Healthwatch Sutton

People's experiences of services for Frailty

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Andrew McDonald,
Health Engagement Project
Officer



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Introduction

In 2024, Healthwatch Sutton (HWS) agreed with Sutton Health & Care (SHC) and NHS South West London Integrated Care Board (SWL ICB) to investigate the experiences of health services of people living with frailty. This was to identify good practice and areas for improvement in those services for that cohort. It was also to identify how people who are frail think about the concept of 'frailty'. Do they consider themselves as 'frail' or find the word offensive?

The report presents answers to these questions based on 12 interviews which HWS carried out with Sutton residents who had used the following services: Maximising Independence Service, St Raphael's Hospice Wellbeing Service, Urgent Community Response, St Helier Frailty Hub and Sutton Virtual Ward.

About Healthwatch Sutton

Healthwatch organisations are statutory (legally required) bodies that have been set up to ensure that the voices of local people are heard in the design and delivery of health and social care services. The Council for every local authority area must procure a local Healthwatch organisation.

HWS is the local Healthwatch organisation for the London Borough of Sutton. We are a charity and a company limited by guarantee. Our principal activities are projects that investigate specific areas of health and social care and we use our statutory power to influence improvements for residents, and for people who work or who are educated in the borough.

We also provide an information and advice service, and support access to NHS complaints advocacy through the Together for Sutton Partnership (https://togetherforsutton.org.uk/)

Methodology

HWS carried out semi-structured interviews with 12 people who were either living with frailty or caring for someone living with frailty. This provided insight on their experiences of health and care services and of living with frailty. The below table lists the number of interview participants who had used each of the following services. These services approached their users and identified those willing to take part in an interview with HWS (see Appendix for Questionnaire and Service descriptions).

Service	No. of participants
Maximising Independence Service	4
St Raphael's Hospice Wellbeing Service	4
Urgent Community Response	2
St Helier Frailty Hub	1
Sutton Virtual Ward	1

HWS completed one interview at St Helier Hospital, five in participants' homes and six over the phone from its offices in Sutton. HWS staff and volunteers carried out the interviews in participants' homes in pairs. Interviews lasted between 30 and 90 minutes and participants were given a £50 gift card. HWS audio recorded the interviews and transcribed them using TurboScribe.

Limitations

Only 12 people took part in the project, so the findings do not represent the experiences of all people living with frailty in Sutton, nor the use of all local services by that group.

Demographics

Demographic	No. of participants
Gender	• 5 Women
	• 7 Men
Age	• 150-64
	• 265-79
	• 780+
	 2 Prefer not to say
Ethnicity	9 White British/ English
	 1 Black Caribbean
	• 1 Sri Lankan
	1 White European

What is 'frailty'?

The British Geriatrics Society (BGS) defines frailty as "a distinctive health state related to the ageing process in which multiple body systems gradually lose their in-built reserves." The Clinical Frailty Scale, sometimes called the Rockwood Frailty Scale, can be used to measure a person's level of frailty. The BGS suggests that some older people do not identify with the term because "it is often associated with increased vulnerability and dependency". In this project, all participants valued their independence and did not want to lose it. Three were uncomfortable with the term 'frailty'.

¹ G. Turner, Introduction to Frailty, Fit for Frailty Part 1 (2014). https://www.bgs.org.uk/resources/introduction-to-frailty [Accessed 20/03/25].

² NHS England, *Rockwood Frailty Scale* [n.d.]. https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2022/02/rockwood-frailty-scale_.pdf [Accessed 20/03/25].

³ G. Turner, Introduction to Frailty [Accessed 20/03/25].

Results

The following results are split into four questions:

- How do people with frailty experience health services?
- What does frailty mean to people?
- How does frailty impact people?
- How do people respond to frailty's impact?

How do people with frailty experience health services?

Finding out about health services

Participants tended to find out about health services through other health professionals. These included Physiotherapists, District Nurses and GPs, who sometimes referred them. Participants also mentioned finding out through other services such as the Royal Marsden, Sutton Council and Age UK Sutton. Participants spoke about using Google and their family to help find out what was available.

