healthwatch

Age well - Heart Failure Rehabilitation Services Report

July 2022

healthwatch Herefordshire

Contents

Summary, recommendations, appreciations.

Summary

Healthwatch Herefordshire carried out this project in partnership with Wye Valley Trust to gather the views and experiences of Herefordshire people that have experienced Heart Failure rehabilitation.

We aimed to look at ongoing self-management and engagements in Heart Failure care.

Thank you to the participants in the survey and to Wye Valley Trust for enabling this insight.

Demographics

Eight people shared their experience of living with heart failure and Wye valley trust rehabilitation services.

Responses were from age categories 25 -49 to 80-84. They were mainly male most with at least one other long term condition. People lived in postcodes distributed across Herefordshire.

Sentiments

The majority of sentiments were positive but there were negative sentiments and comments too.

Positive sentiments included 'excellent and professional and friendly service' neutral sentiments expressed mixed views. Negative sentiments cited administration difficulties, access difficulties (meshing with bus services), and delays due to the need for GP re-referral.

Most useful aspects

Aspects that people found most useful included 'everything', 'exercise', 'location', 'staff', 'discipline taught', 'information', 'practical help and support', 'communication' and 'meeting others'.

What people would add to the programme

What people would add to the programme included ‘follow up advice’, ‘practical support with change in lifestyle’, ‘more information’, ‘communication’ and ‘access’ and ‘nothing to add’.

Other support that people had

Other support that people had included ‘self’, ‘family’, organisations such as Halo, ‘books’, ‘other medical’ and some people have ‘no other support’.

Aspects people were comfortable managing

People were comfortable managing many aspects of their condition including ‘most things’ ‘medication’, ‘exercise’, ‘appointments’, ‘blood tests’, ‘blood pressure’, ‘motivation’, and ‘most things with family support’.

Aspects patients struggle with

A few people said they struggled with nothing. Aspects patients struggle with were ‘to not overdo myself climbing stairs and walking distances’, ‘the mental toll it takes’ and ‘how low exercise tolerance affect well-being and causes weight gain’.

Views on virtual care

Views on virtual care revealed that there was a marked preference for face to face especially for those with no computer knowledge though some felt it was good without reservation.

How important is social support?

People were split roughly 50:50 about the importance of social support some people were emphatically against it, and one commented there wasn't really any other choice. (Because only group sessions were available).

How people keep up their self-help activities and motivation.

People kept up their self-help activities and motivation by family support, GP surgery, Hereford hospital rehab team, Halo leisure centre, physiotherapists, and exercises, ‘self-motivation’ and ‘wanting to stay alive’ and hobbies and interests.

Long term changes in treatment or rehab that helped

Only two people had a heart condition for a longer time. One felt there had been no improvement at all and that they have to do everything themselves.

The other felt it's all about the mind and acceptance of the condition and that knowing the support of the nurses is available, is a big help.

Ideas questions and concerns regarding future needs as conditions progress

A few patients had no concerns. Concerns expressed included delays, knowing where to go for advice, communication between the hospital and their surgery, attitudes of staff and the effect on their mental health. Others wished to continue with treatment and try to live a normal stress free life.

Conclusion

With such a small sample it is difficult to generalise except to say that people's comments indicated that heart failure is a difficult condition to come to terms with physically and mentally and different people react to it in a different way. Their opinions may vary with severity and level of lifestyle change necessitated.

From the comments of eight people rehab has worked well for most and not so well for others. People have made suggestions for areas that could be improved.

It is good to see a willingness to receive feedback about the service and it would be ideal to find an ongoing way to have conversations with people that have experienced heart failure and receive WVT services beyond the scope of this project.

