

NHS Long Term Plan

Hampshire Isle of Wight Sustainability
and Transformation Partnership

Healthwatch Hampshire, Isle of Wight,
Southampton and Portsmouth

wh  **t**

would you do?

It's your NHS. Have your say.

Background:

Healthwatch England commissioned the four Local Healthwatch organisations (Healthwatch Hampshire, Healthwatch Southampton, Healthwatch Portsmouth and Healthwatch Isle of Wight) to carry out a survey to understand people's views of the ambitions set out in the Long Term Plan and in particular, what people felt was important to them in terms of their health and care. Together, we encouraged people to complete two surveys - one general survey which was suitable for everyone and one directed at people with long term conditions. Alongside this, we carried a series of focus groups to reach people who might not otherwise have the chance to share their reflections on the Long-Term Plan.

At the request of the Hampshire Isle of Wight Sustainability and Transformation Partnership, a priority area of focus was given to personalised care, digital and prevention. **We received 166 completed Specific Condition Surveys and 580 completed general surveys**, the majority (93%) responding on their own behalf with 6% completed on behalf of someone else.

Each Healthwatch across the Partnership co-ordinated activity across respective areas, **143 people in total participated in the focus group activity.**

Summary of Findings:

What matters most to people in Hampshire, Portsmouth, Southampton and Isle of Wight?

The main themes from the data collated were as follows:

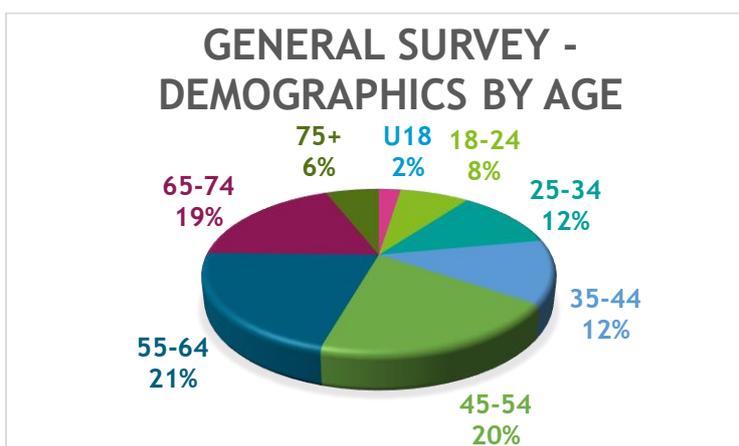
- People want easy and quick access to health care when they need it, especially to GP services, and to be able to receive the treatment and support they need without long waiting times.
- People want to be more involved in their care, to be listened to by professionals and to have their time valued. Choosing the right treatment should be a joint decision between the individual and the professional with people being supported to consider their options to make the right choices for them.
- People want to know their information is secure, but they also want better sharing of information between services, specialities and professionals (as well as access to their own information) to make services more seamless.
- People want clear, concise and timely communication about all aspects of their care.
- People want quick and easy access to clear information to help them make decisions about their health and care. They also want access to support for healthy living, including access to good dietary information and exercise facilities to enable them to stay independent for as long as possible.
- People want local services, accessible easily.
- Finally, people want to feel supported at end of life.

N.B Full data sets are available in the Appendices on Page. 9 onwards.

Participants:

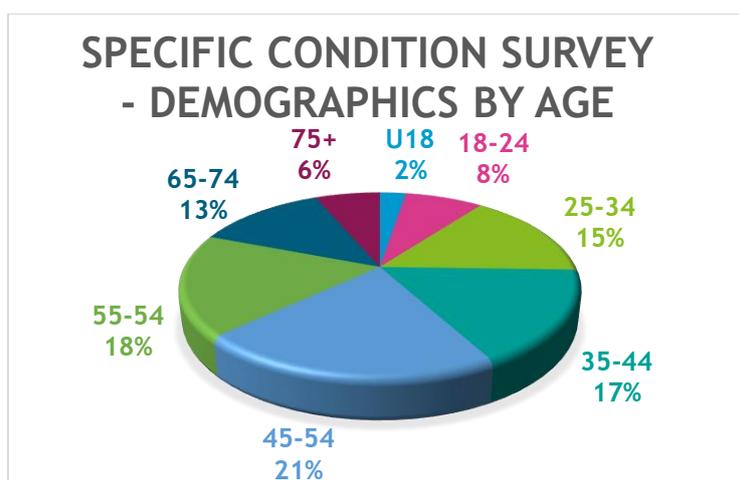
Of the General Surveys completed:

Gender	Number
Female	388
Male	167



Of Specific Condition Surveys completed:

Gender	Number
Female	109
Male	32



Key Headlines:

Quicker and easier access to professionals (esp. GP), better support for ongoing conditions (plus support for general living), more alternative therapies and treatments and better communications across specialities and between professionals.

“Better access to GP services, 4 weeks wait is not acceptable. Even same day, urgent appointment at our practice are only obtainable if you queue up before surgery opens.” (Southampton resident)

“Lack of GPs on the Island means that it’s almost impossible to get an appointment. I have to ring every morning and by the time I get through all the appointments have gone. I then have to repeat this scenario every day, sometimes for weeks on end before I am offered an appointment”. (IOW resident)

“Arts and crafts on prescription, special sessions with a group that meets for health reasons but can focus on making things as we chat. So it’s not like therapy but is affordable rather than £40 a session like some places it could be like £3 contribution or similar.” (IOW resident)

“The individuals who treated me were generally really kind and professional and I’ve many reasons to be grateful to the NHS. But the delays, absence of joined up approach to treatments and difficulties negotiating a way through the system, protocols etc. would benefit from improvements”. (Person with heart & lung problems living in Southampton)

People felt they needed to be listened to more about their health conditions and needs and for their views to be central to their treatment options.

“When a clinician sees me I want them to have complete access to my clinical history without hindrance. I certainly do not want to have the need to ask one clinician if another can see my notes. I want my notes to be regarded as my property and not that of the NHS or someone else”. (Hampshire resident)

The length of time waiting for an initial assessment or diagnosis of a specific condition varied from 14 months to 10 yrs. For autism, 2 weeks to 1 year for cancer, 1 month to 2 years for dementia, 9 weeks to 4 years for learning disability, 6 months to over 10 years for long-term conditions and a few days to a few years for mental health.

Key Areas of Focus for the STP:

Personalised Care:

“We cannot understand why our health records are not shared between hospitals across county boundaries! We live much closer to Dorset than Southampton for any urgent care we might need.” (Hampshire resident)

“I would like a system of comprehensive linked care and support plans for physical and mental health, with a designated lead professional with appropriate experiences and qualifications. This person would build up a sustainable life long relationship and have kudos during times of illness/discussion/conflict in my absence. I would then know that I had a real voice when decisions are made “about” me and my care in my absence”. (IOW resident)

“Recognition that I can be, and want to be, active in my own care and treatment, not just a passive recipient”. (Southampton resident)

“Have less stress from dealing with health personnel who don't listen and think they know best. They should be working alongside me in partnership with me to put me and my needs at the heart of action - advise but not control”. (Hampshire resident)

“Professionals who listen. To have them believe I am the expert of my body and just because I don't look like what they expect 'sick/unwell' people to look like, my conditions are still valid.” (Southampton resident)

Suggested solutions - Personalised Care:

- Better access to information of what is available both from providing service and in the wider community, with clear, consistent links to accessing social prescribing.
- Services putting the individual at the center. People need to be empowered to have choice around their long-term health condition and their own health plan - ‘with me, not to me’.
- Community and peer support groups that give emotional support and also provides information sharing relating to a long-term health conditions.

Digital:

“Acceptance that not everyone understands or is capable of participating in modern technology. I am personally computer-literate, but many are not especially among the elderly, mentally ill and otherwise more vulnerable members of society - it is wrong to place so much dependency on online services although they are an important option for those willing and able to take advantage of them. They must never become the only, or even automatically the most beneficial, option.” (Hampshire resident)

“Stop writing me and my family letters for hospital checkups/appointments. If we’ve opted to use media, use it, consistently. I can go online to book a referral appointment, then you send a letter! Email confirmation.” (Hampshire resident)

“I want a help line where I can obtain information on a 24/7 basis. Not so much a doctor but a nurse who can help me to avoid calling 999” (Hampshire resident)

“I just assumed this was already being done, but I do know that the NHS computer systems are not joined up at all at the moment and that must waste so much money and be very frustrating for staff.” (Southampton resident)

Suggested solutions - Digital:

- There needs to be a recognition of people’s understanding of technology, particularly for those most vulnerable and those who may not be able to access it. Additional support needs to be considered across health and social care to ensure any proposed digital strategy is accessible.
- Could providers (i.e. GP services, community hospitals etc.) have ‘demonstration areas’ to empower people to take responsibility for accessing information safely and securely.
- Any information should continue to be available in ‘easy-read’ formats and distributed widely across the community. It is not always disabled people who benefit from having accessible literature, but older people find it much easier to use too.
- Ensuring that any technology proposed does not come at the detriment of the ‘human connection’.

