healthwatch

NHS Long Term Plan

Patients Views of Learning Disability Services

Healthwatch in Greater Manchester

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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 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'(this report)
    - '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 :

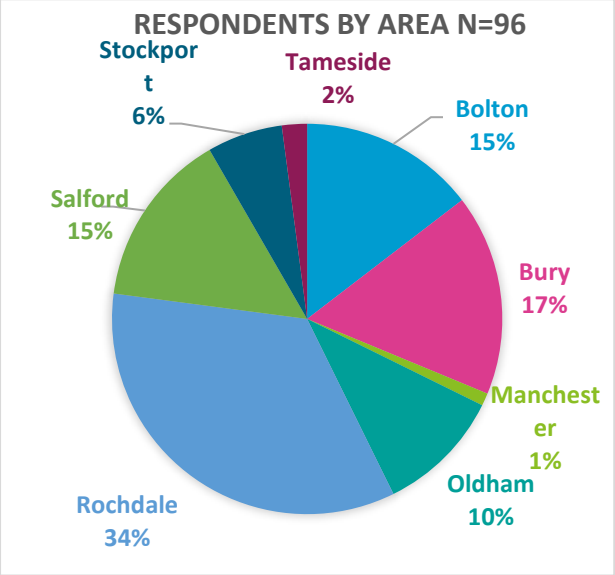
Area	Topic	Participants	Location	Date
Trafford	Autism	8	Fuse Centre, Partington	2019-04-28
Oldham	Cancer	6	Saddleworth community room at reclamation cafe	2019-03-29
Trafford	Cancer	7	Macmillan Centre, Trafford General Hospital	2019-03-22
Tameside	Cardio and Respiratory	10	Volunteer Centre, Penny Meadow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

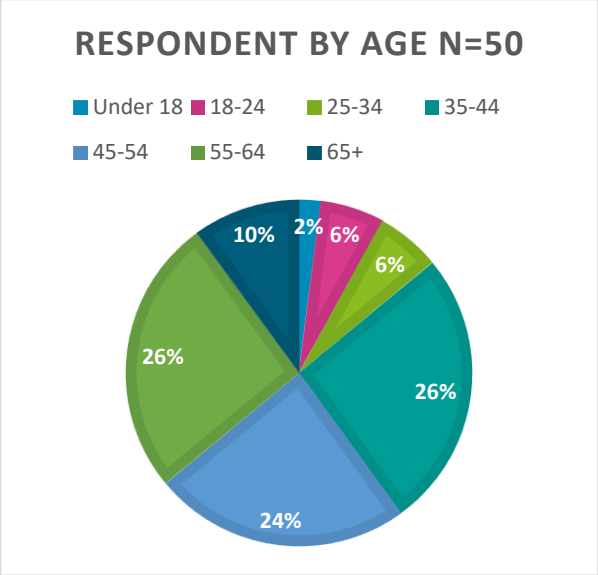
Who we spoke to

Sample Size

96 people took part in this research. 39 people responded to the long term conditions autism survey. A further 57 people participated in one of five focus groups held in Bolton, Bury, Oldham, Rochdale, Salford..

General Demographics





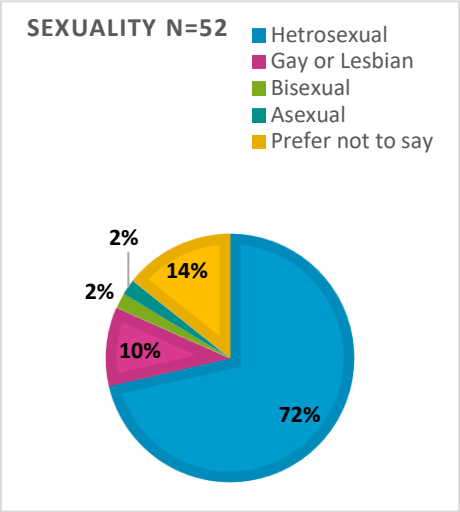
People responded from all 7 of the 10 areas of greater Manchester. Rochdale was the most well represented with 40%, 14 (15 % of all) survey respondents and 19 (20% of all) attending the focus group. Bury (17%, 16 people), Salford (15%, 14 people), Bolton (15%, 14 people) and Oldham (10%, 10 people), all areas where focus groups were held, had the next best representation. There were no responses to this particular survey from either Trafford or Wigan and Leigh.

