healthwatch Herefordshire

Your experience of ageing well in Herefordshire

Project report June 2022

healthwatch

Contents

Summary, recommendations and local GP practice response.

Summary

Thank you to the 52 people who shared their views and suggestions with Healthwatch and to the east primary care network for enabling this contact.

Aim

In partnership with a local primary care network and GP's we aimed to find out experiences of growing older in Herefordshire and keeping as fit and well and independent as people are able.
We explored whether an ageing population in Herefordshire know what services (supportive and preventative) are available.

Who participated?

52 people Living to the east of Ledbury in a rural area of Herefordshire accessing East primary care network practises services, with a Rockwood of three to five were interviewed by telephone and online survey.
People were:

- Aged between 50 and 85
- Roughly half male and half female
- Mainly white British
- 71% without a disability though many had long term conditions
- Three participants were carers
- Approximately 1/3 have a low income as defined by the UK government's current definition and a fifth have a mean annual individual household income of between £16,000 and £24,000.

Experience of ageing

Many participants had a positive experience of ageing with about 7 in 10 people giving a positive score, 1 in 5 people gave a more neutral score and 1 in 10 people expressed a negative experience of ageing in Herefordshire.

People that had negative experiences described difficulties that were physical and mental and worse than they'd hoped. They also cited difficulty gaining access to support Including NHS services and attitudes of people (in general and in services) towards older people.

People that gave a middling score acknowledged declining physical and mental faculties and attitudes towards older people but were philosophical about their situation.

People that had a positive experience of ageing also accepted aches and pains, less energy and memory loss as negative. They listed many positives, including not having to worry about work. They described activities that were a benefit to their health and bought them joy, and that they felt fortunate or lucky in their relationships /companionships, positive living environments and NHS support.

There did not appear to be any patterns to suggest particular demographics were scoring high or low.

What have people found they need help with as they grow older?

Just under 1 in 5 people stated that they have not required help so far. The greatest needs expressed were help with medication and physical health concerns Including deafness and sensory impairment, mental health, mobility issues, home adaptations and equipment and knowing where to ask for help to arrange care.

Knowledge of multidisciplinary teams within GP practise

GP's, practise nurses and clinical pharmacists were most well-known by everyone and about a third knew that there were many other practitioners available however social prescribers, listening service volunteers, health and wealth being coaches, frailty occupational therapists and frailty care coordinator were known by very few people.

People commented on their experiences of services with many compliments, concerns, and suggestions.

The most frequent themes that patients raised were difficulty gaining appointments, importance and appreciation of annual check-ups and access to non-digital face to face help. They also worried about wasting doctors time but, wishing for continuity and information/advice when they need it.

Other services

Participants recognised many of the other services that were cited. Most well-known were Age UK befriending service, ring a ride and weight loss groups. However, just under half of the services had been used by any of the people in this survey.

A few people commented that they have not heard of many of these services and perhaps better publicity would be a good idea. Having one key health worker contact was also mentioned.

Concerns about getting older.

People that answered this question mentioned a wide variety of concerns with the greatest number mentioning memory loss and dementia, poor health, less mobility and unable to do the things I do now.

Many were concerned about losing independence, loneliness, frailty and 'becoming a burden'.

Useful information

Three quarters of those that answered this suggested a general elderly health and care services list, directory or leaflets would be useful.

Most popular mode of information delivery was face to face – somebody people could ask. A close second was printed information, and this was followed by online and telephone delivery of information.

Most viewed the surgery as the place they'd wish to go. Pharmacy and library were second most popular choices.

Most people said they wanted this information when they need it or in advance of needing it or when particular difficulties or frailty occur.

Aspects that are in your control

Roughly 1 in 3 people thought 'everything' or 'all' with the proviso of 'at the moment' and roughly 1 in 5 people thought 'keeping fit/ physical wellbeing/ mobility' and 'Eating healthily and my weight'.

But there were many other suggestions with a strong sense of wishing to have a voice, choice, and independence for as long as possible.

What health and care services could provide differently to help

People suggested a variety of areas with the most popular being 'more self-help advice and information on particular conditions' and making services 'more accessible'.

The most repeated concern about accessibility was 'easier to make an appointment' but people wanted services to be more visible and advertised, more face to face and less rushed and busy.

People suggested 'more face to face appointments', 'a local contact for ordinary ageing enquiries' and 'services proactively connecting you with all services that can help you'.

Other suggestions were the availability of 'more (paid) carers', 'change of attitude' (of some health and care staff / services towards elderly), 'welcoming the need for advice', 'a support line', and 'online support'

Some specific areas were suggested e.g., incontinence, end of life care, bereavement counselling.

Conclusion

It is clear from the varied replies that people in Herefordshire experience ageing in very different ways.

We might have expected people to feel less contented as they grew older or if they had more long term conditions or a lower income, but we could find no such correlation in this study.

Ageing and our experience of it seems to be very individual and personal and driven by a combination of factors including all of the obvious aspects as well as:

- the people and environment that surround us,
- our activities, our attitude,
- our life experience,
- our hopes and fears
- and the treatment we receive from carers and health providers
- – and probably the mood we were in when we filled the survey.

It is difficult to generalise because of this but what came across was the considerable spirit and agency that this group of people showed. Also, their desire to remain as independent as possible for as long as possible, and a willingness to use services that help. Equally this study revealed a recognition in service users that services are under strain and not wishing to 'be a burden'.

It is concerning that some people feel guilty calling services that they need. People want to be responsible for their wellbeing by asking when they need help without being turned away as non-urgent enquiries. They want quality of care and continuity and mostly they desire face to face contact. They want to be respected as people with knowledge and not to be 'stereotyped or treated with condescension', 'patronised' or overlooked.

Most people do not want to consider their potential decline until issues arise. This can make it challenging to roll out preventative public health messages. It also means that often when a crisis occurs people don't know where to go or what to do. Sometimes the solutions are not complicated, and a short discussion is all that is needed.

For a generation that do not like to bother services a less formal chat is attractive, and could prevent overuse of GP surgeries – such as the volunteers that could be called during Covid – as pointed out by a few participants. Perhaps a role for Talk Community hubs.

For all of us, ageing is a new experience – how do we know if that ache or twinge is 'just' to be expected at 'my age'? Where do we go to find out? Should we ignore it and hope it goes away?

Many of us will do this and participants that we spoke with expressed this dilemma eloquently.

The challenge for hard-pressed services is to offer timely information and advice and where necessary medical or care interventions that increase life quality in later life. Also to prevent avoidable decline or isolation and encourage collaborative personalised care and timely forward planning.

The evidence from this group of patients is that they are more than willing to engage with services constructively. They would welcome clear information and advice and easy less formal periodic contact to reassure and nip issues in the bud.

Recommendations

1. Consider ways to encourage and welcome ageing patients to make appointments when they need information or have concerns.
    a. Offer clear information on how to access GP services, make appointments and achieve continuity.
    b. Offer annual check-ups to explore non urgent but developing health issues and enable preventative advice and information.
    c. Offer clear information and guidance, directory or leaflet on services and practitioners with descriptions of what they offer, when to use them and how to access them. (Printed and online). Highlight or send out at a particular age or when a particular Rockwood scale is reached e.g., 3.
2. Offer clear self-help information on different common ageing issues or conditions that will inform and offer suggested actions for prevention and/ or treatment or enable forward planning e.g., Dementia, foot care, constipation, falls prevention, incontinence, sensory deterioration, mobility, end of life care, care options.

    Consider creating local easy to access, alternative face-to-face contacts through coffee mornings/ periodic open days, road shows or events/ support phone line that can disseminate self-help information and advice and signpost about general ageing issues, information, and advice.

    (This may link in where relevant with Talk Community initiatives and directory and Herefordshire Council actions regarding recommendations of Healthwatch Herefordshire's Future Care Report).

"Basically, all services should stop being run for the elderly but in collaboration with them. It would be nice to believe this would be the start of that process".

East Primary Care network response

Action below taken in response to the survey.

1. I have met with our Social Prescribers, Aimee Williams (Talk Community Development Officer for the East PCN) and Jan Bailey from Taurus Communications. We reviewed the survey and noted that the responders were asking how they could access information to keep themselves well. It was suggested that Parish Magazines were a trusted source on information in rural communities and would also reach those who are digitally excluded. We have collectively pulled together an article detailing:
   - Information about roles other than GPs in practices available to patients to enable them to keep well or prevent getting more unwell, such as the Social Prescribers, Health and Wellbeing Coach, and Occupational Therapist.
   - Explained about Talk Community Hubs as the place to go to find out what is available locally to meet their needs, including a link to the website and a phone number for customer services that people can call to find out more about what is available at their local hub.

   I am meeting with the practices this week to obtain sign-off for this work and if it is successful, the other PCN Managers will work with their PCNs to replicate this idea in their area.

2. I will liaise with the PCN Leadership Team about the idea of creating sources of information for older people to stay well, including info packs or roadshows, etc. As said, resourcing the coordination and delivery of this work has its challenges but happy to discuss and see what we can come up with.

Many thanks to Healthwatch for conducting this survey. The results were enlightening and food for thought

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Introduction and methods used.

Introduction, methodology and demographics

Introduction

People in England can now expect to live for far longer than ever before – but these extra years of life are not always spent in good health, with many people developing conditions that reduce their independence and quality of life.

The NHS has a key role to play in helping older people manage these long-term conditions, making sure they receive the right kind of support to help them live as well as possible.

The NHS Long Term Plan aims to give people greater control over the care they receive, with more care and support being offered in or close to people's homes, rather than in hospital.

They will also aim to make better use of technology such as wearable devices and monitors to support people with long term health problems in new ways, helping them to stay well and live independently for longer.

Project purpose

In partnership with local Primary Care Networks we aimed to find out experiences of growing older in Herefordshire and keeping as fit and well and independent as people are able.

We explored whether an ageing population in Herefordshire know what services – supportive and preventative - are available for:

- Home support,
- Mental wellbeing
- Help to live well
- Specialist services like dementia support, foot care or particular disabilities or for carers.

There is an ongoing need to better integrate clinical services more collaboratively with community services that already exist. It is important to know what that would look like.

Self-management is very important as we grow older, and some people struggle with this and may need different support than is available presently or may be

using good support that the health and social care system are unaware of that may benefit others.

Method

Participants lived to the east of Ledbury in a rural area of Herefordshire and were referred to us by East Primary Care Network practices. The practices referred patients with a Rockwood of 3-5 (see Appendix4 for description of Rockwood scale).

Patients don't necessarily know what Rockwood categories are or which they are described as. It is not routinely discussed with people. Carers and GP and patient all may have different views.

Demographics

52 people were interviewed either by telephone survey, online survey or filling a hard copy of the survey by post.

Full details of participant demographics are in Appendix 1 but in summary:

- The largest number of people were in the age range 70-74 but altogether ranged between 50 and over 85.
- 54% were male and 46% female,
- A large majority were white British with a small number of participants, White Dutch, South African, Irish, and European.
- 71% said they did not have a disability though some of the long term conditions might be considered technically as a disability.
- The participants had a range of long term conditions as follows:
    - Alcoholism (in recovery)
    - Atrial fibrillation
    - Asthma, COPD or respiratory condition
    - Blindness or severe visual impairment
    - Cancer
    - Cardiovascular condition (including stroke)
    - Chronic kidney disease
    - Colostomy.
    - Deafness or severe hearing impairment
    - Diabetes
    - Diabetes 1
    - Dystonia
    - Epilepsy
    - Frequent urination
    - Hypertension
    - Hyperthyroidism

    - INR checks following heart surgery.
    - Meniere's disease
    - Mental health condition
    - Musculoskeletal condition
    - Osteoporosis
    - Glaucoma
    - Thyroid condition
    - Trapped back nerve
    - Varicose veins
- Three participants were carers.
- Individual mean annual income in the household was calculated from Household income divided by the number of people included in that income.
    - 27% of participants have a low income as defined by the UK Government's current definition. (Excluding participant's that preferred not to say this rises to 39%).
    - The largest category with 23% of participants had a mean individual household income of between £16,000 and £24,000.
- Most participants had a Worcestershire postcode though they live in Herefordshire and access Herefordshire Healthcare.

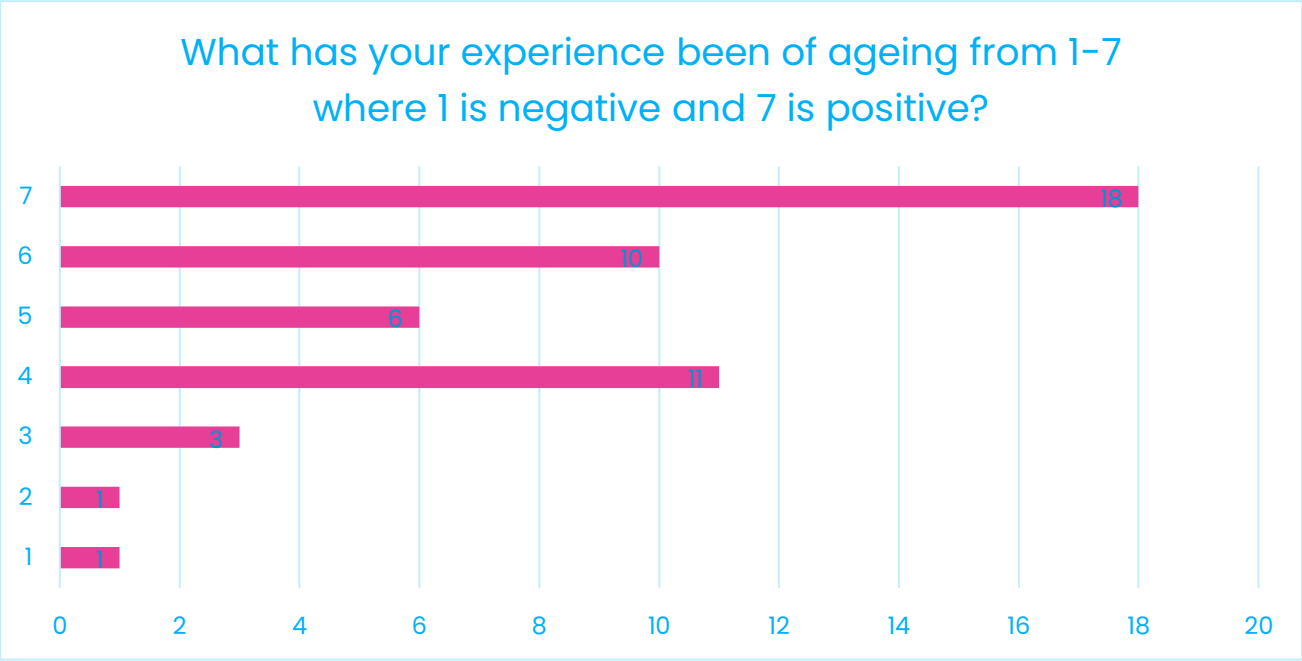
Your Experience of ageing well in Herefordshire

How participants scored their experience

We asked participants: **Thinking about the NHS's aspirations (hopes) for people to be able to age well, what has your experience been of ageing from 1-7 where 1 is negative and 7 is positive? Think about this in terms of mentally and physically.**

Of the people that answered this question:

- 68% (about 7 out of 10 people) gave positive scores of 5,6 or 7,
- 22% (about 1 in 5 people) scored 4 neither a positive nor a negative experience and
- 10% (1 in 10 people) expressed a negative score of 1, 2 or 3.