Recommendations

Continue to provide rehab service in areas that people found most useful and consider areas that may need improvements for example:

1. Consider more accessible rehabilitation session timings for those with transport issues.
2. Consider adding more practical support with change in lifestyle e.g.
    a. Greater input to link people to healthy lifestyle initiatives and providers like Halo, weight loss/ healthy eating apps or other readily available Herefordshire and online activities.
    b. Include alternatives to group support.
    c. Encourage people to participate in new and different activities to keep motivated.
3. Consider how to include help with understanding and adapting to the mental health effects of heart failure e.g.
    a. Greater input to link people to Mental wellbeing initiatives and providers like those described on Talk Community Directory, mental health services, wellbeing apps or other readily available Herefordshire and online activities.
    b. Encourage people to participate in new and different activities to keep mentally well.

4. Consider how to offer more information by e.g.
    a. Increasing opportunities to explore with people what information they need going forward.
    b. Signposting clear follow up routes and opportunities to access information and advice as they need it.
    c. Welcoming calls and enquiries that support self-help and keep people motivated to manage their condition as it progresses.
5. Consider comments about communication and coordination with GP surgeries and whether re-referrals are necessary in patients that have experienced heart failure and are known to the WVT.
6. Proceed cautiously in bringing in any virtual care as it is unsuitable for some people.
7. Consider how to create an effective permanent ongoing method of receiving feedback from patients so that.
    a. Wider views are regularly being considered.
    b. Continuous improvements can be put in place.
    c. There is recognition and confirmation of good practice and effective service.

Wye Valley Trust service comments

Thank you for facilitating this project and providing us with feedback. We welcome these insights and hope to action some of the points raised in order to continue improving the Heart Failure Service based at Hereford County Hospital.

We have considered the recommendations outlined and are pleased to report that some are already being actioned. Those that are not will help shape future development work.

In terms of more accessible rehabilitation, we now offer a comprehensive home rehabilitation programme for patients who find it difficult to travel in to classes or who would prefer not to attend a group environment. We agree that sometimes the education sessions provided in rehabilitation may not provide enough information for some, in terms of lifestyle management. We are looking at other appropriate services we can sign post people to for further support. Ongoing exercise supervision beyond our service is available through Halo Leisure Service, however, this does incur a cost and requires introductory information from us.

Mental health support had been identified as limited in our care provision, and we are assessing how we can improve this element of the service. We currently sign post to Herefordshire Healthy Minds if we identify that someone requires more specific mental health support than we can provide.

In terms of ongoing support for patients on completion of rehabilitation, we have extended our contact window for those under our care and added a formal follow up appointment at six months. After discharge patients are now advised that they can still contact us should they have any questions or concerns.

We appreciate that communication between ourselves and the GP can be delayed and frustrating for patients. Ongoing improvements to speed up typing and delivery of patient letters is currently being undertaken by our service. There is also a bigger project being undertaken within Herefordshire to link standalone electronic patient records in to one shared care record. The aim of this project is to improve access to 'live' patient records across the whole of healthcare in Herefordshire. This means GPs will eventually have access to anything we upload about care immediately.

At present our service does not have any immediate plans to change to virtual care, accepting that it is not a suitable or preferred option for everyone. However, longer term Wye Valley NHS Trust are looking at setting up virtual clinics and wards, in line with the national trend.

In regard to ongoing evaluation of the service we currently post out evaluation forms to patients with their last appointment details. Unfortunately, we don’t get many responses so we are discussing other ways we can capture this data. We welcome the offer made by Healthwatch to support us to capture this information. We are also considering setting up patient feedback forums, where ideas, concerns etc. can be shared, actioned, and reviewed regularly.

Introduction, method, and demographics

Introduction

Healthwatch Herefordshire carried out this project in partnership with Wye Valley Trust to gather the views and experiences of Herefordshire people that have experienced Heart Failure.

We aimed to look at ongoing self-management and engagements in Heart Failure care.

We were keen to hear heart failure patient views, experiences, and ideas to establish what areas are working well and understand where improvements can be made.

Thank you to the participants in the survey and to Wye Valley Trust for enabling this insight.

Method

8 people that had experienced heart failure and rehabilitation services with Wye Valley Trust shared their experiences through a survey.

