

NHS Long Term Plan

Patients Views of Autism Services

Healthwatch in Greater Manchester

**what
would you do?**

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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 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](#)' ([this report](#))
 - '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'

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 :

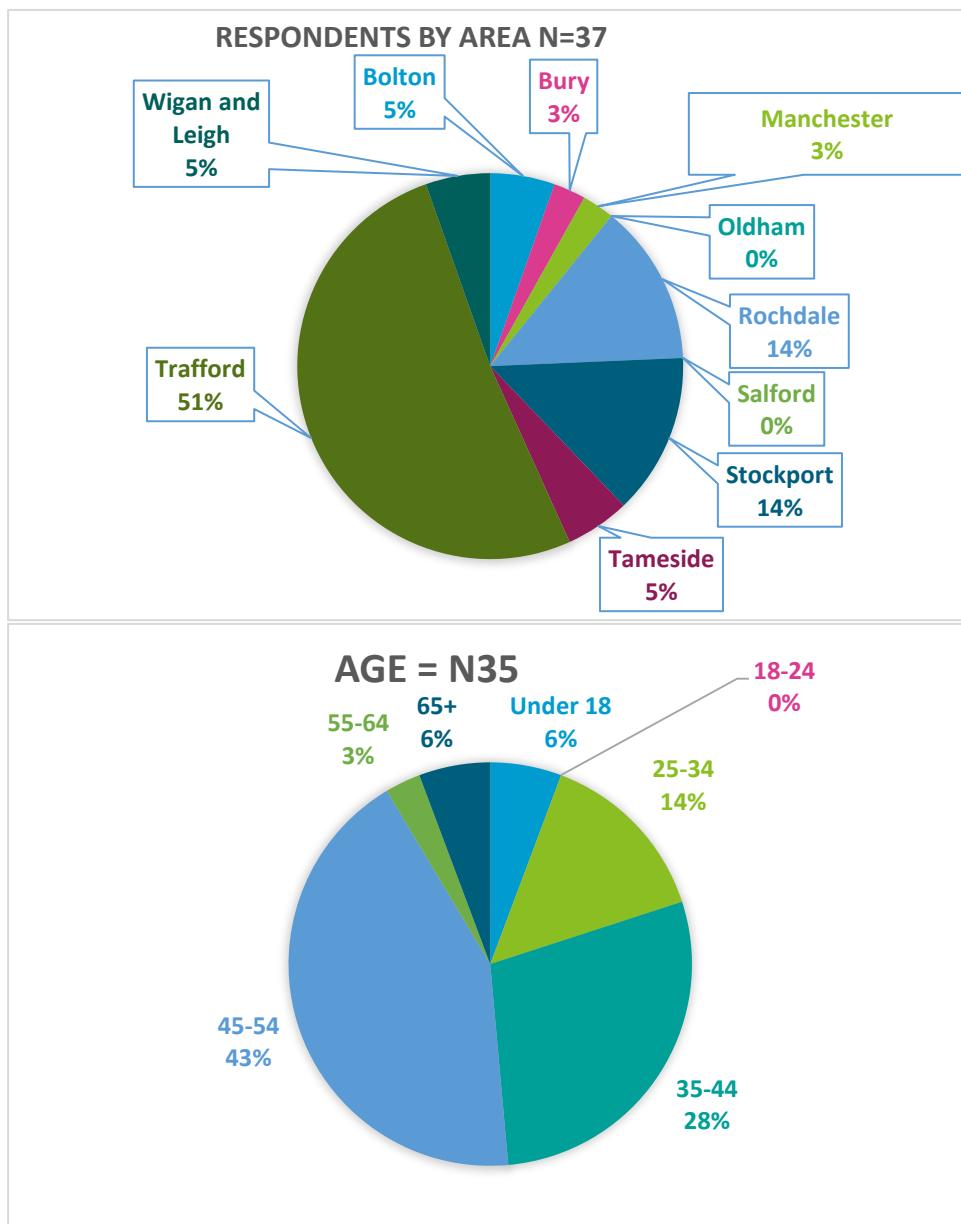
Area	Topic	Participants	Location	Date
Trafford	Autism	8	Fuse Centre, Partington	2019-04-28
Oldham	Cancer	6	Saddleworth community room at reclamation cafe	2019-03-29
Trafford	Cancer	7	Macmillan Centre, Trafford General Hospital	2019-03-22
Tameside	Cardio and Respiratory	10	Volunteer Centre, Penny Meadow	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

29 people responded to the long term conditions autism survey. A further 8 people participated in one focus group held in Trafford.

