The NHS Long Term Plan
Views of Residents of Norfolk and Waveney on Local and National Priorities

Please contact Healthwatch Norfolk if you require an **easy read**; **large print** or a **translated** copy of this report.

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May 2019

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Who we are and what we do

Healthwatch Norfolk is the local consumer champion for health and social care in the county. Formed in April 2013, as a result of the Health and Social Care Act, we are an independent organisation, with statutory powers. The people who make decisions about health and social care in Norfolk have to listen to you through us.

We have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We are here to help you influence the way that health and social care services are planned and delivered in Norfolk.

Your voice can make a difference...

healthwatch Norfolk

Healthwatch Norfolk works with health and social care services in Norfolk to make sure that your views and experiences make a difference to the services we all use.

Your Experiences

We listen

We point you in the right direction

Suggestions
Complaints
Ideas
Issues
Opinions
Compliments
Feedback
Concerns
Good Practice
Frustrations
Questions

Volunteers are our eyes and ears

Powerful Voice

We challenge when services need to improve

You make a difference!

Call us on 0808 168 9669

Website: **www.healthwatchnorfolk.co.uk** Email: **enquiries@healthwatchnorfolk.co.uk**

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Summary

Healthwatch Norfolk (HWN) has undertaken a consultation and engagement exercise on behalf of Healthwatch England to gauge public opinion in relation to both the NHS Long Term Plan and the local Norfolk and Waveney priorities around the delivery of future health and social care services. The work commenced in late March 2019 and finished on 17th May 2019.

The aim was to hold a minimum of two public engagement/focus group events and obtain at least 250 on line responses from a public survey.

In order to help with consistency at a national level, Healthwatch Norfolk opted to utilise both the general survey and conditions specific survey that had been prepared by Healthwatch England. It also opted to utilise the questions posed by Healthwatch England when undertaking the engagement events.

Prior to going out to consultation, all materials and an outline of the proposed approach were shared with the Head of Communications and Engagement of our local Norfolk and Waveney Sustainable Transformation Partnership (STP) along with the Communications Leads from all 5 Clinical Commissioning Groups, 3 Acute Trusts, three Community Trusts and Norfolk County Council – all of which operate under the collective umbrella of the STP.

We collected views from: -

- One hundred and one (101) people attending six Focus Groups
- Seven hundred and thirteen (713) people showing interest in the on-line general survey of which five hundred and thirty-six (536) responses were analysed
- One hundred and thirty-five (135) people responding to the Conditions Specific Survey of which seventy-nine (79) were analysed

In general people felt that the direction of travel was correct both nationally and locally and there was strong support for an integration of services and bringing health and social care together as one entity to ensure they work together successfully. It was also highlighted that one of the most essential aspects of health and social care was getting access to the services in the first instance. Alongside this there were a wide range of ideas and responses to the focus group and survey questions. Some of the key issues and concerns raised included:

- Concerns around staffing levels in Norfolk and being able to recruit and retain health and social care staff in Norfolk.
- Social prescribing and community groups were seen as very important, however it was highlighted how these services would need to be adequately funded and supported by clinical staff as an alternative or complement to medical interventions.
- Several respondents were reluctant for services to become too reliant on technology due to a lack of digital competence particularly in the older population.
- The deaf community highlighted the need for services to be accessible to everyone and in particular how interpreters were essential for them to access services.

- Wider influences which could impact on health and wellbeing, such as education and using schools as a medium to inform children and parents about healthy living and the impact which poverty and work lifestyles may have on how people are able to look after their own health.

Next Steps

1. Share report with STP leads, HWN Board, and to those who participated
2. Publish report on HWN website and hyperlink to STP website
3. Ensure Senior Responsible Officers (SROs) are aware of specific concerns and use statutory powers to obtain feedback
4. Seek commitment to hold at least two public meetings per annum to enable STP/Integrated Care System (ICS) to feedback ensuring transparency
5. Work with partners to ensure appropriate consultation and participation is taking place and "monitor" evaluations of any system changes that are being made.

Acknowledgements

We are grateful to the following organisations for their support in helping us deliver this piece of work: -

- Deaf Connexions
- All Norfolk and Waveney Clinical Commissioning Groups
- All Norfolk and Waveney Acute and Community Trusts
- Norfolk County Council
- Voluntary Norfolk
- Community Action Norfolk
- Healthwatch England
- Norfolk and Waveney STP

1. Our approach

Our approach in undertaking this piece of work was a collaborative and emancipatory one. We gather views and experiences from patients, service users, carers and families from those only wishing to give them voluntarily. We work from the position of wanting only the best services for local people. We strive to conduct our work in an inclusive and robust manner; we have in-built quality controls which are applied to every project we undertake.

We are familiar with the evidence base on best practice in community engagement; as an organisation led by and accountable to, local people, we listen to and embrace their views on effective ways of working. We do not have, nor do we follow, favourite theories or models choosing instead to select the theories, models and approaches to the task in hand.

1.1 About Norfolk and Waveney

Norfolk covers 2,074 square miles and has a population of 880,000 including diverse communities living in the city of Norwich and large towns of King's Lynn and Great Yarmouth. There are many smaller market towns and approximately 46% of Norfolk's population live in rural neighbourhoods. One third of Norfolk's population are aged 65 years or older, whilst the population of Norwich is relatively young compared to many other cities. We endeavour to remove or reduce practical and financial barriers that may prevent people with lived experiences of health and social care from participating in feedback and co-production sessions. For any sessions involving patients, service users and the public, Healthwatch Norfolk's policies align to the Care Quality Commission's payment and reimbursement policy[1].

Our local STP area, Norfolk and Waveney contains a population footprint of 1.1 million people across eight district/borough councils. The STP footprint encompasses both Healthwatch Norfolk and Healthwatch Suffolk's patch, however patients and residents accessing services e.g. in King's Lynn will come from Cambridgeshire and Lincolnshire. Therefore, there are four local Healthwatch implicated in our local STP footprint.

1.2 How we reached people across Norfolk and Waveney for this project

We used our own membership, networks and communication channels to promote the survey and focus groups and recruit appropriate people with lived experience. We utilised our strong relationships to network VCSE partner organisations in Norfolk and Waveney who represent specific patient and service user groups and communities. We worked with these organisations to increase our reach and ensure the most suitable participants had access to all information produced.

In order to cover such a large geography, we chose to undertake 6 Focus Groups, one of which was specifically aimed at the Deaf Community as their voice is often forgotten when designing health and social care services. Focus Groups were held at different times of the day and early evening in order to provide maximum opportunities for people to attend. We produced easy read versions of the two surveys and our Engagement Team provided paper copies with stamped addressed envelopes for people who did not have access to a computer to complete an on line survey.

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[1] Care Quality Commission Jan 2014. Putting People First: Payments and reimbursement policy for people who are involved in the work of the Care Quality Commission.

We actively engaged with the local media and managed to secure articles in the Eastern Daily Press, The North Norfolk Times, the Kings Lynn News and the Holt Chronicle as well as various plugs on BBC Radio Norfolk's "Nick Conrad Breakfast Show" and KLFM.

Each event included the bespoke targeting of poster sites at relevant local libraries, GP surgeries, hospitals and council managed noticeboards as well as direct communication with Practice Managers, PPG chairs and administrators of Facebook community groups.

The survey and events were published further via all our social platforms; Facebook, Twitter and Linked-in, along with an E shot to our 1500 members and promotion via our email footers, newsletter and partner publications such as Clinical Commissioning Groups, hospitals, adult social services, momentum etc. In support of promoting the Long Term Plan survey to a wider audience we ran a two week Facebook Advertising campaign between March 27 and April 10. This activity was a major contributing factor to our overall response, generating over 100 completed surveys and general online comments and engagement.

It is worth noting that despite our efforts to reach a wide range of members of the public we are aware that those who we engaged with for this consultation in both the focus groups and through the online survey may not reflect the diversity of people who live and use services in Norfolk and Waveney. For example younger people and men were underrepresented in survey responses as displayed in *Figure 1* and *Figure 2*.

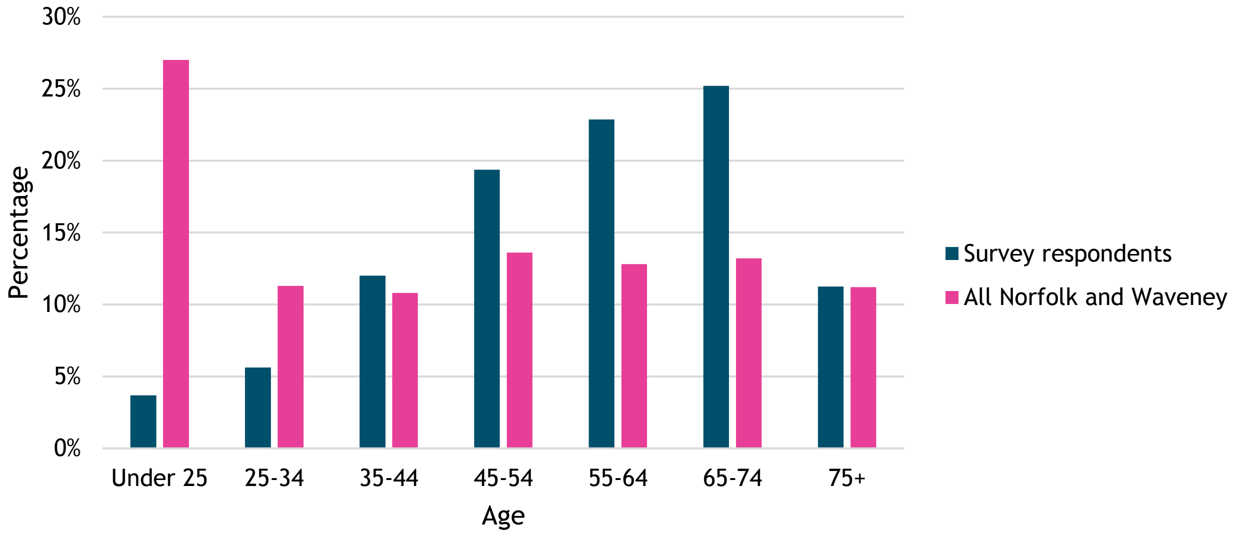

Figure 1. A chart showing the distribution of age of survey respondents and the estimated distribution of age in Norfolk and Waveney[2].

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[2] Norfolk Insight 2017. Population Estimates | Norfolk and Waveney. Retrieved from https://www.norfolkinsight.org.uk/population/report/view/d6fbe2869a3f4dcfbdaeca5c52deae12/E54000022/

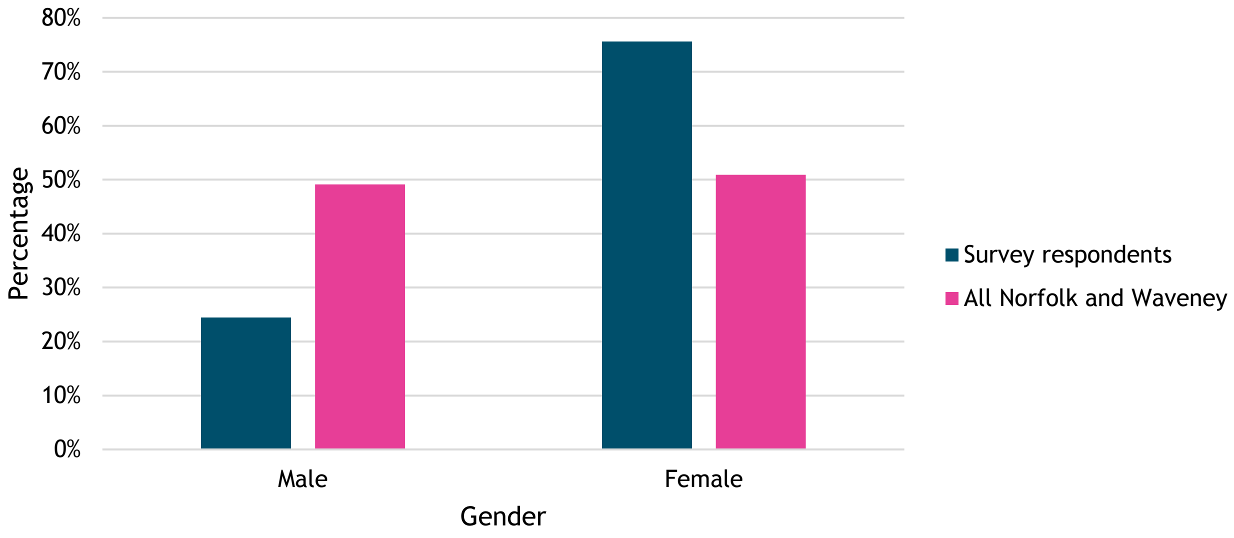


Figure 2. A chart showing the distribution of gender of survey respondents and the estimated distribution of gender in Norfolk and Waveney[2].

Respondents may also be more likely to be currently using health and care services than the general population. This was highlighted by Rt Hon Patricia Hewitt (Chair of Norfolk and Waveney Health and Care Partnership) in response to this Long Term Plan report:

> *"It makes a big difference to how we consider the answers on what would help you look after your own health, for instance. Our prevention and public health work has to focus on people who are pretty well already, or only have minor issues, not only those who are already suffering from one or several conditions"*

2. General survey findings

This survey had interest from 713 people of which there were 536 usable responses. The majority of these people, 95% (493), were completing the survey on behalf of themselves, with 4% (23) answering on behalf of someone that they care for. Responses were received across Norfolk and neighbouring counties. The distribution of the location, based on the first half of postcodes, of respondents is displayed in *figure 3*.

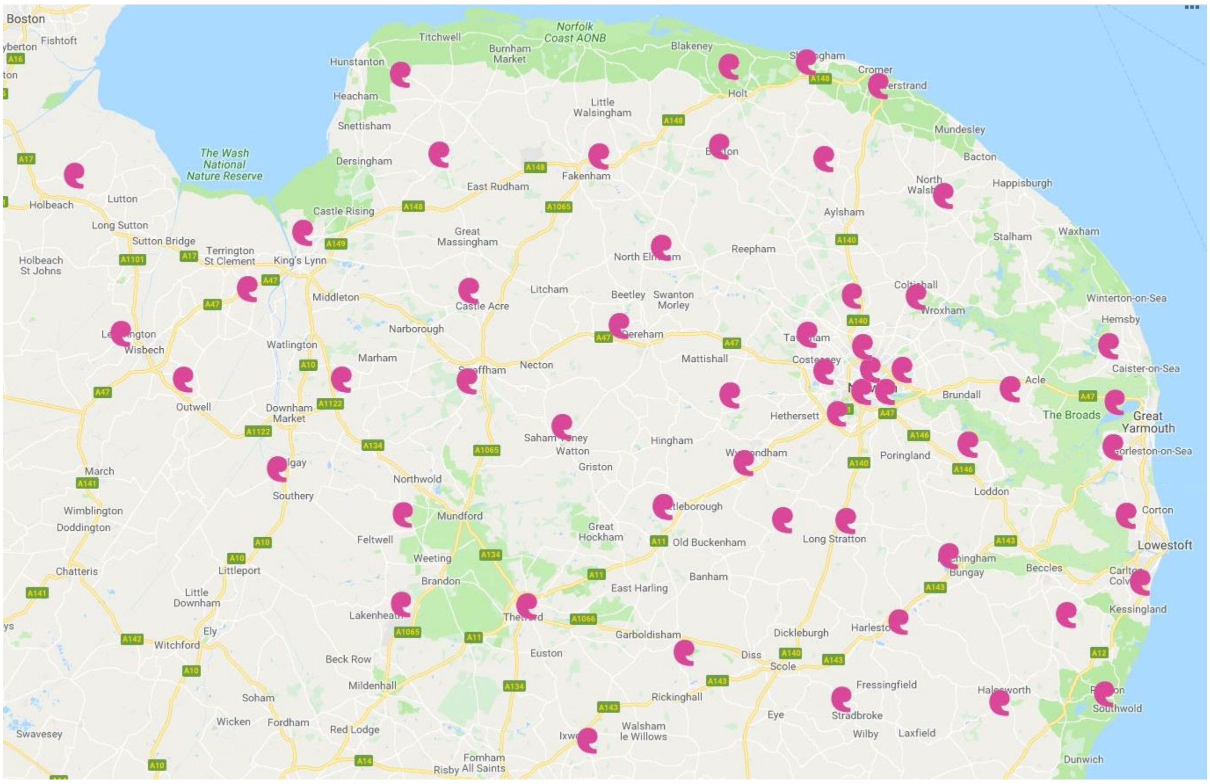


***Figure 3**. A map displaying the locations (first half of postcodes) where responses were received from.*

2.1 Characteristics of respondents

Of those who provided a response to the demographic questions, 74% (330) reported their gender as female (*see figure 4*).

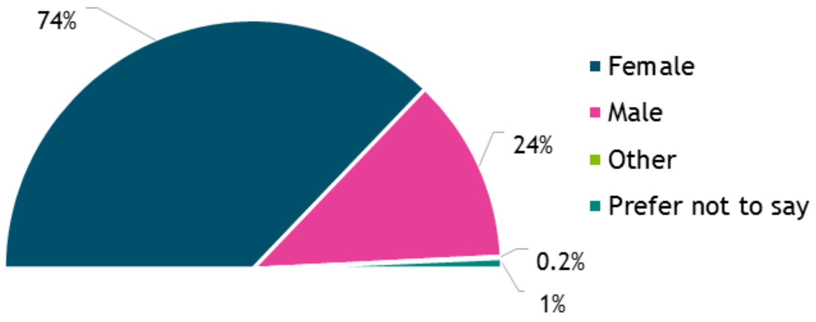


***Figure 4**. Gender distribution of respondents to the main NHS long term plan survey*

The majority, 91% (387), shared their sexuality as being heterosexual and most respondents, 93% (410), reported a White British ethnicity. Forty-six percent (203) reported their religion as Christian closely followed by 42% (185) reporting having no religion. Twenty-seven percent (120) reported having a disability, and 21% (91) said they were a carer. Forty-two percent (181) reported having a long term condition, 17% (75) reported having multiple conditions. The most common age category of respondents was age 65 to 74 with 27% (121) of people. It is important to note that most people were in the older age brackets with 60% (268) over 55, the distribution of age of respondents is in *Figure 5.*

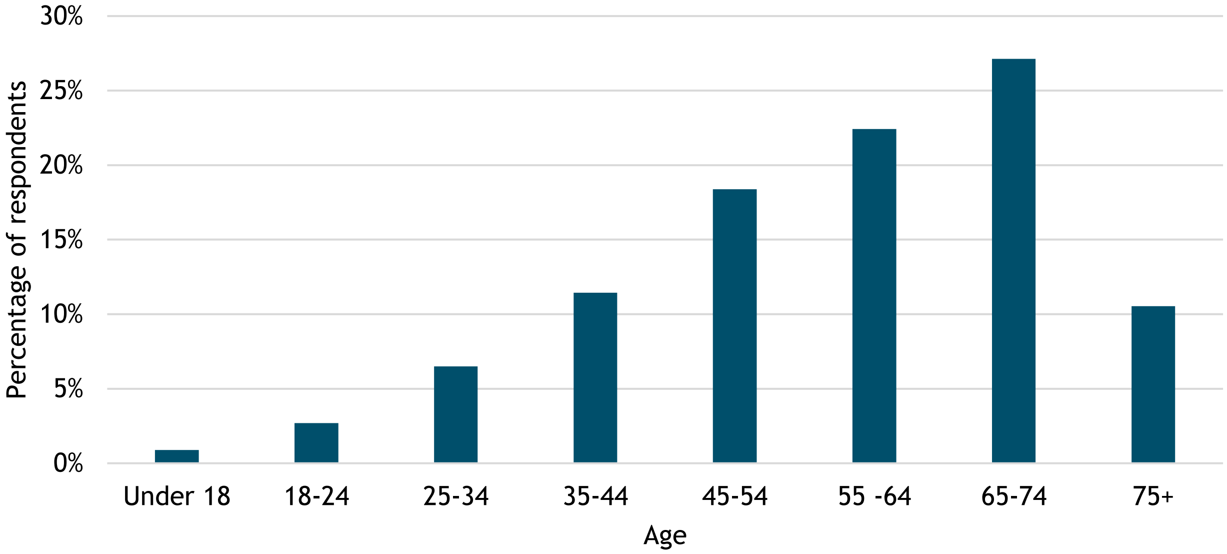
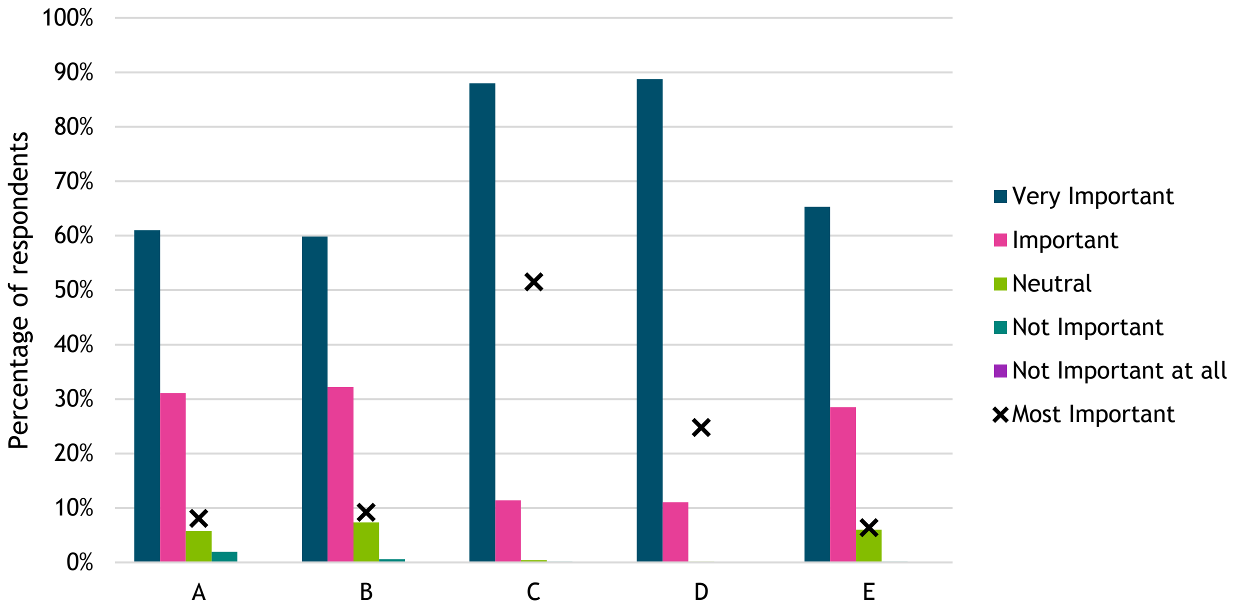


Figure 5. A bar chart displaying the age distribution of respondents to the main long term plan survey

2.2 Having what I need to live a healthy life

Respondents were asked to rate five statements based on how important they felt that they were to living a healthy life, 518 provided an answer to this question. All of the statements were considered 'very important' by the majority of respondents. The statement "*professionals that listen to me when I speak to them about my concerns*" was rated as 'very important' most frequently with 89% (459) doing so. This was closely followed by 88% (255) for the statement "*access to the help and treatment I need when I want it*". Later in the survey they were asked to choose the statement from these that they felt to be the most important to help them live a healthy life, 456 people answered this question. The statement selected most frequently was "*access to the help and treatment I need when I want it*" with 52% (235) choosing it while the least popular statement was "f*or every interaction with health and care services to count; my time is valued*" with only 6% (29). *Figure 6* displays the results to these questions.



