

# Long Term Conditions

## Summary Report

December 2019

**healthwatch**  
Thurrock

## Overview

*Long-term conditions or chronic diseases are conditions for which there is currently no cure, for example: diabetes, chronic obstructive pulmonary disease, arthritis and hypertension. They are usually managed with drugs and other treatment.*

An ageing population, breakthroughs in treatment and management of health conditions and changes to patient needs have led to the Health and Social Care system in England becoming unsustainable.

A shift away from the 'medical model' and towards one that takes into account the expertise and resources of the people with LTCs and their communities is now recognised by the NHS healthcare system.

Self-care is not a new phenomenon; however, it is becoming more pertinent due to the type of needs we as a population require.

There is strong evidence that shows that patients better enabled to care for their own health have better health outcomes.

Self-care / Self-management means different things to different people. For most people it means developing an understanding of how their condition affects their lives and how to cope with their symptoms. People report that it helps them live better lives and puts them in control of their condition.

Research undertaken by The Kings Fund shows that there is no single approach to self-management and neither should there be. All people are individuals, with different reactions to receiving a diagnosis and different ways of coping. Not everyone wants to be more actively involved in managing their own condition, but for the growing number of people who do, more support is needed from the professionals involved in their care.(1)

Nationally long term conditions (LTC) are more prevalent in older people (58% of people over 60 compared to 14% under 40) and in more deprived groups (people in the poorest social class have a 60% higher prevalence than those in the richest social class and 30% more severity of disease) (2).

People with long-term conditions now account for about 50 per cent of all GP appointments, 64 per cent of all outpatient appointments and over 70 per cent of all inpatient bed days.

Treatment and care for people with long-term conditions is estimated to take up around £7 in every £10 of total health and social care expenditure (2).

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## About Healthwatch Thurrock

Healthwatch Thurrock is the independent Health and Social care services champion for the people of Thurrock. We gather and represent views of local residents in order to build up a picture of services that are doing well and where they can be improved.

Along with consultation work and gathering the voices of residents, Healthwatch Thurrock also provide an information guidance and signposting service.

Residents are invited to “speak out” via an online forum as well as through targeted surveys, conversations and face to face engagement within the community.

Healthwatch Thurrock presents the voices of Thurrock to aid in identifying the need for change, considerations before commissioning and to support best practice across services.

## Learning from a user led approach

Through conversation and engagement with people actually using the services Healthwatch Thurrock highlight and promote improvements.

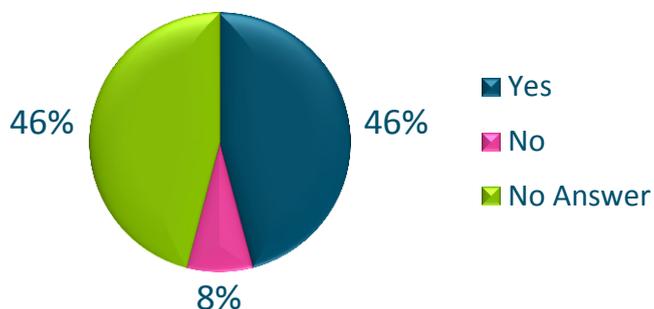
We know that services are better when people are treated as individuals and are actively involved with shaping support.

To do this, services need to learn from examples of real experiences, how they can be adapted and fit around local needs.

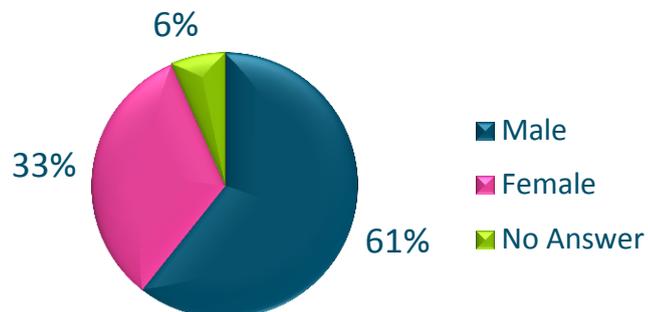
It is also important to understand where services are working well and that should be considered to be a blueprint of change when designing services and support.

