

healthwatch York

Key Messages from the NHS Long Term Plan Engagement Project in York

August 2019

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Introduction

In January 2019 the NHS published a document called the NHS Long Term Plan¹. The plan identified priorities and sets the direction of travel. It also sets out the changes that the NHS is going to make over the next ten years. It highlights areas of health where the NHS want to improve care such as increasing funding for children's mental health, preventing heart attacks, strokes and dementia and also looks at how the challenges the NHS faces can be addressed, such as staff shortages and growing demand for services.

One of the priorities within the plan was to have more involvement from the public and service users. As such, Healthwatch across the country were set an objective to gather information on what people would like to see in their local area.

The Humber Coast and Vale Health and Care
Partnership covers 6 local CCG (Clinical
Commissioning Group) areas including the Vale of
York. The partnership includes representation from local
hospitals, mental health services, local authorities and
CCGs. This partnership must produce plans that show
how they will bring about changes mentioned in the
NHS Long Term Plan in each area. This will be a five
year strategic plan, called the Partnership Long Term
Plan. The findings from this Healthwatch project will
provide insight into the views and perspectives of local
people across the region.



Humber Coast and Vale region

¹ NHS (2019) NHS Long Term Plan. Available at: www.longtermplan.nhs.uk Accessed: 26/08/2019

The research that took place

NHS England funded the Healthwatch network to engage across England. They wanted to understand what people would like to see from their local health and care service, based on the priorities identified in the Long Term Plan.

Healthwatch York along with its 5 partners, (Healthwatch East Riding of Yorkshire, Healthwatch North Yorkshire, Healthwatch North Lincolnshire, Healthwatch North East Lincolnshire, Healthwatch Kingston Upon Hull) across the Humber Coast and Vale area, worked together to gather information on people's views through a range of methods.

These included:

- A general survey given to all members of the public
- A condition-specific survey for those who had experienced specific clinical pathways
- A general focus group
- A condition-specific focus group

Each Healthwatch area carried out a different condition-specific focus group, choosing from those outlined in the Long Term Plan. These included: Cancer, Dementia, Mental Health, Heart and Lung Disease, Autism and Learning Disabilities. Findings from all Healthwatch areas fed into a report for the Humber Coast and Vale compiled by Healthwatch East Riding. You can see this report here².

² Healthwatch (2019) Humber, Coast and Vale. What would you do? It's your NHS. Have your say. Available at: https://www.healthwatchyork.co.uk/wp-content/uploads/2019/07/Humber-Coast-Vale-Long-Term-Plan-Report-Final.pdf

Our report focuses on the NHS Long Term Plan findings for the York area only. The survey was completed by 206 people across York, 172 people took part in the general survey and 33 people took part in the condition specific survey. The surveys included a mixture of closed and open-ended questions. Results of the multiple choice closed questions can be seen in appendix 1 and 2. For the purpose of this report, answers from the open-ended survey questions have been grouped together and summarised into key topic areas in order to present some key overarching themes, views and messages that people shared.

Summary of findings

The general survey aimed to find out what was most important to people in York. 87% of responders stated that having a professional that listened to them when speaking about their concerns was very important and 86% of responders felt that having access to help and treatment when needed was very important.

When asked about what could be changed to improve their health York responders overwhelmingly stated they need better GP access. Others wanted to see better use of technology without losing the human touch. There was also interest in affordable exercise opportunities and support with nutrition.

Focus groups also highlighted concerns about GP access and the challenges as well as benefits of technological improvement. People talked about wanted more control through having access to their records. People spoke about wanting more flexibility in services, better communication between services and greater person-centred approaches across the support and treatment available.

When asked what would help people to maintain their independence as they grow older, many people stated the need for more accessible and regular transport which could connect neighbourhoods in York and enable people to meet the demands of attending appointments across York and maintain independence into older age. People also spoke about wanting more flexibility and affordable care in the home and community.

The condition-specific survey wanted to find out how people with specific challenges experienced the health service. Those who responded answered from their experiences of living with: heart and lung disease, cancer, dementia, mental health, learning disability or long term conditions (for example arthritis or diabetes). People talked about the lack of support available to them; in many cases this support had not met their expectations.

People did report some good experiences and forms of support that had been effective. However, in most cases people's overall experience of getting support had been negative. People spoke about the length of waiting times to receive diagnoses, get access to the right treatment and access support. People felt that more choice was needed in the types of support available. They also felt that support should be tailored to the needs of the individual, rather than having imposed restrictions like time limitations. People spoke about wanting accessible and affordable exercise and nutrition support. People felt that regular check-ups would improve their health and better communication between services would improve their experiences.

Specialist nurses who are easily accessible and able to provide quality information were a positive in people's experiences. People also spoke about support they had received through charities which had been

valuable and effective. Certain types of therapy experienced as effective were also mentioned, such as group CBT (Cognitive Behavioural Therapy).

The dementia focus group brought further attention to many of the issues raised above, from GP access to poor communication across services. People also spoke about the difficulties of trying to navigate the system and access the right support. The variations in standards of care were raised, including the lack of awareness from staff in some settings in supporting people with dementia. People spoke about the importance of involving those with dementia in designing and improving services and enabling them to have more say across all aspects of their care.

In more detail: key messages form the Long Term Plan engagement survey in York

What's very important to York residents?

87% of responders stated that having professionals that listened to them when speaking about their concerns was very important and 86% of responders felt that having access to help and treatment when needed was very important (see table 1 and 2).

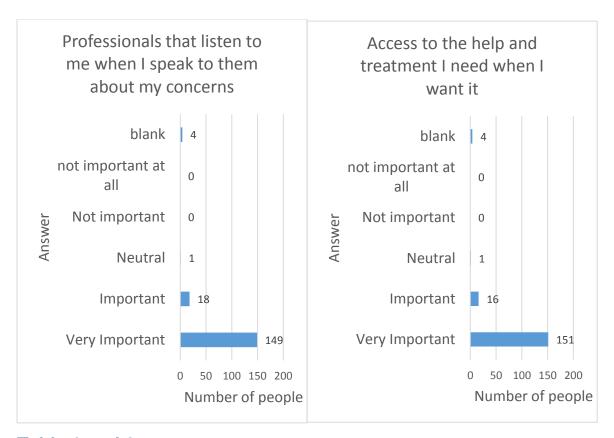
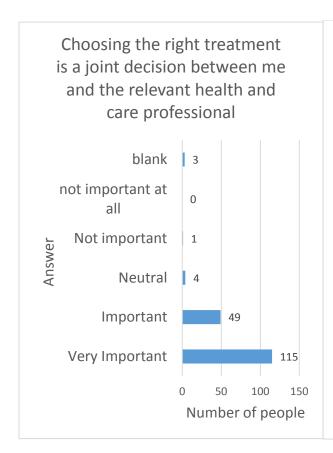


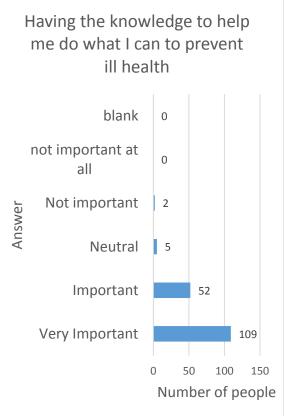
Table 1 and 2

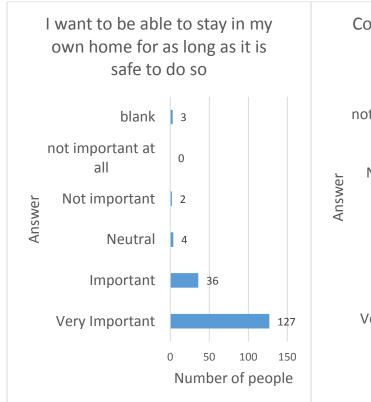
What's also important to York residents?

Rated as the most important or very important were also:

- Being able to choose the right treatment as a joint decision between those receiving the treatment and the health professionals involved
- Having the right knowledge to prevent ill health
- Being able to stay in own homes for as long as is safe to do so
- For communications with the health service to be timely (see tables 3 to 6). See appendix 1 for full list of tables and results.







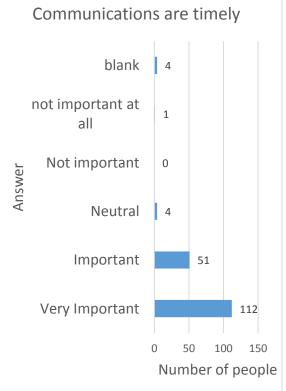
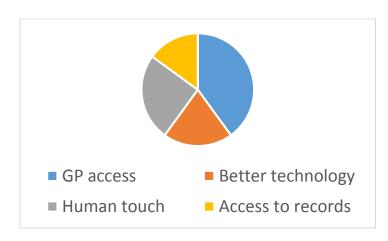


Table 3, 4, 5 and 6

If there was one more thing that you think needs to change to help you to successfully manage your health and care what would that be?

Key themes that many survey respondents highlighted were GP access, better technology, human touch and access to records.



This pie chart demonstrates the weighting of 4 key themes highlighted within responses. Three of these are discussed in more detail below.

"The ability to make doctors and nurses appointments."

GP access

GP access was the most consistently mentioned concern from York's public. People spoke about the current inaccessibility of these services from online platforms that were unworkable to difficulty getting through on phones. People spoke about the length of times to get an appointment and the difficulties with never getting to see the same doctor twice. One person stated how it would be helpful to be able to speak to a nurse or doctor over the phone to ask questions rather than always having to make a face-to-face appointment.

"Technology all very well but do not lose the human touch."

Human touch

Many comments were made around not losing sight of the importance of the human touch in health care. People may benefit from having a person to explore their issues with or ask questions. The attitude of staff was felt to be vital and people spoke about the benefits of peer support. The importance of being able to speak to people who understand was reported and there was a concern about using technology to replace this.

Better technology

"Get with the times, we have to be able to access information on our phone, book appointments, look at blood results etc."

People wanted to be better able to access information, e.g. look at blood tests on their phones. People spoke about utilising apps, skype, video appointments, and text messages. They also recommended making sure facilities that are available are used to their full potential. People spoke about wanting initial support to learn how to use online tools and for these tools to be easy to use.

If there was one more thing that would help you live a healthy life, what would it be?

"Better access to my GP."