General Demographics



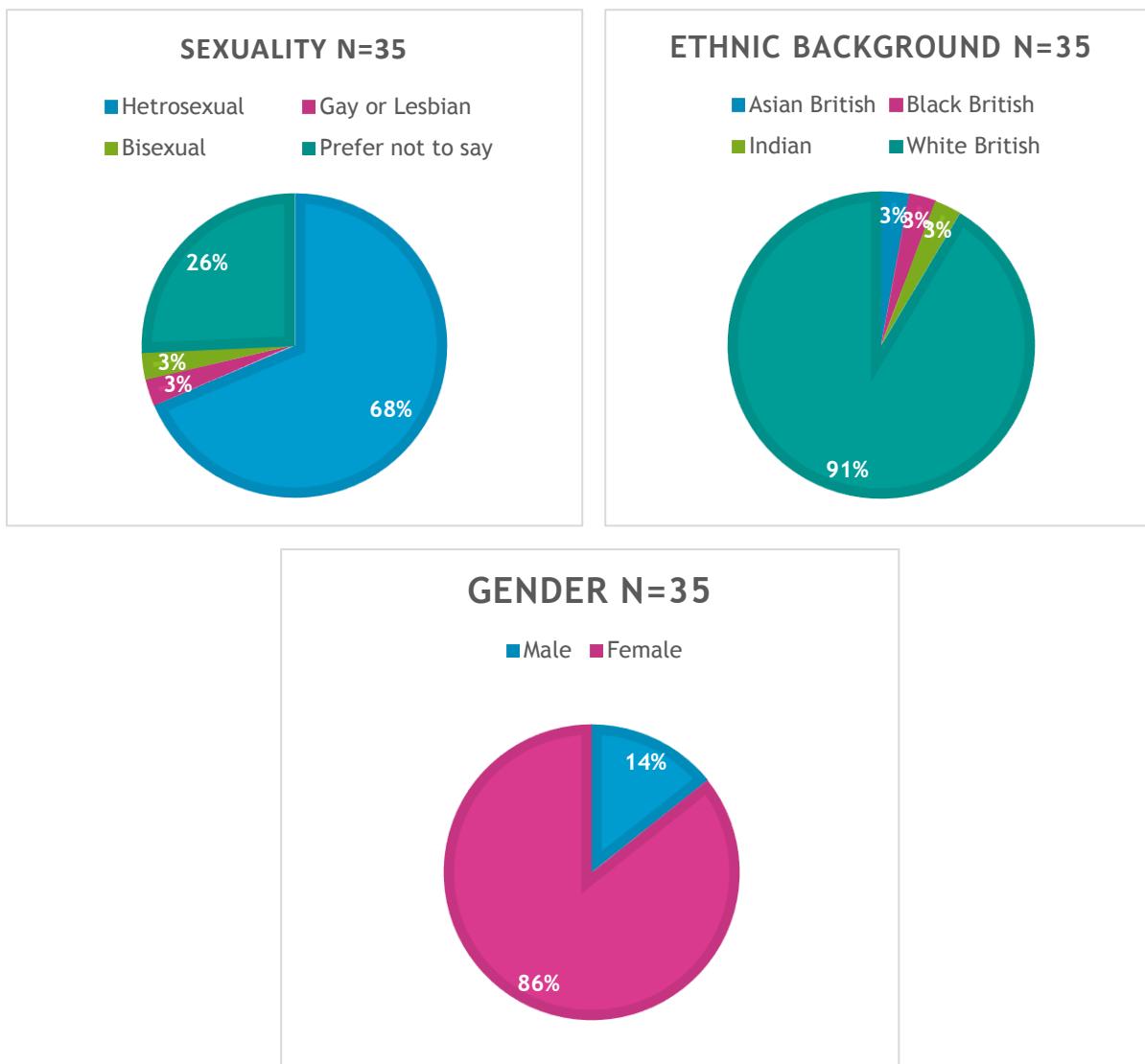
People responded from all 8 of the 10 areas of greater Manchester. Trafford was the most well represented with 51%, 11 (38% of all) survey respondents and 8 (13% of all) attending the focus group. Stockport and Rochdale had 5 survey respondents each (8%). Bolton, Bury, Manchester, Tameside and Wigan and Leigh had either 1 or 32 respondents each. There were no responses to this particular survey from either Salford or Oldham.

With regards to age demographics all age groups apart from the 25-34 year olds were represented. The largest groups were 45-54 year olds 15 people (43%) and 35-44 year olds 10 people (28%). Though there were some individuals who spoke about their own personal experience as people with autism, the majority of respondents were parents of people with autism talking about their experiences of getting support for their children, this is reflected in the age demographics.

In terms of other demographic features 86% of the participant group were heterosexual, 6% identified as LGBTQ and 26% preferred not to say.

For ethnic background the respondents were 91% white British and 9% from other ethnic backgrounds (Asian British, Black British and Indian and were specified).

In terms of gender the respondents were predominantly female (86%).