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

Figure 6. A bar chart showing the response of 518 people asking them to rate statements based on how important they believed them to be to living a healthy life and the response of 456 people asking them to select the statement they considered most important to living a healthy life.

Respondents were given the opportunity to share any further things which would help them live a healthy life. The main themes which emerged were: *easier access to services* and *exercise and diet*.

Easier access to services

Respondents frequently discussed needing “*easier access to professional help*” and *“shorter waiting times”*. Other responses believed that “*easy transport*” would help one respondent shared how they “*live in a rural area but I wish services could be accessible by good public transport”*. As shown in the response of the two following people below, there was an emphasis how timely intervention and easier access to services would be preventative and stop future deterioration:

- *“Faster access to treatment. Long waiting lists mean independence is gradually reduced and then care services will be needed! If independence is reduced it may never return. e.g if a person has to wait 2 yrs for a hip replacement their other joints/faculties/abilities will deteriorate in that time and will never return.”*
- *“Access to help and medical advice when I need it-not after several months waiting time during which I deteriorate and become more anxious.”*

In particular there was a desire for *“accessibility to the right people”* and to make sure that the staff will be “*properly trained and qualified*”, this was particularly relevant for specialist conditions, for instance one respondent wanted “*understanding and knowledge from ALL health professional about autism*”. Respondents also prioritised being able to talk *“to someone who will listen*” and “*to be valued & not just to make me feel like a time waster*”.

There was an emphasis on GP access and how there needed to be *"less wait to get through to GP"*. Other respondents called for more "*flexible GP appointments as sometimes buses can be late [...] or home visits if not able to leave partner, as am her full time unpaid carer"*. While many of the respondents desired *"access to face to face with GP"* interestingly a few respondents would like "*access to timely advice and support online or through telephone / web chat with health professionals*". Although some respondents argued how "*all healthcare provision to be free and accessible across the board*" others were willing to pay *"a reasonable figure to stop time wasters missing appointments."*

Another subtheme here was an interest in having "*improved local facilities*", while this did include an emphasis on health services such as *"more local GPS"* and *"better available local hospital care for minor ailments"* it also included more social services such as "*more local groups/activities*" and *"local groups for motivation and support and to share experiences*". The following quote from one respondent shows how they feel that social groups would benefit health:

- *"Ensuring that there are opportunities for socialisation rather than isolation - doing all treatment & interventions in the home is not always the answer - allow people to mix with others & the situation/problem is often less challenging as experiences & encouragement can be shared."*

Within this, respondents also mentioned carer support and how they *"need to have time out to charge their own batteries for perhaps an afternoon a week"* and suggesting that it would help if they knew *"who to ask for any help and support*".

Exercise and diet

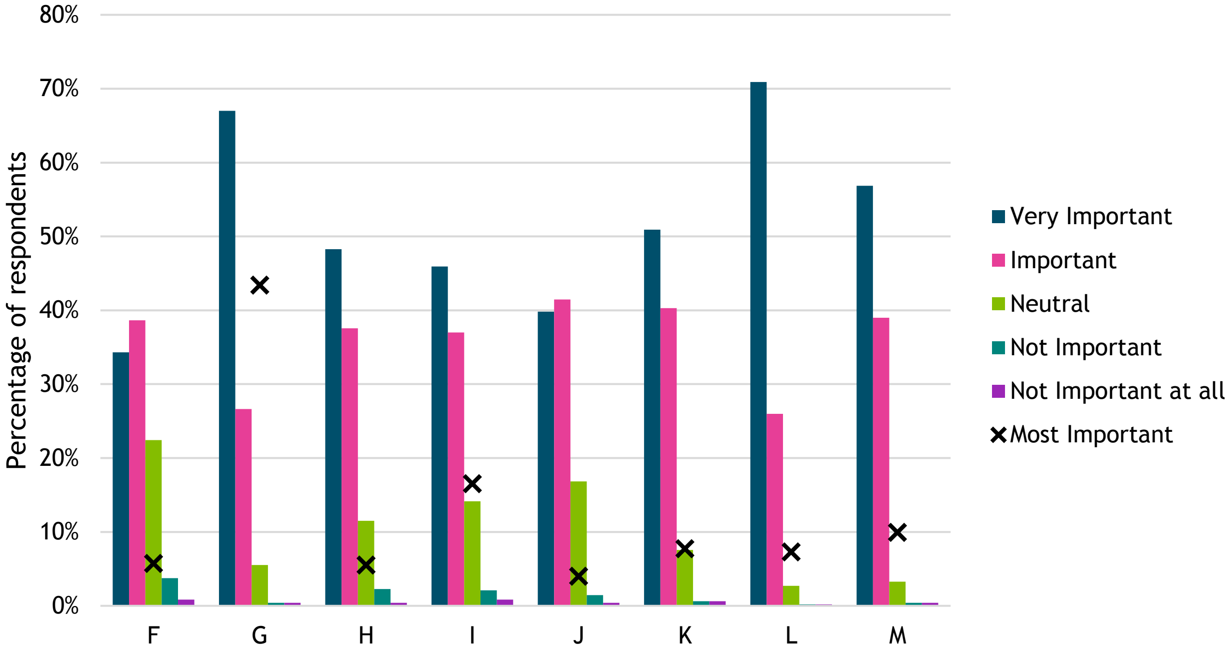
Exercise and diet were frequently referenced by respondents as a way to help them live a healthy life. While some people were already having a "*good healthy lifestyle, I eat sensibly, I exercise, with walking and gardening"* others highlighted a need for better access to exercise and more information about diet. In particular respondents wanted "*more access to exercise, healthy eating etc classes & groups for free or minimal charge"* such as "*free gym usage*", *"free yoga classes"*, *"cheaper access to swimming and other exercise*", and "*reduced healthy meals available at work or vouchers/time for on or off site use of exercise facilities*". The following quote highlights how one respondent believed that GP practices could link into healthy living programmes:

- *"It would be nice if a lifestyle coach was available at GP Practices for the fit and healthy to access to help introduce new fitness schemes and action plans to help us prevent illness. even if it was a 10 week programme or had to pay £5 an appointment for 5 weeks for intensive support."*

Respondents also highlighted the importance of "*better access to education about diet and exercise"* in improving the health of the public, for example suggesting *"being taught how to cook healthy meals at school"* and *"cheap meal planners that are healthy and nutritional [...] teach children in schools. So far all my daughter has made is cakes and biscuits."*

2.3 Being able to manage and choose support

Four hundred and eighty-nine respondents provided an answer when asked to rate eight statements based on how important they were to managing and choosing the support they need. All of the statements were considered largely ‘important’ or ‘very important’, the statement “*communications are timely*” was rated most frequently as ‘very important’ with 71% (341). However interestingly, when 454 respondents answered a question later in the survey to choose the statement they felt to be most important from the same list, this statement was only rated as ‘most important’ by 7% (33) of respondents. The statement which was selected most frequently as ‘most important’ was “c*hoosing the right treatment is a joint decision between me and the relevant health and care professional*” with 43% (197) choosing it.



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

Figure 7. A chart showing the response of 489 people asking them to rate statements based on how important they believed them to be to managing and choosing the support they need and the response of 454 people asking them to select the statement they considered most important to managing and choosing the support they need.

Respondents were then asked “if there was one more thing that would help you to manage and choose how the NHS supports you, what would it be?” The main themes which emerged from these responses were: *GP appointments*, *waiting times*, and *information about treatment and choices*.

GP Appointments

A large focus of responses to this question was on *“better access to GPs*” and *“to be able to get an appointment with my GP a lot quicker*”. Some respondents called for “*out of hours appointments on the day I need them*” and “*better access to GP at weekends and* *evening 7 days a week*". Another respondent shared how they would like "*videolink access to GPs and health advisers*". Furthermore respondents called for "*GPs and consultants having a proper amount of time for a thorough consultation*".

One subtheme within this was that people would like an easier system for booking appointments including "*better online technology to book appointments*" as demonstrated in the following quote

> *"It is not easy to see a GP. To do so we have to phone the surgery at 8am precisely and wait in a queue until we eventually speak to someone. This could be improved to make it easier for appointments to be made. We prefer to use the SystemOnline service where we can choose the date, time and Doctor of our next appointment. The problem with this is that the surgery do not put many appointments on to the system so it is difficult to find any that are available."*

Waiting times

As well as calling for "*reduced waiting time to see my GP*", there was an emphasis in responses for "*shorter wait times*" in general. This was for the time between referral and appointment: "*hospital appointments made without delay, ie within one week of referral*", also for once in the service "*no long waiting times at hospital racking up enormous car park fees*", and "*waiting months to hear back about appointments and tests*". One respondent shares their thoughts on waiting time in the following quote, highlighting how the long waiting time is difficult to navigate alongside day to day life.

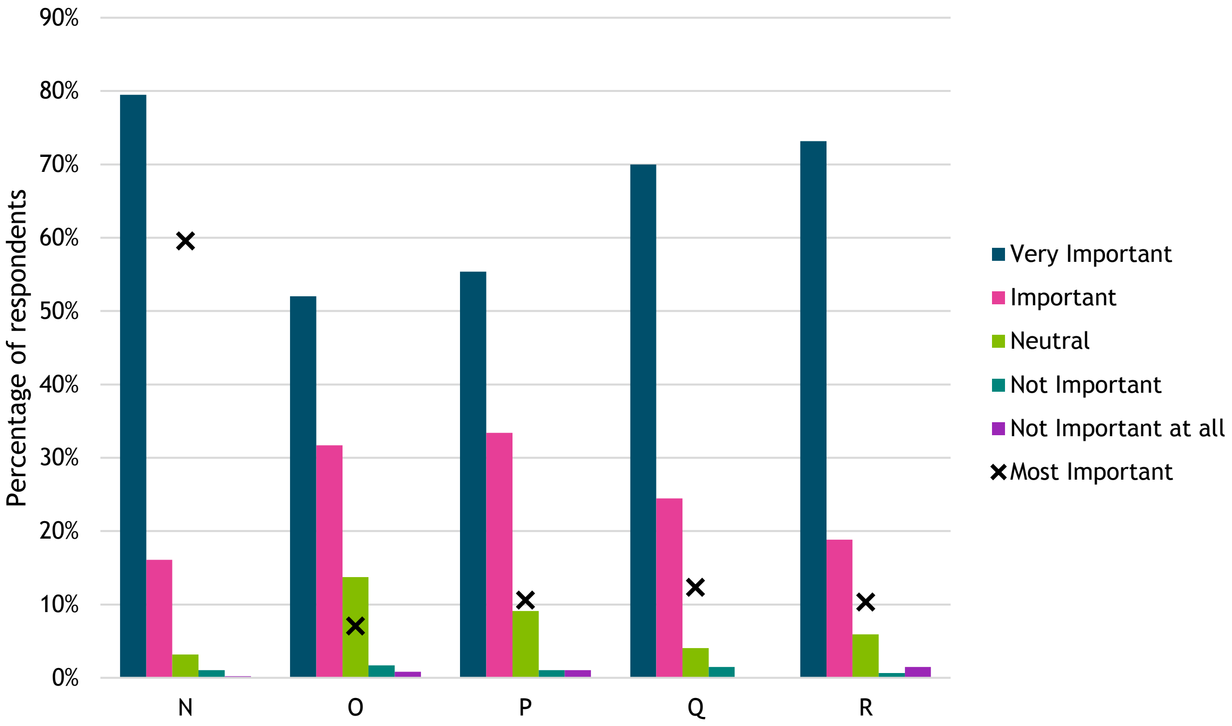
> *"With waiting lists for procedures now so long, the system needs to be much more flexible. Patients are expected to put their life on hold for months, as if they unavailable when the hospital offers an appointment, they are removed from the waiting list."*

Information about treatment and choices

Respondents also pointed out how "*it is important to be given choice where possible but as long as I have the right information/enough information to make that choice*". Respondents not only wanted "*the necessary information about my condition*" and "*complete and readily accessible info on my condition*" one respondent was also interested in "*information about natural, complimentary options as well as medical solutions*" another highlighted that they wanted "*information on waiting times for treatment in local area and areas nearby*" to help them make decisions about their health. It was also highlighted how "*the information I am given to help me make decisions need to be expressed at a level appropriate to my level of understanding, clear and unbiased*". On the other hand, one respondent pointed out how they feel there is "*too much time faffing about "informed choice" and not enough on actually doing*"

2.4 Help needed to keep independence and stay healthy

Respondents were asked to rate eight statements based on how important they were to keeping their independence and ageing healthily, 473 provided an answer to this question. All of the statements were considered 'very important' by the majority of people, the statement "*I want to be able to stay in my own home for as long as it is safe to do so*" was rated as most important with 79% (376) rating it as 'very important'. This was followed by 73% (346) rating the statement "*I want my family to feel supported at the end of life*" as 'very important'. They were also asked to choose the statement out of these they felt to be the most important, 453 respondents answered this question. The statement which was selected most frequently was also "*I want to be able to stay in my* *own home for as long as it is safe to do so*" with 60% (270) choosing it. *Figure 8* displays the results to these questions.



N. I want to be able to stay in my own home for as long as it is safe to do so.
O. I want my community to be able to support me to live my life the way I want.
P. I want my family and friends to have the knowledge to help and support me when needed.
Q. I want there to be convenient ways for me to travel to health and care services when I need to.
R. I want my family and to feel supported at the end of life.

Figure 8. A chart showing the response of 473 people asking them to rate statements based on how important they believed them to be to keeping their independence and ageing healthily and the response of 453 people asking them to select the statement they considered most important to keeping their independence and ageing healthily.

Two hundred and fifty-five members of the public answered a follow-up question asking "if there was one more thing that would help you retain your independence and live healthily for as long as possible, what would it be?" The themes from this question included *care closer to home* and *transport*.

Care closer to home

The comments largely centred on *"keeping services local"* and *"care in my home"*. While comments centred on health and personal care in the home such as *"I would like to be able to have a home visit from a doctor who does not make me feel as if I am a nuisance [...] a visiting nurse service would be helpful if I needed it too"*, some respondents instead called for more *"practical help such as gardening, shopping, housework etc."* and *"easier access to support in home ie cleaning, washing etc."*. Other respondents highlighted the importance of continuity as for one respondent "*over a period of 3 months saw 10 different nurses*", the following comment from a home visitor also discusses how continuity in home care is important.

- *"I'm a voluntary home visitor to an elderly lady. She needs personal and domestic help now.. She dreads the idea of many different carers coming into her home at* *times which are not suitable. She is using her savings to have a carer who is always the same one to call every day to help her stay in her own home."*

However, on the other hand the following respondents did not want all care in their home as explained in these quotes

- *"I would not want to have all my interventions at home. This limits independence as confidence is not increased. Many people consequently never leave their homes. It is important to have a purpose to going out. It is also more costly to the health service. One therapist or nurse can see & treat several patients in a day hospital setting."*

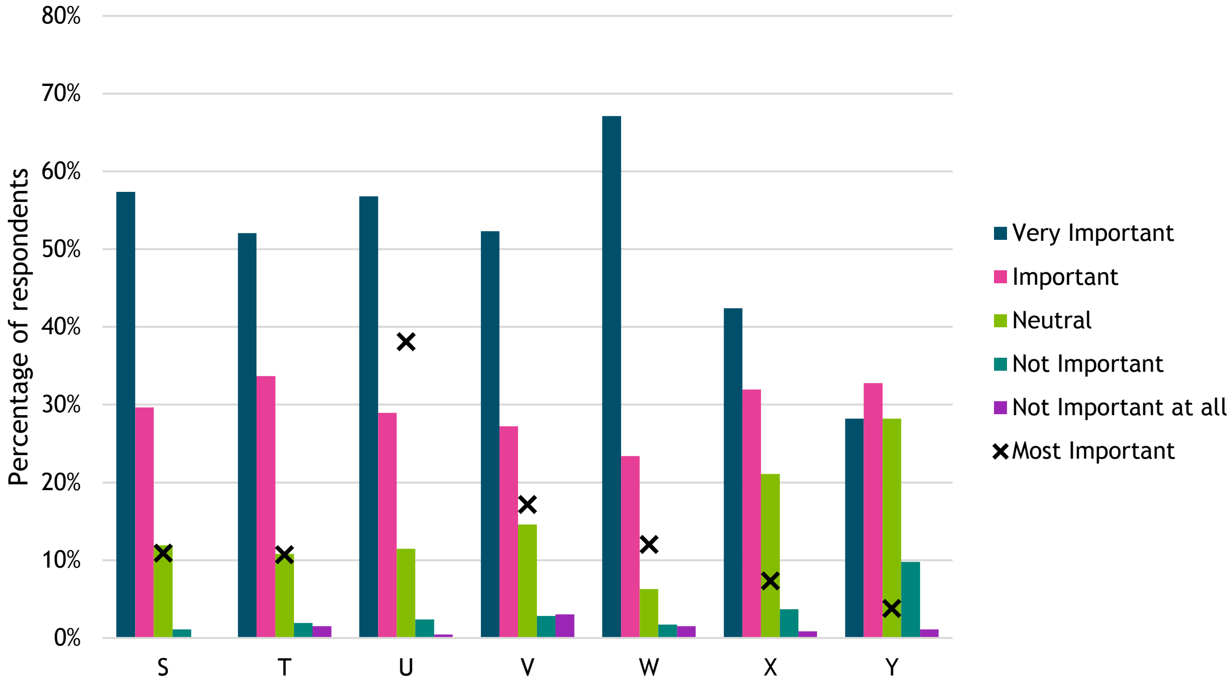
- *"Connections with other people, sometimes a care home is the right option for people. Care in the community may be naively believed to be better and cheaper but not always in the long run."*

Transport

Other comments in response to this question mentioned *"better transport"*. Several respondents were *"unable to travel independently*" and therefore it is "*important services available in local community to avoid distance travel to receive them"*. Alternatively, if services were not able to be closer to home other respondents asked for *"improved transport in rural areas to attend clinics, hospitals etc. maybe volunteer car service"* and *"free travel to medical appointments*"

2.5 Interacting with the NHS

When asked to rate seven statements based on how important they were to keeping their independence and ageing healthily 463 respondents provided an answer. All of the statements were mainly considered 'important' or 'very important', the statement "*any results are communicated to me quickly making best use of technology*" was rated most frequently as 'very important' with 67% (310) of respondents. They were also asked to choose the statement they felt to be the most important from this same list of statements, 449 people answered this question. The statement which was selected most frequently was "*I can talk to my doctor or other health care professional wherever I am*" with 38% (171) choosing it. Only 4% (17) of respondents chose "*I am able to talk to other people who are experiencing similar challenges to me to help me feel better*" as most important, making it the least popular statement. *Figure 9* is a chart showing the results to these questions.