Reasons

We asked people to explain the reasons behind their scores. Reason varied greatly.

People who gave a low score indicating a negative experience of ageing.

"When I was young, 16 or 17, I thought getting old was for old people, other people, NEVER FOR ME. I truly believed that. I feel conned, cheated, that I've had a joke played on me. Physically, I take tablets for cholesterol, blood pressure and frequent urination. I have aches and pains in places I never knew existed. I FEEL CHEATED." Score 1. Male 70-74"

"It concerns me that I find it extremely difficult to even get a face to face appointment with a doctor, and I am expected to wait two weeks for a phone consult. Sometimes older people need to discuss things with a doctor, I have a hip problem and know I need to get on the list soon, but I have to jump through hoops to even see a doctor. I just get despondent". Score 3. Female 65-69"

"Ageing is similar to having children: You THINK you know it all, but the reality still takes you by surprise. You are increasingly frustrated by both physical impairments (mobility and pain for instance) and mental ones (loss of memory), that get compounded by becoming increasingly invisible in the community, if not treated with actual scorn and disdain. Far too often what pretends to be "care" is in reality patronising condescension. The old in this country have always been treated appallingly. It is only now impacting directly on me". Score 2. Male 70-74"

"I am able to maintain physical fitness and my health. I'm concerned that if something goes wrong, agencies don't match support to needs and I dread not being able to determine my own health outcomes as I age and get 'written off' by the NHS". Score 4. Female 65-69"

People who gave a middling or neutral score indicating a mixed experience of ageing.

"Physically as expected. Mentally somewhat depressing. Due to using NHS hearing aids I seldom mix socially as I can't hear very well in company". Score 4. Male 75-79"

"My aging body reminds me daily that I can't do the things I used to... quite as well or as fast". Score 4. Male 50-64"

"I dislike stereotyping of older people and assumptions many doctors \ nurses seem to have. Also being patronised and talked to as if I am completely ignorant and ill-informed". Score 4 Female 75-79"

People who gave a positive score indicating a positive experience of ageing.

"Ageing has been positive in that I worry less about having time to do things, do not have pressure of work and I feel people are respectful of me. Negatives are aches and pains, less energy, have memory loss and worry about final health and ability". Score 5.

"So far, so good. My mobility, mental health, physical condition have been good". Score 7.

"I am lucky to have had only minor physical and mental health problems since retirement. These have been treated well". Score 6.

""I am very happy with the surgery and doctors. It's a long time since I had to see a doctor, however, and I'm worried about the potential delay in seeing him/her". Score 7. Male 70-74

"I like sports and go to the gym a lot and have been lucky to keep myself generally fit and well. I eat well and am careful about what I eat. I have been married fifty years have a good relationship and am not lonely. I have good backup from my children and have good neighbours". Score 6. Male 70-74.

"I live near the wonderful Malvern Hills, and they are a daily inspiration. I take pleasure in all the small little ordinary jewels in my life and really cherish connections and my relationships". Score 7. Female 70-74.

"My answer is based on my GP surgery and especially Dr Sarah Newey who makes people of my age (and my husband who is 82) feel terrific. I feel as if she cares and really understands that I want to live a full, active and healthy life regardless of my age or, indeed, any ailments. If only my younger friends and family were as considerate"!!! Score 7. Female 70-74.

"I am in good health and active. My medical issues are hypertension and some joint discomfort. I am a blood donor and recently have experience low haemoglobin counts; Diet adjustment seems to be working. Our surgery is proactive and responsive". Score 7. Male 65-69.

"My experience has been painless. The local surgery is good at sending for regular blood checks, checking medication and have a very good physiotherapist. There is also a very good fellow re mental health. Colwall medical support extremely good. My spouse and I have lived in Herefordshire for 34 years and would not want to live anywhere else. I am very healthy for my age. Luckily, I have family support living together in a big house". Score 7. Male 80-84.

"As I have a good relationship with a caring partner and sufficient income for my needs plus a warm and comfortable home my experience has been positive! Also have a supportive family not too far away". Score 6. Female 75-79.

Comparisons by demographics

We compared scores against different demographics and with the small sample size saw no obvious patterns.

We compared scores against age group, identified gender, individual annual mean household income, specific long term conditions, number of long term conditions.

It is likely that attitude to ageing and multiple personal circumstances holistically determine score.

These comparisons are shown in Appendix 3.

What have people found they need help with as they grow older?

Responses

The largest response was needing help with medication (49%) followed closely by Physical health concerns/ health checks – access to healthcare (47%).

The next greatest need was help with deafness or other sensory impairment at 31% and mental health support e.g., feeling low or depressed or overanxious at 18%.

13% had needed help with mobility issues and approximately 10% (one in ten) cited practical equipment and adaptations, knowing where to ask for help and planning formal care.

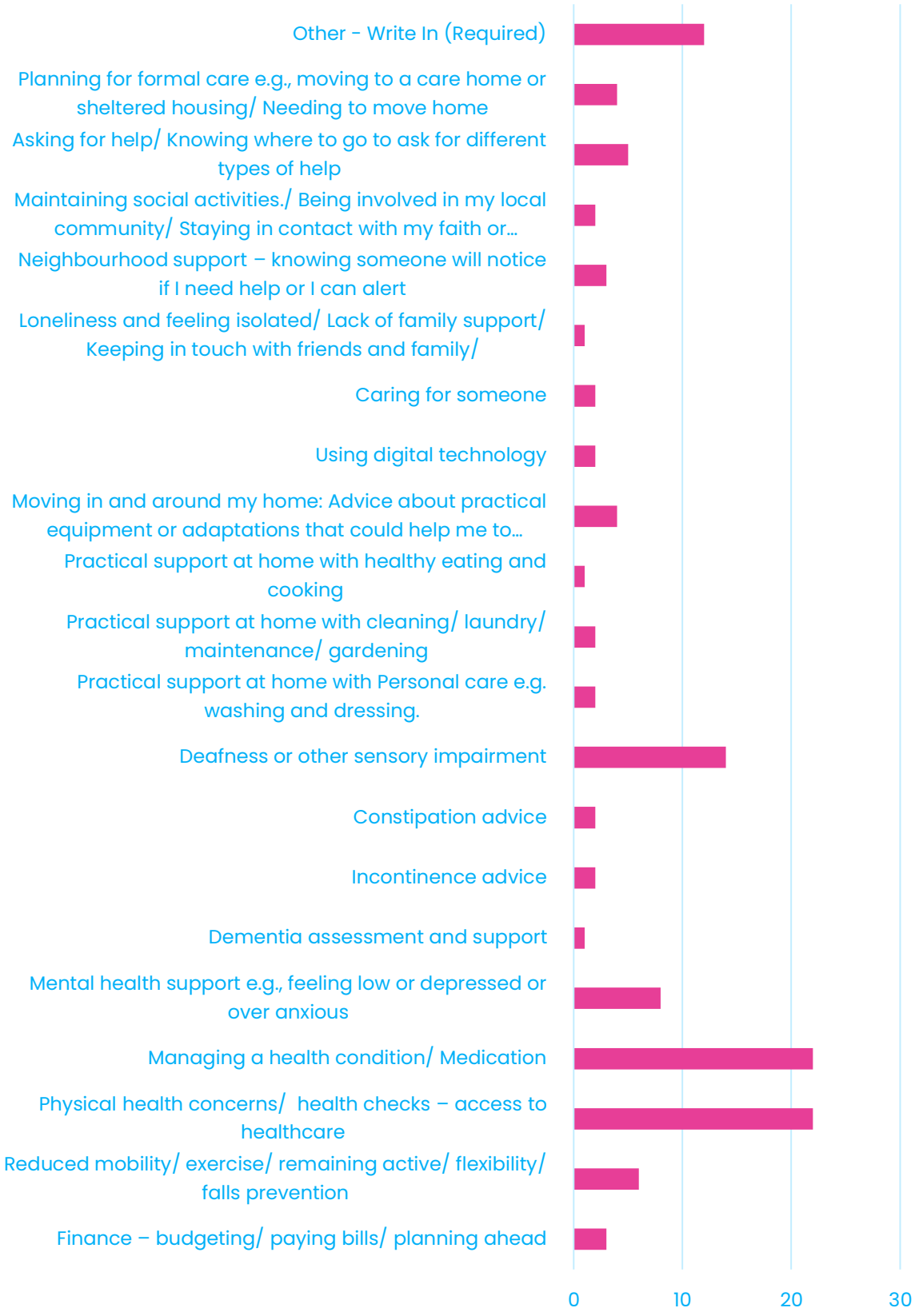
All areas suggested were chosen by some participants.

However just under 1 in 5 people (17%) stated that they had not required help so far.

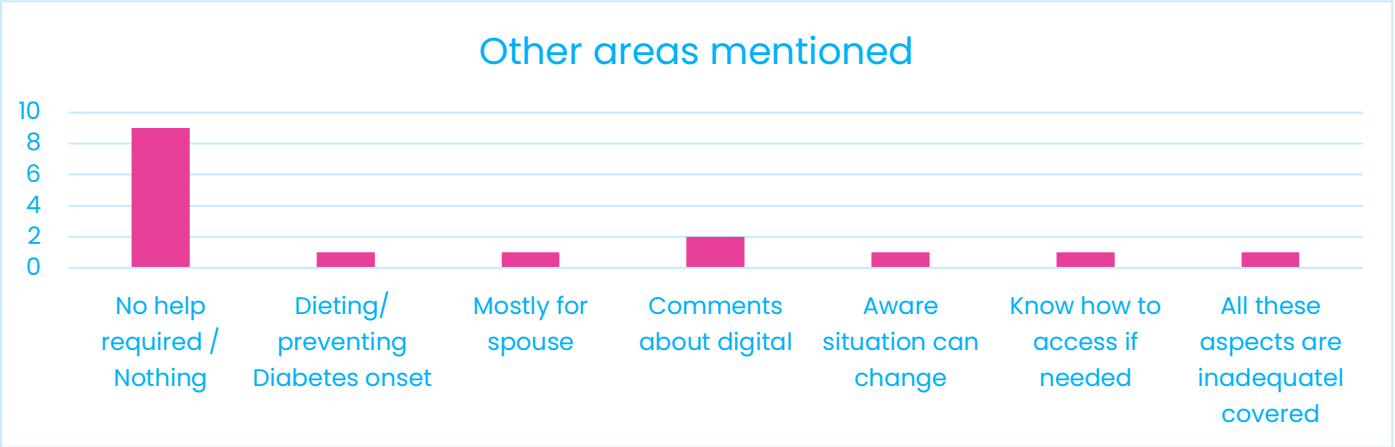
"Again, not yet. But conscious of difficulties when I will need them. I'm lucky and don't think any of this will directly apply to me. But life has already taught me that all right circumstances can change at which point all these points could become issues and I recognise that all these aspects are presently inadequately covered".

"I am aware that some of these services are available, but I haven't needed them. My perception is that they are rather fragmented and not really joined up. Hopefully I'm wrong about this!"

3.As you have grown older what have you found you need help with? (Please tick all that apply). Count



Other areas mentioned



Multidisciplinary Teams within GP practices – are people aware of them and do they use them?

Responses

Collectively the patients were aware of all of the services and between them had used most of them.

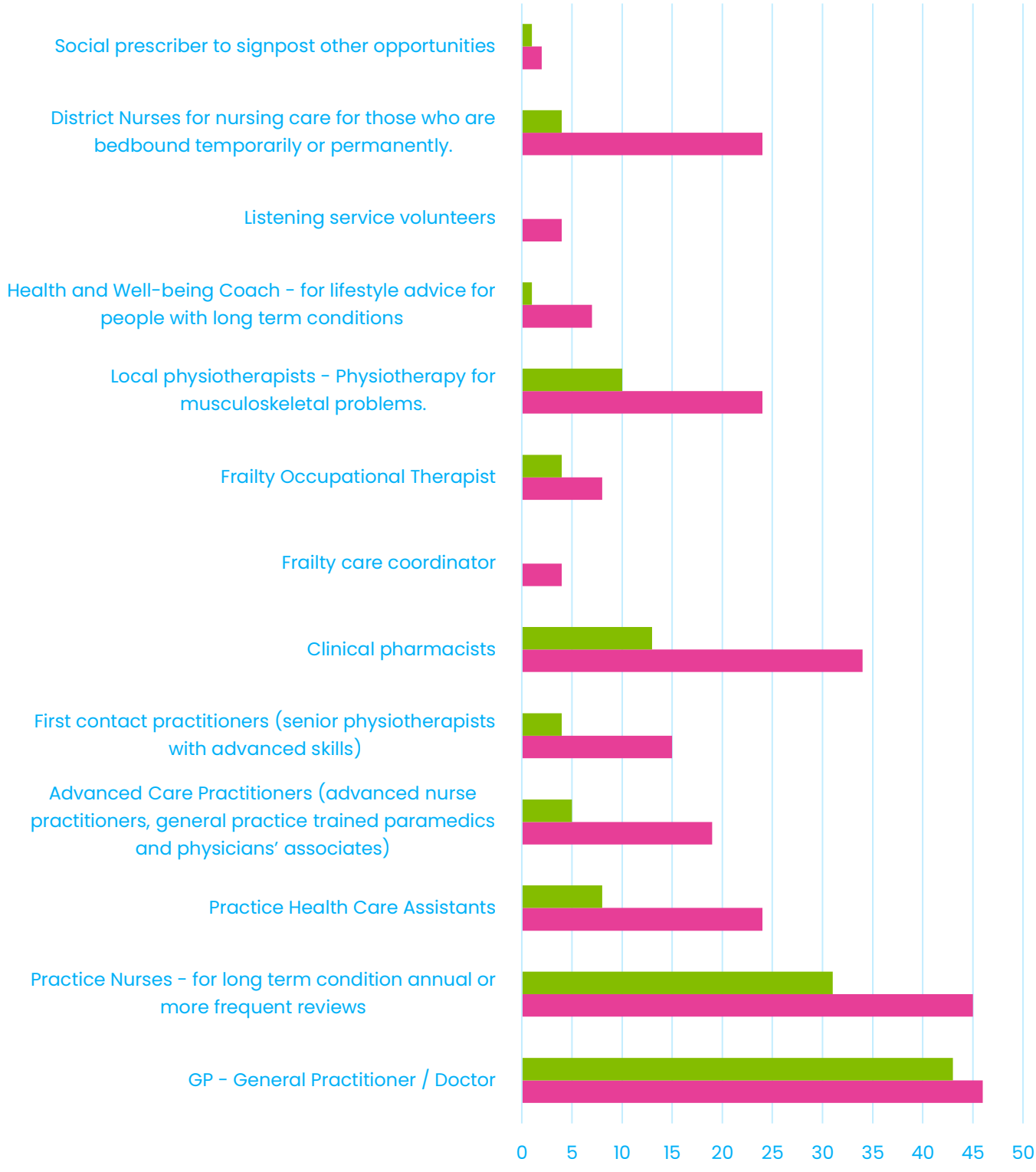
Individually all knew GP's and practice nurses, over half knew clinical pharmacists and just under half knew practice healthcare assistants, Local physiotherapists, and district nurses.

