Health and Wellbeing Board
North Yorkshire

Meeting: Health and Wellbeing Board

Venue: Falsgrave Community Resource Centre, Seamer Road, Scarborough (location plan attached)

Date: Friday 17 March 2017 from 10.30 a.m. to 12.30 p.m.

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Business

No.	Agenda Item	Action	Page Nos	Indicative timings
1	Apologies for Absence	-		10:30 – 10.35
2	Any Declarations of Interest	-		
3	Minutes of the meeting held on 18 January 2017	To approve	7-16	
4	Public Questions or Statements Members of the public may ask questions or make statements at this meeting if they have given notice and provided the text of their question or statement to Patrick Duffy of Democratic Services *(contact details below)* no later than midday on Tuesday 14 March 2017. Each speaker should limit themselves to 3 minutes on any item.			

Enquiries relating to this Agenda please contact Patrick Duffy **Tel: 01609 534546**
or e-mail patrick.duffy@northyorks.gov.uk Website: www.northyorks.gov.uk

	Members of the public who have given notice will be invited to speak:- • at this point in the meeting if their questions/statements relate to matters which are not otherwise on the Agenda (subject to an overall time limit of 30 minutes); • when the relevant Agenda Item is being considered if they wish to speak on a matter which is on the Agenda for this meeting.			
	JHWBS Theme: Live Well			
5	**Green Paper: Draft Carers Strategy 2017-2022 – Supporting the Health and Wellbeing of Unpaid Carers in North Yorkshire** Sponsor: Janet Probert Presented by: Avril Hunter	To comment	17-34	10:35 -11:05
	JHWBS Theme: Age Well			
6	**Green Paper: Draft Dementia Strategy - Bring Me Sunshine, Living Well with Dementia in North Yorkshire** Sponsor: Amanda Bloor Presented by: Michael Rudd	To comment	35-81	11.05– 11.35
	JHWBS Theme: Dying Well			
7	**North Yorkshire Scrutiny of Health – In-depth Study of End of Life Care in the County** Sponsor: Alex Bird Presented by: Councillor Jim Clark and Daniel Harry	To comment	82-127	11.35 – 12.05
	JHWBS Theme: Live Well			
8	**North Yorkshire Tobacco Control, 2016 Report: One Year On** Sponsor: Janet Probert Presented by: Lincoln Sargeant	To note and approve	128-140	12:05 – 12.15

	JHWBS Theme: All Themes			
9	**Development of Future Integrated Commissioning Arrangements in North Yorkshire – Progress Update** Presented by: Amanda Bloor	To note and comment	141-142	12.15 – 12.25
10	**Better Care Fund Update – verbal update** Presented by: Amanda Reynolds	To note		12.25 – 12:30
	General			
11	**Health and Wellbeing Board - Rolling Work Programme / Calendar of Meetings 2017/18**	To approve	143-146	-
12	**Other business which the Chairman agrees should be considered as a matter of urgency because of special circumstances**			-

Barry Khan
Assistant Chief Executive (Legal and Democratic Services)

County Hall
Northallerton

9th March 2017

PLEASE NOTE: “JHWBS” stands for Joint Health and Wellbeing Strategy

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North Yorkshire Health and Wellbeing Board – Membership

County Councillors (3)		
1	WOOD, Clare (Chairman)	Executive Member for Adult Social Care and Health Integration
2	CHANCE, David	Executive Member for Stronger Communities and Public Health
3	SANDERSON, Janet	Executive Member for Children and Young People's Services
Elected Member District Council Representative (1)		
4	FOSTER, Richard	Leader, Craven District Council
Local Authority Officers (5)		
5	FLINTON, Richard	North Yorkshire County Council Chief Executive
6	WEBB, Richard	North Yorkshire County Council Corporate Director, Health & Adult Services
7	DWYER, Peter	North Yorkshire County Council Corporate Director, Children & Young People's Service
8	WAGGOTT, Janet	Chief Officer, District Council Representative
9	SARGEANT, Dr Lincoln	North Yorkshire County Council Director of Public Health
Clinical Commissioning Groups (5)		
10	RENWICK, Dr Colin	Airedale, Wharfedale & Craven CCG
11	PROBERT, Janet	Hambleton, Richmondshire & Whitby CCG
12	BLOOR, Amanda (Vice-Chair)	Harrogate & Rural District CCG
13	METTAM, Phil	Vale of York CCG
14	COX, Simon	Scarborough and Ryedale CCG
Other Members (3)		
15	JONES, Shaun	NHS England NY & Humber Area Team
16	VACANCY	Healthwatch Representative
17	BIRD, Alex	Voluntary Sector Representative
Co-opted Members (2) – Voting		
18	MARTIN, Colin	Mental Health Trust Representative (Chief Executive, Tees Esk & Wear Valleys NHS Foundation Trust)
19	TOLCHER, Dr Ros	Acute Hospital Representative
Substitute Members		
	WARREN, Julie	NHS England NY & Humber Area Team
	CROWLEY, Patrick	Acute Hospital
	COLLINSON, Gill	Hambleton Richmondshire & Whitby CCG
	MELLOR, Richard	Scarborough and Ryedale CCG
	AYRE, Nigel	Healthwatch
	COULTHARD, Adele	Tees, Esk and Wear Valley NHS Foundation Trust
	HIRST, Helen	Airedale, Wharfedale & Craven CCG
	PHILLIPS, Andrew	Vale of York CCG

Notes:

1. The Health and Wellbeing Board is exempt from the requirements as to political balance set out in Sections 15-16, Schedule 1 Local Government Housing Act 1989
2. The Councillor Membership of the Board is nominated by the Leader of the Council. In the event that the number of portfolio holders responsible for health and well related issues increases, the additional portfolio holders will also be a Member of the Board.
3. All members of the Health and Wellbeing Board or any sub committees of the Health and Wellbeing Board are voting Members unless the Council decides otherwise.

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Health and Wellbeing Board
North Yorkshire

These ground rules are about Team North Yorkshire Health and Wellbeing Board and should apply within and outside of Board meetings. They were adopted by Board members in June 2015.

We have made a commitment that when working together we will treat each other with **respect**, with **openness and honesty**. We will make sure that there is **equality – everyone is of equal value in the room.** We will **contribute and take part, committing to listen and ask questions of each other**, **checking that what we heard is what was intended**. We believe **it is good to be passionate**, and we know that constructive **challenge is helpful in getting us to a better place**. We must **voice disagreement, otherwise silence implies consent** but recognise that this should be done **with respect** to other points of view. **We shouldn't expect the same sort of challenge in the public arena.**

We have a responsibility to model exemplary behaviour, inside and outside of the HWB meetings, as Board members we should **give and accept support** and **bring collective experience and knowledge to this Board**. **Our discussions need to focus on added value and outcomes** and we must **take responsibility for our decisions.** We should ensure that we **communicate and cascade to our respective audiences and organisations.**

We believe that we should **continually strive to be better and** wear our **team badges - Team North Yorkshire** with pride.

Falsgrave Community Resource Centre
Seamer Road
Scarborough
YO12 4DH

North Yorkshire Health and Wellbeing Board

Minutes of the meeting held on Wednesday 18 January 2017 at
The Evolution Centre, County Business Park, Northallerton

Present:-

Board Members	**Constituent Organisation**
County Councillors	
County Councillor Clare Wood **(Chairman)**	North Yorkshire County Council Executive Member for Adult Social Care and Health Integration
County Councillor Janet Sanderson	North Yorkshire County Council Executive Member for Children and Young People’s Service
Elected Member District Council Representative	
Richard Foster	Craven District Council Leader
Local Authority Officers	
Richard Flinton	North Yorkshire County Council Chief Executive
Richard Webb	North Yorkshire County Council Corporate Director – Health & Adult Services
Peter Dwyer	North Yorkshire County Council Corporate Director - Children and Young People’s Service
Janet Waggott	Chief Officer, District Council Representative
Dr Lincoln Sargeant	North Yorkshire County Council Director of Public Health
Clinical Commissioning Groups	
Janet Probert	Hambleton, Richmondshire and Whitby CCG
Amanda Bloor (Vice-Chair)	Harrogate and Rural District CCG
Phil Mettam	Vale of York CCG
Simon Cox	Scarborough and Ryedale CCG
Other Members	
Shaun Jones	NHS England, North Yorkshire & Humber Area Team
Nigel Ayre	Healthwatch, North Yorkshire
Alex Bird	Voluntary Sector (North Yorkshire and York Forum)
Co-opted Members	
Adele Coulthard (substitute for Colin Martin)	Mental Health Trust Representative (Tees Esk and Wear Valleys NHS Foundation Trust)
Dr Ros Tolcher	Acute Hospital Representative

In Attendance:-

County Councillor Jim Clark, Victoria Pilkington (Partnership Commissioning Unit)

North Yorkshire County Council Officers:
Kathy Clark, Michaela Pinchard, Amanda Reynolds and Mike Webster (Health and Adult Services), Jane Le Sage and Kate Race (Children and Young People’s Service), Robert Ling (Technology and Change), Patrick Duffy (Legal and Democratic Services), Holly Austin (Business Support), Helen Bawn (Strategic Resources)

Copies of all documents considered are in the Minute Book

192. Chairman's Announcements

The Chairman reported that:-

- a number of the issues discussed at today's meeting would be highlighted via social media, on twitter, by a new health account, which she encouraged all partner organisations to follow and share. Helen Bawn, from the County Council's Communications Unit, was in attendance and would be tweeting, as appropriate;
- a themed approach to the Agenda had been adopted, reflecting the Joint Health and Wellbeing Strategy;
- Ros Tolcher's appointment as the Acute Hospitals representative had now been formally approved by the Council;
- Phil Mettam had been nominated as the representative of the Vale of York CCG. This was subject to formal approval by the County Council; and
- Gill Collinson had been appointed as nominated substitute for Janet Probert, the representative of Hambleton, Richmondshire and Whitby CCG.

193 Apologies for absence

Apologies for absence were submitted by:

- County Councillor David Chance
- Colin Martin
- Dr. Colin Renwick

194. Declarations of Interest

There were no declarations of interest.

195. Minutes

Resolved -

That the Minutes of the meeting held on 14 September 2016 are approved as an accurate record.

196. Public Questions or Statements

There were no questions or statements from members of the public.

The Chairman decided to vary the order of the Agenda by taking the following Item at this stage as the presenter had to attend another meeting shortly.

197. Annual Report of the North Yorkshire Safeguarding Adults Board

Considered -

The report of the Corporate Director - Health and Adult Services presenting the Annual Report of the North Yorkshire Safeguarding Adults Board.

Mike Webster, Assistant Director for Contracts, Commissioning and Quality Assurance, informed the Board that he was presenting the report on behalf of the Chairman of the Safeguarding Adults Board, Colin Morris.

He highlighted the following aspects:-

- The Safeguarding Adults Board is now a Statutory Board, under the Care Act.

- The Board is functioning much better as a result of being restructured and revised governance arrangements.

- The culture of safeguarding is more embedded.

- Whilst having good policies and procedures in place is important, the key is to ensure that these work effectively. Paragraph 3.3 of the covering report illustrated key achievements during 2015/2016. These are evidence that the Board is functioning well, but the Board is not complacent.

- The priorities for 2016/2017 were set out in Section 4 of the covering report.

The Chairman thanked Mike Webster for the update and asked him to convey the Board's best wishes to Colin Morris.

198. Technology Update

Considered -

The report of Robert Ling, Assistant Director, Technology and Change outlining the key developments in the use of technology by the County Council and its partners, how these advances are being used now to improve the outcomes for the people of North Yorkshire and some of the likely impacts of future developments.

The Chairman advised that Robert had accepted her invitation to be the sponsor for technology and welcomed him to his first meeting of the Board. Also, Colin Martin, had agreed, for the time being, to be the sponsor for a new relationship with people who use services. This meant that all themes and enablers now had a sponsor.

Robert Ling mentioned the following points, in particular:-

- Local Digital Roadmaps are key, as is the need to be aware how we work effectively with an array of partners.

- Data governance is important – how do we get the right access at the right time and a shared understanding as to what is required?

- Infrastructure has to be improved e.g. so that partners can access systems to get wifi in all buildings.

- How can we make self-service work to provide the best outcomes for people using our services?

- There should be a drive to digital by default, where appropriate.

- Assisted Living has a vital role to play in helping people stay in their own home longer. How do we drive this consistently?

- Consumer Smart Devices are now available which, for example, can tell a person when there is a fire.

- Sharing information is a risk if we get it wrong, but there is also a risk in not sharing information.

- Work is continuing on the establishment of a Digital Village.

- He would appreciate the names of people in partner organisations who he could link in with to drive the technology enabler forward.

Richard Flinton, Chief Executive, commented on the enormity of the challenge and asked what would be the biggest opportunity for gain? Robert Ling responded that this would be data standards and data sharing, as the more we know about people, the better, in terms of the outcomes that they can be helped to achieve.

Janet Sanderson, Executive Member for Children and Young People's Service, mentioned that she has seen the work that had been undertaken on the Youth Justice System and is impressed. Sometimes there is too much information – how can we put on filters to manage that? Robert Ling responded that physical issues of social capital and stronger communities are more important; do we have the community groups to move this forward?

Adele Coulthard, Head of Operations at Tees, Esk and Wear Valleys (TEWV) NHS Foundation Trust, advised that TEWV had been invited to bid for a national exemplar initiative.

Janet Waggott, Chief Executive of Ryedale District Council, commented that education and reassurance for staff is important, to reinforce the fact that information can be shared.

Richard Webb, Corporate Director of Health and Adult Services, said he is excited by the prospect of the Digital Village and hoped it can be linked to primary care. Data protection still represents a blockage and needs to be overcome – possibly by producing a simple guide for staff. Robert Ling advised that he is looking at the approach in Wigan and Greater Manchester, which has been recognised as good.

Amanda Bloor, Chief Officer of Harrogate and Rural District CCG, felt it should be specified what is required and a rolling programme undertaken to achieve this.

Resolved -

a) That the update be noted.

b) That Members of the Board provide Robert Ling with the name(s) of people in their organisations who he can liaise with to progress the technology enabler.

199. Sustainability and Transformation Plans

This Item was withdrawn from the meeting.

200. Growing up in North Yorkshire Survey 2016

Considered -

The report of the Corporate Director - Children and Young People's Service providing an update on the findings of the 2016 Growing Up in North Yorkshire Survey, which is commissioned by the local authority from Schools Health Education Unit at Exeter University.

Pete Dwyer informed the Board that:-

- This Survey is the largest of its type in ascertaining the views of young people and provided a wealth of information to help in planning services - 70% of young people in each age cohort completed the Survey.

- A specific detailed report on any particular aspect of the Survey can be provided.

- The Survey provides evidence of progress in the Young and Yorkshire Initiative e.g. the gap in educational attainment between pupils who receive free school meals and those who do not has closed and there has been a reduction in the number of pupils in secondary schools who feel anxiety.

- The County Council is ranked fifth highest amongst Authorities for taking Lesbian, Gay, Bi-sexual and Transgender issues seriously. There has been a significant reduction in bullying of these young people.

- There are a number of other encouraging trends too. For instance, respondents now feel safer on line – although this education needs to start at an earlier age. Fewer young people are now drinking alcohol, or smoking.

- The Survey found that very young children have a TV in their bedroom. There is clear evidence that this led to insufficient sleep and impacted on learning. The approach is to tackle this at source by providing advice to parents.

- There is more to do on sex education - just 30% of young people find this useful and this has barely changed over the last decade. Also, 42%% have accessed acute care, which illustrates the need to continue to promote emotional wellbeing.

Janet Probert, Chief Officer of Hambleton, Richmondshire and Whitby CCG, queried whether any attempt is made to ascertain the views of children who are not in school. Pete Dwyer advised that the Survey is completed by youngsters in Pupil Referral Units and there is engagement with Independent Schools too. However, home educated children are not covered.

Richard Flinton referred to the opportunities in Scarborough through new opportunity funding and suggested the Board receive a report on this to consider where resources could be moved. Pete Dwyer commented that increased levels of educational attainment are likely to have a knock on effect, as people are less likely to be reliant on services.

Phil Mettam, Chief Officer at Vale of York CCG, said he will take up the offer of more detailed information as it would be helpful to understand the findings in the east of the county.

Shaun Jones, Head of Assurance and Delivery at NHS England, enquired whether the fact that the Survey is completed at ages 6, 8 and 10 enables tracking of views. Pete Dwyer confirmed that this can be done.

In reply to a query by Richard Foster, Leader of Craven District Council, Pete Dywer confirmed that it is possible to benchmark responses for each District Council.

Resolved -

a) That the report be noted.

b) That partners take this back to their organisations for wider discussion.

201. Learning Disabilities Strategy

Considered -

The report of the Corporate Director - Health and Adult Services "Live Well, Live Longer" the Learning Disabilities Joint Strategy for North Yorkshire, 2016-2021.

The report was presented by Kathy Clark, Assistant Director and Victoria Pilkington, Head of the Partnership Commissioning Unit.

Kathy Clark advised Members that:-

- Comments they had made on the draft at the July 2016 meeting had been incorporated and a lot of work had been done on the format.

- Person-centred approaches and keeping people safe are crucial elements within the Strategy, as is the aim of creating better outcomes with partners and people with learning disabilities and their families.

- Once the content has been agreed, further work will be undertaken to make the design more user-friendly. An easy read version will also be produced.

Janet Waggott asked what if the resources were not available? Did expectations need to be managed? Victoria Pilkington responded that there is substantial commitment to implementing the Strategy across Health and Social Care and the Acute Trusts. There were resources and expertise available, as a consortium.

Richard Webb thanked officers for the work that had been done on the Strategy. He suggested that, due to the financial issues faced, quality and value for money be added as a priority and queried whether the specialist issues for people with high functioning disabilities had been addressed.

Simon Cox, Chief Officer at Scarborough and Ryedale CCG, felt it was important to note the point about resources being brought together to implement the Strategy and that NHS England should be fully engaged in its commissioner role.

Ros Tolcher, Chief Executive of Harrogate District Hospital, fully endorsed the Strategy. She also referred to a report published by the Care Quality Commission (CQC) concerning how mortality is investigated in the NHS. The CQC is consulting on its new inspection regime and this will include how people with learning disabilities will be registered, so there is an opportunity to feed into that. Victoria Pilkington responded that partners are committed to supporting reviews of all deaths.

The Chairman concluded the discussion by saying how heartening it is that this work has been undertaken so collaboratively. It should be a high priority, as supporting people who cannot always support themselves is at the route of what we do.

Resolved -

That the Strategy be agreed and endorsed, having regard to the points made above.

202. Autism Strategy - Update on Progress

Considered -

The report of the Corporate Director - Children and Young People's Service providing an update on the implementation of The Changing Landscape of Autism in North Yorkshire, North Yorkshire Autism Strategy 2015-2020, in the year since launch.

The report was presented by Jane Le Sage, Assistant Director for Inclusion and Kate Race, Consultant for Autism, Inclusive Education Service.

The seven key themes of the Strategy are:-

- Support for people with autism and their families
- Assessment and diagnosis
- Raising awareness and training
- Information and signposting
- Employment and education
- Supporting people with autism through key life changes, including preparing for adulthood
- Working together across agencies

Good progress has been made. Governance had been established and an initial Implementation Plan developed in respect of the key themes.

Specifically, training has been developed as to how best to meet the needs of the 7,000 people across North Yorkshire who experience autism – over 1500 staff had been trained to support individuals with autism and their families by the Inclusive Education Service alone.

Services had been examined to see how people can access them and to ensure they are being referred to the right service – specifically, the Single Point of Access, which refers into the Inclusive Education Service. This work has been praised by OFSTED. In addition, foundation work on diagnostic pathways has been undertaken.

Looking to Year 2 of Implementation, there have been further developments since the Strategy was launched. For instance, the Inspection of Special Educational Needs and Disability (SEND) Services last summer posed the challenge: Is there post-diagnostic support to meet demand? Work is being undertaken to achieve this.

In terms of next steps, a multi-agency review of Year 1 will be held on 26 January. As well as examining progress, the dynamics of implementation will also be considered – e.g. how well are we working together as partners?

The service intends to strengthen engagement with people who use services; refresh information available to parents and update the local offer.

The Chairman commented on the huge ambition that is evident, but queried whether there is sufficient capacity to deliver this? Jane Le Sage responded that she is confident the capacity exists. As mentioned, partners will be reviewing how they work together to ease implementation and to leave sufficient time to deliver the work.

Janet Probert felt that there had been tangible progress in the first year of implementation. In her CCG area, diagnostic recording is higher than the national average – the reason for this needed to be understood. Also, there is a need to pick up how people who fall between the system are dealt with. Kate Race advised that working with the Prevention Service to co-deliver parent training will introduce parents at an early stage as well as up-skilling staff and expanding training capacity.

Amanda Bloor referred to Safe Places being available for vulnerable people per se – not just people who experience autism. Richard Webb advised that Safe Places exist for anyone who may feel vulnerable. He would arrange for a list of these to be sent to Members of the Board.

Alex Bird, Chief Executive Officer, at Age UK, North Yorkshire, asked for further information about the holistic approach referred to. Kate Race advised that this is an all age Strategy, intended to help people through their lifespan. Health and Adult Services were looking at the supported employment element and training in learning is intended to help those who had gone through the education system but who had not received the right support.

In response to a question by Adele Coulthard, Jane Le Sage advised that a piece of work is currently being undertaken regarding the issues of people with high levels of need.

The Chairman commented that the County Council was the first Local Authority to have all its provider services accredited by the National Autistic Society, which demonstrated the raised awareness. She considered that the Board could feel comforted by the excellent work being undertaken in this area and asked for a further update in one year.

Resolved -

a) That the report is noted and a further update be provided in one year.

b) That a list of Safe Places within North Yorkshire be circulated to Members of the Board.

203. Green Paper on Future Commissioning Arrangements

Considered -

The report of Michaela Pinchard, Head of Integration, outlining an approach to future joint/integrated commissioning arrangements in North Yorkshire and seeking the support of the Health and Wellbeing Board for further developing the approach.

Amanda Bloor, as co-sponsor with Richard Webb, introduced the report and highlighted the following:-

- This demonstrated a commitment from commissioners to work together to better use their collective capacity to commission more effectively at a North Yorkshire place-based level

- The key aims were to:

    - drive the transformation required to consistently improve outcomes for the people of North Yorkshire ;

    - establish a focus on supporting people to stay independent;

    - commission around place, prevention and wellbeing to better manage and reduce demand on the health economy; and

    - deliver financial sustainability in the longer term

- An ambitious timeline has been set as there is a desire to move forward.

Richard Webb said that the question being considered is what do we need to do locally and countywide? It made sense to work together. A Work Programme would be brought to a future meeting of the Board.

Janet Waggott commented that it is important for commissioners to find a way of keeping non-commissioners engaged in the process as this is proving difficult. Amanda Bloor responded that commissioners are alive to this issue and will be looking at how other groups/fora are utilised to make these links.

The Chairman stressed that it is important that the Board has oversight of this initiative. Amanda Bloor suggested that the proposals could be progressed via Local Transformation Boards and an update brought to the next meeting of the Board.

Resolved -

That the Health and Wellbeing Board:-

a) Supports the approach.
b) Notes and comments on the report.
c) Endorses the initial Action Pan at Appendix 2
d) Considers opportunities to improve engagement with partners and stakeholders as the approach develops
e) Agrees to receive progress update reports, commencing with an update on the joint work programme in March 2017.

204. Better Care Fund: Sign-off Arrangements for 2017-19 Plan

Considered -

The verbal update of the Assistant Director for Integration.

Amanda Reynolds advised that the Guidance from NHS England was awaited. The Plan would need to be signed off by the Board. If this can be completed in time for consideration by the Board at its next meeting on 17 March it will be. However, this might not be possible and, therefore, she suggested that the Board might want to delegate authority to sign off the Plan.

Resolved -

That if it is not possible to bring the Better Care Fund Plan for 2017-19 to the Board for approval, authority to sign off the Plan be delegated to the Chairman of the Board, the Chief Executive and the Director of Health and Adult Services at the County Council and CCG Chief Officers.

205. Joint Health and Wellbeing Strategy 2015/2020 - Performance Dashboard

Considered -

The report of the Assistant Director for Integration presenting the dashboard for the North Yorkshire Joint Health and Wellbeing Strategy 2015-2020, which was set out at Appendix 1 of report.

Michaela Pinchard presented the report and commented that, overall, the picture was one of improvement, with 10 of the 20 Indicators showing improvement. Notable exceptions include Non-Elective Admissions and Delayed Transfers of Care, which partners are well aware of and are taking action to address, both through their individual organisations and collectively, where appropriate.

Resolved -

That the report be noted.

206. Work Programme/Calendar of Meetings

Considered -

The Work Programme/Calendar of meetings for 2016/17.

The Chairman asked Members to note the dates for forthcoming meetings. Invitations will be sent out when the venues have been determined. If Members had any particular suggestions as to venues they should contact Patrick Duffy.

Resolved -

That the Work Programme be noted.

The meeting concluded at 3.55 p.m.

PD

Health and Wellbeing Board
North Yorkshire

Green Paper: Aspiring to make North Yorkshire's communities' carer friendly

17th March 2017

Presented by: Avril Hunter

Summary: **This draft strategy outlines the themes and actions for Health and Wellbeing Board members to support unpaid carers over the next period,**

Which of the themes and/or enablers in the North Yorkshire Joint Health & Wellbeing Strategy are addressed in this paper?

Themes	✓
Connected Communities	
Start Well	
Live Well	✓
Age Well	✓
Dying Well	
Enablers	
A new relationship with people using services	✓
Workforce	✓
Technology	
Economic Prosperity	

How does this paper fit with other strategies and plans in place in North Yorkshire?

- The strategy links with 'Hope, Choice and Control', North Yorkshire's Mental Health Strategy
- The strategy links with North Yorkshire Dementia Strategy, "Bring me Sunshine
- The strategy links with North Yorkshire's draft Learning disability strategy, "Live Well, Live Longer"

What do you want the Health & Wellbeing Board to do as a result of this paper?

- To provide comments and amendments to this Green Paper
- To approve this Green Paper to go out to consultation

NORTH YORKSHIRE COUNTY COUNCIL

REPORT PREPARED FOR
NORTH YORKSHIRE HEALTH AND WELLBEING BOARD
17TH MARCH 2017

GREEN PAPER FOR:
ASPIRING TO BE A CARER FRIENDLY COMMUNITY

1.0 PURPOSE OF REPORT

1.1 To provide the Health and Wellbeing Board with the Green Paper of the “Aspiring to be a carer friendly community”

2.0 CONTEXT AND BACKGROUND

2.1 North Yorkshire is home to around 65,000 people who have identified themselves as providing unpaid care in the 2011 Census. In reality the number is likely to be far higher than this, accounting for people who provide unpaid care but do not identify themselves as a carer. This accounts for over 10% of the overall population who give up their own time to support friends, families and loved ones who need help.

2.2 Local authorities and the NHS have a duty through the Care Act 2014 to support carers in their role. In addition Carers UK and the University of Sheffield report that nationally unpaid carers save the state £132 billion a year – close to the cost of a second NHS. In austere times it is imperative that unpaid carers are supported from a local level up to support their health and wellbeing and keep on caring.

2.3 The unpaid carers’ agenda in North Yorkshire was previously underpinned by the ‘North Yorkshire Carers Strategy 2012-2015’, a joint strategy developed by North Yorkshire County Council and the NHS in North Yorkshire.

2.4 The actions contained in the strategy above were taken forward or are now incorporated into this carers strategy. For example, a number of issues were taken forward through the commissioning of the carers advice and information service. This strategy for unpaid carers is intended to cover the period from 2017-22 and covers all ages.

3.0 ENGAGEMENT WITH CARERS SO FAR

3.1 Over the summer of 2016 an extensive programme of engagement with unpaid carers was undertaken. This included online feedback, face to face meetings and a ‘one question’ postcard which was available through carers centres and libraries across the County. Several user forums have also been attended to gather feedback including North Yorkshire Older Peoples Forum and North Yorkshire Parent Carers Together (NYPACT).

3.2 A small reference group of unpaid carers was also brought together to input into the development of the strategy and to provide a ‘sense check’ on the work undertaken by officers.

3.3 Over 200 responses were received from the engagement with a wider range of issues raised.

4.0 EMERGING THEMES

4.1 The responses to the engagement were reviewed by the Carers Strategy group and members of the reference group through a workshop. This exercise resulted in the responses being categorised under a number of themes, depending on their content.

4.2 The six most popular themes were put forward and agreed at the workshop, these were:
- Identifying Carers
- Information and Advice
- Giving Carers a Break
- Carer Health and Wellbeing
- Financial Wellbeing
- Carers Being More Involved in Care

4.3 These themes have formed the basis of the draft strategy. The draft strategy has been produced jointly by colleagues from North Yorkshire County Council Health and Adult Services, Children and Young Peoples Services and NHS Clinical Commissioning groups. Further input was received from the reference group, North Yorkshire Carers Centres, North Yorkshire Public Health team, NHS Tees Esk and Wear Valley Trust and a number of individual GP's.

5.0 NEXT STEPS

5.1 The Health and Wellbeing Board are asked to comment on the draft strategy and, subject to any amendments, agree for the draft strategy to go out to formal public consultation in May following the local government purdah period.

5.2 It is proposed that the formal public consultation take place for a period of six weeks from 15th May 2017 to 23rd June 2017. This period will encompass national Carers Week (w/c 12th June) which will be used a vehicle to promote the consultation.

5.3 During the period of consultation, it is intended that there is consideration of the strengthening of the health contributions to the text overall.

5.3 The results of the consultation will then be compiled and the strategy re-drafted to reflect the feedback received. It is proposed that a summary of the consultation results and an updated draft will then be presented to the Health and Wellbeing Board in July for final comment and approval. An official launch would then take place in Summer 2017.

5.4 As the formal consultation for this strategy and the Dementia strategy will be conterminous, officers are working together to ensure that the most effective methods are used to carry this out.

6.0 RECOMMENDATIONS

6.1 The Health and Wellbeing Board approve this green paper to go out to consultation, subject to any amendments and inclusions suggested by Board Members

Richard Webb, Corporate Director Health and Adult Services
County Hall, Northallerton

Report compiled by:
Avril Hunter– Locality Head of Commissioning
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Date: March 2017

Appendix Draft "Aspiring to be a carer friendly community"

Appendix

Health and Wellbeing Board
North Yorkshire

North Yorkshire Health and Wellbeing Board

Green Paper

Draft Carers Strategy 2017 – 2022
Supporting the health and wellbeing of unpaid carers in North Yorkshire

V12 2017.03.07

Aspiring to make North Yorkshire's communities' carer friendly

Contents

Foreword

To follow post consultation.

Introduction

Three in five people will be a carer at some point in their lives and almost everyone will know family members, friends and colleagues who are currently carers. Carers play a vital role in maintaining the health and wellbeing of those who need help. We know that most carers are happy to support the person they care for and want to be able to continue offering that support, but the caring role can often affect their own health and wellbeing.

Carers UK estimate that the value of unpaid care now stands at £132 billion, which is almost the equivalent to the annual spend on the NHS. The role that carers play in our communities is to be celebrated, but providing unpaid care can come at a great personal cost to those who sacrifice their own time, effort and money to become a carer.

This strategy reflects what unpaid cares have told us in North Yorkshire, along with other local and national evidence about the effects of being a carer. The strategy sets out the ways in which cares in North Yorkshire will be supported and how we can protect the health and wellbeing needs of carers alongside the needs of the people they care for.

The Care Act recognised that the mental and physical health and wellbeing of both carers, and those being cared, for should be considered equally. As a result local authorities now have a statutory duty to assess the impact of caring on a carer’s mental and physical health and wellbeing and to agree a support plan with the carer, to meet the carer’s needs. The Care Act Guidance recognises that the best way to meet a carer’s needs may be to provide care and support directly to the person that they care for, for example, by providing replacement care to allow the carer to take a break providing the person needing care agrees.

The vision of the Act is to actively promote wellbeing and quality of life, and not just wait to respond when people and their carers reach crisis point

Wellbeing includes:

- personal dignity;
- good physical and mental health;
- protection from abuse and neglect;

- control over day-to-day life;
- participation in work, education, training or recreation;
- social and economic security;
- domestic, family and personal relationships;
- suitability of living accommodation; and
- making a positive contribution to society.

It makes real sense that at a time when the NHS and local government have increasing financial pressures to continue to make sure that carers are supported and valued as partners and experts. Supporting carers helps to reduce the need for more formal services and it also helps families and vulnerable people to continue to live in the community as they would wish. Carers should be helped to maintain both their caring role and their own health and wellbeing, which at times will include having access to good alternative care and support for the people they care for when they need a break or are unable to provide care. But just as importantly we need to listen to carers and recognise the contributions they make and the skills and understanding they have.

We should also recognise that the ‘carer’s journey’ does not come to an abrupt finish when their caring role ends. Increasingly we hear from cares of the impact on a carer of the loss of the person they have cared for. A carer might well need support through the transition of adjusting to no longer being a carer; a role that may have been a big part of their life for many years.

Our vision

The North Yorkshire Health and Wellbeing Board has set out a vision that people in all communities in North Yorkshire have equal opportunities to live long, healthy lives.
For carers, this will mean that:

Carers themselves can live long and healthy lives and be able to continue to care as long as possible and as long as they would want to. Our vision also includes encouraging more carer friendly communities, and promoting carer issues across wider society.

How does it fit together?

The North Yorkshire Joint Health and Wellbeing Strategy 2015-20 sets out our ambitions in respect of five areas: Start Well, Live Well Age Well, Dying well and Connected Communities. All of the commitments within the strategy apply to carers, but there are specific outcomes that we want to achieve:

Carers have a life of their own (Living well)
All individuals, their carers and families experience good end of life care (Dying Well)

Other Health and Wellbeing Board strategies also recognise the role and importance of unpaid carers in North Yorkshire. These strategies specifically address autism, young people, learning disabilities, mental health, dementia, extra care/supported housing and end of life care. Carers have helped to shape these strategies and are seen as a key partners in addressing the challenges that face us in each of these areas A comprehensive list of these strategies and where to find them can be found in the further information section of this document.

The Carers Strategy as a separate strategy brings together the key messages from all carers about what matters to them *as carers* and sets out the ways in which we will specifically work to support our carers. The strategy will shape the specific 'carers offer' and it will also enable the delivery of the other strategies by setting out our commitment to carers.