Prevention:

“More advice and help for weight loss. Not just diet but complete lifestyle advice and ongoing support to make the needed changes. This is inconsistent and often just recommendation to lose weight but nothing more based on my overweight husbands experience.” (Hampshire resident)

“As a woman - better access to information and support around the changes you will experience throughout your life, especially peri & menopause - well woman clinics, better information, someone with good knowledge to talk to - choices to be able to help myself - access to exercise classes, dietician etc.” (IOW resident)

“More advice and help for weight loss. Not just diet but complete lifestyle advice and ongoing support to make the needed changes”. (Hampshire resident)

“Access to specialists for advice on preventive care - e.g. how to avoid joint replacements, diabetes and other chronic conditions instead of waiting until a problem is so bad it needs major surgery and probably costs more.” (IOW resident)

“Focus groups outside health and care initiatives led by elected community leaders feeding into the CCG so that service users feel part of the financing/decision making process. Investment and incentives so that this is seen as a needed feedback/development system”. (IOW resident)

Suggested solutions - Prevention:

- Better understanding of communities and individual drivers to engage in what is considered 'poor health' choices. "Seek to understand before being understood".
- Accessible mental health services that seek to support when something is 'starting', rather than when an individual is in crisis.
- A lack of opportunities and things to do was identified by some as being a driver to engaging in 'poor' health choices. More awareness raising or sharing of information relating to community groups and activities.
- Better understanding of people's interpretation of social isolation, not just assuming it's an elderly demographic, but in young people too who may engage with risk taking behaviours through boredom or lack 'positive' activities or opportunities.

Next steps - STP response

We are extremely grateful to the four Healthwatch in Hampshire and the Isle of Wight for the work they have done to seek the views of local people on some of the key themes in the Long Term Plan. It is essential that the views and experiences of local people are at the heart of our plans, driving forward the changes needed to improve local services and we would like to thank everyone who took part.

"This report makes an important contribution to the engagement work which has already taken place across Hampshire and the Isle of Wight. It provides us with insight into the views of local people on staying well, using technology to support health and the ways in which they would like us to personalise their care. The Hampshire and Isle of Wight Sustainability and Transformation Partnership, which includes all our local councils and NHS organisations, is absolutely committed to continuing to listen to the views of local people and acting on them wherever possible, alongside acting on the evidence we have about the health of our population.

"The engagement has revealed three areas upon which we need to focus our efforts. People commented that they are keen for care professionals to be more joined up, having the right information to do their jobs well. As we develop our shared care record, it will be important for us to involve local people to understand their views on this topic in more detail. We also need to further investigate the ways in which people would like to use technology to support their health. The report highlighted that technology needs to be complementary to existing approaches, not a substitute, and it will be vital for the public to inform how we best achieve this. People also asked for clear, timely and relevant information to help them take charge of their health and we must respond to that. There are some things we are already doing to improve people's experiences; and there are other things where will make bigger improvements over time, so that we better support people to stay well and access the services they need, when they need them.

"The conclusion of the report, that people want to receive more support to live independent and healthy lives, is a clear sign to us that we must rethink the way we deliver care in Hampshire and the Isle of Wight. We need to keep challenging the traditional way in which we have worked and move to a position where people and communities are in control of their health and wellbeing, with the responsive services to support them."

Acknowledgements

All four local Healthwatch would like to thank the range of patients and public who not only engaged with the survey, but provided additional feedback through a variety of groups, these included:

[Age UK \(Portsmouth\)](#)

[Board In The City](#)

[Friday Forum](#)

[Mencap \(Southampton\)](#)

[October Books](#)

[Umbrella Arts](#)

[West Itchen Community Trust Ltd](#)

[Communicare](#)

[No Limits](#)

[St Denys Activity Group](#)

[Thornhill Baptist Church](#)

[Isle of Wight College](#)

[Prostate Cancer Support Group \(Isle of Wight\)](#)

[Basingstoke & District Disability Forum](#)

[PRISM - Parkinson's Recently Diagnosed Information and Support Meeting \(Basingstoke\)](#)

Appendices:

General Survey and Specific Condition

Survey Data

what
would you do?
It's your NHS. Have your say.

General Survey

Data Analysis

After duplications removed, number of responses received = 580

Question 1: (related to consent to share)

Question 2: Pick the area that best describes where you live:

Area	Number (as %)
Southampton	291 (50%)
Hampshire	136 (23%)
IOW	141 (25%)
Portsmouth	12 (2%)

Question 2b: Who are you responding on behalf of?

Yourself	537 (93%)
Someone Else	37 (6%)
No response	6 (1%)

Question 3a: Rate how important the following statements are to you when it comes to living a healthy life

Statement	Number of Responses (as a %)					No. Resp.
	Very Important	Important	Neutral	Not Important	Not Important at all	
Easy access to the information I need to help me make decisions about my health and care	375 (65%)	170 (29%)	29 (5%)	3 (<1%)	0	3 (<1%)
Having the knowledge to help me do what I can to prevent ill health	362 (63%)	182 (31%)	23 (4%)	6 (1%)	1 (<1%)	7 (1%)
Access to the help and treatment I need when I want it	474 (82%)	89 (16%)	6 (1%)	4 (<1%)	1 (<1%)	7 (1%)
Professionals that listen to me when I speak to them about my concerns	466 (80%)	96 (17%)	10 (2%)	2 (<1%)	0	6 (1%)
For every interaction with health and care services to count; my time is valued	335 (58%)	190 (33%)	46 (8%)	3 (<1%)	0	6 (1%)

The vast majority of respondents rate “Very Important” for all the statements with “Access to the help and treatment I need when I want it” rating the highest (82% for Very Important).

Question 3b: If there was one more thing that would help you live a healthy life, what would it be?

Note - the comments below have been coded from the free text

Comment	Number of times comment recorded
Healthy eating and exercise (includes comments related to help with understanding healthy eating)	35
Quicker and easier access to GP	30
Cheaper and easier access to leisure facilities such as gyms and swimming (inc. alternatives such as yoga etc.)	29
Easier access to services (esp. for working people)	22
Reduce pollution	20
Being listened to by professionals (esp. for people who are experts in their own condition/LTC)	12
More support groups	9
Better health information	7
More self-help support and information	6
Better cycling infrastructure	5
More regular check ups	5
More local services	4
The need for more social contact	4
The need for a better work/life balance	4
More alternative therapies and treatments	3
More mental health crisis services	3
More sharing of health records	3
More staff	2
Cheaper meds and less emphasis on meds	2
More carer support	2
Less emphasis on cost and more on the person	2
More NHS dentists	2
Less paperwork for people on benefits	2
Better awareness on mental health issues	2
More accessible exercise facilities for those with disabilities	1
Better communication from GP	1
More joined up services	1
More falls prevention information	1
More information in different languages	1

Quotes taken from the free text:

“I am reasonably pro-active about my health. But I hadn't realised that I should have had an MOT when I got to 50 years (I've had one now). It would be useful to have a timetable of things I should book into and by what age. That way I can be even more proactive. I would be happy for this to be emailed to me.” (Hampshire resident)

“I think there needs to be much more awareness about responsibility to look after oneself. Many of the illnesses faced today are mostly preventable. I feel many people take the health service for granted and expect someone to fix them, when there is a lot they can do for themselves. I do not consider it my right to have the most expensive treatment that becomes available, at the expense of there being less available for others.” (Southampton resident)

“Subsidised or removed NHS fees for prescriptions and checkups for students - many students avoid going to get vital checkups due to cost of it, and they cannot afford it on a student budget. The choice between buying groceries and a dental health checkup will always sway towards the former and not getting necessary prescriptions and checkups cause problems later in life.” (Hampshire resident)

“More advice and help for weight loss. Not just diet but complete lifestyle advice and ongoing support to make the needed changes. This is inconsistent and often just recommendation to lose weight but nothing more based on my overweight husbands experience.” (Hampshire resident)

“Counselling service on offer by donation at Surgery. Or organised meetings for groups for support and information regarding different aspects of health issues, medication side effects, like a support group to save taking up Dr. time” (Hampshire resident)

“I am in receipt of ESA. This benefit pays so little that it is impossible to eat as healthily as I would like, or go to a gym for exercise like I used to. So a more generous ESA is my answer.” (Hampshire resident)

“To have the counselling I started with the same person ccg won't agree I CANNOT change to someone else. I am suffering daily cannot function have many meltdowns as no service providers understand autism despite training they need to SEPERATE it from learning disability over half with autism do not have an LD nor a MH problem so we slip through net misunderstood so we may appear HF but are in fact left to go from crisis to crisis with little help as we are expected to be clever so can stop having autism behaviours. Change social to having a SEPERATE autism section with proper facilities not shove us under LD where we can't use the facilities and where resources available are not autism tailored. And don't shove us under MH nor keep sectioning people for behaviours that should NOT be sectioned nor given meds...” (Hampshire resident)

“When a clinician sees me I want them to have complete access to my clinical history without hindrance. I certainly do not want to have the need to ask one clinician if another can see my notes. I want my notes to be regarded as my property and not that of the NHS or someone else”. (Hampshire resident)

“As a woman - better access to information and support around the changes you will experience throughout your life, especially peri & menopause - well woman clinics, better information, someone with good knowledge to talk to - choices to be able to help myself - access to exercise classes, dietician etc.” (IOW resident)

“More weight loss support that doesn't cost money. Always referred to WW or Slimming World which cost money or programmes for the elderly that take place during working hours. So few GP surgeries offer weight loss clinics anymore.” (Southampton resident)

“Arts and crafts on prescription, special sessions with a group that meets for health reasons but can focus on making things as we chat. So it's not like therapy but is affordable rather than £40 a session like some places it could be like £3 contribution or similar.” (IOW resident)

“Access to specialists for advice on preventive care - e.g. how to avoid joint replacements, diabetes and other chronic conditions instead of waiting until a problem is so bad it needs major surgery and probably costs more.” (IOW resident)

“Professionals who listen. To have them believe I am the expert of my body and just because I don't look like what they expect 'sick/unwell' people to look like, my conditions are still valid.” (Southampton resident)

“A named GP to coordinate all of my chronic complex medical needs, who I am able to contact at short notice. Training for receptionists and those who answer the phones to prioritise those with chronic illness.” (Portsmouth resident)

“Have less stress from dealing with health personnel who don't listen and think they know best. They should be working alongside me in partnership with me to put me and my needs at the heart of action - advise but not control” (Hampshire resident)

“We cannot understand why our health records are not shared between hospitals across county boundaries! We live much closer to Dorset than Southampton for any urgent care we might need.” (Hampshire resident).

