

NHS Long Term Plan

General responses to our survey

Healthwatch in Greater Manchester

whot

would you do?

It's your NHS. Have your say.

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Background

The NHS published its Long Term Plan on 7 January 2019. The Plan, which was developed in partnership with frontline health and care staff, patients and their families, focuses on several key changes, as summarised below. The full report can be found on the NHS Website at <https://www.longtermplan.nhs.uk/>.

Doing things differently - giving people more control over their own health and the care they receive. Encouraging health teams to work better together and to work more closely with other community assets at a neighbourhood level.

Preventing illness and tackling health inequalities - investing more money in prevention, premature birth, obesity, smoking, problem drinking and gambling and taking action on poor air quality.

Backing the NHS workforce - increase staffing and training places, make the NHS a better place to work.

Making better use of digital technology - providing more convenient access to services and information for patients and staff, a new NHS App as a digital 'front door' and an option of 'digital first' GP access.

Getting the most out of taxpayers' investment in the NHS - identify ways to reduce duplication and make better use of the NHS' combined buying power to achieve savings and cut administration costs.

Specific action - on supporting people living with a range of **specific conditions** (autism, learning difficulties, mental health illnesses, dementia, heart and lung disease, and cancer).

About this Project

This project was commissioned from Healthwatch England by NHS England. Healthwatch England marshalled the national network of Healthwatch Organisations to a) engage with their populations, b) collect evidence, c) produce reports on a regional level (in this case Greater Manchester).

The result of the engagement will be shared with Healthwatch England to produce a national evidence base that will inform the development and implementation of the specific activities discussed within the long term plan.

Results will be published on a regional level and shared with those responsible for transforming health and care services (in this case the Greater Manchester Health and Social Care Partnership).

The Greater Manchester Health and Social Care Partnership is already working on its Prospectus for the next 5 years. The Prospectus will set out how Greater Manchester will respond to the ambitions in the new NHS Long Term Plan published in January 2019 and update how the Health & Social Care Partnership will contribute to the wider vision for Greater Manchester.

This work will be shared with the Partnership and used in tandem with the Prospectus to inform and guide developments across the city.

Objectives

To gather, analyse and present a comprehensive set of responses from the people of Greater Manchester on some of the key the topics raised in the NHS Long Term plan. In particular we wanted to find out:

- What people think would help them to live healthier lives? (prevention)
- What would make it easier for people to take control of their own health and wellbeing? (personalisation)
- What would make support for people with long-term conditions better? (care closer to home)
- What people think about increasing the use of technology in health and care services? (digitalisation and tech)
- What people who have autism, learning disabilities, mental health conditions, heart or lung disease, and cancer think would make their health services better?

Structure of the Reports

We have produced a series of reports to show the findings of this engagement exercise as follows:

Long Term Plan General Findings - this report covers the responses to the general survey, there were 2091 responses. It represents by far the biggest sample and gives a broad overview, in terms of geography and demographics, of what the People of Greater Manchester think about the general themes in the Long Term Plan. General focus group responses are also included in this report.

Six Reports on Specific Conditions - these reports have much smaller numbers of respondents, between 29 and 77 people. The reports combine data from the individual specific conditions surveys and focus groups, but provide a more in depth understanding of actual patient journeys and more specific ideas for improvement and support within the relevant services. These reports are:

- ‘The Patient’s Journey In Mental Health’
- ‘The Patient’s Journey in Autism Services’
- ‘The Patient’s Journey in Learning Disabilities Services’
- ‘The Patient’s Journey in Dementia Services’
- ‘The Patient’s journey in Cancer Services’
- ‘The Patient’s Journey in Cardiac and Respiratory Services’

Methodology

Engagement for this project took place across Greater Manchester between March 4th - April 26th, 2019. Healthwatch in Greater Manchester (HW in GM) worked closely together on this project with all 10 Local Healthwatch (LHW) in the city region using the same locally adapted questionnaires. Individual LHW took mixed methods approaches appropriate to their local area with the survey publicised online, via social media, distributed on paper, and taken to local groups and events.

Summary of general survey responses across Greater Manchester

Area	Bolton	Bury	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan & Leigh	GM TOTAL
TOTAL NUMBER OF SURVEYS ('Yes' to Q1)	333	142	159	306	227	281	128	313	129	73	2091
TOTAL NUMBER OF SURVEYS ('NO' to Q1) - not used	20	0	3	5	8	0	2	1	1	2	42
Number of surveys completed by people living outside of GM	10	2	0	2	0	0	0	0	0	2	16
Number of surveys completed by people living outside of locality but within GM	20	12	4	9	8	0	0	20	0	5	78
TOTAL SURVEYS COMPLETED in GM	2133										

Original dataset = 2133 responses, 42 respondents said they did not want their data used.

Total used responses = 2091.

Details = 16 respondents selected living outside GM, and 78 indicated they lived outside the HW area they filled the survey in for.

A set of companion focus groups were also held, with 19 in total. All LHW were free to choose one of the specific condition questions or the general questions and target participants through their networks. Feedback from these focus groups was collected using a standard feedback sheet to ensure comparable data.

In this report only the general focus group data has been included, with the specific conditions data separated into 6 condition focused reports.

General focus groups = 6 groups and 62 people (2 Bury, 1 Salford, 1 Stockport, 2 Manchester).

Summary of all focus group responses across Greater Manchester

Area	Topic	Participants	Location	Date
Trafford	Autism	8	Fuse Centre, Partington	2019-04-28
Oldham	Cancer	6	Saddleworth community room at reclamation cafe	2019-03-29
Trafford	Cancer	7	Macmillan Centre, Trafford General Hospital	2019-03-22
Tameside	Cardio and Respiratory	10	Volunteer Centre, Penny Meadow	2019-04-26
Tameside	Cardio and Respiratory	5	Volunteer Centre, Penny Meadow	2019-04-17
Bolton	Cardio and Respiratory	35	Friends Meeting House	2019-03-20
Stockport	Dementia	19	Two sessions - Stockport Labour Club and St Michaels and All Angels Church	2019-04-09
Rochdale	Dementia	15	Alzheimers Society wellbeing cafe, Butterworth Hall	2019-04-02
Oldham	Learning Disabilities	7	The Hub, Nelson Community Room,	2019-04-24
Salford	Learning Disabilities	14	Walkden Gateway	2019-04-16
Bury	Learning Disabilities	10	The Elms Community Centre, Whitefield	2019-04-03
Rochdale	Learning Disabilities	19	PossAbilities, Cherwell Centre,	2019-04-05
Bolton	Learning Disabilities	6	St George's Church	2019-04-03
Manchester	General (mixed)	4	HW Manchester Offices	2019-03-15
Manchester	General (LD)	6	HW Manchester Offices	2019-03-13
Stockport	General (mixed)	14	HW Stockport Office	2019-03-13
Salford	General (Visually Impaired)	8	Eccles	2019-04-16
Bury	General (mixed)	20	The Fed, Heathlands Village, Prestwich	2019-04-04
Bury	General (Sensory impaired)	10	Bury Society for the Blind	2019-04-17
Total		223		

General survey questions

Opening questions

Who are you completing the survey on behalf of?

Where in [locality name] do you live?

Prevention

Rate how important the following things are to you when it comes to living a healthy life:

- Easy access to the information I need to help make decisions about my health and care.
- Having the knowledge to help me do what I can to prevent ill health.
- Access to the help and treatment I need when I want it.
- Professionals that listen to me when I speak to them about my concerns.
- For every interaction with health and care services to count; my time is valued.

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

Personalisation

Being able to manage and choose the support you need

- If I have a long term condition I decide how the NHS spends money on me.
- Choosing the right treatment is a joint decision between me and the relevant health and care professional
- I make the decision about where I will go to receive health and care support
- I should be offered care and support in other areas if my local area can't see me in a timely way
- I make the decision about when I will receive health and care support
- My opinion on what is best for me, counts
- Communications are timely
- I have time to consider my options and make the choices that are right for me

If there was one more thing that would help you manage and choose how the NHS supports you, what would it be?

Care closer to home

The help you need to keep your independence and stay healthy as you get older

- I want to be able to stay in my own home for as long as it is safe to do so
- My community can support me to live my life the way I want
- My family and friends have the knowledge, confidence and power to help and support me when needed
- I expect there to be convenient ways for me to travel to health and care services when I need to
- I expect that my family and I will feel supported at the end of life

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?

Technology

How you interact with your local NHS

- I have absolute confidence that my personal data is managed well and kept secure
- I can access services using my phone or computer
- I can talk to my doctor or other health care professional wherever I am
- I can make appointments online and my options are not limited
- Any results are communicated to me quickly making best use of technology
- I manage my own personal records so that I can receive continuity in care
- I am able to talk to other people who are experiencing similar challenges to me to help me feel better

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

If you have any further comments please write them below

Tell us a bit about you (demographics)

- What is your age?
- What is your ethnicity?
- Do you consider yourself to have a disability?
- Are you a carer?
- Do you have a long term health condition?
- Which of the following best describes you?
- What is your gender?
- What is your religion?

General focus group questions

Discussion about *where and by who* people want to be supported (care closer to home)

Ideally talk about:

- Neighbourhoods
- Integrated care
- Treatment in community vs hospital
- Support from voluntary groups
- Non clinical support
- Peer support
- Who should be involved in care
- How often, where and how they can interact with services

Care closer to home/neighbourhood (facilitators summary, cover main points of discussion)

People's direct comments on the care closer to home (please enter all the direct comments you collected).

Discussion about Prevention:**What would help people to act on some of the prevention things?**

Ideally talk about:

- Routine health checks
- Screening
- Information about our health status
- Access to early intervention services (e.g. stop smoking, weight management etc)
- Wider determinants of health
- Access to healthy lifestyle activities
- Environmental aspects (air quality, take away outlets, green space, safe streets etc)

Prevention discussion (facilitators summary)

People's direct comments on Prevention (please enter all the direct comments you collected).

Digital services and technology discussion

What do people think about the NHS using more digital services?

Ideally talk about:

- Digital working in NHS
- Shared care record
- Video consultation
- Remote monitoring devices
- Apps
- Digital first option' for GP services the NHS 'front door' app

Digital services and technology discussion (facilitators summary)

People's direct comments on digital services (please enter all the direct comments you collected).

Personalisation

What would personalised care look like?

Ideally talk about:

- Choice
- Control
- Communication
- Personal budgets

Personalisation discussion (Facilitators Summary)

People's direct comments on personalisation (please enter all the direct comments you collected).

Anything else?

Anything else people said that doesn't fit under the other headings. If you could group the comments by type and give them a sub heading that would help a lot.

Who we spoke to

Discussion on dataset

Please note the following regarding how the data for this project was prepared:

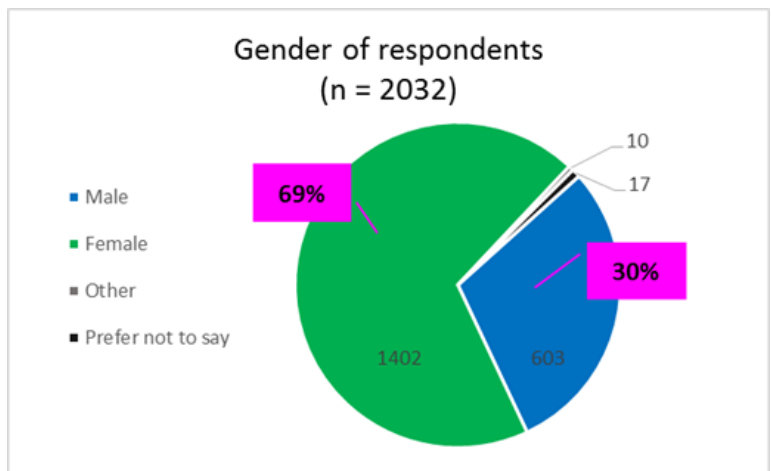
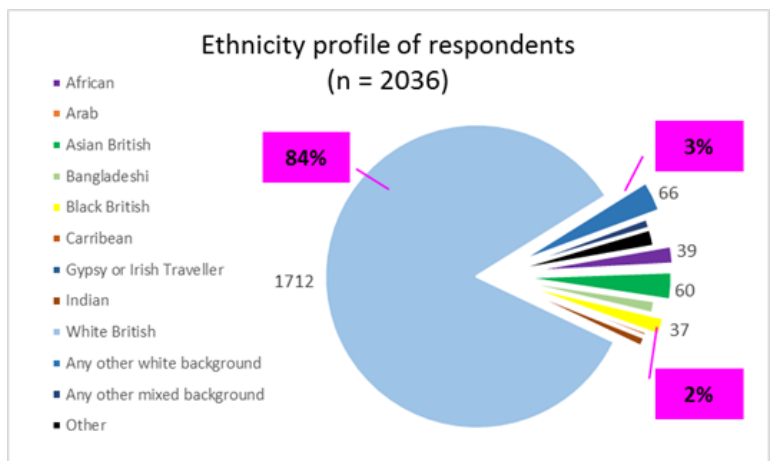
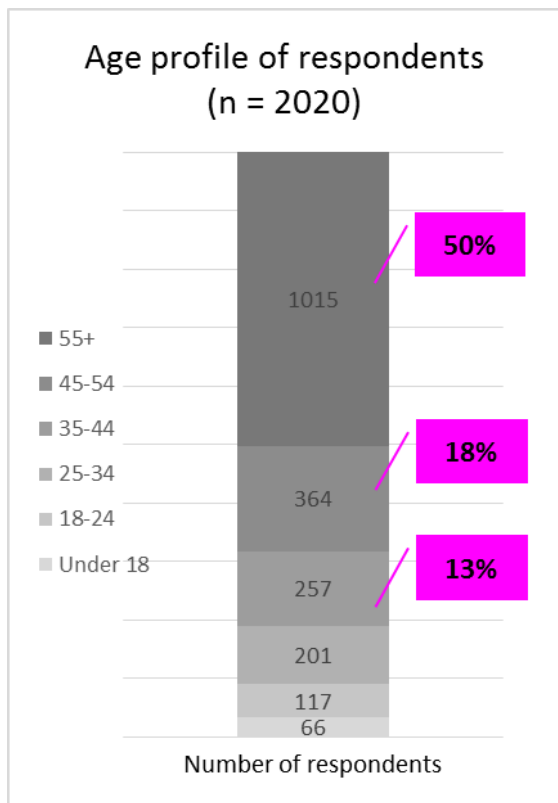
The data was first downloaded from survey monkey as a .csv file.

Any IP addresses and other info that was unnecessary for the analysis were deleted.

Any responses that answered “no” to the consent for data use question had their data removed. The full total of responses are counted in the overall GM statistics but not included in any analysis.

A choice had to be made about respondents that indicated they lived out of the Healthwatch area for which they filled their responses in for. Whether to re-allocate these responses or keep them within the local Healthwatch. In the end we decided to keep them in the area they sent their response to, with the assumption this was done intentionally.

Demographics



Age profile of respondents - We had 2020 people respond to this question. A high proportion of respondents indicated they were over 55+ which equals 50% (1015 people).

Ethnicity profile of respondents - We had 2036 people respond to this question. A majority of respondents indicated they were 'White British' which equals 84% (1712 people).

Gender profile of respondents - There were 2032 responses to this question. A majority of the respondents were female 69% (1402), with 30% selecting male (603).

Disability profile of respondents - Most respondents said they did not have a disability 69% (1411). However 27% (560) did indicate they had a disability, which should still be considered significant.