On a national scale, the government has consulted on a review of the National Carers Strategy and is analysing the results. The revised strategy is due to be published in 2017. The government says that the national strategy needs to reflect carer's lives now, their health and financial concerns, and give them the support they need to live well while caring for a family member or friend. Some of the issues that are important to carers can only be considered at a national level, particularly in relation to national welfare benefits and changes to employment legislation. We will review the national strategy when it is published to see how it can help in North Yorkshire. Plans for the future of the NHS (Five Year Forward View) also emphasise and recognise the importance of unpaid carers.

Who are unpaid carers in North Yorkshire?

There are around 65,000 people in North Yorkshire across all age groups who identified themselves as providing unpaid care in the 2011 census, which is more than one in ten people. This is higher than the average both nationally and through the Yorkshire and Humber region. Only Richmondshire (9.2%) had a lower rate of identified unpaid carers than the national average. In reality there are likely to be many more people providing unpaid care, who either do not recognise themselves as a carer or do not wish to be recognised as a carer.

The number of people providing unpaid care has increased by almost 15% (8,250 people) since the 2001 Census compared with a 2.3% increase in the county's overall population. Almost one in four (24.3%, 15,538 people) of the female population aged 50-64 are providing unpaid care, which rises to 25% in Ryedale and 26.6% in Craven, compared with a national average of 23.5%.

Being an unpaid carer at different times of life can present different challenges. Over a quarter of carers in North Yorkshire are over the age of 65. There are also over 18,000 carers aged 25-49 and over 3,000 under the age of 25, including young carers under the age of 18. We are aware that many carers will also have their own care needs, and some to a level that means they may also require social care support in their own right.

In 2015/16 North Yorkshire the Carers Resource Centres, funded by the Council and the Clinical Commissioning Groups had over 1,800 referrals and supported over 1,200 new, previously unidentified adult carers. 476 young carers have also been supported through North Yorkshire Carers Centres.

In the same time period over 3,200 carers assessments have been undertaken on behalf of the County Council, to help adults look at the different ways caring affects their lives, and agree how their own needs will be met

What's the evidence of how caring affects health and wellbeing?

Our Public Health Team has undertaken a review of evidence on the impact of caring for the Joint Strategic Needs Assessment. It is clear that a caring role has significant impacts on the carer, in terms of their physical and mental health, relationships, ability to socialise and manage their finances. Across all ages of carers this includes the following examples:

- Carers report that they find it hard to look after their own health, doing less exercise and not eating a balanced diet because of their caring roles and responsibilities. When finances are tight, they will ensure that the cared for person gets enough food but the carer will ‘make do’.
- Health being affected by the need for hands-on care which is physically exhausting (especially for young people caring for adults).This is often combined with sleep deprivation, injury and strain.
- Carers can experience loneliness at work and say that colleagues do not understand the impacts of caring and that occasionally they cannot give work their full attention.
- Social isolation and impact on mental wellbeing.

The following examples show how caring affects young people in particular.

- Young carers can be reluctant to disclose that they are a carer due to the stigma associated with certain illnesses.
- They can experience bullying and poor behaviour at school because of their caring role.
- They are also are at risk of missing school trips, not completing homework and have poor school attendance. This impacts on the young person’s education attainment and in later years this can affect employment outcomes, lifetime career prospects and income.
- Emotional wellbeing: stress, tiredness and mental ill-health are common for young carers.
- Feeling different or isolated from their peers and with limited social opportunities.
- Lack of a stable environment: traumatic life changes such as bereavement, family break-up, losing income and housing, or seeing the effects of an illness or addiction.

What do unpaid carers in North Yorkshire tell us?

Over the summer of 2016, we asked members of the public to tell us what they thought the big issues affecting unpaid carers were. We did this through a widely publicised ‘one question’ postcard, online and by attending carers groups across the County to speak face to face. Over 200 responses were received and we talked to a wide range of carers of all ages about their experiences. In addition to this work, we have received feedback from carers who were consulted about the North Yorkshire Dementia Strategy and the new North Yorkshire County Council Care and Support Pathway.

> “I’d like a place within my community to take my daughter and myself that accepts us for who we are and can meet people of our age groups to talk to and have a cup of tea. This would make us feel included within the area, the isolation of North Yorkshire and villages and rural environment does not always allow this for people who are carers.”

The feedback from these conversations have given us rich picture of what matters to carers. From these messages we have identifies a number of themes that affect carers which have underpinned and shaped this strategy.

We got a clear message that carers do not see themselves as carers but as lifelong partners, sons, daughters, siblings, neighbours and friends. People do not resent being carers, but the commitment and social isolation can be overwhelming at times.

Identifying yourself as a carer can be a difficult process, especially for young carers, and even after this many found it hard to get the information they need at the right time for them.

We heard that carers do not think that they are valued by professionals as experts in care and are often excluded from important decisions and not kept informed. Carers were often frustrated that professionals did not seem to communicate with them and have to tell the same story over and over.

We heard how much carers valued being able to talk to people in a similar position to get things off their chest. Many carers told us how valuable they had found help from the local carers centres across North Yorkshire and other groups.

Carers of people with mental health problems who made comments as part of the mental health strategy development echoed the themes: a great many said that carers were undervalued, that they wanted better links with GP's, that it takes too long for carers to be recognised and that they should have a role in assessing the safety and quality of services offered to the person they care for.

What unpaid carers are saying nationally

National organisations that support carers are continuing to provide information about carers views across the UK.

The Carers UK State of Caring UK 2016 report says that "Without practical support with caring from health and care services, carers cannot get the time they need to look after their own health and maintain relationships with others. Replacement care for the person they support is essential in enabling carers to juggle work, study or have hobbies and interests alongside caring, or to manage care with other family responsibilities such as childcare."

"I would like to feel confident that my husband would be looked after if anything happened to me"

The Carers UK reports regarding 'Carers at Breaking Point' and "Caring and Family Finances Inquiry" also report that

- Six in ten felt they had been pushed to breaking point
- 46% said they had fallen ill but just had to continue caring.
- One in five carers were forced to give up their jobs because they were in crisis
- 61% of the carers said they had been in debt as a result of caring.

Views that carers have given in North Yorkshire reflect many of the issues being raised in national reports. Information about national carers organisations can be found in the further information section of the strategy.

Diversity of carers

What is very clear from talking to carers and their responses, is that carers are a diverse group who have a variety of different needs that depend on a range of factors including the needs of the cared for person, gender, age, as well as employment and family circumstances. It is clear from this information that good assessment of both the cared for person and the carer is critical if we are to support carers.

There are particular challenges faced by some groups, which are not mutually exclusive, including the following examples:

- Young carers are children and young people under 18 who provide unpaid care to a family member who is physically or mentally ill, disabled or misuses substances. Being a young carer means balancing the caring role with education, which may lead to anxiety and stress. It can also affect young people's health, social life and self-confidence. The tasks and level of caring undertaken by young carers can vary according to the nature of the illness or disability and the structure of the family as a whole.

- Young adult carers are aged between 16 and 25. They usually face similar challenges to young carers, but are at an important time of life in terms of school progression, further education, career decisions and taking on the responsibilities of becoming an adult. There are also difficult decisions about leaving the person they are caring for or dealing with bereavement at an early age.
- Parent carers are defined by Carers UK as someone who is over 18 who provides care to a disabled child for whom they have parental responsibility. Parent carers are likely to be carers for a longer time period then others and often have to plan long term for how to balance their caring role with their life outside of caring.
- Working age carers are those who carry out a caring role and are of working age. The main challenges for working age carers is gaining and maintaining employment and being able to strike a balance between the caring role and life outside the caring role.
- Older carers are those individuals who have a caring role into their older age. Older carers often provide long hours of care and support, but can be at additional risk of doing this to the detriment of their own health and wellbeing. Older carers can also need additional support with more demanding and physical tasks.
- 'Sandwich carers or 'dual' carers have a caring role for more than one person, often of different generations. The term can also be applied to carers who are caring for someone but also have additional responsibilities, such as having a child. Juggling two caring roles can be overwhelming, even before consideration is given to life outside the caring role. It is therefore even more important that the right support is provided to make sure the carer can maintain their role.
- Carers of people with mental health or substance misuse - who are less likely to identify themselves or to be identified as carers
- Short term carers take up their role over a short time period for reasons such as illness and may have less time and experience to adjust to becoming a carer
- Lesbian, gay, bisexual and transgender carers reported a feeling of 'double isolation' – this being the usual feelings of isolation due to the fact they are a carer, but also because they need to talk to someone openly about the issues that are important because they are lesbian or gay.
- Carers from the gypsy, roma, traveller and showpeople (GRTS) communities - who are much less likely to access health and social care services.
- Carers from black, Asian and minority ethnic (BAME) communities - Language barriers and cultural traditions will impact on whether people see themselves as carers and able to seek support or whether it is seen as part of family responsibilities.
- Carers of people with HIV/AIDS, who can be reluctant to disclose that they are a carer due to the stigma associated with HIV/AIDS.

North Yorkshire County Council's vision is for people in North Yorkshire to have every opportunity to live longer, healthier, independent lives: "We will make sure that support is centred on the needs of people and their carers, allowing them to take control of their health and independence and we will work to keep vulnerable people safe, with individuals, organisations and communities all playing their part". With programmes such as Stronger Communities, North Yorkshire County Council is investing in helping communities and individuals build resilience and find local support.

As part of this, the Council is well on its way to transforming social care services in North Yorkshire, by developing and strengthening services, such as the Living Well Team and the Children and Families Prevention Service, to help people remain independent and prevent them from requiring more formal care services. The way assessment, review and support planning is done is also changing to support people to stay independent for longer in their own homes. Future assessments and reviews will look at solutions involving friends, family and the wider community and will maximise every opportunity for people and carers to remain or become more independent, or achieve their outcomes through creative care and support planning where appropriate.

Across North Yorkshire work is under way to link our health and social care services for adults. This may differ from area to area, but increasingly we will see adult social care staff working alongside GP's, community and primary health services. This will aim to make services more joined up and easier for carers to understand.

Case Study

When Scarborough & Ryedale Carers Resource first received a referral for Penny she was 14 years old and living with her mother. They had fled domestic violence and were living in unsuitable temporary accommodation. Penny's mother has complex physical and mental health needs and Penny is her primary carer. They had no family and no friends to help support them. Penny's older brother had also moved north with them but he had mental health issues and had wrecked the room on a number of occasions so was no longer living with them. He was staying in a flat locally and needed their support daily. Penny had not attended full time school for two years and was awaiting an assessment about her education. She did go into a local school for a day but struggled to cope. She had and still has some mental health issues of her own. Her mother and she are very close, spending all their time together and even sharing the same bed. Penny believed that if she doesn't look after Mum then nobody else will. At the time Penny felt that everyone else has or will let them down.

This was the situation when the Young Carer Service began to support the family. They provided one to one contacts as well as small targeted group sessions for Penny and supported her within a range of professional meetings. The team have been part of a multi-agency support system to getting appropriate housing for the family. They helped to arrange for specialist advice on moving and handling for Penny and supported her to formulate an emergency contact plan for when Mum is ill. Penny now feels safe during times that her mother is in hospital. We arranged for dental care and GP appointments for Penny so that she could start focusing on her own health and wellbeing.

The team encouraged her self-confidence and she attended activities, workshops and a residential trip. Penny had support to process a funding application and help with decorating her own bedroom to give her personal space. They also encouraged Penny to apply for a local College course, helped her get to the interview and took her there on her first day. The team supported Penny to apply for a computer and printer for her personal use. This was successful and has helped Penny to be able to complete her coursework.

Penny's mum was referred to the Scarborough & Ryedale Carers Resource in her role as carer for Penny's brother and was given help to apply for the appropriate benefits. We also helped mum find a new source of support through the MIND befriending service. By taking Penny shopping for essentials such as food and clothing the team encouraged her to think about value for money as well as budgeting skills and helped Penny take responsibility for her own future and financial security.

The themes and priorities for improvement

The six themes that have come through clearly when talking to carers and organisations who are supporting our carers are in line with themes that have been identified nationally:

- Improving identification of carers
- Improving information and advice
- Enabling carers to take a break
- Improving carers health and wellbeing
- Enhancing financial wellbeing
- Involving carers as experts

The following sets out our objectives for each of these themes. In addition to these area we will commit to take into account what carers see as important to them to continue their caring role when redesigning or delivering services.

Identifying carers

> "I would like to see help for people to recognise themselves as carers, because often they just see themselves as being neighbourly or family"

One of the most important steps for unpaid carers in accessing support is being able to identify themselves as a carer. This is not always easy as many carers do not like to ask for help for a number of reasons. For some they do not want to feel like they are losing control, or that they might be judged. Some carers worry that safeguarding workers may become involved if they say they need help or that the person will be taken out of their care. Many also see themselves not as a carer, but as fulfilling a family duty. This makes it difficult to get services to carers that can help them in their role. Carers are less likely to identify themselves or to be identified as carers if they are caring for someone with mental health or substance abuse issues rather than physical health conditions or illnesses.

What happens now?

- Carer's Centres are currently commissioned across North Yorkshire to actively identify new carers in the community.
- North Yorkshire County Council currently identify carers through social care and through schools.
- In some areas carers are identified through NHS settings such as GPs.

To increase awareness of unpaid carers of all ages and help carers access support services, we will:

- Explore how we can effectively identify carers, particularly in hospitals, schools and GP practices and point carers in the right direction for support.
- Make it easier for people to identify themselves as carers, especially those who may not come into contact with health or local authority organisations and those caring for people with mental health or substance misuses issues
- Increase awareness of carers across communities and wider society
- Encourage communities and organisations to become more 'carer friendly'.
- Make it easier for carers for people with mental health or substance abuse issues to identify

Information and advice

> "I'd like to explain to people (public) that saying you are a carer can bring benefits and doesn't necessarily mean that you'll get bombarded with a whole menu of officialdom. Ie. That you can just get information, advice and guidance"

A vital part of being able to help carers in their role is by ensuring they have the right information and advice at the right time. This can be crucial in building a support mechanism to help a carer in their role. When we spoke to carers about what they thought the biggest issues around caring are, the most common response was regarding the availability of information. In addition, the North Yorkshire 'Survey of Adult Carers' 2014/15, showed that 92% of respondents had used information and guidance services during the previous 12 months. This shows that information and advice plays a large role in being able to maintain a caring role

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What happens now?

- Carers Centres, alongside a number of other voluntary organisations, are currently commissioned across North Yorkshire to provide information and advice for adult carers.
- Some carer's centres and Action for Children are currently commissioned across North Yorkshire to provide information and advice for young carers and schools.
- North Yorkshire County Council currently provide information to carers through the customer service centre and assessment process.

- North Yorkshire PACT (a collective voice for parents of children with disabilities and additional needs) support parents and carers by helping them find relevant information about what support is available for their children and how to access this support.
- NHS provide information and advice in a variety of ways, for example GP practices may have their own Carer's policy, and try to identify Carers

In order to help improve information and advice for carers of all ages, we will:

- Think creatively and find new ways to interact with carers.
- Work better together to more effectively get information and advice to carers.
- Make sure we use a 'whole family approach' and use carers as the experts.
- Get the right information to carers at the right time in the right formats and not overwhelming them at the most stressful times.
- Give the same level of information and advice to carers who fund their own care.
- Continue to support carers services to give information and advice to all carers.
- Adopt a proactive approach to supporting carers to plan for the future

Giving carers a break

To help unpaid carers of all ages in maintaining a life of their own outside their caring role, it is important that there are options for them to be able to take a break from caring. When we spoke to carers about what they thought the biggest issues around caring are, the second most common response was regarding the ability to have a break from their caring role. By taking a break, it allows carers to recharge their batteries and help build up long term resilience. However, carers want to be sure that the cared for person is safe and supported. It is essential therefore that we have a range of options to support the cared for person and always take into account the carers needs when agreeing support plans for people

What happens now?

- We have a mixed offer for both carers and those they care for. Some services are currently offered as 'carers services' and some for the cared for person
- 'Carers sitting services' provide short breaks for adult carers in some areas of the County on a volunteer basis.
- North Yorkshire County Council provide and commission a range of short breaks in short stay centres, day services and care homes as part of support plans for cared for people
- North Yorkshire County Council can offer a direct payment which some carers choose to use to take short breaks
- A wide range of carer groups have been established in most areas of the County to give carers and cared for people a place to meet and speak with other carers
- Parent/carers of severely disabled children receive support and short breaks through the Disabled Children and Young People's Service. This could include services in the community, in families own homes and in day or overnight settings.

In order to improve the offer of giving carers a break, we will aim to:

- Review the way we undertake assessments for both carers and those they care for to ensure that where a carer needs help to take a break this is included in the support plan for the person they care for.
- Review the best way to give carers greater choice in the way they use carers personal budgets
- Review our carers sitting services to ensure these work well in conjunction with carers personal budgets
- Promote and raise awareness of what break options are available for adult carers.

- Promote the development of ways that all carers can get information and support from each other.

Carer health and wellbeing

It is essential for carers to maintain their own health and wellbeing in order for them to be able to continue in their caring role and to be able to do this to the best of their ability.

> "I don't like to have to ask friends for help all the time and many of my friends have died."

What happens now?

- Carers Centres and other voluntary organisations provide emotional support to carers on the phone or face to face if appropriate.
- A review of the needs of the cared for person should take place if carers are finding their caring role is putting their health or wellbeing at risk
- Carer groups have been established in some areas of the County to give carers and cared for people a place to meet and speak with other carers.
- Carers can access the universal mental health services such as IAPT and the CYPS Prevention Service.
- Over 3,200 adults have a Carers Emergency Card to help provide additional peace of mind by identifying carers as having a cared for person, should anything happen to them
- Carers Centres and North Yorkshire County Council undertake carers assessments with carers to help identify support that could be provided to assist the carer in their role
- Carers who have been assessed as eligible for a one-off personal budget in the form of a Carers Support Grant from North Yorkshire County Council to help them to pay for things which will help them in their caring role
- GP practices may offer flu jabs and health checks to carers, as well as signposting to Carer's Centres.

In order to improve the wellbeing of unpaid carers, we will aim to:

- Continue to highlight the importance and requirement for emotional support for carers.
- See how we can promote carers being able to support each other through groups, one to one contact and online.
- Raise awareness of the mental health of carers.
- Improve the range of places for carers to go where they feel safe and supported.
- North Yorkshire County Council will ensure that all carers have a keyworker if they have had an assessment
- Provide the right support for carers through end of life care and bereavement.
- Support carers to look at plans for emergencies and introduce a Carers Emergency Card for young carers.
- Give further consideration to wider issues of living in North Yorkshire that impact carers such as transport and accessing services.
- Encourage healthcare providers including GPs to recognise the effect caring can have on a carers mental and physical health.
- Review the best way to give carers greater choice in the way they use carers personal budgets

Financial wellbeing

Becoming an unpaid carer often means that financial circumstances can change. When we spoke to carers about what they thought the biggest issues around caring are, many responses revolved around finances, funding for carers and maintaining employment with the caring role. It is important that being an unpaid adult carer does not become a financial hardship and that they are aware of the assistance that is out there if required.

What happens now?

- Carers Centres work with local employers to raise awareness of carers in the workplace and how they can support them to stay at work.
- North Yorkshire County Council's supported employment service can provide help for carers who need support to continue working and caring.
- The NYCC income maximisation team support carers as part of their role to develop financial resilience in North Yorkshire.

In order to help prevent unpaid adult carers being forced into financial hardship as a result of their role, we will aim to:

- Maintain the principle that the caring role should not become a financial hardship.
- Raise awareness of the challenges carers in the workplace face and support employers to promote carer friendly policies.
- Provide the right support and information to support carers stay in employment or return to employment
- Encourage people to plan ahead for example through setting up power of attorney, living wills
- Ensure advice on how to maximise income continues to be available along with help filling in relevant paperwork.

Case Study

The CReate project at Carers' Resource, Harrogate and Craven empowers carers to find and stay in paid employment alongside their caring role. Specialist advisers support carers through workshops and advice sessions to develop skills, think creatively about their caring role and advise on their employment rights. They work closely with employers to support them in developing a carer-positive working environment, through recognising the contribution of carers on their workforce and introducing carer friendly working practices. They also work with carers supporting them into employment or self employment.

CReate has worked closely with Skipton Building Society, one of the Craven district's largest employers, over the last ten years. This positive relationship has culminated in the development and launch by Skipton Building Society of their new Carer Policy, supported by Carers' Resource. Carers' Resource has worked with managers to strengthen carer awareness throughout the organisation and has provided independent work-based support to carers working for the building society through workplace drop ins and one to one advice sessions.

Carers being more involved in care

Carers have told us that they do not feel they are recognised as experts, and are not included in important decisions about diagnosis and treatment for the person they care for. It is important that we acknowledge the role and knowledge of carers in both health and social care settings. Carers should be valued and wherever possible their views listened to and reflected in any plans made.

> "I would like a carers supporter in my GP surgery. I do not know if GP's fully understand you can have physical symptoms caused by the stress of caring"

What happens now?

- There are some good examples of involving carers in decision making in both health and social care settings.

- North Yorkshire PACT act as a collective voice for parents of children with disabilities and additional needs, supporting parents and carers by helping them find relevant information about what support is available for their children and how to access this support.

In order to make sure carers are included appropriately in the important decisions about the person they care for, we will:

- Support informal carers to develop new skills and techniques, for example through reablement or positive behaviour support training for family carers of those with more complex needs and whose behaviour can be challenging
- Continue to work with, and provide support to North Yorkshire PACT to understand the issues that are effecting parent carers.
- Extend staff training in Triangle of Care to include carers as partners and treat them with respect
- Provide staff training in how to effectively engage with carers. The experience of carers will be included in all relevant training.
- Clinical Commissioning Groups will promote carers involvement throughout the treatment of the cared-for person by GPs and hospitals
- Involve carers in service redesign and commissioning
- Ensure that GP's have a system for agreeing and recording who patients are happy to share information with so that carers do not experience difficulties communicating with professionals

Our key commitments for 2017 – 2019

As well as taking into account all the aims set out above in strategies and redesigning services, Health and Wellbeing Board partners are committed to focussing on the following twelve actions for the next two years. An action plan will be produced to show progress against these commitments which will be brought back to the board on an annual basis.

- We will commit to improving how carers are involved in the co-production and co-design of services at all levels including the way that young carers are involved.
- We will make sure that carers feel more informed and involved in the treatment of the person they care for.
- We will make sure that the Care Act principles for personal budgets are embedded in the adult carer offer from North Yorkshire County Council.
- We will work with employers to raise awareness of flexible working polices to help carers combine their caring role with paid employment.
- We will help carers take a break from caring
- We will make it easier for carers to get the right information they need at the right times for them.
- We will listen to what carers say is important to them and look at solutions involving solutions involving friends, family and the wider community when undertaking carers assessments
- We will work with schools to raise awareness of flexible policies to help carers thrive and be successful in their school.
- We will encourage schools to participate in the Young Carers in Schools Award scheme.
- We will ensure all young carers have been assessed using our comprehensive North Yorkshire Assessment and use the Signs of Safety model.
- We will support schools to recognise young carers and offer additional support as appropriate.
- The Disabled Children and Young People's Service will assess the needs of disabled children and their parent/carers to ensure they receive the right level of support and short breaks to support and sustain their parenting role.

How will we measure success?

The progress on these commitments will be primarily measured in a number of different ways.

- Through the progress on the action plan which will be reported to the Health and Wellbeing Board on a regular basis
- Monitoring of key performance indicators from each partner on the Health and Wellbeing Board, such as:
    - Numbers of new carers identified (including those from harder to reach groups)
    - Number of carers referred to appropriate services
    - Number of services provided to carers
    - Number of carers assessments and reviews carried out
- Monitoring of feedback from the Survey of Adult Carers in England (SACE)
- Monitoring the outcomes of people accessing the carers sitting services and carers information services
- Monitoring the outcomes of carers accessing other carer services including Living Well service

Annexes and Further Information

North Yorkshire carer centres

Further Information and Contact Details Available at www.northyorks.gov.uk/carers

- Carers Resource (Adult Carers Only) – Harrogate and Craven Districts
- Hambleton & Richmondshire Carers Centre – Hambleton and Richmondshire Districts
- Scarborough & Ryedale Carers Resource – Ryedale and Scarborough Districts
- Carers Count (Adult Carers Only) – Selby District
- Action For Children (Young Carers Only) – Harrogate, Craven and Selby Districts

Related Strategies

- North Yorkshire Autism Strategy
- Care and Support Where I Live
- North Yorkshire Mental Health Strategy
- North Yorkshire Dementia Strategy
- Young and Yorkshire
- Live Well, Live Longer - Learning Disability strategy
- Five Year Forward View – NHS England
- North Yorkshire 2020

National Information

- National Carers Strategy
- Carers UK
- Carers Resource
- Care Act

Local Information

- Census Data
- North Yorkshire Carers Health and Wellbeing Evidence Review
- North Yorkshire PACT
- More detailed feedback from those who we consulted

Health and Wellbeing Board
North Yorkshire

Green Paper: Bring Me Sunshine – Living Well with Dementia in North Yorkshire

17th March 2017

Presented by: Mike Rudd – Head of Commissioning, Services for Older People

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Summary: The draft strategy sets out the current position of dementia need and service provision in North Yorkshire and establishes a set of guiding principles and priorities for the strategy partners to deliver over the lifetime of the strategy.

Which of the themes and/or enablers in the North Yorkshire Joint Health & Wellbeing Strategy are addressed in this paper?

Themes	✓
Connected Communities	
Start Well	
Live Well	✓
Age Well	✓
Dying Well	✓
Enablers	
A new relationship with people using services	✓
Workforce	✓
Technology	
Economic Prosperity	✓

How does this paper fit with other strategies and plans in place in North Yorkshire?

- The strategy links with 'Hope, Choice and Control', North Yorkshire's Mental Health Strategy
- The strategy links with 'Aspiring to be a Carer Friendly Community', North Yorkshire's draft Carer's Strategy
- The strategy links with North Yorkshire's draft Learning disability strategy

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What do you want the Health & Wellbeing Board to do as a result of this paper?

- Note distance travelled and wealth of information available
- Agree the 4 Key Principles and 5 Priorities
- Agree that the document be released for public consultation following purdah, on or around Monday 8th May 2017.

North Yorkshire County Council

Health and Adult Services Directorate

Report Prepared for North Yorkshire Health and Wellbeing Board

17 March 2017

North Yorkshire Dementia Strategy

1.0 Purpose of Report

1.1 To provide the Health and Wellbeing Board with the draft North Yorkshire Dementia Strategy for comment and discussion prior to release for public consultation.

2.0 Context

2.1 The previous North Yorkshire Dementia Strategy expired in 2013. This draft strategy looks to define the future strategic direction for all partners when supporting people living with dementia and their carers.

2.2 It is estimated that 10,000 people in North Yorkshire are living with dementia, whilst only 5,800 of these have a formal diagnosis. The number of people living with dementia is set to almost double by 2030.

2.3 With this expected increase it is vital that health, social care and other statutory and voluntary organisations work together to develop solutions that support people to live well and stay independent for as long as possible, whilst also developing the more specialist and acute services that people will need as their dementia progresses.

2.4 The draft strategy aims to bring together thinking across health and social care to agree a joint set of principles and priorities for action in the coming years.

3.0 Content and Style

3.1 The strategy is written for people living with dementia and their carers whilst also being useful and informative for professionals. The style is intended to be clear, concise and free from jargon wherever possible.

3.2 The strategy looks to set out the context of dementia across North Yorkshire, drawing in relevant facts and figures along with descriptions of services and need from across the county.

3.3 It is important to stress that whilst we can and must do better, dementia support is well developed in North Yorkshire and the strategy takes the time to acknowledge some of the excellent work being done across health, social care and the voluntary and community sectors.

3.4 The core of the strategy sets out, in the first person, the responses to the engagement exercise. These are the actual words of people living with dementia and their carers which gives key areas that people want us to focus on.

3.5 Throughout the strategy we have attempted to use ‘we’ as the voice of people who have contributed to the document. The strength of feeling conveyed through the engagement process was such that we felt it important to put the people at the very heart of the strategy by using their voices directly.

3.6 The final section of the strategy sets out the 4 key principles and 5 priorities with associated actions which will form the basis of work for the strategy partners and others through the lifetime of the strategy.

3.7 Part of 2016 Dementia Congress was an artwork exhibition at which people living with dementia could submit pieces of artwork they had created. It is intended that some of this artwork will be used as part of the graphic design for the final strategy document to bring it to life and again place people living with dementia at the heart of the document. A sample of this artwork is attached as an appendix.

3.8 It should also be noted that whilst the draft strategy is submitted as a single Word document, the final strategy will be designed as a more visual and appealing piece. In particular the lists of statistics and facts laid out between pages 8 – 13 will be replaced with infographics and diagrams in a style similar to the North Yorkshire Mental Health Strategy.

4.0 Engagement

4.1 In partnership with the Alzheimer's Society, Dementia Forward and Making Space NYCC and the PCU have consulted with over 1100 people living with dementia and their carers as part of the development of the strategy.

4.2 Consultation was undertaken in a variety of setting including face to face, online and over the phone. The consultation focussed on going to where people already are, including support groups, drop ins and carers events. This approach has been highly successful in securing rich, detailed accounts from people living with dementia and their carers.

4.3 This level of effective consultation would not have been possible without the assistance of the Alzheimer's Society, Dementia Forward and Making Space, their energy and willingness to support the development of the strategy has been invaluable throughout the process.

4.4 The 2016 dementia Congress, entitled 'Bring Me Sunshine' brought together people living with dementia and their carers with health and social care professionals for a day of speakers and workshops around the theme of living well with dementia. This event included several facilitated discussions around the key themes of the strategy the results of which are included in the draft document.

5.0 Priorities and Principles

5.1 In order to begin successfully delivering the strategy the document contains 4 key principles and 5 priorities for delivery. The full set of Principles and Priorities can be viewed on Page 4 of this report.

5.2 These principles and priorities are the end result of the extensive consultation with people and professional and we believe that the successful implementation of the strategy would lead to a strong positive improvement in the health and wellbeing of people living with dementia and their carers in North Yorkshire.

5.3 The 4 key Principles will run through everything that we do when working with people living with dementia and their carers. These are high level principles, articulated by people during the consultation as areas they felt were important at all times and in all places.

5.4 Beneath these principles are 5 Priority areas identified in the consultation with associated commitments which will shape the work of the partners over the lifetime of the strategy. These priorities refer to specific services and areas for development and as such will inform specific actions.

6.0 Consultation and Implementation

6.1 As the formal consultation for this strategy and the Carer's strategy will be conterminous, officers are working together to ensure that the most effective methods are used to carry this out.

6.2 Following formal consultation it is proposed that the strategy will be delivered on a locality basis, drawing in local people living with dementia and their carers, interested professionals and the strategy partners.

6.3 This local approach will allow the strategy to support and enhance the services and support currently in place, and will acknowledge that a one size fits all approach will not work in a place as large and diverse as North Yorkshire.

6.4 Locality strategy groups will develop detailed implementation plans with local meaning and insight, this will be supported and developed by NYCC and the relevant local CCG, with oversight from a countywide implementation board reporting to the Health and Wellbeing Board.

7.0 Recommendations

7.1 The Health and wellbeing Board note the information included within the draft strategy, particularly the level of engagement and enthusiasm from the public and professionals on this subject.

7.2 The Health and Wellbeing Board agree to the draft strategy being released for public consultation following purdah, on or around Monday 8th May 2017.

Mike Rudd, Head of Commissioning, Services for Older People, NYCC

County Hall, Northallerton

Report compiled by:

Adrienne Lucas – Commissioning Manager

Stacey Annandale – Commissioning Officer

Principle 1:
I am Me
I am not dementia
I have a name and I expect it to be used

Principle 2:
Carers Matter
Treat them as well as they treat us

Principle 3:
The Small Things
Small acts of understanding can make a huge difference

Principle4:
Consistency
Where I live shouldn't determine how I am treated

Priority 1: Dementia Friendly North Yorkshire

We will:

- work with local government, businesses and communities to promote dementia friendly communities across North Yorkshire
- develop a schools' dementia awareness programme to create a 'dementia friendly generation'
- work with employers to emphasise the importance of supporting and valuing carers of people living with dementia in employment
- support local Dementia Action Alliances and Collaboratives to make communities accessible and welcoming to people living with dementia and their carers
- develop and deliver accommodation options for people living with dementia and their carers

Outcomes

1. People living with dementia and their carers feel accepted, supported and understood in their communities
2. Support for people living with dementia and their carers is embedded in our communities
3. Improved public understanding of dementia

Priority 2: Workforce Development

We will:

- work to improve the experience and impact of living with dementia amongst health and social care professionals
- review the training and development offer to independent sector care staff and work with providers to assess training and development needs
- ensure that all signatories to this strategy work to become dementia friendly organisations and aspire to all public facing staff undertaking dementia friends training
- support individuals and groups who wish to challenge examples of bad practice
- ensure health and social care professionals are aware of and trained in the importance of carers and the specific challenges carers of people living with dementia can face

Outcomes

1. Greater awareness of living with dementia amongst health and social care professionals
2. People are treated as individuals rather than a person with dementia
3. People will experience a more personalised and coordinated health and social care system

Priority 3 Diagnosis

We will:

- work to ensure that the diagnosis process is clear and transparent to people and involves no more professionals or appointments than necessary
- work towards a target of everyone receiving timely formal diagnosis
- work with professionals to ensure that a diagnosis is delivered in a suitable way that recognises the impact on the person and their carer and that full follow up support is offered
- ensure that everyone who wishes to be is referred on to our dementia support services
- ensure that carers are offered support and advice relevant to their needs and are supported through the diagnosis process

Outcomes

1. More timely and effective diagnosis routes
2. More effective and consistent post diagnostic referrals
3. A better experience both practically and emotionally of the diagnosis process

Priority 4 Support and Advice

We will:

- create simple points of access for information for people living with dementia and their carers in North Yorkshire including improved access to peer support
- review our current information and advice offer to people, look at ways of improving what already exists and where there is scope for a more innovative approach
- monitor and share the progress of new technology and the ways it could support people living with dementia and their carers
- ensure dedicated Dementia Support Services for people living with dementia and their carers from diagnosis through to bereavement
- develop support specifically for people living with young onset dementia and their families

Outcomes

1. Clearer, more accessible information, advice and guidance produced with people living with dementia and their carers
2. Greater access to peer support and learning
3. Adoption of new approaches where technology advances

Priority 5 Planning for the Future and Dying Well

We will:

- develop training and awareness around the importance of planning for the future and having open discussions around people's wishes and fears
- improve and promote information advice and guidance to enable people to make early and informed decisions around mental capacity, planning for the future and end of life care
- work to challenge the social and professional stigma and nervousness around death and dying
- continue to support bereaved carers to ensure they have the physical, emotional and social support they need

Outcomes

1. Improved access to knowledgeable professional support
2. Clearer information around what to expect and how to plan
3. Better support for bereaved carers

Artwork Examples

DRAFT

‘Bring Me Sunshine’
Living Well With Dementia in North Yorkshire

Contents

Introduction/foreword

To be included on completion of final draft document.