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.

The same questions were asked in the survey and at the focus groups however the focus group participants were not asked to give a rating against any of the questions so the quantitative results given here are from the survey participants only (29 participants).

What people told us

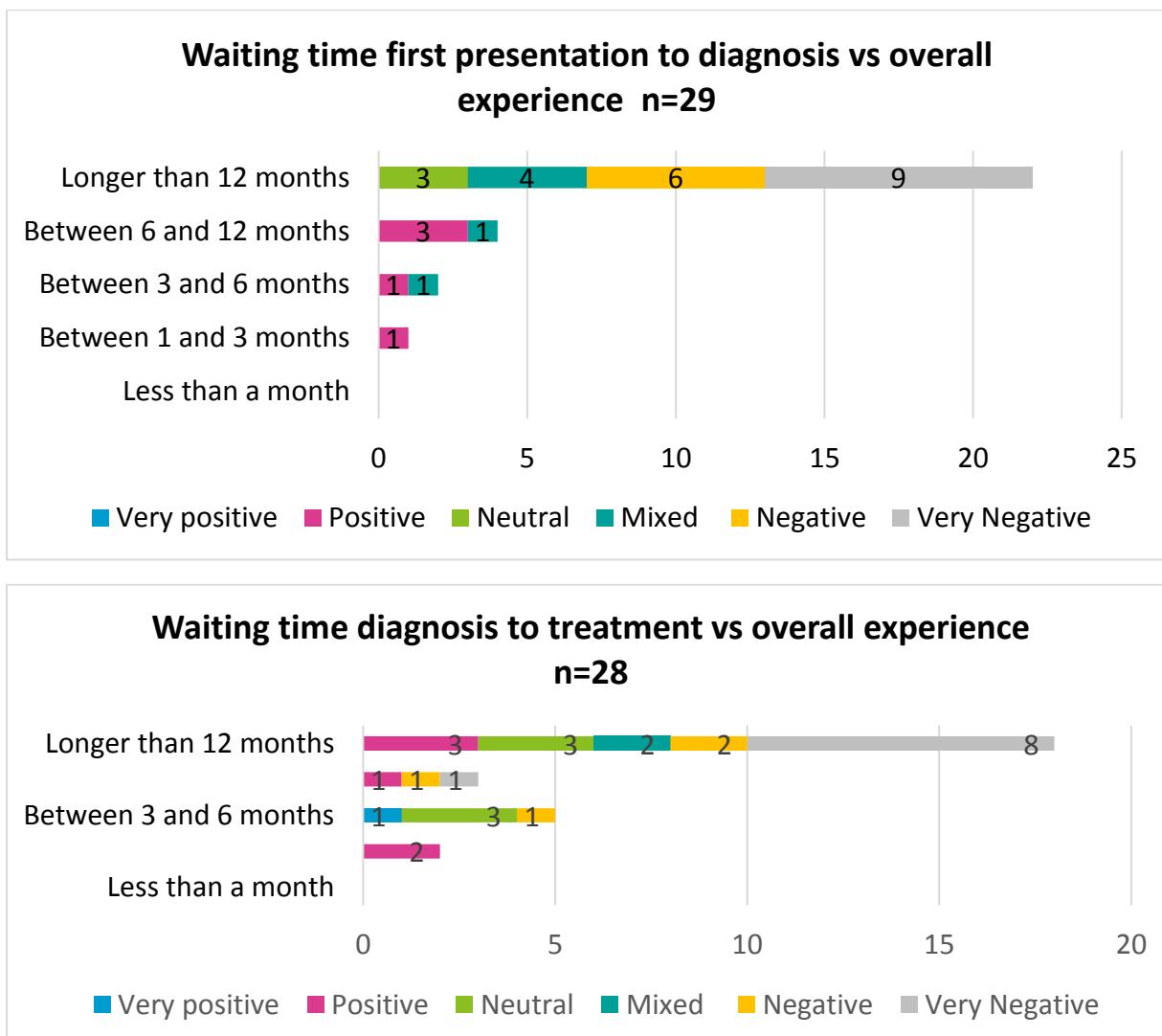
In relation to their experience of getting a diagnosis:

- The biggest group 52% (15)- described their overall experience as negative
- 31 % (9) described their experience as mixed or neutral
- Only 17 % (5) described their experience as positive

In relation to their experience of getting support;

- Again, the biggest group - 46 % (13) - described their overall experience of getting support as negative
- 29 % (8) described their experience as mixed or neutral
- Only 14 % (7) described their as experience as positive

We compared waiting times with overall experience scores and found that there is a strong correlation between waiting times and negative experience in this group.



