old age. This means that the autism population is also aging.



POPPI/PANSI data, November 2016

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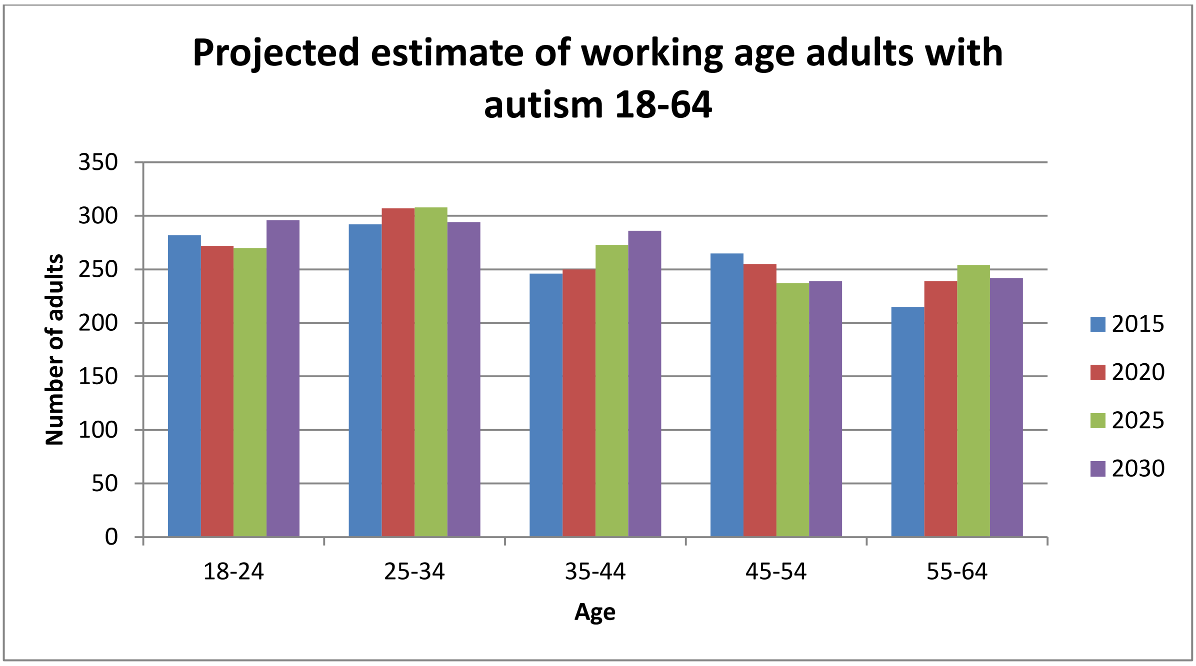
[31] Projecting Older People Population Information (POPPI) and Projecting Adult Needs Service Information (PANSI)

Projections indicate, working age adults with autism will also increase, especially amongst the 18-24 year olds. If the trend of increased diagnosis in childhood continues this will increase the number of working age adults with autism.



POPPI/PANSI data, November 2016

Residents Views

Residents views with regards to living in York with autism or supporting someone with autism are very important.

In March 2016 an engagement event took place in relation to writing the first All Age Autism Strategy for York. Over 100 people attended and the themes discussed at this event have been the bedrock of the Strategy and the work which has unfolded from it.

- ⇨ Diagnostic support
- ⇨ Inclusive communities
- ⇨ Transitions
- ⇨ Training / education
- ⇨ Employment
- ⇨ Parent / Carer support

Views from residents were also sought through a survey which was available on line, by post or by email.

Invitations were also sent out for people to participate in a focus group. This group had representation of an adult with autism, parent/carers and professionals who work both with people with autism and their families.

The All Age Autism Strategy Sub-Group ‘Inclusive Communities’ has also recently undertaken a survey with regards to inclusive venues and feedback from this is also incorporated.

All Age Autism Joint Strategic Needs Assessment Survey

This survey was undertaken during November and closed on 16th December 2016. In total there were 39 responses from individuals with autism, parent/carers and professionals.

Questions and key points were:

- Diagnosis
    - There were no issues with the diagnostic process.
    - The waiting time for an assessment was too long

  “Parents repeatedly report frustration with the wait for an assessment.”

  “The waiting times were quite lengthy, however once the diagnostic process started the diagnosis was pretty quick.”

- Local groups and information

    - Just under 50% of those who responded were not confident that they could find information regarding local groups.
    - Of those that responded. Over 60% said there was not a local group which would fit their needs.

"There are a few groups but I think we need a wider range and maybe one for girls, or groups around specific interests eg cookery group, computer group eg coding, train interest. Also need a support to access groups by someone other than parents eg a befriender to take some young people to a group."

"Sometimes there are suitable groups but not always."

"I have attended one of these groups and did not find people who were interested in the same things as me."

- Mental Health
    - Over 40% of those that responded have not been able to get support from Mental Health services when they needed it.
    - Of those that have accessed Mental Health services over 60% considered the support helpful.

- Other areas of importance (Inclusive communities, support through change, training/education, employment, parent/carer support and access to support / information.
    - The majority of respondents considered all these areas of high importance.

- What information would you find useful – themes in these responses were:
    - Information,
    - Practical strategies for managing behaviours,
    - More links with employment

"It would be useful to have a service that has the skills and knowledge to work with adults with a dual diagnosis – ie autism and complex health needs as going to two different services that can't communicate with each other and often provide conflicting information is helpful."

"I would like to know what is available when the young person turns 18 and he is legally an adult if has not been able to access education due to his condition. I have not been able to find out what the next step to get help for him."

"Comprehensive list of autism services in one leaflet or website that covers mental health support to autism friendly public places likes shops."

"The mistake most people make when dealing with autistics is they "sign post" us rather than "taking us" or "helping us". This distinction is crucial. There is

often information but no one to help or to guide us through it or help us in our lives."

- Other comments – themes in these responses were:
    - Information
    - Parent training courses at different levels
    - Mental health support to be improved
    - More employment support

"We need more Parent training courses at different levels eg pre- 5, school age and teenage to meet the needs of families with CYP with autism. faster referral routes so CYP are not waiting for long periods of time for assessments, ongoing awareness training for communities, the public to enable CYP with autism to feel welcome in their communities. More accessible mental health services with quick easy access, and more training for professionals in mental health and autism, so early intervention can be offered."

"There is a need for a 'drop in' service where people can go for low level advice/ support to help them through a mini 'crisis/ change. There are some people on the Autism Spectrum who currently use the Mainstay drop in for this."

"An information pack with all the above info after diagnosis would be most useful instead of learning as you go on in a hotchpotch manner"

Focus Group

A Focus Group took place in January 2017 and included representation of an adult with autism, parent/carers and professionals who work both with people with autism and their families/carers.

The discussions involved experiences of services and key points were:

- Peoples experiences of waiting for a diagnosis varied but on the whole waiting for a diagnosis took a long time but the actual diagnostic process was fine.
- There have been poor experiences of Lime trees with individuals having to see multiple staff and having to repeat information previously given.
- There has been little support / advice on the effects / implications of a diagnosis for the individual.
- There has been good experience of York Hospital with staff understanding and adjusting practises for those with autism.
- There have been variable experiences of transition from primary to secondary schools and support within secondary seeming to be dependent on the individual teachers understanding of autism.
    - A neurotypical view of a 'good social life' is not always relevant – there should be an acceptance of different lifestyles and different ways / methods of socialising.

Suggestions for a better experience:

- An integrated approach between Health and Social Care.
- Consistency of professionals working with the person / family and where there are changes to be informed in advance. Alongside a robust handover between professionals so the person / family does not have to repeat themselves.
- Consider environments and sensory implications, CYC offices and Lime Trees were given as an example of a poor sensory experience.
- Consistency of procedures and pathways.

Funding for initiatives, broad autism awareness training programmes and support was seen as a barrier. However being creative and trying to do things differently was also seen as a way of making a positive difference.

Inclusive Communities Survey results

As part of the work the Inclusive Communities sub-group are doing a ‘Survey Monkey’ was sent out with regards to accessible venues and public places. A 152 people responded to this survey and some really interesting and useful information was gathered. This has been shared with the organisations who have been on the ‘Train the Trainer’ courses commissioned for public venues / spaces in York.

Key points raised were:

- Staff who are autism aware and are approachable – 89% of respondents said this would be helpful.
- A ‘safe’ / quiet space
- Clear signage showing exits etc.
- A good / accessible website
- An autism friendly guide which tells individuals what to expect (eg sudden noises, smells etc.)
- Autism friendly openings.

Unmet need and information gaps

National and international evidence suggests that people with autism can have increased mental health issues, such as anxiety, as opposed to the general population. If timely support and interventions are readily available this would lead to a decrease in longer term mental health issues. The full use of mental health services by people with autism is not well documented.

There are significant issues in recording of information with regards to people with autism and there are significant gaps in robust data and information which is needed to inform future policy and direction.

Recommendations for consideration

1	Review diagnostic pathways and waiting lists
2	Improve the quality of primary care data including the improvement of recording those with autism.
3	Review uptake of Health and Social Care autism training within York.
4	Review pre and post diagnostic advice, support and information.
5	Ensure Health and Social Services work with people who use their services in a way which looks at peoples strengths and the capacity of the community.
6	Engage with mental health services to work towards timely and appropriate access to services for people with autism.
7	Increase public awareness in the community and work with mainstream services and employers to ensure they are as inclusive as possible.
8	Increase autism awareness across the City.
9	Create a specialist training package for employers, police and others in the criminal justice system.
10	Consult and engage with people with autism, and their families and carers, to understand their particular needs and experiences.
11	Scope information available and gaps and how to make accessible and keep up to date.
12	Aging well with autism – scope information available on those who are aging with autism.

Key Challenges

- Achieving the recommendations without any new investment.
- Development of sufficient local expertise for the needs of the population.

CITY OF YORK COUNCIL

Health and Wellbeing Board 8 March 2017

Report of the Director of Public Health

Monitoring the Performance of the Joint Health & Wellbeing Strategy

Summary

1. This report sets out options by which the Health & Wellbeing Board (HWBB) can maintain oversight of progress and performance against York's Joint Health and Wellbeing Strategy 2017-2022 (JHWBS).

2. The Health and Wellbeing Board are asked to consider the resources required to deliver the different formats and breadth of performance data.

Background

3. At its meeting on 9th March 2016, the HWBB expressed an intention to strengthen the way it exercises its oversight and performance monitoring responsibilities.

4. The Health and Wellbeing Board currently receives reports on the performance of a suite of 22 performance measures, which are matched against the previous high level priorities of the Board and its previous Joint Health and Wellbeing Strategy. To achieve the Board's new aims, it is necessary to review these measures and processes in light of the newly created Joint Health and Wellbeing Strategy 2017-2022.

Principles of any Proposed Framework

5. An effective performance management framework (PMF) helps ensure that the work of the Board stays relevant and reflects emerging concerns of local people, communities of interest and partner agencies.

6. Effective performance reporting demonstrates and communicates how the Health and Wellbeing Board is making things happen, not

just through traditional interventions but also through changing thinking, expectations and behaviours.

7. An effective PMF creates an holistic view of performance to evidence not just what has been achieved but also what the experience felt like for local people and communities.

8. An effective PMF should establish a mechanism by which the Health and Wellbeing Board can maintain oversight of progress and performance against its priorities and principle statutory duties.

Options

9. The following options set out what a Performance Framework might look like. They have been categorised as:

   a. Gold Standard;

   b. Silver Standard; and

   c. Bronze Standard

10. The categories are based upon the breadth and type of data and analysis that might be required; the level of challenge and evaluation of processes and working arrangements and ongoing monitoring of risks and activity.

<u>Option 1: Gold Standard</u>

11. A Gold standard performance framework comprises of four elements:

   a. **Quantitative Data and Analysis** - the bringing together of quantitative multi-agency data; usually through a dashboard of Specific Measurable Achievable Realistic and Time-bound (SMART) measures which communicate progress towards the outcomes and targets in the JHWBS.

   b. **Qualitative Feedback** - reports that collate views/ feedback from customers, patients, carers, families, and staff to understand how arrangements are working and delivering the outcomes people want and making a difference. This may include information from peer reviews or external audits on the quality or efficacy of the services or solutions in place.

c. **Partnership Process Evaluation** - a method for identifying the quality of joint working arrangements to assure that partners are working effectively together towards integration and a person centred approach.

d. **Monitoring of Risks and Actions** – a regular report of activity by partner organisations in order to understand how the partnership is progressing against its commitments.

12. A Gold standard performance framework would look to collect, share, learn and challenge from a range of qualitative and quantitative data, findings from reports and service inspections, responses to surveys, feedback and complaints, risks issues and lessons learned.

13. Reports would be brought back to the Health and Wellbeing Board on a regular basis highlighting performance trends, exceptions and learning for each of the Joint Health and Wellbeing Strategy themes complete with analysis and recommendations for the HWBB.

14. The characteristic of the Gold Standard which differentiates it from the Silver Standard is that the PMF would actively seek to increase the breadth of the data available to the HWBB.

<u>Option 2: Silver Standard</u>

15. A Silver standard performance framework comprises of two main elements:

    a. **Quantitative Data and Analysis** - the bringing together of quantitative SMART multi-agency data which communicates progress towards the outcomes and targets in the JHWBS.

    b. **Qualitative Feedback and Analysis** - reports that collate views/ feedback from customers, patients, carers, families, and staff to understand how arrangements are working and delivering the outcomes people want and making a difference. This may include information from peer reviews or external audits on the quality or efficacy of the services or solutions in place.

16. The reports would be brought back to the Health and Wellbeing Board on a regular basis, would contain analysis of data highlighting analysis of performance trends and exceptions based upon the data.

17. The characteristics of the Silver Standard which differentiate it from the Gold Standard is that the PMF would utilise only existing data and not actively seek to increase the breadth of the data available to the HWBB. It would not seek to monitor partnership activity by theme.

18. Both the Gold and Silver standard options would seek to utilise info-graphics to create an eye catching, shareable and easily digestible view of the data so that professionals and the public might understand the performance or issues identified in the analysis. An example of info-graphics of this type to show variance in life expectancy by ward, customer experience of place and feedback from surveys from Coventry Council is shown in **Appendix 2** of this report.

<u>Option 3: Bronze Standard</u>

19. A Bronze standard performance framework comprises of two main elements:

    a. **Quantitative Data** - the bringing together of existing quantitative SMART data which communicates progress towards the outcomes and targets in the JHWBS.

    b. **Qualitative Data** – the bringing together of any existing qualitative data such as surveys in a dashboard view from customers, patients, carers, families, and staff.

20. The characteristics of the Bronze Standard which differentiates it from the Silver Standard is that the PMF would utilise only existing data and return the outcomes of this data with no detailed analysis or recommendations. An example of this Dashboard is provided in **Appendix 1**.

Analysis

21. Dependant on the complexity of the framework the Board would like there may or may not be a requirement for additional resource to collate and analyse and present this data in a manner which is able to be understood by the Board, its partners and the public.

22. An enhanced PMF (gold or silver standard) would need additional resource likely to be the equivalent of a Grade 7 post in the Council.

It is suggested that any responsibilities for this work sit within the Council's Business Intelligence Hub as this would allow for the connection into existing performance frameworks; existing data and technical knowledge; resilience on staffing; and the embedding and streamlining of any created data model.

23. The potential costs of the options above are shown in the table below:

Standard	Resource	Cost
Gold	- 1x Grade 7 FTE	£22696
Silver	- 0.5 X Grade 7 FTE	£11348
Bronze	- No Additional resource	£0

Strategic/Operational Plans

24. Any changes to the performance management framework could have implications for the arrangements in place in each of the partner organisations.

Implications

25. **Financial** - these are detailed in the body of the report.

26. There are no other known implications associated with the recommendations in this report.

Risk Management

27. The strengthening of the performance management framework for the Health and Wellbeing Board will assist in identifying and managing risks across the whole health and social care system.

Recommendations

28. The Health and Wellbeing Board are asked to consider the different options for monitoring progress against the Joint Health and Wellbeing Strategy and give direction as to their preferred way forward.

Reason: To ensure the most appropriate PMF is put in place, within available resources, to monitor the progress against the Joint Health and Wellbeing Strategy.

Contact Details

Author:	**Chief Officer Responsible for the report:**
Mike Richardson Strategic Support Manager Adults & Public Health City of York Council 01904 554578	Sharon Stoltz Director of Public Health **Report Approved** ☑ **Date** 24.02.2017

Wards Affected: **All** ☑

For further information please contact the author of the report

Annexes / Appendices
Appendix 1: Existing Dashboard (KPI Machine)
Appendix 2: Example Info graphics (Coventry City).

Glossary

HWBB – Health and Wellbeing Board
JHWBS – Joint Health and Wellbeing Strategy
PMF – Performance Management Framework
SMART - Specific Measurable Achievable Realistic and Time-bound

Health and Wellbeing Board 2016/2017

SAMPLE DATA DO NOT USE - SAMPLE DATA - DO NOT USE

				Previous Years			2016/2017						
			Collection Frequency	2013/14	2014/15	2015/16	Quarter 1	Quarter 2	Quarter 3	Quarter 4	Target	Polarity	DoT
Mental Health and Wellbeing	HW1	Take-up of talking therapies in the city	Quarterly	100	100	100	10	10	10	-	100	Up is Good	◀▶ Neutral
	HW2	Rates of dementia diagnosis within primary care	Quarterly	100	100	100	-	-	-	-	-	Up is Good	◀▶ Neutral
	HW3	Rates of premature deaths among people with severe mental illness	Quarterly	100	100	100	17.88	18.27	18.21	-	11.00	Up is Bad	◀▶ Neutral
	HW4	Number of people admitted to hospital for self-harm	Quarterly	100	100	100	-	-	-	-	-	Up is Bad	◀▶ Neutral
	HW5	Percentage of people & families who feel well supported through a crisis and afterwards	Quarterly	100	100	100	-	-	-	-	-	Up is Good	◀▶ Neutral
Starting and Growing Well	HW6	Percentage of mothers in York who are breastfeeding	Quarterly	100	100	100	10	10	10	-	100	Up is Good	◀▶ Neutral
	HW7	Timeliness of visits and reviews in the first year of life	Quarterly	100	100	100	-	-	-	-	-	Up is Good	◀▶ Neutral
	HW8	Obesity levels between different wards in York	Quarterly	100	100	100	17.88	18.27	18.21	-	11.00	Up is Bad	◀▶ Neutral
	HW9	Rate of Hospital admissions for Children with dental cavities	Quarterly	100	100	100	-	-	-	-	-	Up is Bad	◀▶ Neutral
	HW10	Rate of school “readiness” for the most vulnerable groups	Quarterly	100	100	100	-	-	-	-	-	Up is Good	◀▶ Neutral
	HW11	Proportion of young people in York tell us they feel safe, happy and able to cope with things	Quarterly	100	100	100	1371.40	-	-	-	-	Up is Good	◀▶ Neutral
Living and Working Well	HW12	Attendance rates of screening programmes	Quarterly	100	100	100	10	10	10	-	100	Up is Good	◀▶ Neutral
	HW13	Rate of adults classed as overweight or obese	Quarterly	100	100	100	-	-	-	-	-	Up is Bad	◀▶ Neutral
	HW14	Rate of admissions involving an alcohol-related primary diagnosis or an alcohol-related external cause	Quarterly	100	100	100	17.88	18.27	18.21	-	11.00	Up is Bad	◀▶ Neutral
	HW15	Inequality Gap (Richest to Poorest Wards)	Quarterly	100	100	100	-	-	-	-	-	Up is Bad	◀▶ Neutral

Health and Wellbeing Board 2016/2017

SAMPLE DATA DO NOT USE - SAMPLE DATA - DO NOT USE

				Previous Years			2016/2017						
			Collection Frequency	2013/14	2014/15	2015/16	Quarter 1	Quarter 2	Quarter 3	Quarter 4	Target	Polarity	DoT
	HW16	Rates of vulnerable people who tell us they are happy with their health and wellbeing	Quarterly	100	100	100	-	-	-	-	-	Up is Good	◀▶ Neutral
Aging Well	HW18	Rate of older people telling us they have as much social contact as they would like	Quarterly	100	100	100	10	10	10	-	100	Up is Good	◀▶ Neutral
	HW19	Number of unnecessary admissions to hospital for older people	Quarterly	100	100	100	-	-	-	-	-	Up is Bad	◀▶ Neutral
	HW20	Rates of delayed discharges from hospital beds	Quarterly	100	100	100	17.88	18.27	18.21	-	11.00	Up is Bad	◀▶ Neutral
	HW21	Rates of people still at home 91 days after reablement or rehabilitation	Quarterly	100	100	100	-	-	-	-	-	Up is Good	◀▶ Neutral
	HW22	Number of older people taking up volunteering opportunities	Quarterly	100	100	100	-	-	-	-	-	Up is Good	◀▶ Neutral
	HW23	Rates of older people tell us they are happy with the care they receive, and have done the groundwork to prepare for the end of life	Quarterly	100	100	100	1371.40	-	-	-	-	Up is Bad	◀▶ Neutral

Appendix 2: Example Infographics

Fig 1: A Bus journey through the City showing Life expectancy by ward

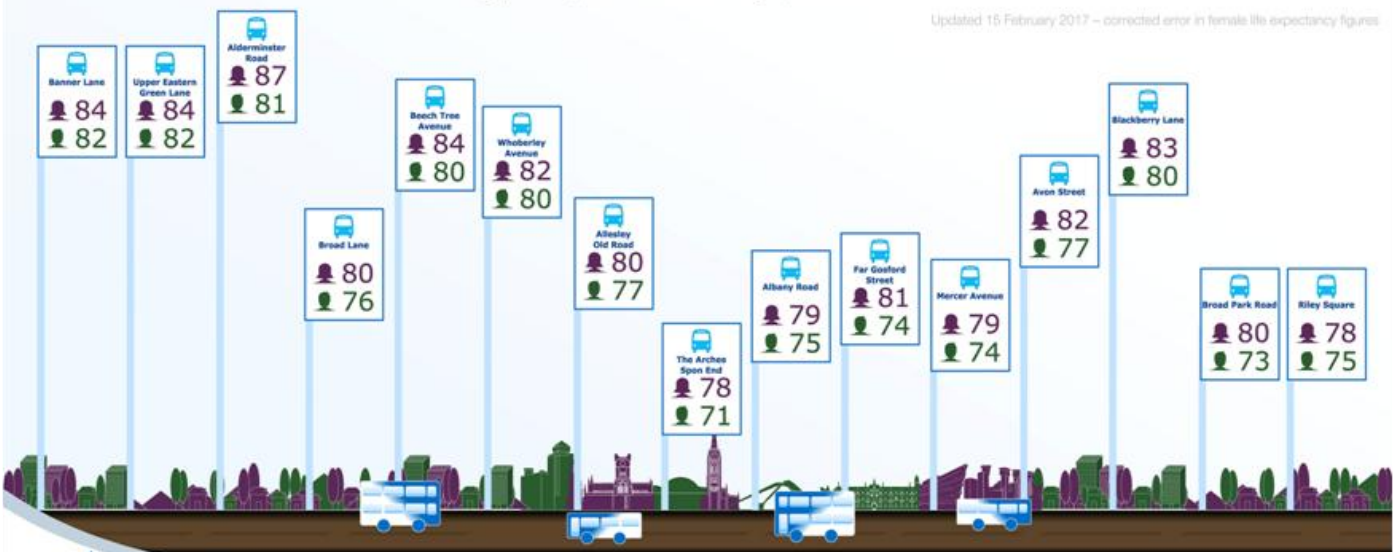
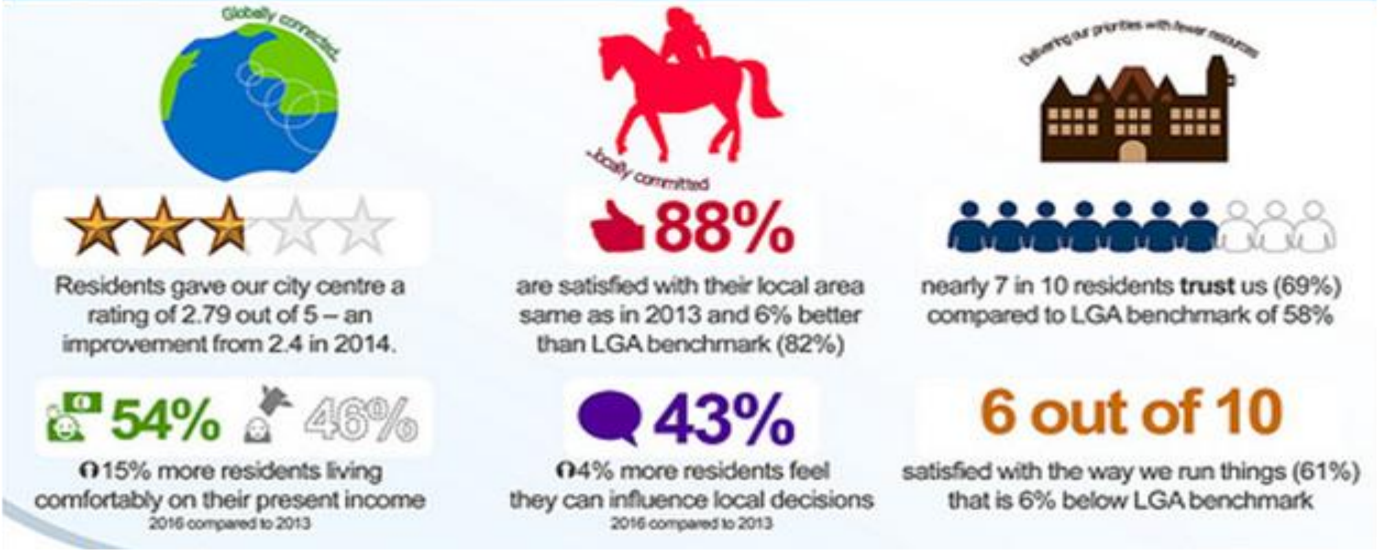


Fig 2: Word Clouds showing Positive and Negative views of localities.

Fig: 3 Representative Infographics of Qualitative Feedback from Survey.



Residents gave our city centre a rating of 2.79 out of 5 – an improvement from 2.4 in 2014.

are satisfied with their local area same as in 2013 and 6% better than LGA benchmark (82%)

nearly 7 in 10 residents **trust** us (69%) compared to LGA benchmark of 58%

15% more residents living comfortably on their present income
2016 compared to 2013

4% more residents feel they can influence local decisions
2016 compared to 2013

satisfied with the way we run things (61%) that is 6% below LGA benchmark

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CITY OF YORK COUNCIL

NHS Vale of York Clinical Commissioning Group

Health and Wellbeing Board 8 March 2017

Report of the Head of Planning & Assurance, NHS Vale of York Clinical Commissioning Group (CCG)

NHS Vale of York Clinical Commissioning Group's Operational Plan 2017/18 – 2018/19

Summary

1. The CCG two year Operational Plan is presented for information to the York Health & Wellbeing Board.

Background

2. NHS Vale of York Clinical Commissioning Group (CCG) is required to present its plans for the next two years in an Operational Plan to its assurance body NHS England (NHSE) for approval by 31st March 2017. The Operational Plan presented here is the plan submitted to NHSE on the 23rd December 2016. It remains unapproved by NHSE as there is a further requirement for resubmission of refreshed finance and activity modelling on the 27th February 2017.

3. This resubmission will incorporate any changes in activity and finance following contract agreement between the CCG and its main provider York Teaching Hospitals NHS Foundation Trust. However, there has been considerable review and discussion with NHSE in relation to the CCG Operational Plan and NHSE have confirmed they are happy to support the CCG in presenting the Operational Plan in public at the CCG Governing Body and local Health and Wellbeing Boards in March 2017.

Main/Key Issues to be Considered

4. The CCG Operational Plan represents how the CCG will address and deliver improvements in health and wellbeing, care and quality

and financial outcomes over the next two years. The plan is presented as a system view for the CCG planning and delivering proposed service improvements alongside its partners in the Vale of York locality. The context for the CCG Operational Plan is the financial deficit the local system must manage from 2017/18. The plan also responds to NHSE planning requirements nationally (Our Must Dos). The Operational Plan for the CCG also represents the Local Place Based Plan for the Vale of York within the Humber, Coast and Vale Sustainability and Transformation Plan (HCV STP).

5. The CCG is now working with its local authority, general practice, provider and voluntary sector partners to develop the programmes of work outlined in the Operational Plan for 2017/18. Members of our Health & Wellbeing Boards are involved in developing these programmes of work. These programmes will focus on driving improvements in the gaps in outcomes articulated in the plan around finance, health and well-being outcomes and care and quality of services for our local populations.

6. The programmes of work will support the CCG in agreeing its contract with York Teaching Hospital NHS Foundation Trust and form part of the CCG’s Local Place Plan as part of the Humber Coast and Vale STP.

Consultation

7. The CCG has engaged widely with all system partners in relation to developing its Operational Plan. Further to confirmation from NHSE on 10th February 2017 the CCG can now present the Operational Plan in public while it remains unapproved. The CCG is working to develop an Accountable Care System (ACS) with its local partners and the Operational Plan with its four emerging programmes of work and six priorities has provided a framework for the locality groups within this ACS to start prioritising work at a locality level. Members of all our local Health and Wellbeing Boards are on each of these ACS locality delivery groups.

Options

8. The York Health and Wellbeing Board is asked to receive the CCG Operational Plan on the 8th March as a draft plan and to direct any queries or requests for further information to the CCG whilst it awaits formal approval from NHSE in March 2017.

Analysis

9. This section is not applicable as there are no specific options for the Health and Wellbeing Board to consider.

Strategic/Operational Plans

10. These are outlined in the paragraphs above.

Implications

11. The CCG Operational Plan provides an overview of the financial, IT (Local Digital Roadmaps) and estates issues which the CCG and its partners in the Vale of York locality are looking to address and some of the emerging transformational programmes of work.

12. The CCG has just finalised an organisational restructure and is mobilising joint programmes of work with consideration of the CCG and partner resources required to deliver these programmes. There will be new governance requirements in relation to the reporting and joint decision-making in the ACS, but there are no changes to current organisational forms as the system partners come together to address system challenges.

13. As with all CCG plans there is an equality impact assessment and quality impact assessment on-going which will be finalised to augment the plan when full NHSE approval is given in March 2017.

Risk Management

14. The CCG is considering the full risk assessments for each work stream within each Programme for 2017/18 as part of its mobilisation. This will be incorporated into the CCG risk register if/ as required.

Recommendations

15. The Health and Wellbeing Board are asked to consider:

    i. The unapproved two year CCG Operational Plan

Reason: For information and engagement while awaiting full approval from NHSE.

Contact Details

Author: Caroline Alexander, Head of Planning & Assurance, NHS Vale of York CCG	**Chief Officer Responsible for the report:** Phil Mettam, Accountable Officer, NHS Vale of York CCG		
	Report Approved	☑	**Date** 20/02/17

Specialist Implications Officer(s)
Tracey Preece
Chief Finance Officer
Finance
NHS Vale of York CCG

Wards Affected: **All** ☑

For further information please contact the author of the report
Background Papers:

Annexes

Annex 1: CCG Operational Plan 2017/18-2018/19

Glossary

ACS – Accountable Care System
CCG – NHS Vale of York Clinical Commissioning Group
HCV STP- Humber, Coast and Vale Sustainability and Transformation Plan
NHS – National Health Service
NHSE – NHS England

Operational Plan 2017-19

for the Vale of York locality

Commissioning as part of the Humber, Coast and Vale Sustainability and Transformation Plan

Final Submitted on: 23.12.16

Update on 22/2/17: the CCG Operational Plan 2017/18 -2018/19 remains unapproved by NHSE until after the final submission of finance and activity plans on the 27/2/17, but is available for presentation to public at Health & Wellbeing Boards and CCG Governing Body.

NHS
Vale of York
Clinical Commissioning Group

Foreword

Phil Mettam, Accountable Officer

Welcome to our Operational Plan. It is an outline of how we propose to improve the Vale of York Health and care system over the next two years.
The CCG is moving to a new phase with collaboration being the underlying principle, transparency and engagement key values.
We look forward to working with partners to help us deliver services that local people deserve whilst recognising the limitations of our fixed financial allocation when compared to the choices and decisions being made by our patients and clinicians.

Organisational Fitness For Purpose

- Our Improvement Plan is the Governing Body response to Directions. It addresses five challenges these are capability, capacity, leadership, governance and the financials.
- We are also delivering our Improvement Plan and transformation programmes within our wider HCV STP system and emerging local Accountable Care System (ACS) and this is pivotal in how we are looking at commissioning for outcomes through new lenses
- We are taking a fundamentally different approach to the deployment of our allocation so it meets population need at a local level
- There is a focus on outcomes and embedding these in frameworks and models for transformation and transacting in a consistent way
- We can only fulfil our ambition for improving health and reducing inequalities if we can optimise the way resources are used

System and Partnership working – we are:

- Unlocking the system and enabling all partners – population and place always taking precedent over organisations
- Galvanising partners to come together as equals and build trusting, respectful and cohesive alliances based on common gain
- Taking our population (they are our patients, our workforce, our carers and their elected members) with us as equal partners
- Developing robust governance structures which support and formalise joint decision-making and accountability for delivery at organisation, local place and system-wide levels
- Doing things once – analysis, planning, making decisions, delivery, contracting
- Making decisions quickly, effectively and using gateways & an emerging governance framework to make sure we stick to them
- Sharing the leadership for delivering
- Understanding the resources, leverage and ‘cover’ required to truly transform and deliver – from partners, from NHSE and NHSI, from the HCVSTP partners and STP funds and sharing our scarce resource
- Efficiency through streamlining (back office, estates, technology)
- Aligning the local place with the wider system – consistent narrative and one set of programmes and contracts for achieving transformed services

Leadership & Corporate Priorities – we want to be:

- While place supersedes organisation, our CCG needs to be fit for purpose to come out of Legal Directions
- Strong, proactive and focused on delivering improvement at pace and first in the system when we need to go fast
- Strategic and ambitious – while rigorous in delivering performance and transformation day in day out
- Focus on new ways of doing things – CCG to lead in the HCVSTP for priority areas where it will deliver the improvement plan (e.g. development and use of new funding and contracting mechanisms)
- Clinically-led, informed and committed community of members
- Collaborative in all we do and building trust & respect
- Resilient and building resilience in our teams and services

Contents

Our Triple Aim: addressing our 3 gaps

We need to ensure our patients gain the most benefit from the health care interventions they receive and we support people to take responsibility for their own health – **there needs to be a fundamental shift in the way local people access care**.

Our **financial gap (£24.1m)** provides the framework for targeting our resources in a completely new way to drive improvement in all our outcomes and achieve Value for Money in every York £ spent on care.

Our Triple Aim: addressing our Three Gaps

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GAP 1: Health & Wellbeing Outcomes

- Smoking, alcohol and obesity rates are higher than average – CVD and stroke outcomes are poor
- Cancer is the leading cause of death in U75s but diagnosis rates are lower than national average
- Mental health – 14% of people aged 16-74 yrs have a mental health disorder

Opportunities to improve how we address:

1. people with complex care needs who attend hospitals multiple times each year
2. prevention of and self-care for people
3. reduce inequalities through changing the way that CCG resources are currently used

GAP 2: Care & Quality Outcomes

- Many people who are in our hospital beds do not need to be there
- Many people can't see their GP when they need to do so to go to A&E and out of hours services 27% of people seen by GPs could have their issue resolved in another way
- Significant waiting times to access some of our services
- Not consistently meeting our Constitutional targets in IAPT, RTT, A&E 4 hour waits, CAMHS and dementia
- Our estate is not fit for purpose or efficiently utilised – this hinders our ability to deliver integrated services in the community and to strengthen primary care and patient access to services 7 days a week
- There are increasing workforce pressures in the healthcare and domiciliary care

GAP 3: Financial Gap

- There is a significant local deficit and unsustainable finances across both our CCG and the HCV STP
- Locally there is a financial deficit forecast of £24.1m in 16/17 and £45.5m in 17/18
- We are currently delivering an Improvement Plan to address this financial gap and must achieve the challenging efficiency targets we have agreed with NHS England

Our operational plan focuses on:

- delivery of this financial improvement in the short-term,
- our programmes for transforming the system in the longer-term to provide the platform for delivering more efficient and integrated services and financial sustainability by 2020/21

Our Population Needs

We are planning in a system based on the needs of our population in each locality within the Vale of York.

The system is complex and aligning planning with all our partners is challenging. **A focus on population and 'place'** allows us to plan together, challenge where things don't work for patients and move away from some of the limitations of working in one organisation.

Our Vale of York system: complexity and boundaries

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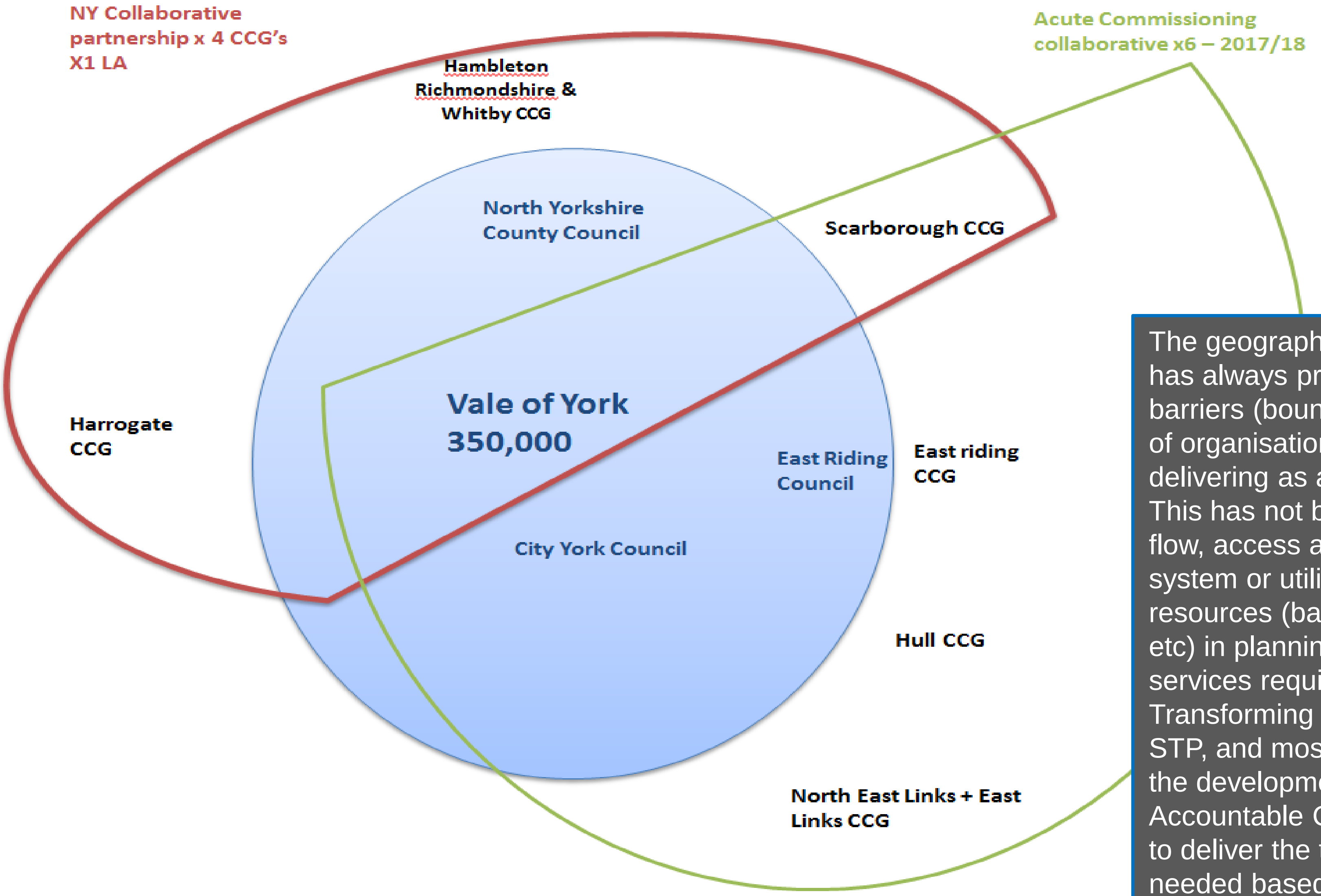

NY Collaborative partnership x 4 CCG's X1 LA

Acute Commissioning collaborative x6 – 2017/18

Hambleton Richmondshire & Whitby CCG

North Yorkshire County Council

Scarborough CCG

Harrogate CCG

Vale of York 350,000

East Riding Council

East riding CCG

City York Council

Hull CCG

North East Links + East Links CCG

The geography of the Vale of York has always provided significant barriers (boundaries and numbe of organisations) to planning an delivering as a system.
This has not benefited patient flow, access and navigation of the system or utilised the system resources (back office, estates etc) in planning and delivering the services required for patients.
Transforming as part of a wider STP, and most importantly driving the development of a local Accountable Care System (ACS) to deliver the transformation needed based on population need in each locality, is critical to manage this geography.

Our population: key health and well being features and outcomes

Overarching population needs

Population of 350,000 (including York 204,000, Selby 85,000 and main population centres include Tadcaster, Easingwold and Pocklington) Fluctuating population – York has two universities, 6.8m tourists pa Commissioning budget £435.3m in 2016/17	We have three local authority areas – City of York Council, East Riding of Yorkshire Council and North Yorkshire County Council (upper tier authority, with 7 district councils, 3 of which overlap with the CCG boundary Selby, part of Ryedale and Hambleton). There are 27 GP practices as at September 2016
People within York have good health overall with above national average life expectancy but with considerable variation in this life expectancy across our patch (up to 6.5 years in men and 5.5 yrs in women), closely linked to the seven areas ranked in the 20% most deprived in England.	Ageing population: Over-85s represent 5% of the population and 20% of non-elective hospital admissions and an increasing acuity of need and demand for healthcare and domiciliary care.
Cancer is the most significant cause of premature death (death under 75 years) in York but not significantly higher than the England average	High numbers of admissions for: myocardial infarctions, respiratory disease, stroke, stage 5 kidney diseases in people with diabetes, chroni ambulatory care sensitive conditions (808-v-778/ 100000 in similar CCG
Significantly higher rates of excess weight in Selby (70% compared to 65%) including children in reception and Year 6 being above the national average	Stroke mortality rates in those aged >75 years are significantly higher than the England average (708-v-608 per 100,000)
Binge drinking 28.8% adults compared to 20% nationally and rates of alcohol related cancers conditions is higher than the England average and regional average (207.8 –v- 176.5 / 100,000	Chronic obstructive pulmonary disease has been steadily rising to 1.4% in 2010/11 but remains below the England average of 1.57%
Smoking quit rates are significantly worse than in similar CCGs (480-v-818/ 100,000) and there is a need to address rates of smoking, particularly in people with mental health conditions who represent a disproportionately high number of people who smoke.	The CCG has poorer outcomes for CVD than other comparable CCGs. MSK spending and rates of major joint replacement surgery are significantly higher than for comparable CCGs and yet health gain per patient is lower.
There are 950 complex patients (3+ different conditions) resident in CCG who are admitted to hospital on average >6 times per year and 75% of them had an 3 A&E attendances per year. 44% of these are over 75 years. The most common conditions are circulatory, neurological, respiratory with co-morbidities in gastro-intestinal. CCG expenditure on these patients is 0.2% above the England 15% av.	Parity of esteem for people with mental health conditions through better physical disease management. is an area of need we need to focus on in order to reduce rates of death from cancer, heart disease, respiratory disease and diabetes in this population group.

Our Financial Context

We are planning to deliver **financial** recovery – there is no additional NHS funding allocation for the Vale of York in 2017/18 and 2018/19 and a forecast £24.1m deficit.

It is our responsibility to deliver the services patients most need within that allocation and for all partners to work together to drive out inefficiency, duplication and unwarranted variation in our system.

Financial context: Financial Recovery

BASELINE 2016/17: commissioning budget of £435.6m. The Vale of York CCG baseline of 2.1% is above the national target allocation but not greater than 5% and therefore viewed as reasonable. As such the CCG received minimum growth in 2016/17.

Allocations, albeit indicative for future years, suggest the CCG will remain over target and therefore can expect to receive minimum growth until 2020/21.

Expenditure on out of hospital care (voluntary sector, community, BCF schemes, winter pressures, system resilience schemes) compared with In hospital care: 15% (£40,575,000) compared to 85% (£228,649,000)


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Improvement Plan
in response to NHSE Legal Directions (issued 1 Sept 2016)
Detail pack
6 October 2016

The best health and wellbeing for everyone.

IMPROVEMENT PLAN TO 17/18: Current Financial Recovery Plan ("FRP") to deliver an in-year deficit of no more than £7m (£13.3m cumulative). The CCG currently forecasts to end 2016/17 with a £24.1m deficit (before further mitigations). Further mitigating actions totalling £1.1m have been identified but the CCG will need to generate a further £5.4m from development of pipeline ideas and system support proposals.

It also sets out an intention for 2017/18 to operate within the annual allocation.

Monthly refresh of financial recovery plan based on validation of agreed and further deliverable mitigations, pipeline QIPP ideas and system support schemes

Forecast outturn 2016/17	**(£m)**
Forecast deficit	(17.3)
Net unmitigated risks	(4.2)
Risk adjusted forecast deficit at M5	**(21.5)**
Update to risk since M5	(2.
Revised risk adjusted deficit	**(24.**
Removal of capital support assumption in m5	(1.
Potential further mitigations	1
Pipeline ideas and system support actions	5.4
Revised risk adjusted deficit	**(18.6)**
Potential capital support	1.0
Potential release of 1% non-recurrent headroom	4.3
Forecast outturn (after further mitigations)	**(13.3)**
Target to meet legal directions	(13.3)

MEDIUM-TERM FINANCIAL STRATEGY 17/18 ONWARDS: Development and agreement of MTFP and associated financial strategy – in development and to be finalised by 23/12/16.

Refreshed and augmented QIPP programme to deliver efficiencies required to stay within allocation development of activity modelling, funding arrangements and contracting options for out of hospital model. increasing contract grip and control and supporting the system wide reallocation of financial resources and risks and driving wider system planning.


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Vale of York Medium Term Financial Strategy

A new approach to commissioning
DRAFT

The best health and wellbeing for everyone.

Our Improvement Plan

We are working under **Legal Directions** with the support of NHS England.

Our operational planning and financial recovery are at the core of our CCG Improvement Plan as we transform internally as a CCG (‘organisation’) at the same time as leading system change alongside our partners (‘place’).

We are working **transparently and at pace** to deliver the improvements needed to come out of Legal Directions.

The CCG Improvement Plan: Five key steps 2016/17

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Clinical Commissioning Group

Stabilisation of finances

- Financial Recovery – Investment and Risk share 2017/18 and 2018/19
- Scoping new models of funding and contracting arrangements (Oct 16)
- Director to drive forward contracting reforms (Dec 16)
- Addressing ‘system opportunity cost’ in Out of Hospital Care

Headline our deliverables – key performance delivery

- Constitutional Delivery
- A&E Delivery and stabilisation
- Improved mental health performance

Clear priorities and purpose for the CCG

- End October - agree 18 month recovery programme setting out the organisational priorities
- Internal refocus of capacity and capability focussed on priorities Dec 16
- New Executive Team to strengthen CCG leadership and capability Dec 16

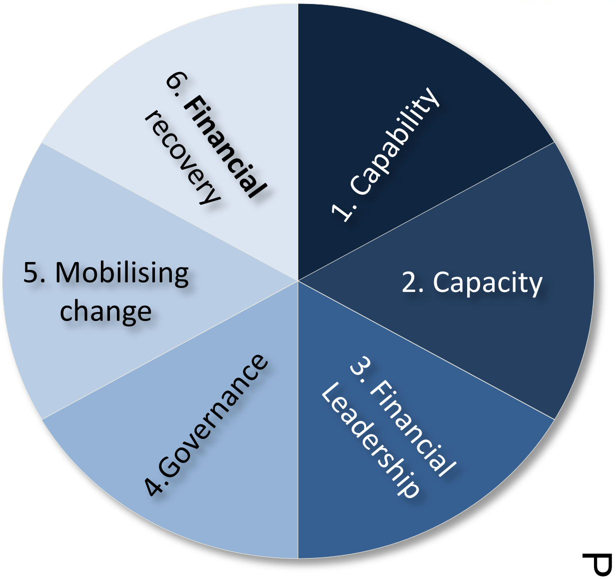
Building key relationships and joint commissioning opportunities

- Director for Joint Commissioning to drive CCG Commissioning arrangements
- Multiplicity of collaborative approaches - commissioning across specific geographies and population groups
- Risk share across CCGs on complex cases 17/18 – 18/19

Positioning the system for sustainability

- Progressive direction to Accountable Care Systems – Mar 17
- Regaining confidence and trust from the Council of Representatives
- Collaborative philosophy- engaging with stakeholders across the system and the local population to set the platform for the future

The CCG under Legal Directions: Improvement Plan



- The CCG understands the scale of the challenge and requirement to comply with the legal directions and has a greater understanding of the true underlying financial position to form the basis for immediate financial stabilisation through the Financial Recovery Plan and development of a robust medium-term financial strategy. The top priorities are:

- Develop strategic partnership working and building trust in local partners alongside strength in financial decision making

- Ensure that the capacity, capability and governance is strengthened in line with the Capability and Capacity Review of 28 January 2016 to deliver sustainable system wide improvement and provide effective commissioning and clinical leadership

- Focus on addressing its immediate challenges and leading a credible longer term programme of sustainable improvement, both internally and for the wider health economy

- Refocus the capacity in the organisation to deliver change at pace

- Develop local services solutions and strengthening support into general practice

- Additional lay support with a focus on finance to enhance scrutiny and challenge

- Continue to deliver against the NHS Constitution and national pledges

- Move to strategic commissioning across both the City of York and the North Yorkshire footprints:
  - New executives with clearly defined roles and responsibilities over: joint commissioning; transformation and delivery; system resources; and performance
  - Prioritising activities to support delivery of the plan
  - shared posts and functional convergence with other CCGs

- Strengthening partnerships to share capacity:
  - Formulation of clear and consistent priorities with partner organisations to reduce wasted time
  - Proactive engagement with the public, patients and key stakeholders through improved direct relations and communications

The CCG Improvement Plan: Progress

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	October – December 2016	January - March 2017
Stabilisation of finances	Strengthened financial decision making: ▪ Financial recovery plan in place (see M8 finance performance) ▪ Exec Director of Systems and Resources in place ▪ Contracting reform – Heads of Terms to manage contract and risks, negotiation & agreement – linked to emerging priorities and programmes of work across system (see Plan on Page and local place based plan)	1. Delivery of contract in line with Heads of Terms 2. Explore hybrid PbR opportunities 3. Further QIPP delivery 16/17 4. Further QIPP pipeline 17/18 development 5. Operationalise programmes in prim y care, unplanned care and planned care to support delivery of system o of hospital opportunities
Headline our deliverables – key performance delivery	▪ Improvement in cancer standards (31 day recovery) and local Trust Action Plans for RTT and cancer December 2016 ▪ Developed and refreshed Action Plans for IAPT, CAMHS and dementia utilising NHSE funding support ▪ Review of PCU commissioning support to ensure local grip on mental health performance ▪ Winter planning and assurance through A&E Delivery Board ▪ STP work on Right Care and clinical thresholds	1. Rapid mobilisation of provider and wider system recovery plans for cancer and RTT through establishment of planned care task & finish – evolve into ACS unplanned and planned care programmes 2. A&E Delivery Board plans with focus on streaming, hospital flow and discharge 3. Work with primary care through CoR to formulate and deliver the collective ‘ask’ to support management of growth in demand

The CCG Improvement Plan: Progress

NHS
Vale of York
Clinical Commissioning Group

	October – December 2016	January - March 2017
Clear priorities and purpose for the CCG	▪ Approved Improvement Plan for CCG in implementation ▪ Consultation on proposed future structure of CCG and new Exec team recruited to (capacity & capability) ▪ Revised and strengthened governance structure including: new Clinical Executive, Executive Committee, refreshed Primary care Committee ▪ Additional lay support with a focus on finance ▪ Refreshed GPFV plan, practice visits and work with CoR & LMC to understand local services solutions and strengthening support into general practice ▪ Clinical Summit for system and v successful	1. Prioritisation and strategic refresh in January 2017 based on system work and engagement 2. Link this to resourcing and shared resources across ACS and STP 3. Linking this to individuals' and teams' medium-term objectives in CCG 4. Linking this to comms & engagement – focus on **coproduction** with local populatio[illegible]s at locality level
Building key relationships and joint commissioning opportunities Positioning the system for sustainability	▪ Exec Director of Joint Commissioning appointed ▪ Emerging ACS (focus on population and place) and CCG leadership to driving this forward ▪ Develop strategic partnership working and building trust in local partners – primary care and CoR, STP, Local Authorities, MPs, DPHs – engage with ACS and Operational Plan ▪ Focused 'deepdive' on CHC, joint packages of care and complex care ▪ PCU as commissioning support review ▪ Development of collaborative commissioning intentions, acute contract and thresholds as STP	1. ACS Partnership Board to meet in Feb 2017 along with shadow locality boards. In delivery from April 2017. 2. Strengthening partnerships to share capacity: BI, PMO, back office, governance 3. Formulation of clear and consistent priorities with partner organisations and populations through locality boards and longer-term programmes of work

Our transformation to date

The work we and partners have delivered during years 1 and 2 of the Five Year Forward View have had a positive impact in our locality and for our patients.

This provides a **strong foundation** for the further system change now needed.