Signatory page

Purpose and scope of the North Yorkshire vision for dementia support

This strategy brings together the experiences of those of us living with dementia and our carers, along with a wealth of health and social care expertise and best practice from both North Yorkshire and beyond to describe a collective ambition for dementia support over the next five years.

This approach centres on our experiences as the people living with dementia and our carers and it is our stories which have informed every aspect of this document.

It has only been possible through the significant input from the Alzheimer's Society, Dementia Forward and Making Space, all of whom have been part of the editorial group and who have been able to involve people living with dementia in the development of the strategy.

In particular they led in the planning and delivery of a hugely valuable and uplifting Dementia Congress, in October 2016, with people living with dementia and their carers. The name of this Strategy is derived from that Congress, 'Bring Me Sunshine' was the title of the conference – suggested by one of the dementia singing groups, as one the songs that they love. It symbolises the message that although living with dementia brings many challenges, it does not automatically have to stop people enjoying life.

Alongside the messages about what matters to people living with dementia, we have set out to describe the current position in terms of the numbers of us currently living with dementia, along with other useful but less well known information about people living with young onset dementia and people living with dementia and a learning disability.

The main focus of the document, however, is the rich information gathered through extensive engagement with over 1200 people and the key priorities that this has allowed us to develop.

These principles and priorities will shape the approach to dementia in North Yorkshire through the lifetime of the strategy. We will aim for a clearer, simpler and more person centred system of support and information for people living with dementia and their carers.
All partners are committed to the delivery of the 4 Principles and 5 Key Outcomes outlined on Page 39

What's the Picture?

N.B. This section will be presented as infographics, as such the statistics may not flow as would be the case if they were to be presented as block text.

Current population estimates are forecasting significant increases in the numbers of people living with dementia

- Of the 700,000 people believed to be living in England with dementia only 419,000 have received a diagnosis.
- 10,000 people are estimated to be living with dementia in North Yorkshire but only 5,793 people have actually been diagnosed.
- By 2025 13,573 people are expected to be living with dementia, in North Yorkshire
- Public Health England estimates that approximately a third of dementia cases might be in part caused by preventable factors such as diet.

In addition we know that:

Over 65,000 people in North Yorkshire identified themselves as carers at the last census. In North Yorkshire in 2015/16 the Carers Resource Centres, funded by the Council and the Clinical Commissioning Groups had over 1,800 referrals. In the same time period over 3,200 carers assessments have been undertaken on behalf of the County Council, to help adults look at the different ways caring affects their lives, and agree how their own needs will supported.

- 16.9% of the population in North Yorkshire live in areas which are defined as “super sparse” (fewer than 50 person/km). The issues of living in a rural area and access can increase people’s feelings of social isolation and has an impact on commissioning and provision of support.

Most people living with dementia are likely to be older people, with 1 in 4 people over 85 at risk of the conditions that cause dementia.

There are other groups of people also experiencing memory loss and other difficulties caused by dementia, with young onset (aged 64 or under) and people with a learning disability as two groups that are often overlooked.

Young Onset Dementia

- It is difficult to know the exact number of people who were originally diagnosed under the age of 65, because of the way data is currently collected. Only those still under the age of 65 are recorded as ‘young onset’.
- In the UK, in 2014 there were over 40,000 people aged 64 and under recorded as living with dementia. Around 4% of people with Alzheimer’s disease are under 65.
- In North Yorkshire, based on these figures it is currently estimated that 173 people are living with early onset dementia[1].

Specific issues for people with young onset dementia include:

  - Having to leave work due to illness or to be a carer for a loved one, people of working age can lose their income,
  - Benefits are different to those over 65 years and may affect income
  - Younger adults may have children who still need support, so any loss of income may be difficult and may lead to challenges for childcare.

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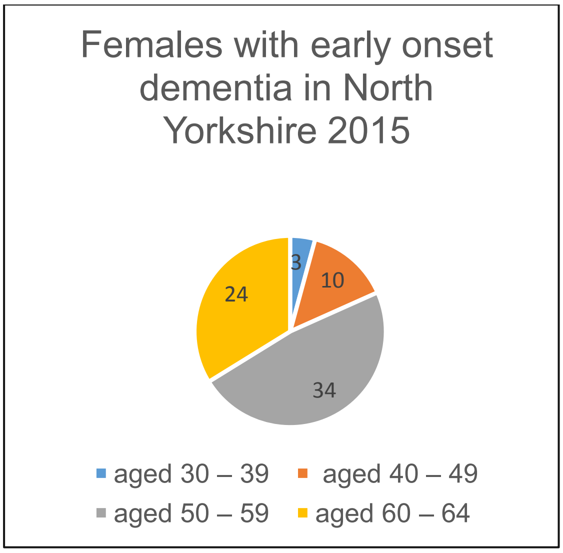
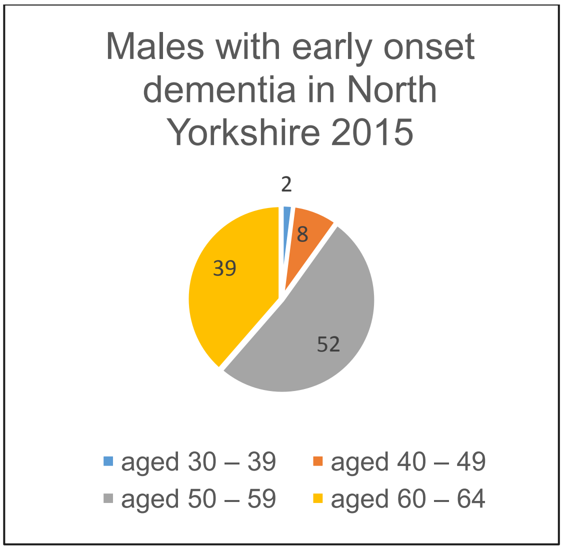
[1] http://www.pansi.org.uk/index.php?pageNo=408&areaID=8640&loc=8640





People with Learning disabilities

- People with learning disabilities, particularly those with Down's syndrome, are at increased risk of developing dementia.
- Studies indicate 1 in 10 people aged 50 to 65 with learning disabilities other than Down's syndrome have dementia.
- It is estimated that 1 in 50 people with Down's syndrome develop dementia in their 30s, this rises to more than half by age 60+. It is likely to develop at a younger age than the general population.
- People with learning disabilities often show different symptoms in the early stages of dementia and are more likely to have other physical health conditions which are not always well managed.
- People with a learning disability are less likely to receive a correct or early diagnosis of dementia.
- People with learning disabilities may experience a more rapid progression of dementia and will need specific support to understand the changes they are experiencing and to access appropriate services.
- People with Down's syndrome are at increased risk of developing Alzheimer's and it is more likely to develop at an earlier age.

Living with dementia and other health conditions

- 70% of people with dementia are living with at least one other long-term health condition.[2]

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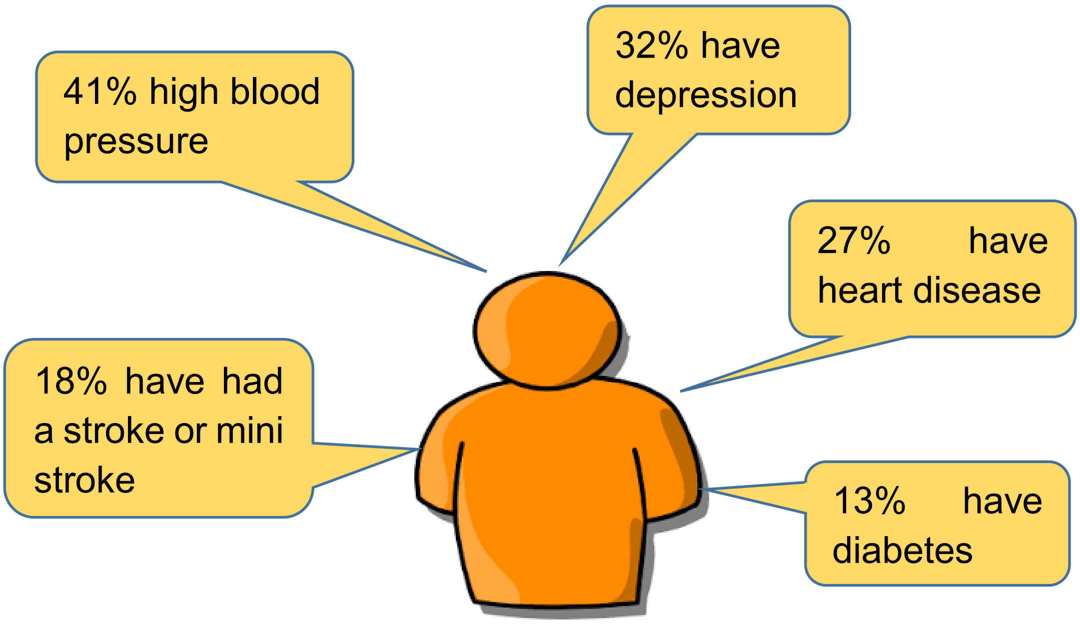
[2] Alzheimer's Society, *People with dementia and comorbidities are receiving disjointed substandard care*, April 2016, https://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2591, last accessed 20/07/16

- Poor management of dementia associated with diabetes, depression and urinary tract infections costs the health and social care system almost £1 billion a year.
- People with dementia are less likely to receive a diagnosis for other health conditions and get the care and support they need to manage them.
- Untreated long term health conditions, such as diabetes, can cause dementia to progress on average one to two years faster.
- Studies have shown that of the 850,000 people living with dementia in the UK they are also likely to have[3]:



Prevention

Support should always begin with prevention of the illness not diagnosis. Vascular dementia is the second most common type of dementia. However there is evidence that individual cases of dementia are often a mixture of Alzheimer's disease and vascular dementia. Vascular dementia has the same risk factors for us as heart disease and stroke therefore the same preventative measures are likely to reduce our risk.

Risk factors for us include getting older, smoking, lack of physical activity along with an inactive lifestyle, drinking too much alcohol, eating a poor diet which has a lot of fat, sugar and salt and for us to be overweight in midlife. Smoking doubles our risk of dementia.

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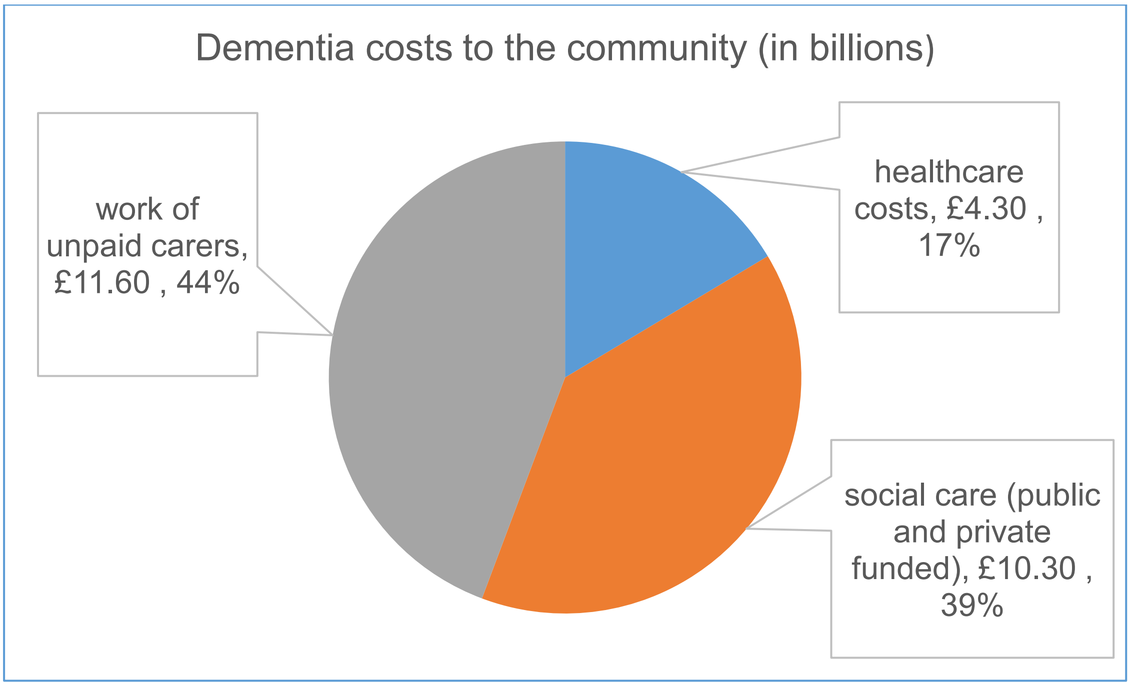
[3] All Party Parliamentary Group on Dementia, *Dementia rarely travels alone: Living with dementia and other conditions*, April 2016, p. 5

NHS Health checks for adults aged 40 – 74 are an ideal opportunity for GPs and other health care professionals to offer advice and to talk to us about a healthier lifestyle.

Financial Impact - the national picture

- Approximately three quarters of the total costs for people with dementia is provided as unpaid care by our family and friends.[4]
- In 2014 the estimated annual cost of dementia was over £26 billion, at £32,250 per person annually.



- For people living with dementia in the community the average health costs are:
  - £2,751 per year for those with mild dementia,
  - £2,695 for those with moderate dementia,
  - £11,258 for those with severe dementia.
- The pattern of healthcare costs is different for people in residential care.

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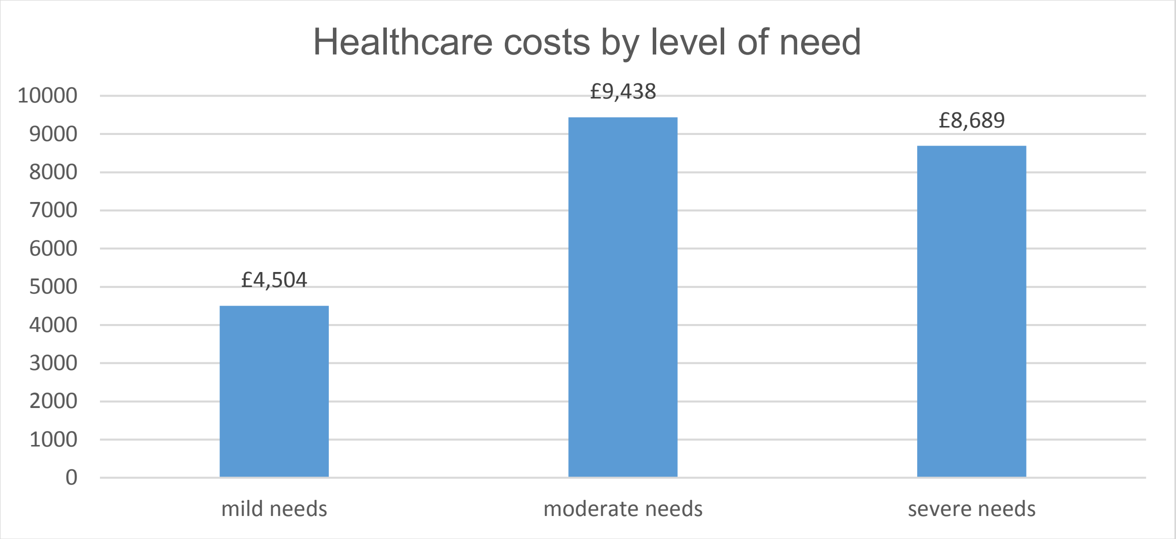
[5] https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy



- For people with early-onset dementia, around 10% of residential social care costs and around 5% of community-based social care costs are met by the person living with dementia.
- Of 17,000 missing persons enquiries it is estimated that one in fifteen are for people with dementia. Police costs for looking for missing persons due to dementia are £22 to £40 million per year.

What else do we know?

National Strategies

The National Dementia Strategy for England 'Living Well with Dementia' 2009[5] identified 17 key objectives to progress improvement in the quality of services for us, including:-

- Improving public and professional awareness and understanding of dementia.
- Good-quality early diagnosis and intervention for all.
- Good-quality information for those with diagnosed dementia and their carers.
- Enabling easy access to care, support and advice following diagnosis.
- Improved end of life care for people with dementia.

The Prime Ministers Challenge[6], launched in March 2012, set out a programme of action to deliver improvements in health and care, create

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[5] https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy

[7] https://shapeatlas.net/dementia/#6/52.955/-2.164/l-p65

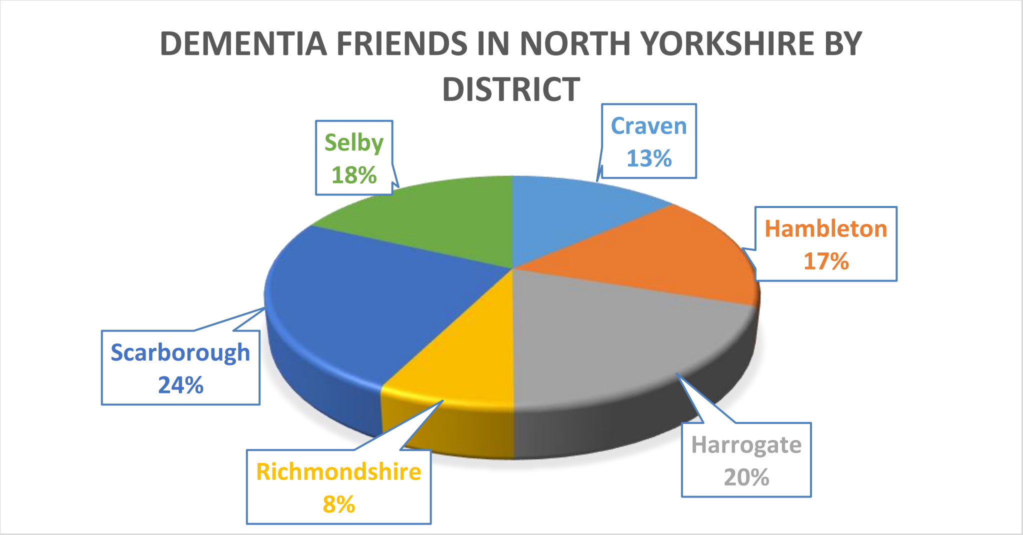
dementia friendly communities, and boost dementia research. They worked with people living with dementia and their carers and created a series of ‘I” statements describing a vision of how people living with dementia wish to be supported by society. These were:

- I have personal choice and control over the decisions that affect me.
- I know that services are designed around me, my needs and my carer’s needs.
- I have support that helps me live my life.
- I have the knowledge to get what I need.
- I live in an enabling and supportive environment where I feel valued and understood.
- I have a sense of belonging and of being a valued part of family, community and civic life.
- I am confident my end of life wishes will be respected. I can expect a good death.
- I know that there is research going on which will deliver a better life for people with dementia, and I know how I can contribute to it.

Public Health England aims to reduce the numbers of people with dementia in midlife. It expects partners in our communities such as health, local authorities, voluntary sector, leisure services, and emergency services, should:

- use routine appointments and contacts to identify those of us at risk of dementia by making every contact count
- talk to us about being healthy during our lives
- give advice on how to reduce our risk factors for dementia

The Alzheimer’s Society Dementia Friends programme encourages greater awareness and supports people of all ages to think about how they can support those of us living with dementia in our communities. It includes the training for children and young people to create a ‘dementia friendly generation’. As of February 2017 there are 22,614 Dementia Friends across North Yorkshire.



The Alzheimer's Society Dementia Friendly Communities is a programme which helps to create dementia-friendly communities across the UK. Everyone, from governments and health boards to the local corner shop and hairdresser, share part of the responsibility for ensuring that people with dementia feel understood, valued and able to contribute to their community.

National Dementia Atlas is an interactive map[7] that plots data about dementia care and support, and allows people to compare the quality of dementia care across the country and in our own communities.

The data is grouped in themes based on NHS England's well dementia pathway which is a framework to ensure people with dementia have a better experience of health and social care support from diagnosis through to end of life.

Dementia Action Alliance launched the National Dementia Declaration. This brings together organisations in our communities to do activities that will make a difference to those of us living with dementia. Members engage in awareness raising, education and encourage organisations to see dementia as their business by work together to use their knowledge to influence change and how our community views dementia.

SCIE Guidance to support people with dementia and their carers sets out how to identify, treat and care for people living with dementia

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[7] https://shapeatlas.net/dementia/#6/52.955/-2.164/l-p65

and the support that should be provided for carers by GP practices, hospitals and social care. Examples are:

- People living with dementia not be excluded from any services because of diagnosis, age or other disabilities.
- The rights of carers to have an assessment of needs are upheld.
- Health and social care managers coordinate the treatment and delivery of health and social care services for people with dementia and their carers.
- Memory assessment services should be the single point of referral for all people with a possible diagnosis of dementia.
- Health and social care managers should ensure that all staff working with older people in the health, social care and voluntary sectors have access to dementia-care training that is consistent with their roles and responsibilities.

NHS Well Pathway for Dementia[8] – describes 5-year plan which covers:

- preventing well – I am given information about reducing my personal risk of getting dementia,
- diagnosing well – I am given a timely diagnosis, an integrated care plan and a review with the first year
- supporting well – I have access to safe high quality health and social care for people with dementia and carers,
- living well – those around me and looking after me are supported and I feel included as part of my community
- dying well – I am given choice and control to die with dignity in the place of my choosing

Local Strategies

North Yorkshire Community Plan sets out its ambitions to support our communities to be able to develop and deliver the services we need and to enhance their ability to support us in a changing world.

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[8] https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf

2020 North Yorkshire sets out the County Councils' corporate vision and plan for Health and Adult services, with an overall objective for people to live longer, healthier, independent lives

- Investing in local services and activities to support people to live independently in their communities, close to family and friends
- Offering advice information and support to help people resolve concerns at an early stage
- More choice and control for people, over the support to meet social care needs
- Developing services with providers to improve the support available to people

North Yorkshire Joint Health and Wellbeing Strategy has five themes: Connected Communities; Start Well; Live Well; Age Well and Dying Well.

The strategy sets out ambitions for

- Vibrant and self-reliant communities in all parts of North Yorkshire.
- More dementia friendly communities.
- A stronger link across health and social care.
- More people receiving personal budgets for their care.
- A range of options in place that help people to keep their independence for longer with fewer older people entering nursing or residential homes for long term care and more Extra Care housing available.

- More support options for people in their last years of life.
- More people receiving support for themselves and their families at the end of life.
- More carers feeling that they can have a life outside caring.

NHS Services in North Yorkshire

The NHS in North Yorkshire is a complex network of organisations all of whom have some degree of responsibility for supporting people living with dementia and their carers.

There are two main types of organisation responsible for health services in North Yorkshire, Commissioners who determine what services are needed in which areas and providers who are paid to deliver the services.

All health organisations across the county recognise the importance of prevention and engagement with Communities – Clinical Commissioning Groups and GP Surgeries are actively involved in the work of dementia collaboratives and in the development of dementia friendly communities across the county. These groups work to raise the profile of dementia, including the early warning signs, and reduce the stigma of dementia in local communities.

a. **Hambleton, Richmondshire and Whitby CCG** have developed a Dementia Collaborative which brings together key stakeholders from across the area including the voluntary, community and statutory sectors to agree key areas of work and drive forward awareness and change across the area.
b. **Scarborough and Ryedale CCG** are actively involved in developing Scarborough into a Dementia Friendly Community where people living with dementia and their carers are at the centre of planning for local development and services.

It is also essential that all mental health services, including those for people living with dementia strive for ‘parity of esteem’ with physical health services. This means that health conditions which mainly affect a person’s mental abilities or wellbeing will be treated with the same sense of urgency and importance as physical health needs.

Primary Care

Primary Care in North Yorkshire is commissioned via the Clinical Commissioning Groups and mostly delivered by GP surgeries across the county. GP surgeries are responsible for the ongoing support of local communities whilst also providing services such as community nursing, pharmacies and a range of clinics. In most instances it is the GP who will be the first point of contact when worries about memory problems begin to emerge.

North Yorkshire's CCGs recognise the importance of delivering effective dementia care in Primary care and there is a lot of work going on across the county to develop and further improve services.

Development focusses on 4 main areas which all CCGS are working towards, below are just some examples of the work which is currently planned or underway:

1. **Improving diagnosis rates and speed of diagnosis** – too often diagnosis occurs too late for the person to make important choices, this is often at a time of crisis which could have been avoided had the diagnosis been made earlier
    a. **Harrogate and Rural CCG** will develop dementia navigators, support for community teams and increased capacity for memory clinics. Ultimately the services aims to have a fully integrated network model which will improve early detection and diagnosis and improves outcomes and quality for people living with dementia and their carers.
2. **Developing Capacity within primary care** - to ensure that people are able to access the diagnostic tests and skilled professional support that they need, close to home and when they need it. This will include new, more effective screening tools and a focus on ongoing post diagnostic support.
    c. **Airedale, Wharfedale and Craven CCG** will expand diagnostic services available in GP surgeries and other community settings, as well as developing a system that supports people to live safely and with social interaction in their own homes for as long as possible
    d. **Scarborough and Ryedale CCG** have a workforce development programme to increase the knowledge, skills and capacity of primary care staff to ensure more effective

early identification, diagnosis and support for people living with dementia.

3. **Workforce Development** – working with practice staff to increase their knowledge and skills of dementia as well as ensuring that all staff are aware of the availability of dementia navigator services and the importance of offering referrals to people with a diagnosis.
    a. **Vale of York CCG** have a workforce development aim to increase the knowledge and skills of practice staff, to improve the efficiency of screening, coding and links to memory and care navigator services.
4. **Ongoing support to maintain independence –** an initial diagnosis of dementia does not mean a person's life stops. Regardless of age or situation there are techniques and coping strategies as well as regular health checks and medications reviews that can help people living with dementia and their carers manage their condition most effectively in the community.

Secondary (hospital) Care

Admission to hospital can be a challenging and upsetting time for people living with dementia and their carers and we know that if this time is not handled correctly it can have a severe negative impact on the person's future outcomes.

The importance of continuity for people living with dementia is recognised by all hospitals routinely accessed by people living in North Yorkshire. All these hospitals are signatories to 'John's Campaign' which operates on the principle that family/carers are able to stay with people when they go into hospital. Access should be easy for family carers and their expert knowledge as carers should be used to support people. John's Campaign applies whether a person with dementia is living in a mental health unit, a nursing home, a rehabilitation unit, supported housing or a care home.

Residents of North Yorkshire access services at hospitals both within and beyond North Yorkshire. These hospitals are managed by a range of NHS providers commissioned by the CCGs.

At any one time it is thought that round 1 in 4 people in an acute hospital are living with dementia, and we know that once in hospital people living with dementia have worse outcomes than the general population. It is vitally important that hospitals are dementia friendly places for people to be treated and that people are supported, wherever possible to return home as soon as possible.

All the CCGs and Hospital Trusts routinely accessed by people living in North Yorkshire have ambitious plans to transform services and improve outcomes for people living with dementia, a flavour of which is set out below, these can be summarised into 4 key themes:

1. **Outreach and Prevention** – There is a strong focus on supporting people to live with dementia away from hospital, whether this be in the person's home, in a residential or nursing home or an Extra Care housing scheme.
    a. **Airedale, Wharfedale and Craven** CCG are working to further develop their care home liaison service which supports people living residential homes to reduce the need for hospital admissions,
    b. Hambleton, Richmondshire and Whitby CCG are developing a collaborative approach with South Tees Acute Trust to ensure that more people receive appropriate care and support and fewer people with dementia are treated in an acute setting.

2. **Workforce Development** – As in Primary Care the experience of a person living with dementia is often dictated by the skills, knowledge and approach of the individual member or members of staff responsible for their care whilst in hospital. Current work focusses on developing knowledge, skills and a broader understanding of the personal impact of dementia beyond the purely practical or medical.
    a. **Vale of York CCG** are developing a dementia awareness training programme for all clinical and public facing staff with a view to having a more rounded and holistic view of what it's like to live with dementia or care for someone who does.

3. **Environment** – Hospitals can be disorienting and confusing places for a person living with dementia especially where the dementia is relatively advanced. The change in location, people and routine can be upsetting and lead to an increase in challenging behaviour which in turn may exacerbate the condition and lead to a longer hospital stay than is necessary. There is an understanding that hospitals need to be configured and run in a

way that is understanding and supportive of people living with dementia and their carers.

   a. **Harrogate and Rural District CCG** together with Harrogate Foundation Trust have improved the environment of the Byland ward at Harrogate Hospital to ensure that people with dementia are able to better orientate themselves within the hospital

4. **New or Improved Services** – as our understanding of dementia and the needs of people who live with it improve, new services are being to developed to ensure that people are supported to retain their independence and that where possible people are not treated in hospital where there is no need for them to be. CCGs and Hospital Trusts are continuing to develop improved ways of supporting people living with dementia as outlined above, this innovation and progress will continue through the lifetime of this strategy.

Mental Health Services:

Tees, Esk and Wear Valleys NHS Foundation Trust provides a range of mental health services across North Yorkshire including supporting people living with Dementia.

Ryedale

We have seen the development of a new build “Springwood” specialist Mental Health Unit in Malton which has 14 en-suite bedrooms and a high dependency suite. Springwood offers specialist assessment and care for people living with dementia who have the most complex mental health needs associated with their dementia.

Harrogate

Under the auspices of the Acute Hospital Liaison Service a programme of dementia awareness training was delivered to large numbers of hospital staff, including nurses, support workers, porters, administrative staff, technicians and hospital managers

Northallerton

The Mental Health Care Home In Reach Service has worked closely with Health and Adult Services in supporting care homes with some training in the care and support of people living with dementia- there have been two planned training events so far.

North Yorkshire Older Peoples Mental Health Services for Older People now deliver dementia care based on a TEWV pathway which recognises not only the clinical presentation of dementia, but also the needs of carers, and focusses on therapeutic interventions and support with some of the side effects of dementia including falls, behaviour that challenges and the management of pain and delirium.

North Yorkshire

The development of Acute Hospital Liaison Services in Harrogate, Northallerton and Scarborough, based on the acute hospital premises. These teams operate 7 days a week and respond to referrals from the medical, surgical and elderly care wards. Their aim is to support ward staff with the assessment and treatment of people living with dementia, who have been admitted to hospital and their mental well-being is affected. These teams also provide advice and some training to acute hospital staff

In addition to this, Memory Services have been developed in North Yorkshire, and in Harrogate and Northallerton, for example, offer post diagnostic support, signposting and advice

TEWV are also supporting dementia research, with designated staff who introduce the scheme to staff working with people living with dementia- this is particularly highlighted in within Memory Services. The research advisors will visit interested people and their families- this can be a person already living with dementia who wants to participate in research or any other person who is considering participating.

How services are currently set up

North Yorkshire County Council Public Health commissions health checks and healthy living services for residents to access. There is a campaign called ‘One You’ targeting people aged 40 – 60 that encourages us to think about how we live. Other ways to improve how we live include:

- Developing, delivering and enforcing local tobacco control plans
- Developing and implementing guidance and policies to reduce alcohol consumption across the population

- Improving where we live and work to encourage and enable us all to build physical activity into our daily lives
- Supporting us to eat healthily
- Addressing loneliness and encouraging us to be socially active and mentally stimulated.
- NYCC Public Health team are working with a range of partners to ensure the above actions are progressed in North Yorkshire.

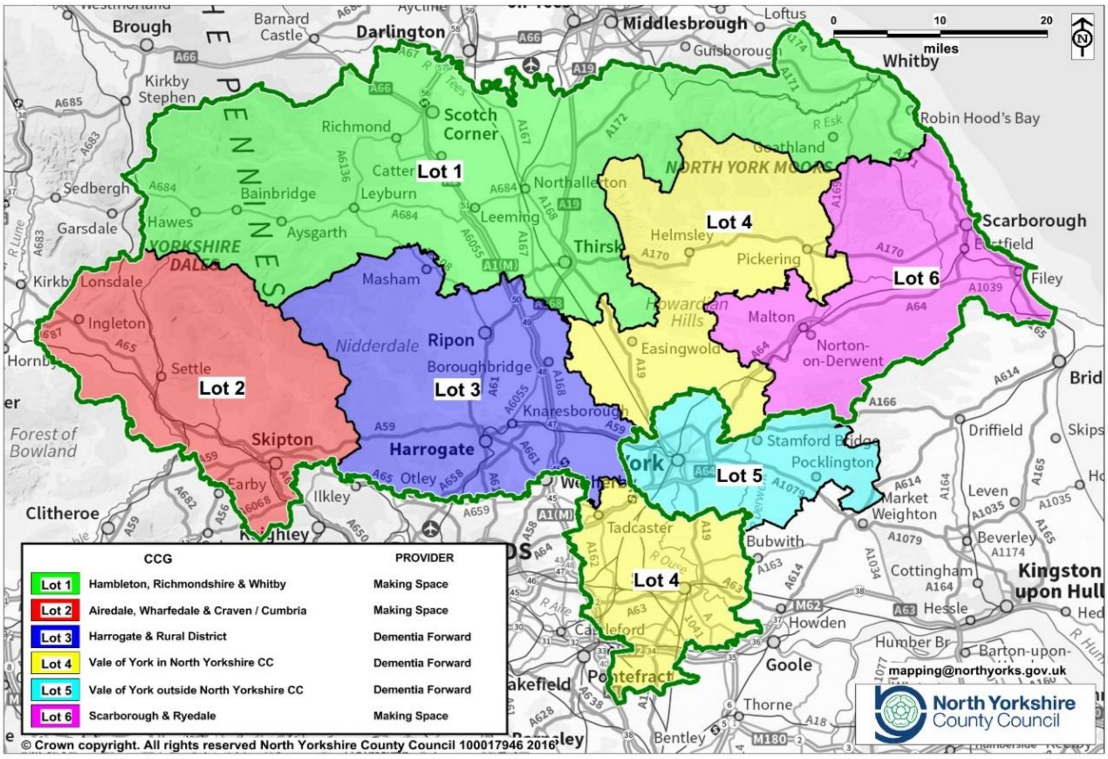
North Yorkshire County Council also has responsibility for Adult Social Care across the county and has 7 district councils to work with. The County Council is responsible for assessing the needs of those of us who may need support with daily living tasks, and the needs our carers. It offers personal budgets to those with eligible needs and commissions support for people. This includes support for people living in their own homes, support for carers and where necessary arranges for residential and nursing home care. Anyone receiving support from social care is assessed to establish what they can afford to contribute to the cost of their care and support.

