healthwatch
Devon
Better services through public involvement

People Living with Long Term Conditions

December 2014

Contents

Introduction 1

Methodology 1

Key Findings 2

Responses 4

  Those who considered the service ‘*excellent*’ commented on: 6

  Those who considered the service ‘*good*’ commented: 8

  Those who considered the service ‘*average*’ commented: 9

  Those who considered the service ‘*poor*’ commented: 10

  Those who considered the service ‘*very poor*’ commented: 11

 Response Demographic 23

Appendix A 27

Appendix B 35

About this Report

This report has been produced by Healthwatch Devon – the independent consumer champion for health and social care in Devon.

Healthwatch Devon would like to thank everyone who took the time to respond to this survey, as well as the organisations and individuals who helped to promote the survey through their own networks.

Registered Charity Number: 1155202 Healthwatch Devon

Introduction

North East West Devon Clinical Commissioning Group (NEW Devon CCG) want to develop a model of care that puts patients with long-term conditions right at the centre and designs care plans around their preferences. To do this they need to understand what patients with long-term conditions think about the care that they currently receive and what changes they would like to see to make their care more patient-centred. The integration and coordination of services which meet the needs of patients has been shown to improve patient experience and outcomes, as well as reduce emergency hospital admissions.

NEW Devon CCG therefore asked Healthwatch Devon via the Engagement Gateway to undertake a survey of as many people as possible with a long-term condition living in Devon. The purpose of the survey was to establish people's opinion on the services they currently receive, if they currently have a Personal Care Plan that they are aware of, and what support they would like in future to help them manage their long-term conditions.

Although instigated by NEW Devon CCG, this piece of work was supported by South Devon and Torbay CCG and Devon County Council.

Methodology

Through consultation between NEW Devon CCG, South Devon and Torbay CCG, Devon County Council and Healthwatch Devon a survey was created to gather the views of individuals living with long-term conditions. A copy of this survey can be seen in Appendix A.

The survey was available in paper format and online. It was promoted through Healthwatch Devon's partners (Be Involved Devon, Devon Carers Voice, Devon Link Up, Devon Carers Voice and Living Options) and by NEW Devon CCG.

Further promotion was made possible by the Alzheimer's society promoting a questionnaire at a similar time and allowing us to send it out together to their members.

It was also sent out with the Mid-Devon Citizens Panel survey.

In total 571 people responded to the survey, of which five people did not tick a long term condition, nor add anything in the 'other' column, and so their responses have not been considered.

199 people have also provided contact details for further engagement about long-term conditions in the form of focus groups.

In addition Be Involved Devon (BID) hosted NEW Devon CCG's long-term conditions commissioning lead and adult mental health commissioning manager to discuss the survey and long-term conditions at a North Devon and Torridge BID Coming Together meeting on 13 October 2014. A summary report of this focus group is included in Appendix B, and the results included within the Key Findings.

Key Findings

1.1 63% of respondents considered the care and support they receive as good or excellent. However, nearly 1 in 5 (18%) consider the care and support they receive as poor or very poor. Many of these considered communication to be a major area of concern. The BID focus group highlighted how communication between Mental Health services and physical health services was particularly poor.

2.1 Nearly three quarters (72%) of respondents felt they received useful information that gave them a better understanding of their condition and how to cope with it. 70% felt they got access to treatment that helped them to manage their condition.

2.2 Only half of respondents felt supported to manage their conditions or felt they knew where to go for help when they needed it. 1 in 3 got access to other support from the community or voluntary groups.

3.1 Consistently, around two thirds of respondents agreed that:

They discussed with a professional what was most important to them in managing their own health.

They were involved in decisions about their care.

They had enough information to help manage their health

The information provided was clear and understandable.

They, with a health professional agreed how best to manage their condition(s).

When speaking to other health professionals they understood how they were managing their condition(s).

They are very or fairly confident they can take care of their own health.

They feel they have control over their care most or all the time.

4.1 70% of respondents play an active role all, or most of the time, in managing their long term conditions.

5.1 Support in understanding how to prevent the worsening of a long term condition would be most helpful for people to take a greater role in managing their care. Information about the long term condition and the treatment or medication received was also an important form of support.

6.1 Two out of three respondents did not have a personal care plan. Of these, 95% have not talked about it with a professional.

7.1 Less than half of respondents considered the sharing of information between health and social care services to be done well or very well. And nearly 1 in 3 (29%) considered this to be done badly or very badly.

7.2 The key way a Personal Care Plan could ensure health and social care providers meet an individual's needs was by improving communication between themselves and with the person involved.

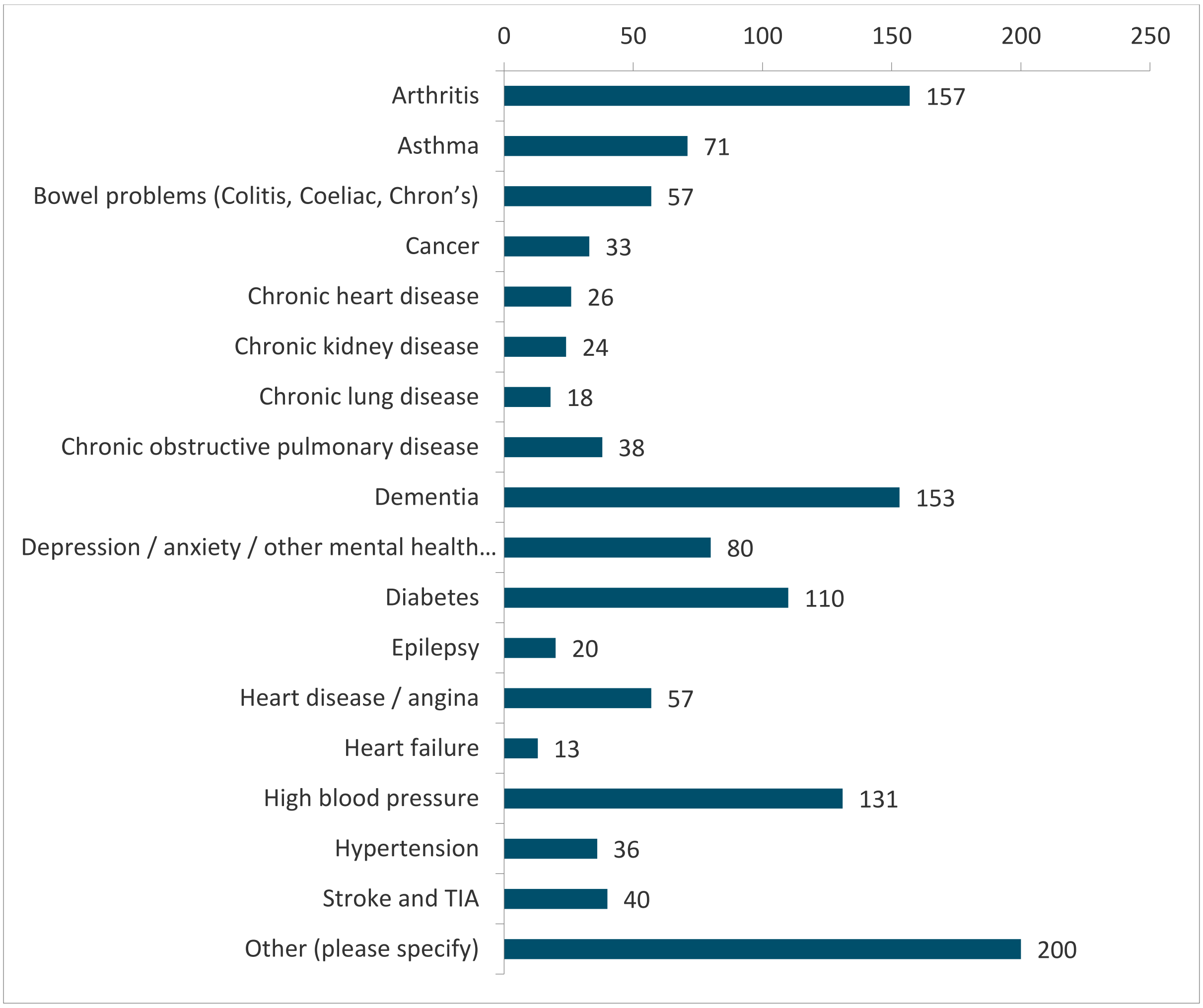
7.3 Additional recommendations included:

- If people were given a personal health budget, the most common additional support required would be information and recommendations about available services.
- Three quarters of respondents would like to have access to test results before they go to their regular appointments.
- Nearly half (45%) would like to receive these results by post.

Responses

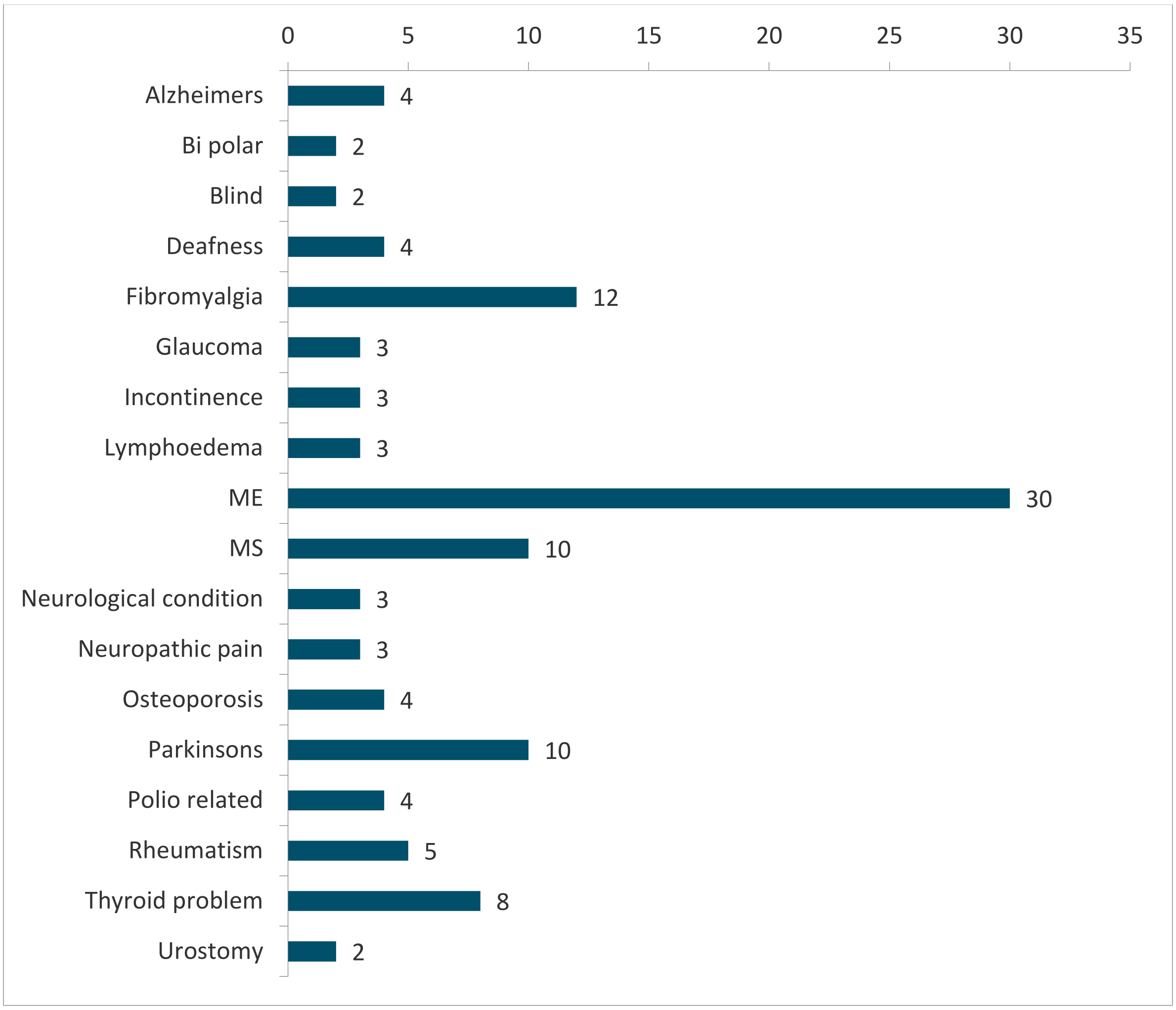
1. Which of the following long-term conditions do you have?