# Demographics of the survey

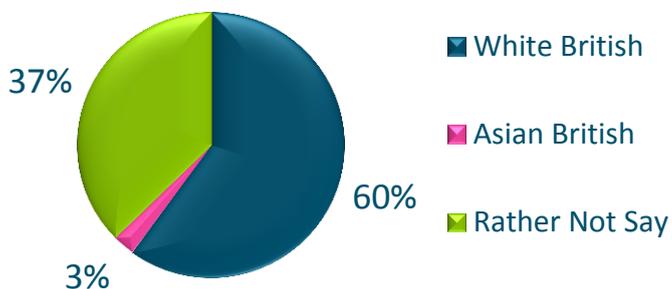
## Disability



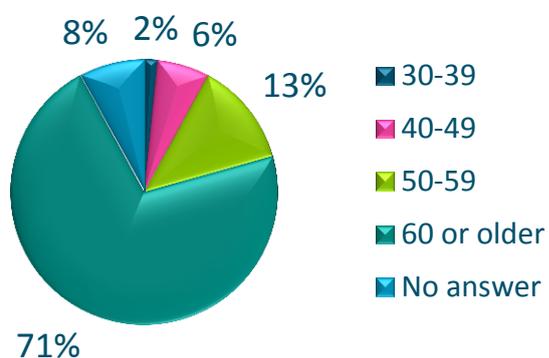
## Gender



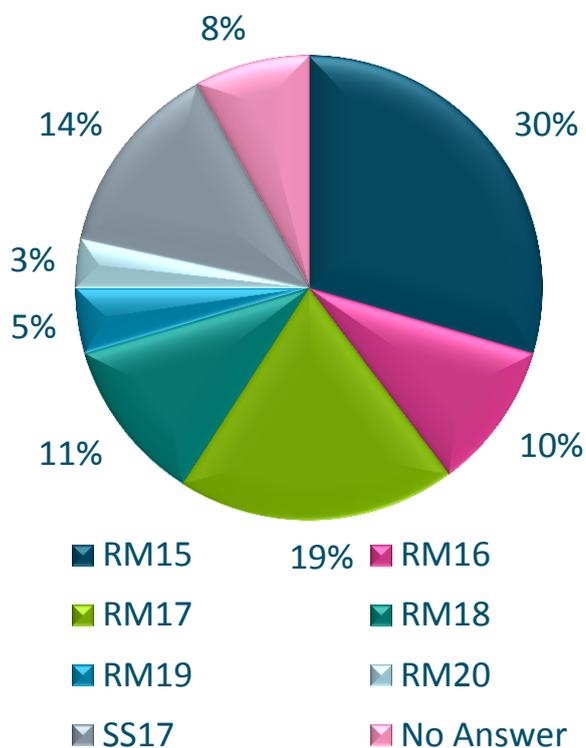
## Ethnicity



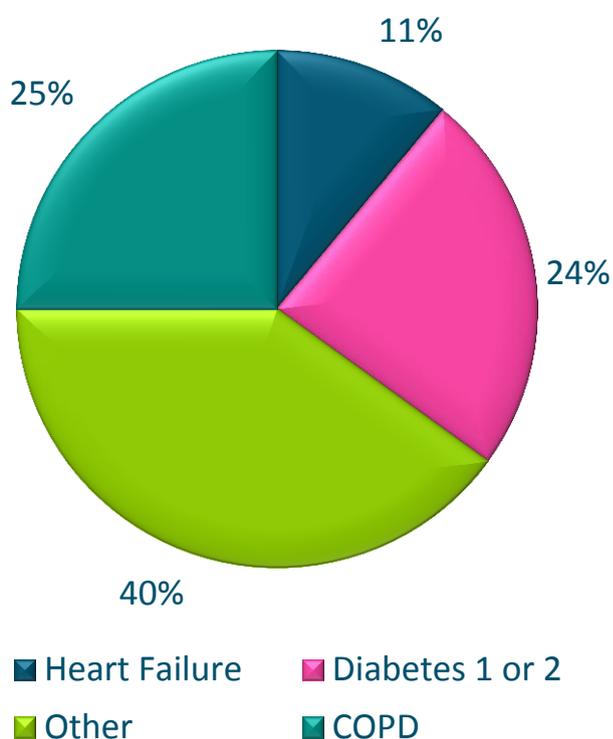
## Age



## Postcode



## Type of Condition



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## The Thurrock Picture

Healthwatch Thurrock were asked to conduct an engagement exercise to explore the views and opinions of people with Long Term Conditions (LTC). This would provide an evidence base for the development and improvement of the care and the ways in which we support and empower patients to self-manage LTCs and their general health in Thurrock.

GP practices in Thurrock are responsible for managing tens of thousands of people with LTC. In 2014/15 there were 54,678 cases of LTC recorded by GP's. The vast majority of LTC are preventable through lifestyle changes. In addition to the diagnosed long term conditions, it is estimated that thousands of people in Thurrock are living with long term health conditions who are unaware that they have them.

Ambulatory Care Sensitive (ACS) health conditions are chronic conditions for which it is possible to prevent acute exacerbations and reduce the need for hospital admission through active management such as vaccination, better self-management, disease management or case management or lifestyle interventions. Examples include COPD, Diabetes and Heart Failure.

In 2015/16 there were 3,869 admissions deemed as ACS. This demonstrates the need to analyse what is available from Primary and Community services to allow patients to Self-manage long term conditions. (3)

## Our Survey Picture

A survey was conducted with people living with single and multiple LTC's. The survey was conducted face to face to get a depth of qualitative data and to capture voices.

A total of 61 responses were gathered using a series of questions based around Public Health guidance and NICE best practice. A total of 21 (34%) of people surveyed had more than one LTC.