Waiting times

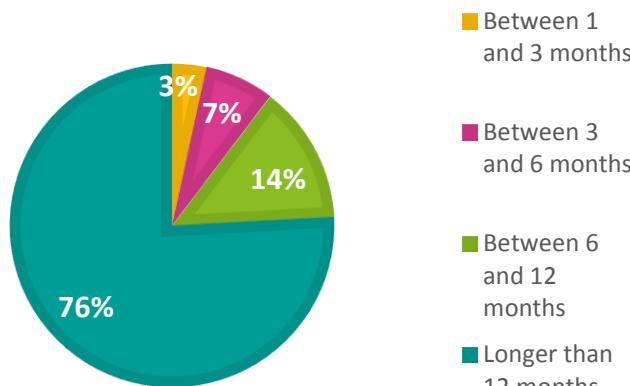
We asked people how long it had taken from first presenting with a problem to getting a diagnosis and how long from getting that diagnosis to getting some treatment or support in place.

The results against both of these measures showed **very long waiting times** for the majority of people both whilst **trying to get a diagnosis** and then whilst **waiting for support to be offered** or put in place.

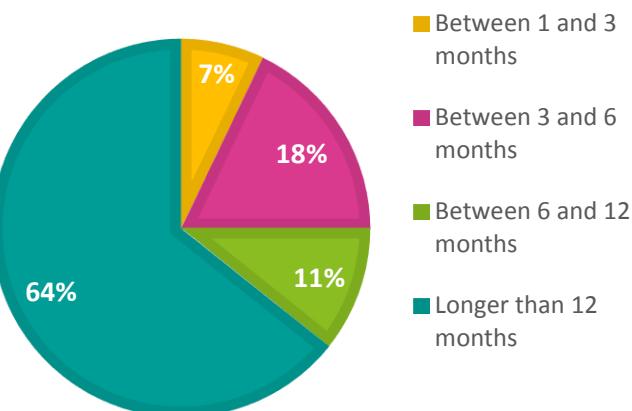
In terms of time from first presentation to diagnosis, it took over a year months to receive a diagnosis for more than three quarters of respondents (76%).

In terms of time from diagnosis to receiving some form of support 64% waited over a year from their time of diagnosis to receive support.

TIME FROM PRESENTATION TO DIAGNOSIS N =29



TIME FROM DIAGNOSIS TO SUPPORT N=28



Late intervention, accessing diagnosis

Comments from the surveys and focus group give a clearer picture of how the ‘pathway’ for care is compromised at the beginning by what some describe as an exclusive and disorderly assessment process. This inability to access early support accounts for the high number of people who state that they have waited over a year (and in some cases many years) to achieve a diagnosis.

“Never got support as was denied access to assessment.”

“Having the opportunity to access diagnostic interviews. I was told the waiting list was closed!”

“The waiting time for diagnosis is unacceptable my son was finally diagnosed at the age of 12, after years of battling for support.”

“Younger son now 14, noticed autism traits at 3 years old but had to battle another 5 years before a diagnoses was received.”

“The whole process is too slow and takes too long. CAMHS needs to offer a much quicker turnaround for diagnosis as my children suffered and were nearly excluded from school whilst we waited for over 12 months for an assessment to happen.”

“No communication, long waiting times, no support, no help, completely demoralising. It actually caused me physical stress, depression, time off work leading to me losing my job. Not positive at all.”

“Constantly battling with the authorities, ends up in a tribunal every year for the last 4 years, probably again this year.”

Several of the respondents described the process of obtaining a diagnosis and/or support as ‘battling’. Some also describe the personal consequences of the absence of early intervention in stark terms, school exclusions, mental health problems, losing their job.

Clearly these effects have a cost to the state in terms of creating problems elsewhere (other health services, schools budgets further down the line, benefits and the costs of defending tribunals to mention but a few). People also talked about direct financial implications for families many of whom resorted to paying privately for assessments and equipment in an effort to either kick start or speed up the process.

“Many parents are paying privately to get various assessments done quickly, sometimes paying out thousands of pounds.”

“We bought some of the equipment my grandson needed our self as it was over 12 months before he received it.”

The experience of a number of participants suggests that, as one respondent put it, '*assertiveness and persistence will pay off*'. One participant gave an example of how by sheer doggedness, and with a bit of common sense behaviour from the service, she had managed, after a wait of over a year, to get her child through an assessment process in just three days proving, it seems, that there is indeed potential to speed up the assessment process considerably.

"Given a 15 month wait for diagnoses, rang every month to check where her child was on the waiting list, after 12 months rang every week to ask, eventually managed to get the meeting that unified three meetings in 3 days. Following 15-24 month wait from referral letter to diagnoses, the mother's persistence paid off: firstly, given date for diagnoses, submitted a detailed report that she had scanned through, agreed to a telephone communication re the diagnoses rather than pushing for a face-to-face, this was suggested to her by the person coordinating the meeting who stated that by doing she would get the face-to-face meeting without further delay. Within three days everything was done."