Transformation and success

The CCG has worked with its partners to deliver transformation in the local care system during the past two years which will provide a strong foundation to the system change now required. These have focused on:

- Demand management through RSS
- Resilience around urgent and emergency care to reduce avoidable admissions and A&E attendances
- Piloting the care hub model
- Addressing poor mental health estates and engagement around mental health strategy

Redesigned diabetes pathways to better support management of diabetes in the community and prevent hospital admission 1

Referral Support Service (RSS) 2

Health Navigator Proactive health coaching 3

Urgent Care Practitioners 4

Integrated Care: Pioneer for Care Hubs 5

Reprocurement of mental health services and associated estates modernisation in progress 6

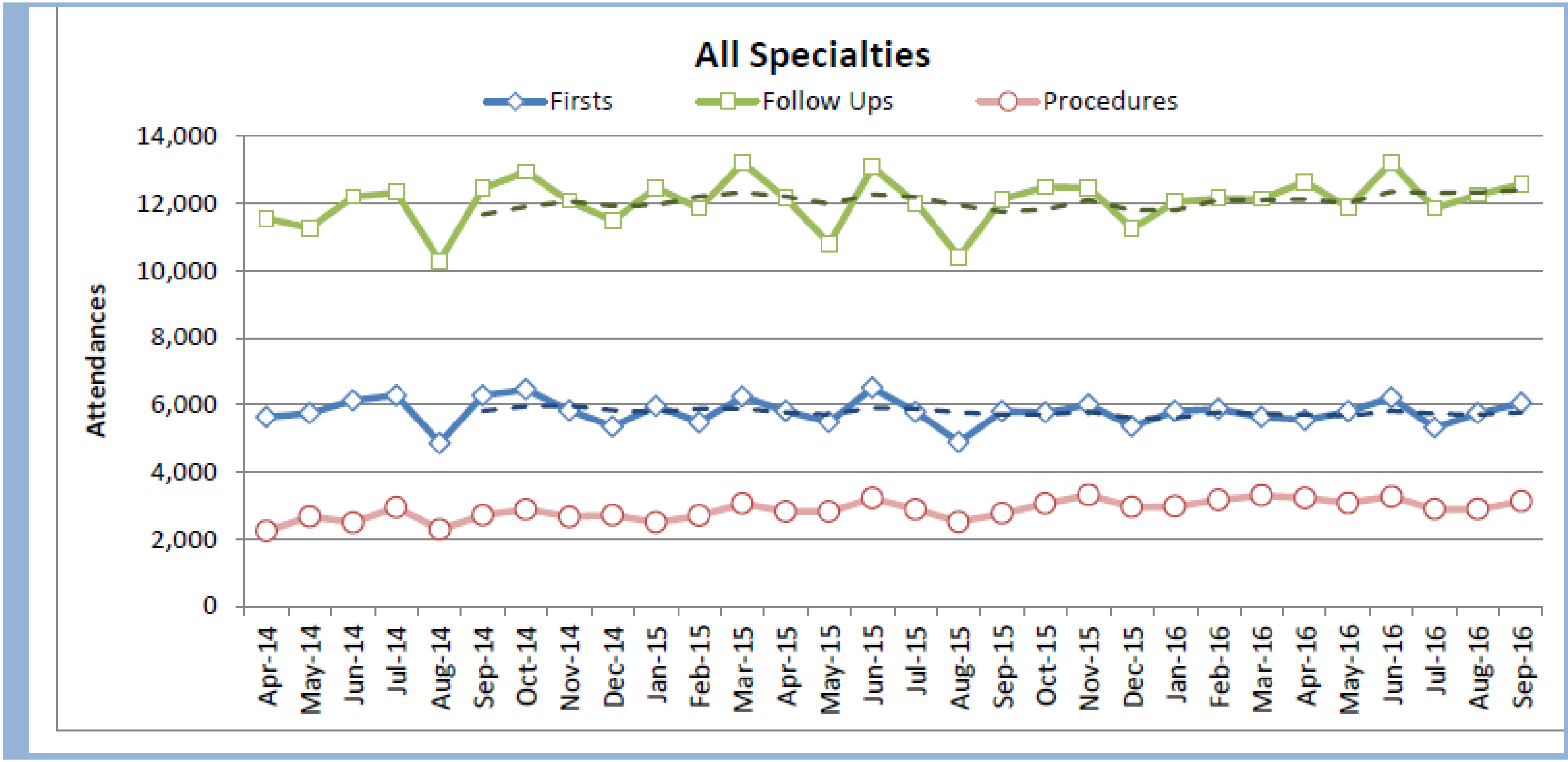
Implementation NICE approved guidance on 2 week wait pathways for the different types of cancer 7

Discover engagement programme for Mental health to inform future strategy 8

Prescribing – lowest per capita prescribing frequencies and costs in the region 9

Impact in the Locality: Managing Demographic Growth

Referral Support Service (RSS): managing demographic growth to keep outpatient activity stable



Impact in the Locality: Managing Demand on the System

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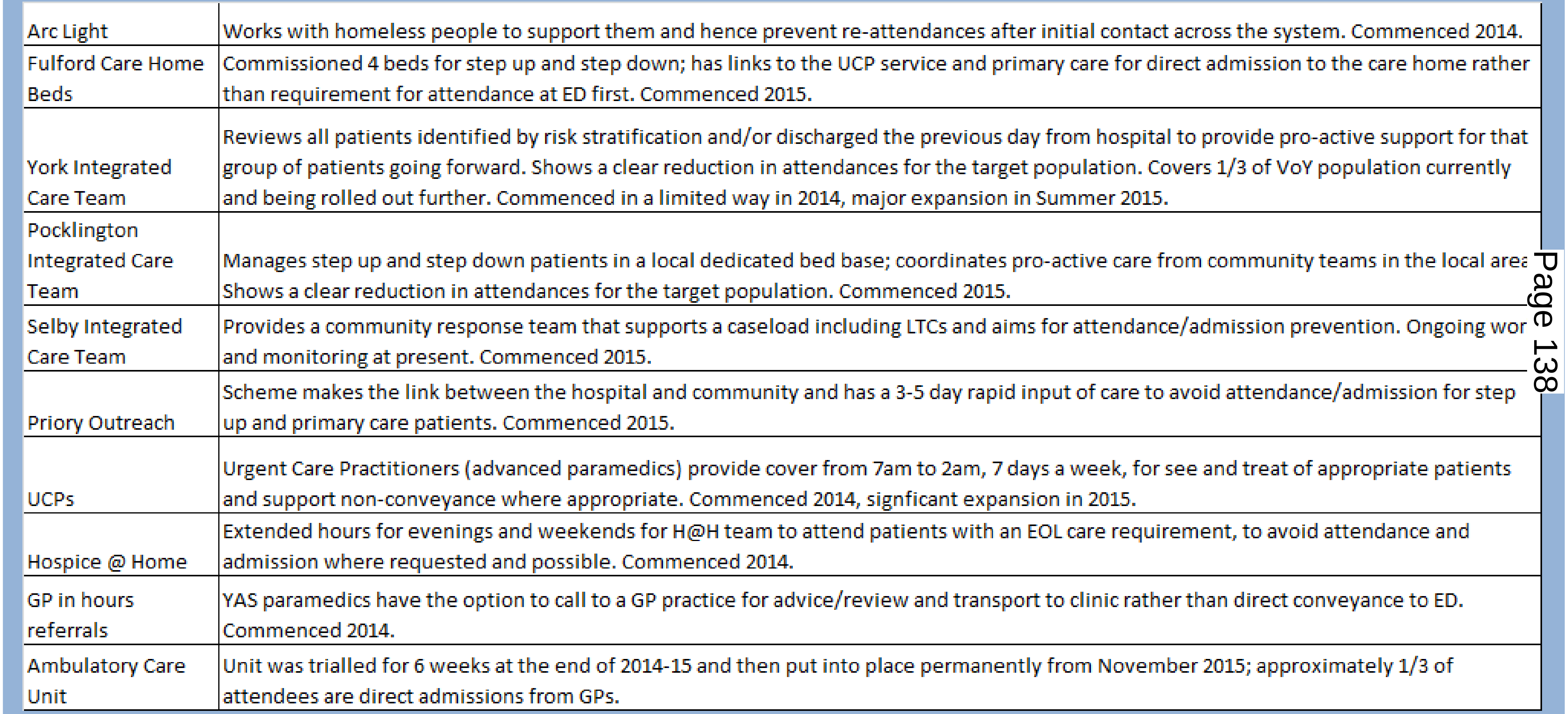
Improvement/ Transformation	Impact
Emergency Department (ED) Front Door schemes	ED attendances for the York Hospital went down 6.8% compared to 12 months previous (Nov 2016) against a rising population
Integration hubs: York Integrated Care Team (YICT) The YICT is in the process of being rolled out to other practices in the City of York during December 2016 and January 2017.	In Priory Medical Practices (part of the York Integrated Care Team) attendances are down 8.7%, admissions are static and excess bed days are down by 13.3%
OptimiseRx software	Supporting nearly £300,000 of efficiencies i prescribing being delivered through the medicines management team
Oral Nutritional Supplements (ONS) – VoY has led work to optimise nutritional care for patients and interventions through the formulary and using OptimiseRx in the past 18 months. Other CCGs have been in touch wanting to replicate our schemes - their ONS prescribing trends have remained high despite some ONS price reductions over the past year.	Quality benefits for patients by optimising their nutritional treatment to reverse/stabilise malnutrition. Downward trend in expenditure and achieving regular monthly ‘savings’ (approx £12,000 per month)
Dermatology indicative budgets in general practice Supported by further expansion of dermascopes into practices and impact on 2WW Cancer (skin)	YTD the CCG can evidence savings of £68,000 with £23,000 of this going to alliances

Impact in the Locality: Driving Integration in the Community

Integration

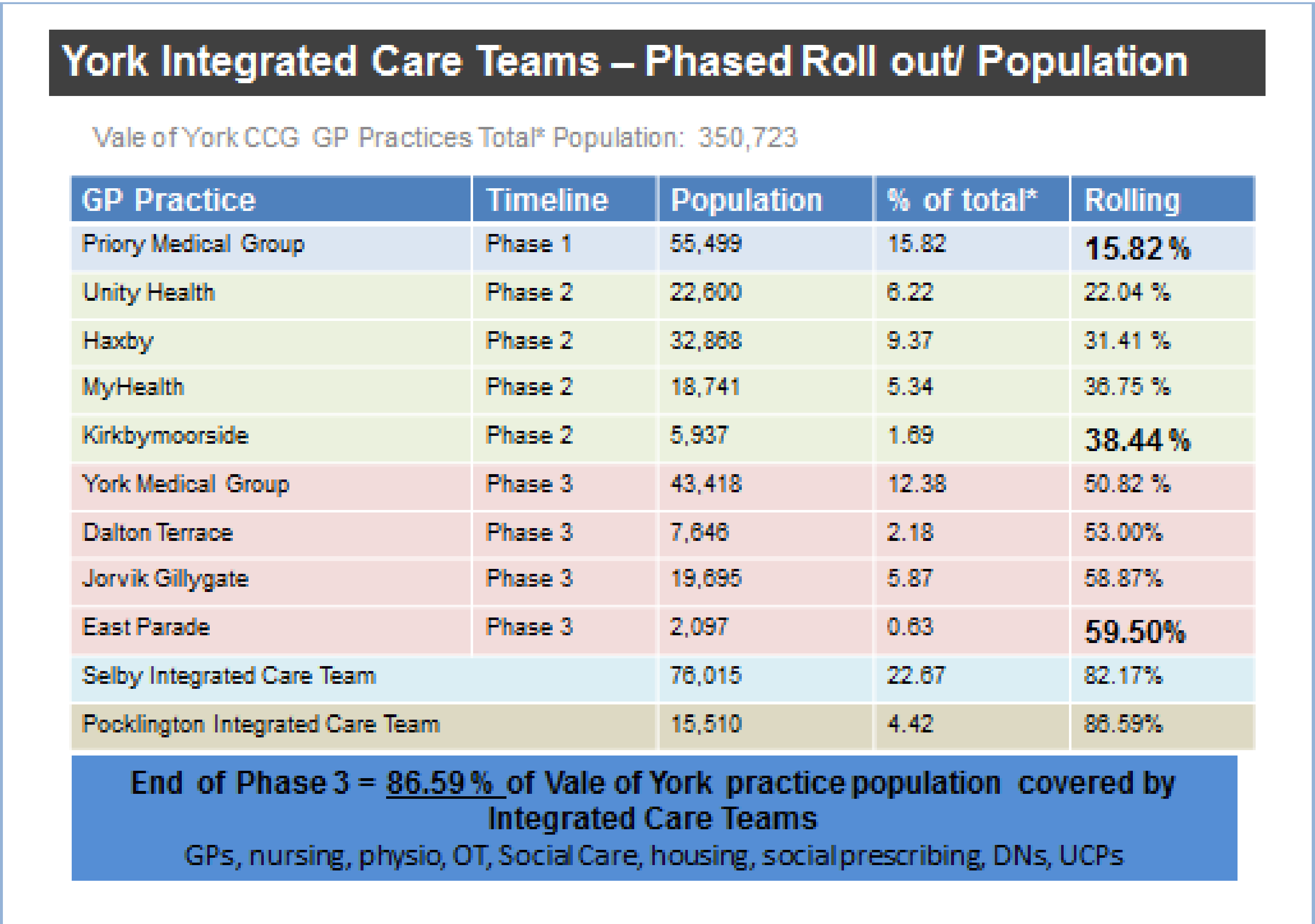


Arc Light	Works with homeless people to support them and hence prevent re-attendances after initial contact across the system. Commenced 2014.
Fulford Care Home Beds	Commissioned 4 beds for step up and step down; has links to the UCP service and primary care for direct admission to the care home rather than requirement for attendance at ED first. Commenced 2015.
York Integrated Care Team	Reviews all patients identified by risk stratification and/or discharged the previous day from hospital to provide pro-active support for that group of patients going forward. Shows a clear reduction in attendances for the target population. Covers 1/3 of VoY population currently and being rolled out further. Commenced in a limited way in 2014, major expansion in Summer 2015.
Pocklington Integrated Care Team	Manages step up and step down patients in a local dedicated bed base; coordinates pro-active care from community teams in the local area Shows a clear reduction in attendances for the target population. Commenced 2015.
Selby Integrated Care Team	Provides a community response team that supports a caseload including LTCs and aims for attendance/admission prevention. Ongoing wor and monitoring at present. Commenced 2015.
Priory Outreach	Scheme makes the link between the hospital and community and has a 3-5 day rapid input of care to avoid attendance/admission for step up and primary care patients. Commenced 2015.
UCPs	Urgent Care Practitioners (advanced paramedics) provide cover from 7am to 2am, 7 days a week, for see and treat of appropriate patients and support non-conveyance where appropriate. Commenced 2014, signficant expansion in 2015.
Hospice @ Home	Extended hours for evenings and weekends for H@H team to attend patients with an EOL care requirement, to avoid attendance and admission where requested and possible. Commenced 2014.
GP in hours referrals	YAS paramedics have the option to call to a GP practice for advice/review and transport to clinic rather than direct conveyance to ED. Commenced 2014.
Ambulatory Care Unit	Unit was trialled for 6 weeks at the end of 2014-15 and then put into place permanently from November 2015; approximately 1/3 of attendees are direct admissions from GPs.

Impact in the Locality: Driving Integration in the Community

NHS
Vale of York
Clinical Commissioning Group

Integration



York Integrated Care Teams – Phased Roll out/ Population

Vale of York CCG GP Practices Total* Population: 350,723

GP Practice	Timeline	Population	% of total*	Rolling
Priory Medical Group	Phase 1	55,499	15.82	**15.82 %**
Unity Health	Phase 2	22,600	6.22	22.04 %
Haxby	Phase 2	32,868	9.37	31.41 %
MyHealth	Phase 2	18,741	5.34	36.75 %
Kirkbymoorside	Phase 2	5,937	1.69	**38.44 %**
York Medical Group	Phase 3	43,418	12.38	50.82 %
Dalton Terrace	Phase 3	7,646	2.18	53.00%
Jorvik Gillygate	Phase 3	19,695	5.87	58.87%
East Parade	Phase 3	2,097	0.63	**59.50%**
Selby Integrated Care Team		76,015	22.67	82.17%
Pocklington Integrated Care Team		15,510	4.42	86.59%

End of Phase 3 = 86.59 % of Vale of York practice population covered by Integrated Care Teams

GPs, nursing, physio, OT, Social Care, housing, social prescribing, DNs, UCPs

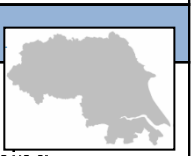
Our Plan on a Page

We have worked with our partners to capture our system and the **joint priorities for delivering care** for our population.

We want to provide a **common framework** for all partners to come to our emerging Accountable Care System and start planning how we transform locally.

This plan is not prescriptive or limiting; it aims to help us find commonality in the way we see and work in our system together **at this point in time**.

Operational Plan 2017-19 incorporating the Humber, Coast and Vale STP Vale of York loc

Vision	To create fully integrated care for all our communities and support the best possible health outcomes for all people	
Goals	Safe, resilient services working across 7 days that can deliver: • All NHS Constitution standards • A sustainable acute hospital delivery system • Out of hospital services joined up in a way so people only need to go to hospital when no other option is available • A financially sustainable system which provides VFM for every Vale of York £ spent on health and care • Access to good services for people with mental and physical health needs, especially those that are vulnerable	
Population Outcome and Prevention Priorities	Reducing LTCs prevalence – Smoking cessation, Obesity, alcohol, Frail elderly and vulnerable people including falls reduction Addressing isolation and quality of life – individual and rural Child health & Early Years – CAMHS, obesity (in utero maternity), SEN & LAC assessment Mental health access and early intervention – IAPT, dementia, smoking cessation, physical health & complex specialised services Holistic care for people with learning disabilities: physical health checks Cancer detection and diagnosis improvement	**Outcomes** **Improved patient outcomes:** • Morbidity reduction • Mortality reduction • Improved quality of life for patients **Acute activity maintained at sustainable levels:** • Reduce avoidable A&E attendances • Reduce avoidable emergency admissions • Reduce LOS and excess bed-days • Reduce outpatient attendances
Sustainability Priorities	1. Legal Directions - improvement plan and return to financial sustainability 2. Reducing demand on acute hospital care 3. Resilient urgent and emergency care networks working across in- and out of hospital care 4. Transformed primary and community care provision – fully integrated out of hospital care at or close to home 5. Transformed workforce across health and social care – Bands 1-4 and practitioner roles across health and care 6. Addressing unsustainable specialised commissioned services across the HCV and wider Y&H footprint (NHSE) 7. Fit for purpose estates and improved utilisation	
	Local 	**STP wide** 
STP Plans aligned with our 3 Health & Well Being Plans	1. Strengthened primary care – capacity and resilience, estates improvement, workforce, integration, specialisation 2. Self care, Empowerment & Prevention – education, information, navigation, decision-aids and clinical advice 3. Integrated out of hospital care and Accountable Care System (ACS) with all partners to support place-based services which target the most frail, complex and vulnerable 4. Transformed mental health and learning disability (LD) services including complex healthcare (CHC) and CAMHS improvements 5. Sustainable acute hospital – outpatients and pathway redesign (RightCare; cancer); shared diagnostics, back office and estates	<u>3 priority collaborative programmes:</u> 1. Strategic commissioning 2. Mental health and joint commissioning 3. In-hospital care and single acute contract <u>Through existing networks:</u> 1. Urgent care and networks 2. Cancer Alliances and diagnostics 3. Maternity strategy and clinical network 4. Specialised commissioning – neuro rehab/ Weight Mgt

Our Priorities and emerging Programmes

Our priorities focus on how we can drive **system outcomes** that address our triple aims.

Some of those priorities will be driven by our work internally as a CCG as a commissioner – strengthening primary care is our number one priority.

Everything else will require us to **work as a system** – in an Accountable Care System and as part of the Humber, Coast & Vale STP.

Our Six Priorities

FINANCIAL RECOVERY AND FINANCIAL SUSTAINABILITY

PRIORITY 1

Strengthening Primary Care

PRIORITY 2

Reducing Demand on the System

PRIORITY 3

Fully Integrated Out of Hospital (OOH) Care

PRIORITY 4

Sustainable acute hospital and single acute contract

PRIORITY 5

Transformed mental health , LD and Complex Care services

PRIORITY 6

System transformations

IMPACT on Three Outcomes Gaps:

Finance: best value for Vale of York £ spent

Single acute contract & strategic commissioning

Consistent demand management and reduction in unnecessary activity in acute hospital

Reduction in variation in reference costs

Reduction in waste and duplication: diagnostics, medicines

Right sized for elective care capacity and optimised utilisation of local estates

Shared informatics, reporting and back office resources

Health & Well-Being: Population needs are met

Whole population and targeted cohorts (most vulnerable) outcomes improvement: mortality, morbidity and quality of li

Patients taking responsibility for their own health and budge for care

Improvement in physical health of people with mental health conditions and learning disabilities

People having the best possible start in life with prevention, early detection rates and survivorship improvement

Care & Quality: Patient experience and rights are met

Consistent delivery of NHS Constitutional targets

Improved access, resilience and 7 day working

Standardisation of clinical practice to ‘best in class’

Evidence-based clinical thresholds

Fit for purpose estate for delivering care (mental health, integrated primary and community care)

Sufficient and right workforce to deliver the care required

Our Emerging Joint ‘Local Place’ Programmes: 2017-2019

PRIORITY 1

Strengthening Primary Care

PRIORITY 2

Reducing Demand on the System

PRIORITY 3

Fully Integrated Out of Hospital (OOH) Care

PRIORITY 4

Sustainable acute hospital and single acute contract

PRIORITY 5

Transformed mental health , LD, Complex Care & CHC services

Primary Care:

- ✓ Driving prevention and self-care
- ✓ Driving demand management
- ✓ Prescribing optimisation

Supported by:

- ▪ GPFV – developing support for practices: capacity, access & capability
- ▪ Development of localities in ACS
- ▪ RSS
- ▪ Devolvement of budgets
- ▪ Development of reporting and monitoring

Unplanned Care (Out of Hospital):

- ✓ Proactive management of:

- Frail elderly
- LTCs/ complex
- vulnerable
- children

Supported by:

- ▪ ACS & locality structure
- ▪ Risk stratification
- ▪ Urgent care stabilisation
- ▪ New models of integrated care
- ▪ Community hubs
- ▪ Review of community beds & care homes
- ▪ Personal Health Budgets
- ▪ Estates investment

Planned Care:

- ✓ Right Care: Gastro; MSK (ortho); Circulatory
- ✓ Outpatients redesign
- ✓ RTT Recovery
- ✓ Clinical thresholds
- ✓ Networked services:
- ▪ Cancer redesign
- ▪ Shared Diagnostics, pathology
- ▪ Maternity & neonatal
- ▪ Specialised commissioned services

Mental Health, LD, Complex Care & CHC:

- ✓ Access, early intervention & crisis avoidance: CAMHS, IAPT, dementia diagnosis
- ✓ Physical health
- ✓ Targeted prevention: smoking, alcoh obesity
- ✓ CHC redesign

Supported by:

- ▪ CHC review joint packages of care
- ▪ Personal Health Budgets
- ▪ MH consultation
- ▪ Modernised MH estate

PRIORITY 6

System transformations

ACS & HCVSTP Shared resources – PMO & BI

HCV STP Collaborative programmes

Shared care record & LDR

Workforce transformation

Shared back office and estate

Better Care Fund

Governance and accountability frameworks

Communications and targeted engagement

Our Existing Work

We are already working in many areas to drive improvement and transformation with our partners.

These include the **GP Forward View, Urgent & emergency care, cancer** and **mental health** – highlights are outlined in Annex 1.

Not all our work is captured in coherent strategies or system-wide programmes, however, which means not everyone understands our work in a consistent way.

Our operational plan will take this work and develop it further as part of the **system-wide programmes** with our ACS and STP.

Getting Started

Our operational plan is a **high level plan** which captures emerging priorities and programmes of work in our care system.

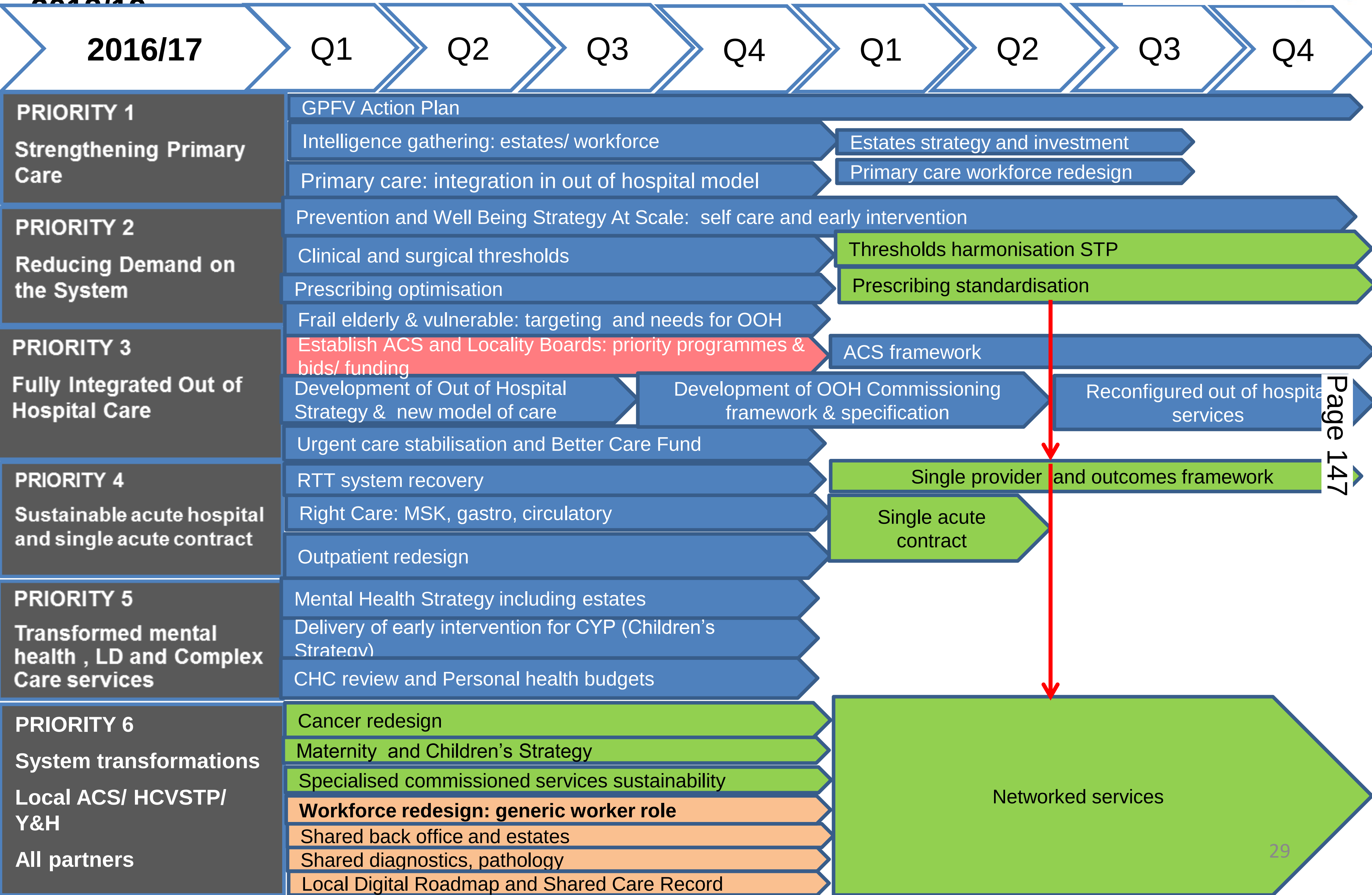
We will work to **scope and mobilise** these programmes with our partners through our emerging ACS and locality boards.

We need each locality to focus on a **few priorities to start working and target improvements** for those people who are most in need and vulnerable.

We will co-ordinate **bids for STP funding** to support transformation wherever possible.

Proposed Two Year Timeline for Delivery 2017/18 2018/19

Vale of York
Clinical Commissioning Group



2016/17 | Q1 | Q2 | Q3 | Q4 | Q1 | Q2 | Q3 | Q4

PRIORITY 1

Strengthening Primary Care

- GPFV Action Plan
- Intelligence gathering: estates/ workforce
- Estates strategy and investment
- Primary care: integration in out of hospital model
- Primary care workforce redesign

PRIORITY 2

Reducing Demand on the System

- Prevention and Well Being Strategy At Scale: self care and early intervention
- Clinical and surgical thresholds
- Thresholds harmonisation STP
- Prescribing optimisation
- Prescribing standardisation
- Frail elderly & vulnerable: targeting and needs for OOH

PRIORITY 3

Fully Integrated Out of Hospital Care

- Establish ACS and Locality Boards: priority programmes & bids/ funding
- ACS framework
- Development of Out of Hospital Strategy & new model of care
- Development of OOH Commissioning framework & specification
- Reconfigured out of hospita services
- Urgent care stabilisation and Better Care Fund

PRIORITY 4

Sustainable acute hospital and single acute contract

- RTT system recovery
- Single provider and outcomes framework
- Right Care: MSK, gastro, circulatory
- Single acute contract
- Outpatient redesign

PRIORITY 5

Transformed mental health , LD and Complex Care services

- Mental Health Strategy including estates
- Delivery of early intervention for CYP (Children's Strategy)
- CHC review and Personal health budgets

PRIORITY 6

System transformations

Local ACS/ HCVSTP/ Y&H

All partners

- Cancer redesign
- Maternity and Children's Strategy
- Specialised commissioned services sustainability
- **Workforce redesign: generic worker role**
- Shared back office and estates
- Shared diagnostics, pathology
- Local Digital Roadmap and Shared Care Record
- Networked services

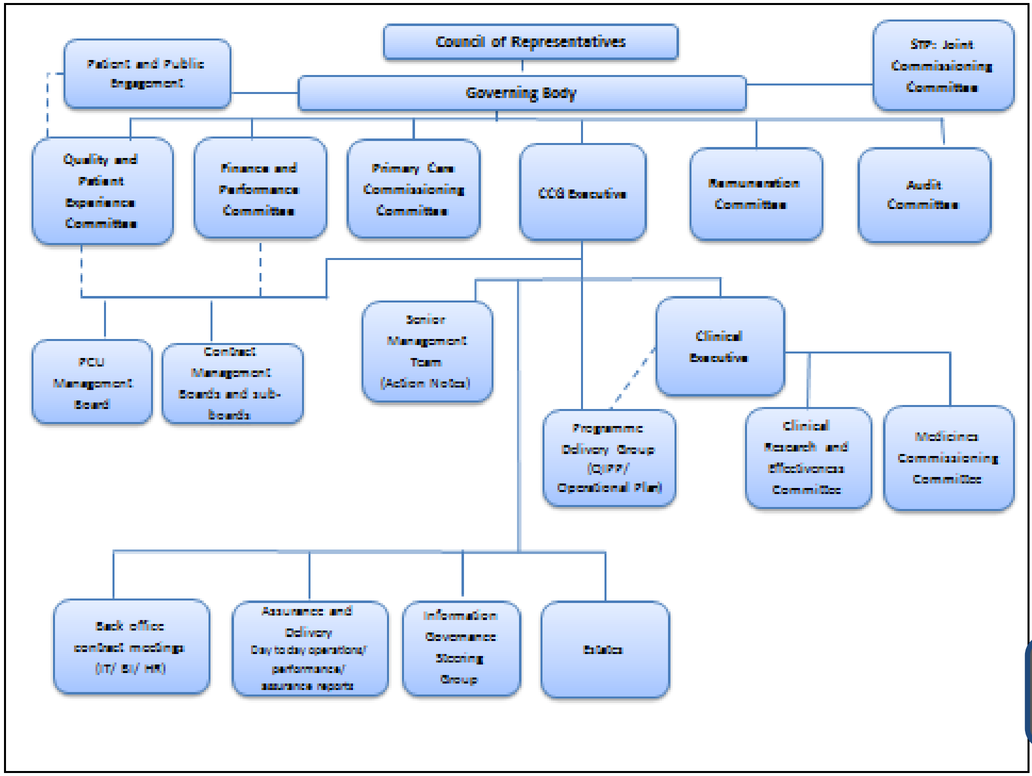
Our Governance

We need the appropriate shared resource and consistent frameworks for managing **governance and risk** if our programmes are to deliver at pace and scale.

We are strengthening our governance internally as a CCG as part of our Improvement Plan.

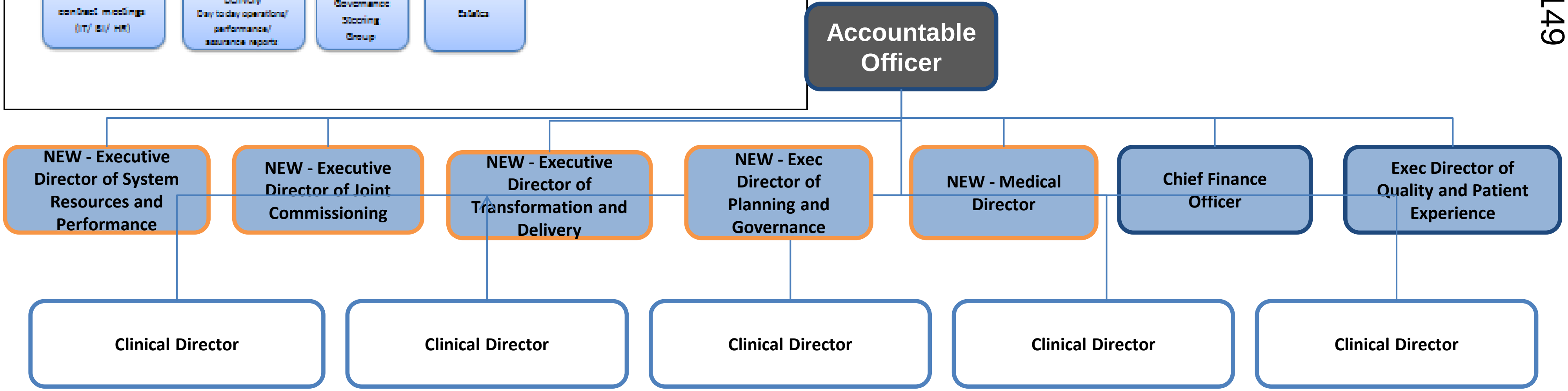
At the same time we are working as an emerging ACS and STP to understand how we can build trust and make decisions as a system. **Principles** and governance which focus on population and place are critical.

CCG Organisational Governance and Strengthening Delivery



Aims:

1. Strengthened executive leadership to drive transformation
2. Clearer accountability and locked in decision-making
3. Focus on performance and rapid escalation if deterioration
4. Leaner reporting process and outputs: focus on delivery of improvement plan, IAF and constitutional standards


Accountable Officer

NEW - Executive Director of System Resources and Performance

NEW - Executive Director of Joint Commissioning

NEW - Executive Director of Transformation and Delivery

NEW - Exec Director of Planning and Governance

NEW - Medical Director

Chief Finance Officer

Exec Director of Quality and Patient Experience

Clinical Director

Clinical Director

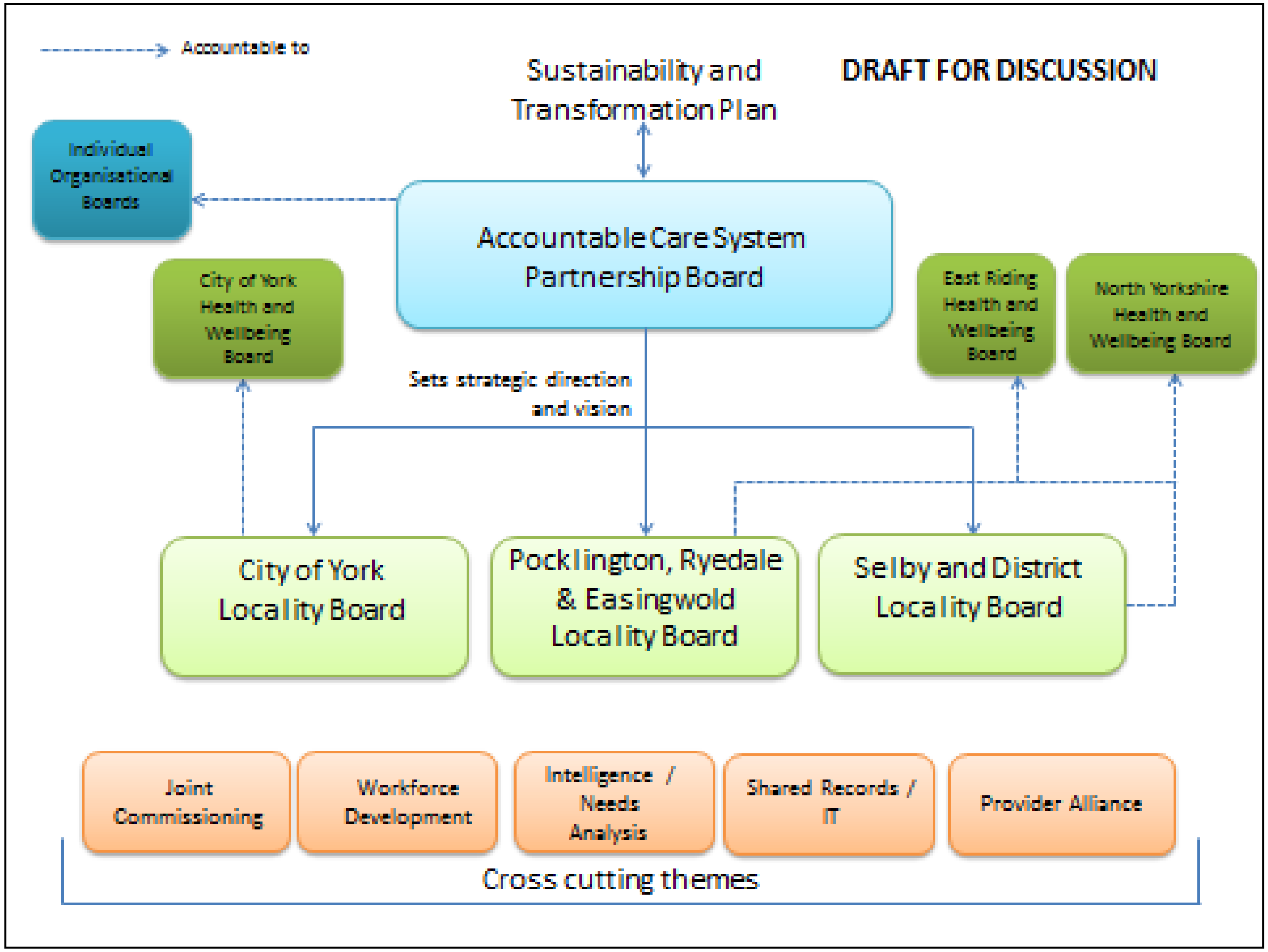
Clinical Director

Clinical Director

Clinical Director

Accountable Care System (ACS) – Emerging Governance Framework (to be discussed in February 2017)

NHS
Vale of York
Clinical Commissioning Group



Accountable to

Sustainability and Transformation Plan

DRAFT FOR DISCUSSION

Individual Organisational Boards

Accountable Care System Partnership Board

City of York Health and Wellbeing Board

East Riding Health and Wellbeing Board

North Yorkshire Health and Wellbeing Board

Sets strategic direction and vision

City of York Locality Board

Pocklington, Ryedale & Easingwold Locality Board

Selby and District Locality Board

Joint Commissioning

Workforce Development

Intelligence / Needs Analysis

Shared Records / IT

Provider Alliance

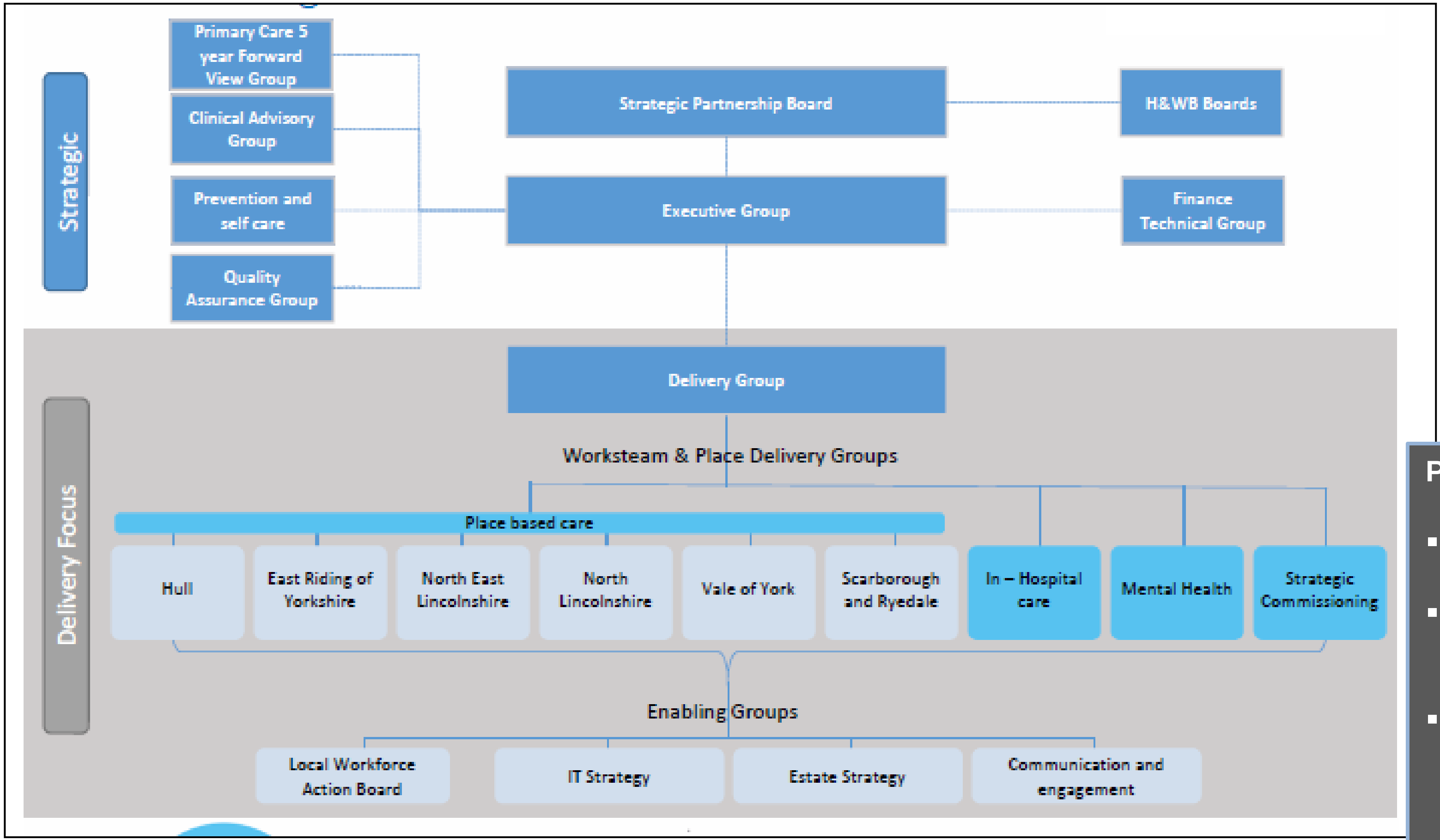
Cross cutting themes

Emerging principles:

Working together our system will:

1. Be person-centred, holistic and individual, involving people in their decisions
2. Promote independence
3. Be underpinned by effective communication and integration software to connect information systems
4. Offer value-for money and be cost-effective, rebalancing investment towards prevention and early intervention and removing/disinvesting in duplication
5. Support increased multi-disciplinary working and empower the front-line, thereby increasing professional satisfaction
6. Give a timely and unambiguous response to need

HCVSTP System Governance (indicative)



Strategic

Primary Care 5 year Forward View Group

Clinical Advisory Group

Prevention and self care

Quality Assurance Group

Strategic Partnership Board

H&WB Boards

Executive Group

Finance Technical Group

Delivery Focus

Delivery Group

Worksteam & Place Delivery Groups

Place based care

Hull

East Riding of Yorkshire

North East Lincolnshire

North Lincolnshire

Vale of York

Scarborough and Ryedale

In – Hospital care

Mental Health

Strategic Commissioning

Enabling Groups

Local Workforce Action Board

IT Strategy

Estate Strategy

Communication and engagement

Principles & Aims:

- System first, organisatio second
- Moving from a reactive system to a proactive future system
- Work closely and collaboratively together to ensure the resources available are used in the most appropriate way for our communities
- System governance to provide rigour and challenge

Our Must Dos

We and our NHS partners have a **statutory duty** to deliver the rights and pledges of our patients in line with the NHS Mandate and **NHS Constitutional targets**.

Financial and workforce pressures in our system mean these targets are not being delivered in all areas or consistently.

We plan to work as a system to ensure we recover our delivery of all targets and can do so in a **sustainable** way – **managing demand on our services and prevention** will be critical to sustainable delivery.

Our STF trajectories have been triangulated with all our partners and represent the current system trajectory.

A&E 4 hour wait

Q2 PERFORMANCE:
Sept 2016: 91% (CCG) & 90.9% (YHFT)
LATEST PERFORMANCE:
October 2016: 85.5% (CCG & YHFT) – 4th consecutive monthly fail
WE 4th Dec: 81.8% (lowest daily to date 59.7%)

Front door (FD) ED schemes have seen a reduction in attendances in ED of 2.1% between July 2015- July 2016.

SYSTEM BOARD & MECHANISMS:
Local Place: Unplanned care programme in ACS
COG: A&E Delivery Board & Steering Group
STP: Y&H UEC network
CCG: Finance & Performance Committee

SYSTEM LEADS:
SRO: Pat Crowley, CE, YHFT
Clinical Lead (CCG): Andrew Phillips, MD
Exec lead (CCG): ED Transformation & Jim Hayburn, ED Systems & Resources
Programme Lead (CCG): Becky Case

Confirmed 2 year trajectory:
Return to 93% in Q3 2017 (September) within forecast activity model. Maintenance at 93% throughout rest of 2017/18 and 2018/19.

RECOVERY PLAN:
Short-term (Q4 2016/17)

- Continued delivery of provision of FD schemes and Ambulance handover concordat action plan: a separate Ambulatory Care, see and treat via Urgent Care Practitioners, e-procurement of Out of Hours services to integrate with NHS111, Community Integrated Care Team rollout, Discharge to Assess pathways, Primary Care services in A&E to support minor ailment streaming, clinical navigator and ensuring staffing levels in ambulance assessment area
- Decision by A&E Delivery Board (7/12/16) to focus on FLOW in hospital and address high bed occupancy with ECIP support to implement SAFER bundles of actions (focus on AMUs, acute elderly, discharge status and lounge) to address 11% increase in NE admissions, and the 28% of those admissions with LOS <24 hrs
- Address high levels of stranded patients (over 7 days in hospital) to reduce from 58% to national average of 30%
- Winter plan assurance and primary care access

Medium-term (Q1&2 2017/18)

- Delivery of full A&E Board Delivery Plan based on national 5 Imperatives
- Agree impact of S&R ED Medical Assessment Model on reporting and delivery of 4 hour target
- STP funding bid for liaison psychiatry

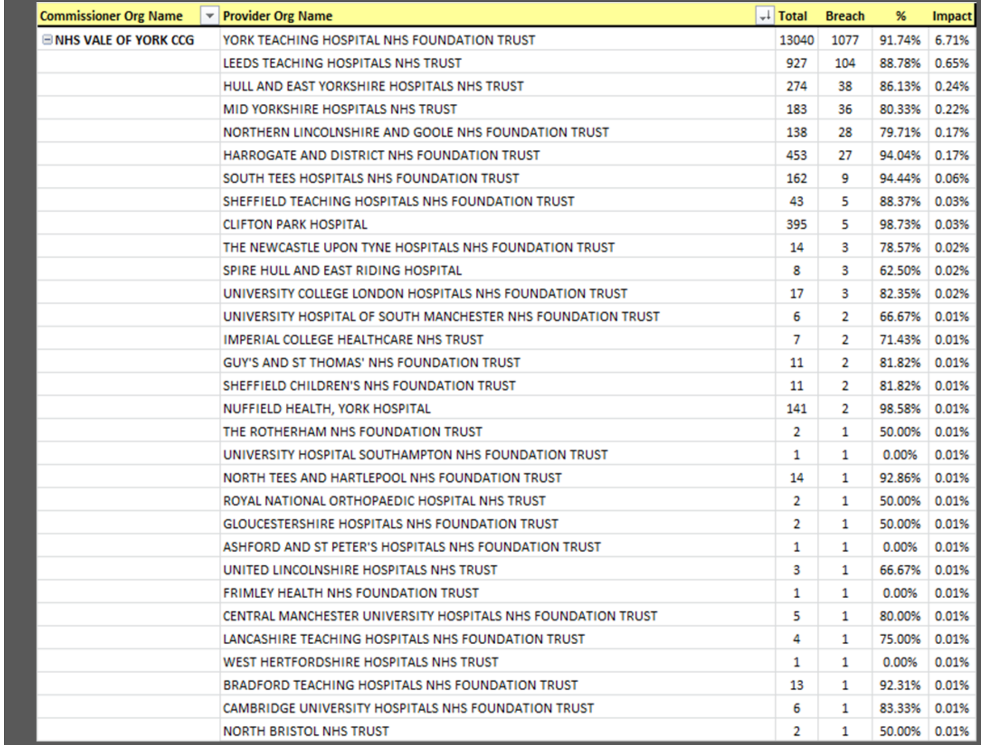
Resources and mitigations required/ to be agreed:

1. System decision on funding/ supporting medical and surgical assessment units and further utilisation of Ambulatory Care Unit from December 2016
2. Approach to delivering and impact of the new NHSI provider A&E scorecard from April 2017

RTT: Performance Summary October 2016

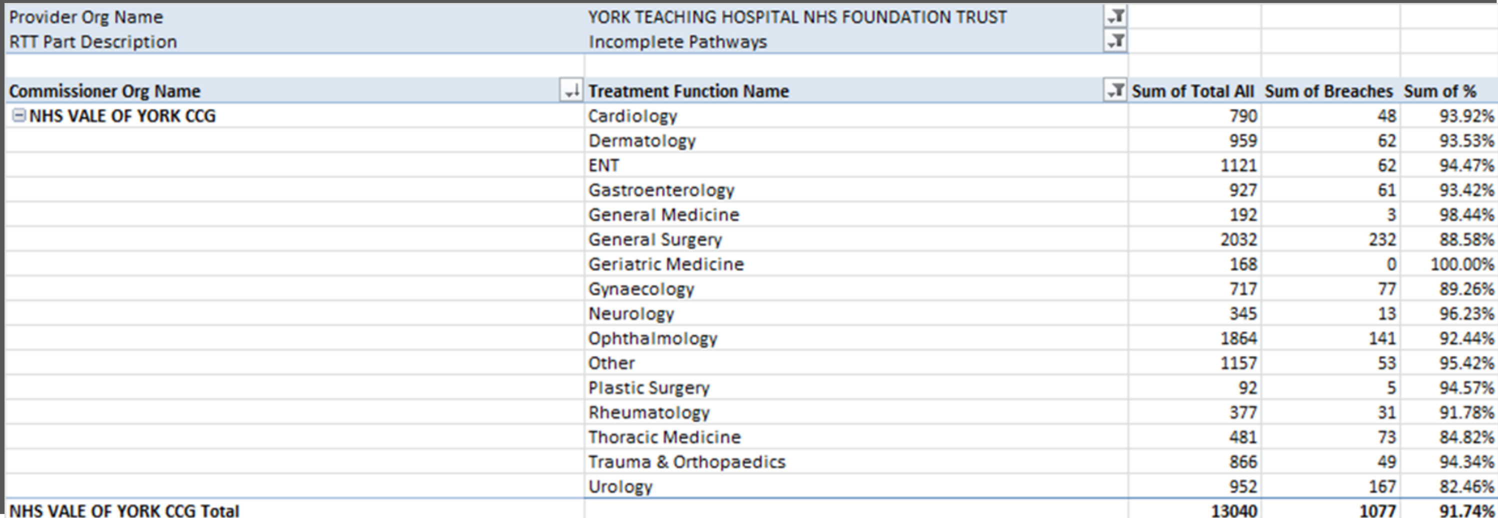
NHS
Vale of York
Clinical Commissioning Group

Summary: RTT performance is below constitutional target of 92% - YTHFT is responsible for 79% of the 8.49% under performance which equates to 6.71%. York tends to be the main driver of the measure in each specialty – except for T&O and Plastics (Leeds TH).