The next most well-known by about a third of the patients were advanced care practitioners and first contact practitioners.

Less well known were social prescribers, listening service volunteers, health and wellbeing coach, frailty occupational therapist and frailty care coordinator.

Survey participants were asked if they had any feedback on the services. Feedback was divided into compliments, concerns, and suggestions.

4.The following services are part of the Multi-Disciplinary Teams within GP practices. Which ones are you aware of? (**Pink** I am aware, **Green** I have used)



Compliments

6 people commented that the GP services generally were “ok”, “very good”, “First class” and “fine/ business like”, that “they are available when needed”, and several individuals commented that they know there are a range of practitioners available and know to ask what is available that could help.

“I am very lucky; I have had two excellent doctors in the past 20 years who really care about their patients.”

“Spouse died a month ago, but support was excellent. St. Michael's Hospice and Surgery. Bringing oxygen and such. Occupational therapist came out and looked at facilities to help them as they had dementia and other health issues. They made the place safer.”

The importance and appreciation of annual check ups was commented on.

“I am well aware many older people around England struggle to ask for assistance, but I very much appreciate the annual check-ups and intermediate checks as GP sees fit. I appreciate the open conversations I have with the GPs, the practice nurses and practice based pharmacist.”

People also expressed praise for nurses and occupational therapists who do a “brilliant job”.

One person said that they recognised the value of a well-qualified pharmacist.

An individual highlighted the effective support they received to lose weight when found to be prediabetic.

Concerns

Many survey participants mentioned difficulties gaining face to face appointments with a doctor and commented that they much preferred previous times when they had a regular GP who knew them well. This was illustrated by this patient:

"I did have a recurring problem and an ulcer developed I was seen by three doctors. One I saw was a locum and they didn't seem to know what they were doing".

Patients observed that services are stretched and felt this limited time available at an appointment, led to a challenging appointment system and "protracted interrogation by receptionists", "long waiting times (weeks) for an appointment" and held the conviction that "face to face appointments need to be bought back especially for the elderly (signs, symptoms, and history)".

There were concerns about elderly patients that recognise that the service is in difficulty, being reluctant to "bother" the surgery and so, miss opportunities for prevention of potentially worsening conditions.

"I have been reluctant to use GP services due to pandemic. I don't like to bother people about seemingly trivial issues"

(Patient who has had cancer)

There were a few concerns expressed about online or telephone appointments and reliance on patients having knowledge of mobiles or digital expertise.

"Very difficult for an elderly person to send photos of conditions via iPhone, iPad etc."

"We should actively be discouraging technology - it is threatening humanity at every conceivable level".

One patient said that they found the NHS website sent them in circles and was not very easy to use or find the information they needed.

"I wouldn't know where to start".

A participant highlighted transport difficulties for elderly that have no access to a car and found their biggest problem was trying to gain an appointment time that fitted in with the buses.

A participant was concerned that often surgeries appear to see drugs as the answer to everything and they would like to see greater consideration of alternatives.

Suggestions

A number of patients made suggestions for improvements.

"I think that regular health checks (annual?) with GPs or practice nurses would provide an opportunity to discuss concerns and to identify health problems before they become critical."

"It is most important to get a regular MOT and keeping on top of one's fitness. I think the surgery is great, but it is difficult having to go through the receptionist. The receptionists are good, but it is so important to speak to a medical professional".

"It can be hard to get through aggressive screening. There are not enough local screening channels to just phone up. Local assessment units - a central point of someone easy to call in village newsletter who can tell you who you need to see. You don't necessarily tell receptionist issue. And it may not be urgent but important. Someone with medical knowledge. Example neighbour needed incontinence pads and wanted to know where to get them and what sort - wanted to know who to talk to about that? Not a complicated request".

Local, easy to access information was a theme that survey participants raised throughout the survey some suggested that listening service volunteers might help:

"Would be happy to volunteer to be such a listener. I think we should know more about them".

"I volunteered in Ledbury for vaccinations and was amazed how many small problems came up just chatting at the door with patients in vaccination centres".

In order to make best use of the variety of services people felt they needed more information about what the services were for and how to access them.

Other comments included a few patients that felt people were overusing the GP because of loneliness.

"However, I feel that some people use the GP too much for having contact/someone to talk to (when they visit for something physical) and that makes waiting times too long".

Are people aware of other services that are available outside of GP practices and do they use them?

Responses

Services most well known included: Age UK befriending service, Ring a ride, weight loss groups. Over half had heard of these.

Then came Diabetic groups and online activities, podiatry/ foot clinics and U3A (University of the 3rd age) Hereford which just under half had heard of.

Between 10 and 15 people (I in 4 people) had heard of memory clinic, online weight loss programmes, smoking cessation, Age UK foot clinics, falls clinic, talk community hubs, deaf direct, speech and language therapist, SAFFA (support for veterans).

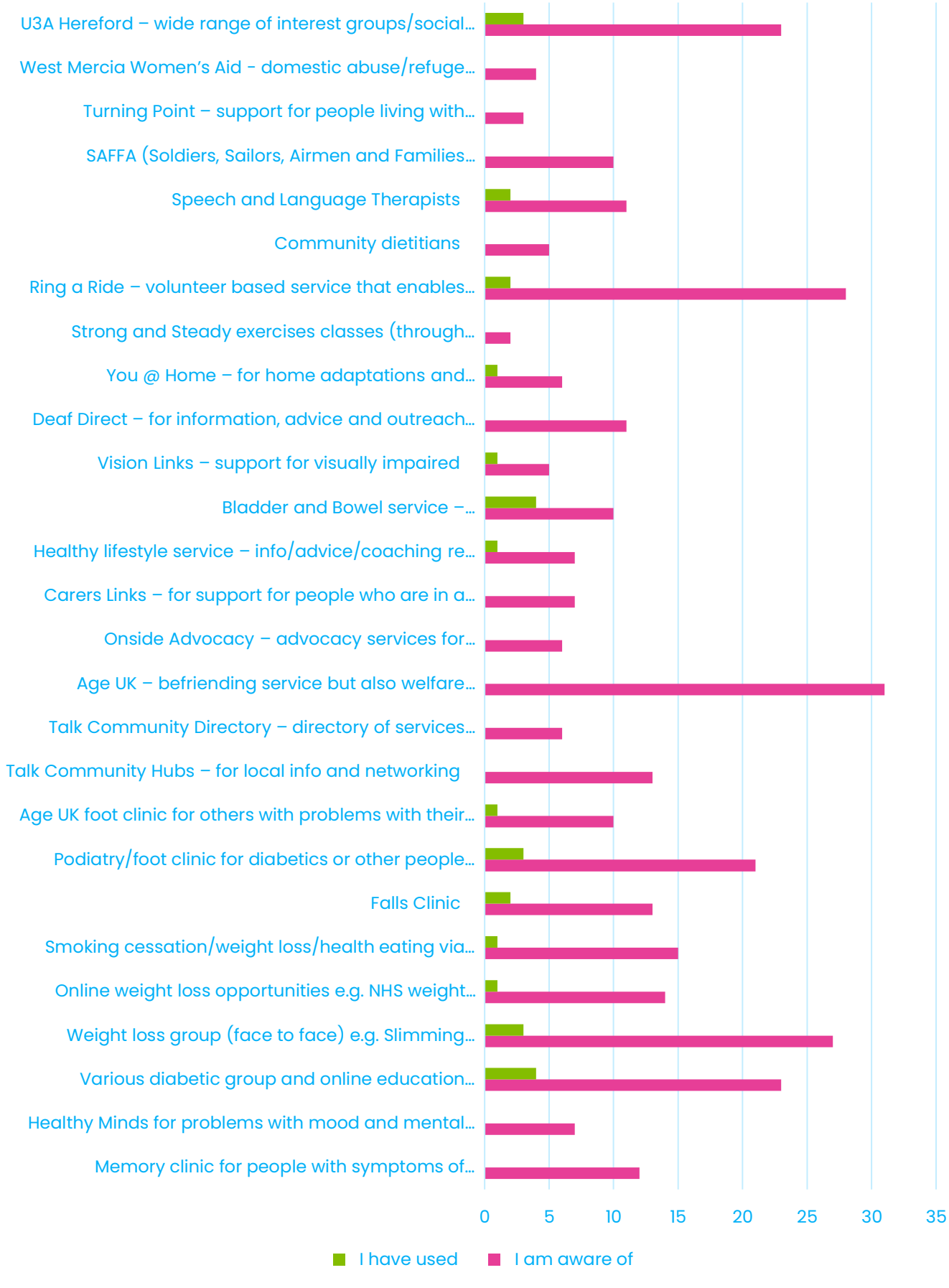
Less than 1 in 10 people had heard of healthy minds, talk community directory, onside advocacy, carer links, healthy lifestyle service, vision links, you@home, and community dieticians.

Less than 1 in 5 had heard of west mercia women's aid, Turning Point, and strong and steady exercise.

Between the survey participants they were aware of all services but only 14 of 27 had been used by this survey's participants – just under half.

Survey participants were asked if they had any feedback on the services. Feedback was divided into **compliments, concerns, and suggestions**.

6.What other services are you aware of often outside of GP practices? (tick all that apply)



Compliments

"Healthy lifestyle service helped me lose weight during lockdown and prevent development of diabetes. I had phone calls, took pictures as I lost weight and advice about what to eat. Help was for 8 months and was very successful and I have kept the weight off".

"Falls clinic gave good advice but spouse didn't much like doing exercises"!

Concerns

"Should be more bereavement counselling because going through loss breads ill health. I know there are organisations like Cruise".

"I know a lot of these must exist but have not used them. I use what I need to when I need to. I try not to use the services especially with Covid as I know they are under pressure".

"Difficult to comment not having used or been aware of the many services available".

"Re: Weight Watchers et al: What? Further supporting infamous multimillion dollar industry??? They should always include in their management people presentation of those who would benefit from the services and serious thought should be given to such people running the services".

Suggestions

"More current information about the services provided, where they are and how to access them".

"There are plenty of places to exercise and swimming pools not too far in Ledbury and Malvern. Plenty of facilities to use. Also went to The Courtyard which was very stimulating. Have not laughed so much in ages. Admirals' cafe was nice to go to share experiences but didn't go a lot".

"Just need to make the elderly in the area aware that these services are available. There are several I was not aware of ".

"Not on what I have ticked. But there is something that would assist me. Years ago, I had a major XXX operation when lived near London. I went private as it was so rare. The work done was fabulous. My surgeon has retired. What I would appreciate is an NHS XXX surgeon referral but GP unaware of this specialty. Also, I have had a couple of skin cancers removed in xxxxx . I would appreciate an annual check-up, again in NHS (so that my GP is aware). I am more than happy to pay for services of this nature. More than happy. But I would like regular checks/any treatment to be 'managed' thru my GP".

"Podiatry support is really important as people can't do anything when they have feet trouble".

"No idea what most of the above services are. I would say there are actually far too many individual services, and they would benefit from being combined, so each old person only had to deal with one health contact, perhaps have an "aging support service manager"

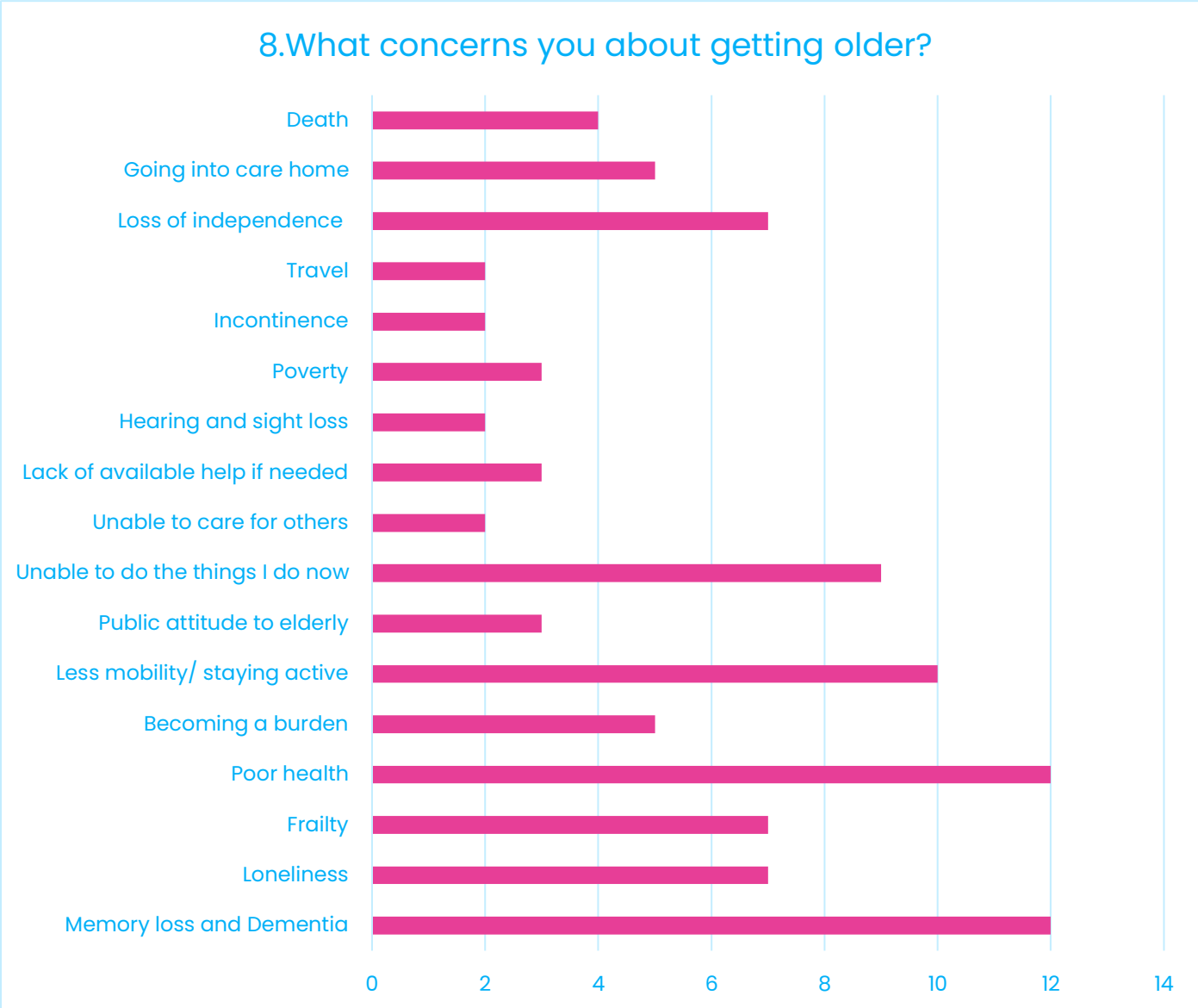
"As I was unaware of a lot of these services maybe some better publicity would be useful. A single point of contact along the lines of the 111 service would be useful. Could you make people aware of this along with their council tax bill"?

