# Self-Managing Multiple Long Term Health Conditions Report

## 1. Introduction

As part of our ongoing commission as a funded health engagement organisation with the Brighton and Hove Clinical Comissioning group (CCG), Possability People's Get Involved Group (GIG) was asked to conduct engagement work with disabled people and carers focusing on a selected topic on a priority area from the recent case for Change, part of the NHS Long Term Plan.

With growing pressure on the NHS, including an ageing population, more people living with multiple long-term health conditions, and lifestyle choices affecting people's health, changes are needed to make sure everybody can receive the support they need from their local NHS. The government is investing an extra £20bn a year in the NHS to help address the inequalities that people face when accessing support for managing their health conditions. The NHS have produced a Long Term Plan, setting out its priorities and aims to help improve health services for people across the country.

This time, the spotlight was on living with multiple long-term health conditions and after consulting with disabled people from our Get Involved Group, we decided to focus on two areas of self-managing multiple long-term health conditions.

- Self-managing through diet, exercise, mindfulness, journaling and complimentary therapy.
- Self-management through a health passport which is modelled on the current hospital passport, but focusing on health over all rather than just hospital stays.

This engagement report, Self-managing multiple long-term health conditions, aims to find out what disabled people do to manage their conditions outside of the GP surgery, what they think a health passport could look like and how they think the NHS can better support them to manage their conditions.

We have asked what people do to self-manage their multiple conditions at home. Whether diet, exercise, mindfulness or something else has worked. We have also asked how their conditions affect each other and how they manage any interplay. During our GIG meeting, the discussion also got on to how a health passport could help both patients and health professionals as being one place where all information needed about patients conditions including what medications they took and how they might interact with each other in an easily accessible place, resulting in better and more effective treatment as well as how the NHS could support them more effectively.

## 2. Methodology

The engagement work on this topic ran between November and December 2019. We used a range of approaches to engage with local disabled people and carers in Brighton and Hove on the topic of self-managing multiple long-term health conditions. A total of 30 people were consulted.

### 2.1 Survey for disabled people and carers

We engaged with a total of 19 disabled people and carers through the sharing of our survey. 15 people responded to the online survey, while 4 people responded by using the paper survey. The survey link was shared with all GIG members as well as partner organisations through the GIG monthly round up. It was also posted to the Community Works forum and on social media.

### 2.2 GIG meeting on the topic of self-managing multiple long-term health conditions.

On Wednesday 13 November, the Get Involved Group held a focus group on the topic of self-managing multiple long-term health conditions. The meeting was held at Friends Meeting House, Ship Street, Brighton. A total of 12 disabled people and carers attended this meeting providing their feedback through a round table discussion, based on selected questions from the survey.

## 3. Demographics

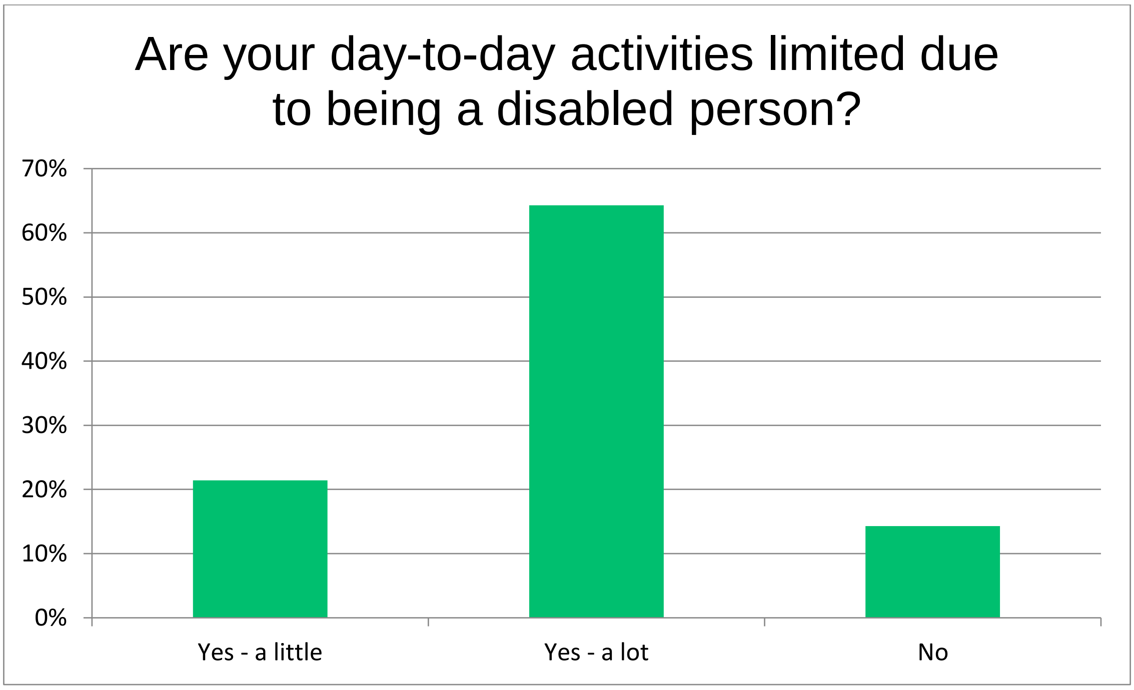
### 3.1 How old are you?

14 out of 19 respondents answered this question

| |
|---|
| 45 |
| 26 |
| 46 |
| 42 |
| 50 |
| 50 |
| 46 |
| 58 |
| 61 |
| 41 |
| 47 |
| 56 |
| 52 |
| 58 |

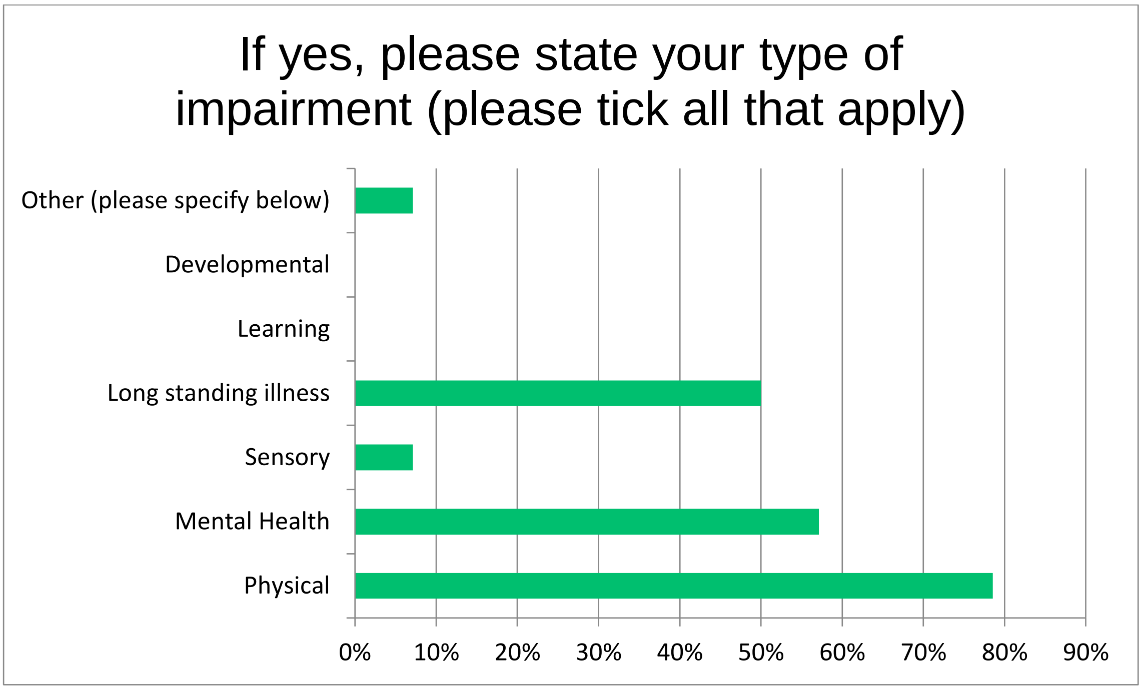
### 3.2 Are your day-to-day activities limited due to being a disabled person?