GP access

Again, people referred to being able to get regular check-ups at their GP and easier access and availability of GP/nurse appointments.

Affordable exercise and nutrition support

"Exercise facilities for people who are very overweight."

A large proportion of people spoke about access to affordable exercise opportunities, with better facilities for those who were overweight and/or have mobility difficulties. People spoke about how eating healthily was more expensive. They felt there should be more funded healthy cooking classes for people to learn about better nutrition alongside this being taught in schools. Quality nutritional support and information was felt to be difficult to find, or inaccessible.

Other comments included having better access to personal records. People commented on communication and the need for more open and honest dialogue with health services. There was interest in a 24 hour helpline and a travelling library. One person spoke about the need for help with long distance travelling to appointments.

If there was one more thing that would help you retain your independence and live healthily for as long as possible, what would

it be?

"Travel is a constant worry."

Transport

Transport was discussed as a key issue within York. People spoke about buses only going into the centre with almost no circular routes to connect neighbourhoods. This causes problems when being re-directed to different GPs. One person spoke about ending up in A&E due to it being in an accessible place. People spoke about transport being a worry when trying to attend appointments, getting access to other kinds of support or combating loneliness.

Affordable care and support in the home/community

"Cost of care to be more realistic."

People spoke about wanting affordable and flexible support at home as well as well adapted, suitable homes so that they could grow older in them safely. People felt good, practical care would stop or reduce the risk of them needing to go into a residential home in later life. People wanted well-funded, inter-generational and accessible community support.

Other comments people made included wanting more individualised care and flexible support. People felt that social prescribing should be available at all GPs and work should be done to build on the benefits of the voluntary sector. People talked about the issues of social isolation in older age and the need for advocates in later life. People spoke about the need to join up services so that people were not waiting for home care in hospital. People spoke about communication needing to improve between people and services and between services themselves.

In more detail: key messages from the condition specific Long Term Plan engagement survey in York

This section of the report feeds back on findings from the condition specific survey in York.

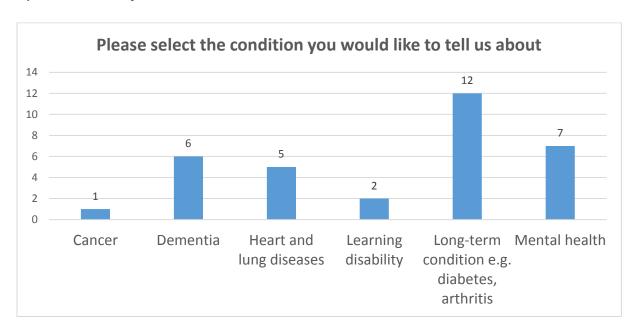


Table 7

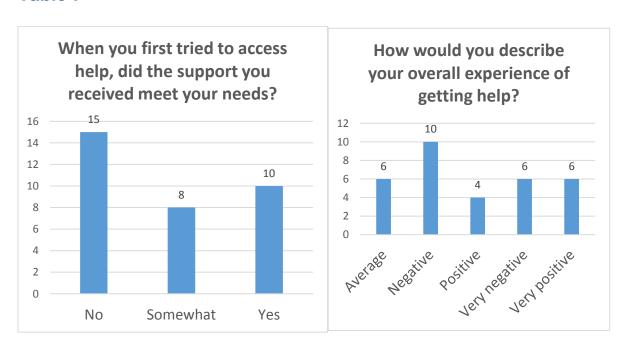


Table 8 and 9

The condition specific survey wanted to find out how people with specific challenges experienced the health service. Those who responded answered from their experiences of living with heart and lung disease, cancer, dementia, mental health, learning disability and long term conditions (e.g. arthritis or diabetes). People talked about the lack of support available to them. In many cases this support did not meet their expectations. There was a mixture of good and bad responses though often people's experiences of getting support had been negative (see tables 8 and 9). See appendix 2 for full list of tables.

What could the NHS do to help you stay healthy?

Easy access to support

"Access to support when I need it...and not having to go through a referral process every time I need some specific help that the GP can't provide."

People spoke about the need for counselling to cope with implications of diagnoses and understanding from a more holistic perspective. People wanted options for other forms of support such as physiotherapy and psychological support. People wanted to feel listened to and feel that services were being pro-active, providing support as and when needed for the individual concerned. People also talked about having carers involved in communication.

Regular check-ups

"Regular medical checkups and guidance."

People felt that regular health checks would help them to stay healthy, provide guidance and regular monitoring.

Accessible and affordable exercise and nutrition support

"More access to subsidised exercise options."

Access to exercise and nutrition support was also mentioned.

What worked well?

Specialist nurses

"The IBD nurses who were very quick to respond. They also provided me with a good quantity of booklets to read."

People spoke about condition-specific nurses (in IBD (irritable bowel disease), heart failure and breast cancer) and the helpful information that had been provided and good access to their support.

Support from charities

"I was directed to charities to avoid NHS waiting times."

People spoke about being referred to charities for support which had worked well. Examples included dementia support, and support with PTSD enabling an individual to avoid the long waiting times of the NHS.

Other forms of support

CBT group therapy was highlighted as effective for some, along with regular check-ups, exercise and information programmes.

If you accessed support, what could be improved?

Waiting times

"Waiting times, so that underfunded and understaffed charities don't have to shoulder the burden."

People spoke about the waiting times for services and diagnosis, especially within mental health but across conditions. Examples

included: 2 years for a fibromyalgia diagnosis, over 1 year to get on the ASCEND course and a 6 month waiting list for rheumatology.

"Greater choice in what support and treatment was available."

Access to a wider range of support and choice

Following diagnosis, a lot of people felt there was a lack of support or a lack of choice and flexibility in the available support. Support from charities was felt to be valuable yet often underfunded. People felt support should be more needs-led and individualised rather than set packages that end on fixed dates.

Better Communication

"You hear one thing from one professional and another thing from another."

People also mentioned how communication could have been better, both in terms of how they were listened to and in how different services talk and work with each other. People reported feelings of not always being listened to. They reported being passed around services. Some people felt stigma still existed in health services around certain issues.

Focus group findings

Overall, 36 people took part in our focus groups at Healthwatch York. We held two - one general focus group and one for people living with dementia and their carers. People provided us with insight, feedback and suggestions across four main question areas. These were:

- What's not working well?
- What is working well and making lives better?
- What could be better/done differently and what matters most to people?
- How do you want to be involved? What is the role of the public/professionals?

The feedback was grouped into key themes which are outlined below with accompanying examples of quotes from focus group data.

Findings from the general focus group



What's not working well?

Continued lack of access to GP appointments

"Not being able to get GP appointments but continuously and desperately trying."

Challenges of access via online systems

"Online booking for appointments doesn't work for everyone."

- Perceived pressures on staff, services and resources
 "It always feels like the staff have to go above and beyond, but it shouldn't be that way."
- Lack of joined up care and lack of flexibility in services
 "There are too many rigid rules that prevent ways that individuals can be cared for."
- Challenges and stress of trying to navigate the health and social care system
 "...there was no understanding of the logistical challenges."
- Payment structures that produce poor patient care

"When a service loses funding and then stops existing, all the information guides then need updating and it might then be replaced by a service that can't run as well. All the people signed up are then affected badly by this."

What is working well and making lives better?



Responsive and accessible services

"Some GP practices have freely available GPs to respond to emergency appointments."

Use of technology

"Once in the system I had access to ongoing apps which were helpful – from GP to secondary care."

• Effective communication

"Having specialist nurses available to discuss things like heart failure. You feel confident in the information they give."

What could be better/done differently and what matters most to people?

Improved access to GP services

"A more centralised system for booking GP appointments to make it fairer for everyone."

Using technology better

"Use of technology for simple things to free up resources for the more complicated things."

Privacy at pharmacists

"At pharmacists, can't there be another room to go for a chat rather than stand in the queue?"

• Better communication between services

"In A&E, and generally, there needs to be more joined up sharing of records. There is disjointed care otherwise and then you have to explain to every clinician about your conditions."

Greater patient control

"To be able to access your care record and for health providers to have this so you don't have to give your whole back story."

Person-centred approach in services

"To be treated as a person. Not a condition or a number."

Greater funding for voluntary services

"More funding generally, perhaps from the NHS, to fund voluntary services that they refer to, as referrals and waiting lists are too long for these services to manage."

How do you want to be involved? What is the role of the public/professionals?

• Importance of public community involvement

"Organisations should be funded to do engagement properly."

• Transparency and communication

"What is the feedback being used towards?"

• Importance of getting feedback

"When I make complaints, we sometimes get an apology but what happens to change things?"

• Using vehicles like Healthwatch for change

"Use people whose roles involve engaging with the public"
"Can you use Healthwatch? This is cheaper and more independent."

Findings from the dementia focus group



What's not working well?

- Lack of access to GP support alongside a lack of speciality
 "The lack of GPs specialising in dementia."
- Poor attitudes and communication

"Services often treat people all the same but every person is different."

Variations in standards of care

"There's wrap around support for people with cancer. It's not the same for people with dementia. You need the same standard of care, the same understanding of the support you need. It should be about you, the person with the conditions."

Over-complicated and inaccessible systems

"Appointment mistakes in the system become so difficult to rectify."

• Difficulties trying to navigate multiple support organisations

"The amount of different community groups and services. How do you know which to use and when?"

What is working well and making lives better?



Greater GP access through new systems in place

"A GP service where there has been a doctor with no pre-booked appointments and therefore has been able to receive a good response to urgency of getting an appointment."

Opportunities for networking in the community

"They were able to put me in touch with networks locally and there was something on every single day."

Voluntary services that respond proactively to people's needs

"York Carers Centre are marvellous. I was going under and they spotted it."

What could be better/done differently and what matters most to people?

- More staff/systems to support staff-to-patient contact in dementia
 services
 "More staff to be able to meet the high support needs of patients without competing admin tasks to do."
- Better communication and increased training for staff

"Better staff awareness of dementia."

Enabling people to have a say and more control

"Having better and simpler guidance about who to use and when (in regard to VCS groups)."

Greater involvement across the system

"Getting more information about dementia research, drug trials from the NHS and having more locally based research in which people could participate."

 Clear and simple guidance to support navigation and access to local support

"Having clear information about treatment options and getting a say."

How do you want to be involved? What is the role of the public/professionals?

Importance of involvement and giving feedback

"We want to be involved in improving services. We can help improve things for those who come along after us."