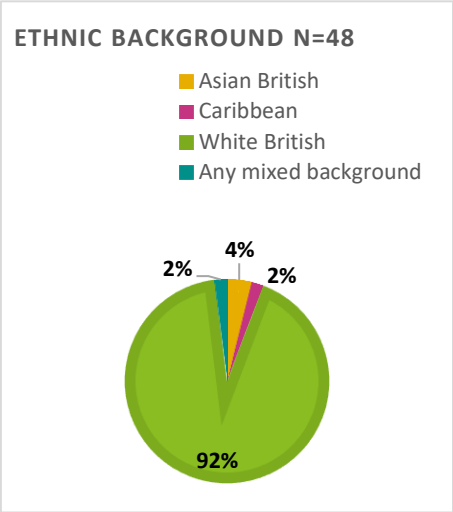
For the broader demographics not all focus groups entered demographic data. We have presented the data that we have which shows the following.

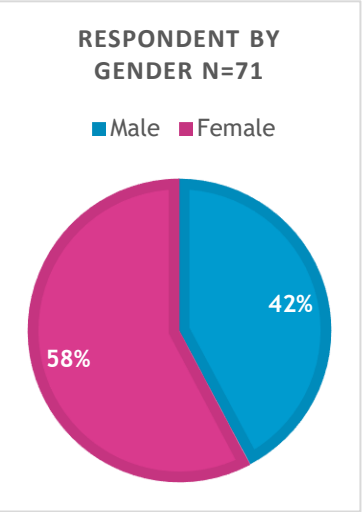
With regards to age demographics all age groups were represented. The largest groups were 35-44 and 55-64 year olds (26% for each group) followed closely by 45-54 year olds (24%).

In terms of other demographic features 72% of the participant group were heterosexual, 14% identified as LGBTQ, 25 as asexual and 14% preferred not to say.

For ethnic background the respondents where 92% white British and 8% from other ethnic backgrounds (Asian British, Caribbean and mixed heritage were specified).







In terms of gender females (58%) were slightly better represented than males (42%).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 (with these questions we 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

Diagnosis and early intervention

In relation to their experiences of getting a diagnosis and acquiring relevant support the respondents tended to give two different kinds of answers.

The adults with learning disabilities in the main were diagnosed as children and understandably did not have clear memories of that time or process.

> "Diagnosis - most people diagnosed at birth."
>
> "Diagnosis was at a very young age so no memory of this."

One person made a very clear statement about prevention, making the point that research and preventative action should not be forgotten in the discussion about learning disabilities.

> "I would like a cure for foetal alcohol syndrome as this is the reason I have a learning difficulty. I would like there to be more awareness about the syndrome and more emphasis being put on prevention."

The parents of children with learning disabilities did provide some details on how they had experienced the process of obtaining a diagnosis and support. Many expressed the view that they had felt services had not understood the impact on the whole family of receiving the diagnosis and had not been particularly well supported post diagnosis.

"(I wish I had) shouted louder and fought harder."

"Far shorter waiting time to be seen and then when we are seen to have access to someone who can effectively guide us rather than just telling us, you are doing all that you can!"

"More empathy of the devastation of finding that your child has LD."

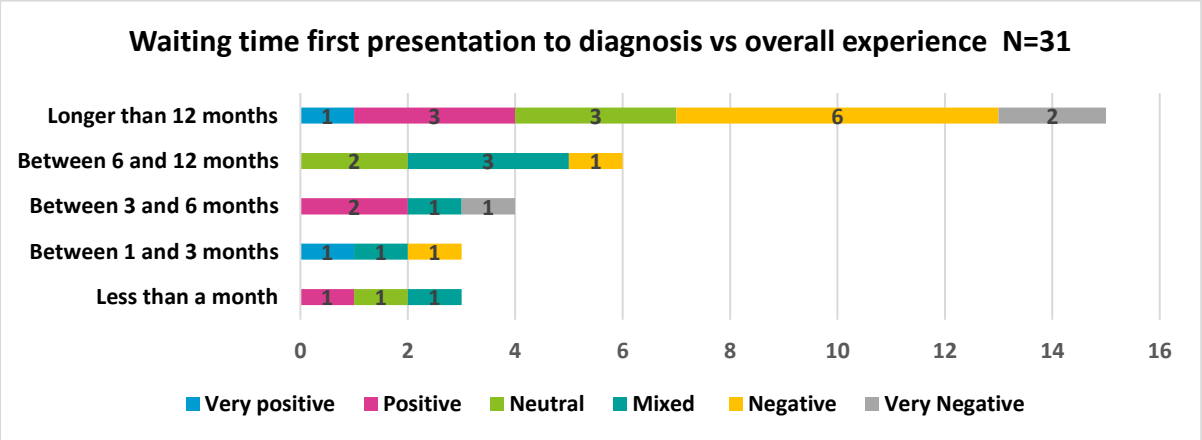
"There are no services. We were left to our own devices. Parents need support when their child has been diagnosed."

