healthwatch

NHS Long Term Plan

The Patients Journey in Mental Health

Healthwatch in Greater Manchester

Contents

Background to this Report

The NHS published its Long Term Plan Published on 7 January 2019. The Plan, which was developed in partnership with frontline health and care staff, patients and their families, focuses on some key changes, as summarised below. The full report can be found on the NHS Website.

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 preventing, 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 get commonly 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 (in our case Greater Manchester) level.

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 our 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 and 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:

1) **Long Term Plan General Findings** - this report covers the responses to the general survey, 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 (2091 responses).

2) **Six Reports on Specific Conditions** - these reports have much smaller numbers of respondents (between 29 and 77). 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 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'
    - 'The Patient's Journey In Mental Health' (this report)

Methodology

Engagement for this project took place across Greater Manchester between March 4th - April 26th 2019. Healthwatch in Greater Manchester (HW in GM) worked together closely 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.

Data sets highlighted in blue are used in this report.

AREA	Bolton	Bury	Manchester	Oldham	Rochdale	Salford	Stockport	Tameside	Trafford	Wigan & Leigh	GM TOTAL
Total Number of Useable Surveys: (For details see General Survey)	333	142	159	306	227	281	128	313	129	73	2091
Long Term Conditions Mental Health	5	5	5	3	3	5	5	5	5	4	45
Long Term Conditions Autism	2	1	1	0	5	0	5	2	11	2	29
Long Term Conditions Learning Disabilities	7	6	1	3	14	0	6	2	0	0	39
Long Term Conditions Dementia	0	1	1	6	7	9	1	2	4	1	32
Long Term Conditions Cancer	1	0	1	1	1	0	3	4	0	2	13
Long Term Conditions Cardio & Respiratory	2	2	0	1	5	0	3	60	1	3	77

A set of companion focus groups (19) were also held, each LHW were free to choose either one of the specific conditions or the general questions and target participants through their networks. Feedback from these focus groups was collected on a standard feedback sheet to ensure comparable data.

Details of the focus groups were as follows :

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 & 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		