Two participants, who were both unpaid carers, said it would help if there was a single source of information about available services. This couldn't be digital only, as it would exclude some people, including some of the elderly and disabled. One participant suggested Hospitals give elderly people a calling card with one phone number when they discharge them: "you need one central place to say, right, OK, well, you need to go here for that."

Forms of this service already exist in Sutton. For example, the Sutton Information Hub and Together for Sutton Partnership. Is there an equivalent for just local health and social care services?

What was good about health services?

Outcomes

Participants naturally talked about outcomes they had from using services. Good outcomes focussed on improved mobility:

- "They've shown me how to get up from the chairs, which has been very, very helpful to me, because I found that much easier than the way I've been struggling." Maximising Independence User
- "she actually taught me how to turn (when walking)" Maximising Independence User
- "I've got this little boot. It's going to stop the pressure on my foot." Frailty Hub User
- "the nurse came round and used to walk me out in the street, and would walk with me to see how I was walking." Maximising Independence User, talking about her Hip Operation follow up

Good outcomes were also about gaining confidence, including around not having a fall. It would be interesting to compare services' impact on their users' confidence against actual improvements in their mobility:

- "It proved that I'm getting over the fear of falling." Maximising Independence
 User
- "So that's been extremely beneficial because I can get up and down and out much more safely, but also with more confidence." Maximising Independence User, talking about a step installed at her home
- "I was walking with two sticks to begin with but when I came back here
 (home), then I was able to sort of walk and gradually go around the block. I
 felt quite confident doing it." Maximising Independence User, talking about
 physiotherapy following a hip replacement

Maximising Independence sessions

Participants explained how it was easier to do exercises in a group than at home on their own. They found being with others gave them encouragement and they didn't have distractions, such as parcels arriving. They appreciated the sessions not being too intense and being able to work at their own level, although one said they couldn't do all the exercises because of their disability. They thought it was helpful to have quite a number of sessions in one go:

"you're doing it all together. And it encourages you to do it." Maximising
 Independence User

- "We're told to do what you can. If you have to sit down, that's fine...So nobody feels under pressure." Maximising Independence User
- "12 weeks is quite a nice long span of time actually because with some things where you're only given maybe four weeks or even six weeks" Maximising Independence User

Responsive services

Participants were impressed when services reacted quickly for them. They saw this as a sign of competency and thought services should have more publicity in recognition of this:

- "If I call somebody, they come out straight away. It's normally a blocked catheter." Urgent Community Response User
- "At half past one in the morning, in they come with a big smile, you know, it's great." Frailty Hub User, talking about District Nurses
- "they assessed that very quickly and did the tests and things like that."
 Daughter of St Raphael's Hospice Wellbeing Services User, talking about her
 Dad's experience of the Sutton Memory Assessment Service
- "I rang my GP at 8am and that day I had the medication delivered and nurses round to look at my knee" St Raphael's Hospice Wellbeing Services User

Signposting

As well as receiving care and support from services, participants appreciated getting information from them about what else was available. Can services use this potential in other ways, to get more relevant information to different audiences in Sutton?

 "I go to Age UK and because I'm recently bereaved Age UK has been very good. There's a leaflet that goes around to tell the elderly what is available in the community. If I want anything, I ring up and they'll connect me to people."
 Maximising Independence User

Manner of staff

One area which received a lot of praise was staff manner. As well as being polite and friendly, participants talked about staff treating them like a normal person. One

participant liked how staff used their first names because it meant "there's no sort of, no strangeness of it."

- "they're very nice people, they do a good job, no complaints." Virtual Ward User talking about his VW visits.
- "They're polite and they do help me as much as they possibly could." Urgent Community Response User
- "they treat you very much as if you were a friend of theirs. Like, you know, they're very level with you" Frailty Hub User

What else could health services offer?

