

# Long-term conditions

November 2015

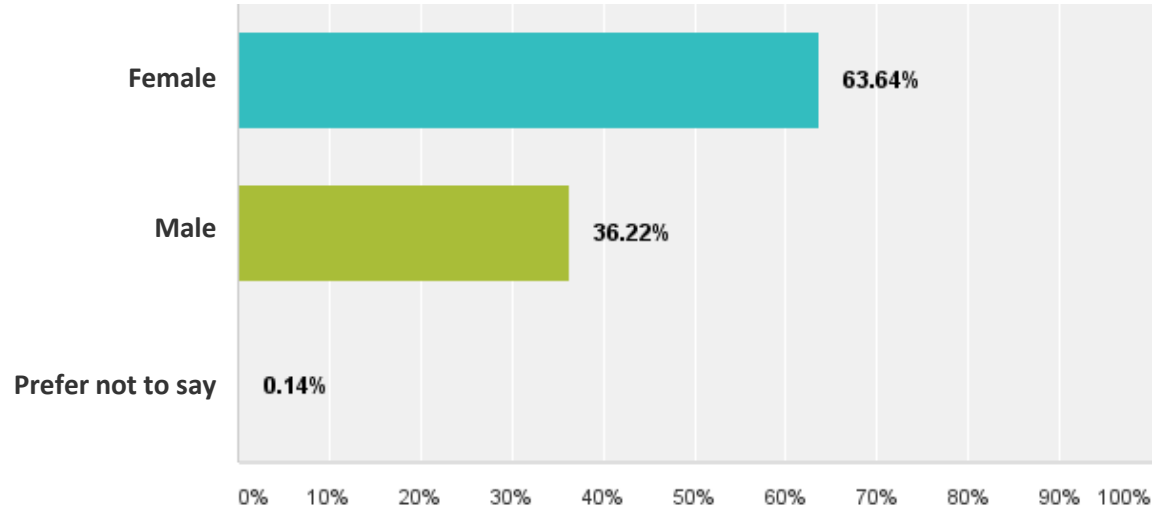
# 709

**Total Responses**

Complete Responses: 509

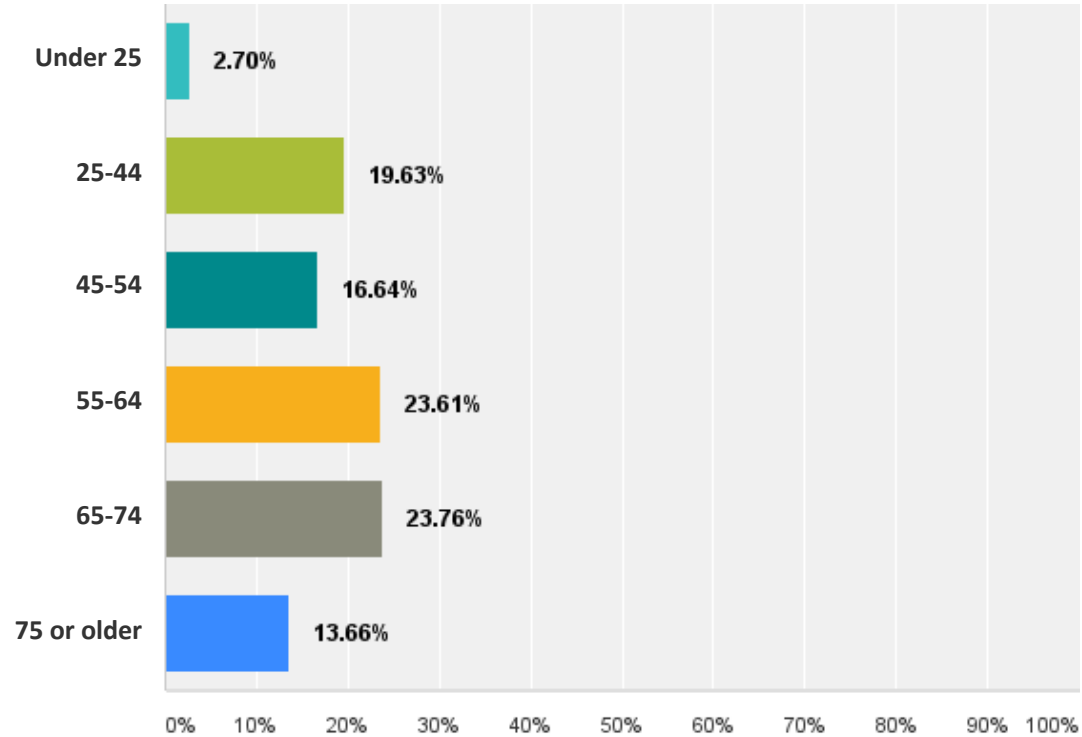
# Q1: Gender: are you...

