



Third and Independent Sector Telecare Stakeholder Engagement Findings

May 2023

Introduction

Scottish Government's Technology Enabled Care Programme (TEC) is supporting Telecare Service Providers (TSPs) across the country to redesign their services, taking advantage of new technologies and service models now available.

Using the principles of the Scottish Approach to Service Design and using person centred design techniques, the National Telecare Team at TEC have been working with TSPs to do this primarily from the perspective of their citizens, while acknowledging the needs of other stakeholders including staff delivering the service. We know that this is a shift in perspective and that TSPs don't always have the resources and skills to be able to undertake co-design. This is part of a package of support which is designed to shift that balance and recognise that using these techniques is an effective way to ensure that the problems you are trying to solve are fully understood before working towards a solution. It is however at an early stage and while the TSP staff we have worked with directly are champions for the approach, it will take time and further work to embed fully.

We also understand that matters including physical and mental health support needs, communication needs including digital skills, or confidence can prevent people from telling us what they need if engagement opportunities are not designed to encourage their participation.

In order to support those TSPs to understand the needs of all their stakeholders, particularly those less heard voices and groups who are unlikely to participate in engagement sessions with their Health and Social Care Partnership or Housing Provider directly, we invited Third and Independent Sector Organisations to apply for a small grant in order to carry out stakeholder engagement sessions on our behalf with their members and the people who use their services. We recognise the expertise of these organisations in engaging citizens and building a trusted relationship, with a different balance of power than might be the case for statutory bodies.

We wanted to hear from citizens who use a Telecare service at the moment, or who might want to in the future.

What is Telecare?

Telecare is a suite of services designed to help people to live more independently at home and in their community. These services, typically delivered by Health and Social Care Partnerships or Housing Providers, are sometimes referred to as Community Alarm Services. At its most fundamental, the basic service may consist of a device, worn around the neck or on the wrist, with a button which the wearer can press if they have a fall, feel anxious or need other assistance. The trigger communicates with a base unit in the person's home, which then uses the phone line to contact an Alarm Receiving Centre (ARC). Staff in the ARC may subsequently notify either a responder service, a nominated contact person or an emergency service depending on the circumstances. Telecare systems used in supported or sheltered accommodation which may similarly contact an internal central support point and/or ARC.

Other devices can be added to this including smoke, heat and CO detectors, door contacts which alert to someone leaving their home at unusual times, activity sensors which help to see if someone is coping well at home. They sometimes also include devices like GPS to prevent people from going missing. Telecare services are also looking at options for introducing consumer devices like smartwatches, voice assistants and apps.

Telecare customers usually pay a weekly or monthly fee for the service depending on where they live.

What did we do?

Third and Independent Sector Organisations applied through a short digital form and were scored by a panel based on the information they provided against an agreed criterion.

Briefing sessions were carried out online where we met with the successful applicant organisations as a group to discuss in more detail the requirements for the work, answer any questions they had and outline expectations on timelines, number of participants, finance procedure, etc. At this stage we provided more information about Telecare as a service and links to resources to allow facilitators to prepare for questions they may be asked during the sessions.

A framework for engagement was provided with a core set of questions we wanted to ask of the citizens participating in the engagement activities. They were designed to promote discussion about telecare, the use of personal data in relation to services and to understand citizens' priorities about their health, wellbeing and lifestyle.

Facilitators were briefed on those and offered the use of online tools including a Miro Board to record the outputs from their sessions. While we supplied resources and the core questions we left the mode of consultation to the facilitators, recognising that they are the experts in engaging with their members and users of their services.

Following that session we met with the organisations individually to answer any specific questions they had which weren't suitable for group discussion or anything which had arisen since.

Which Organisations were Funded?