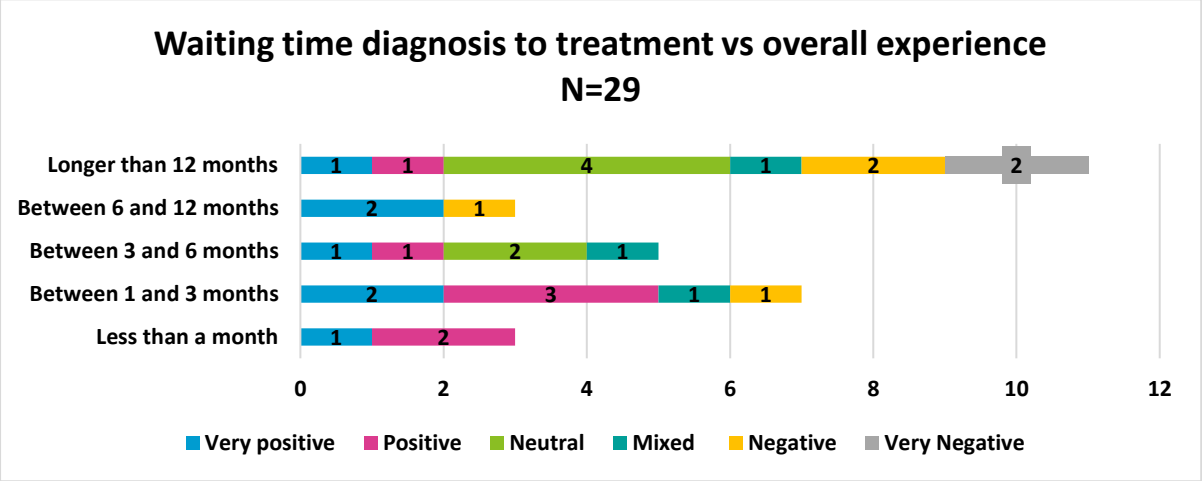
"More understanding of complex needs and how it dramatically affects the whole family unit , more support, time and guidance."

"(what could have been done differently) Actually offered us support. Communicate with us and each other. Offer me as a parent advice and support. Provide information of services/self support we could access."

The charts below illustrate the time from presentation to diagnosis and from diagnosis to support. Both charts show a similar pattern. In relation to first presentation to diagnosis just over half (16) respondents received a diagnosis within a year of presentation. For the remainder (just under half or 15 people) the process of getting a diagnosis took over a year. The variation would seem to be explained in the main by the wide variety of specific conditions covered under the term learning disabilities and the optimum time of diagnosis for that particular condition (some learning disabilities are diagnosed at birth whilst others emerge as the child develops).

Though we are not able to make an exact correlation between specific disabilities and waiting times for diagnostics and support we can conjecture that those people reporting longer waiting times have less visible and /or later presenting learning disabilities.





Accessible information

A lot of the discussion in the focus groups in particular centred on appropriate communications and accessible information. People felt that services did not understand their literacy issues. 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.

> "Some GP's and hospitals send texts for appointments but many either don't have a phone or cannot read therefore this then becomes unhelpful. - Most of the group struggled with their reading."
>
> "I don't like surgeries because they keep asking me to use the machines when I arrive but I don't know how to and I can't read well. (it was said that often there is a queue of people waiting and only one receptionist so no-one is available to help show them how to use it)."
>
> "Surgeries show your name on that thing on the wall but if you can't read its not good."

In terms of accessible written information there was a sense of exasperation that people had been telling services for a long time what is needed to help them to access information directly. People were clear about what works for them in terms of written information and gave some very clear examples (see below).

"We seem to keep having these conversations about making information accessible but nothing happens (advocate)."