Demographics

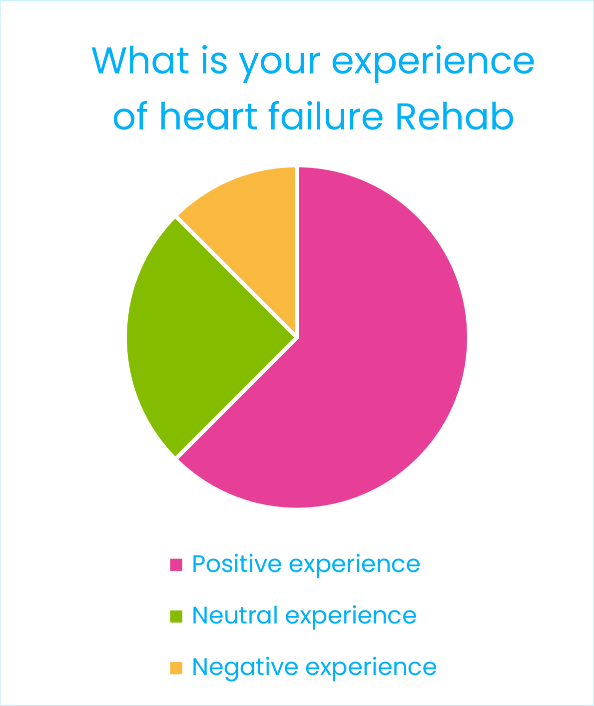
Participants were:

- A broad mix of ages from categories 25-49 to 80-84 years.
- 6 male, 1 female and 1 prefer not to say
- 7 White British, 1 prefer not to say.
- 3 married, 1 divorced/ dissolved civil partnership, 1 widowed, 2 prefer not to say, 1 unknown.
- The majority said they did not have a disability, but most had a long term condition.
- Many had more than one long term condition including diabetes, musculoskeletal condition, fibromyalgia, and hypertension.
- 1 person was a carer.
- Individual mean annual income in the household was calculated from household income divided by the number of people included in that income. 4 of 8 preferred not to answer. Of those that answered, 2of 4 (40%) participants have a low income as defined by the UK

Government’s current definition. Other participants had over £26,000 mean annual income.

- People lived in postcodes distributed across Herefordshire rural, market town and city.

What is your experience of Heart Failure Rehab?



Overall sentiments

5 people expressed a positive sentiment, 2 a neutral and 1 a negative one.

Comments:

Positive sentiment

- It was a great service to go to for what would be useful for you to do as exercise etc.
- Excellent. Very professional and friendly.
- The heart rehab was great.

Neutral sentiment

- Doing exercises medication help only a phone call away.

Negative sentiment

- Not flexible and patronising. I continued to work during my diagnosis, rehab and ongoing treatment. I was told to attend the sessions in order but had to miss one or two and got told that it wasn't acceptable so told to either attend them all or don't bother to continue.
- They listened but no feedback concern or empathy when I told them ‘c/o cp’ radiating to left arm, dyspnoea nor circumstances which led to my heart attack which I was most upset about.

.

What did you find most useful?

Aspects people found most useful were as follows with their comments:

Everything

- The whole experience

Exercise

- The various exercises
- You paced yourself on what you could do and not asked or pushed to do more.

Location

- Not far to travel

Staff

- All the team were very helpful.
- Helpful staff willing to help.

Discipline taught

- The discipline it imposes in monitoring weight, blood pressure, pulse, oxygen et cetera.

Information

- …and information - particularly what to watch out for and diet etc.

Practical help and support

- Practical changes to lifestyle and beneficial support, for example a gym routine and payment for joining a gym.

Communication

- Having communication by phone.
- Local GP liaising with hospital.
- I could contact them when I was worried about my condition.
- Being able to ring cardiac nurses anytime about worries.

Meeting others

- Meeting others with similar conditions

What would you add to the programme? What support do you have?

What would you add to the programme?

People suggested the following areas.

Follow up advice

- There is a need for additional advice afterwards.

Practical support with change in lifestyle

- Practical changes to lifestyle and beneficial support, for example a gym routine and payment for joining a gym.