A mixture of quantitative and qualitative questions were used as well as demographics.

Data has been presented where people have given either a positive, negative or a "no answer" option.

Ethnicity was a wider questions, however, recordable responses only captured a small variety of ethnicities with many (37%) choosing not to answer.

Long Term Conditions were captured around four main areas with an option to select another description. The highest majority of responders did select other and a full list of the condition is detailed at the end of this report.

## Diagnosis

Most people received their diagnosis from their GP (29%) with Hospital/Consultants second (22%). There was a response from over a fifth (23%) who did not know who initially diagnosed their condition. Another group of people cited that either a scan or routine blood test (17%) diagnosed their condition, however, you may consider that this was via a GP or Consultant direction.

The survey questioned how people were given their diagnosis and their assessment of how it was (Good, Bad, Could have been better). The majority of responders were recorded as “didn’t know” or did not answer(61%) as they had responded with a feeling or a practical action which was not suitable in comparing the data (eg: shocked, went to hospital).

From the other responses:

Good	29%
Bad	2%
Could have been better	8%

Of those that were recorded as *Good*, comments were:

*“Very easy”*

*“Nurse explained”*

*“Explained very well”*

The survey questioned how much understanding people had about LTC and the connection between them and their lifestyle or choices. People were asked whether there was anything that they could have been done prior to diagnosis and what that may have been. The data shows the highest impact to health is smoking however, the majority of LTC were not preventable.

Through the survey, other messages evolved from how informed someone was following their diagnosis including gaining more support to self care, understanding or having awareness of the condition as well as prevention information.