"Information needs to be accessible. How can it be in this day and age people still get sent the same style of letters that we have been saying for years are not appropriate i.e. people with LD, those who are deaf etc often can't read well and they contain too much information. They should have a bit at the top with the date, time, location, purpose and contact telephone number. each of these should have a real life human picture (not a symbol they are rubbish and easy read is not good) All the other info could still be on the letter and for those who are capable of reading this that's great however for those who aren't the main information they need is clear at the top."

"That booklet is good (look after your lungs) I can understand it. I like the pictures. It tells me what to do. (Booklet created for those with LD due to one of the main causes of death for those with LD is certain conditions as they don't recognise symptoms or know how to look after themselves in the right way. The booklet shows real human people in pictures that are big and really easy to understand. More should be like this)"

"Nobody's doctor gives easy to read info and they use jargon. We want to understand more."

"Information needs to be clearer and more understandable, using pictorial information and changing words such as phlebotomist to someone who takes blood."

"Information in surgeries, hospitals and especially appointment letters are not understood. They are not written in an accessible way meaning patients are not been given the opportunity to gain the same information as others. The Primary care trust/CCG should work together with groups like this as we are keen to co-design things."

"We need organisations to work with people who have learning disabilities to know how to communicate and support us."

"Places should co-design booklets, letters and ask those with needs what works for them in health settings. We are always keen to do this."

"More people with lived experiences working alongside practitioners."

Focus group members were keen to see information and services more generally shaped by people with lived experience of learning disabilities. Several groups offered to support the NHS in co-producing information and guidance it would seem that there is a real opportunity here for an organised (and funded) national or regional programme to support this and finally get accessible information embedded in NHS communications.

Skilled practitioners

People valued the skills and support of their support workers, advocates, carers and family some felt that the flexibility to allow their regular carers and support workers to continue to support them when they are in hospital would help. In other areas the introduction of hospital based Learning Disability Champions had improved the hospital experience for people. People wanted to see the Learning Disability Champion model rolled out into other settings.

"People felt that they were supported during and after treatments but by family, carers and support workers."

"We need the right support to help communicate and if we don't then our experience in treatments etc become negative ones. People felt that practitioners lacked knowledge and therefore there ended up being a reliance on support workers."

"No-one ever had a Care Act advocate this would be good."

"Disability Champion and now every ward in the hospital has a LDC so they see patients on the ward - The LDC's are clearly a really valued role (started approx 18mths ago but has been more so in last 12mths). They really help support those with LD on the wards and can help ensure they are being treated correctly and that the patients understand what is happening."

"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."

There were a number of comments discussing awareness and skills of health practitioners. People suggested that they sometimes had the experience of being ignored by practitioners who didn't understand Learning Disabilities, did not have appropriate communications skills or spoke over them. This appeared to be more commonly felt within the NHS and particularly in hospital settings.

"People need to be well trained in different disabilities and people skills. If people were more appropriately trained then support workers would provide better support and doctors/nurses would know how best to support someone through any appointments/treatments."

"Nurses and doctors to be trained in learning disabilities and more training given on learning disabilities needs to all NHS staff."

"My LD Nurse was easy to understand. There should be more of them."

"Health professionals need to have more knowledge and respect for those with LD."

"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."

"Within the community it has been positive. Within hospital need more advocacy or better use of DOL's to ensure medical staff comply with legislation."

"Social services were great and helped to break down barriers of understanding NHS on the other hand were not."

"Patients spoke about NHS staff not always understanding learning disabilities which patients felt often resulted in neglect during hospital stay."

"If people with LD do not have anyone to advocate they are very vulnerable and may not cope well in hospital."

Travel and transport

Transport was a particular barrier for people with learning disabilities who rely on other people to go with them for complex journeys. It should be noted that many of the adults rely on elderly parents for transport. For the parents of children with learning disabilities there was a plea for paediatric consultants to make local appointments available.

"If there were more local appointments people could potentially go independently and not have to always wait for support staff to take them."

"Many people said that family take them to appointments and they are usually elderly parents. They do not like to drive on motorways or in the dark so this becomes a barrier to attending appointment quickly."

"(would like to be) offered more choice of appointment time to make it easier to arrange for carer to support at appointments."

"Need paediatric consultant in [locality] not just Manchester as it is a long way to travel when you have so many appointments."