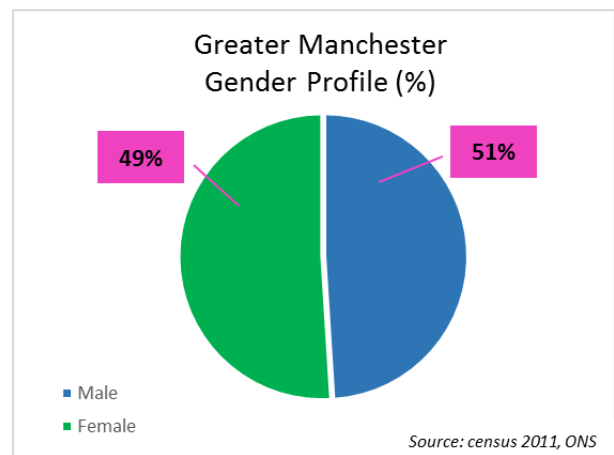
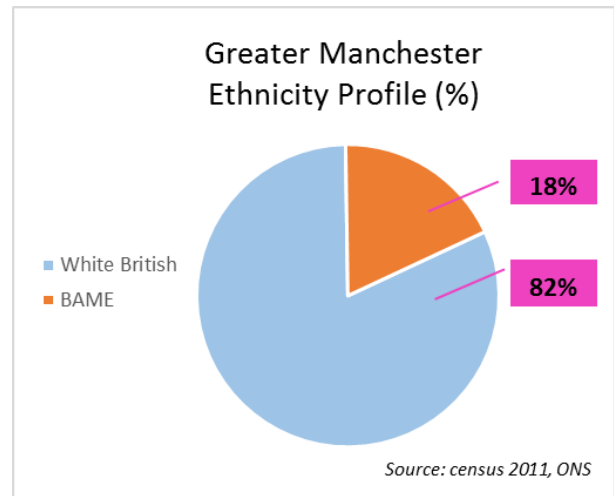
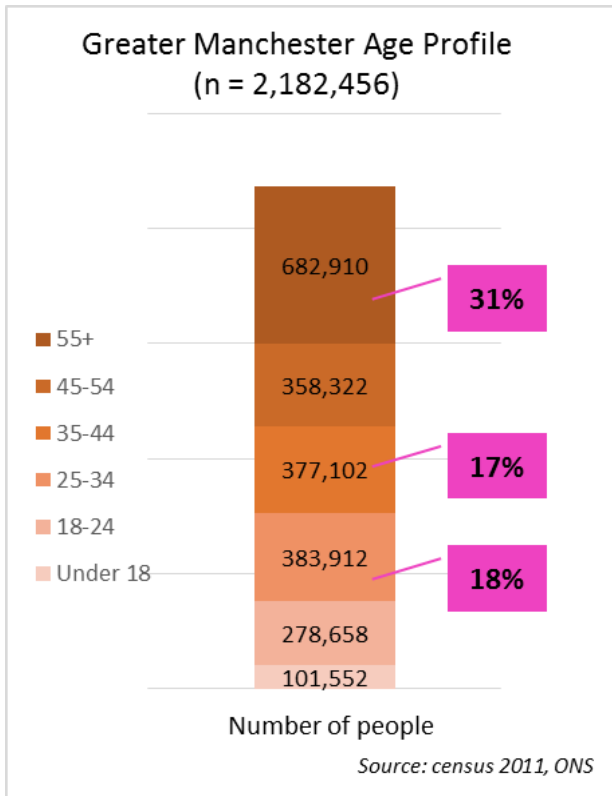
Carer profile of respondents - A high number of people said they were not carers 80% (1617). A significant number 20% (395) said they were a carer.

Health conditions profile of respondents - Just over half of people indicated they had either a long term condition 38% (802) or multiple conditions 15% (309). Just under half of respondents 47% (995) indicated they had no long term or multiple health conditions.

Sexuality profile of respondents - There was a high number of respondents selecting 'heterosexual' for this part of the demographic information 93% (1783). The next largest categories were 'gay or lesbian' 4% (73) and 'bisexual' 2% (46).

Religious profile of respondents - The majority of respondents selected 'Christian' when asked about their religion 56% (1139), the second major category by total was 'no religion' 29% (587). The third largest category was Muslim 5% (93) and the fourth largest category was Jewish 2% (49).

Comparison with Office for National Statistics Census, 2011



In order to check the representativeness of our dataset the above charts have been created from Office for National Statistics census data (2011).

Regarding the age profile from the ONS data for the Greater Manchester region this has the 55+ group making up 31% of the population, our sample had 50%. The next largest category in the ONS data was 25-34 at 18% of the population, our sample showed 45-54 as the second highest category. The third largest category was 35-44 in the ONS data at 17%, our sample has 35-44 as the third largest category at 13%. Overall the Healthwatch dataset includes a higher percentage of older participants compared to the ONS statistics.

When comparing ONS data for ethnicity in Greater Manchester with Healthwatch results the data has a similar profile. ONS data shows a split with 82% White British and 18% BAME. Healthwatch results have 84% White British and 16% BAME. In summary the Healthwatch dataset is representative of the ethnicity profile found in the last census.

A look at the gender profile data set shows a significant difference between the findings. In the ONS data Greater Manchester has a split between 49% female and 51% male, our data included 69% female, 30% male, 1% other. Therefore the findings in the Healthwatch data differ by about +20% for females and -20% for males from the census data

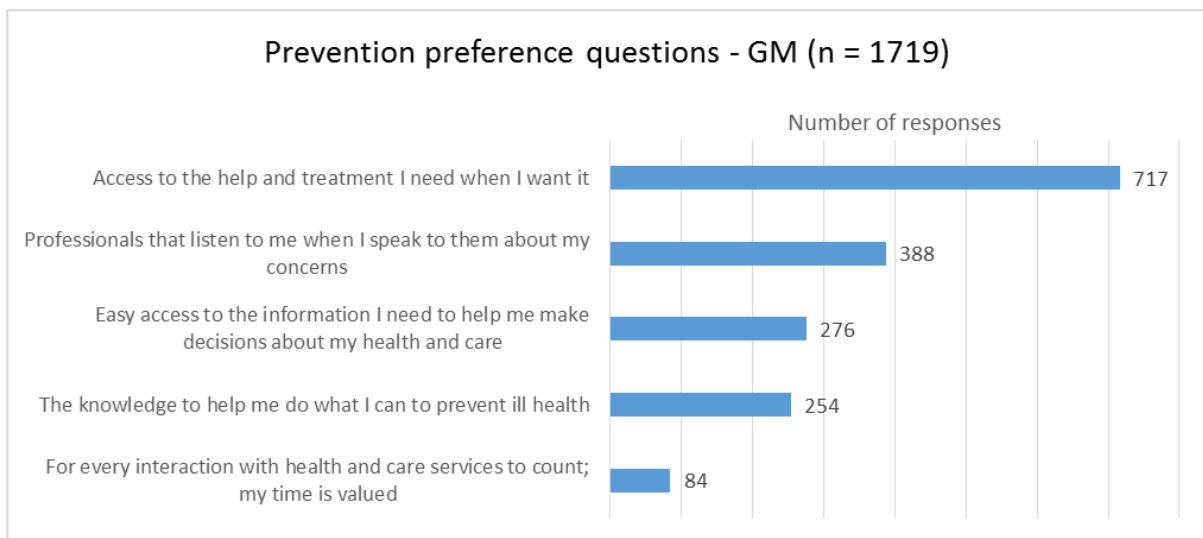
Analysis of key themes

In this section the four main themes from the survey and focus groups are looked at. The themes are prevention, personalisation, care closer to home, and technology.

Prevention

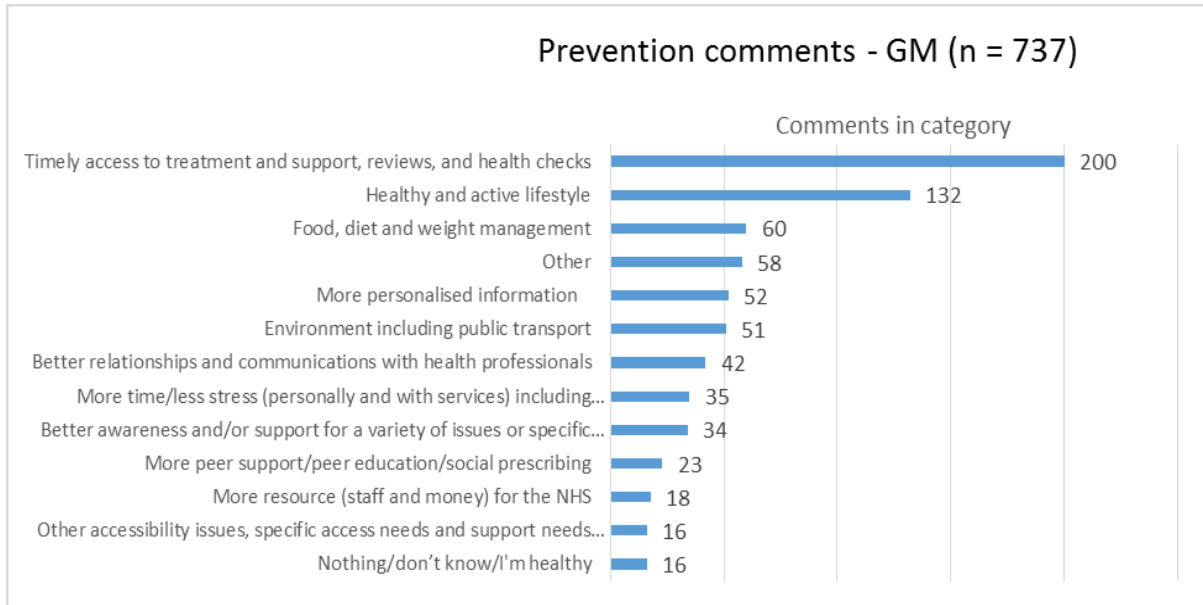
This section looks at people’s first preference across Greater Manchester related to prevention and healthcare.

The ‘prevention preference questions’ asked people to choose the most important statement out of the five given. The chart shows the results.



By a large majority respondents selected ‘*access to the help and treatment I need when I want it*’ as their priority for prevention in health (717 responses). This suggests people think the involvement of healthcare services and professionals to prevent conditions worsening is key to prevention.

The ‘prevention comments’ chart refers to qualitative statements made by people on prevention. People were asked to give any other thoughts or comments they had related to the topic of prevention.



There were two areas people commented on most frequently ‘*timely access to treatment and support, reviews, and health checks*’ (200) and ‘*healthy and active lifestyle*’ (132). This shows much like the quantitative preferences that most people felt access to professionals and services were key topics. A new topic that emerged from the qualitative comments was concern over healthy and active lifestyle, this area included statements related to exercise and also eating healthily.

‘*timely access to treatment and support, reviews, and health checks*’ (200 comments)

Key themes and supporting comment examples:

- Appointment times • A week wait too long •Waiting lists •Check-ups
- Mental health •Location-distance

“Easier access to appointments, whether that is with GP or Hospital outpatients.”

“Being able to get an appointment with a doctor in less than three to four weeks.”

“Much lower waiting lists for treatment.”

“Less of a waiting list for mental health services.”

“Not having to travel to the other side of the borough for a scan at Trafford General Hospital when Wythenshawe Hospital is on my doorstep.”

“A hospital in Bury. We used to have two. Now more people live in this area but we have to travel further for treatment. And it is getting more difficult to get a doctor’s appointment.”

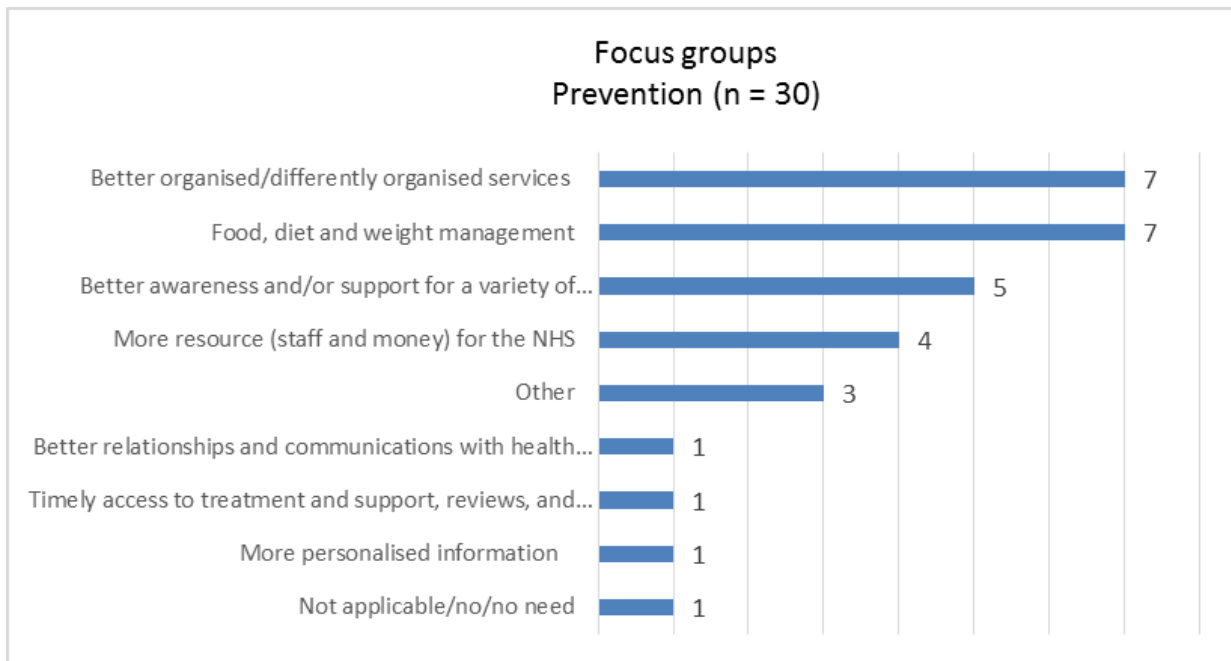
‘healthy and active lifestyle’ (132 comments)

Key themes and supporting comment examples:

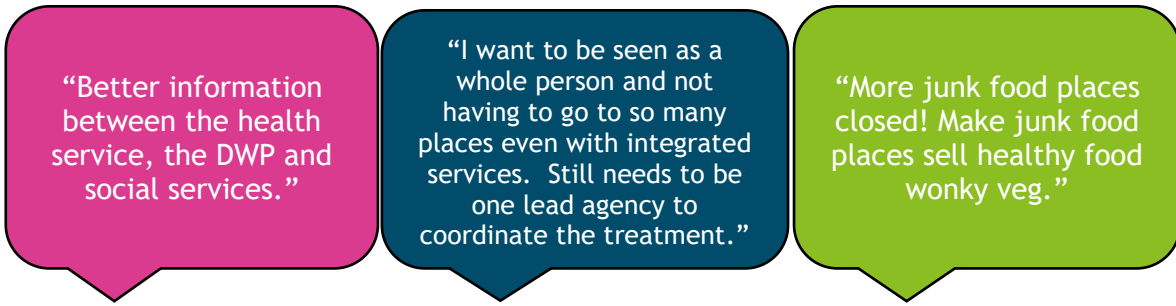
- Gym access •Information •Access •Provision •Time



The chart shows the topics within prevention that were discussed in the general focus groups.



While a range of different topics and issues were raised in the focus groups *‘better organised/differently organised services’* and *‘food, diet and weight management’* were found to have the highest number of comments.