Commissioner Org Name	Provider Org Name	Total	Breach	%	Impact
⊟NHS VALE OF YORK CCG	YORK TEACHING HOSPITAL NHS FOUNDATION TRUST	13040	1077	91.74%	6.71%
	LEEDS TEACHING HOSPITALS NHS TRUST	927	104	88.78%	0.65%
	HULL AND EAST YORKSHIRE HOSPITALS NHS TRUST	274	38	86.13%	0.24%
	MID YORKSHIRE HOSPITALS NHS TRUST	183	36	80.33%	0.22%
	NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST	138	28	79.71%	0.17%
	HARROGATE AND DISTRICT NHS FOUNDATION TRUST	453	27	94.04%	0.17%
	SOUTH TEES HOSPITALS NHS FOUNDATION TRUST	162	9	94.44%	0.06%
	SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST	43	5	88.37%	0.03%
	CLIFTON PARK HOSPITAL	395	5	98.73%	0.03%
	THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST	14	3	78.57%	0.02%
	SPIRE HULL AND EAST RIDING HOSPITAL	8	3	62.50%	0.02%
	UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST	17	3	82.35%	0.02%
	UNIVERSITY HOSPITAL OF SOUTH MANCHESTER NHS FOUNDATION TRUST	6	2	66.67%	0.01%
	IMPERIAL COLLEGE HEALTHCARE NHS TRUST	7	2	71.43%	0.01%
	GUY'S AND ST THOMAS' NHS FOUNDATION TRUST	11	2	81.82%	0.01%
	SHEFFIELD CHILDREN'S NHS FOUNDATION TRUST	11	2	81.82%	0.01%
	NUFFIELD HEALTH, YORK HOSPITAL	141	2	98.58%	0.01%
	THE ROTHERHAM NHS FOUNDATION TRUST	2	1	50.00%	0.01%
	UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST	1	1	0.00%	0.01%
	NORTH TEES AND HARTLEPOOL NHS FOUNDATION TRUST	14	1	92.86%	0.01%
	ROYAL NATIONAL ORTHOPAEDIC HOSPITAL NHS TRUST	2	1	50.00%	0.01%
	GLOUCESTERSHIRE HOSPITALS NHS FOUNDATION TRUST	2	1	50.00%	0.01%
	ASHFORD AND ST PETER'S HOSPITALS NHS FOUNDATION TRUST	1	1	0.00%	0.01%
	UNITED LINCOLNSHIRE HOSPITALS NHS TRUST	3	1	66.67%	0.01%
	FRIMLEY HEALTH NHS FOUNDATION TRUST	1	1	0.00%	0.01%
	CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	5	1	80.00%	0.01%
	LANCASHIRE TEACHING HOSPITALS NHS FOUNDATION TRUST	4	1	75.00%	0.01%
	WEST HERTFORDSHIRE HOSPITALS NHS TRUST	1	1	0.00%	0.01%
	BRADFORD TEACHING HOSPITALS NHS FOUNDATION TRUST	13	1	92.31%	0.01%
	CAMBRIDGE UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	6	1	83.33%	0.01%
	NORTH BRISTOL NHS TRUST	2	1	50.00%	0.01%

Split by specialty as follows October 2016:



Provider Org Name	YORK TEACHING HOSPITAL NHS FOUNDATION TRUST			
RTT Part Description	Incomplete Pathways			
Commissioner Org Name	**Treatment Function Name**	**Sum of Total All**	**Sum of Breaches**	**Sum of %**
⊟NHS VALE OF YORK CCG	Cardiology	790	48	93.92%
	Dermatology	959	62	93.53%
	ENT	1121	62	94.47%
	Gastroenterology	927	61	93.42%
	General Medicine	192	3	98.44%
	General Surgery	2032	232	88.58%
	Geriatric Medicine	168	0	100.00%
	Gynaecology	717	77	89.26%
	Neurology	345	13	96.23%
	Ophthalmology	1864	141	92.44%
	Other	1157	53	95.42%
	Plastic Surgery	92	5	94.57%
	Rheumatology	377	31	91.78%
	Thoracic Medicine	481	73	84.82%
	Trauma & Orthopaedics	866	49	94.34%
	Urology	952	167	82.46%
NHS VALE OF YORK CCG Total		**13040**	**1077**	**91.74%**

RTT

Q2 PERFORMANCE:
July 2016: 91.8%/ August 2016: 91.5%
Sept 2016: 91.6%

LATEST PERFORMANCE:
October 2016: 91.5%

Current non-admitted backlog at YHFT is 3,500 patients more than same time last year (Aug 2015-6) of which 900 patients have now waited more than 18 weeks. Admitted backlog is 1280 (IMAS model identifies sustainable backlog 240)

Key causes:

- Bed pressures (43 cancellations October)
- Theatre list cancellations (6-10 sessions per week/ 102 cancelled in Q2)

SYSTEM BOARD & MECHANISMS:
Local Place: Planned care programme in ACS
COG: TBC – re-establish ‘planned care group’
STP: Strategic Collaborative Commissioning workstream (includes thresholds/ Outpatients)
CCG: Finance & Performance Committee

SYSTEM LEADS:
SRO: TBA
Clinical Lead (CCG): Shaun O’Connell
Exec lead (CCG): ED Transformation & Jim Hayburn
Programme Lead (CCG): Andrew Bucklee

Confirmed 2 year trajectory:
Return to sustainable position at 92%: April 2017 within forecast activity model (growth related to managing the current backlog will be excluded and managed discretely through system RTT recovery plan)
Maintenance throughout 2017/18 and 2018/19

RECOVERY PLAN:

Short-term (Q4 2016/17)

- ✓ YHFT internal recovery plan – recruitment to theatre and key specialties in progress; improved theatre capacity planning; roll validation 14 wks+ non-admitted waiting lists; streamlining validation; additional OP clinics; RTT management tightening; subcontracting to Nuffield (urology), Ramsay (gynae & MaxFax) and Clifton (ortho); specific ophthalmology action plan
- ✓ Work with Clinical Exec at CCG to drive any further primary care-led demand management (e.g. dermatology)
- ✓ Establish system task and finish group as precursor to ACS planned care programme – develop system RTT recovery plan in Q4
- ✓ On-going impact/ expansion of RSS and reduction on referrals and OPAs wi focus on 2WWs (link to cancer recovery)
- ✓ NHSE support: additional demand and capacity planning capacity available
- ✓ Discussion with NHSE re: maxfax (dental) – shortages of capacity region

Medium-term (Q1&2 2017/18)

- Management of growth in demand through impact of clinical thresholds policy from April/ May 2017
- Pathway review (local & STP) including STP funding bid for diabetes
- Rightcare (local & STP): MSK, gastro, circulatory, neuro, resp med
- Outpatients review
- Establishment of ACS and programme for planned care
- Explore extension of devolved budgets to primary care - gynaecology, ENT and gastroenterology

Resources and mitigations required:

1. Some additional funding via NHSE to support subcontracting out to other regional providers (process TBC by NHSE)
2. System review of YHFT of RTT backlog modelling by speciality to inform system RTT recovery plan.

Cancer

Q2 PERFORMANCE:

Sept 2016:

31 days subsequent surgery - 92.1% (2 derm & 1 H&N)

62 days to treatment – 71.8% (demand increase in derm/H&N/colorectal/upper GI)

LATEST PERFORMANCE:

October 2016:

14 days: 88.1% (102/ 854 patients – dermatology & colorectal)

62 days: 75% (21/ 84 patients)

31 days: recovered to 97.5%

SYSTEM BOARD & MECHANISMS:

Local Place: Planned care programme in ACS

COG: York & Scar Cancer Locality Group

STP: Cancer Alliance Board; Y&H Cancer network

CCG: Finance & Performance Committee

SYSTEM LEADS:

SRO: TBC

Clinical Lead (CCG): Dan Cottingham

Exec lead (CCG): ED Transformation & Jim Hayburn

Programme Lead (CCG): Paul Howatson

STP: TBC

Confirmed 2 year trajectory:

Return to sustainable position: Q1 2017 within forecast activity model

Maintenance throughout rest of 2017/18 and 2018/19

RECOVERY PLAN:

Short-term (Q4 2016/17)

- 2WWYork hospital site now back on track with dermatology workload management Locum capacity now in place but Scarborough still experiencing delays
- YHFT recovery plan new being developed – final for approval end Dec 2016 (part of wider Trust performance mgt framework):
  62 days:
  - RCA work with Hull around theatre cancellations
  - RCA work with tertiary centres re: delays in diagnostics
  - Internal YHFT work to reduce pathway from 31 days to 28 days and validati
  - Breach analysis weekly
- Continued demand mgt schemes (RSS both VoY & S&R), improving digital images and work with Clinical Exec at CCG to drive any further primary care-led demand management
- Regional Cancer Alliance Work plan for approval 18/1/17
- Establish system task and finish group as precursor to ACS planned care programme – develop system RTT recovery plan in Q4

Medium-term (Q1&2 2017/18)

- Establish ACS planned care programme to include RTT and cancer
- Start delivery of Cancer Alliance work plan through ACS and STP – includes regional diagnostics capacity model including shared radiology; pathway streaming
- STP transformation fund bids x 3:early diagnosis, recovery, & risk strat

Resources and mitigations required:

1. Approval of final Cancer Alliance workplan after 18/1/17 and rapid mobilisation in VoY locality

Mental Health: IAPT

LATEST PERFORMANCE: October 2016:

- ☐ Access levels 14.1%, up from 12.7% in Sept & above the planned trajectory of 13.1% but below the 15% target
- ☐ Recovery rates 45.9% down from 46.1% in Aug, below the planned trajectory of 47% against a national target of 50%
- ☐ 6 week finished treatment 77.6% down from 79.6% in Aug, above the planned trajectory of 69.0% & nat target of 75.0%
- ☐ 18 week finished treatment 98.2% above 95% target

Improvement has been variable but now approaching the 2016/17 targets

Reasons for poor performance:

- historic lack of funding and access
- new patient administration system (PARIS) was implemented & this led to a number of data quality issues
- data quality has been improved
- workforce development issues/ counsellor contracts

SYSTEM BOARD & MECHANISMS:

Local Place: MH programme in ACS

STP: Collaborative STP MH programme

CCG: Finance & Performance Committee

SYSTEM LEADS:

SRO/ STP: TBC

Clinical Lead (CCG): Louise Barker

Exec lead (CCG): Elaine Wyllie

Programme Lead (CCG): Paul Howatson

Confirmed 2 year trajectory:

Access: 16.8% 17/18 and 19% in 18/19

Recovery: 50% from Q1 17/18 and throughout 18/19

6 weeks access: 75% from Q1 17/18 and throughout 18/19

18 weeks access: 95% throughout 17/18 and 18/19

RECOVERY PLAN:

Short-term (Q4 2016/17)

- CCG to prepare General Practice & primary care MH special bulletin 19th Dec
- New contract with clear expectations, outcomes and KPIs to work towards sustainable delivery of improved performance & managed robustly through CMB and Q&P, with clear commitment by the provider executive team to drive system improvements & ensure sustainable delivery of all metrics/KPIs
- Increased collaboration with the provider to develop and agree joint plans to address the non-achievement of KPIs and trajectory
- Initiatives include:
  - more straightforward referral forms, clearer referral criteria are driving [illegible]e number of increased referrals and the provider now actively encourag[illegible] self-referrals
  - using a combination of different channels and methods of delivery to increase the choice and uptake for service users, including one-to-one, group and web-based sessions
- The provider reviews workforce, workload and distribution by practice to ensure any variability is understood and referral patterns are acted upon
- The local services are monitored by the CCG & supported by additional inputs from the Assurance & Delivery, Clinical Strategy and Intensive Support Teams
- The Intensive Support Team to be involved in a local review of service delivery with CCG and TEWV. Findings from this review will be rapidly acted on to ensure that improvements in delivery are implemented asap. IST starts19/12/16

Medium-term (Q1&2 2017/18)

- Development of VoY Locality/ population based mental health plans

Resources and mitigations required:

1. Impact of/ on current option appraisal of PCU/ joint commissioning for NY CCGs
2. Seasonal referral variations/ workforce pressures in counselling capacity in locality

Mental Health: CAMHS

LATEST PERFORMANCE - October 2016:

- Access 14.1% against target 15%
- Recovery 43.6% against target 50%
- 257 patients awaiting their initial assessment or first treatment appointment
- CQC request validation of no. of looked after children- confirmed none on the validated waiting list

Reasons for poor performance

- increased rates of referrals to services from across the children and young people's age ranges &higher degrees of acuity
- a new patient administration system (PARIS) was implemented & data quality issues
- workforce challenges due to there now being two different providers fulfilling the two commissioned contracts - TEWV now fulfils the CCG contract whereas Leeds York Partnership Foundation Trust fulfils the NHS England inpatient CYPMHS contract

SYSTEM BOARD & MECHANISMS:

STP: Collaborative STP MH programme

CCG: Finance & Performance Committee

SYSTEM LEADS:

SRO: TBC

Clinical Lead (CCG): Louise Barker

Exec lead (CCG): Elaine Wyllie

Programme Lead (CCG): Paul Howatson

STP: TBC

Confirmed 2 year trajectory:

Access target 15% from Q1 17/18 and maintenance in 18/19

Recovery target 50% from Q1 17/17 and maintenance in 18/19

RECOVERY PLAN: Short-term (Q4 2016/17)

Vale of York CCG Waiting List Initiative with CAMHS TEWV

CCG have requested that TEWV lead on and provide capacity to reduce the waiting list and improve access for children and young people.

TEWV to ensure that the range of interventions offered to reduce the waiting list are in line with the Thrive model in providing services for 'getting help' and 'getting more help' cohorts. Project plan in development as follows:

1. York MIND to offer those children and young people on the waiting list with a lower level of need, eg, low mood, anxiety, in the form of 1:1 counselling or group work. 35 cases identified cost of £15,000
2. Focus – ADHD assessments and interventions. 24 cases cost of £25,200.

Private provider 1: 26 cases cost of £20,748 over 13 weeks (from 1st Jan – 31st Mar)

Private provider 2: 26 cases cost of £15,975 over 13 weeks (from 1st Jan – 31st Ma

Total cost of interventions: £76,923 & Reduction from waiting list: 111

Other:

- new contract clear expectations, outcomes and KPIs included to drive performance through CMB and Q&P
- clear commitment by the provider's executive team to drive system improvements thereby ensuring sustainable delivery of all metrics and KPIs
- increased collaboration with the provider with jointly agreed plans to address the non-achievement of the KPIs
- development of a single point of access early in 2017
- additional inputs from NHSE Assurance & Delivery and Clinical Strategy
- CCG to prepare General Practice & primary care MH special bulletin 19th Dec

Medium-term (Q1&2 2017/18)

- Development of VoY Locality/ population based mental health plans

Resources and mitigations required:

1. Additional funding for action plan to support further cohorts of children on waiting list
2. Impact of/ on current option appraisal of PCU/ joint commissioning for NY CCGs

Mental Health: Dementia

Q2 PERFORMANCE:
Sept 2016: 54.7%

LATEST PERFORMANCE:
October 2016: 55.3%
November 2016: 55.69%
Against target 67%

Confirmed 2 year trajectory:
Achieve target 67% Q1 17/18
Maintenance throughout rest of 2017/18 and 2018/19

SYSTEM BOARD & MECHANISMS:
Local Place: MH programme in ACS
STP: Collaborative STP MH programme
CCG: Finance & Performance Committee

SYSTEM LEADS:
SRO: TBC
Clinical Lead (CCG): Louise Barker
Exec lead (CCG): Elaine Wyllie
Programme Lead (CCG): Paul Howatson
STP: TBC

RECOVERY PLAN:
Short-term (Q4 2016/17)

- Existing dementia action plan (see Annex 1)
- Push to drive up primary care coding targeting practices with greatest potential
- Address system toolkit technical difficulties to support Q4 next wave o practices to be targeted
- CCG to prepare General Practice & primary care MH special bulletin 19th Dec

Medium-term (Q1&2 2017/18)

- Development of VoY Locality/ population based mental health plans
- Incorporate dementia as part of a wider ‘ask’ of primary care for support in prevention, access and early diagnosis

Resources and mitigations required:

1. Access and target additional funding to support this additional coding
2. Engagement with primary care including via CoR and practice visits
3. Resources and mitigations required:
4. Impact of/ on current option appraisal of PCU/ joint commissioning for NY CCGs

Transforming Care: Progress against 2016/17 plan

LATEST PERFORMANCE: December 2016:

The CCG has already worked with its provider and closed one inpatient facility with TEWV reinvesting funding in community services including crisis.

VoY CCG had 6 clients out of area, all of whom are jointly funded (led by HAS) and one has recently returned to the locality. The 5 remaining clients are in non-secure hospital beds as follows:

Client:	Inpatient unit:	Progress with discharge and transfer to community/ home care:
1 (long-term)	Lincoln (independent hospital)	CTR April 2016 – decision to proceed with discharge planning. Significant delays due to providers being unable to offer packages and unable to source appropriate accommodation Brokerage also sent out to increase options Clinical team reservations on discharge but family sought legal advice to support discharge ACTION: Local CLDT to review
4	Oak Rise LD acute admission unit	1 x planned discharge confirmed 3 x mental health issues limiting discharge and further MDTs in December (1 x CTR completed April 2016)

RECOVERY PLAN:

- Case managers attending reviews
- Weekly updates from clinical teams
- RPIW discharge planning improvement support to Oak Rise to incorporate CTR process

Confirmed 2 year trajectory: The CCG is currently meeting its trajectory to reduce CCG commissioned beds. However, the TCP area as a whole is slightly off trajectory due to increased activity in specialist commissioned beds. Work to progress achievement of the combined bed reduction trajectory is being managed through the TCP with support from NHSE Area team. Work is ongoing (as described above) to ensure the community support is in place to facilitate discharge from hospital settings and ensure re-admission rates are minimal.

SYSTEM BOARD & MECHANISMS:

Local Place: MH & LD/ complex programme in ACS

STP: Transforming Care Partnership Board (TCP) has been established to manage and deliver the ‘Building the Right Support’ (BTRS) agenda

CCG: Quality & Patient Exp Committee; PCU

SYSTEM LEADS:

SRO: TBC

Clinical Lead (CCG): Louise Barker

Exec lead (CCG): Michelle Carrington

Programme Lead (CCG): Paul Howatson

Resources and mitigations required:

1. Impact of/ on current option appraisal of PCU/ joint commissioning for NY CCGs

Our Financial Modelling

We are working to deliver **financial recovery** through our CCG Improvement Plan with an immediate focus on the 2016/17 financial deficit.

As part of a **longer-term approach** to financial recovery we have undertaken a different strategic approach to financial modelling.

Medium Term Financial Strategy: New system of care

- VoY CCG recognises that it will need to take a new approach if it is to become financially sustainable. Up until now, the health and social system which VoY is part of has failed to produce the correct incentives and behaviours which lead to large scale efficiency savings

- VoY's strategy for delivering change is grounded in the work of the Humber, Coast and Vale STP and includes a vision for commissioning based around the development of an accountable care system for the population of VoY

Characteristics of the new system of care will include:
- Realigning resources within the system through an outcomes-based approach to commissioning
- Supporting the right care and the right workforce to be delivered in the most efficient cost settings
- Incentivising and implementing a whole system approach to prevention
- Employing new contracting models and payment structures, including a phased move away from PbR, to deliver the right incentives and behaviours

- Successfully implementing an **Accountable Care Model** will require the VoY system to demonstrate a series of capabilities and work closely with its STP partners to deliver on this significant programme of change

Medium Term Financial Strategy – a new approach to commissioning

NHS
Vale of York
Clinical Commissioning Group

Executive Summary from the Draft MTFS

VoY's current situation

- Vale of York CCG commissions health services on behalf of a population of 350,000
- The CCG has had an underlying financial deficit since its creation in 2014 and reported a deficit position of £6.3m at the end of 2015/16
- The CCG is one of nine to have recently been put into Special Measures by NHS England and received Legal Directions on 1st September 2016
- VoY responded with the development of a Financial Recovery Plan ('FRP'), submitted to NHSE on 6th October 2016, and including a plan to achieve an in-year deficit of no more than £7m (£13.3m cumulative)[1]
- A new Accountable Officer has also been appointed (in post from 3rd October) to oversee the rapid organisational change required and inject challenge

Purpose of financial strategy

- The CCG recognises the need to articulate a strategic plan which addresses the underlying causes of financial deficit and identifies a path to sustainability
- VoY spends less per head of population than any other CCG within the STP footprint yet receives the lowest allocated spend per head from NHSE (a function of how the allocation formulae recognises the health needs of the population)
- This means that the CCG needs to spend 11% less per person than the STP average in order to live within its means

- The Medium Term Financial Strategy seeks to:
  - **outline a plan** for how the CCG can reach a balanced and sustainable financial position
  - **align with existing system plans**, in particular, the Humber, Coast and Vale Sustainability and Transformation Plan (which VoY is a partner to)
  - **meet key statutory financial targets and business rules**
  - **be consistent with the CCG's vision** and support the delivery of the CCG objectives
  - recognise and **meet the scale of the challenge** in the Five Year Forward View
  - **deliver operational and constitutional targets**
- VoY has taken a fundamentally different approach to the development of its strategy based on a detailed understanding its local population needs which has allowed it to pinpoint a number of areas it needs to focus on

A new approach to commissioning

- The CCG believes that, in order to deliver real change, a radical new approach to system leadership, commissioning and delivery is now required
- Up until now, the health and social care system which VoY is part of has failed to produce the correct incentives and behaviours which lead to large scale efficiency savings

Medium Term Financial Strategy – a new approach to commissioning

NHS
Vale of York
Clinical Commissioning Group

Executive Summary from the Draft MTFS

This is evidenced by the fact that only 24 to 29% of the CCG's targeted QIPP cost savings have been achieved over the past two years

Moving forward, VoY needs to play its part in redesigning and delivering a new health and social care system which is better able to care for patients, whilst also delivering financial sustainability

VoY's strategy for doing this is embedded in the work of the STP and includes a vision for new models of accountable care in VoY, strategic commissioning across the system and new approaches to system governance and risk sharing

This builds on the ideas put forward in the Five Year Forward View and best-practice national and international examples of whole population management and outcomes-based commissioning

VoY has already made progress in a number of areas, for example in articulating a vision for a VoY Accountable Care System

Financial opportunity

The CCG has identified 6 areas of immediate financial opportunity to focus on: Elective Orthopaedics, Out of Hospital, Outpatients, Continuing Healthcare, Prescribing and High-cost Drugs

- Combined, these 6 opportunities have the potential to release savings to the CCG in the order of £50m by 20/21
- This would allow the CCG to reach in-year surplus by 19/20 although a cumulative financial deficit of approximately £24m at 20/21 would still remain
- A number of additional "pipeline" opportunity areas have also been identified but these are at an early planning stage only. If delivered in full, these additional opportunities would take the CCG's financial position to in-year financial balance by 18/19 and cumulative balance by 20/21
- The CCG has agreed delivery plans, next steps and work with stakeholders to progress each of the 6 major opportunities. 5 of these opportunities have the potential to deliver cost savings from 16/17
- Further work to firm up the size and potential for delivery of the additional pipeline opportunities is ongoing

- Next steps
- Moving forward, VoY recognises the need to progress its financial strategy forwards, whilst also delivering on shorter-term goals
- Development of the financial strategy will require close collaboration with providers and other STP partners, as well as a strong and realistic understanding of the capabilities required to deliver the new vision articulated

Medium Term Financial Strategy – a new approach to commissioning

VoY's approach to understanding how we currently spend our population allocation based on population need

Report sections	Key activities
3 *Population analytics and benchmarking*	• Reviewed weighted population allocation to understand areas where VoY does and does not "live within its means" • Conducted benchmarking with other STP commissioners to understand areas of VoY over- and under-spend • Reviewed VoY population characteristics to identify underlying cause of the deficit • Reviewed Right Care analysis to identify potential areas of saving • Reviewed other literature/best practice to identify
4 *Financial opportunity*	• Identified specific financial opportunities based on population analytics/benchmarking analysis undertaken • Quantified opportunities based on evidence available • Phased savings over four year period to 20/21 • Calculated residual financial "gap" for VoY CCG under different scenarios • Reviewed delivery plans and enablers for each opportunity identified • Agreed approach to working with stakeholders and immediate next steps

Medium Term Financial Strategy – a new approach to commissioning

NHS
Vale of York
Clinical Commissioning Group

We have identified 6 specific financial opportunities which we are taking forward to delivery immediately

- The CCG has identified 6 key areas of financial opportunity based on the population analytics and health benchmarking findings
- The annual potential planned savings for these until 20/21 are detailed below and are evidenced in further detail in the following slides
- This chapter also includes VoY's agreed approaches to delivering the opportunities identified, driven by the CCG's overarching new approach to commissioning, described in Section 2

Section reference	Opportunity	Total potential spend reduction (£m)	17/18 (£m)	18/19 (£m)	19/20 (£m)	20/21 (£m)
(4.2)	***1) Elective orthopaedics***	**4.2**	1.3	1.0	1.0	1.0
(4.3)	***2) Out of hospital care***	**21.3**	0.0	9.1	7.2	5.0
(4.4)	***3) Contracting for outpatients***	**5.0**	3.0	2.0	0.0	0.0
(4.5)	***4) Continuing healthcare and funded nursing care***	**9.3**	3.1	2.5	2.5	1.2
(4.6)	***5) Prescribing***	**6.2**	1.7	1.5	1.5	1.5
(4.7)	***6) High cost drugs***	**2.0**	0.2	0.6	0.2	1.0
	Total	**50.0**	**9.4**	**16.7**	**12.4**	**9.6**

Detail and evidence to support the proposed reduction of spend on each of these areas is included in the draft Medium Term Financial Strategy. This is starting a period of engagement and refinement to ensure the messages are clear to everyone in the CCG, partners and stakeholders. A summary stakeholder document has been prepared for this purpose.

2017/18 Financial Plan Summary

Vale of York
Clinical Commissioning Group

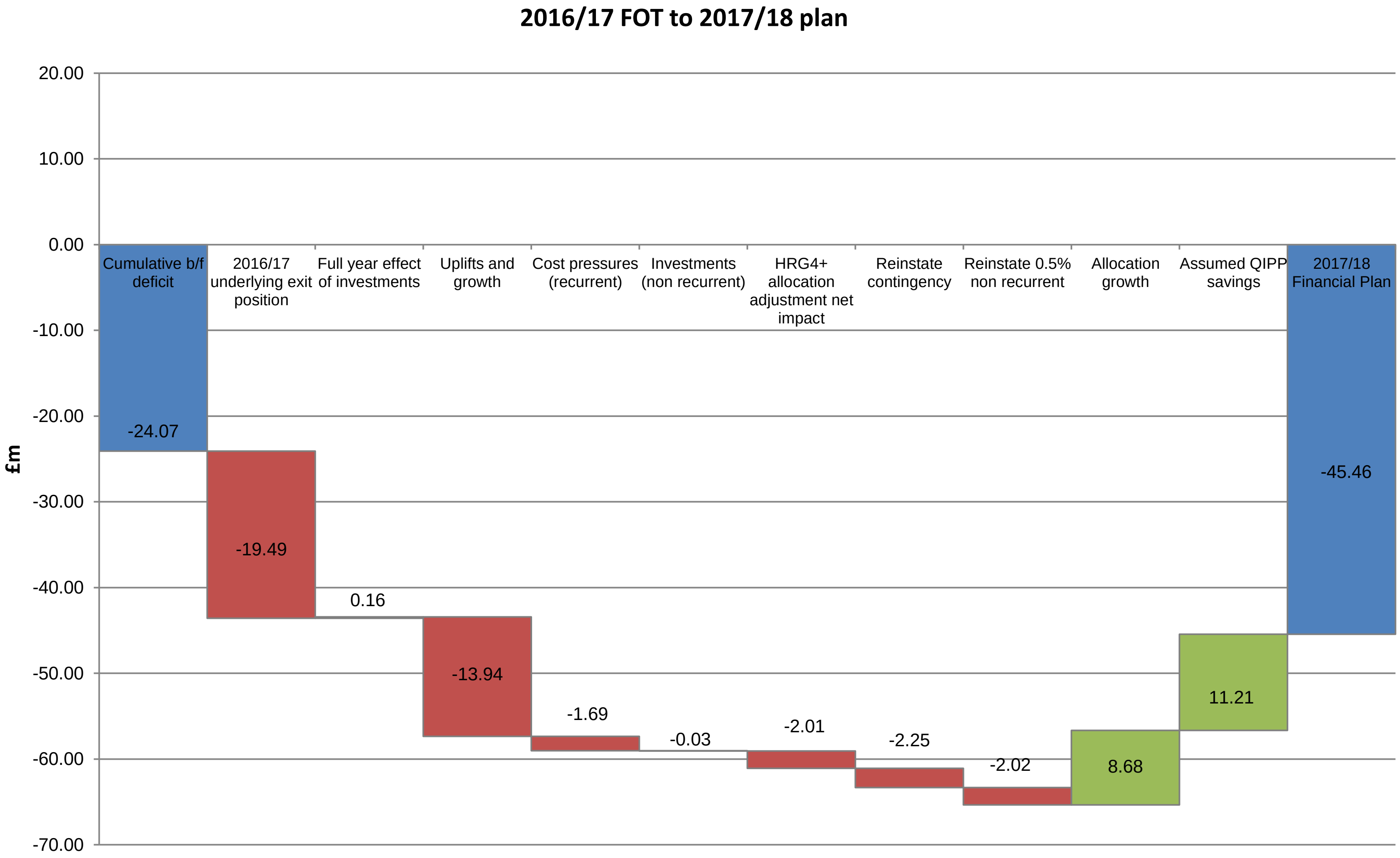
Headlines

- The Plan assumes a 2016/17 position of £24.1m deficit in line with the CCG Improvement Plan submission.
- The underlying deficit position of £19.5m along with inflation and growth of £13.9m have been applied.
- Allocation growth of £8.7m is included.
- A QIPP saving of £11.2m (2.5%) has been applied to the plan.
- This results in a 2017/18 cumulative deficit of £45.5m

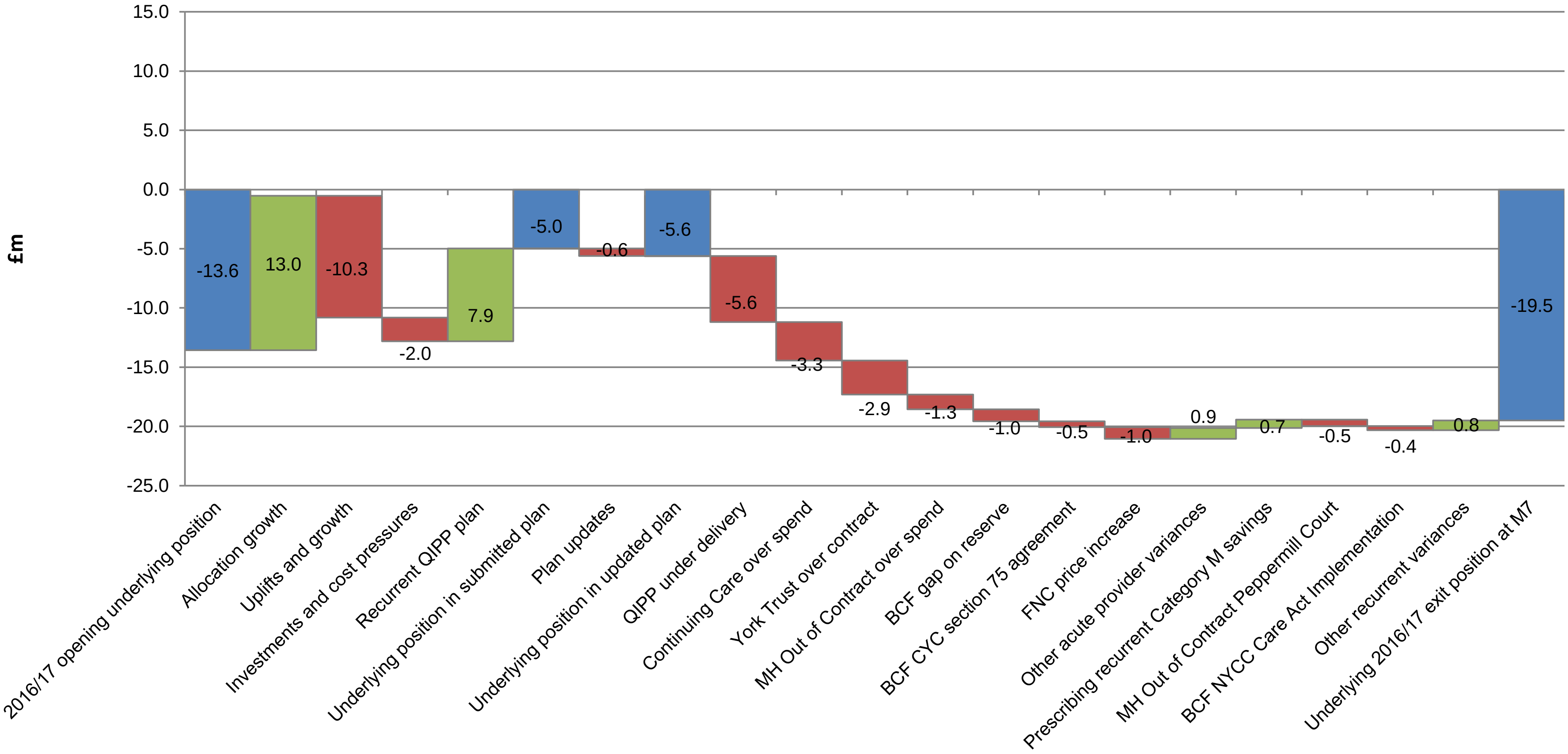
Business Rules

- CCGs should plan for in-year break-even ✗
- CCGs should plan to spend 1% of allocation as non-recurrent expenditure ✗
- Deficit CCG to delivery a in-year breakeven position or deliver 1% of allocation improvement ✗
- 0.5% of non-recurrent expenditure should be uncommitted as a risk reserve ✓
- CCGs should plan for 0.5% Contingency ✓

Bridge chart - 2016/17 Forecast Outturn to 2017/18



Underlying position 2016/17 to 2017/18



- The underlying deficit has deteriorated by £5.9m in 2016/17. The main drivers for this are an increase in acute activity, an increase in continuing care activity along with lower than planned delivery of QIPP.
- A review of the underlying position has taken place between the CCG and NHS England since the 1st draft submission of the 2017/18 plan.
- Assumptions around the treatment of recurrent and non-recurrent expenditure and savings and some assumptions were changed as a result of this.

Planning assumptions

Inflation & growth assumptions

- Inflation accounts for £5.2m of the overall £13.9m Inflation and growth.
- Inflation has been applied in line with national tariff inflation. With the exception of continuing care and Primary care where PCU levels and nationally assumed primary care levels have been used.
- The growth levels that account for £8.8m are based on STP assumptions for growth levels, with the exceptions of continuing care and primary care where PCU levels and population growth have been used.
- An extensive process of challenge and review took place between NHS England and the CCG on the STP and PCU growth assumptions.

Cost Pressures, Investments & Contingencies

Cost pressures:

- Property Services move to market rent £1.7m
- Increase in Running Costs £0.2m

Investments:

- The CCG has been able to include the £3 per head for primary care but this is reliant on additional savings being made to generate it
- Contingency of 0.5% of allocation has been provided for.
- Non Recurrent risk reserve of 0.5% has also been provided

QIPP 2017/18

- A QIPP target of £11.2m has been built into the plan which equates to 2.5% of the overall allocation.
- The critical areas for focus are derived from the Medium Term Financial Strategy and support delivery of the organisation’s priorities.
- These sit alongside a number of other schemes delivering better value for the resources available.
- A joint CCG and NHS England confirm and challenge event has been held to confirm the QIPP target and determine executive responsibility for all areas of programme spend. This event reviewed the full value of the schemes identified in the pipeline and the FYE of schemes that commenced or that are due to commence in 2016/17 alongside new schemes planned for 2017/18 and 2018/19.

Risks to delivery of 2017/18 Financial plan

- **Contracting** – the CCG are in discussion with York Foundation Trust regarding a non-PBR funding mechanism for 2017/18 as well delivering a single contract with the trust across all commissioning partners.
- **Activity and growth assumptions –** based on STU & PCU and also have been subject to challenge but could prove to be incorrect.
- **NHSPS** – increased market rent is built into cost pressures.
- **HRG4+ & IR allocation changes** – the risks and pressures created by changes to tariff are now included in the financial plan
- **BI & data quality/timeliness** – risk for planning activity levels with lack of data.
- **QIPP** – the previous performance of the CCG has been lower than the levels in this plan.
- **BCF** – the minimum amount required is in the plan but discussions are still to take place with the local authorities.
- **CHC** - Although growth has been added this remains a volatile area.
- **Running costs** – increasing the capability and capacity of the CCG has resulted in a fully committed running cost allocation.

Our Activity Modelling

We have worked with our provider partners to incorporate the impact of our known financial efficiency, growth and demand management, and recovery plans on the activity we will contract for.

Our approach to activity modelling

The activity submission is based on an estimation of the planned level of activity for the 2017/18-2018/19 contract, calculated based on the financial plan value for each provider divided by the average activity cost. The methodology applied to calculate the financial plan for each Acute contract (at POD level) is as follows:-

The acute contracts in the financial plan are based on recurrent outturn position at month 6, adjusted for any known full year effects of investments or other changes. Tariff uplift and efficiency is then applied as per national guidance (2.1% uplift, 2% efficiency, plus an additional uplift for HRG specific CNST premium, equivalent to 0.7% of total tariff spend). Demographic growth is applied, based on the national IHAM model and in line with STP plans. The allocation adjustment for HRG4+ and IR rules have been applied based on the Trusts impact assessment. Proposed QIPP schemes have then been applied. The value of these schemes are based on the confirm and challenge numbers aligned with the Financial Plan, these are pending agreement with the Trust. Schemes have therefore been applied to the main contract and point of delivery that they are expected to impact.

The baseline modelling for the York Trust contract is well underway. We have agreed the baseline (should nothing in the system change) and are now finalising and negotiating the contract value to take into consideration the outstanding AQNs, a local assessment of growth requirements and QIPP schemes. The baseline activity is based on the following methodology:-

- 12 months data (July 15 – June 16), adjusted for forecast outturn as at Month 6 (2016/17) at Point of Delivery and Specialty level. The Forecast outturn is pre-populated by NHSE in the activity template for referrals and SUS based on the T&R database and therefore there are likely to be issues associated with using different datasets. The CCG uses referral data directly received from the Trust and adjusts SUS to remove activity which should be excluded for contracting and payment purposes i.e. activity seen in the Ambulatory Care Unit (ACU) which are coded as Day Case or Non-elective but are excluded as they are not admissions funded by PbR and are funded based a partial block and partial fixed local price payment model.
- Growth is included in the baseline based on the STP levels of growth (IHAM) but will be adjusted for based on a local assessment of trends and ONS population change as the CCG has implemented various schemes to manage demand. The IHAM estimated level of growth not take into account the excluded ACU activity (mentioned above) or the impact of the CCG's Referral Support Unit which has historically contained growth.

Our approach to activity modelling

- A further adjustment is applied to reflect the impact of local initiatives and pathway changes not fully reflected in the baseline (such as community diabetes service which reduces acute activity, the implementation of the ACU, coding correction for Palliative Medicine etc.)
- An adjustment for the Trust's coding and counting notification from the 30th September 2016 is applied.
- The impact of the IR rules are included based on the Trusts impact assessment.
- There are three Activity Query Notices currently being investigated being investigated by the Trust which are likely to impact on the baseline once concluded. We aim to resolve these early is the New Year.
- QIPP adjustments will be applied to the baseline and agreed with the Trust to derive the contract financial value.

Our Contracting and Risk position

We have agreed a Heads of Terms document which incorporates all the areas we will work jointly with our providers around in 2017/18 to close the activity and financial gap in the current contract values.

The programmes of work supporting that Heads of Terms will be captured within our ACS programmes to ensure there is a coherent link between the transformation work we do and the impact on our contracts (transactional).

Annex 1: Our Existing Work

We are already working in some areas to drive improvement and transformation with our partners.

These include the **GP Forward View, Urgent & emergency care, cancer** and **mental health**.

Not all our work is captured in coherent strategies or system-wide programmes, however, which means not everyone understands our work in a consistent way.

Our operational plan will take this work and develop it further as part of the system-wide programmes with our ACS and STP.

The following slides provide a high level summary of our work.

Prevention

We have an agreed Prevention and Better Health Strategy that underpins the work on lifestyle improvement prior to elective surgery and more broadly the ambition to improve health and reduce inequalities which requires changes in the way that CCG resources are currently used.

The ACS and STP will work to identify the opportunities for all partners to deliver prevention 'at scale' across the system in order to have the greatest impact for our population well-being and demand on our services.

AIMS:

The CCG's aim as a partner in the local health and health system is to achieve the best health and well-being for everyone. We work with our local authority partners and our joint health and well-being strategies to enable and encourage people to live the healthiest lives possible within the resources available. This supports the system in getting the best value from the resources and prevent any avoidable use of NHS resources.

The Prevention and Better Health Strategy has been developed to demonstrate how focusing our efforts on prevention, self-care and shared decision-making can support a shift in the way health and care resources are valued, and to empower patients in the Vale of York to become more active participants in shaping their health outcomes.

This strategy is focussed on:

- tackling the common risk factors (especially smoking and obesity) for many of the major diseases affecting the population,
- improving the appropriate use of health care (including through increased 'shared decision making' and raising awareness of Patient Related Outcome Measures - PROMS)
- ensuring patients gain the most benefit from the health care interventions they receive
- supporting people to take responsibility for their own health.

This strategy underpins the specific policy approach for improving the MSK pathway and utilisation of elective surgery through the provision of patient support resources and collaboration with local authority partners in the commissioning of weight management and smoking cessation services.

Future prevention work will develop the collaborative commissioning of further prevention services with partner organisations, including detecting pre-diabetes and high blood pressure, reducing inactivity and alcohol consumption, increasing immunisation and uptake of cancer screening and helping people to understand their options and manage their own health through self-care and shared decision-making.

Primary Care: Delivering the General Practice Forward View

AIMS:

1. **Investment in Primary Care – estates and workforce**
2. **Build resilience and patient access across practices in and out of hours, through:**

- Supporting, developing and extending the Primary Care workforce
- Transform the way technology is deployed and infrastructure utilised – developing an estates strategy
- Better management of workload and redesign how care is provided
- Addressing variation and benchmarking
- Improving data quality and continuous improvement
- Implementation of risk stratification tools

Primary care also have a pivotal role in:

- Delivering prevention and managing population health
- Managing system demand
- Developing and delivering new models of out of hospital care as part of integrated care teams in an accountable care system (ACS)

The CCG **GP Forward View Action Plan** outlines the proposed workstreams to drive this programme of work forward and align the plans to the emerging ACS. This has been submitted on 23/12/16 alongside this Operational Plan. The CCG Primary Care Committee has refreshed its governance arrangements in order to more effectively deliver this GPFV and support the Operational Plan and ACS.
The CCG Council of Representatives and the Local Medical Committee are working with the CCG Executive Team and the Clinical Executive to provide steer and support to the delivery of the Operational Plan.

Clinical Thresholds

Opportunities to standardise and optimise across the HCVSTP	
Improving the musculoskeletal (MSK) pathway	Improving the musculoskeletal pathway, for improving lifestyle risks prior to elective surgery and to manage the utilisation of elective surgery. Working with patients, public and partner organisations to improve health and reduce inequalities whilst making better use of resources and delivering NHS England Directions and the journey together towards a sustainable health and social care system that optimises outcomes for patients and the population you serve. Plans for improving the musculoskeletal (MSK) pathway – taking account of RightCare information, the financial challenges faced by the CCG, and your ambition to improve outcomes from surgery and to improve health across the population. Our plans for managing utilisation of elective surgery - taking account of the opportunity to improve lifestyle risks pre-operatively, improve outcomes from elective surgery and the financial challenges fac by the CCG.
Managing utilisation of elective surgery	This strategy is focused on: tackling the common risk factors (especially smoking and obesity) for many of the major diseases affecting the population, improving the appropriate use of health care (including through increased 'shared decision making' and raising awareness of Patient Related Outcome Measures - PROMS), ensuring patients gain the most benefit from the health care interventions they receive and supporting people to take responsibility for their own health. This strategy underpins the specific policy approach for improving the MSK pathway and utilisation of elective surgery.
	The strategy also aims to be consistent with the Local Authorities' Health and Wellbeing strategies and to promote the 'Wanless Report' recommended 'fully engaged scenario'. The strategy provides an analysis of the effects of smoking and obesity on health in general, the impact of smoking and obesity on outcomes of health care interventions and the benefits of stopping smoking and of losing weight / improving fitness pre-operatively.

Urgent and Emergency Care: Delivery Board Improvement Plan

Delivery of the 4 hour A&E standard (including the new provider A&E scorecard) including the implementation of 5 elements of the A&E Improvement Plan	
ED Streaming:	Review of the Ambulatory Care Unit at 12 months is ongoing; colleagues are working to assess sustainability in the current format, and if there is the requirement for additional working hours (staffing) at the weekend in addition to the current provision. This work will be completed by the end of December 2016. There is also an acute frailty plan to improve the proportion of comprehensive geriatric assessment at the earliest opportunity which YTHFT are leading for both their sites.
NHS111:	Our partners have shared with us their design for new pathways across all of Yorkshire. We have a representative on the planning group for the Clinical Advisory Hub and have planned to roll out the expanded DOS to include social and voluntary care in this CCG area before the end of January 2017.
Ambulance ARP:	Our partners have shared their plans for this change in ambulance provision across all of Yorkshire before March 2017 and we are supportive of this.
Improved Flow:	YTHFT are leading the rollout of the SAFER standards across all of their acute and community hospita wards, as well as reviewing the use of clinical checklists and ‘Red & Green days’. Their medical director is leading these workstreams.
Improved discharge processes:	Review and planning for all ‘stranded’ patients with stays of 7 days or more – this is a key area of improvement to which we are committed. The A&E delivery board on 7th December has this as a key agenda item as work with ECIP during 2016 has not yet delivered a significant change. Discharge to assess pathways are in operation for a limited number of areas; this is planned to roll out across all wards prior to April 2017. Work on Trusted Assessor proposals in private care homes has been ongoing for a significant period of time; the scheme has been operational in Council run care homes for some time, however the standard model cannot be implemented in this health economy. More scoping is ongoing to review if there is an in-hospital model that private care homes would support. There is no confirmed implementation date for this workstream for this reason.

Urgent and Emergency Care: Seven Day Hospital Services

Meeting the four priority standards for seven-day hospital services for all urgent network specialist services by November 2017

Steps and actions to implement the Urgent and Emergency Care Review, ensuring a 24/7 integrated care service for physical and mental health is implemented by March 2020 including a clinical hub that supports NHS 111, 999 and out-of-hours calls.

Time to consultant review: this standard has improved significantly during 2016, with the time for initial triage falling from over 100 minutes to 33 minutes across 7 days on the introduction of the Primary Care streaming in July 2016. With the additionality of the Comprehensive Geriatric Review planned as part of YTHFTs frailty plans we do not anticipate a difficulty in meeting this standard.

Diagnostic services: Vale of York CCG are leading a comprehensive review of diagnostic services across 7 days currently. This is working with both primary care to ensure access in and out of hours and refining current pathways within YTHFT, This will deliver against a number of different workstreams over the next 12 months, and anticipate delivery against standards by November 2017.

Consultant directed interventions: YTHFT are again leading on this workstream; a comprehensive review of consultant job plans to provide 7 day services has been commenced and it is anticipated tha this level of service will be delivered by November 2017.

Consultant review: progress against this standard is ongoing, also being led by YTHFT. It is anticipated that this will be met in all areas, including geriatric and HDU care by November 2017.

The Vale of York CCG is a key member of the **STP Urgent and Emergency Care network**; with the Deputy Chief Operating Officer leading a number of workstreams across the region. The Urgent Care lead in the CCG is also a member of the group rolling out the **Clinical Hub (Advisory Service)** and plans are in place to deliver this to the approved trajectory; learning from the lessons in the affiliated West Yorkshire Vanguard/Accelerator site.

Reprovision of the OOH GP service during 2015 included integration of NHS111 and out-of-hours and support is being provided to Yorkshire Ambulance Service to further integrate 999 services over the next two years. They hold the detailed plans for this workstream.

Urgent and Emergency Care: networked & Liaison services

Meeting the four priority standards for seven-day hospital services for all urgent network specialist services by November 2017	The CCG has already commissioned a comprehensive **Urgent Care Practitioner programme** that delivers ‘see and treat’ across all of Vale of York CCG; with direct access for all Care Homes, Community Services teams and the York Integrated Care Team. This has been instrumental in reducing the proportion of avoidable transportation to A&E already; particularly in the area of falls and minor injuries. An improvement to the software used by NHS111 provided by Yorkshire Ambulance Service at the start of November 2016 is anticipated to increase further the proportion of NHS111 patients that are referred through to this part of the system as there is additional capacity available in the service to do this. This will further reduce the proportion requiring transportation.
Initiating cross-system approach to prepare for forthcoming waiting time standard for urgent care for those in a mental health crisis	The CCG has already designed and commissioned an **ED Psychiatric Liaison Service** within the last two years that delivers urgent care for those in a mental health crisis. This has a 1 hour response time within ED at all times, and includes multidisciplinary and multiagency support across Health, Social Care, Police and local Voluntary Sector services supporting those with drug and alcohol issues locally. Our **local** Better Care Funds also support a number of schemes including ‘Pathways’ for those who are hard to reach or are persistent attendees and provision of street triage and a 136 Suite.

Integrated Out of Hospital Care: an emerging Accountable Care System (ACS)

VoY CCG plans to work with its commissioner and provider partners over the coming months to develop an accountable care operating framework for the VoY. An Accountable Care System Board would be accountable for delivering outcomes and represent all partners.

Such a framework would support closer integration between all aspects of care (primary, community, mental health and social) through a focus on realigning resources in such a way that maximises outcomes (end results) for residents and patients

Health and social care outcomes for the VoY population are commissioned through place-based integrated strategic commissioning. Local Accountable Providers provide an integrated set of services determined by local priorities and supported by common standards of governance, operations and decision-making. Delivery of services is based around primary-care focused neighbourhood teams, building on the CCG's pioneering work on integrated care hubs.

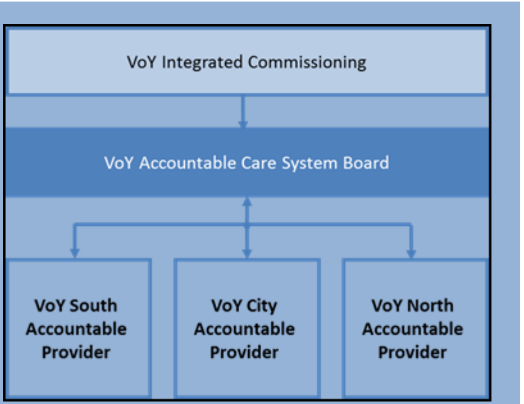
The CCG recognises that development of an accountable care system for the population of the VoY will require much further work.

A high-level five phase approach to the phases of work required is emerging that describe the process from agreeing a strategy to defining the accountable care framework (and the outcomes that it will need to deliver) to being able to negotiate and issue new contracts with providers.

The emerging ACS partners will come together on the 8th December to refine the programme of work and agree the governance required to mobilise this programme of work. . It is anticipated that linking the current pioneer Integrated Care Hubs pilots to the local Accountable Care System will commence in April 2017 and be a continuous programme of work from that point forward.

Principles

1. **Working together our system will:**
2. **Be person-centred, holistic and individual, involving people in their decisions**
3. **Promote independence**
4. **Be underpinned by effective communication and integration software to connect information systems**
5. **Offer value-for money and be cost-effective, rebalancing investment towards prevention and early intervention and removing/disinvesting in duplication**
6. **Support increased multi-disciplinary working and empower the front-line, thereby increasing professional satisfaction**
7. **Give a timely and unambiguous response to need**



Integrated Out of Hospital Care: an emerging Accountable Care System (ACS)

NHS
Vale of York
Clinical Commissioning Group

The Accountable Care System approach proposes new models of care across three place based localities within the Vale of York that allow us to take joint responsibility for improving the care and support of our population. These models will be tailored to the needs of the local population, system partners and geography

Vale of York CCG has been trialling three models of Integrated Care Teams, the forerunner of Multispecialty Community Providers, since June 2014. These include a model supported by General Practice, an outreach/response model supported by York Teaching Hospitals NHS Foundation Trust who provide acute and community services, and a community bed based model supported jointly by community staff and General Practice. Of these models, the first model supported by General Practice is being rolled out wider at present, so that all practices within the City of York boundary area will be participating. Initial results in managing attendances, preventing readmissions and providing proactive care for those with long-term conditions and at end of life have been good. It is planned that the whole of City of York will be incorporated into the existing Integrated Care Team by March 2017. The other models continue to be reviewed for effectiveness.

Additionally, as this team expands, work is ongoing to incorporate a number of other existing and planned schemes into this model. The first of these will be the reablement pathways that were designed with a large amount of patient and staff participation at the start of 2016. This work will be jointly done with City of York Council and joint outcomes are being finalized currently. The next phase will incorporate the Social Prescribing scheme with this; currently this is being run by York CVS. A formal review of effectiveness will be published by York St. John University in January 2017. Planning for current community services to be added and additional services to be transferred from the acute to the community sector is also well underway.

The CCG already support a monthly ‘Partners in Care’ meeting and have tested and implemented a number of schemes to support local care homes. We commission a number of beds in a local care home for rapid reablement with support from the acute sector in providing therapy support, we have provided a direct line for care homes to the Urgent Care Practitioner service and are gradually moving to the single GP/Home model. In addition, there have been a number of projects in both council run and private care homes that have tested new technologies such as dementia alarms, telemedicine support and run initiatives to review medication and improve diet and hydration among residents. We anticipate this will go some way to manage adherence to any future standards.