“I would like a system of comprehensive linked care and support plans for physical and mental health, with a designated lead professional with appropriate experiences and qualifications. This person would build up a sustainable life long relationship and have kudos during times of illness/discussion/conflict in my absence. I would then know that I had a real voice when decisions are made “about” me and my care in my absence”. (IOW resident).

“Lack of GPs on the Island means that it's almost impossible to get an appointment. I have to ring every morning and by the time I get through all the appointments have gone. I then have to repeat this scenario every day, sometimes for weeks on end before I am offered an appointment”. (IOW resident)

“Diabetic care is inconsistent. I used to be prescribed blood testing kits and sticks from my GP but they don't do this now. I now have to buy my own. I've worked and paid taxes for years. Why has this been stopped?” (IOW resident).

Question 4a: Rate how important the following things are to you when it comes to managing and choosing the support you need:

Statement	Number of Responses (as a %)					No. Resp.
	Very Important	Important	Neutral	Not Important	Not Important at all	
If I have a long term condition I decide how the NHS spends money on me	160 (28%)	205 (36%)	159 (27%)	35 (6%)	7 (1%)	14 (2%)
Choosing the right treatment is a joint decision between me and the relevant health and care professional	350 (61%)	185 (32%)	32 (5%)	7 (1%)	0	6 (1%)
I make the decision about where I will go to receive health and care support	232 (40%)	232 (40%)	95 (17%)	14 (2%)	1 (<1%)	6 (1%)
I should be offered care and support in other areas if my local area can't see me in a timely way	256 (45%)	223 (39%)	73 (12%)	13 (2%)	2 (<1%)	13 (2%)
I make the decision about when I will receive health and care support	237 (41%)	219 (38%)	104 (19%)	13 (2%)	2 (<1%)	5 (<1%)
My opinion on what is best for me, counts	278 (48%)	215 (37%)	69 (12%)	10 (2%)	1 (<1%)	7 (1%)

Communications are timely	359 (62%)	184 (32%)	21 (4%)	3 (<1%)	1 (<1%)	12 (2%)
I have time to consider my options and make the choices that are right for me	337 (59%)	205 (36%)	25 (4%)	2 (<1%)	1 (<1%)	9 (1%)

All the statements were rated as being Important or Very Important with a slightly higher neutral rating for how the NHS spends money.

Question 4b: If there was one more thing that would help you to manage and choose how the NHS supports you, what would it be?

Note - the following comments have been coded from the free text

Comment	Number of times comment recorded
Quicker and easier access to GP	32
Listen to patient/carer/family	25
Need shorter waiting times	20
Clearer communication (inc. facts, options and info)	18
More use of IT (skype/email/text)	12
Better sharing of information between services	12
Continuity of which professionals you see	10
More alternative therapies	9
Improved services on the IOW	8
Have access to health records	7
More health info available	7
More money and staff	5
More self-help support	5
More services locally	3
Cheaper hospital parking	3
Cheaper access to exercise facilities	3
More follow up	1
More help with travel costs	1
More access to health checks	1
Better mental health support	1
More support for carers	1
Better appointment times for people that work	1

Quotes taken from the free text:

“Better access to GP services, 4 weeks wait is not acceptable. Even same day, urgent appointment at our practice are only obtainable if you queue up before surgery opens.”
(Southampton resident)

“If health care professionals took notice of patients after all we know when our bodies are not behaving as they should. I was sent home from SGH with life threatening infection after saying to staff how unwell I felt.” (Southampton resident)

“Being able to get support quickly like I had in Inverness in Scotland after fracturing my ankle. They were fantastic. I came back south with all necessary paperwork to pass to my GP and have not had another word. Sad”. (Portsmouth resident)

“When multiple conditions exist there needs to be better communication or some format for conference sharing of what takes priority of treatment and best outcome for patient. Less confusion.” (Hampshire resident)

“Better non-speech communication (text/email). There's been great improvement in this area but some services/facilities are still essentially impossible to access without "just" picking up the 'phone.” (Southampton resident)

“To be able to see the same GP when I visit the surgery. I know they can access all my details via computer, but no GP actually gets to know me as I see a different one every time and they all have different views as well.” (Southampton resident)

“Having ALL options for medication available and talked about, even if the NHS won't supply something, I need to know I can get medication privately if I choose.” (Hampshire resident)

“This should mean real choices - not like the time I was referred for a hip operation and given one choice out of one, because that was the package my GP surgery had bought into! I'm still suffering the consequences of that bad experience”. (Southampton resident)

“I don't want to speak to a centralised national booking centre - I want to book with my provider who actually understands their own appointment system. I don't want to be passed from pillar to post causing many months delay of even getting onto the waiting list”. (Southampton resident)

“I would want an agree protocol of patient contribution and understanding of outcomes of clinics. Notes would not be signed off unless there was a submission by me within my notes, even if my interpretation was different to the professional.” (IOW resident)

“Stop consultants acting like God. It's my body and my life. I am the one that decides about what treatment does and does not happen. Fed up with being treated like I am an idiot. I am perfectly capable of understanding.” (Hampshire resident).

Question 5a: Rate how important the following things are to you when it comes to keeping your independence and ageing healthily:

Statement	Number of Responses (as a %)					No. Resp.
	Very Important	Important	Neutral	Not Important	Not Important at all	
I want to be able to stay in my own home for as long as it is safe to do so	436 (76%)	113 (20%)	18 (4%)	3 (<1%)	2 (<1%)	8 (1%)
I want my community to be able to support me to live my life the way I want	281 (49%)	214 (38%)	67 (11%)	7 (1%)	2 (<1%)	9 (1%)
I want my family and friends to have the knowledge, to help and support me when needed	333 (57%)	196 (35%)	35 (6%)	4 (<1%)	1 (<1%)	11 (2%)
I want there to be convenient ways for me to travel to health and care services when I need to	355 (61%)	181 (32%)	26 (4%)	3 (<1%)	0	15 (3%)

I want my family and me to feel supported at the end of life	435 (75%)	115 (21%)	14 (2%)	4 (<1%)	1 (<1%)	11 (2%)
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Again, all statements were rated as being Important or Very Important. Being able to stay at home as long as possible and support at end of life were rated as the highest on Very Important (76% and 75% respectively).

Question 5b: 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

Note the following comments have been coded from the free text

Comment	Number of times comment recorded
Support to stay at home (inc. social care)	29
More local support networks	27
Better public transport	15
Access to exercise	11
Clear and easy access to info (on healthy living)	10
More local and rural services	8
Support to make choices	5
Better social care	5
Listen to patient	4
More support for carers	3
Better services for the IOW	3
Better support for elderly	2
Better access to physio	2
More funds	2
Shorter waiting times	2
More preventative services	2
Better awareness of support available from the 3 rd sector	2
Better end of life care	1
More respite care	1
Better use of IT	1
Better mental health services	1
More self-help support	1

Quotes taken from the free text

“That I could feel that my concerns about health should not be affected by my age. I am reasonably healthy and always hope that I will be regarded as “equal” to those who are younger than me” (Hampshire resident)

“I wouldn’t want a succession of healthcare staff traipsing in and out of my own home. Whatever has happened to consideration of cross-infection? Care in the community is grossly understaffed and underfunded - and risky!” (Portsmouth resident)

“Option for euthanasia. I want to be in control of what happens to me if I were to be in a situation where chance of survival and time left is minimal. This would minimise my family suffering and would save NHS resources.” (Hampshire resident)

“I want a help line where I can obtain information on a 24/7 basis. Not so much a doctor but a nurse who can help me to avoid calling 999” (Hampshire resident)

“Respect for a DNR , my father , now in a nursing home costing everything he had worked for with dementia, had an advance directive ,was resuscitated then SGH made a DNR which was ignored and he was resuscitated another 7 times. Then we were informed he was not fit to be discharged home to no choice but to put into residential care. It was not the end of life he or his family wanted or planned for”. (Hampshire resident)

“Continue with my daily activities i.e. to be in the environment that I am used to so that I continue living. If I am taken to a nursing home for companionship sometimes it depresses people as they are too unwell (the other patients there)”. (Southampton resident)

“I want the NHS to have the staff in place with the time to discuss with me how to decide when “it is safe to” remain at home, or when help is needed. Without this, a wish list is useless” (Southampton resident)

“Having the care and support I might need at the time I need it. Delay in providing services results in crisis intervention, where timely provision would help to prevent this. It's distressing for the individual to have to struggle whilst waiting for help and it increases the risks as well as, potentially, the cost to the NHS” (Southampton resident)

Question 6a: Rate how important the following statements are when it comes to interacting with the local NHS:

Statement	Number of Responses (as a %)					No. Resp.
	Very Important	Important	Neutral	Not Important	Not Important at all	
I have absolute confidence that my personal data is managed well and kept secure	323 (57%)	182 (31%)	57 (10%)	2 (<1%)	3 (<1%)	13 (2%)
I can access services using my phone or computer	286 (49%)	218 (39%)	48 (8%)	17 (3%)	4 (<1%)	7 (1%)
I can talk to my doctor or other health care professional wherever I am	297 (51%)	208 (37%)	57 (10%)	9 (1%)	1 (<1%)	8 (1%)
I can make appointments online and my options are not limited	279 (48%)	183 (31%)	73 (13%)	24 (4%)	10 (2%)	11 (2%)
Any results are communicated to me quickly making best use of technology	322 (55%)	196 (34%)	30 (5%)	11 (2%)	6 (1%)	15 (3%)
I manage my own personal records so that I can receive continuity in care	223 (38%)	194 (33%)	127 (23%)	23 (4%)	2 (<1%)	11 (2%)
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	190 (33%)	210 (37%)	125 (21%)	30 (5%)	9 (1%)	16 (3%)

Again, the majority of respondents highly rate all statements as being Important or Very Important. Confidence in the security of data and getting results quickly making best use of technology are the highest scored statements.