More information

- Much more information from the onset of the diagnosis. Relying on the internet is no substitute for reliable and factual information from professionals.
- It would be really helpful to have fact sheets available - Cardiomyopathy in my care.

Communication and access

- Offer of alternate times for the class if its difficult to attend at 09-00 hrs due to transport.
- Communication between cardiac team and GP to better coordinate and manage medication to reach a stable level.

Nothing to add

- Nothing to add.
- Nothing all good.

What other support do you have?

People described the support they had.

Self

- I live way out in the countryside and do what my muscles / body will allow me to do before I end up in pain. I learnt from the programme to pace myself and remembering I am not as young and have to do less.

Family

- Family help was what really helped.
- Husband. Daughter and their husband.
- My wife is a great support.
- Only family help.
- My wife.
- Plenty of family help.

Organisations

- Halo.

Books

- Read books about my condition.

Other medical

- I have had to have cardiologist from Australia to put me on the right path .at the moment I need more advice who knows where I am going to get that?

Nothing

- There is nothing that has been pointed out.

What aspects of managing your condition are you comfortable doing yourself and what do you struggle with?

Comfortable doing yourself

People cited these aspects:

Aspects you struggle with

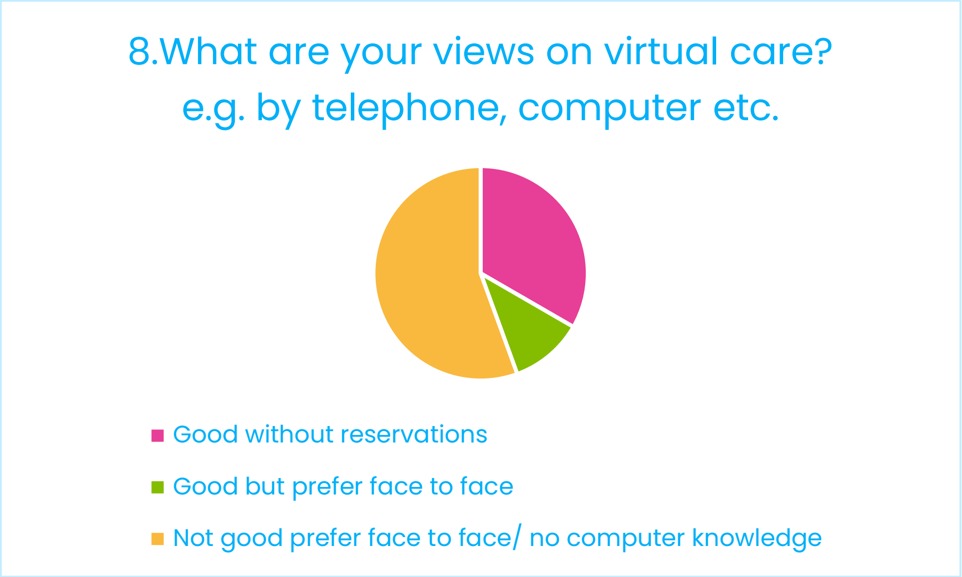
Three people said they struggled with nothing.

Four people said the aspects they struggle with are ‘to not overdo myself’, ‘climbing stairs and walking distances’, ‘the mental toll it takes’ and ‘how low exercise tolerance affect well-being and causes weight gain’.

What are your views on virtual care? E.g., by telephone, computer etc.

Responses overall

There was a marked preference for face to face.



Comments - Good without reservations

"Telephone consultations were good and thorough - cardiac nurse was realistic in lifestyle management and support mechanism. Also, very (good) *support* (to counter) *the poor and on many occasions contradictory advice provided by doctor's surgery heart nurse".*

"Phone calls are very reassuring".

"Good and helpful".

Comments – Good but prefer face to face

"Ok if its just for a review/ check on progress etc. But nothing really replaces face to face..."

Not good - Prefer face to face

"This is rubbish because you cannot judge how the other person feels about your condition"

"I prefer face to face as I have no computer skills".

"Not as good as 'face to face'. It is too easy to miss out what might be important information".