Answered: 704 Skipped: 5



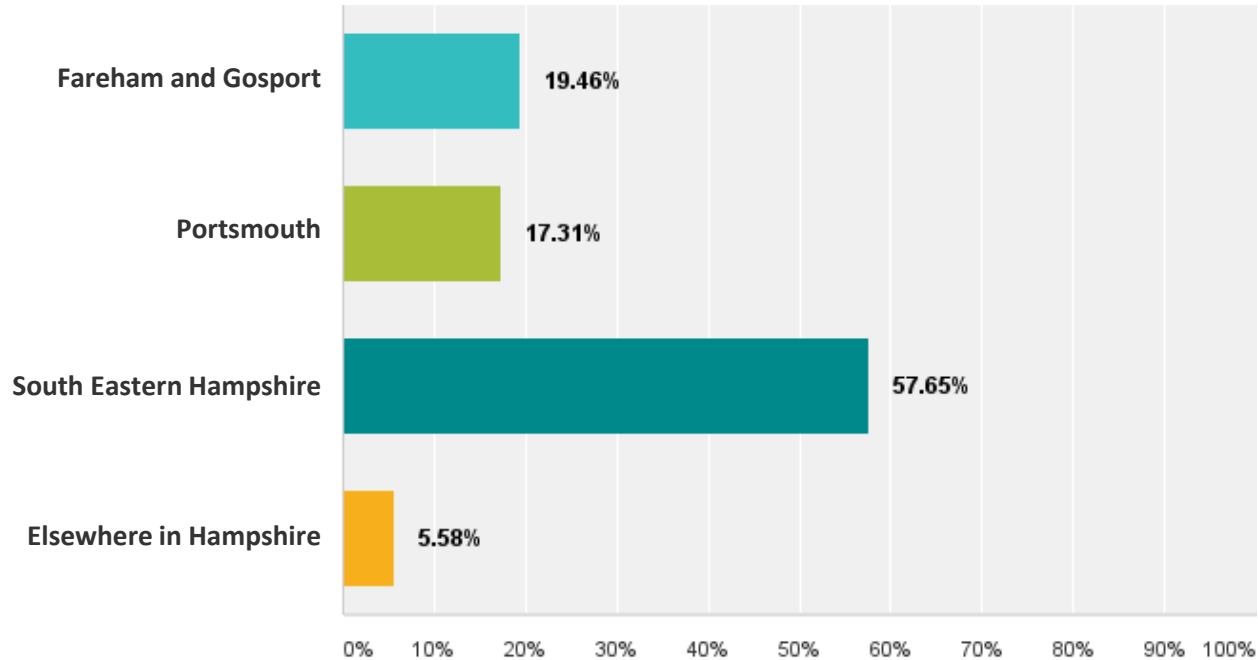
## Q2: Age: are you...

Answered: 703 Skipped: 6



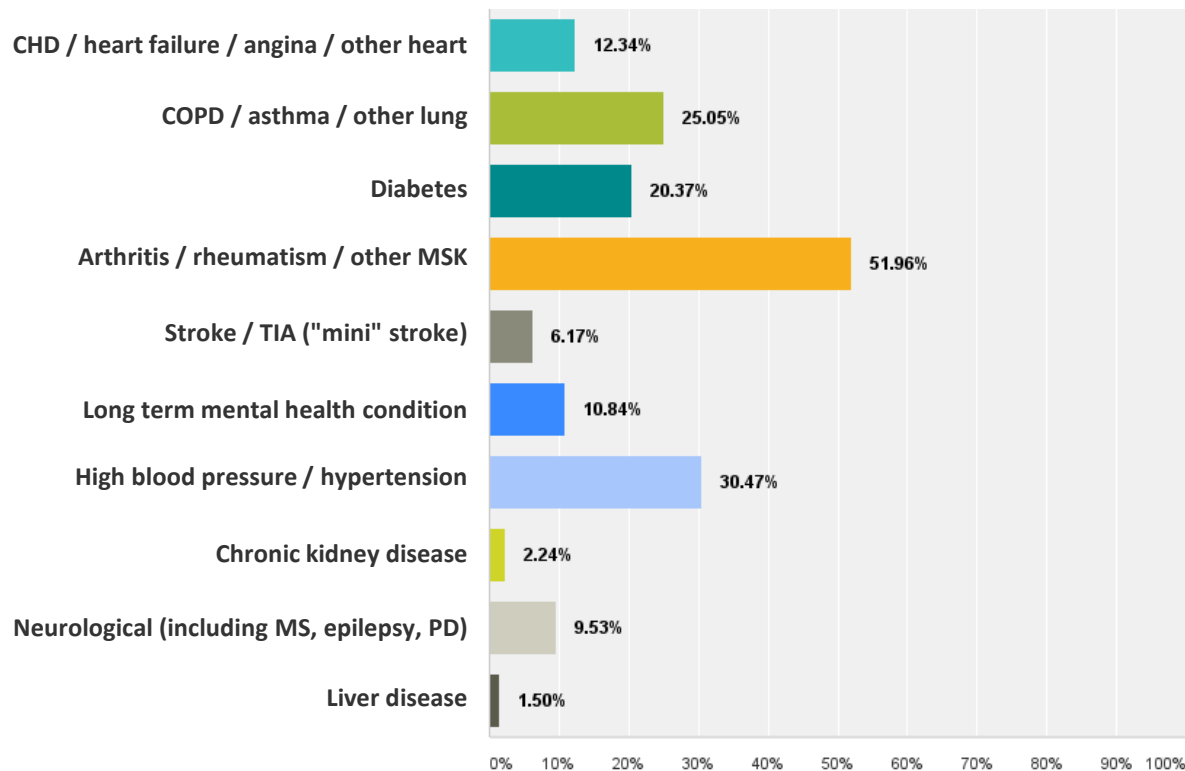
## Q3: Where do you live...?