Question 6b: If there was one more thing that you think need to change to help you to successfully manage your health and care, what would it be?

The following comments are coded from the free text:

Comment	Number of times comment recorded
Quicker and easier access to GP services	31
Share records across professionals and specialities	13
Access to own medical records	9
More health information available (where to access services etc.)	7
More funds for services	7
Listen to the patient	7
Less reliance on IT (esp. for elderly and vulnerable)	7
More online appointments	6
Clearer communication about all aspects of care	4
A consistent/named point of contact	3
More information	3
More community nursing and support services	3
More respite care	2
Better communication between services and professionals	2
Longer opening times esp. for working people	2
Access to specialists to discuss conditions	2
Better access to cheaper transport	1
Better integration of health and social care	1
Ongoing support to stay independent	1
More disability awareness	1
Better podiatry services	1
Properly trained and paid care staff	1
Better non-speech communications	1
More local services	1
More phone appointments	1
More mental health services	1

Quotes from the free text:

“I can't even ring my GP and get an appointment, so whilst all of this is IMPORTANT - I don't expect any of it to happen without a great deal of effort on my part. I do not have confidence that my data is adequately protected and although it is networked so that medical professionals can share records, my experience is that this either does not work or does not get reviewed. I do not book online as I do not trust the appointment system and the appointments I need are never available.” (Southampton resident)

“Acceptance that not everyone understands or is capable of participating in modern technology. I am personally computer-literate, but many are not especially among the elderly, mentally ill and otherwise more vulnerable members of society - it is wrong to place so much dependency on online services although they are an important option for those willing and able to take

advantage of them. They must never become the only, or even automatically the most beneficial, option.” (Hampshire resident)

“My practice has recently joined a group. Previously, although I had to call several times I was able to speak to them on the same day. I recently took a whole week before I finally spoke to someone. I have chronic conditions and the delay may have had drastic results. They do not have on line appointment booking facilities.” (Hampshire resident)

“A return to our local surgery's previous practice of offering bookable online appointments with all of the practice's GPs not just your own GP. While an appointment with my own GP is preferable, sometimes her availability is very limited and under the previous online booking system you could opt to see someone who was available sooner.” (Hampshire resident)

“I worry about my family, my mum has been unable to change her doctor, my partner like many men doesn't know how and when to seek help and support, that my friends have to dip into savings to support themselves, they are not adequately supported financially nor do they feel they can live independently or semi independently, access to addiction help and support needs to be timely in order to be successful and cost effective. I hear people say I will be costing the health service loads of money therefor burdening themselves with guilt, you have to be confident to ask for help by allowing the health service to become stretched every day you are encouraging those in need to stay away, also try and self-assess and self-help when we need the skill and help of professionals. The health service is the caring face of a compassionate society everyone needs to feel they can approach and learn from it.

Care from the health service has changed my life, to think I could be treated so compassionately and non-judgmentally has given me confidence and changed my view of people, I now reach out to friends who are troubled rather than shy away” (IOW resident)

“I find that the security of my personal information carries a higher priority than my wellbeing. For example out of hours still cannot see my GP notes any more that a hospital consultant can do so. Both have to rely on my recollection of meds and treatments and conditions for an up to date history. On this issue I do not have a choice.” (Hampshire resident)

“Better communication - doctor designating "medically untrained surgery secretary" to do phone consultation could not do it because she stated she did not understand my responses or continuing type of pain" Call closed. Receptionists try to do their best but cannot but rarely 'commence a diagnosis at the desk - NOT their role.” (Hampshire resident)

“Have surgery call me if there is an abnormality in my results, rather than having every single patient who has a test blocking the surgery lines. My surgery expects everyone to call then, seems such a waste of manpower” (Hampshire resident)

“More efficient use of personnel at my GP surgery i.e.; general straight forward queries able to be answered quickly and having a good triage system that knows when I need advice from a more qualified professional.” (Hampshire resident)

“Recognition that I can be, and want to be, active in my own care and treatment, not just a passive recipient” (Southampton resident)

“Focus groups outside health and care initiatives led by elected community leaders feeding into the CCG so that service users feel part of the financing/decision making process. Investment and incentives so that this is seen as a needed feedback/development system”. (IOW resident)

“More peer workers, paid, with lived experience to support people and give info, easing GP time” (Southampton resident)

Question 7: What is most important to you to help you live a healthy life?

Multiple Choice Statements (respondents were asked to choose one only)	Number of Responses (as a %)
Easy access to the information I need to help me make decisions about my health and care	81 (14%)
The knowledge to help me do what I can to prevent ill health	88 (15%)
Access to the help and treatment I need when I want it	244 (42%)
Professionals that listen to me when I speak to them about my concerns	131 (23%)
For every interaction with health and care services to count; my time is valued	22 (4%)
No response	14 (2%)

“Access to the help and treatment I need when I want it” was rated (42%) as the most important thing to help people live a healthy life.

Slightly more females (25%) than males (19%) stated “Professionals that listen to me when I speak to them about my concerns” is most important.

Question 8: What's most important to be able to manage and choose the support you need?

Multiple Choice Statements (respondents were asked to choose one only)	Number of Responses (as a %)
If I have a long-term condition I decide how the NHS spends money on me	38 (7%)
Choosing the right treatment is a joint decision between me and the relevant health and care professional	247 (43%)
I make the decision about where I will go to receive health and care support	19 (3%)
I should be offered care and support in other areas if my local area can't see me in a timely way	77 (13%)
I make the decision about when I will receive health and care support	23 (4%)
My opinion on what is best for me, counts	41 (7%)
Communications are timely	38 (7%)
I have time to consider my options and make the choices that are right for me	82 (14%)
No response	15 (2%)

“Choosing the right treatment is a joint decision between me and the relevant health and care professional” was rated as the most important thing (43%) to enable people to manage and choose the support they need.

There were no significant differences for the percentages across genders.

Question 9: What's most important to you to help you keep your independence and stay healthy as you get older?

Multiple Choice Statements (respondents were asked to choose one only)	Number of Responses (as a %)
I want to be able to stay in my own home for as long as it is safe to do so	301 (52%)
I want my community to be able to support me to live my life the way I want	84 (15%)
I want my family and friends to have the knowledge to help and support me when needed	64 (11%)
I expect there to be convenient ways for me to travel to health and care services when I need to	46 (8%)
I expect that my family and I will feel supported at the end of life	67 (11%)
No response	18 (3%)

“I want to be able to stay in my own home for as long as it is safe to do so” was rated as the most important thing (52%) to help people keep independent and stay healthy as they get older.

There were no significant differences for the percentages across genders.

Question 10: What is most important to you when interacting with the NHS?

Multiple Choice Statements (respondents were asked to choose one only)	Number of Responses (as a %)
I have absolute confidence that my personal data is managed well and kept secure	81 (14%)
I can access services using my phone or computer	51 (9%)
I can talk to my doctor or other health care professional wherever I am	172 (30%)
I can make appointments online and my options are not limited	79 (14%)
Any results are communicated to me quickly making best use of technology	90 (15%)
I manage my own personal records so that I can receive continuity in care	39 (6%)
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	41 (7%)
No response	27 (5%)

“I can talk to my doctor or other health care professional wherever I am” was rated as the important thing (30%) to people when interacting with the NHS

More males (15%) than females (7%) said “I can access services using my phone or computer”. Percentages for all other statements were similar across genders.

Question 11: Any further comments

The following comments are coded from the free text:

Comment	Number of times comment recorded
Better communication between services/specialities and professionals	8
Listen to the patient/carer/family	6
More funds needed	3
Quicker and easier access to GP services	3
Share information better	3
Communicate with people in their preferred way	2
Reduce waiting times	2
Make better use of IT	2
More mental health services	2
Make better use of walk-in centres	1
Reduce isolation for older people	1
Meds should be free for people born with conditions	1
Make more use of volunteers	1
Should be more alternative therapies on offer	1

Quotes taken from the free text:

“It is so important that people living alone are not left in isolation which can be very difficult with some elderly folk. Maybe contact once or twice annually.” (Southampton resident)

“I feel there should be free medicine for those who are born with medical conditions they cannot help and could not prevent like asthma” (Southampton resident)

“My biggest problem is different services communicating with me and one another. One hand rarely knows what the other is doing and I am left to pick up the pieces.” (Southampton resident)

“It’s difficult to put a priority on these questions. Luckily I am in excellent health and rarely need the NHS. When I have recently (following a faint and subsequent blow to the face and concussion) I felt I received excellent care.” (Southampton resident)

“Stop writing me and my family letters for hospital checkups/appointments. If we’ve opted to use media, use it, consistently. I can go online to book a referral appointment, then you send a letter! Email confirmation.” (Hampshire resident)

“This survey makes various assumptions about what is important to patients, e.g. choice over their care. It doesn’t cover the more important topics of preventing ill-health, the quality of care, adequacy of funding (for social care as well as healthcare) and balancing competing funding priorities.” (Hampshire resident)