Who we spoke to

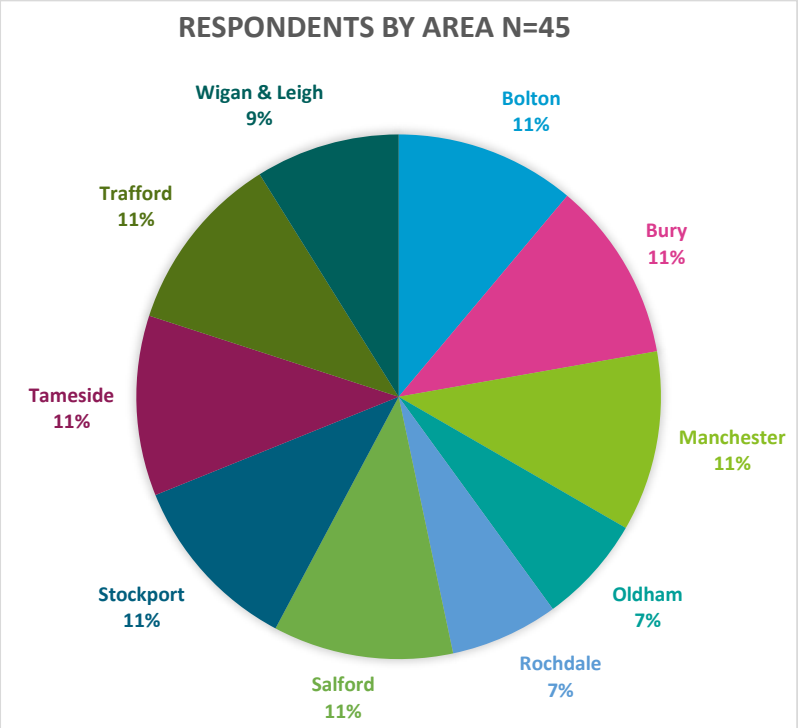
Sample Size

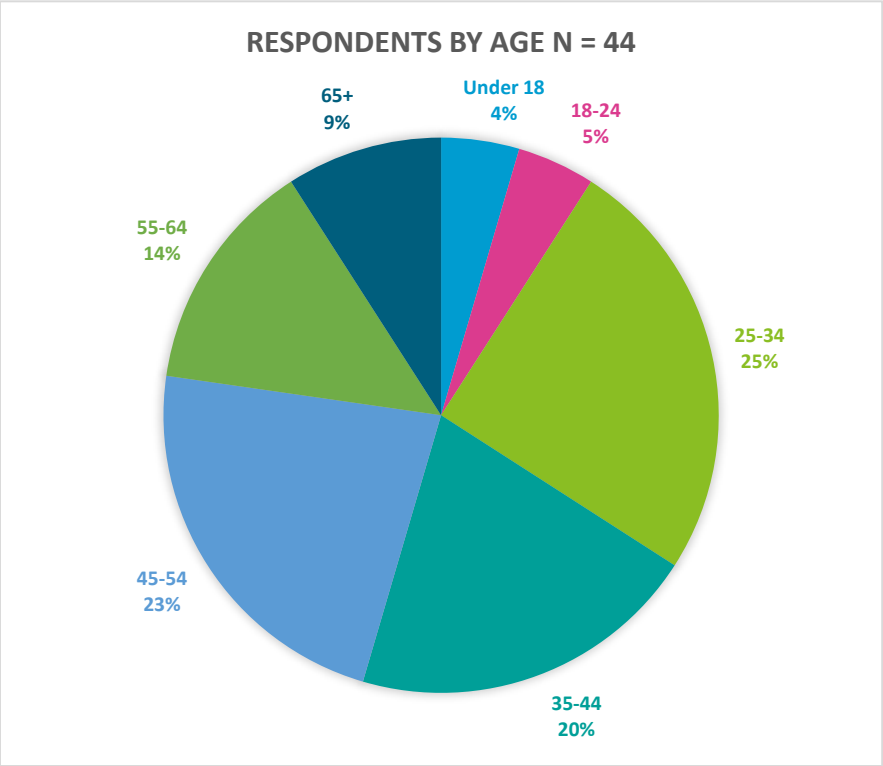
45 people responded to the long term conditions mental health survey. There were no focus groups on this topic.

Specific Conditions

We did not ask a specific question about what mental health conditions people were suffering with, however, the free write responses reported a broad range of mental health illnesses including, bi-polar disorder, OCD, anxiety, depression, personality disorder, schizo-affective disorder, PTSD, eating disorder, ADHD and dual diagnosis (mental health problem with associated drug or alcohol addiction).

General Demographics





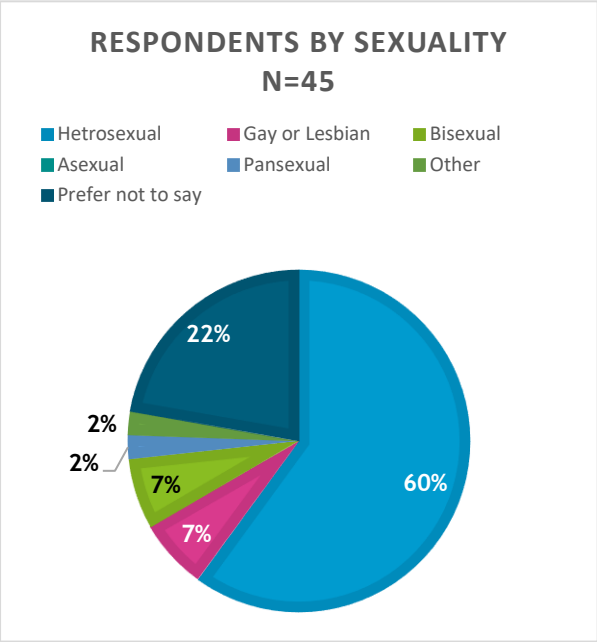
People responded from all 10 areas with a roughly even split between them (range of 7-11%).

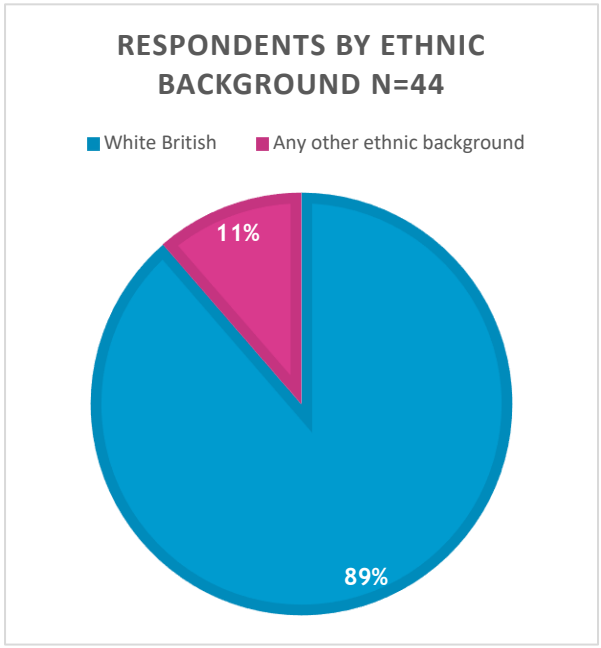
With regards to age demographics again all age groups were represented and there was a good spread.

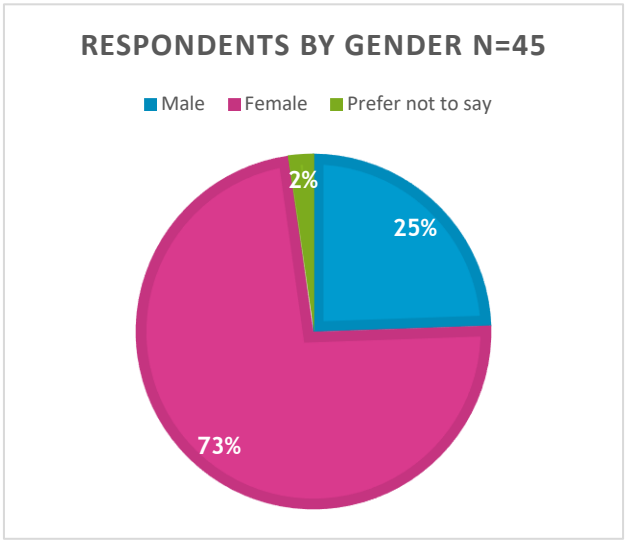
In terms of other demographic features 60% of the participant group were heterosexual, 16% identified as LGBTQ, 2% as other and 22% preferred not to say.