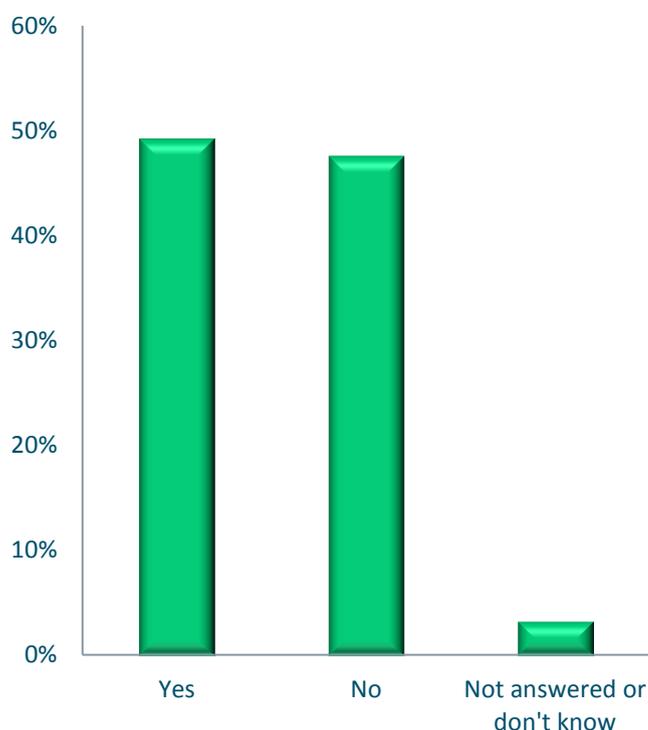
## Support after diagnosis

Following diagnosis of a LTC, the survey measured how much and what information was given to support people to self manage.

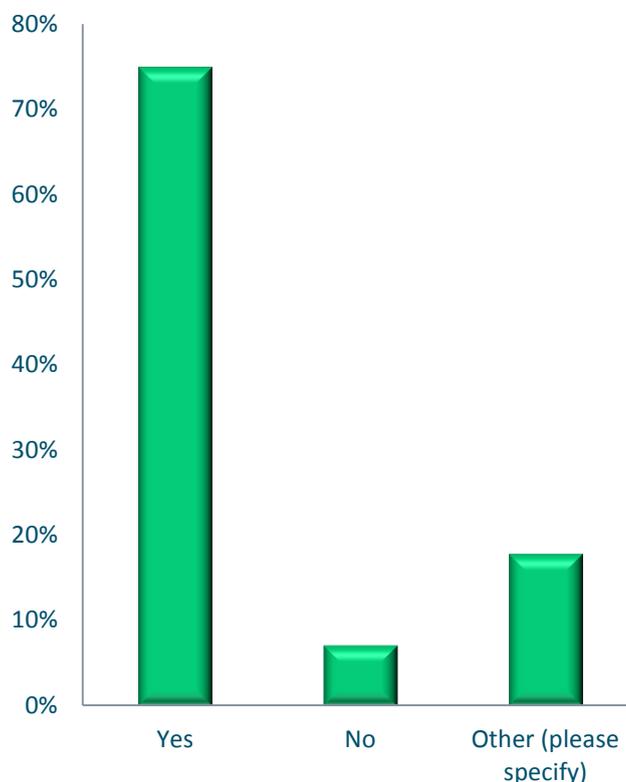
From the 61 respondents, 53 answered with 8 choosing not to. There was a variety of responses including receiving leaflets, signposting to the internet and information about diet. There were however, 6 responses that felt they were not given enough information and a further 7 that said they received no information at all.

Following diagnosis an even amount of people were referred to a service along with the same that were not. Of the near (50%) that were referred to a service, 75% of people felt the referral was easy.