Information and guidance

A common theme of the responses to what could be improved was information and guidance. People described a dearth of relevant, up to date information about the condition and the support available.

"No parent knew where to get information. Information was via friends, magazines, research, support group and google."

"Where information was given out, it was not in a manner that explained what groups and services did, so it was hard for parents to assess whether it would be useful for them or not."

"More detailed correct information. Was given the diagnosis and discharge at the same meeting. All leaflets were out of date and most services were no longer available due to funding cuts."

"The Greater Manchester Autism Consortium website is very out of date with facts such as contact details, it is inconsistent and also very outdated language about Autism. Having chased this up previously, I discovered that the website is managed by the National Autistic Society who are totally reliant on each local authority to update them with current information and any changes. They are aware the website is inconsistent across each local authority and are attempting to bring all this into line, but needs each local authority to cooperate, which apparently doesn't appear to be a priority."

People wanted a clearer understanding of what a diagnosis means and what particular issues, strategies or support might be helpful for them.

“What does ADOS score even mean - ‘what does my child need’ would be more helpful.”

“Diagnoses explanation - what it means and seek that help.”

“No information, no help from any professional and parents are very much on their

Professional Awareness

Lots of respondents called for improved levels of awareness of autism particularly among linchpin professionals (CAMHS staff and GP's) who have the power to make referrals and who are charged with providing support.

“More professionals aware of the different presentations of ASD”.

“I was offered counselling and then CBT. Both of which was very traumatic as the staff had no understanding of Autism and did not make reasonable adjustments. According to the NICE guidelines, CBT should only be offered with staff properly trained in Autism.”

“The first GP I saw and disclosed too could have been more empathic instead of saying I didn't look autistic.”

“Ensuring that specialists are 'autism aware' and know how to appropriately interact and liaise with those diagnosed with autism as opposed to causing their ongoing anxieties to rise due to conversations being had that were not appropriate to that persons level of understanding.”

“As the GP's is the where people go first, the GPs should know or have the information about all the places to go to for advice.”

Suggestions for improvements

The participants in this research had a lot of practical ideas for improving the system, gave some examples of good practice/helpful interventions and showed a high level of motivation to do something to help to fix what they generally see as a broken system. Some of the ideas are presented below.

“What support???????? Is this a serious question? I have had to set up my own support group due to no support.”

“One mother wrote a book ‘what is autism’ to start a conversation, because there is nothing out there suitable.”

Listen

Many people felt that they had not been listened to at some point during the process of trying to get a diagnosis. Parents in particular felt that they had been railroaded by professionals who did not know their children and possibly (considering the points made above about professional awareness) did not have a detailed understanding of autism.

“It would help if people listened to what you the parent was saying instead of thinking they know best.”

“No one gets to know the child if they won’t comply that day you are just sent home.”

“A paediatrician who actually listened.”

“Actually listen to parents we know our kids best.”

“Told so many times ‘we see no signs of autism’ in my son. They were so wrong. We knew we were right. This meant our son went without appropriate support for many years leading to MH issues that could have been avoided.”

Make the contacts count

Many people felt that there had been numerous opportunities for services to take a more proactive view of the situation. Many of these missed opportunities came in the pre-diagnostic stages during the long ‘battles’ of parents to get their children assessed can be perceived as a series of missed opportunities for early intervention. But the assessment process in some areas also seemed to be missing opportunities (by not referring to SALT or OT’s for example).

In addition people described numerous examples of what might be considered ‘unnecessary transactions’ between departments, professionals, authorities etc all of which seemed to serve the purpose of delaying progress towards diagnosis or support.

“A family might be referred to a paediatrician or possibly CAMHS for diagnosis, they may have a long wait for an ADOS test, they probably won’t get to see an OT unless they have done their homework and ask to be referred. Also referral to speech & language doesn’t appear to be an automatic thing either.”

“We have had ZERO support since my son was 18 months old. He’s now 14.”

“More ready availability of services to move things along quicker.”

“Stop passing you from one department to the other never seeing the same person more than once.”

“Educational Health Care Plan took five drafts, shambles! Just fobbed off by professionals.”

“I feel like we are just shoved from pillar to post all the time and no one want to actually help but are quite willing to fill in a form for a referral to a different department.”

Joined up, multi-agency assessments

Several respondents spoke favourably of Manchester’s multi-professional meeting approach to diagnosis. This kind of approach speeded up progress from diagnosis to support, eliminated some of the missed opportunities and pointless transactions described above and was seen as the way forward for improving the assessment process.

“System for diagnosing autism needs to be more like Manchester’s where families see all professionals in one visit and get the diagnosis within weeks.”