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

Figure 9. A chart showing the response of 463 people asking them to rate statements based on how important they believed them to be when interacting with their local NHS and the response of 449 people asking them to select the statement they considered most important when interacting with the NHS.

Two main themes emerged in response to the question *"If there was one more thing that you think needs to change to help you to successfully manage your health and care, what would it be?"* These themes were *technology* and *communication*.

Technology

In the previous question respondents were asked to rate statements relating to technology, therefore several of the follow up responses were also related to technology. In particular respondents were reluctant to have a reliance on technology in NHS services. This may be reflective of the older demographic of responses which this survey received. The public argued that *"not everyone is technically proficient or has a mobile phone that does anything other than make phone calls & receive texts"*. For some respondents they had had experience with technology and did not feel it was successful *"trying to access things online with them in the past, has not been good or worked properly."*

Other respondents used this opportunity to criticise the wording of the questions pointing out that they may be comfortable with some level of technology but not all kinds as shown in the following quote.

> *"Phrasing of questions doesn't allow for practical answers! Of course I want to be able to access GP services by phone, but by saying "yes" I also have to agree to computer! I might be ok with making an appointment by phone but it's entirely*

different to a skype/face time consultation. Obviously regardless of answers this survey will be used to prove we want to move to on line services, not true in my case."

Despite a general dislike of technology other respondents believed that online technology could benefit services and called for *"online appointment booking"* and *"online access to all medical records"* and also online appointments as shown in the following quote

- *"The ability to ask questions of my GP & hospital care team without having to arrange a visit or wait for an appointment. A quick online interaction may mean that a full visit in person is not required."*

Communication

Another theme in responses to this question were in reference to wanting *"improved communication"*. This was for *"better communication between consultants and me"* but also for *"improved communication between all healthcare settings"* and *"sharing of medical records"*. As shown in the following experience computer systems were seen by some to be limiting this communication ability.

- *"Hospitals/GP's using the same computer systems to prevent having to wait for information to be transferred/ found. I have been to many appointments where professionals are unable to "see my records" due to technology and therefore something has to be carried out or looked into "next time" or I have to wait/ or it is up to me to explain my situation (of which I may not have all of the facts or I have had to explain this several times to various medical professionals which in some circumstances can be upsetting)"*

2.6 The law and integration between NHS and Social Care

When asked whether they think that the law needs to be changed to prioritise integration and collaboration between the NHS and social care 69% (312) answered 'Yes', 5% answered 'No'(23), and 26% (118) answered 'Don't Know', see *Figure 10*. They were then asked why they felt that way and some of the main reasons for the answers are presented below.

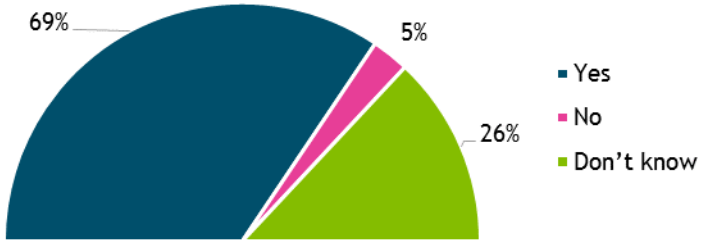


Figure 10. A chart displaying the responses of 453 people to the question "Do you think that the law needs to be changed to prioritise integration and collaboration between the NHS and Social Care?"

The comments from people who answered 'yes' indicating that felt that there needed to be a law change mainly mentioned how it would *improve communication* between services and how it would *help prevention of future health problems.*

Improve communication

Many respondents suggested that integration would help *"health and social care learn to communicate effectively with each other"* there was a belief that *"health and social care need to be seamless to avoid in fighting between the two as happen currently"*. It was also pointed out how by improving communication it would *“avoid duplication of effort”* and that *“people wouldn’t have to constantly repeat themselves to different services and would allow for better continuity of care*”. Respondents understood that without integration the two services find it difficult to work together as shown in the following quote:

- *“There are a lot of very good and capable people who could work together very well and efficiently but are prevented from doing so by the system they are bound by.”*

Help prevention of future health problems

It was also highlighted how by improving integration of health and social care it would prevent future health concerns. This integration was seen to benefit all stages of health issues, for instance “*the more information that is shared the quicker you can make a diagnosis*” and “*working together as a team should result in better aftercare*”. The following response provides an example of how it could be beneficial:

- *“Social care is as much a part of our overall health and well-being is as well and can often be preventative to future acute medical needs. E.g, elderly person falling at home ending up in A&E when perhaps she didn't have the right care at home.”*

Twelve respondents who answered ‘no’ explained why they did not believe the law needed to be changed, some examples of their reasons are presented below:

- *“They have different functions and should do what they are best at.”*
- *“Because social care is means tested and mainly delivered by private profit making companies, the NHS is not about making profits. The social care budgets have been drastically cut. Staff are not paid or trained to the same level as NHS staff.”*
- *“There should be a three way integration and it should include housing too. However, better ways of joint working and the ‘buy in’ from health would be a step in the right direction!”*
- *“Both sectors should have a symbiotic relationship regardless of legislation”*

The main reason that respondents answered ‘don’t know’ was that they did not feel they had enough information on the topic to provide an answer.

2.7 Any other comments

The respondents to the survey were given the opportunity to share any further comments they had about the Long Term Plan. While most of these comments have been discussed earlier in the report, a few new ideas and comments not already discussed are shown below.

- *“I think the main thing that needs to be changed is to remove the private organisations who use NHS funding to generate income for their shareholders. The NHS should be publically funded and all services should be directly supplied by the NHS. No sub-contacting or private tenders. Private medical companies should not be part of the organisation. If people want that let them pay for BUPA.”*
- *“The GP resources need to be closely linked with planning in the area. You cannot put a quart into a pint pot and this is putting lives at risk, pressurising GP's who*

are leaving the profession in droves and as a result putting a completely unnecessary strain on hospital services."

- *"I feel passionately that mental health should come under one umbrella instead of having separate groupings ie Asperger's syndrome gets less inclusion than for example dementia and the condition needs more provisions."*

- *"There needs to be more information sharing across health professionals in respect of special requirements. For example my parents are both profoundly deaf but their needs for sign language interpreters has to be reiterated and requested for every single appointment, nothing is automatic - their circumstances do not change, they are deaf and will remain deaf with sign language as their first language."*

Respondents also shared their thoughts on the Long Term Plan survey in general and some of their opinions are below.

- *"This feels like a very tokenistic exercise passed off on to healthwatch so the NHS can tick a box to say its 'consulted' the public."*

- *"I dislike that the questions in this survey are not autism-friendly - some of your statements could mean different things, depending on how you read them, and that creates a barrier to me accessing it."*

- *"One answer is not enough. Doing it this way is not fair. All the answers are equally important."*

3. Conditions specific survey findings

3.1 Characteristics of respondents

We have received interest from 135 people of which there were 79 usable responses. Responses were received across Norfolk and neighbouring counties. The distribution of the location, based on the first half of postcodes, of respondents is displayed below in *Figure 11*. All findings will be presented by the number of people not percentages, due to the lower number of responses for this survey.

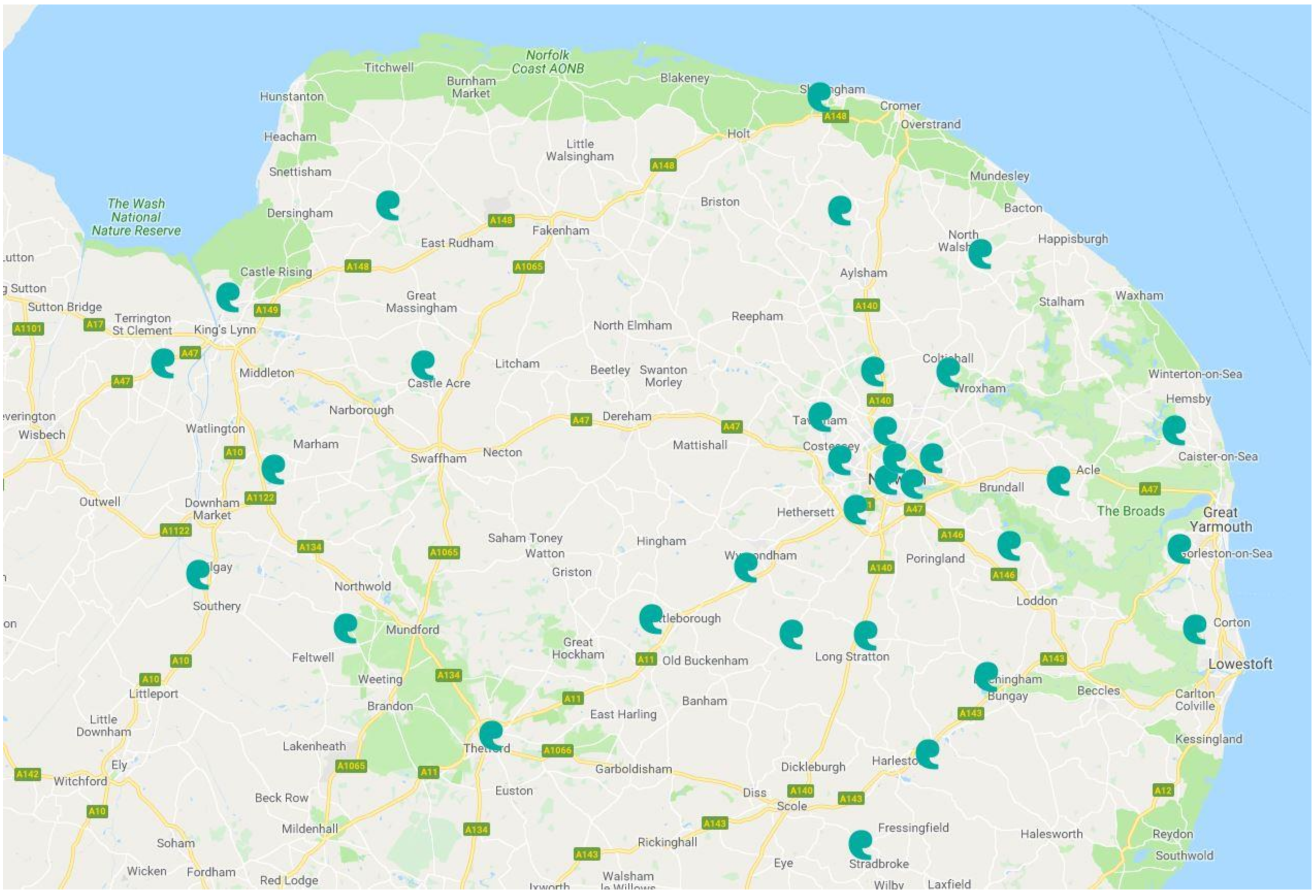


Figure 11 . A map displaying the locations (first half of postcodes) where responses were received from

Forty-four (44) respondents were female and 14 were male, whilst a further 19 chose not to disclose their gender. As a result, male representatives were slightly underrepresented within this sample. Respondents ranged from under 18 to 75 and over, showing a vast range of ages reported (see *Figure 12*). Thirty-eight (38) out of the 59 that answered were over 55 years old, with the most common age category highlighted as age 55-64.

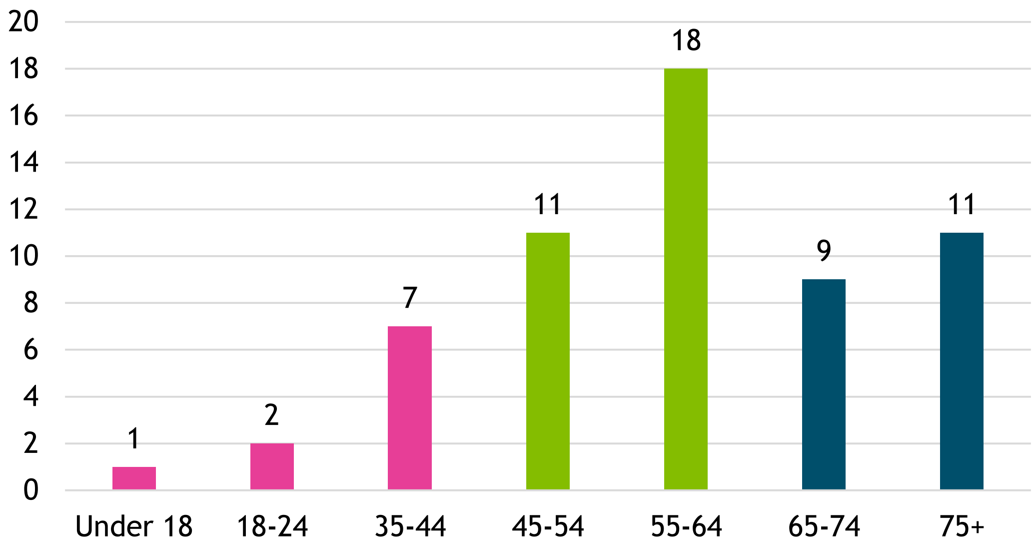


Figure 12. A bar chart displaying the age distribution of respondents to the conditions specific long term plan survey

Thirty-four (34) of the 59 respondents disclosed they had a disability and 19 respondents said they were a carer. The majority of respondents were predominantly White British (54), in addition to a small amount of those describing themselves as ‘any other White background’ (4) or ‘Arab’ (1). Twenty individuals did not disclose their ethnicity. The majority (52), shared their sexuality as being heterosexual and 23 individuals did not disclose their sexuality. Twenty- five (25) respondents described themselves as Christian and a further 25 stated that they did not belong to any religion at all. Four respondents selected they ‘prefer not to disclose’ and two respondents said they had an ‘other religion’. Twenty one respondents did not detail their religion.

3.2 Long term Conditions and getting help and support initially

From the sample of 60 respondents, 29 identified they had long term conditions, 26 declared they had multiple conditions and a further 5 had ‘neither’. Nineteen respondents did not answer this. Seventy-six (76) patients highlighted the condition they had when completing the questionnaire. Nearly two thirds of the participants (49) most commonly had a long-term condition such as diabetes, a further 13 identified themselves as having a mental health condition. Heart and lung diseases, cancer and autism were also conditions highlighted by respondents (see table 1).

Condition	Number of people
Autism	4
Cancer	3
Heart and lung diseases	6
Learning disability	1
Long-term condition e.g. diabetes, arthritis	49
Mental Health	13
Total	76

Table 1. Conditions identified and reported

Most commonly respondents (63) were responding on behalf of themselves compared to 16 who were responding for ‘someone they care for’. Interestingly, the majority of respondents (73) reported that their condition had not started in the last three years, it dated back further than that. Only 6 respondents' condition had started more recently.

Respondents were asked if when they first sought help if the support met their needs, there were mixed views on this. Thirty-two respondents (32) stated the 'support **did not** meet their needs', and 22 felt the 'support **did** meet their needs' and a further 24 felt it '**somewhat** met their needs'. When asked to explain their reasoning on how their initial support could have been improved often respondents noted the long waiting times and delays to accessing help in a timely manner, with limited treatment available; *"Primary care was good but I was told I would need to wait over 3 months for a consultant appointment. I decided to go private":*

- *"It takes far too long to access support for mental health through the wellbeing service and the group setting is not appropriate. The response at the end of the meeting regarding any questions you may have was also very cold."*

- *"There was a long wait for any support services - referral to general hydrotherapy took about a year. There was a limited amount of treatments that could be given for a very limited time e.g. only 6 acupuncture treatments at a time or 6 hydrotherapy treatments with it being very difficult or impossible to renew treatments."*

Varied experiences with services

- *"Good care from carers who visit to support each day. My husband lost the ability to stand/walk while a patient in the QEH for nine weeks. He therefore has to be hoisted from bed to chair, commode etc. Response for assistance from GP practice not always positive but has improved lately. Too dependent on receptionist putting the correct message 'on screen'. Took nine days for a critical blood test to be arranged the result of which revealed chronic kidney failure and a further hospital stay. Support from community nurses NCHC VERY variable. Responses to request for assistance when catheter blocked [took] many hours on [this] occasion. Never aware when nurses are planning to visit which causes problems as we go to the QEH for physio."*

It was also noted by one individual that that things had not always been picked up at first which delayed treatment again:

- *"My chronic pain was not taken seriously by the health professionals at my surgery. It took almost a year to be referred to the hospital, but once I got referred the treatment and care has been superb. Health professionals at my surgery have changed and the care I receive now from my doctor is very good."*

Despite this some felt well supported by services: "I can't fault my GP practice. They have always, without fail, given me the support I need. They are genuinely concerned for my welfare and do their utmost to help on all occasions."

- *"I feel I'm well supported by the Rheumatology Dept at JPH. I have access to the RA nurse if I need help between appointments. The staff in the infusion clinic are excellent too. I also get a lot of peer to peer support through the local NRAS group."*

On the whole when asked to describe how they would rate their experiences of accessing help the 77 respondents had mixed reviews. Twenty six (26) described it as ‘Average’, a further 15 rated it as ‘positive’, 13 people rated it as ‘very positive’, 12 as ‘very negative’, and 11 as ‘negative’.

Nearly three quarters of the respondents had another long term condition (57) leaving 21 respondents who did not. Again there were mixed views on if having another condition impacted on their ability to get support. Twenty three people (23) felt it made ‘no difference’, 21 people felt it made ‘getting help harder’, compared the 9 how found it made ‘getting help easier’. Six people ‘didn’t know’.

3.3 Support received after initially seeking help

Respondents were asked to describe the time they had to wait for their initial assessment/ diagnosis. Most commonly it was described as ‘slow’ (18) or ‘very slow’ (18), ‘ok’ (18), and only 14 respondents reported it was ‘fast’ (11) or ‘very fast’ (3) see *Figure 13* below.

When commenting on the length of time they waited respondents recalled the long waits had experienced and the impact this had on their care. One individual suggested that they believed the NHS system was failing:

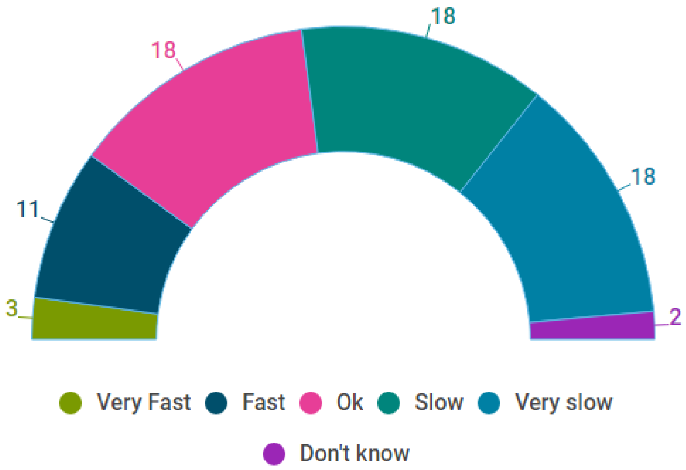


Figure 13. Time respondents had to wait to receive initial treatment/diagnosis

- *“One and a half years. That is the ‘normal’ time you wait from visiting your GP, to referral, then surgery. It’s happened 4 times to me. The standard of care is equivalent to a third world service. It might be ‘free’, but it’s definitely broken. I know foreign nationals who’ve got an indefinite leave to stay visa, and have worked here for over a decade who still choose to fly thousands of miles home to get medical and dental care. They say it’s rubbish here and don’t know how we put up with it.”*

- *“I had to wait 3 weeks for an X-ray to be sent to the GP and then 4 weeks to get an appointment with the GP who knew about my condition.” Again with similarities to the previous question highlighting missed diagnosis leading to delays. It took years before one diagnosis was made and it was only picked up by a physiotherapist. The GP apologised for not thinking of it. Another diagnosis was only picked up as a result of my insistence on some blood tests.”*

Often it was recalled the referral took most time and once that was through treatment was quicker; *“It took years for the condition to be recognised as the GP didn’t recognise it. When it was recognised the waiting time was short.” “A year for my surgery to refer me to a specialist but once referred the wait was only a couple of weeks.”*

Similarly, our findings indicate that when respondents were then asked how long they waited between their initial assessment/diagnosis to receiving treatment, likewise respondents commonly reported this to be ‘slow’ (16) or ‘very slow’ (14) (See *Figure 14*).