How important is social support to you?

Comments

People were split roughly 50:50 but some people were emphatically against it and one commented there wasn't really any other choice.

Good

"They are good, if that is what you like".

"I enjoyed rehab".

"Good as need support".

"It's a rather lonely existence/ experience. People don't really want to talk much about it - or are embarrassed to ask.

Not wanted/ Not good

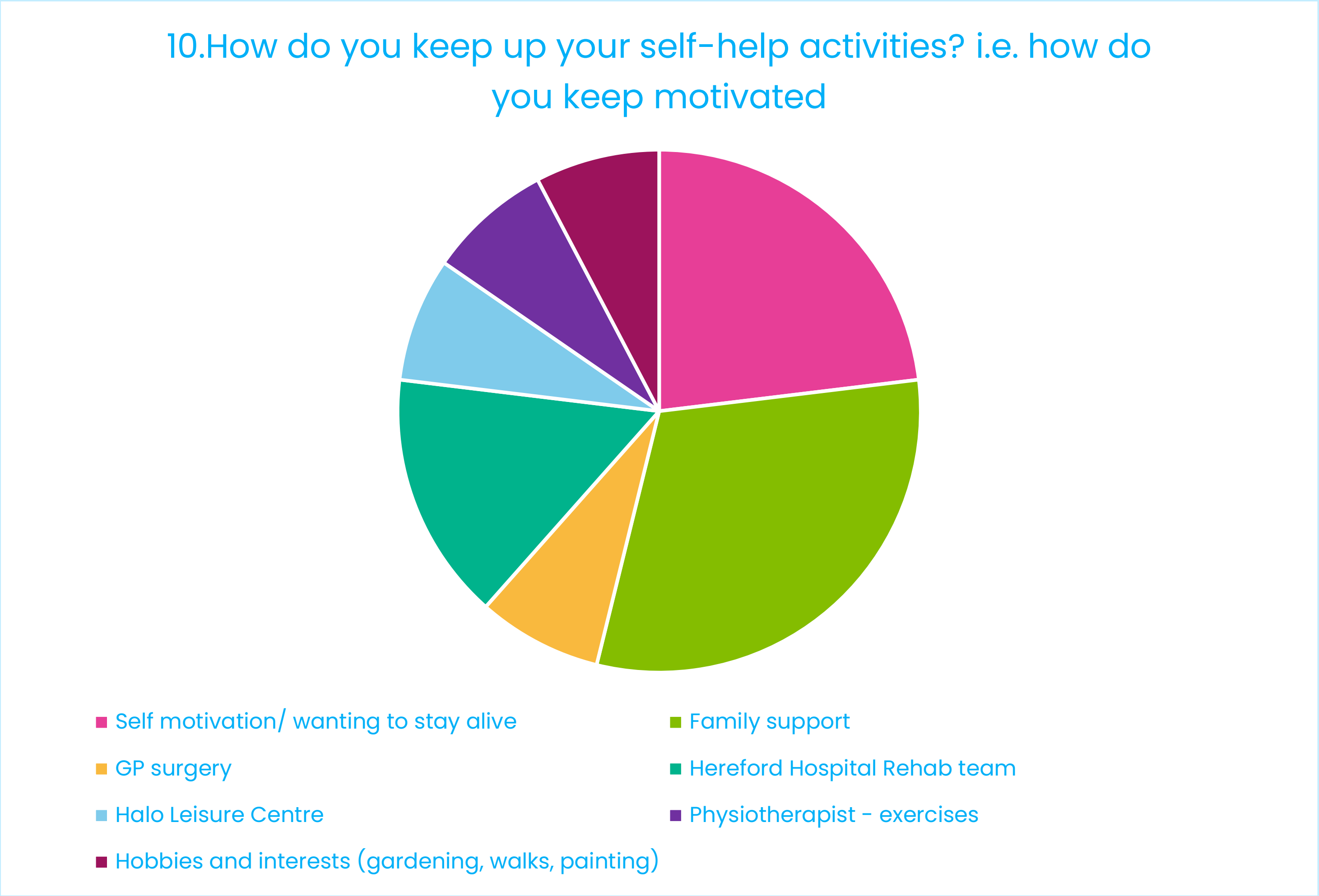
"Group support is not for everyone, but this is all that is on offer".