Creating meaningful change

"The importance of getting a response and action."

Access to feedback channels

"To have those people with responsibility for improving things to actually meet with and talk to people with the conditions they want to improve things for."

"There shouldn't be one method of giving feedback."

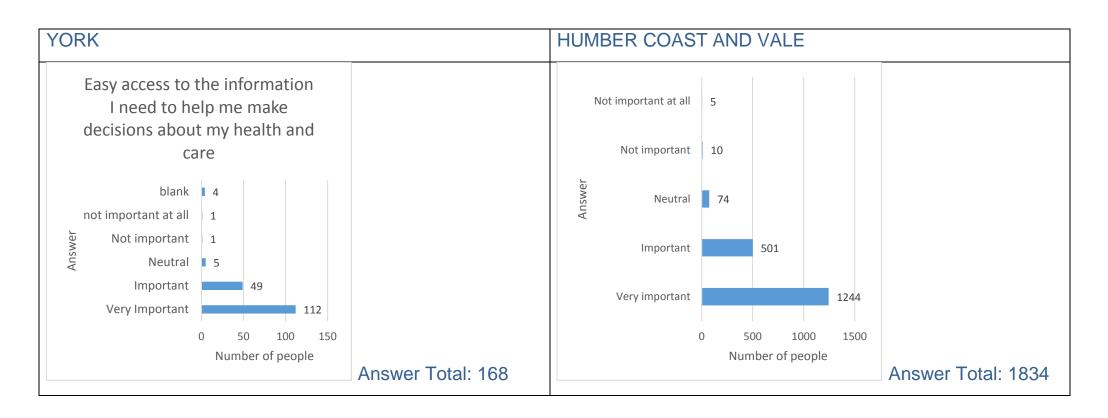
Conclusion

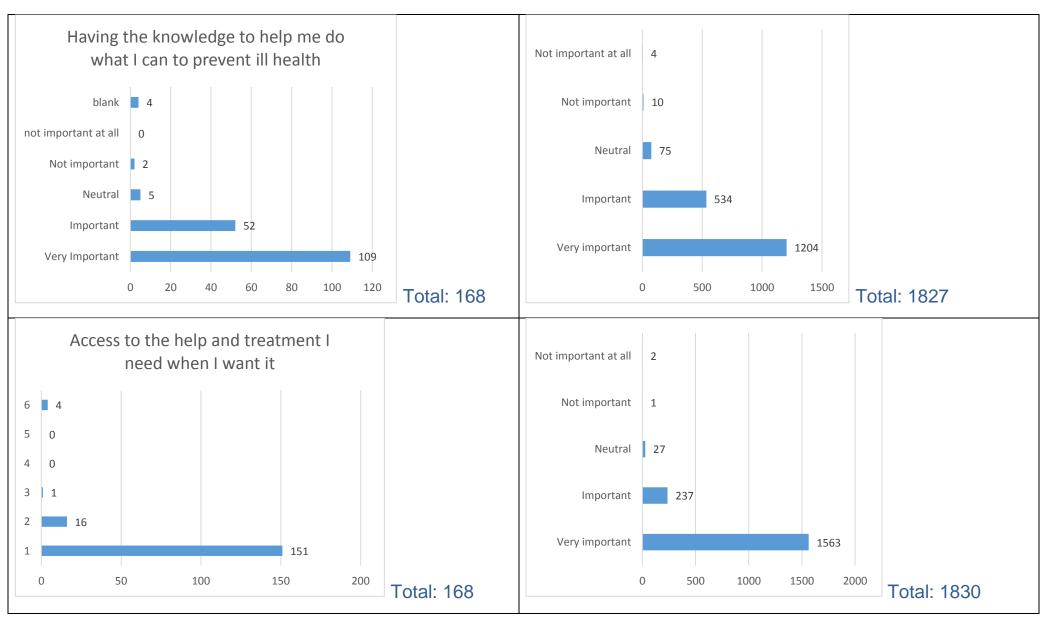
Findings from our local NHS Long Term Plan engagement work highlighted many issues and ideas that are felt across York. Throughout the engagement project, people spoke about the importance of being involved in improving services in the future, having more control and having a say. This project has been effective in NHS England demonstrating a commitment to involving local people in their work. We hope this sets a precedent for continued engagement going forward. Though people provided many examples of when health, social care and voluntary services had been responsive, supportive and beneficial to their health and well-being, people also fed back many views on what needed to be improved in the future across York. Key issues which arose from the data were:

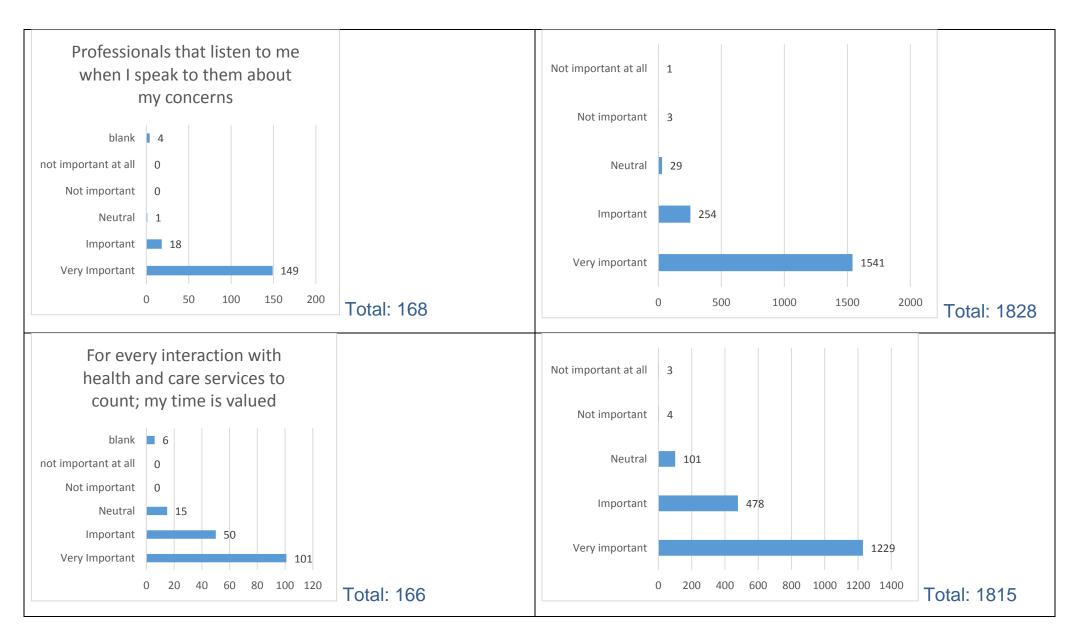
- GP accessibility. This was the overwhelming concern amongst York residents.
- Better use of technology. This was suggested as one option but not as a replacement to vital forms of human support. People also wanted support to learn to use new technology.
- More control through having improved access to personal health or care records, so that conversations with multiple professionals are more time effective and efficient.
- More flexibility in services and greater capacity for them to offer support on a needs-led, person-centred approach. People wanted greater choice in the support available.

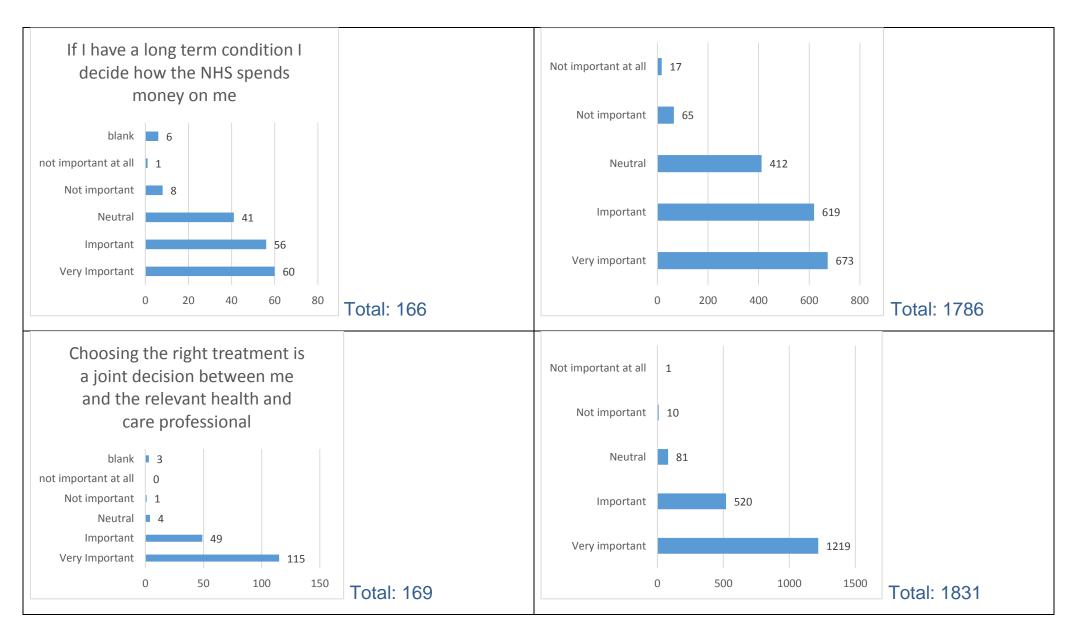
- Access to affordable exercise opportunities, especially for those with mobility needs, and greater access to support with, and information about, nutrition.
- Better communication across people's interactions within health services. Improvement in how services talk to each other and work together to support individuals who are involved with a multitude of services.
- Better transport, which is regular and connects neighbourhoods, so that people can meet the demands of attending appointments across York and maintain independence into older age.
- More thought put into enabling all people to navigate very complicated health, care and voluntary sector support systems effectively.
- Adequate funding and sustainable payment structures for voluntary sector services providing support to people.
- Improvement in attitudes towards dementia across services and a reduction in the variation of standards of care between services.