For Ethnic background the respondents where 89% white British and 11% from other ethnic backgrounds (Asian British and other white were specified).

In terms of gender the respondents were predominantly female (73%).







What we asked

We asked people to comment on waiting times, overall experience and suggested improvements at two separate points in their patient journey;

- From first presentation to diagnosis
- From diagnosis to commencement of support

We also asked people to tell us about the support they currently receive, support they would like to receive or would be interested to try (these questions were particularly interested in exploring people's thoughts on non-traditional support such as social prescribing and tech options).

Finally we asked those who had multiple conditions to what extent they felt that those other conditions were taken into account in their treatment or support.

What people told us

Overall Service satisfaction

In relation to their experience of getting a diagnosis

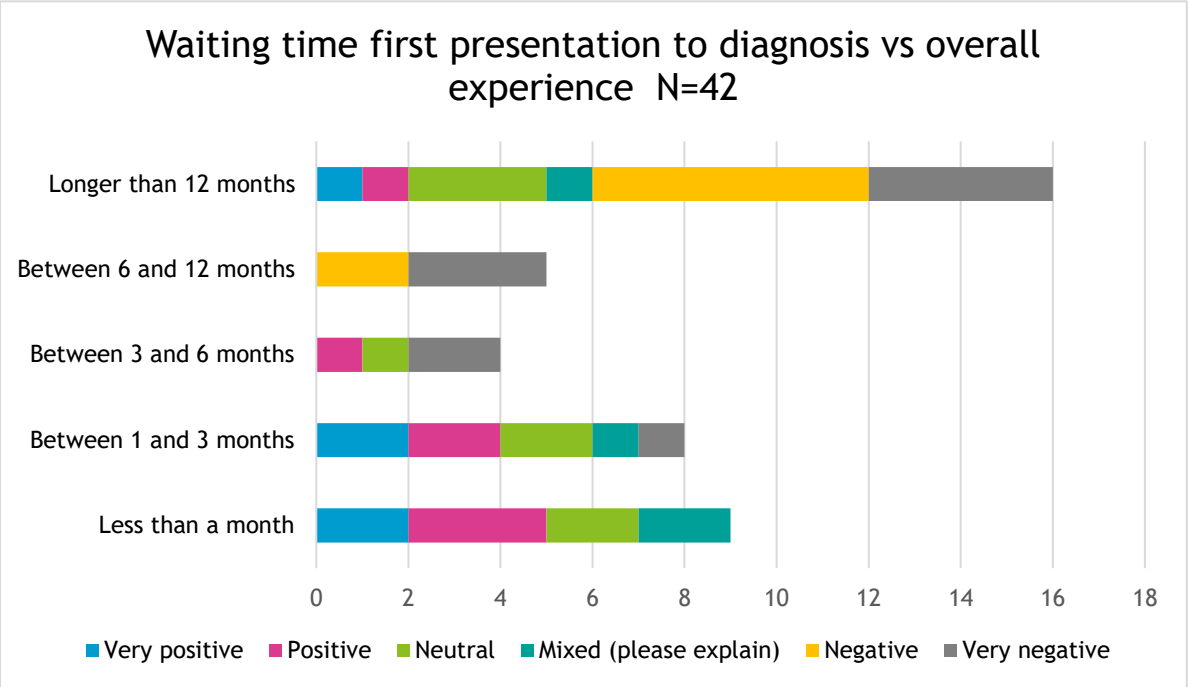
- The biggest group - 41% - described their overall experience as negative
- 29% described their experience as positive
- 29% described their experience as mixed or neutral