"I do not have and do not want social support in the form of group therapy".

"Not important for me".

How do you keep up your self-help activities and motivation?

Responses summarised



Comments

"As much as possible - wanting to stay alive".

"Wife support".

"Self-motivation and family support".

"Family member support but knowing I can contact the heart rehab team if have concerns / questions. I have had a very bad experience with my doctor's surgery and now have no confidence or desire to use them".

"I do this through self-motivation and have no help from anyone".

"Local GP and surgery. Hereford hospital rehab team/ cardiologist. Husband. Daughter and their husband. Halo leisure centre. Physiotherapist for exercises".

"5 years ago, I lost my wife to a xxxxxxx so I had to keep busy and with only x neighbours. Covid did not help with the shutdown. The garden kept me busy and taking XXXXX for walks. I also went back to drawing and painting of wildlife".

"I have lots of hobbies".

If you have been managing your condition a long time

- What changes have improved your experience and being able to live well with heart failure and what have not?

Only two people had a heart condition for a longer time, and these were their comments:

"There has been no improvement at all I do it all myself".

"It's all about the mind and acceptance of the condition - knowing the support of the nurses is available is a big help".

Ideas, questions, and concerns

Concerns regarding future needs as your condition progresses or as you grow older. Anything else to share?

A few patients had no concerns. People shared their concerns including about delays, knowing where to go for advice, communication between the hospital and their surgery, attitudes of staff and the effect on their mental health. Others wished to continue with treatment and try to live a normal stress free life.

"I was diagnosed in January when an outline programme was set out, but it was not adhered to by the NHS. All sorts of delays led to my increased anxiety".

"Yes, I need. To know where to go for advice ".

"I know my life expectancy is less. My biggest issue has been the doctor's surgery cardiac nurse and her effect on my mental health. I have come out of seeing them feeling low on numerous occasions.".

"I haven't dared ask exactly how it progresses. But each individual is different, and the answer may only be available with longitudinal evidence i.e., next ECHO".

"I am increasingly concerned about the lack of connectivity between the hospital and GP practise. There does not seem to be any dialogue. I was diagnosed in XXX when an outline programme was set out, but it was not adhered ".

"Been doing well for seven months and want to continue to (get) *better".*

"Hopefully live a normal life and not too much stress".

“Be bloody minded the NHS is of O help“.

“It was a shock as got diagnosed at xx (young age) and for some time not knowing what caused it / still not knowing 100% why but having to be on numerous tablets for the rest of my life and lifestyle changes have been a must”.

“Diagnosis was slow during covid. How can you diagnose a heart issue over the phone?! But, once diagnosed things moved fairly quickly but I had to push. But once in hospital/ heart rehab/ cardiology department system, everything like clockwork. Once diagnosis of cardiomyopathy given, there was an 8 month wait for an echocardiogram (covid backlog probably). I was lucky enough to pay privately and hear within 3/4 weeks. I cannot imagine how I, or anyone for that matter, could possibly be expected to wait that long with what turned out to be the severity of my condition. Although I was found to be asymptomatic it is not the case as I have been complaining of breathing difficulties wheezing and light headedness for over a year - and then finally swollen ankles and legs”.

“Keep positive. Seek medical help early”.