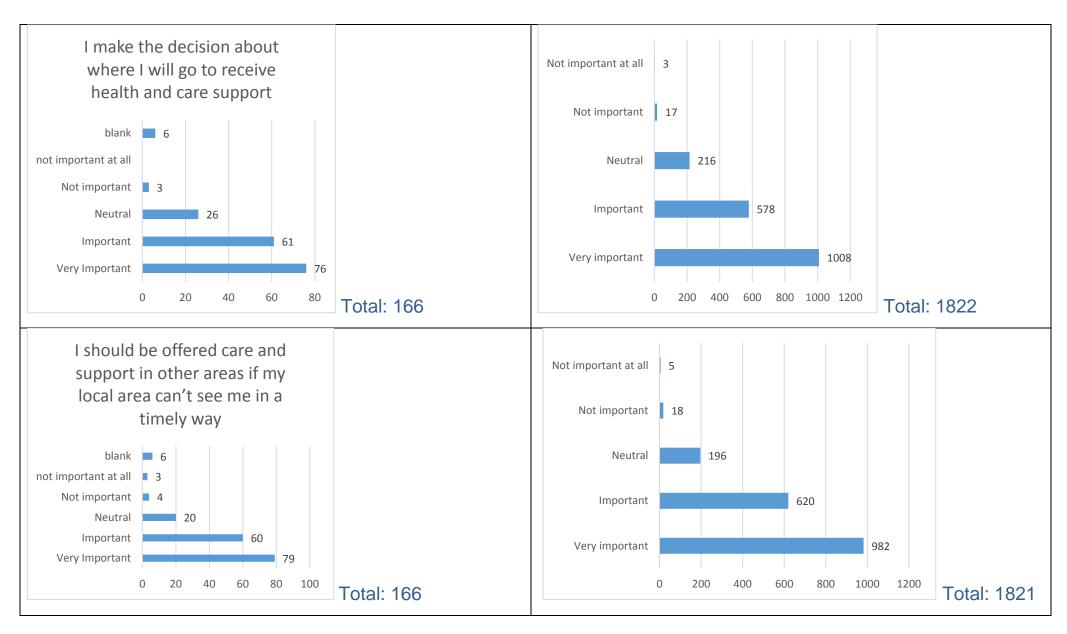
Appendix 1: General survey results in York and across Humber Coast and Vale