Ongoing health problems

Two participants explained that their arthritis and back pain was ongoing after treatment. They didn't think they could do much more about it and accepted a level of ongoing discomfort. How could services ensure they don't overlook any other support that is available to them?

- "they can't really cure arthritis. But I do the exercises and that's all I can do"
 Maximising Independence User. This mindset discouraged her from seeing
 her GP, particularly as she found it difficult to book appointments over the
 phone: "So I try not to go around there too often."
- "All I do is take painkillers. But, you know, I've done as much as I can." Virtual Ward User, asked if he wanted more support for back pain.

Another participant spoke about no longer walking. He said the physiotherapist had told him his legs weren't strong enough to walk. He also spoke about losing confidence following a fall. Despite this, he wanted to walk again, possibly using a Zimmer frame or crutches. How can services assess his mobility in a way which is clear to him?

"Physio come and said "No, your legs aren't strong enough to support you. So
you can't walk." I went, "Okay." I accepted that." Urgent Community Response
User

One participant explained their Dad wore a Medequip watch. However, if he had a fall, he would shake on the floor due to his Parkinson's. This made the watch think he had got up so it didn't send an alert. Another participant who also wore the watch said it was effective but would sometimes raise a false alarm when they were sitting down. Are others having these problems and can Medequip resolve them?

Doing exercises

One participant explained that they were having chemotherapy whilst going to Maximising Independence sessions. They said this made the sessions very tiring, but they still thought they were beneficial. How can services for frailty remain aware of peoples' wider health and how it impacts their activation?

"the exercises we're doing and the concentration, I'm really really tired. I think that's probably a side effect of the chemo as well. You know, you do one thing in the day and then you've just got to sit down...It's horrible but you know most of the time I'm not like that. So I think it's been beneficial. "Maximising Independence User

Three participants said they found it difficult to maintain exercises they were given. They said it would be easier if they had more follow up and fewer exercises. Do services think these demands are reasonable? Can they respond to them with available resources?

- "They give you a big book with exercises in. But with the best will in the world, and I'm sure I'm not the only one, I'm not terribly good at learning them. I did try but eventually it tails off and so you need to know what's the next step" Maximising Independence User, talking about their follow-up for a hip replacement at SWLEOC
- "if they gave you four exercises and said it will be good for you to continue
 with this. Because you know the focus is there...But you give me all these
 exercises to go away with. How many people are going to continue doing all
 these exercises?" Maximising Independence User

Continuity of care and sharing information

Participants often wanted to see the same staff over time. They liked to get to know the staff they saw and build confidence in them. What is the position of services for frailty on offering continuity of care?

- "You don't see the same lady or man who knows you and knows your situation." Maximising Independence User, talking about treatment for their neck and knees at St Helier Hospital and Jubilee Health Centre
- "at the moment, I've got locums...they're not committed like a GP" Frailty Hub
 User, talking about his GP surgery
- "Not having to muck around and keep changing and going from A to B. And having to explain everything and start again." Urgent Community Response User, asked if it was important to have the same carer

A Virtual Ward user complained that the information from their Virtual Ward visits hadn't reached their GP. They were frustrated by this and it would be interesting to check with the Virtual Ward what happened:

"Well, they said, you know, it (medication) needs reviewing, there was too
much and not the right stuff and I went to the doctor yesterday and they said
that they hadn't any information from the virtual visits." Virtual Ward User

Manner of Staff

As already discussed, staff manner mattered to participants. They wanted staff to be personable, polite and culturally-competent. One participant explained that if staff didn't chat to him, he didn't relax. Another participant thought staff appeared overworked, highlighting that members of the public recognise that NHS staff are under pressure.

- "If they're not polite, they're not going to get off on the right foot, are they? I
 mean, if someone was an NHS worker and they were rude to you, how would
 you feel?" Urgent Community Response User
- "I had to get my Husband's results or whatever when they did the test. And I said, he's from Guyana. He's from South America. And they said Ghana, Africa.