Mental health: Adult

Adult mental health

Strategic Aims	Specific targets	What we intend to do
That by 2020/21, there will be increased access to psychological therapies for people with common mental health conditions with the majority of new services being integrated with physical healthcare.	19% access in 2019 25% access in 2020/21 (National target of 3000 therapists to be co-located with GPs by 2020/21) 75% accessing therapy in 6 weeks (2020) 95% accessing therapy in 18 weeks (2020)	• Commission IAPT services with mental health therapists being co-located in primary care • Develop joint agency plans with the provider to meet access and timeframe targets • Implement the pilot in Harrogate for Integrated IAPT Early Implementer • Participation in NHS England programme for digitally-enabled IAPT (details to be available autumn 2016)
To provide timely access to evidence-based, person-centred care for people with first episode psychosis, which is focused on recovery and integrated with primary and social care and other sectors.	53% of people experiencing a first episode to begin treatment with a NICE-recommended package with a specialist early intervention in psychosis (EIP) service within 2 weeks of referral (2018/19) 25% of teams rated as good in CCQI assessments (2018/19)	• Develop joint agency plans with the provider to meet quality and timeframe targets following national audit for 2017/18
A reduction in premature mortality of people living with severe mental illness (SMI) and more people having their physical health needs met by increasing early detection and expanding access to evidence-based physical care assessment and intervention each year	30% of people with SMI registered with a GP to have physical health screening / interventions (2017/18) 60% of people with SMI registered with a GP to have physical health screening / interventions (2018/19)	• Develop joint agency plans with the provider

Mental health: Adult

Adult mental health

Strategic Aims	Specific targets	What we intend to do
Increase access to Individual Placement Support enabling people with severe mental illness to find and retain employment.	Increase by 25% in 2019 against 2017/18 baseline	• Collect data to create a 2017/18 baseline • Develop joint agency plans with the provider • Implement workplace support workers as part of the IAPT services 2017/18
For all areas to provide crisis resolution and home treatment teams (CRHTTs) that are resourced to operate in line with recognised best practice – delivering a 24/7 community-based crisis response and intensive home treatment as an alternative to acute in-patient admissions.	To meet recommended best practice guidelines.	• Implement plans that will develop as a result of a review of current provision against core standards during 2016/2017. • Develop joint agency plans with the provider to ensure properly resourced crisis resolution and home treatment teams • Implement the safe haven schemes in York • Plan the safe haven schemes in Harrogate, Hambleton and Richmondshire and Scarborough • Consideration of potential additional crisis care capital investment bids in 2017/18 to improve health-based places of safety.
Eliminate inappropriate out of area treatments (OATs) for acute mental health care	Elimination of out of area placements for non-specialist acute care (2020/21)	• Develop joint agency plans with the provider to ensure robust monitoring of OATs for all bed types • Develop joint agency plans with the provider to ensure demonstrable reduction in acute OATs
Provision of 'core 24' mental health liaison services in emergency departments and inpatient wards in acute hospitals	Liaison mental health teams to be in place in all acute hospitals (2020/21) 'Core 24' services to be in place in 50% of acute hospitals (2020/21)	• Develop joint agency plans with the provider • Work within STPs to achieve buy-in across the organisations which will commission, provide and partner with those services and ensure that savings are identifiable in order to be reinvested. • Consideration of acute hospitals within the STP footprint that can serve as centres of excellence. • Consideration of models of crisis care for children and young people evaluated by NHS England during 2016/17

Mental health: Adult

Adult mental health

Strategic Aims	Specific targets	What we intend to do
To provide timely access to diagnosis and evidence-based, person-centred care for people with dementia	By 2019 half of CCGs should have diagnosed 67% of estimated local prevalence. By 2020 the number being diagnosed and starting treatment should be increased by over 5% compared to 2015/16 baseline.	• Review of services against forthcoming NHS implementation guidance focusing on post-diagnostic care and support and development of a plan to address the gaps. • Increase the diagnostic rates in all CCGs
Work with TEWV NY who are a pilot site on an NHS England led programme to put in place new approaches which strengthen care pathways to improve access to community support, prevent avoidable admissions, reduce the length of in-patient stays, and eliminate inappropriate out of area placements.	The pilot will be formally monitored and outcomes evaluated	• Develop a joint agency plan with the provider

Mental health: Adult

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Adult mental health		
Strategic Aims	Specific targets	What we intend to do
Provision of armed forces / veteran mental health services.	By 2020/21, all NHS-commissioned mental health providers will have armed forces champions and a specific named clinician with an expertise in military trauma.	• Develop joint agency plans with the provider 2017/19 • Support co-commissioning work with NHS England for the national procurement of local specialist community services, and investment in research to improve the evidence base on effective interventions for the armed forces community. 2017/18
Expand community-based services for people who require them to prevent avoidable admissions and support 'step down' and ongoing recovery in the community as soon as appropriate for the individual and as close to home as possible.		• Evaluate current pathways in and out of mental health secure care with a focus on expanding community-based services
Reduction in suicide levels	Reduction of 10% against 2016/17 baseline	• Implement local multi-agency suicide prevention plans together with local partners 2017-2020

Parity of Esteem	The CCG is working closely with partner organisations to raise the profile of mental health across the local economy giving it true parity of esteem. Several key strategic objectives for mental health have been included in the local Health and Wellbeing Strategy.
Carers	The local provider has begun to work with mental health carers to ensure that their voices are heard and services are further developed in terms of crisis response services. The local system was also successful in a capital bid to develop a local Safehaven facility.

Mental Health: Crisis and Liaison

Liaison mental health services (for adults, older adults children and young people)	The CCG and Provider are implementing an agreed and funded service development and improvement plan for a dedicated mental health crisis and liaison response for children and young people presenting to emergency departments, in wards and community settings which includes provision for a response across extended hours. The liaison service commissioned needs to provide a 1 hour response time following an Emergency Department referral and 24 hour response time following a ward referral (adults). The CCG is partially compliant currently.
	The CCG is working closely with the provider TEWV to quantify the number of patients and reasons for OAT and validate action plans to reduce the use of all types of mental health out of area placements. A trajectory for 2017/18 will be confirmed in Q4 of 2016/17. These will inform an Out of area treatment and plans to reduce the usage of out of area placements fo non-specialist acute mental health inpatient care. The CCG is partially compliant currently.
	Crisis resolution home treatment teams (adults) are being commissioned which offer intensive home treatment in line with recommended practice (i.e. by routinely visiting people at least twice a day the first three days of home treatment, providing twice daily visits when required thereafter, and routinely offering visits that allow enough time to prioritise therapeutic relationships and help with social and practical problems) The CCG is fully Compliant currently.
Crisis Concordat including Suicide	Likewise there has been a very strong crisis care concordat which has been very progressive in supporting projects such as Pathways Together which employs support workers to assist people with complex lives reduce their dependence on crisis, emergency and other statutory services. Psychiatric liaison and crisis response services are developing now across the Vale of York and are a key part of the local service offer in-reach into acute hospitals and emergency departments which will continue to grow and develop further. After a recent suicide audit the CCG and partners will develop an action plan to tackle future suicide rates by 10% against the 2016/17 baseline. All partners are committed to making the Vale of York a safer place.

Mental health: Children and Young People

Children and young people's Mental Health

Strategic Aims	Specific targets	What we intend to do
Increase access to high-quality evidence based mental health care treatment for children and young people.	Increase access by 7% in 17/18 Increase access to 32% by end 18/19	• Implement actions resulting from Local Transformation Plans for children and young people's mental health to be published on 31 October 2016 • Commission improved access to 24/7 crisis resolution and liaison mental health services which are appropriate for children and young people • Develop joint agency plans with the provider to achieve targets
Increase access to evidence-based community eating disorder services	95% of children in need receive treatment within one week for urgent cases, and four weeks for routine cases	• Commission dedicated eating disorder teams in all areas • Join QNCC ED • Baseline current performance against the access and waiting time standard 2016/17 and plan for improvement from 2017/18 • Develop joint agency plans with the provider to achieve targets
For in-patient stays for children and young people to only take place where clinically appropriate, to have the minimum possible length of stay, and to be as close to home as possible to avoid inappropriate out of area placements.	By 2020/21 elimination of in-patient stays where clinically inappropriate. Zero out of area placements for non-specialist acute care. Zero use of beds in paediatric and adult wards	• Implement actions resulting from collaborative commissioning plans with NHS England's specialist commissioning teams to be published by December 2016. These plans will include locally agreed trajectories for aligning in-patient beds to meet local need and where there are reductions releasing resources to be redeployed in community-based services • Move towards all general in-patient units for children and young people to be commissioned on a 'place-basis' by localities, so that they are integrated into local pathways • Utilise money released from pump-priming of 24/7 crisis resolution and home treatment services to achieve further improvements in access and waiting times • Develop joint agency plans with the provider to achieve targets

Mental health: Children and Young People

Children and young people's Mental Health

Strategic Aims	Specific targets	What we intend to do
For all areas to be part of CYP IAPT including taking part in workforce capability programme.	National target for at least 1,700 more therapists and supervisors to be employed to meet additional demand.	• Commission CYP IAPT in all areas in 2017/18 • Ensure that all services are working within the CYP IAPT workforce programme. • Implement joint agency plans between CCGs and providers to ensure continuing professional development of staff
To ensure availability of 24/7 urgent and emergency mental health services for children and young people.		• Collect data to create a 2017/18 baseline • Develop joint agency plans with the provider to achieve targets

Perinatal mental health

Strategic Aims	Specific targets	What we intend to do
Increase access to evidence-based specialist perinatal mental health care	100% access by 2020/21	• outcome of bid to perinatal community fund expected October / November 2016 • If bid unsuccessful plan 2017/18 for service • Include service in mainstream CCG allocations from 2019/20

Mental Health: Children and young people

Vale of York
Clinical Commissioning Group

The CCG is working closely with key partners to building sustainable system wide transformation to deliver improvements in children and young people’s mental health outcomes	
The CCG is working with partners updated and re published the assured local transformation plan (LTP) from 2015/16 which includes baseline data The CCG has published the refresh of the Local Transformation Plan on its website. Baseline data is being currently being collated, which needs to be incorporated into the published plan to make this action fully compliant..	Partially compliant
The CCG is working closely with the provider TEWV on developing collaborative commissioning Tier 3 and 4 CAMHS plans. In addition TEWV are part of a pilot for Tier 4. It is expected this action will be compliant by end of December 2016.	Partially compliant .
The CCG will publish the joint agency workforce plans detailing how they will build capacity and capability including implementation of Children and Young People’s Improving Access to Psychological Therapies programmes (CYP IAPT) transformation objectives. This action is part of the Local Transformation Plan, to be completed this year (16/17).	Partially compliant
Development of new adult and older people’s inpatient, treatment and assessment facility. The CCG has identified the need for fit for purpose mental health estate and facilities supported by significant consultation as a key priority for transformation since 2015.	Partially compliant

Mental health: Quality Targets

Vale of York
Clinical Commissioning Group

Other areas		
Strategic Aims	Specific targets	What we intend to do
Increased levels of patient satisfaction as recorded by the Friends and Family test	Maintain or increase the number of people recommending services (currently 88-96%)	• Work with providers to ensure feedback improves services
Increase uptake of Personal Health budgets	1-2% of population to have a personal health budget by 2020	• Review and implement action plan developed by Personal Health Budget Steering Group • Work with CCGs to promote the PHB service
Improved access to healthcare	75% of those with LD on a GP register to receive an annual health check	
Support delivery of a 24/7 integrated care service for physical and mental health	An integrated care service for physical and mental health should be implemented by March 2020 in each STP footprint including a clinical hub that supports NHS 111, 999 and out-of-hours calls.	• Work with partners to develop a delivery plan including using a cross-system approach to prepare for a forthcoming waiting time standard for urgent care for those in a mental health crisis.
Use of accountable payment approaches which have a payment component linked to quality and outcomes.		• Implement for adult mental health in 2017/18.

Mental health: Dementia Access Plan

NHS
Vale of York
Clinical Commissioning Group

Item	Action	Lead	Start	Measure/outcome	By when	Progress
1	Monthly review of activity from eMBED	PH/LB	w/c 7/11	October primary care coding result	10/11	Complete
2	Draw up list of practices to contact	PH/LB	w/c 7/11	6 larger practices identified	10/11	Complete
3	Discuss with clinical executive	LB	w/c 7/11	Garner support as agents for change	10/11	Complete
4	Contact 7 key practices	LB	w/c 14/11	Practices booked in diary	21/11	Complete
5	Discuss with Council of Representatives	LB	w/c 14/11	Gain commitment to improve	17/11	Complete LB spoke to PE
6	Update NHS England Quality Team	PH/LB	w/c 14/11	Work through funding agreement	24/11	Complete
7	E-mail to promote increased levels of coding	PH/LB	w/c 21/11	E-mail to "targeted" practice managers	24/11	Complete LB to chase 19/12
8	Raise profile at GP Education Event	LB	w/c 28/11	Gain greater uptake	28/11	Complete
9a 9b	Update Finance & Performance and Governing Body	PH LB	w/c 28/11 w/c 28/11	- Update performance report - Provide verbal update on progress	01/12 01/12	Complete Complete
10	Monthly review of activity from eMBED	PH/LB	w/c 5/12	November primary care coding result	08/12	Complete
11	Update SMT	PH/LB	w/c 12/12	Provide update on progress	13/12	Complete
12	Review practice activity & contact next group of practices below 67%	PH/LB	w/c 12/12	Gain commitment to improve	16/12	Complete
13	Discuss with Clinical Executive	LB	w/c 12/12	Gain support to improve further	16/12	Internal discussion To update January 2017
14	TEWV new Older People Community Team to support initiatives	TEWV	w/c 9/1/2017	Support to practices & care home settings to raise & sustain coding levels	31/3/17	Awaiting further details
15	Draft GP bulletin – mental health	PH/LB	w/c 19/12	Focus on dementia coding feature	20/12	To draft
16	Update Council of Representatives	LB	Feb 2017	Raise coding level beyond 67%	28/2/17	To be completed

Services for People with Learning Disabilities

Learning Disability

Strategic Aims	Specific targets	What we intend to do
Implementation of Transforming Care Partnership plans		• Deliver published plans with local government partners enhancing community provision for people with LD and/or autism • Develop alternatives to hospital care, crisis services and community support 2016/17/18
Reduction of LD inpatient bed capacity	By 2019 there is a national target of a reduction of CCG-commissioned beds to 10-15 per million and of NHS-commissioned beds to 20-25 per million.	
Improved access to healthcare	75% of those with LD on a GP register to receive an annual health check	• Work with primary care and providers to develop
Reduction of premature mortality for those with autism and/ or LD		• Work with partners to reduce mortality by improving access to health services, education and training of staff and by making reasonable adjustments

Services for People with Learning Disabilities

Building The Right Support agenda	With the approval of NHS England the CCG has joined with neighbouring CCGs to developing a shared plan to deliver the Building The Right Support agenda by creating a transforming care partnership across North Yorkshire and York
Reduction in inpatient capacity target	Mindful of the requirement to reduce inpatient capacity to the required levels, the CCG has already worked with its provider and closed one inpatient facility. Plans are progressing to support the provider in creating responsive teams to support people in their own homes rather than admitting people to hospital environments. The CCG is working closely with local authority partners, NHS England and its fellow North Yorkshire and STP CCGs to ensure that the system has the capacity to do this in the safest way possible as service users pass down through forensic and acute services in the national drive to transform the care of people with learning disabilities.
Coding of LD in general practice	Locally and in conjunction with its provider organisation and the local authority partners the CCG is developing resources to improve coding in primary care records as well as promoting the uptake of annual health checks. Although this will be challenging, the provider is willing to support education events for primary care staff.
Building The Right Support agenda	With the approval of NHS England the CCG has joined with neighbouring CCGs to developing a shared plan to deliver the Building The Right Support agenda by creating a transforming care partnership across North Yorkshire and York.

Services for People with Learning Disabilities

Deliver Transforming Care Partnership plans with local government partners, enhancing community provision for people with learning disabilities and/or autism.	A **Transforming Care Partnership Board (TCP**) has been established to manage and deliver the 'Building the Right Support' (BTRS) agenda across the York and North Yorkshire geographical footprint; including representatives from Clinical Commissioning Groups (CCGs) supported by the Partnership Commissioning Unit (PCU), Local Authorities and Provider organisations. An 'Enhanced' Community Learning Disability Service; providing Positive Behavioural Support (PBS), the introduction of an out of hours Learning Disability Crisis service covering North Yorkshire and York, and the introduction of specialist early intervention nurses to prevent admission to hospital will be operation from early 2017. Work is also ongoing to enhance the learning disability workforce, develop the provider market and ensure seamless transitions through preparing for adulthood through specialist workstream groups. A programme of co-production is underway.
Reduce inpatient bed capacity by March 2019 to 10-15 in CCG-commissioned beds per million population, and 20-25 in NHS England-commissioned beds per million population. Consideration needs to be given over as to how the CCG will prepare for these developments.	The Transforming Care Partnership (TCP) has set a downward trajectory to ensure meeti the required reduction of inpatient beds over the three year length of the programme. The CCG is currently meeting its trajectory to reduce CCG commissioned beds. However, the TCP area as a whole is slightly off trajectory due to increased activity in specialist commissioned beds. Work to progress achievement of the combined bed reduction trajectory is being managed through the TCP with support from NHSE Area team. Work is ongoing (as described above) to ensure the community support is in place to facilitate discharge from hospital settings and ensure re-admission rates are minimal.
Improve access to healthcare for people with learning disability so that by 2020, 75% of people on a GP register are receiving an annual health check.	Latest figures the CCG has shown that across Vale of York 51% of people with a Learning Disability have had a health check within Primary Care. Clearly there is further work to be undertaken to achieve 75% and we are working with Primary Care Colleagues to progress this. Increasing the offer of Annual Health Checks and Health Action Plans is a CQUIN in 16/17 for our statutory Learning Disability Provider.
Reduce premature mortality by improving access to health services, education and training of staff, and by making necessary reasonable adjustments for people with a learning disability or autism	The CCG is part of a countywide Learning Disability Screening Task Force. This group is working to increase the numbers of people with a Learning Disability who have cancer screening (particularly Breast, Bowel and Cervical Cancers). The CCG is working with Primary Care and providers to ensure accessible information and reasonable adjustments. We are heavily involved in the local Partnership Boards to progress this work.

Complex Healthcare Services: CHC

Although Vale of York ranks at an average position across CHC and FNC in total, there are potentially areas of savings, if the CCG were to move closer to the lower end of the comparators.

The area for which Vale of York CCG is an outlier, primarily relates to Joint Funded Care. The CCG is both an outlier in terms of activity and unit cost.

For Joint Funded Care, however, VoYCCG has the second highest volume of activity per 50,000 population and the second highest unit cost, with only Scarborough and Ryedale CCG ranking higher. This would suggest that the health contingent of Joint Funded packages is significantly higher than other CCGs or that these joint packages are higher cost in total.

CCG will review potential areas of savings related to CHC and FNC in more detail and through discussion with other commissioning organisations. For example the CCG could consider approaches such as:

- Applying a block contract to a range of providers for blocks of activity, rather than negotiating individual packages of care

- As stated in previous CCG recommendations, the CCG could consider linking with Local Authorities and passing over negotiation of packages to them. Evidence suggests that Local Authorities are more successful in generating lower rates than for health

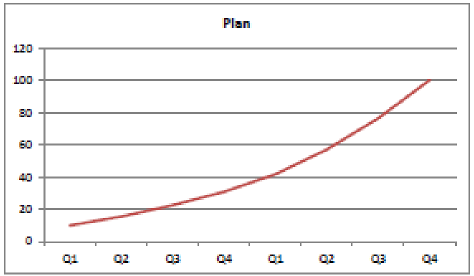
- Investigating whether the strengthening of community and primary care services may be a more cost-effective approach than necessarily commissioning expensive nursing packages

Personal Health Budgets (PHBs)

NHS
Vale of York
Clinical Commissioning Group

The current trajectory based on identification of 1-2% of the CCG population by March 2019 is outlined below and has been submitted on behalf of the CCG on 24.11.16

		E.N.1	Q1	Q2	Q3	Q4
Personal Health Budgets	2017/18 Plan	1) Personal health budgets in place at the beginning of quarter (total number per CCG)	20	35	55	80
		2) New personal health budgets that began during the quarter (total number per CCG)	15	20	25	30
		3) Total number of PHB in the quarter = sum of 1) and 2) (total number per CCG)	**35**	**55**	**80**	**110**
		4) GP registered population (total number per CCG)	356,701	356,701	356,701	356,701
		Rate of PHBs per 100,000 GP registered population	**9.81**	**15.42**	**22.43**	**30.84**
	2018/19 Plan	1) Personal health budgets in place at the beginning of quarter (total number per CCG)	110	150	205	275
		2) New personal health budgets that began during the quarter (total number per CCG)	40	55	70	85
		3) Total number of PHB in the quarter = sum of 1) and 2) (total number per CCG)	**150**	**205**	**275**	**360**
		4) GP registered population (total number per CCG)	358,917	358,917	358,917	358,917
		Rate of PHBs per 100,000 GP registered population	**41.79**	**57.12**	**76.62**	**100.30**



The CCG has started to develop the delivery programme required to start meeting the challenging trajectory for PHBs identified by NHSE and Local Government.

This will include both the associated programme requirements and costs, and the running costs of delivering the PHB assessment and implementation once clients are identified from the cohorts identified by national mandate as being appropriate for PHBs.

It is likely that this programme of work would be taken forward collaboratively on a HCVSTP level in order to ensure consistency of approach and shared good practice.

In line with the Five Year Forward View, personal health budgets are part of the wider drive to give people more choice and control. They have real potential to improve outcomes, quality of care and reduce people's reliance on unplanned acute care by enabling people living with long term conditions and disabilities to manage their health in ways that work for them. Both the Government's Mandate to NHS England for 2016-17 and NHS Operational Planning and Contracting Guidance for 2017-19 reaffirm the Government and NHS England's commitment to the rollout of personal health budgets.

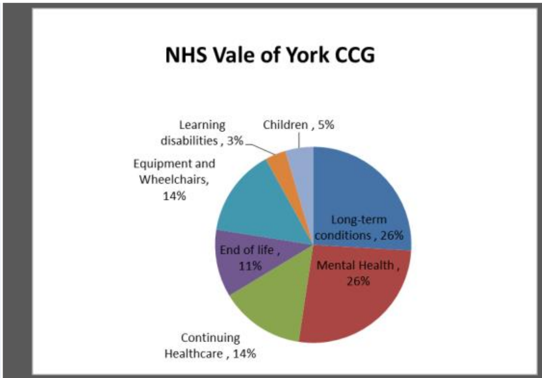
CCGs should consider making personal health budgets a mainstream way of delivering NHS Continuing Healthcare. The Mandate sets a clear expectation that 0.1% of every local population will have a personal health budget or integrated personal budget by 2020. The Integrated Personal Commissioning (IPC) Programme is shaping the way the health and social care system will work for people with complex needs in future. CCGs need to ensure they are considering equally the access to personal health budgets for mental health.

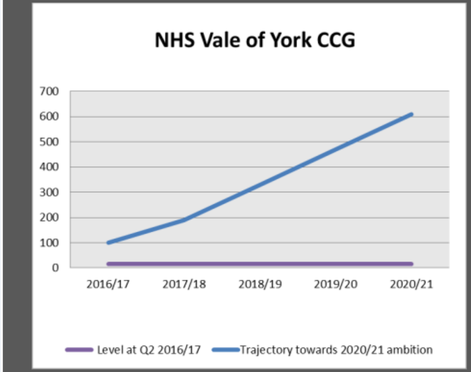
Personal Health Budgets: National Mandate requirements

NHS Vale of York Clinical Commissioning Group

The STP Aide-Memoire on personalisation and choice describes the actions STPs and CCGs need to undertake in relation to PHBs.

- Local areas need to set out what they have done or are doing to identify groups of people who may benefit from having a personal health budget.
- Local areas need to consider the financial aspects of introducing personal health budgets and integrated personal budgets at scale, for example how to avoid double running costs.
- Local areas need to set out how they plan to work with providers to free up funding (or identify sources of funding) for personal health budgets and integrated personal budgets. It is important that personal health budgets and integrated personal budgets are introduced in a sustainable way so areas will want to take a staged approach to avoid destabilising current services.
- Local areas need to set out how they will ensure people have the right level of support and that processes are in place to enable this support to be available.
- It is important that CCGs/STP Footprints work with local people to develop their commissioning intentions and the local offer for personal health budgets.
- Local areas need to set out how they will work across health and social care to ensure integrated personal budgets become a reality and how they plan to keep abreast of the latest learning from IPC Programme.
- As local STP Footprints are cross agency, areas should align their personal health budget systems and process, sharing elements of the process where possible. This will ensure that people can move seamlessly from one system to another, particularly where place-based systems of care are beginning to emerge, for example, for people with learning disabilities or for children with special educational needs and disabilities.





The population cohorts outlined for targeting include:
NHS Continuing Care
Joint-funded arrangements
Mental health
Learning Disabilities & Autism
Children and Young People
Long-term conditions
End of Life
Equipment including wheelchairs

Better Care Fund

Three Better Care Funds with three local authorities covering 100% of our population	The Better Care Fund link between CCG and local authorities will progress and build in 2017/18 through the emerging Accountable Care System and associated Partnership Board and locality delivery groups. Local delivery groups will be developing a shared agenda and priorities/ areas of common concern for their local areas which will deliver measurable benefit and impacts to their local population. The current BCF schemes could be integrated within these emerging transformative partnership programmes. The intention is to maintain or grow current levels of BCF investment through this partnership working.

Elective Care and delivery of our RTT Targets

The CCG will deliver the NHS Constitution standard that more than 92% of patients on non-emergency pathways wait no more than 18 weeks from referral to treatment (RTT), returning to a sustainable position in 2018 based on the following improvements:

Reduce unnecessary outpatient appointments

1. Maintaining and continually improving its demand management through its ongoing development of referral guidelines and clinical thresholds; continuation and expansion of its Referral Support Service (referral management centre) and expanding the number of specialties where clinical review of referrals (i.e. peer review of referrals) take place.
2. Looking at innovative ways in which referrals can be confirmed as appropriate e.g. use of dermatascopic images for dermatology referrals reviewed by clinicians before being confirmed as appropriate
3. Collaboratively working with specialist consultants (dermatology, endocrinology, neurology, diabetes)to provide an initial review of referrals
4. Utilising Referral Support Service to review all 2 week waits to ensure that all those needing such appointments are seen in a timely manner.
5. The RSS was introduced in April 2013 and in that financial year reduced overall outpatient demand by 8%. During the intervening years it has helped maintain demand at or below growth levels – see next slide to show that the CCG is still within the top 10 performers for North CCGs for benchmarking of demand.
6. The CCG continues at innovative ways of maintaining services in the community and has introduced a gain/share approach with GP Federations to reduce the number of dermatology referrals going onto secondary care (April-August figures indicated a £45,000 reduction in expenditure for those federations taking part)
7. The CCG is scoping the potential of expanding this scheme to gynaecology, ENT and gastroenterology

Elective Care and delivery of our RTT Targets

NHS
Vale of York
Clinical Commissioning Group

Delivery of patient choice of first outpatient appointment, and achieve 100% of use of e-referrals by no later than April 2018 in line with the 2017/18 CQUIN and payment changes from October 2018

Note the ERS service is undertaken by the CCG's Referral Support Service on behalf of GP practices
Latest figures from NHS Digital indicates 65% usage of e-referrals (as at July 2016 – an 11% improvement from the previous year).
During 2017/18 CCG will be working with secondary care colleagues to achieve identified target through:
Taking all MSK and onward Orthopaedic referrals through the RSS (currently undertaken by the existing MSK provider)
Work with secondary care colleagues to ensure that they will only accept electronic referrals

Streamline elective care pathways, including through outpatient redesign and avoiding unnecessary follow-ups

Please note that in 2013 the CCG in collaboration with York Hospital introduced a Conditions Register that identified areas/conditions for follow-up – this successfully reduced the 1st:Follow Up rate to below 1:2. Consideration to be given to utilise this to audit the appropriateness of follow-ups in relation to this during 2017/18. This incorporates improvements in both elective and non-elective pathways

- During 2016/17 the CCG was a first-wave organisation to implement the new RightCare programme and is currently working pathways to improve performance across, all to be in place during 2017/18:
- MSK services (including Orthopaedic activity, particularly looking to reduce hip and knee surgery rates and knee arthroscopies). To support this the CCG in collaboration with all partners in the health system, will implement a new integrated MSK model by April 2017
- Circulation – looking across the whole health system to improve performance in chronic heart disease, stroke and arterial fibrillation
- Gastroenterology

All the above link in to work incorporated into the Hull, Coast & Vale STP work programme and as such the CCG will take the lead for the RightCare approach for MSK (including General MSK/Pain Management/Orthopaedics/Rheumatology/Osteoporosis/Trauma & Injury) & Gastroenterology across the whole footprint.

- The CCG will also instigate a second phase of RightCare that will reflect elective care pathways for Respiratory and Neurology
- Work will also take place with STP partners identifying the potential for developing options for Ophthalmology service provision across the whole footprint. This to be initiated by a meeting in December of all concerned providers and commissioners. A finalised approach to confirmed by April 2017.
- Workstream to review outpatient service provision and scoping out how this can be delivered in a more effective, efficient and viable manner

Cancer Alliance: Workplan (for approval January 2017)

Working through Cancer Alliances and the National Cancer Vanguard, implement the cancer taskforce report:

The Cancer Alliance will be acting as the delivery arm of the STP Cancer Plan. The cancer element of the STP plan is aligned to delivery of the cancer taskforce recommendations. An initial piece of work reviewing the STP cancer work plan against the 96 recommendations has been undertaken and is attached for information.

- VOY and SR CCGs are represented on the Cancer Alliance Board and will actively work together across organisations to implement the Cancer Task Force Recommendations.
- The STP cancer plan also contains potential for simplified arrangements between providers and commissioners.
- The Scarborough/York Cancer Locality Group will update its existing work plan to ensure it underpins the STP priorities and delivers at local and COG (VoY and S&R) level

Ensure all elements of the Recovery Package are commissioned, including ensuring that:

- **All patients have a holistic needs assessment and care plan at the point of diagnosis**
- **A treatment summary is sent to the patient’s GP at the end of treatment and**
- **A cancer care review is completed by the GP at the end of treatment**

The STP section on digital enablers contains the need for sharing information on holistic need and treatment summaries. The ambition is to make the recovery package available to all people living with and beyond in 2017/18. A baseline assessment of what is in place across the region is being undertaken by the network. There are both CCG and STP level groups in place to support advancement of this agenda. A working group, including providers and commissioners has been formed across York and Scarborough.

Cancer Alliance: Workplan (for approval January 2017)

Deliver the NHS Constitution 62 day cancer standard, including by securing adequate diagnostic capacity and the other NHS Constitution cancer standards. If this standard is not currently being consistently delivered then please describe the anticipated date of recovery:	The cancer work stream of the STP is working together with the acute and specialist work stream re diagnostics. Initially providers are tasked with undertaking demand and capacity reviews and these are underway. They are also advising of estimated gaps in kit such as CT and MRI for the next 5 to 10 years so that the capital and estate impact can be quantified. As part of this we will also be looking at GP direct access. There is a Yorkshire and Humber intention to procure a PAC system that will initially support shared viewing of images and later potentially, also shared capacity for diagnostics and reporting. The Humber, Coast and Vale providers are linked into this (York/Scarb trust is not part of the procurement as they have just procured new kit but they are hoping to be linked in to the sharing of images and perhaps capacity). A decision will need to be made regarding whether this system is best used Yorkshire and Humber wide or on Humber Coast & Vale footprints. We will be looking to design a new model of sustainable diagnostics and the solution to this will need to fit urgent and emergency care ambitions as well as with any redesign that results from the acute and specialist work stream. We are also linking with the West Yorkshire alliance to determine where we can gain greater benefit from working together on this. We work with our local provider to monitor performance and to understand where and why breaches are occurring. We have an agreed provider IPT policy in place that will support the identification and removal of barriers to achieving 62 days. Additionally, the pathways work (including lung) and the high value pathways work across Yorkshire and the Humber should support streamlining of pathways and adherence to best practice, enabling patients to move more effectively through the system. A piece of work reviewing current achievement against 28 day diagnosis has been undertaken and actions required as a result of this will be identified through the cancer STP work stream and taken forward.

Cancer Alliance: Workplan (for approval January 2017)

Make progress in improving one-year survival rates by delivery a year-on-year improvement in the proportion of cancers diagnosed at stage one and stage two; and reducing the proportion of cancers diagnosed following an emergency admission: **In addition to the diagnostic programme of work mentioned above which will increase the capacity within diagnostics to support earlier diagnosis we will also:**	• The work of the lung element of the cancer STP aims to increase the proportion of lung cancers diagnosed at Stage 1 and 2 and to match the current best in England. Similarly, we would hope that further work on the high value pathways across Yorkshire and Humber will drive improvements in early diagnosis, (through reviewing the place of diagnostics in each pathway) quality of care and consequently survival rates. • We will continue to support primary care to refer suspected cancer cases early via the 2 week wait system through the use of site specific 2ww forms (developed by our Cancer Clinical leads & provider colleagues). • Our CRUK facilitator is available to provide GP training in cancer related issues via the GP Educational Development forum. • CRUK are also working with the lead GP to support practices to review their cancer Practice Profiles through 1:1 meetings with practices and will continue to monitor for improvement. • We will work with CRUK to explore the potential for community champions that can increase public awareness of signs and symptoms of cancer and the need to present early.
Ensure stratified follow up pathways for breast cancer patients are rolled out and prepare to roll out for other cancer types:	The STP plan contains the intention for implementation of risk stratified pathways for breast, prostate and colorectal patients. The lead nurse is working within the trust to develop plans for this, and the breast team are already looking to develop a pathway. A risk stratified pathway for colorectal is already in place at the York site. The team also has strong links with the HCV wide Living with and Beyond Programme which aims to support developments across the regional footprint.

Cancer: local CCG programmes

Cancer Alliance	By deploying our Network Support managers the CCG has had regular and sustainable attendance at the developing Cancer Alliance and STP led cancer strategy meeting. The alliance and STP led groups are tasked with working with providers to develop plans and implement the cancer taskforce report.
Constitutional targets – sustained performance	Although the CCG is proud to be one of the top seven CCG's in the country in terms of cancer performance, it is determined to work hard to continue to deliver sustained performance in line with constitutional targets. It has successfully implemented the NICE approved guidance on 2 week wait pathways for the different types of cancer and these are now an integral part of the local Referral Support System.
Chemotherapy	Locally, the York Against Cancer charity has purchased a mobile chemotherapy truck to deliver services closer to home. The same charity has also worked with the CCG to purchase dermatoscopes to facilitate electronic referrals being supported by photographic evidence of suspicious skin lesions.
Screening uptake increases	Our provider and our Macmillan GP clinical lead for cancer are working to develop screening packs to encourage and support the increased uptake of cancer screening.
Survivorship recovery	Macmillan have agreed to fund two local projects bids supported by the CCG. One will look at improving care co-ordination for people on cancer pathways over the next two years whilst the other will work on delivering a complete Recovery Package for the next three years, promoting survivorship.

Maternity: emerging strategy for local and HCVSTP collaborative development

NHS
Vale of York
Clinical Commissioning Group

CCG Maternity quirements Nov 20

Draft maternity strategy HCV

Implement the national maternity services review, Better Births	**Reduce stillbirths, neonatal and maternal deaths and brain injuries caused during or soon after birth, (measurable reduction by 2020, 50% by 2030).**
• Develop an STP maternity commissioning strategy to reflect the national maternity review including VoY specific actions. Implement service redesign through service specifications to increase provision of choice of place of birth • Consideration of options for out of hours appointments • Monitor the implementation of providers Action Plan, detailing how they will implement the recommendations by 2020 • Development of new service specifications	• Work with providers to implement all aspects of the 'Saving Babies Lives' care bundle. • Provider to consistently collect and review data at multidisciplinary forum,=. Include implementation of lessons learnt, on all stillbirths on an annual basis as a minimum. • Providers to promote external review of cases • Providers to communicate all the outcomes to the lead commissioner through an agreed governance route with evidence of responding to local trends or themes • Provision of specialist postnatal bereavement support

Maternity: emerging strategy for local and HCVSTP collaborative development

Smoking reduction (Latest data from the IAF for VoY CCG (Q 1, 16/17) shows that the % of smokers at the time of delivery is 12.0%, national rate of 10%)

- Providers to continue to receive detailed data as per the service specification
- Obtain assurance that providers are providing brief intervention at booking and every contact where appropriate and have had training
- Work with CYC colleagues to review provision of smoking cessation support
- Work with primary care colleagues to support smoking cessation advice and support

Increase access to evidence-based specialist perinatal mental health care (100% access by 2020/21)

- Plan to bid in 2017/18 for increased service provision
- Include service in mainstream CCG allocations from 2019/20
- Review access to midwives postnatally
- STP review of available services and models of care
- Establishment of a specialist postnatal de-brief service

Healthy weight promotion during pregnancy

- BMI recorded at booking
- Support extension of healthy eating and weight maintenance programme in pregnancy to patients with raised BMI as well as gestational diabetes
- Work with Public Health to support access to Healthy weight support and exercise information
- Work with PHE/CYC colleagues to develop/implement a local obesity strategy

Maternity Choice and Personalisation Pioneers test i the concept of a Personal Maternity Care Budget (PMCB)

Developing a Local Offer programme.

Tools and resources developed for the programme will help STP Footprints and CCGs to think through how to successfully implement personal health budgets and integrated personal budgets in line with the mandate Requirements

Review of Quality Indicators

- Receive and review regional and local maternity dashboards
- Regular meetings to review quality of all aspects of maternity services with providers develop quality indicators across STP footprint through the STP Quality Leads meeting

Specialised Commissioned Services: complex neuro-rehabilitation services

NHS
Vale of York
Clinical Commissioning Group

NHSE Specialised Commissioning (Yorkshire and the Humber) review of Specialised Rehabilitation for patients with complex needs (adults with TBI and ABI)

The CCG awaits the outcome from the NHSE Yorkshire and Humber review of specialised rehabilitation services for complex neurological conditions and will appraise the options for the future commissioning of these services. We will aim to work collaboratively to support the development of the Yorkshire and Humber wide commissioning pathway with standards as set out in the NHS England Specialised Rehabilitation for patients with complex needs service specification.

During 2017/18, Phase one of the delivery plan will address NHSE specialised commissioning and the preferred option will be presented to SCOG on the 2nd December.

Phase two in 2018/19 will address the neuro-rehabilitation services that are commissioned by CCG's.
The aim of the review is to improve and standardise the quality and availability of specialised rehabilitation for patients with complex needs due to acquired brain injury by providers able to meet the requirements as set out by the British Society of Rehabilitation Medicine (BSRM) and the Commissioning Guidance for Rehabilitation (NHS England 2016 https://www.england.nhs.uk/ourwork/qual-clin-lead/ahp/improving-rehabilitation/)

There is evidence within 'The Commissioning Guidance for Rehabilitation' that maximising an individual's independence and activity levels will reduce care costs, keep them in work and reduce the risk of their acute admission.
Collaborative commissioning is important, but so is collaborative delivery; complex neuro-rehabilitation lends itself to cross system delivery partnerships.

Improving Quality in Our Organisations

Our plans to improve quality of care, particularly for organisations in special measures.

Draft Quality
egy VoYCCG Nov

Each commissioned provider is contractually required, to submit information on recognised indicators relating to patient safety, quality and clinical effectiveness of services. These include

- Patient experience information from internal and external surveys, Family and Friends, complaints and PALS information
- Incident and Serious Incident reporting data, compliance with national and local reporting timeframes. Quality of reporting, analysis, including medication errors, never events and completed investigation reports
- Infection prevention and control measures, including clinical practice, environmental audit data and numbers of healthcare –associated infections and outbreaks of infections identified

Where the CCG is not the lead contractor robust systems exist to challenge quality assurance based on the recognised indicators above.

In addition the CCG has developed their Quality Assurance Strategy and Action Plan which describes how the CC

- Routinely measure and monitor all quality indicators and data within the contract in line with NHS England's Qua Monitoring and Escalation Process.
- Continues to plan clinical visits and walk rounds across provider organisations
- Hears and recognises the voice of the person, their carers and families through complaints / compliments / surveys and development of key relationships with Healthwatch and others such as the Maternity Services Liaison Committee and Older Peoples Forum
- Ensures there is on-going scrutiny of Risk Registers
- Collects and scrutinises soft intelligence through the CCG portal 'Yor-Insight' and partnership working
- Maintains dialogue with Quality Leads across Yorkshire and Humber and participation in key pieces of work such as the National Maternity Review Assurance
- Contribution to inspections and monitoring of action plans from CQC and others
- Shares information and intelligence across the system and enacts appropriate escalation via Quality Surveillance Groups (NHSE)
- Rigorously applies safeguarding processes (currently there are no providers in special measures)

Improving Quality in Our Organisations

National Quality Board's resources, measure and improve efficient use of staffing resources to ensure safe, sustainable and productive services

Utilising skills in patient safety improvement, the CCG has mechanisms in place to support providers, relevant to the Carter productivity and efficiency report which makes clear; improving workforce efficiency can benefit patient care through better recruitment and retention of permanent staff, better rostering, reduced sickness absence, matching work patterns to patient need, and reduced dependency on agency staff.

The development of new service models means building teams across traditional boundaries and ensuring they have the full range of skills and expertise to respond to patient need across different settings. The CCG is an active participant in developing workforce plans that support the Sustainability and Transformation Plans and new models of care.

The National Quality Board's safe staffing improvement resource is integral to the CCG's clinical visits and walk rounds with provider organisations.

Participation in the annual publication of findings from reviews of deaths, to include the annual publication of avoidable death rates, and actions they have taken to reduce deaths related to problems in healthcare

The CCG continues to support providers to develop effective strategies for learning from mortality and reduction of avoidable deaths. Development of assurance based on the robustness of the investigation behind the Standard Hospital Mortality Rate figure is key as part of this process.

The CCG's main provider is participating in the National Mortality Case Record Review Programme. The aim of the 3 year programme is to understand and introduce a standardised methodology for reviewing case records of adult patients who have died in acute general hospitals in England and Scotland.

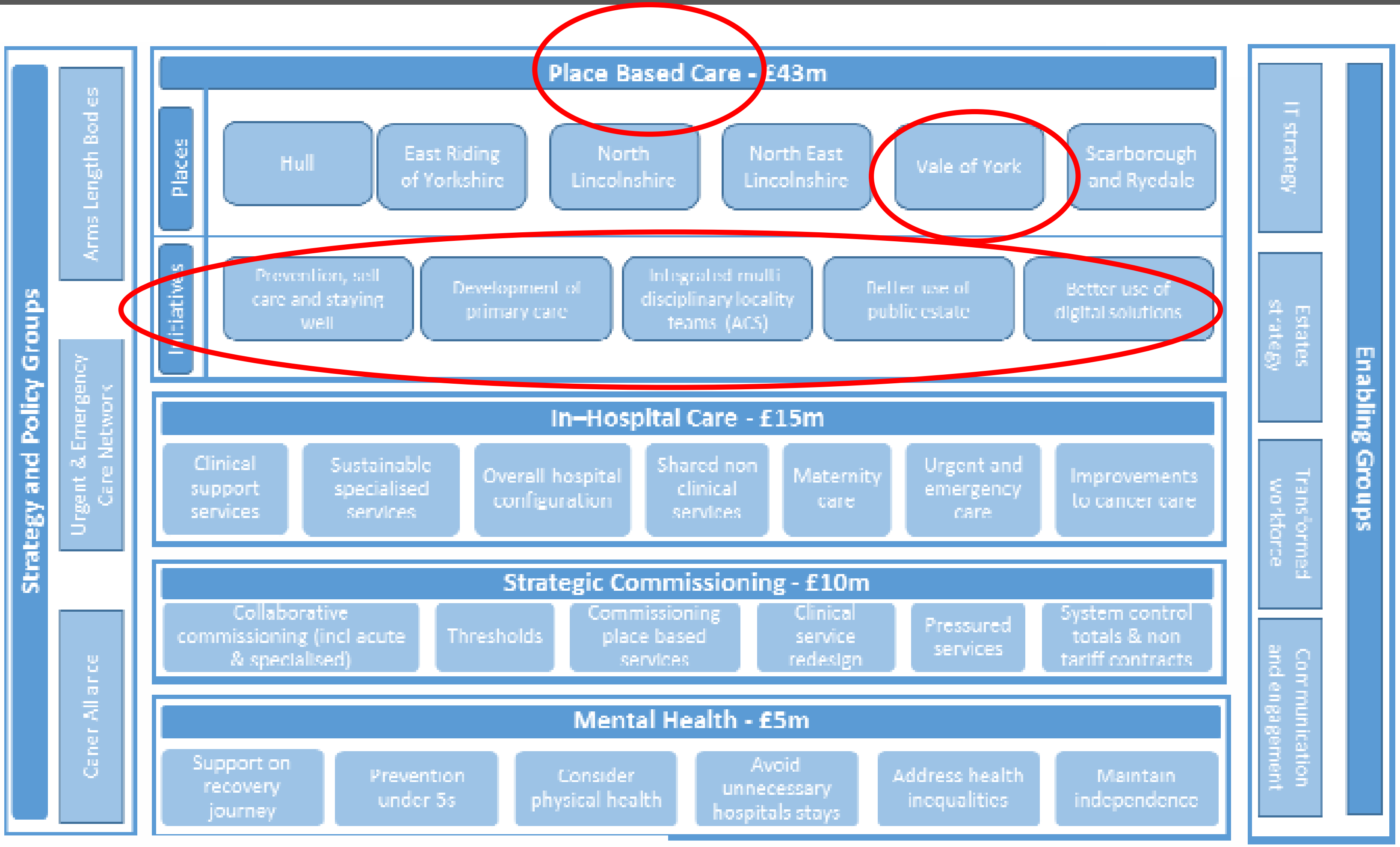
Alongside the work relevant to reduce premature mortality as part of the countywide Learning Disability Screening Task Force the CCG is seeking assurance from all providers about their action to reduce death related problems. In addition, the CCG will continue to seek assurance from our providers in response to the Learning Disability Mortality Review (LeDeR) pilot and work with Primary Care to raise awareness. This includes strengthening Learning Disability Registers and the requirements for annual health checks.

The CCG is also an active participant in reducing mortality for people with serious mental health and ensuring that Mental Health Providers are feeding back progress and developments. In addition the North Yorkshire and York Suicide Task Prevention Group and Early Suicide Surveillance Group review data on a quarterly basis to detect themes and subsequent actions to address this. The plans are to also include all drug and alcohol deaths and apply the same process.

The HCVSTP – Local Programmes for Place Based Care

NHS
Vale of York
Clinical Commissioning Group

The CCG collaborates across the Humber Coast and Vale STP along with the 5 other local ‘places’ (CCGs). The HCV STP currently identifies a range of local ‘place-based’ transformations which all 6 CCGs are delivering. These are captured in our Plan on a Page with our local VoY system partners and define our priority programmes of work.



Strategy and Policy Groups
- Arms Length Bodies
- Urgent & Emergency Care Network
- Cancer Alliance

Place Based Care - £43m

Places
- Hull
- East Riding of Yorkshire
- North Lincolnshire
- North East Lincolnshire
- Vale of York
- Scarborough and Ryedale

Initiatives
- Prevention, self care and staying well
- Development of primary care
- Integrated multi disciplinary locality teams (ACS)
- Better use of public estate
- Better use of digital solutions

In–Hospital Care - £15m
- Clinical support services
- Sustainable specialised services
- Overall hospital configuration
- Shared non clinical services
- Maternity care
- Urgent and emergency care
- Improvements to cancer care

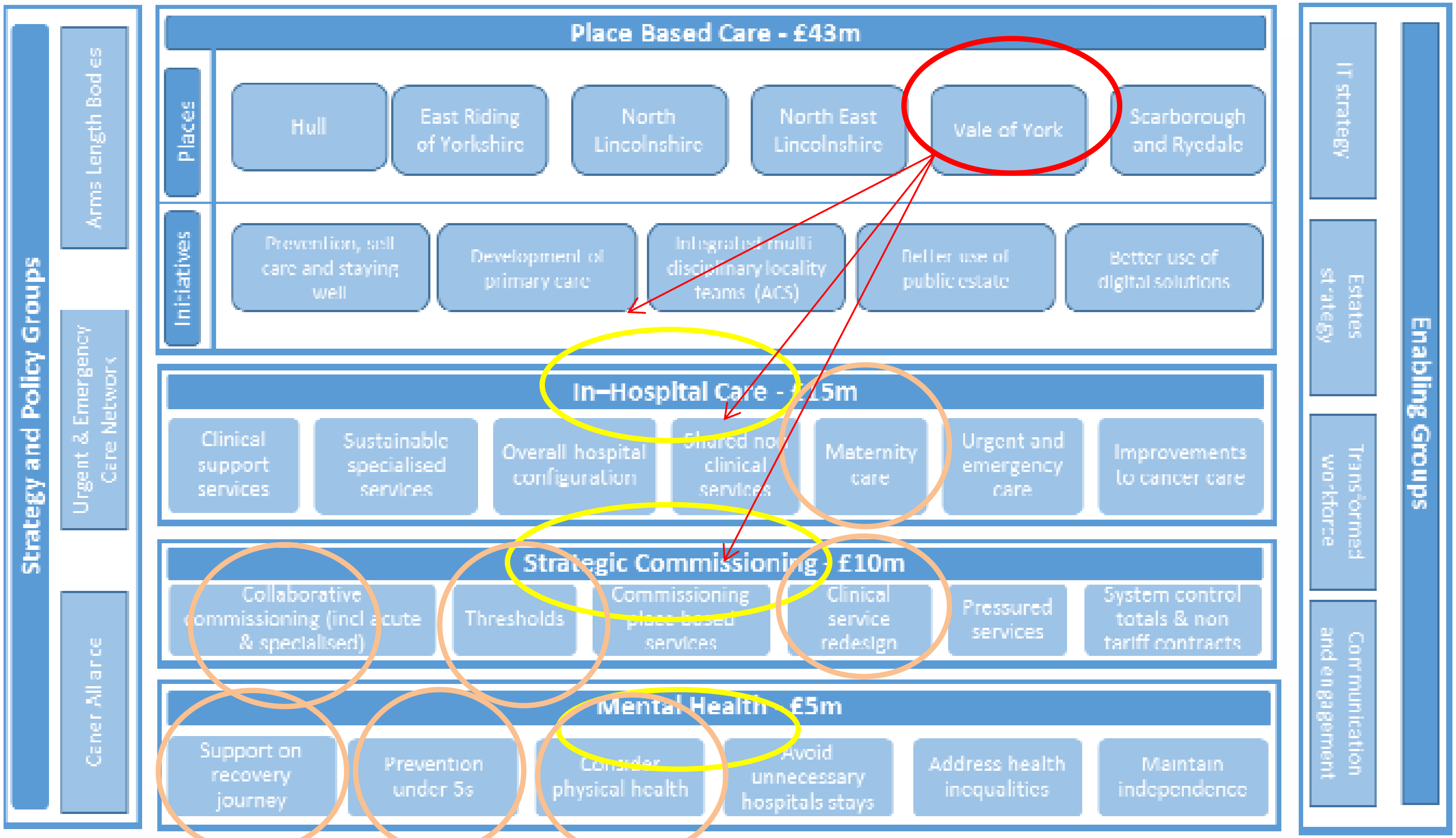
Strategic Commissioning - £10m
- Collaborative commissioning (incl acute & specialised)
- Thresholds
- Commissioning place based services
- Clinical service redesign
- Pressured services
- System control totals & non tariff contracts

Mental Health - £5m
- Support on recovery journey
- Prevention under 5s
- Consider physical health
- Avoid unnecessary hospitals stays
- Address health inequalities
- Maintain independence

Enabling Groups
- IT strategy
- Estates strategy
- Transformed workforce
- Communication and engagement

HCVSTP Collaborative Programmes – Supporting Delivery of Local VoY Priorities

The HCV STP is also mobilising a number of collaborative improvement work programmes with all 6 local CCGs and STP partners which will support us in delivering transformation and improvement at scale and pace in a way which we would not be able to do commissioning alone. Our Plan on a Page shows the links through to these collaborative programmes. Standardisation of thresholds, prescribing and single contracts are core to this work to drive out efficiency and provide consistency in outcome improvement at pace.



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Health and Wellbeing Board 8 March 2017

Report of the Joint Chair(s) of the York Better Care Fund (BCF) Performance and Delivery Group.

Status report on the BCF programme

Summary

1. This report updates the Health and Wellbeing Board (HWBB) on progress in relation to the BCF programme for 2016/17 and 2017/19.

2. The risks and issues reported at the January meeting remain much the same in relation to the BCF for 2016/17. That is:
    a. Performance risks and;
    b. Financial risk in relation to the Section 75 risk share agreement

3. Detailed national guidance is still awaited in relation to requirements for the 2017/19 plan and assurance process. Discussions that have taken place in advance of the national guidance being issued suggest that there are additional risks, relating to the CCG's financial flexibilities under Legal Directions.

Background

4. The BCF Task Group was established to provide a specific, operational focus on the programme. The Terms of Reference aspired to:
    i. Monitor performance of the programme, support and challenge delivery.
    ii. Consider what else can be pooled and jointly commissioned
    iii. Evaluate the contribution towards transforming care and support
    iv. Make recommendations to Integration and Transformation Board.

5. In reality, performance and delivery issues have dominated the agenda, reflecting concerns about performance from previous years – largely due to setting an unrealistic performance target / financial benefit from BCF investment. Ultimately this masks the fact that the majority of the schemes in the BCF have made a positive contribution to managing demands and as a minimum been successful in reducing the growth in demand. Risks have been escalated to the Health and Well Being Board through regular updates on activity through the local Integration and Transformation Board.

6. A more recent development in relation to integration across the wider system, involves the proposal to establish a York focused Delivery Group reporting to an Accountable /Joint Care Partnership Board, along with two other locality delivery groups across NHS Vale of York Clinical Commissioning Group's footprint. The intention at the moment is that this Board reports to the HCV STP and is outside the formal governance structure of the Health and Well Being Board.

7. As stated above the Accountable / Joint Care Partnership Board will cover a geography much wider that CYC boundaries and will be comprised of three locality boards. This broader system approach provides a framework for system wide conversations at a local level aligned to a population base that, broadly, reflects the York HWBB footprint and is currently described as the 'Central Locality'.