In addition to statutory and commissioned services there is a large range of both formal and informal support groups within our communities, and the Council has invested in a Stronger Communities Team and a Living Well service, both funded by Public Health, to help people to find and access some of the more informal support available in communities.

The National Health Service in North Yorkshire is made up of Clinical Commissioning Groups (CCGs) which are groups of family doctors and other health professionals responsible for the planning and commissioning of health care services for our local areas. NHS England has put together a 5 year plan for a better NHS. The CCGs in North Yorkshire link to three Sustainability and Transformation Partnerships which between them cover West Yorkshire and Harrogate; Humber Coast and Vale; and Tees Durham and Darlington.

The Tees, Esk and Wear Valleys NHS Foundation Trust delivers Mental Health services across the county.

NYCC and the CCGs jointly commission Dementia Support Services and Carers Resource Centres. The Dementia Support services are delivered by two providers – Making Space who deliver services in Hambleton, Richmondshire, Whitby, Craven, Scarborough and Ryedale and Dementia Forward who deliver services in Harrogate, Vale of York (Selby and South Hambleton / North Ryedale) as well as City of York.



	CCG	PROVIDER
🟩 Lot 1	Hambleton, Richmondshire & Whitby	Making Space
🟥 Lot 2	Airedale, Wharfedale & Craven / Cumbria	Making Space
🟦 Lot 3	Harrogate & Rural District	Dementia Forward
🟨 Lot 4	Vale of York in North Yorkshire CC	Dementia Forward
Lot 5	Vale of York outside North Yorkshire CC	Dementia Forward
🟪 Lot 6	Scarborough & Ryedale	Making Space

There are many other services which are important particularly in the voluntary sector to support us locally e.g.:

- Practical support
- Activity based groups
- Advocacy
- Befriending

Care and Support

North Yorkshire County Council commissions care from over 100 domiciliary care providers and 210 residential and / or nursing homes registered with the Care Quality Commission.

Of the 210 residential and nursing homes, 81 (36%) are registered to offer care and support to people living with dementia.

The availability of residential and nursing support for people living with dementia varies by area due to market capacity, as of February 2017 there were the following number of homes registered to provider dementia support in each district:

Craven – 10 homes
Hambleton – 5 homes
Harrogate – 24 homes

Richmondshire – 18 homes
Ryedale – 0 homes
Scarborough – 16 homes
Selby – 7 homes

Residential and Nursing Quality

The Care Quality Commission together with NYCC's Quality and Monitoring team have responsibility for the inspection and support of all regulated care providers in North Yorkshire.

CQC rate providers on a scale of 'Inadequate', 'Requires Improvement', 'Good' and 'Outstanding'.

The chart below shows a comparison between the UK wide care sector, the wider North Yorkshire sector and homes registered to provide dementia care.

Rating / Area	UK	North Yorkshire	NY Dementia
Outstanding / Good	72%	85%	65.8%
Requires Improvement	26%	14%	22%
Inadequate	2%	1%	6.1%

In 2015 NYCC launched a dementia self-assessment tool for residential and nursing homes, which allowed providers to assess their current position in terms of delivering effective dementia care. The results from this self-assessment can then be used to highlight areas of need and development. This process will continue to be developed over the lifetime of the strategy.

Achievements

- Dementia Support services commissioned by North Yorkshire County Council and CCGs provides support to people living with dementia and their carers._Within the first six months of the Dementia Support Services being set up in 2014, they had offered support to nearly 750 people living with Dementia and almost 700 carers in North Yorkshire. Over 230 people had also benefited from the education and awareness raising sessions provided by this service.

Since April 2016, there have been 2393 new referrals for people living with dementia and 1771 new referrals for carers. Additionally 1154 people have undertaken the education and awareness raising sessions.

- A pilot is underway at Kings Road GP Surgery in Harrogate who are working with Dementia Forward to help those of us who are worried about our memory. It helps GPs find out more about us and our families, listens to our carers who know us best and helps those of us who may problems understanding what is happening such as a learning disability. Support workers will link with GPs, raise any concerns and also collect our experience on what it is like to access support in the health system.

- John's Campaign[9]- all the larger hospitals covering North Yorkshire, James Cook, Friarage, Harrogate, Scarborough, Airedale and most community hospitals have signed up to the national 'John's Campaign' where family/carers are able to stay with us when we go into hospital. Access should be easy for our family carers and their expert knowledge as our carers should be used to support us. John's Campaign applies whether a person with dementia is living in a mental health unit, a nursing home, a rehabilitation unit, supported housing or a care home.

- Alzheimer's Society, Dementia Forward and Making Space are delivering dementia advice clinics in GP practices across North Yorkshire for people diagnosed with dementia or worried about memory loss.

- Scarborough hospital, working with the Alzheimer's Society, has reviewed their dementia awareness and led to training for all staff from porters to nursing staff. This has led to changed support and benefits people with dementia during stays. The 'forget me not' logos are used on beds to indicate that we have dementia and for our beds not to be moved which can lead to increased confusion.

- Dementia Action Alliances involve all 7 District Councils in North Yorkshire. They are at different stages depending upon when they

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[9] http://johnscampaign.org.uk/#/about

started. All promote dementia activities and events such as Dementia Awareness Week. A number of cross cutting themes for the District councils linked with Dementia Action Alliance work has emerged this includes:

  - Supermarkets reviewing their interior design, black mats which are often seen by people living with dementia as a black hole to fall into are removed. Staff awareness sessions to improve interaction with people who may have dementia. Coin recognition charts at checkouts dementia friendly symbols added to exit, toilet and checkouts.
  - Recruitment of banks, Town Halls, hospices and community groups e.g. scouts, theatres, leisure pools, museums. Plans being developed with the wider community.
  - The Dales Pharmacy in Hawes completed a dementia friendly refurbishment of shelving, displays, carpeting, décor, lighting and layout to improve orientation and navigation. A safe haven is provided with seating for people with dementia. Its staff became dementia aware with training extended to local care homes where the pharmacist is the registered provider of prescriptions and medication.
  - Doctors Surgeries have worked to refurbish practices as Dementia Friendly.

- North Yorkshire County Council Police[10] have implemented the Herbert Protocol which is for when people with dementia go missing. Vital information about the person such as medication, description, photograph, significant places in the person's life and their daily routine are recorded. This information is essential to locate the person quickly, at any time of day or night.

- Sporting Memories provide training for carers, relatives and health and social care staff working to use sport as a way to help people living with dementia reminisce. Memories are stimulated giving opportunities for conversations with us and inclusion.

- North Yorkshire Sport is a charity which encourages us to take part in sport either by watching or doing it. It is working with Dementia Forward promote sport and its benefits for those of us living with dementia, our families and our carers

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[10] https://northyorkshire.police.uk/content/uploads/2016/01/Herbert-Leaflet-2016.pdf

- NYCC dementia awareness training is mandatory for all 2010 Health and Adult Services staff and must be refreshed every 3 years. As the Council's first point of contact all 38 of the Customer Service Centre's specialist advisors have received the dementia awareness training. As a further first contact point all the library staff have dementia awareness training.

- October 2016, North Yorkshire Dementia Congress. This event was attended by 150 people living with dementia and their carers, professionals from health, social care, private and voluntary sector and school pupils. Presentations included a gentleman living with dementia who told his story, a joint presentation from the Alzheimer's Society, Dementia Forward and Making Space about dementia support across North Yorkshire. Pupils from St Aidan's High School in Harrogate and Harrogate High School talking about dementia as an intergenerational subject and Airedale, Wharfedale and Craven CCG and Dyneley House GP surgery in Skipton talking about health approaches to dementia. There was a market place, art exhibition and songs from the Harrogate Singing for the Brain group and workshops which have contributed to the collective themes identified by surveys and the priorities and actions outlined in this strategy.

- Dyneley house Surgery have undertaken significant work to refurbish the practice as Dementia Friendly, colour schemes, signs, staff training have led to this GP Practice winning a national award recently.

Accommodation

North Yorkshire County Council is engaged in an ambitious project to develop accommodation with care to meet the needs of our current and future communities.

This includes the development of extra care housing schemes and other specialist housing and supported accommodation to meet the needs of vulnerable people in the county, including those living with dementia. North Yorkshire County Council's Design and Good Practice Guide, Dementia Care and Support in Extra Care Housing, focuses on design principles and supporting people living with dementia in extra care housing.

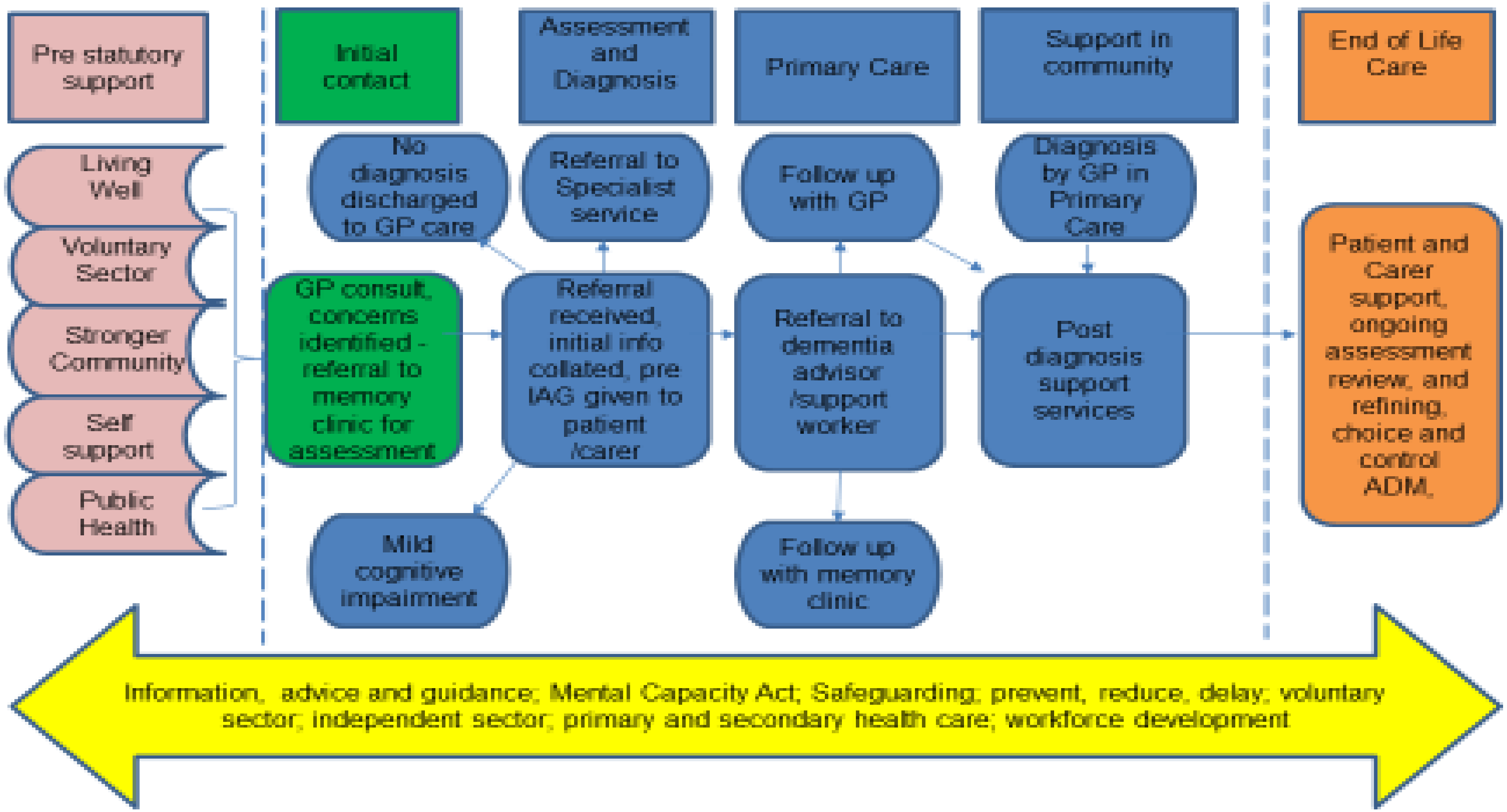
There are currently two schemes where we have already achieved this, Limestone View in Settle (below), and Kirkwood Hall in Leyburn.

Pathway

The pathway below describes how support should ‘wrap around us’ when we need it and is dependent upon how much we need at each point in time. Sometimes close and intense and sometimes more distant but there if we need it. This includes prevention in the community with information, advice and guidance to enable us to make informed choices and potentially prevent, delay or reduce the impact of dementia on our lives; through to respecting our wishes at the end of our lives.

This pathway has been identified by the organisations contributing to the development of the strategy to illustrate what needs to happen for those of us worried about or living with dementia.   We are aware that currently this pathway is far from consistent across North Yorkshire, with peoples experience dependent on the level of knowledge and capacity in different parts of the county. For example we have heard great things about the one stop shop approach to diagnosis taken in both Scarborough and Northallerton, but this is not available in all parts of the County.

Community pathway for dementia awareness, diagnosis and support.



End of Life Care and Support

It has been recognised that for people with dementia the ‘end of life’ period may be longer and less well-defined than for those with other conditions such as cancer. Similarly, the Care Quality Commission has identified people with dementia as a group at particular risk of receiving poor end of life care.

This strategy aims to ensure ‘access for all’ to early advance care planning, the same quality of end of life care and the importance of providing support for carers, both before and after the death of a loved one is made available for everyone regardless of their condition or location.

What matters most to people living with dementia - Consultation and engagement across North Yorkshire

Overview

The most important part of developing this strategy has been talking to those of us who live with dementia and our carers in order to fully understand the day to day challenges we faced. We have asked what is already done well, where people living with dementia feel supported and effectively helped to live healthy and independent lives, but we are even more interested in where support falls short and the lessons that can be learned for the future.

The development of this section has also been greatly helped by face to face conversations with individuals and groups across the whole of North Yorkshire, on line surveys, workshops and a dementia congress attended by people living with dementia and their carers.

During the engagement process over 1200 people assisted us with their responses, the following themes and recommendations have been identified as below.

We would like to thank those people living with dementia and their carers who have illustrated key points of emphasis. These contributions more than any statistic or policy are at the core of what this strategy is all about and the document is richer and more meaningful for their inclusion.

Key themes

Challenging the stigma and raising awareness

21% of responses to the survey said that awareness of dementia was the most important issue for them. Places we live and places we go to such as GP Practices, Dentists, shops, Hospitals, Local Authorities, Housing, Police, residential homes, voluntary groups need to be dementia aware and dementia friendly.

- “Educate children to have knowledge around younger people with dementia and family members. There is still a social stigma around dementia and too many of us are too scared or embarrassed to tell even those closest to us”
- “Modern society is very fast paced, we need a space where we can take a little more time whether it’s in shops, on the bus or just going about our day to day lives”
- “We need people to understand what dementia is all about and what it means for us, we don’t want pity but more understanding of what it’s like to live with dementia and how much the little things can help”
- “We should be educating our grandchildren from an early age, kids are great at asking questions and having open minds without any fear or embarrassment”

Accessibility

20% of responses said that accessibility was important e.g. Signage, Dementia Friendly Communities, Transport, Inclusivity and Equalities.

- Transport – taxis, buses, aware of dementia and “Extra space in parking bays for people with dementia using a logo such as the forget me not”, “I can’t get my husband into the car in usual spaces and if I stand him by the car he runs away”
- Being able to get around my community with “signage simple and clear, shops thinking about what it means when the change layout/offer”
- Systems not working together e.g. health, social care, district councils, voluntary sector - duplicate information activities, partnership working, planning, lack of funding, cost implication for clients.
- Simple English/easy read - We need more information and the right sort of advice, sometimes it’s a lot to take on board all at once

Early diagnosis and support

5% of responses said that diagnosis and support was important. There was a real appreciation of the support provided by the two Dementia support services and other organisations, but still a number of issues that could be improved:

- “GPs are separated from the problem. Because of confidentiality they won’t share with carers not present at consultations what was said”
- “District nurses from the surgery are fantastic, I don’t know what I would do without them. It’s important to know they are there and will come out. They do more than just put a plaster on”
- “When I was first worried that my husband had memory problems, our GP did not listen. They did a very simple diagnostic test but was too low functioning and we had to go back to 3 different GPs before they listened and referred to memory clinic”
- “Good GP access and support here, that’s important to help me and my family manage”
- “It can be hard to know what the real symptoms of dementia are – there is not enough general awareness or information”
- “Whilst many of us receive a timely diagnosis this is not always the case, often we are passed between doctors and clinics with no-one taking responsibility for making a final decision”
- “Doctors need to understand the impact of saying ‘you have dementia’, they might say it a lot but hearing it is life changing and often terrifying”
- “We need clear, concise and relevant information at the right time – simple things like ‘am I still allowed to drive’ as well as the longer term health and social care information” Evidence indicates people want different types of support, small amounts of information and directions in the early weeks of having received a dementia diagnosis and then on-going in small amounts at the right time.
- “Booklets and leaflets were given, but in large amounts at a time of crisis or when a ‘shattering’ diagnosis had just been given and we could not take it in.”
- “We were bombarded with leaflets & left to our own devices - no advice given”.

Ensuring consistent care and support

13% of responses said that experience of living with dementia is far too varied, whether in the individual’s residence, care home or hospital setting the some of us receive excellent support, a quick diagnosis and manage to make connections with groups and professionals who are knowledgeable and supportive. Too many of us do not have this experience and are left to fend for ourselves in a disjointed and often bewildering system

- “This goes wrong in hospitals” evidence of lack of dementia awareness in hospitals by all staff from consultants to nurses.
- “different response depending on the GP and resources”

- "it's important for people to listen to me and what I need, I might be old but I'm still all there"
- "People living with dementia should be identified easily for staff to support them on wards e.g. butterfly/forget me not scheme"
- "Regardless of the type of dementia I have I am still offered treatment and support and this is reviewed"
- "Too many of us wait too long for a diagnosis or receive conflicting messages from healthcare professionals, there should be a quick and simple process for finding out if we have dementia"
- "Once we receive a diagnosis there should be a consistent process that offers advice, support and lets us know what to do next, too many of us feel lost or abandoned with the life changing news of a diagnosis"
- "Those of us living in residential or nursing home shouldn't be written off and forgotten about"
- "Health and social care professionals need to work together more effectively, we don't care about your organisational boundaries, we care about getting the support and help we need at the right time"
- "We should be able to consent to our information being shared between organisations when it would benefit our care, especially as our dementia progresses"
- "Co-ordination and continuity of care planning for people living with Dementia to live well, this should include GPs playing a leading role in ensuring co-ordination."

Planning for the future and dying well

17% of responses said that planning for the future and dying well was important e.g. "having control as far as possible", advanced care planning, decision making and end of life care for people living with Dementia.

- "You only die once, let's get it right please"
- "Making sure carers are supported after death of loved one"
- "Acceptance of having a 'dying plan' as you would have a 'birth plan' before the delivery of a child"
- "Parallel approach to Macmillan nurses for people diagnosed with Dementia…. it's hard to know who to approach for what"
- "Power of Attorney, Wills…. wishes met, choice, it's hard to know what all the options are or mean"
- "Professionals need to be sensitive but honest with us on what the diagnosis means in the long term"
- "We should be supported to put our affairs in order at an early stage"

- “We need the opportunity to discuss our wishes for the end of our lives and for how we wish to be treated once our dementia has developed to a stage where we will no longer be able to fully express ourselves”
- “Don’t forget about our loved ones as soon as we are gone”

Communities and networks - seeing the person, not the dementia

10% of responses said that networks were important to use local facilities more to spread info e.g. libraries/churches, drop-in facilities

- “I want to continue the things that I have always done but with support”
- Dementia is part of my life, not my life”.
- “I am a person not an illness. I can live positively with my illness that I can continue my interests e.g. gardening, thinking about my house/home and my memories so I can stay there in familiar surroundings where possible.”
- “People Living With Dementia are not separate, but part of the community”
- “Local community networks are our strongest asset if we can motivate and educate them”
- “As dementia progresses we are seen less and less as ourselves and more as a ‘dementia’, we have names and we expect them to be used”
- “Professionals need to understand the emotional toll of our diagnosis, we won’t always be happy or polite, sometimes we may be upset, angry or rude – this doesn’t mean we don’t want or need help”
- “We are not defined by dementia, we want to live active lives for as long as we can and not be treated any differently to our friends and families”
- We want to live in our homes and communities for as long as possible

The value and importance of carers support

7% of responses said that carers support was important

- “All carers given opportunity to attend a carers course, essential!”
- “Ensure carers are equipped with knowledge, aware of rights, carers assessment and support to cope”
- “Listen to carers/don’t let confidentiality get in the way”
- “Carers need to be more involved in planning and care prior to and during their stay [hospital]”
- “The people who care for us are vital to our health and independence, they need to be recognised and supported properly and given the rest they deserve from what is a 24 hour a day job”
- “Those of us who live alone should be properly supported and recognised as having additional needs to people with active support networks”
- “Our carers need advice and education around what to expect as dementia progresses, they know it won’t be easy but shouldn’t have to learn everything for themselves”
- “Our carers should also have early access to emotional support to help them cope with the diagnosis”
- “When things get too much there should be someone with the power to make decisions available for our carers to speak to at all times of the day or night”

Workforce Development

7% of responses said that workforce development was important e.g. people have told us of their experiences with GPs, hospitals, communities and whilst some comments were positive there is room for improvement.

- “Where does the business person go to get information about being more dementia friendly? “
- “Hospital should have nurse specialist in dementia care all wards should be dementia friendly”
- “Sometimes we may be upset, angry or rude – this doesn’t mean we don’t want or need help”

In addition we have heard specific issues that affect people with young onset, and with a Learning Disability

Young onset dementia

- Diagnosis is taking too long and young onset is too often misdiagnosed.
- Diagnosis rate is improving but still needs to get better.
- Memory services could be better if they had a specialist lead.
- GPs need to be better at recognising and understanding young onset dementia.
- Specific services, in particular residential care is rare and often people are placed out of area.
- Traditional day services and respite are not appropriate for young people with dementia – they are not age appropriate and do not support those more physically able.

People Living with a Learning Disability and Dementia

As outlined in earlier in this strategy the number of people living with a learning disability and dementia continues to grow and is becoming of increasing importance to health and social care.

It is important that we develop the right support services and mechanisms for people living with a learning disability and dementia that recognise the needs of both long term conditions. As this is an emerging area we will wait for the publication of Social Care Institute for Excellence (SCiE) guidance in early 2017 before committing to specific actions.

This strategy contains a number of commitments and priorities and these will apply equally to people living with a learning disability and dementia. The overriding principle of seeing the individual, offering suitable and accessible information and allowing the person to make informed decisions will form the core of future work in this area.

Delivering the strategy - action plan

The key areas outlined above have allowed us to develop 4 key principles which will run through everything we do and 5 key Priorities which will form the focus of the work to be done to improve the support and information we provide for people living with dementia and their carers.

These priorities have been developed and agreed in partnership between health and social care professionals and people living with dementia and their carers.

Principle 1:
I am Me
I am not dementia
I have a name and I expect it to be used

Principle 2:
Carers Matter
Treat them as well as they treat us

Principle 3:
The Small Things
Small acts of understanding can make a huge difference

Principle4:
Consistency
Where I live shouldn't determine how I am treated

Priority 1: Dementia Friendly North Yorkshire

We will:

- work with local government, businesses and communities to promote dementia friendly communities across North Yorkshire

- develop a schools' dementia awareness programme to create a 'dementia friendly generation'

- work with employers to emphasise the importance of supporting and valuing carers of people living with dementia in employment

- support local Dementia Action Alliances and Collaboratives to make communities accessible and welcoming to people living with dementia and their carers

- develop and deliver accommodation options for people living with dementia and their carers

Outcomes

1. People living with dementia and their carers feel accepted, supported and understood in their communities

2. Support for people living with dementia and their carers is embedded in our communities

3. Improved public understanding of dementia

Priority 2: Workforce Development

We will:

- work to improve the experience and impact of living with dementia amongst health and social care professionals

- review the training and development offer to independent sector care staff and work with providers to assess training and development needs

- ensure that all signatories to this strategy work to become dementia friendly organisations and aspire to all public facing staff undertaking dementia friends training

- support individuals and groups who wish to challenge examples of bad practice

- ensure health and social care professionals are aware of and trained in the importance of carers and the specific challenges carers of people living with dementia can face

Outcomes

1. Greater awareness of living with dementia amongst health and social care professionals

2. People are treated as individuals rather than a person with dementia

3.People will experience a more personalised and coordinated health and social care system

Priority 3 Diagnosis

We will:

- work to ensure that the diagnosis process is clear and transparent to people and involves no more professionals or appointments than necessary

- work towards a target of everyone receiving timely formal diagnosis

- work with professionals to ensure that a diagnosis is delivered in a suitable way that recognises the impact on the person and their carer and that full follow up support is offered

- ensure that everyone who wishes to be is referred on to our dementia support services

- ensure that carers are offered support and advice relevant to their needs and are supported through the diagnosis process

Outcomes

1. More timely and effective diagnosis routes

2. More effective and consistent post diagnostic referrals

3.A better experience both practically and emotionally of the diagnosis process

Priority 4 Support and Advice

We will:

- create simple points of access for information for people living with dementia and their carers in North Yorkshire including improved access to peer support

- review our current information and advice offer to people, look at ways of improving what already exists and where there is scope for a more innovative approach

- monitor and share the progress of new technology and the ways it could support people living with dementia and their carers

- ensure dedicated Dementia Support Services for people living with dementia and their carers from diagnosis through to bereavement

- develop support specifically for people living with young onset dementia and their families

Outcomes

1. Clearer, more accessible information, advice and guidance produced with people living with dementia and their carers

2. Greater access to peer support and learning

3. Adoption of new approaches where technology advances

Priority 5 Planning for the Future and Dying Well

We will:

- develop training and awareness around the importance of planning for the future and having open discussions around people's wishes and fears

- improve and promote information advice and guidance to enable people to make early and informed decisions around mental capacity, planning for the future and end of life care

- work to challenge the social and professional stigma and nervousness around death and dying

- continue to support bereaved carers to ensure they have the physical, emotional and social support they need

Outcomes

1. Improved access to knowledgeable professional support

2. Clearer information around what to expect and how to plan

3. Better support for bereaved carers

Moving Ahead

This chapter highlights the key steps we will take to ensure that the immense amount of support, information and goodwill that we have encountered as part of the development of this strategy is turned into positive action and a visible improvement in the lives of people living with dementia and their carers.

Leadership and Governance

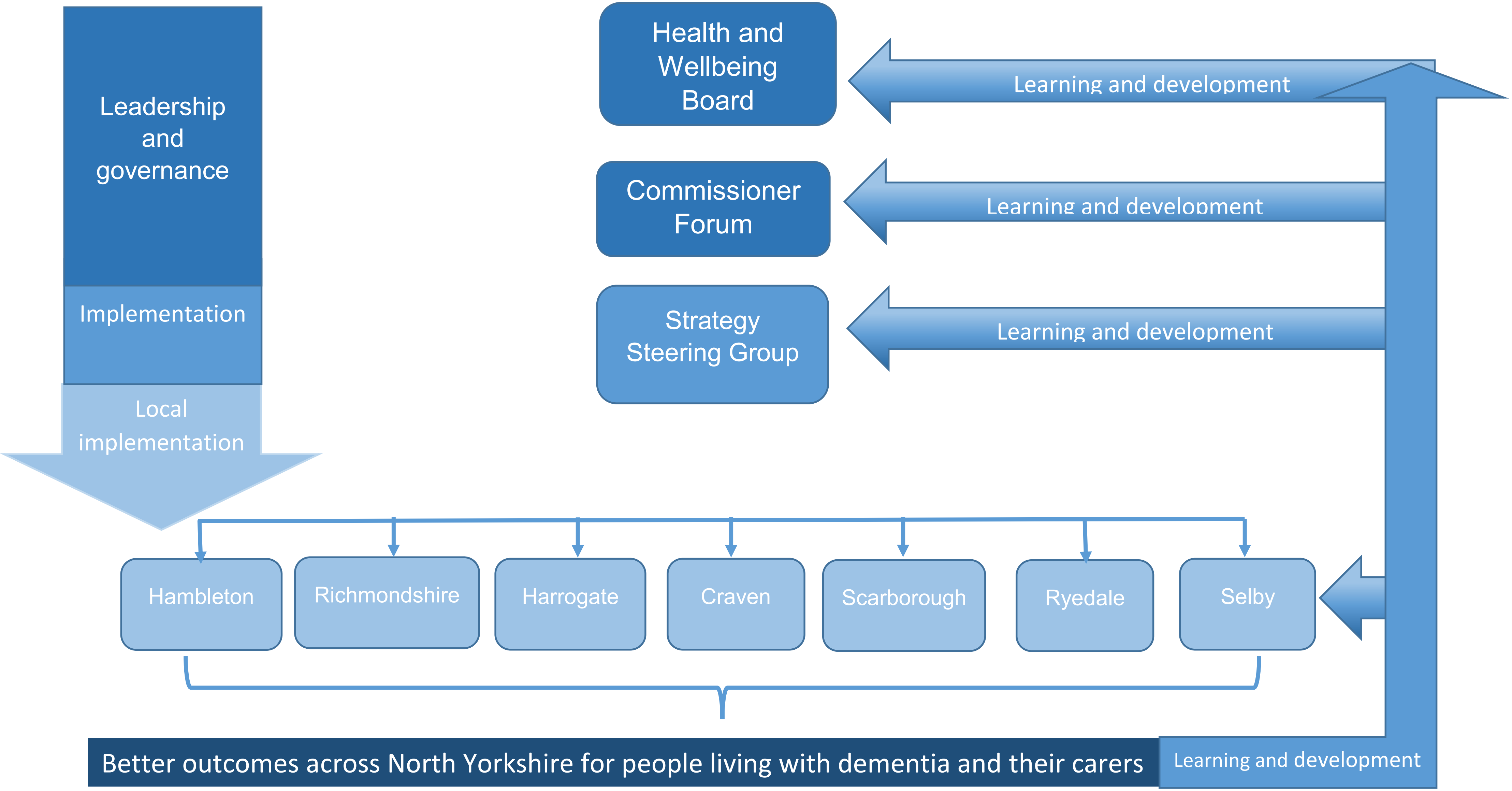
The overall leadership for this strategy rests with the North Yorkshire Health and Wellbeing Board which commissioned and approved this document.

Beneath the Health and Wellbeing Board, sits the Commissioner Forum which is made up of NHS and local authority partners and then below that is the Strategy Steering Group made up of the partners involved in the development of this strategy along with representation from people living with dementia and their carers, this group will oversee the progress of the implementation of the strategy.

Responsibility for the delivery of change in communities will be delegated to local groups, either already established or specifically developed for this purpose.

The role of these groups will be to develop and deliver local action plans for the implementation of the key priorities set out in Page 39, action plans may be variable based on the current position of services and need in each area but all will be co-ordinated to ensure that across North Yorkshire the current inconsistency is minimised.

Working together, see below, these groups will commit to produce an annual report on progress. In addition NYCC will continue to host an annual Dementia conference in order to highlight best practice and discuss new and emerging issues with both health and social care professionals and people living with dementia and their carers.



Leadership and governance

Implementation

Local implementation

Health and Wellbeing Board

Commissioner Forum

Strategy Steering Group

Learning and development

Learning and development

Learning and development

Hambleton

Richmondshire

Harrogate

Craven

Scarborough

Ryedale

Selby

Better outcomes across North Yorkshire for people living with dementia and their carers

Learning and development

ITEM 7

Health and Wellbeing Board
North Yorkshire

North Yorkshire Scrutiny of Health - In-depth scrutiny of End of Life Care in the county

17 March 2017

Presented by: **Cllr Jim Clark, Chairman, North Yorkshire Scrutiny of Health Committee**
Daniel Harry, Scrutiny Team Leader, North Yorkshire County Council

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Summary:

The North Yorkshire Scrutiny of Health Committee has undertaken an extended piece of scrutiny looking into the commissioning and provision of end of life care services in the county. This has involved engagement with a broad range of commissioners, service providers, patients and the public.

There are 9 recommendations in the report, many of which flow from the first recommendation to establish a multi-agency forum for commissioners and providers of end of life care in the county.

This extended scrutiny relates directly to the JHWS theme of ‘Dying Well’.

Which of the themes and/or enablers in the North Yorkshire Joint Health & Wellbeing Strategy are addressed in this paper?

[Please tick as appropriate]

Themes	✓
Connected Communities	✓
Start Well	
Live Well	
Age Well	
Dying Well	✓
Enablers	
A new relationship with people using services	✓
Workforce	✓
Technology	✓
Economic Prosperity	

How does this paper fit with <u>other</u> strategies and plans in place in North Yorkshire?

The recommendations in the report relate to a number of strategies across health, public health, social care and the community and voluntary sector.

What do you want the Health & Wellbeing Board to do as a result of this paper?

Consider the recommendations and agree a way in which they can be taken forward.

In particular, consider recommendation 1 ‘to establish a multi-agency forum for commissioners and providers of end of life care in the county’.

Daniel Harry
Scrutiny Team Leader
North Yorkshire County Council.

North Yorkshire County Council

Scrutiny of Health

In-depth scrutiny of End of Life Care in the county

Executive Summary

The objective of this piece of extended scrutiny work has been to engage with a broad range of commissioners, service providers, patients and the public to better understand the current provision of end of life care in North Yorkshire and identify any areas where recommendations for improvements could be made.

The challenge has been to keep a focus on adding value to the work that has been done to date nationally, regionally and locally and highlighting areas for improvement or further investigation that are realistic and achievable.

Key findings from this piece of extended scrutiny include:

- People are neither used to nor comfortable with talking about death. This is a societal issue that has far reaching consequences for people in the last months of their lives
- The type of patient for whom end of life care services and interventions are provided is changing
- The support that is given to people in the last 12 months of their life is overwhelmingly provided by carers and close family members
- Bereavement counselling and psychological therapies are not widely available or accessible to people in need
- Whilst hospital may be the appropriate place for many people to die, there are significant costs associated with end of life care in hospital and any unplanned or emergency admissions
- There is a strong financial case to support increased funding for multi-agency community-based end of life care packages on the basis of an ‘invest to save’ argument
- New ways of working may be required to meet the challenges posed by the rural nature of the county
- At present, there is no shared, common vision or strategy for end of life care commissioning and provision throughout the county
- Hospices have over 30 years of specialist knowledge and expertise and could be better involved in the development of a co-ordinated approach across the county
- The planning and co-ordination of care for people in the last 12 months of their life is hampered by the lack of a common electronic system for sharing and updating care plans and patient notes
- The provision of 7 day services and/or out of hours care remains a challenge in health and social care in general and it is also the case for end of life care
- End of life care does not stop at the point in which a patient dies. The way in which family members and carers experience the death of a loved one and how that person is treated after their death will have a lasting impact.