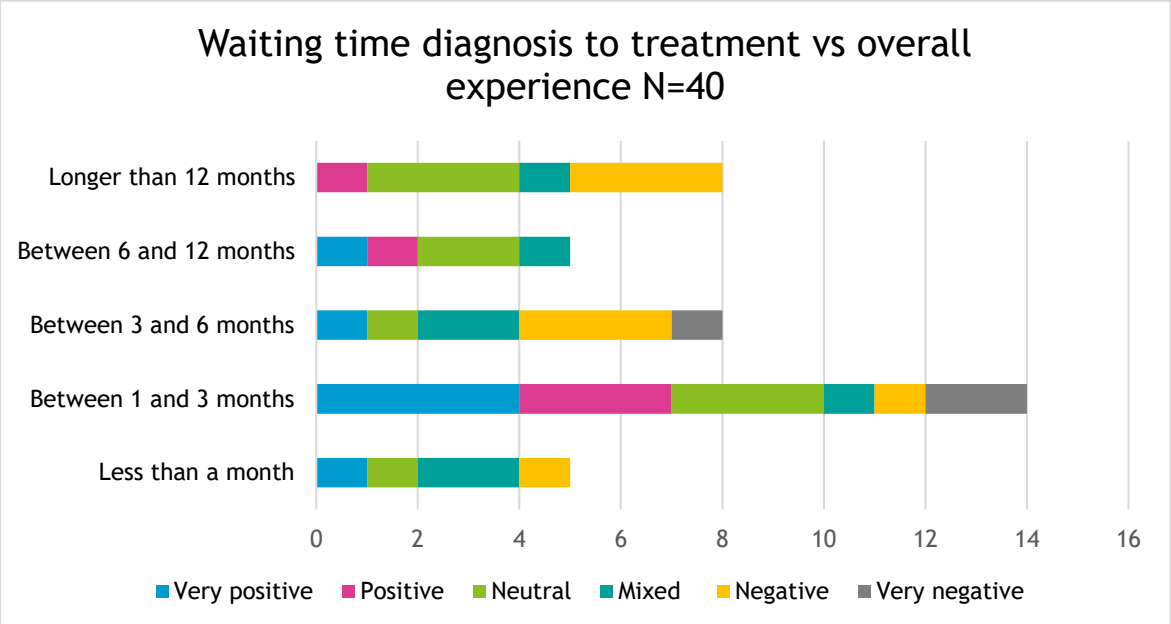
In relation to their experience of getting support:

- The biggest group - 39% - described their overall experience of getting support as mixed or neutral,
- 32% described their experience as positive
- 29% described their experience as negative

We compared waiting times with overall experience scores and found:

- In general it is a very mixed picture
- In relation to waiting time from first presentation to diagnosis there does appear to be a correlation between waiting time and negative experience - the longer the wait the higher the likelihood of the experience being negative
- In relation to waiting time between diagnosis and overall views of the treatment and support there is no strong correlation between waiting time and overall experience of support/treatment.





Waiting Times

We asked people how long it had taken from first presenting with a problem to getting a diagnosis and how long from getting that diagnosis to getting some treatment or support in place.

The results against both of these measures were extremely mixed showing a wide range of difference in waiting times both whilst trying to get a diagnosis and then whilst waiting for a treatment/support to be put in place.

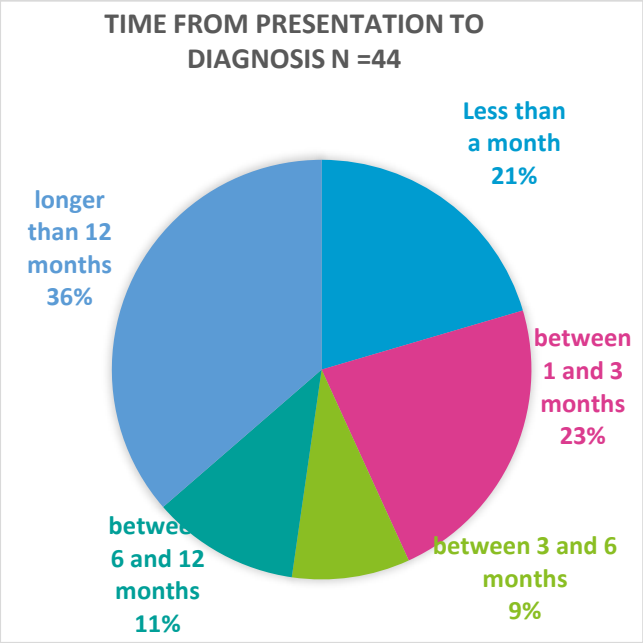
In terms of time from first presentation to diagnosis:

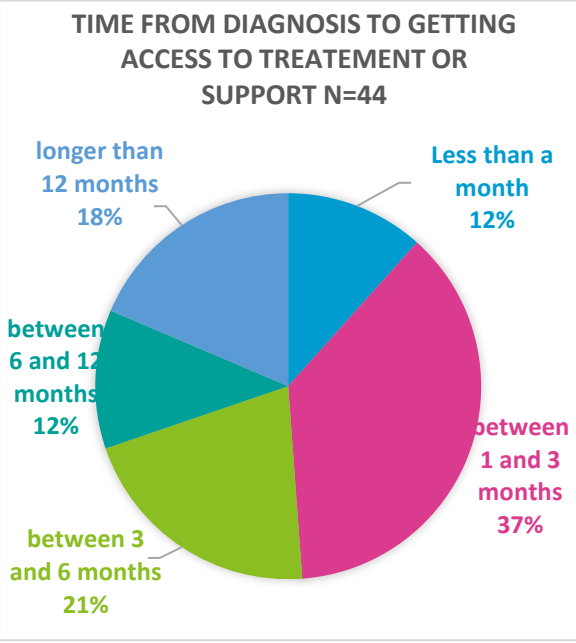
- Just over a fifth (21%) received a diagnosis within a month of first presentation
- Slightly less than half (44%) received a diagnosis within 3 months of first presentation
- More than a third of respondents (36%) waited longer than 12 months to receive a diagnosis.

In terms of time from diagnosis to receiving some form of treatment or support:

- Only 12% received treatment/support within a month of diagnosis
- Again slightly more than half (49%) received treatment/support within 3 months of diagnosis
- 18% waited over a year to receive treatment support from their time of diagnosis.