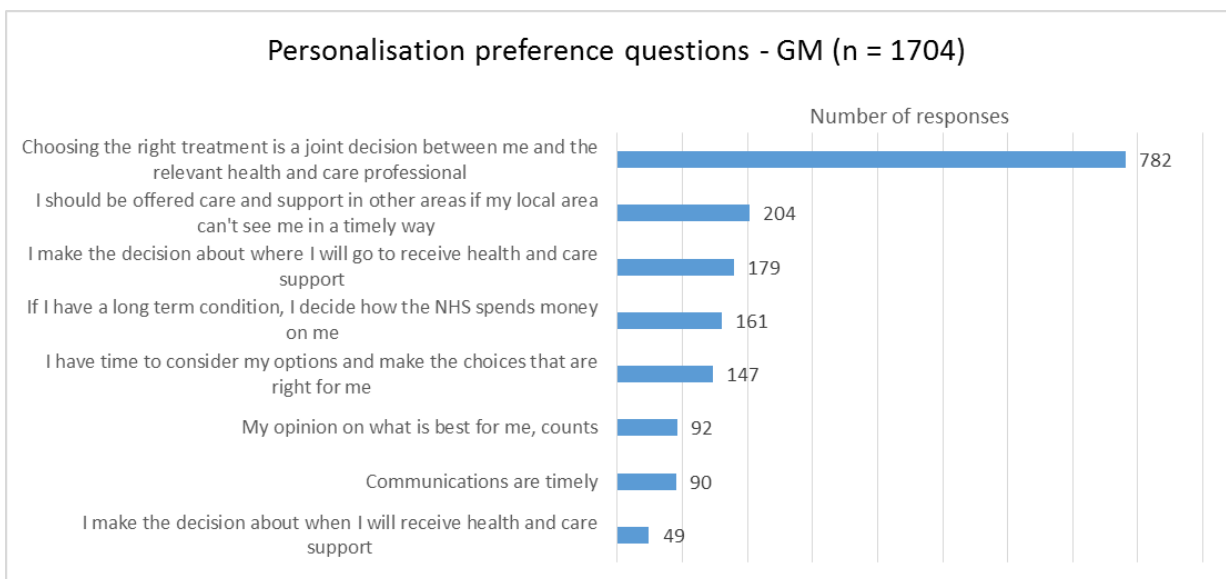
Overall issues for prevention:

- This section has assessed people’s opinion on prevention by looking at preferences from quantitative questions, qualitative open ended comment, and focus group discussions.
- Responses suggest that improving access to appointments and health checks would reassure people that health concerns would not develop into more serious conditions.
- People also recognised more exercise and physical activity could contribute to staying healthy and well. In order to increase take-up of physical activity many people thought improving access could encourage use, access in this case referred to more gyms, cheaper or free places, having more time to spend exercising.

Personalisation

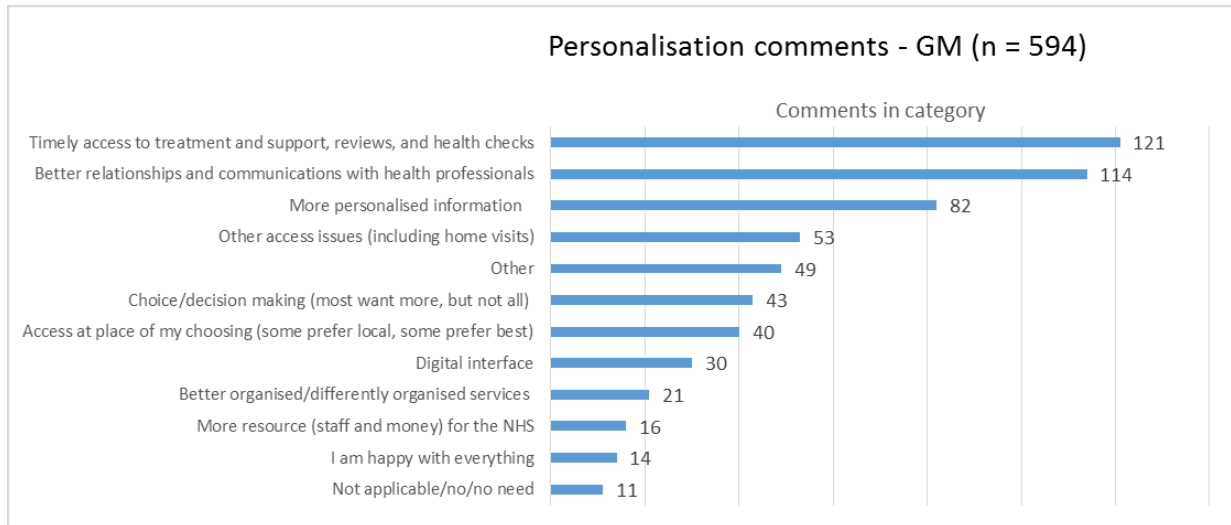
This section looks at people’s first preferences across Greater Manchester related to personalisation and healthcare.

The chart shows that of all the statements ‘*choosing the right treatment is a joint decision between me and the relevant health and care professional*’ was most popular (782 responses).



The result of the ranking question shows people wanted to have a dialogue and choice with those delivering their care.

A chart was created to show a summary of the free comments people wrote related to personalisation.



The personalisation comments chart shows ‘timely access to treatment and support, reviews, and health checks’ (121), ‘better relationships and communications with health professionals’ (114) and ‘more personalised information’ (82) as key areas within the comments. As the most preferred statement in the quantitative question was on collaborative decision making, the comment preferences suggest collaborative relationships could be improved by focusing on access, communication, and tailored information.

‘timely access to treatment and support, reviews, and health checks’ (121 comments)

Key themes and supporting comment examples:

- Waiting times
- Time of appointments
- Travel

“The time between referral and receiving the treatment / service is excessively long.”

“Ease of getting appointments, not having to wait weeks and weeks just to see a doctor in the first instance.”

“Appointment times outside working hours are useful.”

“Easier access to seeing a GP...if early morning and after 5pm appointments could be held for working people I feel that would benefit as I know myself and colleagues have suffered though lots of things we should have seen a doctor for but couldn't get an appointment and couldn't get leave off work.”

“To be able to go to my nearest hospital. Not one miles away. Not everybody has a car or can get an ambulance.”

‘better relationships and communications with health professionals’ (114 comments)

Key themes and supporting comment examples:

- Clarity •Care •Information sharing •Continuity •Dialogue •Supportive •Time to talk

“Health professionals who listen, and care. Not rushed.”

“I have experienced lack of communication important circumstances. Therefore keeping us up to date is important.”

“More communication and information on what’s available.”

“That my own GP is sufficiently available to me and not endless unknown locums.”

“Improved communication between all parties involved in my support.”

“Having a trusted member of staff who knows me and cares about my interests/needs.”

‘more personalised information’ (82 comments)

Key themes and supporting comment examples:

- Records •Information •Clarity •Formats •Guidance and signposting

“Access to my records.”

“See my records to see if COPD is improving or not.”

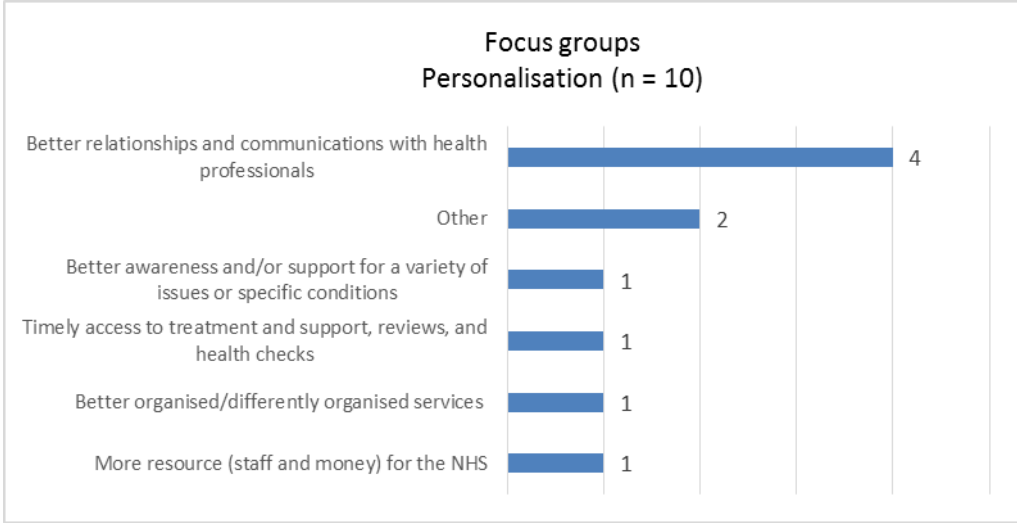
“Being told about all options and not just the ones that are convenient to the NHS.”

“NHS needs to be more honest and upfront about waiting times and to communicate these times without being asked.”

“Information given in easy to understand format. Explanation given when asked by me.”

“It must be someone's job to navigate my path through the various departments that may [be] needed for my full recovery.”

Finally the summary of comments from the general focus groups conducted found that ‘improved relationships and communication with health professionals’ was important to people in personalisation.



Examples of comments that supported the most popular topic:

“I get asked questions all of the time but never seem to get long to consider my options before I'm pushed for an answer - we need more time.”

“Even with choice and PBs the skills and the knowledge isn't there. He had paid for care through a Personal Health Budget but the care was not up to standards. His clothes were dirty and he hadn't been shaved properly. People at the margins of this don't qualify for personal budgets but they still need the benefit of personalisation.”

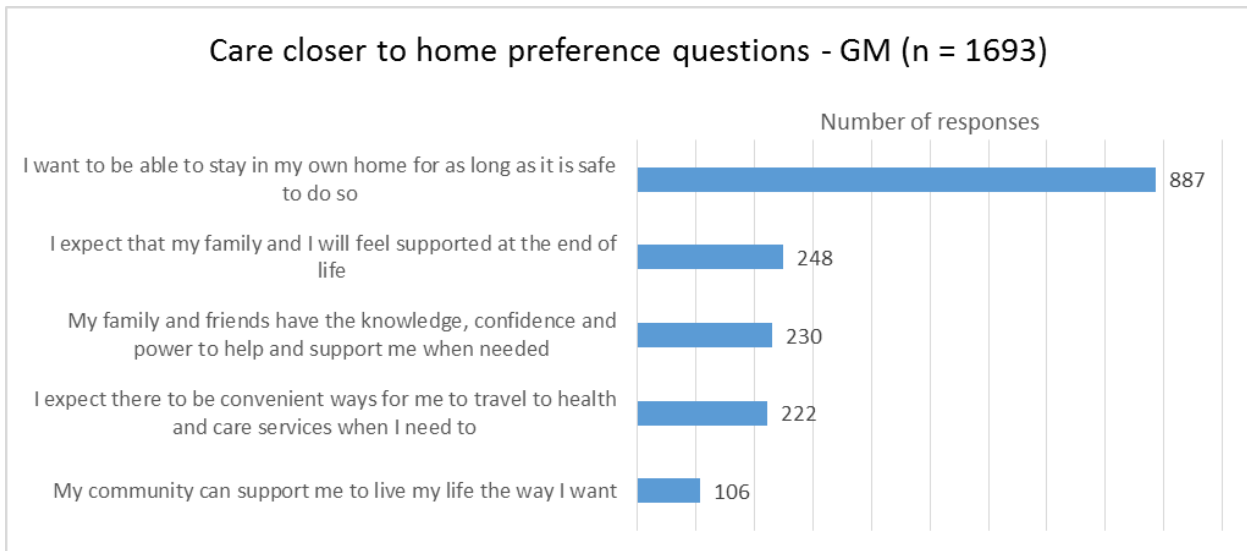
Overall issues for personalisation:

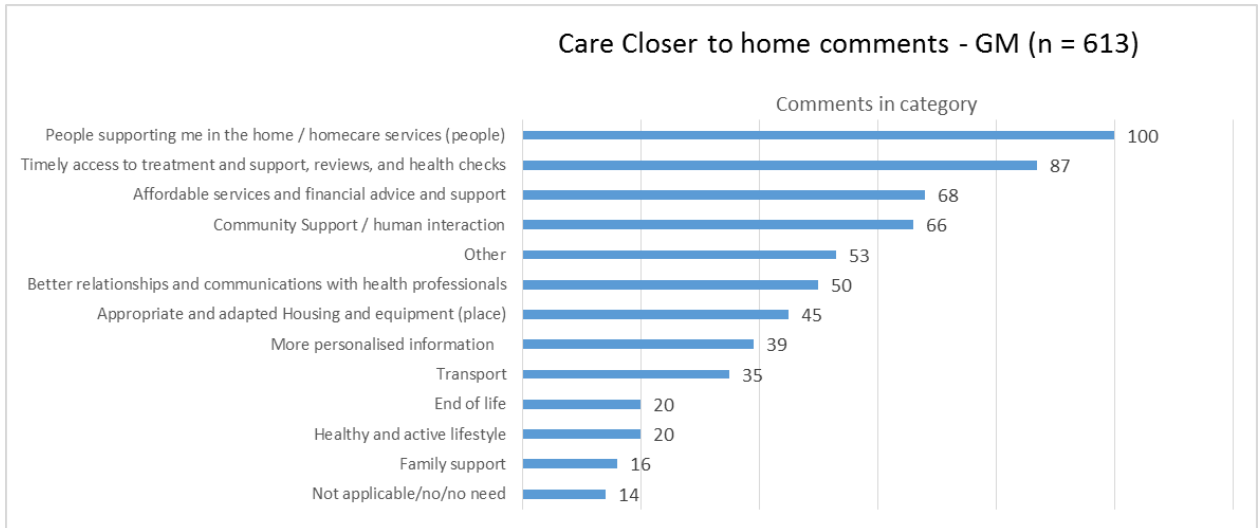
- The opinions gathered related to personalisation were analysed for common themes and relevant suggestions. Choice stood out as an important priority from the quantitative preference questions asked, with people wanting a joint way of deciding treatment with professionals.
- The desire to improve or maintain good communication was also important in the qualitative comments we received, with better relationships and communication emerging as a priority.
- Comments showed that a caring attitude, clarity, continuity of professional and the sharing of information were features of a positive relationship between people and healthcare professionals.
- People also thought access to treatment was important to personalisation. People said they wanted information to be clear and accessible to them, this would help improve trust between individuals and the healthcare system as a whole.

Care closer to home

Preferences for the care closer to home related statements are shown in the chart that follows.

Within the quantitative question ‘I want to be able to stay in my own home for as long as it is safe to do so’ was the most preferred option (887 responses).





When we summarised the comments for the care closer to home qualitative question ‘people supporting me in the home/homecare services’ (100), ‘timely access to treatment and support, reviews, and health checks’ (87) and ‘affordable services and financial advice and support’ (68) were the most popular areas for comment.

‘people supporting me in the home/homecare services’ (100 comments)

Key themes and supporting comment examples:

- Quality •Time •Reliability •Affordability •Resources •Availability

“Good, caring people to support me in my own home when I choose, that are properly trained and caring.”

“...the transition between being able to live independently but need some support. It seems to me that services are not able and don't have the adequate time to help people that need this support.”

“Continuity with care workers so they are known to me and not always changing.”

“More help for people without family. It would help if there were more care homes not costing a fortune.”

“More resources for social care.”

“The availability of reliable and well qualified carers, and the provision of suitable aids and equipment.”

‘timely access to treatment and support, reviews, and health checks’ (87 comments)

Key themes and supporting comment examples:

- Location •Pharmacy •Speed of access •Easy access •Home visits •Language

“Accessible locations for support and health and well-being in my area.”