Answered: 699 Skipped: 10



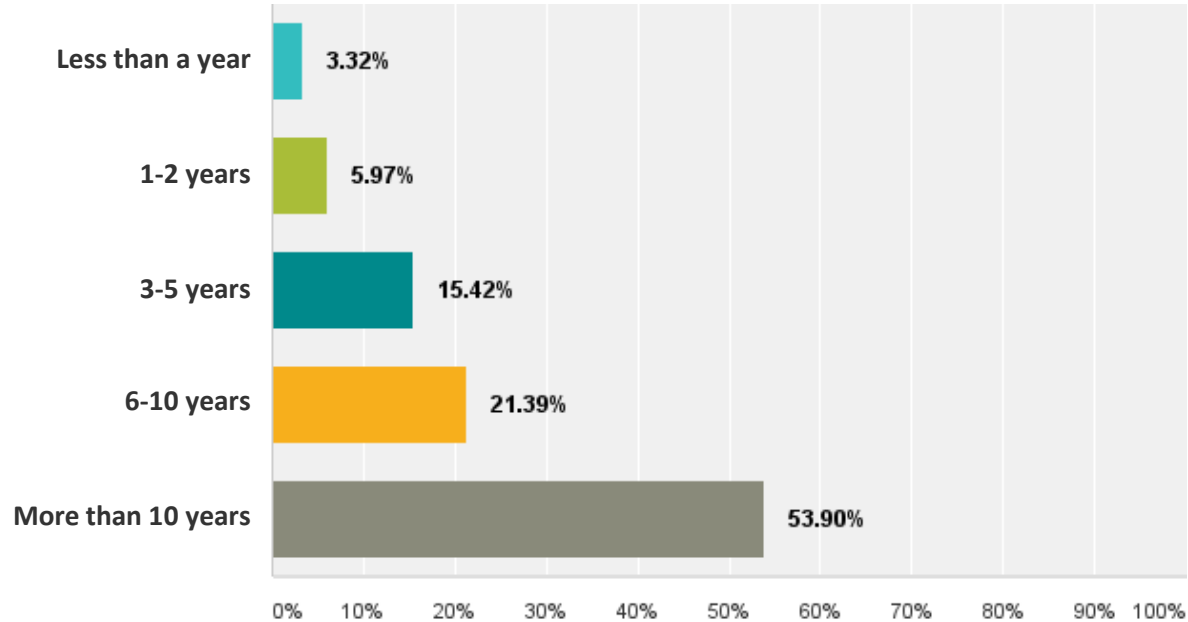
## Q4: Do you (or someone you care for) have one of the following long-term conditions? (you may select as many or as few as apply to you)

Answered: 535 Skipped: 174



## Q5: How long have you had your long-term condition(s)? (If you have more than one condition, please refer to the one diagnosed with first)

Answered: 603 Skipped: 106



## Q6: How many times have you used the following during the last 12 months? (for LTCs only) *Answers as % of those visiting specific staff group*

	Not at all	Once or twice	A few (up to 5)	More than 5	Total	'Score' (1-4)
GP/practice nurse	14.92	35.08	26.27	23.73	590	2.59
Pharmacist	29.23	20.38	12.69	37.69	520	2.59
Doc/nurse (inpatient)	68.32	19.25	6.00	6.42	483	1.51
Doc/nurse (outpatient)	38.31	27.20	16.28	18.20	522	2.14
OOH GP	83.22	13.29	2.61	0.87	459	1.21
NHS 111	78.13	18.90	2.12	0.85	471	1.26
A&E	78.91	16.52	2.39	2.17	460	1.28
MIU / WIC	83.87	13.12	2.15	0.86	465	1.20
Community nurse	88.22	7.07	1.93	2.78	467	1.19
Physio / OT	63.92	14.23	13.81	8.04	485	1.66



## Q7: What are the best things about the care you receive for your long-term condition(s)?

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Answered: 450 Skipped: 259

In terms of the positives about current NHS care, there were a large number of people who highlighted staff, or access, and relatively few who made specific references to the services themselves (with one notable exception, see next slide).

For example, there were 31 general and unspecified comments **praising staff**, and a further 21 positive comments about the **attitude of staff** (caring, understanding, etc)

There were 47 responses praising primary care staff particularly (both GPs, practice nurses and others), and also 26 comments praising specialist/acute sector staff

In terms of **access**, respondents were more likely to refer positively to specialists – 28 responses mentioned getting good access to consultants (this included the use of phone or emails, not just face-to-face), and a further 17 praised access to specialist nurses, both in acute and community settings. There were also a separate 13 specific references to the value of a helpline.

There were 14 positive references to access to primary care staff (mainly GPs but a few references to practice nurses too).

## Q7: What are the best things about the care you receive for your long-term condition(s)? (Continued...)

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Answered: 450 Skipped: 259

With regard to specific mentions relating to positive experiences of services, there was only one comment which was brought up by a significant number of respondents – **regular checks and reviews**.

There were 75 separate references to regular reviews / blood tests / appointments / monitoring – the most frequently-cited theme by far.

Related to the theme of regular contact, there were a further 19 positive references to the benefits of **continuity** in terms of staff (also ‘ongoing relationship’ and ‘ongoing support’).

**Medication** was one theme which was mentioned relatively frequently – there were 23 positive, general comments about medication, and a further 16 comments about the effectiveness of treatments. There were also 23 positive comments about **access to medication** – including repeat prescriptions, online ordering, and delivery.

There were also 29 unspecified positive comments, just praising the NHS or care received but without any further detail.

## Q8: What would you like to improve about the care you receive for your long-term condition(s)?

Answered: 432 Skipped: 277

Asking people to suggest improvements, inevitably, produced a more varied response than was received at Q7.

Unsurprisingly, **access** was important. There were 36 responses regarding unspecified 'shorter waits' or quicker access to professionals. A further 10 comments referred to the specific need for quick access in the event of a deterioration / when treatment was needed.

A related issue was **access to specialist knowledge** or staff. There were 23 references to wanting better/faster access to specialist staff, and – in similar vein – another 20 references to a desire for GPs / other generalist staff to be better informed about the patient's condition.

This sense of missing out on specialist/informed input was also evident in terms of some comments about the **quality** of ongoing care – 16 felt there had to be greater continuity (of staff), 10 people referred to wanting their clinicians to have a greater focus on the underlying problems rather than simply seeking to manage the pain, and another 6 references to wanting a long-term care plan, rather than ad hoc, short-term fixes.