Screening and testing

Some of the focus groups specifically discussed tests and screening. Two points came up suggesting how take up could be improved. Improve the letters - so people understand what the test is for. Improve the communication at the time of the test - so people understand the procedure better and are prepared for discomfort.

"We asked about tests/screening and it was clear that most of the group didn't attend appointments for most of these as they didn't really understand the letters."

"I don't go for tests."

"I have been for a smear before but not again. Got a letter but I won't go back. It hurt me."

"I had a test for my boobs once but it really hurt so told them to stop. Why does it hurt?"

Groups and services to support self-care and healthy living

A lot of respondents where engaged in community groups of some kind. They valued the groups that they attended and understood the need to stay healthy and active. Participants in Bury in particular listed a wide range of activities they enjoyed including; Keep fit gyms, Wheels for All, Bury People First, Outreach groups where staff help people to stay healthy, eat healthy, healthy cooking, drama and fitness activities, Jigsaw, Allotments and Castle Knights.

People wanted peer support and group support and generally felt that disability / inclusive groups better understood their needs than mainstream groups.

"Groups in our communities are not always easy to access as they do not have the understanding our disabilities. Therefore we need more groups for people with disabilities and services need to access these groups too."

"We want peer support and group support with people with learning disabilities going through the same issues so we can talk about things without being judged."

In terms of what could be done differently there were a number of requests for accessible sports facilities including, swimming, hydrotherapy and gyms. People noted that they often needed support to access these facilities (which is not always available from individual support workers) so supported group access was desirable. Some people felt that physio and occupational therapy was needed in their case.

There were a number of specific requests for inclusive/disability specific support in terms of mental health and wellbeing groups.

"Cerebral palsy is neglected as a condition in adults. Ongoing physiotherapist or specialist gym services or yoga or swimming needs to be encouraged to keep people active."

"Used to receive physio therapy and OT as a child but doesn't now as an adult. It is needed."

"Hydrotherapy: Need support to go, Physios in the pool, hot water in the pool. Our staff will not go in the pool with us."

"Healthy Food – Cooking class not just cakes and buns (a group member will ask for this)."

"Mind and Body – Being part of groups helps people's mental health."

"Currently looking for low level mental health support around his emotions and managing this in a better - there are children's courses and sessions and adult courses and sessions but no LD adult."

"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."

Digital services

There were a few enthusiastic adopters of technology among the learning disabled adults but the majority were not comfortable. Most did not have access to a smart phone or a computer and some were fearful of using these. Some of the carers who responded felt that digital support might be useful for carers and support workers if adapted to their needs.

"There was a mixed response from participants on the use of digital services with some wanting to use technology and others preferring face to face interactions."

"Only one member of the group used a smart phone and said that he might be able to try using it for appointments etc."

"I have a mobile and laptop. I could try skype."

"Nobody has a smart phone."

"The group did not really understand how you could use things like apps etc to manage their care."

"I don't have a mobile. Not allowed as called 999 before and got in trouble (this incident occurred over 20 yrs ago but this individual now believes he is not allowed a phone as he will call 999 and get in trouble)."

"I would find it difficult to use this."

'I would have to let my mum do it'

"None of the above are relevant to [patient], but they are useful for his carers."

"Individuals would struggle to manage these suggestions but there may be some way of incorporating them into the staff team but the needs of our people are very specific and require specific input."