What concerns people about getting older?

Responses

People that answered this question mentioned a wide variety of concerns with the greatest number mentioning memory loss and dementia, poor health, less mobility and unable to do the things I do now.

Many were concerned about losing independence, loneliness and frailty and 'becoming a burden'.



Examples

People's comments about their concerns:

Concern: Poor health/ being a burden

"Developing a serious debilitating illness and knowing when to seek help/diagnosis. The NHS is very busy, and I wouldn't want to burden them unnecessarily with a trivial or minor condition. I'm concerned to get the right balance."

"That I will be a burden on my family, as I do not want to go into a care home".

"Lack of independent function. Most don't want to be dependent for long. Being a burden. Some other cultures get it right".

Concern: Loneliness

"Most older people are petrified of being on their own".

"Losing my husband and therefore being on my own".

"How long will I survive by myself"?

Concern: Concern about going into a care home

"Unable to manage at home and have to move to a care home".

"I am not going into a home; I want the right to end my life when the quality has gone".

Concern: Not being able to do what you can do now

"I love sport and still go to see Birmingham City home and away. I am concerned I may not be able to do that sort of thing anymore. Doing the things, you used to do will be a concern. Mostly I live for the day and am quite positive. I enjoy what I can while I can. I don't like getting older but there isn't much I can do about it"!

"Losing independence and persistence of health service in seemingly keeping people alive. Quantity rather than quality of life".

"Feeling that things are out of my control".

Concern: Unable to care for others

"Whether I will be able to provide adequate care for my wife if she becomes more frail or ill".

"I have a child with special needs.
I " look after " them.
I worry what will happen when I am no longer able to keep an eye on them, manage their finances etc".

Concern: Lack of help available

"Nothing at the moment, but I am not aware of what services are available at all for the elderly and who anyone would contact".

"I hope there is help if/when I suffer with any of these"!

Concern: Public and service attitude

"Dissociation from younger age groups too many people same age as me together".

"The general assumption that any condition I have is assumed to be age related, even injuries which can happen to anyone of any age. The tendency to assess my needs based on my date of birth rather than me as a person".

Concern: Specific health issues

"Incontinence".

"Dementia".

"Memory as well but I have taken steps (abroad) to end life when this gets out of hand".

"Process of dying. May be quick and not drawn out like 6 months gradual decline spouse experienced".

"Mobility might become an issue".

Concern: Poverty

""My inability to continue working as a live in carer. I do not have any financial support or family or friends that I can turn to. I don't know what I am going to do".

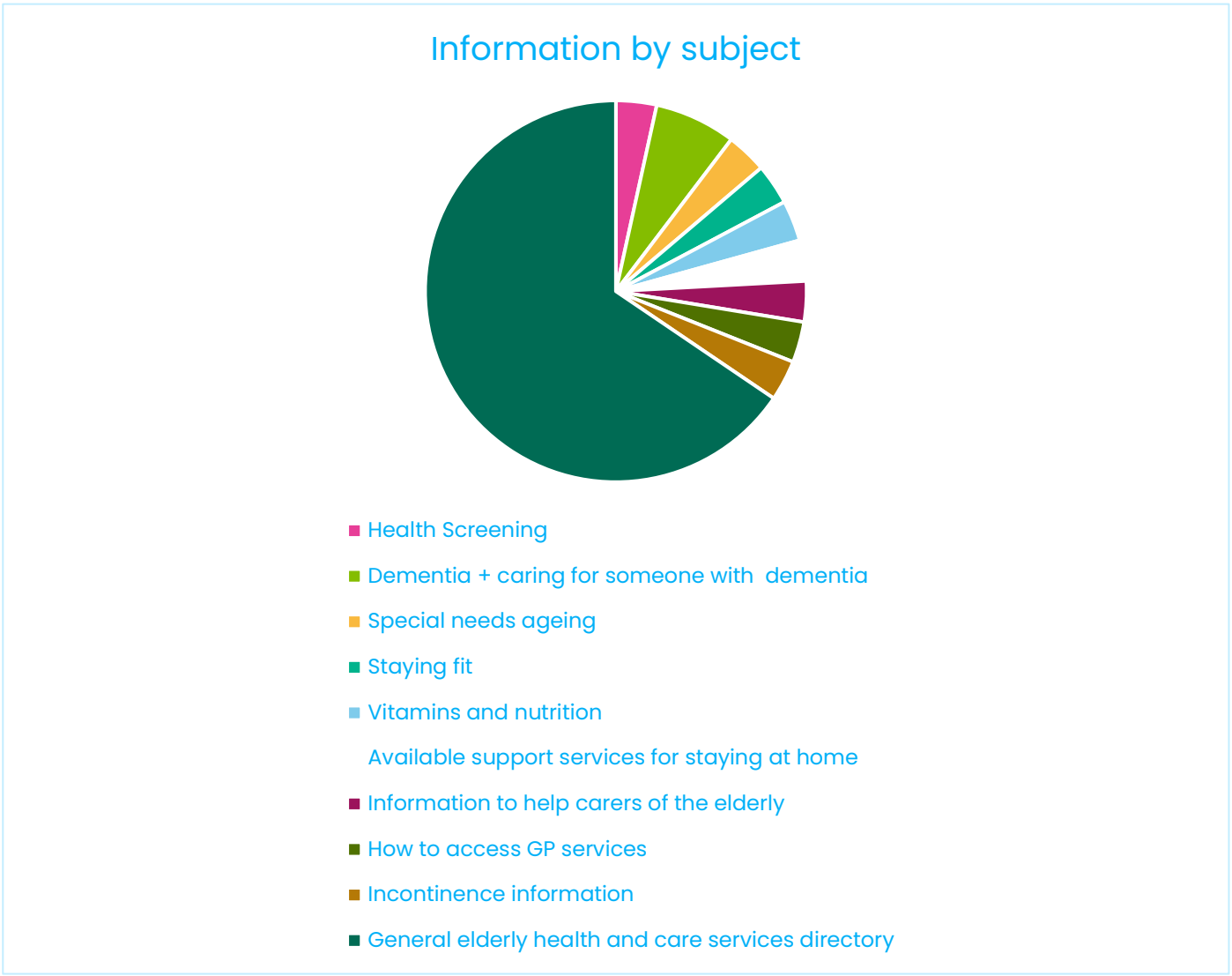
"Not having any/enough cash in order to go into a home if necessary".

What information would be useful and when and where would be best to deliver it?

Responses

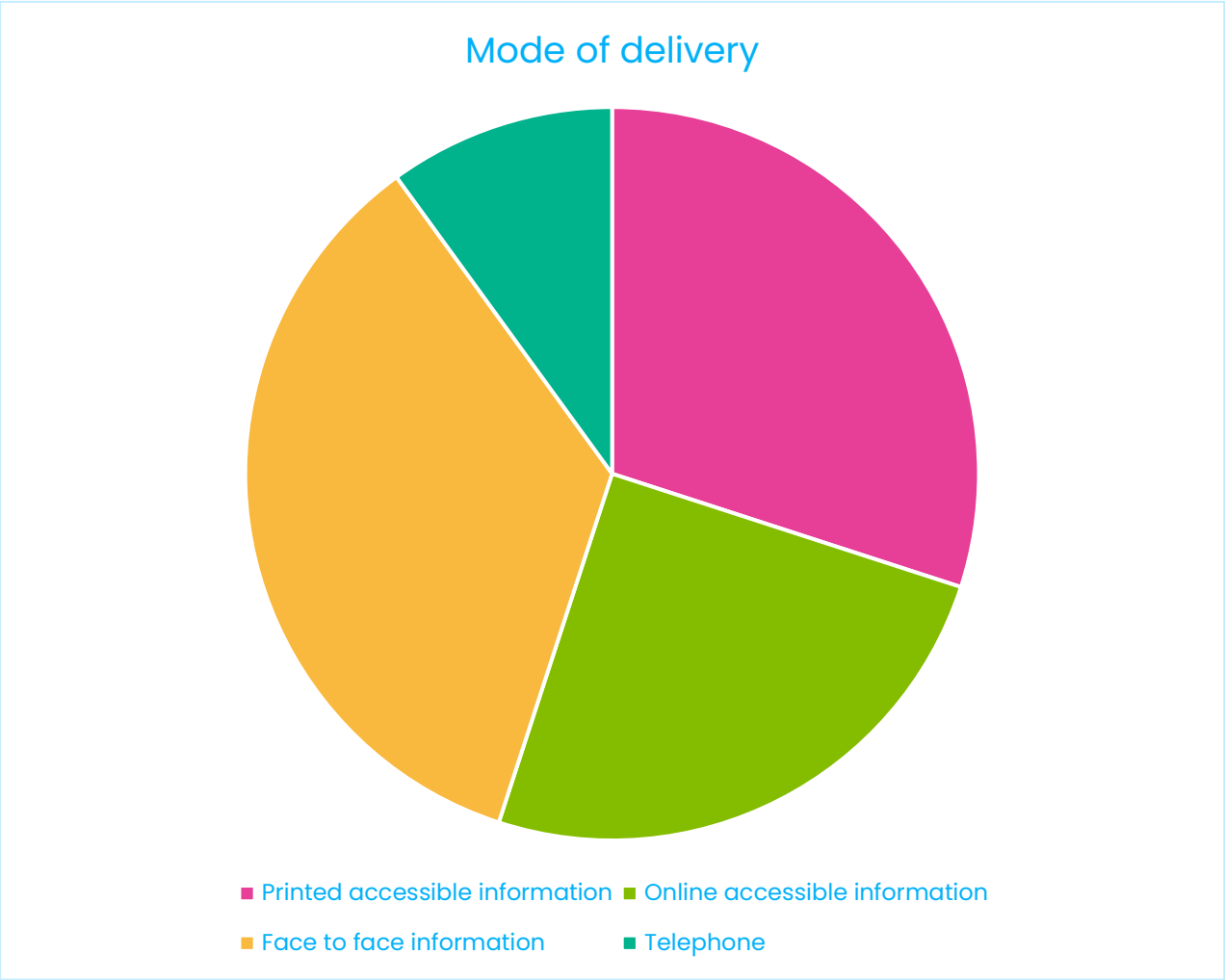
What

Half of participants left this blank. A few commented “nothing”. Three quarters of those that answered this (19 people) suggested a general elderly health and care services list or directory or leaflets would be useful.



Mode of delivery

Most popular mode of delivery was face to face – somebody people could ask. A close second was printed, and this was followed by online and telephone.



Comments

"Nothing, I have always had a good communication with the doctor and nurse and all of the NHS".

Face to face

"Just a general information explanation via GP".

"A central information point which could direct me to the particular help services that I needed. Carers would also be able to use this".

"Information coffee morning".

"A face to face conversation with somebody in the know about facilities and health concerns".

Printed

"A directory of available services would be useful even those one has to pay for".

"It would be useful to know what services are available to people. More advertising maybe, or leaflets in people's doors, with any additions and services that are available".

Online

"A comprehensive guide as a booklet or online book with links".

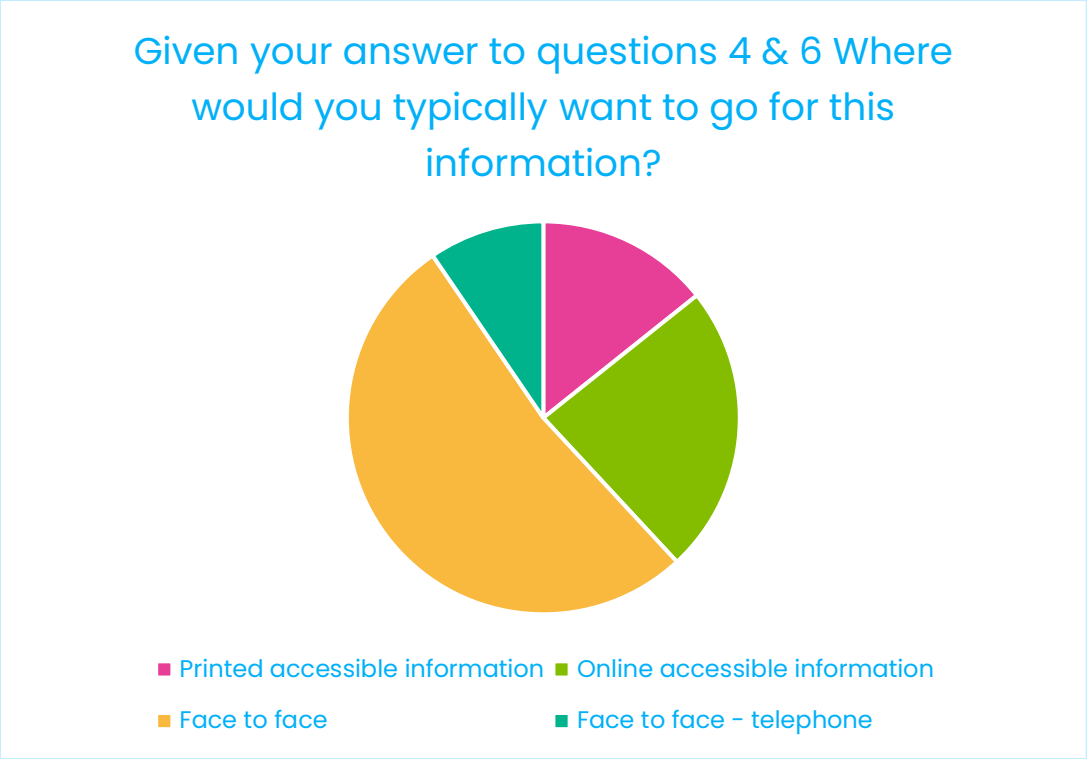
"Access to a website which would provide more information".