Some felt that the **attitude** of staff could be better. There were 14 mentions of a lack of compassion /understanding, and 6 people wanting more listening to / involving of the patient.

## Q8: What would you like to improve about the care you receive for your long-term condition(s)? (Continued...)

Answered: 432 Skipped: 277

There were a variety of ways in which the subject of **technology** was raised. There were 23 references to the need for more 'joined up' or 'holistic' care, and this was often implicitly linked to the need for better information sharing between professionals. More explicitly, there were 10 references to a desire for electronic access to records / results / care plans, and another 8 mentioned the benefits of GPs accessing hospital notes, and the irritation of telling their story many times because information was not portable. There were also 7 comments about wanting virtual access to doctors and nurses, such as via email.

A desire for more **information** was a common theme, albeit in different forms. A general wish for more information about services, or the condition was mentioned 21 times, and a further 15 comments related to a desire for more information about new treatments/drugs/options, even experimental treatments. A further 12 comments specifically referred to wanting more support to allow them to self-manage more effectively.

The need for (more) **reviews** / tests/ checks / monitoring was mentioned by 35 respondents. In some cases this was very much a case of wanting more clinical oversight, in other cases it was a more *emotional* need, linked to comments such as wanting someone to talk to, or feeling lost once treatment had ended.

## Q8: What would you like to improve about the care you receive for your long-term condition(s)? (Continued...)

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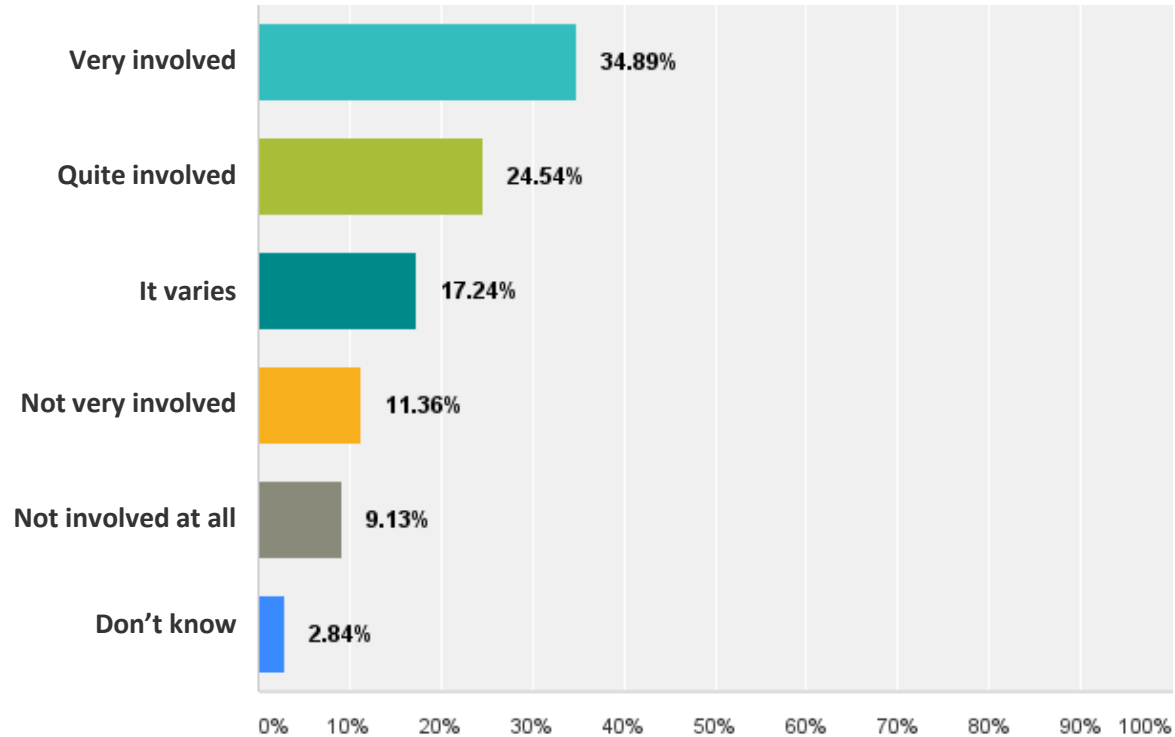
Answered: 432 Skipped: 277

Respondents also raised the issue of **access**, in more tangible terms. There were 8 references to wanting care closer to home / more options for venues, 6 references to the need for longer appointments, and 4 wanting more face-to-face access.

In terms of **specific services** or support there were comments relating to more / ongoing physio (9), pain management services (4) and counselling (4).

## Q9: How involved do you feel in the decisions which need to be made regarding the care you receive for your long-term condition(s)