“Easier access to some prescription only meds, pharmacists who can prescribe more services.”

“Easy and quick access to local healthcare.”

“Easier ways to get to appointments without having to wait ages for a return ambulance to take me home.”

“Access to health care professionals in my own home.”

“Older people who cannot speak or read English should have the same access to provisions as everyone else - support services should offer interpretation routinely and adjustments should be made for people of other ethnicities and religion. More support workers who speak community languages should be recruited.”

‘affordable services and financial advice and support’ (68 comments)

Key themes and supporting comment examples:

- Elderly •Free care •More money •Advice

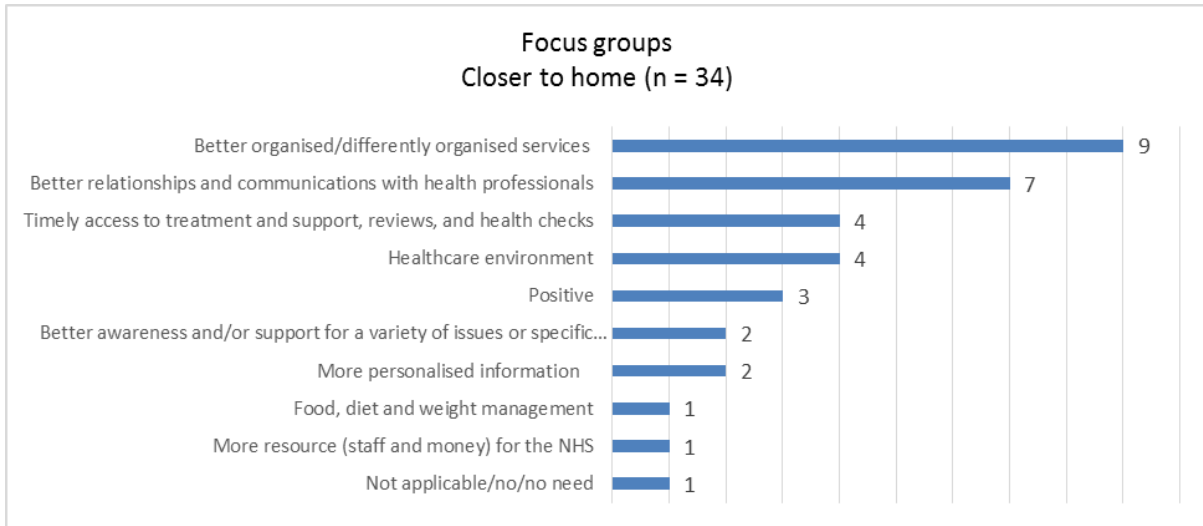
“The elderly are every bit as important as the very young. Funding for their care should not be cut to the bare minimum. They are not second class citizens. People should be educated from an early age to look after the vulnerable & elderly, particularly family members.”

“Not having to burden my family to have to pay for my care either at home or in a home.”

“Properly funded Adult Social Care budgets.”

“Timely advice. My friends were told they couldn’t get help as they had too much money, i.e. £500 over limit. It turns out they could have been given advice on what adaptations were needed - but the social workers didn’t think that was their job.”

“Financial advice.”



Comments on ‘care closer to home’ at focus groups were wide ranging. The most popular area the comments focused on was *‘better organised/differently organised services’*.

‘better organised/differently organised services’ (9 comments)

“Telling everyone (services) what is happening and what care I’ve had. Really I shouldn’t have to do it - there should be a lead person or service doing it on my behalf.”

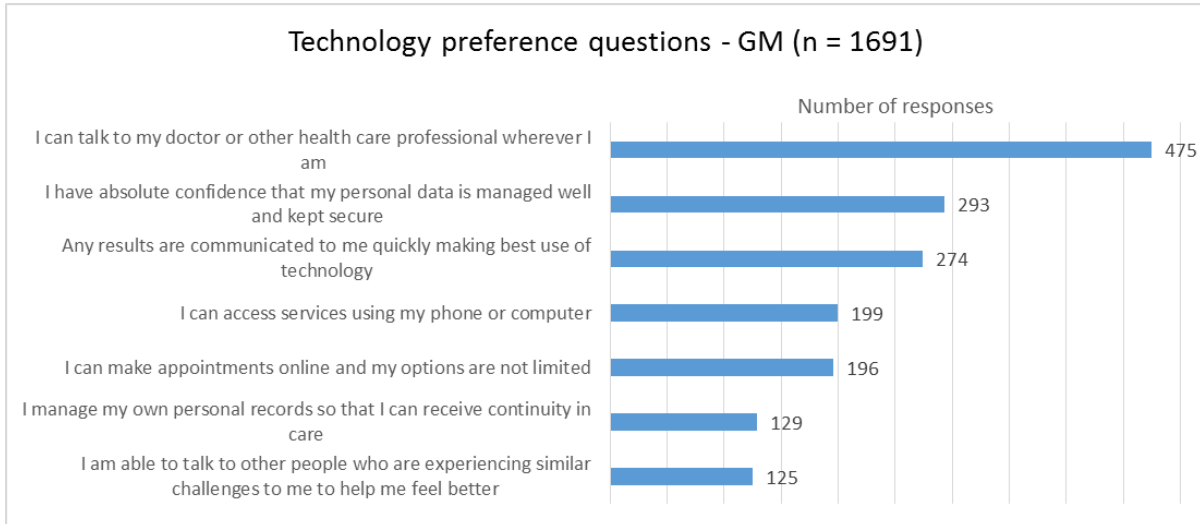
“Someone I know went to see their GP and was told to go to A& E. When they got to A&E they were told to deal with it and go back to her GP. It is very confusing.”

Overall issues for care closer to home:

- Staying within the home and having appropriate care there were the key themes in both quantitative, preference based, questions, and people’s free comments.
- Care services should be of high quality, reliable, on time, and well resourced. Access to treatment and support was also important within this topic, and comments received highlighted location, speedy access to appointments, clarity and using the pharmacy to improve access to healthcare as options.
- The theme of affordability also emerged from the comments, people highlighted the need for free care, supporting the elderly and having services well-funded. Focus group comments highlighted the need for improved organisation.

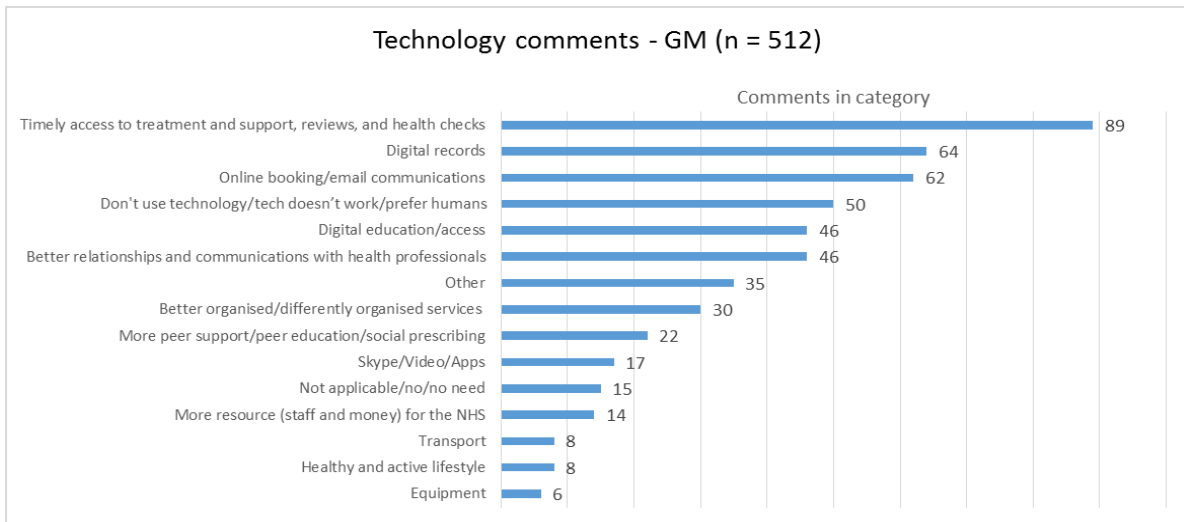
Technology

A summary of the quantitative results ranking preferences for technology in healthcare are shown below.



The most popular selection for technology in healthcare was ‘*I can talk to my doctor or other health care professional wherever I am*’ (475). As technology is quite a broad area it is difficult to say what the topic selection means exactly for each person, but this statement suggests support for technology supported access to healthcare.

A summary of the technology related free comment responses is shown below.



When commenting on the issue of technology and healthcare people most commonly mentioned ‘*timely access to treatment and support, reviews, and health checks*’ (89 responses), ‘*digital records*’ (64 responses) and ‘*online booking/email communications*’ (62 responses). The spread of topics here shows more clearly the range of different ways the term ‘technology’ can be interpreted.

People want technology to support them in their interactions with healthcare services, improving access, communication, and efficiency.

‘timely access to treatment and support, reviews, and health checks’ (89 comments)

Key themes and supporting comment examples:

- GP/times •Availability

Three speech bubbles containing comment examples:

- “Being able to make an appointment with a GP as soon as needed.”
- “Being able to access the doctor when needed, instead of waiting in a phone queue then told there are no appointments.”
- “Access to support services outside of office hours as I work full time.”

‘digital records’ (64 comments)

Key themes and supporting comment examples:

- Access •Speed •Security

Three speech bubbles containing comment examples:

- “Full and instant access to my medical records without having to go through a long procedure.”
- “Access to records needs to be paramount - shouldn't have to wait for somebody else to decide if I can see a result or not.”
- “Private firms are not given access to my personal health data.”

‘online booking/email communications’ (62 comment)

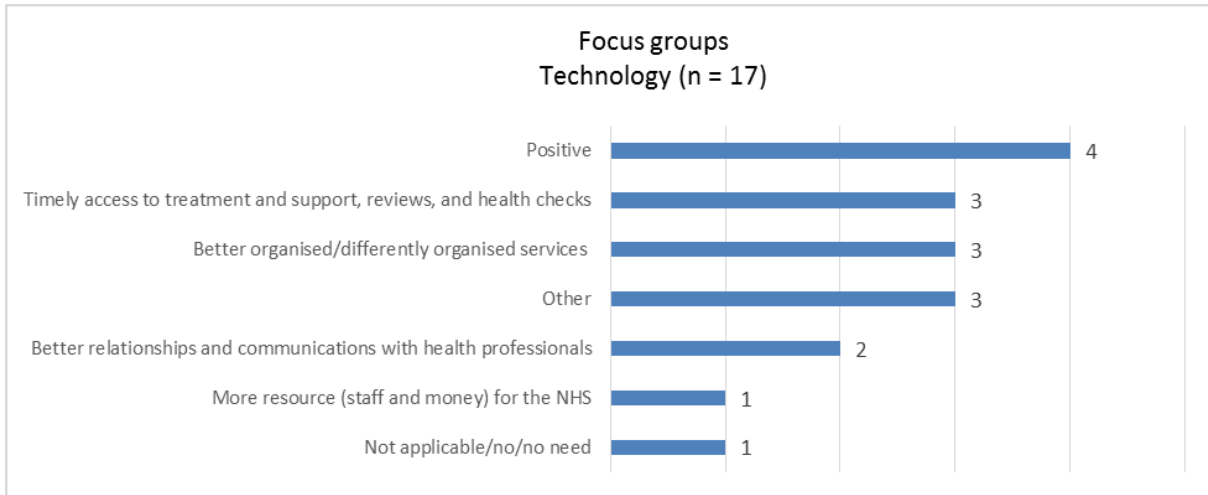
Key themes and supporting comment examples:

- Communication •Appointments

Three speech bubbles containing comment examples:

- “Regular communication with healthcare professionals and a non-bureaucratic approach to all aspects of the health and social care of the individual.”
- “Change GP appointment system.”
- “When accessing online services that appointments are actually available even when inputting any future appointment's nothing has come up.”

People were also asked to comment on technology during the focus groups held for this project. An illustration of the broad comment areas can be seen below. The chart shows that a number of generally *‘positive’* comments related to technology had the highest number of mentions. There were also notable mentions for *‘timely access to treatment and support, reviews, and health checks’* and *‘better organised/differently organised services’*.



Focus groups on technology emphasised the possibilities of technology when used in healthcare. There were concerns over whether technology could be used by everyone and whether data was secure, but largely people were more interested in the variety of possibilities.

“Someone I know used their Personal Budget to get internet access. Now that means they can shop online and have their prescriptions delivered.”

“I use my iPad regularly so would be happy with IT systems. People with dementia would suffer if they made everything digital. It removes personal touch and face to face contact which is critical (alarms etc).”

“Shared/summary care record info sharing and access to GP record important emergency access and info.”

Overall issues for technology:

- The use of technology was seen as a way of improving access to healthcare as well as improving the way people interact with and have control over their healthcare.
- The range of responses was quite wide within the comments, with the concept of technology having a variety of interpretations. For example technology might enable GP appointment systems to be arranged more efficiently; with access to GPs a recurrent theme across all four areas of this report.
- Some comments referred to enabling access to digital versions of medical records, with the belief this could assist communication between professionals and prevent mistakes.
- Focus groups comments highlighted the opportunity to use technology for improving healthcare, though some users did express concern for those less able or willing to adopt new ways of engaging with healthcare through technology.

Conclusions

This report has looked at the responses to the Healthwatch general survey and general focus groups held across Greater Manchester following the NHS 10 year plan publication. Whilst people were not directly required to read the NHS 10 year plan to respond to this study, their views are useful in showing what local people's priorities and experiences are, and whether the 10 year plan aims match.

People were asked to consider four main areas for this research. The areas chosen were prevention, personalisation, care closer to home, and technology, these areas cover the broad themes within the NHS 10 year plan itself.

It is worth noting that our sample of respondents in some ways matches that of Greater Manchester as a whole, particularly regarding the ethnicity profile. However this sample includes a greater number of older people and more women, when compared to ONS census 2011 data for Greater Manchester. Further research would be advised to explore young people's and men's opinions in more detail.

Looking at the quantitative questions 'access to the help and treatment needed', 'choosing the right treatment and this being a joint decision', 'wanting to stay in the home as long as possible', and 'being able to talk to a health professional anywhere' emerged as key priorities from all the choices given. The reasons for these choices are explored in more detail through the qualitative statements people made.

Drawing on qualitative free comment responses, people equated the concept of prevention with access to healthcare services, though they also recognised the need to support their health through lifestyle choices. People were aware of the need to exercise and eat healthily but thought this needed more support; particularly with greater availability of gyms and possibly their subsidy through free or reduced entrance fees. The counterpoint was a desire for GP and other medical services to be responsive to the need for timely appointments.

Regarding personalisation people wanted their relationships with professionals to be clear and honest. We had many responses which rated having time to talk, listening, and clarity as important. A more personalised service could be supported by easier access to medical records so patients do not need to repeat themselves, and professionals know more about the people they see. Once again access was mentioned as being central to healthcare that is responsive and effective; people want their concerns to be taken seriously with long waiting times giving some the message their illness was of low priority, or that the system works for its own convenience, not theirs.

Care closer to home was a wide ranging topic area which could be interpreted as referring to care services provided in the home environment, or the priority people give generally to local availability of services. As a result of the ways this area could be interpreted we had people comment on the need for home care services to be of high quality, reliability, and affordability. There was concern amongst some for the elderly and how they would be treated. It was also recognised that more funding might be needed to achieve a better quality of care service. We also had people comment on how health services might be made more convenient and accessible, for example through the use of pharmacies for medication management. As found in comments on prevention, people wanted to be able to easily access GPs and other healthcare services, with appointment availability key.