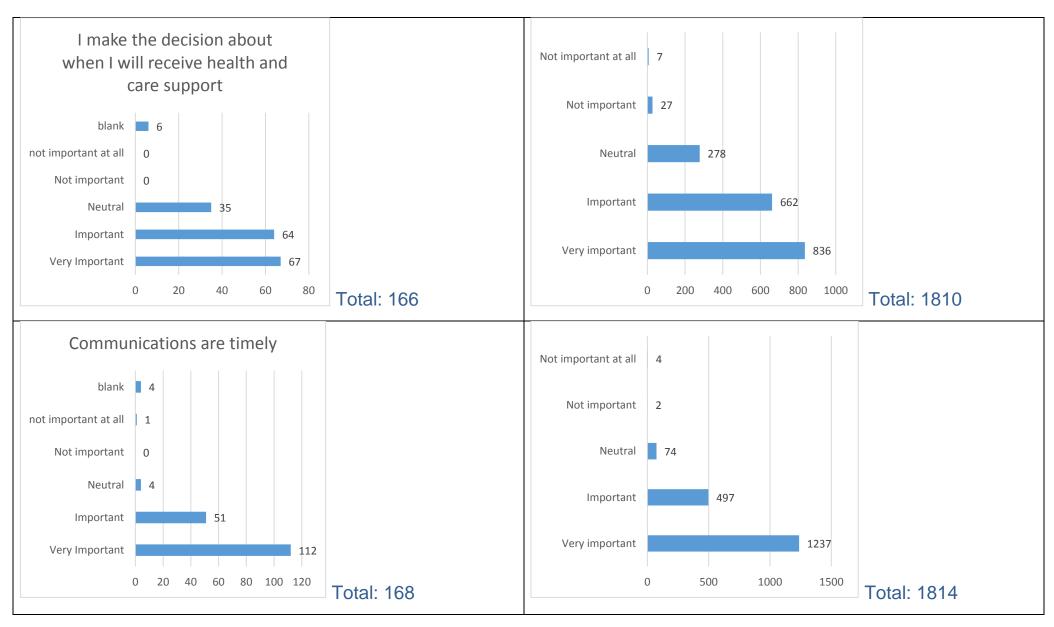


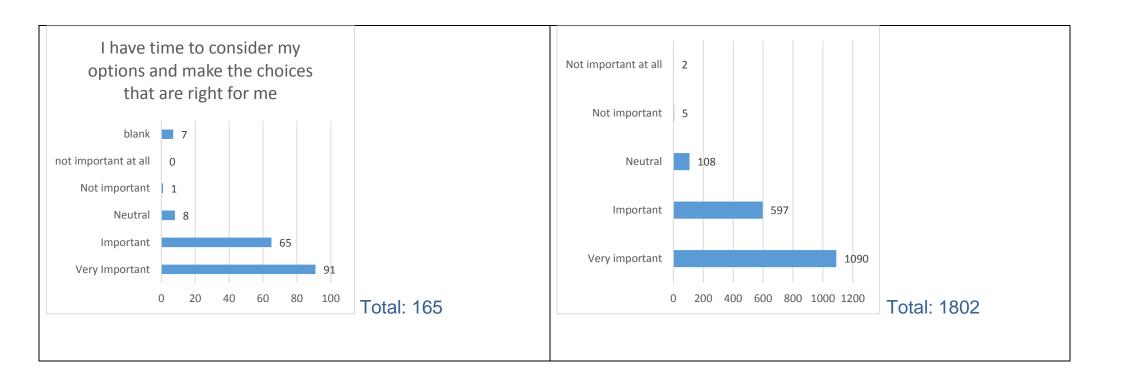


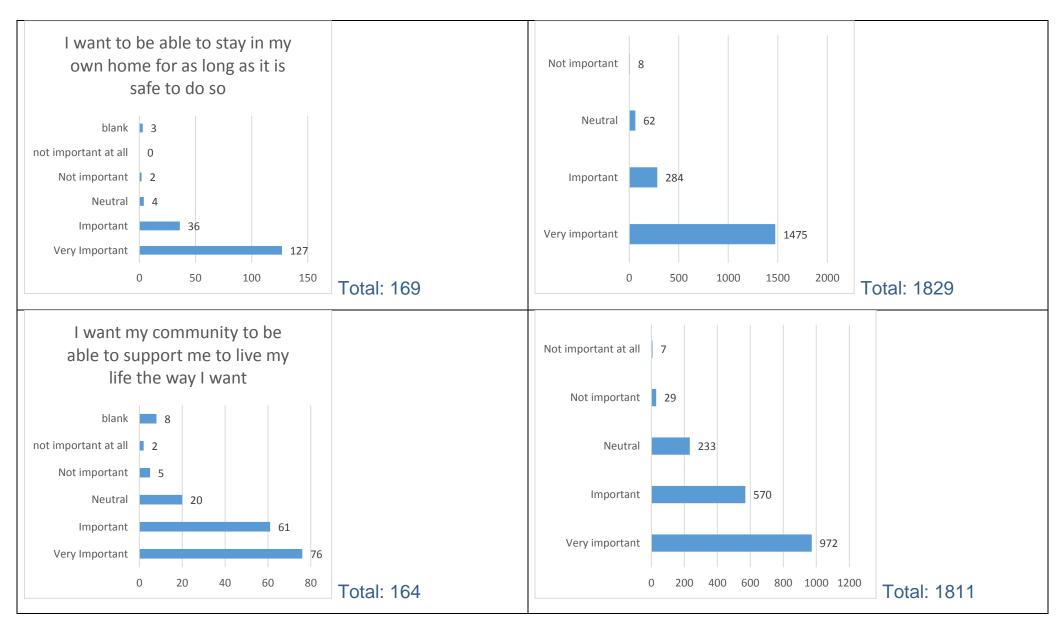


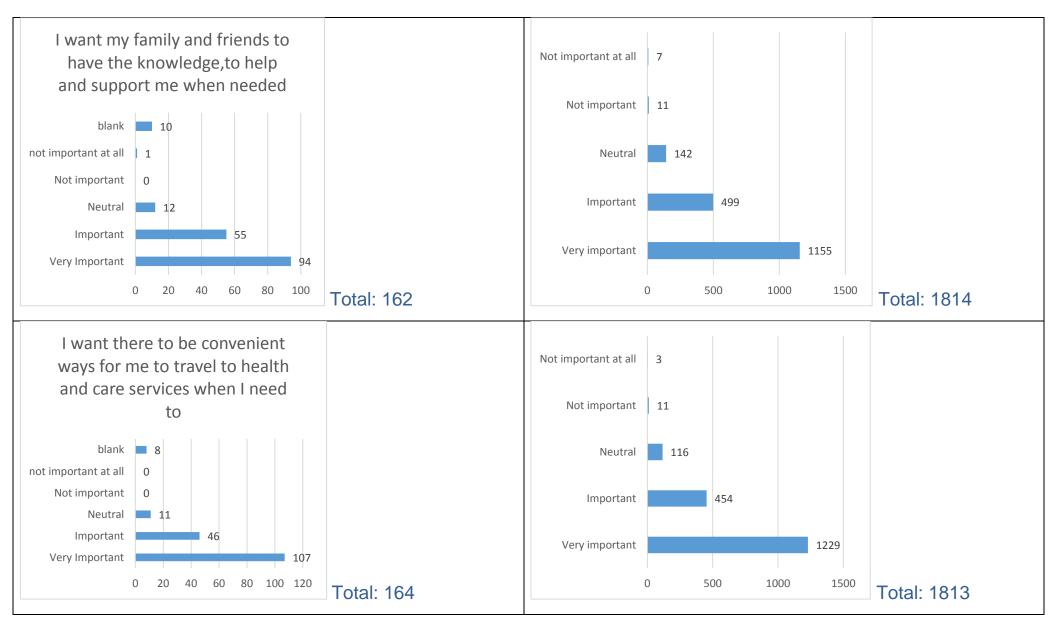


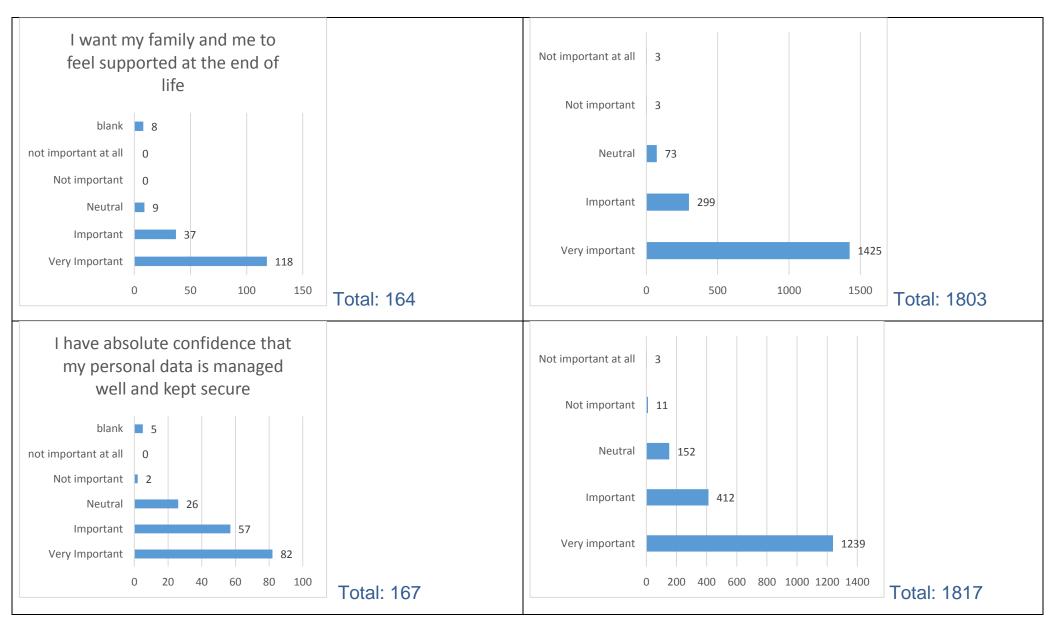


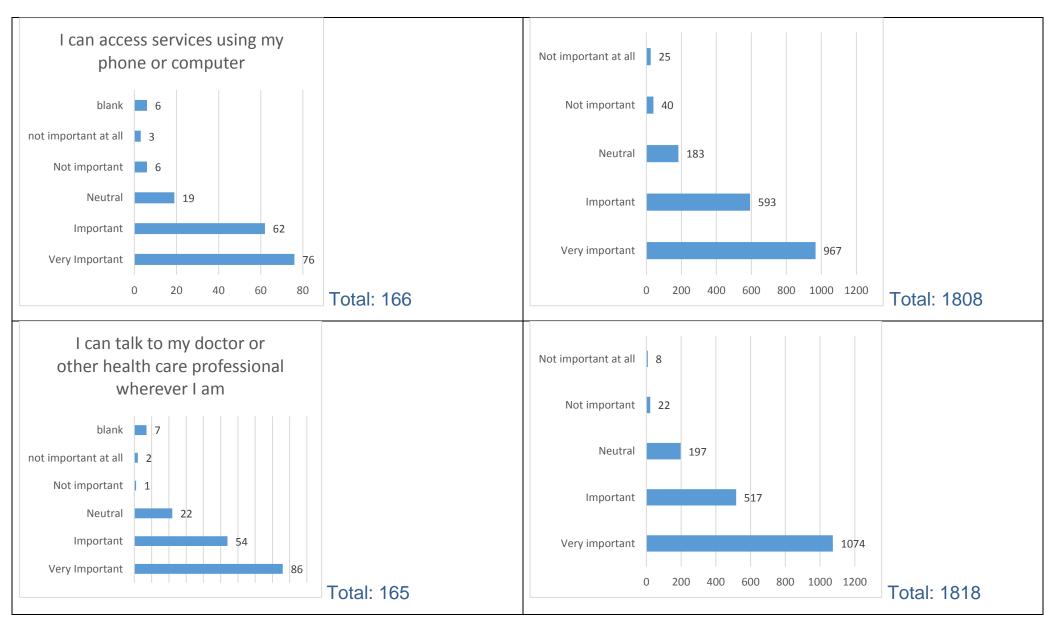


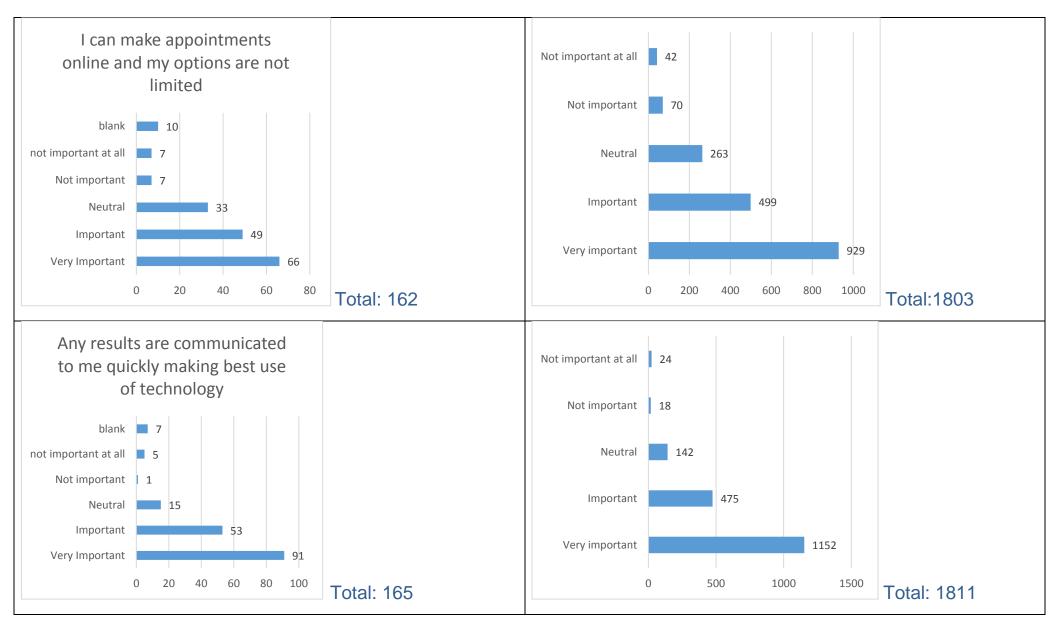