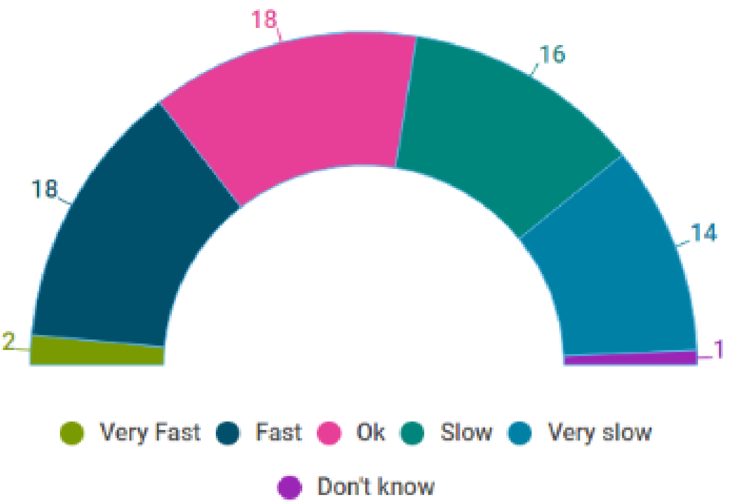


Figure 14. Time respondents had to wait between initial assessment/diagnosis to receiving treatment.

Over half of the respondents were offered further support after diagnosis (40) whilst 31 were not. For some that support was a lifeline and invaluable. *“Choice of location for support, clinic, home or school. Mobile numbers for support workers so we could text re prescription changes or to make appointments or pose queries. This was absolutely invaluable to us.”*

Respondents highlighted that receiving specialist information and advice, from kind, friendly and supportive staff worked well in services they had accessed. “An excellent GP and practice nurses who are very professional and supportive.” “Complex Needs teams in Paediatric worked very well with Diabetes, Team, EACH and Special School then managed Transition to Adulthood well as his needs were so complex.”

For others support proved more problematic due to a lack of communication and availability of services. *“Support for one diagnosis has been good, second one rubbish and not really known about, and hard to know which diagnosis impacts what.” One patients described what could be improved in services, “Communications between different trusts. Communications between local hospitals [,] GPs and communications between GP and hospitals.” Some called for “more time [to be] given to the individual” and more patient centred holistic care that considers other options as well as medication, “Better adult services looking holistically like a paediatrician does, so many [departments] in adults for each symptom, e.g. Migraines, digestion, joints, even though it is all due to one condition!” “Support from the Pain Clinic other than drug based. Information available on other sources of heated pools - this was like trying to find out state secrets.”*

3.4 Accessing specialist support

Fifty three of the 70 who responded to this question had been referred to a specialist and most commonly the time they waited for this was referred to as ‘ok’ (15) or ‘slow’ (15). A further 10 participants reported access as ‘very slow’ yet in contrast 9 respondents described it as ‘fast’. Some felt that considerable waits were unacceptable and GPs waiting times were an issue, commonly people referred to 2-3 months wait to see a specialist.

- *“When people are living with chronic conditions, especially ones that means they live in daily pain, any extended wait for support from a specialist is not acceptable.”*
- *“I waited several weeks to see a specialist but the main wait was at the GP as they sat on my condition for a while and requested several unnecessary test without making a diagnosis while all they needed to do is to take a simple neurological*

history and examination. The problem is that GPs never gave time to do such things…”

- *“I think I waited about 3 weeks between receiving the diagnosis and seeing the gynae surgeon. Bearing in mind there had been a 3-4 month wait between GP referral and seeing a specialist gynae doctor (in Yarmouth), the referral on to surgeon was relatively fast.”*

Respondents were asked how easy they found it to access ongoing support once diagnosed and interestingly there were quite mixed views (see *Figure 15*). Twenty (20) people identified it was ‘ok’ getting ongoing support, 17 found it ‘very difficult’ a further 11 found it ‘difficult’. Very few suggested that it was easy to get help.

As a result, patients felt that on the whole support did not always meet their expectations completely. Twenty-eight (28) stated it met their needs ‘somewhat’ whilst 21 stated ‘no’ and only 16 saying it had met their expectations (see *Figure 16*).

Linked to this there were mixed findings on the support that was offered to patients and how useful it was in this instance. One respondent mentioned that their options were limited if medication did not work: *“I haven't received any support. Just diagnosed, medication given and sent on my way.”*

Figure 15. How easy it was to seek ongoing support after diagnosis

- *“The care by my GP, is second to none. However, if the medication recommended by the Psychiatrist does not help, I was offered no further support and no other support.”*

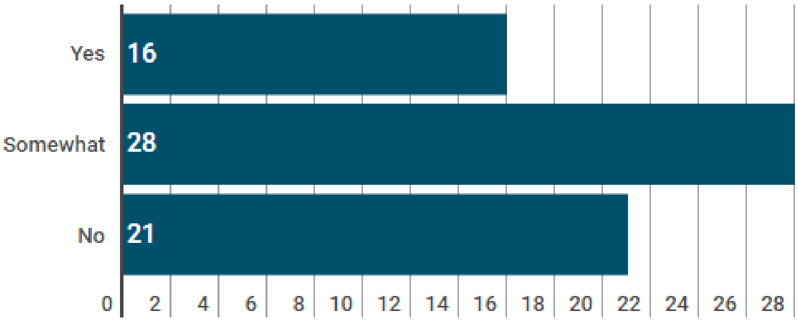


Figure 16. Did the ongoing support meet your expectations

One patient called for better access to ongoing support in relation to mental health, “…better access to face to face 1-2-1 mental support/counselling.” More information was also seen as a crucial component to getting better support, “…more information and how it was going to affect me would have been nice.” “Entirely provided by charities. Photocopies of out of date leaflets provided by NDS [Neurodevelopmental service- ASD] so I googled. Why not direct to the Norfolk county Council "local offer" website?” A lack of ongoing support available to patients was also emphasised with the reliance on medication.

- *“One physio referred me back to a consultant because I couldn't commit to the exercise programme he suggested due to the severity of my condition. Although some treatment and support helped for the time it was available to me, it did not cure any of my conditions and at the end of it, I was left with the conditions and no ongoing support.”*

- *“When you are told you have ILD , I looked online to find out what it was and what I could expect, Went back and he couldn't give me any help till it gets worse , But I do think that someone to talk to about it might help as you go away feeling like you are just a statistic.”*

On the whole nearly half of the respondents (29) highlighted that they **did not receive** timely and consistent communication from services, given previous findings this is not surprising. A further 19 felt it was ‘somewhat so’ and 16 felt the communication was timely and consistent. Many comments highlighted the need to push for answers to receive the right care and support due to a lack of congoing communication, *“We had to take the initiative and push for treatment.”*, *“You have to chase everyone up…”*, *“I felt more time should have been available to discuss the problem.”* “Care was ok but information was nearly non-existent.” *“I constantly had to do the pushing at times I felt I was being ignored as if my level of pain wasn’t sufficient to move on.” Often this lack of communication also was further impacted upon due silo working across Health and social care services, “Lack of joined up thinking in all departments working together instead of in isolation.”*

One patient highlighted that their expectations of their care and medication was not met due to delays in receiving medication and not feeling supported:

- *“Some hospital specialists prescribe and issue drugs, others write to the GP suggesting that they prescribe them, which necessitates another visit to the GP which can take up to three or four weeks to find an appointment with the GP that knows your medical history best. During this time, the patient is doing what they can to manage their chronic conditions and feeling very unsupported. One specialist ran tests for suspected conditions and when he didn't find them, stopped making appointments to see me and has a quick word with me on the back of my husband's appointments which are infrequent. This leaves me feeling very neglected and not receiving the care that my GP suggested I could expect.”*

3.5 Travelling time when accessing treatments

For rural Norfolk it is not surprising that 47 out of the 65 respondents identified they would use their own car as their main means of transport to appointments. Thirteen (13) said they would use another person’s car for a lift, and another 5 would get a taxi and 3 would get a bus. Patients were asked **about their willingness to travel to receive treatment and diagnosis.** Sixty three (63) respondents answered how long they would be willing to travel for an accurate diagnosis and patient’s views on this were mixed. Most commonly (23) respondents said they would be willing to travel ‘30 minutes to 1 hour’. Sixteen (16) respondents said they would be willing to travel ‘1-2 hours’, 13 were willing to travel ‘over 2 hours’ and 11 were willing to travel ‘less than 30 minutes’ (see *Figure 17* below).

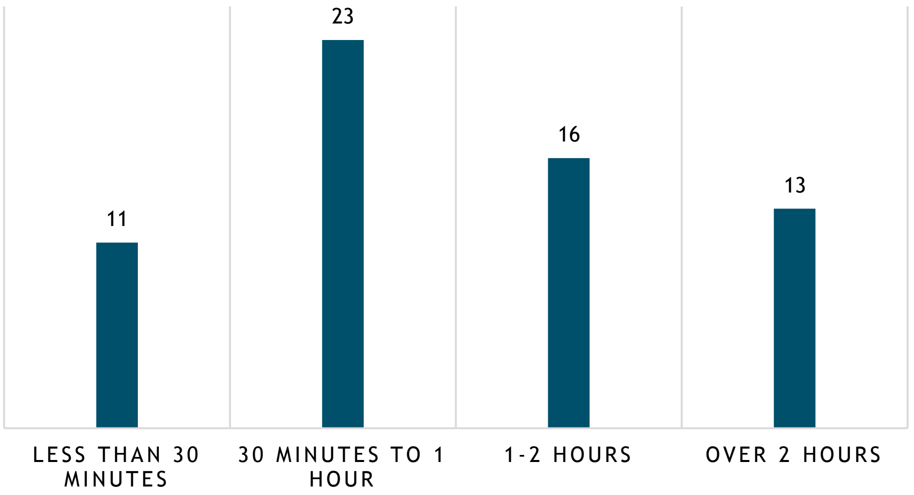


Figure 17. Time willing to travel to get an accurate diagnosis

Interestingly most commonly a higher number of people (23) were willing to travel 1-2 hours to receive specialist treatment (see *Figure 18* below). In contrast 11 people were willing to travel ‘less than 30 minutes’.

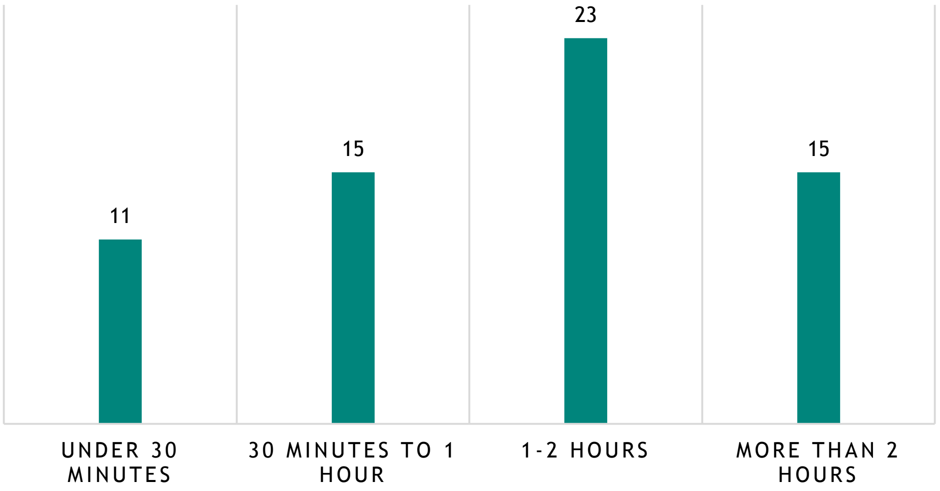


Figure 18. Time willing to travel to receive specialist treatment

3.5 Support patients to have more control over their care. When patients were asked about what was important to them, it is not surprising that for many of the options 'seeing any medical professional who is free immediately' was favoured when first seeking help (39), during the initial appointment (29) and getting a diagnosis (28). Patients wanted that immediate access to help and support. However, when receiving long term support continuity of care was reported as most important, 'seeing a health professional you normally see but you may have to wait' (42).

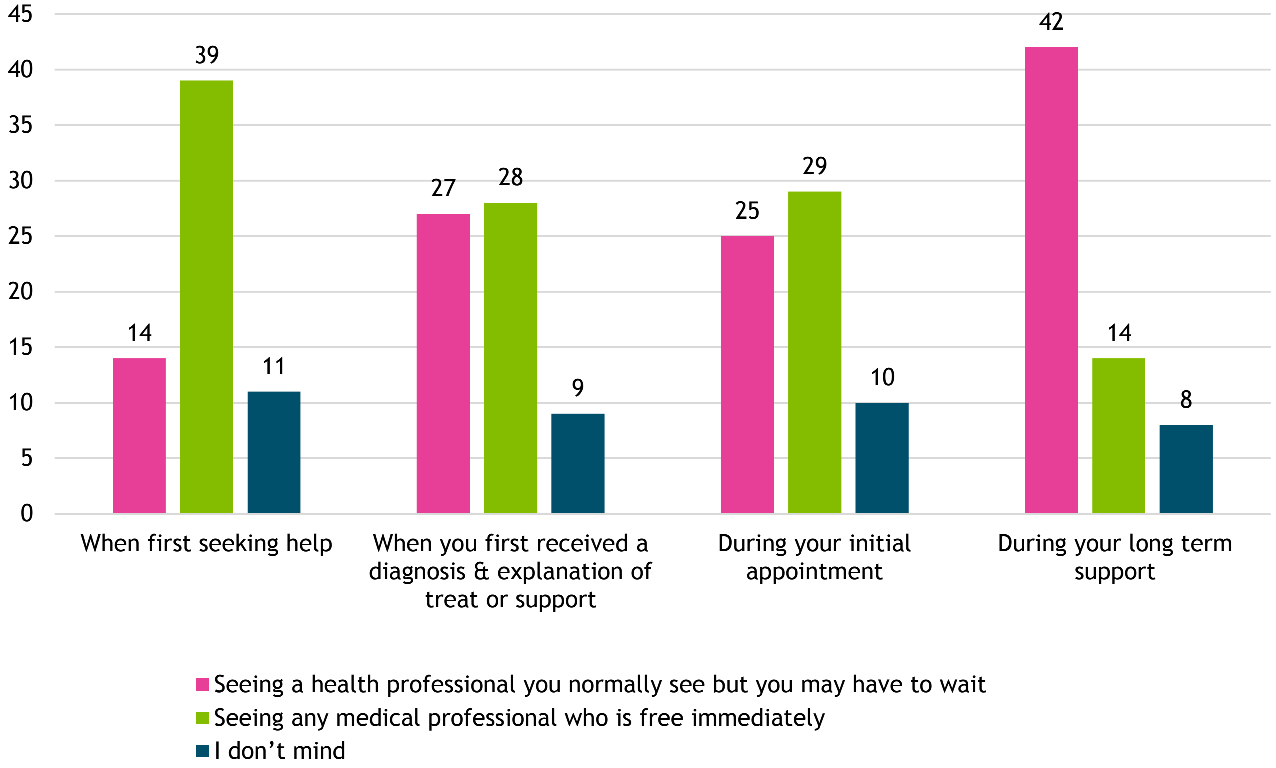


Figure 19. A chart displaying responses to the question "what is most important to you?"

Patients were asked about what level of support they expected from the NHS to help them stay healthy. Over half of the patients wanted 'some support' (40) out of the 62. Eighteen (18) people suggested that they wanted 'a lot of support' and a further 3 felt they needed 'no support'. Respondents felt that more holistic care and improved communication from services was needed to enable them to stay healthy. Timely access to appointments also proved critical with more ongoing support available especially within the community to enable them to better manage their condition, *"reduce waiting time. The NHS are making people suffer unnecessarily. It is beyond frustrating." "Offer advice. Just found out I have on top of everything else diverticular disease, but have no idea what to eat to manage this, diabetes, IBS, and ME [*Myalgic encephalomyelitis*]."*

> *"To be flexible and responsive to my needs. My condition is variable and I can have long periods where I'm well and manage independently, other times I might need to just check in with someone and in some cases I need significant support. Having access to support when I need it (rather than needing to go through a lengthy referral and assessment) based on my experience and self-management would be invaluable. I think my demand on services would be less over time if I felt I wasn't on my own or unsupported."*

- *"Improve communications between Hospitals and GPs. Continue to advise on Health group sessions/clinics. This is a good endeavour at the grass roots e.g., Diabetes Clinics, asthma Clinics, Lung Club etc. These are all good initiatives."*

- *"Any medical professional that I see needs to take a holistic view as some of my conditions conflict with each other and can have adverse effects on each other. Drugs should not be the only considered treatment and access to physio and complementary therapies as well as personal support for your mental wellbeing when living with chronic conditions would be very welcome."*

- *"Ensure waiting times are reduced for hospital appointments. Ensure you can see a GP in an acceptable time frame, ensure clinicians make decisions regarding one's condition rather than reception staff acting the triage role. Use locally based pharmacists more effectively to give advice for minor conditions."*

Forty-two (42) out of 63 patients felt that the law needed to be changed to prioritise integration between health and social care services, whilst 21 people were 'unsure'. Patients explained that this would in turn hope to reduce duplication across the system as good will was no longer enough, *"good will of a few key professionals is not enough, there needs to be equity of access across the country…" "I was a social worker for over 40 years. I have seen gross wastage and poor care due to organisations arguing about who is responsible."*

- *"…As Social Care funding is stretched health is being expected to pick up needs and vice versa - especially regarding delayed discharge or delayed transfer of care ie. lack of community support for those well enough to go home but in need of a robust support package to stay home and stay well."*

- *"Hopefully merge budgets, reduce duplication of staff and manage patient care in one continuum. Again hopefully be able to ensure that medically fit patients are discharged in a timely manner from hospital freeing up beds and enabling the hospital to manage flow more effectively."*

- *"One doesn't know what the other is doing, and one tries to pass the problem to the other…all about who is paying for it, not patient centred at all. Treat in the community is cost effective!!!"*

- *"One set of care notes mean I won't have to be asked the same questions again and again if they were accessible by all professionals 24/7. Integrating services will ultimately save money."*

One respondent felt that the law did not need changing as integration has worked better in services in the past, they felt that lack of funding was the issue:

- *"I have worked as a nurse in the NHS and a social worker in adult services in local government. Despite the bad press they receive, local authorities can provide more flexible and accountable services than NHS. There are issues about funding which cause divisions. However, at a local level health and social care staff can work extremely well together and, during the late 90's and early 20's, some really innovative joint working initiatives developed. Sadly, all these have disappeared under 'austerity' funding cuts. So, I'm ambivalent about collaboration as, in fact the legislation is already there to make it work (section 33?) but the funding issues* *(free at point of need versus means -tested) need to be sorted out. My opinion is that both health and social care should be free at the point of need and any 'means testing' should be via the tax system. Simples!"*

3.6 Any other comments

Respondents were given the opportunity to share any further comments they had about the Long-Term Plan. Most of the findings have been discussed throughout this report so far, however patients did highlight the importance of transparency, holistic and personalised care across all health and social care services and that if you are older there seems to be little support.

- *"Health service managers should be far more open and transparent. There's been far too much secrecy about STP."*
- *"I feel that after a certain age i.e.: 60 nobody really cares about the older person we are helped to live longer but when we do there is very little support for us."*
- *"More individual advice tailored to me and not my condition in general would be a great help."*
- *"The NHS is doing a fantastic job in dealing with people's health problems. We are all lucky to have such dedicated Doctors and Consultants who, in the main, 'live the job'. Please can the NHS have a better public Relations team to deal with the broadcast/news negativity we all get. There are few examples of the good the NHS is doing. Sure, not all is ideal but there is a better storey to be told than the Press wish to broadcast."*
- *"I do have a 'further comment'. Get the wretched Tories out of power. No one blames the NHS. Primary Care and education is important. There should be GP referrals to Slimming World as there are too many obese children and adults. It would save money further down the line. Treasure your own 'temple'. Because no one else will."*
- *"In my experience, the care I have received from the NHS has been excellent, but bureaucracy is unnecessarily costly and time consuming for the health professionals involved. These professionals should be trusted and our health should not be decided on an accountant column in a spreadsheet. It's much more complex than just money."*

4. Focus groups findings

In support of gathering feedback on the NHS Long Term Plan Healthwatch Norfolk carried out a series of focus groups across the Norfolk and Waveney STP footprint in spring 2019. The meetings were held on different dates and times at the following locations: -

- Healthwatch Norfolk HQ, Wymondham
- Knights Hill Hotel, Kings Lynn
- Hotel Victoria, Kirkley Cliff, Lowestoft
- Deaf Connexions, Norwich
- Innovation Centre, Thetford
- Holt Community Centre

4.1 Characteristics of attendees

The events were attended by a total of 101 people across 6 workshops. Predominantly an older white audience, but included some attendees from BME communities and 18-25 year olds, as well as local councillors, health professionals, retired health professionals, unpaid carers, people with long term conditions and members of the local Deaf community.