- I said, no, Guyana, South America. And she was insistent that I meant Ghana." Maximising Independence User
- "I have accepted that the poor people are overworked. They're doing a good job." Virtual Ward User

Knowing about other services

When asked if they wanted to use other services they weren't currently using, some participants said they weren't aware of what else was available. Some went on to say this was because they were content with what they currently had.

- "No, I don't know of any other services..., I'm happy with what I'm receiving, really." Maximising Independence User
- "I would quite like more information either written or sent by email or text. It would be interesting to see" Virtual Ward User
- "When I had had that for a week (private hydrotherapy, following hip replacement), I did feel maybe I could carry that on but I didn't know how to find out about any local hydrotherapy so I didn't know if that was even a thing on offer." Maximising Independence User

One participant, who had home visits under the Virtual Ward, said he didn't know about the visits in advance. It would be interesting to check this with the service. He wanted to be clear about the visits before they took place.

 "they came unannounced and suddenly they were there and I thought they should have at least announced when they came so that I was able to open the door and be prepared." Virtual Ward User

Travelling to services

Participants spoke about how they travelled to services. Some used public transport or were taken by members of their family. Others used Taxicard, Dial-a-Ride and Hospital Transport. One participant explained that her Dad would soon need Dial-a-Ride, but she didn't know much about the service. Two others explained how using a car was difficult because they couldn't easily get in and out.

- "GP said, can't you get a taxi? I said no, I cannot get in one. Sometimes this
 leg will go and whoever's driving me will have to come round and get that leg
 in." Maximising Independence User
- "I'm confined more to the house because of my being unable to park wherever you go." Maximising Independence User. They said a Blue Badge would help them to park nearer to their destination and have more room to get out.
- "Things like Dial a Ride. If there was a phone number that I could just call and talk to a person, and they can then, you know, guide us" Daughter of St Raphael's Hospice Wellbeing Services user, wanting support arranging Dial-a-Ride

Another participant wanted their GP to visit them at home. It would help if their surgery had a conversation with them about whether this was possible. If it wasn't, how could they explain this?

 "Well, it would be nice if they (GP) just came, and could see what's wrong with my legs." Maximising Independence User

Managing Appointments

It was clear from the interviews that participants wanted to manage their own health appointments as far as possible. They found it more efficient than going through another service. Participants' support networks helped them book appointments when needed. How many of the services for frailty in Sutton can people access through self-referral?

- "And if you can get hold of people yourself, that's a better way of doing it"
 Maximising Independence User, talking about contacting Occupational
 Therapy
- "Now you have to ring up the GP for it. Before I could ring up transport myself and organise it" Maximising Independence User, talking about arranging hospital transport.
- "I'm not finding it easy at all, actually, to actually get things set up in a timely manner and effective way" Daughter of St Raphael's Hospice Wellbeing Services user

Day Centres

Two participants talked about day centres. Both were unpaid carers for their parents, so day centres helped them to manage. One explained that her relative used to go to an NHS-run day centre. They had a meal, played games, socialised and could access some services, such as a hairdresser. She said similar services run by volunteers were "lovely and they will help", but she thought volunteers could not offer the same input as trained staff, for tasks like going to the toilet and pushing wheelchairs: "They're there for well-being and support, but not physical handling." She gave the impression that publicly-funded day centres were no longer as available, and this was a loss of useful support: "The council stop the day centres now. You have to pay."

Hospital Night Staff and Corridor Care

One participant explained that her Dad was an inpatient at St Helier Hospital for several weeks. She said although he could walk to the toilet with support, night staff put a pad on him "so they didn't have to go to the toilet during the night." She also said they "barricaded him in the corner" by putting the bed frames up and blocking the gap by his bed with his wheelchair. She added that he spent a night in a "corridor right by the entrance where the ambulances come in". This is concerning and there needs to be action to avoid experiences like this.

What does frailty mean to people?