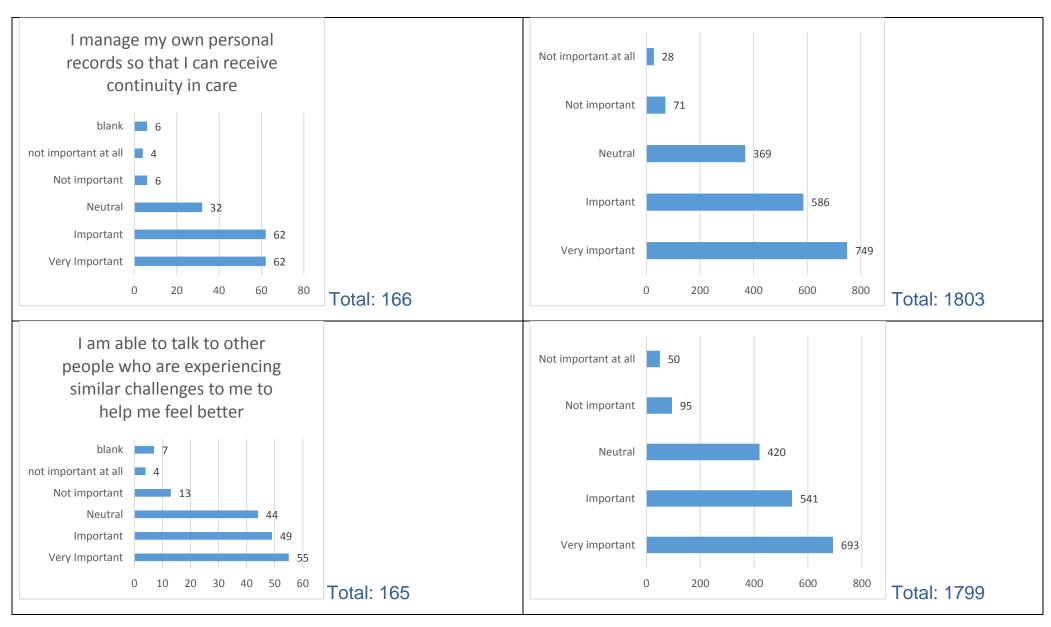


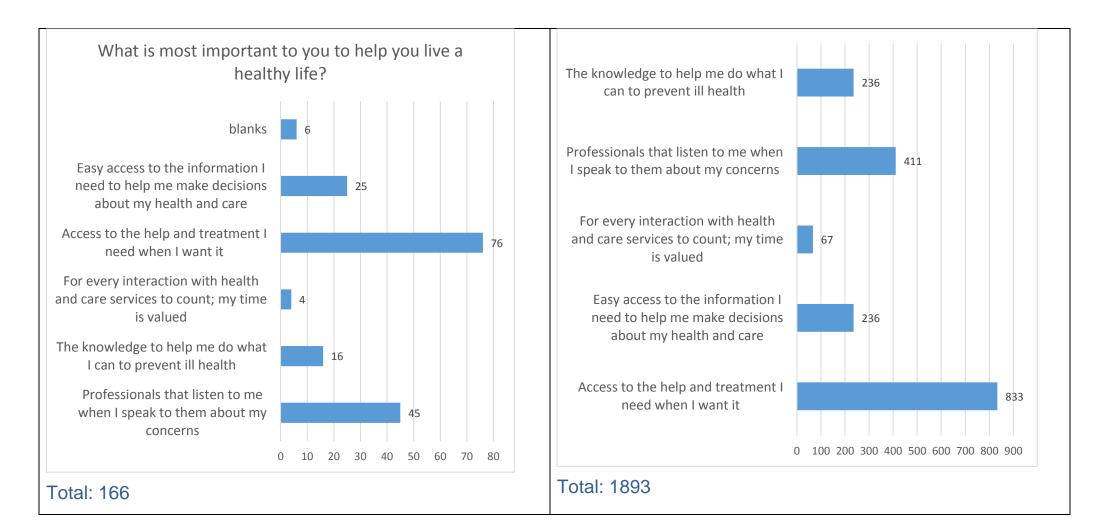


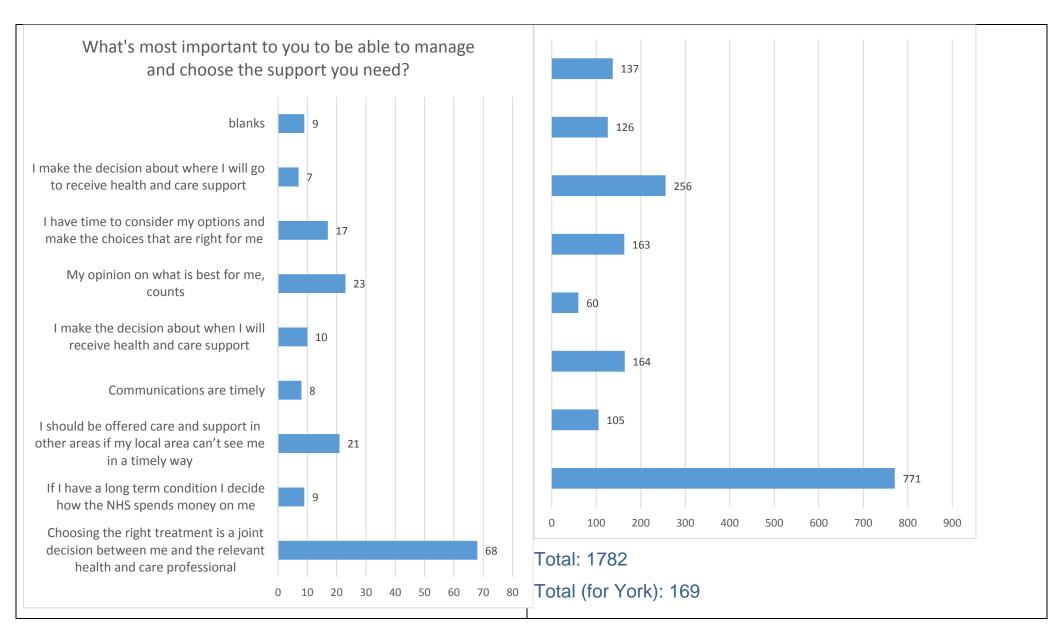


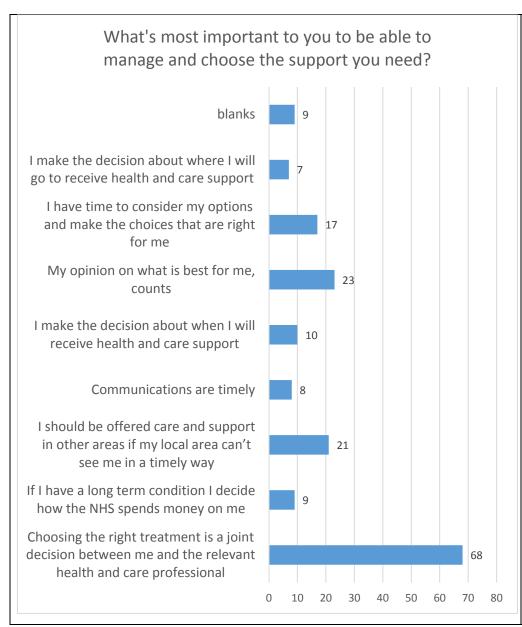


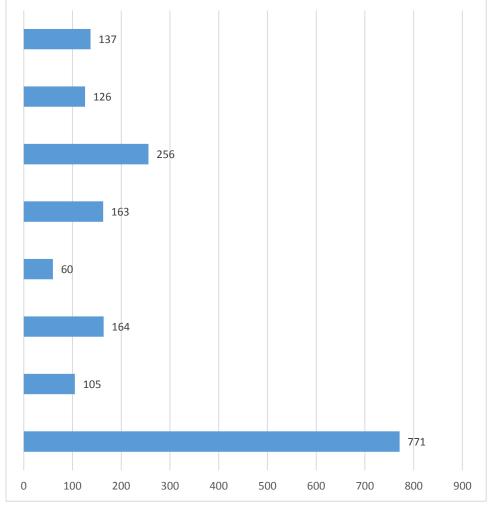






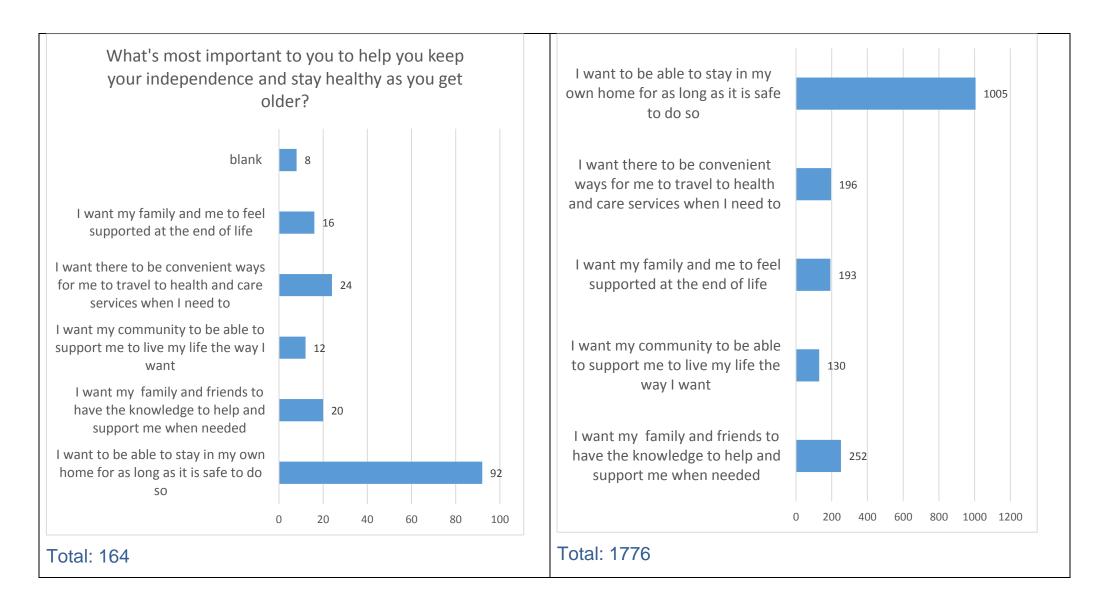


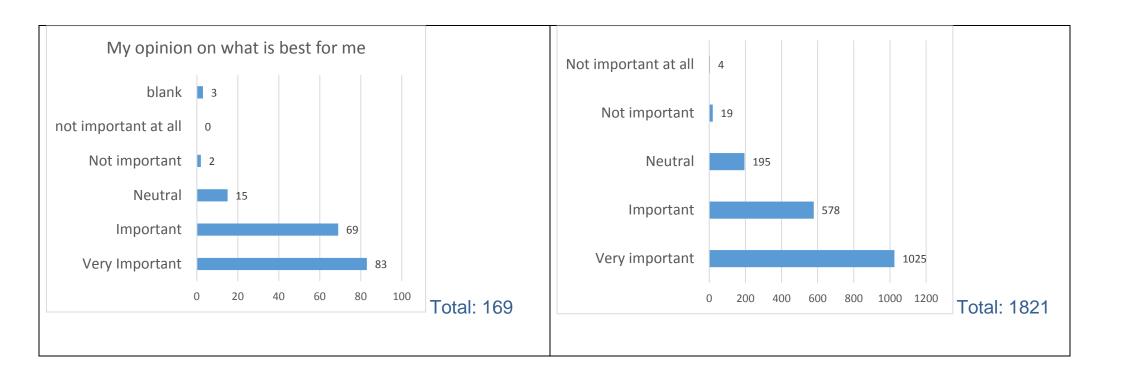