“I have a rare condition and am seen in two different hospitals I find it frustrating when I don’t get written communication after my appointments and my GP doesn’t know what is going in or he gets a letter but I don’t!” (Hampshire resident)

“I can’t easily access services. Information is important, but only after establishing that you can access care when needed. With information, there should be choice. It should be a basic

right to have information about and make informed decisions about our care.” (Southampton resident)

“The NHS is an amazing institution but is not always tailored to the individual- money could be saved by ensuring individuals get regular blood tests and advice on how to stay fit and healthy into old age.” (IOW resident)

“This is more of a policy beauty contest than a survey. The options are from your perspective and not from that of healthcare recipients. We need to rethink the bureaucracy and resourcing of healthcare and make it fit for purpose in the 21st century. Like so many things this means starting at school. We lay people don't know enough about our body's systems and weaknesses, the impact of nutrition, exercise and stress. We should know more. Medics should be trained for free, society is the beneficiary and standards could be raised above financial thresholds. Clinicians and others so trained should pay back for a minimum duration of service to the NHS. Not all clinical jobs need a degree, most need skill and experience. Learn lessons from how Cuba manages its system; tests confirm and don't make diagnoses, this means the emphasis on diagnosis is much more about the thinking. GPs visit every one of their patients in their own homes twice a year. We get things so wrong because of our single dimension of value - money.” (Southampton resident)

“Your lists are ridiculous! For example the most important thing for me when interacting with the NHS is actually to be able to see a Dr. in a timely fashion. I don't want to speak to one in a supermarket on a mobile phone. I don't want to be stuck in front of a computer with questions and queries it can't answer I want to talk to a receptionist who can make special arrangements for my autistic son or whatever. I want human contact!” (Hampshire resident)

“I want genuine control over the extent to which my records can be accessed by those seeking to provide clinical and social support. I want to feel that health advice is provided in the context of my clinical history rather than what I can remember when asked” (Hampshire resident)

“...Autism isn't mental health but if people don't listen or learn our triggers many can get MH problems as well... Why should my life be constant suffering and meltdowns cos people don't accept I know what I need to stay well...” (Hampshire resident)

Demographics (where stated)

Age	Number
Under 18	14
18-24	44
25-34	68
35-44	72
45-54	114
55-64	120
65-74	107
75+	34
Ethnicity	Number
African	21
Any other mixed background	9
Any other white background	18
Asian British	12
Arab	3
Bangladeshi	8
Black British	3
Caribbean	1
Gypsy or Irish Traveller	1
Indian	4
Other	11

Pakistani	3
White British	465
People who responded “Yes” to having a disability	Unable to record
People who responded “Yes” to being a carer	Unable to record
Gender	Number
Female	388
Male	167
How you would describe yourself	Number
Having a long-term condition	189
Having multiple conditions	64
Sexuality	Number
Heterosexual	471
Gay/Lesbian	12
Bi-sexual	12
Pansexual	7
Asexual	2
Religion	Number
Buddhist	6
Christian	236
Hindu	2
Muslim	42
Sikh	1

SUMMARY

The main themes from the data are as follow:

- People want easy and quick access to health care when they need it, especially to GP services, and to be able to receive the treatment and support they need without long waiting times.
- People want to be more involved in their care, to be listened to by professionals and to have their time valued. Choosing the right treatment should be a joint decision between the individual and the professional with people being supported to consider their options to make the right choices for them.
- People want to know their information is secure but they also want better sharing of information between services, specialities and professionals (as well as access to their own information) to make services more seamless.
- People want clear, concise and timely communication about all aspects of their care.
- People want quick and easy access to clear information to help them make decisions about their health and care. They also want access to support for healthy living, including access to good dietary information and exercise facilities to enable them to stay independent for as long as possible.
- People want local services, accessible easily.
- Finally, people want to feel supported at end of life.

In terms of differences between genders the following may be of interest:

- When asked “What is most important to you to help you live a healthy life?” slightly more females (25%) than males (19%) stated “Professionals that listen to me when I speak to them about my concerns” is most important.

- When asked “What is most important to you when interacting with the NHS?” more males (15%) than females (7%) stated “I can access services using my phone or computer” is most important.

END

Specific Condition Survey

Data Analysis

After duplications removed, number of responses received = 166

Question 1: Pick the area that best describes where you live:

Area	Number (as %)
Southampton	75 (45%)
Hampshire	72 (43%)
IOW	13 (8%)
Portsmouth	6 (4%)

Question 2: Select the condition you would like to tell us about:

Condition/s	Number (as %)
Mental Health	53 (32%)
Long-term conditions	46 (28%)
Autism	20 (12%)
Dementia	15 (9%)
Cancer	13 (8%)
Learning disability	10 (6%)
Heart & Lung	8 (5%)
Mental Health and Long-term conditions	1 (<1%)

Question 3: Who are you responding on behalf of?

Condition/s	Myself	Someone else
Mental Health	44 (83%)	9 (17%)
Long-term conditions	40 (87%)	6 (13%)
Autism	2 (10%)	18 (90%)
Dementia	6 (40%)	9 (60%)
Cancer	8 (61%)	5 (39%)
Learning disability	9 (90%)	1 (10%)
Heart & Lung	7 (87%)	1 (13%)
Mental Health and Long-term conditions	0 (0%)	1 (100%)

As may be expected more people responded on behalf of someone else for the conditions of autism and dementia.

Question 4: Has the condition you are telling about started within the last 3 years?

Condition/s	Answered Yes to the question
Mental Health	17 (32%)
Long-term conditions	15 (33%)
Dementia	7 (47%)
Cancer	7 (54%)
Heart & Lung	4 (50%)
Autism	3 (15%)
Learning disability	1 (10%)
Mental Health and Long-term conditions	1 (100%)

Question 5: When you first tried to access help, did the support you received meet your needs?

Condition/s	No	Yes	Somewhat	NA
Mental Health	28 (53%)	9 (17%)	16 (30%)	0
Long-term conditions	20 (43%)	8 (17%)	16 (35%)	2 (5%)
Autism	15 (75%)	0	5 (25%)	0
Dementia	7 (47%)	4 (26.5%)	4 (26.5%)	0
Cancer	6 (46%)	3 (23%)	3 (23%)	1 (8%)
Learning disability	3 (30%)	5 (50%)	1 (10%)	1 (10%)
Heart & Lung	3 (37%)	3 (37%)	2 (26%)	0
MH and LTC	0	0	1 (100%)	0

The majority of respondents advised that the support they received did NOT meet their needs with Autism and Mental Health both over 50% for a “No” response. Only those commenting on learning disability suggested more were happy with the support (50% saying Yes).

Question 6: Tell us how whether the support met your needs and how it could be improved:

The following tables are coded from the free text responses:

Autism	Comment	No. of times comment recorded
	Long wait for assessment	10
	Lack of support/signposting	8
	Lack of access to CAMHS	3
	Lack of respite at night/weekends	1
	No support from Steps to Wellbeing	1
	Good support from school	1
Ideas for Improvement		
	Earlier access to support	
	Quicker diagnosis	
	More local support	
	More training and support for families	
	Better support in school	
	More respite care at night and weekends	
	More emotional support and advocacy	
	Autism clinics at GP and hospital	
	More training for professionals	
	More information on various conditions for families	

Quotes from the free text:

“Support for families caring for someone with severe, classic autism/ learning disabilities. There needs to be more in the way of respite care, namely weekends and nights. There are plenty of services accessible for day care and support. In our situation our autistic son is 20. He has epilepsy, severe learning disabilities and challenging behaviour. There are no options for weekend and night respite. The one centre he can access will send him home when he displays challenging behaviour which means the family still cannot plan anything just in case. All holidays need to be taken separately with one parent remaining home and the other taking our other children. In the long run residential care will have to be sought which will be much more expensive to the government than if there were more services available. With regular,

suitable respite lots of families would happily keep their young people at home which would save the government millions.

(Family of person with autism living in Hampshire)

“Took a while to be listened to when I first brought it up. Was told I was 'just shy'. After eventual diagnosis of Autism, there was little follow up on what assistance I could look for and no advice given on how to approach people at work. The Steps to Wellbeing counselling I had was stopped because 'we do not offer support to people with Autism'. There was a definite feeling that I was not 'fixable' that it would be an ongoing problem so they would not be able to help me.

I would like people to be listened to earlier, given more information on Autism if they suspect it, told more about how to get support and then for there to be more of a follow up service available after diagnosis and more actual support available (such as help for the mental issues that go alongside Autism, for how to get help organising day to day tasks, for where to go for help with things like monetary support and help with other challenging things like new job, buying a house, having children etc.).”

(Person with Autism living in Southampton)

Cancer	Comment	No. of times comment recorded
	Long wait for diagnosis	2
	Lack of support/signposting	2
	Lack of access to physio	1
	Lack of mental health support	1
	Mis-diagnosis	2
	Lack of GP awareness of certain cancers	1
	Confusing amount of info on treatment options	1
	Great support from MacMillan	1
Ideas for Improvement		
More awareness about counselling, hospital transport and benefits		
IOW patients should not have to go to the mainland for tests and treatment		

Quote from the free text:

“We are seriously lacking in healthcare on the island, my initial consultation was at the local hospital, great, but!!all care ,tests, operations etc.is on the mainland, which involves a ferry journey, if they are running and you can afford it ,or your well enough to travel, it's very upsetting and embarrassing to go on the ferry wanting to be sick ,needing to sleep ,with bandages and sore wounds, plus the travelling and waiting, also my GP hadn't got a clue what is going on ,tried to reduce my meds when they should be increased ,luckily I called the specialist nurse team ,on the mainland, as wasn't well, and was told not to reduce and most GPs do not understand my particular cancer, my GP and the surgery are really good over all but completely over whelmed, we need a bigger , better hospital that meets the needs of the people on the island for now and future generations, people are going to die because they cannot access the help they need, I'm dreading the day I'm old.”