14 out of 19 respondents answered this question



### 3.3 If yes, please state your type of impairment (please tick all that apply)

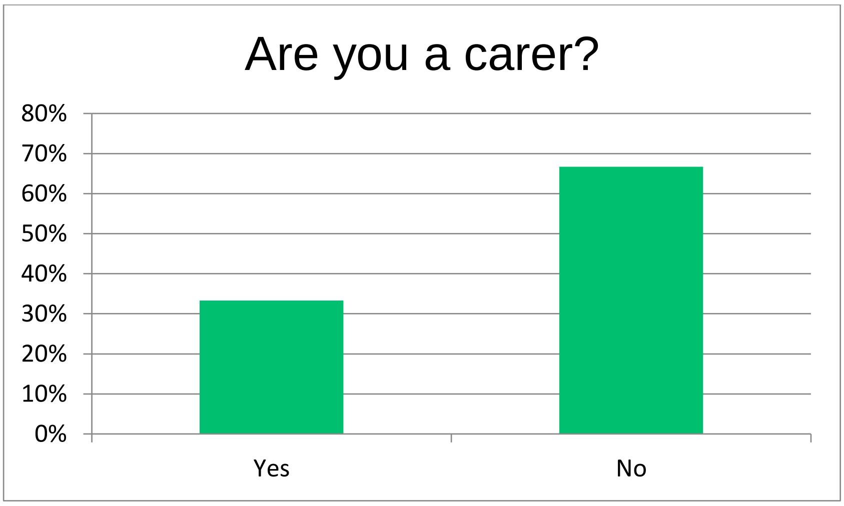
14 out of 19 respondents answered this question



| |
|---|
| Chronic pain |
| always tired, easily stressed, joint aches, emotionally low |
| Kidney failure |

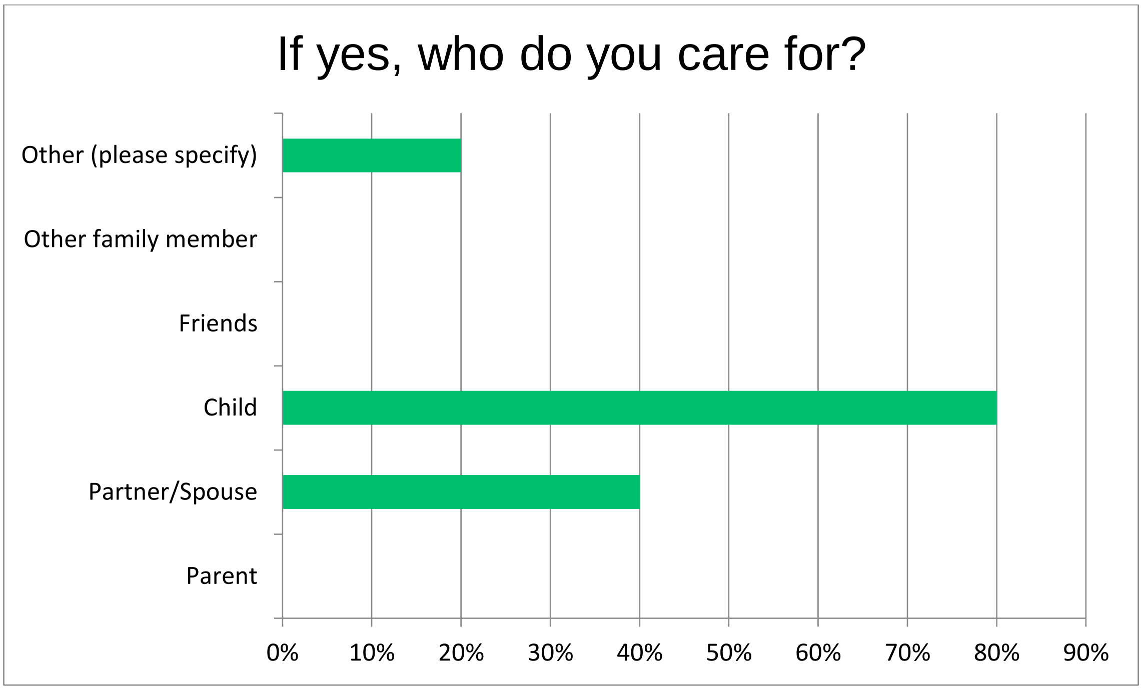
### 3.4 Are you Carer?

15 out of 19 respondents answered this question



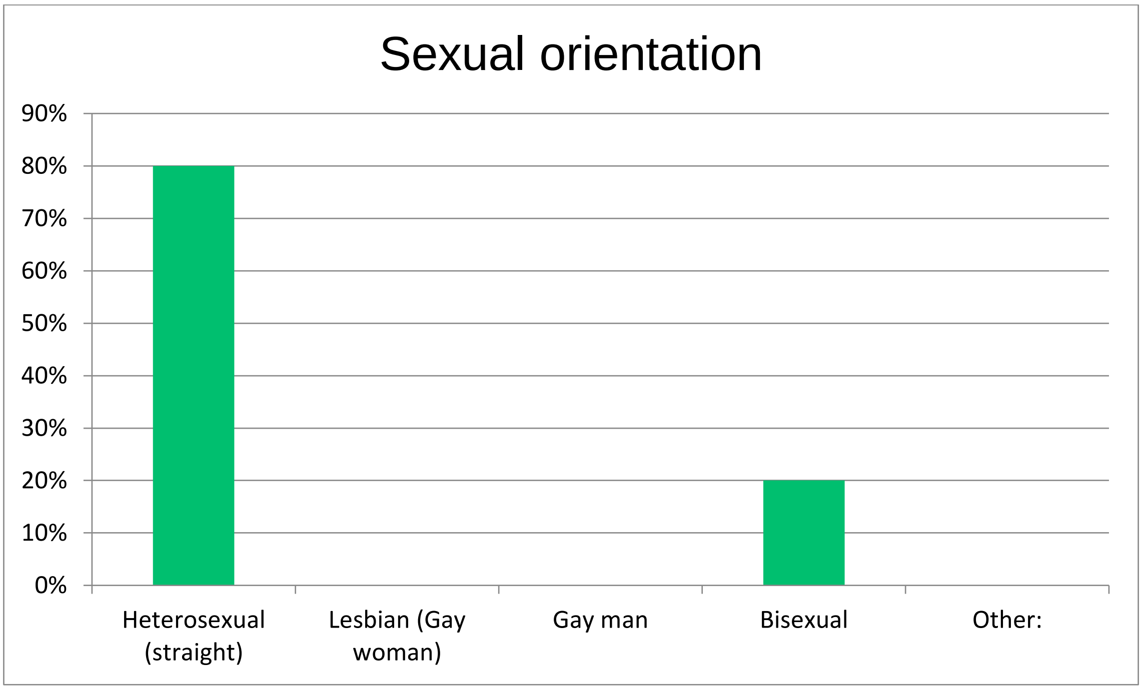
### 3.5 If yes, who do you care for?

5 out of 5 respondents who answered yes to the previous question answered this question