General view

Participants associated frailty with ageing, physical limitations and vulnerability. They did not mention the Clinical Frailty Scale when asked what it meant:

- "Well I'm getting frailer I know that. As I get older I'm more prone to certain things, falls and all that bits and pieces, that's what it means to me frailty."
 Maximising Independence User
- "It usually applies to an older person." Urgent Community Response User
- "Well, frailty means that I depend on other people, like my wife mostly. That's what I don't like, but unfortunately, I can't help it." Virtual Ward User

The last comment is interesting as it focusses on the threat to and loss of independence which frailty can cause. The next section will cover this in more detail.

Did participants find the term offensive?

Participants' reaction to the term varied. Some did not find it offensive because they saw it as objectively describing their health, and they readily applied the term to themselves:

- "I don't find it offensive. I'm getting older, I'm getting frailer, I know that. I'm more fragile and I have to take care of myself because I've become more fragile." Maximising Independence User
- "I don't feel insulted or belittled, it's just a word, isn't it?" Frailty Hub User
- "It is what it is. I'm not being rude. If they're frail, they're frail." Urgent Community Response User
- "(Do you consider yourself as frail?) I am. I can't walk very far anymore."
 Virtual Ward User

However, one participant who was younger preferred to describe himself as 'physically disabled'. This was due to his association of frailty with old age. Such an association may mean younger people who are frail do not always access services which could support them, because they think they are for older people. They may also be embarrassed to use them for that reason.

Another participant said her parents, both in their 80s, found 'frailty' offensive and preferred 'disability'. This was partly because one of them had Parkinson's. To her, Parkinson's was a "definite illness or disease", whereas 'frailty' meant "end of life...someone that can't do anything." 'Frailty' seemed to imply a general decline which didn't fit with her parents' experience of specific health conditions: "they've got their senses, you know, and they know what they want".

One participant said he felt like punching someone who called him frail, but in the same interview described himself as "Very frail. You know, I'm unsteady. Even when I was walking, I was unsteady." This could be difficult for HCPs to manage but establishing a good rapport would help.

Even some participants who were comfortable with the term did suggest alternatives. For example, 'fragility'. They emphasized the need to name services using terms which people would recognise as applying to their health, which may mean frailty isn't the right term if people associate it with old age rather than a particular health state:

 "I know if it says fragile, I know it's talking about me, and it must be a service for me. It's not going to talk about a young man" Maximising Independence User

How did participants approach living with frailty?

Whether participants were comfortable with the term or not, they tried to live with frailty in a stoic way:

- "But you just get on with it. I'm alive, yes. Sometimes I'm a bit creaking and whatever, but you just get on." Maximising Independence User
- "You've got to be quite positive about yourself and your health. You've got to try and, you know, do things for yourself and have that input." Maximising Independence User
- "I just get on with it. What I can do, I do. What I can't do, I can't." Urgent Community Response User

One participant thought that retiring could leave people feeling overlooked by services. She thought it was important to avoid this. Whilst ageing and frailty are not the same thing, although related, how can older people with frailty in Sutton feel comfortable accessing health services?

 "You retire and it's like you're non-existent you're just there just that number and you have to stand up and say well I'm not just a number I'm a person and I need to access services like everybody else." Maximising Independence User

How does frailty impact people?

Loss of independence

Losing independence and not being able to do as much was a key impact for participants:

- "there are lots of things I'd like to do and I can't, like gardening, for example.