**Were you referred to a service for support?**



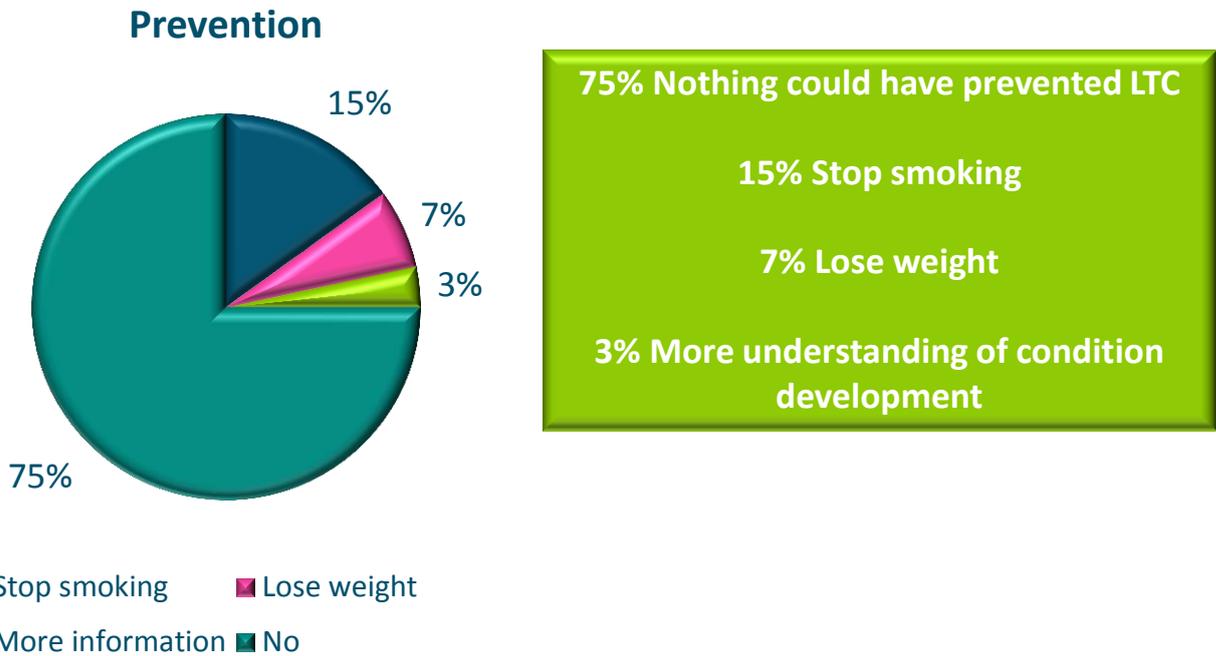
**Was the referral easy?**



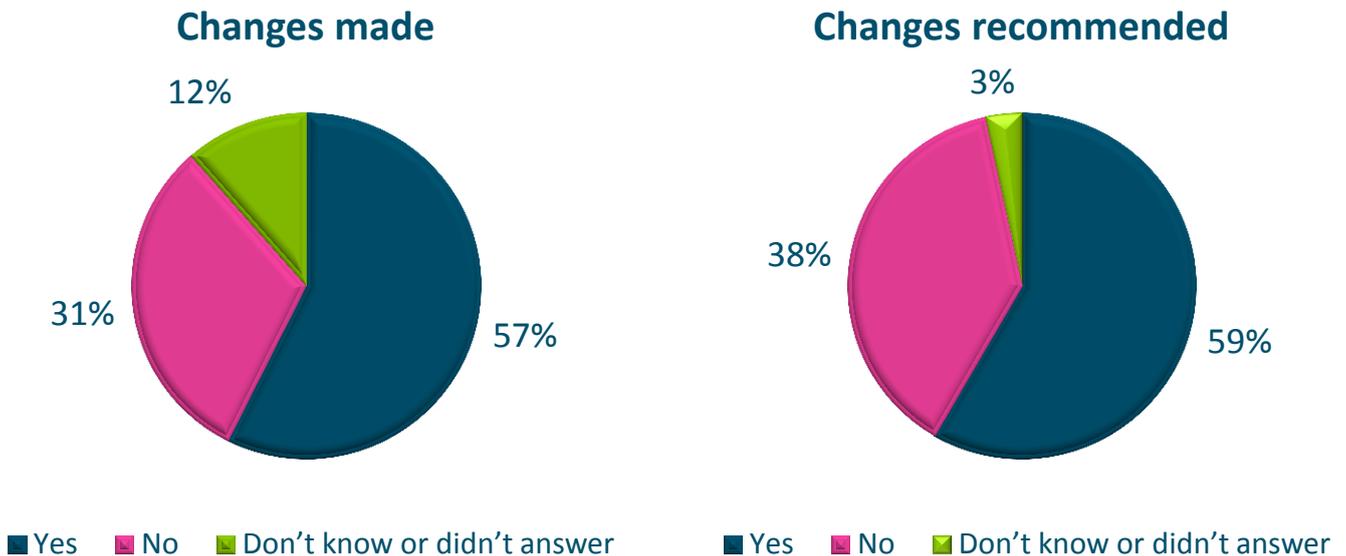
Examples of services people were referred to were: COPD groups, Vitality and the home nursing team.