(Person with cancer living on IOW)

Dementia	Comment	No. of times comment recorded
	More carer support	1
	Long wait for diagnosis	3
	Long wait for memory service	1
	Poor communication between services	1
	Lack of support	2
	Lack of follow up services	1
	Good support from Age Concern	1
Ideas for Improvement		
Better access to SALT and dieticians		

Quote from free text:

“I am dealing with my husband’s dementia which started 11 years ago. It took 2 years to get a first assessment with a dementia specialist, and then was dismissed from the records. Had to apply again then dismissed again even though dementia was diagnosed. One home visit, which arranged 3 hours take a break for me, then left to get on with it. Lung cancer diagnosed 10 months ago, no treatment. There needs to be more done for the Carers who become trapped in a situation they cannot get out of.” (Carer from Hampshire)

Heart & Lung	Comment	No. of times comment recorded
	Lack of support	1
	Inappropriate discharge	1
Ideas for Improvement		
Better communication between specialties so treatment is more holistic and joined up		

Quote from free text:

“I had pneumonia and atrial fibrillation. I was discharged too early on 3 occasions and had to be re-admitted each time. I have the feeling that shortage of beds leads to premature discharges I was diagnosed with atrial fibrillation whilst on the respiratory ward, but was discharged after 3 weeks having not seen a cardiologist. I waited at home for a month with atrial fibrillation and when I finally saw the cardiologist as an outpatient, I was immediately admitted to a cardiac ward. I needed an ablation to correct the situation. There needs to be MUCH better communication between different specialties so that treatment is more holistic and joined up. Everything is too compartmentalised”. (Person with heart & lung disease living in Southampton)

Learning Disability	Comment	No. of times comment recorded
	Lack of understanding/awareness	1
	Lack of advocacy	1
Ideas for Improvement		
Need information quicker		
Need more advocacy		

Long-term Conditions	Comment	No. of times comment recorded
	Symptoms dismissed	2
	Lack of training	2
	Mis-diagnosis	1
	Lack of information	1
	Patient not listened to	5
	Lack of support/info for certain conditions	8
	Long wait for treatment	6
	Long wait for referral	2
	Lack of pain management	2
	Fragmented care	1
Ideas for Improvement		
More testing		
Listen to patients more		
More person centred care		
Better access for wheelchair users		
More help with everyday issues like keeping a job, effects of meds, choices on self-help		

Quotes from free text:

“It took 11 months to be referred to rheumatology where I was diagnosed with Rheumatoid Arthritis. My GP initially referred me to physiotherapy for which I had to wait three months for an appointment. The physio couldn't do anything for me and referred me on to MSK. It was here the urgency of my condition was recognised, x-rays and an MRI scan were completed and a letter written to my GP suggesting an urgent blood test. The care I've received from rheumatology has been excellent, but why did I have to suffer for 11 months and deteriorate to the extent that I needed a wheelchair before a referral was made? I suggest that tests are completed initially and referrals made more promptly. Surely it's better for patients to start treatment quickly in order to prevent them from requiring more intense, aggressive and expensive treatment later”. (Person with a long-term condition living in Portsmouth)

“I am in 'supervised' housing because of my disability. Unfortunately this supervision includes no help whatsoever in any of my medical conditions. I have been treated like an incontinent old demented idiot. I am none of these. The local district nurses complain (quite rightly) that I call them for any medical matters, wounds etc. but the provided 'carers' are specifically barred from providing any help. They are not even allowed to help me eat despite the fact that I am unable to use my kitchen in the flat provided. I refuse to use 'patient transport' ever again. They have already cost me much discomfort, pain and a whole day in shock. I have an electric wheelchair with all the tie-down points necessary for safe ambulance transport but they refuse to take it. They insist I try and walk about inside the ambulance. This is dangerous, painful and I am never doing it again”. (Person with a long-term condition living in Southampton)

“Everything I read says my condition should be assessed by a team of various qualified workers who will liaise with me on how and what is best for me as an individual, not my experience. Every aspect revolves around difficulty for me i.e. Attending appointments with GPs and hospital are not easy when you have compromised mobility issues that are constantly changing but if your appointments aren't kept they want to strike you off their lists. If you don't drive attending is also an issue, as well as other aspects such as ,tiny chairs (reminiscent of school) to try to sit in and get out of without resulting in a loss of dignity would help . Waiting endlessly for tests ,x rays etc. without adequate seating , trying to undress ,when at home you need all kinds of appliances to help you with this ,and hardly being able to stand after sitting / waiting for so long, not to mention the difficulties of anybody who may have incontinence issues. Endless blood tests to attend! With no real productive outcomes, totally frustrating.

Expecting very elderly people to attend the hospital for blood tests even when a nurse has been sent to that person's home but refuse s to do so as the patient is considered capable because they are able to totter around their own home unaided. Constantly being asked to attend GPs for tests that are obviously being 'recommended ' by government, by are not necessarily relevant to patient. Just a few things that make things personally frustrating ,but realise that every patient is individual and no two people necessarily want the same / need the same treatments ,making the NHS work more difficult .!"

(Person with a long-term condition living in Hampshire)

Mental Health (inc. MH and LTC)	Comment	No. of times comment recorded
	Lack of training/awareness	2
	Long wait for support	14
	Lack of ongoing support/aftercare	10
	Over prescription/use of meds	7
	Patient not taken seriously	9
	"italk" not effective	2
	No access to crisis help	2
	Help from third sector is good	2
Ideas for Improvement		
More support outside "normal" hours		
More mental health nurses		
All GP surgeries should have a mental health specialist		

Quotes from free text:

"When I was first referred to the community mental health team by my doctor, during which time I was signed off work with (historic) PTSD & depression and suicidal, I saw a doctor who, after one appointment, increased my antidepressants dosage (despite the fact I expressed my dosage had been increased multiple times over the last year and wasn't making any difference) and then discharged me back to my GP. I expressed that I wanted more support - I was 19 at the time, a care leaver and had long term mental health issues. I was struggling with living independently and trying to balance this plus working full time, whilst still recovering from a particularly bad episode three years prior where I'd made a serious suicide attempt. The doctor told me it was great I was holding a job down and I just needed to stick at the medication. I wasn't offered any ongoing support, despite telling her I was suicidal depressed and struggling to keep myself safe. Over a year later and I've been referred back, re-diagnosed and have until recently been on shared care as I've been acutely suicidal. There have been so many times I've barely managed to keep myself safe over the last year and I feel that if I'd have been offered some kind of ongoing support the first time I might have actually started recovering by now. I find it worrying that 'being in work' - even if you're signed off frequently - is considered enough of a reason to not need treatment. I wish I'd been taken seriously, and so many areas of my life have been jeopardized - including my work - due to my ongoing mental health problems and the lack of support. You shouldn't have to wait until you're either too ill to work altogether or have actually tried to kill yourself to get support (the last time I was in hospital from an overdose was the last time I was offered any help). In light of this, I also think it's crucial that there are services available outside of typical working hours, for those who want to get better before they hit rock bottom". (Person with mental health problems living in Hampshire)

"When people are in mental health crisis the only place they can go to keep safe is the emergency department which is inappropriate. We need an emergency department for mental health with a crisis café and trained mental health staff and volunteers of people who have

lived experience to add to the help people receive. Out of hours crisis teams should be available to meet patients in their homes when in crisis and now they don't even answer the phone at times". (person with mental health problems living in Southampton)

Question 7: How would you describe your overall experience of getting help?

Condition/s	Very Negative	Negative	Average	Positive	Very Positive	Don't Know	No resp.
Autism	7	3	9	0	0	0	1
Cancer	2	3	0	4	3	1	0
Dementia	3	4	2	5	1	0	0
Heart & Lung	0	1	4	2	2	1	0
Learning disability	1	1	3	1	3	1	0
Long-term cond.	9	13	11	8	3	2	0
Mental Health (plus MH/LTC)	12	12	19	9	2	0	0

Majority of responses reflect an average to negative/very negative response.

Question 8: Do you have any other/additional conditions including long term conditions or disabilities?

And Question 9: If so, how would you describe the experience of seeking support for more than one condition at a time?

Condition	Number of respondents who said yes to Q8	Q9 Experience of seeking support for more than one condition	
Autism	13 (65%)	Made it harder	8 (61%)
		Made it easier	1 (8%)
		No difference	3 (23%)
		NA	1 (8%)
Cancer	7 (54%)	Made it harder	3 (43%)
		Made it easier	1 (14%)
		No difference	3 (43%)
Dementia	7 (47%)	Made it harder	4 (58%)
		Made it easier	1 (14%)
		No difference	1 (14%)
		Don't Know	1 (14%)
Heart & Lung	4 (50%)	Made it harder	1 (25%)
		Made it easier	1 (25%)
		Don't Know	2 (50%)
Learning disability	5 (50%)	Made it easier	1 (20%)
		No difference	1 (20%)
		Don't Know	2 (40%)
		NA	1 (20%)
Long-term Conditions	24 (52%)	Made it harder	13 (54%)
		No difference	8 (33%)
		Don't Know	2 (8%)
		NA	1 (5%)
Mental Health (inc. MH/LTC)	29 (54%)	Made it harder	22 (76%)
		No difference	7 (24%)

In general it made it harder to seek support for most conditions.