There are 9 recommendations in the report, many of which flow from the first recommendation to establish a multi-agency forum for commissioners and providers of end of life care in the county. It is anticipated that this would enable:

- greater co-ordination of service planning and delivery across health, social care and the voluntary sector
- the agreement of some common standards and principles for equitable end of life care, possibly in the form of a charter or a similar statement of intent
- the identification of a set of outcomes to be achieved with milestones and a mechanism in place for tracking progress against those milestones
- sharing of good and best practice
- the identification of areas for service improvement
- patient and carer representation and involvement and opportunities for co-design
- health and social care strategic planning to be influenced
- inequalities in the access to end of life care services across the county to be addressed.

The recommendations in this report will be presented to the North Yorkshire Health and Wellbeing Board at their meeting of 17 March 2017.

Section 1 – Background, objectives and methodology

Background

In July 2015 the North Yorkshire Scrutiny of Health Committee was consulted on the 2015 update of the North Yorkshire Joint Health and Wellbeing Strategy (JHWS) 2015-2020. The Committee concluded that there should be a greater emphasis on improving End of Life Care and supporting friends and relatives deal with bereavement and, in some cases, the longer term problems around isolation and loneliness.

The Committee recommended that End of Life Care should be given greater prominence in the Strategy and that there should be a specific priority of ‘Dying Well’. This recommendation was accepted by the Health and Wellbeing Board.

The Joint Health and Wellbeing Strategy 2015–2020 was revised to include the ‘Dying well’ theme. Under this theme a number of improvements to the quality of end of life care services and interventions are listed that will be progressed by 2020, as below:

- A greater range of support options for people in their last years of life
- More people receiving support for themselves and their families at the end of life
- More people dying at home or in the place that they choose
- Greater numbers of trained staff and carers with deeper understanding about the range of issues in end of life care
- Adoption of new and emerging best practice and principles around end of life care (Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 - www.endoflifecareambitions.org.uk)
- End of life care being planned in an effective and sensitively appropriate way, and for staff to be adequately trained.

A copy of the North Yorkshire Joint Health and Wellbeing Strategy 2015–2020 is available here - http://www.nypartnerships.org.uk/CHttpHandler.ashx?id=21125&p=0

The role of the Scrutiny of Health Committee

The role of the Scrutiny of Health Committee is to review any matter relating to the planning, provision and operation of health services in the County.

The aim is to act as a lever to improve the health of local people, ensuring that the needs of the local people are considered as an integral part of the delivery and development of health services.

This includes:

- Focus on action to achieve health improvement
- Examine healthcare in the context of the wider determinants of health

- Examine how health services address the needs of local communities
- Address health inequalities
- Ensure that local health and health related issues are being tackled jointly and in a coordinated way across agencies.

The extended scrutiny of end of life care services and interventions in the county supports the aim to ensure that ‘the needs of local people are considered as an integral part of the delivery and development of health services’.

Objective

The objective of this piece of extended scrutiny work has been to engage with a broad range of commissioners, service providers, patients and the public to better understand the current provision of end of life care in North Yorkshire and identify any areas where improvements could be made.

Recommendations for any improvements will be reviewed at the Scrutiny of Health Committee on 27 January 2017. The intention is then for the final version of the report to be signed off at the committee’s Mid Cycle Briefing on 3 March 2017. Thereafter, the report would be formally submitted to the North Yorkshire Health and Wellbeing Board at their meeting of 17 March 2017.

Methodology

The approach taken has been extended scrutiny over a 6 month period. The project has been overseen by the Committee Chairman in consultation with the group spokespersons.

The project was launched at the Scrutiny of Health Committee meeting on 1 July 2016 and a project plan endorsed at committee on 2 September 2016.

The approach has included:

- Desktop research into national guidance, policy and best practice
- Written reports and presentations to the full committee
- Expert witnesses
- Visits to hospices
- Consultation/focus group discussions with stakeholders, carers and patients.

Children and adults

Whilst the majority of people who die are older people, in North Yorkshire typically 85 years of age or older, children, young people also die and so the end of life care services that are on offer to them and their families have also be considered within the scope of this extended piece of scrutiny.

Work plan

The following version of the work programme was agreed by the Scrutiny of Health Committee on 2 September 2016:

Date	Action
July 2016	Committee meeting on 1 July - project launch, initial meeting, and engagement with Hospices.
	Mid Cycle Briefing on 29 July - identification of issues (lines of enquiry) to explore at focus group meetings.
August 2016	Further research and contacts, refinement of the project plan and preparation for 2 September committee meeting.
September 2016	Committee meeting on 2 September - update on Joint Strategic Needs Assessment and evidence from 'expert witnesses'. Joint Strategic Needs Assessment (JSNA) report 'Dying Well: an Overview of End of Life Care in North Yorkshire' report and presentation - Victoria Turner, Specialty Registrar in Public Health. Expert witness - Alex Bird, Chief Executive Officer, Age UK North Yorkshire – Health and Wellbeing Sponsor for Health and Wellbeing Strategy priority of 'Dying Well'.
October 2016	Mid Cycle Briefing on 14 October – CCG perspective – overview of the current and planned provision and commissioning of End of life care services by the 5 CCGs in North Yorkshire.
	21 October – North Yorkshire Wider Partnership Conference workshop on End of Life Care.
November 2016	10 November 2016 – site visit to Saint Michael's, Harrogate - convened by Tony Collins. 16 November 2016 – site visit to St Catherine's Hospice, Scarborough - convened by Mike Wilkerson.
	A joint press release to be issued, by NYCC and NY Healthwatch, inviting people to share their experiences of End of Life Care. Responses to be gathered and analysed by NY Healthwatch.
	Committee meeting on 18 November – update on programme of work, outcome of site visits and evidence from 'expert witnesses'.

Date	Action
	Expert witness – Clair Holdsworth, Deputy Director of Clinical Services, Martin House - Hospice Care for Children and Young People.
December 2016	Mid Cycle Briefing on 16 December – early draft of report for discussion.
	13 December 2016 – site visit to St Leonard's Hospice, York - convened by Emma Johnson.
	Healthwatch to undertake a survey and analysis of findings to feed into December early draft report.
January 2017	Healthwatch to undertake 'Enter and View' visits and feed the analysis of findings into the report in February 2017. Early January 2017 - circulate report to partners and contributors for comment, additions and amendments. Committee meeting on 27 January – draft report for review.
February 2017	Finalisation of report.
March 2017	Report to Scrutiny of Health Mid Cycle Briefing for sign off on 3 March 2017 Report to Health and Wellbeing Board on 17 March.

Definition of terms

End of life care - End of life care is for people who are considered to be in the last year of life, but this timeframe can be difficult to predict. End of life care aims to help people live as well as possible and to die with dignity. End of life care continues for as long as it is needed. End of life care includes the palliative management of pain and other symptoms.

Palliative care - Palliative care is generally for people living with a terminal illness where a cure is no longer possible. It can also be used by people who have a complex illness and need their symptoms controlled. The goal of palliative care is to help the person and everyone affected by their illness to achieve the best quality of life.

Own home – The definition of 'own home' is broad as people in the last 12 months of their life may be living in a range of different settings, which they may call home. These could include: a home that they own or rent; the home of a relative or friend; a residential care home; a nursing home; and a hospice. It may be more useful to refer to 'familiar surroundings'.

Last 12 months of life – throughout policy and practice reference is made to the last 12 months of life as the period during which end of life care planning should be undertaken. Medical professionals make an informed judgement as to when a patient is in the last 12 months of their life.

Section 2 – Literature review

Introduction

There is a wide range of research, policy, strategy, guidance and best practice on the subject of end of life care. This reflects the position of the UK as an international lead in the provision of end of life care services and interventions. This also reflects the momentum that has been gained since the publication of the 2008 National Strategy for End of Life Care.

The literature review summarises the key issues identified in a range of documents that have been identified as the most significant. It is, by necessity, exclusive.

National data and needs assessments

Office for National Statistics (July 2016) Statistical bulletin: Deaths registered in England and Wales: 2015

https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/previousReleases

The annual data on death registrations highlights:

- There were 529,655 deaths registered in England and Wales in 2015, an increase of 5.6% compared with 2014
- Age-standardised mortality rates (ASMRs) increased in 2015 by 5.1% for females and 3.1% for males; a change to the general decrease in rates in recent years.
- In 2015, mortality rates for respiratory diseases (including flu) increased notably for both males and females.
- Cancer was the most common broad cause of death (28% of all deaths registered) followed by circulatory diseases, such as heart disease and strokes (26%).
- The infant mortality rate remained at 3.9 deaths per 1,000 live births in 2015.

Office for National Statistics (2015) National Survey of Bereaved People (VOICES)

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/previousReleases

This national survey has been run for 5 years. The summary findings from the 2015 survey are as below:

- 3 out of 4 bereaved people (75%) rate the overall quality of end of life care for their relative as outstanding, excellent or good
- 1 out of 10 (10%) rated care as poor
- Overall quality of care for females was rated significantly higher than males with 44% of respondents rating the care as outstanding or excellent compared with 39% for males
- 7 out of 10 people (69%) rated hospital care as outstanding, excellent or good which is significantly lower compared with care homes (82%), hospice care (79%) or care at home (79%)
- Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (29%) compared with the least deprived areas (22%)
- 1 out of 3 (33%) reported that the hospital services did not work well together with GP and other services outside the hospital
- 3 out of 4 bereaved people (75%) agreed that the patient's nutritional needs were met in the last 2 days of life, 1 out of 8 (13%) disagreed that the patient had support to eat or receive nutrition
- More than 3 out of 4 bereaved people (78%) agreed that the patient had support to drink or receive fluid in the last 2 days of life, almost 1 out of 8 (12%) disagreed that the patient had support to drink or receive fluid
- More than 5 out of 6 bereaved people (86%) understood the information provided by health care professionals, but 1 out of 6 (16%) said they did not have time to ask questions to health care professionals
- Almost 3 out of 4 (74%) respondents felt hospital was the right place for the patient to die, despite only 3% of all respondents stating patients wanted to die in hospital.

Nuffield Trust (2014) Exploring the cost of End of Life Care
http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end_of_life_care.pdf

The Nuffield Trust conducted research into the costs associated with non-hospital care services and how people were using them at the end of their lives. Key findings include:

- Hospital costs were by far the largest cost elements of end-of-life care. These averaged over £4,500 per person for those who died, during the final 90 days of their lives. The bulk of this cost was due to emergency hospital admissions. Hospital costs increased rapidly in the last few weeks of life.
- Approximately two thirds of patients saw their GP at least once during the last three months of life, and there were an average of four to five GP visits per person in this time – costing an average of £147 per patient
- Just over a quarter of patients used local authority funded social care during the last 90 days of their life, but the high costs of nursing and residential care meant this averaged out at £1,010 per person who died.

A health economics report is being written by Public Health England and University of York on the costs of end of life care. At the time of writing, this report had not been published.

The Choice in End of Life Care (2015) Programme Board 'What's important to me - A Review of Choice in End of Life Care'
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf

The Choice in End of Life Care Programme Board was a multi-agency group tasked by Government to provide advice on improving the quality and experience of care for adults at the end of life and those around them. The programme board agreed the following commitment for the provision of end of life care services.

Each person who may be in need of end of life care is offered choices in their care focused on what is important to them and that this offer is:

- made as soon as is practicable after it is recognised that the person may die in the foreseeable future
- based on honest conversations with health and care staff, which supports the person to make informed choices
- consistently reviewed through conversations with health and care staff.

A total of 30 recommendations were made covering: the individual; family and carers; workforce; health and social care; Government; society and community.

Royal College of Physicians (May 2014) National care of the dying audit for hospitals
https://www.rcplondon.ac.uk/projects/outputs/national-care-dying-audit-hospitals

The 2013/14 audit involved a case note review of a sample of all patients dying in hospital. A total of 131 trusts (90% of those eligible) submitted data to the organisational audit. The key findings were:

- Less than a quarter of hospitals had face-to-face palliative care services 7 days per week
- The provision of mandatory training on end of life care for doctors and nursing staff was low
- Documentation of key decisions, assessments and needs in case notes was either inconsistent or key actions were not being taken. For example, there was evidence of only 21% of patients being asked about their spiritual needs
- Local surveys of bereaved relatives showed that 24% did not feel they were involved in decisions about the care and treatment of their family member at all
- Three quarters of bereaved relatives surveyed felt adequately supported during the patient's last 2 days of life.

Local data and needs assessments

North Yorkshire Joint Strategic Needs Assessment

The North Yorkshire Joint Strategic Needs Assessment (JSNA) provides an overview of the current and future health and wellbeing needs of the people of North Yorkshire. It does not look at the particular needs of individual people but seeks to identify where needs are not being met as well as they could be. Specifically, it sets out to answer the following:

- What do people need?
- What are we doing already?
- Is it working?
- Are there things we should be doing but are not?
- Are we targeting services properly?

At the Scrutiny of Health Committee meeting on 2 September 2016, Dr Victoria Turner, Public Health Registrar, presented the findings of the JSNA review of end of life care, as summarised below:

Headline data
Place of death in North Yorkshire in 2013:

- In 2013 there were 6,197 deaths in North Yorkshire across all age groups (1.03% of the total population)
- Of these, 22.2% (1,375) deaths occurred at home
- 26.4% (1,636) deaths occurred in a care home
- 5.8% (358) deaths occurred in a hospice
- 43.3% (2,681) deaths occurred in hospital
- 2.4% (147) deaths occurred in other places.

The place of death does not necessarily indicate the range of different settings a person may have received treatment or support in the period leading up to their death.

The top three causes of death in North Yorkshire in 2013:

- Cancer – 27%
- Circulatory disease – 31%
- Respiratory disease – 13%.

Unmet need
Areas of potential unmet need identified:

- Access to preferred place of dying
- Integration of end of life care into all care pathways, particularly for illness pathways other than cancer
- Co-ordinated IT system to enable greater data sharing
- Access to inpatient hospice facilities – there are none in Craven*, Hambleton, and Richmondshire. Also, there is no children's hospice within North Yorkshire
- Training in palliative care
- Out of hours access
- Holistic care.

*Craven residents can access Hospice facilities outside of the county.

Areas for further investigation
It also highlighted areas for further assessment and/or investigation, as below:

- Training, particularly for those people working in more general palliative and end of life care, such as social workers, care home staff and primary care staff. Examples include, e_ELCA (End of Life Care for All training on line) http://www.e-lfh.org.uk/programmes/end-of-life-care/learning-paths/
- Accuracy of recording on the palliative care register
- Information on patient experience at a North Yorkshire level
- Preferred place of death - what proportion of those who express their preference actually die there?
- Assessment of non-health needs, such as social care, spiritual care, legal assistance, general wellbeing advice and emotional support
- Access to services among different socioeconomic groups
- Detailed funding arrangements
- Cost-effectiveness of End of Life Care.

The full report entitled 'Dying Well: an Overview of End of Life Care in North Yorkshire - Joint Strategic Needs Assessment - July 2016' is available on the North Yorkshire County Council website – http://hub.datanorthyorkshire.org/dataset/2cb529f6-4715-4c2d-9364-a770deb03472/resource/21e21b0d-54a1-4eb0-9665-bddf2efa24ac/download/eolc-jsna-report-13-07-16.pdf

National strategy

Ambitions for Palliative and End of Life Care - 2015
The key policy document that has been issued by the Government in the past 5 years is the National Palliative and End of Life Care Partnership (2015) 'Ambitions for Palliative and End of Life Care: a national framework for local action 2015-2020' - http://endoflifecareambitions.org.uk/

This national framework, aimed at local health and social care and community leaders, builds upon the Department of Health's 2008 Strategy for End of Life Care. It has a strong emphasis upon local delivery, partnership, collaboration and co-operation.

The delivery of the national framework is not supported by additional funding. Instead, the emphasis is upon inspiring a wide range of agencies and organisations to drive forward improvements in end of life care.

The national framework has six positive ambitions for palliative and end of life care:

1. Each person is seen as an individual – Honest conversations, Systems for person centred care, Clear expectations, Access to social care, Helping people take control, Integrated care, Good end of life care includes bereavement.
2. Each person gets fair access to care – Using existing data, Community partnerships, Generating new data, Unwavering commitment, Population based needs assessment, Person-centred outcome measurement.

3. Maximising comfort and wellbeing – Recognising distress whatever the cause, Addressing all forms of distress, Skilled assessment and symptom management, Specialist palliative care, Priorities for care of the dying person, Rehabilitative palliative care.
4. Care is co-ordinated - Shared records, Clear roles and responsibilities, A system-wide response, Everyone matters, Continuity in partnership
5. All staff are prepared to care – Professional ethos, Support and resilience, Knowledge based judgement, Using new technology, Awareness of legislation, Executive governance
6. Each community is prepared to help – Compassionate and resilient communities, Public awareness, Practical support, Volunteers.

These ambitions are founded upon:

1. Personalised care planning
2. Education and training
3. Evidence and information
4. Co-design
5. Shared records
6. 24/7 access
7. Those important to the dying person
8. Leadership.

Strategy for End of Life Care - 2008
Department of Health (2008) End of Life Care Strategy - Promoting high quality care for all adults at the end of life
https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life

The intention of the 2008 Strategy was to raise awareness of the importance of end of life care provision and increase access to high quality care for all people approaching the end of life.

Adopting a whole system and care pathway approach, the strategy defined a set of minimum expectations around a 'good death' as being

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends.

The strategy outlined what its successful implementation would mean for patients and carers, as follows:

- The opportunity to discuss your personal needs and preferences with professionals who can support you, have them recorded in a care plan and acted upon
- Coordinated care and support
- Rapid specialist advice and clinical assessment
- High quality care and support during the last days of your life

- Services which treat you with dignity and respect both before and after death
- Appropriate advice and support for your carers at every stage.

To achieve this, services will be:

- Well planned and coordinated
- Quality assured and delivered to a high standard
- Monitored and assessed to ensure quality
- Informed by the experience of others who have been in a similar situation to you.

The strategy is credited with having managed to reverse the upward trend of people dying in hospital. Also, that it generated momentum and energy, which led to significant improvements in end of life care.

One chance to get it right - 2014
Leadership Alliance for the Care of Dying People (2014) ‘One chance to get it right - Improving people’s experience of care in the last few days and hours of life’.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

In 2014 the Leadership Alliance for the Care of Dying People published a report setting out an approach to caring for dying people that should be applied system wide, in all settings. In summary, the Priorities for Care are that, when it is thought that a person may die within the next few days or hours:

- The possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed
- Sensitive communication takes place between staff and the dying person, and those identified as important to them
- The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants
- The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
- An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

The Leadership Alliance, a partnership of 21 organisations from health, social care and the community and voluntary sector, was set up in response to the independent review of the Liverpool care Pathway for the Dying Patient (LcP), which reported in July 2013.

Actions for End of Life Care – 2014
NHS England (2014) Actions for End of Life Care: 2014-16
https://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf

This national policy statement set-out a series of commitments for the period 2014-16, based upon a ‘House of Care’ model, as below:

- People who are living with progressive, life-limiting conditions must be at the centre of any decision, plan or action for their care or treatment
- Health and care professionals build and sustain their commitment to working in partnership with each other, and with the people they care for and those close to them
- Consistent, coordinated care is a crucial component of person-centred care, especially for people with progressive, life-limiting conditions, and those close to them
- Improve the commissioning of palliative and end of life care services so that people living with progressive, life-limiting conditions, and those close to them, can receive the best possible care which matches their level of need and, as far as possible, preference.

It pre-dates the 2015 national framework and represents a restatement of much of the 2008 Strategy.

Clinical guidance and best practice

NICE commissioning guidelines - CMG42 (December 2011) 'Guide for commissioners on end of life care for adults'

https://www.nice.org.uk/guidance/qs13/resources

The guidelines identify a number of areas in which clinical practice and quality can be improved:

- Reducing inequalities and improving identification through de-stigmatising death and dying and encouraging healthcare professionals and people with end of life care needs and their families and carers to engage in open conversations
- Improving the quality of care including care after death, through holistic assessments and timely interventions in the right place by a knowledgeable, caring and competent workforce
- Increasing choice and personalisation through care planning and advance care planning, including advance statements and advance decisions to refuse treatment and provision of resources that enable these choices to be achieved.
- Ensuring care is coordinated and integrated across all sectors involved in delivering end of life care
- Improving the psychological, physical and spiritual well-being of people with end of life care needs and their carers through access to an appropriately trained and resourced workforce
- Timely access to information and support to enable people with end of life care needs and their families and carers to make informed decisions
- Timely provision of continuing NHS healthcare funding to support people to die in their place of choice
- Supporting carers and ensuring access to an assessment of need as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004
- Timely access to generalist and specialist palliative care services on the basis of need and not diagnosis. This includes the provision of community based support

and access to specialist advice (which may be via telephone) 24 hours a day, 7 days a week

- Reducing unnecessary hospital admissions and length of stay by developing capacity to deliver expertise to the person's usual place of residence through pathway redesign and workforce development. This includes supporting staff in social care settings such as care homes and domiciliary workers; supporting relatives and friends who are caring for a person with end of life care needs; and providing the necessary clinical expertise, medicines and equipment
- Improving cross-boundary and partnership working, through close working between health and social care services to ensure flexible and integrated services that have the infrastructure to enable this (for example shared IT networks). This should improve care coordination, minimise unnecessary duplication and reduce costs
- Improving knowledge and skills in generalist and specialist palliative care settings, and in social care settings including independent residential and nursing homes and domiciliary workers.

Care Quality Commission (May 2016) 'A different ending: End of life care review' - Addressing inequalities in end of life care
http://www.cqc.org.uk/content/different-ending-our-review-looking-end-life-care-published

The report found that there were significant variations in end of life care and that a number of groups were under-represented:

- people with conditions other than cancer
- older people
- people with dementia
- people from Black and Minority Ethnic (BME) groups
- lesbian, gay, bisexual and transgender people
- people with a learning disability
- people with a mental health condition
- people who are homeless
- people who are in secure or detained setting
- Gypsies and Travellers.

Specific actions that have been identified to enable everyone to access the care that they need:

1. Leaders of local health and care systems to work together to develop a plan for delivering good quality, equitable end of life care for everyone in their community.
2. Commissioners and providers to fulfil their duties under the NHS Constitution, the Health and Social Care Act 2012 and the Equality Act 2010 to reduce inequalities, eliminate discrimination and advance equality when developing, arranging or delivering end of life care.
3. Commissioners and providers to ensure that staff who care for people who may be approaching the end of life, including care home staff, have the knowledge, skills and support they need.

4. Hospices to champion an equality-led approach, engage communities, deliver equitable end of life care, and support others to do the same.
5. GPs to ensure that everyone with a life-limiting progressive condition has the opportunity to have early and on-going conversations about end of life care, and is given a named care coordinator.

Non-governmental guidance and best practice

End of Life Care Coalition ‘On the Brink: The Future of End of Life Care’
http://endoflifecampaign.org/wp-content/uploads/2016/02/End-of-Life-Report-WEB.pdf

The following are identified as making a difference:

- Well-funded high quality care available both inside and outside hospital for all who need it
- Investment in palliative care specialists and generalist health and social care professionals with the knowledge, understanding and time to deliver choice and provide high quality care for people at the end of their lives
- Access to good quality advice and support, including out of hours, to provide families and carers with practical assistance and guidance if the person they are caring for has a change in symptoms or needs additional help
- Fully co-ordinated and integrated care across all teams and services supporting a person at the end of their life, including fair access to social care, using appropriate care plans in a joined-up way
- Training for all health care professionals, so they know how to support someone approaching the end of their life confidently and sensitively
- A higher proportion of the medical research budget dedicated to developing better ways of caring for terminally ill people and their families.

Together for short lives ‘Charter’

‘Together for short lives’ is a UK charity that represents all children and young people who are expected to have short lives.

- Every child and family member should be treated with respect and dignity
- The child and family should be offered an individual care and support package that is built around their unique needs
- A multi-disciplinary team should work together to support the family, and communicate with the child and family in an open and honest manner
- Children and families should always be listened to, and be encouraged to talk through their wishes and care choices
- At all stages of care, from diagnosis to death and bereavement, families should be provided with accurate and relevant information that they can understand
- Where possible, children should be cared for in the family’s place of choice – in hospital, a hospice, or at home
- Emotional, psychological and spiritual support should be offered to the child, and those close to him or her

- Children and young people should be given the opportunity to access education and employment that is right for them
- The child and family's wishes concerning end of life care should be discussed and planned for well in advance
- Support and care should extend to all family members, friends and all those involved with the child.

Further information is available from the Together for short lives website, as follows http://www.togetherforshortlives.org.uk/

Summary of key findings from the literature review

There are a number of themes that have been identified in the literature review, as below:

- The majority of people, about 75%, experience good quality end of life care, whether that is at home, in a care home or in a hospital. However, 25% do not.

- Whilst most people state that the preferred place of death is their own home, most people, 43%, die in hospital. It is recognised, however, that a person's view on where they would like to die depends on the nature and progress of their disease and how their quality of life and ability to exercise personal choice can best be supported. Often, this will mean that a hospital bed is preferred to their own home.

- In 2013/14, less than a quarter of hospitals had face-to-face palliative care services 7 days per week and mandatory training for doctors and nurses on care of the dying was not universally provided or taken up.

- The question that should be posed is not one of 'where would you prefer to die' but 'what would you like to have in place to make your death the best it can be for you and those around you?'

- There remains a reticence to openly discuss death and make plans and decisions about how someone will live out the last 12 months of their life. This reticence is cultural/societal and so inhibits the ability of patients, carers and health and social care staff to plan care packages and make informed choices.

- There are an excessive number of unplanned hospital admissions for people in the last months of their life. Typically, these admissions are via Accident and Emergency Departments. This reactive approach is not in keeping with good quality care and effective symptom management and can generate unnecessary costs to the health system.

- Care is not consistently co-ordinated throughout the health and social care system. The wishes of an individual are not routinely recorded and shared as a personalised care plan, which can be accessed by all relevant health and social care agencies and organisations.

- Not all health and social care staff are trained and in assessment and symptom management.

- There is a shortage of specialist end of life care and palliative care knowledge and experience within health and social care services.

- Family members and carers are not routinely involved in dying people's care planning.

- Out of hours support for patients and their carers, when in their own home, is varied and inconsistent. As a result, many people who could be supported to live in their own home during their last 12 months of life are unable to.

- There is only limited assessment of non-health needs, such as social care, spiritual care, bereavement support, legal assistance, general wellbeing advice and emotional support.

- There is not consistent and fair access to end of life care services and interventions, with variations in access to among different socioeconomic groups.

- There are no inpatient hospice facilities in Craven, Hambleton, and Richmondshire district council areas.

- Over time, end of life care services and interventions have been based around people suffering from terminal cancer. There are a number of other terminal diseases for which end of life care pathways need to be developed and improved.

- There is no new central Government funding and securing additional local funding will depend on whether end of life care is a local priority.

Section 3 - Organisations Giving Evidence

County Council – Health and Adult Services

Ian Spicer - (Interim) Assistant Director, Care and Support, attended a Mid Cycle Briefing of the Scrutiny of Health Committee on 14 October 2016 and provided an overview of the role that the County Council plays in supporting adults in the last months of their life. In particular, what is currently in place and where there were further opportunities for joint working and/or service improvements.

Existing approach

- A service specification is in place for independent care Homes and Nursing Homes that sets out some minimum standards for end of life care and for the promotion of dignity.
- There is a commitment to promote choice and for people to be enabled to plan the last 12 months of their life, including where they would prefer to die.

- The key role that carers have to play is recognised, as is the need to provide consistent support to them.
- A new role within Health and Adult Services (HAS) has been created, 'Practice lead', which has responsibility for end of life care, amongst other. The focus here will be upon promoting good practice and high quality assessments of need, under the new model for care and support that HAS adopted.

Service improvements

- There are opportunities for joint training and staff awareness across the health, social care and community sector.
- There could be closer working with hospices in the county, drawing upon their extensive experience of end of live care service development and implementation. The Hospice UK website has a number of examples of joint working across hospices, health and social care - https://www.hospiceuk.org/policy-advocacy/briefings-consultations
- Improvements could be made in end of life care planning, particularly following any changes in placement.

County Council – Children and Young People's Services

Emma Thomas, Children's Commissioning Manager – Healthy Outcomes, attended a Mid Cycle Briefing of the Scrutiny of Health Committee on 14 October 2016 and provided an overview of the role that the County Council plays in supporting children and young people in the last months of their life.

Children are subject to the 'continuing care' process of assessment. A continuing care package will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.

'Together for short lives' is a UK charity that represents all children and young people who are expected to have short lives. The aim of the charity is to help children and families make the most of their time together. Together for short lives has produced a summary of how end of life care for children and young people is different to adults, as below:

- The number of children who die is small
- Many of the conditions are extremely rare with diagnoses specific to childhood
- Palliative care may last only a few days, weeks or months, or may be delivered on and off for a number of years.
- Many of the conditions are genetic
- Children's palliative care embraces the whole family
- Children's palliative care providers need to be aware of and respond to the continuing physical, emotional and cognitive development throughout childhood Provision of education and play when a child is seriously ill is essential.

Further information is available from the Together for short lives website, as follows http://www.togetherforshortlives.org.uk/

Clinical Commissioning Groups

Representatives from the five Clinical Commissioning Groups that commission services in North Yorkshire attended a Mid Cycle Briefing of the Scrutiny of Health Committee on 14 October 2016, to discuss end of life care provision in the county. The key issues identified are summarised as below.

Key challenges

- Both a dispersed population and a dispersed system of health and social care resources having an impact on the effective delivery of packages of end of life care in people's homes
- Lack of domiciliary care and difficulties in commissioning Fast Track Continuing Healthcare
- Fragile market of specialist and generalist health and social care providers
- End of life care for people who are frail, have dementia or a number of different conditions
- Delivery of an equitable approach across the county that reflects local needs, infrastructure and services
- Shortages of trained health and social care staff who can support delivery of end of life care
- Need to better understand the 'disease trajectories' and what specific conditions, other than cancer, mean for people's end of life care
- Need to provide support for carers and families, once a package of end of life care has been put in place. Otherwise, the package of care can fail as carers and families struggle in the final days of a loved one's life.

Key infrastructure

- Strong working relationship between the Acute Trust and the CCGs
- Electronic Palliative Care Coordination System (EPaCCS) – question as to whether this will be put in place across North Yorkshire
- Community nurses play a key role in delivering and coordinating community-based end of life care
- Reliance upon the community and voluntary sector
- The 111 directory is helpful but only if kept up to date
- Rapid relief teams as a replacement for fastrack, in some areas.

Sustainability Transformation Plans

- Concerns that end of life care may not be a priority under the new planning regime
- CCGs and need to ensure that, despite the large geographic coverage of the STPs, a local approach to end of life care is implemented
- STPs are focussed upon the centralisation of specialist services but end of life care is best provided locally and in the community
- The STPs may offer some economies of scale and enable the provider market to be strengthened.

Engagement

- Some patients and carers are fiercely independent and do not accept the care or support that they need until it is too late for an end of life care package to be put in place
- Need to ensure that health and social care practitioners are trained in and have confidence in having discussions with people, as they approach the last year of their life, about their choices
- Queries about how you identify someone as being in the last year of their life
- If you get it right for one person, then others will hear of it and it will increase confidence amongst service users and providers.

Examples of local good practice

- Gold line 24/7 service for patients thought to be in their last year of life and their carers. Patients who use Goldline have better outcomes and reduced hospital admissions (14% die in hospital compared to 35% of all deaths in Airedale, Wharfedale and Craven (AWC) CCG area. Covers AWC CCG and 2 Bradford CCGs
- AWC CCG is part of the National Pioneer Programme that is testing out new models of care
- System 1 – shared across GPs, hospitals, community nurses and hospices in AWC CCG area
- Serious Illness Care Programme UK, which looks at improving joint planning of patient care
- Use of step up and step down beds and commissioning of nursing home beds for end of life care – Hambleton, Richmondshire and Whitby (HRW) CCG
- Wrap around care in people’s homes and community therapy, intermediate care and community nursing services AWC CCG
- Joint work with pharmacies to ensure access to medication – Harrogate and Rural District (H&RD) CCG
- PalCall Service – nurse led out of hours helpline in Scarborough and Ryedale (S&R) CCG
- Voluntary and Community sector care and support through the Carers’ Resource and home from hospital services.

Possible next steps

- Create a forum for commissioners and providers of end of life care to meet and work through shared challenges, share best practice, coordinate activity and tackle gaps in provision
- Retain a strong focus on commissioning community based palliative care in people’s homes
- Agree a shared vision for the outcomes that we collectively want to achieve for end of life care in North Yorkshire. The focus is upon outcomes and standards and not processes.
- Join up the health and social care workforce strategies
- Review level of support, information and advice provided to carers of people who are nearing the last 12 months of their life
- Articulate the financial argument in favour of supporting people to die in their own home
- Clarify care home training needs

- Review fast track commissioning arrangements/intentions
- Agree realistic targets to work to for people dying in the place of their choosing
- Strengthen links with Yorkshire Ambulance Service.

Hospices

Tony Collins, Saint Michael's Hospice

Tony Collins, Chief Executive, Saint Michael's Hospice, Harrogate presented a report to the Scrutiny of Health Committee on 1 July 2016. The key points raised are summarised as below.

A copy of the full report is available on the North Yorkshire County Council website. http://democracy.northyorks.gov.uk/committees.aspx?commid=23&meetid=3368

North Yorkshire End of Life Care

North Yorkshire has a statistically higher than average:

- Older population (those above 65, 75 and 85) for males and females
- Death rate
- Percentage of deaths
- Deaths in care homes
- Deaths from heart disease.

North Yorkshire has a statistically lower than average:

- Deaths in hospital
- Residents in urban localities
- Deaths from respiratory disease
- Deaths from liver disease.

It has been estimated that 3,600 will die within the population each year. It is likely, however, that from the 16,448 people over 85 years of age, some end of life care service will be required and could be required for longer than the last months of life.

Value for money

Taken from a number of sources, including Hospice UK and Marie Curie, evidence suggests that Hospices are value for money. Hospices provide value for money:

- Hospices can support in the reduction of unnecessary admissions
- Hospices can reduce hospital deaths by 20% each year generating a saving of £80m to the NHS
- The palliative care funding review for England found extending 'specialist and core' services could result in net savings.