Sharpen Her: The African Women's Network - bringing together African women living in the UK to support each other, network, connect, socialise, motivate, and build each other's capacity.
<http://www.sharpenher.org.uk/>

Eidyn Care – a Care at Home provider based in Edinburgh specialising in palliative and end of life care.
<https://www.eidyncare.co.uk/>

Alzheimer Scotland - providing support and information to people living with dementia, their carers and families. Campaigning for the rights of people living with dementia and funding vital dementia research.
<https://www.alzscot.org/>

Support in Mind Scotland - working to ensure individuals experiencing mental health challenges can access quality support in their own communities, before reaching the point of crisis.
<https://changemh.org/>

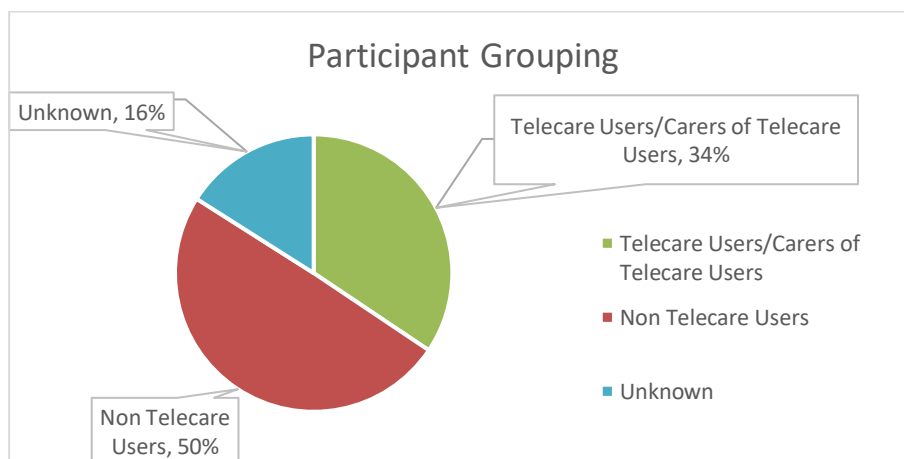
Getting Better Together - a community-based health initiative which promotes the education, health and wellbeing of North Lanarkshire residents.
<https://shottshealthyiving.com/>

Six additional organisations were successful in their applications but were unable to complete engagement sessions for a variety of reasons such as capacity of staff and volunteers, conflicting priorities and staff sickness.

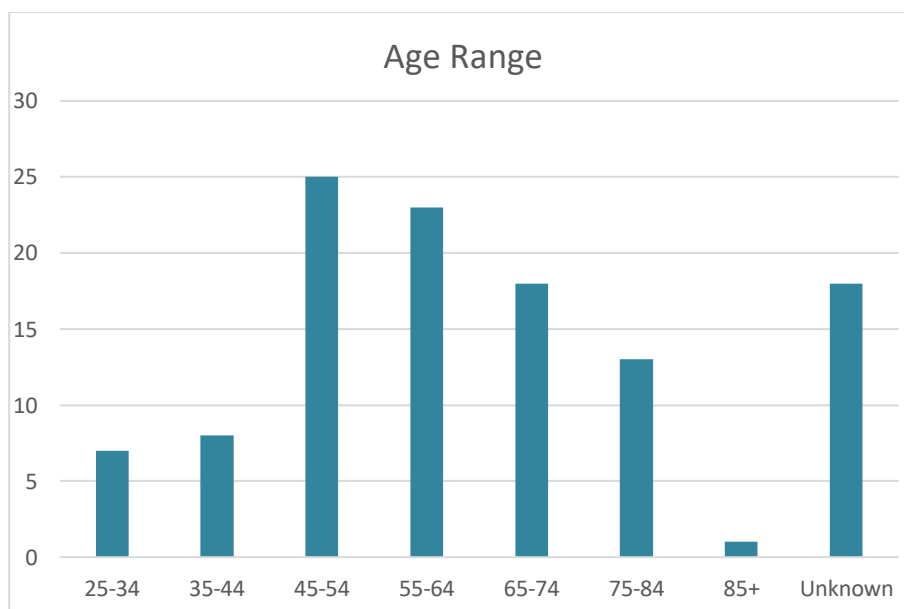
I believe that this reflects widespread issues within the social care sector generally and was not surprised that some of the organisations found it difficult to carry out the activities. These latter organisations did not receive any funds.