Telephone

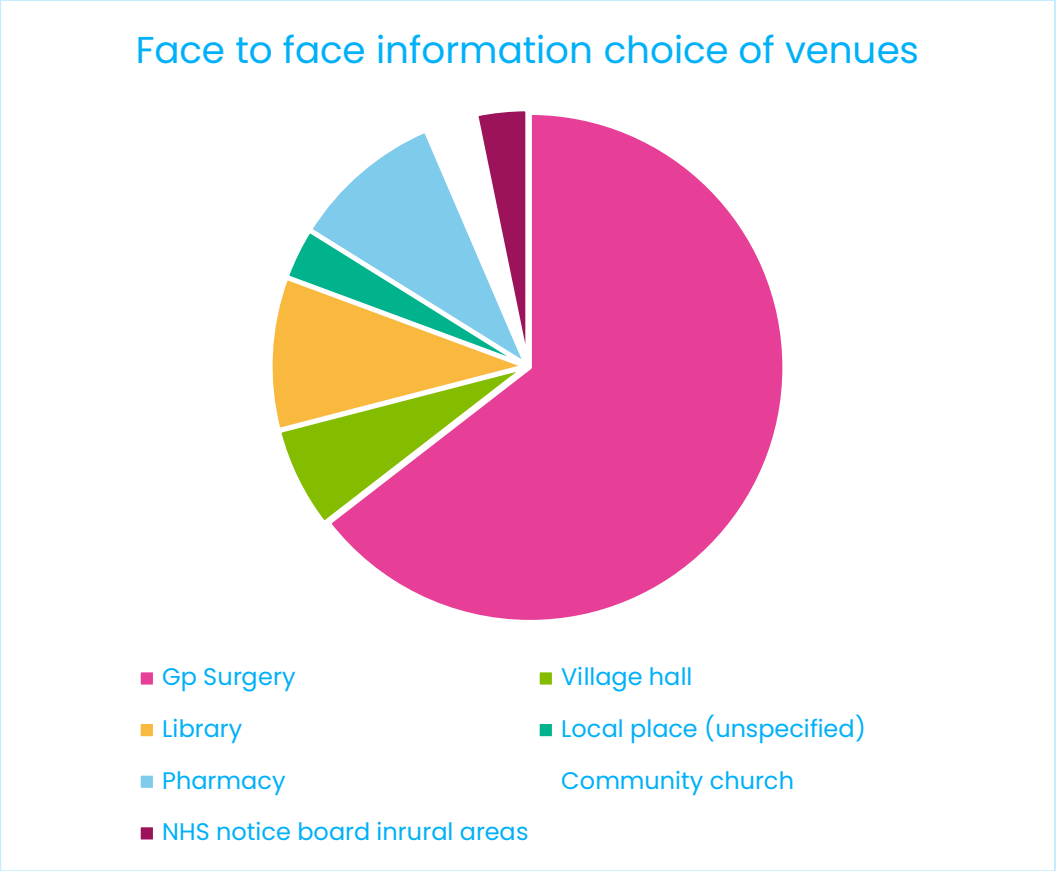
"Knowing locally when I reach place when I am infirm and frail and find it difficult to get out and communicate it would be good to know there is someone at the end of the phone to talk to get physical needs met e.g., shopping. Knowing the contact is out there."

Where

When asked where you would typically want to go for this information replies indicated an even larger proportion would typically seek face to face followed by online, then printed and telephone.



Breaking down face to face preferences in terms of choice of venue most viewed the surgery the place they'd wish to go. Pharmacy and library were second most popular choices.



Comments

We counted the frequency of different suggestions to judge preferences however, many people suggested more than one idea as the comments below illustrate.

"Surgery web pages, patient Access web pages, pharmacist, local government web pages".

"Pamphlets with contact numbers".

"Doctors surgery, which should be a hub for information about aging and health"

"Surgery, Library, village hall. Information by word of mouth is best. A person if possible. Even a national number. Non digital for the unsavvy".

"Why would I need to go anywhere if there was a phone line"?

"Obviously when accessing a service, I would want it to be as local as possible but being realistic this will be difficult to organise and pay for in a rural area like Herefordshire".

"Certainly, online should not be the only source. And if online phrased not for geeks but human beings and on sites that are very, very easily navigable".

"Not online. I think you would start to imagine you have all sorts of conditions! I think talk to a medical person".

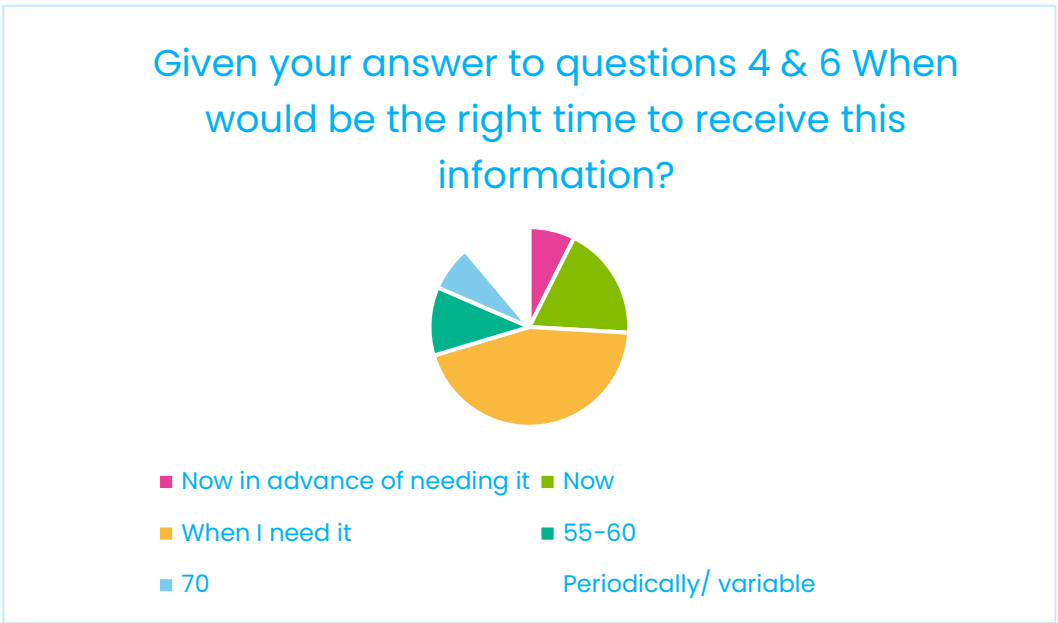
"Leaflets. surgery would be good too. I don't tend to use online I find it frustrating. Local community church are good could give information through them".

"I'm not sure, where can one go nowadays - library if you have one, doctors if you can get through the door, pharmacy but unfair on them, as they do a fantastic job already. You said in your preamble "near to your homes" maybe each village should have an NHS notice board or maybe each village hall used on a regular basis to highlight NHS services".

"I don't mind, online, at the GP, whatever, it needs to be advertised so I know it exists and then I can pick out what I need".

When

Most people said when they need it. Other suggestions were age related – 3 people said 55-60 and 2 said 70. Others said now or in advance of needing it or when particular difficulties or frailty occur.



Comments

"When I ask for or need information".

"I personally found 70yrs old a big turning point in how I felt and more aches and pains which due to the difficulty in seeing anybody at the surgery, I haven't yet done anything about it".

"? Hard to say when frailty increases!"

"As you get older it may become an issue for all of us as it all becomes a bit "loose"".

"When I am no longer able to cope with day to day matters or if I am widowed".

"Totally dependent on the information concerned".

Until you reach a point when you need particular help you don't know what you'll need or what you need to know".

Collaboration

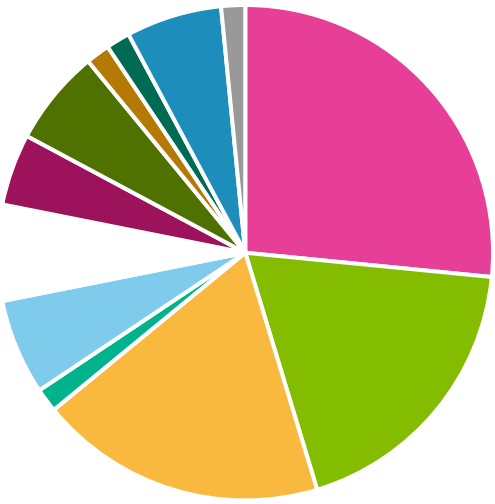
A plea for collaborative services from one person welcomed the opportunity to have a say and influence services.

"Basically, all services should stop being run for the elderly but in collaboration with them. It would be nice to believe this would be the start of that process".

What aspects of getting older are in our control?

Responses

a) What aspects of getting older: Do you think are in your control?



- Everything/ All at the moment
- Keeping fit/ Physical wellbeing/ mobility
- Eating healthily and my weight
- Taking medication correctly
- Mental wellbeing
- Looking after yourself
- Living environment
- Planning ahead, using your voice, taking responsibility
- Keeping Busy
- Finances (if not in poverty)
- Avoiding accidents
- Nothing/ Cant stop ageing

Aspects of getting older that people thought were in their control

Roughly 1 in 3 people (27%, 17 people) thought everything or all with the proviso of 'at the moment'.

Roughly 1 in 5 people (19%, 12 people) thought 'keeping fit/ physical wellbeing/ mobility' and 'Eating healthily and my weight'.

"Trying to keep as fit as possible. Eating well, not too many foods with preservatives, salt, and sugar. Having nice environment - I couldn't live in a city now after Spain and here., Don't eat rubbish. Don't eat sugary and processed stuff".

People flagged up a large number of other areas that they thought were in their control including:

- Having a voice and using it.

"I have a voice and I am aware of that voice, and I have to voice my concerns about my welfare. As long as I am aware or have people who are aware of issues I am having".

"Diet, fitness, weight. I have control also by my attitude of inquiry and willingness to look for and ask for help".

- Taking responsibility finances allowing…

"You have to take an element of responsibility for your own health otherwise you can bring illness on yourself. Have a good balanced diet, one glass of wine in the evening, don't be silly. Can look after yourself quite well. It is easy if your financial situation is not bad. A lot of people are struggling".

- Other areas age, fitness and memory allowing…

"At present my fitness, mind, mobility are the main aspects - that said, eyes, hearing and back related pain due to erosion are out of your control - "getting old aint good".

"Most of them while I am mobile and compos mentis".

"My whole life I can do what I want when I want. I guess if your memory goes, you'd lose that control".

One person felt that nothing was in your control as you can't stop ageing.

"No. No one is ready to accept that they are ageing. You lose control and just worry about it".

What aspects of getting older could health and care services provide differently to help?

Responses

What health and care services could provide differently to help?

People suggested a variety of areas with the most popular being 'more self-help advice and information on particular conditions' and making services 'more accessible'.

"Advice on when to seek help/advice on major illness symptoms".

"Let you know about useful information you may come across e.g., incontinence, dementia".

"They could make themselves more visible and accessible".

"Be more transparent about what help is out there".

"It would be great if you could be confident of accessing the help you needed when you needed it".

People suggested 'more face to face appointments', 'a local contact for ordinary ageing enquiries' and 'services proactively connecting you with all services that can help you'.

"I think they could if there were more face to face appointments with nurses or Doctors, sometimes just for advice".

"Services tell you all the things that they can connect you with that will help you".

"Clear sources of advice and support and a local network of supporters for practical stuff on an ad hoc basis (as during COVID!) We had a local volunteer group you could call on… Something like that ongoing would be amazing…"

Other suggestions were 'more carers', 'change of attitude', 'welcoming the need for advice', 'a support line', and 'online support'

"More involved, less busy".

"Regular conversations by appointment so that we don't feel guilty about calling a GP surgery".

b) What aspects of getting older: Could health and care services provide differently to help?

- More self help advice and information on particular conditions
- More carers
- Local contact for ordinary ageing enquiries
- Change of attitude
- More accessible
- More face to face appointments
- More involved
- More joined up
- Welcoming need for advice
- Advice on when to seek advice
- Quicker responses
- Guilt free appointments
- Services proactively connecting you with all the services that can help you
- Support line
- Online support

Specific areas suggested

People suggested specific areas of ageing that services might deliver more information or advice about.

Comments

"I do not know how good the pension is i.e., cost, accessibility, wait time the services need to be more high profile, advertised, made apparent".

"Hard to access post pandemic - however, end of life care seriously needs looking at - we need to end our lives with dignity – Please"!!!

"Bereavement counselling".

"Information to help you help yourself e.g., about dementia effects".

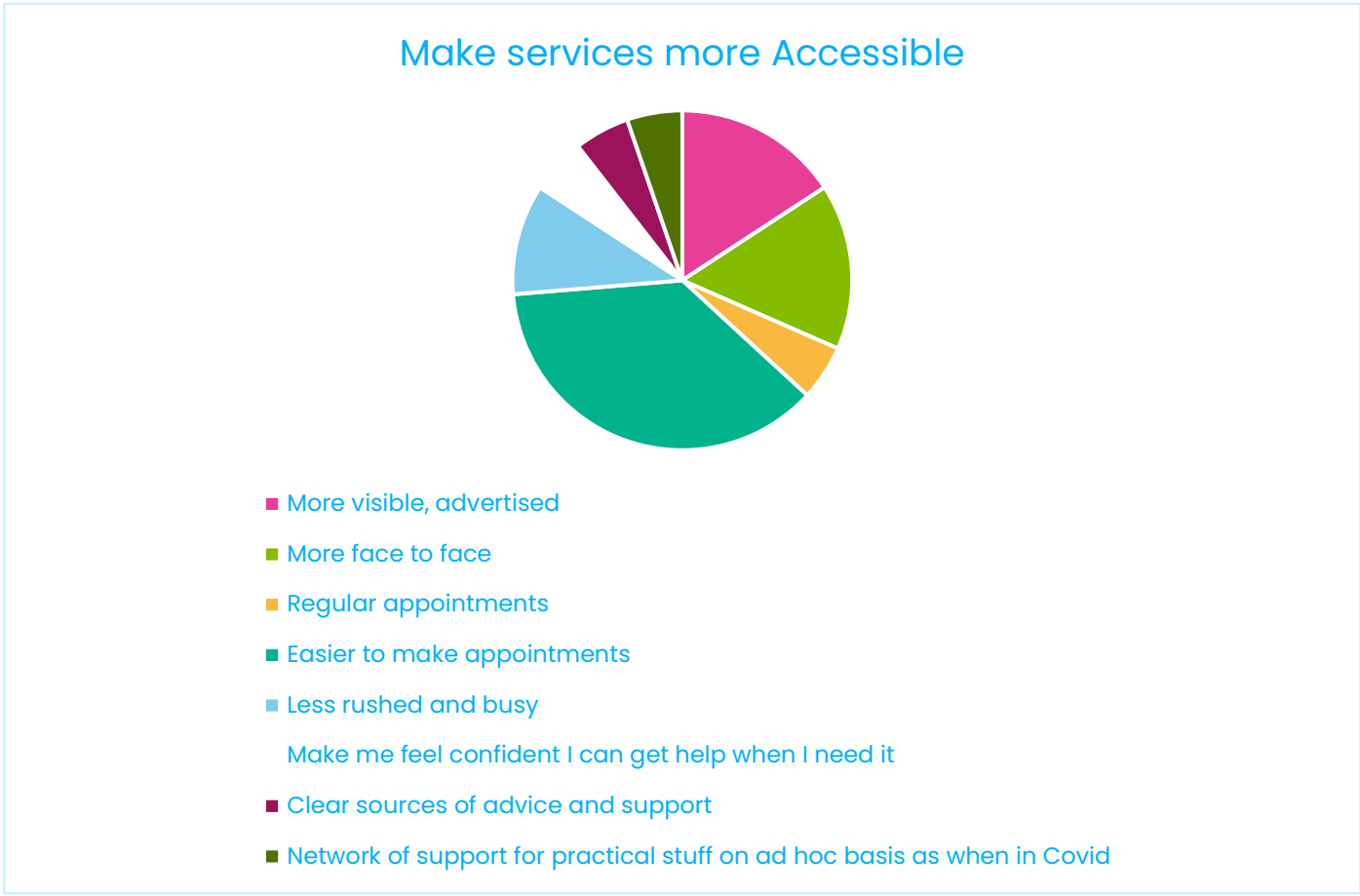
"Let's be real here - You're all tired - However, understanding the basics, getting old means - we don't hear well, don't see well - maybe that's a good start"!!!