Figure 1



Of the 200 people who responded ‘other’, the following conditions were most common.

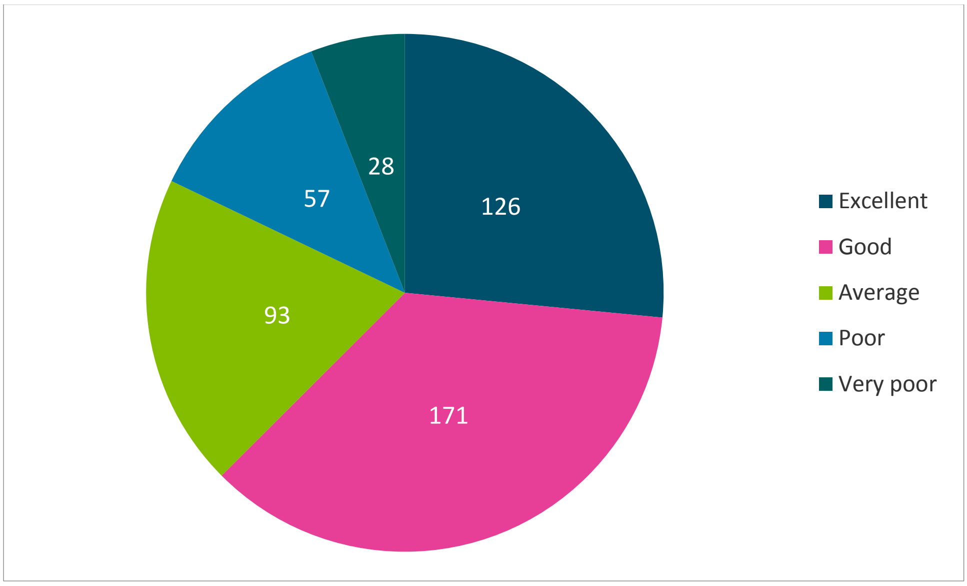
Figure 2



There were 5 people who answered the survey without ticking any long term conditions and wrote ‘none’ in the other box. These responses have not been considered further.

2. How would you rate the care and support you receive to help you with your condition(s)?

Figure 3



377 respondents added comments.

Those who considered the service '*excellent*' commented on:

Access and the availability of staff to respond to their needs:

> *"The GP is always willing to see my mother at short notice and refers immediately to other services to help with her condition. Excellent response and immediate support."*
>
> *"As soon as we had a problem, people would immediately act and solve it."*
>
> *"The service I receive is friendly and available easily by phone with regular appointments."*
>
> *"I am given a yearly check-up by my surgery."*
>
> *"The regularity of check-ups, having a named nurse specialist and the useful advice on understanding the results of blood sugars all help."*
>
> *"Regular check-ups and assessments, with consequent revisions to treatment if necessary. These at the instigation of our local GP surgery mean that I am "looked after"."*
>
> *"A good combination of day-to-day care from GP practice, with well-defined routes to more specialist care as and when I need it."*

Diagnosis, referral and monitoring work well:

> *"Early diagnosis and assessment. Regular prescriptions arrive well on time."*
>
> *"Because once I had my diagnosis the support, investigations and treatment I needed happened very quickly and efficiently. I could ask all the questions I wanted, there was always someone on the other end of the phone or via email and my follows up occurred as regularly as I needed."*
>
> *"My blood pressure is regularly monitored."*

And excellent communication throughout:

> *"There is communication and cooperation between my GP and the consultants who manage my various conditions. They all listen to what I have to say. I have coordinated ongoing care medically. I can ask to be referred back if I need to be and I can refer myself to the soft tissue clinic if I need injections."*
>
> *"The condition is under control and my GP practice nurse keeps in touch."*

There were also many general comments:

> *"I get a great deal of support."*
>
> *"I am given a yearly check-up by my surgery."*
>
> *"My GP is very supportive and understands. Boots the Chemist pharmacist also keep a close eye on me."*
>
> *"Because of the wonderful staff who treat me."*

Those who considered the service ‘*good*’ commented:

There were many positive comments in this section, most around similar themes to those who rated the service excellent, such as communication and availability of staff:

> *“Info from GP and diabetic nurse is clear and helpful.”*
>
> *“My doctor sees me monthly and reviews my medication.”*
>
> *“Doctors and nurses explain about the medication.”*
>
> *“Feedback and lots of paper material and telephone numbers.”*
>
> *“My family doctor knows me and knows my history.”*
>
> *“Because they listen to me.”*

However there were some concerns raised. These were most often regarding the ongoing care beyond initial diagnosis and care

> *“I am listened to when I have a problem with the existing regime of medication, but there is no systematic, regular review.”*
>
> *“Good general care from GPs and staff. But no on-going group help.”*
>
> *“More continuity needed between ie GP and hospital.”*
>
> *“Could do with more continuity.”*
>
> *“More continuity would be good.”*
>
> *“Could be better, lacks continuity.”*

There were also some individual concerns raised:

> *“Mostly, the care and support is very good, but I find occasionally one of the nursing staff is a bit hard to relate to.”*
>
> *“Pressures from demand for services limit the ability to provide support at an excellent level consistently.”*
>
> *“There doesn't appear to be any care and support for circulation problems. Good help and advice for angina.”*

Those who considered the service ‘*average*’ commented:

Some chose this option because the services they receive vary as to whether they are good or poor:

> *“Good in some clinical areas, not so good in others.”*

> *“Quality of professional care ranges from useless to excellent.”*

Some were concerned that the system was overwhelmed and response times were slow:

> *“Because, despite all these services, all that is delivered is very slow - presumably overwhelmed with numbers.”*

> *“I am pleased with finally being given support from Mental Health Services, but it shouldn’t have taken more than 10 years to finally gain this and receive a correct diagnosis.”*

There were also concerns that services were working in isolation and did not consider the whole person or the impact upon their life:

> *“Each doctor only looks at their own bit and I am a whole person with multiple problems. My GP doesn't have time to go into detail in the rare times I can get an appointment to see him. Usually it is a telephone conversation.”*

> *“Sometimes the care is good, sometimes average. It depends on the individual treating you if you get the information you need to make informed decisions. The fact that I am blind, sometimes professionals treat me with dignity and empower me, whilst other times I feel my intellect is questioned. Often consultant (for other conditions) see my disability NOT the person I am.”*

> *“The Rheumatology consultants are very focussed on the joint disease but not the impact it has on my life.”*

Another concern is a lack of appropriate communication:

> *“Agencies do not seem to liaise with each other over my varying health problems, or keeping my family informed.”*

> *“It is assumed you are coping if you don't complain.”*

> *“No one checks to see how I am getting on, but I think if I wanted help I would have been given it. I had consultation in the beginning.”*

> *“I need information to be in audio format as this is not always the case.”*

> *“I have to make the running to maintain health checks, the GP practice are not pro-active.”*

Those who considered the service '*poor*' commented:

Most commonly people commented on poor communication and lack of support:

> *"Very little care and support for condition and rely on personal care from husband."*
>
> *"I get very little support."*
>
> *"We have received good help and support from Alz Soc but very little from the Health Service."*
>
> *"Little support or information. Difficult to see GP."*
>
> *"The support varies between average and poor. Both my carer and myself feel isolated at times in seeking information and support."*
>
> *"No information provided at diagnosis. No signposting to support services. Consultant not very interested or helpful. No local specialist for Lupus down here."*
>
> *"Complex care management is split between 2 health trusts and community care is only available part time and you never know who is working when!"*
>
> *"Very little advice and guidance."*

There were also a number of comments from people comparing the services they receive now to an earlier time and consider the situation to have got worse:

> *"Initially good after the diagnosis but non-existent for the last year."*
>
> *"Years ago I had regular support from GP/nurse with blood tests since NHS changes this has come more erratic also for about the last 7/8 years."*
>
> *"The care I receive is not even up to the standard I had prior to my move to Devon nearly 15 years ago."*
>
> *"My care was just cut from an hour a day to half an hour a day as the council has been told to find so many £million in savings. It is not enough time for my care so I forego care on Sun, Tues and Thurs so I get an hour on Mon and Fri. So frustrating."*

Waiting times were also commented on:

> *"The pressure on health professionals curtails the opportunity for a chat to discuss symptoms and problems during a 3 monthly cancer check. To have to wait for sometimes over half an hour for a scheduled appointment which may in itself last five minutes. No time to discuss patient worries!!"*
>
> *"I waited nearly a year for a replacement MH support worker."*
>
> *"To get any help takes ages. I've been waiting for necessary adaptations for about a year."*

Those who considered the service ‘*very poor*’ commented:

That they received no care, or were unable to access it:

> *“I do not receive any care input.”*
>
> *“Because the condition is rare and very little is known is about the condition itself, nobody is prepared to put their stand up and fight your corner. However I have a very good occupational therapist, who carries out regular checks on me, the only other support is the yearly visit I have to my Hospital Consultant.”*
>
> *“You are helped at first but then left to your own devices.”*
>
> *“No support provided at all.”*
>
> *“The only practitioners who understand and can alleviate my condition are private practitioners/therapists.”*
>
> *“Once given the diagnosis and completed the self-help course recommended by NICE I was left to cope on my own.”*

ME, as a particular condition received several comments:

> *“ME/CFS continues to viewed as a ’non-disease’ with the main focus on CBT and little else.”*
>
> *“However, in relation to the ME the care and support have been very poor. MY GP has been as supportive as she can be, but there is currently no "treatment". I have been seen by the ME OT but she too could only offer limited support and I was discharged from the ME service as they are so small and the waiting lists are very very long.”*