“The approach that Professor Green at Manchester clinic, where a child is seen by him and 3 other consultants i.e. all professionals involved in the child’s assessment are around the table at the same time in the same meeting. This is the way forward.”

Help people to keep track

There were some practical suggestions for how to help individuals and services manage the multiple contacts and documents required in order to obtain support for autism. One person suggested an online tracking tool that would help people keep their documents and appointments in one place as well as helping them to chart their progress and another suggested a register of children with a diagnosis that would help professionals to make good referrals, organise appropriate support and keep in touch with people affected by autism.

“Online tracking of progress so you can visibly chart progress without having to constantly chase for updates. The process needs to be clearer and more user friendly because you are bombarded with information and you are already stressed enough with dealing with your child's needs.”

“Keep a register of children with a diagnosis and maintain it to make it easier to access services!”

Support people to live with the condition

Many people discussed the problems they faced in managing their condition/helping their child to manage their condition. People wanted more information about the condition, support and advice on sensible strategies to take in managing it and contact with other people who understood their situation and could provide further insight.

There were numerous examples given of valued support including summer schools and post diagnostic workshops and courses though many felt these were not accessible (day time only) or were no longer available.

“Parents not being helped in any way to ease their child’s anxiety.” “floating support service.”

“Support of what to do to help him.....Information or suggested reading list.”

“Post diagnosis workshops are really useful but there is no funding for them anymore.”

“Summer schools - quoted that the group session that were provided by the Pictor school after diagnoses were brilliant. More of this.”

“Post diagnosis workshops were useful. However, you were offered 6 weeks, one day a week. The workshop time were not flexible offering Monday to Friday office hours only. Not conducive for working parents.”

“This support group has been more helpful than any interaction with professionals.”

Address specific gaps

People noted a number of specific gaps in their areas or more generally these included low availability of speech and language therapists, lack of sensory assessments lack of support for social skills, absence of support between referral or diagnosis (many people cited anxiety as a specific problem emerging in this period) and a general lack of support for adults.

“More availability of speech therapy and work on social skills.”

“Not really any support for adults.”

“Parents are paying privately for sensory assessments as the NHS doesn’t cover this assessment, which is challenging as a majority of children with Autism have sensory requirements.”

“Between referral and diagnoses anxiety is a major concern. CAMHS useless. A need for group, open sessions Before diagnoses a child needs to be around other children - group session so important, willing to pay £10 a time for group sessions, maybe voluntary contribution for people who cannot afford the whole amount.”

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

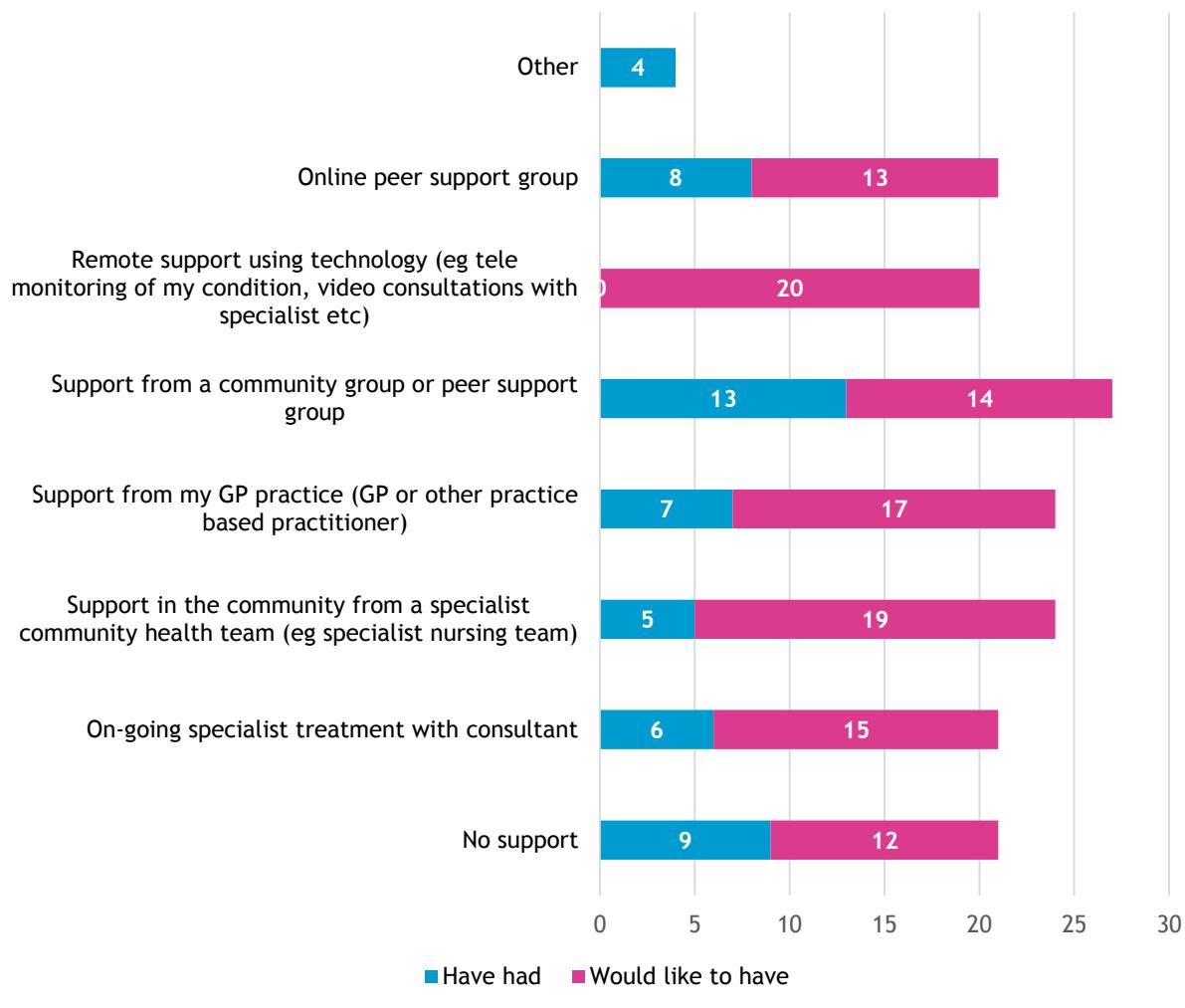
The graph below shows that most people had been offered some support, with some offered support from one than one place. However 9 people (31%) of respondents had been offered no support.