Finally people were asked to comment on the role technology might play in healthcare. Broadly people felt that technology could be a positive solution to identified problems in the healthcare system. For example technology might be employed to allow appointments to be managed more easily, with availability made clear, and avoiding long queues on the telephone. Other people mentioned the way technology could mean easier access to medical records, this was thought to have potential to ensure better understanding of people's conditions and also allow oversight regarding mistakes within their records. A more straightforward suggestion for technology was to allow patients and professionals to communicate via email, it was hoped this would increase the speed of responses and allow letters and queries to be collected in one place.

Across the four topic areas in this study people in Greater Manchester expressed a range of views, which have been explored through the ranking of preferences, as well as the analysis of open comments. People were keen for their healthcare to be managed efficiently, wanted the healthcare system to be close to them, and be responsive to their needs and wishes. Those delivering healthcare should make use of technology in an appropriate way to improve access, dialogue, and personalisation. Respondents looked to a healthcare system provided by people with time to care, a willingness to communicate and understand them and accessibility which extended not just to convenient physical locations, but forms of communication and information sharing that were clear and efficient.

Acknowledgements

This report was created by Healthwatch Bolton on behalf of Healthwatch in Greater Manchester, Healthwatch England and NHS England.

Thanks to the staff and volunteers of the 10 local Healthwatch in Greater Manchester for making this project possible and to the people of Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford and Wigan and Leigh who shared their views and experiences.

Appendix 1 - Full results

Demographics

Age profile of respondents - n = 2020

Age	Bolton	Bury	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan & Leigh	GM TOTAL
Under 18	0	0	3	2	39	0	2	16	1	3	66
18-24	15	3	19	17	14	16	2	28	1	2	117
25-34	42	11	18	47	17	32	4	15	10	5	201
35-44	61	16	17	55	19	29	14	15	28	3	257
45-54	67	21	32	76	46	37	15	31	31	8	364
55+	140	85	67	103	89	158	88	184	53	48	1015

Ethnicity profile of respondents - n total = 2036

Ethnicity	Bolton	Bury	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan & Leigh	GM TOTAL
African	23	0	2	3	4	4	0	2	1	0	39
Arab	2	0	2	0	0	0	1	1	0	0	6
Asian British	17	1	7	8	15	3	2	5	2	0	60
Bangladeshi	2	0	1	15	6	1	0	2	0	0	27
Black British	17	3	8	3	1	4	0	1	0	0	37
Caribbean	5	0	2	0	1	0	0	1	0	0	9
Gypsy or Irish Traveller	1	0	0	1	0	0	0	0	0	0	2
Indian	5	1	0	4	3	3	0	3	1	0	20
White British	240	126	114	254	179	233	119	261	115	71	1712
Any other white background	8	3	9	10	5	15	2	9	4	1	66
Any other mixed background	3	1	4	4	5	1	1	1	0	1	21
Other	5	6	9	2	2	7	1	1	4	0	37

Gender profile of respondents - n total = 2032

Gender	Bolton	Bury	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan & Leigh	GM TOTAL
Male	95	43	52	84	58	104	42	77	29	19	603
Female	225	96	105	217	161	165	85	200	94	54	1402
Other	5	0	1	0	3	0	0	0	1	0	10
Prefer not to say	3	1	1	0	1	5	0	3	3	0	17

Disability profile of respondents - n total = 2037

Disability	Bolton	Bury	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan & Leigh	GM TOTAL
Yes	102	48	38	42	64	75	43	98	26	24	560
No	218	85	112	251	155	188	81	181	95	45	1411
I'd prefer not to say	9	5	6	9	5	9	3	9	7	4	66

Carer profile of respondents - n = 2012

Carer	Bolton	Bury	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan & Leigh	GM TOTAL
Yes	100	22	21	55	47	45	27	37	24	17	395
No	224	111	135	249	175	222	101	241	103	56	1617

Health conditions profile of respondents - n = 2106

Condition	Bolton	Bury	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan & Leigh	GM TOTAL
A long term condition	135	73	62	104	82	102	55	98	57	34	802
Multiple conditions	44	20	33	19	37	42	17	74	11	12	309
Neither	164	54	76	182	111	130	60	126	63	29	995

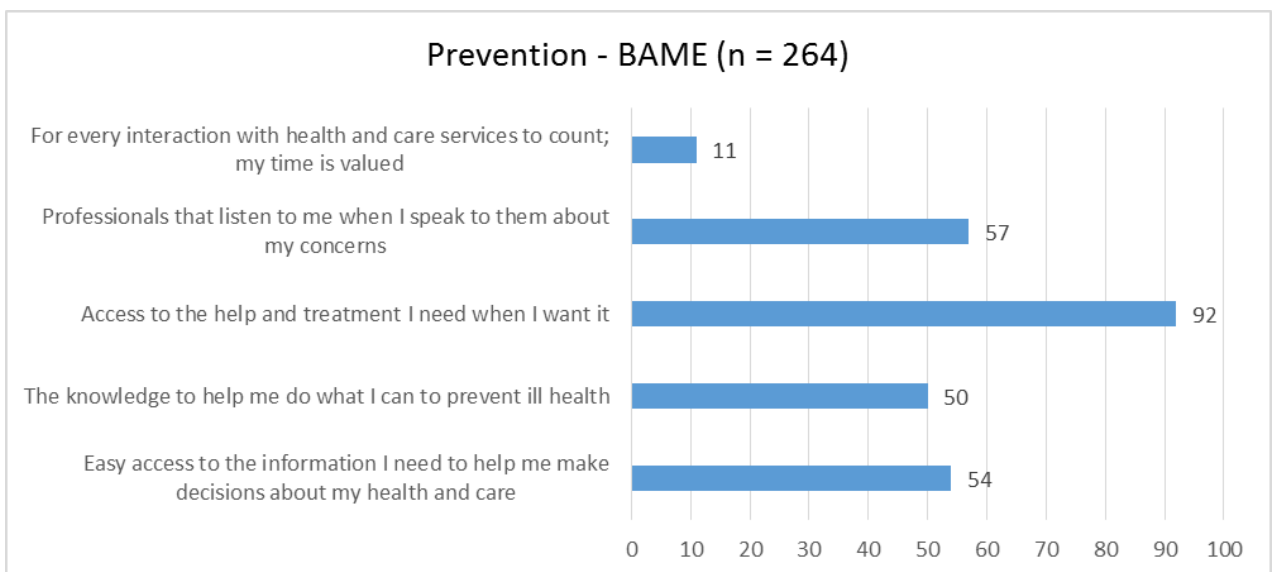
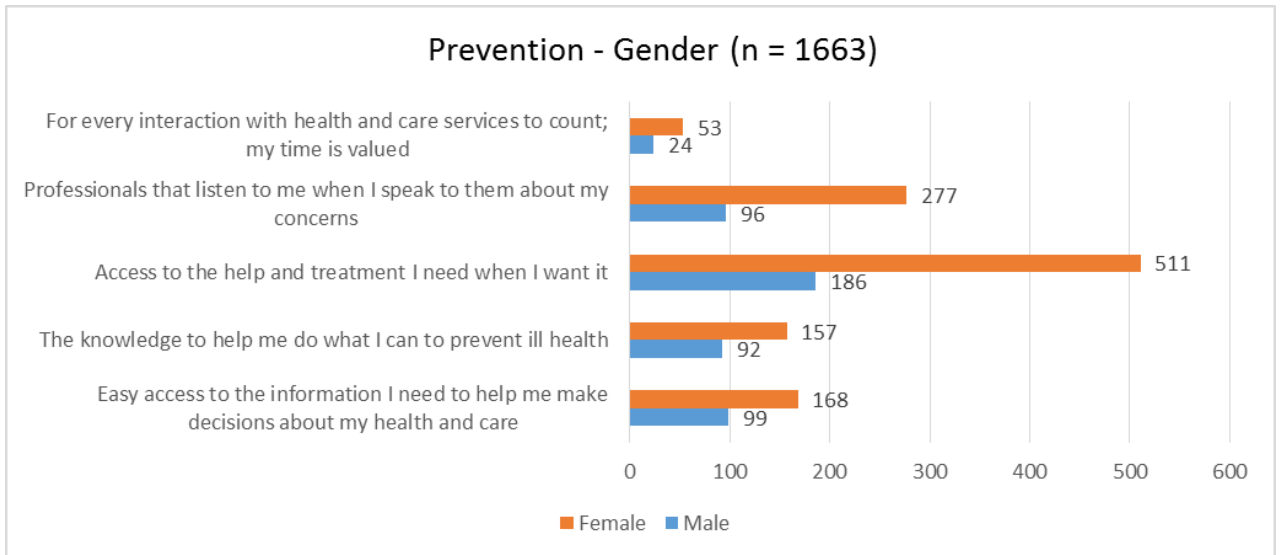
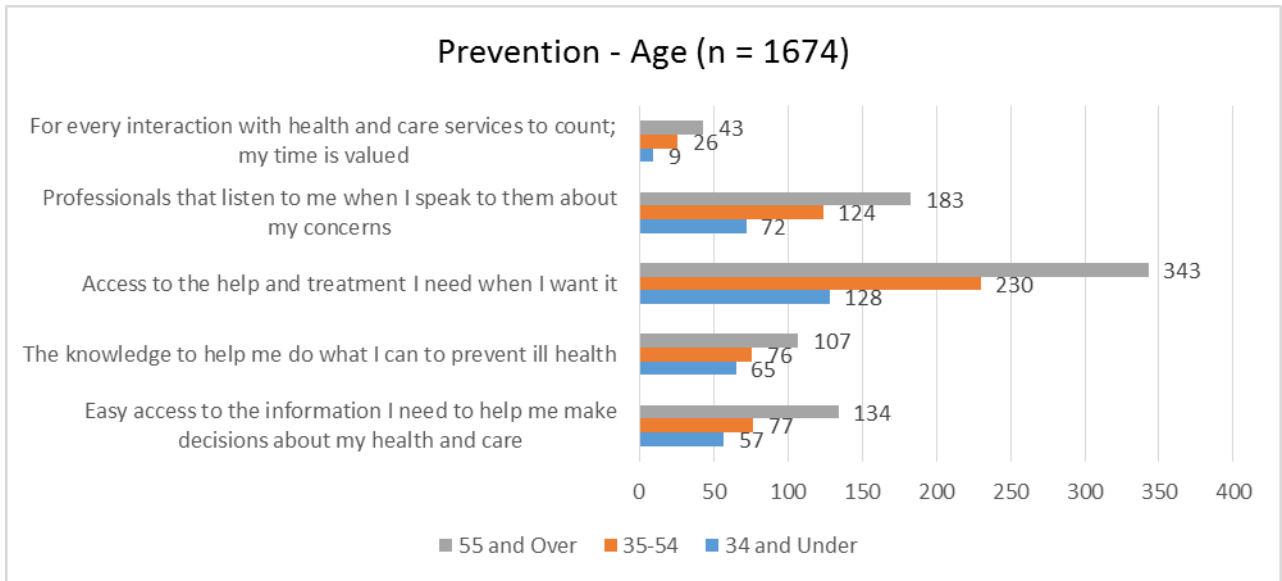
Sexuality profile of respondents - n = 1912

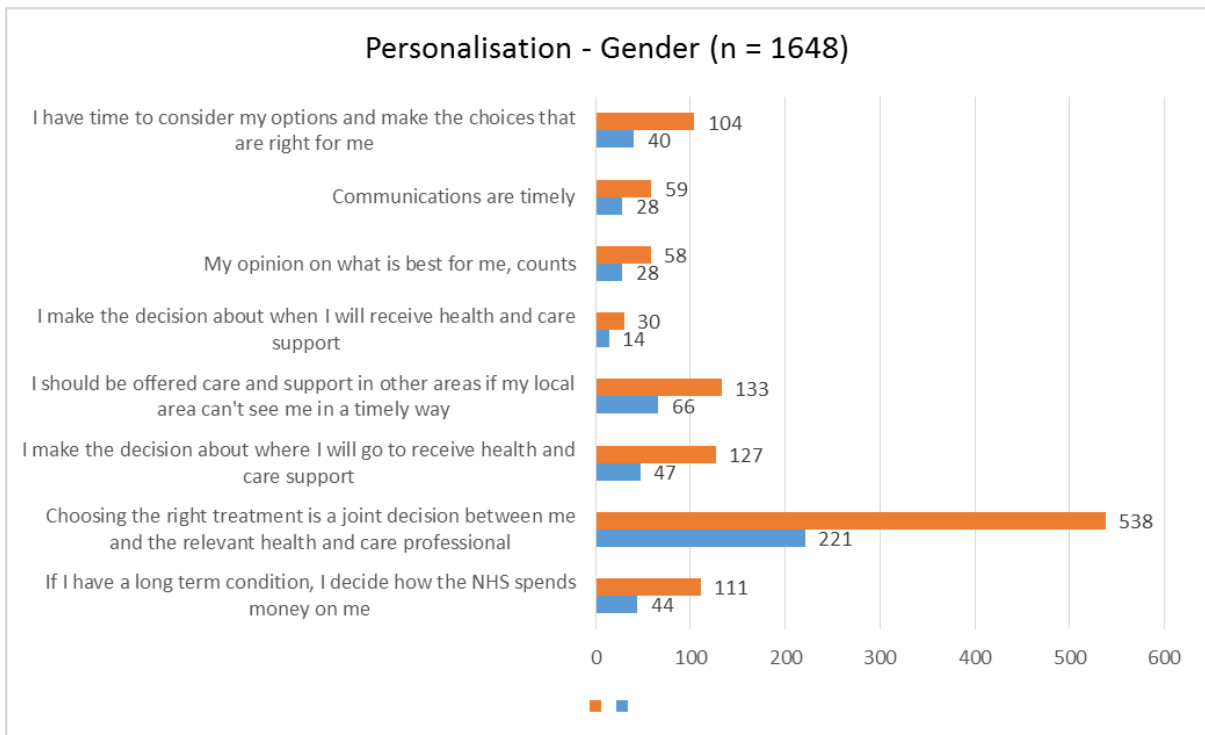
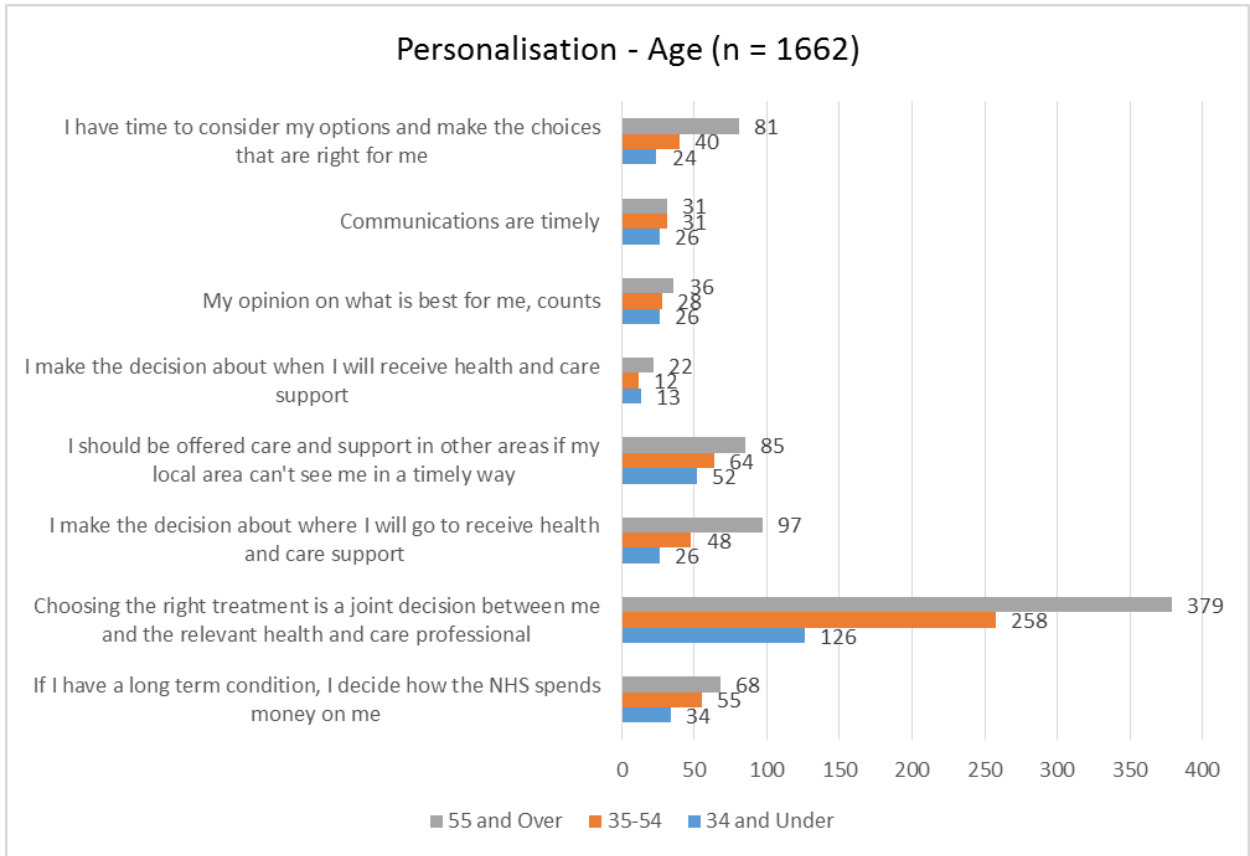
Sexuality	Bolton	Bury	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan & Leigh	GM TOTAL
Heterosexual	284	125	106	284	195	235	113	261	112	68	1783
Gay or Lesbian	8	6	22	8	11	6	1	5	5	1	73
Bisexual	9	5	11	3	5	6	1	3	3	0	46
Asexual	0	0	1	0	0	1	0	0	0	1	3
Pansexual	0	0	2	1	1	1	0	1	1	0	7