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Conclusion and next steps

Conclusion

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Recommendations

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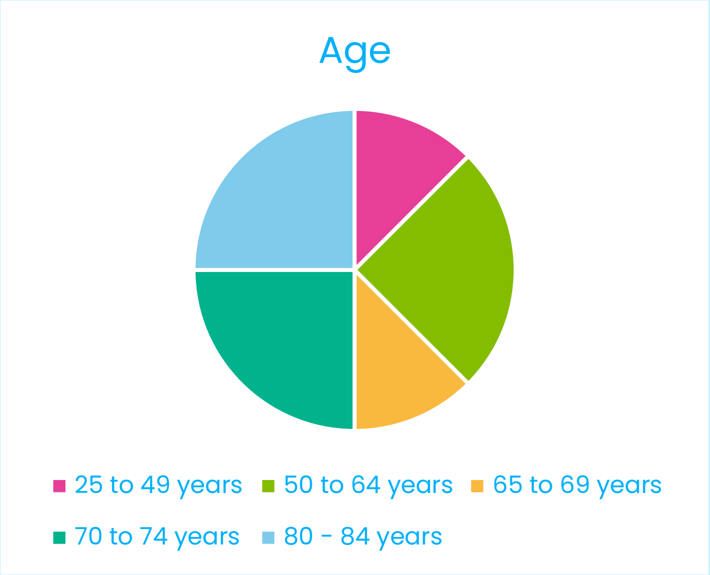
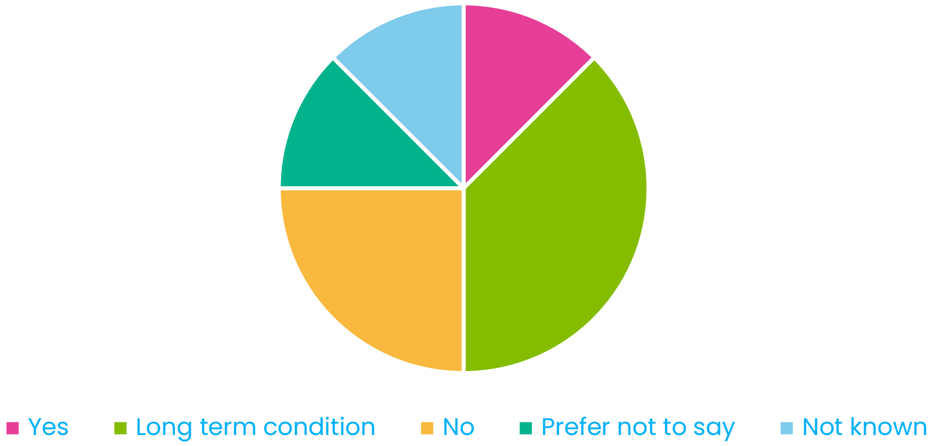
Appendices