# Prevention and Lifestyle Changes

Most people surveyed reported that they did not feel the development of their LTC could have been prevented. The only behaviours that could have been modified was around smoking and being overweight. These preventions related to COPD and Diabetes respectively. Two responders (3%) who felt they did not know how the LTC developed, both suffered from Diabetes.



Following diagnosis a similar question was asked around whether they were advised to make some changes. They were also asked whether they had made these changes. The findings were very similar.



## Information about LTC

Information about a persons LTC and the medication can come from various sources and the ability to understand or research the condition can support a persons ability to self-care.

Of the responders, 38 (62%) were advised about how their medication works and the possible side effects and 18 (30%) reported that they were not.

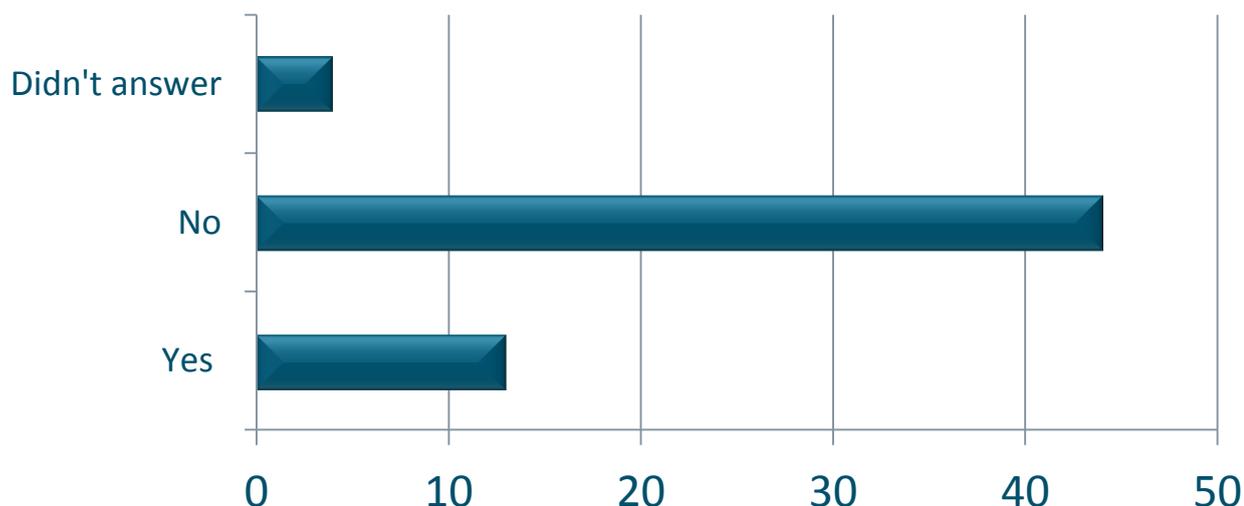
However, when questioned whether they feel they are taking their medication properly, most (91%) said they did.

Research using online resources are a way that people can understand their LTC but a higher proportion (59%) did not use this resource whereas 23 people (38%) did.

A small number of responders used friends, family and the library to research online.

The reason for not using online research may be due to the age of the responders and possible lack of skills or equipment to do this. As most of the responders were over 60 (71%) this is not unexpected. There is a similar picture when asked if people used technology to enable self-care or improve health.