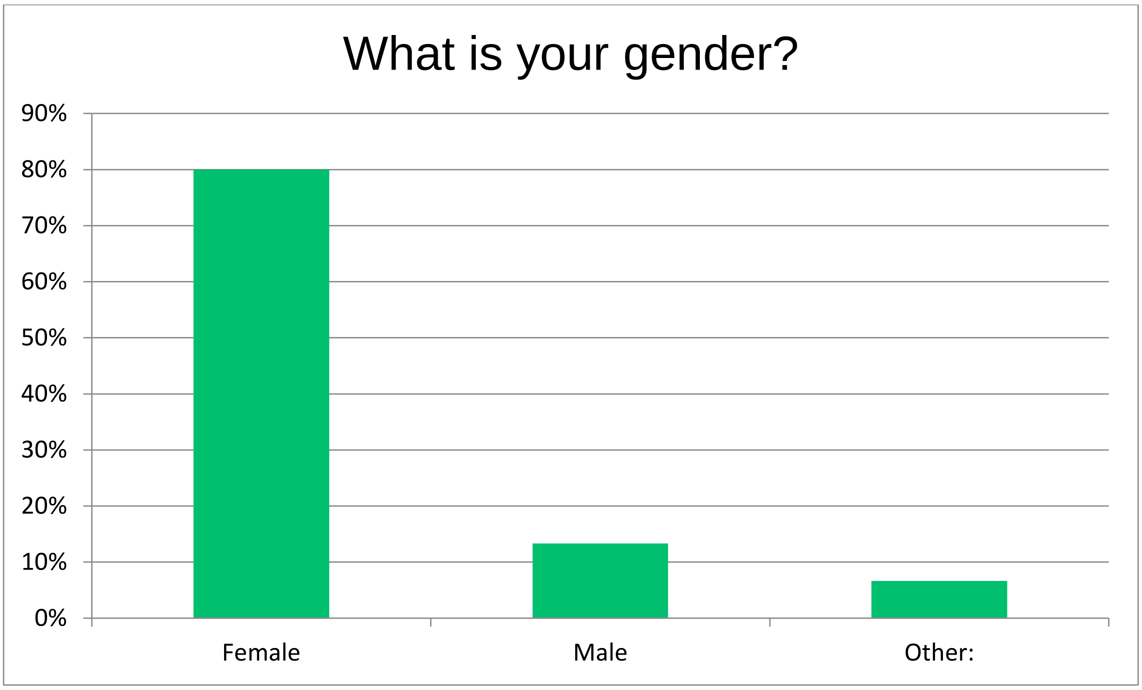
### 3.6 Sexual orientation

15 out of 19 respondents answered this question



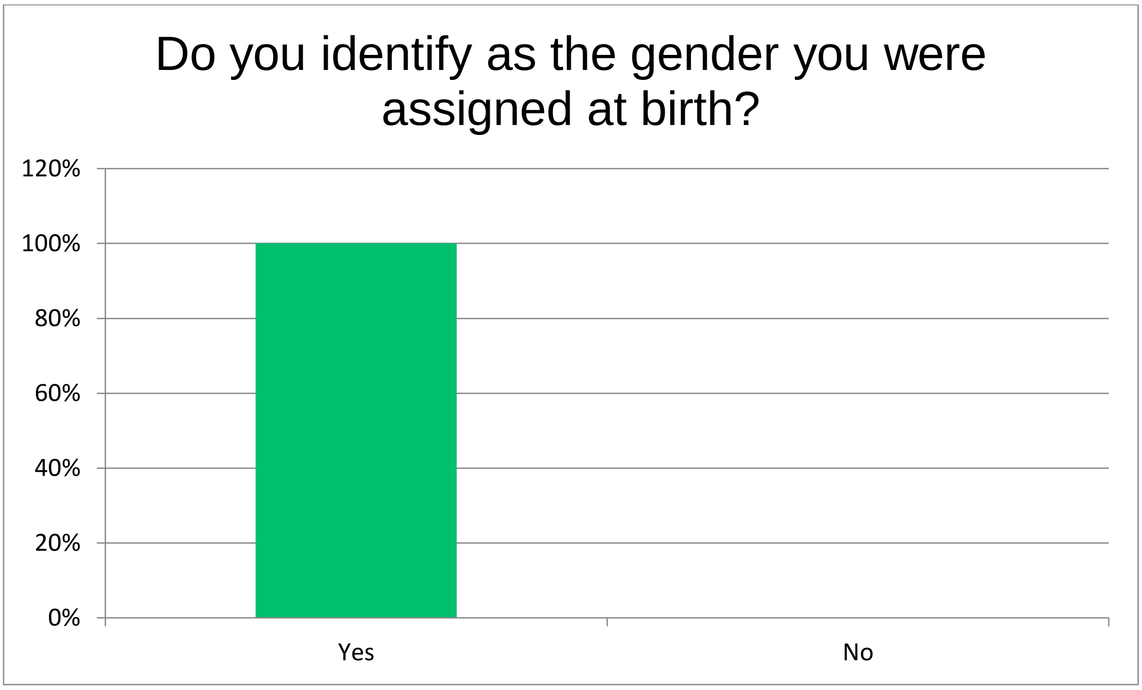
### 3.7 What is your gender?

15 out of 19 respondents answered this question



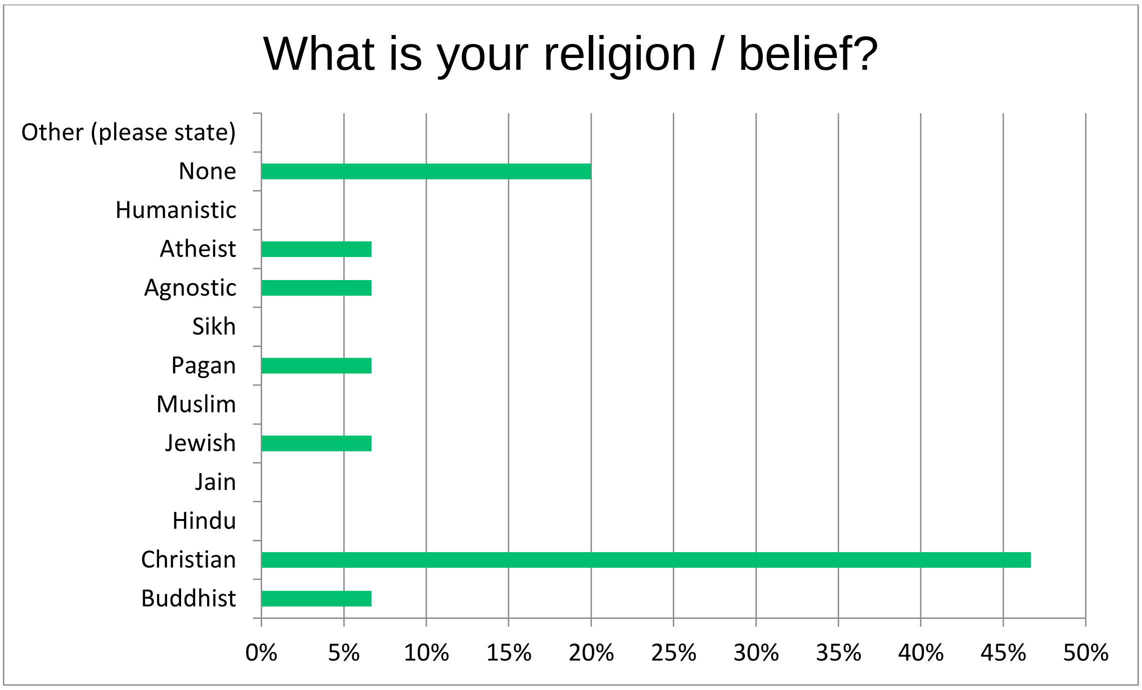
### 3.8 Do you identify as the gender you were assigned at birth?

14 out of 19 respondents answered this question



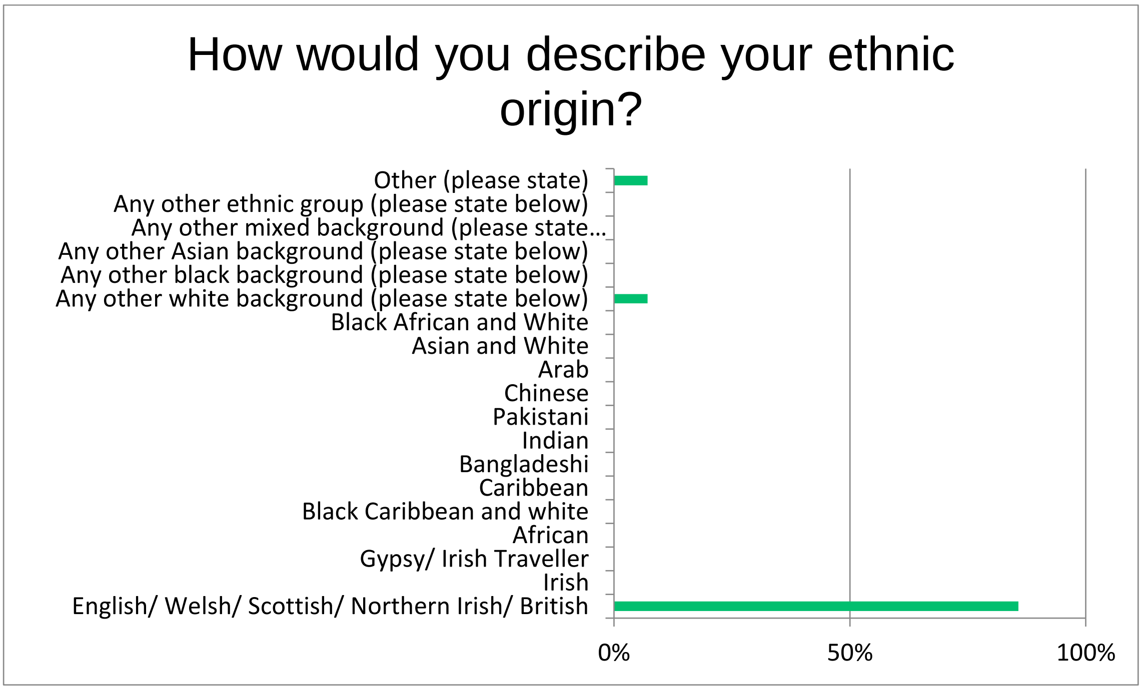
### 3.9 What is your religion / belief?