What people meant by 'more accessible'

The most repeated concern about accessibility was easier to make an appointment but people wanted services to be more visible and advertised, more face to face and less rushed and busy.

People wanted to be confident they could get support when they need it and wanted good easy clear information sources.

A number mentioned that it had been very helpful being able to ring one number for local help around 'practical stuff' during Covid.



Conclusion, thanks, and next steps.

Conclusion

It is clear from the varied replies that people in Herefordshire experience ageing in very different ways.

We might have expected people to feel less contented as they grew older or if they had more long term conditions or a lower income, but we could find no such correlation in this study.

Ageing and our experience of it seems to be very individual and personal and driven by a combination of factors including all of the obvious aspects as well as:

- the people and environment that surround us,
- our activities, our attitude,
- our life experience,
- our hopes and fears
- and the treatment we receive from carers and health providers
- – and probably the mood we were in when we filled the survey.

It is difficult to generalise because of this but what came across was the considerable spirit and agency that this group of people showed. Also, their desire to remain as independent as possible for as long as possible, and a willingness to use services that help. Equally this study revealed a recognition in service users that services are under strain and not wishing to 'be a burden'.

It is concerning that some people feel guilty calling services that they need. People want to be responsible for their wellbeing by asking when they need help without being turned away as non-urgent enquiries. They want quality of care and continuity and mostly they desire face to face contact. They want to be respected as people with knowledge and not to be 'stereotyped or treated with condescension', 'patronised' or overlooked.

Most people do not want to consider their potential decline until issues arise. This can make it challenging to roll out preventative public health messages. It also means that often when a crisis occurs people don't know where to go or what to do. Sometimes the solutions are not complicated, and a short discussion is all that is needed.

For a generation that do not like to bother services a less formal chat is attractive and could prevent overuse of GP surgeries – such as the volunteers that could be called during Covid – as pointed out by a few participants. Perhaps a role for Talk Community hubs.

For all of us, ageing is a new experience – how do we know if that ache or twinge is 'just' to be expected at 'my age'? Where do we go to find out? Should we ignore it and hope it goes away?

Many of us will do this and participants that we spoke with expressed this dilemma eloquently.

The challenge for hard-pressed services is to offer timely information and advice and where necessary medical or care interventions that increase life quality in later life. Also to prevent avoidable decline or isolation and encourage collaborative personalised care and timely forward planning.

The evidence from this group of patients is that they are more than willing to engage with services constructively. They would welcome clear information and advice and easy less formal periodic contact to reassure and nip issues in the bud.

Recommendations

3. Consider ways to encourage and welcome ageing patients to make appointments when they need information or have concerns.

    a. Offer clear information on how to access GP services, make appointments and achieve continuity.

    b. Offer annual check-ups to explore non urgent but developing health issues and enable preventative advice and information.

    c. Offer clear information and guidance, directory or leaflet on services and practitioners with descriptions of what they offer, when to use them and how to access them. (Printed and online). Highlight or send out at a particular age or when a particular Rockwood scale is reached e.g., 3.

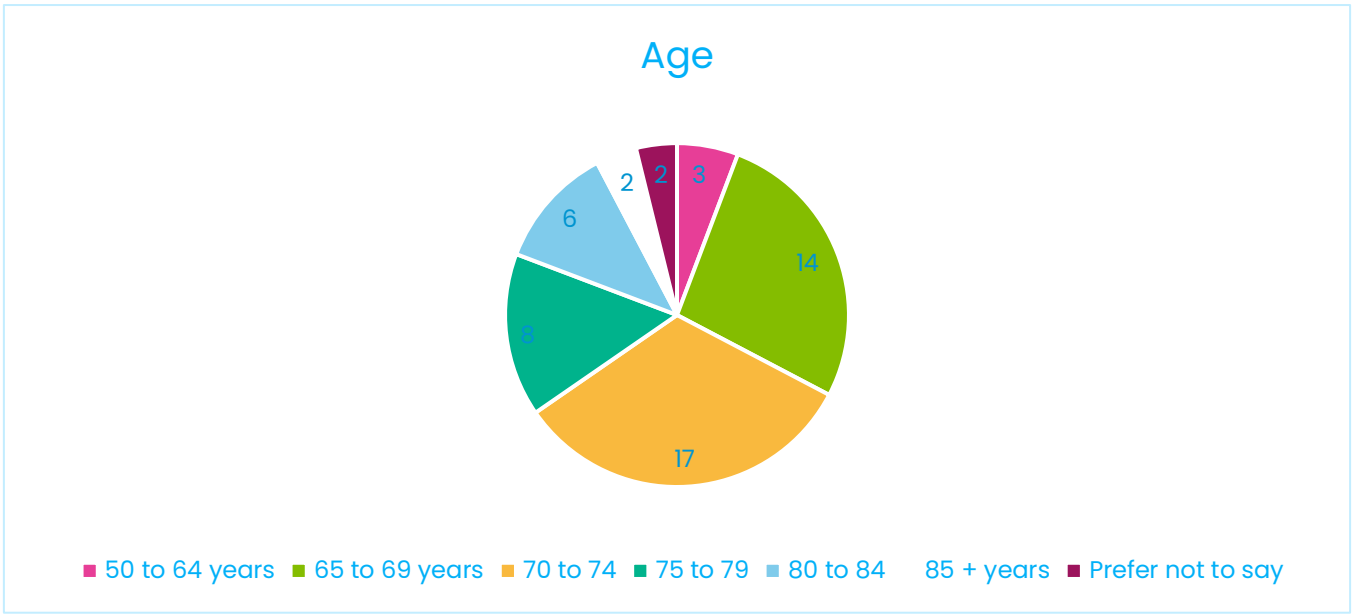
4. Offer clear self-help information on different common ageing issues or conditions that will inform and offer suggested actions for prevention and/ or treatment or enable forward planning e.g., Dementia, foot care, constipation, falls prevention, incontinence, sensory deterioration, mobility, end of life care, care options.

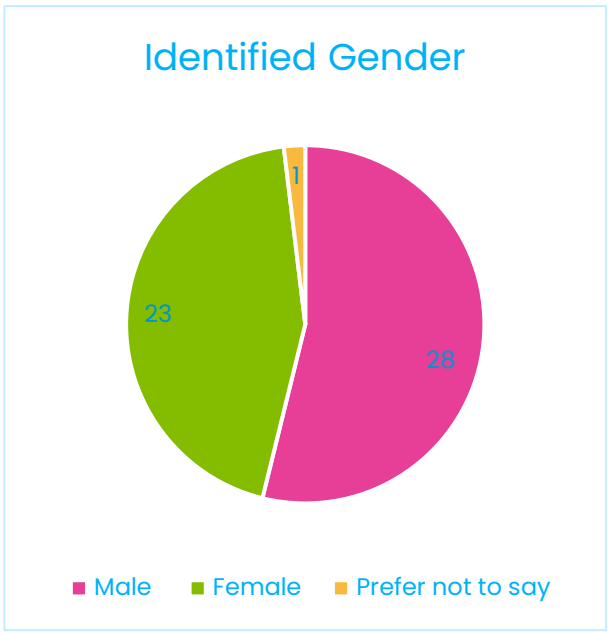
    Consider creating local easy to access, alternative face-to-face contacts through coffee mornings/ periodic open days, road shows or events/ support phone line that can disseminate self-help information and advice and signpost about general ageing issues, information, and advice.

    (This may link in where relevant with Talk Community initiatives and directory and Herefordshire Council actions regarding recommendations of Healthwatch Herefordshire's Future Care Report).

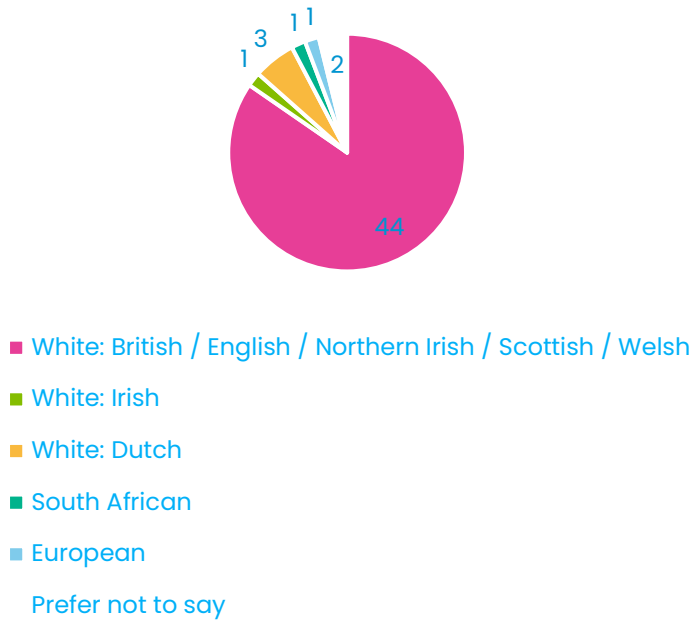
Appendices

Appendix 1 Demographics

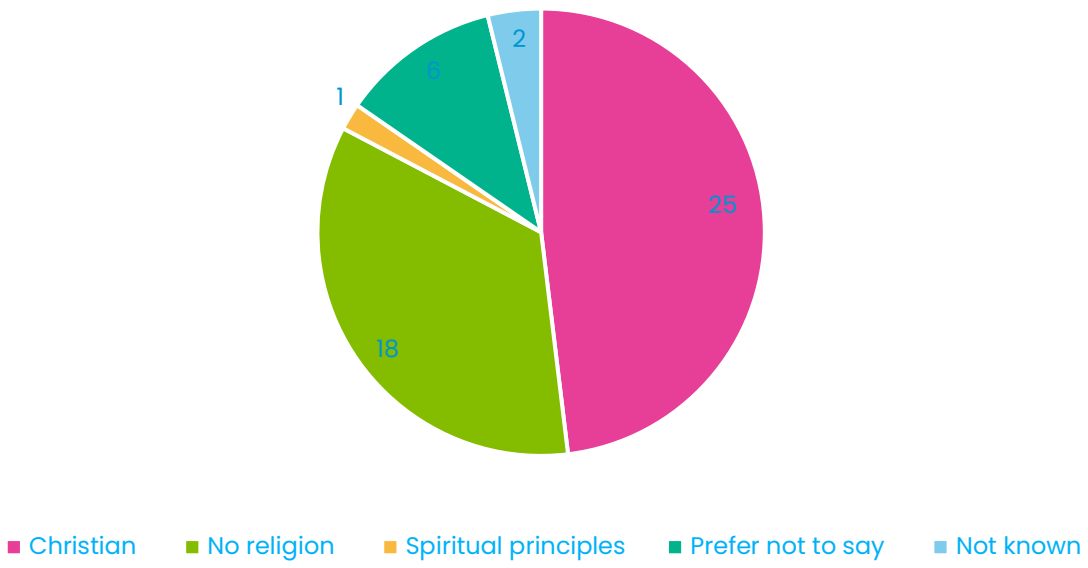




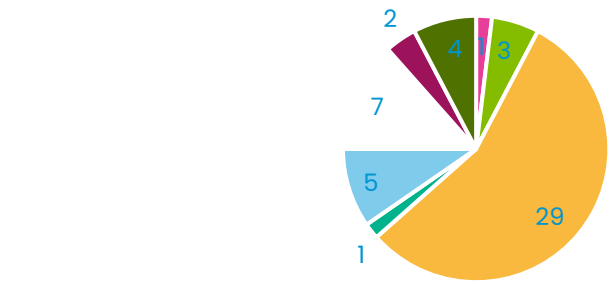
Ethnicity



Religion or belief

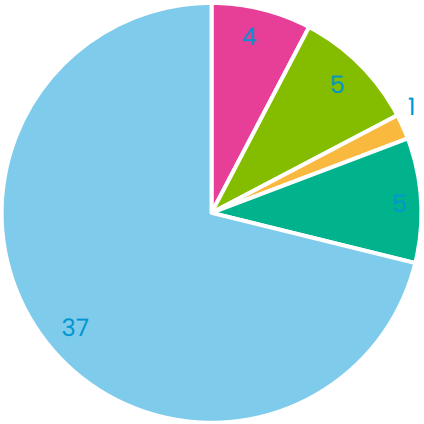


marital and civil partnership status



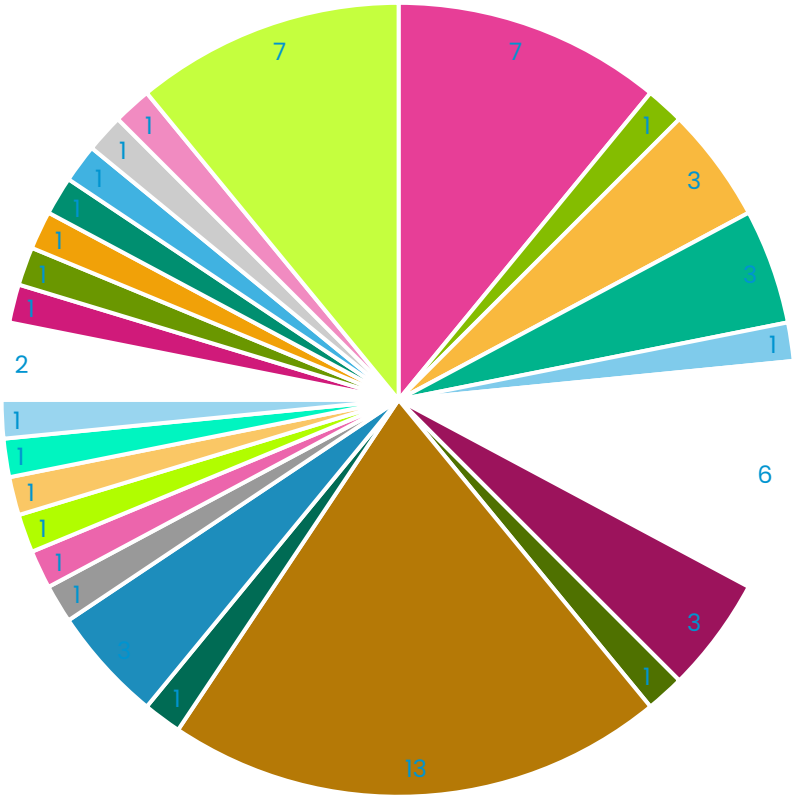
- Single
- Cohabiting
- Married
- Separated
- Divorced / Dissolved civil partnership
- Widowed
- Prefer not to say
- Not known

Do you have a disability?