Who did we speak to?

In total, delivered through a number of sessions, we heard from 125 people, of whom about a half were people who did not currently use a Telecare service. Not all questions were asked of every participant. Some questions were only asked of those who use Telecare at the moment or have done in the past. Organisations advertised the sessions and participants self-selected. While we didn't ask people to state it, it emerged through discussion that some of the participants were carers for family members.

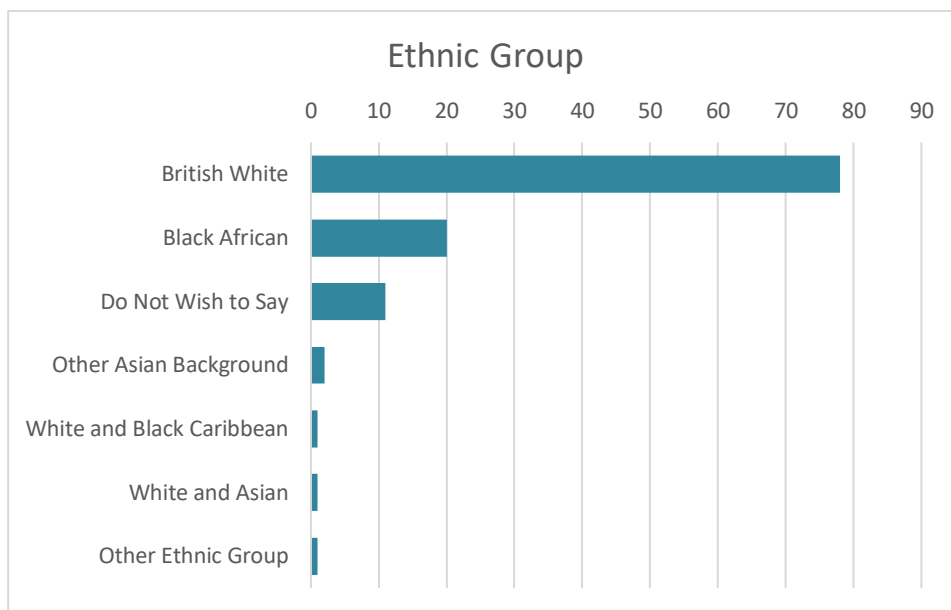


The three charts below present the age, ethnic group and housing status of the participants. While Telecare currently serves a population who are mainly older – 72% of users are aged 75 years and over ⁽¹⁾ (and among people aged 75+, at least one in five receives a Telecare Service ⁽²⁾) - there are clear use cases for people of any age, such as for some people with a learning disability or experiencing domestic violence. For this reason we were keen to hear in the workshops from adults irrespective of their age, as reflected in the Age Range chart below. No-one under the age of 25 took part in these workshops.

