HEALTH & SOCIAL CARE ALLIANCE SCOTLAND

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DISCOVER DIGITAL

A report on the level and type of user engagement by older ethnic minority communities of digital tools to support self-care, health and wellbeing

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Introduction

Discover Digital was established to raise awareness and potential benefits of the digital tools available that endeavour to empower the user to take charge of their personal health and wellbeing, or that of someone in their care. By creating a permanent documented guide to the location and use of these digital tools, it is hoped that the user who wishes to understand and engage with technology will be signposted to the most effective tools or services that align with their needs.

Among the groups that Discover Digital is seeking to obtain feedback on the accessibility of the guide is that of ethnic minority communities.

This report sets out to illustrate the challenges faced by ethnic minority older people who can face multiple and complex barriers to accessing information and services, ironically at a time in their lives when they are in most need of both to make vital decisions.

The inequality of access to information and services that face people from ethnic minority backgrounds is well documented, and never has the stark imbalance of accessibility to health and social care been made more apparent than during the Covid-19 pandemic. Language barriers, digital poverty/literacy or inaccessibility have all proven to be grave hindrances to those whose first language is other than English, the consequences of which could be found in the disproportionate numbers of people from these backgrounds who lost their lives as a direct or indirect result of Covid.

Most participants agreed that the use of digital technology to access information about health and social welfare services would eventually become the norm. Whereas participants did not shrink from the theory of self-management, the operational aspect of this did give wider cause for concern.

Methodology

Over the course of July, the following consultations were undertaken:

- Phone consultations with Chinese older people from Glasgow, Aberdeen, Edinburgh and Bathgate. (4 participants)
- Online group consultation of Chinese older people. (4 participants)
- Phone consultations with community representatives/support workers of various ethnic groups (Bangladeshi; Pakistani; African) from Glasgow, Aberdeen and Edinburgh). (4 participants)
- Online group consultation of Indian older people. (13 participants)

The Language Barrier

One of the first and most common hurdles a person from an ethnic minority background has to jump is that of language. The dependence on language support, particularly in a scenario that involves personal healthcare, shifts the power away from the individual to make independent decisions while compromising their confidentiality. Most of the people consulted spoke little or no English and relied on community workers or family members to provide information in a way they could understand.

Any contact with health and social care services is almost always made by a community worker who speaks their language, acting as intermediary. However, if the person in need of assistance is not a member of a community group where the staff is known and trusted, they sometimes have to rely on a friend or neighbour to act as interpreter. There is genuine concern amongst many in the communities of a breach in confidentiality, but some are willing to take the risk if they have no other means of support.

One participant said:

'In an emergency, during weekends and evenings they ask their children who live away in other cities or different parts of the city or a relative or a friend to contact services on their behalf'.

For some in this group, using printed material to obtain information is not going to serve its purpose, due to their being illiterate. In this case, seeking alternative means to convey the message, other than through the medium of print, is worth exploring.

Another participant said:

'Some people have a good level of English, but don't have the vocabulary for medical/ health terms'.

Participants stated a preference for face-to-face consultation when doctors can carry out a visual examination, providing valuable understanding through non-verbal communication as:

'body language is important, especially for patients who are unable to express themselves directly'.

Cultural Awareness

When designing services, it's often the case that they are designed around the people and environment we are most familiar with and which count as the majority in the population. It may not readily occur to business designers to consider the cultural variances that form the basis of interactions with and between members of the ethnic minority communities. For true inclusion to exist, there must first be a willingness to accept cultural variances and real effort made to understand and learn what works for other cultures and what does not.

One participant explained:

'In some cultures, women rely on the men in the family, or other women from the community, or even community support workers. Community support workers are a lifeline for many women, otherwise they would have no privacy'.

If they are widowed, they have to rely on a son or nephew, which in the case of issues concerning personal health, is extremely uncomfortable and may be reason enough to avoid seeking help.

It's also worth noting that in some cultures, the influence of the family cannot be under estimated. For example, the children of one participant exerted a certain amount of control over his phone, taking the decision to not install any apps on it so as to prevent him from falling victim to scams.

Regardless of how much time and other resources are invested in attempts to increase digital autonomy among certain groups, a high number of the participants preferred face-to-face contact with their GP, as they believed that 90% of the worry and anxiety can be alleviated with personal interaction and care. As one participant put it:

'…in some cultures they [the doctors] are regarded as gods, as they save lives'.