Of those that had been offered support most of this was coming from **peer support** provided outside of the medical structures. 49 % (13 people) had had support from a **community or peer support group** and a further 28% (8 people) from an **online peer support group**. Furthermore if we add ‘support offered’ and ‘support desired’ together community peer support came out as top choice with 93% of people saying they either are accessing or would like to be able to access this support. For online peer support 72% stated the either are or would like to be able to access this.

In terms of support from traditional medical structures (GPs, consultants, specialist community health teams) a lot more people would like to have some of this than are currently being offered it.

- Only a quarter (24%, 7 people) were getting help from the GP compared to 83% (24 people) who would like this.
- Only 17% (5 people) were getting help from a specialist community health team compared to 83% who said they would like this.
- Only 20% (6 people) were getting any ongoing specialist health treatment as compared to 72% (21 people) who said they would like this.

WHAT SUPPORT OFFERED AND DESIRED

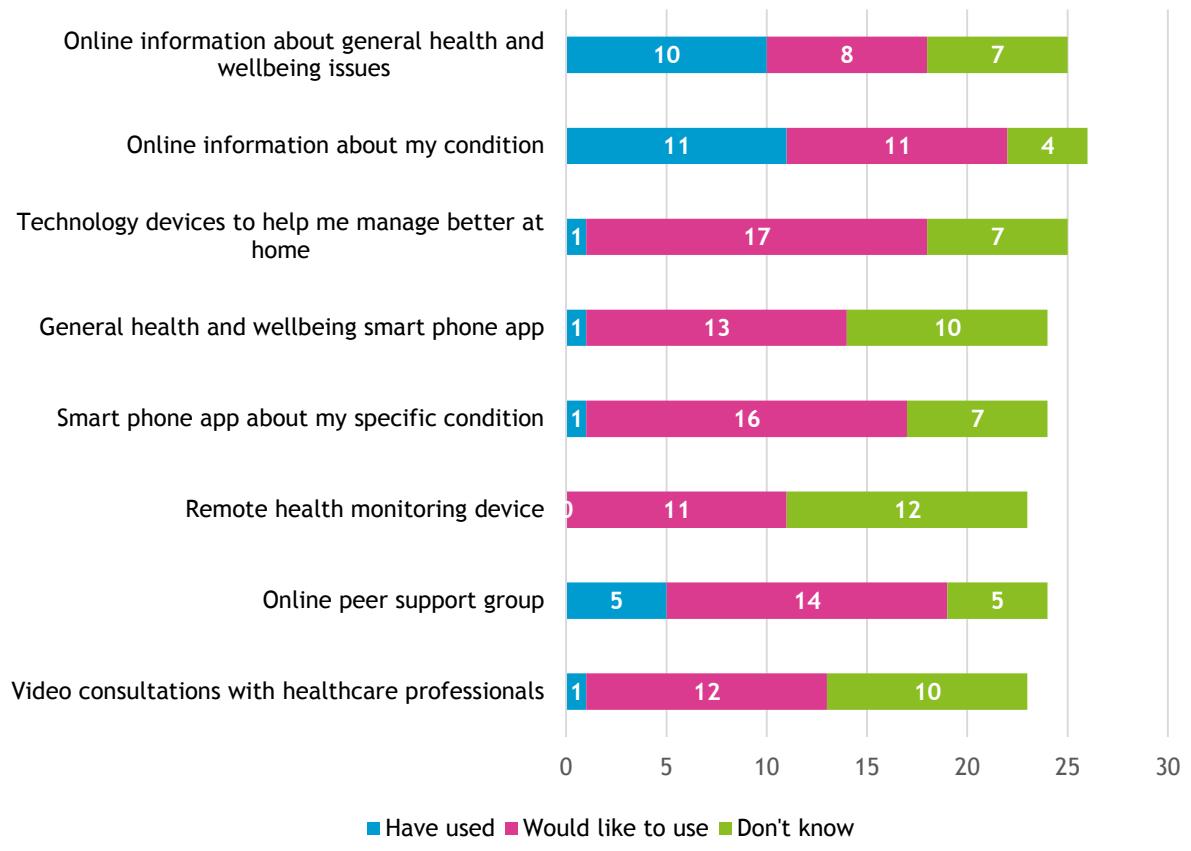


It is interesting to note that nobody in the study had been offered remote support using technology but more than two thirds of participants (69% or 20 people) said that they would like to be offered this.

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.

DIGITAL OFFER



Conclusions

The overall conclusion from this work is that the current system appears not to be working well for anyone. Years of battling for support and coping with very little of that have left us with a group of expert patients and carers who have lots of ideas, examples of good practice and high levels of motivation (particularly from parents of children with autism). This being the case a co-designed approach to developing a new system would seem like a first step to a way forward.

Early Intervention

From the experiences shared here it seems that there is no early intervention strategy in place and in fact the opposite (intervention avoidance) seems to be the default position. Lots of people described long battles over many years to achieve diagnosis and support with significant numbers having not achieved either.

People wanted to be listened to, to have a chance of an early diagnostic assessment and to be supported to develop skills and strategies for managing life with autism. A number of people questioned the effectiveness of using paediatricians and CAMHs services as gatekeepers feeling that these professionals had little to offer in the way of appropriate ongoing support.

Multi-professional single meeting assessments as used in Manchester were considered to be the way forward. Sensory, speech and language and OT input provided at the outset was considered essential.