Overall this represents an enormous amount of waiting for people who are often very ill indeed.





Many of the comments about what could be improved focussed on waiting times. 53% (24/45) of respondents made negative comments about waiting and/or suggested improved waiting times as being an important factor in improving services.

The references ranged from frustration and dismay at how difficult it is to get seen in the first place through to references to waiting times to get an accurate diagnosis and waiting times for specific treatments (both generic and specialist). Many people described long battles for their problems to be recognised in the first place (multiple visits to GPs and A and E, having to change GP or resort to going for private consultations). Then, once their problem is recognised, they face 'assessments'. Here some people describe multiple assessments whilst others described a series of assessments and then 'kick backs' (don't meet the criteria for that specific service and kicked back to the GP), some described battles to both find and then get referred to specialist provision (for example eating disorder services).

A particular issue that was raised by many was that, having had an assessment (in several cases this was only on the telephone) and been referred for support/treatment they faced

long weeks of waiting during which time they had no contact at all with services. During this time many described feeling 'forgotten' and experiencing worsening mental health as a result of that. A number of comments spoke directly about the incredible difficulties people had faced whilst waiting for treatment and being in crisis. These points are picked up in the next section.

"Access to a professional person to help me with my diagnosis. I was given a telephone interview and received a diagnosis that required urgent action I am still waiting to meet with someone from the service I was told the waiting time was 10 week that has been and gone No one followed up to find out if I have deteriorated or self-harmed. I have telephoned and written to the service with no action taken . This is appalling."

"Clarity as to how long the wait was, why I was waiting. Some confirmation that I hadn't been forgotten."

"The time between referral to diagnosis and then treatment. Waiting lists are insanely long and all the while symptoms worsen and the feeling of rejection can be overwhelming for someone struggling with mental health issues."

"More information about services available. We had to wait 4 years from first signs of changes to any services and that was only because he tried to take his life. Even after that we had to wait months for a follow up assessment."

"Taken more seriously by GP - went back 4 or 5 times before referral to mental health."

"Changed GP recently and received anti OCD medication. After 31 visits to A&E eventually opened to Healthy Minds. Waiting for appointments."

"Three assessments to decide I need a couple of different assessments to access care that has months of waiting list is making my mental health deteriorate especially as I suddenly don't have any health professionals round me that know me...it's distressing having to form new relationships as it is but this is breaking me (this person had moved city and was previously in services elsewhere)."

"I had to fight with the NHS to find a service that was funded to address my complex needs. There needs to be easier access to specialist psychological therapies, and that access needs to be rapid."

Crisis support

Seven people (16%) of respondents spoke about actual suicide attempts, self-harm or suicidal thoughts that they or their loved ones had experienced during the period of waiting between assessment and referral.

All of these people felt that regular contact with services during the waiting period should have happened and might have helped them to manage the situation differently. People in

these situations feel that services have not effectively triaged their situations and feel abandoned to manage the crisis as best they can without any support. Some people reported attending at A and E (which is the standard advice in these situations) but not being helped there as they already had a referral.

"[Patient] was left waiting for help and no one intervened in the time waiting for an appointment, he was suicidal and no help was given, leaving people without intervention until an appointment was given is too long. Watching someone struggle with lengthy times is unacceptable and often too late."

"Just because you've been stable on meds for a long time and your current problem appears to be 'social' it doesn't mean you are miraculously going to sort yourself out in a crisis. People need to act on the cries for help much faster and in a much more holistic way - a month is a long time in the life of someone who wants to end it all..."

"[Patient] was referred by our GP to CAMHS. CAMHS took 6 months to reject our referral and directed us to Early Help Hub. I called EHH who told me they had no idea why we would be referred to them. Our GP stepped in and arranged for CAMHS to see us. The appointment came 11 months after our initial referral by which time my daughter's [condition] was at crisis level and she was attempting to jump in front of cars. We saw a CAMHS occupational therapist for 4 months with one psychiatrist assessment who confirmed [patient] (diagnosis) and we stayed on a waiting list for CBT the whole time. Symptoms got worse and the [condition] was out of control. The whole family was in crisis just about getting through each day. It was exhausting and debilitating. We decided to pay for private care because our daughter was suffering too much unnecessarily while she received no actual treatment for her [condition].'

People made a variety of suggestions about how contact might be maintained with people after assessment and whilst they are awaiting an initial appointment. The suggestions included regular phone calls, pre-booked GP visits and visiting people at home.

The issue is covered in more detail with further ideas from patients in the section 'Opportunities for non-traditional prescribing'.

"Telephone call -home visit- email -letter any kind of personal contact or the offer of an alternative provider to take over my case."

"Someone could of stayed in contact with us."

"having someone to speak to without being told to wait until the appointment is a must. A& E will not intervene if an appointment has been made therefore there is no intervention prior to the appointment. [patient] became desperate and suicide risk was high in his mind."

"Need to pre-book regular appointments with GP when waiting for therapy/treatment. People with mental health conditions don't always want to see a GP but if an appointment is pre-booked then they are more likely to."