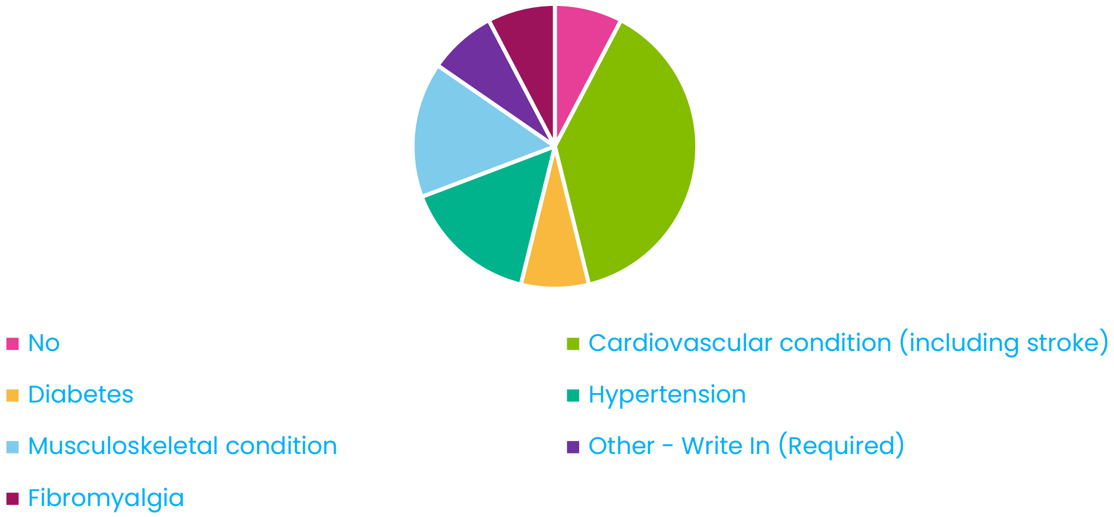
Appendix 1 Demographics



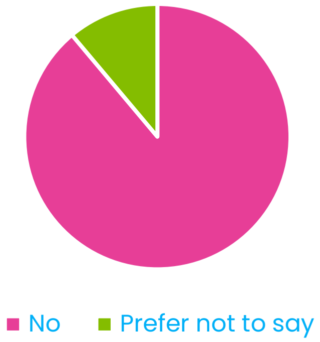
20.Do you have a disability? Select all that apply.



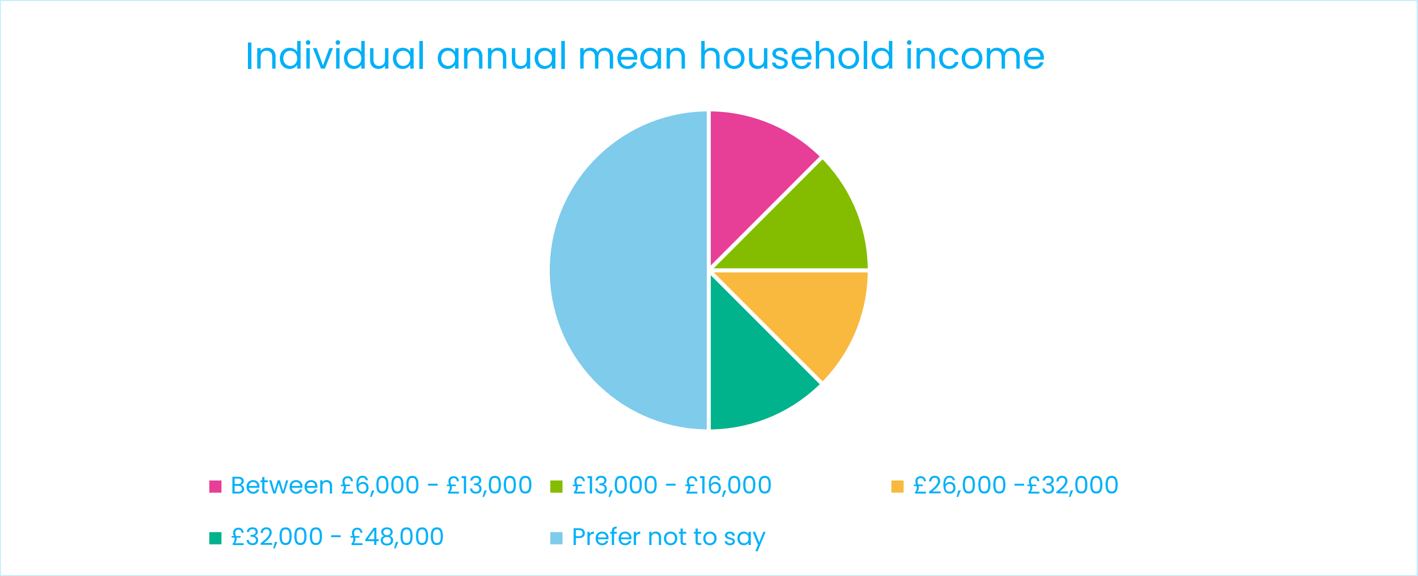
21.Do you have a long term condition? Select all that apply.



22.Are you a carer? (A carer is someone who cares for a friend or family member for 3 hours a week or more on an unpaid basis).



Individual annual mean household income



What classifies as low income UK?
a household is in low income if they live on **less than 60% of the UK's median income** (a couple with no children would be in low income with an annual household income of up to £17,100 before housing costs and £14,800 after housing costs)16 Jun 2022
https://www.ethnicity-facts-figures.service.gov.uk/work-pay-and-benefits/pay-and-income/people-in-low-income-households/latest

25. Where do you live in Herefordshire (Post code)

People lived in postcodes distributed across Herefordshire.

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