### Use technology to self-care or improve health

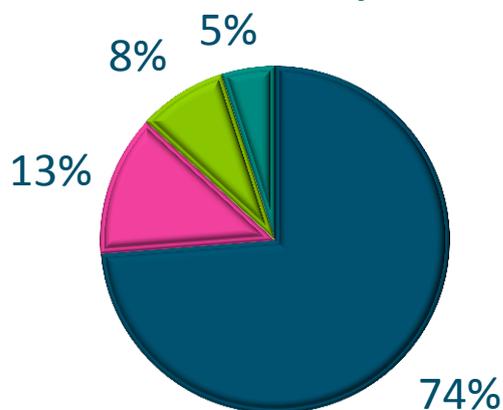


There is a wealth of information and advice through NHS sites and specific LTC sites including contact details for support groups in the area. From the survey, this resource appears underused at present.

## Self-care

Feeling in control of a LTC can help to maintain wellbeing and confidence in managing or increasing the ability to self-care. A large proportion of people do feel in control of their condition (74%).

### Do you feel in control of your condition?

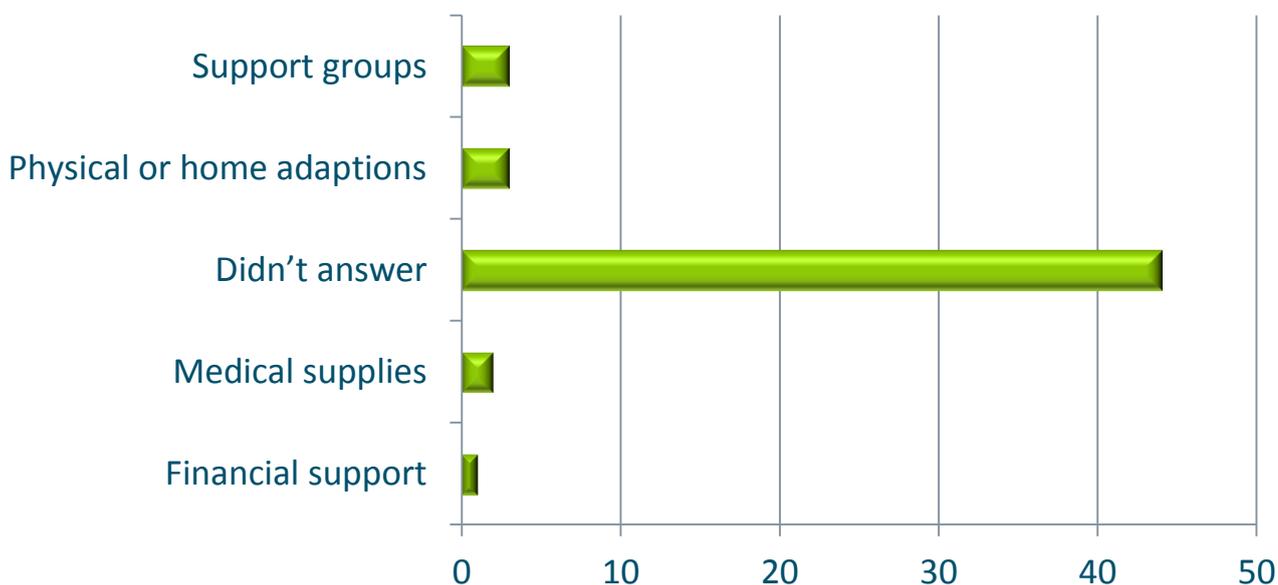


Over half of people (53%) said that services have really helped them to self-care and manage more confidently.

The highest response was around GP or Hospital teams helping to self-care, followed by LTC groups and then community support like Local Area Coordinators.