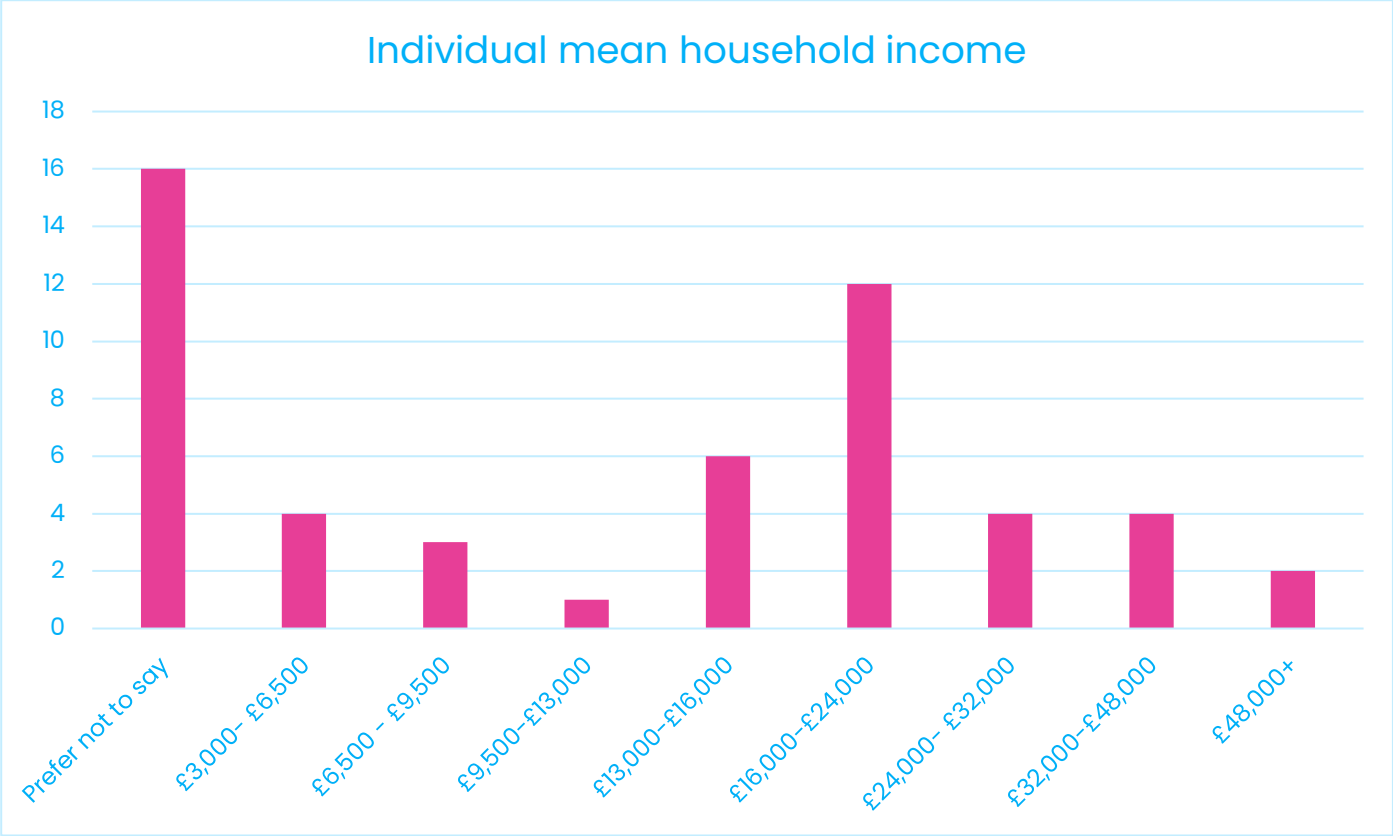


- Physical or mobility impairment
- Sensory impairment
- Mental health condition
- Long term condition
- No

Do you have a long term condition?



- Asthma, COPD or respiratory condition
- Blindness or severe visual impairment
- Cancer
- Cardiovascular condition (including stroke)
- Chronic kidney disease
- Deafness or severe hearing impairment
- Diabetes
- Epilepsy
- Hypertension
- Mental health condition
- Musculoskeletal condition
- Alcoholism (in recovery)
- Atrial fibrillation, osteoporosis, glaucoma
- Colostomy.
- Diabetes 1
- Dystonia
- Frequent urination
- High Cholesterol
- Hyperthyroidism
- INR checks following heart surgery.
- Menieres disease
- Thyroid
- Trapped back nerve
- Varicose veins
- Prefer not to say
- No



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

Participant postcodes

- Most participants had a Worcestershire postcode though they live in Herefordshire and access Herefordshire Healthcare.

Appendix 2 Draft Recommendations of Future Care report for comparison

Herefordshire Council with Healthwatch Herefordshire will consider how to:

Produce a plain English Guide.

Produce a plain English guide that highlights areas to consider and sets out choices available for future care. Sent out if certain diagnoses or age reached e.g., by GP, employer, social care or with pension?

Create a map to find information.

Create a clear map of where to find reliable up to date information about areas to consider, choices and options.

Clarify financial information.

Provide a clear explanation of the financial costs of different options and how to work out what you would pay for your individual circumstances and health or social care funding that might be available.

Clarify options for specific conditions.

Highlight what is available to match the needs of people with specific requirements e.g., disabilities (like ME, Autism, learning disability), and dementia including early onset dementia. Include respite care.

Show rural availability and options for couples.

Highlight what is available to match the needs of people that wish to live in a rural area and couples that wish to stay together.

Accessible information in different formats

Consider ease of access to information including for people that are digitally excluded and people that require Easy Read.

Provide community activities that inform and encourage forward planning

Provide information, activities and events that can be accessed at Talk Community hubs + elsewhere including online videos about subjects such as choices for care, Lasting Powers of Attorney, Wills, RESPECT and End of life pathways and choices e.g., Ageing well fairs.

Provide a list of places to find independent reviews

Provide a list of places that people can find independent public reviews of providers for example Healthwatch Herefordshire feedback centre and CQC.

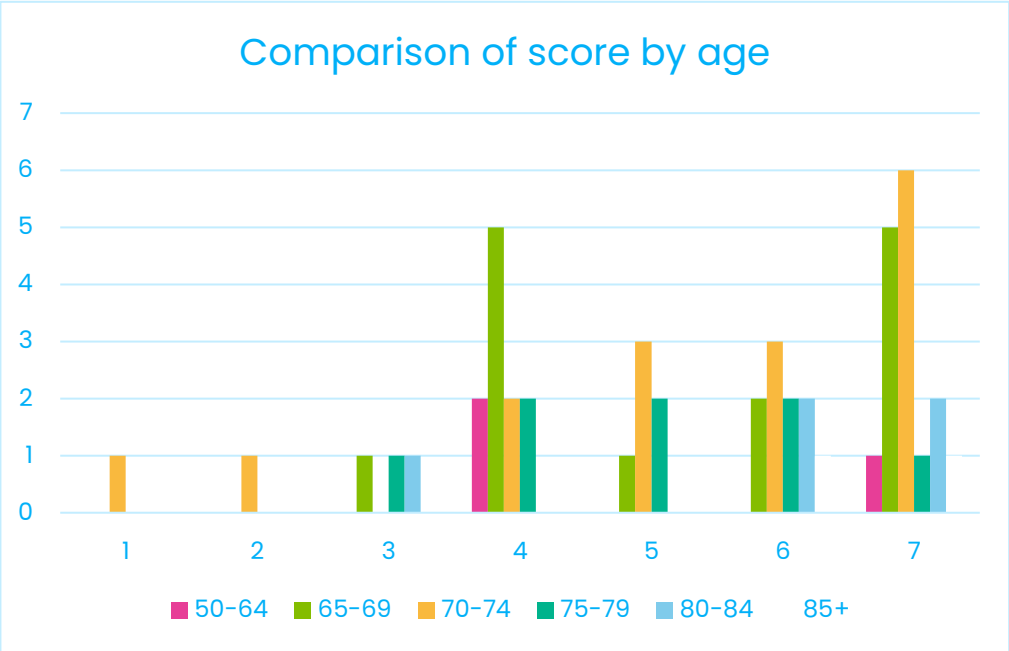
Encourage online future care forums

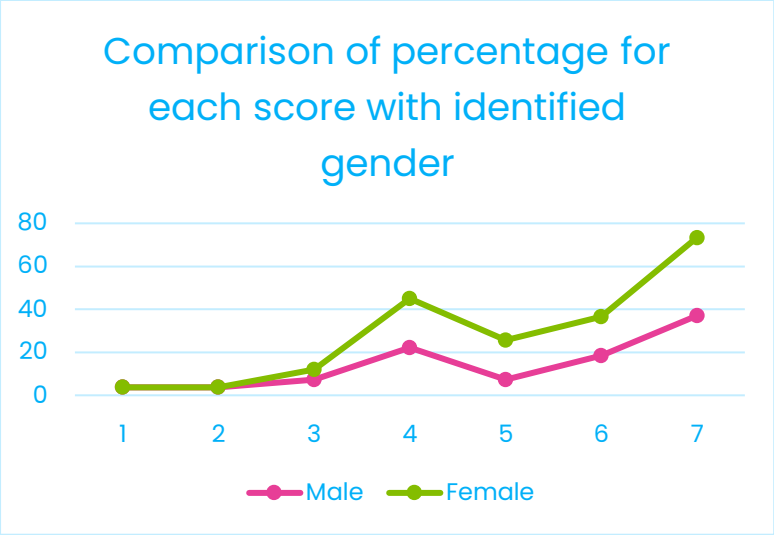
Encourage the voluntary sector to form online forums for older people to discuss their future care and their experiences and to gain mutual support.