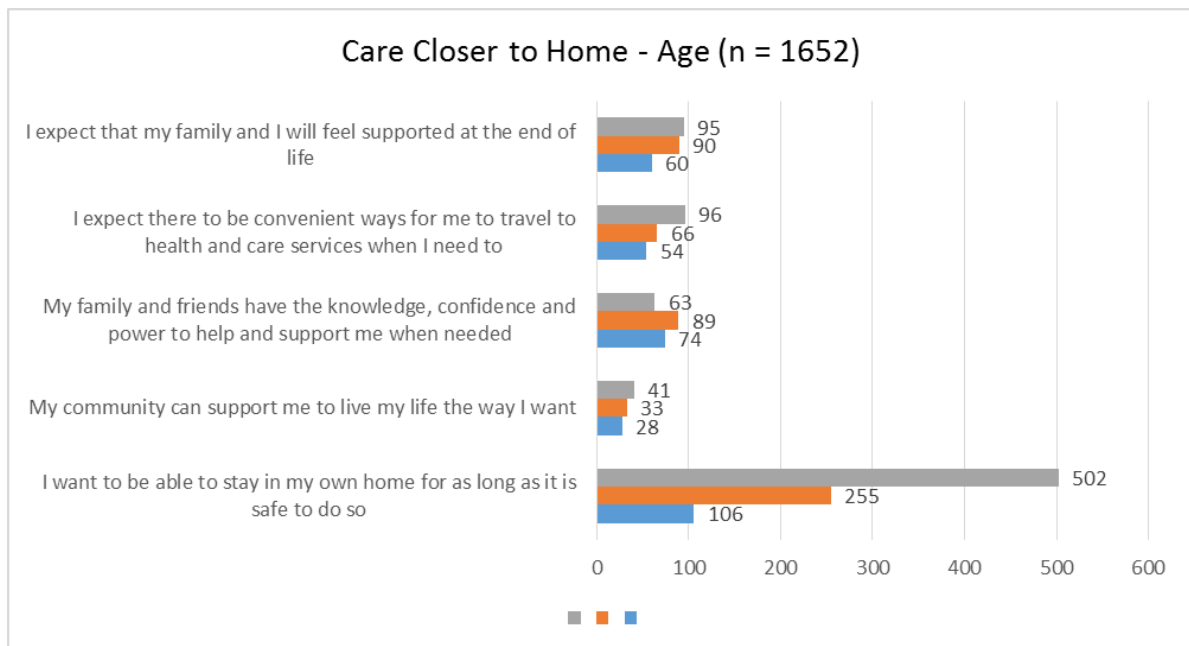
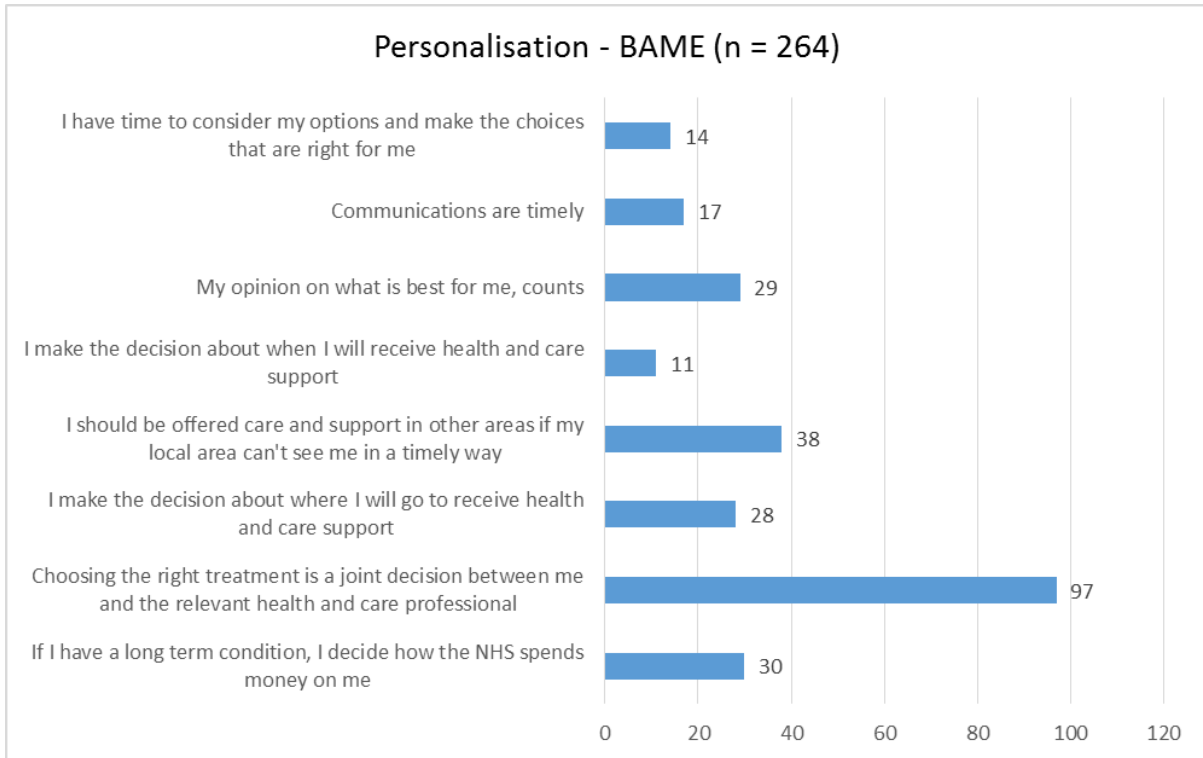
Religious profile of respondents - n = 2023

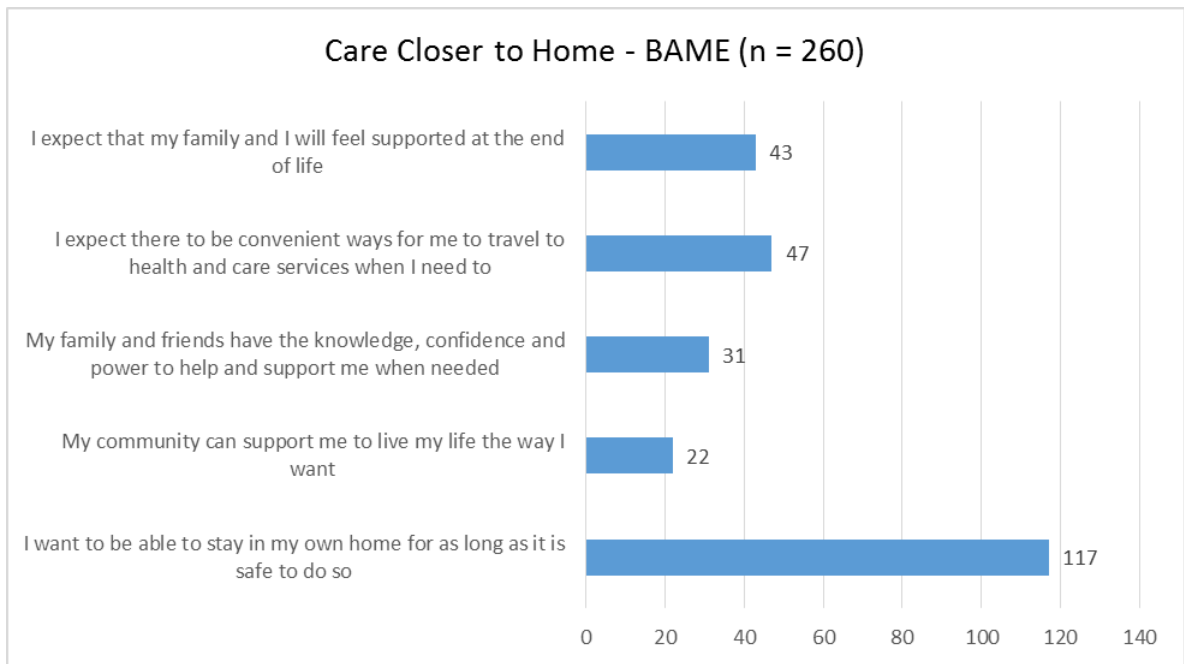
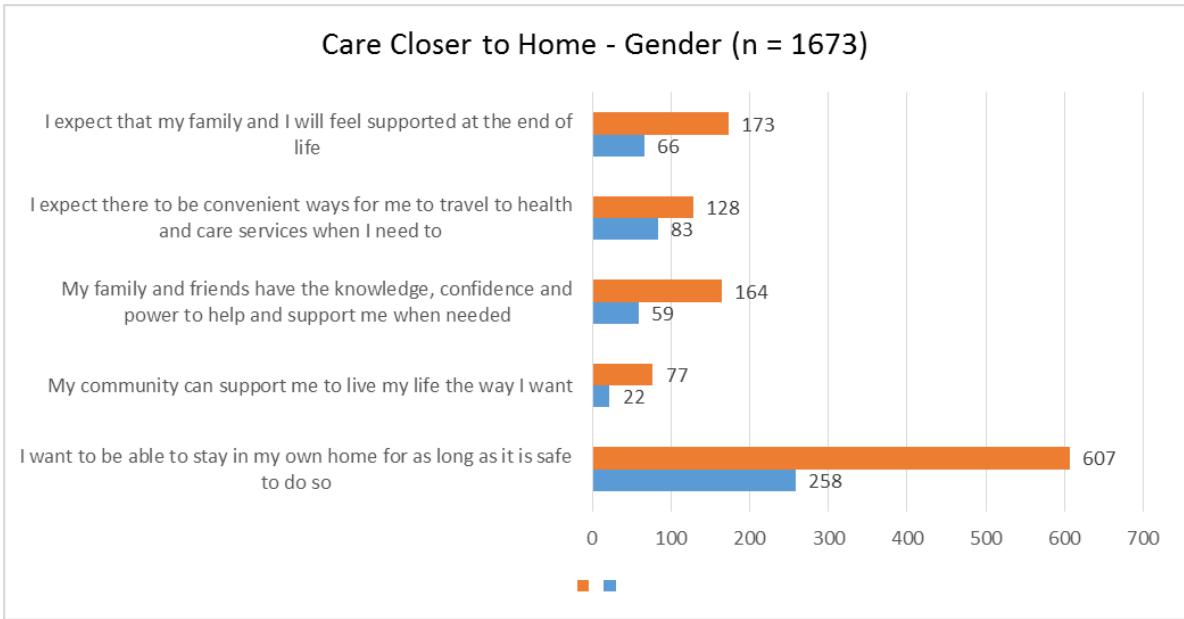
Religion	Bolton	Bury	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan & Leigh	GM TOTAL
Buddhist	1	3	2	1	0	1	1	0	0	0	9
Christian	202	67	65	179	107	147	77	188	61	46	1139
Hindu	4	1	1	3	5	3	0	3	0	0	20
Jewish	2	24	3	1	3	13	1	0	2	0	49
Muslim	20	0	9	24	19	7	3	5	5	1	93
Sikh	0	0	0	0	0	0	0	0	0	0	0
Other	4	3	2	6	4	5	0	5	5	0	34
No religion	81	36	67	78	66	82	40	72	44	21	587
I'd prefer not to say	12	6	8	12	14	11	5	10	9	5	92