8. In advance of the first Accountable Care Partnership Board meeting to be held on 1 March 2017, a partnership workshop was held on 17 January 2017 to take forward discussions at a locality level. This was followed up by the first 'formal' Central Locality Delivery Group meeting on 14 February 2017. The group considered a number of issues that required a system approach whilst recognising the challenges faced by individual organisations. This wider partnership approach provides an opportunity to recognise the BCF plan, and associated investment, as part of a much bigger health and care economy.

9. The Health and Well Being Board ultimately have responsibility for oversight and sign off of the BCF Plan. This has been delivered through the Integration and Transformation Board, supported by a Performance and Delivery Task Group. These arrangements will need reviewing in light of the developing accountable care arrangements described above.

Main/Key Issues to be considered

Performance

10. Non-elective admissions (NEA) – As set out in the BCF report for January 2017, activity for this national metric continues to be reported by York Teaching Hospital NHS Foundation Trust which includes inpatient spells that arise from activity generated through the Ambulatory Care Unit. When the local adjustment is made for this activity the target is on track (see Appendix 2). This means that patients are being treated and managed in a more suitable setting, e.g. paediatric ambulatory unit.

11. Delayed Transfers of Care (DTOC) – Current performance shows that the level of DTOCs is above trajectory with a risk that the yearend target will not be met. Although the overall DTOC number remains higher than plan, increased focus on the numbers of delays has led to a much better understanding of systems and processes, especially in the non-acute mental health pathway. There is now recognition from agencies that there has been historic under reporting of the position and the reasons for discrepancies in recording. A robust process has now been agreed to ensure that the numbers agreed will be formally and jointly recorded prior to submission.

12. The BCF Task Group has reviewed activity which shows a consistent reduction on acute pathway since March 2016 when the Escalation policy was implemented and pin-points the deterioration in the overall position to June 2016 in line with the change in non-acute mental health reporting.

13. All partners recognise the need to move the focus to improving pathways that reduce in-patient activity with the appropriate support in place to maintain independence.

14. Injuries due to falls - Current performance shows that this indicator remains above plan with data analysis not providing any conclusive root cause. Unvalidated figures for December show an improved position but this will need to be verified and may impact on the final year end. Discussion within the BCF Task Group has confirmed that a specific investment in falls services was removed in 2014. The funding was transferred, along with the activity, into the broader community service. This decision was taken with clinical input about how to make the best use of this resource.

15. Continuing Healthcare (CHC) – Management and clinical resource is currently supported within a shared service which supports 5 Clinical Commissioning Groups (CCGs) and two local authorities. Following discussions with partners, a staff consultation is underway which proposes that the Vale of York (VOY) CCG team are realigned directly to the core CCG establishment. To help inform this transfer, a review of existing CHC processes has been undertaken using external clinical expertise. Once the report has been considered by the CCG an action plan will be developed to smooth the transition and address any opportunities for improved systems and processes.

16. In summary, performance metrics associated with the BCF are being considered within the BCT Task Group. This has led to increased understanding of the issues and allowed actions to address pressures and remedial action taken to be taken by partners, at a system level, where necessary.

Section 75 for 2016/17

17. It is now almost certain that the risk share agreement set out in the Section 75 Agreement will be invoked with a cost of £1M risk to the system, shared on a 50:50 split between CYC and the CCG.

Plans for 2017/19

18. Discussions are on-going with regard to the composition of the BCF plan for the next two years. Partners are working together to develop a draft plan based on local assumptions in advance of national guidance being issued.

19. Annex 1 sets out a list of the current investment schedule for the York HWBB BCF Plan. A number of these investments will potentially be at risk if investment funding cannot be found to match the current level of expenditure. It is prudent, if not essential, to carry out a full impact assessment before decommissioning any these schemes.

20. The developing Accountable Care System approach will provide additional opportunities for these discussions within the constraints of the finances available to the health and care economy.

21. National guidance is still awaited which will support the detailed development of the plan.

22. Given the pressures in the local system and the fact that the York HWBB plan was considered within the escalation process, a request for additional resource/support has been made to the national team to:
    i. Provide of constructive challenge and support to system leaders recognising the difficult financial context locally
    ii. Help to quantify and agree the risks to the system (financial, performance, reputational, etc) from any decommissioning of activities that are proposed due to financial constraints, in order to minimise negative impacts on the ability of the whole health and care system to deliver good outcomes for people.
    iii. Ensure that the BCF plan meets national guidance, particularly in relation to the conditions for the maintenance of adult social care as set out when the guidance is published.
    iv. Ensuring that agreement on the BCF is reached positively and fruitfully in order to move forward with the wider system transformation required, avoiding national escalation.

Consultation

23. The issues summarised in this report have been subject to discussion and agreement involving a wide range of partner organisations within York and North Yorkshire.

Options

24. There are no options provided in this report.

Strategic/Operational Plans

25. The BCF plan is part of wider strategic plans of all partner organisations, including the CCG and CYC and should not be considered in isolation.

Implications

26. One of the key challenges facing partners is our stated desire to progress shared initiatives and grow the level of pooled resource whilst managing the on-going system pressure.

Movement towards an Accountable Care System with localised planning and delivery provides an additional platform to develop this intent.

Risk Management

27. The BCF is part of a wider set of risks as the system moves towards implementation of strategic plans, some of which are reflected in the separate paper on the Integration and Transformation Board.

28. Ongoing risk management of the issues outlined in this paper remain with the lead organisation for the relevant performance metrics. The broader system efficiencies lie within the interests of all partners, however, the financial risk rests with the CYC and CCG. Discussions will continue to try to reduce the current anticipated £1M risk both in relation to the final position for this year's plan and in setting the 2017/19 plan(s).

Recommendations

29. The Health and Wellbeing Board are asked to note the issues set out in this report:

    Reason: HWBB oversight of BCF

Contact Details

Author:	**Chief Officer Responsible for the report:**
Elaine Wyllie Director of Joint Commissioning Vale of York CCG 01904 555870	Phil Mettam Accountable Officer Vale of York CCG 01904 555870
	Report Approved ☑ **Date** 28.02.2017

Wards Affected: **All** ☑

Background Papers:
None

Annexes
Annex 1 – List of BCG Schemes for 2016/17
Annex 2 – Performance Metrics Table

Glossary
BCF – Better Care Fund
CHC – Continuing Health Care
CCG – NHS Vale of York Clinical Commissioning Group
CYC – City of York Council
DFG – Disabled Facilities Grant
HWB – Health and Wellbeing Board
NEA – Non-Elective Admissions
TEWV – Tees, Esk & Wear Valleys NHS Foundation Trust
YFT – York Teaching Hospital NHS Foundation Trust

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Annex 1

List of BCF Schemes for 2016/17

2016/17 Schemes = £12,203M	**£000s**	**Lead**
York Integrated Care Hub	625	CCG
Urgent Care Practitioners	569	CCG
Hospice at Home	170	CCG
Street Triage	150	CCG
Remaining acute activity from 15/16 savings target	2,696	CCG
Community Support packages	2,174	CYC
Reablement Social Work provision	137	CYC
Carers Support	655	CYC
Community Facilitators	40	CYC
CCG Community Services Reablement and Carers Breaks	1,684	CCG
Reablement	1,099	CYC
Step Up/Down Beds	300	CYC
Telecare Falls and Lifting	192	CYC
Community equipment	180	CYC
Home adaptations	75	CYC
Carers assessments/support, Independent MH Advocacy (Care Act)	454	CYC
Disabled Facilities Grant	1,003	CYC
Additional benefit schemes contributing to BCF = £1,196M efficiency savings required to meet £12,203M expenditure of fund		
Mental Health	200	CCG
Extra DFG	250	CYC
Roll out of YICT	513	CCG
Continuing Health Care	233	Joint

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Performance Metrics Table

Metric type	Metric description	Target	Q1 position	Q2 position	Q3 position	Year End Forecast	Performance
National:	Reduction in non-elective admissions (General & Acute)	20,781	5,528	5,641	5658	22,254	Deteriorating
*Local metric (outwith routine reporting framework)	Reduction in non-elective admissions (General & Acute) *National data adjusted for Ambulatory Care Recording issues	20,781	5,326	5,456	5227	20,553	Static
National:	Delayed Transfers of Care: Number of bed days per 100, 000 of population	9,837	2,332	2,815	3,117	11,019	Deteriorating
National:	Long-term support needs met by admission to residential and nursing care homes, per 100,000 population	657.8	112.46	345.6	463.5	619	Improving
National:	Number of permanent admissions to residential & nursing care homes for older people (65+)	238	68	58	169	252	Improving

Metric type	**Metric description**	**Target**	**Q1 position**	**Q2 position**	**Q3 position**	**Year End Forecast**	**Performance**
National:	Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services	0.644		This metric is measured annually therefore no data is currently available for the period			No data
Local:	Injuries due to falls in people aged 65 and over per 100,000 population	2,454.7	588.4	657.5	676.2	2,625.1	Deteriorating
Local:	Overall satisfaction of people who use services with their care and support	0.758		This metric is measured annually therefore no data is currently available for the period			No data

***Data taken from BCF Task Group Dashboard as of 23 February 2017**

Health and Wellbeing Board 8 March 2017

Report of the Health and Wellbeing Board Healthwatch York Representative

Healthwatch York Reports

Summary

1. This report asks Health and Wellbeing Board (HWBB) members to receive three new reports from Healthwatch York namely:

    a. Continuing Healthcare (Annex A)

    b. Support for Adults with Attention Deficit Hyperactivity Disorder (ADHD) (Annex B)

    c. Making York Work for People Living with Dementia (Annex C)

Background

2. Healthwatch York produce several reports a year arising from work undertaken as part of their annual work programme. These reports are presented to the Health and Wellbeing Board for consideration.

3. A new procedure has been put forward for managing Healthwatch York reports and the recommendations arising from them. This is discussed as part of a previous report on this agenda. For ease of reference the new process is also set out below:

- **Step 1:** Completed Healthwatch reports to be sent to the HWBB in the first instance
- **Step 2:** Chair of the HWBB to send a formal letter to all organisations who need to respond to the recommendations asking that a named representative feedback to Healthwatch York within 20 working days
- **Step 3:** Healthwatch York reports to the Health and Adult Social Care Policy and Scrutiny Committee twice a year already.

Updates on recommendations and the responses received should be included within this report (including any concerns).

- **Step 4:** (only if required) – escalation back to the Joint Strategic Needs Assessment/Joint Health and Wellbeing Strategy Steering Group for further consideration.

Main/Key Issues to be Considered

4. There are a number of recommendations arising from the three Healthwatch York reports on today's agenda and these are set out in the tables below:

Table 1 – Continuing Healthcare

Recommendation	Recommended to
Look at ways to improve staff training and awareness around Continuing Healthcare, eligibility and assessment.	NHS Vale of York Clinical Commissioning Group, City of York Council, Care Homes, GP practices, York Teaching Hospital NHS Foundation Trust
Look at ways to improve access to information about Continuing Healthcare for individuals, families and carers.	City of York Council, Care Homes, GP practices, York Teaching Hospital NHS Foundation Trust, working with York Carers Centre
Consider options to increase proactive support and advocacy services to those going through the Continuing Healthcare process. This may include, but is not limited to, increasing awareness of the NHS England commissioned BEACON information and advice service.	NHS Vale of York Clinical Commissioning Group
Increase access to Personal Health Budgets and consider ways to make this possible for fast tracked patients.	NHS Vale of York Clinical Commissioning Group

Recommendation	Recommended to
Look at ways of increasing flexibility for families facing end of life. This should include consideration of issues like top-up fees and where these might be permitted.	NHS England
Work together with existing providers of care services to identify ways of increasing choice and access and encourage a wider range of placement options.	City of York Council / NHS Vale of York Clinical Commissioning Group
Work together with existing providers of care services to encourage more feedback, helping the system better understand the experiences of people going through the NHS Continuing Care process, including making routes outside the NHS and social care system clear to patients and families (for example York Carers Centre, York Advocacy, Older Citizens Advocacy York, Age UK York, Healthwatch	NHS Vale of York Clinical Commissioning Group

Table 2 - Support for Adults with Attention Deficit Hyperactivity Disorder

Recommendation	Recommended to
Commissioners and Providers commit to working together with people with ADHD to find a creative (if necessary) and sustainable solution to provide support services for adults with ADHD in the York area. This should include considering the needs of people with ADHD in newly emerging pathways around	NHS Vale of York CCG (VoYCCG) Tees Esk & Wear Valleys NHS Foundation Trust (TEWV) City of York Council (CYC)

Recommendation	Recommended to
low level / community based support for people experiencing mental ill health.	
Consider the creation of a multi-agency task group to look at how a ‘system wide’ pathway to provide the efficient and effective pathways regarding support for people with ADHD and their carers can be developed.	VoY CCG TEWV CYC The Retreat SOAAC
A patient/service user reference group should be established with links to the task group to embed co-production approaches and to develop peer support networks locally.	Health & Wellbeing Board
Consider creative approaches to personal budgets and personal health budgets to support those with ADHD having access to a wider range of potential support services.	VoY CCG CYC
Clarify where responsibility sits in York for Autism, and where concerns about the implementation of the National Autism Strategy can be raised	Health & Wellbeing Board

Table 3 – Making York Work for People Living with Dementia

Recommendation	**Recommended to**
As part of the renewal of the Health and Wellbeing Strategy for the city, clarify the structures relating to strategic responsibility for making York a great place to live for people with dementia, and how this fits with the Dementia Action Alliance in York. This should include clearly identifying the route for people with dementia to be heard.	Health and Wellbeing Board
Bring together people with dementia and GPs to explore the importance of diagnosis and consider effective signposting. Co-produce a consistent dementia pathway to make sure individuals have access to the support, information and advice they need (and improve our dementia diagnosis rate).	NHS Vale of York and the Council of Representatives, Minds & Voices, Healthwatch York
Consider ways of making sure engagement with people with dementia continues in York, making sure their voices are at the heart of all dementia initiatives	Health and Wellbeing Board
Consider ways to support and refer onto a co-produced post-diagnostic course, involving people with dementia as tutors and course designers.	Health and Wellbeing Board
In embedding co-production as a way of working in York, consider how we make sure involvement of people with dementia moves beyond token representation and directly involves them in decision making and shaping services	Health and Wellbeing Board

Consider the needs of people with dementia when reviewing York’s volunteering strategy, to include how we enable more people with dementia to take up volunteering opportunities, and how volunteer involving organisations can provide good volunteering experiences	York CVS
Consider ways of embedding dementia awareness within secondary schools PHSE, making sure people with dementia are involved	YorOK
Consider ways of embedding dementia awareness into contracting arrangements for the city, making sure people with dementia are involved	Health and Wellbeing Board / Joint Commissioning Group
Consider additional ways in which small opportunities to do things separately can be developed and supported for people with dementia and their carers	Commissioners and providers of dementia support services
Tap into the passion and willingness of people with dementia to get positive messages out there in all awareness raising activity	Dementia Action Alliance, Health and Wellbeing Board
Consider ways of increasing advocacy, mediation and support for couples and families to work through changing relationship dynamics	Health and Wellbeing Board
Consider how we make sure those who need face to face information, advice, and customer service are not left behind by increasing reliance on modern technology and “digital by default” approaches to information.	Health and Wellbeing Board

Consider producing a map of accessible toilet facilities in York and making this available through tourist information, as well as through existing information channels within the city.	Make It York
Consider whether there are sufficient accessible toilet facilities in York to enable people to stay independent.	City of York Council / Make it York
Undertake further work with key partners (e.g. Citizens Advice York, York Carers Centre) to understand the impact of the PIP assessment process on people with dementia	Healthwatch York / Dementia Service Providers and the Dementia Action Alliance

Consultation

5. There has been no consultation needed to produce this accompanying report for the Board. Healthwatch York has consulted extensively to produce their reports.

Options

6. This report is for information only and as such there are no specific options for members of the Board to consider.

Analysis

7. The Chair of the HWBB will write to the organisations that have recommendations assigned to them; as per the procedure at paragraph 3 of this report. However; some of the recommendations are for the HWBB itself Board members may wish to respond to these at today’s meeting.

Strategic/Operational Plans

8. The work from Healthwatch contributes towards a number of the themes, priorities and actions contained within the Joint Health and Wellbeing Strategy.

Implications

9. There are no implications associated with the recommendations set out within this report. However there may be implications for partners in relation to the recommendations within the Healthwatch York report.

Risk Management

10. There are no known risks associated with the recommendations in this report.

Recommendations

11. Health and Wellbeing Board are asked to:

- Receive and comment on the reports from Healthwatch York at Annexes A, B and C;
- Agree to the Chair writing to organisations asking them to respond to the recommendations in the Healthwatch York reports within 20 working days.

Reason: To keep members of the Board up to date regarding the work of Healthwatch York.

Contact Details

Author:	**Chief Officer Responsible for the report:**		
Tracy Wallis Health and Wellbeing Partnerships Co-ordinator Tel: 01904 551714	Sharon Stoltz Director of Public Health		
	Report Approved ☑	**Date**	27.02.2017

Specialist Implications Officer(s) None

Wards Affected: **All** ☑

For further information please contact the author of the report

Background Papers:
None

Annexes

Annex A – Continuing Healthcare

Annex B - Support for Adults with Attention Deficit Hyperactivity Disorder (ADHD)

Annex C - Making York Work for People Living with Dementia

Glossary

ADHD	Attention Deficit Hyperactivity Disorder
CYC	City of York Council
HWBB	Health and Wellbeing Board
NHS	National Health Service
PHSE	Personal, Social and Health Education
PIP	Personal Independence Payment
SOAAC	Solution Orientated Adult ADHD Carers' Group
TEWV	Tees, Esk and Wear Valleys NHS Foundation Trust
VoY CCG	NHS Vale of York Clinical Commissioning Group

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Continuing Healthcare

March 2017

Contents

Continuing Healthcare

What is Continuing Healthcare?

NHS Continuing Healthcare is the name given to a package of care that is arranged and funded solely by the NHS for people who are not in hospital and have been assessed as having a ‘primary health need’.

It can be provided:

- in your own home – the NHS will pay for healthcare, such as services from a community nurse or specialist therapist, and personal care, such as help with bathing, dressing and laundry
- in a care home – as well as healthcare and personal care, the NHS will pay for your care home fees, including board and accommodation

NHS Continuing Healthcare is free, unlike social and community care services provided by local authorities. For social care, you may be charged depending on your income and savings. [i]

Eligibility

To be eligible for NHS Continuing Healthcare you must be over 18 and have substantial and ongoing care needs. You must have been assessed as having a "primary health need". [ii]

When assessing your eligibility for NHS Continuing Healthcare, staff must follow certain processes. You must be assessed by a team of healthcare professionals as having a ‘primary health need’ which means that you need care primarily because of your health needs.

Whether or not someone has a ‘primary health need’ is assessed by looking at all of their care needs and relating them to four key indicators:

- **nature** – the type and particular characteristics of their needs and the overall effect these needs have on the person, including the type of interventions required to manage those needs

- **complexity** – the complexity of the person's needs and the level of professional skill required to monitor the symptoms, treat the condition and/or manage the care
- **intensity** – how intense and severe the person's needs are and the support needed to meet them, including the need for sustained and/or ongoing care
- **unpredictability** – how hard it is to predict changes in a person's needs that might create challenges for the professionals who manage them, including the risks to the person's health if adequate and timely care is not provided

Eligibility is always based on these needs, it does not depend on:

- a specific illness, diagnosis or condition [iii]
- who provides the care, or
- where the care is provided

If you are assessed as eligible for Continuing Healthcare, your care will be funded by the NHS. Eligibility is subject to regular reviews and if your care needs change, the funding arrangements may also change. [iv]

Having a disability or having been diagnosed with a long-term illness or condition, this doesn't necessarily mean that you are eligible for NHS continuing healthcare.[v]

When should you be considered for NHS continuing healthcare?

If you have ongoing health needs, there are times when staff should consider whether you may need a full assessment for NHS continuing healthcare.

The times include:

- when you are ready to be discharged from hospital and your long-term needs are clear
- when a period of intermediate care or rehabilitation following a hospital stay has finished and it is agreed that your condition is unlikely to improve

- whenever your health or social care needs are being reviewed as part of a community care assessment
- if your physical or mental health deteriorates significantly and your current level of care seems inadequate
- when your nursing needs are being reviewed. Nursing needs should be reviewed annually if you live in a nursing home

There is also a Fast Track process for Continuing Healthcare:

- if you have a rapidly deteriorating condition and may be approaching the end of your life

In the circumstances listed above, discharge staff, staff co-ordinating your intermediate care, your GP or a member of the social work team should tell you about Continuing Healthcare and assess your eligibility for a full assessment. If they don't you can ask for an assessment.[vi]

How people are assessed – the National Framework

The purpose of the National Framework is to provide fair and consistent access to NHS funding across England, regardless of location, so that people with similar needs are equally likely to get all their health and nursing care provided free of charge, no matter where they live.[vii]

What the assessment process should be like:

The whole decision-making process should be 'person-centred'. So if you are being assessed you, and your views about your needs and the care and support required, should be at the centre of the process. It also means making sure that you play a full role in the assessment and decision-making process and get support to do this if you need it. For example you can ask a friend or relative to help you explain your views. [viii]

The process has a number of steps.

1. Health and social care staff use the four key indicators (listed earlier on pages 3-4) to assess whether a full assessment is required.

2. If a full assessment of eligibility is required, the Clinical Commissioning Group (CCG) will arrange for a multi-disciplinary team (MDT) to carry it out. If permission is given, the assessment will involve contributions from all health and social care professionals involved in your care. The MDT can request a more detailed, specialist assessment carried out by these professionals.

   To help them make decisions on eligibility, staff use a *Decision Support Tool,* which looks at 11 different types of needs including mobility, nutrition and behaviour as well as the key indicators of whether you may have a primary health need.

   If your health is failing and you are close to end of life you may need an 'urgent package of care due to a rapidly deteriorating condition which may be entering a terminal phase'.[ix] In this case a *Fast Track Tool* is used, which is completed by an appropriate clinician, and sent directly to the CCG.

   After the assessment, if you are eligible, a recommendation for NHS Continuing Healthcare is made to the CCG. The recommendation will be accepted unless there are exceptional circumstances.[x]

3. Following every assessment or review a written decision should be sent to you.

The process for putting care in place

The CCG should discuss the options for meeting and managing your care and support needs with you, including which organisations will be responsible.

You should have your wishes and expectations of how and where care is delivered taken into account and documented.

Reviews

Reviews should take place after 3 months, and then at least every year.

Neither the NHS nor the local council should withdraw from an existing care or funding arrangement without a joint review and reassessment of the person's needs. They must consult one another, and the person receiving care about any proposed changes and make sure that alternative funding or services are in place. [xi]

What happens if you are denied funding?

- If some health needs have been identified alongside social care needs, the NHS may fund part of a package of support – this is known as a 'joint package' of care which can be through NHS-funded nursing care, or other services
- Where the local council is also part funding a care package then, depending on income and savings, you may have to pay a contribution towards the costs of their part of the care. There is no charge for the NHS part of a joint package of care[xii] and it is not means tested
- You will continue to receive free care from universal services, for example their GP, community teams and hospitals

What can you do if you are unhappy?

If you disagree with a decision not to proceed to full assessment of eligibility for NHS continuing healthcare following completion of a checklist you can ask the CCG to reconsider the decision.

If you disagree with the eligibility decision made by the CCG (after a full assessment and the Decision Support Tool has been completed) or if you have concerns about the process used to reach the decision, you can write to the CCG to request a local resolution review of your case. If the matter cannot be resolved locally you may appeal to NHS England requesting an Independent Review Panel.

Everyone has a right to complain about any aspect of the service they receive from the NHS, the local authority, or any provider of care. The details of the complaints procedure are available from the relevant organisation, including details of advocacy services.[xiii]

How many people receive NHS Continuing Healthcare?

From April 1st 2013 to December 31st 2015, the number of people newly eligible for Continuing Healthcare in the Vale of York area was 21.8 per 50,000 population. This means that, during this period, about 150 people (out of a total 350,000 population) across the Vale of York were newly eligible for Continuing Healthcare. The proportion of the population newly eligible in the Vale of York is lower than the regional and national averages during this period.[xiv]

Vale of York	21.8 per 50,000 population
Yorkshire and Humber regional average	30.1 per 50,000 population
National average	27 per 50,000 population

The total number of people receiving Continuing Healthcare in the Vale of York from April 1st 2013 to December 31st 2015 was 45.7 per 50,000 population. The national average is 67.5 per 50,000.

These figures relate to Continuing Healthcare only. Within this report, we also talk about joint funded packages, fast track, and funded nursing care.

Why is Healthwatch York looking at Continuing Healthcare?

From 2013 to 2015 Healthwatch York received a small number of serious concerns about the Continuing Healthcare process. In January 2016 the topic was chosen in our work plan survey when 32% of respondents voted Continuing Healthcare as one of the top three priorities for Healthwatch York to look at.

Comments made in survey responses included:

> *I have a long term illness and was in the financial position to take out health insurance easily in my working life. I have benefitted from that since… others are not so fortunate…*
>
> *The criteria for Continuing Healthcare are often misunderstood and wrongly applied, resulting in hardship from wrong assessments.*
>
> *Totally unfair that my father was in a residential and nursing home and it cost £150,000 of our inheritance to fund it when he was in with people who had not paid taxes all their lives and did not have their own home to sell. We are in the process of appealing as he should have been in nursing care.*
>
> *The whole picture is complex and considerably difficult to navigate.*

Continuing Healthcare has been the subject of ongoing local concern, highlighted regularly through NHS Vale of York CCG's Quality and Patient Experience Reports and Risk Registers.[xv] Most recently, at the CCG Governing Body meeting of 5 January 2017, the following concern was noted in the risk register:

> *"Continuing Healthcare (CHC): Costs of packages remain high across a number of patient cohorts which is impacting on the overall cost of both Funded Nursing Care (FNC) and CHC activity. A range of options to address the specific pressures relating to this issue are being explored with partners as part of the wider system conversations."*

Within the risk register, there is acknowledgement of “resourcing issues in relation to regular and timely assessments in accordance with best practice guidance.” Actions taken in mitigation are that “PCU [The Partnership Commissioning Unit, which acts for the 4 CCGs across North Yorkshire and York] have now got a plan in place and additional resource to tackle the historic backlog of cases and have a deadline of 31st October 2016 to achieve clearance of the backlog.” The latest update confirms that “PCU is now working closely with local authority and health partners to address the concerns highlighted in recent reviews and these should be implemented during 2017.”

Within the Quality and Patient Experience report at the same meeting, the CCG provided an update on retrospective appeals concerning Continuing Healthcare. This update included one instance of a family who had appealed the decision to an independent review panel, facilitated by NHS England.

Description	**Status**	**Total**
Local resolutions	Pending	28
	Complete	7
Independent Review Panels	Pending	0
	Complete	1

Continuing Healthcare has also been the subject of national media attention, with the Mirror online in particular running regular stories about entitlement to “secret” funding.[xvi] A recent article, on Wednesday 26thOctober 2016 “Putting the fair back into NHS care” highlighted a drop in the total number of people receiving Continuing Healthcare – from 62,939 in 2014/15 to 59,377 in 2015/16. The article also highlighted differences in eligibility across different localities, with 237 per 50,000 people receiving CHC in Salford, compared with only 57 per 50,000 in London.

More recently, NHS England have launched a new national NHS Continuing Healthcare Strategic Improvement programme[xvii]. They confirm that a collaborative engagement method will be at the centre of the programme. Through this, they will work with CCGs to identify best practice and explore new approaches to improve NHS Continuing

Healthcare. Introductory webinars ran on 10th and 12th January 2017. NHS Vale of York Clinical Commissioning Group were involved in these.

What we did to find out more

We undertook desk research, looking at local media stories and comments about experiences of continuing healthcare.

We ran a survey which, although we did not receive many responses, gave us an understanding of how it feels to go through a Continuing Healthcare assessment. These responses included some from across the wider North Yorkshire area, although we have limited our recommendations and actions to our own geographical area.

We invited people to a focus group to discuss Continuing Healthcare. At the focus group we spoke with two carers about their experiences of the Continuing Healthcare process. One of these experiences is described in detail as a case study later in this report (Case study 1). The second experience is subject to a review regarding retrospective funding and in order not to compromise the review we have only provided a brief summary of the concerns raised (Case study 2).

We also reviewed our issues log, which contained further personal experiences around Continuing Healthcare.

What we found out

Local media stories and comments

The Press, 21 April 2014 – “Families wrongly selling off their family home to pay for care home fees”[xviii]

“*Too many families in North Yorkshire and York are wrongly selling off their family home to pay for care home fees, according to the authors of a new guide launched by Gloria Hunniford.*

The average cost of a UK nursing home is £738 per week – that’s almost £40,000 a year. But many families struggle needlessly to come up with the cash in a situation where they may be eligible for full funding from the NHS, although few people know about it specialist care funding solicitors Farley Dwek, which produced the new guide, have warned.

This is known as NHS Continuing Healthcare and is not means-tested. It is based on assessments of healthcare needs, such as mobility and severity of conditions, the firm said.

The latest figures, from 2013, show just 537 people in the old North Yorkshire and York PCT (now the four separate CCGs) were receiving continuing health care funding from the NHS.

There could be hundreds or thousands more who are missing out on financial support. Gloria Hunniford said: “The funding process can be complicated and not enough people understand it. Too many families feel as though there is a lack of help out there and are missing out on funding they are entitled to as a result.”

To download the free guide visit www.farleydwek.com”

The Press, 20 August 2015 - “Man, 81, stranded in York Hospital for 6 weeks due to bed blocking crisis” [xix]

In August 2015 Debra Edwards raised concerns about the treatment of her father, Michael Fitzsimmons. She held power of attorney for her father. She stated “I feel he has been treated really badly. I believe it’s to do with finances. I’m worried if something is not done, my dad will die.” Michael, 81, had dementia and complex needs following a serious stroke 2 years earlier. In August, he had been in hospital for 6 weeks having become ill with pneumonia. The care home he was in previously stated they were not equipped to continue looking after him. The nearest home offered to the family was in Hornsea. As Debra and her husband visited daily and helped him to eat she was concerned about the detrimental impact of him being placed so far away.

Michael passed away in hospital on January 22nd 2016.[xx]

The Press, 1 August 2015 - comment[xxi]

Ehullis3823, commenting on a story about the awarding of the mental health services contract:

Given my experience of the Vale of York CCG over another matter regarding NHS Continuing Healthcare for a member of my family they are clearly a “closed shop” when it comes to criticism. Something has to change. They, in my experience, are only concerned with budgets and power. It would be interesting to see whether they will give open discussion because in my experience they get all legal when they are challenged.

Healthwatch York Continuing Healthcare Survey results

We received 12 responses to our survey in 2016, 2 from people receiving continuing healthcare, 1 waiting for assessment, 5 relatives, and 4 health professionals. 8 were from York, 3 from Scarborough, and 1 from Ryedale.

Only 6 respondents had been through the initial application process. We asked whether people were familiar with Continuing Healthcare before applying for an assessment. The survey showed that half of respondents were. Half had heard about Continuing Healthcare from a social worker, and the rest heard from a nurse, other health professional, or voluntary sector agency. Half of the respondents were supported by a health or social care professional to apply. One respondent commented “was not supported – was told would not get continuing care, so not to bother”. Only 2 were consulted before the application was made.

3 people commented on their experiences of the application process:

> *“I didn’t realise that it was ongoing”*

> *"After we were told, in so many words, not to bother, we pursued legal action but it was so expensive we decided not to pursue it at that point"*

> *"The continuing care was for my mother who was admitted into a residential and combined nursing home – we felt that she needed nursing and were told not, although within a couple of weeks they found in the home that she did indeed require nursing. We were not informed of the differences between continuing care and other care. We were told by the Carers Centre, who we approached by phone for a different reason, and their advisor asked if we had applied or been informed of continuing care. Despite having a social worker and a range of physio / doctors involved in my mother's care and admitting her into a home we were not told of any carers assessment or the continuing care application / options."*

3 people responded to a question asking how long they had waited for the initial assessment checklist to be completed. 1 was completed within 1 week, 1 took 1-3 weeks, and 1 took 1-2 months.

5 people responded to a question asking whether they had been given a copy of the completed checklist. Only 1 of the 5 respondents had.

We asked "were you told that being referred for a full assessment doesn't necessarily mean they were eligible for Continuing Healthcare?" 3 people responded to this question, 2 felt the reasons for the decision were fully explained, 1 did not. 2 received feedback in person, 1 by letter.

Respondents told us that waiting times for the full assessment following completion of the initial checklist varied, from 1-3 weeks to over 6 months.

Three quarters of survey respondents felt the assessor asked the right questions, understood their condition and care needs, felt listened to during the assessment process, and felt their views and those of family members were taken into account. Half said they felt respected, and that the assessor focused on them and their needs.

Of the 2 respondents who were receiving Continuing Healthcare, 1 was receiving care in their own home, the other in hospital. We asked “were you given any choice about how and where your care would be provided?” 1 was unsure, the other said “yes – limited choice.” We also asked if they had been given the option of a personal health budget. 1 said no, 1 did not know.

1 person had received a review of their care needs, between 9 and 12 months ago. They were satisfied with the review process, and hope it continues.

Case studies (from Healthwatch York’s Continuing Healthcare focus group August 5th 2016)

Case study 1 - Naomi* (her story was told to us by her friend and carer) *not her real name

“It was a good death for Naomi but the lead up was horrendous for friends and family. Naomi did not get the outcomes she wanted. She had cancer – a mango sized tumour by the time it was diagnosed. Naomi was a smoker. She’d given up a couple of times but on diagnosis she started again. She enjoyed smoking and it seemed pointless not to now.

Naomi had been a home care worker. She did not want a package at home because of this, but it was where she wanted to die. She was on chemo and radiotherapy, but it was palliative care. She was also on opiates. The tumour was pressing on her oesophagus, causing her to be sick. She was put on a syringe driver, which needed to be changed every 24 hours. But she had issues with the community nurses, they could only do this in twos, and there was no flexibility on the times.

Naomi always rose at 5am. It was mid-December, and she was still getting up early but she was tired. She ended up on the floor, with her foot wedged under the commode. On Boxing Day she was taken to St Leonard’s Hospice. She had 2-3 spells there. The nurses were lovely and the food was great. But there is nowhere at St Leonard’s Hospice where you can smoke. She had to be taken out to smoke, but it wasn’t easy to help her get about. She could not get any support from care assistants working at the hospice to go outside. The smoking area is a *long way from the hospice. You can understand it, but for Naomi she was unsteady and it was the middle of winter. It wasn't ideal.*

Just to restate, her goal was to die at home, surrounded by friends, and smoking when she wanted to. We couldn't get her home easily, so we all mucked in, did the next best thing and set up a rota so she'd have her friends and family around, from December through til March, from 8am to 8pm at St Leonards.

Naomi had no money. She worked for a care agency. She was on statutory sick pay only. She didn't want to send off the Employment Support Allowance form. Someone from the council was helping her with filling in the forms. We wanted to get her home. Then someone asked, are you on Continuing Healthcare. She was being assessed, but not fast tracked. She was at end of life.

There was a real danger point between 3 and 5am. But no-one would put in overnight care at home. She had to have either 4 calls plus whatever Marie Curie could offer, or residential care. A social worker offered to arrange live in care for the same cost as residential, working with the family and friends who were caring for Naomi.

Eventually, Naomi did get Continuing Healthcare and got carers in to support her through an agency. One carer asked to smoke her cigarettes, one talked about not having any money. We didn't have any faith in the agency. Marie Curie could do 2-3 nights a week. But they could only say which 1 week before. We never saw a nurse during this time.

The ideal scenario for Naomi was to be at home, smoking when she wanted to, with some companionship. We were told, if we organised care as she wanted with each of us stepping in and using agencies we trusted, the Continuing Healthcare package would stop. It's so sad when we know we could have put this care in place if she knew she could have the money to cover it.

She knew she was at end of life in January. Before she died, she ended up back in the hospice. I believe this was purely because she was not *free to arrange the care she wanted. She died on 8th March. She had a very peaceful death, but it wasn't what she wanted.*

The process is really rigid, there's no flexibility. This makes it harder for people to get what they need from it. There are frameworks, checklists and timescales.

Naomi got Disability Living Allowance quite quickly, based on having less than 6 months to live. When you are given a terminal diagnosis, you have to deal with grief and fear. The last thing you want to worry about is money. You want to do things with the limited time you have left. Naomi and her daughter asked about direct payments. They were told this would take too long.

There are market challenges in York – there is no flexibility as there is a lack of available carers. It is impossible to set things up quickly.

For those of us left behind, along with our grief, we're left questioning whether we did enough. Could we have worked around the system better, could we have done more to give her the death she wanted?

It also doesn't feel like there's a lot of knowledge out there to help. I think more training is needed, to make sure everyone – social workers, GPs, nurses, voluntary sector agencies – knows what Continuing Healthcare can be used for, and how it can work.

Naomi had fallen out with her GP as they had missed the signs of cancer. She lost a stone in a month, steady weight loss of 2-3 lbs a week. By the time the GP acted it was too late. She had already been in to AMU twice, was put on IV antibiotics and sent home.

It's a really complicated system, and there needs to be more support to navigate through the process."

Case study 2

We are unable to use this as a review regarding retrospective funding is still pending and we have concerns about compromising that review.

The main issues are:

- failure to involve carers within the process, specifically giving short notice of meetings, excluding the main carer from meetings, and refusing to provide information against official guidance
- attitude of the staff completing the reviews throughout, reinforcing the idea of them as ‘gatekeepers’
- having to explain rights under the process to staff working within it
- abilities of staff outside the Continuing Healthcare process to support those going through it
- differing opinions between those within and outside the process
- no access to ongoing advice, information and support throughout the complex process

Continuing Healthcare issues reported to Healthwatch York

September 2016

A woman contacted us. Her son had moved back to York from out of area in June 2013. He had autism, epilepsy and learning difficulties and was non-verbal. He had a continuing healthcare package for his support. He moved into supported living run by a national charity. There were lots of discussions and some dispute about his funded hours. Eventually the hours were agreed but the family felt this made no difference to the care he was receiving – they felt it was just about funding.

During 2014/15 his parents noticed a deterioration in his behaviour, and observed that he was getting distressed. His parents felt that there was no access to suitable support in York, so they paid for a behavioural analyst who worked with their son and staff to put a support plan in place.

Their son died in August 2015 following a seizure.

The family believe that health professionals were not involved in any of the review meetings. There was confusion regarding his budget and spending – they were told at one meeting that there had been an overspend of his budget at a previous home. This had to be paid back in instalments, meaning he had less money to spend on activities. However, after his death they received a cheque for over £1,000 with a note that this was his money.

The family had a number of concerns. Those most relevant to this report relate to the sharing of information to allow good financial management and personal choice and control. They questioned who was keeping a check on how the budget was spent, in line with the wishes of the individual? They felt this was particularly important where the budget is for someone who is non-verbal and has limited capacity. They felt there needed to be greater flexibility to adjust to changing needs. They also felt that recognising need is only part of the story – "what is the point in a care plan which recognises needs if they are not able to be met due to funding and staffing issues?" There was a review meeting a few months before his death. However, the family felt that the notes did not bear any relation to what happened. There was also no review of his continuing healthcare budget.

August 2015

A woman whose father has been assessed for Continuing Healthcare contacted Healthwatch York over issues with the language used by the Continuing Healthcare team and the suitability of the place offered. She was very unhappy about the impact both on her father's wellbeing and her wellbeing as a carer. She accepts that her father exhibits challenging behaviour but is concerned over the lack of options.

May 2015

A man, aged 92, was given fast track Continuing Healthcare status by Plymouth CCG in September 2014. His children both live in York, and wanted to move their father to a local home. They were told by two homes that "Continuing Healthcare patients could not be accepted as funding was insufficient". The family were happy to top up funding to allow their preference to be met but were told this is not allowed. Their father was ‘stuck on an acute, busy ward for 6 weeks’ until a home in Dorset was found. He died there 5 weeks later. The family are concerned about the responses of care homes in York, and the lack of options available to people.

February 2015

A woman supporting her daughter following a serious accident in May 2014 asked about Personal Health Budgets in October 2014. She is still awaiting the follow up to this request. She believes that delays with Continuing Healthcare assessments are the biggest barrier to people receiving Personal Health Budgets.

January 2015 (Issue regarding joint package of care)

A 46 year old man with acquired brain injury has a care package co-funded by City of York Council and Vale of York CCG. He has been admitted to hospital twice due to deteriorating physical health.
His family feel he is “now stuck on ward 21”. The family state that Archways refused a referral for rehabilitative physiotherapy due to his challenging behaviour. His care provider states that they cannot take him back unless his physical health improves. His carer is struggling to get alternative options for rehabilitation. She is worried about him being placed in a nursing home. She feels if this happens he won't get the rehabilitation support he needs, and he's only 46. The Patient Advice and Liaison Service at the hospital have been involved. However, they only arranged a conversation with the Archways manager who explained why treatment has been declined. His family feel that carer involvement has been poor throughout – they have received short notice of meetings about care plans, and limited explanation of the options available to them. The carer states that the social worker is not helping and it “feels like no one wants to help resolve the situation.”

July 2014

We were contacted by staff and friends supporting a man with dementia, at a care home with nursing in York. They had tried to get a Continuing Healthcare assessment. The man had continence issues and limited mobility, but those supporting him struggled to get any information about when he might be assessed.

December 2013
A family contacted us after a conversation with the Care Quality Commission about their experiences. They have been looking for a nursing home for their father to move to following a stay in an intermediate care facility in York. They feel that their experience has been ‘awful’, and that they are being pushed hard to find something quickly. They believe that their father has only had a social care assessment, not a continuing care assessment. The family were not made aware that a formal report had been completed. They have had to push for information all the time, and there is no communication or involvement in decisions as they are being made. Their father has capacity, but a number of physical health needs. They believe that the nurse in the discharge team who completed the assessment did not see their father in completing the assessment.

The family believe that the attitude has been "well, he can pay" rather than assessing his needs. They were looking into a nursing home in York, but were informed about a safeguarding issue within the home. They informed discharge staff of this to explain why they were not pursuing a place in that home. When they arrived to visit their father shortly afterwards they found a representative of the same nursing home speaking to him.

The family felt staff at the intermediate care unit had called in the nursing home representative as they "want to get rid of him". Their father went into hospital in August, and on to intermediate care in October. But they feel that no one communicated with the family through the process. Now, they feel that because the unit wants him out, it is demanding instant decisions about long term plans involving compromises which the family are not willing to make.

Other issues related to funding of care – where it is not clear if Continuing Healthcare was involved

July 2016

A family reported that their father, who has dementia, was in hospital from early April to mid-June in 2016. The hospital informed the family they needed the bed, so the family began looking for a suitable care home. There was limited availability. The family were told that a particular home would not take him as he wanders in the night. That home sent someone to assess him, and he moved into the home in the middle of June 2016. He was in the home for a month before the family were called into the office. The manager said their father was getting up in the night, walking around naked. They informed the family the home wasn't set up to cope with this behaviour so the family needed to pay £214 per night for 1-2-1 care. They state that the care home said the hospital had lied to them as they hadn't known he would need care overnight. He did have a pressure sensor on the mattress which raised an alert if he got out of bed. The family initially agreed. They subsequently realised this additional charge doubled the cost for them and started to question this. They contacted the home to explain they did not want to pay the charge. The manager said that the home would have to do an emergency eviction. The family live 150 miles away. They feel they were forced into accepting a place at an unsuitable home and then forced into paying for additional care. Their father has now moved to a different home, and is much happier.

May 2016

A man with lung cancer and significant care needs was admitted to York Hospital. His daughter lives in York and was invited to a discharge meeting at the hospital, at which her father was not present. She wanted to get him home and was willing to be his carer as her work was very flexible so she could do so. But he needed oxygen, a hospital bed, plus some care, roughly a day a week to enable her to attend work commitments. At the discharge meeting, she was told that they could have either 4 daily visits at home, or he could go into a care home. She asked about Personal Health Budgets as a way of meeting his healthcare needs. She was informed that York doesn't do Personal Health Budgets for people who are fast tracked. She was also told to put it in writing to them because they are "sourcing new care." A further comment was "If you apply for a Personal Health Budget he will die before we respond. He only has 6 weeks to live." At this point she had believed her father had 2-3 months to live and it was left to her to inform her father he had 6 weeks to live.

The man went home and had the 4 daily visits from a home care agency. His daughter reported that the home care agency were great. He also received support from hospice at home.

The daughter had concerns about the discharge – she was given a big bag of medicines but did not feel she received adequate information about what these drugs were for. She also felt that overall there was a lack of communication, co-ordination and clarity of responsibility between the hospital, hospice team and home care agency. She felt that the process was as far as it could be from being person centred.

She believes there is a need to improve staff awareness of Continuing Healthcare. She felt that both cancer care staff and Macmillan nurses should have been aware of the Continuing Healthcare process, and proactively informing patients and families about it. She stated that none of the staff she spoke to at the cancer care centre had heard of it.

She also recommends that there should be an end of life care helpline for people locally.

April 2016

A man with learning difficulties and communication challenges was diagnosed with cancer in February 2015, but refused an MRI scan. The family have been informed his condition is terminal. He went into hospital and was discharged in June 2015. He accessed the reablement team, which was originally meant to be for 6 weeks, but this continued until December 2015. The family received a call from City of York Council about completing an assessment which the family believed was for Continuing Care. They came to complete the assessment in January 2016. This was witnessed by a Macmillan nurse. A financial assessment was completed and it was determined that the man had to pay a certain amount towards his care. The family assumed this was from the date of assessment, but the council has now said it was from the date of discharge from hospital. The family say they are being asked for thousands of pounds. The man is on benefits and does not own his home. He and the family are all very unhappy, and feel they were never given any information about costs or options. There was no contact from June through to the end of November. The family are now trying to make alternative arrangements but they do not live locally. They have queried some of the charges, and state that the council has said they can't amend the invoice but will reimburse for any care not provided at the end of the year.

March 2016
A person contacted us seeking advice on addressing challenges with securing Continuing Healthcare funding for an individual. Healthwatch York signposted the caller to York Advocacy.

February 2016
A person on Continuing Healthcare fast track with nursing care needs is adamant they do not want to go into a nursing home but they need considerable care. They wanted to look at having a live in companion to help under a personal budget but were told this is not possible. They feel they are being left with no choice, and that their last weeks of life will not be lived in the way they want them to be.

January 2016
A person made contact with Healthwatch York to seek advice on appealing a decision not to provide Continuing Healthcare funding. They were signposted to York Advocacy for support.

November 2015
A woman's relative is currently living in a residential care home but needs to move to a care home with nursing. She is not in a position to top up fees and her social worker has told her that she can move to one of three nursing homes.

The caller was aware of some work to address concerns at one of the homes, and wanted to know what would happen if placements at all homes were suspended. The council confirmed that this would be looked at on a case-by-case basis.

She is also currently investigating whether or not her relative qualifies for Continuing Healthcare and wanted to know whether there would be additional choice if they were eligible. She was encouraged to make contacting with the Continuing Healthcare team to discuss this.

September 2015

A family contacted us regarding the appropriateness of supported housing where no staff members are able to communicate in British Sign Language (BSL) with the individual. The family member is now exhibiting signs of depression due to isolation and lack of external stimulation. The current housing was meant to be temporary but the family member has now been there for 2 years. The family has proposed alternatives, but all have been turned down. The family has never been offered the chance to explore personal budgets or personal health budgets.

Further information

At the end of the process of writing this report we were made aware of Beacon Continuing Healthcare.[xxii] NHS England have a contract with Beacon to provide an NHS Continuing Healthcare information and advice service.

They say:

“If you have a question, would like us to discuss your assessment or need to talk to someone independent about your situation, please call us on 0345 548 0300 or send us a ‘Talk to us’ request to schedule a free consultation with a trained NHS continuing healthcare adviser.

We are able to provide you with up to 90 minutes of free written or verbal advice in addition to our free literature. We will also signpost you to other trusted not-for-profit organisations where we feel they may be able to provide you with expert advice on matters related to your situation. Please note that our free advice service is kept entirely separate from our casework services – we will not try to sell you anything and will only put you through to the casework team if you ask us to.

This free information and advice service is officially supported by a number of the UK’s leading charities including Age UK, Parkinson’s UK, Spinal Injuries Association and First Stop EAC.”

We hope the inclusion of this information helps to raise awareness. This service was not mentioned by any of the people who contacted us during the writing of this report.

Conclusion

Continuing Healthcare conversations and assessments take place at a highly stressful time in peoples' lives. Patients and families going through the process struggle when they don't have access to support.

Patients and their families don't have enough information about NHS Continuing Healthcare at the time they need it.

Some health and social care staff lack awareness about Continuing Healthcare and Personal Health Budgets and so they are unable to provide support to patients and their families.

The Continuing Healthcare assessment process is supposed to be person centred, but from the experiences we have heard about, it doesn't always seem to be.

There are also challenges with accessing the care needed. The levels of funding and care availability in our area mean the options are often severely limited. More work is needed to encourage care homes and home care agencies to help address the lack of choice.

It is even more important to get this right when patients have received a terminal diagnosis.

Recommendations

Recommendation	Recommended to
Look at ways to improve staff training and awareness around Continuing Healthcare, eligibility and assessment.	NHS Vale of York Clinical Commissioning Group, City of York Council, Care Homes, GP practices, York Teaching Hospital NHS Foundation Trust
Look at ways to improve access to information about Continuing Healthcare for individuals, families and carers.	City of York Council, Care Homes, GP practices, York Teaching Hospital NHS Foundation Trust, working with York Carers Centre
Consider options to increase proactive support and advocacy services to those going through the Continuing Healthcare process. This may include, but is not limited to, increasing awareness of the NHS England commissioned BEACON information and advice service.	NHS Vale of York Clinical Commissioning Group
Increase access to Personal Health Budgets and consider ways to make this possible for fast tracked patients.	NHS Vale of York Clinical Commissioning Group
Look at ways of increasing flexibility for families facing end of life. This should include consideration of issues like top-up fees and where these might be permitted.	NHS England
Work together with existing providers of care services to identify ways of increasing choice and access and encourage a wider range of placement options.	City of York Council / NHS Vale of York Clinical Commissioning Group
Work together with existing providers of care services to encourage more feedback, helping the system better understand the experiences of people going through the NHS Continuing Care process, including making routes outside the NHS and social care system clear to patients and families (for example York Carers Centre, York Advocacy, Older Citizens Advocacy York, Age UK York, Healthwatch	NHS Vale of York Clinical Commissioning Group

York, single condition groups such as York MS Society, York Parkinson’s Support Group, etc)	

Acknowledgements

We would like to thank everyone who took the time to share their experiences with us.

We let the Partnership Commissioning Unit know about our work, and encouraged them to contact those individuals they were working with. We always want to hear from as many people as possible, to show the range of experiences people have. We wish to champion the good alongside the areas where improvement is needed. Unfortunately, despite this, we were only able to reach a small number of people through our own publicity and networks, most of whom had experienced problems either with the process or the care provided. This is perhaps to be expected, given the low number of people who receive Continuing Healthcare, and the complex health needs people who do are living with.

However, every example we share is somebody’s story. Every experience could be our experience. Our role is to give voice to those who want to be heard. We could not do this without you. We believe that together we can all make York better. Thank you for trusting us with your words.

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Support services for adults with ADHD

March 2017

Contents

Support services for adults with ADHD - learning from people's experiences

Introduction

This report aims to explore the experiences of adults with ADHD in accessing support services in York. Some of the adults will have been diagnosed when they were children, whilst others will not.

We consider support services to range from getting an assessment and diagnosis for ADHD to getting the help and support that is needed to manage the symptoms. This help can include NHS care and social care support.

In addition we consider the experiences of families, friends and carers who live with and support adults with ADHD. We aim to understand their experiences in accessing information, advice and other relevant support.

What is ADHD?

Attention deficit hyperactivity disorder (ADHD) is one of the most common childhood disorders. It can continue through adolescence and into adulthood. Symptoms include difficulty staying focused and paying attention, difficulty controlling behaviour, and hyperactivity (over-activity).[i] There are challenges with diagnosis, since similar but less severe symptoms are common within the 'normal' experiences of childhood.

Half of all individuals with ADHD experience other health issues such as anxiety, depression, obsessive compulsive disorder, learning difficulties, or emotional or neurological problems. These may be secondary, triggered by the frustration of dealing with ADHD, or distinct conditions occurring alongside ADHD.[ii]

There is no single cause of ADHD, though recent studies indicate genetic factors are important and it does run in families.[iii] Despite this, and widespread medical acceptance of ADHD as a neurobiological condition, it is still seen as a controversial subject. Parents in particular face stigma, with accusations of poor parenting, and a belief that the symptoms indicate their failure to restrict the food additives and sugar their child has consumed.[iv]

ADHD has three subtypes:

- Predominantly inattentive
- Predominantly hyperactive-impulsive (very rare)
- Combined inattention and hyperactive impulsive (most prevalent)

An individual with inattention may have some or all of the following symptoms:

- Be easily distracted, miss details, forget things, and frequently switch from one activity to another
- Have difficulty maintaining focus on one task
- Become bored with a task after only a few minutes, unless doing something enjoyable
- Have difficulty focusing attention on organising and completing a task or learning something new
- Have trouble completing or turning in homework assignments, often losing things needed to complete tasks or activities
- Not seem to listen when spoken to
- Daydream, become easily confused, and move slowly
- Have difficulty processing information as quickly and accurately as others
- Struggle to follow instructions

An individual with hyperactivity may have some or all of the following symptoms:

- Fidget and squirm in their seats
- Talk nonstop
- Dash around, touching or playing with anything and everything in sight
- Have trouble sitting still during dinner, school, doing homework, and story time

- Be constantly in motion
- Have difficulty doing quiet tasks or activities

These hyperactivity symptoms tend to lessen with age and turn into "inner restlessness" in teens and adults with ADHD.