Bereavement increases the risk of mortality and poor health. In Scotland, this cost was estimated to be £20 million, which when extrapolated to England was between £150 and £190 million.

There is estimated to be between 80,000 and 124,000 people living with Lymphoedema in the UK. Lymphoedema is a swelling that develops as a result of an impaired lymphatic system. This may be as a result of the lymphatic system not developing properly or through damage or trauma, such as cancer. For every £1 spent on Lymphoedema treatments it is estimated that it would save £100 in reduced hospital admissions due to swelling and infection.

Clair Holdsworth, Martin House
Clair Holdsworth, Deputy Director of Clinical Services, Martin House gave a presentation on end of life care to the Scrutiny of Health Committee on 18 November 2016.

Clair gave an overview of the service provided by Martin House, how palliative and hospice care for children and young people differs from that provided to adults, and some of the issues encountered by children, young people and their families when seriously ill and in need of palliative care. Specifically:

- The need for care and services that is right for their age – from neonates to young adults
- Short breaks, with nursing and medical support when required
- To be able to continue with their education and have the opportunity to participate in social activities and be with their friends
- Specialist support for siblings
- Bereavement support for the family.

Clair Holdsworth stated that a piece of research had been undertaken that suggested that there were 398 children in North Yorkshire that needed specialist palliative and hospice support. It is understood that this is an under-estimate and that the real figure is likely to be around 560.

Clair Holdsworth noted that the main referral routes were via consultants and social care.

A number of challenges were identified, as below:

- Recruitment of qualified/skilled staff – albeit that in-house training schemes are in place to up-skill workers
- Shortages of some specialist staff within the NHS locally, which creates gaps in community-based service provision
- Identifying ‘hard to reach’ children and young people
- A shortage of counselling services for children in the community.

Voluntary and Community

Alex Bird, Age UK North Yorkshire
Alex Bird, the Voluntary Sector Representative on the North Yorkshire Health and Wellbeing Board and the Sponsor for the End of Life Care Theme, gave a presentation on end of life care to the Scrutiny of Health Committee on 2 September 2016. The key issues identified are summarised as below:

The End of Life (EoL) for everyone is a time of significant vulnerability both for the person who is dying, and the family/friends they choose to have around them.

Everyone should have the right to high quality palliative care when they have a terminal illness, regardless of their condition, where they live, or their personal circumstances.

The UK has been ranked as the best country in the world for palliative care on offer but access to care is patchy and one in four people who need palliative care miss out each year.

Whether a dying person is cared for at home/hospital/care home/hospice- right to expect that their pain will be managed actively, treated with respect and compassion, and that they are listened to.

National approach
The "Review of choice in End of Life Care" was published in 2015 and set out the elements of EoL Care that people most care about and where people felt choice should play the greatest role.

In July 2016, the Government unveiled a new national commitment on EoL care setting out its vision for improving care for dying people and their families. The key components of personalised care are set out that everybody should expect to receive.

Key partners
Local ownership and accountability will be critical to help achieve the central government vision. Key partners will be the CCGs and the Health and Wellbeing Board. As well as these named players, other important partners include Care Homes, Hospices, voluntary organisations e.g. Macmillan, Marie Curie, Sue Ryder as well as local community based charities and most of all, individuals and the families and carers.

Some key issues identified by people at the EoL include:
- Discrimination and lack of understanding by care and support services
- Religious and spiritual needs
- Assumptions about sexuality or gender identity and family structures
- Varied support networks
- Unsupported grief and bereavement
- Increased pressure on carers.

Recommendations
Making good EoL care happen is not the responsibility of one persons or organisation. It happens because professionals and organisations work together, share information and focus on the individual's needs. Some key aspects include:

- Training for staff
- Work with national and local charities e.g. MacMillan, Sue Ryder, Hospices
- Ensure that literature and materials about EoL services reflect all diverse groups
- Share examples of local excellence in EoL care
- Strengthen accountability and transparency (June 2018- new Clinical Priority Area) and leadership

- Equality - understand, acknowledge and action variations in EoL care.

As providers, funders and leaders we all have a role to play in helping to deliver improvements and to use our influences to help more people achieve their wishes and preferences at the end of life.

NY Wider Partnership Conference

A workshop on ‘End of Life – Dying Well’ was held at the North Yorkshire Wider Partnership Conference on 21 October 2016. The workshop was hosted by Alex Bird, the Voluntary Sector Representative on the North Yorkshire Health and Wellbeing Board. The key issues raised from the group discussions at the workshop are as summarised below:

Key questions
- How do we effect cultural change and encourage people to plan for the last 12 months of their life?
- Processes as an enabler for choice and not a barrier?
- Pain management well covered but what of practical day to day needs of people that ensure a high quality of life in their last months and days?
- Can we agree a common set of performance indicators and targets?
- Do we need a Charter for North Yorkshire that sets out a shared set of principles and goals?
- Is there a role for the private sector in end of life care provision?

Challenge 1 – about 80% of people want to die in their own home but only about 20% do. How do we close the gap?

Challenge 2 -for the 20% that opt to die elsewhere, do they get the care that they wanted?

Areas for development
- Training a range of health and social care staff to enable them to have difficult conversations with people about how they want their last 12 months of life to be
- Look at the disease pathways for non-cancer diseases so people are better able to help people plan their last 12 months of life
- Sharing of best practice like ‘Goldline’
- Support for carers, including pre-bereavement work
- Documenting, sharing and adhering to an end of life care plan with all those who need it
- End of life care for people who are learning disabled
- Role of GP in having the initial conversation with patients about their end of life care
- Care home and residential nursing home policy and practice
- Awareness of the range of different needs of people at the end of life, including cultural and religious
- Better communication from specialists when a patient is felt to have exhausted all possible active treatment for their long term condition. It is not always clear to a GP when a patient is moving from active care to palliative care phase of illness.

Other

- A hospice can play a key role in helping to stabilise someone who has deteriorated before then returning them home
- Death cafes enable a broad range of people to work through some of the practicalities around end of life care
- Voluntary and community sector often have a key role to play but can find it difficult to connect with and work with the NHS and other public sector services.

The presentation from the workshop can be accessed here - http://www.nypartnerships.org.uk/CHttpHandler.ashx?id=35439&p=0

Hospitals

A number of questions, informed by the overview of CQC reports in section 4, were sent by email to the Chief Executives of the three main hospital trusts in the county: Harrogate and District NHS Foundation Trust; York Teaching Hospital NHS Foundation Trust; and Airedale NHS Foundation Trust. The replies that had been received at the time of writing are included below:

Dr Ros Tolcher, Chief Executive, Harrogate and District NHS Foundation Trust
The Specialist Palliative Care (SPC) team take a lead role in delivering and supporting others to provide End of Life Care (EoLC) in both the hospital and community setting. The team ethos within the organisation is to work collaboratively with many agencies across health and social care and would value the opportunity to discuss this further.

Is there a strategy or plan for the delivery of End of Life Care?
A draft work programme for EoLC has been drawn up and is due to be ratified at the HDFT End of Life Steering Group meeting towards the end of January. This piece of work reflects comments from the most recent CQC report and feedback from clinicians and service users. Its content is structured around and informed by the national framework document ‘Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020’ which emphasises the need to make decisions and deliver services based on local need.

Are specialist End of Life Care services available 7 days a week?
Currently there is a SPC service which provides advice and support for patients in the hospital and community Monday to Friday 08:30-17:00. Out of hours there is access to telephone advice for health care professionals from Saint Michael’s Hospice. This is provided by hospice nurses, the hospice doctor on call, or the consultant on call as appropriate. This is an informal working arrangement that enables out of hours cover.

The team has compiled an options paper on a 7 day per week service which describes the evidence for delivering such a service and the investment required to meet this. This paper will aid discussions with the Trust and the Clinical Commissioning Group (CCG) about moving towards this in the future.

Are all staff able to identify anyone who might benefit from specialist End of Life Care services?

For all staff to identify patients who may benefit from EoLC every time requires an appropriate level of education and training and we recognise that more is required. Training in EoLC is not mandatory for community and hospital staff at present. The SPC team does however, plan to appoint a Clinical Nurse Specialist in the near future who will lead on education and will develop a comprehensive education and training strategy for all staff groups in the hospital and community, the aim being that all staff are prepared to care for patients at the end of life.

Health care professionals are able to use the SPC team referral criteria to help guide them in their decision making. The community SPC Clinical Nurse Specialists aim to attend all the Gold Standards Framework / Palliative Register meetings at GP Practices to guide Primary Care teams in whom to include on the register and in managing the patients effectively in a timely and responsive manner.

To what extent are hospital staff able to access End of Life Care plans that have been developed by GPs and others?
GPs aim to create care plans for the 2% of patients most likely to have unplanned hospital attendances. This 2% will include some patients who are approaching the end of life. If a care plan is created, a template is completed on SystemOne and the patient is given a paper copy, but the plan is not shared with the hospital (most hospital staff cannot access SystemOne). So the plan will only be accessed if a paper copy comes in to hospital with the patient; this does not often happen.

There is an opportunity to improve communication around end of life decisions and discussions by enabling shared access to patient information by using an Electronic Palliative Care Coordination System (EPaCCS). A business case has been developed by the New Care Models IM&T and the Local Digital Roadmap Group but there is no definite plan currently to take this forward. The introduction and implementation of EPaCCS is a key area for improvement in the End of Life work plan.

Is there an issue relating to the breakdown of End of Life Care in the community and unplanned hospital admissions?
We do not currently collect data on unplanned hospital admissions related to a breakdown of care in the community, although a significant issue would be captured via incident reporting. It is therefore difficult to draw clear conclusions.

Fast track services are not currently commissioned through HDFT as they are provided by independent providers which are booked through the Partnership Commissioning Unit on behalf of the CCG. They are frequently unable to source care packages. Care is sometimes picked up by the Community Care Teams wherever they have capacity as an interim.

There are delays in discharging patients in the last weeks of life in a timely manner for the above reasons. Anecdotally, patients are waiting several days to a week or so for discharge home, often due to care packages being unavailable. Again this is a key area of exploration for the EoLC work programme.

Are there any obvious gaps in services that prevent Hospitals from playing a fuller role in End of Life Care planning and delivery? What more could be done to fill such gaps?
There are actions that can be taken to enhance care planning and delivery and these have been discussed: for example

- Funding and provision of a 7 day face to face assessment SPC service,
- Implementation of EPaCCS across the locality and consideration of solutions to share information between community and hospital setting,
- Timely rapid discharge home to die (last weeks /days of life) from hospital and further collaboration with social care.

We would welcome the opportunity for a fuller discussion around commissioning of services in the community around End of Life Care. We hope this information is helpful and look forward to further discussions.

Local Medical Committee

The following questions were sent to YORLMC, the Local Medical Committee for North Yorkshire, on 6 January 2017.

In response, a series of telephone interviews were conducted, in the week commencing 16 January 2017, with YORLMC representatives, as summarised below:

Do GPs routinely discuss End of Life Care with patients in the last 12 months of their life?
Yes. GPs play a key role is starting a discussion with patients who are in their last 12 months of life, their families and carers about the type of care that can be made available to them. There is a strong focus on symptom control (all symptoms and not just pain), a collaborative approach and providing support to family members and carers.

Are End of Life Care plans developed with GPs and shared with all relevant partner agencies?
Yes. End of Life Care Plans are initially developed by GPs, District Nurses and Macmillan Nurses with the patient, family members and carers. These are then shared with partner agencies and organisations. Regular Gold Standards Framework / Palliative Register meetings are convened by GPs and attended by community ad hospital based nursing staff.

There can be difficulties associated with sharing the care plans with all those that need to see them, particularly at a point of crisis. There is no common means across all health and social care agencies in the county that has been adopted that allows the sharing electronic versions of care plans in a format that can be updated.

A software system, called the Medical Interoperability Gateway (MIG), is available that can connect health and social care organisations and enable the sharing of patient records (in a read-only format).

NHS Digital is currently reviewing how special patient notes can be made accessible to all health and social care agencies involved in the delivery of a care plan.

Are there any obvious gaps in services that prevent GPs from playing a fuller role in End of Life Care planning and delivery?
There are a number of gaps in services and care pathways, as outlined below:

- District Nurses - the District Nurse Service in the county is not 24/7. Service provision ends each day at 10pm. North Yorkshire is one of only 2 areas in the country not to have a 24/7 service.
- Do Not Attempt Resuscitation (DNAR) forms are only applicable to people suffering from a cardiac arrest. For people with other conditions, a Living Will or Advance Directive is needed. If not, then people may well be admitted to hospital contrary to what they have previously requested for their care.
- Palliative Clinical Nurse Specialists – there is a shortage of these specialist nurses.
- Hospice admission – further work could be done to clarify the admissions procedures for hospices, particularly out of hours and for respite care. At present, GPs can admit directly to hospices out of hours.
- Respite care – there is a shortage of respite care.
- Psychological therapies – there are significant gaps in the provision of psychological therapies and support for people who are dying and their carers and family members.
- Palliative care drugs – there are concerns that there is insufficient access to and availability of palliative care drugs from community pharmacies, particularly out of hours. There are also issues of cost (£3,000) and time (6 months of more) around applications for licences to stock Schedule 2 palliative care drugs.
- Patient records - there is no common means across all health and social care agencies in the county that has been adopted that allows the sharing electronic versions of care plans in a format that can be updated.

Any additional comments?
Out of hours GP services have a key role to play in the delivery of End of Life Care Plans, particularly at a point of crisis. Links with other health and social care services who operate out of hours are good but more could be done to look at how the out of hours system works and to improve patient outcomes.

GPs regularly conduct reviews of the quality of End of Life Care that has been provided, as part of the Significant Event reporting system. This provides opportunities for lessons to be learned and services to be improved.

Local Pharmaceutical Committee

Jack Davies, attended a meeting of the North Yorkshire Scrutiny of Health Mid Cycle Briefing on 16 December 2016 to discuss Government changes to the funding of community pharmacies. The following possible impacts of reduced funding were highlighted:

- Reduced opening hours and staffing levels

- End free services, such as the home delivery of medicines
- Reduced investment in facilities and services
- Reduced stock held on the premises, with the result that people may not be able to get the medicine they need then and there.

The reduction in stock and the end of free services, such as home delivery of prescriptions could impact upon the availability of and access to palliative care drugs, particularly at a time of crisis.

Jack Davies also suggested that an independent community pharmacy was contacted to further understanding of the role that they play in supporting the delivery of end of life care services in the community.

A telephone interview was conducted with an independent community pharmacy in the county on 6 January 2017. The outcome of the interview is summarised as below:

What role do community pharmacies play in End of Life Care and supporting people in their own home?
The key role is one of ensuring that palliative care drugs are available as and when needed. The pharmacy also operates a free delivery scheme, as part of its general business operation, of prescriptions to people in the community. This includes palliative care drugs.

Are community pharmacies involved in care planning and do they work with the GP and Hospital?
There is no role for community pharmacies in palliative care planning but the pharmacy works closely with local GPs and District Nurses to ensure that the drugs that are needed are made available promptly and often out of hours.

Are community pharmacies able to maintain a sufficient stock of palliative care drugs?
The pharmacy is commissioned under the Palliative Care Drugs Service to maintain a stock of a locally agreed list of palliative care medicines. A small number of community pharmacies will be commissioned to provide this service across any given area, with a view to maintaining sufficient coverage. Individual community pharmacies may also have stocks of various palliative care drugs.

Follow up questions with Jack Davies revealed that a Palliative Care Drugs Service is only commissioned by the Vale of York and Scarborough and Ryedale CCGs. It was noted, however, that a number of community pharmacies elsewhere in the county have volunteered to maintain sufficient stocks of palliative care drugs.

Summary of key findings

There are a number of themes that have been identified, as below:

- There are opportunities for joint training and awareness raising on end of life care planning across health, social care and the voluntary sector that are not currently being realised.

- Hospices have been providing end of life care in the county for over 30 years and have built up years of specialist knowledge and expertise that could be used to support training and awareness raising.

- Whilst end of life care for people with terminal cancer is well established, it is not for people suffering from other terminal diseases. Further work is needed to better understand the ‘disease trajectories’ and what this means for end of life care planning.

- Good practice or best practice is not routinely shared across agencies and organisations in the county and there is no place or forum for work to be co-ordinated at a county-level.

- There is no agreed set of principles or standards for the provision of end of life care in the county, against which the performance of organisations and agencies can be judged and for which people can be held accountable.

- The financial arguments supporting co-ordinated end of life care and enabling people to die in their own homes are well known but not used as part of the evidence for service development. Investment in community based end of life care services and interventions will save hospitals significant amounts of money, reducing demand for beds and reducing unplanned admissions through Accident and Emergency.

- The broader welfare and wellbeing needs of people in the last 12 months of their life are not always being met. Whilst medical needs such as symptom control and pain relief are well understood, in many cases basic quality of life issues are not addressed. For example, bathing.

- The lack of one single IT system for the creation, sharing and updating of end of life care plans across key agencies and organisations results in unplanned admissions to hospital through Accident and Emergency. It also results in the Ambulance Service making journeys that could have been avoided.

- A number of Delayed Transfers of Care that are attributed to short falls in community based provision relate to people in the last months or weeks of their life. This can lead to the breakdown in an end of life care plan and significant distress to the patient, their family and carers.

- The business case for an Electronic Palliative Care Coordination System (EPaCCS) has been developed by the Harrogate and Rural District End of Life

Care Locality Steering Group and a number of organisations but it is unclear whether there is the necessary support to implement such a system countywide.

- A seven day a week Specialist Palliative Care Service is not routinely provided in hospital. Out of hours support, information and advice is provided through a number of routes, including hospices. Harrogate and District NHS Foundation Trust are currently reviewing options for a seven day a week Specialist Palliative Care Service.

- Training in end of life care is not mandatory for community and hospital staff at present. There may also be a need to consider how specific end of life care training and awareness raising is provided to locum GPs, particularly those working in the Out of Hours Service.

- It is not clear whether there is sufficient availability of and access to palliative care drugs across the county. A Palliative Care Drugs Service is commissioned by 2 of the 5 CCGs in the county. In the other 3 CCG areas voluntary arrangements are in place for the stocking of palliative care drugs. Service user evidence gathered as part of this extended piece of scrutiny suggests that there are gaps in availability and access, gaps that are often filled by people going to Accident and Emergency.

- In the next 3 to 5 years, changes to Government funding to community pharmacies may result in a reduction in the range and coverage of a number of pharmacy services, including free home delivery. This may, in turn, impact upon the viability of some community based end of life care plans.

- It is not always clear to a GP when a patient is moving from active care to palliative care phase of illness. This could be resolved if there was better communication by specialists when a patient is felt to have exhausted all possible active treatment for their long term condition.

- There are gaps in the provision of community nursing. The District Nurse Service in the county is not 24/7 and at present the service provision ends each day at 10pm. There is also a shortage in Palliative Clinical Nurse Specialist provision.

- There may be a need for some awareness raising about the need for a Living Will, Advance Directive or the ReSPECT form, as opposed to the use of Do Not Attempt Resuscitation (DNAR) forms.

- There are gaps in out of hours provision across agencies and organisations that provide elements of end of life care. There may be value in undertaking a system wide review to better understand the gaps and their impacts.

Section 4 – Care Quality Commission

Care Quality Commission inspection reports

The Care Quality Commission (CQC) regularly conducts both announced and unannounced inspections of hospitals. Inspection reports include an assessment of the quality and effectiveness of End of Life Care. The elements relating to End of Life Care are summarised below.

Harrogate District Hospital Quality Report 27/07/2016

http://www.cqc.org.uk/location/RCD01
This report followed an inspection from 2 to 5 February 2016. End of Life Care was rated as 'good' overall and for the criteria of safe, effective, caring and well-led. The criteria of responsiveness was rated as 'requires improvement'. The issues that were identified by the CQC are summarised below:

- A strong culture of incident reporting
- Participated in the National Care of the Dying Audit of hospitals
- A care planning process had been developed and was being used based on current national guidance
- Working with the Clinical Commissioning Group and community teams to develop a five year strategic plan for end of life care
- Face to face specialist support for end of life care was not available 7 days and week
- Staff are not able to identify everyone who might benefit from palliative care team support because of work pressures in the hospital and the limited palliative care cover available
- There was no locally agreed service plan in place for end of life care with commissioners.

Scarborough Hospital Quality Report 08/10/15

https://www.cqc.org.uk/location/RCBCA
This report followed an inspection over the periods 17 to 20 March 2015, 30 to 31 March 2015 and 11 May 2015. End of Life Care was rated as 'good' overall and for the criteria of safe, effective, caring, well-led and responsive. The issues that were identified by the CQC are summarised below:

- Specialist nurses and medical staff provided specialist support in a timely way that aimed to develop the skills of non-specialist staff
- Staff were caring and compassionate and responsive to patients' needs
- Good use of auditing to identify and improve patient outcomes
- A vision and strategy for end of life care services was in place
- Development of a number of initiatives, such as non-cancer end of life care.

The York Hospital Quality Report 08/10/15

http://www.cqc.org.uk/location/RCB00
This report followed an inspection over the periods 17 to 20 March 2015, 30 to 31 March 2015 and 11 May 2015. End of Life Care was rated as 'good' overall and for

the criteria of safe, effective, caring, well-led and responsive. The issues that were identified by the CQC are summarised below:

- Good use of auditing to identify and improve patient outcomes
- A vision and strategy for end of life care services was in place
- Consistent leadership
- Development of a number of initiatives, such as non-cancer end of life care.

Airedale General Hospital Quality Report 10/08/16
http://www.cqc.org.uk/location/RCF22
This report followed an inspection over the periods 15 to 18 March 2016, 31 March and 11 May 2016. End of Life Care was rated as 'good' overall and for the criteria of safe, effective, caring, well-led and responsive. The issues that were identified by the CQC are summarised below:

- Seven day face to face specialist palliative care support available to patients was in place
- Staff were trained and demonstrated a consistently good knowledge of end of life care issues
- Pain was well managed
- The Gold Standards Framework was in use throughout the hospital to support the development of good quality end of life care
- An electronic palliative care coordination system was in use
- Positive multidisciplinary team work and a high standard of collaborative working internally and externally
- There was below the national minimum staffing recommendations for hospital specialist palliative care doctors
- A lack of engagement with Black and Minority Ethnic (BME) communities.

Darlington Memorial Hospital Quality Report 29/09/15
http://www.cqc.org.uk/provider/RXP
This report followed an inspection over the period 5 and 6 February 2015. End of Life Care was rated as 'requires improvement' overall and also 'requires improvement' for the criteria of safe, effective and well-led. The issues that were identified by the CQC are summarised below:

- Staff were caring and compassionate
- Monitoring of the safe use of syringe drivers for end of life medication was not being recorded consistently
- Mental capacity assessments were not being recorded
- Development of pastoral and spiritual services were planned
- Specialist palliative care regularly attend wards to support staff to develop skills a round end of life care
- Staffing difficulties had impacted on the ability of the specialist palliative care team to develop the service
- A focus on preferred place of care for patients at the end of life wishing to be at home.

James Cook University Hospital Quality Report 28/10/16
http://www.cqc.org.uk/location/RTRAT
This report followed an inspection over the period 8 to 10 June and 21 June 2016. End of Life Care was rated as 'good' overall and for the three criteria of safe, effective and well-led. The issues that were identified by the CQC are summarised below:

- Patients were provided with an end of life care service that was safe and caring
- A culture of incident reporting
- Clear, well documented and individualised care of the dying documents
- Mandatory training in place with 100% compliance
- A clear vision for the service but no overall strategic lead for palliative care
- Poor performance against the 2015 National Care of the Dying Audit criteria, achieving only two of the eight organisational indicators.

Hull Royal Infirmary Quality Report 29/07/15
This report followed an inspection over the period 28 to 29 January 2015. End of Life Care was rated as 'good' overall and for all of the criteria. The issues that were identified by the CQC are summarised below:

- A dedicated palliative care team are in place that consists of palliative care consultants, specialist nurses and an end of life care facilitator. The team was available Monday to Friday with a helpline service during evenings and weekends
- Individual wards had end of life care champions
- Patients received safe and effective end of life care, which involved patients and relatives/carers
- Care was flexible and responsive to individual needs and there were good systems to facilitate preferred place of care.
- There was a retrospective end of life case review group, which met regularly to review care practice and identify areas for learning.

St James University Hospital Leeds Quality Report 27/09/2016
This report followed an inspection over the period 28 to 29 January 2015. End of Life Care was rated as 'good' overall and for all of the criteria. The issues that were identified by the CQC are summarised below:

- Safety incidents were investigated when things went wrong and lessons learned were widely shared
- There was clear guidance for staff to follow within the care of the dying person individual care plan when prescribing medicines at end of life
- There were some very good examples of record keeping in the individual care plans.

Summary of key findings

People living in North Yorkshire access a broad range of hospitals depending upon where they live and what treatment they are undergoing. The CQC reports vary in the breadth and depth of their assessment of end of life care and interventions provided at the hospitals but offer an insight into some of the key issues faced in a busy clinical environment.

- Face to face specialist end of life care is not available 7 days a week across all hospitals.

- Strategies for the delivery of end of life care services and interventions in hospitals are either in place or under development.

- Non-cancer end of life care is either in place or under development.

- Staffing pressures had impacted in some hospitals upon the consistency and quality of end of life care being offered.

- The quality and suitability of mortuary services was highlighted as a concern in a number of cases, in particular the room where the body of someone who has recently died is viewed by bereaved relatives.

Anecdotal evidence gathered as part of this extended piece of scrutiny suggests that there may be a conflict between resource management and end of life care in a hospital setting. Where someone in the last days of their life is admitted to a busy hospital ward, there have been cases where good quality of end of life care has not been provided.

Section 5 – site visits to hospices

Structured visits were undertaken to three hospices in North Yorkshire and York. These hospices were selected on the basis on being the major providers of hospice care to in-patients, day patients and community patients.

The hospices visited were:

- St Michael's Hospice, Harrogate – 10 November 2016
- St Catherine's Hospice, Scarborough – 16 November 2016
- St Leonard's Hospice – 13 December 2016

The visits were undertaken by members of the Scrutiny of Health Committee along with the Chair of the Scrutiny of Health Committee and the Scrutiny Team Leader. The visits tended to have the following format:

- 10.00am – Welcome and introductions
- 10.10am – Meetings with staff
- 11.00am – Meetings with in-patients and day patients (where possible)
- 12.00noon – Informal discussions – to involve a number of people from social work, bereavement support, a carer, community team leaders and fundraising
- 1.00pm – Site tour
- 1.45pm - Reconvene for wrap up questions and discussions.

What follows is a summary of the key issues identified at all three site visits:

Funding

- Savings to the system that the hospices in North Yorkshire make cannot be realised and funding cannot be diverted as it is all taken up by the larger acute trusts
- A large proportion of funding is unpredictable and high risk. This makes service planning difficult year on year. Budget deficits are likely in 2017/18 and beyond, if the funding position is not improved. There will then be a review of services to ascertain a sustainable delivery model for the future
- Do not want 100% public funding as need to retain independence, aim for 35% public funding. Currently around 20%.
- Strong argument for ‘invest to save’

Service delivery

- Wide range, including: bereavement counselling; Occupational Therapy; in-reach into residential and nursing homes; hospice at home; neurology nursing; Palliative Clinical Nurse Specialist provision
- Concerns over the long term impacts of reductions in both NHS and social care services and budgets
- A large number of volunteers support the delivery of hospice services both at the Hospice itself and in the wider community
- There are shortages of skilled staff across health and social care, which has a knock on effect to the services provided by the hospice as they take up more of the slack and fill gaps
- Need for more respite care for carers – this makes community based packages of support more robust and less likely to breakdown
- Need to start thinking collectively about the patient of the future, what their needs will be and what options will be available to them. Likely to have dementia and not be a cancer patient
- Community based bereavement services make significant savings for mental health services
- Pain control best managed in a hospital or hospice, less well at home.

Out of hours

- There is very little routine out of hours care in place across health and social care. Hospices and other organisations often fill the gaps, particularly at the weekend, but this is not sustainable in the long term. The lack of out of hours care often results in unplanned admissions to hospital, unnecessary ambulance journeys and increased stress upon the patient and carers
- PALCALL in Scarborough and Ryedale offers 24 hour support for carers of people undergoing community based palliative care (similar to Goldline in Airedale, Wharfedale and Craven).

Referrals

- Most referrals, approximately 50% to 80%, are from GPs and hospitals and are typically people with terminal cancer. More could be done to highlight the hospice services and interventions that are available to people with other terminal diseases.

Education and training

- The hospices deliver a range of formal, accredited training courses, professional development and mentoring and coaching
- Training for nursing and residential care homes helps ensure that more people are able to die in their home, as opposed to a hospital
- Considerable programme of education run by the hospice: communication skills; advanced care planning; symptom management; ceilings of care; palliative care.

Coordination

- Lack of a forum for commissioners and providers of End of Life Care to meet and plan through a system wide approach
- Lack of places for people to be discharged to from hospital.
- There is no single case record management system in place that enables all relevant organisations to access the care plans of patients in their last months of life. This can result in unplanned admissions to hospital, unnecessary ambulance journeys and increased stress upon the patient and carers
- Hospices are part of the solution and can help support the wider health and social care system through establishing good practice norms and educating.

Sustainability and Transformation Plans

- End of life care does not feature in the STP planning process, at present
- STP may present an opportunity for system-wide commissioning.

Approach

- Overly focussed on the place of death and not the quality of the last 12 months of life. Key questions to ask :
    - How do you want to die?
    - Where do you not want to die?
    - What experience do you want of dying?
    - What things will be important to you?

Summary of key findings

There are a number of themes that have emerged, from the visits to the three hospices, relating to the gaps in services and areas for improvement. These include:

- High quality and wide ranging end of life care is provided by hospices on an in-patient basis and in the community at little or no cost to the public sector. The majority of hospice funding, typically 80%, comes from retail, fundraising, donations and legacies.

- Hospice funding is increasingly unpredictable and under stress. A number of hospices are planning to run a budget deficit in 2017/18. This will impact on the range of services that hospices can provide.

- Hospices have responded to gaps in provision and developed services that meet new and emergent needs, such as community based support and nursing for neurology and lymphedema.

- There is uncertainty about what impact increasing demand for health and social care services, shortages of skilled health and social care workers and budgetary pressures in health and social care will have upon the demand for hospice services and interventions.

- The delivery of community-based services in the county is expensive due to the travel costs and times associated with accessing rural areas.

- Informal and formal education and training is provided by hospices to health and social care workers. More education and training could be done with providers of residential care and nursing homes but there are limited resources and providers of residential and nursing care under significant financial stress.

- The type of patient that health and social care organisations is working with is changing. In the longer term, people in the last months of their life are likely to be frail and suffering from a number of long term conditions, including dementia. More needs to be done to plan the countywide response to this changing disease profile and the development of end of life care services and interventions for people with dementia.

- Carers are critical to the effective delivery of any end of life care plan. More could be done to provide support and respite for carers in the community.

- Hospices often serve as a default out of hours service to support end of life care in the community, as most health and social care services are not commissioned on a 7 day basis.

- There is no one single IT system for the creation, sharing and updating of end of life care plans across key agencies and organisations. This creates unnecessary delays and inefficiencies and care lead to breakdowns in continuity of care provided.

- GPs are key to the provision and co-ordination of End of Life Care. They are already stretched and there are emergent shortages of GPs.

- The discussions are end of life care have tended to focus upon the where people want to die, with a working assumption that dying in your own home is the preference. However, the question could better be asked as to what things do people need to have in place to make their death the best it can be for them and those around them?

Section 6 – patients, carers and family members

Focus groups
Convened by Tony Collins, Chief Executive, Saint Michael's, Harrogate - Bereavement counselling – 23 November 2016

Case study 1 – bereaved wife

- Key role played by the GP in supporting the family and providing continuity of care in the community
- Concerns raised about the level of care that can be provided on busy hospital wards to people in the last days of life
- Concerns raised about the ability of District Nurses to provide support when and where needed
- Concerns about the ability of the Hospital to provide continuity of care in the community and respond to changes in patient condition
- Difficulties in maintaining an uninterrupted supply of prescribed palliative care drugs
- Multiple visits to A&E.

Case study 2 – bereaved teenage son

- Excellent standard of hospital care
- Stress upon the immediate family leading to family breakdown after the death of the mother
- School not able to provide the necessary support, leading to a disrupted education and unresolved emotional problems associated with grieving and loss
- Key role of the grandmother in providing support.

General

- There are some concerns about the quality of end of life care provided in some cases in hospitals. Concerns that this may not be picked up as part of CQC inspections
- 'Just-B' bereavement service receives no funding from CCGs or local authorities and the service covers Harrogate District only
- Most referrals to 'Just-B' are from GPs
- Most people who attend the 'Just-B' service are grieving for loved ones who did not 'die well'.

The website for 'Just-B' can be found here - http://justb.org.uk/wordpress/

Summary of key findings

The openness and willingness of patients, carers and family members to speak with the members of the Scrutiny of Health Committee was much appreciated. Some of the key issues raised are highlighted below:

- There is only limited bereavement support that can be accessed in a timely way in the county. This is provided in part by the NHS and in part by the voluntary and community sector.

- The way in which the death of a close family member is experienced can have a significant impact upon the mental wellbeing of someone who has been bereaved. Where support is not available, it can lead to a disrupted education, job loss and family breakdown.

- It is unclear what systems are in place to identify children and young people in school who have been bereaved and what support is in place or can be accessed by them.

- There is a question as to whether general CQC inspections of a hospital are able to assess the quality of end of life care services.

Section 7 – Areas for further investigation

It has not been possible to undertake a complete and exhaustive assessment of the state of end of life care in the county. As such, there are a number of areas for further investigation, as below:

Schools

The role that schools have to play in identifying and supporting children and young people through the last months of a parent or sibling's life is unclear. As is the ability of the school to provide or access appropriate bereavement support for a child or young person.

Former service personnel

The Armed Forces Community Covenant for North Yorkshire has as one of its aims to 'encourage local communities to support the armed forces community in their areas, and vice versa'. There is a question as to whether former service personnel in the county have specific needs around end of life care and whether these are currently being met.

Equality and diversity

There is further work to be done to understand and address the barriers that exist to people accessing end of life care services and interventions, specifically for Lesbian Gay Bisexual and Transgender people, Black and Minority Ethnic groups, gypsies and travellers, people who are homeless.

Patient and family and carer experience

There is an opportunity to do further work with Healthwatch North Yorkshire to gather the views of patients, family members and carers on end of life care services and interventions in the county. The results of this could then inform targeted 'Enter and View' visits.