Question 10: How would you describe the time you had to wait to receive your initial assessment or diagnosis?

Condition/s	Very Slow	Slow	OK	Fast	Very Fast	Don't Know
Autism	13 (65%)	5 (25%)	2 (10%)	0	0	0
Cancer	1 (8%)	3 (23%)	5 (38%)	2 (15%)	1 (8%)	1 (8%)
Dementia	6 (40%)	4 (27%)	4 (27%)	0	0	1 (6%)
Heart & Lung	0	1 (13%)	3 (37%)	2 (25%)	0	2 (25%)
Learning Disability	3 (30%)	5 (50%)	0	0	0	0 (2 no resp.) (20%)
Long-term conditions	15 (33%)	10 (22%)	10 (22%)	6 (13%)	2 (3%)	2 (1 no resp.) (7%)
Mental health (inc. MH/LTC)	26 (48%)	10 (18%)	10 (18%)	3 (5%)	2 (4%)	2 (1 no resp.) (7%)

Responses in general (apart from cancer and heart/lung) suggest patients found the process of waiting for initial assessment/diagnosis slow to very slow with autism and mental health being the worst.

Question 11: Please tell us more about the length of time you waited

In general the responses to this question were about the length of time patients waited with waits from 14 months to 10 yrs. for autism, 2 weeks to 1 year for cancer, 1 month to 2 years for dementia, 9 weeks to 4 years for learning disability, 6 months to over 10 years for long-term conditions and a few days to a few years for mental health. Issues of multiple appointments and having to see multiple disciplines and professionals were recorded for long-term conditions and mental health. Due to the complexity of the conditions there are no obvious correlations to be made here.

Quote from free text:

“Hard to get GP appointment, GP not sure, back and forth to hospital, hospital not sure. ended up feeling like a crap Xmas present that's unwrapped on the morning and unused by tea time. everyone got bored with me”. (Cancer patient from Southampton)

Question 12: How would you describe the time you had to wait between your initial assessment /diagnosis and receiving treatment?

Condition/s	Very Slow	Slow	OK	Fast	Very Fast	Don't Know
Autism	10 (50%)	4 (20%)	2 (10%)	1 (5%)	0	3 (15%)
Cancer	3 (23%)	1 (8%)	6 (46%)	2 (15%)	0	1 (8%)
Dementia	7 (47%)	3 (20%)	0	2 (13%)	0	3 (20%)
Heart & Lung	1 (13%)	0	5 (61%)	1 (13%)	0	1 (13%)

Learning Disability	2 (20%)	3 (30%)	2 (20%)	1 (10%)	0	2 no resp. (20%)
Long-term conditions	11 (24%)	9 (21%)	14 (30%)	3 (6%)	3 (6%)	4 (2 no resp.) (13%)
Mental health (inc. MH/LTC)	22 (42%)	11 (20%)	7 (14%)	6 (1%)	3 (6%)	3 (1 no.resp) (7%)

Apart from cancer and heart /lung conditions the majority of people responded that they felt the wait was slow to very slow with autism, dementia and mental health the worst.

Question 13: After being diagnosed or assessed, were you offered access to further health and care support?

Condition/s	Yes	No	No resp.
Autism	9 (45%)	9 (45%)	2 (10%)
Cancer	7 (54%)	6 (46%)	0
Dementia	8 (53%)	7 (47%)	0
Heart & Lung	6 (75%)	2 (25%)	0
Learning disability	3 (30%)	5 (50%)	2 (20%)
Long-term conditions	25 (54%)	20 (37%)	1 (9%)
Mental health (inc. MH/LTC)	24 (44%)	26 (48%)	4 (8%)

For most conditions the response was mostly an even split between Yes and No. However, responses for Heart and lung and long-term conditions were more positive and negative for learning disability.

Question 14: If you accessed support, what aspects worked well?

Condition	Coded comments from free text (with no. of comments if more than 1 in brackets)
Autism	3 session course
	Access to CAMHS
	1 to 1 therapy
	Parenting courses
	3 rd sector support (2)
Cancer	Specialist nurses (4)
Dementia	Memory café
	Admiral nurse
Heart & Lung	Self-help support
Learning disability	Help at home
Long-term conditions	Financial support
	Self-help
	Support groups
	Diabetic clinic
	OT home visits (2)
	Specialist nurses (2)
Mental Health (inc. MH/LTC)	Various treatment options

	Counselling (2)
	Family therapy
	Same person point of contact
	CBT (2)
	3 rd sector support (2)
	Support groups (2)
	Wellbeing centre

Question 15: If you accessed support, what could be improved?

Condition	Coded comments from free text (with no. of comments if more than 1 in brackets)
Autism	More staff (3)
	More courses
Cancer	More services on IOW
	Listen to patients/carers
Dementia	More carer support
Heart & Lung	A more holistic approach
Learning disability	Continuity of staff
	Weekly support worker visits
Long-term conditions	Better access for IOW
	Education
	Better therapy
	More staff (2)
	Better support post diagnosis
Mental health (inc. MH/LTC)	More information
	Better awareness/understanding (3)
	Counsellors from other cultures
	Less meds
	Shorter waiting times (7)
	Better quality letters
	Broader range of options
	Self-referral made easier
Not asked same info by each different practitioner	

The need for shorter waiting times is the main issue in mental health

Quote from free text:

“Make it less medical. I’ve found life coaching has been much more positive than the idea of therapy. Going for a walk makes it much easier for me to communicate, I don’t have to look at my worker as we’re walking side my side. I think an outdoor space would be really good. Walls are plain and could be more cheerful. They need to stop the rotation of staff as you get to know someone and then in 6months they’ve moved on”. (Mental health patient living in Southampton)

Question 16: Were you referred to a specialist? For example, a hospital consultant, psychiatrist or physiotherapist

Condition/s	Yes	No	No resp.
Autism	7 (35%)	11 (55%)	2 (10%)
Cancer	10 (77%)	3 (23%)	0
Dementia	12 (80%)	3 (20%)	0
Heart & Lung	6 (75%)	2 (25%)	0
Learning disability	7 (70%)	2 (20%)	1 (10%)
Long-term conditions	31 (67%)	13 (28%)	2 (5%)
Mental health (inc. MH/LTC)	32 (59%)	20 (37%)	2 (4%)

For most conditions people advised they had been referred to a specialist apart from autism (55% said No)

Question 17: How would you describe the time you had to wait between initial appointment and seeing the specialist?

Condition/s	Very Slow	Slow	OK	Fast	Very Fast	Don't Know
Autism	5 (72%)	0	1 (14%)	0	0	1 (14%)
Cancer	1 (9%)	2 (18%)	3 (28%)	3 (27%)	0	2 (18%)
Dementia	1 (9%)	6 (50%)	2 (16%)	0	1 (9%)	2 (16%)
Heart & Lung	0	2 (44%)	4 (66%)	0	0	0
Learning Disability	2 (28%)	2 (28%)	2 (28%)	1 (16%)	0	0
Long-term conditions	8 (26%)	9 (30%)	10 (32%)	2 (6%)	2 (6%)	0
Mental health (inc. MH/LTC)	10 (31%)	8 (25%)	7 (22%)	5 (16%)	2 (6%)	0

For most conditions waiting times were slow to very slow with autism being the worst at 72% for very slow.

Question 18: Please tell us more about the length of time you waited

Again most of the responses here related to actual waiting times with responses varying from 11 months to 18 months for autism, a couple of weeks for cancer, a few weeks to months for dementia, a few weeks to months for heart and lung, a few weeks to 2 months for learning disability, a few days to 2 or more years for long-term conditions and a few days to 7 years for mental health (with a couple of months being the average wait).

Question 19: If you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed?

Condition/s	Very Easy	Easy	Ok	Difficult	Very Difficult	Don't Know	No.resp
Autism	1 (5%)	2 (10%)	0	0	12 (60%)	1 (5%)	4 (20%)
Cancer	1 (8%)	1 (8%)	4 (30%)	2 (15%)	4 (31%)	1 (8%)	0
Dementia	0	1 (7%)	4 (26%)	6 (40%)	3 (20%)	1 (7%)	0
Heart & Lung	0	0	3 (38%)	2 (25%)	0	2 (25%)	1 (12%)
Learning disability	0	0	2 (20%)	4 (40%)	2 (20%)	0	2 (20%)
Long-term conditions	1 (2%)	4 (9%)	11 (24%)	10 (22%)	14 (30%)	2 (4%)	4 (9%)
Mental Health (Inc. MH/LTC)	0	5 (9%)	11 (20%)	15 (29%)	17 (31%)	1 (2%)	5 (9%)

Again, for most conditions people found it difficult to very difficult to access ongoing support. The worst area being Autism (60% very difficult)

Question 20: Did the support options you were offered meet your expectations?

Condition/s	Yes	No	Somewhat	No resp.
Autism	3 (15%)	14 (70%)	1 (5%)	2 (10%)
Cancer	4 (31%)	4 (31%)	5 (38%)	0
Dementia	6 (40%)	6 (40%)	3 (20%)	0
Heart & Lung	5 (64%)	1 (12%)	1 (12%)	1 (12%)
Learning disability	2 (20%)	5 (50%)	2 (20%)	1 (10%)
Long-term conditions	9 (19%)	24 (52%)	12 (26%)	1 (3%)
Mental health (inc. MH/LTC)	12 (22%)	27 (50%)	13 (24%)	2 (4%)

Again, most respondents seemed to feel support options either only somewhat met expectations or did not meet them. The main area of concern appears to be autism (with 70% of respondents saying support options did not meet expectations) and long-term conditions.

Questions 21: Please explain how the care did or did not meet your expectations and how it could have been improved.