An individual with impulsivity may have some or all of the following symptoms:

- Be very impatient
- Blurt out inappropriate comments, show their emotions without restraint, and act without regard for consequences
- Have difficulty waiting for things they want or waiting their turns in games
- Often interrupt conversations or others' activities[v]

The National Institute for Clinical Excellence (NICE) Clinical Guideline for the diagnosis and management of ADHD states that “People with ADHD require integrated care that addresses a wide range of personal, social, educational and occupational needs. Care should be provided by adequately trained healthcare and education professionals.”[vi]

The World Health Organisation estimates that it affected about 39 million people as of 2013.[vii] ADHD affects 3-9% of all children, and is diagnosed approximately three times more in boys than in girls.[viii] It is believed that this might be as much about cultural and societal stigma as prevalence, with girls being more likely to have low mood or difficulties socially than display disruptive behaviour that would lead to diagnosis.

About 70% of children with ADHD will continue to have symptoms in adolescence.[ix] Between 30 and 60% of people diagnosed with ADHD in childhood continue to have symptoms into adulthood and it is thought that between 2 and 5% of adults have the condition.[x] [xi]

ADHD and the Criminal Justice System

Studies have shown that adults with ADHD are disproportionately represented in the criminal justice system, with up to two thirds of young offenders, and up to half of the adult prison population screening positively for childhood ADHD.[xii] [xiii] Childhood ADHD is the second greatest predictor of total offending behaviour behind heroin use, and the greatest predictor of violent offending. Young people with ADHD are more vulnerable to involvement with the criminal justice system as they tend to commit offences that are opportunistic and reactive rather than well planned and organised, making them more likely to be caught. They are less likely to appreciate the seriousness of their actions. Young people with ADHD are less able to cope with arrest, questioning and the court process. They may face difficulties answering questions when experiencing pressure and stress. They are more likely to accept or comply with suggestions from those in authority. This may lead to increased false confession by those with ADHD. They may also struggle to cope with the stress of prison life, resulting in high rates of aggressive behaviour within institutions[xiv]. Subsequent studies suggest offending behaviour is linked more to conduct challenges, and dealing with emotional adversity, rather than hyperactivity[xv]. This emphasises the need for supporting young people with ADHD to develop coping strategies and develop emotional resilience.

Key Issues for adults with ADHD

Diagnosis

There is no simple test to diagnose ADHD in childhood. Assessment may include:

- a physical examination, which can help rule out other possible causes for the symptoms
- a series of interviews with you or your child
- interviews or reports from other significant people, such as partners, parents and teachers

For adults, similarly, there is no single test to identify ADHD. In some cases, an adult may be diagnosed with ADHD if they have five or more symptoms of inattentiveness, or five or more symptoms of hyperactivity and impulsiveness, listed in diagnostic criteria for children with ADHD.

Under current diagnostic guidelines, a diagnosis of ADHD in adults can't be confirmed unless symptoms have been present from childhood.

For an adult to be diagnosed with ADHD, their symptoms should also have a moderate impact on different areas of their life, such as:

- underachieving at work or in education
- driving dangerously
- difficulty making or keeping friends
- difficulty in relationships with partners

If problems are recent and didn't occur regularly in the past, the adult is not considered to have ADHD. This is because it's currently not thought that ADHD can develop for the first time in adults. [xvi]

People with adult ADHD have more trouble with self-management and time, self-organising and problem solving, self-discipline, self-motivation, and self-activation and concentration. In other words they are likely to have more difficulty organising tasks, make careless mistakes, lose things, and struggle to prioritise their daily activities. These symptoms for adult ADHD describe challenges many of us might experience periodically, but may make it seem impossible for an adult to seek employment, hold down a job, or pursue further education unless the person is able to manage their condition. An appropriate diagnosis is essential if a person has the condition, because only with professional care and support will it be possible for them to gain control over their life and integrate successfully and productively.

Additionally, it is common for those with other health issues such as autistic spectrum, anxiety, depression or bi-polar disorder to have symptoms of ADHD. The challenges for 'good' diagnosis are complex and significant, as are the challenges for the individuals and their carers.

Alienation

With limited understanding of the causes and impact of ADHD, many living with the condition face problems with acceptance. The assumption is that the person could control their behaviour if they really wanted to, and if they had been taught to behave properly.

Adults with ADHD can behave in ways that people do not like, and which are usually associated with 'bad' or 'irresponsible' behaviour. As a result, reactions to this are often negative, aggressive and even more so when the person confronted fails to react 'reasonably' or change their behaviour. Faced with frequent hostility and rejection adults with ADHD can find life traumatic. Defensiveness can become a learned response to others.

Untreated, people with the disorder experience increasing psychological and emotional stress, desperation, and anger, and they can feel alienated. Without the right help it is hard for adults with ADHD to develop coping strategies that present their positive potential and manage those aspects of their behaviour that others find challenging.

Access to services

Across the UK, there are only a handful of places with specialist NHS services for adults with ADHD. These include:

- South London and Maudsley (SLAM) National Adult ADHD Service, the first adult ADHD clinic in the UK;
- Avon & Wiltshire Mental Health Partnership NHS Trust adult ADHD Service, established in 2007
- South West Yorkshire Mental Health NHS Trust specialist adult ADHD Service, established in 2009, with their main base in Wakefield and clinics in Barnsley and Kirklees
- Sheffield Adult ADHD service, one of the first adult ADHD clinics integrated into general adult mental health services
- Leicester Adult ADHD service, operating since 2002, initially as a special interest clinic and since January 2009 as a commissioned service
- The Adult ADHD Research Clinic in Cambridge, founded in 2000 as a joint venture between the Department of Psychiatry,

University of Cambridge and the regional mental health trust, Cambridgeshire & Peterborough NHS Foundation Trust
- Lothian Adult ADHD service, based at Royal Edinburgh hospital
- Leeds & York Partnership NHS Foundation Trust specialist ADHD assessment and management service[xvii]

The Tuke Centre is part of the Retreat in York. It has been commissioned since January 2016 by the four Clinical Commissioning Groups (CCGs) across North Yorkshire – Vale of York, Scarborough & Ryedale, Hambleton, Richmondshire & Whitby, and Harrogate & Rural District – to provide an Autism and ADHD assessment Service[xviii]. However, the clinic is only contracted to offer a limited number of follow-up sessions to help people understand their diagnosis, not provide ongoing treatment.[xix]

The National Institute for Clinical Excellence (NICE), was set up *"...to reduce variation in the availability and quality of NHS treatment and care"*[xx]*.* The intention was that British people, wherever they live, have equal access to NHS health care. Services for adults with ADHD is one of the services that the Government expects every adult to have available to them if they need it.

NICE guidelines set out expectations that both NHS commissioners (the CCGs) and NHS provider trusts (the local mental health trusts) deliver, *"...a person-centred, integrated approach to providing services (that) is fundamental to delivering high quality care (to) people with ADHD."* NICE further says, *"commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duty to avoid unlawful discrimination and to have regard to promoting equality of opportunity."*

It is important to note that NHS Vale of York Clinical Commissioning Group (VoYCCG) has lower levels of health funding than many other areas. For every person in the Vale of York area, the VoYCCG has around £1,140 to spend per year. In an area like Liverpool, that amount rises to £1,560[xxi]. The four North Yorkshire CCGs were the only ones in the country to inherit debt from the Primary Care Trust they succeeded, originally indicated to be £19M[xxii], though the actual figure was later said to be £8.5M[xxiii]. Although local CCGs wiped out this debt in their first year, Vale of York CCG is currently forecasting a deficit of £28.1M for 2016/17[xxiv]. It is clear that investing in new services will be challenging given this situation.

Nutrition

An internet search using the words “nutrition” and “ADHD” brings up around 11 million results, mainly dealing with dietary approaches for children and young people. However, there is a lack of consistent advice about good nutrition for people with ADHD. NHS Choices suggests cutting out certain food colours if your child shows signs of hyperactivity or ADHD[xxv]. There is also reference on a number of sites to “leaky gut syndrome”[xxvi] which sites like NHS Choices suggest a lack of evidence to support[xxvii]. A number of websites suggest trying an elimination diet, cutting out allergens one group at a time[xxviii]. Others recommend dietary supplements[xxix], or following a specific dietary programme[xxx]. NICE guidance, however, contradicts most of these suggestions.[xxxi]

As such, there is a challenge for people living with ADHD and their families in deciding which advice to follow. There may be a range of things that work for some people, even though they are not supported by current guidance.

Why is Healthwatch York looking at support for adults with ADHD?

Healthwatch York has been made aware of difficulties adults with ADHD have had in finding and accessing support services. The issue has been raised with us in a number of ways:

- At a conference looking at mental health in York, a number of individuals asked questions about diagnosis and ongoing support for adults with ADHD and autism
- Carers have approached us, particularly through Solution Orientated Adult ADHD Carers (SOAAC)
- Individuals living with ADHD have approached us looking for information and advice, and have shared their stories

The majority of people contacting Healthwatch York stated they were not aware of any support available to people living with ADHD in York.

City of York has a population of approximately 200,000[xxxii]. NICE guidance estimates that 3-4% of the adult population have ADHD[xxxiii]. Based on an estimate of 3.5 adults in every hundred having ADHD, and just under a quarter of the population being under 19, then York could have around 5,250 adults in the city living with ADHD. However, we cannot state with certainty the actual extent of need/demand in the area.

What we did to find out more

We attended meetings with SOAAC, and supported them with activity to publicise their carers group. They kindly shared their report, which gives detailed insight into the challenges faced by carers and family members of people with ADHD.

Healthwatch York held two focus groups with carers of people living with autism and / or ADHD, to understand their experiences. Whilst this work did not focus solely on adult ADHD there were a number of issues raised that were directly relevant to this work.

We also held one to one meetings with a number of individuals with ADHD.

What we found out

Findings from the SOAAC report

The voices of families and carers are captured in the ADHD Carers SOAAC report "The Impact of Adult Attention Deficit Hyperactivity Disorder on the Individual, their Carers, and on Society"[xxxiv].

Here, we reproduce short extracts from the SOAAC report to highlight the sense of frustration at the lack of support available to carers of people with ADHD, and the impact ADHD has had on their lives. All names have been changed.

Tom's story

"I became aware my son Tom was different from the other children at an early age. He was more sensitive than his peers and found it hard to fit in… Teacher's would write that Tom "finds it difficult to produce much written work, lacks concentration, lacks patience, is easily distracted, makes mistakes…, is disorganised, needs to learn to listen and follow instructions." There were also positive comments like, "he is a bright and intelligent boy…"

“He was afraid of things that were unfamiliar… he struggled to apply himself… he would fidget a great deal… he was not obviously hyperactive. I have since learned this is not unusual. People can have ADHD with the hyperactivity manifesting in other ways.”

“I took him to the child development centre when he was five but following a ten minute appraisal, was told there was nothing wrong.”…

“When asked what he would like to be when he grew up Tom said he would like to be a doctor or a rock singer. His teacher responded “You are more likely to end up in prison.”…

“I knew my son was struggling, I knew he was bright, and suspected he had ADHD, but I was not listened to… I believe I was dismissed as an overprotective neurotic mother.” …

“(At seventeen) we sent Tom for weekly support at the Dyslexia Institute which consisted of tools and strategies geared to his ADHD…. (he) began attending a private clinic where the consultant prescribed methylphenidate, monitoring him at regular intervals…”

“(Tom) wished to continue his education… studying history, law, psychology and sociology. He gained two A’s and two B’s… and went to University to study law. This from a boy who (at school) was told he was not A-level material… Now aged 19 Tom thought he no longer needed (medication) and stopped taking it. He…believed he could manage without support from the university. Without structure to his life of medication, he soon lost focus… I believe he turned to alcohol and drugs as… a means of self-medication and to hide from the growing awareness he was not coping….”

“He ‘dropped out’ of University and came back to York. He moved in with a girl which was the first of four dysfunctional relationships over the next 10 years… After the first relationship failed Tom was devastated. He felt abandoned and desperate. … An old friend … came back into his life… a drug dealer …with a regular supply of cocaine or M-CAT (mephedrone). Tom said this helped him feel ‘normal’ …but… he would sleep most of the day and stay up at night. He became more irritable, aggressive and his mood swings were more marked….”

“There is a tendency to attribute the dysfunctional behaviour of those with adult ADHD to substances and alcohol rather than recognising it as a consequence of this disorder when left untreated. …”

“Due to his condition Tom found it difficult to deal with everyday problems. He was unable to focus on more than one thing at a time therefore he couldn’t hold down a job at the same time as being anxious about a relationship. His self-esteem was poor and his emotions fragile. …”

“We received a call from the police at 2am telling us our son was in custody. It came as an enormous shock… the judge sentenced them to three years in prison with immediate effect….”

“A business colleague gave Tom a job…. The demise of his existing relationship followed by problems with the subsequent relationship… made it impossible for him to function at work. He would sometimes fall asleep at his desk because he had been awake all night in a state of anxiety…”

“The stress of dealing with our son put a great deal of strain on our marriage and contributed to my husband and I separating for 7 months in 2010. When I returned home Tom’s girlfriend told me she wanted him to see his GP, to be referred for a mental health assessment as she was concerned about his behaviour… we eventually persuaded him to see his GP but after explaining his symptoms and behaviour we were told there was nothing wrong. Tom’s relationship ended and … his behaviour deteriorated further…. He would say he wanted to die and that he was going to kill himself… we would go to his house and find mirrors smashed and furniture broken… blood everywhere and cuts on Tom’s arms and wrists…”

"As there is so little support for those with Adult ADHD… I feel I am alone with the responsibility of caring for my son… (which) has taken its toll on my physical and psychological well-being. I often go to bed with a heavy heart and find it hard to sleep… sometimes a feeling of rising panic and thinking I might be overwhelmed by it… I am constantly tired… inside I feel trapped and desperate. I feel frustrated an angry with myself for being this 'pathetic' human being…. "

"It is not easy to relax… as there is a feeling of guilt that accompanies this. It stems from a conviction that somehow I have let my son down knowing that more could have been done… I feel I was part of the system that failed him."

Matthew's story

"Although (Matthew was) an engaging and lively child and an early developer, he had little regard for the consequences of his actions. He didn't want to stay at school on his first day so he bit the teacher… a few months later he cycled out of the school and straight onto the main road where he hit the side of a passing car."

"From the age of about 12 he began to develop serious behavioural problems… refusing to go to school… started using alcohol and soft drugs to… help him cope with the difference between the world as he saw it and the expectations of those around him. If asked to do something he didn't want to do… he would respond with disproportionate violence; throwing bottles or coffee mugs, kicking holes in doors and walls and threatening us with knives. During this phase he was suspended from school for drinking on the premises and … permanently excluded for possession of a knife. Matthew was also stopped by the police and was arrested on many occasions for various offences…."

"Looking back it is clear Matthew's inability to link actions to consequences was the underlying reason for his behaviour but… this was never suggested or explored. An intensive session of therapy… focussed exclusively on relationships within the family, and Matthew himself was **never** assessed by a qualified therapist. Limetrees gave this task to a second-year student who produced a 4-page report saying that he was bright but lazy… The first experienced doctor to be involved diagnosed Matthew's condition as likely to be caused by severe ADHD simply by listening to our descriptions and looking at his old school reports – this of course begs the question as to why his school or GP did not have access to anyone with this experience and knowledge to see this at the time… He was seen and assessed… as having severe ADD and the options for his treatment were outlined. However as adults with ADD don't fit into the remit of any of the services available in York he was unable to follow up any of the recommendations…"

"It is too late for our family, but we hope that by sharing our experience this condition will be picked up…. Even now, the lack of ongoing support for Matthew in adulthood means that he remains at real risk of poverty and homelessness."

The report details the challenges Matthew faces:

- Money – impulse spending, finds budgeting difficult, disorganised and forgets to pay bills, finds saving very difficult – his mother helps by holding his money for him and managing household bills
- Food – inability to plan, shop for and prepare meals, forgets to eat, shops on impulse, cannot cook a meal using more than two sources, e.g. cannot grill sausages, boil potatoes and microwave beans as too much going on
- Hygiene – forgets to bathe, wash hair or shave, wears the same clothes for days or weeks
- Household tasks – doesn't like help from other people, washes up regularly, but other tasks like cleaning, laundry and shopping are sporadic, forgets to buy replacements for things like toilet paper
- Appointments – finds remembering and planning appointments difficult, gets anxious about going somewhere unfamiliar
- Friendships – difficulty in making and sustaining friendships
- Medication – receives support from parents to get repeat prescriptions, leaves some medication with them

Andrew's story

"Following a difficult birth Andrew was an unsettled baby… we did not realise he had problems until I started taking him to toddler groups. Initially we were sent to Limetrees. The main focus was on us as parents which we found patronising and upsetting. They tested Andrew's IQ which was high. Following problems at Primary School Andrew was eventually given an ADHD diagnosis with no further plan. We then saw our GP who advised us to see a Paediatric consultant in London. She assessed Andrew over several hours and diagnosed him with ADHD. He was prescribed Ritalin which seemed to help…"

"Secondary school did not help with Andrew's ADHD. He started to self-harm and became very disruptive. The school dismissed his problems as purely bad behaviour."

"In year 10… (he) gained new (friends) who had a negative influence on him… He started taking cannabis becoming very aggressive at home and ceasing to try at school. We went to the GP as his problems were escalating. We were referred to Limetrees and he saw a counsellor who seemed to make him more agitated. Violence started to increase….
No one seemed to know what to do. On one evening things became very violent with Andrew smashing two laptops in his room and jumping out of his window. We had to call the police who agreed he needed help but said the only way was for us to agree to him being arrested which we reluctantly did. He was then referred to the Youth Offending Team (YOT). The person he saw had a good influence on Andrew and was very helpful (but) the nurse who works alongside YOT dismissed his ADHD after only one appointment. Andrew soon relapsed, threatening to kill us in our sleep. A social worker started to see him after the YOT order and the police had to be called on several occasions. Andrew's father was too afraid to work away (which is part of his job) fearing what might happen at home… After three months we were told it would be the last visit, despite his problems increasing and the police being more involved."

"We started to feel very vulnerable and afraid for all our safety including Andrew's as he regularly threatened to kill himself. He would taunt us with knives when he was angry… We desperately called the manager of child social services on several occasions, sometimes in tears…."

"Social services contacted us and gave us a family intervention worker for problem families… this person said Andrew did not have ADHD and could be easily sorted out also saying they didn't really see nice families like ours… Andrew had deteriorated and was taking M-CAT. More items were stolen from our house… drug dealers would turn up at our house and we had to call the police frequently… which ended with Andrew having to move to Howe Hill Hostel…."

"Andrew didn't engage and slept rough and on people's floors. He was only 16 and getting into more trouble with the police, culminating in him being placed in the custody of the local authority… the foster carers allowing their son to tattoo Andrew's neck, chest and arm and sending us the bill…. Andrew was also getting cannabis from their son…
Other than Andrew's reviews there was only 2 or 3 visits from social services to see him in 11 months and when the placement collapsed there were no written notes regarding his case. On the day he left we got a call from Andrew at Kings Cross station saying he was sleeping rough so we arranged for him to come home..."

"A week after his 18th birthday Andrew took an overdose in London then ran away from hospital. The police found him… he was sectioned under the Mental Health Act… To our horror he was discharged the next day… he rang us saying he was going to jump off a building… he was sectioned again and sent to the Friarage… but escaped… the following day."

"Andrew had further stays in hostels, made further calls about taking his own life, self-harmed, got involved with drug dealers, and threatened and intimidated family members."

"Andrew ended up in Hull prison for 9 weeks… things continued to go badly…. After committing several offences, Andrew was sentenced to 15 months in prison… He is not allowed contact with me until February 2016…. We are so afraid that without some intervention he will continue on this destructive path.

Summary of Issues from the SOAAC Report

In summary, the Solution Orientated Adult ADHD Carers (SOAAC) report indicates that despite a parents' concern:

- a GP may be reluctant or refuse to refer a child for assessment;
- a school may not identify potential ADHD underlying difficult behaviour, and thus not involve an educational psychologist;
- a school psychology service may refer an older child to CAHMS, but long waiting times may lose a vital window of opportunity to intervene when the 'child' or young person may have been willing to grasp an opportunity;
- even when parents resort to private mental health resources and help is found, they face challenges when a child becomes a young adult. When they face a new environment such as university, their previous trusted support relationships are cut off. They enter a new academic environment in which greater independence is expected of all students. Most new students will thrive and make new and lasting relationships with their peers, but for someone with ADHD or other mental health conditions the new life can feel exposed, potentially hostile and hugely challenging.

Voices of Adults with ADHD

A number of adults with ADHD living in York contacted Healthwatch York to share their experiences (all names have been changed):

Xanthe

Xanthe says: “I was only diagnosed in 2005, in my 30s. I came to York as a mature student. I was meant to have care and support transfer with me but this didn’t happen. I have direct payments which allow me to pay for a life coach. This is essential for me. At transfer the payments stopped, I couldn’t see my life coach, and my life fell apart. I went to a GP in York, to ask for help. I knew I needed a referral into Mental Health services. I was anxious, and I lost it on the telephone to the GP – I became irrational and used inappropriate language. I got a letter saying my behaviour was unacceptable. The in-house mental health nurse said the letter was wrong – people who understand ADHD know it isn’t how I would choose to behave but when upset I literally cannot help myself.
I want to work. I’ve been unemployed for over 10 years. But to work, I need support. I need help with structuring my life to get the balance right between work, life and home. I take on lots of voluntary projects, throw myself in wholeheartedly doing hours and hours of work every week, and exhaust myself and then need time to recover.”

Xanthe believes that mental health services should be available. She has been told by the NHS in adjacent areas that she should be monitored every 6 months, but has also been told that this impossible in York. Xanthe feels she has been rejected by services because she is not classified as having ‘mental health issues'. She says, “I have trouble fitting service categories”. However, she seems to suggest that as a 'service user' or patient she is made to feel at fault because she does not fit. She feels that it is the 'system' that defines and redefines categories and sets criteria.

Her social worker, not trained in ADHD, admits not understanding the condition, but wants to. Xanthe wants employment, but is worried about this because of the challenges involved. She has been able to access coaching, which has helped her set boundaries, and gain insight into how others perceive her, which has helped her think about going back to work. But she is worried that she may not still receive this support if she goes back into employment. However, without proper support she does not believe she has a good chance of making a success of work. Xanthe feels that services make an assumption that she has family support. She is living and coping on her own but feels that everyone “thinks I must have a carer somewhere.”

She provides further insight into living with the condition. She shared that she finds too much input overwhelming. She described it as being like trying to watch TV, read a book, listen to a radio station and hold a conversation all at the same time. She finds it easy to become overloaded:

- I can't go to the CYC offices...they cause sensory overload
- I can't stand the heating system at night... the ticking sound is too penetrating.

Xanthe also confirmed she finds it difficult to form strong relationships, as people can find her behaviour challenging. Xanthe’s experience echoes those passed on by carers: the condition caused people to feel bullied. In turn, Xanthe was bullied at school and moved schools often. Xanthe was diagnosed in adulthood. Prior to diagnosis, she frequently felt angry and frustrated. She is clever, but dyslexic, and has found written work and reading a problem. As she grew older, she felt she was seen as a 'misfit'. Without support, she drifted into drugs and poor relationships.

Xanthe needs 'space' to think and process thoughts and feelings. She has had a number of different diagnoses, including being thought to be bipolar or depressed by health professionals. She believes that “doctors don't look for a pattern.” She feels they are looking for symptoms or criteria rather than trying to see the whole person.

Xanthe has offered many other experiences and insights. She is now aware of her condition, and how others perceive her. But she feels that in effect she is just marking time. In order to move forward the services already outlined, and in place in other areas, need to be provided in

York. Xanthe has found real help from a 'life coach' who has helped her to recognise and engage with her condition. But to take the next steps into employment, she needs this support to continue.

James

James contacted Healthwatch York after coming to live in York. James had previously been diagnosed with ADHD and was looking for services in support of his condition. He approached his GP in York and found the experience 'shocking'. He was told “there is no money in mental health” in York, particularly for autistic spectrum disorders and ADHD. He states that his impression was that “the system is in chaos”. James asked for to change to a different medication as he was having side effects. His GP again told him there was no money for a referral to a psychiatrist for a medication review. James states that his appointment went nowhere until he showed the GP a letter from a Maudsley psychiatrist. He was then prescribed more of the old medication. When he once again asked for a medication review, the GP responded with further negative comments about the state of mental health services.

James hopes to find another GP who may give different and more supportive answers. But his negative encounter has left him feeling neglected by the Health Service. James says:

> “I am back on the medication that I previously wanted to change from, without any therapeutic support or even any hope of ever getting (it)”.

Sarah

Sarah is a young adult with family responsibilities. She contacted us “at her wit's end”. She informed us that her world had collapsed - her partner had gone, and her children. Sarah has ADHD. She contacted us wanting to know who could help her turn her life around. Sarah was trying to put her “life back together”.

Sarah already had an ADHD diagnosis before coming to York. Fit and active, Sarah has had useful input from a community mental health team in the past. She became ill with glandular fever. She told us that three

GPs had made referrals for social worker support, but that City of York Council refused to provide one. She also states that the Council refused help with a 'managed move', and her attempts to obtain a 'personal budget'. Sarah recounted “repeatedly (being) passed from pillar to post”, and being “misdiagnosed by a CPN (community psychiatric nurse)” who was provided only after her 'breakdown' – a crisis that she feels probably need not have happened if she had been given support to manage her condition appropriately in the first place.

Sarah feels like she has been “treated like dirt”. She says “we are literally going out of our minds”. Sarah is also convinced that the CPN's 15 minute assessment of her mental health situation, which she disputes, now forms part of her recorded medical history. She believes this has affected further decisions that have been made regarding fitness to care for her children. She wanted to understand whether this assessment can be removed from her records.

Sarah actually says little about having AHDH, other than noting that he/she has the diagnosis, but talked about her experiences of rejection when trying to obtain help from all agencies, whether statutory or voluntary and community sector, as she did not fit the criteria. These rejections add to underlying challenges when simply wanting to be, “back at work and enjoying family life”, adding “…is that too much to ask?”

Alex

Alex was recently diagnosed with ADHD at the Tuke Centre, part of the Retreat in York. Despite this diagnosis, he does not believe he has very extreme symptoms. He feels that his condition probably contributed to difficulties with forming or sustaining positive personal relationships.

Alex’s GP who made the referral “was brilliant” and the referral resulted in an assessment 12 weeks later.

The Tuke Centre recommended ADHD-specific Cognitive Behavioural Therapy (CBT). Alex was told that the therapy sessions were chargeable, but that the Tuke Centre were confident the costs would be 'covered'. The sessions have since ceased as it became clear that ongoing care and support might be a problem. Alex understands that the Retreat submitted a bid to become a provider of ADHD pathway services in addition to providing diagnosis support across North Yorkshire to the 4 CCGs but this had not been agreed at the time he spoke to us. Alex was also prescribed medication. He tried several types until Alex's GP received a letter from TEWV declining funding for ongoing care for Alex. Alex himself was not copied into this communication.

Alex still seeks CBT and the right medication. In addition he has sought out a 'support group', finding one at Wakefield Pinderfields Hospital. As with others who have contacted us, he stated that being able to be in contact with others 'who get it' is helpful, but Alex feels the Wakefield group is probably geared more to parents of people with ADHD than the individuals directly affected.

Alex concludes that the Government is failing to take ADHD seriously, and as a result incur social and economic costs. In addition, he believes they risk alienating many adults with ADHD who, without help and support, end up with ruined lives. As Alex explains, he has other 'problem behaviour' which he also want to overcome. Alex is angry that although an ADHD assessment/diagnosis service was put in place nearly 2 years ago, he has yet to receive agreement on funding for his ongoing care needs. Alex's GP has sought to obtain further funding for ongoing care, but when the request was passed to TEWV, the Trust declined it. “It took them over 8 months of ping pong to come to that decision!” He believes he is “just another adult with ADHD left high and dry.”

Mary

Mary is in her 40s. She feels under pressure to sign on whilst waiting for diagnosis and treatment, probably for ADHD. There is no ADHD consultant in York, she has to get an appointment with Wakefield. (Note: The Tuke Centre at the Retreat has an ADHD consultant, Thomas Elanjithara, and people can be referred to him). It takes 7 weeks to get an appointment. She has no food in the cupboard and no credit on her phone. She needs support with claiming benefits. She wants an advocate to support with pressure from the Job Centre. She is feeling very overwhelmed by circumstances.

Healthwatch York Focus groups on Autism and / or ADHD, February 2015

Findings from the Focus Groups

We spoke with 13 people across 3 groups. 11 were carers, 2 were professionals working with people with ADHD. It is important to note that the discussion covered experiences of both autism and ADHD, though these two conditions are not always present together. Feedback received from the focus groups has been divided into 3 distinct sections:

1. People's experiences of autism and ADHD
2. Themes and comments on how life for people with autism and ADHD could be improved in the city
3. Gaps identified by a coach with experience of working with people living with ADHD who attended the focus group

1. People's experiences

All names have been changed.

Ellen

Ellen used to go to St John's University, she has Asperger's, but walked out and effectively became a recluse. Her confidence went, and she didn't want any formal support, she just wanted a drop-in space, to take the pressure of support off, 2 years ago. Ellen ended up going home, got so depressed she just couldn't cope, but she feels she was left to get worse. "It's difficult when you get into the mental health system – to understand what issues are due to the autistic spectrum disorder and what actually is mental health."

Ben

"Last week the police came twice for my son, Ben, because he didn't want to go back to his flat, ended up in the police car having a 'meltdown'. Police asked "what has happened since we were here last? What support is in place?""

"He has gone missing for over 8 hours, and suddenly he's the family's problem. He's at the family home more than at his own home. He has a specific number of hours of care, mainly delivered by young girls of around sixteen. He's never given choice in this and he probably finds them quite intimidating."

Mark

"Mark will be 29 this year, we're worried we will have to move him to somewhere else, due to behaviours and rituals. He previously lost his job. He had a job at a shop, he was then sacked as he was taking too long. This was five years ago. He got really depressed, no intervention at this time, hadn't declared his Autism to his employer, he didn't work fast enough – very meticulous, felt he couldn't explain the condition. His mental ill health led to paranoia. Services will only provide support at crisis."

Jason

"It feels like there is very little provision for those with ADHD. What's happening to address this? Jason was placed with a provider outside York aged thirteen, he's now twenty two. At eighteen we received a letter from City of York Council telling the family they had provision for him now, in York, in a flat that hadn't yet been built. Jason's current provider has become his whole world, it's very scary to think it could all be stopped. It sometimes feels like bullying tactics – that they can withdraw provision if you protest too much. When Jason heard about it he said "I don't want to go back there, they don't understand me." It feels like it always comes down to money – is bringing our child back about saving money?"

"Jason has a care plan, but I'm not sure if it's used. There's no prompting, he's not learnt to go shopping or prepare food. I would like him to have personal assistants who would work one to one to support him. He needs life preparation support. We've not been offered 'personalisation', would be willing to be part of developing a personalised plan for Jason, testing activities to see what works."

Nathan
“I would like to see lots of opportunities for young people to do things in York. It feels like there is a difference between mainstream children and people with autism. It’s particularly challenging for those who are high functioning- where do they fit? My son doesn’t see himself as disabled but mainstream schools are not a supportive environment.”

“This leads to a decline in mental health. There is no open door policy with Limetrees, so we’re back to the beginning as a re-referral when he has a dip. My son is nearly 14. He has dips - peaks and troughs, and the lows happen in a split second, with very little warning. He has medication which could enable him to take his own life. At that stage we want significant intervention from Limetrees. But when it happens, they say he’s been OK for a period beforehand, then he’s a closed case. Which means we have to go back to our GP, have to wait for support to be available, and by the time we get back in to services, we’ve sorted it out. But at an emotional and physical cost to us each time.”

“With interventions you maybe get 3 months of support, and then things are checked 6 months later. If all is OK they close the case. It’s a really challenging situation for the whole family. There’s no consistency - staff have moved on, so you have to start again, building new relationships which is one of the real challenges for our children. So we as a family sort it ourselves, but we worry about the impact on our other children. It’s exhausting, just existing. We both still have to go to work, sometimes we leave him with others looking after him and all we can do is hope he’s OK. Realistically when he has these dips we need a response and support within a couple of days. We’re not the only ones – we’re connected with a big group of people going through the same thing.”

“Someone last year couldn’t cope and took his own life. We want something ongoing to help with maintaining mental wellbeing. But we’ve been told this doesn’t exist.”

“School has been great - looking at 1 to 1 support with a Personal Assistant to do something and they’ll allow him time out of school. He’s looking at yoga, looking at self-care and how he can help himself. But he struggles with social skills.”

“As parents we’re on suicide watch but we get no training. It feels like they make you look after everything yourselves and it’s a struggle to maintain normal family life whilst crises are happening around you. You juggle work whilst thinking of ways to bring him out of it. Sometimes it feel like I don’t know my son at all. He doesn’t talk. So I’ve no idea what’s in his head, sometimes.”

“Because my son has an autism label, it’s an excuse for the challenges, so I feel like he’s not seen as in as great a need as a one-off incident when he experiences mental ill health as it would be for, for example, a “normal” 15 year old. A staff member at Limetrees once said to me “The parents become better equipped to deal with it.” My daughter now has a really good support network through Young Carers at the Carers Centre but it took time and effort to get this in place.”

“I’m worried about transition. I know other parent carers who say “you’re where we were 10 years ago.” I think that Limetrees don’t know enough about autism. But it’s not their fault, they are very stretched. You have to be in crisis to get support.”

“It’s great to hear about psychiatric liaison in A & E. But I don’t want to get to that point. My son tried to kill himself at 13 years old. He threw himself under a bus. As a parent, you always have this hanging over you.”

“In school the Physical Disability Specialist teacher did a big programme of social activity. But autism speciality teachers are too stretched - so I feel like those with social challenges rather than a physical impairment are not getting the same deal.”

“Some interventions are amazing but they’re not a permanent fix. When I said this I was told he’ll need to learn to cope, and our family does too. I was also told children with autism have dark moments but they're not really suicidal."

"Nathan says he doesn't see the point in referrals. He will have an experience, then he'll get the intervention but then it will all come to an end and he'll be back without support."

"The good thing is that all the interventions he's had have been age appropriate, so for example, when he was 10, he talked about what's happening in the brain, drew pictures of his brain and how he feels. It's all good person centred stuff. But what next? I'm always trying to think of the next thing that might help. But I've no experience of where he goes next. We've been offered different therapies to deal with aftermath. But I actually want training on what to do when things start to fall apart. What's 'usual?' I've never had a fourteen year old boy before. What's hormones? What's Autism?"

"This all has an impact on health – feeling exhausted and anxious. We're in a constant vicious circle of services. I'd like a holistic approach. I need advice, training, and guidance to plan for what comes next. There can be triggers, usually around school, bullying at school, and his behaviour takes a dip, but the school is very supportive. Sometimes though, there's no indication why."

"With some of the options we're offered Nathan asks "Why would I go there? It's full of disabled people, I'm not used to them." But he also can't go to some other groups as "they talk too fast and I can't process it.""

"Nathan says "All I want to do is fit in, I don't want to be singled out. I want to fit in, want to 'blend' in and not be the person that has a meltdown." Nathan will try anything, he's not scared of doing things. Last week, when he felt better, we went shopping. He said he wanted to look 'less different.'"

“We get a direct payment. But it’s a struggle to find individuals of the right age. He had a Personal Assistant recently who had a friend with Autism. They both used to sit and not speak for a while.”

“He went on a residential recently. But the next youngest person was seventeen. He loved it but he couldn’t cope in the canteen, so he sat apart from everyone else. He feels damned if he does and damned if he doesn’t. He doesn’t want to exclude himself but he can’t cope.”

“I spoke to one of the specialist teachers, sharing my view that we first need to look at the social side. It’s the biggest area where support is needed. When you are doing this with young children, you need to keep revisiting this for children who are high functioning.”

“I’ve been told things that aren’t right. I’ve been told he wouldn’t get sarcasm. He does. We’re a very sociable family. Nathan is sharp, witty, quick, but take him out and the barriers he has get in the way. He won’t allow his friend to come round. He needs people he trusts around. It’s taken a long time to build that trust. He’s an intelligent, talented chap, but struggles to show this outside of the house.”

“We keep looking for positive stuff. We started off years ago with the sports directory. He tried everything but he’s not sporty. He likes TV and Youtube. But he’s looking at Yoga to do with his Dad. He’s decided he could have a Facebook account. He wants very limited public exposure, so he’s looking at IT, at non-direct contact. He’s looked at clubs at school, but it’s outside his comfort zone.”

“If we were was starting over, back at Primary school then I’d focus on social interaction. He did the programme about social interaction, but I would do so much more with children with autism then. That’s the time when they are still having some social capacity with their peers. They need Emotional Intelligence and support at this point. I’d also want to see more support for parents – we went on the ASSEND course, but we had already read a lot. It was good to meet parents though.”

“There used to be a siblings group at Limetrees. When Nathan was diagnosed with Autism they had a group that met with siblings to help them through it. Just for siblings. But then the rate of referrals increased, so they had to redirect funding to diagnosis work. So all peer support stopped. Peer support can help but it is not enough, they need professional intervention.”

“You can access City of York Council Workforce Development Unit training as a parent. CANDI (now York Parent Carer Forum) set this up. Does it still apply? But it would be good if they could provide training around managing specific behaviours through Mental Health. We’ve had some really good training, for example about sensory processing. But for us it’s all about social skills and mental health.”

2. Themes and comments on how life for people with autism and ADHD could be improved in the city

Understanding the potential links between autism and other conditions

One parent felt it was important to understand that for many people with autism, there are usually a minimum of two things going on. These could be for example ADHD, Dyspraxia, learning difficulties, Mental Health Conditions, which are experienced alongside and as well as an Autistic Spectrum condition. The parent emphasised that for her child, change is difficult. With this in mind, she invited us to imagine how people with autism feel when they have to leave York because there is no provision here. She feels that they are removed from everything familiar. But she is aware that we don’t have the services here to support them.

What is missing and what people would like to see

The focus group came up with a number of issues highlighting improvements that could be made

- People need reminders for medical care, from health checks and dental appointments, through to remembering to brush your teeth.
- There are challenges around access to information. It’s hard to find any help about what is available in the city.

- We need easy access to services, including low level support such as Millers Yard.
- There is a need for structure. A timetable, with a range of meaningful activities.
- There needs to be initial investment in early support to reduce the challenges in later life.
- We need someone realising when things aren't working.
- Children's Services have an independent reviewing officer - completely independent, reviews things every year – what's working, what isn't. Can we have this in Adult Services?
- We need to look at how we can nurture and support creativity, skills and employability? Everyone has skills, it is how you use them e.g. a person who enjoys ripping up paper can help create mosaics.

Medication

Participants made a number of comments on medication for ADHD:

- Medication – this can be a major breakthrough
- Anxiety management is a big issue – they don't seem to change medication for this if it's not working.
- Reviewing the use of anti-psychotic medications – by impact. These may help short term but should not be used long term.

Care and support

The focus group identified the following issues around support

- People need a keyworker, who knows about their condition, to support with structure, understand what they really want, and help them establish routines.
- It takes years to build relationships of trust with professionals working with your child.
- Good care workers: need patience, don't raise their voice, must be factual and give details such as timings, get to know people, don't overwhelm them, stay calm, motivate people, are good at reading body language, are positive, avoid intimidation.

- Care workers need training. United Response are good, they have specialisms, their staff stay longer, they enjoy the job and are paid more for specialist skills.
- Some staff who work with people with autism show a lack of awareness.

Other issues raised by the group

- Where does the strategic responsibility for Autism and ADHD sit in York? It would be good to have clarity over where issues can be raised and who to hold to account.
- The economic impact of failing people with Autism and ADHD needs to be taken into account. Where is the money for people with these conditions? The challenges of austerity are reducing inclusive practice.

3. Gaps identified by a coach with experience of working with people living with ADHD in York

There needs to be more focus on adults who may not have been diagnosed. They are on the periphery. I've been approached by parents of adults in their twenties, who wanted specific help for their social skills, anxiety. I am not qualified to provide this. There is no training on how to work with people. I'm a bit at a loss on where to signpost to.

There are recommendations on how to work with people with Autism. A lot of standard psychotherapy is not helpful, and can actually make things worse. A structured approach is more beneficial. Another gap is support for couples, who need counselling, where one partner is on the spectrum and they are experiencing difficulties. I am looking at and willing to co-ordinate a partners group in York. There are gaps in information and emotional support. We need to increase understanding of the effects of Autism on adult relationships. How do we identify if this is due to Autism and where can support be found? There's just not enough support out there. Currently the nearest support groups are in Halifax. Everyone involved in education needs training in disability awareness, equality and Autism awareness before they start to work in schools.

Conclusion

Drawing on all the information the testimony above describes a poor picture, both for adults and for families living with ADHD in York. If an adult sees their GP because of concern about whether they might have ADHD, there is no guarantee that this visit will lead to a referral for an assessment. These stories indicate some GPs remain sceptical about ADHD as a medical condition.

If they do receive a referral for assessment and possible diagnosis, there is still limited access to ongoing support.

It is clear that in order for this to change, there needs to be a consistent pathway and options for treatment and support. The financial, emotional and societal costs of failing to do so are evident from the experiences people have shared with us.

Recommendations

Recommendation	Recommended to
Commissioners and Providers commit to working together with people with ADHD to find a creative (if necessary) and sustainable solution to provide support services for adults with ADHD in the York area. This should include considering the needs of people with ADHD in newly emerging pathways around low level / community based support for people experiencing mental ill health.	NHS Vale of York CCG (VoYCCG) Tees Esk & Wear Valleys NHS Foundation Trust (TEWV) City of York Council (CYC)
Consider the creation of a multi-agency task group to look at how a 'system wide' pathway to provide the efficient and effective pathways regarding support for people with ADHD and their carers can be developed.	VoY CCG TEWV CYC The Retreat SOAAC
A patient/service user reference group should be established with links to the task group to embed co-production approaches and to develop peer support networks locally.	Health & Wellbeing Board
Consider creative approaches to personal budgets and personal health budgets to support those with ADHD having access to a wider range of potential support services.	VoY CCG CYC
Clarify where responsibility sits in York for Autism, and where concerns about the implementation of the National Autism Strategy can be raised	Health & Wellbeing Board

Appendix 1 - Information and Support providers

NHS Choices provides information on diagnosing and managing health conditions. This page is mainly about ADHD in children, but provides links to a wide range of information.
http://www.nhs.uk/conditions/Attention-deficit-hyperactivity-disorder/Pages/Introduction.aspx

The ADHD Foundation, in partnership with individuals, families, doctors, teachers and other agencies, works to:

- Build a positive foundation for life.
- Improve life chances through better understanding and management of ADHD.
- Raise awareness & understanding of ADHD - change the negative perception of ADHD into positive.
- Bring about positive change and inclusion within policy and practice.
- Support schools, GP's, youth justice services and other professionals who work with people living with ADHD.
- The ADHD Foundation supports achievement, educational attainment, mental health and employability.

The Foundation works in partnership with those living with ADHD, enabling them to understand and manage ADHD.
http://www.adhdfoundation.org.uk

ADHD Together is a resource to help parents, carers and teachers from across Europe work together in supporting school-age children with ADHD. The following sections have been developed to cover the key steps needed to encourage them to thrive both at home and in the school environment.
http://www.adhdtogether.com

ADDISS, The National **A**ttention **D**eficit **D**isorder **I**nformation and **S**upport **S**ervice provides people-friendly information and resources about Attention Deficit Hyperactivity Disorder to anyone who needs

assistance - parents, sufferers, teachers or health professionals. Whatever you're looking for in ADHD, they'll do their best to help.
http://www.addiss.co.uk

The Hyperactive Children's Support Group
HACSG aims to provide information and advice to Parents, Carers and Professionals seeking solutions for children and young people who may be affected by Hyperactivity and/or ADHD.
The HACSG is unable to offer diagnosis or medical advice. We are more than happy to talk over any concerns Parents, Carers or Professionals may have and will do our best to investigate a dietary and nutritional approach.
http://www.hacsg.org.uk/

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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.

Making York work for people with dementia

March 2017

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A note about language

Language shapes our reality. The words we use not only illustrate our thoughts and feelings, but also play a role in either reinforcing or challenging stereotypes.

At Healthwatch York, we follow the social model of disability and therefore use the term disabled people as a political one. People may have physical or sensory impairments, mental health conditions, or learning difficulties, but they face barriers in daily life because of the way society has developed. They are, in essence, disabled by society. For example, a wheelchair user may have a physical impairment, but if buildings are developed with ramps and lifts, they are not 'disabled'. Similarly, if we provide sign language interpreters at meetings, Deaf people who use signing are not disabled. But if we do not, they are.

We feel it is important to use terminology that reflects our belief in empowering people and removing barriers to their inclusion. We have worked closely with a number of disabled people who are passionate campaigners for a greater understanding of the social model. We believe this applies equally to how we talk about and describe the experience of living with dementia. Never has there been an illness where so little support is aimed at those living with the illness. To change this, we must shift the emphasis, focussing much more on people with dementia.

In this report when we use the term ‘people with dementia’ or ‘people living with dementia’ we are talking only about those with a dementia diagnosis, or experiencing symptoms of dementia. We are not using it about people caring for those living with dementia. We believe it is important to identify separately the needs of those with dementia, and those caring for them. We heartily endorse the work of both the Dementia Engagement and Empowerment Project and the Dementia Friends programme in challenging the words we use to talk about dementia.

For more information see:
http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf https://www.dementiafriends.org.uk/

Making York work for people with dementia

Introduction

The purpose of this report is to build on the work already done through the Joseph Rowntree Foundation, to consider how we can make York work for people with dementia, their carers and families.

Dementia Facts & Figures

Dementia is caused by a number of diseases that affect the brain. The most common is Alzheimer's but diseases also include vascular dementia, dementia with Lewy bodies and Pick's disease. Different types of dementia affect the brain at different rates and in different ways, but other things like someone's personal circumstances, the people around them and the environment in which they live, will affect their experience of dementia. Dementia progresses in a way that is unique to each individual.[i]
In 2014 the Alzheimer's Society published their findings on the impact of dementia in the UK and they suggested that by 2015 there would be over 850,000 people with dementia. They also predicted this figure would increase to over 1,000,000 by 2025. Whilst dementia is often talked about as an issue affecting older people, there are over 40,000 people diagnosed with early onset dementia (before the age of 65).

In 2015, approximately 2,700 people in York aged over 65 were predicted to have dementia.[ii] This number is expected to rise to over 4,000 by 2030.
Of those currently living with dementia in York, roughly half will have a diagnosis. Two thirds live in the community, with a third in residential care. Around half of those living in the community live alone. The Government's dementia diagnosis target – wanting 67% of people with dementia to have a formal dementia diagnosis - is not yet being reached within the city. Despite a recent increase, NHS Vale of York Clinical Commissioning Group reported the rate stands at 55.3%.[iii]

Why is Healthwatch York looking at dementia?

Since Healthwatch York began in April 2013 until April 2015 we had contact with over 20 individuals raising concerns about support for people living with dementia. Usually these are one-off signposting queries, where people have struggled to get the information they need. The enquiries received indicate:

- People still struggle to get diagnoses, with significant variation in practice between GPs.
- People are not being routinely signposted to sources of support by GPs or social care providers.
- People have poor access to information about available support, particularly at times of crisis.
- People who approach us have often already made contact with up to four other agencies, but have been unable to get the information they need.
- There are serious concerns about the availability of suitable care homes and care homes with nursing support for people with living with dementia.

Each year Healthwatch York surveys the public to identify areas of concern and in our latest survey, 58% of respondents felt that we should look at dementia services. Comments regarding why this should be a priority included:

- You should look at dementia. I've spoken with a number of people about dementia services, and we don’t have a good strategic approach in the city to make sure people's needs are met and concerns responded to.
- Dementia is an increasing problem - with 50% of over 80s affected. This will increase in the community.
- It would make a huge difference to Carers if there were more 'day care' opportunities. We all want to keep people at home, but it is exhausting without regular breaks.

We secured funding from Joseph Rowntree Foundation which made it possible for us to take on this work, which we hope builds on their excellent reports:

- Evaluation of the York Dementia Friendly Communities Programme[iv]
- Developing a national user movement of people with dementia[v]
- How can we make our cities dementia friendly?[vi]

What we did

We worked with York Minds & Voices dementia forum. We invited both people with dementia and their supporters to be involved with this work. We met monthly for a year. At the first meeting, we identified topics that the Forum were keen to explore, using the JRF Evaluation of the York Dementia Friendly Communities Programme as a starting point. At each subsequent meeting, we then took a topic in turn and discussed people's experiences. In some meetings, we split up into two groups – people living with dementia and people caring for those with dementia. This allowed space to explore sensitive topics freely.

We also ran a survey. We made this available electronically and in paper form. We shared copies of the survey with the key dementia support organisations in York. We received a limited number of useable returns. We also had our highest ever number of returns where only the first question was answered – 32 people began the survey without going beyond the first question. Although only from a small sample, it gives an indication about the potential challenges of a digital-by-default approach for people living with dementia.

Key findings

Key themes emerged from our work. These are:

1. Everyone's experience of dementia is unique

It is one of the 5 key facts about dementia that the Dementia Friends programme promotes, but it is still not universally understood.

2. The need for genuine engagement with people with dementia.

People living with dementia in York are keen to share their experience. They can help organisations understand what it means to be dementia friendly. However, engagement opportunities need to move beyond tokenistic representation. Assumptions about what people with dementia can and cannot do limit our abilities to collectively create a dementia friendly York. Many education initiatives are delivered in the absence of people living with dementia.

If you want to know what people with dementia think about something, talk to people with dementia.

3. Diagnosis is vital, but experience of this is inconsistent.

In the Vale of York we are falling short of the national target of making sure 67% of people with dementia have a formally recorded dementia diagnosis. We miss this target by 13%.

The importance of diagnosis was identified repeatedly as an area where improvement is needed and is possible. It was clear that the quality of experience of the diagnostic process varied dramatically.

This tallies clearly with Wendy Mitchell's experience, which she blogged about for JRF:

> My GP asked me, "Why would you want a diagnosis?" I wanted a diagnosis to put an end to the uncertainty and give me the ability to start focussing on what I could do. Early diagnosis offers you the opportunity to talk to your loved ones about what you want and develop strategies to give all those around you a more positive experience.[vii]

People with dementia were very keen to support GPs to understand the importance of diagnosis. They also had examples of how to share this news in a supportive manner. Diagnosis can also be a gateway. Where people are effectively signposted to other support services, this can allow them, and their carers, to get information, advice, support, and access activities, all of which can reduce the need for statutory health and care interventions.

As part of this work, we began developing a guide to dementia support. This was initially based on some work by Salford Dementia Champions. We hope to launch this guide early in 2017, and hope that this can support GPs in their signposting role.

4. Being active and involved, being heard, and helping change things has positive health benefits

Those involved in our sessions repeatedly highlighted how important this was for them. Alongside the well-documented benefits of volunteering[viii], particularly for older people[ix], positive meaningful activity for people living with dementia helps them maintain their skills, feel connected, and most importantly continue to enjoy life. Some in the group talked about how challenging it was initially before they were aware of activities they could be involved in. They talked about a sense of ‘prescribed disengagement’, of being “sent home to fade and die”.

5. Everyone has a role to play in making life better for people with dementia and can help create communities that are better for us all

The work to address stigma, improve understanding, and enable people to be dementia friendly is vital. However, this work is not just about being dementia friendly, it’s about being friendly to all. Underpinning dementia friendly communities are some fundamental ideas – being patient, slowing down, taking time, being supportive of each other, giving good customer service, providing clear signage and information – all these things not only improve the lives of those with dementia, but help create a society that is better for us all. Simple things like fixing wobbly pavements have a positive impact, not just for people with dementia and for people with mobility challenges, but also for all of us going about our daily lives.

What we found out (in more detail)

Participants

Twenty people took part in the monthly meetings. These were for Minds & Voices forum members and supporters, but ran as ten separate focus groups in a local community venue. Of these 20 people 13 were people with dementia. The remaining seven were carers. The members of the focus groups had been invited through Minds & Voices to take part in the study.

Symptoms

Participants were asked to recall the signs and symptoms that they or their partners were experiencing which suggested there may be a problem. The symptoms of dementia appeared to present themselves in a variety of different ways.

Many raised issues of forgetfulness:

Participant [Carer, Male] ***"My wife came to me and said that she was having some problems forgetting things. I hadn't really noticed."***

Participant [Carer, Female] ***"He started to put a notice beside his bed to say it was Wednesday. I thought it was a bit odd and wasn't like him."***

Participant [Carer, Female] ***"He simply didn't know where the dishwasher was, yet he had always been totally aware."***

Participant [Carer, Male] ***"If you took her out of the house she would lose her sense of direction. Gradually at home she couldn't work out where the bathroom is."***

Comments were also made that the symptoms go beyond memory, and public awareness of this is limited. Many had experienced comments from friends along the lines of:

"Oh, I should come too! My memory is shocking!"

The group confirmed that denial is a factor:

Participant [Person with dementia, Male] ***"The fear of finding out you may have dementia is worse than the reality of having it."***

Participant [Carer, Male] ***"It was our daughter who started to worry about her mum, I was in denial. She started the ball rolling."***

Participant [Person with dementia, Female] ***"We need to challenge the fear of dementia to stop denial."***

The time before diagnosis can be difficult for the person facing a dementia diagnosis, and for those closest to them.

Participant [Carer, Female] ***"He would forget the answers to questions and accuse me of not answering or telling him lies."***

Diagnosis

Despite approaching health professionals with their symptoms, for many the process of getting a diagnosis was drawn out, fraught and beset with difficulties.