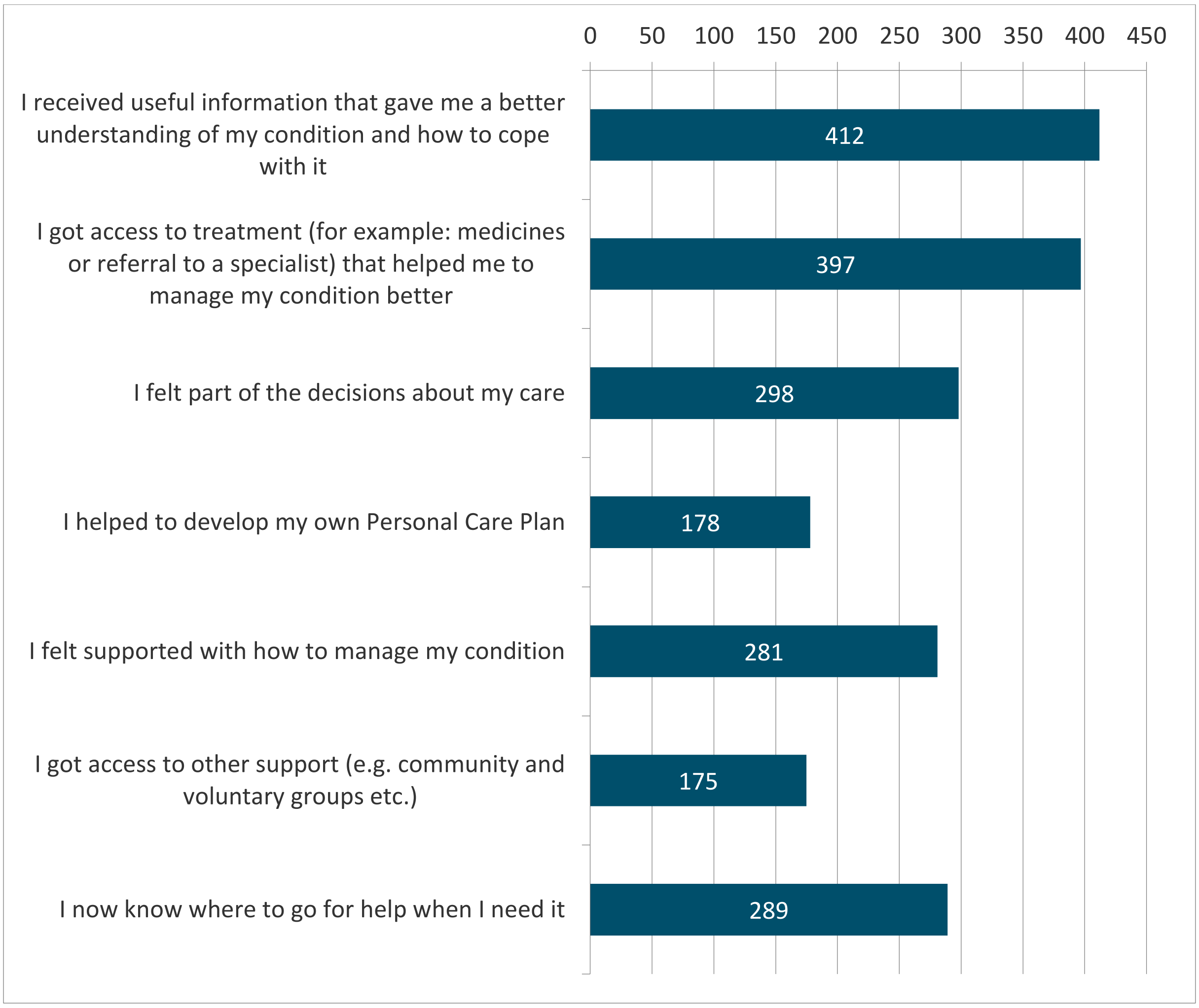
Communication was also highlighted as a concern:

> *“I am with Derriford Hospital and RDE. Neither hospital share notes and I have had to instigate the transfer of notes from Derriford to RDE. Derriford - appointments cancelled last min, notes lost, notes not transferred from one clinic to another. When I had a suspected stroke last year, the consultant’s secretary failed to see 3 urgent faxes from my gp to my consultant and I had to co-ordinate the information to go through myself. OTs have failed to give me suitable equipment/adaptations to help me, when I complained, the complaint was not upheld and the results hand delivered through my door late at night.”*

3. This question considers a range of health and social care professionals that you may have had contact with about your long-term condition. Please tick all of the following statements if you feel any of the listed health and social care professionals helped you with.

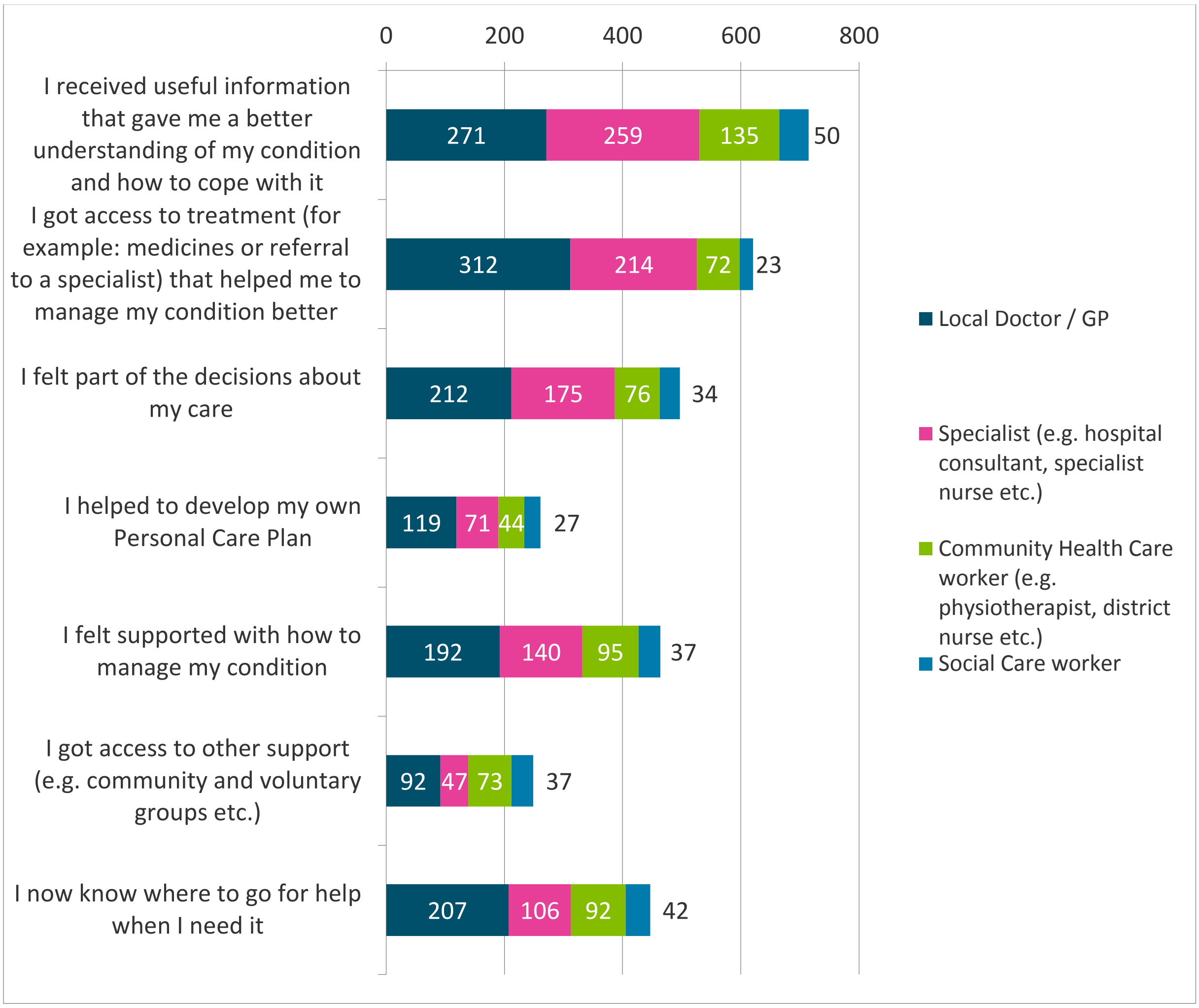
First, considering the response totals for each statement:

Figure 4



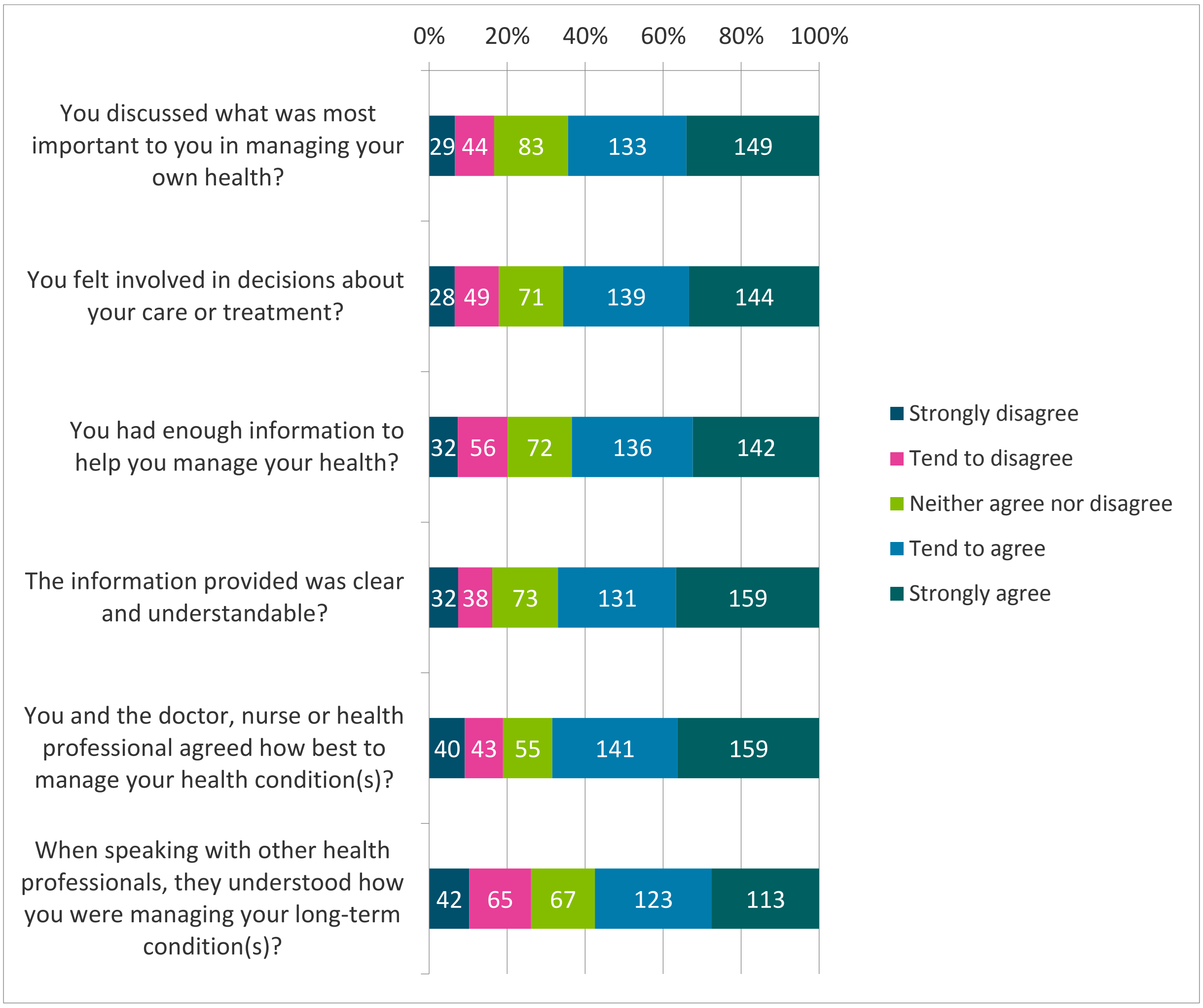
Secondly, each statement is considered with a breakdown of the service providing the help:

Figure 5



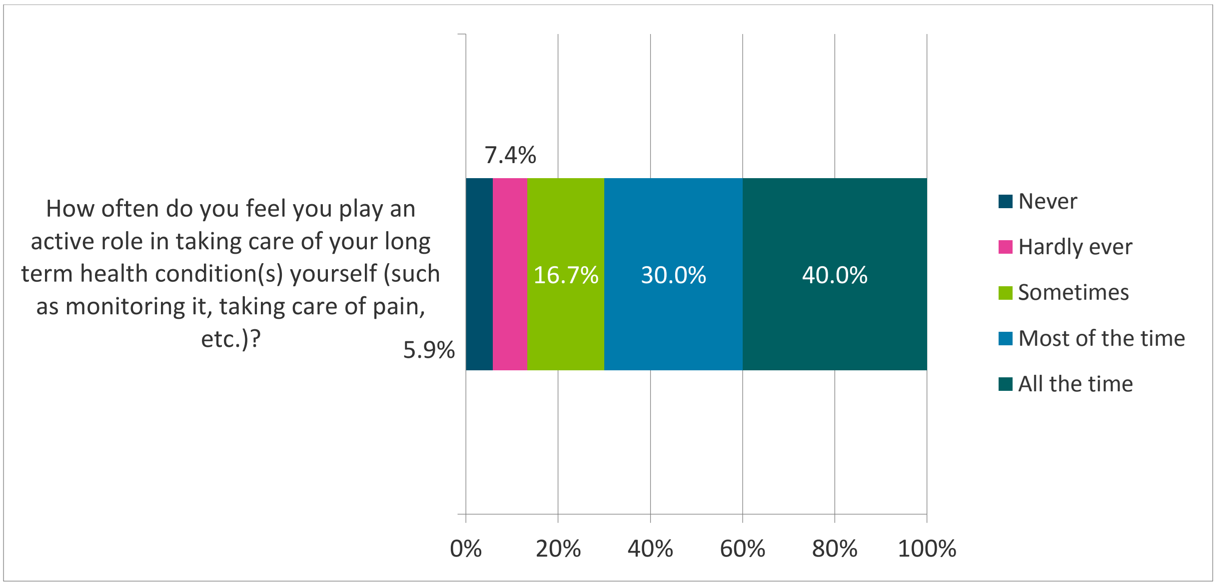
4. This question is specifically about the support you received from a health care professional. In conversations about your long-term condition(s) with your doctor, nurse or other health care professional, do you agree or disagree that…

Figure 6



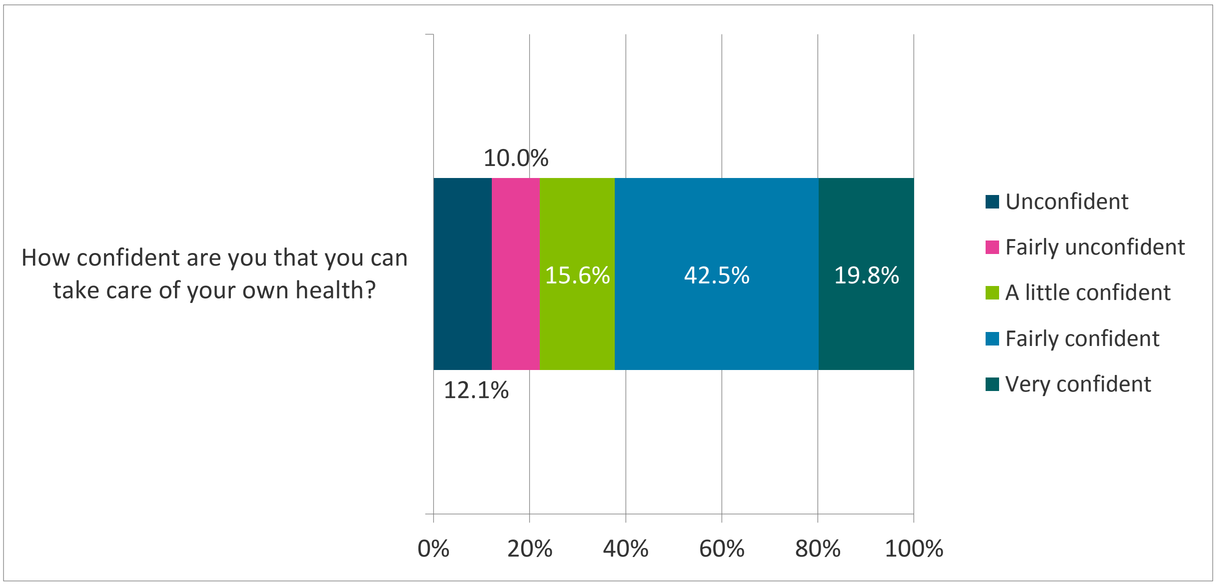
5. How often do you feel you play an active role in taking care of your long term health condition(s) yourself (such as monitoring it, taking care of pain, etc.)?

Figure 7



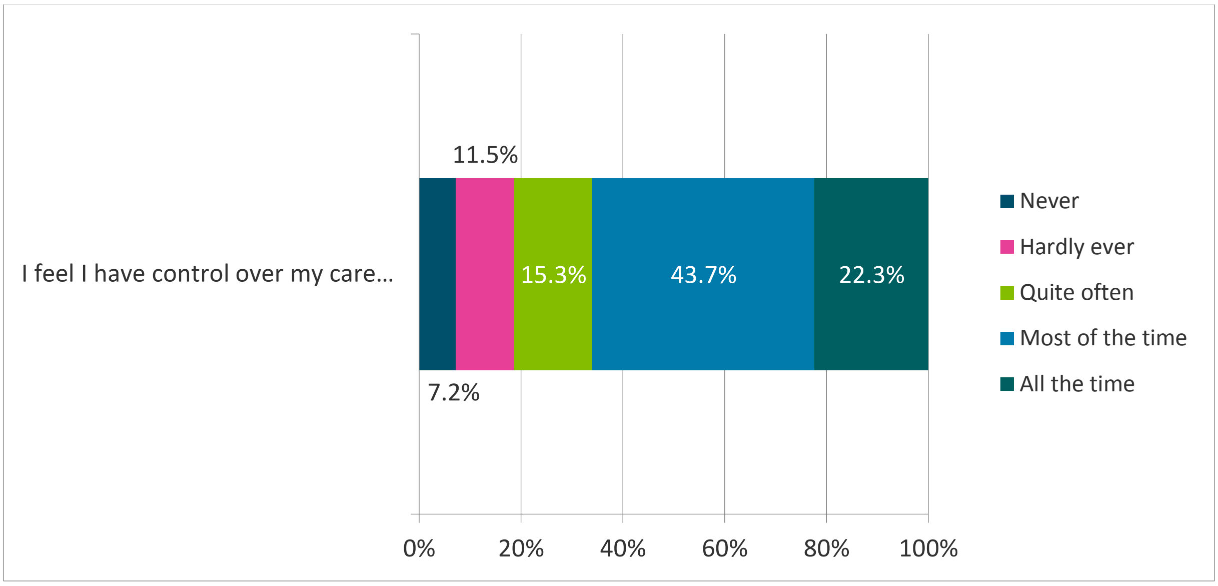
6. How confident are you that you can take care of your own health?