Answered: 493 Skipped: 216



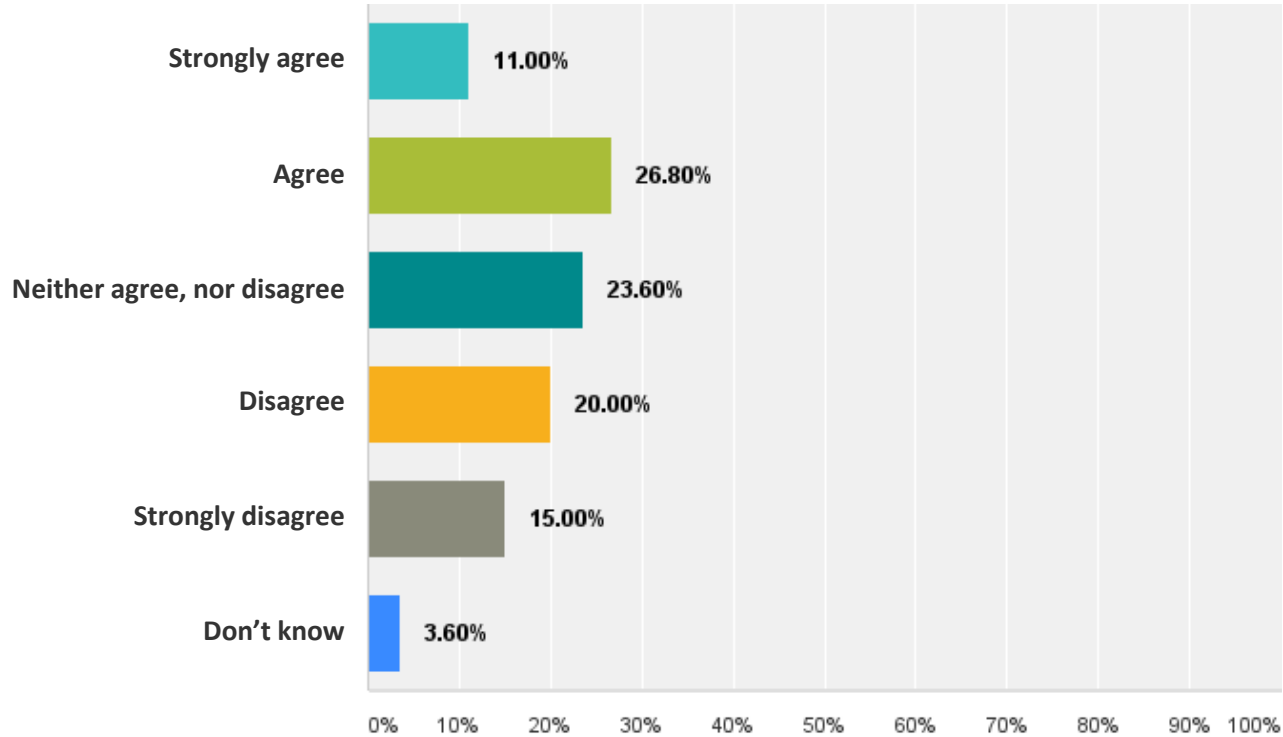
## Q10: Please rank the usefulness of the following options (1 = most, 7 = least).

Answers as % of those ranking each option – note response rates

	1	2	3	4	5	6	7	Total	'Score'
More information to help you do more to manage the condition yourself	30.66	13.94	15.33	14.98	10.80	6.27	8.01	287	4.88
More chances to talk with other people who have your condition	9.02	11.28	7.89	13.53	20.30	22.18	15.79	266	3.45
Longer appointments with your doctor	24.34	15.13	16.45	17.11	12.83	9.87	4.28	304	4.74
More support from charities / voluntary groups	3.31	4.04	9.19	12.50	14.71	23.16	33.09	272	2.67
More hospital appointments	7.99	10.86	13.74	8.95	13.74	13.10	31.63	313	3.25
More convenient ways to consult with your doctor (eg email, online)	29.41	23.16	17.65	12.87	9.93	4.41	2.57	272	5.26
More convenient ways to consult with nurses, other HCPs, voluntary sector (eg email, online)	19.12	21.47	18.82	13.82	11.18	6.76	8.82	340	4.68

## Q11: How much do you agree with the statement: "The local NHS gives me 'joined up' care, so I don't feel as though I am being passed from one part of the system to another".