Participant [Person with dementia, Male] ***"It is cruel and it took years for the doctors to say you have early onset dementia. The process of getting the diagnosis was the worst. It felt really hard when trying to get a diagnosis."***

Participant [Carer, Female] ***"I had to fight for two and a half years. One of the doctors came to visit us but nothing happened. Eventually one of the doctors said to me 'Well what do you think is wrong with [husband]' and I said 'he has Alzheimer's' and then she said 'but you knew that all along didn't you?'"***

Participant [Carer, Female] ***"We were told initially that he [my husband] didn't have dementia when he went for tests at Bootham. However, when Bootham closed. He was sent to Limetrees and was then given the diagnosis of Alzheimer's disease and Vascular dementia."***

However, some did report a more positive experience of the diagnosis and subsequent treatment and care service.

Participant [Carer, Male] ***"Gillygate surgery sent her to see the consultant, but that GP has gone now."***

Participant [Carer, Female] speaking about how her husband was diagnosed and it appeared more straightforward than for some ***"It was a lumbar puncture that pinpointed the markers."***

Participant [Carer, Female]: ***"We were lucky really. We went to the GP and then everybody [health professionals] came to see us."***

Participant [Person with dementia, Female] ***"I agree, my getting a diagnosis was also quite straightforward but I think it was because my daughter works in mental health and she was very good, she just did it all."***

There was an acknowledgement between these two ladies that it may have been easier for them because a family member works in health care. This meant they had support from someone who understands the process and helped them get appropriate medical intervention. The process of assessment and subsequent diagnosis didn't appear a 'one size fits all' for all the participants in the study. One of the participants described the way in which he was assessed for having dementia by a local clinician:

Participant [Person with dementia, Male] ***"She*** (GP) ***just chucked a pen on the floor and asked me to pick it up."***

A couple of members had initial diagnoses that were incorrect.

Participant [Person with dementia, Female] ***"I kept being told that I had labyrinthitis."***

Participant [Carer, Female] ***"He (speaking about partner with dementia) was treated for depression."***

One of the participants in the group gave his rationale for why he believed there may be such variation in getting a diagnosis.

Participant [Carer, Male] ***"There is perhaps a lack of a pathway or protocol for people displaying problems with memory or cognition …. some clinicians are perhaps reticent about diagnosing too early as there is such a lack of treatment options."***

Treatment / Continued Professional Support

Many of the forum members spoke about the lack of help and support from health and social care professionals since their diagnosis. Despite lack of treatment options many people reported feeling abandoned and unsupported. It appeared that for some gaining a diagnosis was the end of any professional involvement and they felt they were largely left to cope alone.

Participant [Carer, Male] "***I have been caring for my mum for over three years but we have had only one visit from the health services. Initially you cope alone but as things progress you do need help, support and social activities."***

Participant [Carer, Male] ***"My wife was diagnosed over ten years ago and we have had very little support by the health and social services during this time."***

Participant [Person with dementia, Male] ***"I was discharged from Bootham and told that someone would come and see me from somewhere in Acomb, but no one ever did."***

Participant [Carer, Female] ***"We saw no one in six years."***

Some reported a belief that the general message being communicated was that there is nothing that can be done. There is no effective treatment, it is progressive and you are going to die.

Participant [Carer, Female] ***"Many people were told to go home, put your affairs in order, and basically wait to die."***

However, one carer spoke about how at a local General Practice they had employed a 'dementia champion'. This had positively impacted on the service that people received at the practice. There was a greater understanding of the disease, signs and symptoms and the importance of subsequent 'signposting' to further services. In addition, one of the carers reported that one of the local GP practices has strong links with a nursing home for people living with dementia and they visit weekly to check on the residents.

The needs of people with dementia are not always considered when changes to services they need are brought in:

Participant [Person with dementia, Female] ***“I used to get blister packs from (name of pharmacy). They won't do them any more as they've ‘got too much on.’ I get lots of different medications, but if I call my previous pharmacy for any of them I am now told I have to ring (different branch of same pharmacy). They will only deliver medication when the blister pack is due, so anything outside of these has to wait. I take some medication which stops me from passing out. At the moment I only have three of these tablets left, but the pharmacist will not deliver more until the next blister pack is due in a week. I’m worried that this puts me at additional risk of falls. It is all so confusing - why are our medical services making it harder for people to look after themselves?”***

Some of the study participants discussed how when drug manufacturers change their tablet design and packets. They felt that this can have a big impact for someone with dementia because of the issues around learning new information and coping with visual changes.

Participant [Person living with dementia, Female] ***“When tablets change it is really confusing. They used to be all red but now they are all yellow.”***

Participant [Carer, Female] ***“It totally throws you when they change the boxes. He used to recognise the packaging.”***

Participant [Carer, Female] ***“They don't realise the confusion it causes. We used to have to halve his long pills but now they have changed and substituted them for small round ones.”***

Family and Relationships

Many of the participants spoke how important family and friends are in order to cope as there were such lack of support from health services.

Participant [Carer, Male] ***“You need a good family around you and we have.”***

Participant [Person with dementia, Female] ***“I can't go into town any more as I get lost. But I have a friend who goes with me once a month. I have someone to talk to, someone who is different to your husband or carer.”***

Participant [Person with dementia, Male] ***“I have friends that I have always had and we still go out together regularly”.***

However, telling family and friends could be problematic. Group members believed this was because of the lack of understanding and awareness around what it means to have dementia. For some this meant that friendships had ended and family relationships became difficult or had broken down completely. The idea that being diagnosed with dementia means immediately becoming incapable of functioning was a source of huge annoyance for some. The group talked of the importance of recognising that people are still the same person they were before the diagnosis was made:

Participant [Person with dementia, Male] ***“My children can drive me around the bend, because they say Dad you can't do this or that 'cos you have dementia.”***

Participant [Carer, Female] ***“Our daughter-in-law comes every week not every day and starts saying to me you should do this or do that. They are not here for us, they don't see what is happening every day and they don't know what it is like.”***

Participant [Person with dementia, Female] ***“My brother can't cope with my dementia. My son thought I should be in a mental home.”***

Participant [Person with dementia, Male] ***“Friends I had have now gone. I don't know if it is the dementia or they have just backed off.”***

Participant [Carer, Female] ***“We have lost friends you know, good friends, friends that we have had for a long time. I don't think they could handle it, his diagnosis.”***

Sometimes the loss of memory associated with dementia impacted upon how much that person remembered about those individuals, the friendship and what it had been and meant to them throughout their life.

Participant [Carer, Female] ***“We went to friends one lunchtime. These people we have known for over twenty years. When we left he (person with dementia) asked me ‘Are they good friends of ours?’ He forgot he knew them.”***

York’s Dementia Friendly and Dementia Unfriendly Places and Spaces

The forum members were asked about what they understand by the term 'Dementia Friendly'

Participant [Person with dementia, Female] ***“People helping you who understand how you feel and that you are not as quick as you might be.”***

They discussed what makes an environment dementia friendly and what the requirements would be to receive 'dementia friendly' status. If dementia is a disability what are the equivalent requirements for those with dementia that handrails, ramps, or lifts are for wheelchair users? What should people expect to be in place in order for someone with dementia to access services and facilities? There was a suggestion that some of the group’s members could carry out audits into the suitability of places for people with dementia. Members of the group felt this was an important idea.

Nearly all the participants described experiences where they felt that a place, space, individuals or organisations were not being 'dementia friendly'.

Participant [Person with dementia, Female] speaking about her experiences in a well-known department store in York ***“A few years ago I asked for a nightdress. They said use your eyes they are over there.”***

Participant [Person with dementia, Male]***"I went into a shop in town and the staff were stood chatting. I asked for a book and he pointed to a mass of books but he wouldn't come and show me."***

However, the difficulties experienced weren't confined to shopping. Many of the forum spoke about frontline staff providing health or social care support who were not dementia aware. The group felt this was surprising as they had an expectation of greater understanding of what dementia is and how that impacts upon an individual amongst health and care professionals.

One participant living with dementia spoke of a situation which caused him upset and confusion. He was involved with a local housing trust. They were encouraging him to move out of his home into other accommodation:

Participant [Person with dementia, Male] ***"They give you 24 hours to decide if you want it. If you don't (make a decision) then in 24 hours it is gone. I couldn't cope, they were very abrupt. I said if I live there I will need three buses to get to places which would be a problem as I have dementia."***

The physical environment of an establishment could also present challenges for someone living with dementia. The group spoke about the hospital and how the layout, signage, long corridors, lack of wheelchairs, poor lighting and at times lack of staff available to help support people to access where they needed or wanted to be.

There were also problems reported using public transport. These included issues getting on and off the buses, accessing seats for disabled and older people. One of the participants recalled a time when she took the wrong bus in confusion.

Participant [Person living with dementia, Female] ***"The driver wouldn't stop but a young man on the bus was really helpful and made the bus driver stop and wait for him whilst he showed me what to do."***

Similarly, when organisations like banks, building societies and even GP surgeries introduce touch screens these can become prohibitive to people living with dementia. When humans are replaced with technology and machines this can be devastating for someone with dementia as they rely on human engagement in order to access services etc. and to retain their independence as much as possible.

Participant [Carer, Female] speaking about how dementia has affected her husband's ability to use technology ***"He can't do anything with technology, not even the telephone or TV controls."***

Participant [Person living with dementia, Male] speaking about a high street banking branch, ***"Faced with the machines, I have given up with the banking machines."***

Participant [Person living with dementia, Male] speaking about the railway station and the ticket machines ***"I used the machine once but now go to the desk."***

However, there were many examples given by the forum members of how people and some local organisations were 'getting it right' for people with dementia. Often it simply came down to the attitude and the approach of the staff members.

Participant [Carer, Male] ***"There was this cashier at (Name of shop) who was wonderful with this guy who was confused over his money."***

Participant [Person with dementia, Female] ***"(Name of shop) are wonderful, a friend told a member of staff that I had Alzheimer's, so the lady said she is still a human being and took me by the arm and chatted to me."***
Even when the physical environment or the layout of a business or store can appear to be the most 'awkward' for a person living with dementia, it was again the attitude and approach of the staff working within it that turned a seemingly 'dementia unfriendly' environment into a 'dementia friendly' place. One very well-known local family business in York was highly praised by several members because despite the chaotic layout, the many entrance and exit doors, the several flights of stairs, and the lack of a lift, the staff were always helpful and for one of our members who lives with dementia they

allowed her dog in the store too. Similarly, with another local department store, they too were recognised by the participants as being supportive.

Many of the participants insisted that the key is to tell people that you or your partner is living with dementia because it can often lead to greater understanding and a better service.

Participant [Carer, Female] ***“Once people know, most will fall over themselves to be helpful.”***

Participant [Carer, Female] ***“There are pockets of good practice, lots of good stuff out there already. You just have to tell people and often they will be only too willing to help if they know. My husband tells people you have to bear with me as I have dementia.”***

Another of the participants who is living with dementia also believes that the best way to cope is just to tell people that you have dementia

Participant [Person living with dementia, Male] ***“I go and play bingo. Daughter went to the desk and explained that Dad has dementia. That's (Name of Bingo) they are marvellous really.”***

Participant [Person living with dementia, Female] talking about her local pharmacy ***“You know since I have told them that I have Alzheimer’s, they have been great and now they have my medication ready for collection.”***

Coping and Caring - Living with Dementia

Without exception, the carers discussed the initial shock that they or their loved one felt when either they or their partner was diagnosed with dementia and how they coped with the news.

Participant [Carer, Male] **“She (person with dementia) was devastated, she was in shock when she got diagnosed.”**

Participant [Carer, Male] ***“When my wife was diagnosed I was in denial but she came to terms with it – it took two years to tell people that she [my wife] has dementia.”***

Although there was the acknowledgement that dementia does have an impact on one's life and independence, the idea that it was inevitably the end of the useful happy, fulfilling part of your life was not a view held by any of the group. The participants shared with the group the strategies and routines they had introduced to help them cope and the activities they were now participating in since diagnosis.

Participant [Person with dementia, Female] ***"We are all normal. We just have an impairment. Like any other disabled person."***

Participant [Person with dementia, Male] ***"Going on the panel for JRF grants really reminded me of being a parish councillor. It links to who I am, what I do. I felt useful again."***

Participant [Carer, Female] ***"He has coped well with it, there were lots of tears and now we said so let's get on with living, so we went to Australia and that was six years ago. We have long silences and sometimes he doesn't answer if I speak to him. He is happy with his life, it is as full as possible."***

Participant [Carer, Female] ***"He*** (person with dementia) ***will sit, but he is always doing something and if I ask him he will go and do it."***

Participant [Carer, Female] ***"We are brilliant at going out for coffee."***

Participant [Carer, Female] ***"Once a month we go to a carers group in the village (Haxby). We learn such a lot talking to each other."***

Participant [Carer, Female] ***"You do have fun, we have fun at our singing group." (speaking about Vocal Flourish)***

Participant [Carer, Male] ***"She (partner with dementia) likes doing crafts, especially making cards."***

Participant [Carer, Female] ***"We still like to get away. Went on holiday with Shearings to Torquay. Went on a few trips with them, had a good experience with them."***

Participant [Carer, Male] ***“We go on holiday with Diamond holidays to Scotland, they are good.”***

When asked what it was that made those holidays successful:

Participant [Carer, Female] ***“Ah they are just very good, they just treat you like you are all normal and look after you from door to door.”***

Participant [Carer, Male] ***“It doesn’t seem to matter that she’s got dementia like, they just are good and everything is done for you.”***

The participants spoke about some of the difficulties they experienced at times being cared for or caring for someone with dementia as the disease appeared to affect people in a variety of different ways and with most relationships there are challenges. Before dementia, couples would not usually be with each other 24 hours a day, but pursuing their own work, hobbies or interests. There is a need for more opportunities for both people living with dementia and carers to spend time apart, as well as activities they can take part in together.

Participant [Person with dementia, Female ***“There is friction between people with dementia and carers. Always wrong assumptions about what you can and can't do.”***

Participant [Carer, Female] ***“I do the best I can but sometimes I say to (my husband) that you can't speak to me that way. He can sometimes use really bad language*** [he didn't swear before diagnosis] ***and I tell him, I am not standing for that.”***

Participant [Carer, Female] ***“He*** (husband with dementia) ***just sits and closes his eyes. It drives me mad.”***

Participant [Carer, Female] ***“It’s very restrictive when you can't leave them alone.”***

However at times, and like most relationships, the group confirmed the need to have space and time apart.

Participant [Carer, Female] ***“You cope best when you get time away.”***

Participant [Carer, Female] ***“I like the theatre festival as I need to keep up my independence.”***

Participant [Carer, Female] ***“I am glad I am away from him for those five hours. I love my day at the hospital.”***

Participant [Carer, Female] ***“It is essential to have time away. He*** *(person living with dementia)* ***goes to his club (day centre) he loves it and I just go phew and breathe a sigh of relief. I can go to the hairdressers or meet with friends or family for coffee.”***

Participant [Carer, Female] ***“My husband (person with dementia) loves to go to the Gym once a week, they all know him in there so he is fine.”***

Moving On - 'York a Dementia Friendly City'

The group were asked what they felt could be done to help York become a great city for people with dementia. These are the key suggestions that were made:

Education/Raising Awareness

Education was seen as the most important step in raising public awareness. The group felt that with prevalence and incidence of dementia on the increase, it is likely that most people will know someone with a dementia now or in the future. However the group don't want a 'doom and gloom' scenario like the media describes. They want very clear factual information about dementia. This should cover what it is and how it can affect many aspects of people’s lives. They wanted to be clear it does not just affect memory but how people can tolerate crowds, social situations, colours, lighting, and noise levels. Many of the forum wanted to highlight that since and in spite of their diagnosis, they are living full and interesting lives. Some now take part in and enjoy more social activities than ever before.

Participant [Carer, Female] ***“We need to talk to people because I think people are frightened by dementia.”***

Participant [Person with dementia, Male] ***"I've never had such a good social life till I got dementia. My diary is full now!"***

Participant [Person with dementia] ***"The public have to be taught, they don't know what to say."***

One of the couples in the group became involved in making a film. This aims to raise awareness and dispel some of the stereotypical views about living with dementia.

Participant [Carer] ***"We made a film, sharing normal life, he*** (partner with dementia) ***doing what he likes*** (playing the piano)***."***

Several members of the group are actively involved in giving talks to people to help raise awareness of what can be achieved with a diagnosis of dementia.

Participant [Carer, Male] ***"She*** (wife with dementia) ***gave a talk in London. She has never done anything like this before. She was brilliant."***

One of the group discussed a talk that they went to about a dementia study, attended by many health professionals. The study findings were that there was a low level of dementia awareness amongst clinicians. Many lacked knowledge about dementia and how it affects and impacts upon people. The person attending the conference felt these statistics were worrying. Others agreed because, as one of the participants who lives with dementia suggests, ***"If clinicians are not informed and educated about dementia what will happen to us? We rely on them to refer us for diagnosis and further support."***

Participant [Person living with dementia, Female] ***"There is a need to get levels of awareness in clinicians up as they act as the gateway to services."***

Participant [Person living with dementia, Female] ***"No-one gives us a manual. We need help and support to know what to do."***

One of the members suggests that there may also be a reluctance to diagnose too early due to lack of effective treatments available. They felt that it can be 'scary' for clinicians to give the diagnosis because of the perceived 'doom and gloom' scenario around the condition.

All participants stressed the importance of raising awareness within the wider population. They felt that where people were informed and aware this has a positive impact on those living with dementia. Awareness of dementia was often delivered through the 'Dementia Friends' programme. This has been created by Alzheimer’s Society, usually delivered by volunteers within the community. The group felt these awareness raising sessions provide significant benefits for those working with or offering a service to people who may have dementia. However, they felt these sessions could be improved through the direct involvement of people with dementia. Other awareness raising opportunities in this area have been provided by Dementia Forward.

Participant [Person with dementia, Male] ***“We need people to know that Alzheimer’s is not just one thing. Not everyone is GaGa.”***

Participant [Carer, Female] ***“I think that any of the groups that have had people in to explain, I think anyone who has learned are more aware of it.”***

Participant [Carer, Female] ***“We are lucky in Haxby, nearly all the shops are dementia friendly”.***

Participant [Carer, Female] ***“He*** (husband with dementia) ***loves to go to Aroma cafe in Haxby. All staff are 'Dementia Friends'.”***

There was a feeling things are improving with the wider public. Many appreciated the ***“unexpected kindness of strangers.”***

Participant [Person with dementia, Male] (speaking about a situation when he became confused)***“A young lady sat on the doorstep and said ‘are you OK, you look a bit confused’ and I said ‘I am.’ She helped turn me round and as soon as she did I knew where I was.”***

Participant [Person with dementia, Female] ***"A person I did know stopped when I had a funny turn. Another person who I didn't stopped in their car. They took me home, the other person took my walker home. They were lovely."***

There was also a view that it is never too early to educate young people about dementia as it likely that either now or in the future children will experience a family member, friend or neighbour with dementia. One member recalled that 'Joseph Rowntree School' showed their pupils a film about people with dementia and this is what they had to say about it.

Participant [Carer, Female] ***"One of the pupils reported 'we realised that they are still people inside' which was brilliant."***

Several suggested that dementia awareness for all people working in the health and social care services should be mandatory and not optional as it appears to be at the moment. This awareness raising activity could be extended to everyone who deals with the public so that all people have a greater understanding of the disease and implement changes in their organisations to accommodate people with memory impairment. The idea is that more places could become more accessible for people with dementia and perhaps there could be a 'ten step' action plan to have some sort of accreditation.

Work/Employment

For many of the group a diagnosis of dementia meant the end of their careers and working life. The group discussed whether this was an inevitable consequence of the disease. There was discussion about what people should expect and want from employers. Should reasonable adjustments be made to accommodate their needs? What are the employment rights of people with dementia? Should work be done to challenge the expectation that people with dementia become immediately unable to work?

Participant [Person living with dementia, Female] ***"I went to work and told them I had been diagnosed with dementia. I never went back again."***

Participant [Person with dementia, Male] ***"I was in the police and they just tell you 'You can't do your job so off you go.'"***

However, one of the forum members with dementia did continue working after his diagnosis. His employers agreed to a "sideways shift". They worked with him to understand what was challenging within the role and made reasonable adjustments.

There was hope that things are beginning to change. Recently, another one of the group has been approached about doing some form of employment appropriate for his needs and with the correct support. As another member commented:

Participant [Carer, Female] ***"Shops like Sainsbury's have been doing it for ages taking on disabled people."***

Participant [Carer, Female] ***"Aroma Cafe in Haxby are special and they have a person with dementia working alongside someone else."***

Participant [Carer, Female]: ***"We were employed by Tees Esk and Wear Valleys NHS Foundation Trust to interview staff, as part of the recruitment panel. We really valued this opportunity, but had a lot to contribute too."***

Clubs/Organisations

There was a recognition that York has lots of clubs, classes, cafes, and events that are suitable for people with dementia. Some of the forum members have never been so busy.

Participant [Carer, Female] ***"There are pockets of good practice, lots of good stuff out there already".***

However for many this hadn't always been true. Some of the group spoke about the impact that being part of 'Minds and Voices' had made in their lives. The support and company that they had since joining the group was significant.

Participant [Person living with dementia, Female] ***"After all these years our lives have come back once meeting up with this group."***

Participant [Person living with dementia, Male] ***"It's a good life and since coming to these forums it has been really great."***

Many reflected on the positive benefits of involvement:

Participant [Person with dementia, Female] ***"My family said 'you've really improved since you got involved in activities."***

Participant [Carer, Male] ***"It's great when I look at their diary, it's full of things she wants to do, and she's better when she's involved in things."***

When discussing what prevents people getting involved with activities, transport was identified as a significant barrier. As one participant stated ***"the success of an activity depends on making sure I can get there".*** The main barriers identified were:

- Money (taxis are expensive)
- Difficulties using public transport
- Making sure everything was arranged
- No longer driving
- Family or friends being unable to drive you at the time of activities

Several of the group are concerned that there are still many more people isolated at home with dementia. As this is quite a small group given that there are over 2,700 people with dementia in York, they are keen to know the circumstances of these other people. Considering how challenging many of these people found accessing good information, they worried that isolated people are even less likely to be able to access some of the groups etc. which support people with dementia. They questioned how different organisations can work together to identify how they get information to these people who need it most. They suggested a task force to reach out and identify those people with dementia who are not connected with any support or social activities.

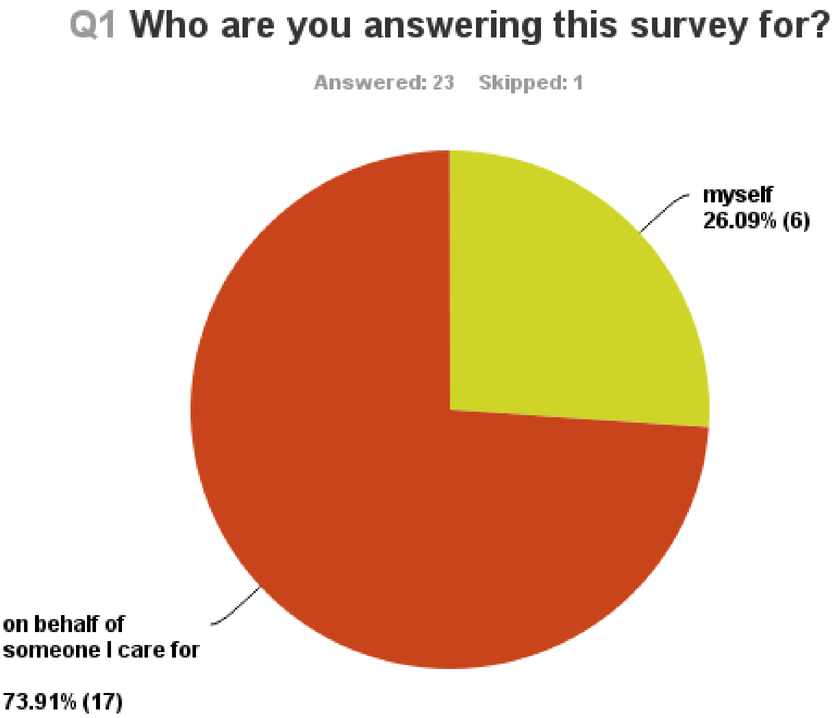
Participant [Person with dementia, Male] ***"I just want to go round and bring people out."***

Participant [Person with dementia, Male] speaking about himself getting out there and talking to people about living with dementia ***"If you have got it, flaunt it."***

The group discussed where people look for information when they receive a diagnosis. The group felt people usually look for it at health services. From their experiences, quite often they have found very little or no information available. One member of the group suggested there is demand for information for people with dementia – he had recently placed some leaflets in his GP surgery and by the next day they were all gone. However, it is possible that staff simply moved it.

The group were asked to think about information. What did they need to know and how do they want it? Many suggested the need for information at diagnosis. This way they can move forward in their lives - come to terms with their diagnosis and live life the best way possible for them. Not having appropriate information can make them feel more isolated and less able. The group felt having a dementia support service that helps people navigate and access relevant support and information is vital. Dementia Forward are contracted to provide this support in York. Some of the group had been signposted to them, but experience of being signposted was inconsistent. They felt that improved signposting by clinicians to this service was vital. They also felt information needed to be available face to face, in writing, and through peer support.

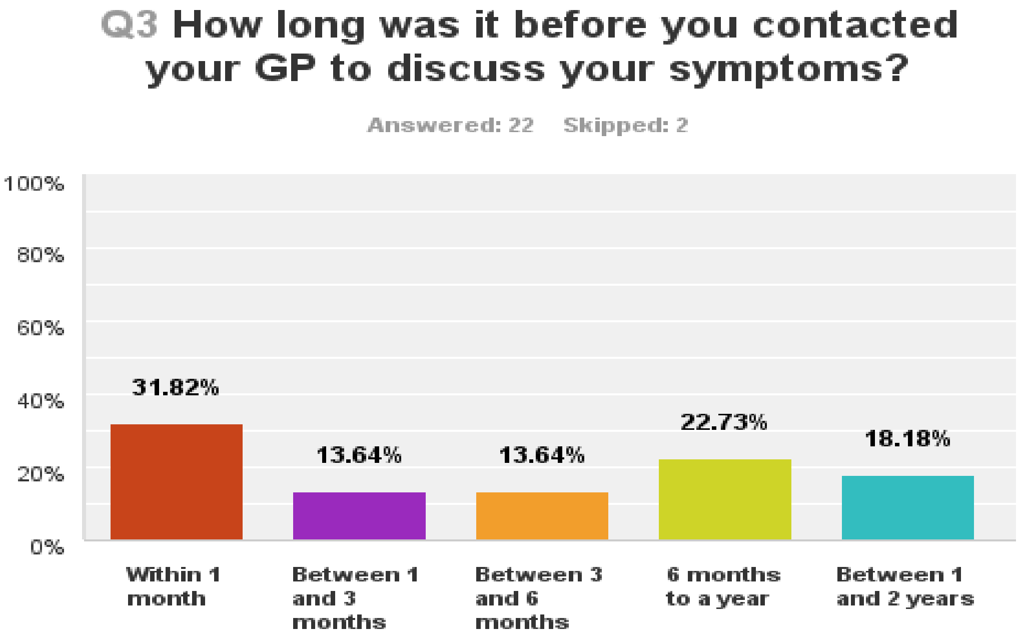
Survey results



Q2 Can you tell us what made you think that there might be a problem with your memory?

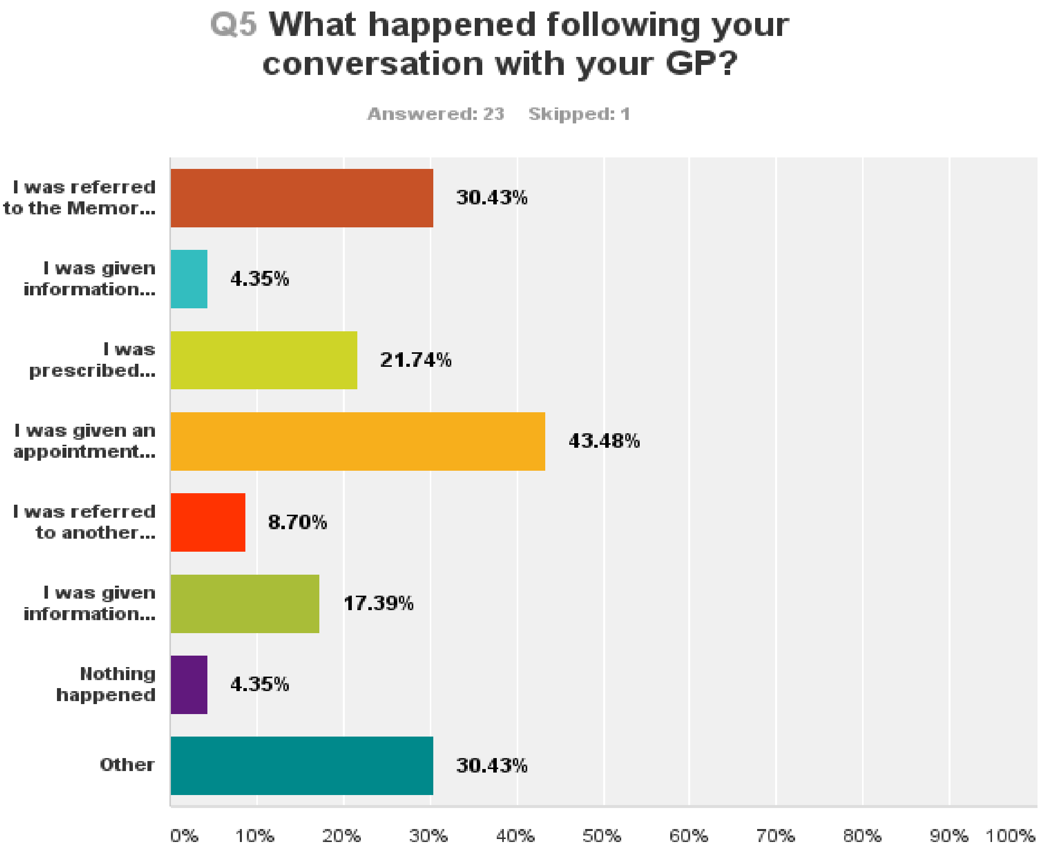
Answers included:

- I started forgetting my children’s names 8 years ago
- Lack of co-ordination and general confusion rather than forgetting facts
- General forgetfulness, leaving oven on, hand / brain co-ordination slightly affected
- I didn’t, my doctor realised it
- Relations said I was not myself and I kept getting lost and forgetful
- Previous family members have had dementia and so as it can be hereditary I always knew that it was a strong possibility for me. I started forgetting things occasionally in my early 70s and it gradually was getting worse. I decided to phone the doctors surgery for an appointment to have a test



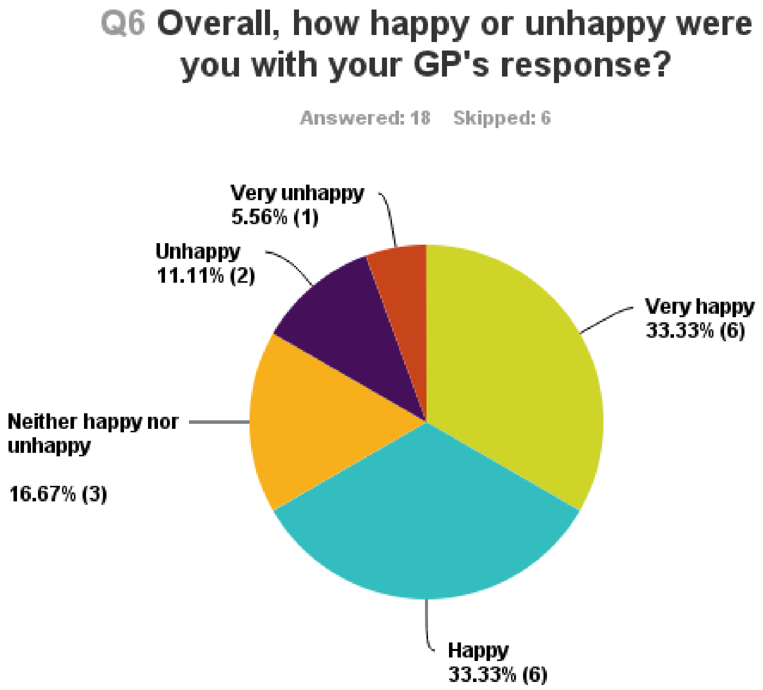
Comments included:

- Maybe more
- Hard to say as I don’t think my mum herself contacted the GP, she simply carried on and adapted to life with my dad gradually taking over more tasks. Only as I became more concerned did I go to the GP



'Others' included:

- I went to a private hospital and consulted a neurologist
- Nurse at surgery was excellent. She asked me several questions. Blood was taken for various tests and then we had a talk about family history of dementia. This was followed with a CT scan then an appointment with a doctor at Bootham Park
- I have attended the GP twice and am waiting for further help which is in the pipeline
- I was asked 4 questions to which I did not know the answers and was told I had pre-senile dementia!!!
- Referred to CMHT
- Did a quick memory test which was ok
- Having taken the standard memory test, initial score 28/30 was recommended to repeat the test in 6 months



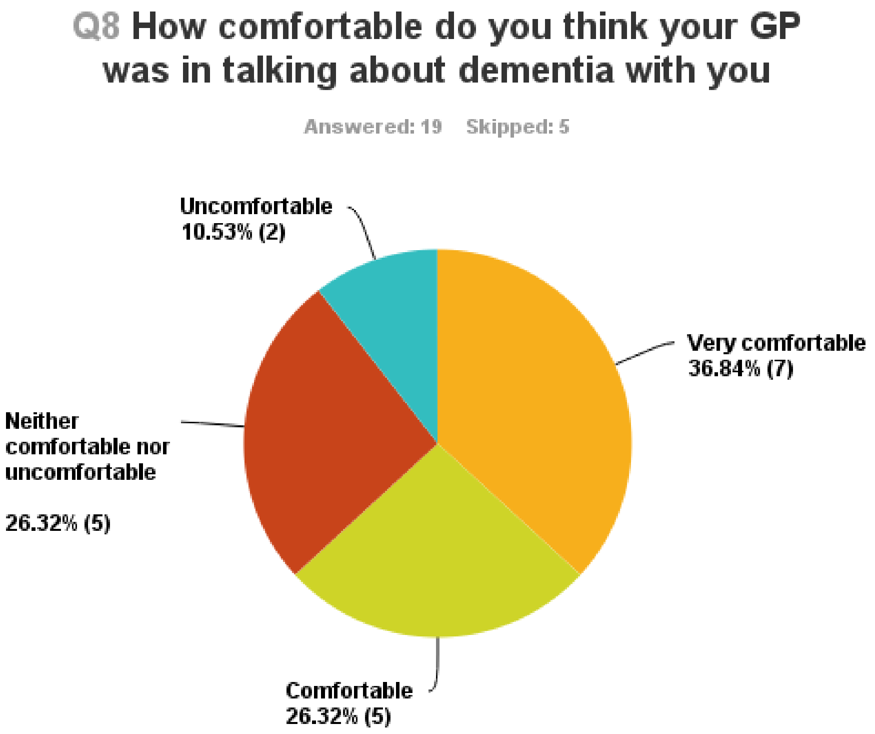
Comments included:

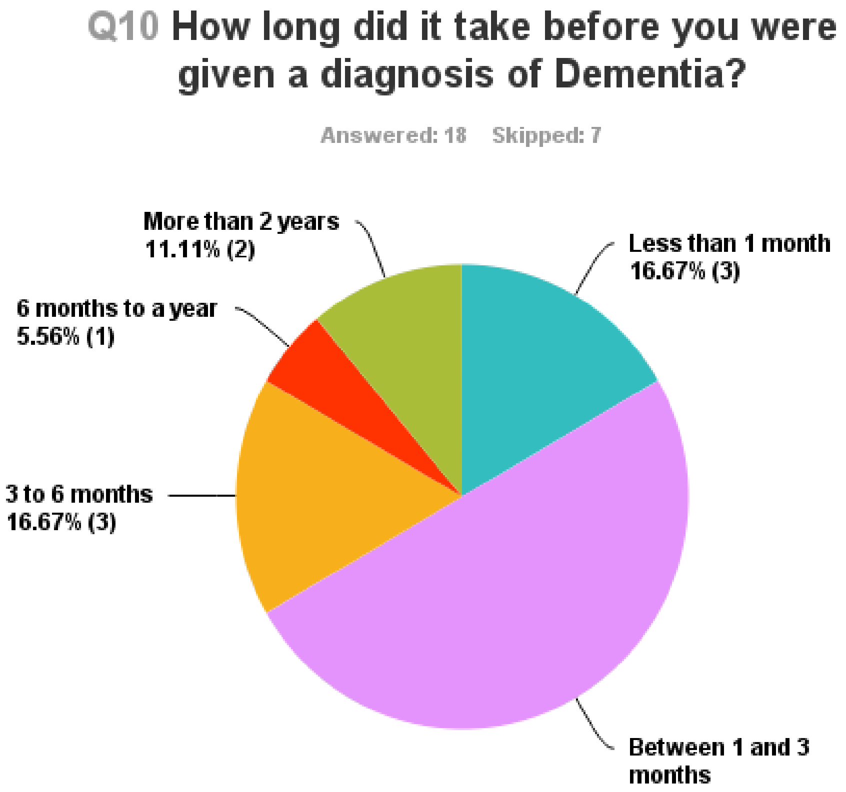
- Happy after the second consultation, ignored at first consultation
- Been over long period sometimes good, sometimes not so good
- Didn't believe him

Q7 Please tell us in your own words about your experience

- The GP handled it in a friendly and efficient manner
- It was scary
- Told to come back "when dinner down your shirt" by GP. 2nd visit with another GP made immediate referral and prescribed daily tablets.
- 4 questions to determine dementia, I was totally disgusted. I was then left to my own devices to try and get something done about it.
- On arrival in York I was referred to a consultant. One year later I saw a memory nurse
- Prescribed medication for Parkinson's – referred to Parkinson's clinic. No further information given
- It took several repeat tests at which each score got progressively lower and it took pressure from carers to finally get referral to a consultant after 2 years

- I had some difficulty in getting to speak to the GP on my mum's behalf to express my concerns and request assessment, hence time passed further and symptoms progressed. Eventually I managed to get a home visit by the GP to assess my mum but only because I knew want to say. I used my professional knowledge and experience to do so. I think if my father had done this himself without my support he would have struggled to achieve this.
- First I wasn't happy with this response as he didn't believe me. Then went a second time and he did something.



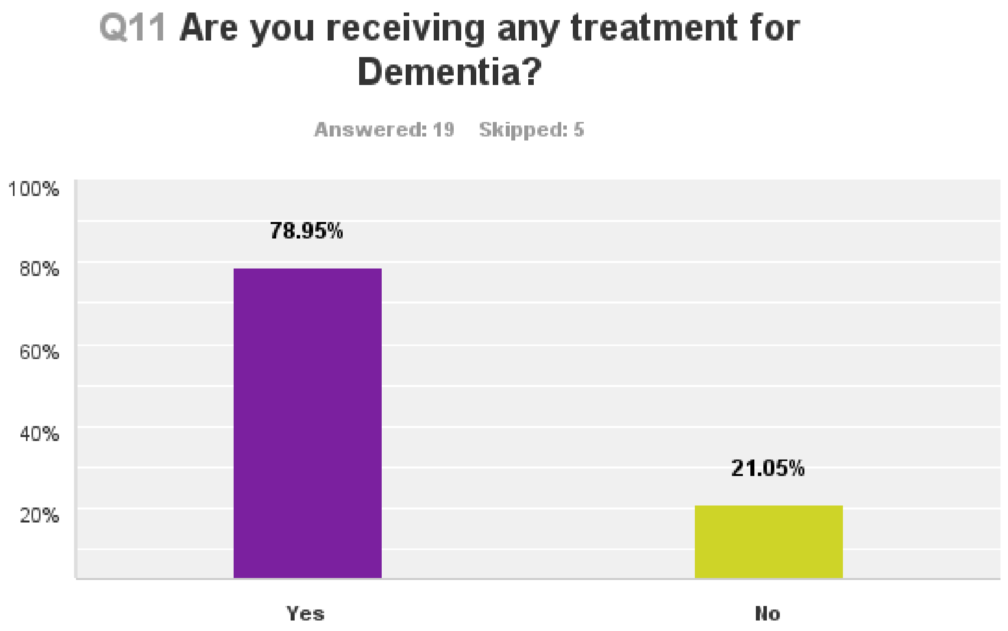


Q10 How long did it take before you were given a diagnosis of Dementia?

Answered: 18 Skipped: 7

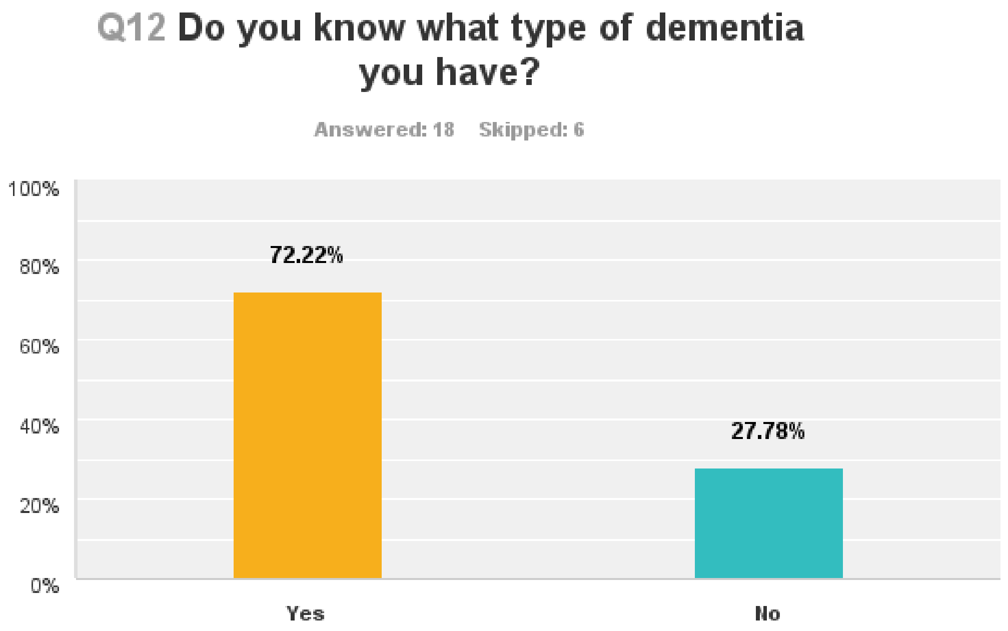
Comments included:

- The consultant never actually said that I had Alzheimer’s. I was told I had some short term memory problems. I found out years later that she had diagnosed me as having Alzheimer’s
- Initially 2 years with GP before referral to consultant, then about 6 months for consultant to confirm

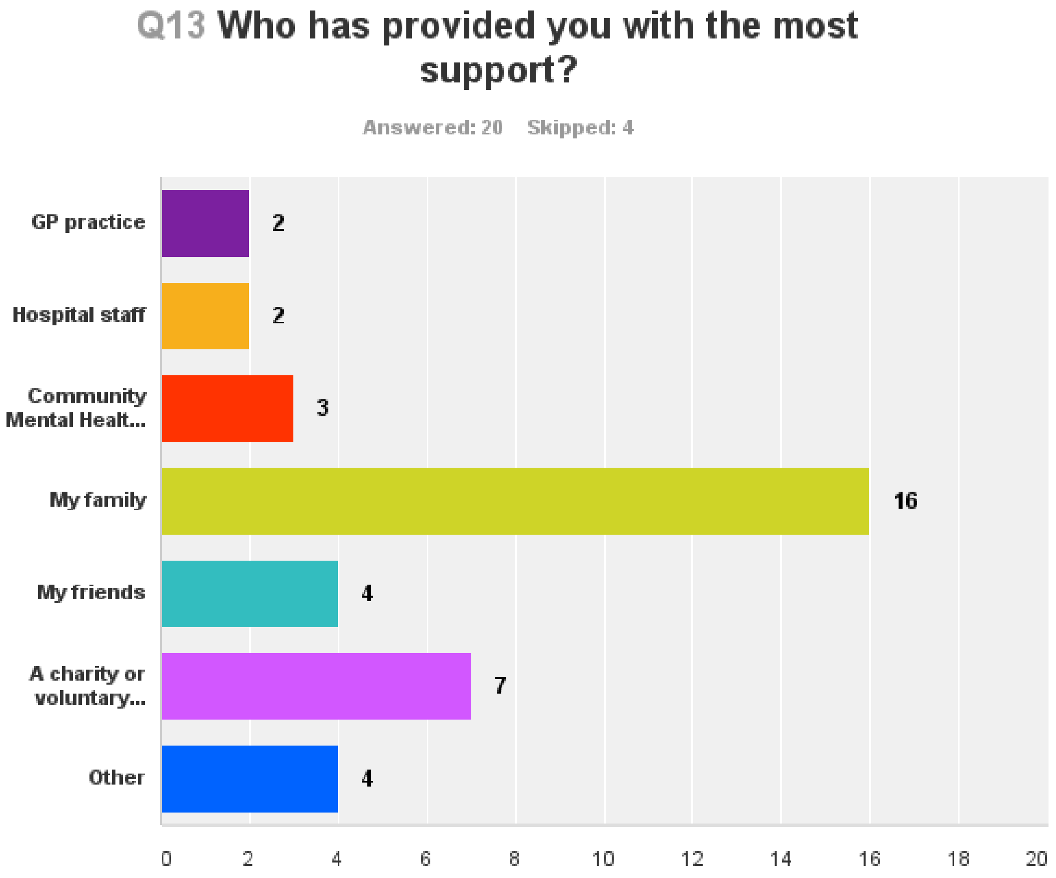


Comments included:

- Nurse used to come and visit. Not much support, found it difficult in the community
- Eventually after seeing 2 more GPs knowing they would not contradict the original GP I went to see a very RUDE psychiatrist. “I think you have Alzheimer’s” was his diagnosis. My husband had to ask for medication for me. “What did you have in mind?” was the reply from the psychiatrist.
- I receive a monthly injection
- Donepezil
- Voleze transdermal patch
- Aricept (+ trial drug via Alzheimer’s Society dementia research)
- Consultant gave treatment for drugs within a month
- Not Doneprizil as this didn’t suit, had side effects. Memantine



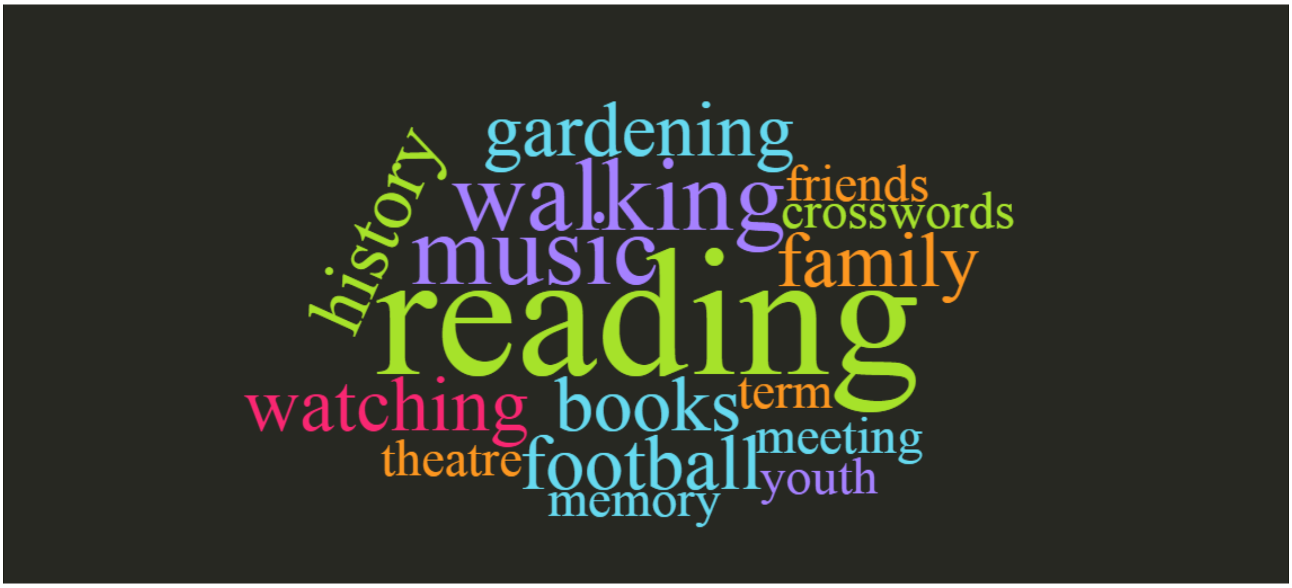
13 respondents provided more detail: 7 respondents were told they had Alzheimer’s, one being early onset, 4 had vascular dementia, 1 Parkinson’s related, and 1 was told it was not vascular.



Comments included:

- Aroma Café, Haxby
- Up until this year only GP. Now coming to this café that is providing support. Had 2 nurses from Selby to do a memory test. Still under York Hospital.
- Everyone – thank goodness
- Dementia café – Clements Hall. Visit from Dementia Forward initially.
- Nurse and family
- My husband and Dementia Forward
- My niece
- Nursing home

Q14 What hobbies did you have before your diagnosis?



Most popular answers: 12 mentioned sports (including walking, football, cricket, keep fit, and dancing) 7 mentioned reading, 7 games including chess, solitaire crosswords and bingo, 5 music , 4 meeting friends and family, 3 each for gardening, crafts and history, 2 holidays and days away, and 1 each for cooking, church, shopping and theatre.

Q15 Are you still able to enjoy these hobbies?

10 respondents said no, with 2 qualified answers

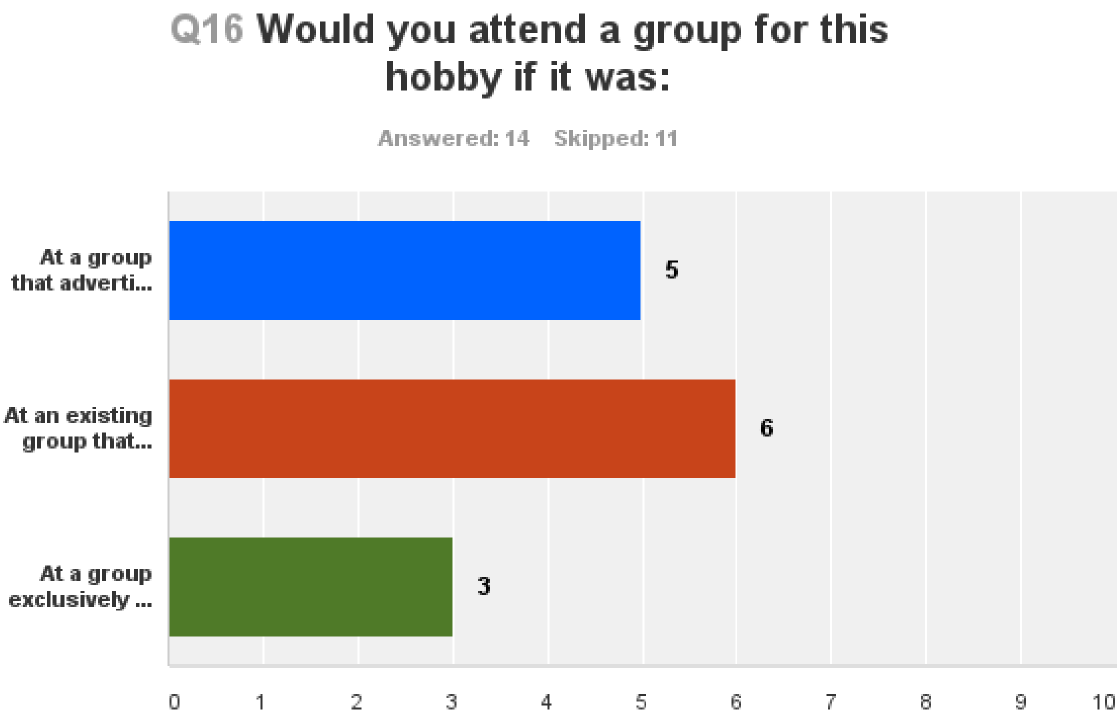
- Only normal every day walking. I wouldn't like a walk leader to have the responsibility of me getting lost when my dementia deteriorates
- not really. I am in a nursing home and wheelchair bound).