### What may be, if anything hindering your ability to self-manage your condition at home?

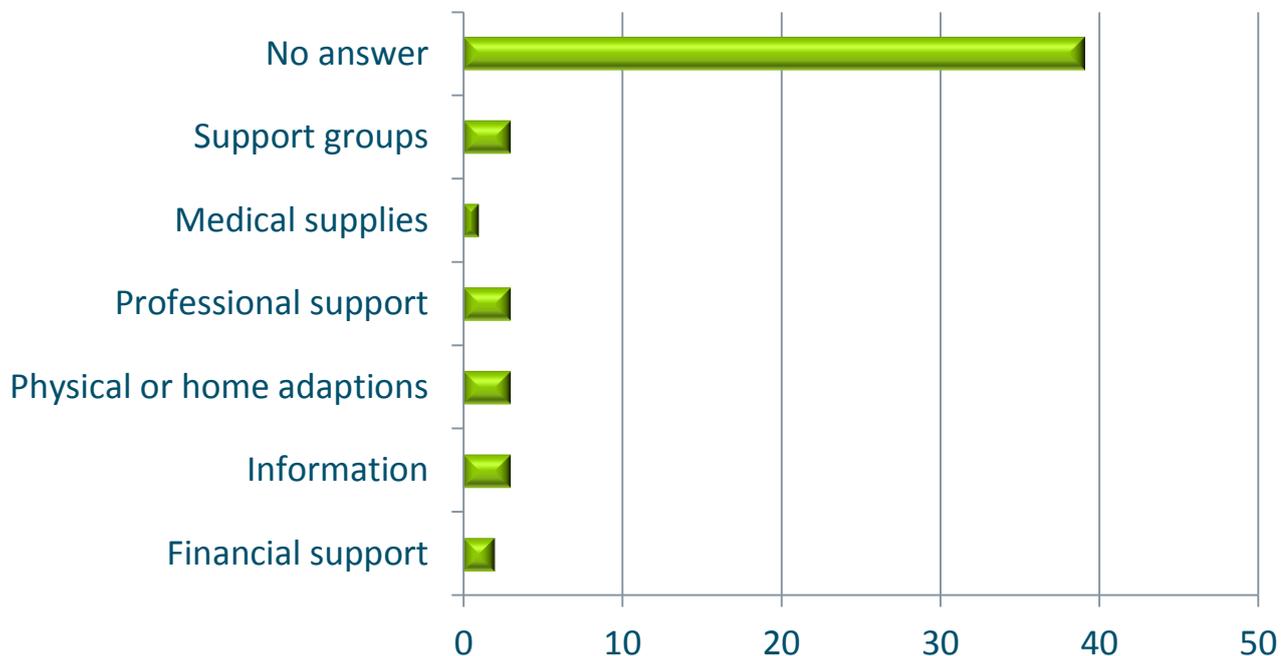
This was another free text answer which was themed:



## Self-care

### What do you feel would help you to self-care?

The survey asked what people felt could help to support them to self-care.



*“kitchen oven is too low down”*

*“a bath”*

*“easy access to GP”*

*“access to steroid injection at Basildon hospital”*

*“Eye sight issue, diagnosed partially sighted”*

*“find support groups. Useful to share with others and not feel so alone”*

*“someone at the end of the phone”*

*“I would like access to more information and treatment advice. I would like my condition reviewed to track its progression. It is becoming disabling”*

*“toe nail cutting service, I have to pay”*

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## Other points of support

Nearly half the people surveyed had joined a local support group although slightly more had not.

The groups they had joined ranged from specific LTC groups to more community based around weight loss and exercise.

Pharmacy support is a feature and useful resource, however, only just under a third (31%) said they had gone to a local pharmacy for support. The survey revealed that over double the amount (65%) had not chosen to contact their pharmacy for support.

Self-care for patients with LTC is a prominent part of the NHS Long Term Plan including Patient activation and the PAMS assessment.

Key to self care in LTC is also information and digital resources. This increases knowledge and confidence in people to manage their own care. The survey showed a need to develop digital skills and communication around wider support, particularly in the community by way of support groups. There could also be a potential need for more self management education around specific conditions following a diagnosis along with additional preventative knowledge among the general public.

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## References

- (1) [Self-Management for Long Term Conditions, Sara Corben and Rebecca Rosen](#) [accessed 20/10/19]
- (2) [Long Term Conditions Compendium of Information: Third Edition](#) [accessed 20/10/19]
- (3) [Annual Report of The Director of Public Health 2016](#) [accessed 20/10/19]