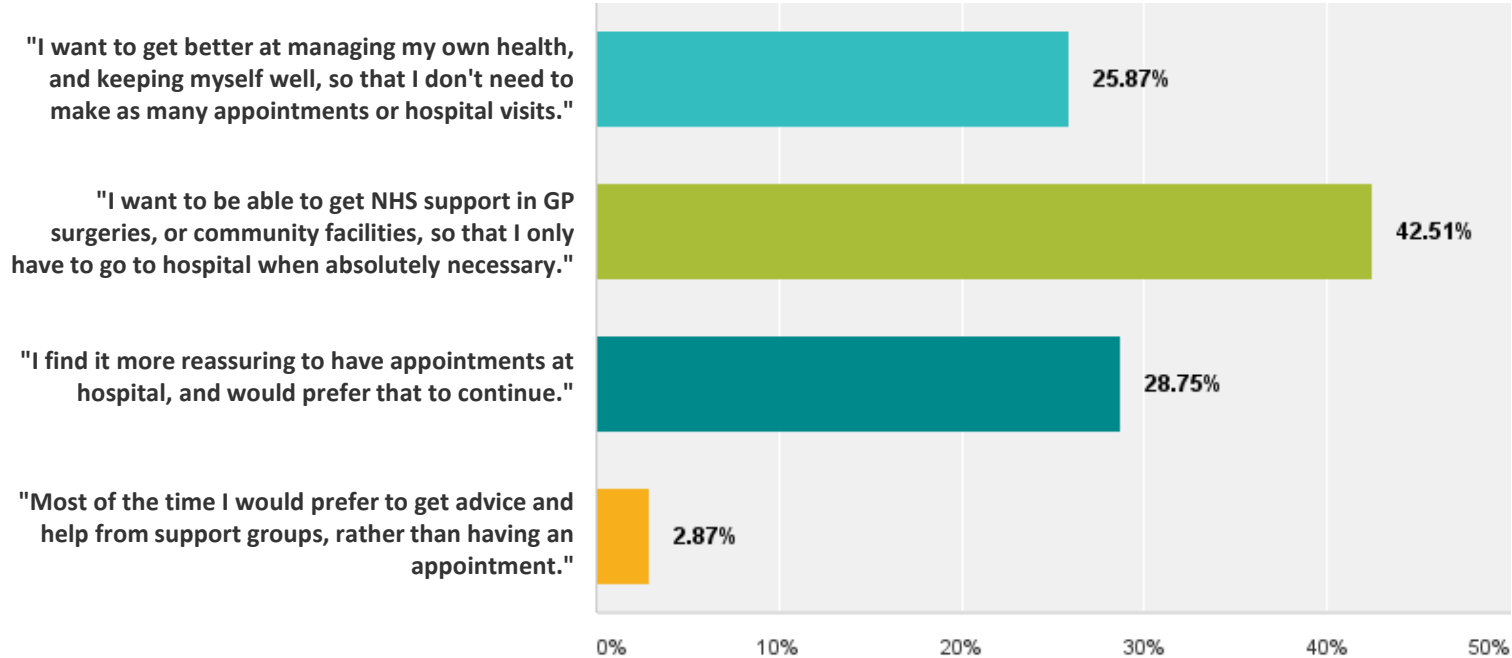
Answered: 500 Skipped: 209





## Q12: Which one of these statements most closely reflects your views about how you would like your long-term condition to be managed in the future?

Answered: 487 Skipped: 222



## Q13: Is there anything else you would like to say about how the local NHS can improve support for people with long-term conditions?

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Answered: 295 Skipped: 414

When asked to set out anything else which they would like to say, many respondents referred to the **attitude** of staff caring for them. There were 24 comments asking for more understanding or compassion, or even for staff to believe them. A further 16 said that staff had to listen to their patients more, and involve them, and 3 more comments relating to the need to understand the health problem rather than simply 'chucking pills at it'.

In terms of better access to **information**, there were a few main themes. There were 12 comments relating to better provision of (unspecified) information but there were also 19 references to wanting more information about local patient / support groups, and how to contact them. A further 10 comments specifically referenced the need for information to support self-management.

There were also a range of comments around the theme of **technology**. There were 28 references to a need for more joined-up services with reference to the advantage of shared records, and another 13 comments about the need for better linking between acute and community-based services. Another 8 people wanted to use phone/email/Skype to be able to either book, or actually conduct, appointments.

## Q13: Is there anything else you would like to say about how the local NHS can improve support for people with long-term conditions?

Answered: 295 Skipped: 414

Several respondents mentioned a wish for more **ongoing contact** – either more proactive care via regular reviews/tests/monitoring (9), or a more general sense that they feel cut off when active treatment stops, for example “keep communicating”, “no further contact” or “just left to take the meds”.

There were 23 comments concerned with making it easier to make **appointments/cut waiting times**, either in unspecified terms or in terms of a need for more resources / staff.

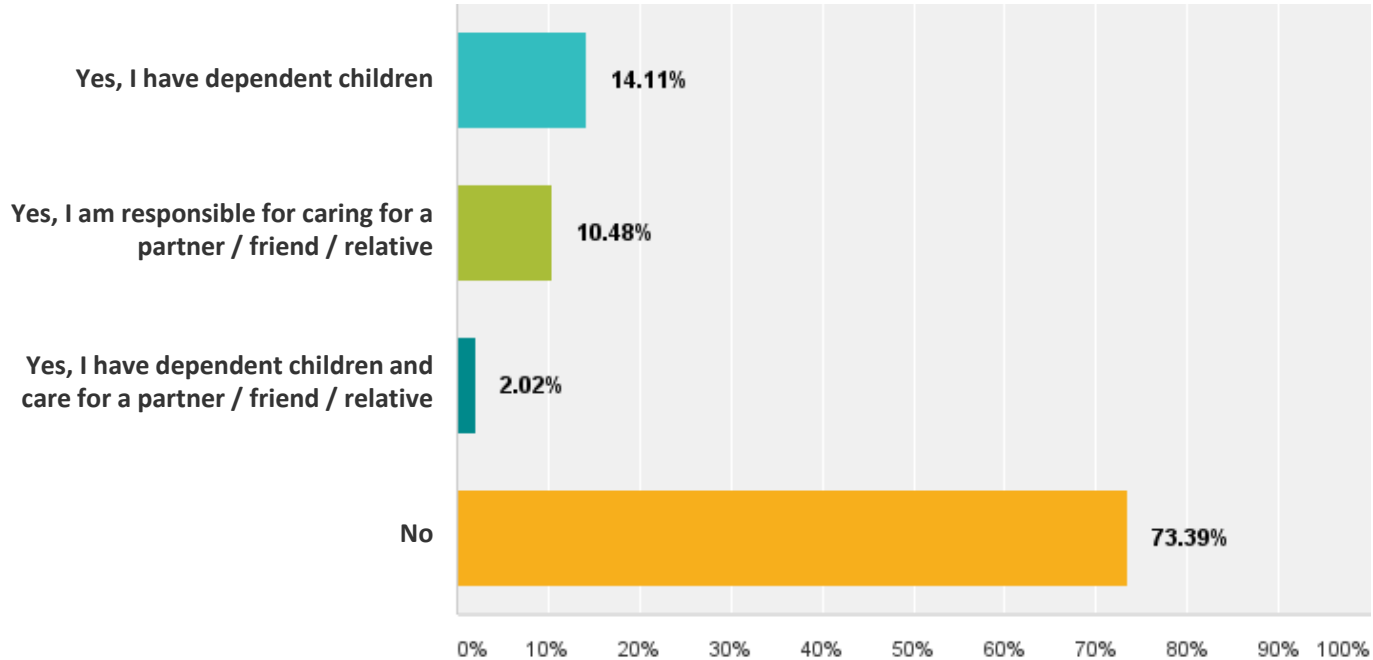
There were 10 comments about ensuring more ready **access to specialists** (both nurses and doctors), another 7 relating specifically to making specialist care/tests/clinics closer to people’s homes, and 3 references to the need for more specialist nurses / AHPs.