Respite care for carers

The critical role that carers have to play in the delivery of community based end of life care plans in widely acknowledged. What is not clear is the extent to which the needs of carers are identified and opportunities for respite care provided.

Befriending

Befriending and support to patients, carers and family members as part of end of life care has been seen in some cases to be beneficial. Further work could be undertaken to better understand the benefits of befriending and whether it has a role to play in end of life care provision in North Yorkshire.

Private sector
The role of private sector providers of end of life care services and interventions has not been fully explored. Nor has the potential for markets for private sector providers to be developed.

Yorkshire Ambulance Service
The role of the Ambulance Service in the delivery of end of life care planning and the costs incurred when packages of community-based care breakdown. It is noted that lack of an electronic system to share and update patient notes and end of life care plans means that staff responding through the 999 or 111 services are not aware of what care has been agreed.

Section 8 – Recommendations

Recommendations

The following recommendations are made for consideration by the North Yorkshire Scrutiny of Health Committee:

1. That a multi-agency forum is established for commissioners and providers of end of life care in the county to enable:

    - greater co-ordination of service planning and delivery across health, social care and the voluntary sector
    - the agreement of some common standards and principles for equitable end of life care, possibly in the form of a charter or a similar statement of intent
    - the identification of a set of outcomes to be achieved with milestones and a mechanism in place for tracking progress against those milestones
    - sharing of good and best practice
    - the identification of areas for service improvement
    - patient and carer representation and involvement and opportunities for co-design
    - health and social care strategic planning to be influenced
    - inequalities in the access to end of life care services across the county to be addressed.

2. That a local financial analysis of community-based end of life care and bereavement services be undertaken, with a view to assessing what efficiency gains could be made within the health and social care system. The methodology to be informed by the Public Health England and University of York health economics report on the costs of end of life care.

3. That a multi-agency programme of training in end of life care and care for the dying be developed and implemented, covering as a minimum:

    - Communication skills and honest conversations

- Advanced care planning, including holistic care
- Symptom management
- Palliative care.

Consideration also to be given as to how this training could be targeted at different priority groups of health and social care workers across the county.

4. That existing joint work between the NHS and the County Council on health and social care workforce planning, takes into account the need for skilled, specialist staff to co-ordinate end of life care and palliative care.

5. That a way of enabling the sharing and updating of end of life care plans and patient notes electronically is developed for all health and social care agencies and organisations in the county.

6. That a local analysis of ‘the patient of the future’ is undertaken that looks at the changing disease profile of people in their last 12 months of life and what this means for the development and delivery of end of life care.

7. That a system-wide analysis is undertaken of the current provision of out of hours, specialist end of life care and palliative care, including access to palliative care medication, to assess where there may be gaps in provision and suggest what could be done to fill any such gaps.

8. That agencies and organisations work together to promote a culture of open and honest discussions about death and planning the last 12 months of someone’s life.

9. That the areas for further investigation listed in Section 7 of this report are looked into further.

In making these recommendations, it is recognised that the health and social care system is under increasing financial strain and that there is no new funding available. There are, however, efficiency gains to be made from a change to the way in which end of life care services and interventions are commissioned and provided in the county, which will also improve outcomes for patients, carers and family members.

Daniel Harry
Scrutiny Team Leader
North Yorkshire County Council
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- Mike Wilkerson (Chief Executive), St Catherine’s Hospice, Scarborough
- Emma Johnson, St Leonard’s Hospice, York.

Thank you also to those people who took the time to attend meetings of the North Yorkshire Scrutiny of Health Committee to give an overview of the provision of end of life care from their perspective:

- Clair Holdsworth, Deputy Director of Clinical Services, Martin House
- Gill Collinson, Hambleton, Richmondshire and Whitby Clinical Commissioning Group
- Joanne Crewe, Harrogate and Rural District Clinical Commissioning Group
- Dr Sarah Hay, Governing Body Member, Harrogate and Rural District Clinical Commissioning Group
- Colin Renwick, Airedale and Wharfedale Craven Clinical Commissioning Group
- Paul Howatson, Vale of York Clinical Commissioning Group
- John Turner, Scarborough and Ryedale Clinical Commissioning Group
- Ian Spicer - (Interim) Assistant Director, Care & Support, Health and Adult Services, North Yorkshire County Council
- Emma Thomas, Children’s Commissioning Manager – Healthy Outcomes, Children and Young People Service, North Yorkshire County Council
- Jack Davies, Chief Executive Officer, Community Pharmacy North Yorkshire (LPC).

Thank you to the following for responding to questionnaires and participating in telephone interviews:

- Dr Ros Tolcher, Chief Executive, Harrogate and District NHS Foundation Trust
- YORLMC, the Local Medical Committee for North Yorkshire.

Finally, I would like to express my gratitude to those people who participated in focus groups on bereavement and related their personal experiences of the end of life care that was provided for their loved ones.

Health and Wellbeing Board
North Yorkshire

North Yorkshire Tobacco Control 2016 Report: One Year On
17 March 2017

Presented by: Dr Lincoln Sargeant, Director of Public Health

Summary:

The Tobacco Control strategy was developed by the North Yorkshire Tobacco Control Steering Group, a partnership of organisations committed to tackle the harm caused by tobacco in our communities.

The ambition for the strategy is to 'inspire a smoke free generation', to see the next generation of children born and raised in a place free from tobacco. This is in line with the regional Breathe 2025 campaign. The North Yorkshire strategy was approved and endorsed by the Health and Wellbeing Board on 30 September 2015.

This report (Appendix A) highlights of all the work achieved in the last 12 months, under the following five priorities outlined in the strategy:

1. Prevention for children and young people
2. Normalising a smoke-free lifestyle
3. Reduce illegal tobacco in the community
4. Support smokers to quit and reduce smoking rates during pregnancy
5. Carry out marketing and communication programmes

Key achievements in the year 2015-16 include: undertaking an illicit tobacco survey, re-commissioning the stop smoking service, initiation of the Baby Clear programme, the roll out of smoke free playgrounds and a number of successful communications campaigns including Breathe 2025 and 16 Cancers campaign, on a regional level.

The report also outlines the priorities for the coming year.

Which of the themes and/or enablers in the North Yorkshire Joint Health & Wellbeing Strategy are addressed in this paper?

Themes	✓
Connected Communities	
Start Well	✓
Live Well	✓
Age Well	✓
Dying Well	
Enablers	
A new relationship with people using services	
Workforce	
Technology	
Economic Prosperity	

How does this paper fit with other strategies and plans in place in North Yorkshire?

- Provides an update to the North Yorkshire Tobacco Control Strategy 2015-2025
- Contributes to the Start Well, Live Well and Aging Well priorities in the Joint Health and Wellbeing Strategy

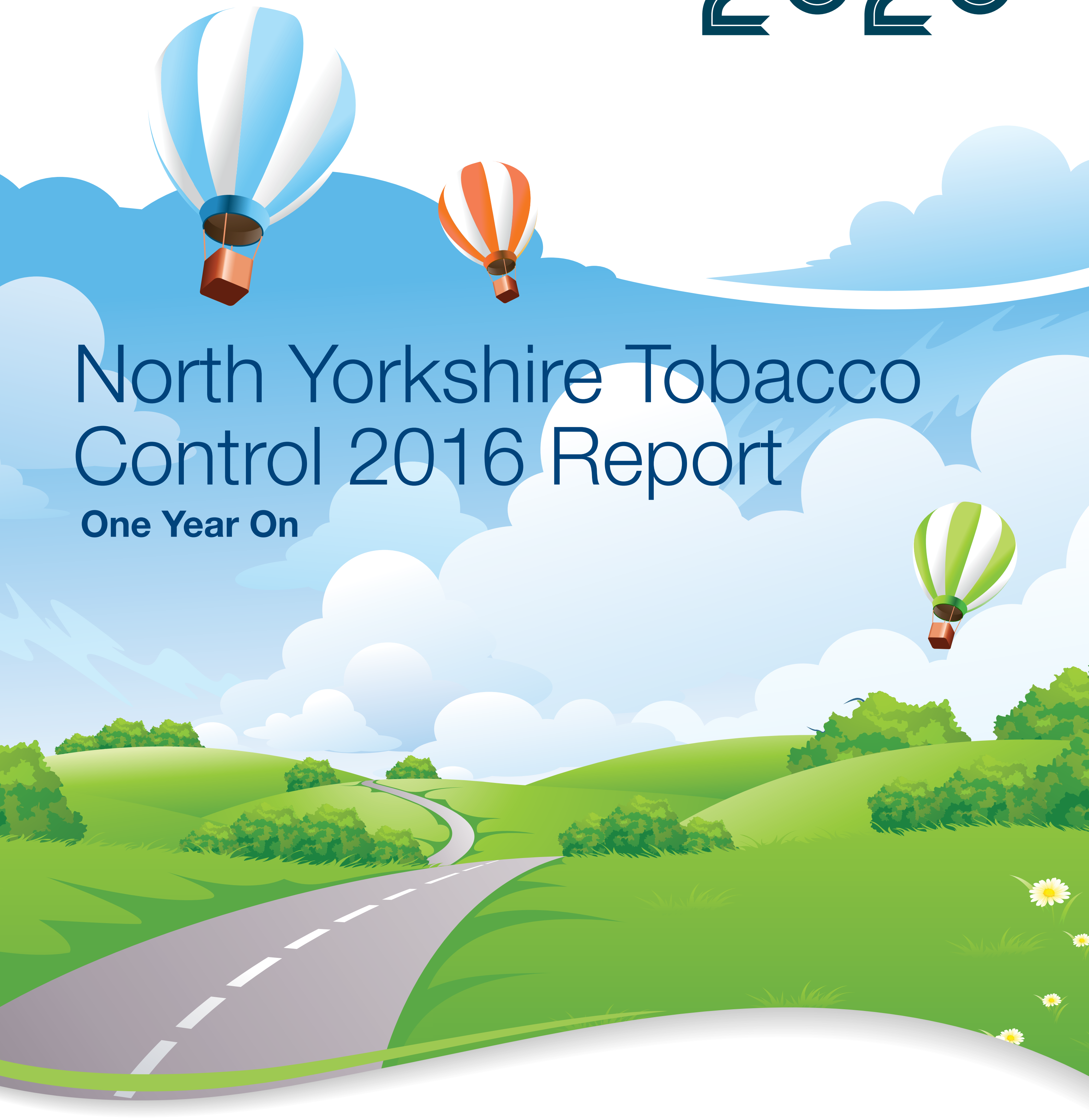
What do you want the Health and Wellbeing Board to do as a result of this paper?

- Note the progress that has been made on the tobacco control agenda in North Yorkshire
- Approve the priorities for the coming year

Appendix

North Yorkshire
County Council

BREATHE
2025



North Yorkshire Tobacco Control 2016 Report

One Year On

Introduction

Welcome to our first Tobacco Control Report. This report highlights the activity that has taken place over the last year to support our vision to inspire a smokefree generation in North Yorkshire. This report provides updates under the 5 priorities of the **North Yorkshire Tobacco Control Strategy 2015-25**.

North Yorkshire has successfully come together to tackle tobacco control under a strong partnership approach. A multi-agency North Yorkshire Tobacco Control Steering Group, formed in 2014, leads this work across the county. This group developed a 10 year strategy and implementation plan following self-assessment, extensive engagement and consultation with partners and North Yorkshire residents.

Contents

New Tobacco Plan for England

The five-year strategy set out in the Government's Tobacco Control Plan for England came to an end in 2015. 'Smoking Still Kills' was published by Action on Smoking and Health (ASH) and was funded by Cancer Research UK and the British Heart Foundation. 'Smoking Still Kills' proposes new targets for a renewed national strategy to accelerate the decline in smoking prevalence over the next decade. The report sets out short-term objectives and longer term aims and develops the agenda for tobacco control launched in 2008 with 'Beyond Smoking Kills'.

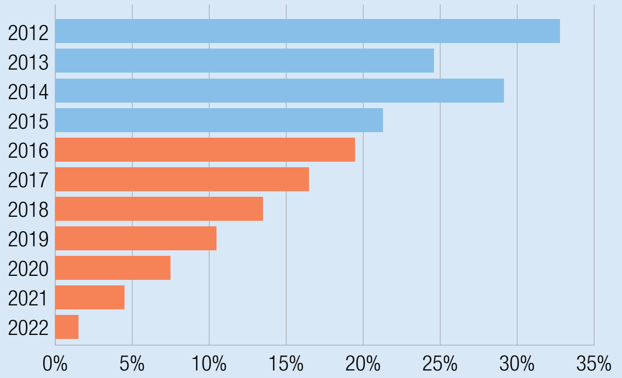
The report proposes new targets for a national strategy, a challenge to all stakeholders in tobacco control to increase their efforts and accelerate the rate of decline of smoking prevalence over the next decade, specifically to:

- Reduce smoking in the adult population to 13% by 2020 and 9% by 2025
- Reduce smoking in the routine and manual socio-economic group to 21% by 2020 and 16% by 2025
- Reduce smoking among pregnant women to 8% by 2020 and 5% by 2025
- Reduce regular and occasional smoking among 15-year-olds to 9% per cent by 2020 and 2% by 2025

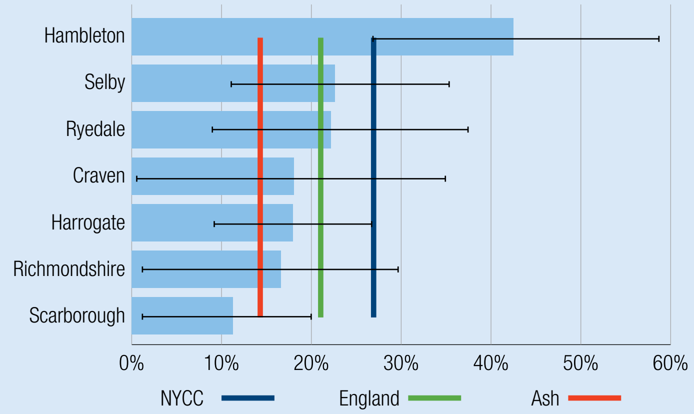
The new national plan is due in early 2017.

Rates of smoking and performance indicators

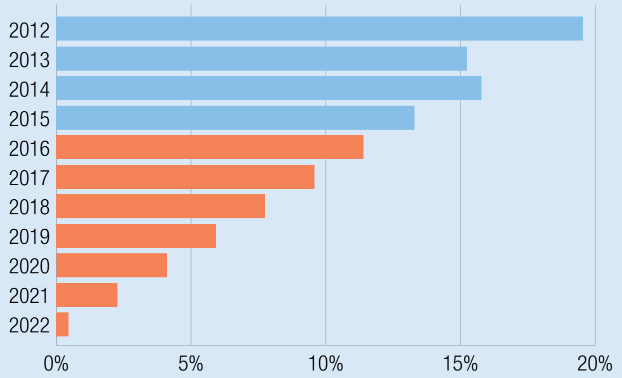
Smoking remains the single biggest cause of premature and preventable death in North Yorkshire. Smoking prevalence in adults is 13.3% across North Yorkshire (Local Tobacco Control Profiles, 2015). The profiles are available at District level and there is wide variation across the county. Please note: There has been a recent change in the data source for the indicators below, from the Integrated Household survey to the Annual Population Survey, which is based on much smaller sample numbers. Therefore we must interpret these trends with caution.



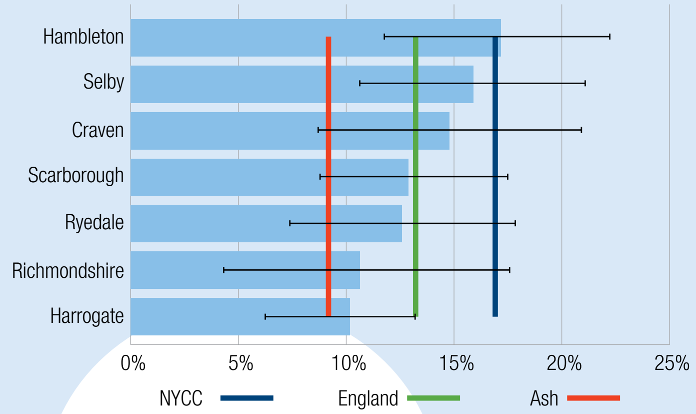
Smoking Prevalence (%) in adults in routine and manual occupations - current smokers (APS)



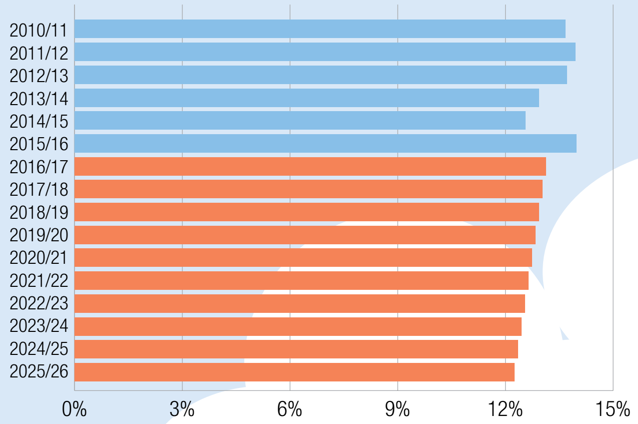
Smoking Prevalence in adults in routine and manual occupations - current smokers (APS) - 2015



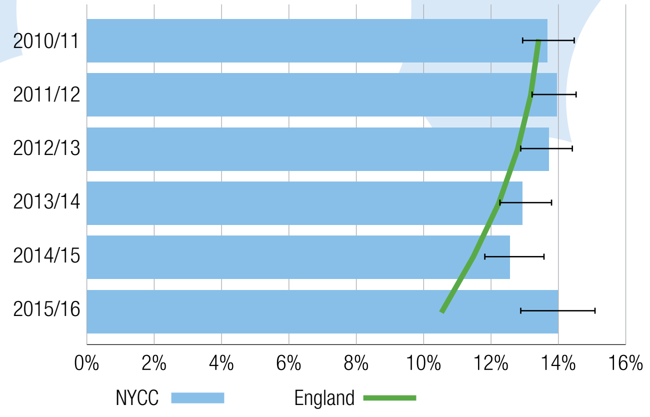
Smoking Prevalence (%) in adults - current smokers (APS)



Smoking Prevalence in adults - current smokers (APS) - 2015

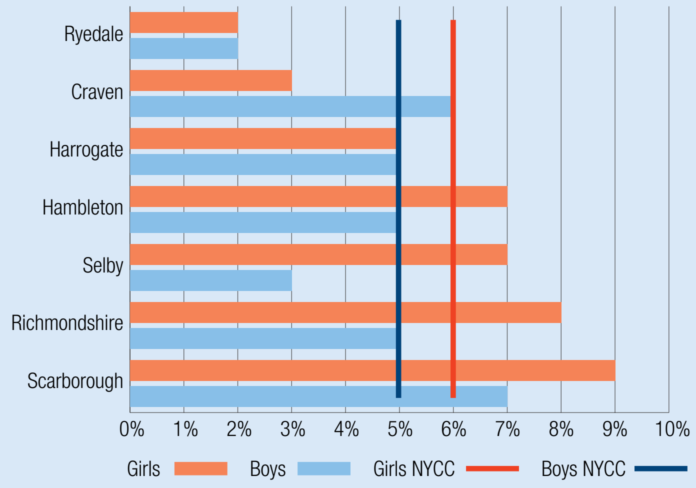


Smoking Status at time of delivery (%)
(Based on PHOF data to 2015/16)

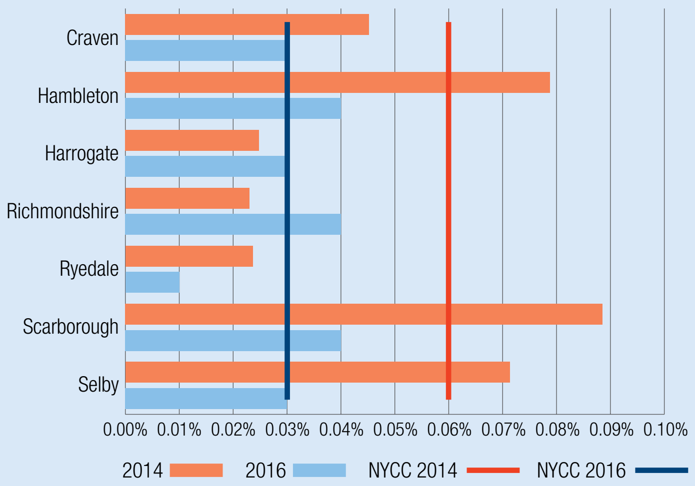


Smoking status at time of delivery - 2015/16

Year 10 - % Stating they smoke regularly - 2016 GUNY



Year 10 - % Stating they smoke regularly - 2014 / 2016 GUNY



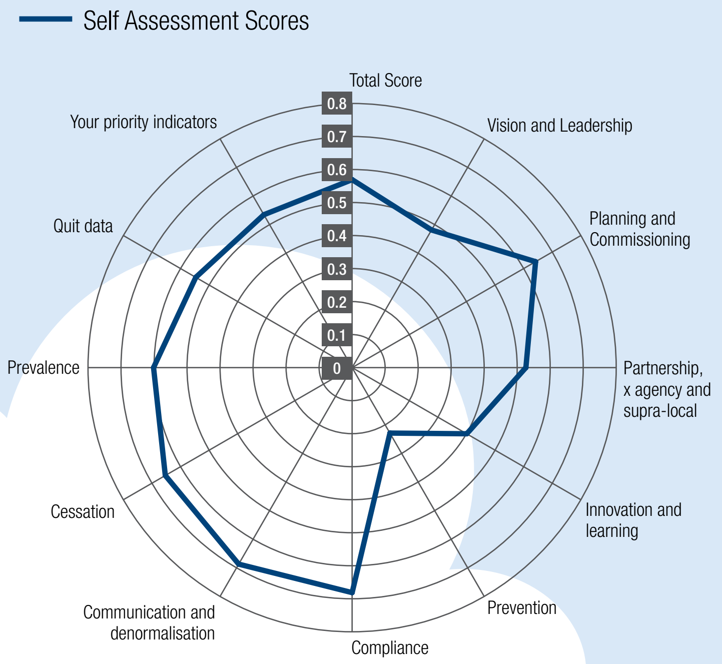
CLeaR Self-Assessment

The CLeaR model is a national approach to improving local tobacco control in England through self-assessment, followed by a peer assessment. The tobacco control steering group score their local approach against items in the CLeaR questionnaire. North Yorkshire completed this assessment in 2014 and significant gaps in activity were identified. The analysis set out areas for improvement across tobacco control in North Yorkshire, which underpinned the strategy and implementation plan.

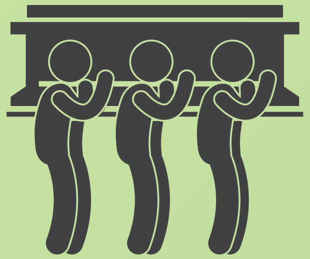
The questionnaire was repeated in 2016 and has shown a vast improvement in scores (comparative results shown below).

CleaR Profile: North Yorkshire 2014

CLeaR Profile: North Yorkshire 2016

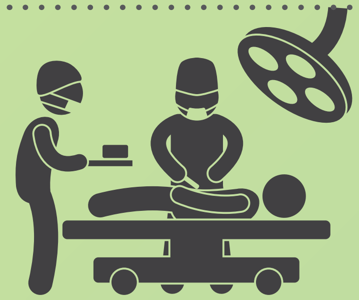


Why smoking remains a top priority for North Yorkshire



16.9%

Smoking is still the primary cause of premature mortality and preventable illness in North Yorkshire. In 2011-13, 16.9% (3128) of all deaths in the county were attributable to smoking, equating to over 1000 deaths a year.



Tobacco is linked to more than 200 diseases

and is the primary cause of lung cancer and Chronic Obstructive Pulmonary Disease (COPD); almost half of smoking-related diseases are cancers.

£22.5 million

The estimated annual cost to the NHS across North Yorkshire is £22.5 million: £21.4m is as a direct result of treating smoking related ill health and £1.1m is due to treating the effects of second-hand smoke in non-smokers (ASH Ready Reckoner, 2015).

£14.6 million

Current and ex-smokers who require care in later life as a result of smoking related illnesses cost society an additional £14.6 million each year in North Yorkshire.

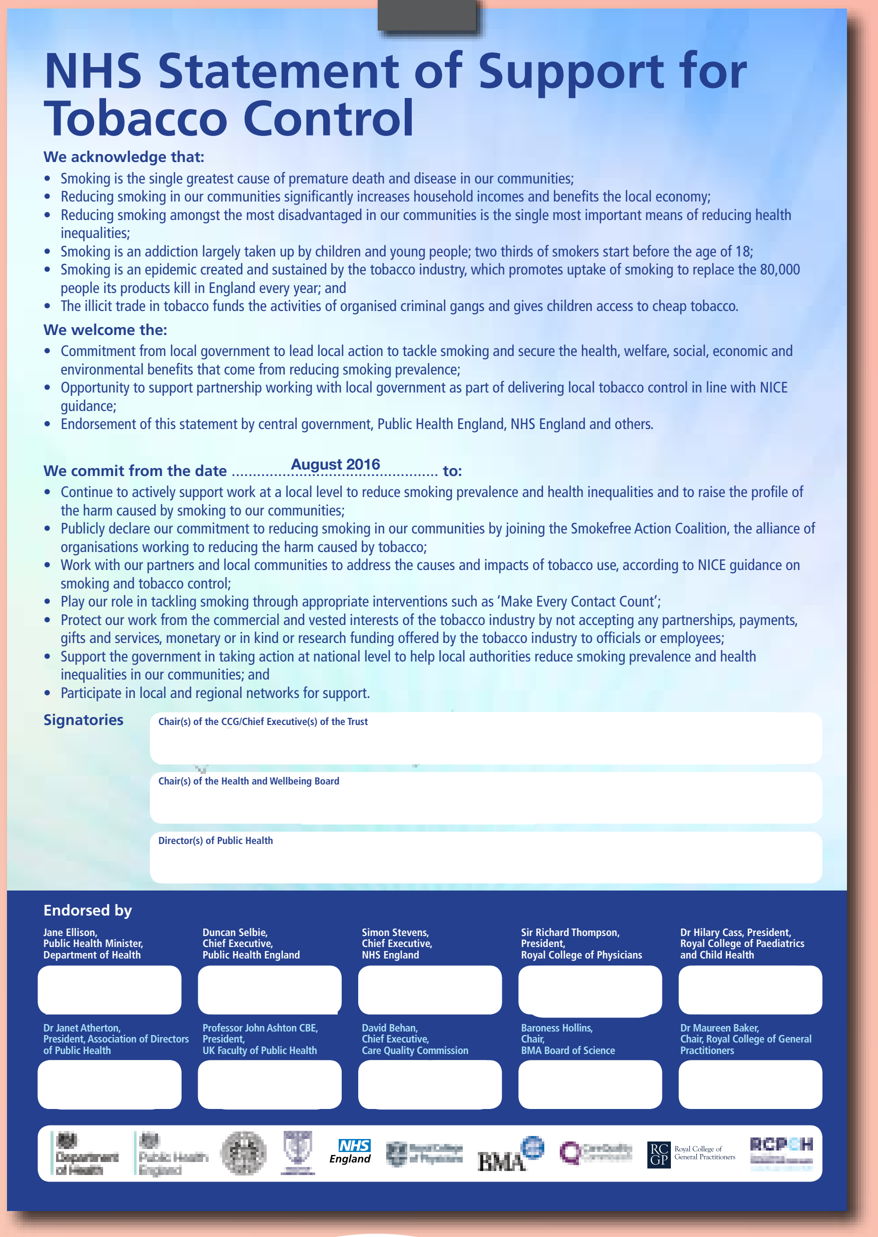
£8,358,951

The social care costs of smoking to North Yorkshire County Council are approximately £8,358,951 a year, and this is considered an underestimate (ASH, 2014).

Comprehensive tobacco control will help to reduce the number of smokers in North Yorkshire, address health and social inequalities, reduce the health and social care burden and reduce mortality and morbidity. Research shows that coordinated multi-faceted tobacco control programmes are required to effectively tackle tobacco use locally.

NHS Statement of Support for Tobacco Control and Local Government Declaration on Tobacco Control

In September 2016, North Yorkshire County Council (NYCC) signed up to the local government declaration on tobacco control, alongside all five of the North Yorkshire Clinical Commissioning Groups (CCGs) who signed up to the NHS Statement of support for tobacco control. (Hambleton, Richmondshire and Whitby CCG, Airedale, Wharfedale and Craven CCG, Scarborough and Ryedale CCG, Harrogate and Rural District CCG and Vale of York CCG). The statements provide a public commitment to work towards further reducing smoking prevalence in their locality. This commits NYCC to tobacco control as mainstream public health work and to take comprehensive action to address the harm from smoking. This is an impressive display of commitment across North Yorkshire.



NHS Statement of Support for Tobacco Control

We acknowledge that:

- Smoking is the single greatest cause of premature death and disease in our communities;
- Reducing smoking in our communities significantly increases household incomes and benefits the local economy;
- Reducing smoking amongst the most disadvantaged in our communities is the single most important means of reducing health inequalities;
- Smoking is an addiction largely taken up by children and young people; two thirds of smokers start before the age of 18;
- Smoking is an epidemic created and sustained by the tobacco industry, which promotes uptake of smoking to replace the 80,000 people its products kill in England every year; and
- The illicit trade in tobacco funds the activities of organised criminal gangs and gives children access to cheap tobacco.

We welcome the:

- Commitment from local government to lead local action to tackle smoking and secure the health, welfare, social, economic and environmental benefits that come from reducing smoking prevalence;
- Opportunity to support partnership working with local government as part of delivering local tobacco control in line with NICE guidance;
- Endorsement of this statement by central government, Public Health England, NHS England and others.

We commit from the date ......**August 2016**...... **to:**

- Continue to actively support work at a local level to reduce smoking prevalence and health inequalities and to raise the profile of the harm caused by smoking to our communities;
- Publicly declare our commitment to reducing smoking in our communities by joining the Smokefree Action Coalition, the alliance of organisations working to reducing the harm caused by tobacco;
- Work with our partners and local communities to address the causes and impacts of tobacco use, according to NICE guidance on smoking and tobacco control;
- Play our role in tackling smoking through appropriate interventions such as 'Make Every Contact Count';
- Protect our work from the commercial and vested interests of the tobacco industry by not accepting any partnerships, payments, gifts and services, monetary or in kind or research funding offered by the tobacco industry to officials or employees;
- Support the government in taking action at national level to help local authorities reduce smoking prevalence and health inequalities in our communities; and
- Participate in local and regional networks for support.

Signatories

Chair(s) of the CCG/Chief Executive(s) of the Trust

Chair(s) of the Health and Wellbeing Board

Director(s) of Public Health

Endorsed by

Jane Ellison,
Public Health Minister,
Department of Health

Duncan Selbie,
Chief Executive,
Public Health England

Simon Stevens,
Chief Executive,
NHS England

Sir Richard Thompson,
President,
Royal College of Physicians

Dr Hilary Cass, President,
Royal College of Paediatrics
and Child Health

Dr Janet Atherton,
President, Association of Directors
of Public Health

Professor John Ashton CBE,
President,
UK Faculty of Public Health

David Behan,
Chief Executive,
Care Quality Commission

Baroness Hollins,
Chair,
BMA Board of Science

Dr Maureen Baker,
Chair, Royal College of General
Practitioners

Consultation responses

The North Yorkshire Tobacco Control Steering Group co-ordinate a local response to national consultations, to ensure our views are represented on a national level. The steering group liaise with organisations such as Action on Smoking and Health (ASH) and Cancer Research UK to develop responses on consultations on topics such as advertising and illicit tobacco monitoring systems. This helps to advocate for legislative and regulatory changes.

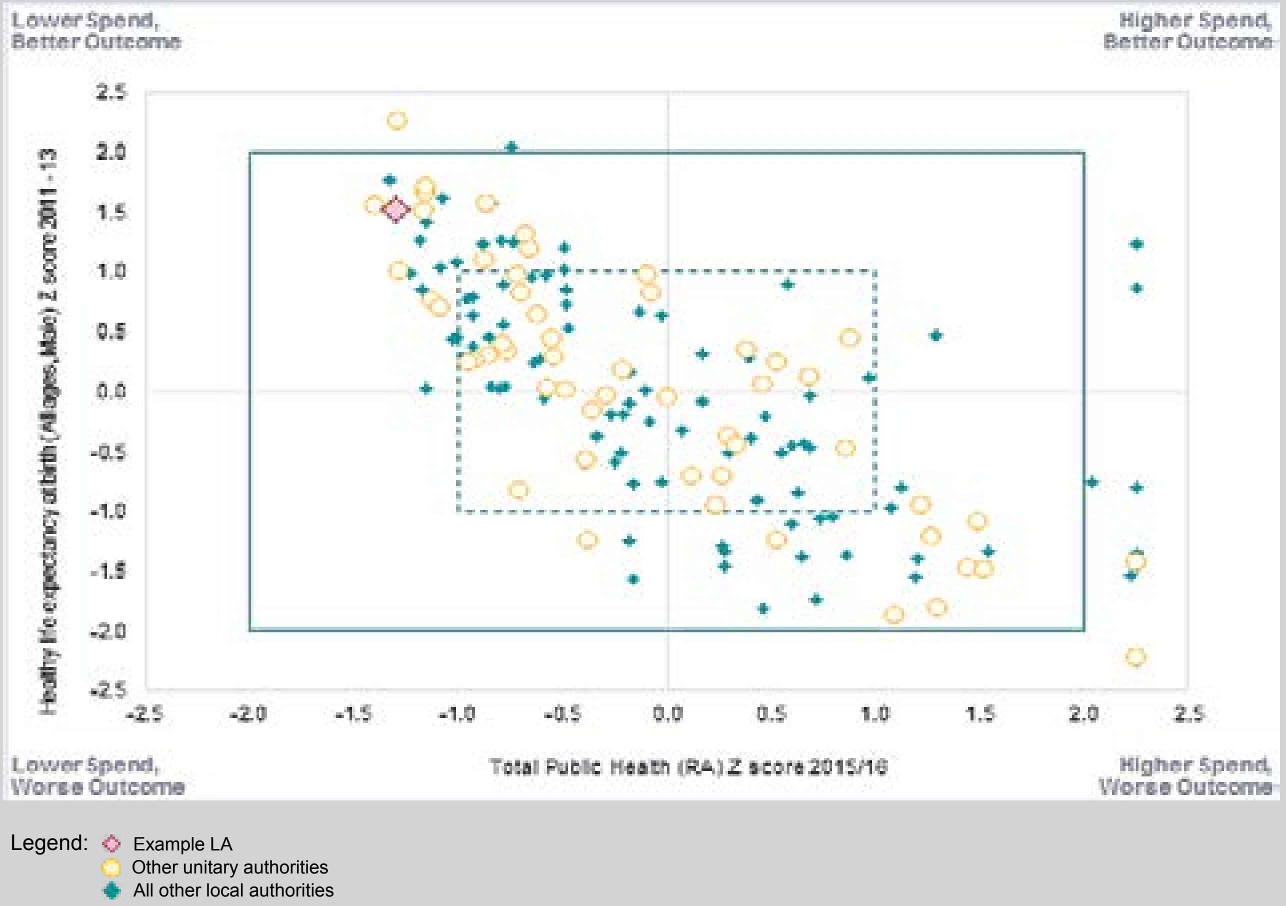
Spend and Outcome Tool (SPOT)

The Spend and Outcome Tool (SPOT) gives an overview of spend and outcomes across key areas of business.