 But, you know, I just have to watch my wife do it all." Virtual Ward User
- "And, you know, sadly I can't do a lot for them now physically, which I used to.
 That I find really hard because I just feel as if I can't be as useful." Maximising
 Independence User asked about their family
- "That's the bit I miss, going to the toilet on my own... It's embarrassing." Urgent Community Response User

However, participants held onto their independence as far as possible, often wanting to carry out tasks by themselves. This seemed onerous at times, making life harder for them compared to if they had more help. One participant talked about pushing herself to wash and dress and two others said they hadn't been offered care at home because they hadn't asked for it. They adapted on their own by having, for example, a strip wash rather than a bath, or using a chair in the shower:

- "I don't need anybody day to day. I'm independent." Maximising Independence User
- "No, no. I've got to do these things on my own. I can't keep relying on other people" Maximising Independence User
- "He still wants to be independent, maybe a bit too much." Daughter of St Raphael's Hospice Wellbeing Services User

Travelling and moving around

Losing independence also meant not being able to independently travel, or requiring a Blue Badge to do this. This had a knock-on effect on whether participants could access services and activities:

• "(Before) I could just nip up to the shops myself. And right now I've got to be taken" Maximising Independence User

- "I can drive there to the church car park, I've got a blue badge". Maximising Independence User on travelling to their weekly choir group
- "I can't go down to the pub like I used to." Urgent Community Response User

Participants used different mobility aids to move around, such as a mobility scooter, perambulator, wheelchair or walking stick. They were particularly concerned about falling. One explained her dad, who wore a Medequip watch, fell at home. She said he remained on the floor for three hours before someone arrived to help him. How can these incidents be prevented?

- "When I came here (current housing), I used to walk everywhere. Now I don't go anywhere." Urgent Community Response User
- "I get my relator out of the boot and walk down with that, just to be sure of the ground, because obviously in the dark, it's not very well lit. You know, I don't want to risk falling over." Maximising Independence User
- "We always have to be careful. It just happens (falling). I've fallen several times, but it's the only time I've ever ended up in a hospital". Frailty Hub User

How do people respond to frailty's impact?

Support Network

All participants had a strong support network which enabled them to live as they did. Their support network was mostly family members, particularly their children and partners. What was interesting was that participants still saw themselves as independent in this context. However, some did acknowledge that support from others enabled them to live independently:

"To be truthful, she (my daughter) makes it possible for me to live on my own"
 Frailty Hub User

Participants received different kinds of help from their support network. Help accessing health services was very common. Participants had help with booking appointments, sorting medication and arranging carers. Their support network used digital tools on their behalf and took them to the Hospital, GP and different community services. One participant explained how their daughter came in with

them to their appointments "which is great because then she hears everything first hand."

Outside healthcare, participants had help with daily living and tasks at home which they couldn't do. These included shopping, cooking and washing. Two spoke about their family installing handles and railings for them. These family members, as well as others providing support, are clearly unpaid carers.

One participant explained that she had given up her job to be her parents' full time carer. She said she was "on call 24 hours a day". She had caring responsibilities for other family members too and had had talking therapy to help manage the stress. Another participant said she would not be able to cope if she had to work full time alongside caring for her parents, who were frail and had Dementia. Health services used by people with frailty are likely to have contact with these unpaid carers, so what role can they play in signposting them to relevant support?

- "I go and spend the weekends with my son. Because it's easier, because I haven't got a walk-in shower. It's easy for me to go there and I've got people there to help me." Maximising Independence User
- "I would say (she does) as much as she can. She helps in the evening or makes meals." Virtual Ward User talking about support from his wife.
- "we've both got degrees but we both needed a spreadsheet keeping like on top of all their (parents) appointments and what needed to be done"
 Daughter of St Raphael's Hospice Wellbeing Services User

Two participants also spoke about their neighbours' role in looking out for them, including when they had a fall:

- "when I've had a couple of falls, in the garden, they'd come over and help me out." Maximising Independence User
- "One of my neighbours gave me her number. She says, if you hear any rattling on the windows or anything like that, just ring me in secret"
 Maximising Independence User

Socialising and Clubs

Participants spoke about enjoying regular clubs and seeing friends and family. Whilst not directly responding to frailty's impact, it was clear from the interviews that these were a significant source of their wellbeing, which in turn helped them deal with the negative impact of their health issues:

"Even though you might feel really down or tired or you've got leg pain or whatever it is, and you go along reluctantly. And it's usually raining on a Wednesday evening. And then you get there and then you do this hour's singing. And everybody's such good company, you know, everybody is really friendly and we all just have a laugh. So it's very, very beneficial." Maximising Independence User, talking about her weekly choir group

Being able to access these activities was critical to participants. In the case above, the participant had a Blue Badge, which meant she could park there. Another explained how she also needed nearby parking for all of her clubs. One participant was fortunate in that they lived in assisted living accommodation, meaning they could socialise at home every day:

- "I go to three or four different clubs for elderly people, which is easy. And each one of these, there is parking... I can't do these things if there's too much walking involved." Maximising Independence User
- "Where I live, we've got a big communal lounge. And what we normally do is wander up there in the afternoon and gather and have a chat and talk about things that are happening (every day)." Frailty Hub User

Practical adaptations

As mentioned, participants had practical adaptations to their home to make living there more manageable. These included handles, railings, stairlifts and ramps. One participant praised the Occupational Therapy team for installing these quickly, but another wasn't aware of that service:

 "And so I had a phone call from them (Occupational Therapy) very quickly and then they came around for an assessment within a matter of days. I was really impressed." Maximising Independence User "afterwards (after installation), we managed to find out that actually we could have gone through the NHS and occupational health" Daughter of St Raphael's Hospice Wellbeing Services User

Faith

Two participants said their faith helped them to cope with health issues. How can services be culturally-competent and recognise this role faith plays for some people?

- "It's been a part of our life and the clergy will always come and talk with you and pray with you if you want." Maximising Independence User
- "I know that He is looking after me" St Raphael's Wellbeing Services User

Recommendations

Accessing services

- Is there a single point of information for finding out about services for frailty in Sutton?
- How many of the services for frailty can people access through self-referral?
- How accessible are services for frailty? Is there parking available and does this include Blue Badge spaces? Is transport also available?
- People's support networks play a significant role in taking them to healthcare appointments and collecting their medication. Is there any work in Sutton to identify those with frailty who are isolated, don't have a support network and therefore may not be accessing services?

Communication from services

- Should services for frailty explain to users what frailty is and what level of frailty
 they have? This could address people's assumptions about frailty e.g. it only
 applies to end of life. Services could also clarify the difference between 'frailty'
 and other terms e.g. 'disability'.
- Do services for frailty play a role in communicating key information to users
 e.g. how to apply for a Blue Badge, how to access Dial-a-Ride, how to contact
 Occupational Therapy?

 Do services for frailty, such as the Virtual Ward, tell users about each home visit from a HCP in advance?

Medequip

- Is there an issue with Medequip watches and Parkinson's? Does the watch fail
 to send alerts when people with Parkinson's fall and shake on the ground?
 Does this apply to people who have other tremor conditions too?
- How long do Medequip watch wearers wait for someone to come and help them up when they fall? Is there data available on this for Sutton residents?

Wider support

- Participants wanted to remain as independent as possible. Should they be encouraged to accept more support, particularly at home?
- Services for frailty are likely to have contact with unpaid carers. Do they play a role in identifying them and signposting them to relevant support?
- How can services for frailty be culturally-competent and recognise the role that faith plays for some in coping with their health?

Conclusion

Participants clearly used a variety of services for frailty which they found beneficial. Some accepted that they were frail whilst others didn't identify with the term or found it offensive. Participants made the following key points:

How do people with frailty experience health services?

Participants found out about services for frailty mostly from other health services. It would help if there was single source of information about these services available. It would also help if residents could self-refer to services where appropriate.

Participants praised services for improving their mobility and their associated confidence. They appreciated sessions in groups and short waiting times between contacting services and receiving care. They valued staffs' personable manner.

Participants weren't always clear on whether further support was available for certain health conditions. There was an issue with a Medequip watch not sending an alert and a wearer waiting a long time for someone to help them after a fall. Some participants found it hard to keep to the exercises they had been given. Participants wanted to know about visits from HCPs in advance. They also needed support to travel to services, such as a Blue Badge, Taxicard, Dial-a-Ride and Hospital Transport.