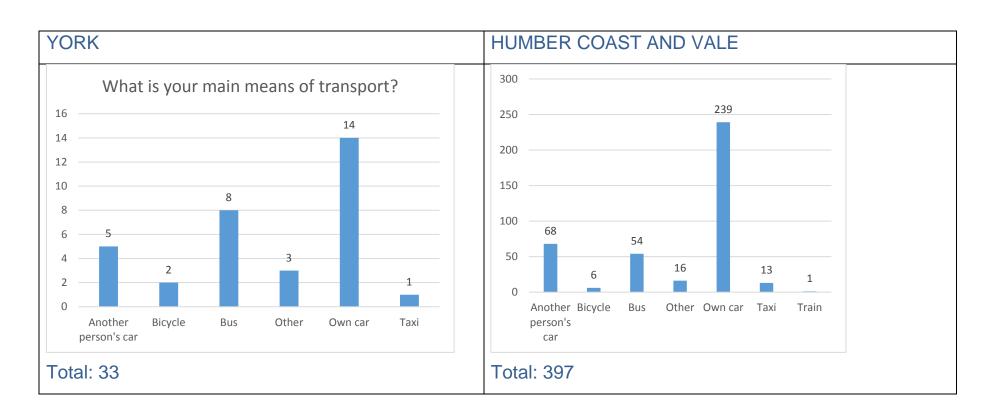
Total: 1782

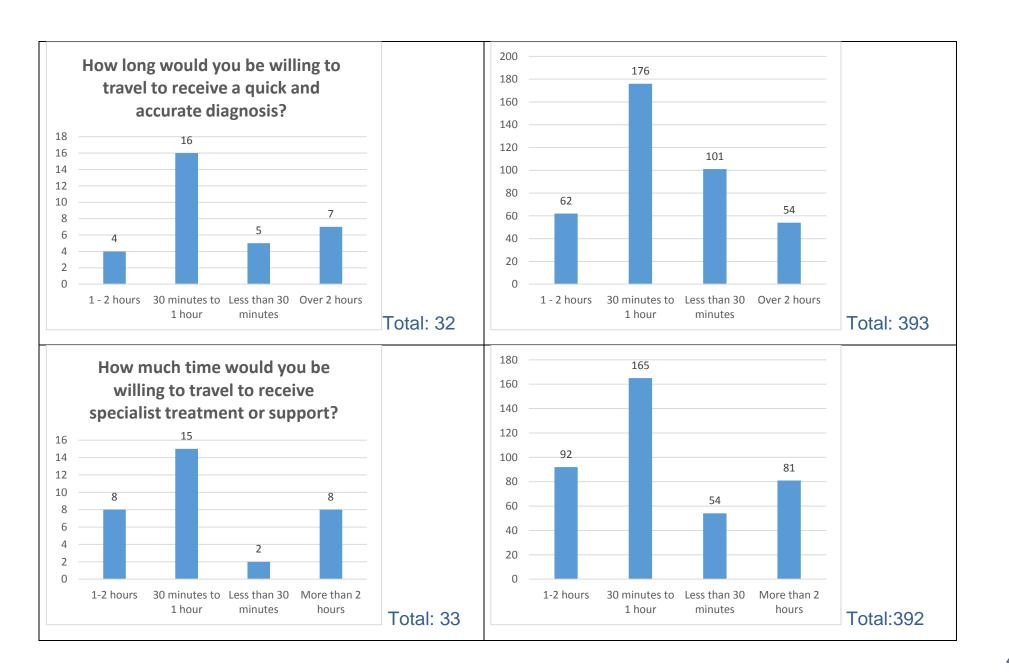
Total (for York): 163

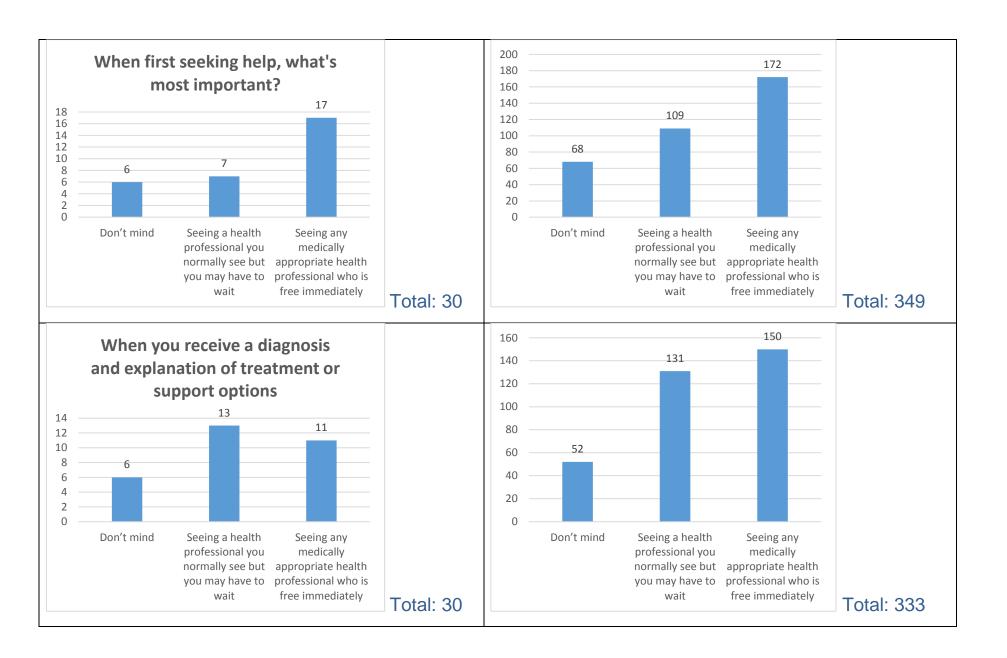


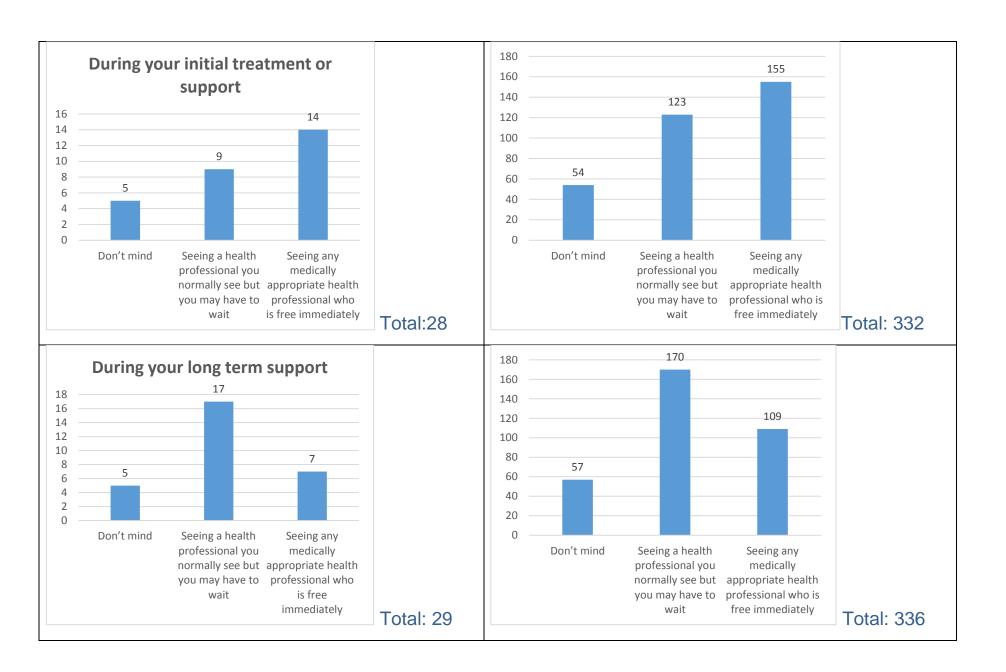


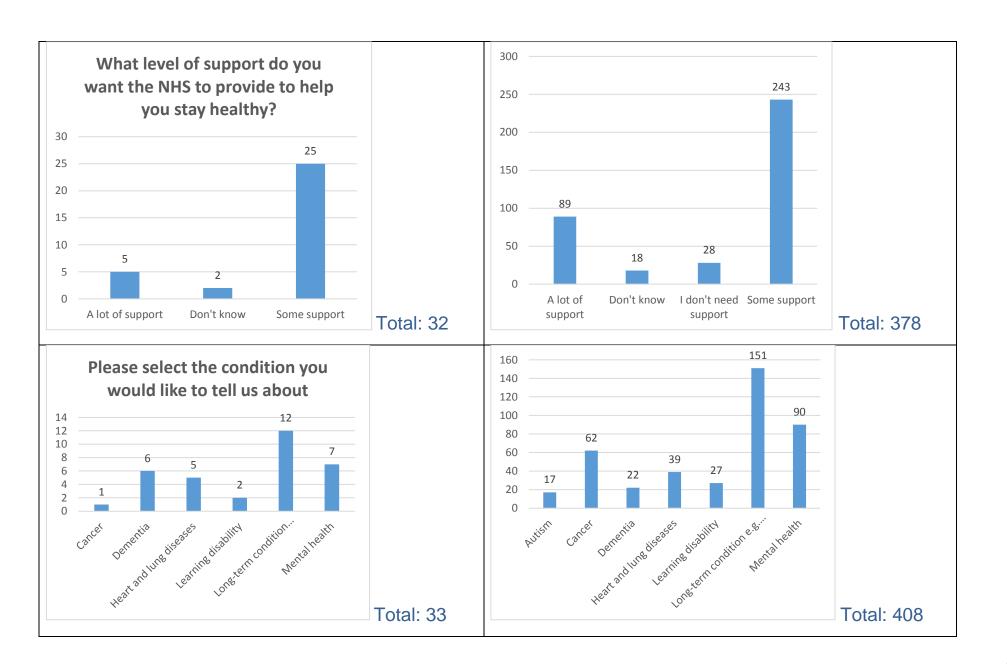
Appendix 2: Condition specific survey results in York and across Humber Coast and Vale