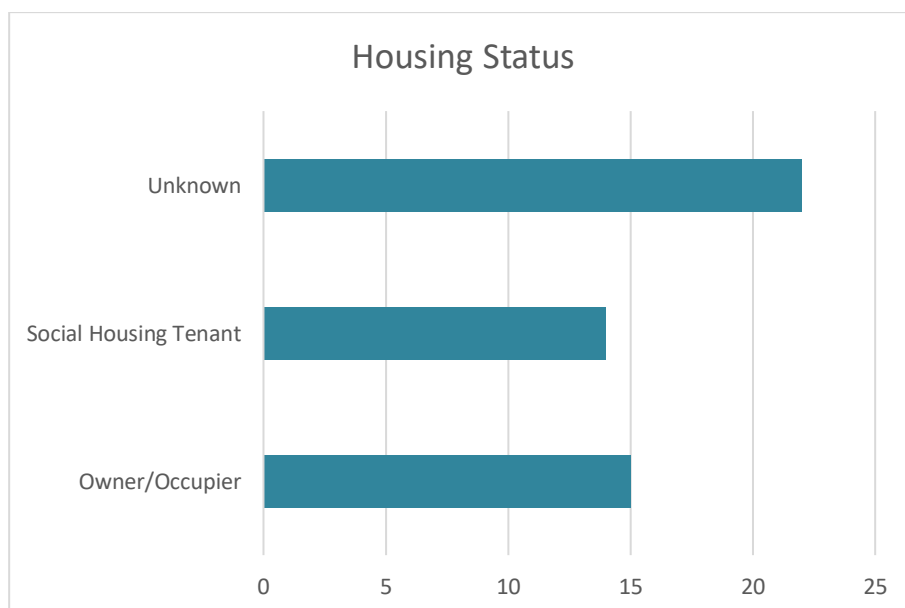


We wanted to understand if there are barriers to access faced by people of different ethnicities. The risk is that if we don't engage with our whole community including those who are New Scots, we risk excluding them by design. At present Telecare users are predominantly people who describe

themselves as White ⁽⁴⁾. While we had some engagement from people from our Black and Minority Ethnic communities, more work should be done to fully understand specific requirements.



Of those who answered the question about their housing tenure, responses are largely in line with what might be expected, ⁽¹⁾ with just over half being owner occupiers. We did not have any participants who chose to share that they lived in private rented or other types of accommodation.



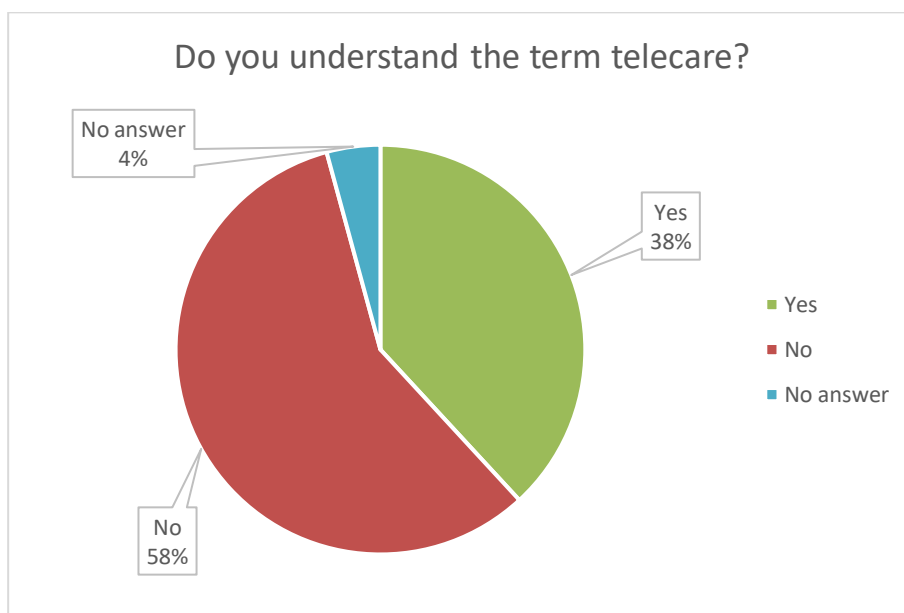
What did our participants understand about Telecare and Social Care?