What does frailty mean to people?

Participants associated 'frailty' with ageing, physical limitations and vulnerability. Some did not find the term offensive because they saw it as objectively describing their health. However, three were uncomfortable with the term. Two of them preferred 'disabled'. Participants were quite stoic about their health and wanted to continue living a full life despite any health issues.

How does frailty impact people?

Participants lost independence due to frailty. They couldn't do as much as they wanted, which meant relying on others. Participants disliked this but accepted it as inevitable and still tried to remain as independent as possible. This sometimes seemed onerous. They used a variety of aids to travel, such as a mobility scooter, perambulator, wheelchair or walking stick. Falling was still a real concern and affected their confidence in moving around.

How do people respond to frailty's impact?

Participants relied heavily on their support network, even when they wanted to remain independent. Support was mostly from their children and partners, who acted as unpaid carers. These individuals helped them with accessing health services and tasks for daily living. They also provided a social outlet.

Participants enjoyed attending clubs and other social activities. It was a clear source of their wellbeing. Being able to access them was crucial, such as through parking nearby. Participants had practical adaptations at home and two spoke about their faith helping them to cope with any health issues.

Healthwatch Sutton hopes these insights help services for frailty support their users and their carers. It would be happy to meet with services to discuss them in more

detail. Healthwatch Sutton would like to thank the individuals who gave an interview and the services which arranged them. It would also like to thank its volunteers who helped to carry out the interviews.

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Appendix

Interview Questions

Section One: Community services use

- 1. How have you found X service (whichever service HWS contacted to arrange interview)? What was good about this service and how could it improve?
- 2. Have you used any of these other services in Sutton:
 - Reablement Unit
 - Home First
 - o 2 Hour Urgent Community Response
 - Falls Service/Maximising Independence
 - Virtual Ward
 - St Helier Frailty Hub

3. (Going through each service mentioned) What was good about this service and how could it improve?

Section Two: Other support for frailty

- 4. What do the terms 'frailty'/'living with frailty' mean to you? Do you consider yourself frail?
- 5. Do you need more help with your frailty than you're getting at the moment?
 - o What do you need?
 - Where would you go to get this help? Which service should be giving it? Should it be a new service?
- 6. Do you find the word 'frailty' offensive? If so, is there a better word?

Section Three: General health

- 7. How would you describe your health and wellbeing at the moment?
- 8. What helps you look after your health and wellbeing?
- 9. Is there anything that you are unable to do that you would like to be able to do?

End of Questionnaire

Service descriptions

These descriptions are taken directly from the services. If you need more information, please contact Healthwatch Sutton.

Maximising Independence Service

A multidisciplinary team in Sutton Health and Care which provide a therapyled service to people 18 years and over. The service's aim is to assess and provide intervention for those people who have a physical/medical condition which affects their functional ability, such as walking, balance, hand function etc. **Website:** https://www.suttonhealthandcare.nhs.uk/mis

St Raphael's Hospice Wellbeing Service

This service offers a number of activities to support the wellbeing and independence of people living with a life-limiting illness. It includes the Wellbeing Centre which offers social, practical and therapeutic support.

Website: https://www.straphaels.org.uk/Listing/Category/wellbeing-services

Urgent Community Response

This service provides urgent care within two hours to people across Sutton (both in their own homes and within care homes) experiencing a medical crisis. The aim is to keep people independent preventing an avoidable hospital admission. **Website:** https://www.suttonhealthandcare.nhs.uk/ucr

Sutton Virtual Ward

Virtual wards (also known as hospital at home) allow patients to get hospitallevel care at home safely and in familiar surroundings, helping speed up their recovery while freeing up hospital beds for patients that need them most.

Website: https://www.england.nhs.uk/virtual-wards/what-is-a-virtual-ward/

St Helier Frailty Hub

Part of St Helier Hospital, the Frailty Hub supports patients with frailty before they are discharged.