"Someone could of stayed in contact with us."

Lifelong conditions need lifelong support

People with lifelong mental health conditions felt strongly that they needed to maintain contact with services even when well. In general this group felt that services did not respond well to the reality of their fluctuating conditions.

People talked about being 'in and out' of support, obtaining help in a crisis, being 'dropped' when considered they were deemed to have 'recovered' only to repeat the cycle when the next crisis came along.

People described this approach as 'counter-productive' and described a number of consequences as follows;

- Going through the same processes multiple times
- Being offered the same basic treatments multiple times
- Needing more expensive/intensive treatments as a result of lack of early intervention

People felt that regular monitoring would help them and their loved ones to manage their health better, achieve early intervention when their mental health deteriorates, lead to more timely and appropriate interventions and prevent crisis.

"Earlier intervention before a crisis hits, ongoing support to maintain a level of stable mental health."

"Been in and out of support services for years. I self-harm and can sometimes manage them thoughts and sometimes need more specialist support from GP or counsellor. There needs to be easier access to early intervention treatments/support as you can end up in full crisis before you can get seen which is counterproductive and requires longer intervention."

"Support was offered sporadically 5 years ago, though was retracted as [patient] was not seen as a priority so we just had to do our best for him. As his health deteriorated we didn't know where to go or who to ask for help. Once he made suicide attempts we felt 'jumped' on by services and each had their own demands and agenda but didn't speak to each other...all deteriorated until he was sectioned and the service providers reminded us often, how much he was 'costing' the authority!!! It cost us a lot more than the money spent on him and the effects of such poorly co-ordinated and informed services have had a long reaching impact on the whole of our family."

"Offer more than the basic treatment as after decades with a condition, you have almost always had the basic care numerous times."

"Regular GP check-ups. Leaving someone with bad mental health for the family to try and manage on their own with no support or advice damages their mental health too."

"Regular checks from the MH team to check how MH symptoms are - if they are stable or worsening etc. Also advice on what to do if it is getting worse."

"When you get to the right people it can be good - getting to the right people (even when you know what you need) is a nightmare and takes far, far too long, especially in moments of crisis which sadly come along several times in the lives of people with serious and enduring mental health conditions."

Three people spoke specifically about the difficulties of transitioning between different service models both from children's to adults services and when relocating geographically.

"The transition from child to adult services was abysmal. My mental health deteriorated. Regular monitoring is vital for severe and fluctuating mental health conditions. Usually when you've recovered for a while you're dropped."

"Liaison with my old CMHT team in another city. Making sure there wasn't a massive gap and having to start the whole process again...The number of assessments I've had is ridiculous and each one has a nuclear fallout attached to it in my brain. I thought my social worker would be a good kind base but actually haven't seen them despite booking an appointment...tired of having had to start all over again, missing my old psychiatrist, no regular GP, just feel so unsupported and alone without any base."

Listen and communicate

People described the value of listening to patients and in particular felt that time taken to do social and family histories and to engage with families and loved ones helped in achieving more accurate diagnoses and thus more relevant support.

"Listen to family's concerns and theories, especially when considering family's medical history."

"Until I was properly diagnosed with Bipolar II 7 years down the line by a consultant taking the time to do a social history, I could not be offered the proper treatment."

"Time, history taken, a health care professional who listened."

"First time I tried, I wasn't listened to. The second time I was, but I was a bigger mess because I hadn't received help the first time."

Elsewhere (and in common with users of many NHS services) people sited frustrations with the basic business communications processes of mental health services.

"I was given a letter of appointment that arrived after the appointment had taken place so I missed the appointment and was discharged back to GP - this made me extremely disheartened. Communication needs to be better."

"The services seem to be outdated in their communication."

"Staff to recall information given to them...in my case the first person that called me did not record my impairment - the 2nd person that called to carry out an assessment over the telephone was unaware of my impairment (person with communication access needs)."

The naming of things

A number of respondents commented on the 'confusing naming and distribution of services' in general but specifically felt that services across the conurbation of Greater Manchester should have the same names, referral pathways and parameters.

"Great CBT and now undergoing great CAT. Long waits and as mentioned before, confusing naming and distribution of services."

"Clearer system. One service for whole city. Clearer naming and sign posting."

"People with lifelong conditions have experiences from many different health systems at many different times it would really help if everyone's access and treatment pathways looked the same, were called the same thing and did the same thing. Have been told lots of times over the years that this is not how it works here. For example you can't self-refer to crisis services in Bury but you can in Bolton, what's that all about?"

Parity

A couple of people specifically mentioned parity of esteem between physical and mental health conditions. Neither felt this existed. A number of the other comments in this report including those around waiting times and ongoing monitoring and support for people with long-term conditions suggest that others still feel that mental health illnesses are not yet viewed nor treated equally with physical illnesses.