Figure 8



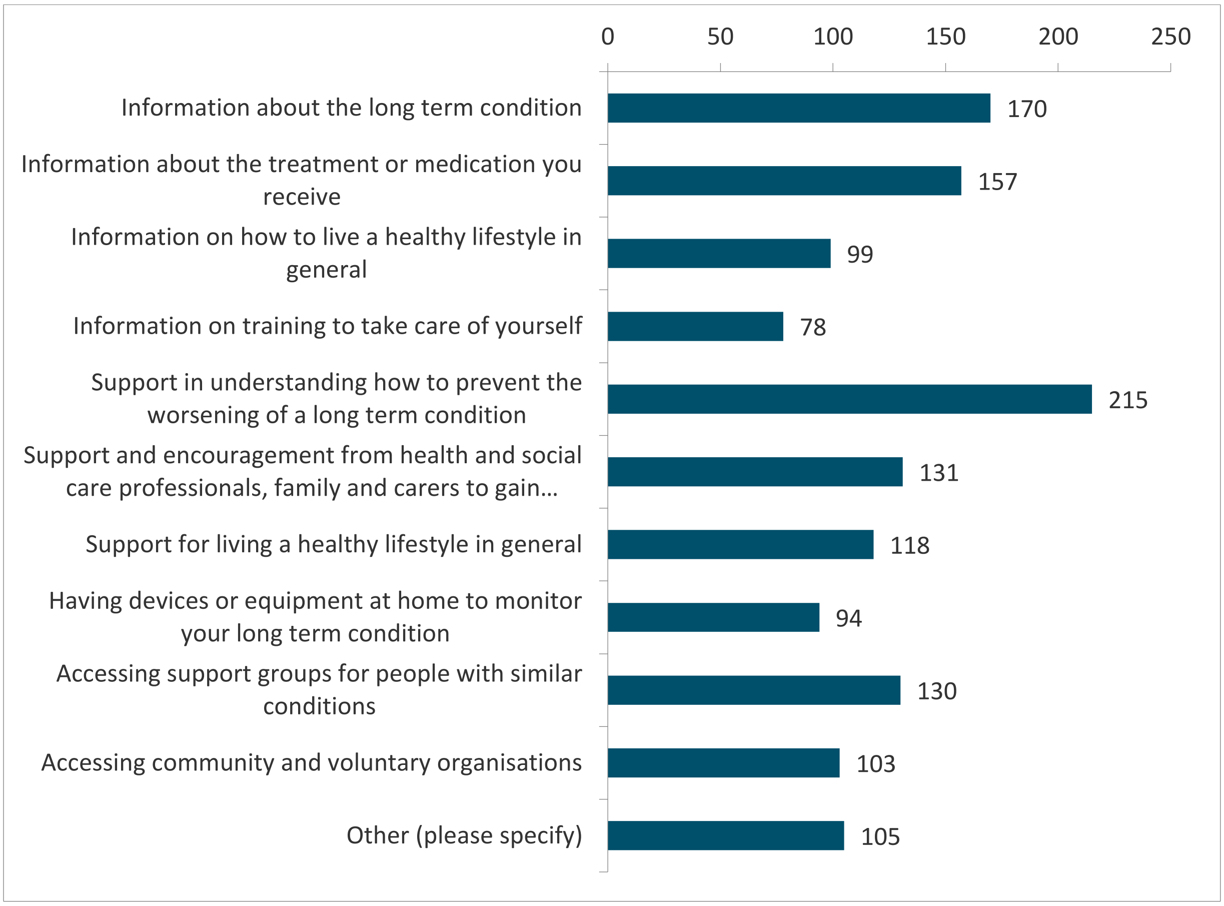
7. I feel I have control over my care…

Figure 9



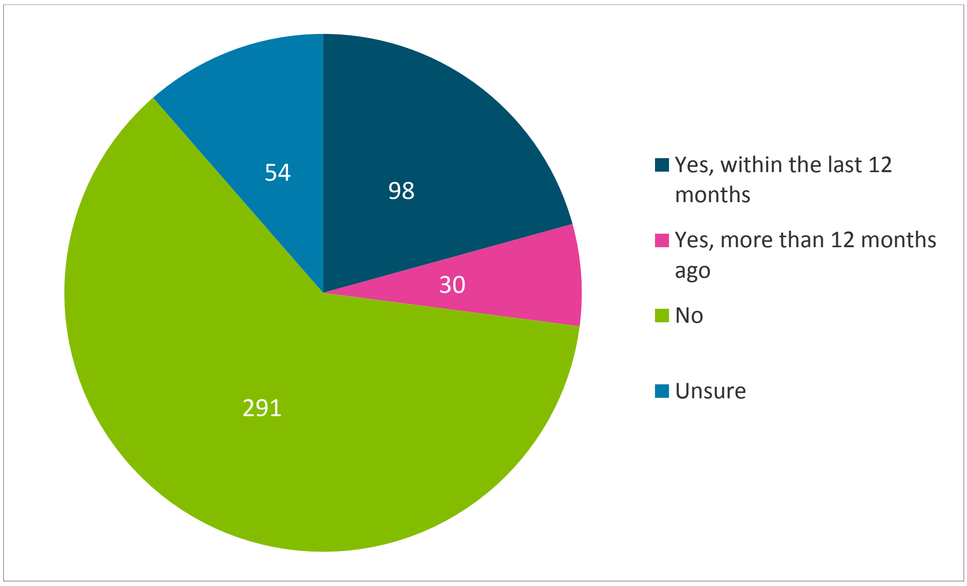
8. What do you think would help you to manage and take a greater role in the care of your long term health condition(s)?

Figure 10



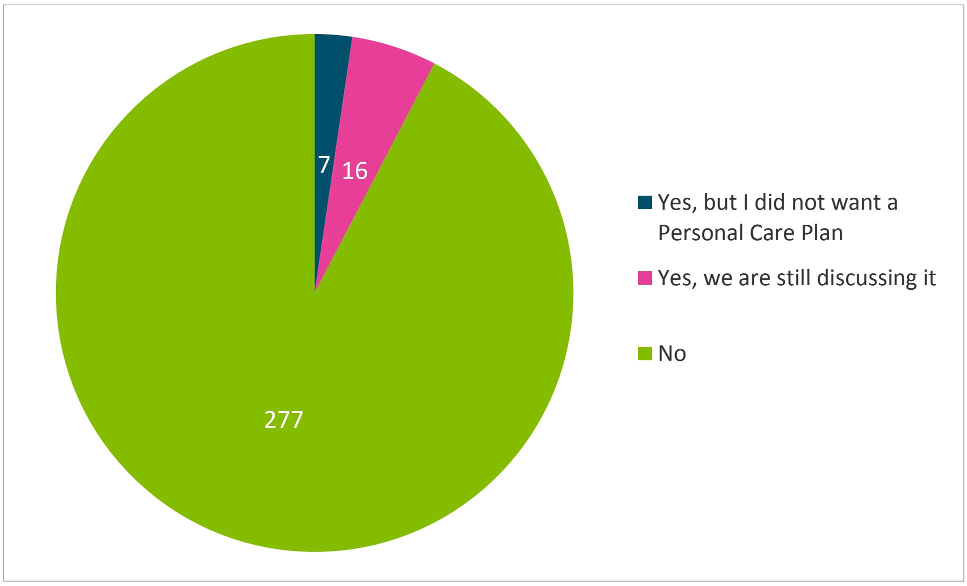
9. Have you and a health or social care professional agreed a Personal Care Plan for your overall health and social care needs?

Figure 11



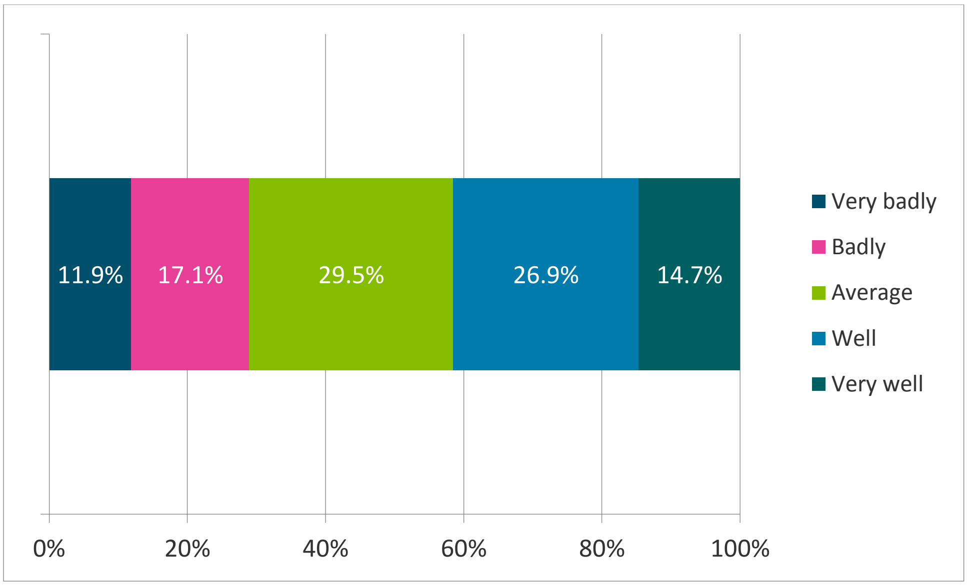
10. If you answered No to question 9, have you talked about a Personal Care Plan with a health or social care professional?

Figure 12



11. In your experience how well do the different health and social care support you use share information to ensure your needs are met?

Figure 13



12. As part of a Personal Care Plan, how could health and social care providers ensure all your needs are met?

By far the most common comments regarded better communication, both between professionals and with the individual.

> *“Talk to me”*
>
> *“Communicate better maybe email/letters with my doctor”*
>
> *“Share information”*

People wanted to be treated as individuals, to be listened to and considered as equal partners in determining their care:

> *“Understanding that I do know about my condition and accepting that my own experiences of it are valid.... and not to allow their professional insecurities to overtake them. To pledge to listen to me.”*
>
> *“By listening to my needs and acting upon them. Not going off and thinking and how my needs are and how my illness affects me.”*
>
> *“Listen to the patient, work in partnership. Look outside conventional, allopathic medicine to alternative therapies especially talking therapies.”*
>
> *“Try listening properly and recording what was actually said rather than just the bits that suit them!”*

Respondents also wanted to be treated as people, and their care considered holistically:

> *“By being better informed and taking a holistic view of my several conditions and treatments. And by asking me what my needs are!”*
>
> *“Deal with me as a person and not a number.”*
>
> *“Looking at all aspects of my health and having a holistic plan where all health professionals involved work together.”*
>
> *“Have more understanding of the condition itself, and how it affects me on a day-to-day basis.”*

This was further supported by a comment from the BID focus group:

> *“People shouldn’t be defined by their mental health.”*

In addition look at the root causes rather than treating conditions:

> *“By greater understanding of the root causes…and addressing those rather than merely the symptoms - especially as symptom management has other side effects.”*

A few respondents thought it would be better to have one person to communicate with for the variety of care they receive:

> *“An assigned personal 'first call' adviser, not necessarily a GP”*
>
> *“Have one identified person in charge of the treatment to plan, control and monitor all aspects of the treatment”*

> *"Patient should have a named person they can contact if necessary between official check-up appointments eg if aspects of health or ability to care for oneself"*

> *"By communicating more effectively between themselves and by having one clear leader who plans, co-ordinates and monitors treatment"*

Alternatively the person who the care plan is for could be responsible for taking it to each appointment:

> *"It would be useful for people with long term conditions to have a care plan at home to be taken to all medical appointments. It would aid seamless care."*

> *"Talk to one another & perhaps you have a care plan folder that could be taken to each appointment & get updated each time."*

After communication the other very common comment related to ongoing monitoring of conditions:

> *"By regular monitoring and checking of my long term condition and general health"*

> *"A 6 month blood test to maintain diabetes and cholesterol"*

> *"By having appointments more than once a year"*

> *"Reviewed at regular intervals"*

> *"I think a 6 or 12 month review would be good. My GP and I discuss my wellbeing when I have an appointment. I realise GPs are very busy, but the review does not need to be long and if not needed I can always cancel."*

Some other individual comments related to:

Management and delivery:

> *"Ensure carers actually deliver what is agreed. More care managers manage to support carers appropriately and effectively."*

Respite care:

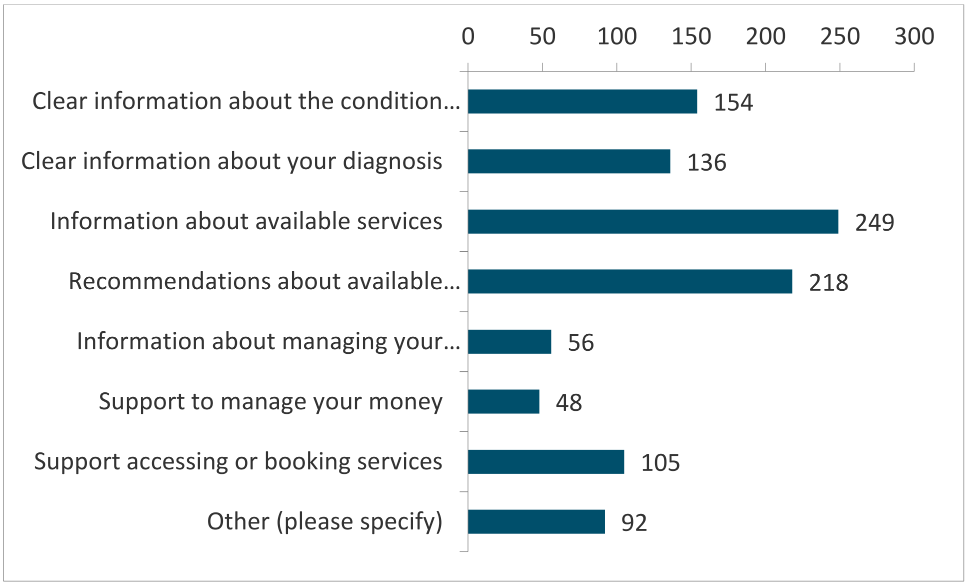
> *"Ensure there is a rolling programme of respite available to give my daughter a break."*