4.2 What did we ask people?

At each workshop all attendees received the same presentation (see Appendix B) which outlined the NHS Long Term Plan, the current context of our local health system, and explained the future aspirations of the Norfolk and Waveney STP to become an Integrated Care System (ICS).

Attendees were invited to make comments and ask questions as the presentation progressed and at the end of the presentation all attendees were given a summary of the NHS Long Term Plan (see Appendix C) and a list of the priorities set for Norfolk and Waveney (Appendix D) before splitting into discussion groups and asked to consider the following questions:

Discussion One Questions

1. Do you think the local priorities are correct?

2. What would you like to see in the local 5yr plan for health and care services?

3. Do you think that the law needs to be changed to prioritise integration and collaboration between the NHS and Social Care?

Discussion Two Questions

1. How would you help people live healthier lives?

2. How would you make it easier for people to take control of their own health and wellbeing?

3. What would you do to make support better for people with long-term conditions?

All comments made by members of each group were captured by HWN staff and feedback to the room at the end of each discussion where applicable. Individual summaries/records of notes from each event can be found in Appendices E to J.

4.3 What people told us

While we were inviting comment on personal experiences and views about care, people often offered comments on their perceptions of public policy and of this exercise. There was broad consensus across all workshops that plans seem to have already been made. Many people felt this was not a 'consultation', merely a tick box exercise on a national scale and their views would not be listened to.

People agree in principle with the ideals of the national plan and the local priorities but feel they are deliberately vague/optimistic to garner the desired response of broad public support. More detail is required as to how the 'extra funding' will be apportioned across the country and how these plans will be delivered, particularly given the local context of mass staff shortages/issues with staff retention, crippling PFI debt, reliance on expensive agency staff and three (out of the entire country's 14) trusts in special measures.

Mental health and social care are key areas to be addressed, along with staff recruitment across all services. Patients would like to see more apprenticeships, placements and on the job training, the re-introduction of bursaries and incentives to practice in Norfolk – particularly for GPs.

There were also large concerns over privatisation, under funding of services, bureaucracy and too much wastage on management as opposed to frontline services.

Concerns were also expressed around the future of Social Care, that there appears to be little evidence of a Green Paper being published and that health should not be considered as a singular entity.

There was broad support for social prescribing but a feeling it should be made uniform across the STP.

There was also a desire for those responsible for delivery of services (locally, regionally and nationally) to attend an annual meeting and provide a report identifying what changes, if any, are made, along with details as to how this has improved outcomes for both patients and carers.

In direct response to the questions posed the public response can be summarised as follows:

Are the local priorities correct?

- Participants at the focus groups were broadly in agreement that the priorities were correct but expressed some scepticism about how will they be delivered/achieved in Norfolk and Waveney and whether they are realistic for example when "*considering the amount of time it takes to secure funding, get plans in place and resource services.*"

- There was a general agreement that mental health and social care should be the top priority, and similarly better support is needed carers with one attendee emphasising that *"they are virtually prisoners in caring"*.

- Participants acknowledged the difficulties that the local acute trusts have in recruiting for example how West Norfolk *"doesn't have anything that draws staff to want to practice there"* and suggested solutions such as the *"government needs to provide financial incentives for them to come here", "more should be done to advertise the benefits of working here"*, and *"the three hospitals in Norfolk* *should develop specialisms to make them more alluring to junior doctors and medical students"*

- While the health and social care services were seen as important, participants also highlighted wider issues which could impact on health and wellbeing. Schools and education were particularly seen as a key to prevention such as suggesting that *"monitoring everyone not necessarily in the GP it could be done in schools, we need more school nurses*". Other participants highlighted how there's *"a bit of a contradiction because prevention is very important, looking after yourself but we live in a society that is encouraging people to eat more"*. Poverty and benefit services were also seen as a major health issue that cannot be addressed by health services, for instance highlighting how "*there is much lower engagement in services within deprived areas, zero-hours contracts mean that work is unpredictable and many people employed on them can't always attend appointments"*.

What should be in the local 5 year plan for health and care services?

- It was believed that fixing mental health and social care should be the top priority, in particular mental health services for children and young people and addressing issues around diagnosis and support for ASD conditions and dementia. One attendee who worked in benefits system highlighted how "*people have so much trouble accessing services at the minute because they are in crisis they come to us the amount of suicide and mental health first aid preventions I have to do now"*.

- As in the previous section, attendees felt that staffing issues should be addressed. They highlighted how *"a lot has been cut back over the years, like staff they stopped training in say 2010/11 and so overseas staff are coming in"*. Some ways in which they believed staffing issues could be addressed was through bringing back bursaries and incentives to train, eliminate student debts, stop using agencies and overseas recruitment and have more apprenticeships and training programmes.

- Social prescribing and tackling social isolation was seen to be beneficial but they felt that "*demand for social prescribing is very intense right now, and the limited resources to deliver it are strained."*

- Participants also highlighted administration problems such as a need to have joined up computer systems across all health and care services, and that *"all computer systems need to talk to each other!"* They were also keen to reduce wastage of money and middle management, and appointment non-attendance, with one PPG member pointing out that *"we find that non-attendance is the biggest problem in our surgery, yet I don't see that mentioned in any local or national plans. It would be good if we could sanction people for not attending"*.

- There was also an understanding that a lot of the health service "*is driven by finance and cost cutting"* and that this resulted in the cutting of community hospitals even when the acute hospitals were not prepared to cope with it:
    - *"are you sure if you remove this have you got sufficient resources to cover for all eventualities, but no they went ahead they closed Halesworth hospital, closed Southwold hospital and now they are just about to close all hallows hospital as well."*

Should the law be changed to prioritise integration and collaboration between the NHS and Social Care?

- Across the focus groups there was broad support for bringing together health and social care that *"there's a lot that could be improved with joint working"* and a feeling that *"we shouldn't be talking about them separately one relates to the other and vice versa*".

- Participants felt that people are currently passed back and forth with no one taking ownership, there is too much concern with protecting their own budget and therefore *"the idea of an ICS is good, but it has to properly incorporate social care, which at the moment is financed separately to NHS services."* They found that there currently is not equality in financing health and social care and how *"if you are just above the financial threshold you have to pay for most of it yourself"* they felt that to remove these inequalities would be *"to introduce some form of national insurance system for social care*". In general, people were in favour of higher taxes/national insurance, for example *"need higher taxes to pay for better services like in Germany"*. Other participants suggested that if necessary to pay for these services and feel money should be put aside from new housing developments and through charging people for missed appointments across all services. Another issue with funding raised was the fact that *"boundary issues are out biggest problem, they should define areas in terms of what hospital people look to not where they live"*.

How would you help people live healthier lives?

- A general consensus was that to help people live healthier lives a priority would have to be simply giving them better access to services. This was covered by an emphasis on more *"lighter-touch services in the community*" and closer to home, including community hospitals, day centres, social groups, support groups, and exercise programmes. One participant highlighted how social groups are *"an opportunity for isolated people to make social connections*". Similarly it was seen as a way to give *"people other viable treatment options"*, for example *"you might not need to get an anti-anxiety drug you might be able to join a wellbeing walk*". To improve health and increase engagement in these community activities it was suggested that it could be compulsorily prescribed by GPs or there should be incentives for example *"involvement in sport should be incentivised by making it cheaper and having more facilities in the community"*. They also suggested that there should be more funding for VCS, funding in a way which would provide long term security to small local organisations.

- Another large theme in the focus groups was on the positive influence schools, children's centres, and education beyond schools could have. It was suggested that educational interventions should be increased *"as early as preschool"*. This education was emphasised to be on *"wider health conditions such as the impact of social media on mental health*" and other areas such as keeping active, confidence building, healthy lifestyles such as *"teach cooking and health eating in schools and not how to bake cakes!"* Also in schools it was suggested that they could be used for *"early detection initiatives such as eyesight and auditory checks*" arguing that *"if a pupil can't engage because they can't see or hear properly it presents all sorts of other behavioural and health complications"*. Another service which was suggested as being brought into schools were wellbeing services and how *"there* *should be a mental health nurse within each school who can educate families in the community too".*

- Focus group attendees also raised additional wider initiatives such as initiatives being paid through higher taxes on sugar and fatty foods, reduce smoking by doing *"more to push smoking cessation every single time you interact with health services"*, how *"a lot of ill health is caused by poverty and inequality […] people aren't overweight because they're ignorant"*, and to reduce UK working hours since they are "*the longest working hours in Europe, which means people don't have time to look after their wellbeing"*

How would you make it easier for people to take control of their own health and wellbeing?

- As before, education was seen to be key to making it easier for people to take control of their own health. This included education for parents with one attendee sharing that their *"wife was a primary school teacher and there were children in their first year of school who would turn up unwashed and were really lacking in basic language skills"*. It was also felt that children's centres would be helpful since *"when support structures aren't in place, it leaves people without the tools to look after themselves, which is how lifestyle problems develop into adulthood"* however this attendee pointed out that *"centres have been cut meaning that chronically under-funded third sector organisation have been picking up the slack"*.
- Financial support was also seen to be helpful in encouraging healthy eating particularly since *"feeding your child a healthy diet is difficult too if you don't have money; it costs to have a healthy lifestyle"*

- Also as previously, attendees highlighted how more social prescribing being consistently delivered across all areas would be beneficial. They also suggested that there should be more initiatives to tackle social isolation such as 'Adopt a grandad' etc. and how prevention initiatives could help like 'Beat the street' which encouraged families to be more active in Lowestoft for which funding was cut.

What would you do to make support better for people with long-term conditions?

- Participants suggested that clearer pathways through services and better transitions between services would support people with long-term conditions. One participant pointed out that *"with all these private providers everything is so fragmented"* they shared a personal example how they *"have to go to book an appointment at the hospital for any health-related issues with my arthritis, then make a separate call to the private provider about my medication"*.

- It was highlighted that regular advice and treatment drop in clinics could benefit people with specific, long term conditions and this would mean *"knowing that you are going to be looked after at every stage of the journey and get support wherever you go and are monitored"*. This ongoing support should also be extended for mental health conditions and carers, particularly *"because mental health is such a fluid thing"* meaning that *"people need to be kept in the system in some form or another […] someone may be formally discharges but if that's the case they are often back to square one again"*

- Another theme in the discussions surrounded access to carers particularly with continuity of care and the rurality of Norfolk so therefore *"we need to make sure* *there is domiciliary support for older people even in the rural parts of Norfolk".* It was suggested that a way to improve care this could be through bringing all care back under council, *"they used to have a patch where they would see the same clients every day"* they felt that *"this was so much better because staff understood the needs of the client, who was also reassured by knowing who is coming in to their house every day".*

- Other suggestions shared in the discussions around this question included:
  - Ensure appointment reminders are shared with family members and carers so they can get vulnerable patients to their appointments.
  - Better access to Personal Independence Payments
  - Increase support available rather than simply giving out leaflets and ensure the VCS is properly funded to deliver it
  - Remove distinction between health and social care

Deaf Specific feedback

- In relation to the Deaf community, they reported they would like to see more deaf awareness across all NHS services and return to the use of locally based interpreters. *"I had to travel to Nottingham and I mean they knew my background, you know they don't seem to have any kind of deaf awareness. There was no interpreter there and when I arrived in Nottingham it was a real struggle."*

- A commonly raised concern was the availability of interpreters and the practicalities of not having one available for medical appointments. *"…so most people when they go to hospital they go and have an operation they are actually worried about the operation itself. But because I'm deaf when I go to the doctors my first worry is actually am I going to have an interpreter? You know I feel quite nervous about that…You know and actually that's a bit of a strain on the mental health for people to have this amount of anxiety."*

  It was also highlighted the importance of consistency of interpreters, especially during medical appointments, *"The interpreter needs to be able to stay there the entire time that I have the operation. So when I wake up after the operation I have been in a situation before where I have then seen a different interpreter and they have changed…whilst I have been having that operation…I feel it need to be the same interrupter from the start to the end."*

- One patient expressed similar concern, *"…when I went to Birmingham back in January I was reassured that I would have an interpreter and then there wasn't…I did then have an interpreter there for 45 minutes and then she had to go I needed an extra hour but she couldn't she had to leave so that meant I had to make another appointment. I had to go to Birmingham again with an interpreter but I only had an hour and that was it. Completely different services and I really didn't like that and I would have liked the same service with the same interpreter, I think that's a problem."*

- The deaf community felt that they would like to see in the five year plan that services were better for deaf patients. *"Can the NHS actually improve this NHS 111 as part of the 5 year plan?"* They would like to see that the interpreter service was 24/7 and improvements are made to access the NHS 111 service for the deaf. *"What I would like to involve in the five year plan is the interpreter service is*

really provided 24/7. It's the same for anywhere the police, ambulance service there service is 24/7 as it's an emergency service, deaf people need an interpreter to be able to respond quickly..."
"What happens in the middle of the night or it's really early in the morning and I'm ill, I don't really want to have to wake up my neighbour to ask for help. What do I do? …the NHS 111 we can't access…where is our independence"

- Often patients highlighted the lack of time they seemed to have in medical appointments and called for longer appointments, *"I feel that you have limited time with the nurses actually and I don't feel that we have enough time. So more time to discuss and fully understand health problems would be good. More information in BSL." Alongside this, they also called for more information to be provided in BSL and the use of videos for specific conditions that are signed would be very helpful. One participant explained she has to test her blood sugars and could benefit from videos to support this. "…I think it would be better to use the DVDs and will help us feel a little bit more aware you know we could re-watch the DVD if we need to. When we meet with an interpreter we just have that one chance to get all that information and we may forget it. I don't think a DVD just for diabetics I think for other conditions may also be useful…"*

- To enable the deaf community to take control of their own health they felt that having access to deaf friendly classes and local support groups such as dementia, would be supportive. *"…having a support group for those with Dementia say. It would be nice to meet other people if they had an interpreter there for deaf people only. As if you are deaf you can't access a hearing support group."*

- To make services easier to access the deaf community felt that loop systems and name/number calling systems should be made compulsory in all GP surgeries with greater use of signed videos. *"Not all doctors' surgeries have the loop and they don't have them in every room they should all be the same really. Maybe include that in the five year plan add in a loop system so that all doctors' rooms do have a loop system so for some of us that can use it that would help."*

  "I'd like to make a suggestion that perhaps in the doctors waiting rooms they have a television in the corner and they have an interpreter on there. Deaf people can see the TV and see people talking but they don't understand what is going on the television, if they turn the sound off hearing people will understand what this is like!"

Other comments/concerns

- Greater transparency needed over PFI.
- Appropriateness of digital technology, many patients have low levels of digital literacy and there are many rural areas in Norfolk with poor digital infrastructure.
- Clinical care models would be good to use, for example Consultants Paediatrics on call and parents have access to a consultant where necessary and a passport to admission where necessary, this could be expanded in other areas.
- There were some concerns around not all professionals being fully qualified, and not clear what decisions they would be making.
  It was also felt that the 111 service unnecessarily sends people to A&E when there are other routes and that a lack of social care also puts extra strain on A&E.

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Norfolk

What would you do to make your Norfolk and Waveney NHS better?

Share your views about the NHS Long Term Plan at our King's Lynn event.

On Thursday 28th March from 2.00pm-5.00pm we will be at the Knight's Hill hotel to find out what local people think of the NHS Long Term Plan.

Booking is essential.

Book online or take the survey:
https://www.smartsurvey.co.uk/s/NorfolkWaveneyLTP

#WhatWouldYouDo

www.healthwatchnorfolk.co.uk/events
t: 0808 168 9669
e: enquiries@healthwatchnorfolk.co.uk

what would you do?

It's your NHS. Have your say.

Appendix B

Slide 1

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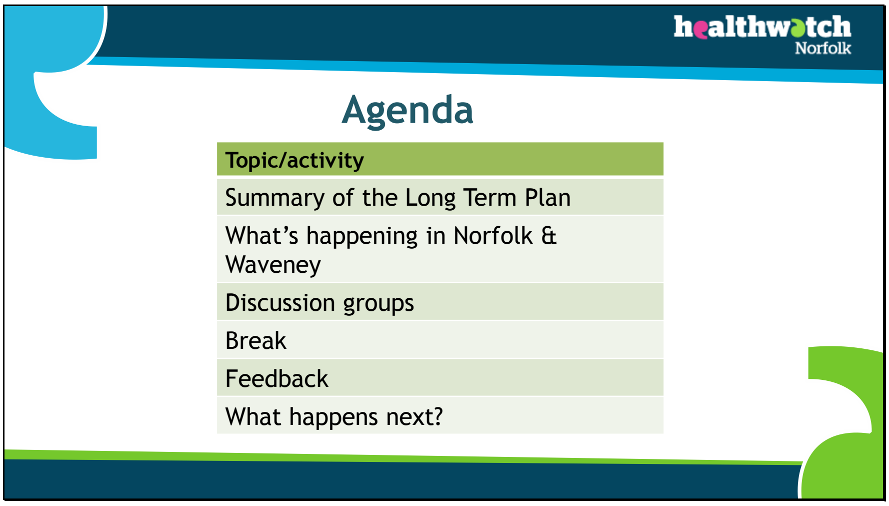
The NHS Long Term Plan

Slide 2



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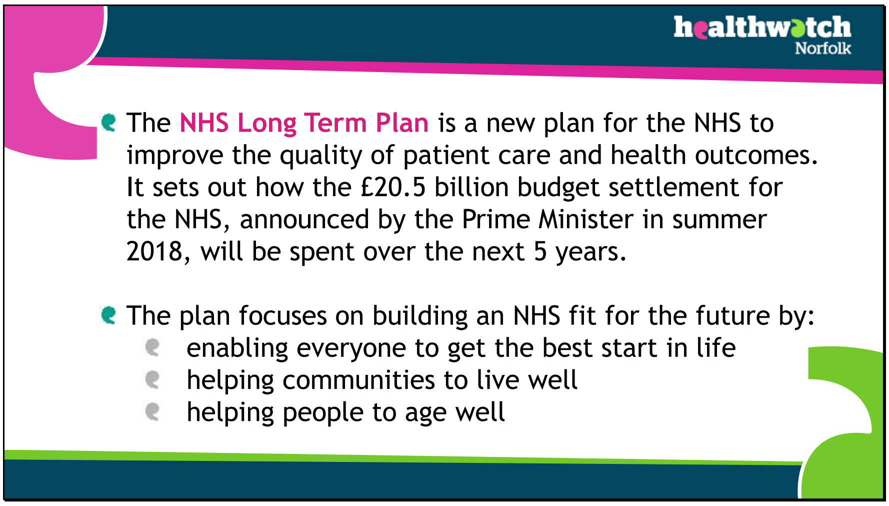
Agenda

Topic/activity
Summary of the Long Term Plan
What's happening in Norfolk & Waveney
Discussion groups
Break
Feedback
What happens next?

Slide 3



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- The **NHS Long Term Plan** is a new plan for the NHS to improve the quality of patient care and health outcomes. It sets out how the £20.5 billion budget settlement for the NHS, announced by the Prime Minister in summer 2018, will be spent over the next 5 years.
- The plan focuses on building an NHS fit for the future by:
  - enabling everyone to get the best start in life
  - helping communities to live well
  - helping people to age well

Slide 4

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Summary

- The plan has been developed in partnership with frontline health and care staff, patients and their families. It will improve outcomes for major diseases, including cancer, heart disease, stroke, respiratory disease and dementia.

- The plan also includes measures to:
  - improve out-of-hospital care, supporting primary medical and community health services
  - ensure all children get the best start in life by continuing to improve maternity safety including halving the number of stillbirths, maternal and neonatal deaths and serious brain injury by 2025
  - support older people through more personalised care and stronger community and primary care services
  - make digital health services a mainstream part of the NHS, so that in 5 years, patients in England will be able to access a digital GP offer

Slide 5

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What the NHS Long Term Plan will deliver for patients

These are just some of the ways that we want to improve care for patients over the next ten years:

- saving 55,000 more lives a year by diagnosing more cancers early
- increasing funding for primary and community care by at least £4.5bn
- bringing together different professionals to coordinate care better
- helping more people to live independently at home for longer
- making further progress on care for people with dementia
- giving more people more say about the care they receive and where they receive it, particularly towards the end of their lives.