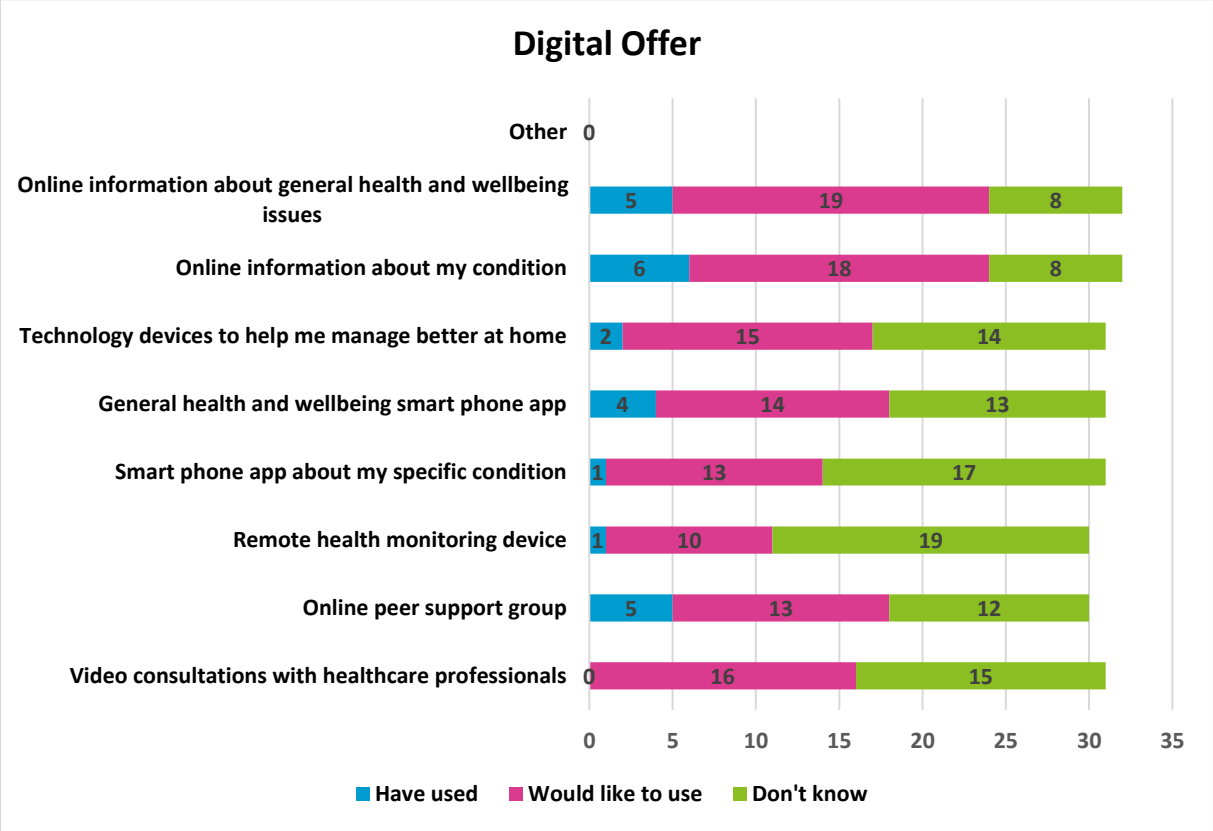
The responses to these questions brought out the issue of literacy, which was a challenge for many of the respondents. People felt that limited literacy hampered their ability not just to cope with personal technology but also to cope with some of the everyday technology used in the NHS (such as appointment screens, check in machines and text reminders.)

"Some GP's and hospitals send texts for appointments but many either don't have a phone or cannot read."

"Most of the group struggled with their reading."

"I don't like surgeries because they keep asking me to use the machines when I arrive but I don't know how to and I can't read well."