More than half of our participants didn't know what Telecare is, which suggests that visibility of Telecare is not widely recognised and this could be a barrier to increasing the scale of the services available. It raises some important concerns such as where the public would locate essential information about Telecare, how we describe it, how we name the service. We need to understand more about how people search for the services they need-the search terms the public uses, and who

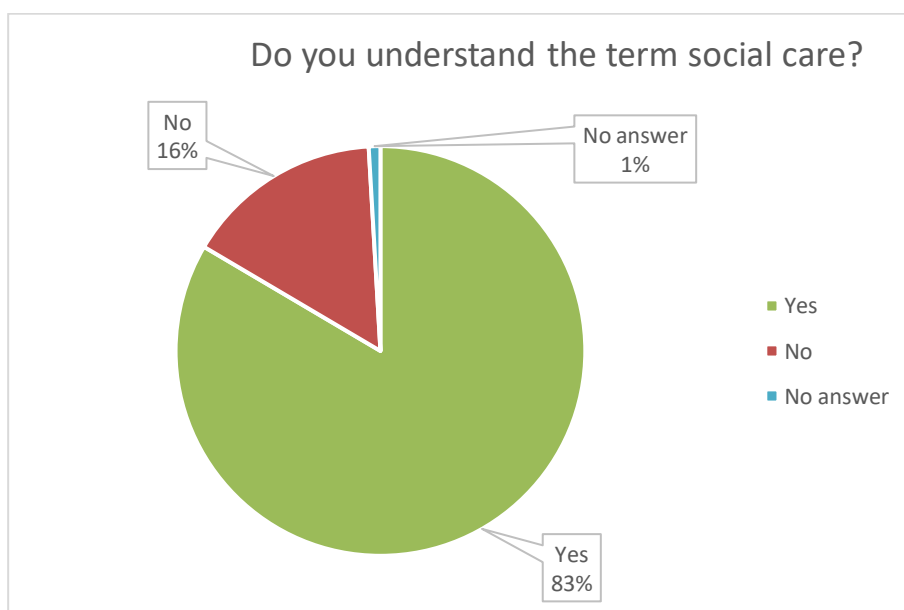
do they ask. We found out a bit more in these engagement sessions about the Scottish public's trust, but it requires a deeper understanding if we are really to achieve a breakthrough.

For participants who thought they knew about Telecare services, in some cases they were only aware of the community alarm element [and not the range of peripherals that exist and how they can be tailored].

Benefits of the services for carers are not widely understood. Information about the service is often aimed at the person they are caring for, and the tangible benefits for carers can be overlooked in the process.



The term Social Care was significantly better recognised as a provision of services including care at home, respite care, reablement or residential care. Overall our participants said that they felt more comfortable with using the term Social Care than they did with Telecare.



We asked participants if they knew how to find information about Telecare or how to apply for it. Of the 64 participants who were asked, 31% strongly disagreed or disagreed that they had found the application process clear.

We also asked if information about Telecare was readily available, in a range of formats. Nearly 20% of participants strongly disagreed or disagreed that it was - a not insignificant proportion. Only 16% strongly agreed or agreed that they could easily find information, with the remaining proportion having no opinion.

These responses lead us to conclude that Telecare could benefit from clearer marketing - and consistency in the way that services are accessed. Indirectly, work towards a national Telecare Information Framework makes this a possibility as it may naturally lead to the design of a uniform shared referral form (something which is being discussed).

Participant Priorities

We asked participants to spend a notional fixed “budget” across a number of topics, allocating the largest amounts to the things which they considered their highest priorities.

Sharing information comes quite near the top and several discussions focused on how frustrating and detrimental to their health and wellbeing it is to go over their full history every time they need to access a new service. When asked specifically about data sharing in the next part of the session, participants gave caveats relating to specifics of the body requesting data and intended purpose.

Interestingly, in their rankings giving reassurance to people who care about them was a relatively low priority for our participants.

The results here show possible contradiction between the priorities of people using, or who might use, Telecare and the reasons for referral to Telecare services as reported by services through the Scottish Telecare Benchmarking Collaborative (a group of circa. 15 TSPs who submit quarterly data on a number of key markers [\(1\)](#)). The services data appear to show a less aspirational perspective and concentrate more on reducing risk to the citizen than improving wellbeing. This may be due to the way that referral reasons are reported, and we expect to have more detailed information available in the coming year as the TSPs involved begin using an updated benchmarking tool which incorporates the National Telecare information Framework.