Slide 6

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What the NHS Long Term Plan will deliver for patients

These are just some of the ways that we want to improve care for patients over the next ten years:

- making sure everyone gets the best start in life
- reducing stillbirths and mother and child deaths during birth by 50%
- expanding support for perinatal mental health conditions
- preventing 150,000 heart attacks, strokes, and dementia cases
- providing education and exercise programmes to tens of thousands more patients with heart problems, preventing up to 14,000 premature deaths

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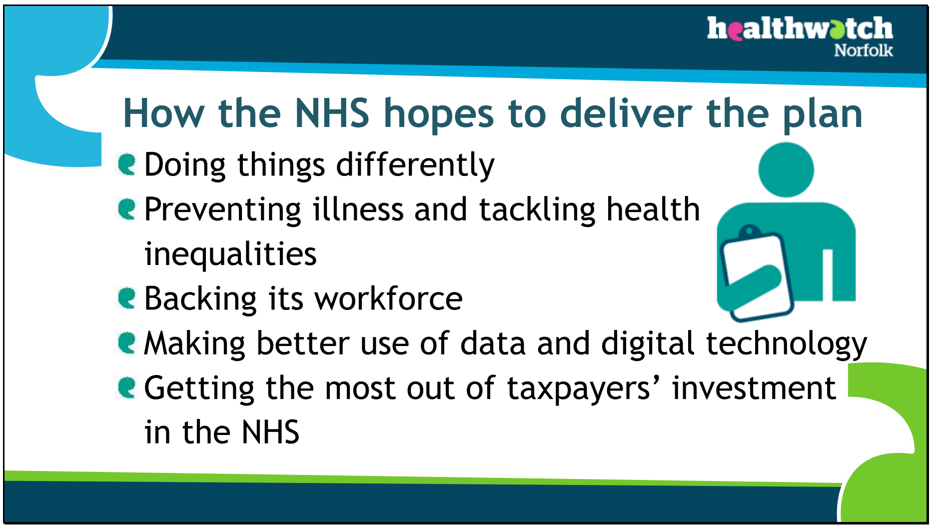
What the NHS Long Term Plan will deliver for patients

Slide 8



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How the NHS hopes to deliver the plan

- Doing things differently
- Preventing illness and tackling health inequalities
- Backing its workforce
- Making better use of data and digital technology
- Getting the most out of taxpayers’ investment in the NHS

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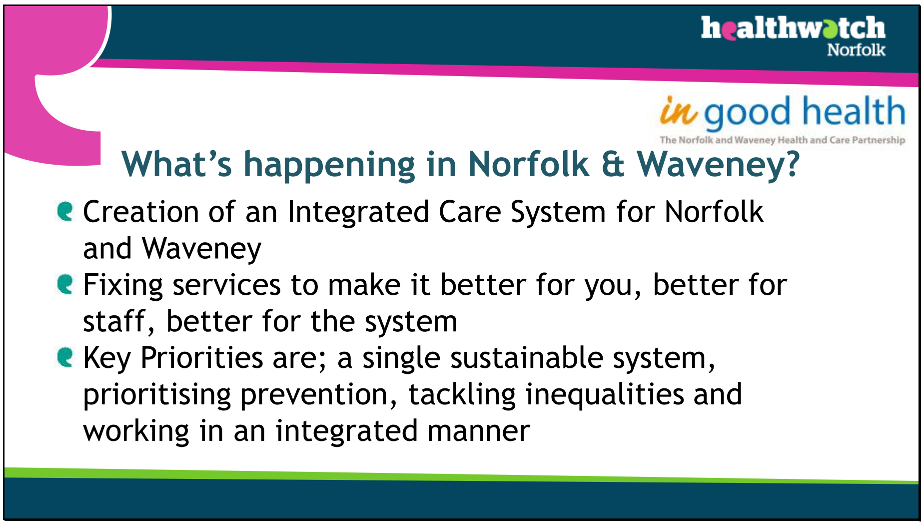

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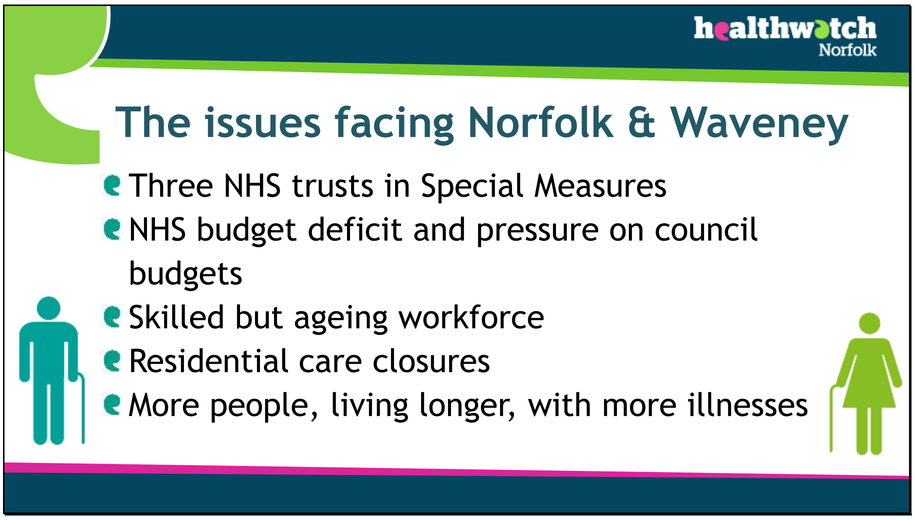
in good health
The Norfolk and Waveney Health and Care Partnership

What’s happening in Norfolk & Waveney?

- Creation of an Integrated Care System for Norfolk and Waveney
- Fixing services to make it better for you, better for staff, better for the system
- Key Priorities are; a single sustainable system, prioritising prevention, tackling inequalities and working in an integrated manner

Slide 10



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The issues facing Norfolk & Waveney

- Three NHS trusts in Special Measures
- NHS budget deficit and pressure on council budgets
- Skilled but ageing workforce
- Residential care closures
- More people, living longer, with more illnesses

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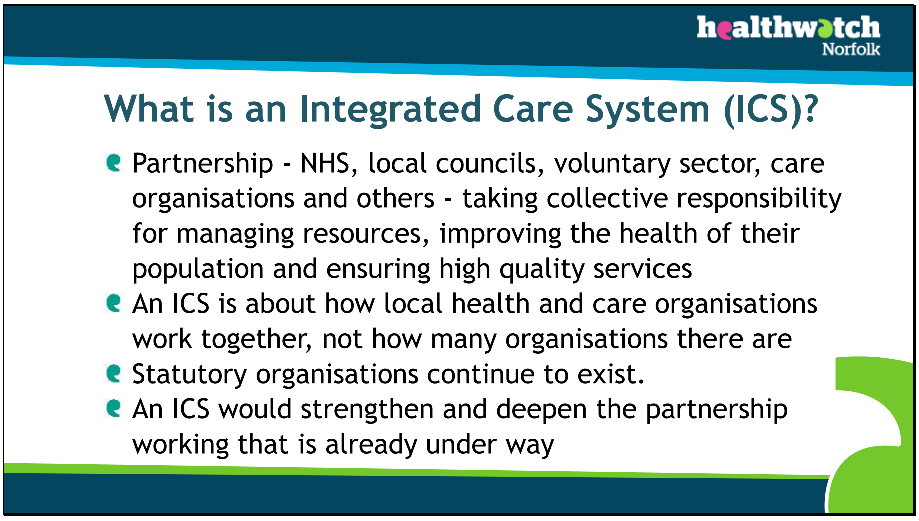

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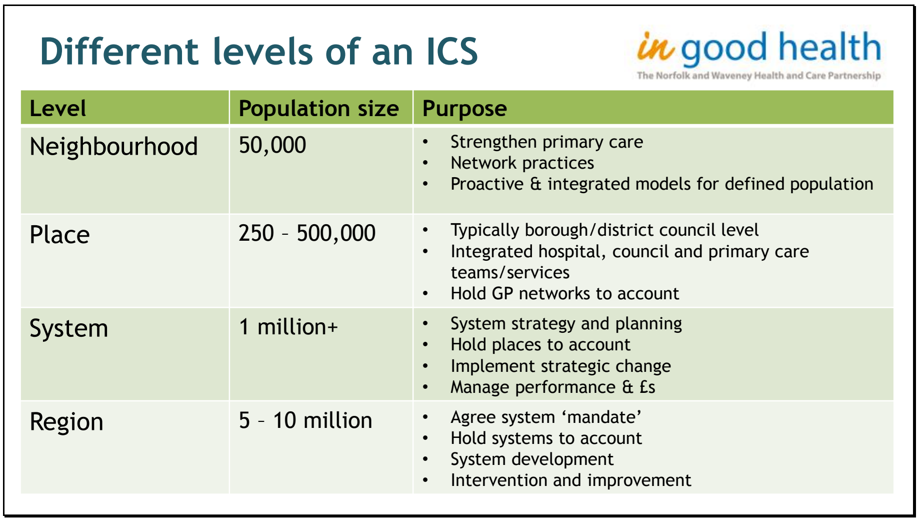
What is an Integrated Care System (ICS)?

- Partnership - NHS, local councils, voluntary sector, care organisations and others - taking collective responsibility for managing resources, improving the health of their population and ensuring high quality services
- An ICS is about how local health and care organisations work together, not how many organisations there are
- Statutory organisations continue to exist.
- An ICS would strengthen and deepen the partnership working that is already under way

Slide 12



Different levels of an ICS

in good health
The Norfolk and Waveney Health and Care Partnership

Level	Population size	Purpose
Neighbourhood	50,000	• Strengthen primary care • Network practices • Proactive & integrated models for defined population
Place	250 – 500,000	• Typically borough/district council level • Integrated hospital, council and primary care teams/services • Hold GP networks to account
System	1 million+	• System strategy and planning • Hold places to account • Implement strategic change • Manage performance & £s
Region	5 – 10 million	• Agree system ‘mandate’ • Hold systems to account • System development • Intervention and improvement

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Neighbourhoods

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The Norfolk and Waveney Health and Care Partnership

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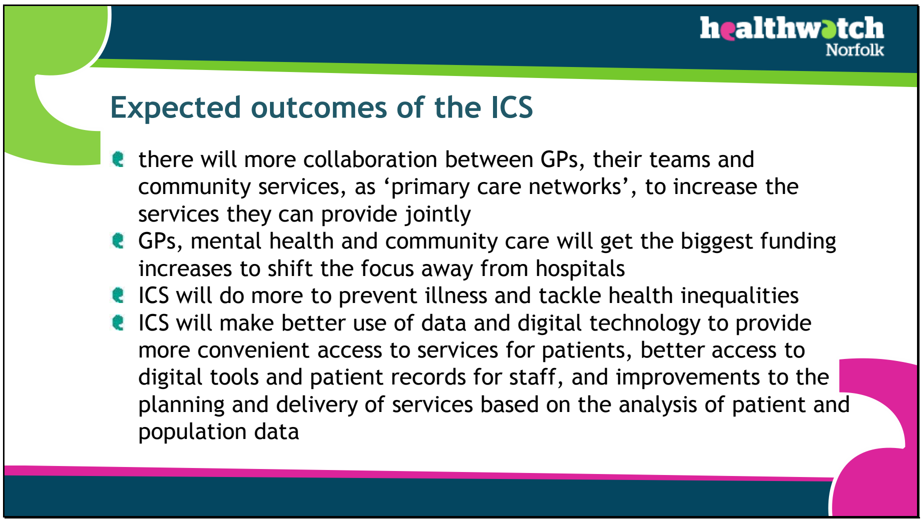

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Expected outcomes of the ICS

- there will more collaboration between GPs, their teams and community services, as ‘primary care networks’, to increase the services they can provide jointly
- GPs, mental health and community care will get the biggest funding increases to shift the focus away from hospitals
- ICS will do more to prevent illness and tackle health inequalities
- ICS will make better use of data and digital technology to provide more convenient access to services for patients, better access to digital tools and patient records for staff, and improvements to the planning and delivery of services based on the analysis of patient and population data

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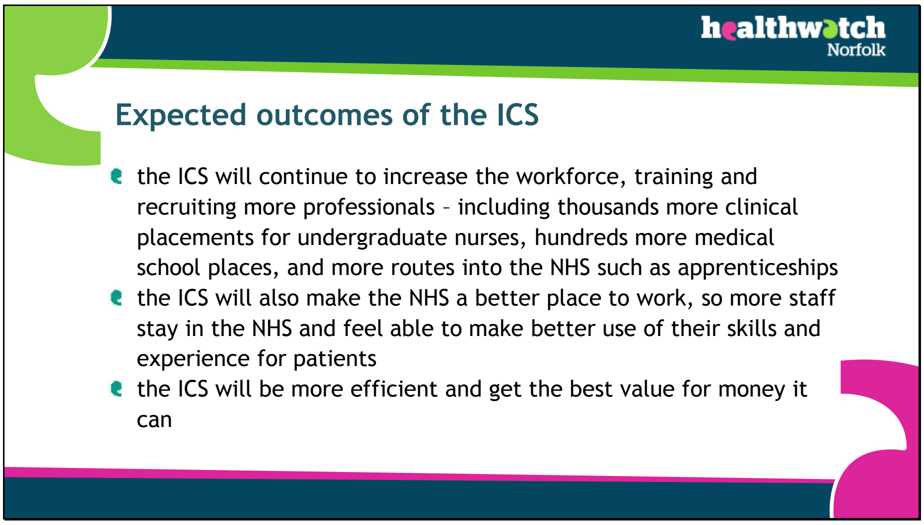

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Expected outcomes of the ICS

- the ICS will continue to increase the workforce, training and recruiting more professionals – including thousands more clinical placements for undergraduate nurses, hundreds more medical school places, and more routes into the NHS such as apprenticeships
- the ICS will also make the NHS a better place to work, so more staff stay in the NHS and feel able to make better use of their skills and experience for patients
- the ICS will be more efficient and get the best value for money it can

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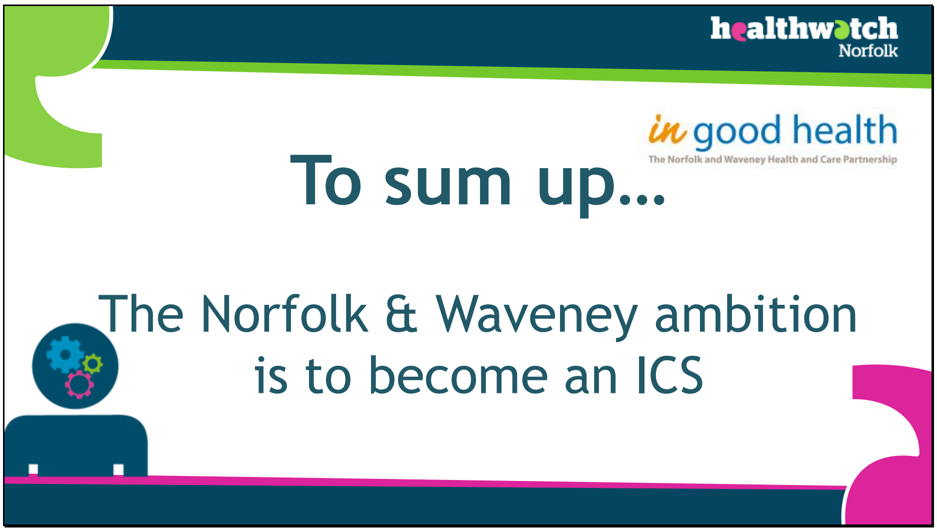

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The Norfolk and Waveney Health and Care Partnership

To sum up…

The Norfolk & Waveney ambition is to become an ICS

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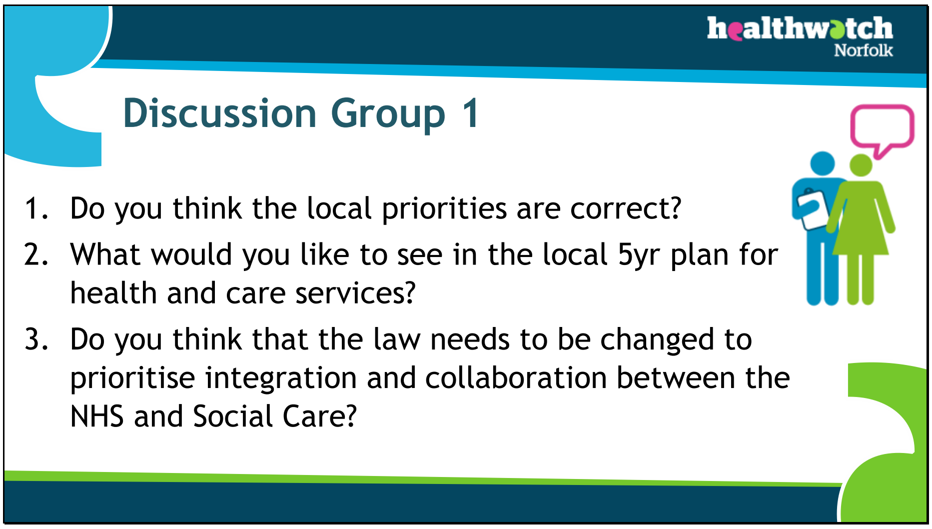

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Discussion Group 1

1. Do you think the local priorities are correct?
2. What would you like to see in the local 5yr plan for health and care services?
3. Do you think that the law needs to be changed to prioritise integration and collaboration between the NHS and Social Care?

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Break

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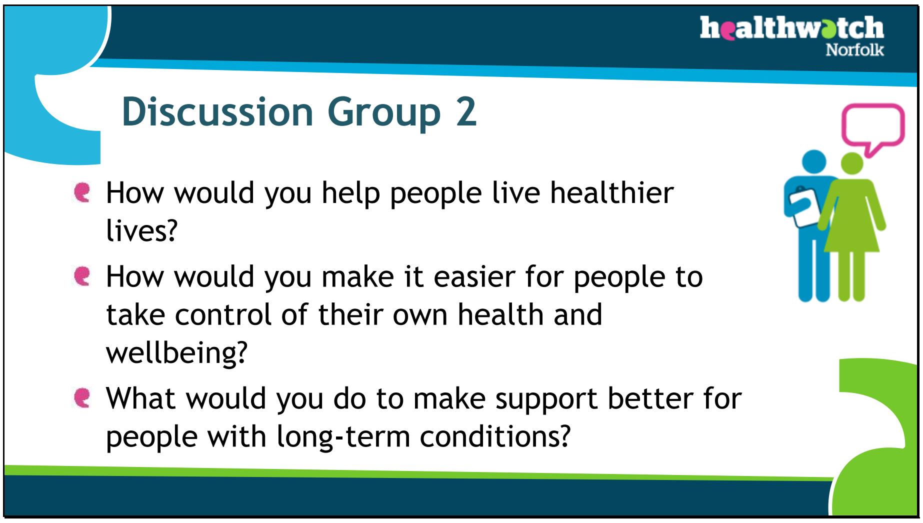
What will patients get out of the NHS Long Term Plan?

Slide 20



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Discussion Group 2

- How would you help people live healthier lives?
- How would you make it easier for people to take control of their own health and wellbeing?
- What would you do to make support better for people with long-term conditions?

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Feedback
Summary & Next Steps

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enquiries@healthwatchnorfolk.co.uk

www.healthwatchnorfolk.co.uk

@.healthwatch.norfolk

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Slide 23


Thank you

Appendix C

The NHS Long Term Plan – a summary

Find out more: www.longtermplan.nhs.uk |

Join the conversation: #NHSLongTermPlan

Health and care leaders have come together to develop a Long Term Plan to make the NHS fit for the future, and to get the most value for patients out of every pound of taxpayers' investment.

Our plan has been drawn up by those who know the NHS best, including frontline health and care staff, patient groups and other experts. And they have benefited from hearing a wide range of views, whether through the 200 events that have taken place, and or the 2,500 submissions we received from individuals and groups representing the opinions and interests of 3.5 million people.

This summary sets out the key things you can expect to see and hear about over the next few months and years, as local NHS organisations work with their partners to turn the ambitions in the plan into improvements in services in every part of England.