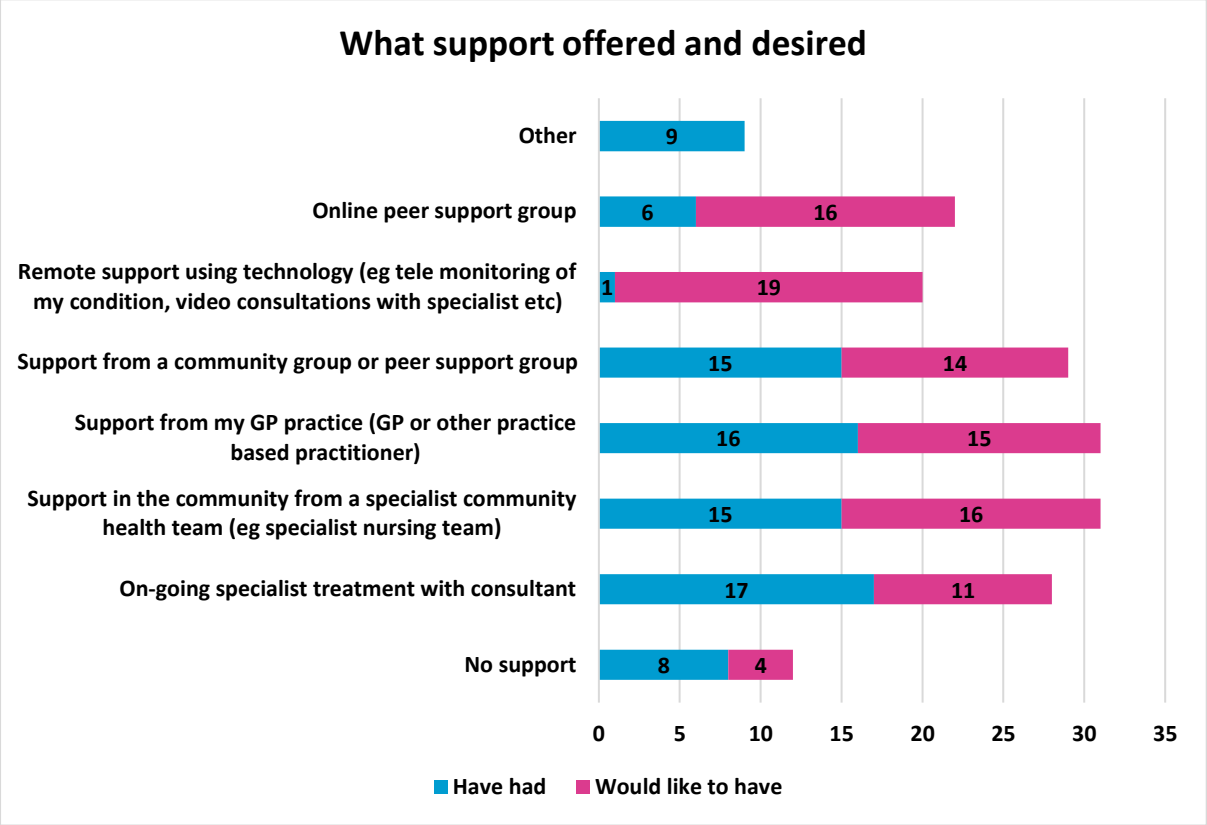
"Surgeries show your name on that thing on the wall but if you can't read it's not good."



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

The graph below shows that around half of the respondents were receiving on-going support from both traditional clinical structures (GP, specialist nurses, consultants) and from community groups/provisions. The comments suggested that these included day centres, learning disability specific social and support groups, more generic community services (such as healthy living services) that are well adapted for people with learning disabilities, dedicated support workers, respite services and peer support groups (principally for parents of disabled children). Almost all those who were not receiving these services said that they would like to receive them.

Around a quarter of respondents (8) where receiving no support at all. In the main these were people who were still awaiting a diagnosis.



In terms of online support and tele monitoring only a small minority had been offered these. Of those who had not been offered these there was a high level of interest. Again some of this interest coming from parents and carers. The comments made above about digital services should be taken into account here.

Conclusions

Early Intervention, Prevention and Social Prescribing

In terms of early intervention when disabilities are diagnosed this is a mixed picture depending on the nature of the disability and the time when this would normally become apparent as a child develops. Most of the adults in the survey understandably had no memory of the diagnostic process though 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.

With regards to maintaining good health, good communication skills from professional and accessible information are seen as key in ensuring people with learning disabilities engage in preventative services and seek medical advice at the earliest opportunity. A good number of people reported not attending health appointments due to not understanding the letters, not understanding what the appointments were for. Accessible information with brief, clear and pictoral explanations would help people understand the need for attending at prevention, check up and screening appointment.

Adapted facilities and disability specific health and wellbeing support groups were seen as vital in supporting people to stay healthy. Many of the respondents were engaging with these types of activities and enjoying them. There were a number of specific requests for particular services for example mental health/emotional wellbeing groups aimed at people with learning difficulties were difficult to find.

Personalisation

Many people in the study were supported by personal support workers and family members. People valued this personal support feeling these people were best able to help them with their communications needs in particular. Non the less people felt that the NHS could do more to be learning disabled friendly by providing more training to staff, rolling out the learning disability champion model and, crucially, making information accessible.

A number of people reported that their or their loved ones needs were extremely complex and that a highly personalised approach, supported by advocates, support workers and carers was vital.

Technology

Though there were a few enthusiastic tech adopters in the group, in the main people were not habitual users of personal technology devices such as smart phones or laptops and so could not see how these devices could be used to help them with their health and wellbeing. Parents and carers did feel that some tech based support for carers and support workers could help however. A lot of the participants struggled with reading and their experiences with everyday technology such as touch screen check in and digital notice boards made them wary of other technological solutions.

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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It's your NHS. Have your say.

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