Local authority data for 2015 has been refreshed and clinical commissioning data for 2015 has been included.

SPOT includes a large number of measures of spend and outcomes from several different frameworks. Similar organisations can be compared using a range of benchmarks and potential areas for further investigation identified.

North Yorkshire for tobacco control sits within the lower spend, better outcome quadrant.



Priority 1: Prevention for children and young people

Smoking in cars legislation

It is illegal to smoke in a car (or other vehicle) with someone under 18. The law changed on 1 October 2015, to protect children and young people from the dangers of secondhand smoke. Both the driver and the smoker could be fined £50. The law applies to every driver in England and Wales, including those aged 17 and those with a provisional driving licence.

Every time a child breathes in secondhand smoke, they breathe in thousands of chemicals. This puts them at risk of serious conditions including meningitis, cancer, bronchitis and pneumonia. It can also make asthma worse.

NYCC supports this change and circulated a press release to raise awareness of this change for North Yorkshire residents.

The NYCC schools smokefree workplace policy and guidance for North Yorkshire schools and other settings to implement a smokefree environment for pupils and staff

The schools smokefree workplace policy was recently refreshed and approved in line with best practice and legislative changes. The fundamental change to the existing policy is that support is now offered to staff who wish to quit, allowing flexi-time to be used to attend stop smoking appointments where appropriate. The policy also covers e-cigarettes. School based staff are not permitted to use e-cigarettes on school sites as they are illegal for under 18 year olds.

The guidance for schools implementing a smokefree environment has also been updated to reflect a new service provider and contact details. The new service offers stop smoking advice to children from aged 12 and above, free of charge. Pathways into the service are being developed from schools and the Healthy Child Programme to ensure access is available when required. The guidance also details the smoking in cars legislation. This has been sent to all schools across North Yorkshire.

Smoke free playgrounds

Smokefree play areas protect children from second hand smoke, help to normalise a smokefree lifestyle and provide positive role models for children and young people at play. Ongoing work is underway to create smokefree play areas across the county. Play areas are managed by different organisations in each district, usually by district councils or community groups. Therefore different approaches are required across North Yorkshire.

In 2016, Scarborough Borough Council launched a smokefree play area, and has committed to including a smokefree message in all replacement signage over the coming years. Harrogate Borough Council has launched smokefree play areas in Valley Gardens, Harrogate, Knaresborough Pool and Ripon Spa Park, in response to requests from local parent groups championing this agenda.

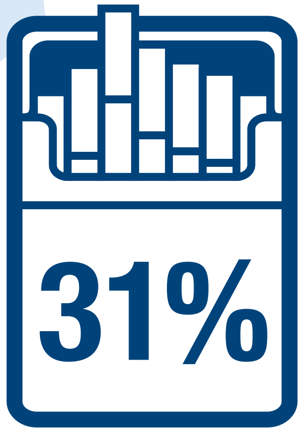
In summer 2016, Richmondshire District Council launched a consultation for local people to have their say on smokefree play areas and will be sharing the results in due course. A member of the Public Health team attended the first meeting of the Hambleton Play group, which brings together community groups managing play areas across the district, and discussed the benefits of smokefree play areas and how community groups can work on making their facilities smokefree. The partnership aims to increase the number of smokefree play areas across North Yorkshire in the coming year.

Priority 2: Normalise a smoke-free lifestyle

Underage Sales

E-cigarette use is not recommended for young people. In October 2015, UK protection was put in place via prohibitions on the sale of e-cigarettes to under 18s, and purchase by adults on behalf of under 18s, and restrictions on advertising were brought in May 2016.

The NYCC Trading Standards team has seen a significant increase in complaints relating to the availability of e-cigarettes and nicotine inhaling products to under 18s. Further work is required to engage with retailers to ensure minors cannot buy them. Work to tackle tobacco sales to under 18s continues. A test purchase is where a trained young person aged under 18 attempts to make a purchase of tobacco with Trading Standards officers nearby.



Between September 2015 and September 2016, 70 test purchases of tobacco were attempted with 22 sales occurring. This equates to a sale rate of 31%.

Proxy sales

A proxy sale is where an adult buys tobacco products on behalf of a person aged under 18. Between September 2015 and September 2016, Trading Standards received 9 reports of proxy sales occurring at off-licenses in the Hambleton district. CCTV footage has helped officers to identify the purchasers and the minors asking for the purchase to take place. In one instance, despite the purchaser being warned that the act of purchasing on behalf of a minor was illegal, the person continued to do it and as such committed further offences. It is expected that several instances of these proxy sales will be put before the courts later this year, with a view to prosecution.

Ambition for Health: Prevention task group (Scarborough and Ryedale)

The prevention task group is a partnership group for the Scarborough and Ryedale locality tasked with improving the health of the local population, with a particular focus on smoking and obesity. The group chose to tackle smoking initially. An audit was undertaken to assess the current position of all workplaces in relation to the smokefree agenda. Commonalities were found and the group agreed to make improvements to their smokefree workplace policies and seek Workplace Charter accreditation.

Standardised packaging

The introduction of standardised packaging legislation in May 2016 heralded an opportunity for North Yorkshire to ‘seize the moment’ and capitalise on engagement with smokers coming into contact with the new packs for the first time. Standardised packs feature more prominent health warnings and graphic images, are a consistent dark green colour and feature no company branding. A similar legislation change in Australia resulted in increased calls to a national quitline, smokers reported feeling that their cigarettes tasted different, and the number of children who have ‘never tried’ smoking is increasing. North Yorkshire took part in the Breathe 2025 challenge #trackthepack, which saw residents across the Yorkshire and Humber region Tweet the locations where they had spotted the new packs. Promotional work regarding the new packs and their potential impact is underway across the county.

Workplace Charter and NYCC Smokefree workplace refresh

North Yorkshire County Council are working towards Workplace Wellbeing Charter accreditation, and being a smokefree workplace features prominently in the criteria. The North Yorkshire County Council smokefree workplace policy has been reviewed and refreshed to incorporate best practice outlined in the Charter and NICE guidance. There is now a stronger focus on support for those employees who wish to quit, offering free access to local stop smoking services. Employees are now able to use flexi time to attend stop smoking appointments in the same way as a doctor or dentist appointment.

Priority 3: Reduce illegal tobacco in the community

Facebook project

In September 2015, Trading Standards officers concluded a project in which they monitored North Yorkshire based ‘Buy, sell, swap’ Facebook sites to evaluate the extent of illicit tobacco being offered online. Over a four week period, officers accessed 17 community groups and identified 70 people offering suspected illicit tobacco, via 105 posts. These adverts equated to a minimum value of £6314, with a standard retail value of £12,438. On every occasion the sellers were warned that they were committing criminal offences by supplying illicit tobacco. Facebook screening will be repeated in 2016/17 with enforcement action being undertaken against persistent offenders.

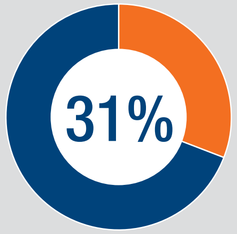
Operation Henry

In February 2016, Trading Standards took part in Operation Henry 2. This regionally funded operation allowed access to illicit tobacco detection dogs in order to identify illicit tobacco at premises subject to allegations of illegal activity. Four establishments in the Selby area were visited, all subject to previous intelligence. No illicit product was found however engaging with traders and the future deterrent effect was seen as a major success. Indeed, no further intelligence has been received regarding illicit activity in the area since the operation.

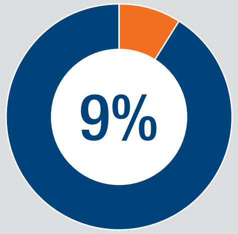
Illicit tobacco

In April 2016, NYCC commissioned a survey evaluating the prevalence of illicit tobacco in the county. The supply of illicit tobacco is a criminal offence, the profits of which fund organised crime and its availability to minors can lead to addiction later in life. Furthermore, illicit is cheaper than genuine tobacco, allowing users to continue to smoke and smoke more, making quitting more difficult.

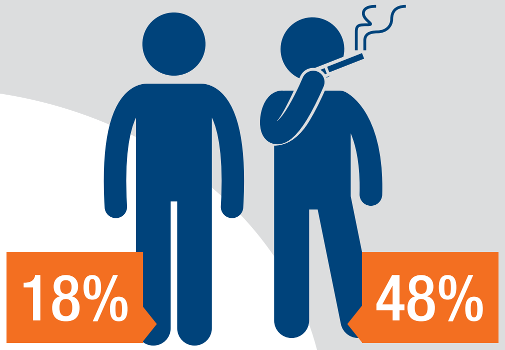
The survey indicated that, in North Yorkshire:



31% of smokers have tried illicit tobacco



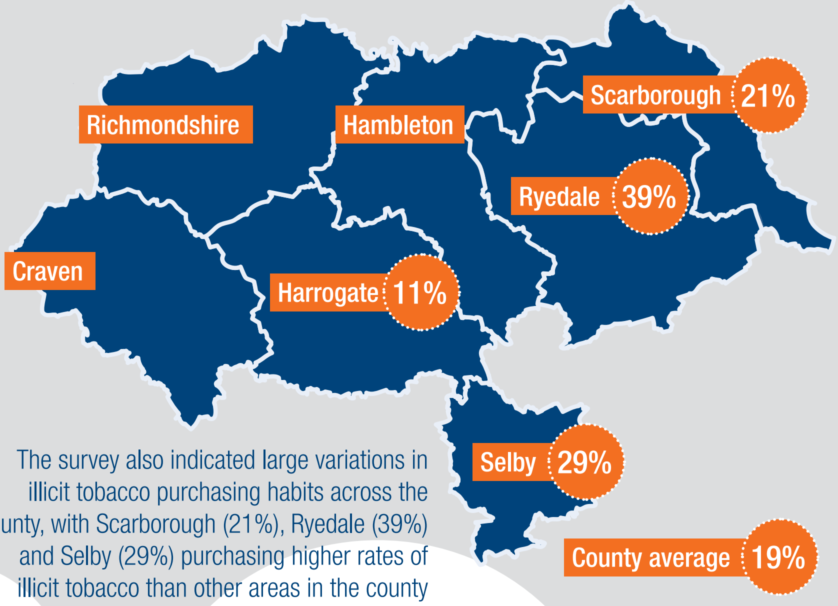
Illicit tobacco makes up 9% of the tobacco market



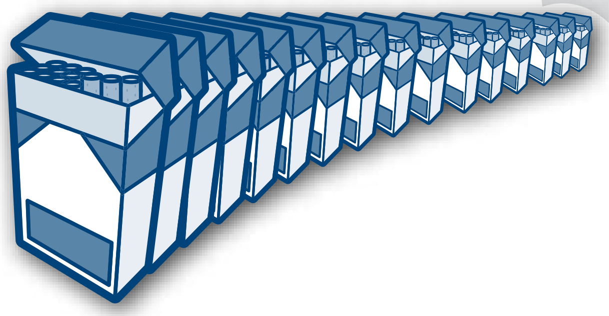
18% of non-smokers and 48% of smokers have encountered the sale of illicit tobacco

16% of smokers are comfortable with the sale of illicit tobacco

Variations in illicit tobacco purchasing habits across the county



The survey also indicated large variations in illicit tobacco purchasing habits across the county, with Scarborough (21%), Ryedale (39%) and Selby (29%) purchasing higher rates of illicit tobacco than other areas in the county (average 19%, lowest in Harrogate 11%).



113,459 cigarettes seized

Investigations of illicit tobacco have been ongoing which have involved the seizure of illegal tobacco amounting to 113,459 cigarettes and 2040 50g packets of tobacco.

In response to the survey, Trading Standards undertook a variety of activities to raise awareness of the consequences of illicit tobacco use in key communities, and to encourage individuals to report illicit activity. Trading Standards officers attended Scarborough and Ryedale Pubwatch meetings, conducted 50 advisory visits to tobacco retailers, and visited and inspected Ryedale and Selby car boot sales. A comprehensive marketing and communications strategy across local, regional and social media was developed. Trading Standards also engaged with the Ryedale Local Delivery group and the Scarborough and Ryedale Ambition for Health Board, to raise awareness of the impact of illicit tobacco use on North Yorkshire communities.

Trading Standards investigate every allegation of illicit tobacco supply and with the assistance of North Yorkshire Police have already made seizures of illicit tobacco from a variety of premises including independent newsagents, a travellers' site and private vehicles.

In Quarter 3 of 2016/17 Healthier Futures CIC will conduct further insight work in the Scarborough, Ryedale and Selby areas on behalf of NYCC and partners. This insight will identify key messages for the general public to discourage illicit tobacco use and will inform a communications campaign aimed at reducing the acceptability of illicit tobacco within our communities.

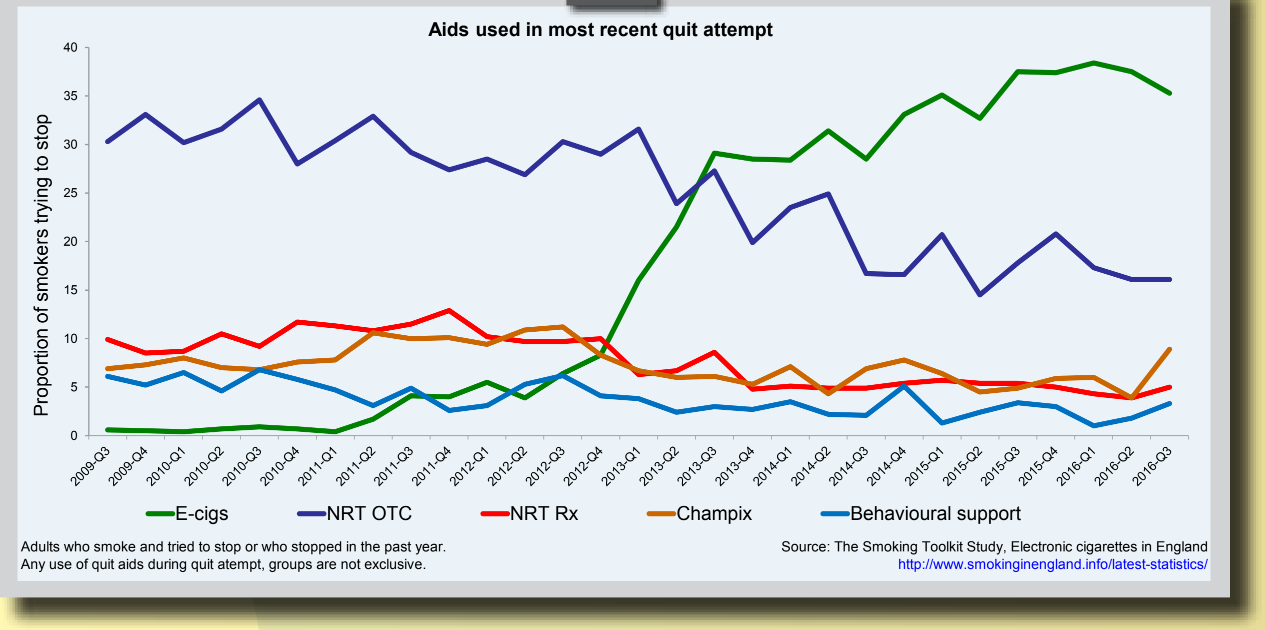
Priority 4: Support smokers to quit and reduce smoking rates during pregnancy

E-cigarettes and stop smoking support

E-cigarettes have become the most popular stop smoking aid in England. There is growing evidence that they can be effective in helping smokers to quit, particularly when combined with behavioural support from local stop smoking services.

Currently, there are no medicinally licensed e-cigarettes available on the market and they cannot be prescribed for smoking cessation.

However local stop smoking services are encouraged to be open to smokers who want to use an e-cigarette in their quit attempt, and to provide the expert support that will give them the best chance of stopping smoking successfully.


Aids used in most recent quit attempt

Adults who smoke and tried to stop or who stopped in the past year.
Any use of quit aids during quit atempt, groups are not exclusive.

Source: The Smoking Toolkit Study, Electronic cigarettes in England
http://www.smokinginengland.info/latest-statistics/

BabyClear - Scarborough Hospital

BabyClear was launched at Scarborough Hospital in January 2016, a national programme developed by Tobacco Control Collaborating Centre which aims to ensure that every woman smoking during pregnancy is given full, frank and factual information from a trained health professional about the harmful effects of tobacco and is provided with behavioural support to quit smoking. The project was approved at the Scarborough and Ryedale Locality Transformation Board and is funded via The Better Care Fund. The Scarborough and Ryedale Clinical Commissioning Group leads the project with support from Public Health and is delivered by the Hospital Trust.

The BabyClear service includes additional training to up skill all midwives who interface with patients at booking to accurately detect smoking status. Providing enhanced brief intervention training to midwives encourages patients to access and better engage with local Stop Smoking Services. The minority who refuse referral to local Stop Smoking Services during first booking are signposted into an additional clinic which aligns with the dating scan appointment. The clinic, named Risk Perception Intervention (RPI), is delivered by a smoking specialist midwife. The clinic begins with a CO monitor reading which changes the colour of the computer generated image from green, amber to red depending upon the extent of the elevated reading. This provides an opportunity to outline more detailed factual information on the harmful effects of smoking for both baby and Mum, and for the midwives to make an onward referral into the Stop Smoking Service.

The service has had a challenging 10 months and improvements are needed to increase quit rates through this pathway. Planned changes to the set up and delivery of this intervention are in progress.

Re-commissioning the North Yorkshire Stop Smoking Service and profiled spend

Effective commissioning of interventions and services is key to improving outcomes and achieving best value on investment. The Local Authority was required legally to re-tender the Stop Smoking Service, but importantly this was also an opportunity to review and develop a new commissioning model which supports better outcomes for North Yorkshire's residents and is more effective and efficient.

Following an extensive engagement and consultation period and a full review of the evidence, a new model was developed for a North Yorkshire Stop Smoking Service. The model of delivery had an emphasis on 8 priority groups where smoking rates continued to be stubbornly high, as opposed to the general population where smoking rates have reduced significantly over the years. The model was to include text, online and web based support alongside the traditional group and 1:1 support. The targeted service would be delivered by a main provider with sub-contracting arrangements in place with GPs and Pharmacies. The new provider Solutions4Health were awarded the contract which started in January. Smokefreelife North Yorkshire officially launched in March on No Smoking Day, with media coverage.

Quitting smoking before surgery

There is strong evidence of higher risks and worse surgical outcomes when a patient continues to smoke. Quitting smoking before surgery reduces the risk of postoperative complications. It reduces lung, heart and wound-related complications, it decreases wound healing time and reduces the average length of stay in hospital.

Scarborough and Ryedale CCG, Harrogate and Rural District CCG and Hambleton, Richmondshire and Whitby CCG have all recently approved plans to establish a Stop Before Your Op type scheme.

Harrogate and Rural District recently launched their scheme, on the 1 November 2016. The approved commissioning policy is that patients who smoke are to be offered a referral to the local stop smoking service for a 6 month period of health optimisation, before being considered for referral for a routine surgical outpatient appointment.

Priority 5: Carry out marketing and communication programmes

A range of campaigns have been run across North Yorkshire in the past year. Tobacco control campaigns feature prominently in the wider Public Health communications calendar, and form part of a co-ordinated programme of health promotion messages. A North Yorkshire County Council Communications employee sits on the steering group and leads on delivering tobacco control messages alongside partners.

The partnership has been involved in the regional campaign 'Breathe 2025', which aims to see a smokefree generation by 2025. Organisations and individuals were encouraged to make a pledge to help realise the vision of Breathe 2025. A website was established as part of the regional campaign, which captured pledges and shared ideas about how to promote the smokefree message in different contexts.

16 Cancers

In February 2016, Breathe 2025 and FRESH pooled resources to adapt and implement a hard hitting quit smoking campaign aimed at raising smokers' awareness of the links between smoking and 16 types of cancer, and to trigger quit attempts.

This is now thought to have been among the most successful quit campaigns ever to have run in England in terms of awareness, attitudes and actions taken. It builds on the strong existing evidence as to why campaigns are a vital part of efforts to reduce smoking.

The five week campaign featured:

4.4m

A TV advert reaching around 4.4m adults across the North East (NE) and Yorkshire and Humber (Y&H)

16 Cancers website with contact details for local stop smoking support and facts about smoking

Campaign posters and flyers for local authority and NHS partners

Engagement tool to help GP surgeries/ pharmacies to raise campaign messages with patients

15m

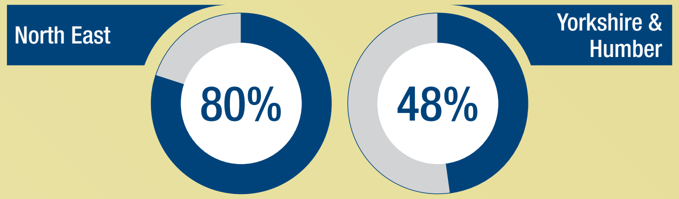
Online display, Facebook and video advertising creating around 15m impressions and 700,000 video views

42000

Over 42,000 website visits

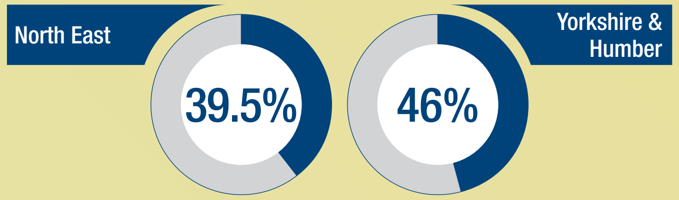
Evaluation (survey of smokers)

Number of smokers who recalled the campaign:



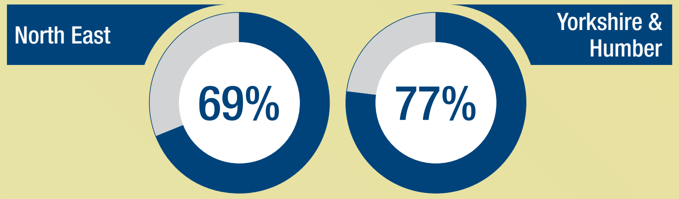
80% in NE/ 48% in Y&H (est. 740,000 smokers) recalled the campaign

Smokers who took a quit related action:



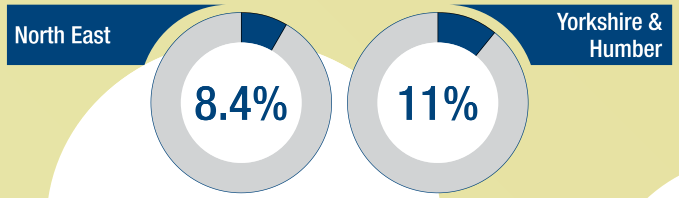
39.5% (NE) and 46% (Y&H) took a quit related action (est. 319,000 smokers)

Number of smokers who are "more concerned" about their smoking:



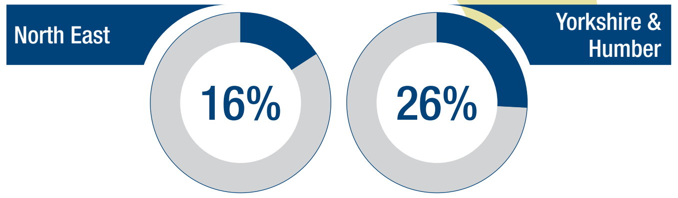
69% (NE) and 77% (Y&H) "more concerned" about their smoking

Smokers who saw it made a quit attempt:



8.4% (NE) and 11% (Y&H) who saw it made a quit attempt (est. 72,800 smokers)

Smokers who cut down: (159,400 people)

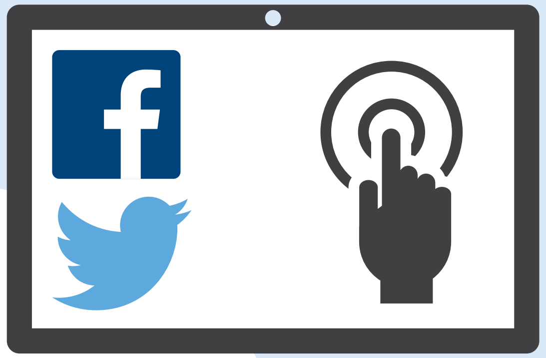


An estimated **17,000** smokers switched to an e-cigarette.

National campaigns were also promoted by the partnership, ranging from Health Harms in January 2016 to Stoptober, a national mass quit attempt. World No Tobacco Day and No Smoking Day were also marked and promoted. The partnership wrote press releases, used internal NYCC communications routes such as blogs and news stories, disseminated information and shared resources with partners.

Social Media

Trading Standards have a bespoke Twitter and Facebook account which is used to distribute key messages such as national initiatives like Stoptober or more localised messages relevant to individual communities. In addition to this the partnership also uses the Community Messaging system, which communicates crime prevention and public safety messages to a wide audience within each community.



County signs pledge to cut smoking toll

Bid to cut county's smoking deaths

Smokers are urged to quit for good

SMOKERS in the North East and North Yorkshire are

New service set up to support smokers who kick the habit

Priorities for the coming year

Priority 1:

Prevention for children and young people

- Develop a programme to roll out smokefree sports clubs, in order to increase the number of smoke free zones in North Yorkshire, and to provide positive role models to children and young people
- Continue to provide targeted support to schools where smoking rates amongst children are a concern

Priority 2:

Normalise a smoke-free lifestyle

- Continue to influence change and to promote smokefree workplaces across North Yorkshire
- Tackle allegations of proxy sales and potential associated safeguarding implications for children and young people

Priority 3:

Reduce illegal tobacco in the community

- Continue to identify and prosecute sellers of illicit tobacco
- Identify key messages through commissioned insight work to discourage illicit tobacco use and develop a communications campaign aimed at reducing the acceptability of illicit tobacco within communities

Priority 4:

Support smokers to quit and reduce smoking rates during pregnancy

- Continue to promote and embed the Smokefreelife North Yorkshire stop smoking service
- Engage with secondary care to become smokefree, in line with NICE Guidance PH48: Smoking: acute, maternity and mental health services
- Continue to develop and improve the BabyClear programme, and work with CCGs and the Partnership Commissioning Unit to reduce smoking at time of delivery across all hospital trusts

Priority 5:

Carry out marketing and communication programmes

- Ensure the tobacco control agenda and stop smoking messages are highly visible across North Yorkshire, using a range of marketing techniques

This report was written on behalf of the North Yorkshire Tobacco Control Steering Group by:

Emma Davis - Health Improvement Manager

Tessa Johnson - Health Improvement Officer

David Miller - Divisional Trading Standards Officer

For more information, please email **nypublichealth@northyorks.gov.uk**

BREATHE 2025

INSPIRING A SMOKEFREE GENERATION

Contact us

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(closed weekends and bank holidays).
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Health and Wellbeing Board
North Yorkshire

Development of future integrated commissioning arrangements in North Yorkshire
Progress Update
March 2017

1. Purpose

The purpose of this briefing paper is to provide Health and Wellbeing Board with an update on progress towards developing an approach to future integrated commissioning arrangements in North Yorkshire.

2. Background

A draft paper was presented to and supported by Health and Wellbeing Board in January 2017 which included a short term plan of deliverables and timescales.

The paper set out a vision and level of ambition for more integrated commissioning to consistently deliver better health and care outcomes across the North Yorkshire population and deliver financial sustainability in the longer-term.

Some early thinking has identified the key touch-points between Health and Social Care where a joint programme would make sense and includes:

- Continuing care (all age)
- Mental Health
- Autism
- Public Health
- Learning disability
- SEND reforms
- Section 117
- BCF investments
- Out of Hospital/Community Services
- Market sustainability and developments

Within the approach commissioners recognise the need to increase the scale and pace of progress whilst being both mindful and respectful of the different demands and requirements of partner organisations. This will necessarily determine the pace at which progress can be made.

The principle of subsidiarity is also fundamental to the approach to ensure that the focus on locality based planning and delivery remains, whilst aligning to and avoiding duplication with planning and delivery mechanisms at all levels.

In supporting the approach, Health and Wellbeing board requested an update on progress in March 2017

3. Progress update

While the timeframe since the last Health and Wellbeing board has been short the following progress has been made:

- Commissioner Forum met on the 9th of February with extended membership which included the County Councils Director of Public Health and Assistant Director for Commissioning and the Director of Commissioning Operations, NHSE
- Draft TOR were tabled
- Options to support the development of the new arrangements are being explored with a view to delivering a short term programme of facilitated workshops which will challenge and support commissioners on the level of ambition, scope and capacity to deliver
- A session on governance and the legal context of health and social care commissioning will be facilitated by the County Councils Directorate of Legal and Democratic services and a CCG Legal Service manager at the March commissioner forum
- Further joint work has been agreed to progress recommendations from the End of Life deep dive and to establish joint principles for Discharge to Assess.

4. Next Steps

Next steps include:

- Finalising and delivering the programme of facilitated workshops which will support development of the work programme
- Continuing to explore options for integrated commissioning based on national and local good practice and learning
- Finalising the Terms of Reference and launching the Commissioner Forum in its revised form
- Commencing the joint work on End of Life care and Discharge to Assess

Author

Michaela Pinchard

Head of Integration

ITEM 11

North Yorkshire Health & Wellbeing Board, Delivery Board (DB) and Commissioner Forum (CF)

ROLLING WORK PROGRAMME/CALENDAR OF MEETINGS 2017/2018 - Updated 8th March 2017

Date	Meeting	Details	Item (contact)
March 2017	**Commissioning Board** *Report Deadline: Tuesday 28 February*	Time: 1.00 pm (for 1.30 pm start) Date: Thursday 9 March Venue: Sovereign House, York	• Development of future commissioning arrangements (Barry Khan and Abigail Combes) • Facilitated discussions, moving forward • Rolling HWB Work Programme
	Health and Wellbeing Board *Report Deadline: Tuesday 7 March*	Time: 10.30 am Date: Friday 17 March Venue: Falsgrave Community Resource Centre	• Draft Carers Strategy Green Paper (Kathy Clark) • Draft Dementia Strategy (Kathy Clark) • End of Life Care – Scrutiny of Health Committee recommendations • Annual North Yorkshire Tobacco Control Report (Lincoln Sargeant) • Development of future commissioning arrangements - update (Amanda Reynolds and Michaela Pinchard) • BCF Update (Amanda Reynolds) • Rolling HWB Work Programme

Date	Meeting	Details	Item (contact)
May 2017	**Commissioning Board** *Report Deadline: Tuesday 2 May*	Time: 10.30 am Date: Thursday 11 May Venue: TBC	• Locality and Sustainability and Transformation Plans – Update (CCG Representatives) • Integration between health, care and blue light services (Owen Hayworth, North Yorkshire Fire and Rescue Service) • Rolling HWB Work Programme
	Health and Wellbeing Board *Report Deadline: Thursday 18 May*	Time: 10.30 am Date: Wednesday 31 May Venue: TBC	• Mental Health Strategy 2015/2020 (Hope, Control and Choice) – Annual Update • Rolling HWB Work Programme
June 2017	**Commissioning Board** *Report Deadline: Tuesday 30 May*	Time: 10.30 am Date: Thursday 8 June Venue: TBC	• Locality and Sustainability and Transformation Plans – Update (CCG Representatives) • TBC: Tier 2 Adult Weight Management Service (Paul Walker). • Rolling HWB Work Programme
July 2017	**Health and Wellbeing Board** *Report Deadline: Tuesday 11 July*	Time: 10.30 am Date: Friday 21 July Venue: TBC	• Dementia Strategy (final sign off) • Carers Strategy (final sign off) • Draft Pharmaceutical Needs Assessment • Joint Alcohol Strategy (2014/2019) – Annual Update • Rolling HWB Work Programme

Date	Meeting	Details	Item (contact)
August 2017	**Commissioning Board** *Report Deadline: Tuesday 1 August*	Time: 2.00 p.m. Date: Thursday 10 August Venue: TBC	• Locality and Sustainability and Transformation Plans – Update (CCG Representatives) • Rolling HWB Work Programme
September 2017	**Health and Wellbeing Board** *Report Deadline: Thursday 24 August*	Time: 10.30 am Date: Wednesday 6 September Venue: TBC	• Director of Public Health Annual Report • Healthwatch Annual Report • Complaints Advocacy Service Annual Report • Safeguarding Adults Board Annual Report • Rolling HWB Work Programme
	Commissioning Board *Report Deadline: Tuesday 29 August*	Time: 10.30 am Date Thursday 7 September Venue: TBC	• Locality and Sustainability and Transformation Plans – Update (CCG Representatives) • Rolling HWB Work Programme
November 2017	**Commissioning Board** *Report Deadline: Tuesday 31 October*	Time: 10.30 am Date Thursday 9 November Venue: TBC	• Locality and Sustainability and Transformation Plans – Update (CCG Representatives) • Rolling HWB Work Programme

Date	Meeting	Details	Item (contact)
November 2017	**Health and Wellbeing Board** *Report Deadline: Tuesday 14 November*	Time: 10.30 am Date: Friday 24 November Venue: TBC	- Safeguarding Children Board Annual Report - Rolling HWB Work Programme
December 2017	**Commissioning Board** *Report Deadline: Tuesday 28 November*	Time: 10.30 am Date: Thursday 7 December Venue: TBC	- Rolling HWB Work Programme

DATES FOR MEETINGS IN 2017/18 NOT INCLUDED IN ABOVE TABLE AT THIS STAGE

Health and Wellbeing Board
Wednesday 24 January 2018 - 2.00 p.m. till 4.00 p.m.
Friday 23 March 2018 - 10.30 a.m. till 12.30 p.m.

Commissioner Forum
Dates for 2018 to be confirmed

Delivery Board
Dates to be confirmed