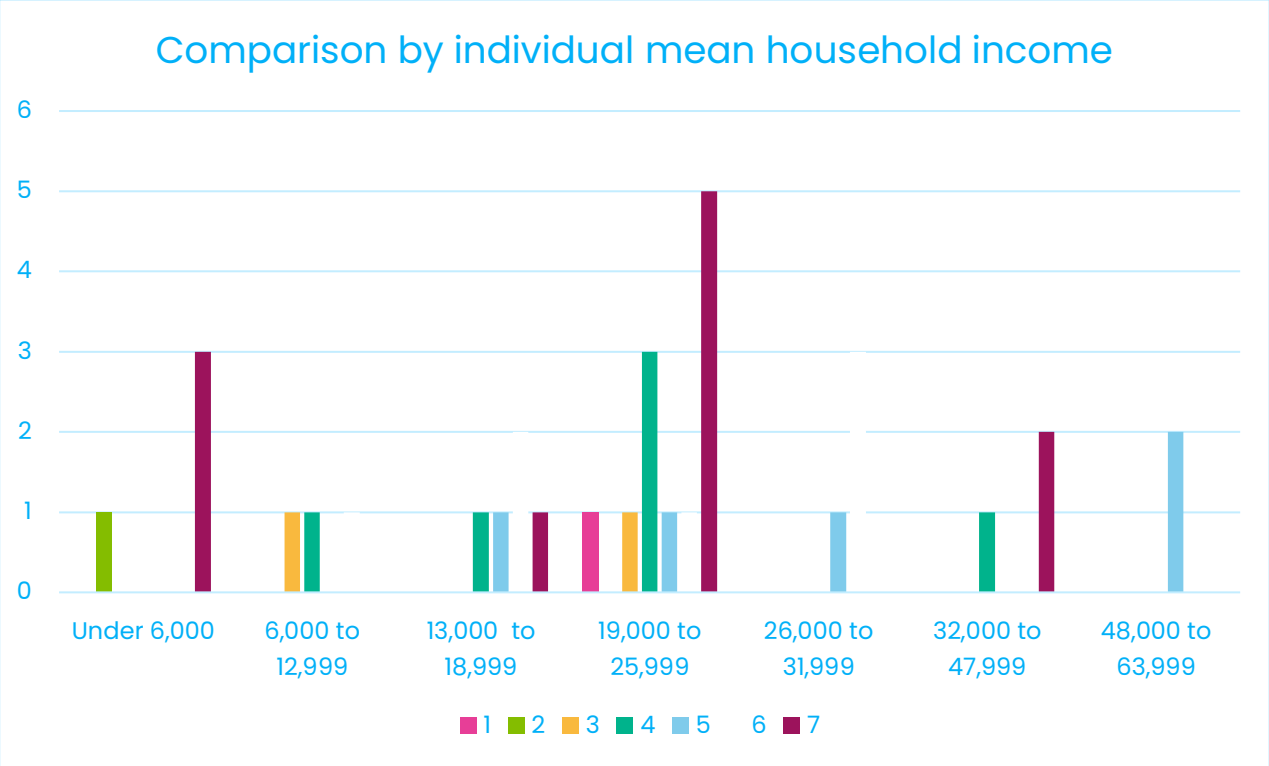
Consider a department for future care

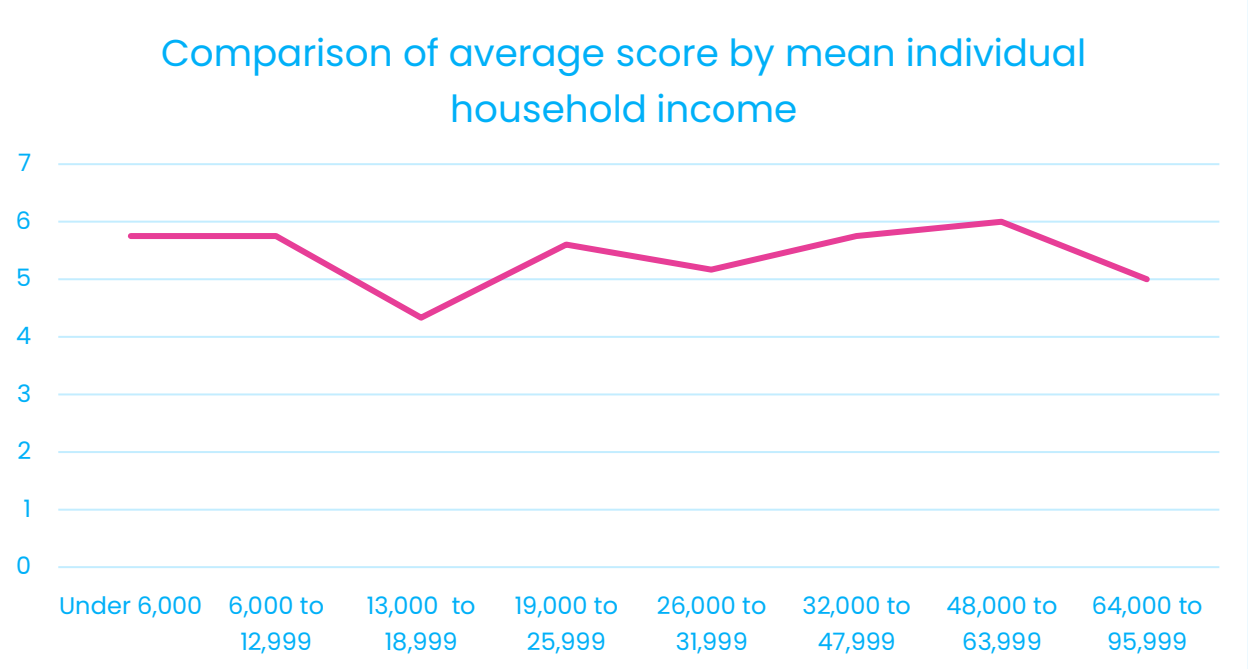
Consider creating a single department for future and elderly care (one place that people can identify) to help to deal with all issues associated with future care such as household adaptations and aids, incontinence advice, dementia, disability, frailty and falls prevention as well as carer support.

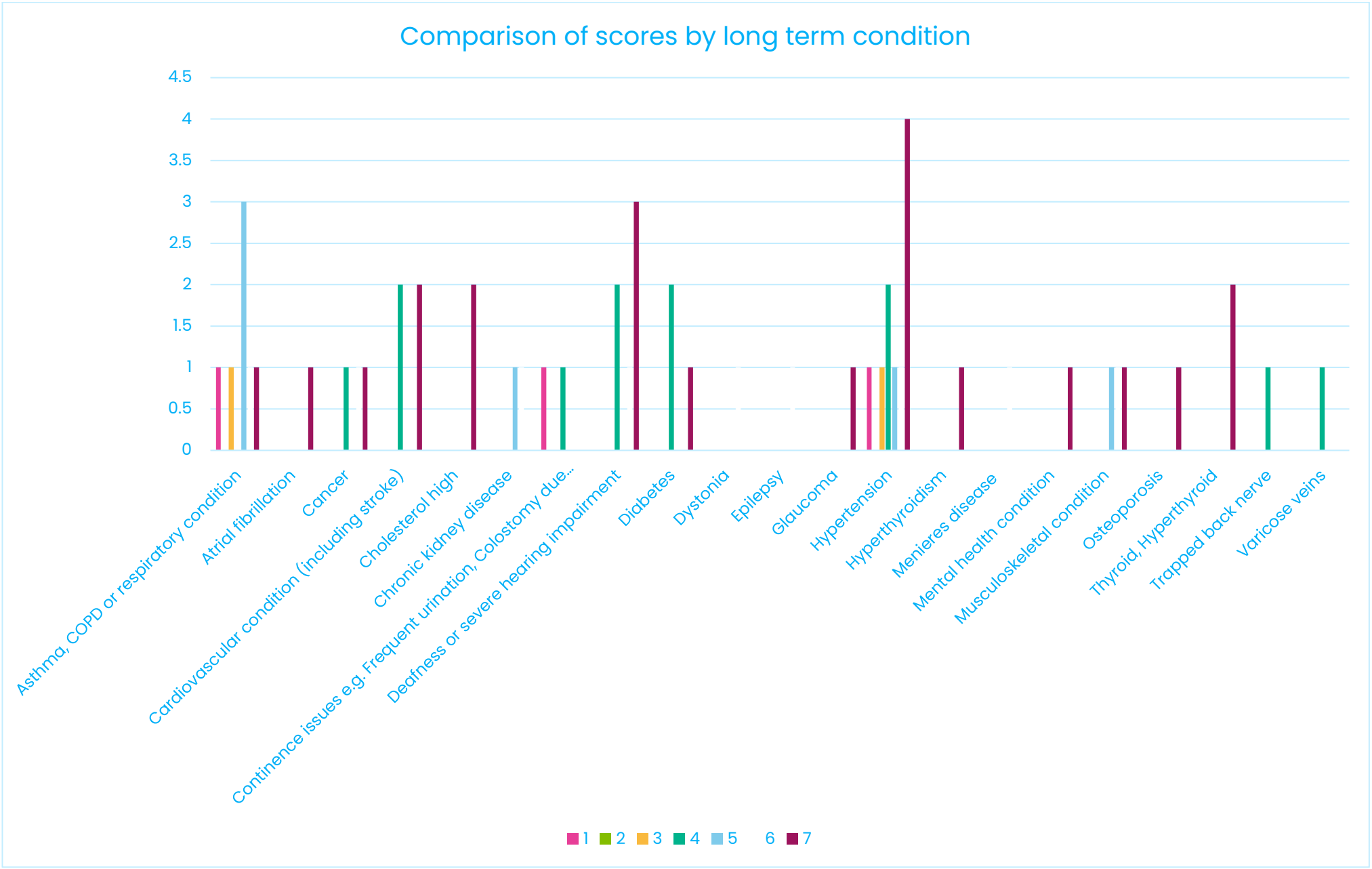
Appendix 3 Comparison of participant score by different demographics

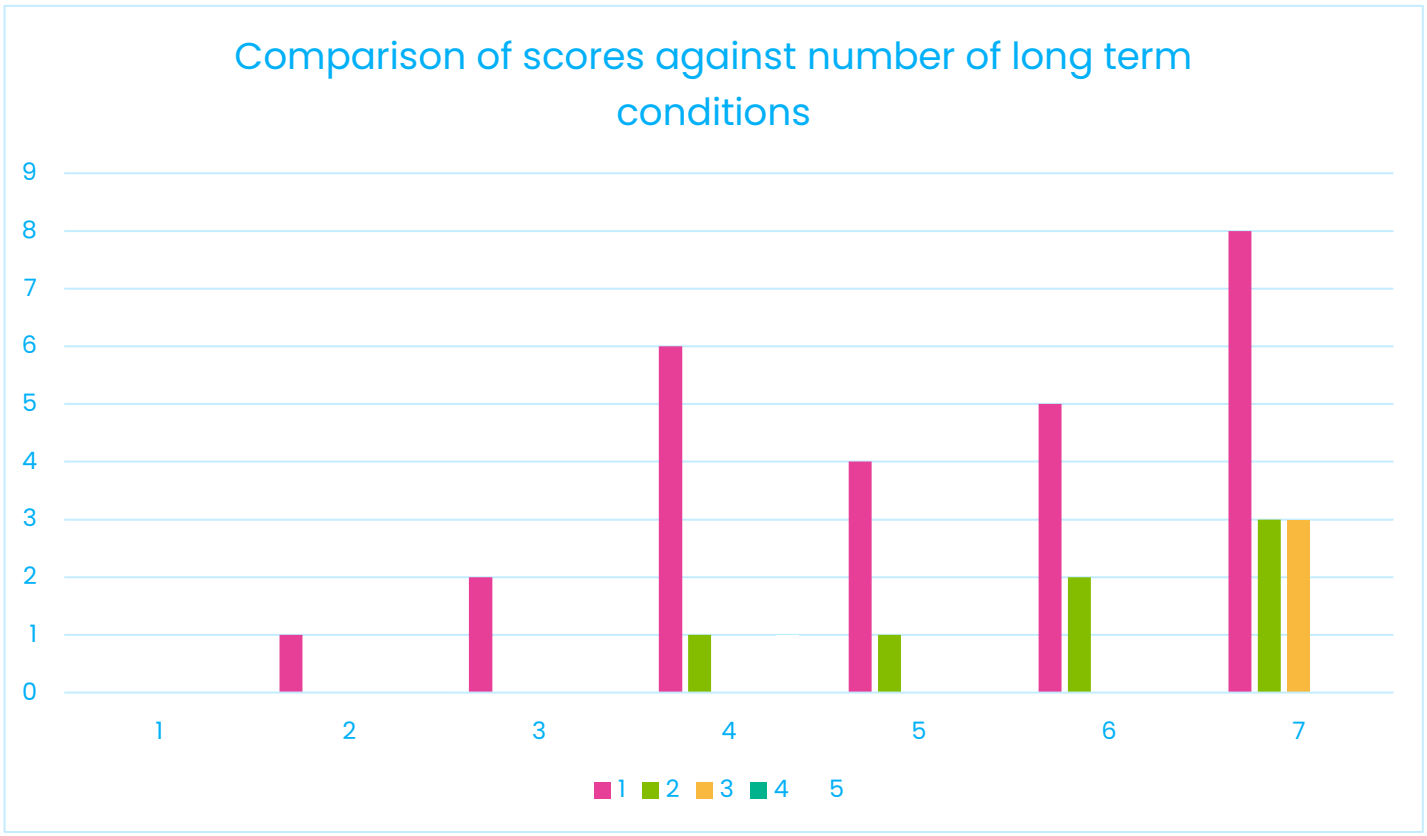





Comparison by individual mean household income
6
5
4
3
2
1
0
Under 6,000
6,000 to 12,999
13,000 to 18,999
19,000 to 25,999
26,000 to 31,999
32,000 to 47,999
48,000 to 63,999
1 2 3 4 5 6 7


Comparison of average score by mean individual household income
7
6
5
4
3
2
1
0
Under 6,000
6,000 to 12,999
13,000 to 18,999
19,000 to 25,999
26,000 to 31,999
32,000 to 47,999
48,000 to 63,999
64,000 to 95,999


Comparison of scores by long term condition
4.5
4
3.5
3
2.5
2
1.5
1
0.5
0
Asthma, COPD or respiratory condition
Atrial fibrillation
Cancer
Cardiovascular condition (including stroke)
Cholesterol high
Chronic kidney disease
Continence issues e.g. Frequent urination, Colostomy due...
Deafness or severe hearing impairment
Diabetes
Dystonia
Epilepsy
Glaucoma
Hypertension
Hyperthyroidism
Menieres disease
Mental health condition
Musculoskeletal condition
Osteoporosis
Thyroid, Hyperthyroid
Trapped back nerve
Varicose veins
1
2
3
4
5
6
7


Comparison of scores against number of long term conditions
9
8
7
6
5
4
3
2
1
0
1
2
3
4
5
6
7
1
2
3
4
5


Comparison of scores for people with one long term condition
10
8
6
4
2
0
1
2
3
4
5
6
7

Appendix 4 Rockwood scale

Clinical Frailty Scale*

1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 Managing Well – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 Vulnerable – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 Mildly Frail – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 Moderately Frail – People need help with **all outside activities** and with **keeping house.** Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9 Terminally Ill - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

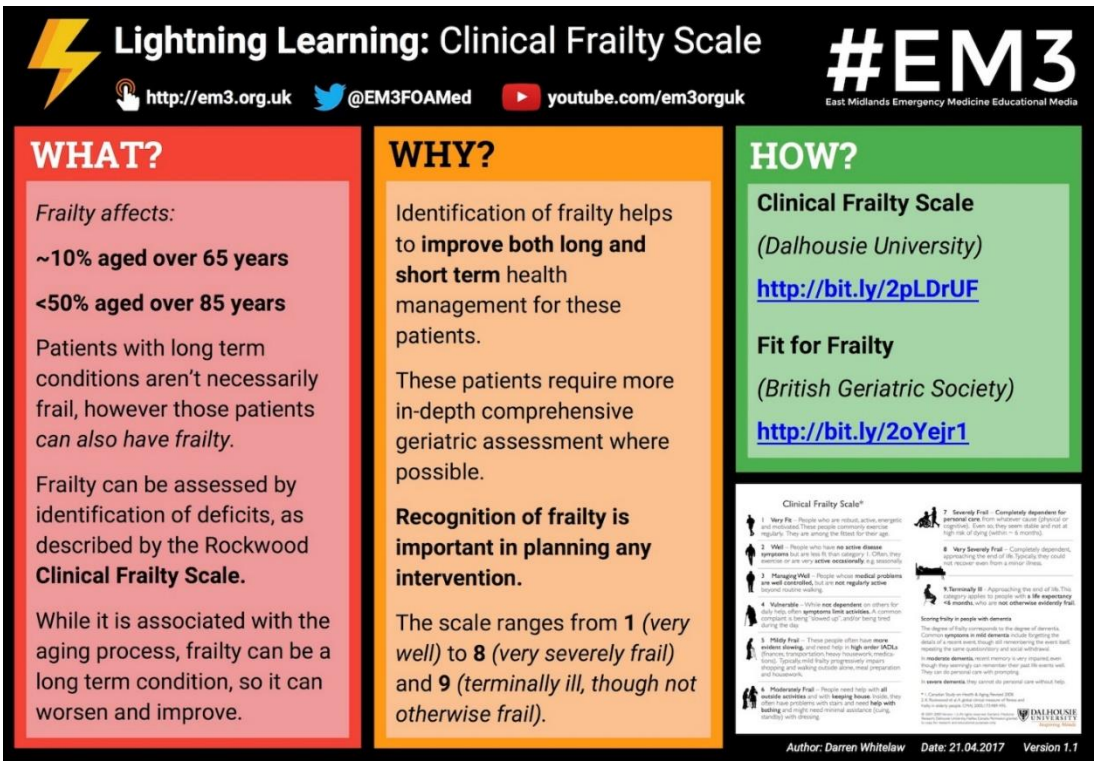
Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.



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