5 said yes, with 2 qualified answers:

- at the moment
- except football

There were 4 other responses:

- Still enjoy music but don't bother about the garden any more
- Unable to continue with reading however now look at books with photos of certain areas in which we spent time walking, reads captions under photos
- Only solitaire
- To a small degree



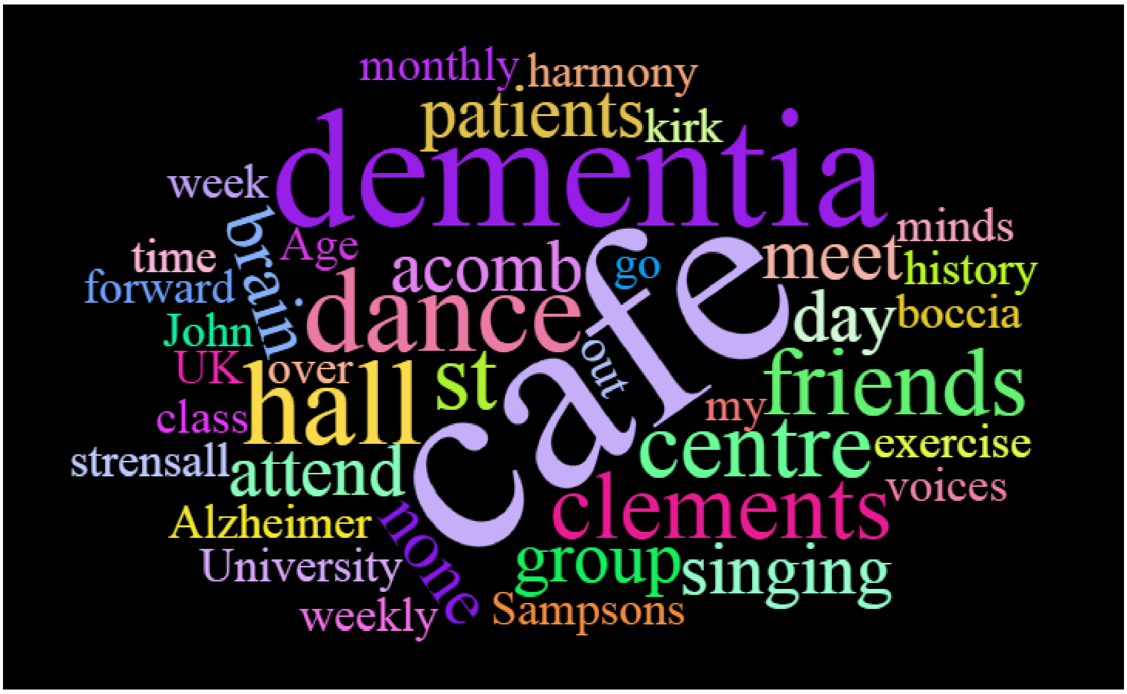
Choices were:

- At a group that advertised it was dementia friendly
- At an existing group that included people with dementia
- At a group exclusively for people with dementia

A number of people commented that they would attend all 3. Other comments received included:

- Lost confidence so would not attend a group
- Yes, still go to groups. And enjoy the café
- Possibly beyond this now
- Concentration difficulty

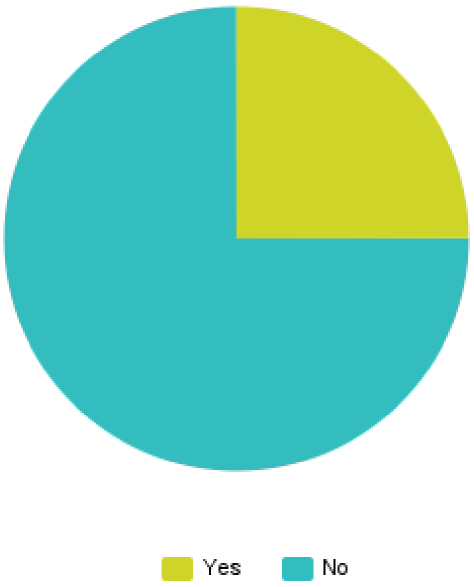
Q17 What activities, clubs, day centres etc do you attend if any?

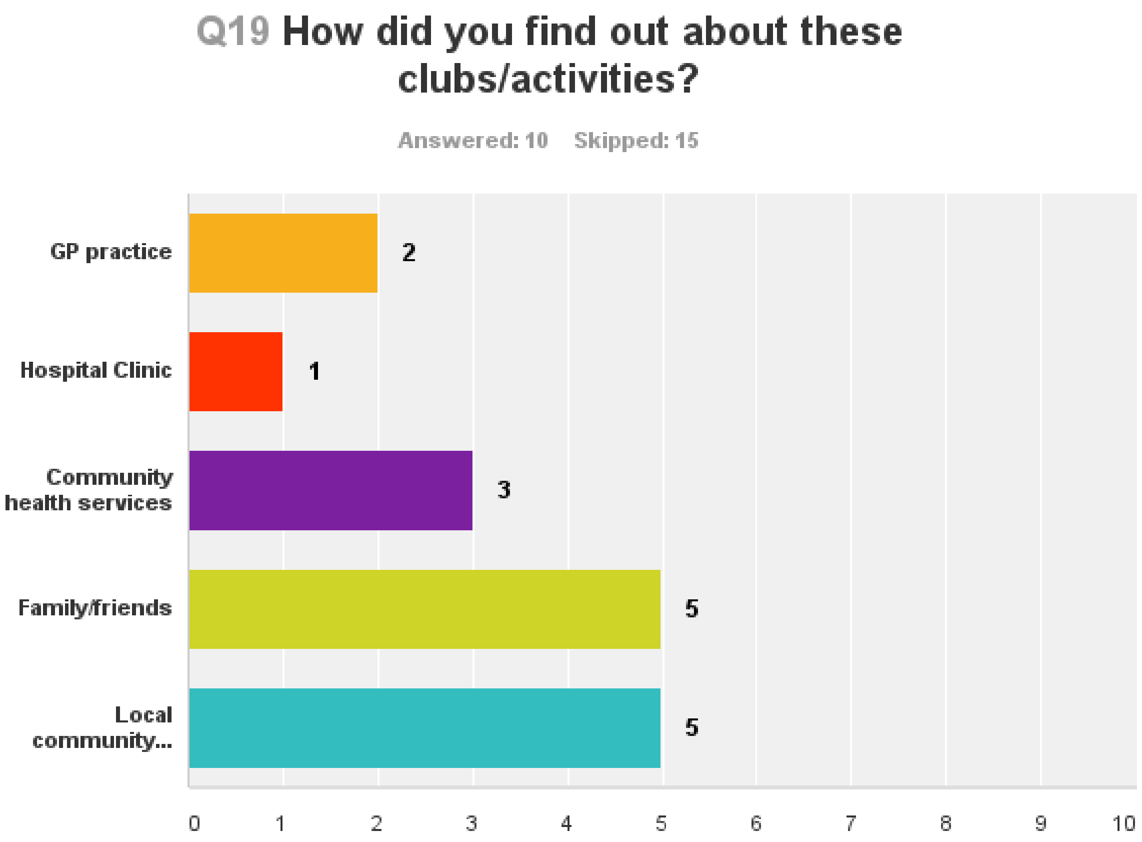


Scale: Word size here relates to number of times used. Café 11 mentions, dance 5 mentions, none 3 mentions, voices 2 mentions

Q18 Did you attend these before you were diagnosed with Dementia?

Answered: 16 Skipped: 9





Other sources of information were:
4 - specifically named voluntary sector agencies
1 - internet searches
1 - found out by chance
1 - told at home visits
1 - information from a nursing home

Q20 How well do these clubs and activities meet your needs?

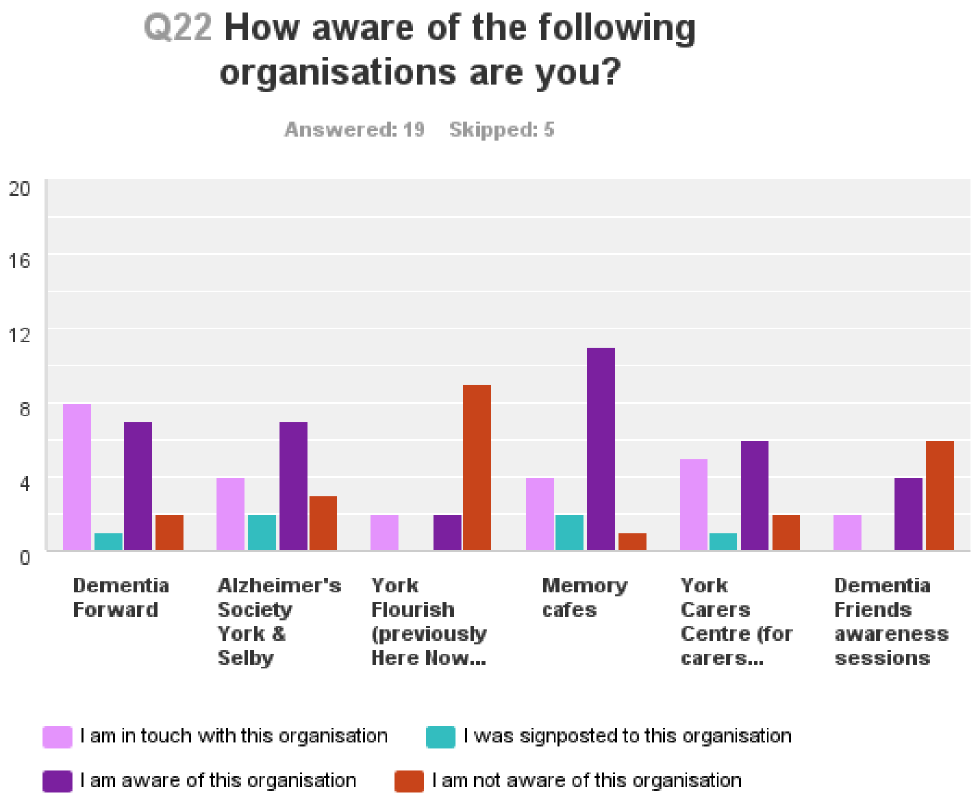
10 respondents made very positive answers, including “We are very happy with everything that is on offer. We never imagined there would be so much help out there” and “It helps to meet people experiencing the same problems as you. You don’t feel on your own and can talk things through and get advice”
3 respondents gave more qualified responses:

- We are at an early stage in the onset of dementia and are still trialling some of the different activities to see which currently suit us the best and also to identify activities for the future
- Only just been once as a new group so cannot say
- Good for social but little information retained

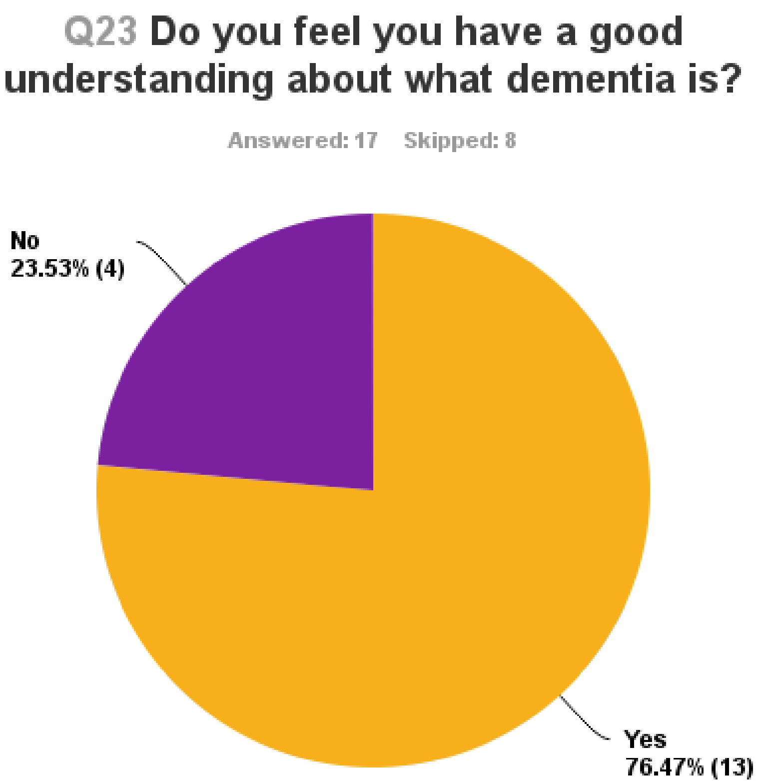
Q21 What would you like to see more of? Do you have any ideas for improvement of these services?

Suggestions included:

- Activities starting later – most start at 10.30am at a distance and I can’t be dressed, washed etc before that
- Persuade more people to join in the fun!
- Perhaps coach trips leaving late morning, as they miss drives into the countryside
- Groups aimed at male carers of women with dementia. My dad like many men has never been the socialiser within their marriage and finds it very hard joining things as most are female dominated. He would really appreciate some male support
- Transport is the challenge, depending on voluntary cars

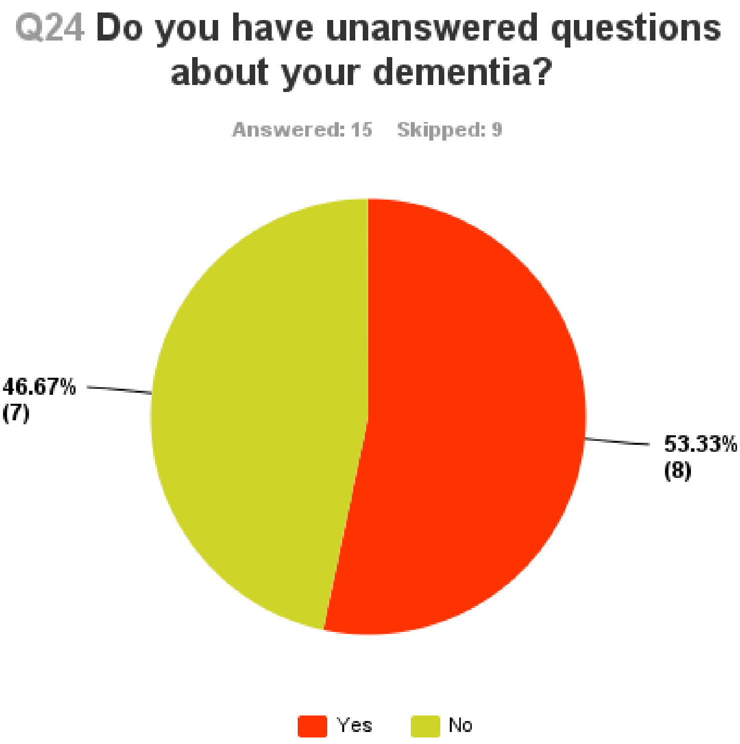


Note: Within the survey we asked about York Flourish, which was previously Here Now dementia. We have since found that there is greater awareness of Minds and Voices, one of the activities this organisation provides.



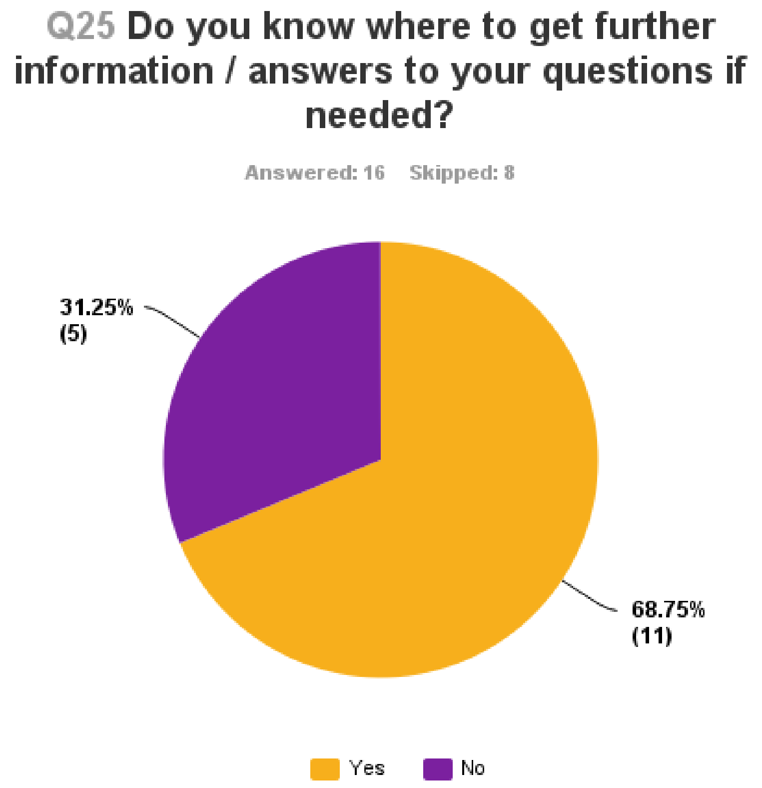
Comments included:

- Could be improved
- Is dementia a disease or something other?
- Don’t know much about
- I do but my dad who is the main carer has never really from CMHT involvement had time taken to explain the diagnosis or the progression and impact on my mum and him over time
- A lot of research needed

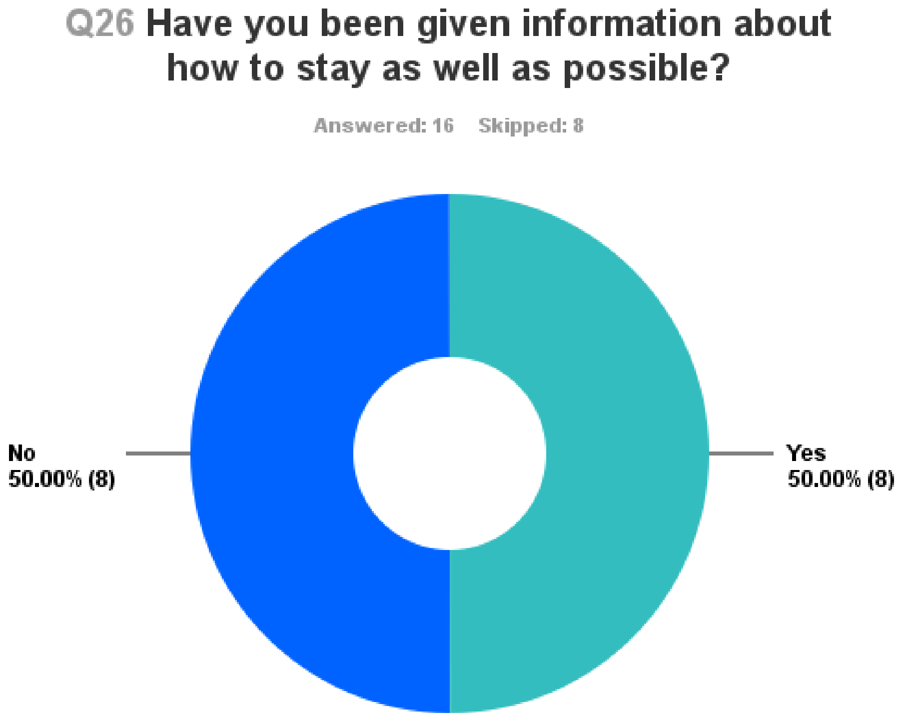


Comments included:

- Not at present, however as the dementia progresses I will need more advice
- Lots of unanswered questions. I think the tablets I have been on since 1980 have addled my brain a lot!!
- Nothing has really been explained since first diagnosis
- Why isn't more done to try and prevent symptoms worsening, i.e. brain / memory stimulation
- More info on how this will progress and affect over time. Only this way can people plan a bit and take control of their future.


Q25 Do you know where to get further information / answers to your questions if needed?

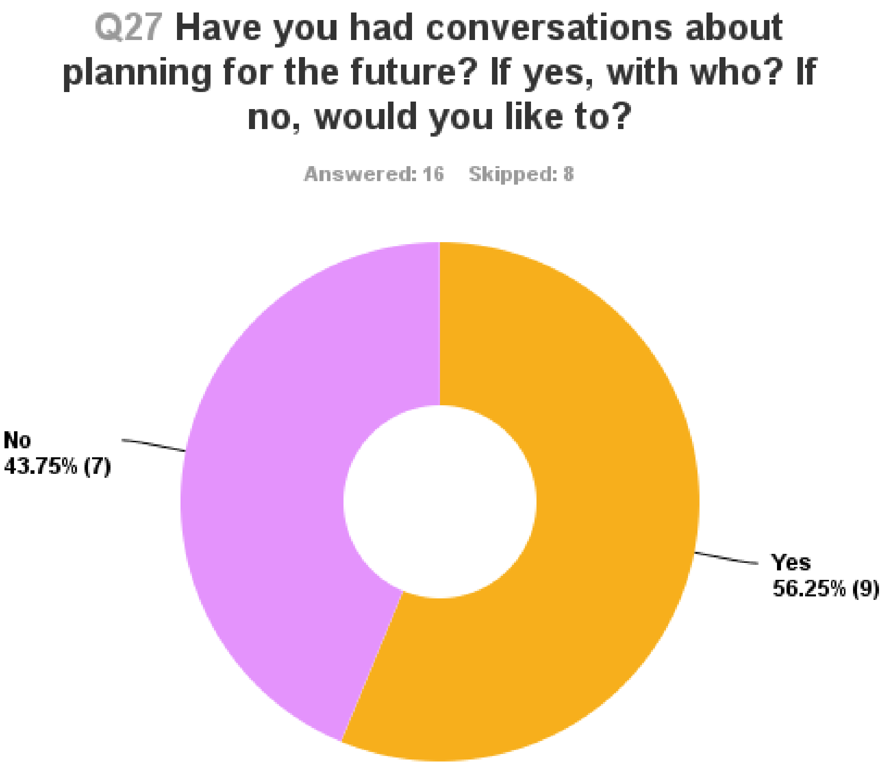
Answered: 16 Skipped: 8


Q26 Have you been given information about how to stay as well as possible?

Answered: 16 Skipped: 8

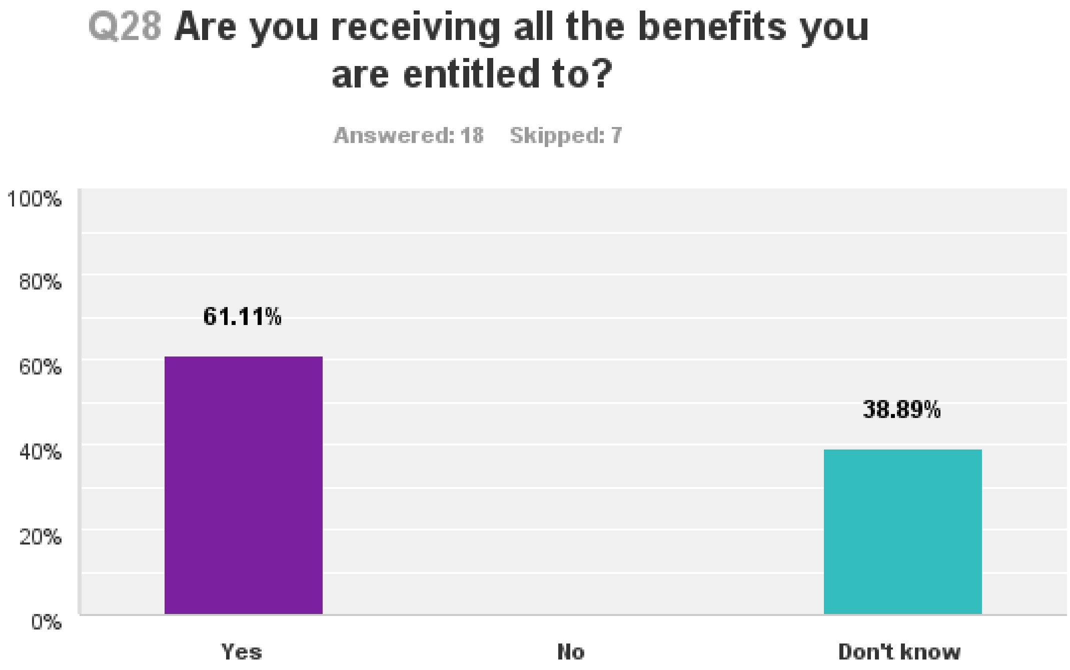
Comments included:

- Not really
- Some, at first
- Only what I have seen on TV. But so many contradictions foodwise.



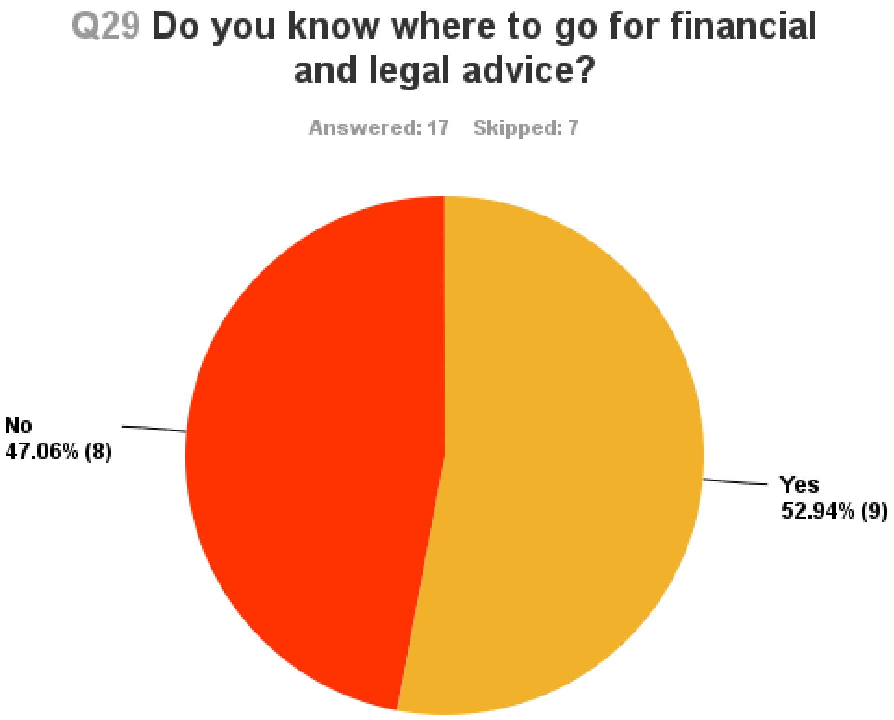
Comments included:

- Information on planning for the future would be helpful.
- Yes would like info
- Would like to discuss the future with someone
- Help is always appreciated
- This is very poor. At no time do GPs discuss this and neither did the CPN she simply turned up for a chat for a short period of time.
- With family online



Comments included:

- My husband had a pension
- I've got one benefit and don't think we are entitled to any more
- I have made sure through my professional knowledge that this is in place



Comments included:

- City of York Council advised us on the benefits, but I don't know where we would go for legal advice. We've learned what we know from relatives of others with dementia

Q30 What forms of transport do you currently use?

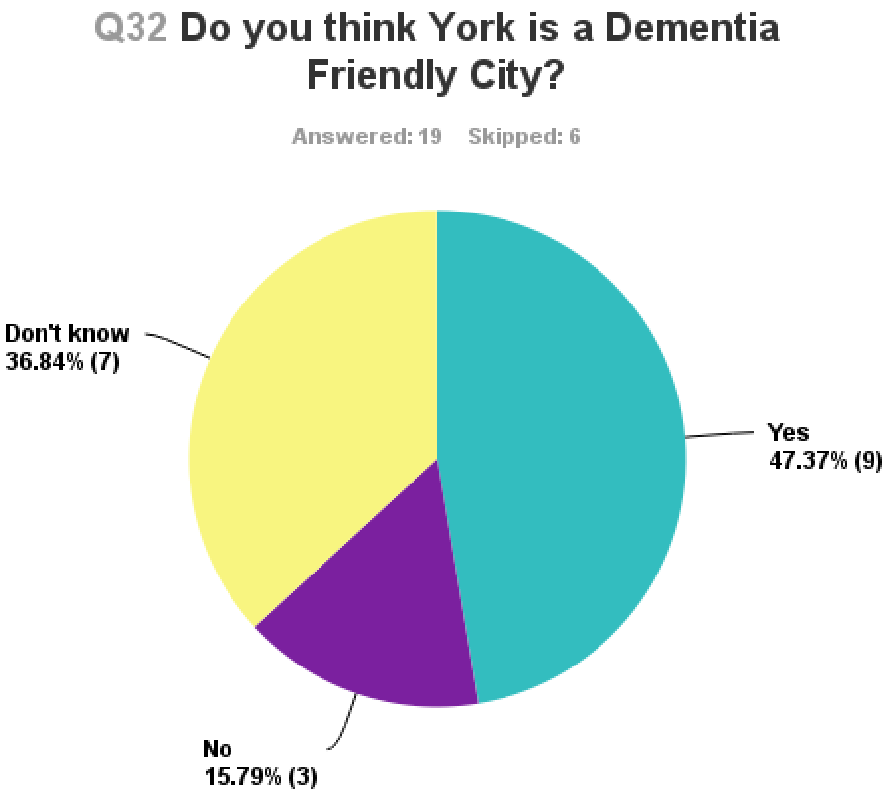
Most popular were cars (3 people specifying a carer who drove them)and buses with 8 each, 4 people also used the train, 3 taxis, 1 coaches, 2 mentioned community transport. 1 person also indicated they used public transport if accompanied.

Q31. Do you have any comments about your experiences of transport since being diagnosed?

11 comments received. These included:

- Usually nice friendly people drivers and passengers. I use buses mostly.
- I need a blue badge. I become very tired returning to a car park.
- I use a walker to get to the bus stop. I have had this pushed away in a bus to make room for pushchairs.

- Yes! Difficulty parking at the hospital for appointments.
- Disabled car blue badge very helpful for my driver door's open widely in disabled spaces. Supermarkets are so narrow they are a nightmare



If yes, why and if no why not?
Comments included:

- More and more people and organisations have become aware of dementia and this helps
- I have lived in York for 70+ years and a very high percentage are really friendly and kind
- Plenty of activities
- 1. Plenty of info. 2. Public awareness. 3. Significant elderly population
- Lots of training but no good to my relative who does not leave her home, mobility and confidence issues
- Support from voluntary organisation good
- I'm sure it's okay if you are able to be out and about. However, for those who are quite limited in their social outlets I think York with dementia is very isolating. If it were not for me then I believe that no-one would have had contact with my parents since the CPN last visited

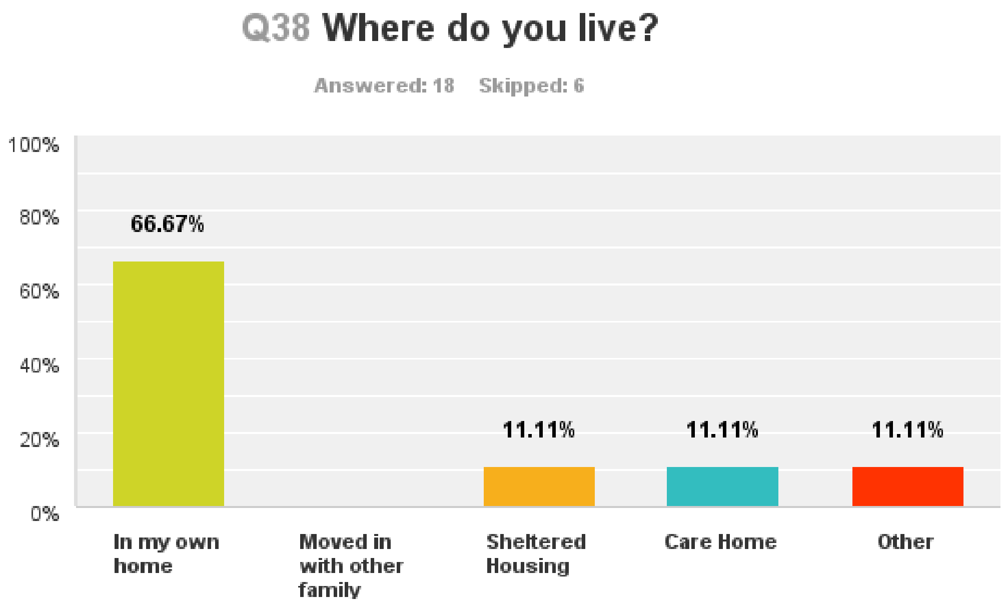
(probably 3 years ago). They are in contact with their GP for medication and as matters arise but still there is little appreciation of the dementia impact here. For example letters simply get sent to mum from health, e.g. for routine checks. We have already asked that post is not addressed to her as she cannot process the info and will read the letter and simply do nothing with it, yet my dad still feels obliged to give her her post. This may seem simple but it is very impersonal and doesn't acknowledge the dementia at all. Even then to arrange and get her a routine appointment is difficult. If you have to wait too long at the surgery even for the planned appointment it can be really problematic as her mood can change in an instant, causing upset to her, embarrassment socially for us, and her desire to leave. Also busy noisy waiting rooms are not helpful for this reason, she is very noise sensitive due to the dementia and this can add to her mood quickly turning and her need to get out. On the last occasion we went I did explain this to the receptionist and they were excellent getting her straight into the GP. However it does feel like files really need red flagging a little more and a bit more personal service. This is also where having a regular GP would help. Being dementia friendly needs to be more about reaching out into communities to identify (via GPs) those who may be in need and are isolated with this problem alongside educating the population as a whole. Too often we wait for crisis point instead of some good outreach work via GPs who remain the key point of access for older people.

Q34. If you could ask for one thing to make York more dementia friendly, what would it be?

Comments included:

- Theatre performances as the Playhouse do in Leeds
- More groups to study our health
- More understanding from people of York.
- More awareness
- A better system
- An organisation that got in touch with me instead of me trying to find out who and where they are!

- More updates on trials and someone who would give me HOPE that I do have a future and not to resign myself that I have dementia and nothing can be done
- Increased mental health services / support that could operate more of an outreach service
- Better understanding that people with dementia may be disabled in other ways too



Q35 Do you have any further comments you wish to make?

Comments included:

- I haven’t found any groups yet. I am hoping to
- I would like the cafes to be longer than 1 ½ or 2 hours
- More help for carers as behaviour can get bad quickly, slow referrals
- They all seem to act independently of one another
- The only help we get is from Dementia Forward to refer me to other organisations
- Following discharge from hospital and despite the obvious signs of memory loss we were given no support from the hospital social worker other than returning home with the same care package – which we have as carers been left to sort out

Other feedback

We spoke to a number of individuals throughout the production of this report. These include:

October 2016

A woman got in touch looking for information about organisations and activities available for people with dementia. We sent a range of leaflets, the dates for future Minds & Voices meetings, and details of books about dementia available from the library.

November 2015

A woman with dementia and learning difficulties was taken into York Hospital. She has a really detailed passport which explains her communication challenges in detail. The nurses pushed back the bed to use the hoist and the passport ended up on the floor. None of the information in it was used throughout her stay. Staff were trying to communicate with her, saying things like "can you move up the bed a bit?" but did not seem to understand why she was not responding to them as they expected.

October 2015

A man contacted us. He has been waiting for a referral to the memory service. He got a telephone message from someone inviting him to a short notice appointment due to a cancellation. He couldn’t make it so he tried to call back to find out where and when he should be coming in. He felt this was not very helpful if you are already struggling with your short term memory. He asked for an email to confirm his appointment. They seemed reluctant to do this but eventually agreed.

June 2015

A woman contacted us about her experiences of caring for her mother. She was pleased to hear the remit of the report was being defined by people with dementia. She confirmed “My mum had insight into her condition until a late stage, and she was so tired of people telling her what she ought to be thinking / doing when actually she could have expressed quite clearly what she felt about many things.”

She was interested in how former carers could become volunteers working alongside people with dementia, or with organisations that people were involved with. She felt that she had learnt a lot about dementia through her mother's experiences, and wanted to keep using her skills and experiences to contribute to improving the lives of people with dementia.

She highlighted one particular thing which had caused real difficulties for her mother, from quite an early stage. She has noticed this is also a problem for an older friend she goes shopping with who has mixed dementia. Many entrances to large shops and banks are not easy to use for people with visual or spatial difficulties. She found where there were banks of glass doors next to shop windows, this seemed to be intimidating and caused a loss of confidence. Dark floor mats in entrances also caused problems for her mother, as she perceived them as a step down although they were flat.

June 2015
A woman called about her husband. He has dementia and Parkinson's and has been in York Hospital for 3 months. He is desperate to go home and she feels his condition is deteriorating as a result of being in hospital. They have been told he needs a full package of care but there are not the carers available to do this. He has been on the waiting list for carers for 9 weeks.

May 2015
A woman in her 70's whose husband was diagnosed with dementia. They coped at home until 13 months before he died, when he became unable to walk.

She stressed how important it is to her that others have an awareness of dementia. She is a dementia friend, and is now training to become a champion. She wants to encourage more places to become dementia friendly.
She valued the coffee mornings available, and used to go to one in Acomb with her husband. But many came without the person they were caring for. She felt it was very difficult to talk openly about your personal circumstances as a carer in front of others who are living with dementia. She did not want to embarrass or upset anybody. For example, she felt carers would not say "we had a dreadful night last night, when he soiled the bed and then was awake

for hours”. So she felt it was really important, whilst maintaining life as a couple, to provide separate spaces for carers and people living with dementia to share their experiences.

She and her husband used to go out for lunches. This was something they enjoyed and was important for them. She feels that a big issue is accessible toilets. Often in shops they are in one or other gender specific toilet space. E.g. at the Range this was inside the ladies. This meant she had to take her husband into the ladies toilet. She felt it wasn’t right for men to have to do this. She said something this simple – knowing there was a toilet they could use together or worrying one wouldn’t be available - made such a difference to the quality of their day.

May 2015
A woman contacted us. Their relative has dementia and is moving to York. They wanted advice on how to choose a suitable care home.

May 2015
A woman whose relative has dementia contacted us. Their relative is in a care home, but they want her to leave. The family have been told “she has been exhibiting difficult behaviour and trying to leave”. She is struggling to find the right information to help her understand her options. We sent details of possible care homes in York, plus information on choosing a care home.

March 2015
A man whose wife has Alzheimer’s contacted us about his concerns that there is a lack of day care provision in York. He told us that his wife is able to go to excellent day care in York 2 days per week. However, this involves 4 car journeys from home each day. He feels there should be more provision available throughout York.

February 2015
A woman contacted us for advice regarding care homes in York for her brother. He does not need care at the moment but is becoming a bit forgetful & worried. He has decided it is best to go into care. He will have to fund this himself. She had phoned a local charity who suggested she contact City of York Council. She felt she spent "3 hours going round in circles", being

passed around a number of people at the council without her query being resolved. We provided a number of leaflets and booklets about choosing care.

February 2015

A woman contacted us about problems with accessible parking at Bootham Park Hospital. She could not find the accessible parking bays, and wheelchair access to the building not obvious. Her mother is a wheelchair user and has mixed dementia. The problems with parking increased the stress and anxiety for both mother and daughter. She appreciates the issue is probably not wholly in the power of Bootham Park Hospital to address, but feels it must be. She also had difficulties finding the hospital as although her mother lives in York she does not. She believes that improved signage would help.

Changes to the benefits system

We became aware, towards the end of our information gathering phase, that a number of individuals living with dementia had been invited for a PIP assessment. One of these people saw their benefits cut, and their appeal was turned down. Another was in the process of being reassessed, and had found the first interview challenging. She felt that the whole focus of the interview was to identify ways of removing or reducing support, rather than understanding her circumstances and what could help her keep independent for as long as possible. This reassessment process now seems to be picking up momentum and it would be useful to revisit this when more people have experienced it.

Recommendations

Key theme	Recommendation	Recommended to
2. 5	As part of the renewal of the Health and Wellbeing Strategy for the city, clarify the structures relating to strategic responsibility for making York a great place to live for people with dementia, and how this fits with the Dementia Action Alliance in York. This should include clearly identifying the route for people with dementia to be heard.	Health and Wellbeing Board
3.	Bring together people with dementia and GPs to explore the importance of diagnosis and consider effective signposting. Co-produce a consistent dementia pathway to make sure individuals have access to the support, information and advice they need (and improve our dementia diagnosis rate).	NHS Vale of York and the Council of Representatives, Minds & Voices, Healthwatch York
2	Consider ways of making sure engagement with people with dementia continues in York, making sure their voices are at the heart of all dementia initiatives	Health and Wellbeing Board
2. 4	Consider ways to support and refer onto a co-produced post-diagnostic course, involving people with dementia as tutors and course designers.	Health and Wellbeing Board
2. 4. 5	In embedding co-production as a way of working in York, consider how we make sure involvement of people with dementia moves beyond token representation and directly involves them in decision making and shaping services	Health and Wellbeing Board
4. 5.	Consider the needs of people with dementia when reviewing York's volunteering strategy, to include how we enable more people with dementia to take up volunteering opportunities, and how volunteer involving organisations can provide good volunteering experiences	York CVS
2. 5.	Consider ways of embedding dementia awareness	YorOK

	within secondary schools PHSE, making sure people with dementia are involved	
2. 5.	Consider ways of embedding dementia awareness into contracting arrangements for the city, making sure people with dementia are involved	Health and Wellbeing Board / Joint Commissioning Group
4.	Consider additional ways in which small opportunities to do things separately can be developed and supported for people with dementia and their carers	Commissioners and providers of dementia support services
4. 5.	Tap into the passion and willingness of people with dementia to get positive messages out there in all awareness raising activity	Dementia Action Alliance, Health and Wellbeing Board
1.	Consider ways of increasing advocacy, mediation and support for couples and families to work through changing relationship dynamics	Health and Wellbeing Board
1. 3. 5.	Consider how we make sure those who need face to face information, advice, and customer service are not left behind by increasing reliance on modern technology and “digital by default” approaches to information.	Health and Wellbeing Board
4. 5.	Consider producing a map of accessible toilet facilities in York and making this available through tourist information, as well as through existing information channels within the city.	Make It York
4. 5.	Consider whether there are sufficient accessible toilet facilities in York to enable people to stay independent.	City of York Council / Make it York
1. 2.	Undertake further work with key partners (e.g. Citizens Advice York, York Carers Centre) to understand the impact of the PIP assessment process on people with dementia	Healthwatch York / Dementia Service Providers and the Dementia Action Alliance

Appendix One - Reflections on the carers sessions from Damian Murphy[x]

Dementia Friendly Communities:
An interesting session where we posed what does dementia friendly mean to you. With Barnitts being a local favourite, we had our answer – it's not about stickers in windows, it's about good customer service**. If it's dementia friendly then it's friendly**.

Support and Information
There was a common theme emerging that many people found out about various forms of support and information via chance meetings.
Some had a 'switched on' doctor. Others did not get any support for a long time.

Based on what people were saying about inconsistent post diagnostic support, the question was posed, 'how much medical involvement is needed after diagnosis?' If it is very little (apart from six monthly check-ups) **then should we really be surprised that the support we seek is not forthcoming from professionals with an understandable medicalised focus?**

The group all mentioned the many questions they and their partner were left with following a diagnosis and the need for something simple to understand and something that also focusses on addressing the fear. The positive message – 'you CAN live well with this.' **Appropriate face to face contact rather than overwhelming with leaflets** was the favoured option at this crucial post-diagnostic period. Good examples out there are that Tang Hall Surgery has a link worker.

One carer mentioned the powerful phrase:

'you want to feel as if you are still part of the world' – this is certainly a message that I imagined was also being sent by the group of people living with dementia.

The carers were asked what would be the one essential in their eyes. **More knowledge at the GP surgery** – at least being able to point people in the right direction for the REAL information. One carer mentioned the idea of our input here being used for surgeries and groups to adopt a common, consistent local standard across all surgeries in York.

Peer Support - a safe place to express thoughts, feelings, emotions etc. (We all agreed this was vital for both carer AND the person with dementia.)

Not to feel embarrassed – why should we worry if our partner does things or says things that others see as different or strange – this is clearly their problem not ours. 'Why should we ask permission to join in, remain part of a group etc?' – a powerful point made by one of the participants that highlights the need that dementia is seen as a disability and that remaining part of communities is a disability rights issue and probably something at the heart of what a dementia friendly community is.

This is all the more relevant now since the publication of the powerful 'Our Dementia, Our Rights' booklet from DEEP.[xi]

Transitions – all agreed that it is difficult to keep readjusting as people's needs change and this is not helped by the many periods of transition involved along the way – in/out of respite, day care, hospital. So a smoothing out of these sensitive periods of transition is essential.

Still remaining as husband, wife, lover – the importance of keeping one's independence, voice, control, identity.

We asked, 'how much time had passed at home, wondering what was happening, before going to the GP for the first time?' The insidious nature of the onset of dementia made it hard to pinpoint exactly, but answers were around the 18 month – 2 years mark. It's important to get access to practical support services (usually psycho-social support at early stages) whilst the diagnostic process is underway. **This is why diagnostic involvement should begin long before diagnostic process is complete.**

In summary the overall feel was that we want a more upbeat positive message – information on how we can all live well with the presence of dementia and just information that is consistent and easily understandable.

Thoughts about a pathway from Healthwatch York meetings
The first point of call is always the GP. It is important that the patient requests ‘referral to the specialist consultant in Old Age Psychiatry for further investigation of an obvious impairment’ - always a good phrase to use rather than hoping that the GP refers or not.

Various people/services seem to be saying how there is a ‘pathway’ yet no-one seems to have taken the same route! But how might one expect people with a cognitive impairment and a whole range of unique experiences, feelings, symptoms and life histories, to follow a linear pathway?

Notes on: The experience of living with dementia and what you think people should know about the experience of living with dementia.
It was striking the extent to which the years of a prevailing ‘care for carer stress and burden’ model can really inhibit seeing the other side of the story. It was not the case with everyone, and a few became extremely thoughtful in thinking back and really putting themselves as far as possible into the shoes of their partner.
The passage below highlights what dementia-friendly means within a relationship. **Carers spoke a lot about the ‘difficulties’ and ‘aggression… when they’re angry.’** We looked at possible reasons behind such anger. The group offered a whole range of valid reasons:

- **frustration at not being able to express oneself as well**
- **feeling bossed about and told off**
- **frustration at being tested and questioned when seeking quiet time**
- **a whole range of other physical illnesses (cancer / heart disease / arthritis)**

One carer astutely pointed out that when looking back, he could nearly always pinpoint a logical trigger to any ‘outbursts’. The powerful message was that such ‘aggression’ is not down to dementia. Rather it is down to situations that we can all find ourselves in. One carer mentioned his wife who has dementia saying, ‘Sometimes I have a bad day’ – don’t we all?’

‘It’s like looking after a 2-year old’ was another comment. I asked how it made people feel if they were treated like a child. I pointed out that no-one in the other group would be describing themselves as like infants.

There were however lots of insight into the experience of their partner:

- Everyone mentioned the tears and devastation at point of diagnosis
- Everyone acknowledged how their partner frequently wants their own space and independence
- They acknowledged how their partners complain about being ‘bossed about’ – (a difficult but necessary balance to strike when thinking about support and safety and one’s own concerns)
- The importance of a safe space to switch off (and also ‘let rip’ sometimes!) after a day that may have included the difficult task of putting on a social veneer – in a way a real compliment to the carer (however painful it might be!)
- Wanting to keep your independence with just about the right support
- Wanting the reassuring presence of familiar faces
- All acknowledged the frequent ‘You know I love you, don’t you’ – very much a recognition and insight into the condition – and perhaps also a plea implying no little sense of insecurity, ‘don’t leave me’ or ‘don’t hold this against me’

We finished with one statement from each of the seven carers present. I asked them to say one thing that they feel their partner would want to say about their experiences:

1. ‘You can live with this, I just need to adapt’
2. ‘You just have to get on with life’
3. ‘Bugger off, Dementia, you’re not going to stop me living my life’
4. ‘I’m glad I enjoy my ‘club’ and the love of my family
5. ‘It doesn’t bother me but I do worry if I’ll get like that’ (when seeing negative stereotypes in TV and media)

6. 'I love routine and regular things'
7. 'I do love you, you know'

In summary.
The opportunity to share and acknowledge each other's feelings and perspectives is so limited for families where one partner is living with dementia.

The comment 'I'm not bothered' (reported words of a partner with dementia in response to a complaining spouse) really poses a question 'Then who is it a problem for?' Clearly the early statements associating dementia with aggression indicate that the problem may lie with the lack of understanding and knowledge, acknowledgement of care partners about feelings and experiences, and about the nature of dementia too. This is no criticism. Dementia does not come with a handbook.

This session revealed clearly the type of practical support needed around the time of diagnosis. It repeats a message that has been a real theme through these sessions. Groups complain about lack of follow up 'from the doctor' yet what we seem to be looking for is very much the emotional support, the relationship-centred approaches that can equip families in just living the day to day. I understand the other group made up of individuals with dementia spent a lot of time mentioning some of the antagonisms they experience in their close relationships with family and friends. This does not surprise me.

References

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[i] https://www.dementiafriends.org.uk/WEBArticle?page=what-is-dementia#.WI8b8VWLRc4

[ii] http://www.healthyork.org/the-population-of-york/specific-population-profiles/frail-elderly/dementia.aspx

[iii] http://www.valeofyorkccg.nhs.uk/data/uploads/governing-body-papers/5-january-2017/item-10-quality-report.pdf, page 19

[iv] https://www.jrf.org.uk/report/evaluation-york-dementia-friendly-communities-programme

[v] https://www.jrf.org.uk/report/developing-national-user-movement-people-dementia

[vi] https://www.jrf.org.uk/report/how-can-we-make-our-cities-dementia-friendly

[vii] https://www.jrf.org.uk/blog/dementiaville-failed-give-people-dementia-voice downloaded 10th November 2016

[viii] http://www.nhs.uk/LiveWell/volunteering/Pages/Whyvolunteer.aspx

[ix] https://www.helpguide.org/articles/work-career/volunteering-and-its-surprising-benefits.htm

[x] York-based Director of Innovations in Dementia, and one of the facilitators of the Minds and Voices Forum and the meetings with Healthwatch York

[xi] http://dementiavoices.org.uk/deep-groups-news/our-dementia-our-rights/

Other useful information:

Reasons why people with dementia are admitted to general hospitals in an emergency http://www.yhpho.org.uk/resource/view.aspx?RID=207311

Barriers to finding a cure for dementia

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/447529/Dementia-Report.pdf

Portrayals of dementia and debate

http://theconversation.com/films-like-still-alice-are-crucial-to-keeping-debate-about-dementia-alive-38675

http://livingwelldementia.org/2015/07/14/living-better-can-become-a-reality-for-people-with-dementia-if-they-lead-policy/

Acknowledgements

When we informed people that as part of our work we were going to be spending time each month with people with dementia, the usual reaction was an expression of sympathy. It seemed inevitable to friends, family and colleagues that this was going to be a difficult time. In reality, this was nonsense. We've had the privilege of spending time with a great bunch of people who all happen to have a dementia diagnosis. We talked about so much, for example:

- fighting for a diagnosis
- trying to find help and advice
- ideas to change the world
- the way that chance meetings could open up opportunities to be part of new activities
- getting involved nationally and internationally in the fight to involve people with dementia in improving their futures

In discussing their experiences of dementia, whilst there were poignant and sad moments, our overriding memories are uproarious laughter.

Thanks to everyone who spent time with us during this project, especially the members of York Minds & Voices Forum. It has been an honour and a privilege, and it's not over. We look forward to working with you on making the recommendations in this report a reality.

Grateful thanks too to the amazing Emily (Abbott, York Flourish) and Damian (Murphy, a Director of Innovations in Dementia), both of whom support the York Mind & Voices Forum. Their unstinting support in doing this work made this project possible. When you work with great people, it doesn't feel like work at all. Your passion and commitment to making sure people with dementia are heard and making their worlds better is infectious.

Thanks also to the Joseph Rowntree Foundation, for their funding, their ideas, and their commitment to making the world a better place for all.

healthwatch
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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

Health and Wellbeing Board – Meeting Work Programme 2016/17

Wednesday 8 March 2017 - West Offices

Item/Topic	**Lead Organisation & Officer**	**Other Contributing Organisations & Participants**	**Scope**
Appointments Report	City of York Council Judith Betts		• To appoint a second substitute for NHS England
HWBB Governance	City of York Council Sharon Stoltz Martin Farran	City of York Council Tracy Wallis	• To provide an update report on the governance of the HWBB
JSNA/JHWBS Steering Group	City of York Council Sharon Stoltz	All HWBB Partners	• To approve and launch the renewed Joint Health and Wellbeing Strategy for York • To receive the work programme and a progress report on the work of the JSNA/JHWBS Steering Group
Performance Management Framework	City of York Council Tom Cray		• To present a refreshed performance management framework to the HWBB
CCG 2 Year operational Plan	NHS VoY CCG Phil Mettam Rachel Potts Caroline Alexander		• To receive the CCG 2 Year Operational Plan
Better Care Fund	NHS Vale of York Clinical Commissioning Group	NHS Vale of York Clinical Commissioning Group Elaine Wyllie	• To receive a progress report on the Better Care Fund

Health and Wellbeing Board – Meeting Work Programme 2016/17

Wednesday 8 March 2017 - West Offices

Item/Topic	**Lead Organisation & Officer**	**Other Contributing Organisations & Participants**	**Scope**
	Phil Mettam		
Healthwatch York	Healthwatch York Siân Balsom		• To receive recent Healthwatch York reports on: • Continuing Healthcare • Support for Adults with ADHD • Making York Work for People with Dementia

Wednesday 17 May - West Offices

Item/Topic	**Lead Organisation & Officer**	**Other Contributing Organisations & Participants**	**Scope**
Focus tbc			
Other Business			
Healthwatch York Reports (to be confirmed)			
Joint Strategic Needs Assessment/Joint Health and Wellbeing Strategy Steering Group	City of York Council Sharon Stoltz	All HWBB Partners	• To receive an update from the JSNA/JHWBS Steering Group

Health and Wellbeing Board – Meeting Work Programme 2016/17

Wednesday 8 March 2017 - West Offices

Item/Topic	Lead Organisation & Officer	Other Contributing Organisations & Participants	Scope
NHS Vale of York Clinical Commissioning Group's Annual Report & Accounts	NHS VoY CCG Phil Mettam Rachel Potts Caroline Alexander		● To receive the CCG's Annual Report and Accounts
The Local Digital Agenda	NHS Vale of York Clinical Commissioning Group Phil Mettam Pennie Furneaux		● To pull together various themes around the local digital agenda ○ Local digital roadmaps ○ Primary care forward view ○ STP digital technologies ○ Enabling digital systems access ○ Enabling system integration

Dates are to be confirmed for the following items

Item/Topic	Lead Organisation & Officer	Other Contributing Organisations & Participants	Scope
Mental Health and Learning Disabilities Partnership Board	NHS Vale of York Clinical Commissioning Group Paul Howatson		● To receive the Annual Report of the Mental Health and Learning Disabilities Partnership Board
Director of Public Health's Report	City of York Council Sharon Stoltz		● To receive the annual report of the 2016 and approve the recommendations

Health and Wellbeing Board – Meeting Work Programme 2016/17

Wednesday 8 March 2017 - West Offices			
Item/Topic	**Lead Organisation & Officer**	**Other Contributing Organisations & Participants**	**Scope**
YorOK Board	City of York Council Jon Stonehouse	City of York Council Eoin Rush	- To receive the Annual Report of the YorOK Board