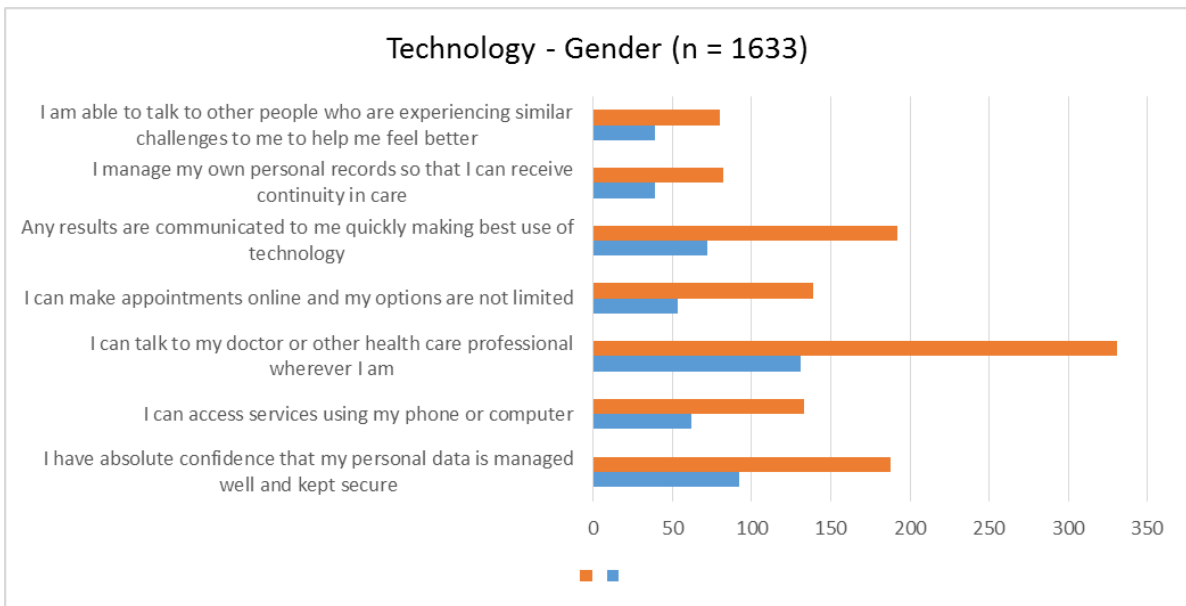
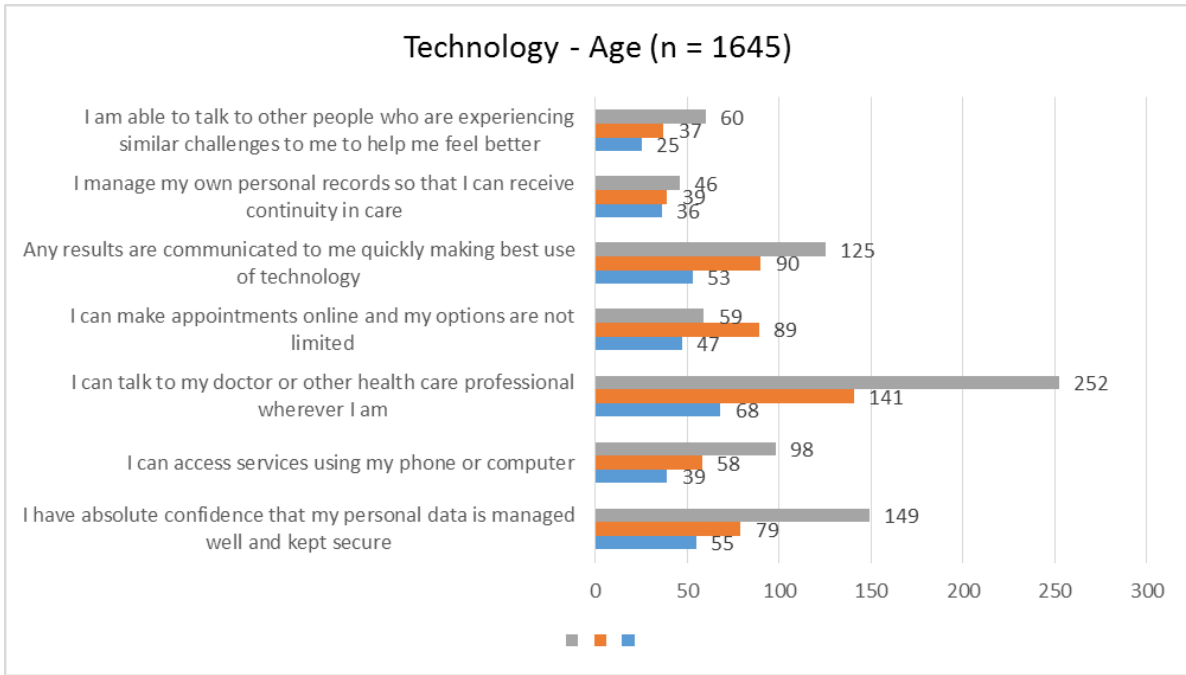
Survey results - age, gender, BAME (ethnicity)

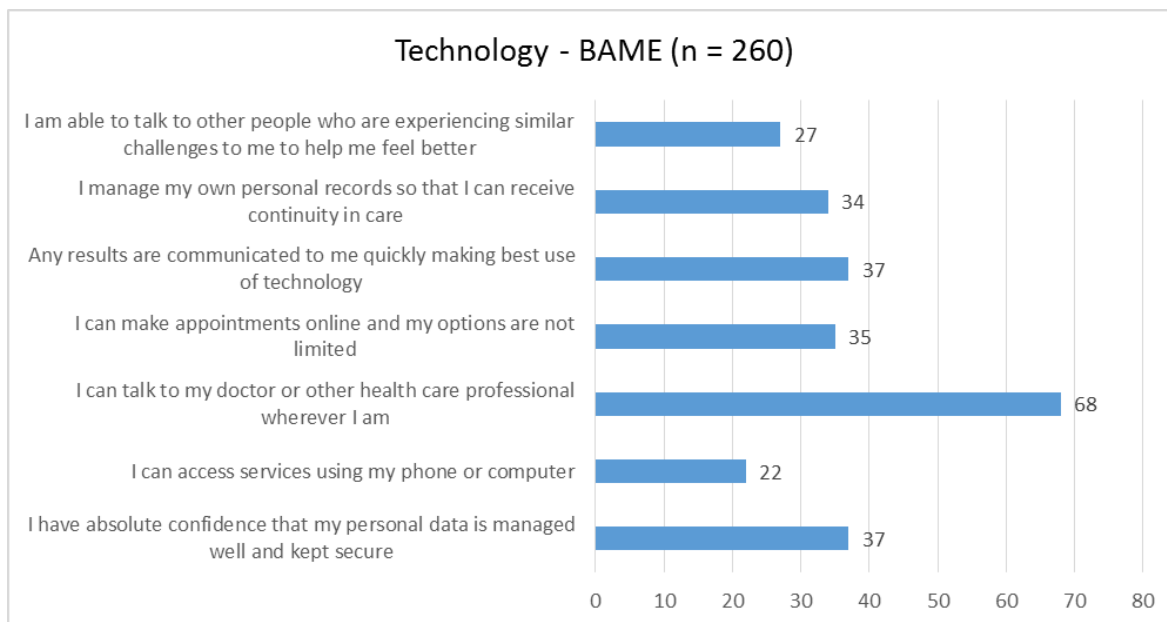












Appendix 2 - Response from GM Health and Social Care Partnership

The full response from the Greater Manchester Health and Social Care Partnership can be found on the following pages.

The response provided is to the whole set of reports created as part of the NHS Long Term Plan engagement by Healthwatch in Greater Manchester. It is included in full.

**RESPONSE TO
HEALTHWATCH IN GREATER MANCHESTER
NHS LTP PUBLIC ENGAGEMENT FEEDBACK**

2019



Introduction

The following report is the Greater Manchester Health and Social Care (GMHSC) Partnership response to the Greater Manchester public engagement feedback on the NHS Long Term Plan. This was commissioned from Healthwatch England on behalf of NHS England during February to March 2019.

We are committed to the delivery of the NHS Long Term Plan and simultaneously, Greater Manchester are taking a population health focus, working on plans across the wider public sector in our city-region and at the same time consulting on those wider issues that ultimately affect our long-term health and care.

With this in mind, the summaries in this report have been provided by each of the Greater Manchester programme leads in reply to the following engagement – general survey, mental health, learning disabilities, autism, dementia, cancer, cardiology and respiratory specialisms.

On behalf of GMHSC Partnership programme leads, we value the feedback provided by Healthwatch in Greater Manchester, although we recognise that this is only a snap shot of citizens comments that will contribute to our ongoing plans and the Greater Manchester Health and Social Care Prospectus for the next five years.

The final version of the Prospectus, due out in Autumn 2019 would, in the same way our first plan, Taking Charge of Health and Social Care 2016, build on the work we have been doing following devolution, including all the ten refreshed health and care locality plans. It will also explain how we intend to deliver on our responsibilities under the NHS Long Term Plan.

We would like to invite Healthwatch and any of those people who took part in the engagement to join the advisory groups as we continue to use the ongoing feedback we gain from our existing [engagement networks and forums](#) to inform our plans; not only for health, but also those that impact on health determinants, such as housing, employment, transport and clean air; plus other wider strategies including: the model of Greater Manchester public services; the Government Spending Review in 2019 and the national and local Industrial strategies.

Therefore, within our response, we have provided background context and further information on what we are doing to address concerns and the improvements we are undertaking to transform health and care across Greater Manchester.

To find out more about our plans on the work programmes listed below see [here](#)
Or find out more on [our website](#)

General survey

Overview of the Living Well at Home Programme

The aim of the Living Well at Home (LWAH) programme is to support people to stay well and independent in their own homes and communities of choice, as well as ensure high quality support where needed; by developing a strong, attractive and aspirational workforce offer with careers in health and care. This offers progression routes through education, training, apprenticeship opportunities and a good career pathway. Living Well at Home is not just about formal paid care but embraces innovative and alternative opportunities and support solutions such as Wellbeing Teams and independent living models, all underpinned by an asset-based approach which first and foremost recognises individuals and communities' strengths and resourcefulness. The programme will ensure interventions and prevention models are in place so that people can avoid going into long term support services and it will also change the way the money drives the outcomes, with payment reform incentivising the retention of independence and improved outcomes for people. It will also build on the unique infrastructure in GM, with LCOs and Single Commissioning Functions presenting opportunities for wholesale reform.

Living Well at Home and the Healthwatch general survey response

We welcome these findings which give additional weight and impetus to the change management programme being undertaken across Greater Manchester to support more people to live well at home. One of the themes running throughout the programme is the emphasis on quality and personalisation, and that this should apply wherever you live, (whether an individual tenancy, care home or supported living setting), as that is still your home and the same values and principles of quality of life and care should apply. The themes from the Healthwatch Survey align very closely with the priorities of the programme as can be seen below.

- a. As noted within the outline of the Programme above, the Greater Manchester Living Well at Home Programme (LWAH) is actively engaged in seeking to address many of the issues highlighted within the Healthwatch general survey and general focus; particularly with reference to some of the key themes highlighted within the Healthwatch general survey. Within the Healthwatch survey, people were asked to consider four main areas for this research; Prevention, Personalisation, Care closer to home and Technology. These four areas align very closely with themes within the NHS Long term plan itself and also the priorities of the LWAH programme. All these areas form part of the programme of work identified as priorities over the next six months. Within the LWAH Programme there are workstreams on Personalisation, Prevention and Technology and Innovation; all with the aim to support people to live well at home, 'wherever you live'. All are being actively developed and tested within designated local areas. Other LWAH workstreams, such as housing and Healthy Ageing, and nutrition and hydration, extend the scope of this work as they relate to the broader range of factors necessary for people to enjoy a good quality of life closer to home.
- b. Similar themes arose from the Independent Inquiry into Care at Home conducted over a similar period which has also been aligned with the Greater Manchester Programme.
- c. The feedback on 'access to the help and treatment needed', 'choosing the right treatment and this being a joint decision', supports the prioritisation of the work being undertaken through the LWAH programme to support people to stay at home and avoid hospital or care home admission, for as long as possible, along with the work on Personalised Care and Support, having different conversations about 'what matters to you'.

- d. The priority people raised regarding ‘being able to talk to a health professional anywhere’ links to our work on blended roles and working in local multi-agency teams to try to make the journey through the system simpler and easier to navigate or find the right person to talk to.
- e. The comments on healthy lifestyle go slightly beyond the remit of the LWAH programme but we have linked up to the Healthy Ageing Programme so that these programmes can work closely together. We are also working with the Primary Care team to see how working with GPs and other medical professionals can be mutually supportive in enabling people to live well at home.
- f. A further workstream which relates to the experience of care and its quality, reliability & affordability, is System Reform; this is exploring ways to put more emphasis on outcomes particularly in care at home. Another piece of work relates to a shared quality framework for Greater Manchester which emphasises consistency in the Quality of Care, Quality of Life and Quality of Partnerships, all of which work together to improve the experience of individuals and families.
- g. Through localities working together across Greater Manchester there has been a demonstrable improvement in quality ratings in care homes over the last two years, and the intention is to continue with that journey of improvement so that everyone who needs it, can be in receipt of good quality care and support.
- h. The Quality Improvement and Best Practice Group meets monthly, sharing best practice and developing an improvement plan. This group holds an oversight of both care homes and care at home programmes across Greater Manchester. This includes work on the ‘Red Bag Scheme’ (hospital transfer), Trusted Assessors, links to urgent and primary care, working with the medicine optimisation team to produce a draft guide for good principles for safe medicines in care settings, support and training for Registered managers, flu vaccinations and pressure ulcer prevention, frailty and falls. Data is collected routinely from across Greater Manchester and is used to demonstrate real tangible achievements in performance as well as highlight areas for continued improvement. Greater Manchester also works closely with several Universities and colleges to promote best practice through research, as well as offering placements and training opportunities for students. The Teaching Care Homes works with a cohort of Care Homes to help understand and share what is working well, and what can be scaled up across the region.

Mental health

Mental health is one of the top priorities for Greater Manchester Health and Social Care Partnership. This was exemplified with the announcement of significant investment plan of £134m into Greater Manchester Mental Health services. The investment is the biggest and most ambitious of its kind in the country. Nearly 60 per cent, £80m, supporting the mental health needs of children, young people and new mums, it also reflects the commitment to increase the proportion of the budget focused towards young people.

Greater Manchester has already invested in a Mentally Healthy Schools programme supporting teachers to embed resilience, with 125 schools and colleges benefiting from this investment. Further investment has gone into the Greater Manchester Colleges network and we are aiming to launch a new Greater Manchester Mental Health University Service in September 2019.

As part of Greater Manchester’s continuous engagement in mental health, we have also involved various Voluntary, Community and Social Enterprise (VCSE) organisations including Back on Track, Citizen’s Advice Bureau (Manchester) and START Mental Health among many others. We have worked closely with the GM Mental Health VCSE Reference Group to recruit VCSE representatives to sit on our

constituent Boards and coordinated a dedicated mental health VCSE forum. The mental health reference group also supports ongoing engagement requirements, including transformational projects with embedded equality impact and health inequalities process.

Learning disabilities

We welcome the comments and feedback as they certainly reflect the views of people with learning disabilities in Greater Manchester we have already captured and have been working with for some time now. In Greater Manchester we have built a very strong relationship with people with learning disabilities through our partnership with North West Training and Development Agency and Pathways Associates CIC. These have played a major role in enabling people to speak out and provide an advocate for their needs and rights.

Because of this, we now have a Greater Manchester Learning Disability strategy which was launched in 2018 with all 10 boroughs signed up to it. It addresses the feedback captured in the Healthwatch report and all boroughs are currently working to implement the plans.

The strategy was written by people with lived experiences and it focuses on 10 priorities:

- **Strategic leadership:** Coproduction and leadership to reduce inequalities experienced by people with a learning disability
- **Advocacy:** Supporting people and their families to speak up for themselves
- **Bespoke commissioning:** Embedding person-centred planning approaches and new commissioning arrangements for people who need the most support
- **Good health:** Reducing health inequalities by improving access to health services, screening and reasonable adjustments; implementing learning from Learning Disabilities Mortality Review Programme (national initiative)
- **Belonging not isolation:** Supporting people to make friends and have relationships
- **Employment:** Enabling more people to obtain paid employment and supporting young people to consider their employment options during transition. A GM target of 7% of people with LD in employment by 2020 has been approved as part of the Strategy
- **Homes for people:** Ensuring people have a choice about where they live and which kind of housing they live in and are supported to live as independently as possible.
- **Workforce:** A skilled workforce and quality providers that know how to support people and demonstrate humanity and values
- **Early support for children and young people:** Ensuring children, young people and their families get early help and support which meets their needs
- **Justice system:** Ensuring offenders are being represented, treated fairly and supported not to reoffend; ensuring victims have a voice

Each borough is co-producing their delivery plans with people with learning disabilities and their families/carers. The plans are also shared with the Greater Manchester Confirm and Challenge group to make sure the progress is being made and that the outcomes achieved continue to reflect what the people said was important to them.

There is also a Greater Manchester Learning Disability Strategy Delivery group which provides the assurance to the Health and Care board on the implementation of the strategy.