15 out of 19 respondents answered this question



### 3.10 How would you describe your ethnic origin?

14 out of 19 respondents answered this question



# 4. Survey Results

## 4.1 Who are you responding on behalf of?

19 out of 19 people responded to this question

18 out of 19 were responding for themselves (95%)
1 person was responding for their husband (5%)

## 4.2 Please list your conditions in the order you feel they affect you the most. Please state the one having the biggest impact first.

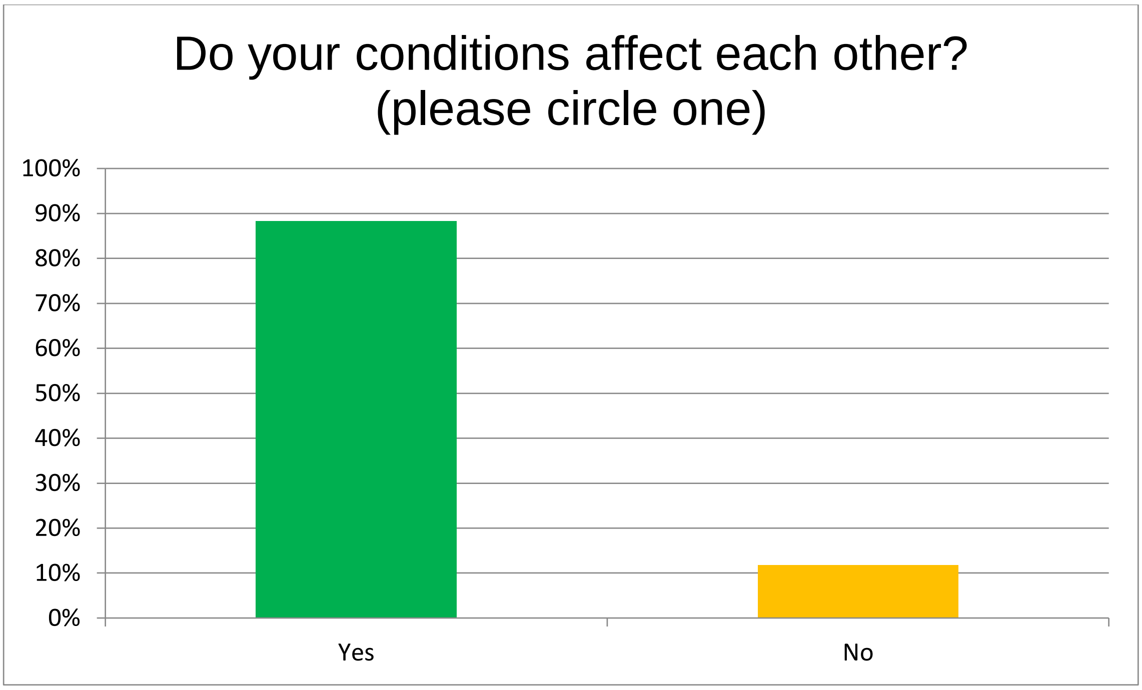
19 out of 19 people responded to this question

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Huntingdon's Disease | Depression Anxiety | Osteoarthritis | Glaucoma /cataracts | Hiatus Hernia |
| Back pain | Mobility problems | Depression / Anxiety | | |
| (ME) | Spinal problems back/neck | Arthritis | Repetitive Strain Injury (RSI) | |
| Fatigue | Migraine | Pain | | |
| CFS | Anxiety | Depression | | |
| Rheumatoid and osteoarthritis | Fibromyalgia | Osteoporosis due to early Menopause | Hyperkinetic movement disorder and spinal stenosis | Reduced heart function and Reynaud's syndrome |
| Epilepsy | Neurological gait disorder | Dizzy spells | | |
| Chronic Migraine | ME | Depression / Anxiety | Hypermobility | Insomnia |
| Autoimmune condition | Hypothyroidism | Depression / Anxiety | | |
| Primary Biliary Cholangitis | Sjorgrens | Other autoimmune condition | Other autoimmune condition | Osteoarthritis |
| Fibromyalgia | Arthritis | | | |
| Stage 5 Kidney failure | Depression | | | |
| Arthritis | Diabetes | Sciatica | | |
| Breast Cancer | Fatigue | Joint pain | Atrophy causing recurrent UTIs | |

| | | | | |
|---|---|---|---|---|
| Ehlers Danlos Syndrome | Bipolar | Postural Orthopedic Tachycardia Syndrome (POTS) | MAST Cell activation syndrome | Asthma |
| Chronic obstructive pulmonary disease COPD | | | | |
| Asthma | Depression | | | |
| Cauda Equina Syndrome | Depression | | | |
| Blindness | Depression | | | |
| | | | | |

### 4.3 Do your conditions affect each other? If yes, how do they affect each other?

17 out of 19 people responded to this question (88%)