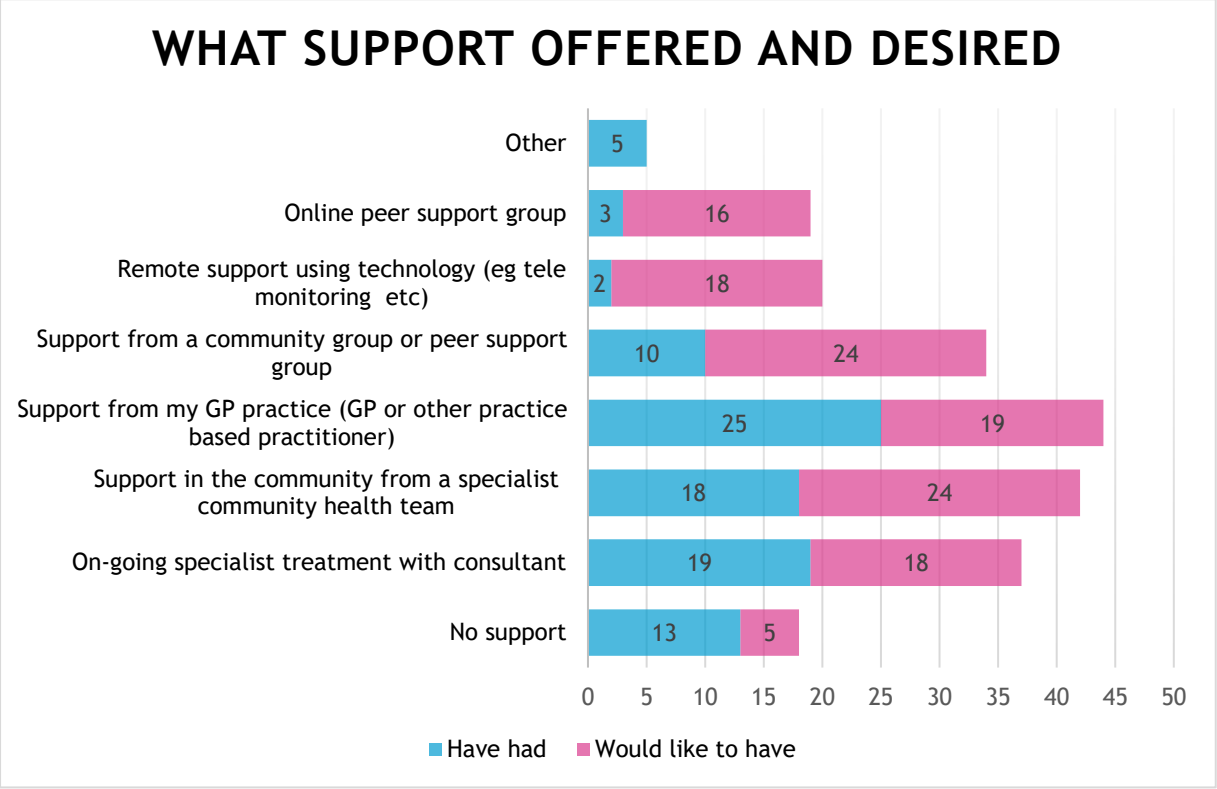
"You would not expect to wait 12 months for a respiratory consultant if you had pneumonia or a cardiologist if you had a heart attack so why when in crisis is there a 12 month wait for a psychologist?"

"Never suffer from depression as the NHS do not want to know. Services are sparse and not very effective."

Services offered vs services desired: Opportunities for non-traditional prescribing

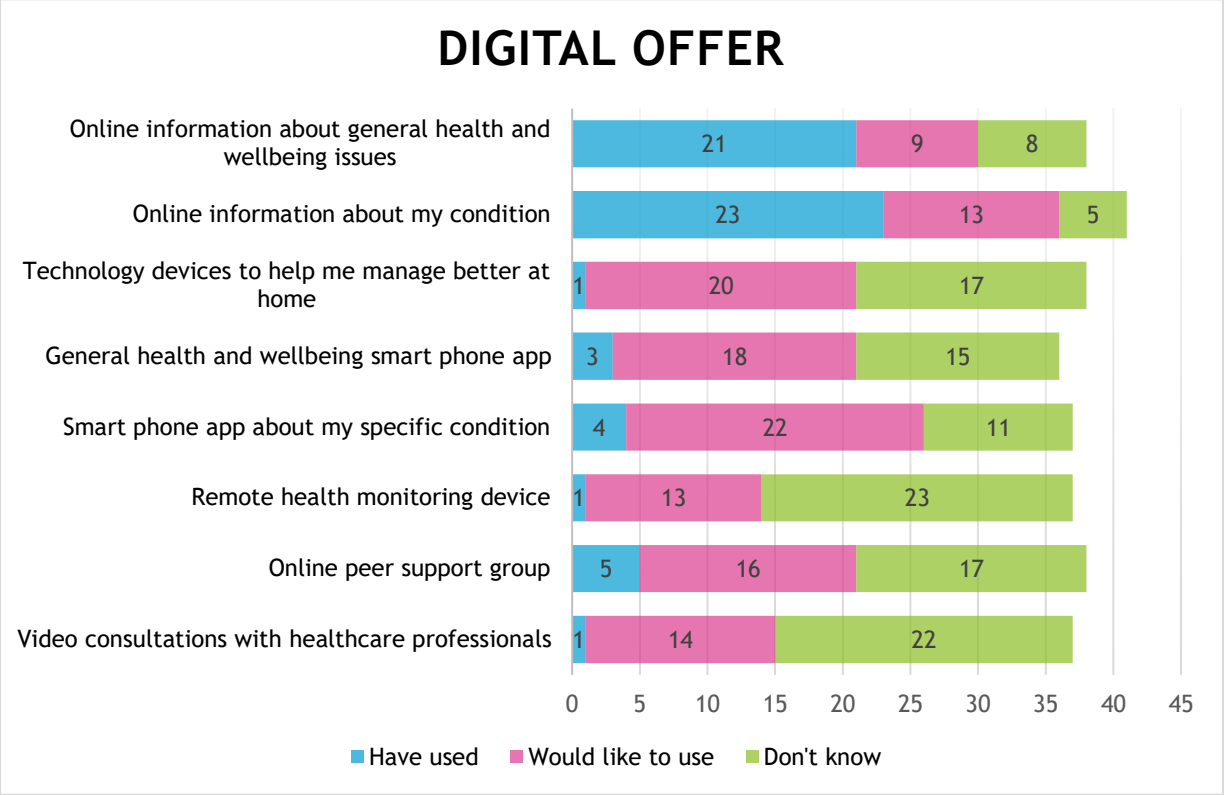
The graph below shows that most people had been offered some support, with some offered support from more than one place. However 13 people (29%) stated that they had been offered no support. Of those that had been offered support in the vast majority of cases this was coming from the traditional medical structures (GPs, specialist treatment team, community mental health teams).