What the NHS Long Term Plan will deliver for patients These are just some of the ways that we want to improve care for patients over the next ten years: Making sure everyone gets the best start in life • reducing stillbirths and mother and child deaths during birth by 50% • ensuring most women can benefit from continuity of carer through and beyond their pregnancy, targeted towards those who will benefit most • providing extra support for expectant mothers at risk of premature birth • expanding support for perinatal mental health conditions • taking further action on childhood obesity • increasing funding for children and young people's mental health • bringing down waiting times for autism assessments • providing the right care for children with a learning disability • delivering the best treatments available for children with cancer, including CAR-T and proton beam therapy. Delivering world-class care for major health problems • preventing 150,000 heart attacks, strokes and dementia cases • providing education and exercise programmes to tens of thousands more patients with heart problems, preventing up to 14,000 premature deaths • saving 55,000 more lives a year by diagnosing more cancers early • investing in spotting and treating lung conditions early to prevent 80,000 stays in hospital • spending at least £2.3bn more a year on mental health care • helping 380,000 more people get therapy for depression and anxiety by 2023/24 • delivering community-based physical and mental care for 370,000 people with severe mental illness a year by 2023/24. Supporting people to age well • increasing funding for primary and community care by at least £4.5bn • bringing together different professionals to coordinate care better • helping more people to live independently at home for longer • developing more rapid community response teams to prevent unnecessary hospital spells, and speed up discharges home. • upgrading NHS staff support to people living in care homes. • improving the recognition of carers and support they receive • making further progress on care for people with dementia • giving more people more say about the care they receive and where they receive it, particularly towards the end of their lives.

How we will deliver the ambitions of the NHS Long Term Plan To ensure that the NHS can achieve the ambitious improvements we want to see for patients over the next ten years, the NHS Long Term Plan also sets out how we think we can overcome the challenges that the NHS faces, such as staff shortages and growing demand for services, by:

1. Doing things differently: we will give people more control over their own health and the care they receive, encourage more collaboration between GPs, their teams and community services, as ‘primary care networks’, to increase the services they can provide jointly, and increase the focus on NHS organisations working with their local partners, as ‘Integrated Care Systems’, to plan and deliver services which meet the needs of their communities.

2. Preventing illness and tackling health inequalities: the NHS will increase its contribution to tackling some of the most significant causes of ill health, including new action to help people stop smoking, overcome drinking problems and avoid Type 2 diabetes, with a particular focus on the communities and groups of people most affected by these problems.

3. Backing our workforce: we will continue to increase the NHS workforce, training and recruiting more professionals – including thousands more clinical placements for undergraduate nurses, hundreds more medical school places, and more routes into the NHS such as apprenticeships. We will also make the NHS a better place to work, so more staff stay in the NHS and feel able to make better use of their skills and experience for patients.

4. Making better use of data and digital technology: we will provide more convenient access to services and health information for patients, with the new NHS App as a digital ‘front door’, better access to digital tools and patient records for staff, and improvements to the planning and delivery of services based on the analysis of patient and population data.

5. Getting the most out of taxpayers’ investment in the NHS: we will continue working with doctors and other health professionals to identify ways to reduce duplication in how clinical services are delivered, make better use of the NHS’ combined buying power to get commonly used products for cheaper, and reduce spend on administration.

What happens next Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs), which are groups of local NHS organisations working together with each other, local councils and other partners, now need to develop and implement their own strategies for the next five years.

These strategies will set out how they intend to take the ambitions that the NHS Long Term Plan details, and work together to turn them into local action to improve services and the health and wellbeing of the communities they serve – building on the work they have already been doing.

This means that over the next few months, whether you are NHS staff, a patient or a member of the public, you will have the opportunity to help shape what the NHS Long Term Plan means for your area, and how the services you use or work in need to change and improve.

To help with this, we will work with local Healthwatch groups to support NHS teams in ensuring that the views of patients and the public are heard, and Age UK will be leading work with other charities to provide extra opportunities to hear from people with specific needs or concerns.

Find out more More information is available at www.longtermplan.nhs.uk, and your local NHS teams will soon be sharing details of what it may mean in your area, and how you can help shape their plans.

Local Priorities for Norfolk & Waveney

Preventing illness and promoting wellbeing – supporting people to live longer, healthier lives by targeting lifestyle risk factors. Aligning community services with local authorities and the third sector, supporting people to live independently.

Care closer to home – people living independently with better access to primary and secondary care, as well as the third sector, thereby reducing demand on hospital and residential services.

Integrated working across physical, social and mental health, delivering holistic care, improved patient experience and better outcomes. Services focusing on social care and mental health parity of esteem.

Developing sustainable hospital services.

Delivering cost-effective, high quality services within the funds available.

Appendix E

Wymondham Event Summary

General Comments

Technology used for appointments/consultations not appropriate for lots of people

Issues around CCGs refusing to find diagnosis of Autism/Asperger's Syndrome

More transparency needed regarding PFI

Not enough nursing staff to provide the care that is needed

Do you think the priorities are correct?

Can't disagree with priorities but would like to know more detail about how they propose to achieve them.

Context – Supply and demand. Issues around staffing/staff retention (especially nurses) is a worry

Does the law need to change?

Yes. Change in the law needs strong outcome measures to bring health and social care together.

Will social care use all the money up? Seems to be a lot of competition between NHS trusts. We need more information on the finances of social care etc. before we can decide this

Revisit programme budgeting

How would you support people to live healthier lives?

Care in the community, support to attend/make/confirm appointments

Other comments

Plan seems to have been made. This 'consultation' is happening too late. It is not a consultation, more like a presentation.

Clinical care models would be good to use – Consultants Paediatrics for example – on call and parents have access to a consultant where necessary and a passport to admission where necessary – good mileage for this to be used in other areas.

Concerns around not all professionals being fully qualified, not clear what decisions they would be making.

Lack of knowledge for individuals about the pathway and how the system works. This is hard for older people and people with LD especially.

A feeling that A&E becomes what used to be social care.

111 sends people to A&E a lot unnecessarily and calls for ambulances too. Seems they are unable to put people in touch with OOH doctors, dentists etc and just end up referring to A&E.

Example of individuals having to pay for their own support (not entitled to the same benefits as they used to be) this has resulted in individuals being without food and ending up in A&E for various reasons. PIP can routinely be denied on reassessment, appeal denied and goes to tribunal. In that time the person has suffered or possibly even died.

Appendix F

King’s Lynn Event Summary

1. Do you think the local priorities are correct?

Sustainable hospital services - recruitment is key. Participants acknowledged the difficulties that the local acute trust have in recruiting, and suggested a number of solutions such as, financial incentives, advertising campaigns and developing a specialism, so to attract trainees that have a particular interest in the field.

The QEH serves a large population in West Norfolk, but doesn’t have anything that draws staff to want to practice there, meaning they have spent a lot of money on agency staff and recruitment campaigns abroad. The same goes for GPs, government needs to provide financial incentives for them to come here. For some medical professionals King’s Lynn is seen as a bit of a dead end, so more needs to be done to advertise the benefits of working here. For example, the cost of housing in Norfolk is relatively cheap compared to other parts of the country, and if you’re active it has a great natural environment and plenty of sporting opportunities.”

The three hospitals in Norfolk should develop specialisms to make them more alluring to junior doctors and medical students. QEH could become a centre of excellence for geriatrics, for example, which would make young talent want to come and practice here.”

The other discussion group summarised the following points:

Prevention – you can’t argue with it but what does it mean? People don’t have the money to eat??

So how are they meant to worry about staying healthy.

I was overweight, diabetic – no support from GP whatsoever, paying for weightwatchers, gym etc out of my own pocket. Offered nothing by NHS.

Some things are self inflicted – I eat too much cake and don’t exercise – people need support networks in place

2. What would you like to see in the local five year plan for health and care services?

Participants spent some time discussing the importance of social prescribing. In particular, improving access to social prescribing and ensuring that staff – such as the local ‘Living Well Workers’ – are adequately trained to understand the needs of the local population.

- “Demand for social prescribing is very intense right now, and the limited resources to deliver it are strained. My big concern is that those people being appointed as ‘Living Well Workers’ don’t come from a mental health background, so don’t always refer people to the most appropriate places.”

- “Social prescribing should be offered to patients with physical needs as well; chronic physical illnesses always have a have a psychological element attached to them.”

The other discussion group summarised the following points:

Apprenticeships

Stop agencies poaching staff and sending them back to work in the same hospital on 3 times the pay.

No debts for people to train.

Removal of bursaries for young people here then brining in staff from overseas?? What’s that all about.

3. Do you think that the law needs to be changed to prioritise integration and collaboration between the NHS and Social Care?

One attendee raised the discrepancy in funding for health and social care, suggesting that, nationally, social care should be funded through national insurance contributions, whereby employers also contribute to the funding of health and social care services.

- “A portion of money spent on new housing estates should have to include residential care to cater for an aging population. The idea of an ICS is good, but it has to properly incorporate social care, which at the moment is financed separately to NHS services. There are huge inequalities in the way it is currently administered, in that if you are just above the financial threshold you have to have to pay for most of it yourself. The only way to remove these financial inequalities is to introduce some form of national insurance system for social care.”

Participants also stressed the need for patient records to be available to all health and social care practitioners:

- “There ought to be one shared system across all health and social care services in the country, so that doctors, nurses, paramedics and social workers are all aware of patient’s history. But data protection gets in the way of this ever being achievable, we just don’t have the resources to make it happen.”

The other group stated:

NHS England need to get their house in order first.

They need to support the VCS properly. Fund initiatives in a way that provide security to small local organisations.

Discussion 2

1. How would you help people live healthier lives?

Educational interventions were perceived to be the most effective way of helping people live healthier, according to group members. Participants highlighted the need for a less academic syllabus to be taught - especially in early years – and for education to be more focused on areas such as: keeping active, confidence building, healthy lifestyles and social media awareness.

- “Education is vital for parents, teachers and children to tackle chronic conditions like diabetes. Of course there should be education in schools around healthy lifestyles, and also wider health considerations such as the impact of social media on mental health. Resources should also be moved upstream to educate children in their early years – as early as preschool. Alongside this children need to be active and engaged in activities that build confidence. Academic education is not always the answer. "

- Early detection initiatives such as eyesight and auditory checks should be made mandatory again in school. If a pupil can't engage because they can't see or hear properly it presents all sorts of other behavioural and health complications.

The other group stated:

Education – cooking in schools, train parents too.

Use childrens centres – don't close them.

Social prescribing could work but they should make it more like a clinical prescription so it is a direct instruction.

Better wellbeing services in schools to keep kids on the right track

Compulsory exercise programmes and higher taxes on sugar/fatty foods.

2. **How would you make it easier for people to take control of their own health and wellbeing?**

"Parents need to be educated on basic things. My wife was a primary school teacher and there were children in their first year of school who would turn up unwashed and were really lacking in basic language skills. Obviously feeding your child a healthy diet is difficult too if you don't have much money; it costs to have a healthy lifestyle."

The other group stated:

Social prescribing

More initiatives to tackle social isolation etc. 'Adopt a grandad' stuff like that.

3. **What would you do to make support better for people with long-term conditions?**

- "There needs to be a private nurse in every care home, someone who can spot medical difficulties before they get worse. They could then run a triage system and be used to prevent ill-health in residents."
- "My elderly mother forgot about her appointment two times in a row, and was then automatically discharged for not attending. We were angry because the carer had specifically asked for appointment confirmations and reminders to be sent to her, so that she was aware and could remind my mother. This is yet another example of care providers not communicating effectively with each other."
- Better transition between services.

Appendix G

Lowestoft Event Summary

General Comments

In reference to Simon Stevens video:

Political Party Talk

What legislation is he talking about?

Should there be one footprint for each STP area?

How is the money going to be allocated?

Will it be drip fed?

Will there be criteria, hoops etc. that CCGs need to jump through

Lot of CCGs in Deficit so money will just be absorbed by that.

Lowestoft Rising – beat the street initiative – a great local initiative getting all families exercising – children and adults – good first step in prevention but funding was cut!

1. Do you think the local priorities are correct?

Are the NHS going to enough career's fairs??

They need to sell the importance of GCSEs and career paths into health.

If these priorities are implemented correctly they can be of benefit.

If social prescribing is not holistic it will not generate the desired uplift in wellbeing and reduction in demand for primary care services.

Social prescribing is often time limited support and people can become reliant upon seeing a social prescriber.

There are too many different models/names for social prescribing across the STP – needs to be uniform

Social prescribers should be employed by the surgery as part of a GP team not council funded.

More GP hubs that are one stop shops with wrap around services the better.

7-day care is highly relevant to care closer to home – they should make better use of walk in centres.

Prevention needs to start when kids are young. Children are currently being forgotten.

Kids are vaping from age 10 and we don't know the risks.

They need to get into schools early. Tackle drug dealing etc.

Children aren't inspired in school.

Careers fairs are very limited in their scope – needs to be a greater push towards health careers.

People need to take more responsibility for themselves

Prevention and education are key.

2. **What would you like to see in the local five-year plan for health and care services?**

All computer systems need to talk to each other!

Major data issues for Waveney residents using Ipswich hospital.

Sports physio and reflexology.

Promotion of clinical pharmacists, more weekend appointments and social prescribing.

Although the more access you give people the more they will abuse the system.

3. **Does the law need to change?**

Do people really know what the law even says in respect of health and social care?

Boundary issues are our biggest problem. They should define areas in terms of what hospital people look to not where they live.

No. Too controversial. Will cause more issues.

Just say here's the budget – just go and deliver it. Leave it to clinicians. MPs don't have the time or the knowledge to read all the paperwork.

Need higher taxes to pay for better services like in Germany.

We should also fine non-attenders.

Table discussion 2

1. **How would you help people live healthier lives?**

Education – children have the power to be able to turn the world around.

Too many things are being pushed onto schools though. Needs to be better thought out how education around health issues takes place.

CPR and first aid should be taught in schools and made mandatory – this would potentially get more people into health related careers.

There should be a GCSE in health too.

Subjects now don't reflect modern day workforce needs of the country.

By giving people access to employment and training – the current lack of opportunity for young people is very demoralising and has a real impact on their health.

It's too hard for people to take apprentices. There's no support and the pay is rubbish.

Too many are encouraged to go to uni but there's no jobs for them.

2. **How would you make it easier for people to take control of their own health?**

Challenge unhealthy behaviours.

More to push smoking cessation every single time you interact with health services for example.

Some people get paid by NHS to go to the gym and they are just sitting in the sauna or café. Who's actually checking what they do there?

They should be given a programme and made to follow it. Should be a direct link between doctors and PT instructor.

Children's health checks in schools – although a feeling that BMI is not the best indicator and can have a negative impact on a child's mental health.

Teach cooking and health eating in schools and not how to bake cakes!

3. **What would you do to make support better for people with LTC?**

Terminology used plays a big part. Teach people to 'live well' rather than labelling them in ways that can in themselves be debilitating. People can live with stuff with appropriate physio etc.

There needs to be better signposting to services. Suffolk info link is not easy to navigate. Older people are probably not going to use it.

There is a real issue with accessing support – people need access to their GP and other health professionals.

Take dementia for example. You've got 111 but people need a dedicated support worker they can call upon.

More could be done to promote community pharmacy a lot more but can they cope with an increase in demand or have space to host additional services??

General points from summing up

Celebrate and communicate successes – there is a real opportunity with the LTP to change the narrative. Have seen this already at NSFT just in the way the new leadership are talking.

All the negative media doesn't help with us constantly being told how bad everything is all the time – so people don't seek help.

Staff are extremely passionate and dedicated so it's demoralising for them too.

We need more positive stories out there from the trusts. Sell the positives!

The regulator abuses its position and causes more problems – All Hallows community hospital spent all their money to buy their way out of being inadequate and that then brought them down financially – meaning patients are the ones who suffer.

Deaf Connexions Event Summary

In April, we ran an NHS Long Term Plan focus group at Deaf Connexions in Norwich. We spoke to two cohorts: one with members of the deaf community, and another with local residents who were not hard of hearing.

Workshop 1: Deaf Community

Deaf connexions Long Term Plan event with the deaf community: 10th April 2019

Please note: this event and feedback is structured slightly differently as Deaf connexions had to set the scene/context a lot more frequently than for the average member of the public.

Discussions One:

1. **Do you think local priorities are correct?**

On the whole people thought the priorities were ok but they felt that general deaf awareness was needed over all NHS services. Interpreters and availability of interpreters were raised as a key concerns for the community especially when interpreters don't turn up. many had specific examples of experiences they have had trying to access health and social care services Linked to this DA Languages came up a lot having newly taken over the contract and people were unhappy that services were no longer locally based which seemed to have worked well in the past. Improving digital access is ok but it's not for everyone, deaf community felt that the NHS needed to understand that not everyone can access that due to differences in understand and reading written English.

Please see detailed comments below:

Participant "I think it's good that we are talking about the future, you know it seems like a long time I have one question about the 5 different colours that's on the screen, I know that they are hubs but the dark blue is bigger than the other areas and the greens quite big actually as well, but the pink area is very small. Is that related to the doctor's surgeries that are there locally? I understand that they are working together in the different areas but why are they bigger and smaller? Why is Norwich so small to the local area? It's because of the population, that's how they have split it up.

Deaf connexions explained "It's how many people live in the area so if you look at the pink one that's the city, Norwich so there's a lot more people that live in Norwich than there are say on the North Norfolk coast so although it's a bigger area there is actually a similar amount of people that live there."

Participant "I'm very concerned, why do doctors text you messages, why can't doctors reply when you send them a text message? Some deaf people can't use the internet and I'm one of those people myself and so why can't doctors just simply reply to my text."

Deaf connexions explained "That's a good questions, it's because they just don't have a system set up to do that but who knows as part of this five year plan they may improve that and develop that, but they just don't have a system that can do that. The system they have that texts you the reminder appointment. It's not a receptionist sitting in the surgery looking at an appointment book and texting you that comes from a computer it *generates a text, so that's why they can't text you it's not the same as sitting there with a mobile phone, it comes from a computerised system that generates a text."*

Participant "I live quite close to the doctors myself, when I went in the doctors myself to make an appointment for my husband for his ear. His ear need to be washed out or something. My daughter came round to my house and my daughter was really confused, she asked me what I was doing and I was quite surprised. I told her that I had been here a to the open door service (deaf connexions) and spoken with someone. An my daughter was quite surprised and then she told me that you need to go to a different doctors, but I asked her why because our own doctors wouldn't do anything and we needed to bring a letter to see if me and x could go. So my daughter explained that her dad was deaf, so there was a complete communication breakdown and so actually we need to travel to Loddon to get this done. I wasn't very happy."

Deaf connexions explained "Sometimes it's because they maybe haven't met a deaf person before and they are quite sorry and will try and improve their service."

Participant "These questions aren't actually from me they are from my son. If we are talking about the five year plan that will be in the future, to talk about going to the doctors and being referred to different places if you do have a problem or something. Will they have a system where if the person needs and interpreter that will automatically come up on their computer because that would be quite good?"

Deaf connexions explained "They do have a system now where they can put a flag on your records that means a note on your records to say that you are deaf and that you need an interpreter BUT they will only do that if you ask them to. Do you remember the letter we have that we brought to Tuesday group that you can sign and fill in and give to them and they will put that on your medical records. Once they are on there that should then be shared with all services."

Participant "I've got two more questions, so most people when they go to hospital they go and have an operation they are actually worried about the operation itself. But because I'm deaf when I go to the doctors my first worry is actually am I going to have an interpreter? You know I feel quite nervous about that. You know I am very worried about is the interpreter going to be there, you know as soon as I see that there is an interpreter there for me I feel quite relieved but you know two-three weeks prior to the appointment I will be worried about this. You know and actually that's a bit of a strain on the mental health for people to have this amount of anxiety."

Deaf connexions explained "as you know here at deaf connexions that's why we let you know that your interpreter is booked and the name of the interpreter too. We will try and do that as much as we can but as you know we do not have the service for the doctors and the dentist anymore so…hospitals we still have so we are still providing the interpreters."

Participant "the last question I have, this actually happened to me personally. I went t to the doctor and explained that I had a problem with my jaw and that doctors could actually provide the service that I needed. So I had to travel to Nottingham and I mean they knew my background, you know they don't seem to have any kind of deaf awareness. There was no interpreter there and when I arrived in Nottingham it was a real struggle. Then I got moved from Nottingham to Birmingham. For some injections for my jaw, you know how come I had to move twice? You know I wanted it to all happen in one place. And when I went to Birmingham back in January I was reassured that I would have an interpreter and then there wasn't an interpreter there. I did then have an interpreter there for 45 minutes and then she had to go I needed an extra hour but she couldn't she had to leave so that meant I had to make another appointment. I had to go to Birmingham again with an interpreter but I only had an hour and that was it. Complete different services and I really didn't like that and I would have liked the same service with the same interpreter, I think that's a problem."