Participants felt that getting out and about and staying connected to their communities was of equal importance to them as staying safe in their own homes. The advent of digital telecare should have an impact on the ability of TSPs to meet the aspirations of citizens, as reflected in the participant priorities reported. Analogue telecare equipment has technical limitations and only works if the user is within range of the unit, effectively limiting its use to a person’s home and garden. The new digital range of equipment makes use of mobile telephony networks, which could afford more flexibility in the way that signals are received and transmitted, allowing it to be effective when the user is out of their home. We expect to see a period of innovation as new suppliers come to market and existing suppliers update their offerings to take advantage of this functionality.

This comes with questions about how a service might manage the needs of citizen if they require support when away from their home area. Considering these needs are part of the process of service redesign.

PARTICIPANT PRIORITIES



Views on Data Sharing

In the previous section, sharing data to help them get better support was identified as being important to the participant group. A repeated theme was that anyone sharing data must have control over and clear visibility of what they are sharing and that what they would be expected to share should be clear from the outset.

“It really improves the services for better perspectives especially from Black and ethnic minorities to give the right support.”

“I have found that some research projects start to become quite intrusive for my data after a while.”

Also important was that citizens wanted data generated about them to be shared back to them in order to better manage their own health and wellbeing. This aligns with opportunities for self-management in order to provide earlier intervention and diversion from crisis points further down the line.

Many of the findings from the participant group are reflected in the new Data Strategy for Health and Social Care ⁽⁵⁾.

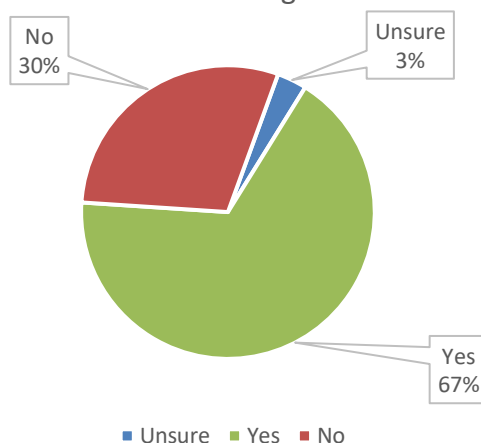
The charts here reflect participants answers to 6 specific scenarios where they may be asked to shared personal data.

Over half of the people asked didn't want to share data with friends and family, which is something we often work on the assumption of being desirable. There is also a clear distinction on how people feel about institutions such as Health and Social Care Partnerships or the NHS and corporate entities like Samsung, or Apple, with there being more trust for the former

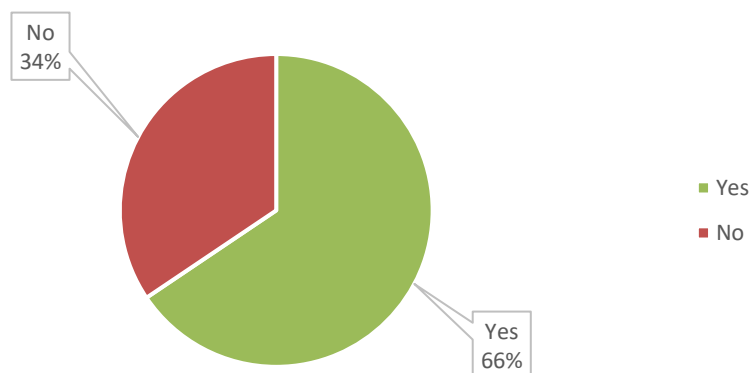
The most significant reason that participants would be willing to, and in fact expected to have their data shared , is to relieve the significant frustration from participants that they had to keep going over the same thing again and again as they moved through, what appears to them to be related, services.