In terms of the Healthwatch report we feel that overall the same issues have been captured within the strategy and actions are now being put in place to address them. With regards to some specific feedback in the report we have noted some specific actions we are taking below:

Healthwatch: A comment suggested *support and advice for parents at the point when their child is diagnosed – comments that describe a devastating and difficult time; in conclusion the report found “some of the parents of children with learning disabilities spoke of a need for more supportive interventions to help them to understand how to support their child”.*

Our response: One of the objectives of the Transforming Care national programme, that Greater Manchester are involved in, is to develop parent forums and support parents with strategies they can use

Healthwatch: Healthwatch concluded that *“Accessible information with brief, clear and pictorial explanations would help people understand the need for attending at prevention, check-up and screening appointment”*; Healthwatch found that *“Touch screen check-in, text messages re appointments and digital signs calling people to appointments all came under fire as examples of difficulties people faced as a result of this lack of understanding”*; *In the groups people said they don’t often attend appointments because they don’t understand the letters they are sent ie. cervical screening, cancer screening*

Our response: GM Health Inequalities Working group (Healthwatch has been invited to join) has got a specific action on the delivery plan to address accessibility to universal health services and make reasonable adjustments

Healthwatch: Healthwatch found that *people value having advocates to support people when accessing health services*

Our response: as part of the Advocacy priority on our strategy we are looking to develop a GM approach to citizen advocacy by spring 2020

Healthwatch: **Discussion to Have Learning Disability champions in all community settings e.g. dentists, GP surgeries, pharmacists etc.** *The group have raised this previously and will be raising again with the CCG.; A comment on “Good support from the district nurse team and GP surgery – it’s once you hit hospital that quality and support from the hospital services disappears.”*

Our response: GM Health Inequalities Working group brings together representatives from the settings mentioned above to ensure the needs of people with Learning disabilities are better understood; one of the key deliverables is increasing the number of people on GP Learning Disability register and improving the uptake of Annual Health checks

Healthwatch: In the report Healthwatch found *transport can be a barrier*

Our response: This is being picked up as part of tackling social isolation, but we have also recently connected with Transport for Greater Manchester with regards to improving public transport

Healthwatch: Healthwatch noted *requests for inclusive/disability specific support in terms of mental health and wellbeing groups; A comment mentioned “So many people seem to get anxiety and depression as they get older and they are not encouraged to stay active and watch weight for example”.*

Our response: Within the Health Inequalities Working group we are addressing the above within the promoting health and wellbeing priority and localities are leading on this by linking with Population health campaigns, sport and leisure providers and local wellbeing groups.

Autism

We value the comments made in the Autism engagement report and have already started to implement the work needed to make Greater Manchester the first ‘autism friendly’ city-region in the country. In 2019 we launched an Autism strategy at an event where autistic people and their families attended to hear about the strategy and plans for delivering it across the region. They were also invited to continue shaping the strategy and its projects in the future.

The Greater Manchester Autism Consortium is a partnership of the 10 local authorities and the 10 Clinical commissioning groups as well as the GM Health and Social Care Partnership. The consortium funds the GMAC project, which is hosted by the National Autistic Society. The project has two main functions:

- Information, advice and sign posting to autistic people of all ages, family members and professionals via phone calls/emails and parent workshops.
- Implementing the [GM Autism Strategy 2019-2022](#) - Making Greater Manchester Autism Friendly.

The Autism strategy sets out four key areas for improvement; making sure public services are accessible, placing autistic people at the heart of our communities, improving health and care so autistic people stay healthy and receive the support they need and improving employment opportunities as well as the transition to adult services for young people. One example is that Greater Manchester libraries are working, with the Arts Council and Heritage Fund, to create a network of autism champions and make improvements so the libraries are a pleasant experience for those who experience sensory differences.

Two Greater Manchester Autism Committee (GMAC) advisory groups have been established, one for autistic adults and one for families/carers. They report into the GMAC steering group and represented by the Advisory group coordinators.

In addition, each of the 10 localities have local stakeholder groups such as Autism Partnership boards or strategy meetings and these will be overseeing the local implementation of the autism strategy.

Response to specific issues raised within the NHS LTP report by Healthwatch:

The report posed the following questions, (29 people by survey and 8 by focus group)
Comment on waiting times, overall experience and suggested improvements at 2 points;

-From first presentation to diagnosis

-From diagnosis to commencement of support

In relation to the first question 52% found it negative, 31% found it mixed/neutral and 17% found it positive.

In relation to the second 46% found it negative, 29% as mixed or neutral and 14% as good

Our Response

Diagnosis

The findings are similar to what we found through our own stakeholder engagement. Because of this, we have developed a Greater Manchester service specification for diagnosis and post diagnosis, based on NICE guidance and the Autism Act statutory guidance, which asks the localities to grade themselves red, amber or green. This year we will be developing an implementation plan for the 10 localities. Early

in 2020, those localities who are not green will be asked to develop a business plan to meet the service specification by April 2021.

Best Practice event

GMAC are also running a best practice event on post diagnostic support (for all ages) in the autumn of 2019 which will enable us to ask stakeholders what they think a core post diagnostic offer in should include.

Information and Guidance

Improving information and guidance is also a key commitment within the autism strategy. GMAC will continue to produce resources for localities to use and we are investing in the GMAC website further.

Professional Awareness Training

Once the mandatory Learning Disability and Autism training plans and the Health Education England training on Autism is published (expected autumn 2019); GMAC will be devising a Greater Manchester Autism training plan. As part of this, we will be asking localities to tell us what training is on offer. We feel that training of GPs and other health practitioners who could or should be supporting individuals and families towards accessing a diagnosis will be a crucial element of the plan. If the strategy is extended to become all-age the list of agencies that will need to be better aware of diagnosis will likely increase and need to be reflected in the Greater Manchester training plans.

The report suggested four recommendations:

- Early Intervention
- Social prescribing
- Personalisation
- Technology

These areas are all suggestions that could be explored within the implementation groups developed or additional work streams may need to be created if they do not clearly fit with the existing priorities.

Dementia

Across Greater Manchester there are more than 30,000 people living with dementia. Our aims are to improve the experience for those affected by Dementia in Greater Manchester, along with reducing the dependence on health and social care provision. With a £2.29m investment working with Dementia United we want to make Greater Manchester the best place in the world for people with dementia and carers to live. Dementia United, our dementia strategy, continued to develop partnerships within all localities in Greater Manchester. Strong pan-GM links have also been forged with key partners such as Transport for Greater Manchester, Health Innovation Manchester and the Alzheimer's Society. Lived experience of people living with dementia and carers is fundamental to our work. We have established an expert reference group for carers in conjunction with TIDE (Together in Dementia Everyday - a network that seeks to build a better future for carers of people living with dementia). A similar reference group for those living with dementia is currently in the process of being established in conjunction with the Alzheimer's Society.

Diagnosis:

The pathway for diagnosis is known to be variable between boroughs and different parts of the health care system, such as Primary Care and Mental Health services. Greater Manchester (GM) has consistently had a diagnosis rate (older than 65-year olds) above the national target of 66.7%. However, we are aiming to achieve higher. This target also does not include those with young onset dementia (under 65-year olds). Lived experience of people living with dementia and carers is fundamental to our work. We have established an expert reference group for carers in conjunction with TIDE (Together in Dementia Everyday - a network that seeks to build a better future for carers of people living with dementia). A similar reference group for those living with dementia is currently in the process of being established in conjunction with the Alzheimer's Society.

Post diagnostic support:

Dementia United has a key focus area around post diagnostic support as it is recognised as being weak. Dementia United are working on a standard across Greater Manchester that following diagnosis, people affected by dementia will be offered more focussed care planning (person centred care), with practitioners who can offer navigation through to the appropriate post diagnostic support that is tailored to people's needs. These practitioners who will be based in health, social care services or the voluntary sector will work in collaboration with people affected by dementia, at whatever stage they are at on their dementia journey, ensuring close integration across all sectors to support people affected by dementia.

Dementia United are working in partnership with Social Sense and Hitch to design, develop and test a platform that will measure in real time, the experience of people living with dementia and those who care for them. This is a unique, innovative project which is the first of its kind and will enable Dementia United to understand what it is like to live with dementia in Greater Manchester. The intelligence we can gather from this platform will contribute to service improvements and ultimately help us achieve our ambition for Greater Manchester.

Dementia initiatives are already underway in many areas, with success already being seen through initiatives such as the Salford Way dementia app, which has been launched by Salford CVS. Pharmacies across Greater Manchester are becoming more dementia-friendly thanks to a scheme developed by the Greater Manchester Pharmacy Local Professional Network and launched by the Greater Manchester Health and Social Care Partnership in 2016.

Greater Manchester has a governance structure for Dementia that aligns to the Greater Manchester Health and Social Care Partnership aims. On each of the two groups we have experts including carers, lived experience, academia, finance, Primary Care, Nursing, Public Health, Health watch, VCSE sector, NWAS, workforce and care/residential homes. Representatives have been chosen due to the networks they belong to and channels they must engage with a wider number of people in the specialism. The Strategic Clinical Network manages the clinical engagement.

The key focus areas for Dementia United are shown below (not exhaustive):

We have already developed and designed Greater Manchester Standards for Mild Cognitive Impairment and Delirium and are now able to spread this best practice across Greater Manchester.

Key steps in 2018/19 include (not exhaustive):

- Start to standardise post-diagnostic support with a single GM Care Pathway and Plan
- The goal of a dementia-friendly transport system has been included in Transport for Greater Manchester's work on age-friendly transport

- A partner for the development of the Lived Experience Barometer - an innovative tool to measure improvement in the lives of those living with dementia has been selected and the Barometer is in the early stages of development
- The introduction of a Mild Cognitive Impairment leaflet to improve levels of knowledge about the condition among those who have been diagnosed and their family
- Spread the Greater Manchester approach to delirium
- An End of Life framework to increase access to Advance Care Planning training for those working with people living with dementia. The goal is to ensure that more people living with dementia receive the care they want and need at the end of life
- An event with 300 participants focused on the lives of those affected by dementia. Feedback from the event has been overwhelmingly positive and has raised the profile of the work on dementia being undertaken in Greater Manchester

General comments on the Healthwatch engagement:

- The variation described in one of the main drivers and being of Dementia United (Greater Manchester's dementia strategy). There is a set of dementia standards that all 10 localities have agreed to covering the full dementia journey from pre-diagnosis to end of life care. Work to make improvements is happening across all 10 localities based on their individual needs.
- As the dementia report uses such a small sample size difficult to give meaningful feedback.

Cancer

The Greater Manchester Cancer Programme has a dedicated team for engagement, who work with members of the public and those affected by cancer to contribute to all aspects of the cancer programme. The cancer work programmes continuous engagement is supported by:

- The User Involvement Group: People Affected by Cancer Group
- Cancer community champions
- Pathway Board representatives
- Cancer steering group
- VCSE advisory group

Patients are involved in all cancer service decisions, with more than 120 people affected by cancer supporting programmes. Therefore, as only a small number of patients were asked in the Healthwatch engagement, we found it difficult to ascertain that this was the views of the cancer community we work with.

Please note Healthwatch are invited to attend the GM Cancer senior meetings to discuss how we can better integrate going forward.

We have had recent success of cancer care in Greater Manchester over the last five years due to several key factors: We have a comprehensive connected integrated cancer system led by clinicians and patients driving real change and providing leadership, not just in Greater Manchester, but across England and the UK. Through the devolved health and social care system we have a supportive system facilitating links across the region, and we have centres of excellence such as The Christie, The University of Manchester, The Manchester Cancer Research Centre, Salford Royal and Manchester

University Foundation Trusts bringing cutting edge research, technologies and innovation to our population.

We have improved earlier diagnosis, stage 1 and 2, closing the gap on rest of country, with four best performing out of the top ten trusts in England. Our drive to improve early diagnosis has meant more demand for treatment, but we are looking at ways to tackle this, including a more integrated workforce and use of more technology.

In 2018, we opened NHS England's first Proton Beam Centre and now have a single surgical site for stomach and oesophageal cancers, the largest in Europe.

We are doing several big programmes including faster diagnostic testing (in lung cancer, prostate cancer and colorectal cancer). We have successfully done a lung health check programme for high risks smokers, finding significantly more cancers earlier and have supported the CURE pilot scheme in Manchester to help patients quit smoking, with excellent success rates to date.

Working with the Christie, we launched "Get fit for surgery" initiative in April 2019. Providing nutrition, exercise and improved emotional wellbeing, supported by free gym membership and coaching advice before and after surgery.

From a digital perspective, we have been leading the implementation of the recovery package, in which electronic documents of how patients are doing are collated as a health needs assessment. We are also doing a programme of work called E-Proms (with the Christie) in which patients can submit information on their health care needs on an electronic system.

To reduce the number of hospital appointments, breast cancer patients can have a choice of face to face, electronic or telephone follow ups, if appropriate. These are just some steps we are taking to move to a more digital programme of work.

Cardiology

Heart disease is still one of the biggest killers nationally. In one year alone, 4,330 admissions to hospitals in Greater Manchester were related to heart failure, with treatment costing more than £17 million. However, by better understanding and supporting patients to manage their condition this could be much less.

We are constantly looking at ways to improve this, by focusing on prevention, management of the disease and use of technology. For example, around 1,000 patients with heart failure across Greater Manchester are now being monitored by a new digitally-enhanced service using data from existing implantable devices to transform care and better meet their needs.

It is great to see so much activity around the improvement in cardiac and stroke care across the system in line with the requirements of the NHS long term plan. The Cardiac and Stroke Strategic Clinical Network are embedding the patient voice within the five workstreams that are currently in place. These include:

- 1) Hypertension
- 2) Heart failure
- 3) Stable Chest Pain
- 4) Rapid Access for Acute Coronary Syndrome
- 5) Out of Hospital cardiac Arrest

It is reassuring to see that what citizens are asking for is reflected in our work; e.g. remote support using technology, post treatment support from GP/community specialists.

Respiratory

The Greater Manchester Respiratory Framework is reviewing the range of services offered to maximise education and improve self-management support. The aim is for people to be offered options as part of their disease review. Such offers will include; early education sessions, Pulmonary rehabilitation, peer support, British Lung Foundation contacts and information, MyCOPD, access to psychological therapies and other local offers that work toward improved outcome measures.

Digital Offer

MyCOPD is currently the main digital platform being offered with 7 out of the 10 localities investing in this self-management support tool. It is envisaged all 10 will eventually offer this and moving forward MyAsthma may also be offered soon. In the meantime, NHS England are exploring technologies to aid lung function testing and reporting.

Communication

The long term aim of the GM Respiratory Framework is to embed consistent pathways, which in turn should result in consistent referrals, templates and information. This should reduce some inconsistencies or lack of information and support.

Professional relationships, referrals and management

Greater Manchester are already piloting new education sessions that are more patient focused by asking ‘what is important to you right now?’ Given all the information and options, people will then be able to set their own goals and clinicians will support them. In addition, other health factors will be considered. Examples include, early detection for other common illnesses such as frailty, depression and anxiety, and heart conditions (where breathlessness is involved). This is to address conflicting disease/condition related goals. Person centred goals as part of management plans will help clinicians to prioritise their own support and listen to the persons needs in their reviews.

Support

We are aiming to give consistent information from diagnosis onward and to offer local support during a person’s review to address their needs. Whether it is information, education, social interaction requirements, physical activity, psychological support or clinical opinion.

In future, it would be good to see heart and respiratory reviewed separately, so we can get down to the needs of the individual patient, but still gather great feedback to consider in our working groups.

GET IN TOUCH

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