There were 9 references to the need for **GPs to be better informed**, and a further 4 comments about the need for clinicians to offer more holistic ‘person-centred’ care.

Amongst the other comments there were references to the need for better access to services supporting mental/emotional health (6), cheap or free parking or prescriptions (4), and more physio (3).

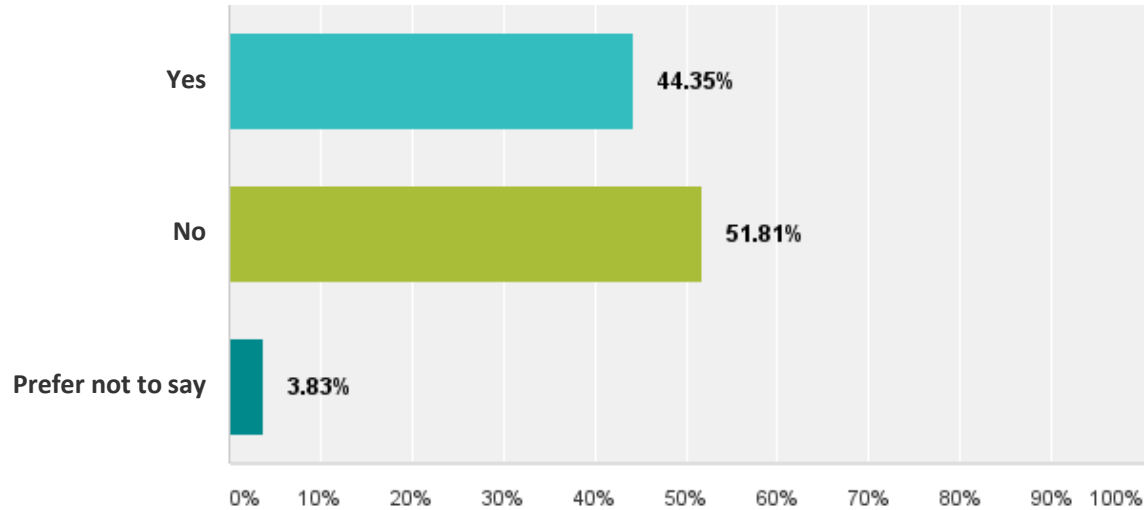
## Q14: Do you have dependent children, or do you care for someone?

Answered: 496 Skipped: 213



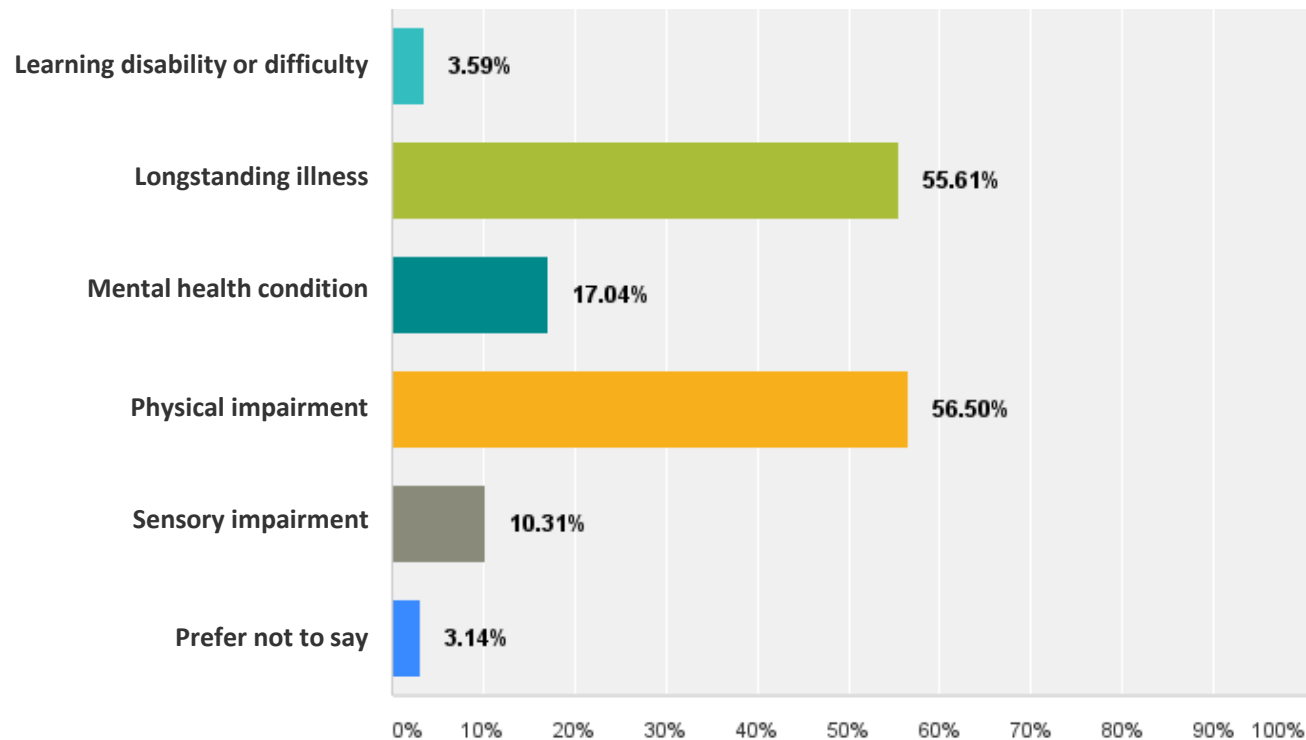
## Q15: Do you consider yourself to have a disability?