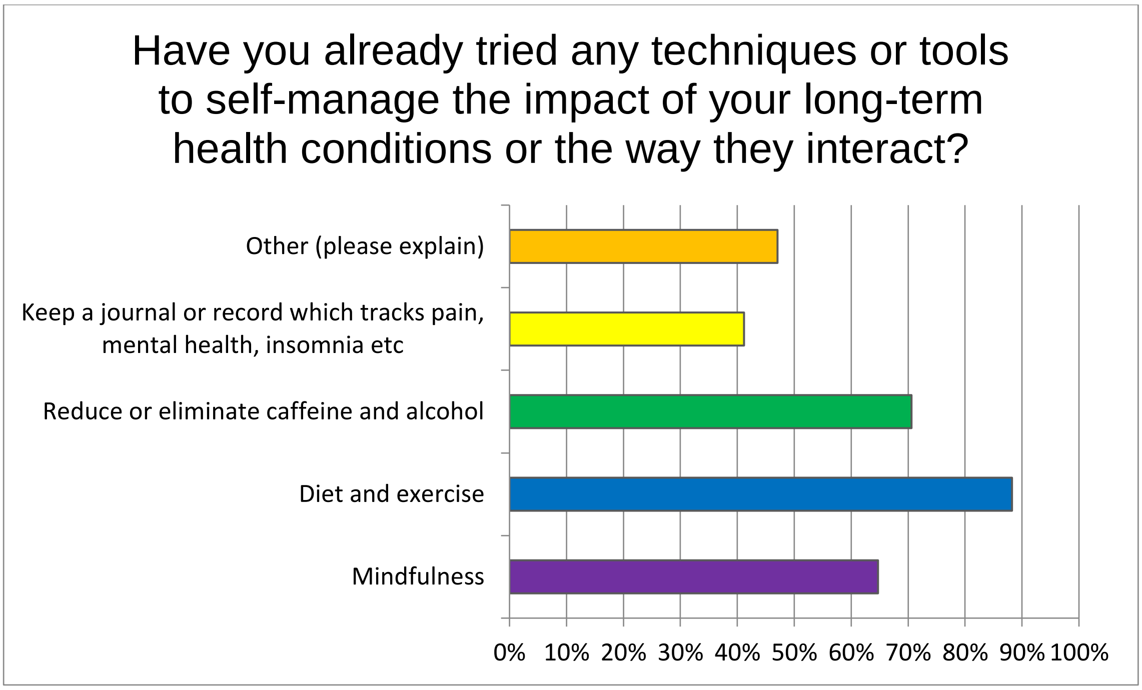


### If yes, how do they affect each other?

| |
|---|
| Going out and meeting with people, lack of motivation to do things |
| Sleep problems and pain management, also kidney stones more than I'd like |
| Need to keep active to prevent back being in pain but can't with ME. Arthritis makes my spinal problem worse. RSI is connected to having neck problems |
| Fatigue impacts my ability to positively act. Depression impacts how I can manage fatigue |
| The more fatigue I get due to my heart the more rheumatoid and fibromyalgia flares up. |
| In so many ways! I am usually on a boom and bust cycle, I have regular days of very bad pain from the migraines when I am very limited in what I can do, then I feel slightly better and need to catch up with everything so overdo it, my moods go in similar cycles too. That's just some of the ways they affect each other. |
| the effect of lethargy pain and foggy head leave me stressed as I can't always work, then I get depressed being isolated at home |
| They interlink. The pain from the fibro has a direct impact on my cervical arthritis |
| The physical health condition affects my mood. |
| Yes - 3 of my auto immune conditions give me fatigue and joint pain, I cannot take medication for Sjogrens as it affects my liver (PBC) Having PBC means most of the medication I am prescribed has to be checked that its safe for me to take for my other conditions. Also, I have to take 11 different tablets per day at 5 separate times - due to side effects of medication |
| Weight on knees for arthritis and weight re diabetes |
| EDS, POTS and MCAS are all linked and I find a flare in one cases a flare in the others. My mental health seems somewhat linked - when pain and inflammation is bad my mental well-being dips. |
| I am disabled myself, but my husband cannot walk far and is now becoming afraid to go out, I cannot carry even light shopping, I worry so much for my husband and his condition. I am stressed out, he is stressed about his condition and its effects on his body - his being unable to remember things, being unable to breathe, being unable to come up to bed, being stuck in the house constantly amongst others |
| The Cauda has impacted my mental health as I have had to accept the changes in my life. Also the pain impacts my mental health and ability to cope and then a decline in my mental health makes it harder to manage the pain and deal with the limitations, vicious circle |
| Blindness is pretty much the cause of my depression. My depression related episodes are all linked to not having the sighted help I need when I need it. |

### 4.4 Have you already tried any techniques or tools to self-manage the impact of your long-term health conditions or the way they interact? (please tick all that apply, or tell us about anything else you've tried that isn't listed)

17 out of 19 people responded to this question



**Tell us about anything else you've tried that isn't listed:**

| |
|---|
| Diary/Calendar, Art Group |
| Reducing working hours, changing working hours to later in the day, working from home, removing unhealthy family relationships, exercise, building healthy relationships, reducing 'screen time' |
| Relaxation techniques for pain |
| Functional and holistic medicine, (acupuncture, osteopathy, nutrition, talking therapies etc) |
| I try lots of things, and added complementary therapies when I feel capable, but can't always afford to do things locally due to the costs. |
| massage and reflexology and resting frequently |
| Well-being exercises, self affirmation mantras, pain control exercises |

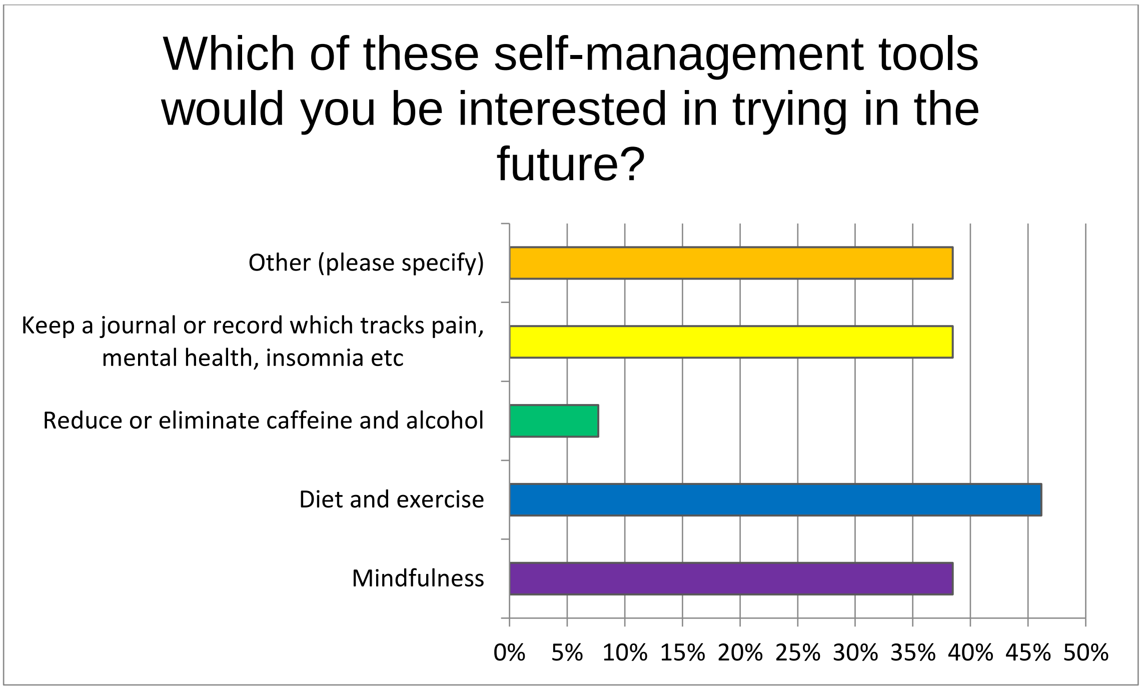
### 4.5 If you have tried any of the above, what effect did they have on you?

15 out of 19 people responded to this question

| |
|---|
| Mindfulness does not always work when I'm in a bad place mentally. |
| I have been extremely hypersensitive to caffeine and alcohol, can only tolerate little amounts. I eat a very good vegan diet so helps keep my weight down. I have sleep disturbance (part of ME) only sleeping tablets work, can't get them at surgery so I have to buy them!<br>I've tried mindfulness and hypnotherapy to try and help me sleep and loads of other things but none of it worked.<br>I do some very low level physio exercises to help with arthritic neck but have to be careful with that as can get spinal pain trapped nerve in neck. |
| As I have been so ill with severe ME, I have to keep my level of activity low and pace myself, a lot of it is common sense, I'd like to be loads more active which would be better for my back BUT that would make my ME a lot worse. I have been housebound with ME and my back was much worse. It's a Catch22 |
| Gave me more understanding |
| Caffeine positive - reduces short term anxiety<br>Mindfulness - reduces short term fatigue |
| Some, especially in the management of symptoms. I'm convinced I would be loads worse without them and without all the self-care practices I do and my healthy lifestyle |
| I have noticed when I have had acupuncture or reflexology, I am more relaxed, someone is listening and supportive, I don’t feel so alone and it boosts my confidence and helps me cope better. |
| They do help a little but don't help with fatigue. It’s really frustrating when I'm told that changing my diet and exercising more will help me - it often makes my conditions worse or increases my pain and makes no overall difference |
| Mindfulness helps with the pain in being able to focus on the body. It helps for my mental health in being able to cope with pain and fatigue. Diet and nutrition is essential in maintaining health. I work extremely hard on ensuring that I eat little and often throughout the day to balance energy. |
| A good diet helps with the blood tests. Poor bloods means worse health, including heart and breathing problems. |
| Couldn’t maintain or afford |
| journaling my symptoms has been really useful when dealing with health care professionals as it relies less on me having the energy to explain/re-explain everything, especially when fatigue is bad.  When I'm hypomanic or depressed alcohol can be somewhat of a problem so I try and cut it out. Swimming is the only exercise I can do without experiencing pain. |
| My husband mainly only drinks water, has smaller meals, used to try and walk the dog, his insomnia is bad. All were useless, he punches himself to try to loosen his chest expectorant, but even this is not as effective now. |
| Some effect which increases as I use the tools longer |
| Eliminating alcohol has helped a lot with mood swings as has reducing caffeine because that allows me to sleep. Exercise has increased seratonin levels and mindfulness has made me become more aware of what types of situation triggers my depression. |

### 4.6 Which of these self-management tools would you be interested in trying in the future? (please tick all that apply or tell us about anything else you've tried that isn't listed)

13 out of 19 people responded to this question (68.4%)