In most cases people stated that they would like more support from all quarters. Additional support from CMHT support and community group/peer support came out tops (more than half of the participants said they would like this) followed by support form GP practice (19 people), followed by remote support using technology and ongoing specialist treatment with consultant (18 each) and online peer support (16). A small number (5) said they didn't want any support.



Further examination of where people are at with digital and tech support options shows quite high levels of engagement in those areas where support is easy to access (online information about conditions).

In other areas where tech/digital solutions might be available (Tech devices, video consultations, Apps and online peer support) there appears to be little experience (not many people have used them) but a strong appetite (lots of people would like to use them) for all the potential tech/digital options.



These results show that since fewer people had been offered non-traditional support (from peers, community and tech solutions) than from traditional medical structures there may be 'quick win' type opportunities available to services in offering a wider variety of support options to this group of patients.

Digital options (in particular video consultations and apps) might be a useful resource in ensuring people get some support whilst waiting for clinical appointments and apps, tech devices, video consultations and peer support might provide useful ways of maintaining low-level contact with people with lifelong, fluctuating conditions.

Conclusions

"Longer support, more involvement & better quality therapy"

Prevention / Early Intervention

The most commonly mentioned issue in terms of prevention / early intervention was waiting times to access services. In particular people talked about the lack of support or even basic contact between assessment and referral. For most people this was a period of many weeks. People described feeling forgotten and abandoned by services during this period and some described in harrowing detail the effect that this gap had had on their and their loved one's mental health.

As with cancer services – mental health patients should stay registered with specialist providers until their diagnosis is clarified and some support is in place. Direct referrals between different parts of the mental health system would eradicate the kick backs, free up GP time, increase the chances of getting an accurate diagnosis and - most importantly - give patients a sense of hope (as oppose to the feelings of abandonment that people describe).

People with lifelong conditions described a situation of repeated referral, worsening crisis (due to waiting times described above) and then discharge when they were deemed to have recovered. Most felt this approach missed opportunities for early intervention.

People with lifelong conditions need lifelong support both to help them (and their loved one's) manage the fluctuations in their condition, to achieve effective early intervention when crisis looms and to help them to manage transitions in their lives such as when they move house.

Personalisation

The weight of the comments around personalisation suggest that some people feel that their problems have not always been treated holistically. A number of people report inappropriate initial diagnosis later rectified when full life story histories have been taken, for example.

As stated above the lack of any contact between service users and services between assessment and referral reported by many does not describe a personalised approach. A number of people also report difficulties with general communications (both routine communications and for those with specific access requirements) and a number commented that they had not felt listened to by services or professionals.

Technology and Social Prescribing

This report seems to show that people with mental health conditions are not routinely offered support options that involve technology or social prescribing. The report also seems to suggest an appetite from mental health patients engage with these forms of support.

Since:

- There are both long waits and clear support gaps for people with mental health problems between assessment and referral
- Most people in this survey wanted more support
- A variety of tech and social prescribing options for people with mental health problems are already available or being piloted in the City

It would seem useful to consider some pilot activity to employ some of these new options in these contexts.

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 - Response from Greater Manchester 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.

Greater Manchester Health and Social Care Partnership

RESPONSE TO HEALTHWATCH IN GREATER MANCHESTER NHS LTP PUBLIC ENGAGEMENT FEEDBACK

2019

GMCA GREATER MANCHESTER COMBINED AUTHORITY

NHS in Greater Manchester

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 wholescale 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 be 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 inconsistences 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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In Greater Manchester

what would you do?

It's your NHS. Have your say.

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