Answered: 496 Skipped: 213



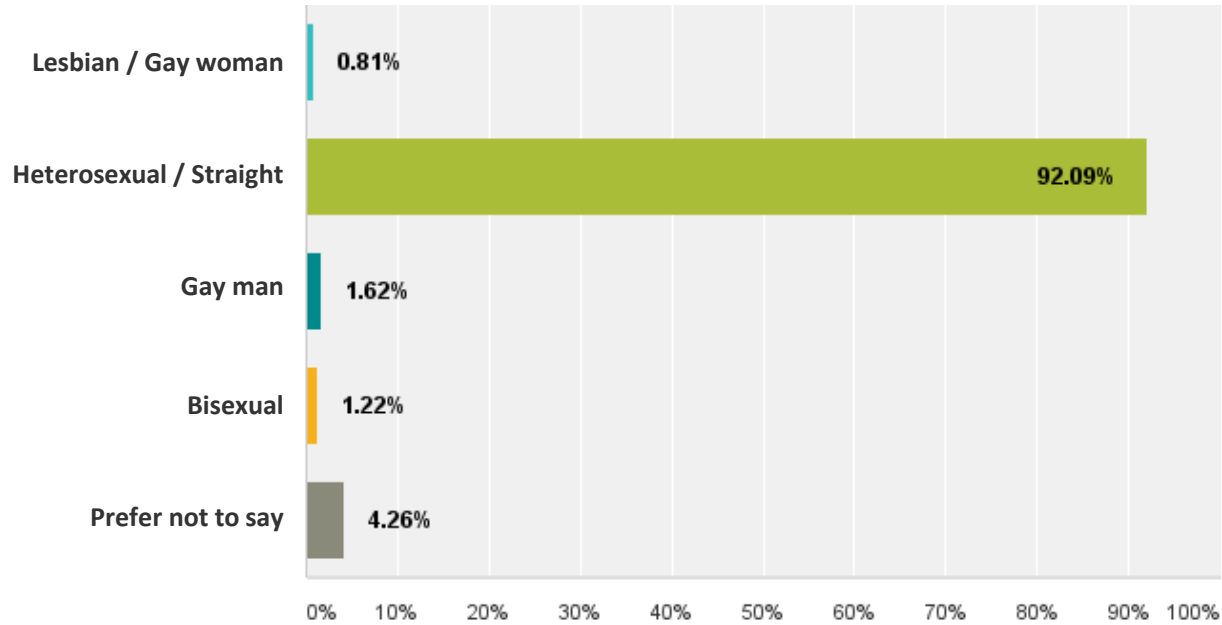
## Q16: If 'yes', please tell us what your disability is. You may select as many options as are applicable.

Answered: 223 Skipped: 486



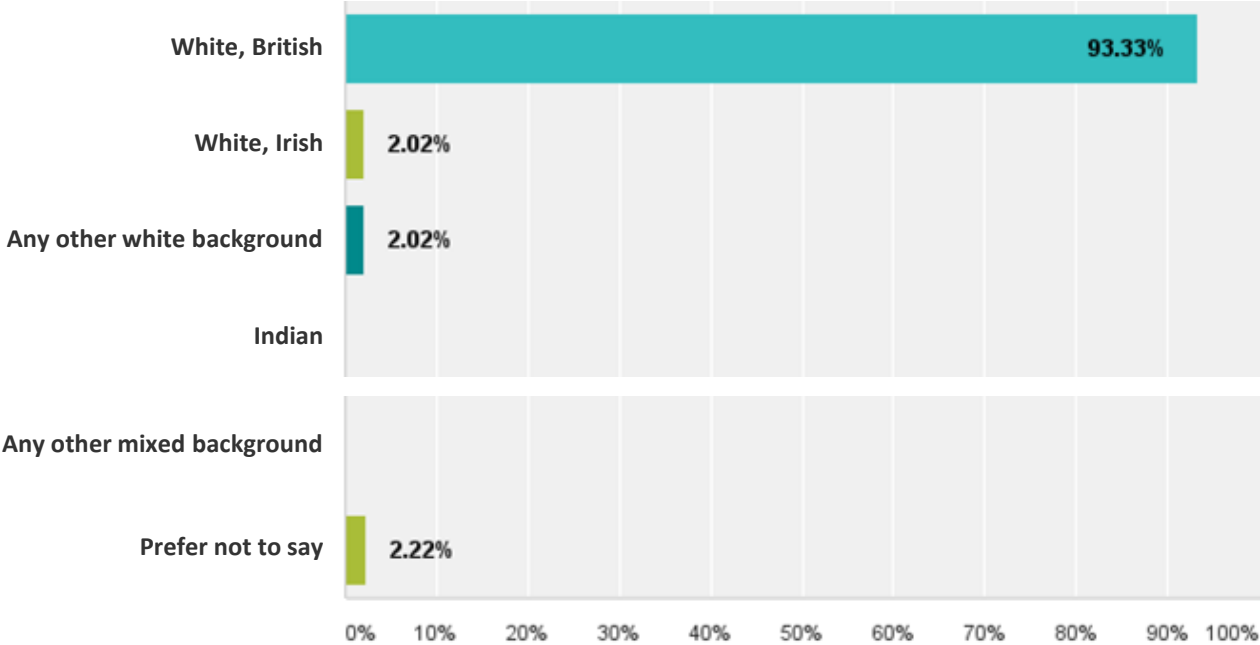
## Q17: Would you describe your sexuality as:

Answered: 493 Skipped: 216



# Q18: Would you describe your ethnic origin as:

Answered: 495 Skipped: 214





## Q19: Your religious belief is:

Answered: 485 Skipped: 224