For some, this repetition of their information was having a significant effect on their mental and physical health -something that should be borne in mind when designing future services of any type.

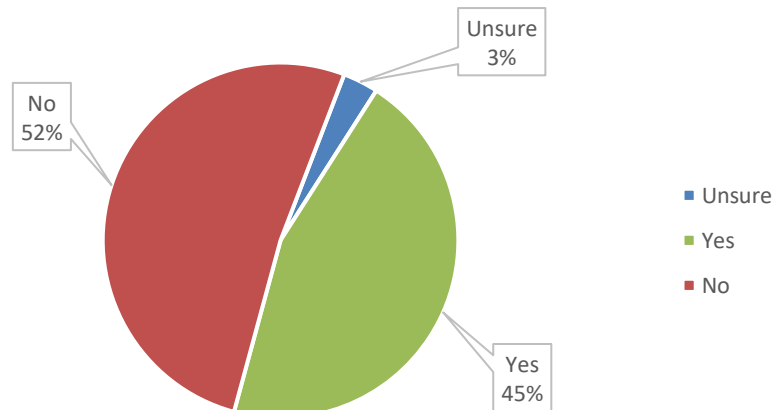
I would be prepared to share my personal data to know more about my health and wellbeing in order to better manage it



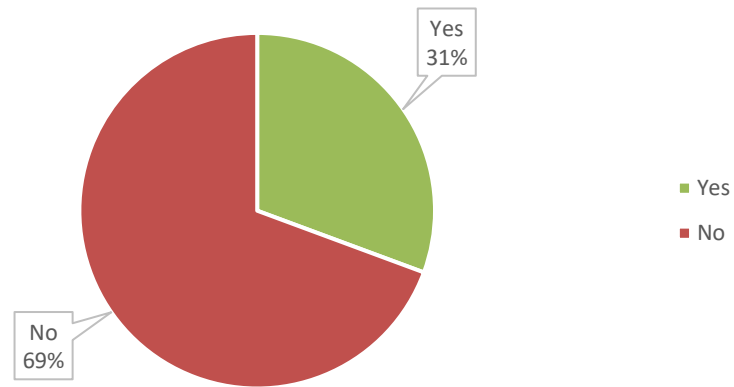
I would be prepared to share my personal data to share information about my health and wellbeing with services support me in order for them to offer me appropriate support



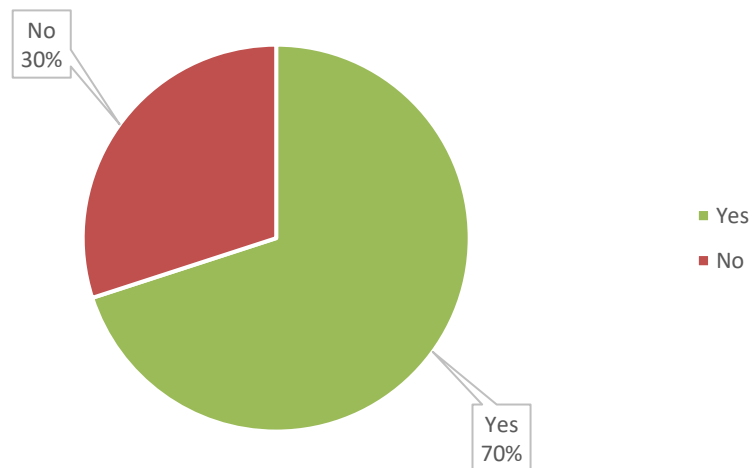
I would be prepared to share my personal data to give reassurance to my family and people who care for me that I am well