Transport:

> *"I have poor transport links and cannot manage. I have no human contact other than my land line."*

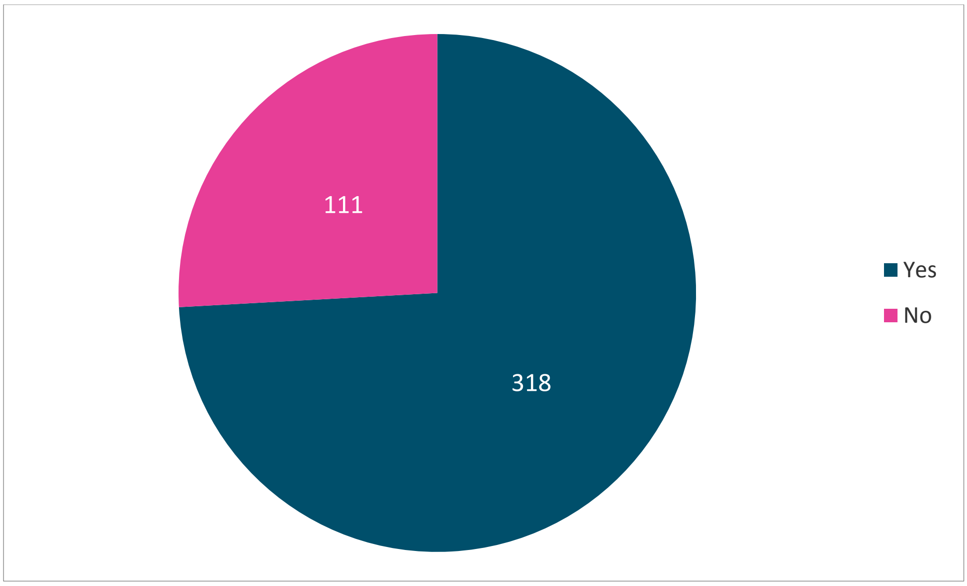
13. What additional support do you think you would require if you were given a personal health budget?

Figure 14



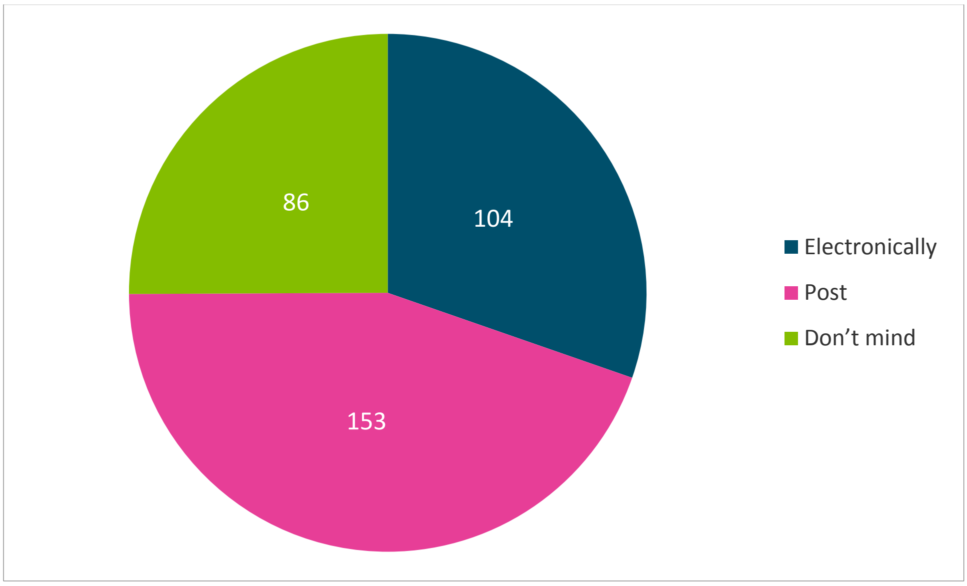
14. Would you find it useful to have access to test results relating to your long-term conditions before you go to your regular appointments with your doctor or nurse?

Figure 15



15. If you answered yes to question 14, would you prefer these results to be sent:

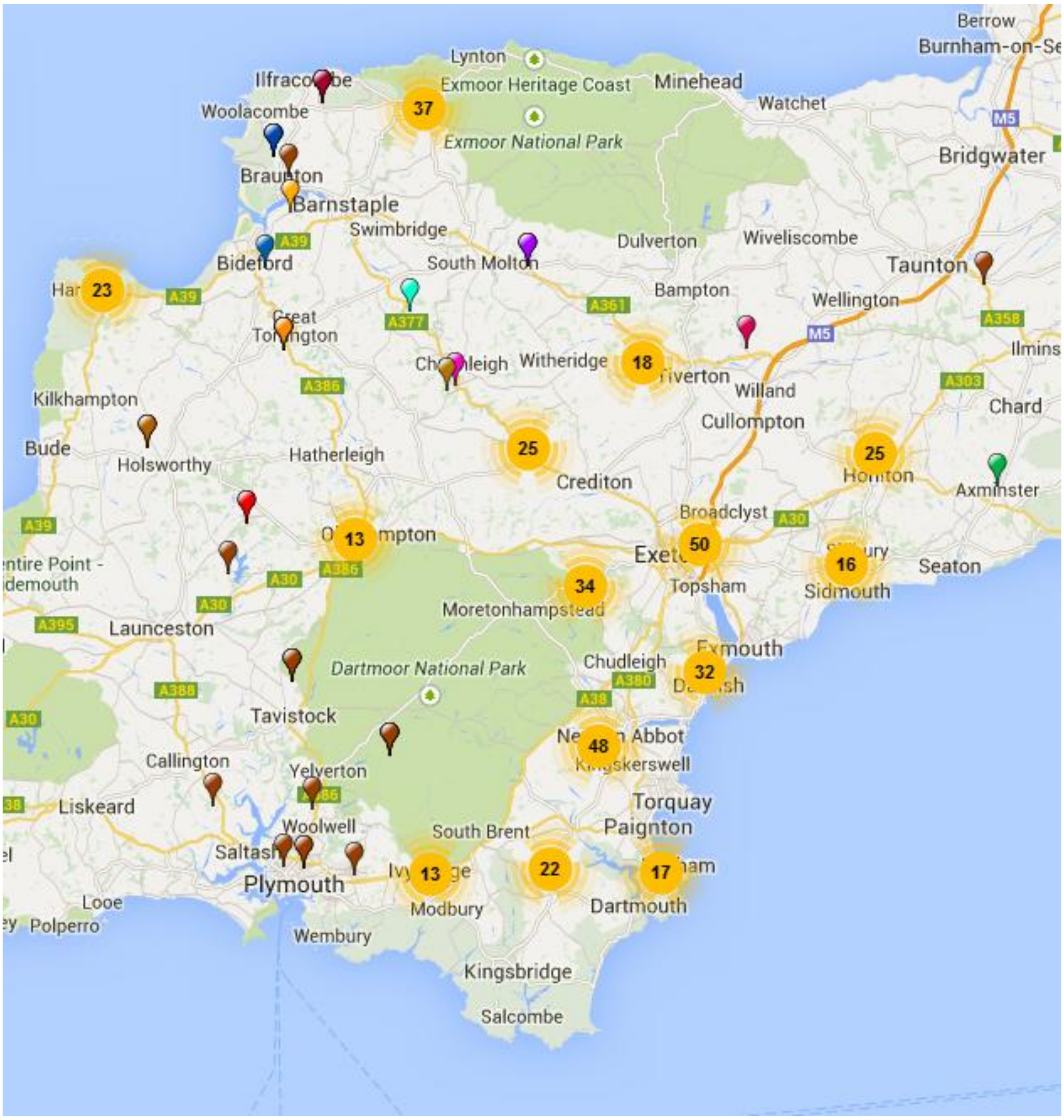
Figure 16



Response Demographic

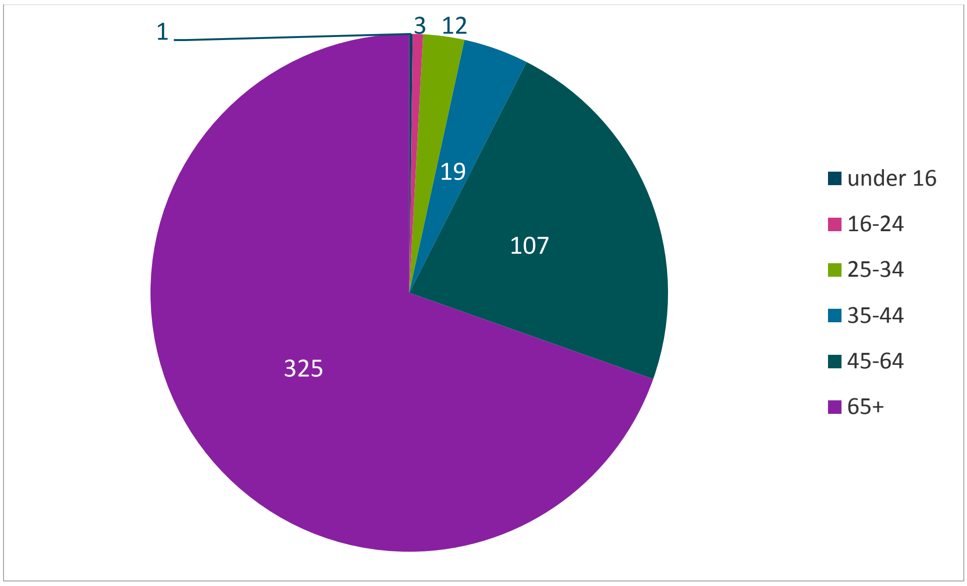
Location of respondents:

Figure 17



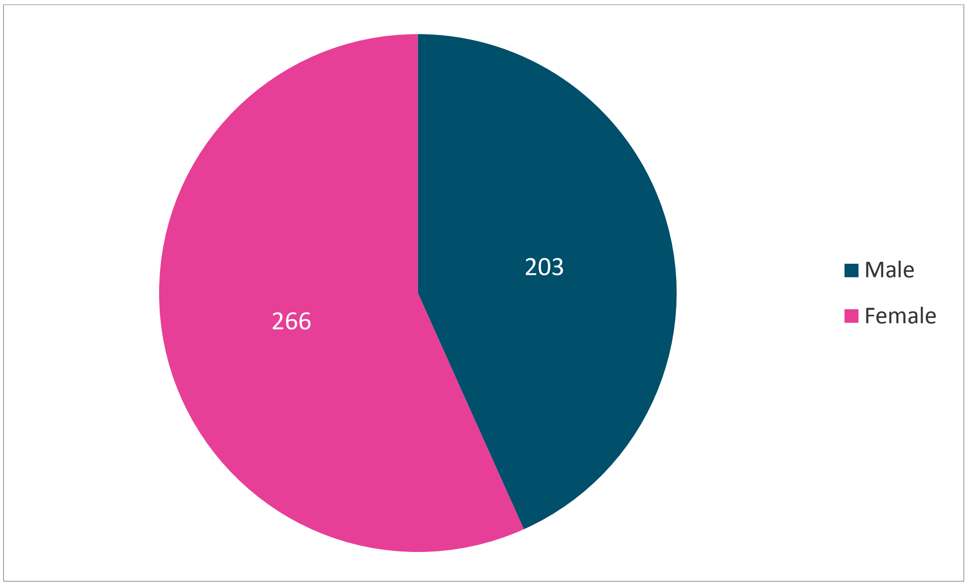
Age profile:

Figure 18



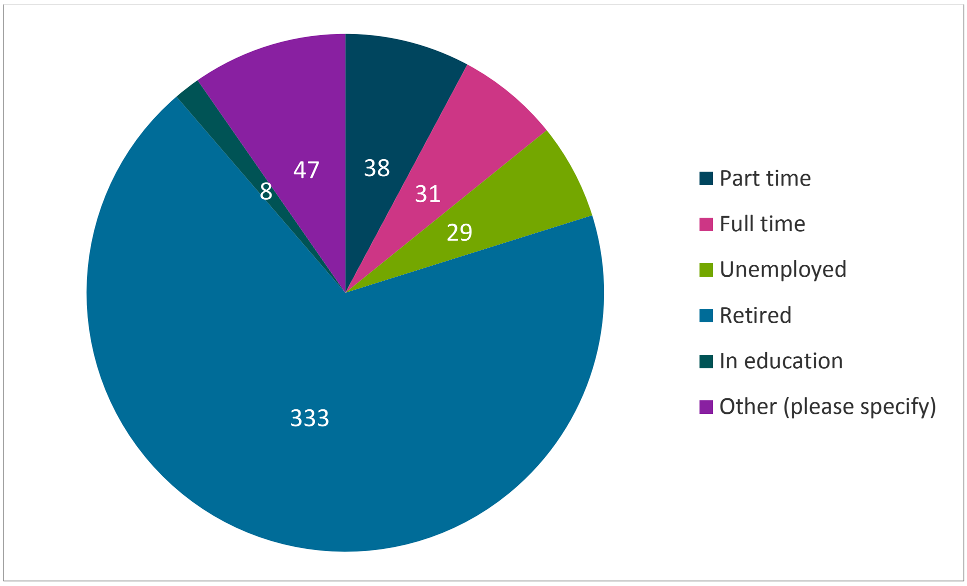
Gender:

Figure 19



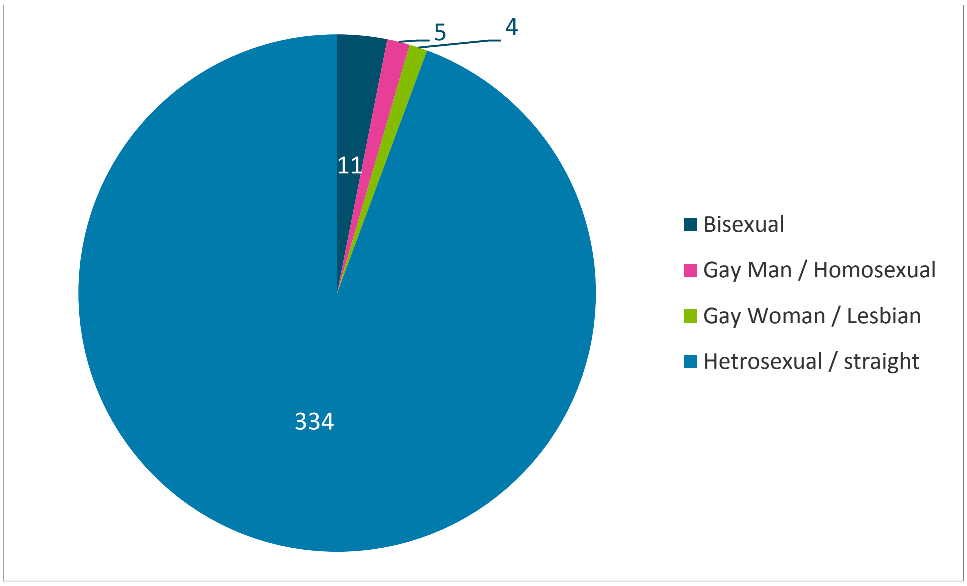
Working pattern:

Figure 20



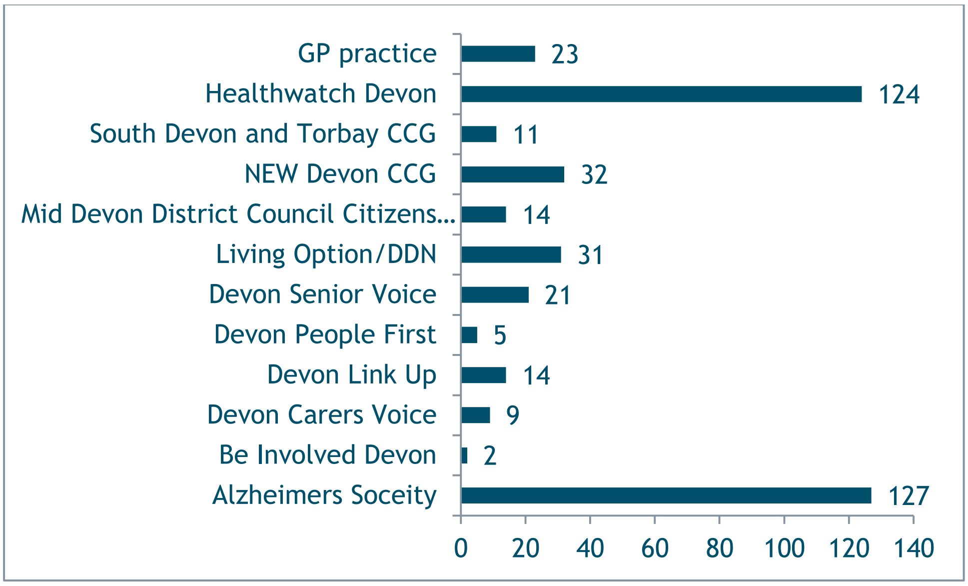
Sexual orientation:

Figure 21



How did you hear about this questionnaire?

Figure 22



Appendix A

Managing Your Own Care

We want to hear what people in Devon living with 'long-term conditions' think about the support they get from health and social care services. When we say 'long-term conditions' we mean health conditions that people may live with for years and even decades, for which there is no cure, but may be helped by medication and life style choices. We will use the feedback we get from this survey to inform how we can best support people living with long-term conditions in Devon. This may mean making changes to the services we provide as well as developing new ways of providing services.

healthwatch Devon

On behalf of:
- NEW Devon CCG
- South Devon and Torbay CCG
- Devon County Council

Responses to this questionnaire are anonymous and we do not require your name or contact details.

Please send completed questionnaires to:
FREEPOST RTEK-TZZT-RXAL, Healthwatch Devon, 3 & 4 Cranmere Court, Lustleigh Close, Matford Business Park, Exeter. EX2 8PW.

The questionnaire is available online:
https://www.surveymonkey.com/s/managingyourowncare

The closing date for responses is: Friday 21 November

For further information, or, if you require a large print version, would like to complete the questionnaire over the telephone, or would like to be sent a freepost return envelope, please contact Martin Parkes: mparkes@devonrcc.org.uk or telephone 01392 248919

1. Which of the following long-term conditions do you have?

[ ] Arthritis
[ ] Bowel problems (Colitis, Coeliac, Crohn's)
[ ] Chronic heart disease
[ ] Chronic lung disease
[ ] Dementia
[ ] Diabetes
[ ] Heart disease / angina
[ ] High blood pressure
[ ] Stroke and TIA

[ ] Asthma
[ ] Cancer
[ ] Chronic kidney disease
[ ] Chronic obstructive pulmonary disease
[ ] Depression / anxiety / other mental health condition
[ ] Epilepsy
[ ] Heart failure
[ ] Hypertension
[ ] Other long term condition, please state below

The following questions are about how professionals have supported you to care for yourself.

2. How would you rate the care and support you receive to help you with your condition(s)?

[ ] Excellent [ ] Good [ ] Average [ ] Poor [ ] Very poor

Please tell us why you chose that option?

3. This question considers a range of health and social care professionals that you may have had contact with about your long-term condition. Please tick all of the following statements that you feel any of the listed health and social care professionals helped you with.

		Local Doctor / GP	Specialist (e.g. hospital consultant, specialist nurse etc.)	Community Health Care worker	Social Care worker
3.1	**I received useful information that gave me a better understanding of my condition and how to cope with it**				
3.2	**I got access to treatment (for example: medicines or referral to a specialist) that helped me to manage my condition better**				
3.3	**I felt part of the decisions about my care**				
3.4	**I helped to develop my own Personal Care Plan**				
3.5	**I felt supported with how to manage my condition.**				
3.6	**I got access to other support (e.g. community and voluntary groups etc.)**				
3.7	**I now know where to go for help when I need it**				

4. This question is specifically about the support you received from a health care professional. In conversations about your long-term condition(s) with your doctor, nurse or other health care professional, do you agree or disagree that…

		Strongly Agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
4.1	**You discussed what was most important to you in managing your own health?**					
4.2	**You felt involved in decisions about your care or treatment?**					
4.3	**You had enough information to help you manage your health?**					
4.4	**The information provided was clear and understandable?**					
4.5	**You and the doctor, nurse or health professional agreed how best to manage your health condition(s)?**					
4.6	**When speaking with other health professionals, they understood how you were managing your long-term condition(s)?**					

The following questions are about how you take care of yourself and what would make that easier.

5. How often do you feel you play an active role in taking care of your long term health condition(s) yourself (such as monitoring it, taking care of pain, etc.)?