Social Prescribing

Peer support appears to be highly valued by this group of people many of whom felt that almost all their information and support had come from peers, either in groups or online. People particularly felt these approaches could be useful in the period between referral and diagnosis when they felt particularly unsupported. Having said that there was frustration that there were not effective referral mechanisms in place to direct people to peer support and that information about available support was inaccurate, out of date or unhelpful (not enough details).

Several people described interventions that had helped them, such as post-diagnostic workshops and the Pictor summer school, though there was a feeling that these valuable interventions had been casualties in commissioning decisions and were no longer being funded. There were also some questions around accessibility of some of these interventions, especially for working parents.

Providing funding and effective referrals to community based and online peer support groups would seem to be a useful and relatively low cost strategy for providing effective support to a large number of people at a time when they needed it most.

Personalisation

Listening is key, many people felt their concerns and theories about their child's conditions had gone ignored for a very long time. This problem, if anything, seemed to be even more pronounced in adults presenting with autism.

People felt that personalised information and guidance was badly lacking. Generally people appeared to be less interested in the finer points of diagnosis and more interested in getting personalised help with support strategies.

Technology

Hardly anyone had been offered Tech related support and there was a lot of interest in trying targeted apps, remote support and tech monitoring/assistance devices in the home. There were numerous suggestions from this group for digitally enabled support whether that be from

a digitally enabled specialist team (using technologies already available in for example, admissions avoidance from care homes into hospitals), via online peer support or via online tracking of referrals and assessments for example.

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.

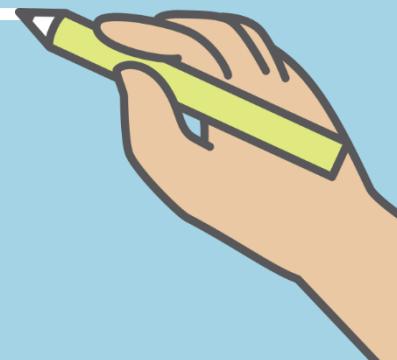
The response provided is to the whole set of reports created as part of the NHS Long Term Plan engagement by Healthwatch in Greater Manchester. It is included in full.

**Greater
Manchester**

**Health and
Social Care
Partnership**

RESPONSE TO HEALTHWATCH IN GREATER MANCHESTER NHS LTP PUBLIC ENGAGEMENT FEEDBACK

2019



GMCA GREATERT
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 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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