**Tell us about anything else you've tried that isn't listed:**

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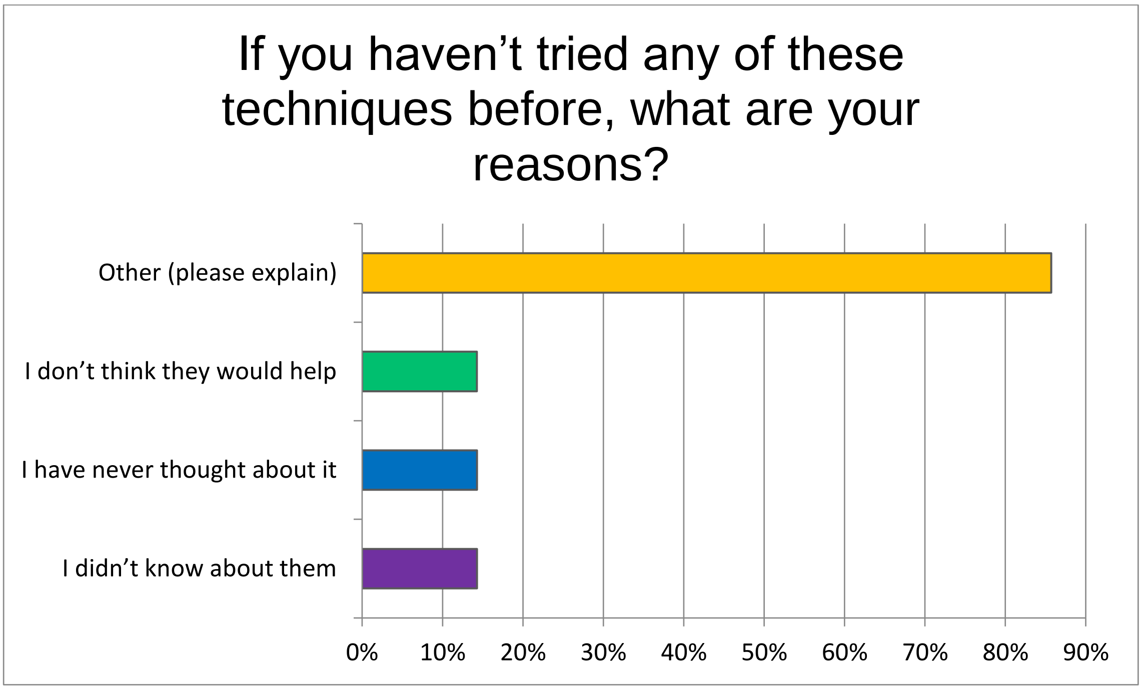
|---|
| Meeting with other people to share experiences |
| Access to low cost treatments e.g. social prescribing for acupuncture etc |
| Free gym membership |
| Warm water spas and therapies for arthritis |

### 4.7 If you haven’t tried any of these techniques before, what are your reasons? (please tick all that apply or tell us about anything else you’ve tried that isn’t listed)

7 out of 19 people responded to this question (36%)



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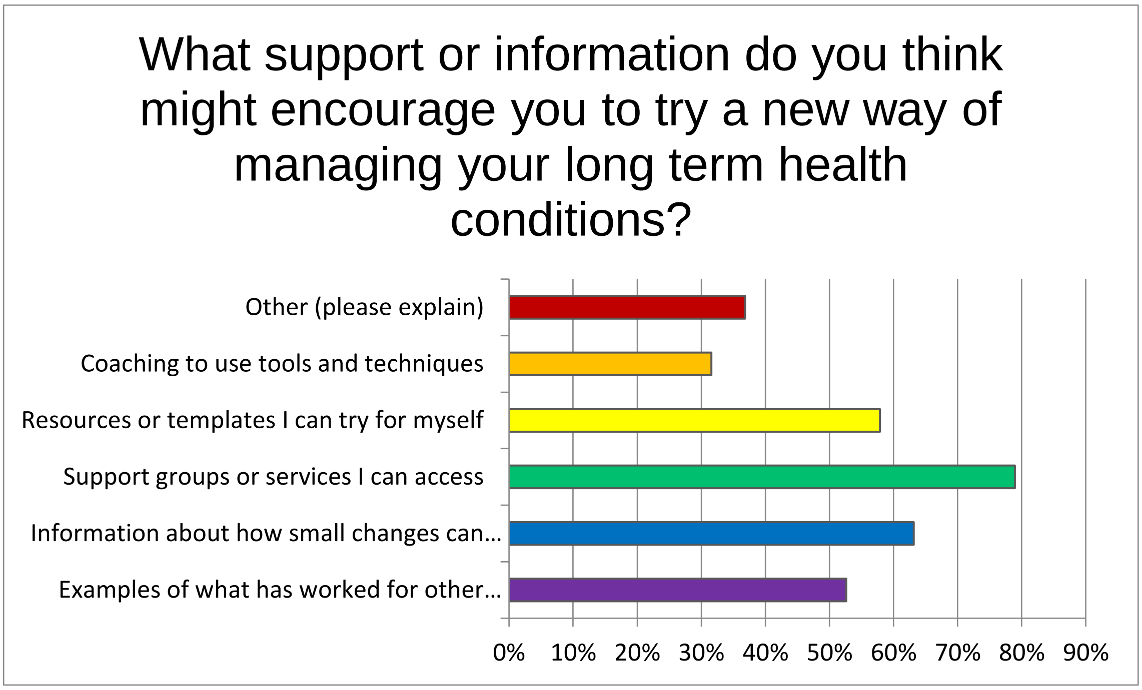
| Trying to find ways around my problems takes lots of energy both physical and mental. |
| I know the things not to do because they make my conditions worse, had back/neck spinal issues for 35yrs and ME for 20yrs so very much aware of my limitations. Like I say I'd like to do a lot more but my ME will get much worse. |
| It is hard to maintain a healthy diet with minimal time / knowledge. Keeping a journal is most likely a lot of time and energy but I'm not sure if it will help. |
| Money and pain or being too busy |

### 4.8 What support or information do you think might encourage you to try a new way of managing your long term health conditions?

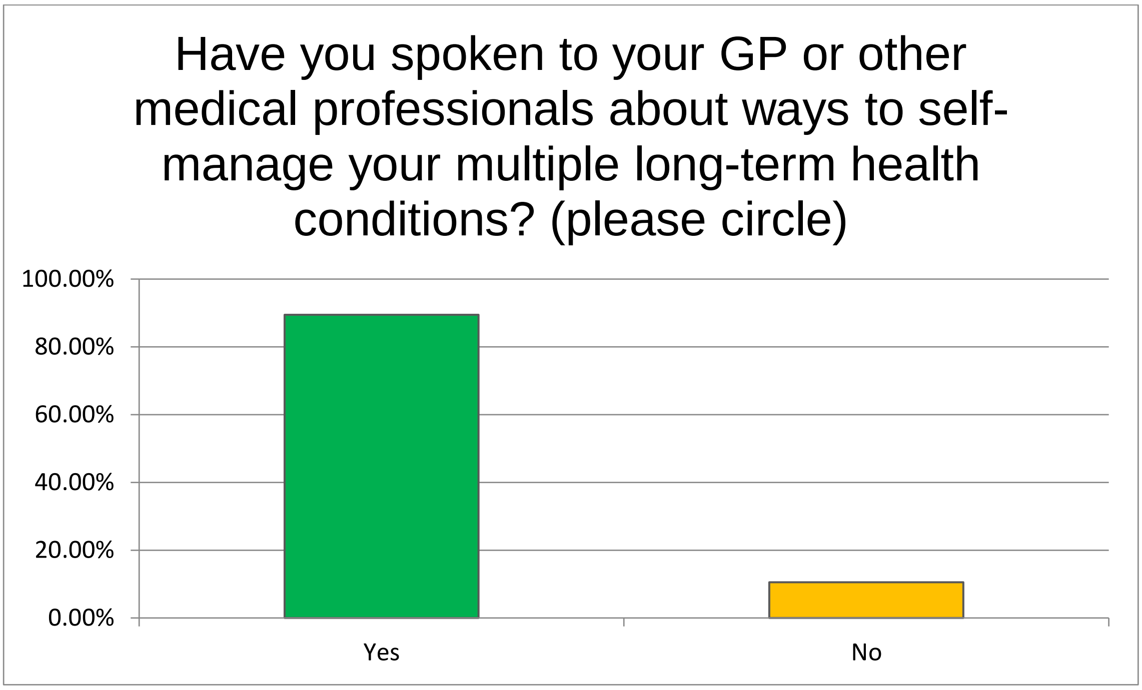
19 out of 19 people responded to this question



| |
|---|
| Huntingdon's Disease Association used to be local group support and HDA support advisor - no longer available |
| I'd like more services to be available in the afternoons. I don't sleep until really late so can't do mornings, things I'd like to do / try are always in the mornings, eg Pilates, health walk, table tennis! |
| A person who has the role of helping me to oversee all of my conditions, and help me manage all my appointments etc, a kind of caseworker or coach who can help to navigate the minefield that is chronic long term conditions |
| Being sign posted from my doctor to what they think is proven, so I am not wasting my time or money |
| Psychotherapy relating to weight loss. |
| Low cost access to pools / classes. |