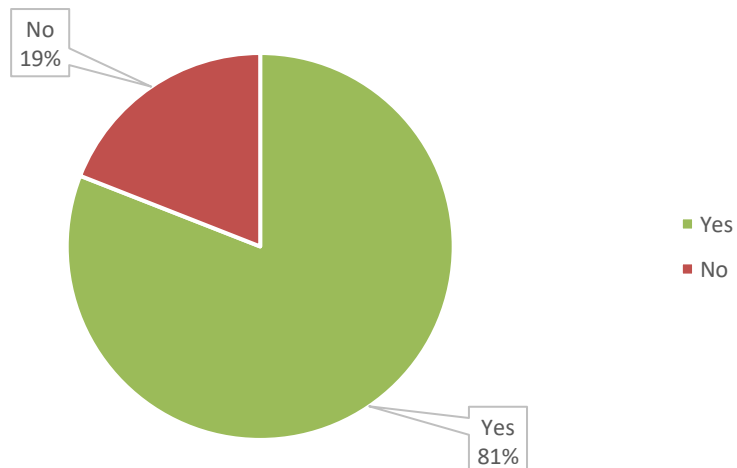
I would be prepared to share my personal data to help services and product manufacturers to improve what they can offer me



I would be prepared to share my personal data to contribute to research



To prevent me having to repeat the same information to multiple services



Additional Learning

- We learned that there is a general lack of awareness about Telecare and what it can offer. The name is ambiguous and doesn't describe the service. People don't know as well as they could where to find information about the service or how to apply. Note at least one participant was unable to read to a level which would have allowed them to understand or apply for the service.

“Technology is a real enabler & something we don't fully explore. Especially if you don't know about it.”

- Even where participants thought they knew about Telecare services; in several cases they were only aware of the basic community alarm element.
- Benefits of the services for carers are not widely understood. Carers are a vital link and if their wellbeing is not being paid attention to, the implications can be catastrophic for both the carer and the person they care for.
- Carers participating were very aware of their time constraints. They need to find accurate information quickly and this hasn't always been the case when they have needed to access telecare.
- The discussions showed people who have moved to the UK from other countries still maintain ties with their home countries health care providers, and often look for guidance from them to understand what to ask for and how to navigate systems here. Our systems should be open and transparent for everyone in our community.
- Trusted networks even include “Google” before our health and care systems in some cases. Family and friends feature heavily, despite them not necessarily having direct experience of the system.
- Waiting times to access GP services for referrals were highlighted.
- Participants highlighted that pathways between Telecare Services and Community Mental Health Services could be strengthened. People living with serious mental health issues, for example those experiencing psychosis such as enduring delusions, hallucinations and cognitive impairments could benefit from a GPS which would help someone to orient them.
- The Third and Independent Sector organisations who carried out these engagement sessions said that they would welcome the opportunity to have more information about telecare in order to assist their members and users of their services to apply and benefit from the services. There is an opportunity perhaps to have increased referral routes with staff from other sectors supporting access.
- Making the service more accessible to all sectors of our community should be a priority, not least to ensure that it fulfils the Public Sector Equality Duty⁽⁶⁾ – there are some basic things like translation of materials which would make a real difference, but the whole service needs to be examined, from marketing and assessment through to routine usage.

Who do I contact if I have questions?

You should contact Gillian Fyfe, Transformation Support Lead, Technology Enabled Care Programme on gillian.fyfe2@nhs.scot

References

1. [Telecare Benchmarking Impact Report, 2021/22](#)
2. [Deloitte Telecare Feasibility Study Report, 2017](#)
3. [Farrpoint Telecare Call Handling Report, 2019](#)
4. [Insights in social care: statistics for Scotland, 2021/22](#)
5. [Greater access, better insight, improved outcomes: a strategy for data-driven care in the digital age, 2022](#)
6. [Public Sector Equality Duty](#)

Acknowledgements

The Telecare Team would like to thank the people who took time to share their views and experiences with us and to acknowledge your individual expertise. The depth of your knowledge and experience is apparent in the reports which were received and will help to inform the design of services.

Thanks also go to the facilitators from the organisations who worked with us to host these sessions and compile the outputs from the discussions they had.