Condition	Coded comments from free text (with no. of comments if more than 1 in brackets)
Autism	No support for adults diagnosed later in life
	Lack of funds
	Better awareness/understanding needed (2)
	More counselling needed (2)
	Lack of follow up
	Better support for carers/family needed (7)

Cancer	More options on the IOW
	Long waits for treatment (3)
	There are too many cancelled appointments
	Keyworkers are good
Dementia	Specialist nurses are good
	More understanding needed (2)
	More carer support needed
	Better communications across specialties needed/between professionals
	3 rd sector support is good
Heart & Lung	Getting to the right support can be hard
	Waiting times are too long
Learning disability	Need more night/weekend respite
	More alternative therapies needed
	Lack of staff
	Be more proactive
	Options need to be tailored to the patient
Long-term conditions	Prefer more involvement in own care
	More ongoing support needed (21)
	Better and quicker diagnosis (2)
	More options for IOW
	Better public transport needed
Mental health (inc. MH/LTC)	Quicker diagnosis needed (4)
	Listen to the patient more (3)
	Need counsellors from different cultures
	More 1 to 1 treatment options (2)
	More options for people that work
	Need to see the same practitioner/consistency
	More therapy options needed (4)
	CMHT should turn up when they are supposed to
	More ongoing support needed
	Better communications across specialties needed/between professionals

Main issues in autism are about better support for carers, in dementia it's a need for better understanding, for long-term conditions it's the need for ongoing support and follow up and for mental health it's about quicker diagnosis, listening to the patient more and the need for a better range of treatment/therapy options.

Question 22: During your whole experience of getting support did you receive timely and consistent communication from all of the services that you came into contact with?

Condition/s	Yes	No	Somewhat	No resp.
Autism	2 (10%)	12 (60%)	4 (20%)	2 (10%)
Cancer	4 (31%)	5 (38%)	3 (23%)	1 (8%)
Dementia	5 (33%)	7 (47%)	3 (20%)	0
Heart & Lung	5 (62%)	2 (26%)	1 (12%)	0
Learning disability	3 (30%)	2 (20%)	3 (30%)	2 (20%)
Long-term conditions	13 (28%)	19 (41%)	13 (28%)	1 (3%)

Mental health (inc. MH/LTC)	8 (16%)	25 (47%)	17 (32%)	2 (5%)
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The best area for communication appears to be Heart & Lung (Yes 62%) with the worst being Autism (No 60%) although all areas (apart from Heart & Lung) score under 50% for Yes

Question 23: Please explain how the care did or did not meet your expectations and how it could have been improved.

Condition	Coded comments from free text (with no. of comments if more than 1 in brackets)
Autism	Listen to us more (4)
	Need more appointments
	More information needed
	More staff and resources
	More follow up needed (2)
Cancer	More information and communication
	Less paper, more email
	Better communication across specialties and between professionals
	Listen to the patient (2)
Dementia	Better communication (2)
	Listen to the patient more (2)
	More follow up needed
	Information to take home
	More carer support (2)
Heart & Lung	More follow up/ongoing support (2)
	Better communication across specialties and between professionals
Learning disability	Shorter waiting times for therapy (2)
	Consistent care/key workers needed
Long-term conditions	Need to get info from other GP surgery staff then actual GP
	Listen to the patient more (3)
	More ME specialists (2)
	Quicker treatment times (2)
	More follow up (2)
Mental health (inc. MH/LTC)	Lack of communication is an issues (6)
	Listen to the patient/carer/family (2)
	More follow up needed (3)
	More consistency with staff (5)
	Less paper, more email
	Speed up the pathway (4)
	More CBT needed
	More info on self-help (2)
	Better communication across specialties and between professionals
	Better crisis support (2)

The main areas across all conditions appear to be the need for patient/carer/family to be listened to more, more consistency with staff (especially in Mental Health) and a theme is the need for better communication across specialities and between professionals.

Question 24: What is your main means of transport?

Condition	Another person's car	Bike	Bus	Own car	Other or No.resp	Taxi	Train
Autism	4	1	1	13 (65%)	1	0	0
Cancer	1	0	3	7 (54%)	2	0	0
Dementia	6	0	2	6 (40%)	1	0	0
Heart & Lung	1	0	3	3 (37%)	0	1	0
Learning disability	2	0	1	5 (50%)	2	0	0
Long-term Conditions	12	0	6	21 (46%)	3	3	1
Mental Health (inc. MH/LTC)	4	2	14	26 (48%)	5	3	0

There does not appear to be any useful extrapolation to be made from this information, with around 50% of all conditions using their own car.

Question 25: How much time would you be willing to travel for to receive a quick and accurate diagnosis? And Question 26: How much time would you be willing to travel to receive specialist treatment or support? The answers to these 2 questions are combined in the following table for comparison, although it should be noted that the multiple answers provided in the survey are slightly different for each question.

Time	Travel for diagnosis (no. of responses)	Travel for specialist treatment (no. of responses)
Less than 30 minutes	46	34
30 mins to 1 hour	69	66
1 to 2 hours	25	37
Over 2 hours	19	23
No. resp	7	6

These figures appear to suggest that slightly more people would be willing to travel longer for their specialist treatment although there is no significant difference.

30 mins to 1 hour is the time most people would be willing to travel for diagnosis and treatment (approx... 40%)

Question 27: What is most important to you?

	When first seeking help	When you received a diagnosis and explanation of treatment or support options	During your initial treatment or support	During your long term support
Seeing any medically appropriate health professional	69 (41%)	54 (33%)	52 (31%)	26 (16%)

who is free immediately				
Seeing a health professional you normally see but you may have to wait	40 (24%)	53 (32%)	50 (30%)	82 (49%)
Don't Mind	23 (15%)	27 (16%)	28 (17%)	22 (13%)
No.Resp	34 (20%)	32 (19%)	36 (22%)	36 (22%)

The figures suggest people are happy to seek help from any appropriate professional when first seeking help, diagnosis and treatment but prefer to see their usual practitioner for long term support.

When looking at the responses for specific conditions there more people with learning disability or mental health issues would seek initial support from their usual practitioner.

Question 28: What level of support do you want the NHS to provide to help you stay healthy?

Condition/s	A lot of support	Some support	Don't need support	Don't Know/No.Resp
Autism	4	13 (65%)	2	1
Cancer	5	6 (46%)	1	1
Dementia	4	9 (60%)	2	0
Heart & Lung	4	4 (50%)	0	0
Learning disability	4	3 (30%)	2	1
Long-term conditions	12	25 (54%)	5	4
Mental Health (inc. MH/LTC)	18	31 (57%)	1	4

Approx. half of all respondents advised they want Some Support, with those having dementia or autism having a higher response (60%) and (65%) respectively to wanting Some Support. Those with Learning disability needing "A lot" to "Some" (50% each)

Question 29: What could the NHS do to help you stay healthy or manage any condition you have? And Question 30: If you have any further comments combined.

The top responses include:

Better support/aftercare ongoing (the top response with 25 respondent commenting across all conditions)

More understanding of mental health and autism required

Easier access to GPs

Listen to the patient more

More alternative therapies to stop relying on meds

In general the main themes across all the questions are quicker and easier access to professionals (esp. GP), better support for ongoing conditions (plus support for general

living), more alternative therapies and treatments and better communications across specialities and between professionals. More understanding and awareness of mental health and autism is also a theme.

Quote from free text

"I can't tell you how much I hate having to help a dad who barely took the time to help me ever. A lot of assumptions are made by providers that we will do it. My own health has suffered. I have a daughter and grandchildren to support and a father yet I'm supposed to work until I'm 66!!! Hello!?!?!? How's that supposed to work?" (Carer for someone with dementia living in Southampton)

"The individuals who treated me were generally really kind and professional and I've many reasons to be grateful to the NHS. But the delays, absence of joined up approach to treatments and difficulties negotiating a way through the system, protocols etc. would benefit from improvements". (Person with heart & lung problems living in Southampton)

"I am a perfect example of how patients with long term conditions HAVE to self-manage. The quality of service and information you get is so dependent on which doctors you get to see and their response to your needs that you have to just learn to battle the system really hard for anything that you need and just keep trying and trying to get a support that works. Invariably this is when you feel worst and the medical focus is so often on a chemical fix. My best experiences have always been when the medical professional has helped me to improve my quality of life - when they have focused on my needs and not on a diagnosis or a quick prescription-based fix." (Person with a long-term condition living in Southampton)

"Health care staff has to be willing to accept that they don't know everything. I refuse to be told that I can't feel certain way, when I do! The fact that they don't understand and not willing to accept that their knowledge has limitation is beyond shocking. (Ps: I am a nurse) Better working with patients is the only way." (Person with a long-term condition living in Hampshire)

"Early intervention in a first episode of psychosis is extremely important to minimise risk and improve treatment outcomes. I lost three years of my life due to an unresponsive health system, which could have been avoided." (Person with mental health issues living in Southampton)

Demographics (where stated)

Age	Number
Under 18	4
18-24	12
25-34	24
35-44	26
45-54	33
55-64	28
65-74	20
75+	10
Ethnicity	Number
African	1
Any other white background	10
Asian British	3
Black British	3
Caribbean	2
Other	5
Pakistani	1
White British	129

People who responded “Yes” to having a disability	79
People who responded “Yes” to being a carer	31
Gender	Number
Female	109
Male	32
How you would describe yourself	Number
Having a long-term condition	20
Having multiple conditions	8
Sexuality	Number
Heterosexual	60
Gay/Lesbian	4
Bi-sexual	7
Pansexual	1
Religion	Number
Buddhist	2
Christian	48

END