[ ] All the time [ ] Most of the time [ ] Sometimes [ ] Hardly ever
[ ] Never

6. How confident are you that you can take care of your own health?

[ ] Very confident [ ] Fairly confident [ ] A little confident [ ] Fairly unconfident [ ]
Unconfident

7. I feel I have control over my care…

[ ] All the time [ ] Most of the time [ ] Quite often [ ] Hardly ever
[ ] Never

8. What do you think would help you to manage and take a greater role in the care of your long term health condition(s)?

[ ] Information about the long term condition
[ ] Information about the treatment or medication you receive
[ ] Information on how to live a healthy lifestyle in general
[ ] Information on training to take care of yourself
[ ] Support in understanding how to prevent the worsening of a long term condition
[ ] Support and encouragement from health and social care professionals, family and carers to gain confidence to take care of yourself
[ ] Support for living a healthy lifestyle in general
[ ] Having devices or equipment at home to monitor your long term condition
[ ] Accessing support groups for people with similar conditions
[ ] Accessing community and voluntary organisations
[ ] Other, please write below

The following questions are about some changes that are taking place to health and social care services.

Sometimes a doctor, nurse or another health or social care professional will agree a Personal Care Plan for someone with a long-term condition, where they write down how the condition will be managed and who is involved in providing care and support.

9. Have you and a health or social care professional agreed a Personal Care Plan for your overall health and social care needs?

[ ] Yes, within the last 12 months
[ ] Yes, more than 12 months ago
[ ] No
[ ] Unsure

10. If you answered No to question 9, have you talked about a Personal Care Plan with a health or social care professional?

[ ] Yes, but I did not want a Personal Care Plan
[ ] Yes, we are still discussing it
[ ] No

11. In your experience how well do the different health and social care support services you use share information to ensure your needs are met?

[ ] Very well
[ ] Well
[ ] Average
[ ] Badly
[ ] Very badly

12. As part of a Personal Care Plan, how could health and social care providers ensure all your needs are met?

People living with long term conditions are often best placed to decide what care and support will make the biggest difference to their health and well-being. Personal Budgets are being introduced to allow some people to decide where money is spent on their own health care.

13. What additional support do you think you would require if you were given a personal health budget?

[ ] Clear information about the condition you have
[ ] Clear information about your diagnosis
[ ] Information about available services
[ ] Recommendations about available services
[ ] Information about managing your money
[ ] Support to manage your money
[ ] Support accessing or booking services
[ ] Other, please write below

14. Would you find it useful to have access to test results relating to your long-term conditions before you go to your regular appointments with your doctor or nurse?

[ ] Yes   [ ] No

15. If you answered yes to question 14, would you prefer these results to be sent:

[ ] Electronically   [ ] Post   [ ] Don't mind

To help put this information in context and ensure we are successfully reaching all parts of Devon, we would like to ask a little bit about your personal situation.

16. What is the first part of your postcode? (e.g. TQ11)

17. Age:

[ ] under 16   [ ] 16-24   [ ] 25-34   [ ] 35-44   [ ] 45-64   [ ] 65+

18. Gender:

[ ] Male   [ ] Female   [ ] Prefer not to say

19. Gender identity (if appropriate):
If you identify as transsexual, transgender (in that you have effected a permanent change of gender identity) or as intersex, which group do you identify with?

[ ] Transsexual
[ ] Transgender
[ ] Intersex

20. Working pattern:

[ ] Part time
[ ] Full time
[ ] Unemployed
[ ] Retired
[ ] In education
[ ] Other

21. Sexual orientation:

[ ] Bisexual
[ ] Gay Man / Homosexual
[ ] Gay Woman / Lesbian
[ ] Hetrosexual / straight
[ ] Prefer not to say

22. Ethnic origin:

Asian or Asian British
[ ] Bangladeshi
[ ] Indian
[ ] Pakistani
[ ] Any other Asian background

Black or Black British
[ ] African
[ ] Caribbean
[ ] Any other Black background

Chinese or Other ethnic group
[ ] Chinese
[ ] Any other

Mixed
[ ] Black and White Caribbean
[ ] Black and White African
[ ] Asian and White
[ ] Any other mixed background

White
[ ] British
[ ] English
[ ] Irish
[ ] Scottish
[ ] Welsh
[ ] Any other White background

[ ] **Prefer not to say**

23. How did you hear about this questionnaire?

[ ] NEW Devon CCG
[ ] South Devon and Torbay CCG
[ ] Healthwatch Devon
[ ] GP practice
[ ] Other, please state:

Thank you for filling out this questionnaire. A report outlining the key messages coming from these questionnaires will be published on the Healthwatch Devon website by December 2014. http://www.healthwatchdevon.co.uk/

This questionnaire is anonymous and we do not require your name or contact details.

However, we will be conducting a number of focus groups later in the autumn and winter of 2014/15 about long-term conditions. If you would be interested in being involved in these please leave your name and contact details below. These will be stored by Healthwatch Devon, separate from your answer to this questionnaire and will only be used to contact you regarding future engagement opportunities about long-term conditions.

24. Name:

25. Address:

26. Email address:

27. Telephone number:

Appendix B

The mental health
engagement strand of
Healthwatch Devon

Helping people with mental
health issues to have a say

Exeter CVS, Wat Tyler House
King William Street
Exeter EX4 6PD

Tel: 01392 201218
Web: www.beinvolveddevon.org.uk
Email: enquiries@beinvolveddevon.org.uk

Be Involved Devon

North Devon and Torridge BID Coming Together meeting

13 October 2014

Alex Road Resource Centre

Present: 7 people (not including BID Workers and Guest)

Apologies: 1 person

Guests: Jon Saunders, Northern Localities Commissioning Lead for Long Term Conditions, NEW Devon CCG and Tim Francis, Adult Mental Health Commissioning Manager (Northern and Eastern Locality) NEW Devon CCG

BID Workers: Ed and Charlotte

Guest: Jon Saunders, Northern Localities Commissioning Lead for Long Term conditions, NEW Devon CCG

Jon was welcomed to the meeting along with his colleague Jeni Davies. Tim Francis, Adult Mental Health Commissioning Manager (Northern and Eastern Locality - NEW Devon CCG) also attended as part of this slot.

Jon is the Long Term Conditions commissioning lead for the Northern Locality of NEW Devon CCG. The main remit of this survey is physical health but there is a recognition that it needs to better reflect mental health and become more person-centred.

Jon is working with Healthwatch Devon to find out what people’s views are about their care for long term conditions; what the current situation is and what could be improved. Hard copies of the survey are available, but it can also be completed online until late November. Feedback will be used to develop the proposals. The plan is in two stages:

1. Get feedback and identify priorities
2. Suggest some changes and test them out with people with long term conditions.

This is a shift away from healthcare ‘silos’ to being more person-centred and joined up.

Point - the importance of peer support and self-help groups was highlighted. Also the Expert Patient Programme which now has a mental health programme but unfortunately no one is trained in this area to deliver it. It provides the tools to self-manage, giving control back to the individual.

Jon asked how can we best support people and their family and carers to manage long term conditions?

He further clarified long term conditions as ongoing health problems such as diabetes, respiratory conditions and coronary heart disease, depression and anxiety. He pointed out that there was a list on the front of the summary.

Point - people may have more than one long term condition and one may well impact on another.

Response - Jon agreed that services need to be better at joining these up.

Point - Ed pointed out that mental health units are expert in mental health, not necessarily in physical health. Another person added that physical healthcare services are also not good with mental health issues.

Point - one person stated they had experienced good physical healthcare on a mental health unit when they had a stroke.

Point - Ed referenced a recent Plymouth Herald article about mental health and diabetes which raised awareness of Rethink Mental Illness's +20 campaign, which highlights the fact that people with schizophrenia are at risk of dying on average 20 years earlier than the general population.

Point - one person pointed out the personal dilemma for them of either taking their medication and putting on weight as a side-effect, or not taking their medication and relapsing.

Response - Tim agreed that better information was needed.

Point - the same person said they had learned from being involved in the Passport to Health meetings what he was entitled to ask for. He had therefore enquired about gym on prescription and was told this wasn't by GP referral even though some GPs were referring. They highlighted the inconsistency with GPs.

Point - one person stated they had taken part in a fun run to promote breast cancer awareness. They went to the gym to prepare and have continued with this. They now go three times a week. They strongly feel that maintaining a healthy lifestyle helped with both their physical and mental health. It took a great deal of courage to get there, but they have found it really helpful and there is no need to talk about mental health.

Point - people shouldn’t be defined by their mental health. Buddying support or walk and talk would be helpful to help people access fitness opportunities if they aren’t feeling confident to access them on their own.

Response - Tim thought encouragement was needed to make this happen.

Point - one person had an experience of running a befriending scheme and pointed out that even going for a coffee can be hard. They also noted that a buddy system doesn’t have to be peer led.

Response - it’s important to ask about people’s lifestyles as part of their health check.

Point - Ed gave an example of the Leg Clinic in Torrington. This provides both a clinical and social service which addresses both physical and mental wellbeing issues.

Response - Jon pointed out what was available on prescription for health and wellbeing, although not all of the following were available in all areas of Devon:

- Weight management
- Walk and talk
- Art on prescription
- Jigsaw project
- Books on prescription
- Men in sheds
- Gym on prescription

Response - Tim noted that there were also accredited resources online.

Point - it was highlighted that there were difficulties in accessing all the above information as GP websites were often not up to date and it was difficult to get hold of GPs. Also libraries have shorter opening hours now.

Point - Ed noted that Holsworthy Link Centre kept their resource noticeboard up to date.

Response - Jon acknowledged that there was a lack of one-stop-shops for this information. Feedback from people suggests that the GP surgery is the most appropriate place for this. A paid post is needed, but this is a resource issue.

Response - Tim pointed out that the Depression and Anxiety Service (DAS) is available. People can self-refer and DAS can give advice on other resources and will signpost. It’s not an exclusive service.

Tim also highlighted that there is a duty on GPs to promote positive health, but there is not much mental health promotion and therefore no parity of esteem. Supermarkets are also being used for the promotion of wellbeing.

Point - a lot of people don't go to the GP as they don't want to be seen as wasting GP time.

Point - much of the information available fits in well with 'recovery' such as 5 Ways to Wellbeing. This sort of information could be put on the visual display units at the surgeries.

Response - Rani Bora, Devon Partnership Trust has this information, which can be circulated. Also the Devon Partnership Trust website information is endorsed and can be used.

Question - whose role is it to get information to health centres? Should patients take it upon themselves or is it a role for CCGs?

Response - Ed felt there may be inconsistencies if left to individuals.

Response - CABs and Healthwatch Champions are another information resource.

A brief discussion then followed on how information gets to surgeries. It was felt it very much relied on individual relationships with practices and there was a need to be diplomatic. It was also pointed out that surgeries often don't reply.

Point - Patient Participation Groups (PPGs) may have a role to play here. An example was given of a local PPG that had a representative of the Devon Pharmaceutical Association as a guest speaker. They had a vast amount of knowledge and seemed to know more about medication than other professionals.

Response - Tim noted that some PPGs are more active than others. Ed commented that Budleigh Salterton PPG was very vibrant.

Point - the work of Exeter University should also be acknowledged and their involvement.

Response - Tim pointed out that the Mood Disorders Centre at the university is funded by the CCG.

Point - Ed mentioned the 'It's ok to talk about suicide' leaflet produced by Devon County Council and Exeter University.

Jon, Jeni and Tim were thanked for attending the meeting.