### 4.9 Have you spoken to your GP or other medical professionals about ways to self-manage your multiple long-term health conditions? (please circle)

19 out of 19 people responded to this question



| |
|---|
| New GP 18 months ago due to move - good listener and suggested regular appointments every 2 months. |
| Got support from ME specialist (had to see privately) and initial ME clinic in London 20yrs ago. I'm an intelligent person with lots of insight and common sense so I know how to manage my conditions. As I / we live with them all the time. We are the experts, NOT the NHS |
| By not overdoing it |
| It was quite a few years ago and I can't remember all of the techniques. I feel like ongoing support would be more useful than a one off meeting at a sleep clinic. |
| Only medication offered now |
| I had a worker from the Possability People At Work team, who help people with long term MSK conditions manage at work. It was a great experience, and she came to see me at home which made a huge difference to me being able to access the service. She helped me with pacing and recording symptoms, and helped me have a bigger picture view of my current situation. |
| Yes but not very helpful re. sign-posting me. |
| Mostly GP is helpful and kind but shrugs at what else is possible. There is nothing to help fatigue and I have to manage the pain due to side effects of pain meds – I've tried pain management courses and other techniques. Other doctors give unhelpful and judgemental advice. |

| |
|---|
| To be honest they have very little knowledge regarding these conditions. The only useful information was given by the MSK partnership and Fibro UK |
| I get plenty of opportunity to talk with health professionals at the Sussex Kidney Unit (at RSCH). |
| Some medical professionals suggest things as if you weren't smart enough to explore for yourself what might be helpful. I'd prefer my GP, care co-ordinator to be supporting with access to treatment, referrals and support services rather than prescribing me a book. I find that very insulting. |
| GP seemed to lack awareness of my condition therefore following my own extensive research I saw my oncologists who supported a change to my medication and gave me some advice |
| the GP said that he is on the highest medication and then sent us home, we have not been seen at hospital for a couple of years now and the doctors seem to have just told him to get on with it |
| Not a lot of support from GP but consultant at Montefiore is amazing - even though I am NHS not private |
| I haven't spoken to my current GP about my situation, but I have never been able to receive help in the past for my depression which is the condition I need more help to manage. GPs keep telling me I need to self-refer but when I do that, I have only been offered options that are inaccessible to me, so it hasn't helped. I had to go private to get counselling. |

### 4.10 Would you like to receive support from the NHS on ways you can self-manage your multiple long term health conditions? (please circle)

19 out of 19 people responded to this question

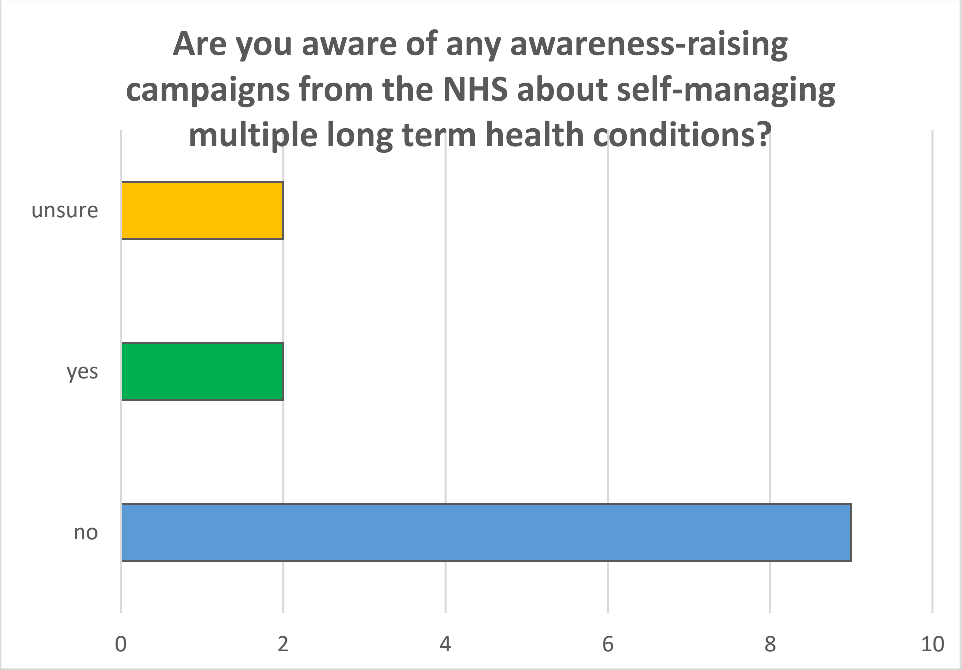
100% answered Yes

**If yes, what do you think that support could look like?**

| |
|---|
| More support regarding HD - more understanding of the condition. Previous HDA advisor (Kent/Sussex) did go to Mental Health team and talk about condition |
| I still don't think generally the NHS understands the complexities of ME and the wide variation of severe impacts it has on people. More training needed in NHS. I could say a lot more. |
| Meeting people having a chat |
| I would like up to date information and someone to speak with me about it, regularly and on an ongoing basis. |
| To see the right person about getting the nerves cut to my legs. |
| How to spot triggers, How to overcome seizures |
| See above for my ideas on having some kind of support worker |
| Access to treatments and workshops, meet up groups and downloadable info to try at home |
| low cost alternative treatments - reflexology , acupuncture, meditation class, etc |
| We need access to exercise that does not cost the earth. Nutritional information would be helpful specific to the conditions. I know the general information which is not that helpful. |
| One to one chats, about 30 minutes long, about every 2 -4 weeks |
| Free gym membership |
| Facilitated groups, peer support. |
| Information leaflets, a specialist nurse to provide ways of self managing |
| Please, any support for him would be brilliant, what to expect, how to deal with things, how he can help himself. Any assistance available (nebuliser/ oxygen ) any particular exercises that he could do, or even how to manage his condition. |
| referral to more specialist agencies or other health promoting options eg low cost swimming |
| Information - a one to one with someone to get to know me and the impact on my life of my health and then to refer me to supports or send info |
| I personally find that I've been better off looking for support on my own as the NHS hasn't really helped. But I think more leaflets in surgeries, including receptionists in GP surgeries informing that the leaflets are there, would help. Of course, if you'd need the leaflets in a different format, it should be easy to order it. Perhaps by having some information on the leaflet stating that "if you need this mindfulness leaflet in braille, contact X Y Z." |

### 4.11 Are you aware of any awareness-raising campaigns from the NHS about self-managing multiple long term health conditions? Please tell us about what you have seen and where, and whether or not you feel it was relevant to your situation

13 out of 19 people responded to this question



| |
|---|
| Yes I have done a Living Well course with the NHS about 12 years ago, but found the information was very basic and didn't really much new stuff on it. I think there should be different types of courses depending on where people are at. I don't need a course suggested I stop eating junk food and do more exercise for example, but for some people that kind of level is just what they need. |
| Yes, I attended a 12 week course but I didn't learn anything new. |
| Not as such - seem to be several organisations offering contact / support etc so difficult to choose - more co-ordination. Mental Health team seemed to be unaware of some of these. |
| I'm aware of social prescribing, I rarely get to GP surgery as it's not very accessible. Book on the day surgeries are only for fit able bodied people who are up early and can ring at 8:30am |

### 4.12 Do you think the NHS should do more to raise awareness about self-managing multiple long term health conditions and the reasons for this?