Participant "…but my biggest worry is for deaf people when they go to the hospital or doctors and the interpreter or the communicator or whichever support service is and there not there. I can tell the interpreter or the other problem is I can sign to the interpreter and it is misunderstood. That's my worry that I may not be able to understand them either. And if it is to do with my personal illness, I'm not just speaking for myself here I do think other people within the deaf community do struggle and I might need more tablets for example."

Deaf connexions explained "If you are not happy with your interpreter you must tell your doctor and you must complain, not everybody will be able to do that so you can come to open doors here (deaf connexions) and we will help you do that.

Participant "…I can't even mention DA Languages it really does make me sick to even think about it. What does DA stand for? What's the meaning of DA? Specifically what does that stand for? DA…DA Languages what is that? Also what's the level of their interpreters are they level 1, 2, 4? You know deaf connexions doesn't know either and I don't know and I feel that, that is really bad. I also will say that all these people here may be feeling vulnerable it's very difficult for them. So Cambridgeshire have a service called 'clarion' and they have some good people that work there you know level 6 and things like that. Why couldn't a service like clarion have it instead because they are closer than DA Languages who are much further away?"

Deaf connexions explained "yes we know of Clarion but DA Languages is now providing this across the whole of the country not just for Norfolk, its national. Ok so it's one organisation for the whole country that's what the NHS has done they have stopped all the little local bits that worked really well and they have just contracted with one big one to provide everything. Now there is one little bit of good news, they are based in Manchester, they provide for foreign languages all over the world they work not just England. But I have to tell you that DA languages have called us for some booking and the new contract started on 1st of April. In this last two weeks they have phoned us and said, have you got an interpreter for, we have said yes and our interpreter has gone. That's not for every booking, they have used some freelance interpreters but they are using us for some as well so fingers crossed, we are keeping a close eye on it to make sure you get an interpreter and as I have said before you must let us know if you don't. It's silly really as they call us and then we provide interpreter but before we used to just provide interpreter so where the NHS want to save money it's now actually costing them more as they have put another level up."

Exercise classes to lose weight from the GP: How are we going to access that if there is no interpreter? Everything they do must be accessible for everybody.

Participant "I recently went for an x-ray on my knee, I was referred from my GP. Then I received and email from the doctor for physiotherapy. But they needed me to apply for this physio online I couldn't understand this at all so I had to get somebody to help to help me access it. They said they would let me know within 2 working days again through the email. They said they would let me know the exercise that I need to do but how are deaf people meant to read this? **We don't understand the written information in the same**

way as everybody else. I need to go with an interpreter to a group to actually learn it properly I can't understand it from words as to what to do I need it in BSL translation."

Participant **"Part of their plan is to improve digital access but we must make sure that the NHS knows that, that doesn't work for everybody. Not everybody can access the internet or read or write and understand that. They MUST make sure they can still do things face to face with an interpreter."**

2. What would you like to see in local 5yr plan?

GP surgeries working closer together is good but the problem is transport. The deaf community would like to see improvements to the NHS 111 service and providing interpreters 24/7 for NHS services as part of the long term plan.

See comments below:

Participant "What about the people that can't drive? "I can't access any other surgeries so yes I would feel quite trapped."

Participant "Before I wanted to see a doctor on a Saturday but it wasn't open at my surgery but was at Dereham so I went there instead."

Participant "What happens in the middle of the night or it's really early in the morning and I'm ill, I don't really want to have to wake up my neighbour to ask for help. What do I do? So what do we do in this situation? Yes we can contact deaf connexions that's an option, but the NHS 111 we can't access…where is our independence?

Deaf connexions explained "You can't text them, you can't email them they do have an online interpreter, but that's only up till 11pm at night and obviously you need access to the internet for that and not everybody will have access to that."

Participant **"Can the NHS actually improve this NHS 111 as part of the 5 year plan?"**
Participant "I have actually accessed this myself, online 3 times and I actually found it very very good."

Participant "What I would like to involve in the five year plan is the interpreter service is really provided 24/7. It's the same for anywhere the police, ambulance service there service is 24/7 as it's an emergency service, deaf people need an interpreter to be able to respond quickly not some persons who's from far away to travel down here . Before when it was a local service 24/7 that's a better service as it gave use better and fast access if we needed to go to the doctor of hospital for whatever we need. That needs to be involved in the plan also I want to discuss operations. The interpreter needs to be able to stay there the entire time that I have the operation. So when I wake up after the operation I have been in a situation before where I have then seen a different interpreter and they have changed the interpreter whilst I have been having that operation. The interpreter before know what had happened in my operation. Does the new interpreter know what has happened before? She needs to know. I feel it need to be the same interrupter from the start to the end."

3. Do you think that the law needs to be changed to prioritise integration and

Collaboration between the NHS and Social Care?

Participant “I’m not sure I’m feeling 50/50 about it myself.”
Participant “When my husband was in hospital, a doctor came and let me know that they had a arranged for a social worker to come and I was a little bit surprised by this. He didn’t let me know if it was a socials work especially for the deaf or just a general social worker. It was just a general social worker, which was no good”

Deaf connexions explained “We do have social services for deaf people and they are obviously going to know more about your husband and what they might need because some of the equipment and support he may need like and interpreter and so on, so that’s quite important too, thank you.”

Participant “My mum was in hospital for about 4 months and she was in a bad way and they moved her to a home. The social worker actually only visited her once and I mean I visited here every day. I had a meeting with the general social worker about 24 hours care for her at home, so I needed support from a care home. I expected there to be a social worker for the deaf there which was no good. I just work with Deaf connexions and my family and forget social services now.” *[Sensory support - social services for the deaf community.]*

Participant “There’s a lot that could be improved with joint working.”

Discussions two:

1. How would you help people live healthier lives?

Participant “I had a bad back before and the doctor referred me for physiotherapy and advised me to go swimming to help to keep fit. So they agreed to give me cheap membership so I could go regularly and I explained I was profoundly deaf so I decided I would go swimming. I joined a classed and some of the ladies there knew I was deaf and most were hearing and I was confused as to what was happening, so I didn’t go again and quit.”

Participant “Quite a long time ago now in 2009/2010 I went to my doctor and explained that I was actually having a few problems and felt quite depressed. He actually advised me to go to the gym with an interpreter for 6 weeks for 2 hours each time and it was amazing! I could fully understand what I needed to do but now I can’t have an interpreter but they were there with me before and the doctor referred that and that was a fantastic service but now in 2019 the services have got worse!”

Participant “Facebook would help with their wellbeing - there’s a deaf women on Facebook that does work out videos and things. Using social media to promote healthy lifestyles. TV adverts to promote healthy lifestyles when it’s just the subtitles I don’t fully understand it having an interpreter on the TV would really help.”

Participant “I’d like to make a suggestion that perhaps in the doctors waiting rooms they have a television in the corner and they have an interpreter on there. Deaf people can see the TV and see people talking but they don’t understand what is going on the television, if they turn the sound off hearing people will understand what this is like!”

2. How would you make it easier for people to take control of their own health?

Participant "For my diabetes I now have to test my blood and I'm really not sure how to do that. So better information that is accessible to me would be better. So if I had some information in sign language or I had an interpreter with you for a different appointment that could explain things differently to you and they had the time to interpret and we ask questions that would be helpful. I feel that you have limited time with the nurses actually and I don't feel that we have enough time. SO more time to discuss and fully understand health problems would be good. More information in BSL."

Participant "I think perhaps everyone here, I think it would be better to use the DVDs and will help us feel a little bit more aware you know we could re-watch the DVD if we need to. When we meet with an interpreter we just have that one chance to get all that information and we may forget it. I don't think a DVD just for diabetics I think for other conditions may also be useful.

3. What would you do to make support better for people with long-term conditions?

Participant "having a support group for those with Dementia say. It would be nice to meet other people if they had an interpreter there for deaf people only. As if you are deaf you can't access a hearing support group. Communicating with a person who is profoundly deaf and has dementia may be harder as well and that's very different from people that are born profoundly deaf and those who have partial hearing. Everybody has different ways of communicating. All the doctors in this area have the same problem. You know before I had the motorbike accident and banged my head quite bad and I completely lost hearing in one side and a little in the other and they gave me hearing aids. But when I went to the appointment with the doctor, I went to ask at the reception and the lady didn't sign at all. Oh they did have a hearing loop but once I discovered I could use that it was fantastic and I could hear a lot better but what's the actual problem? Not all doctors' surgeries have the loop and they don't have them in every room they should all be the same really. Maybe include that in the five year plan add in a loop system so that all doctors' rooms do have a loop system so for some of us that can use it that would help."

Participant "I went into the doctors and I used the screen to let them know I was here for my appointment and I sat waiting and then a person came in calling out the names and I'm trying to desperately lip-read to see if it's may name being called. Then the interpreter suddenly comes out and says that we are ready they need one of those screens so I can see my names called. My surgery know about this is have raised this many times."

Participant "In our surgery they have it for the doctor but they do not have the same service if you want to see a nurse." *[screen with name on when called]*

Participant "The NHS services do work really hard for us. I've before at a doctors and there not been an interpreter before and so I've used signed videos. I've had to use signed videos before and some doctor's surgeries do have that. Banks have them too. Could this be something that happens in all doctors surgeries?

Workshop 2

After delivering the presentation, the initial reaction from many of the attendees was that of concern about the resources required to achieve the aims set out in the Long Term

Plan. Points were made about the implications of the plan on NHS finances and workforce, which group members perceived to already be in a fragile state:

“To me this seems to be a continuation of a fairy story that will never happen – there is no clarity as to how any of it is possible. We have major problems with workforce and funding, meaning current objectives can’t be delivered, let along the new ones outlined in the plan!”

“I think NHSE is trying to pull wool over our eyes. There is a massive under-resourcing problem and all sorts of strings attached to funding services. I think this is a unachievable wish list that £20bn isn’t going to deliver.”

1. Do you think the local priorities are correct?

In reference to the local priority of bringing ‘care closer to home’,

“The CCGs balanced the books by closing down important community services and transferring the deficit and demand to the community hospitals. When James Paget ran all the community hospitals in the area it was in credit. Not anymore.”

“The NHS still does quite a good job as a universal service, but there is much lower engagement in services within deprived areas. Zero-hours contracts mean that work is unpredictable and many people employed on them can’t always attend appointments. There are other access issues that local CCGs should work to tackle, maybe by bringing services closer to those communities.”

There is a massive need for support for carers; they are virtually prisoners in caring. Therapists for carers can do the most amazing things, whereas pill prescribing often doesn’t work and costs a lot of money. There’s an awful lot more we could be doing which would prevent carers from ending up at mental health crisis point.

2. What would you like to see in the local five year plan for health and care services?

They need to bring back community services such as walk-in centres. They closed the one in Yarmouth which put extra pressure on JPUH. Since the central surgeries have merged they can’t handle the pressure either and now staff are leaving because of it.

Care cooperatives should be fostered within Norfolk & Waveney as a model of delivering support.

I think the PCN structure is totally unsuitable for a rural area like Norfolk. Surely GPs don’t have the facilities to offer more specialist care. And having a manager for each PCN area will be another expensive salary.

3. Do you think that the law needs to be changed to prioritise integration and collaboration between the NHS and Social Care?

The fact that GPs get paid for achieving a certain number of targets such as blood pressure assessments is silly. It means that they are wasting time by doing things unnecessarily.

The closure of children's centres is such a shame. If health and social care had a shared budget and were brought closer together it would be easier to keep them open, and the benefits of having them would be more evident in the admittance figures etc. Having the support for children and families in their early years is so important.

Nobody stays anywhere for long, the NHS should directly employ GPs and put them all on the same salary. That would remove the incentive for GPs to move to bigger cities so that they have more patients to make money from.

I have a monthly blood test at the hospital, but receive reminders about it from my GP, so this 'joining up' that they're trying to achieve is already happening. Another example is when I was offered physio via my surgery, which was delivered at a community hospital.

Competitive tendering is inhibiting CCGs, because they're forced to re-procure services. It's forced upon them by central government, and because providers are acting independently from each other it prevents collaboration.

Discussion 2

1. **How would you help people live healthier lives?**

There should be a mental health nurse within each school who can educate families in the community too.

Social prescribing is a good idea, but local authorities need to make sure that the group or service they are being referred to is properly resourced and has sufficiently knowledgeable staff to provide support.

A lot of ill health is caused by poverty and inequality. For example, people aren't overweight because they're ignorant, it's just cheaper to buy junk food, or people don't have the skills to be able to cook a health meal. Things like this need to be addressed.

2. **How would you make it easier for people to take control of their own health and wellbeing?**

We need a state that helps to improve people's lives, not just fix them when they're broken. Help centres have been taken away and Sure Start centres have been cut, meaning that chronically under-funded third sector organisations have been picking up the slack. When support structures aren't in place, it leaves people without the tools to look after themselves, which is how lifestyle problems develop in adulthood. The state isn't taking responsibility.

3. **What would you do to make support better for people with long-term conditions?**

We need to make sure there is domiciliary support for older people even in the rural parts of Norfolk. My 90-year-old mother can't get a health visitor to North Walsham to do her legs, so my husband has had to drive her to the community hospital, which is very painful for her.

There should be a network of carers responsible for some of the simple things like managing pain in toes or ears. Carers who work for outsourced agencies are so stretched that they don’t have time to do these small things, but they can make a big difference.

When carers were employed through the council, they used to have patch where they would see the same clients every day. This was so much better because staff understood the needs of the client, who was also reassured by knowing who is coming in to their house every day.

With all these private providers everything is so fragmented, meaning people don’t get all the information they need. For example, I have to go to book an appointment at the hospital for any health-related issues with my arthritis, then make a separate call to the private provider about my medication. Before the provider was commissioned I used to like going to the hospital because I could pick up my meds and get some quick advice off a rheumatology nurse.

<u>**Appendix I**</u>

Thetford Event Summary

Discussion 1

1. **Do you think the local priorities are correct?**

- "To me, 10 years doesn't seem long enough for a 'Long Term Plan' considering the amount of time it takes to secure funding, get plans in place and resource services."

Participants also questioned the likelihood of executing priority 3, 'Integrated Working' when Thetford and the wider region struggle to recruit sufficient numbers of fundamental medical professionals such as GPs:

- "We can't start integrating services if we don't have enough baseline staff to begin with. We need to offer GPs and other medical professionals incentives to come and work in Norfolk. For example, are we offering a high enough salary at the moment? Do we make the most of the UEA medical school as a potential source of staff that will want to stay in East Anglia?"

- "We have a major problem with getting enough GPs so we need to make training to be a GP more appealing. At the moment general practice is at the bottom of the popularity list amongst trainee doctors, and when you read the exit interviews from GPs who have quit you can see why. It's such a stressful job."

2. **What would you like to see in the local five year plan for health and care services?**

Throughout the discussion, group members referenced a number of priority areas including; mental health in young people; social isolation; staff recruitment; development of community services; and reducing non-attendance/wastage.

- "At the moment I don't think we resource end of life care properly. Hospices take on so much of the case load at the moment, so they are forever having to fundraise just to keep being able to operate."

- "I'm chair of a PPG in Thetford, and we find that non-attendance is the biggest problem in our surgery, yet I don't see that mentioned in any local or national plans. It would be good if we could sanction people for not attending, I think that would make an enormous difference and save surgeries both time and money."

3. **Do you think that the law needs to be changed to prioritise integration and collaboration between the NHS and Social Care?**

Notably, wastage in the NHS was raised fervently by participants. In order to combat this, there was a general consensus that some form of small payment should be attached to missing appointments unnecessarily. One individual also suggested a charge for treatment. Potential solutions to addressing 'repeat offenders' were also proposed, such as communicating more closely with social services.

- "The problem with the NHS being free is that people abuse the system such as missing appointments or making unnecessary ones. I think some kind of small charge should be involved if you are capable of paying. Personally, I think there's no reason I shouldn't pay for my treatment."

- "The amount of wastage through repeat prescriptions and people not collecting their prescriptions is phenomenal. If somebody is a repeat offender, they shouldn't be charged, but should be referred to social worker who can understand why they're not picking up medication and stop it from happening in the future."

Attendees also spoke passionately about the need for schools to be more closely involved in drafting services for young people, and have their powers to support students enhanced through the mandatory introduction of school psychologists.

- "Teenagers have huge problems with mental health in particular. I think schools have a responsibility to provide support, so the number of school psychologists needs to be increased and made widespread across the country. This will encourage and equip children with the means to look after their emotional health, and hopefully relieve pressure off mental health services."

- "Schools need to find more ingenuitive ways of teaching and be more involved in planning services with councils and CCGs. More practical and health-related education for children would help them carry those skills on in later life. For example, kids need to know the basis of cooking and nutrition. We live in a world of convenience where junk food is cheaper than healthy food, but issues around this need to be raised at a young age. Kids should also be encouraged to volunteer at a younger age to give them practical experience and explore their interests."

Discussion 2

1. **How would you help people live healthier lives?**

One group member cited long working hours as having an adverse influence on health and wellbeing:

- "We have the longest working hours in Europe, which means people don't have time to look after their wellbeing."

Other attendees alluded to the importance of a solid community support network, where specific community-run groups can improve people's wellbeing and prevent admission to mainstream services:

- "More lighter-touch services in the community would help a lot of people. For example, in Thetford there is an open drop-in bereavement café, and also 'Meet Up Mondays' which is for people who live on their own. It's an opportunity for isolated people to make social connections."

- "There should be more opportunities for people over 50 to get active. Involvement in sport should be incentivised by making it cheaper and having more facilities in the community."

- "For these groups to be effective in preventing illness, there needs to be more consistent referring to them from GPs. At the moment it's a bit hit and miss depending on the persuasion of your GP."

2. **How would you make it easier for people to take control of their own health and wellbeing?**

- “More and more people are falling in to a black hole – you’ve got to be virtually unable to walk to access a lot of services now. After you’ve seen a GP there is no information about local options, such as voluntary and community groups that could help people manage conditions. There needs to be more widespread knowledge of such groups amongst medical professionals and more advertising of them in the community. There are a lot of vulnerable people out there, and if they don’t know there is support available they won’t get any help.”

3. **What would you do to make support better for people with long-term conditions?**

- We have a healthy living centre here in Thetford which could be used to greater effect. For example, why can’t some advice or treatment clinics be run out of it once a week? People would be very interested in attending if it run locally.

Appendix J

Holt Event

Given the size of the group, discussions were broader and more in depth, which is reflected in the feedback below.

General comments

Simon Stevens video – parity of physical/mental health not mentioned.

What are the timescales for these changes to be implemented?

Is it realistic? I know a lot of people who work at the NNUH, there's been a lot of IT disasters and I think things are lot more complicated than what's been made out.

Take GP Services – appointment waiting times have gone from a few days to several weeks over just the last few years. They cannot recruit/retain GPs in Norfolk so how is any of this going to be achieved?

I've been a carer so I understand the pressure on GP's etc but where's the distinction between health and social care. Dementia is treated as a condition, not a disease and it feels like they hide behind the terminology to get out of paying for stuff.

There a loads of leaflets but no support. NHS are essentially promoting private businesses to provide the care the state should be providing in the first place.

'Bookable rest bite care for carers' Is there provision for that within the long term plan?

If you have cancer you're cared for – if you have dementia you'll have to pay yourself. How is that fair? There's definitely parity needed and until that's fixed what's the point in all this.

How is dementia not a health issue? Your slides say it's a disease, health professionals say it's a condition!

The NHS exists to prolong lives essentially, but they are prolonging some more than others and that's where the inequality comes in. That is what needs to be addressed.

It also has a totally self serving structure full of bureaucracy. Why isn't all that money going into services for patients.

I don't appreciate people telling me how to spend my money. If you're a carer, you're basically a slave. They can't be cured so you're handed to social services and have to beg for healthcare every step of the way. If you're dealing with someone with parkinsons and dementia you don't need a social worker, you need health support!

Won't delivering more services locally mean we're just paying consultants to travel rather than just paying them to treat people?

Do you think the priorities are correct?

Mental health in Norfolk – we have one of the highest suicide rates and virtually no support available to people – mental health needs to be recognised.

We need to know what the Government are prepared to fund for people and a bill of rights on what people can expect from health services.

Concerns voiced around Privatisation.

No one would disagree with the priorities themselves, who wouldn’t want that stuff, but it’s the lack of detail in how they are going to be delivered that is of concern.

What local priorities would you like to see?

A noticeable difference in services or at least some movement in the right direction.

Do what you’ve actually said you’ll do for once.

‘Sustainable hospital services’ What does that even mean? What does sustainable look like?

Access to and support for mental health conditions needs to be a lot clearer.

Priority 3 around mental/physical health this should be the top priority. Access to mental health and social care is what lets services down in this area.