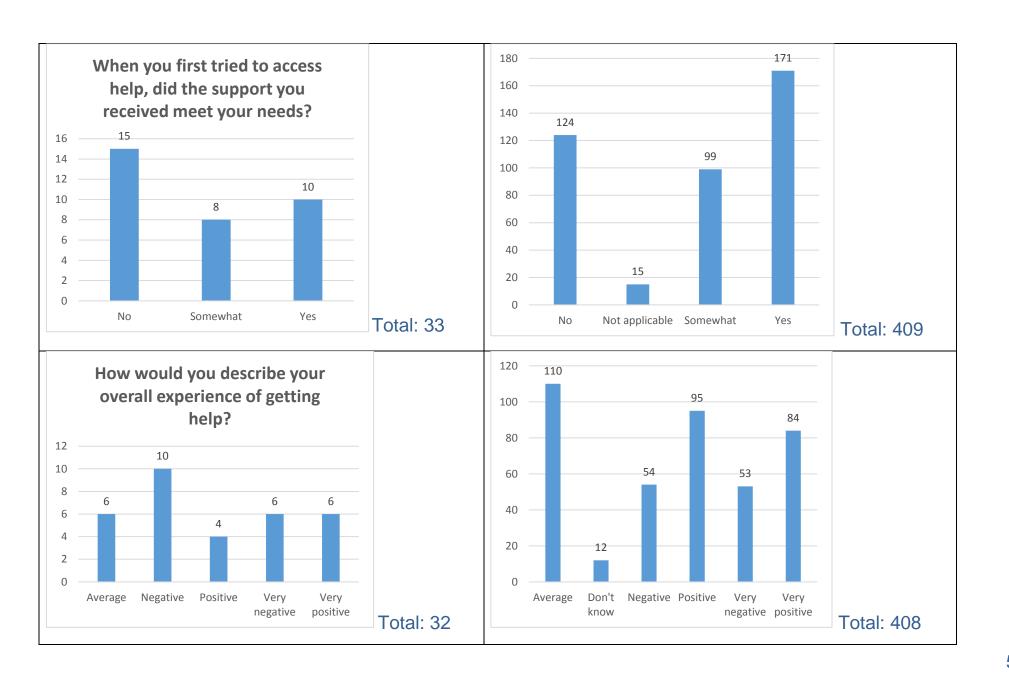


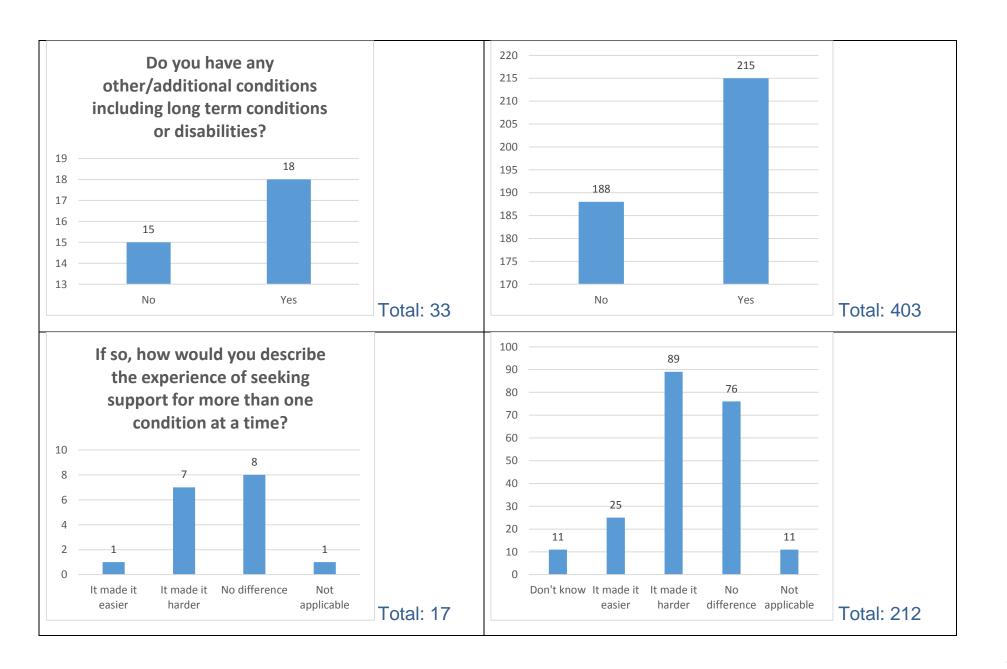


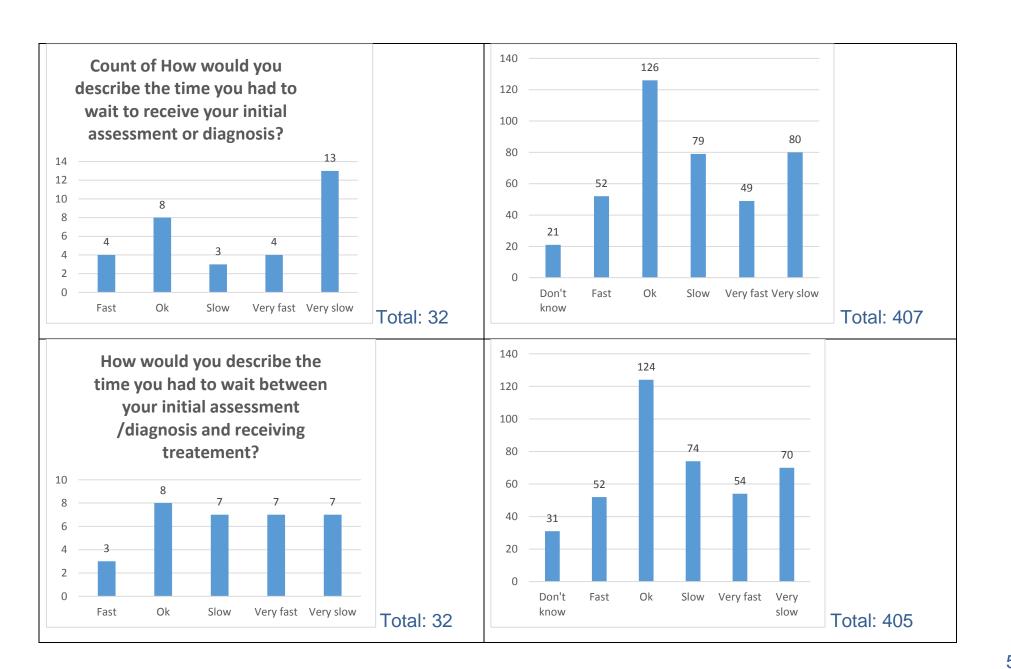


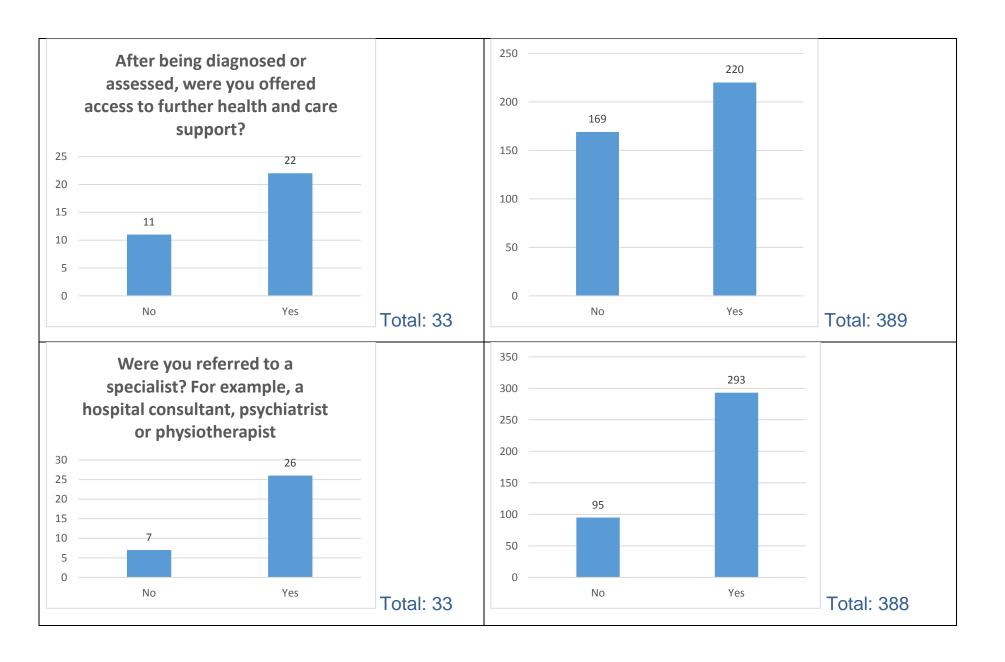


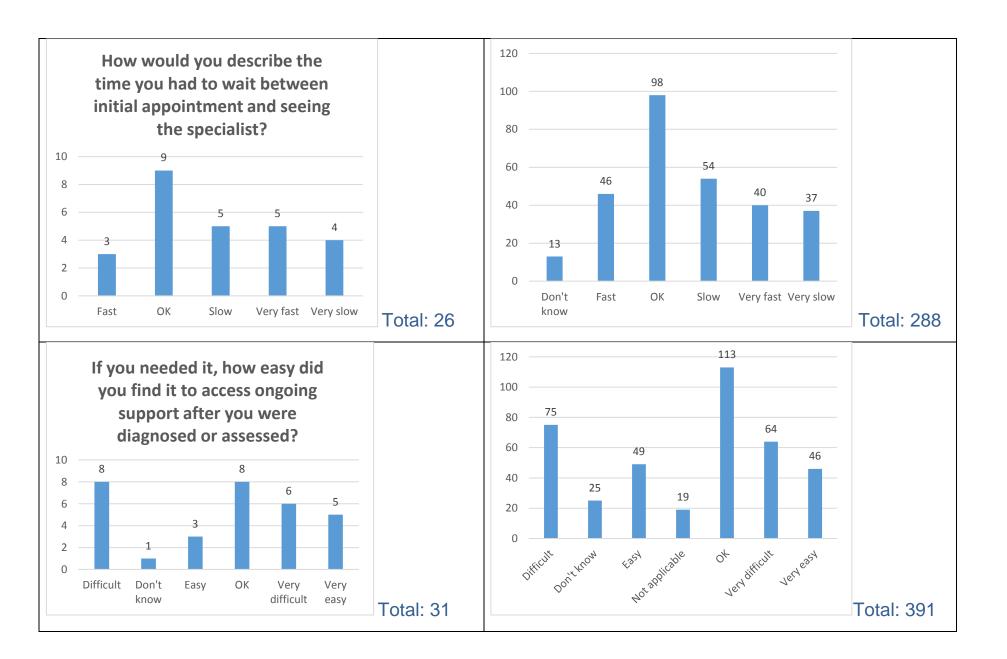


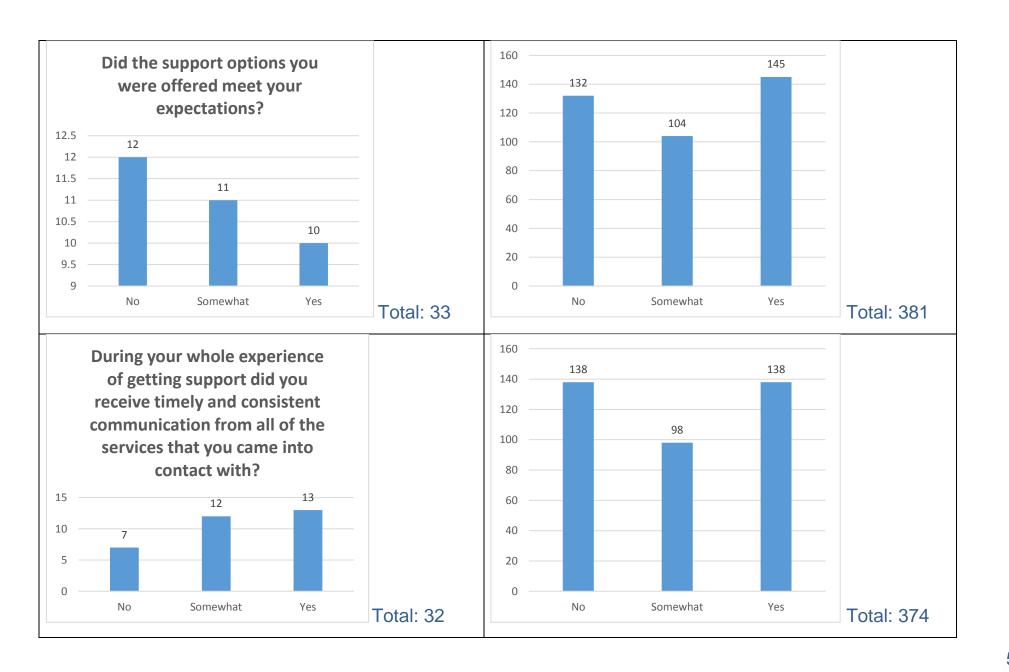












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York CVS

Healthwatch York is a project at York CVS. York CVS works with voluntary, community and social enterprise organisations in York. York CVS aims to help these groups do their best for their communities, and people who take part in their activities or use their services.

This report

This report is available to download from the Healthwatch York website: www.healthwatchyork.co.uk

Paper copies are available from the Healthwatch York office

If you would like this report in any other format, please contact the

Healthwatch York office