17 out of 19 people responded to this question

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|---|
| where the money permits that would be great |
| Yes - more working together. It's been up to me to tell my mental health worker what I've found out. When I was with 'working age' mental health team they were more informed and helpful |
| I think it's quite a patronizing statement and so is the opening paragraph on the front to say to us disabled people that you call self-management "living well" It's suggesting that we are so stupid and have no idea how to manage our long term conditions. We are quite aware of our limitations and our impairments, after all, we have to live with them every day!!! I don't like the term 'living well' it diminishes the huge impact of the limitations it places all the time on people and diminishes disability and how for many people that is permanent. No amount of 'living well' can minimise the loss of faculty. It also suggests that we aren't doing enough to help ourselves. It's like blaming disabled people for something they didn't choose to be. |
| I think they give enough advice |
| Yes and actually do something to help |
| Yes much more! Less emphasis on medications and more on holistic ways to manage please. |
| Yes I do. Especially long term health conditions that are not visible. It’s ok diagnosing the condition but if you do not have the latest information for condition management we go away feeling overwhelmed and deflated. |
| Yes. At the end of the day, the individual has to live with the condition. Anything that can help them with it has to be good. |
| Yes, so less people need to visit GP's, especially for little known about or the more embarrassing conditions |
| Yes being able to self manage puts you more in control of your own conditions |
| Yes - if people don't know they can’t put anything in place |
| Yes, by providing information in terms of leaflets like I mentioned above. The leaflets could, as well as stating where to order in a different format, also contain the link to the online version of said leaflet. I think it's important to give people information on how to self-manage their condition as it might lead people down new avenues in taking control of their health which would otherwise have been unknown to them. |

### 4.13 Do you have any further comments?

| |
|---|
| Lots of support for older people with Alzheimer's / dementia but not much info and understanding of older people with mental health needs i.e. talking and sharing groups not just music, singing etc |
| Trying to get help to pain management shouldn't take over 9 months and then you passed from one person to another trying to pass you back to the previous person ‘as they're not the right person’. Also sending you back to the GP to get any referrals done, when all they need to do is send an email. Another thing consultants should be doing is reading your file before you see them instead of going through history every time you see them!! |
| Our current health care system, on the whole, isn't about helping people to get well, it is about making money, and always has been. I appreciate critical care usually very good on the NHS, but for people with chronic conditions, it is a total let down. I call it the National Sick Service and not a National Health Service! There's no profit in people getting well. So while this is the case these kinds of things feel a bit like lip service. |
| In some countries, people with many conditions like myself are awarded a budget, and then they get to choose what kind of treatment they have. That would be a fantastic idea for people like myself who don't just want to take more medications that aren't working and give me side effects. I would use the money to pay for Functional Medicine practitioners and pay for proper tests and supplements that aren't available through the NHS. |
| I think much more support is needed in this area. I love that social prescribing is becoming more popular and hope that will continue. I also think ACT (Acceptance and Commitment therapy) is great, and hope that can be used more in the NHS. |
| The training that doctors get is so focused on medications rather than how to prevent illness and stay well (by use vitamins and other tools like nutrition, lifestyle and CBD). How long do doctors get on nutrition and healthy lifestyle in their extensive training for example?! There have been no reported deaths from vitamins in the last 30 years and yet they are rarely used as a tool by doctors despite being much safer and often more effective than the majority of medications. |
| When will social prescribing allow me to choose what works for me and pay for me to take part on any workshops or treatments locally? |
| I think that we need to be careful about making people feel like mindfulness, yoga etc are the magic solutions. They are the things that are often patronisingly repeatedly suggested by people who feel entitled to chip in on your health whether invited or not. When you have bipolar and you're hyper, for example, mindfulness is a nightmare. When you're in severe pain and someone goes, have you tried exercise? It makes me want to punch them in to the sun. |

# 5. GIG Focus Group Results

## 5.1 Introduction

The GIG meeting on this topic was held on Wednesday 13 November at our usual accessible location which is Friends Meeting House in Ship Street, central Brighton. 12 disabled people and carers were present and an initial presentation about journaling and how it could help make communication of MLTCs more effective between doctors and patient was held. Prior to the presentation, Hospital Passport had been mentioned during the Possability People news and updates part of the meeting and these two elements merged into a discussion of a general health passport which would serve a similar purpose to the hospital passports, but focus more on all aspects of health. This discussion quickly proved to be both engaging and relevant and therefore became the focus of the rest of the meeting.

## 5.2 Discussion Results

**The following are ideas resulting from the discussion as to what the health passport ought to contain and how it could work.**

- Listing all allergies, medications you take etc.
- Access needs and preferences, E.G. wheelchair access, guiding for visually impaired people, sign language interpreters and preferences for patients with autistic spectrum conditions.
- List of consultants (Who are you seeing for your multiple LTHCs?)
- List of medications and possible interactions. (Hard to remember what meds you might be on if taking multiple ones and good to have written down so medical consultants can advise about any interactions.
- Authority to communicate etc. with informed carers. (Sometimes this is important when patients who normally can communicate for themselves are unable to due to illness. Also for people who depend on carers to communicate on their behalf. Particularly carers who are non-medically trained.)
- Folders/ways of updating sections of the health passport, without necessarily having to keep replacing it.
- Summarise conditions – common symptoms experienced and the impact on the person, emergency and general. (This would be good for a first page in a health passport so the GPs can take a quick glance at it. This could alternatively be like the digital first page of a regular passport).
- The time you take your medications. Sometimes there are instructions on medications which tell you what time to take them. However, these are not always necessary to follow as medications need to be taken when it best suits the patient. E.g. if a certain medication interacts badly with someone during the day, don’t take it even if it says to take it in the morning. Also inform hospital staff of this. Especially because they like to have a medication round at a certain time.
- “Notes to self” of how conditions interact and interplay flare-ups to monitor. This is almost like a journal part of the passport. Can be used to track symptoms and fluctuations in conditions.
- Indestructible and robust, passport sized. No A4 papers.

- Credit cards would be one option, then people can select they inserts they feel relevant e.g. red= emergency appointments, blue=GP appointments, green =self-management, yellow = Pharmacies
- Hydration and nutrition (Any food allergies you might need to communicate allergy or intolerance to, as well as knowing to stay clear of them if they flare up symptoms. E.g. Milk gives me a headache.)
- The idea of a QR code was explored for distally savvy patients, this could then link to a page with all relevant and up to date information
- There are ways this could be linked and related to the different types of medical alert systems
- Who else have I seen? This is linked to multiple consultants. What appointments need following up? Would also help medical professionals to know who else is involved with the patient and who might need records updating etc.
- Voice recognition actually recording your words, not relying on note taking e.g. at A&E not having to keep repeating.

## 6. Recommendations

### 6.1 The CCG and NHS to look at creating general health passport which can be used in different settings:

- Different colour passport/sections for different situations, E.G. Hospital, treatments, GP treatment and self-management.
- Front page, possibly digital summarising the main points of MLTCs such as condition interplay, medication, which specialists they see etc.
- This will make treatment by multiple doctors for the same patients a lot easier.

### 6.2 The CCG to train GPs in working with patients to find the type of social prescribing best suited to them:

- The CCG is to enable community support groups where people with similar conditions can meet and get facilitated peer support.
- The CCG to look at ways people with MLTCs can have regular talks with the same health professional, for example named GP, on a regular basis which would help the GP get a better knowledge of how the MLTCs impacted the patient’s life and refer them to appropriate support and treatment.
- The NHS to promote a more holistic approach to managing MLTCs including the promotion of low cost alternative treatments such as reflexology , acupuncture, meditation class, etc. which can complement medical treatment.

### 6.3 The CCG and NHS to widely promote free and low cost exercise options.

- Free/low cost gym membership,
- Referral to more specialist agencies or other health promoting options e.g. low cost swimming.
- Access to treatments and workshops, meet up groups and downloadable info to try at home.
- Promote a variety “living well” workshops to provide people with different choices. Somebody may need a basic nutrition workshop and some people may need workshops on anger management for instance.
- The NHS to promote leaflets in GP surgeries and hospitals on various ways to self-manage MLTCs, including leaflets on complimentary treatment, workshops and support. And also train surgery staff to direct the patients towards these leaflets.
- CCG to consider broadening the use of a personal health budget providing a fixed sum of money so a patient with MLTCs can decide for themselves what treatments is most important to them and pay for it using the PHB.

# 7. Conclusion

This report on self-managing multiple long-term health conditions (MLTCs) has highlighted the need for a simpler way for people to communicate with health professionals about managing their MLTCs. The health passport, modelled on the hospital passport, but which would be used slightly differently, was raised as a great suggestion to solve this. The health passport would contain easily accessible information for both doctors and patients which included everything about the patient from how their conditions interplayed and what medications they took to other ways they could self-manage their MLTCs. A version of this idea is already being looked at the BSUH patient portal meeting and the report strongly suggests that this is something the NHS and CCG should look into further.

A more holistic look at health was also identified as being important. And with social prescribing being rolled out, the importance of patients having power in what type of social activity they were prescribed was seen as one way of enabling people to have more choice and control, and a positive step to self-manage MLTCs.

As part of the holistic approach, access to free and low cost exercise options was mentioned multiple times as was free and low cost access to different forms of complimentary therapy.