Digital Skills

It is difficult for some people to unlearn years of experience of working with non-digital phones, to set that aside and embrace the rapidly changing systems that have brought us smart technology. Quite simply, one community worker informed us:
'They can't work out how to use [smart] phones. Even learning how to take a photo can take hours and then they forget and ask again. They find learning very hard and return to using their old phones. It is a common problem'.

Another community worker added:

'Many older people don't understand, and it is very difficult for them to learn something new they have never used. Some have never been to school, have had no education and will never learn'. Staff at one day centre went so far as to produce a handbook in Chinese for their group to use, but even then, they found the directions hard to follow. They quickly forgot anything they learnt and repeatedly requested assistance from staff, rather than search for the answers themselves in the handbook.

According to the group, there are 'too many steps to get to the information they are looking for'. Staff have admitted it can be very time consuming, particularly since they already have other duties and activities to run. Add to that, the various makes of phone available requiring different methods, adding another layer of complexity to the challenge.

A similar challenging process was expressed when members of the group consulted spoke of trying to contact NHS 24. The difficulty in navigating through the system and its constituent parts or stages, provoked anxiety and raised stress levels among several from the group.

Many older people can experience acute anxiety when forced out of their comfort zone and routine. The process of calling a GP surgery to make an appointment can be arduous for them, particularly when they have to explain their condition before speaking with the doctor.

Even when an older person does have access to a smart device, with basic competency, the level of expectation by the medical service is disproportionate to the individual's personal circumstances. For example, an older person living alone, with a language barrier, being requested to take a photo and email it to the GP surgery. Firstly, many older people don't have an email address, so the expectation to use that service is already redundant. Secondly, the expectation of an older person living alone, or with an equally incapacitated partner, could not be expected to reach to take a photo of their own body parts.

Another reason for preferring personal contact in a healthcare scenario is the fear of misunderstanding or misinterpretation. One participant had an experience where her physio had given her exercises to do. When there wasn't any improvement, she discovered she had been doing the exercises incorrectly. The participant felt that had she been able to attend her sessions face-to-face, the matter would have been resolved much quicker. As she said:

'Doing it wrong could have damaged my condition further'.

Ability and Capacity to Learn

As well as a language barrier, an issue which older ethnic minority people are likely to share with their indigenous counterparts, is the ability and capacity to learn new technological skills. This is an age group for whom demand for health and social care is likely to be greater than for any other age group.

One participant explained that she had never learned to use a computer and feels she is too old to learn at this stage. She would be afraid of making mistakes or even damaging the computer.

Another participant believed that digital technology is not for the elderly. She lives on her own and it took her a long time to learn to use WhatsApp. She found the process very stressful and tiresome for the young family members who would visit her to help her make adjustments.

One participant took the step of attending a computer training session. Even though the tutor was bilingual, she found it hard to learn, and couldn't even remember the basics, such as to turn on/off the computer. She wasn't sure if maybe she was just too old to learn a new skill or just had a poor memory.

The overall consensus was that digital technology is important for the future; it's a 'good idea but is not for everyone'.

However, it was suggested that having to rely on family members to provide technological assistance could damage relationships.

Furthermore, assistance given to older people who spend long periods of time alone at home will not work, or if they live with additional physical or sensory barriers, such as poor hand-eye co-ordination, hand tremors, muscle weakness (in hands/arms), rheumatism, and of course, poor memory.

One participant spoke of having attended a training session arranged through a local community organisation. Despite finding digital technology fascinating, he too experienced difficulties trying to learn and retain the new information. He was also concerned about the possible breach of his privacy and falling prey to online scamming.

One group agreed that digital knowledge doesn't happen 'overnight'; it can take years to acquire through participation in technology classes and making unlimited errors. However, 'the [Chinese] elderly are so afraid to make mistakes'.

One community worker spoke of the varying levels of capacity to learn within just her own group of older participants:

'Those who can learn, will do so. Some will be able to learn up to a point but will struggle to understand the full process. Many others will never gain the skills or have the capacity to learn'.

Other Concerns…

Data security is also a great concern among the Chinese older people consulted. They fear a breach in privacy or even that their personal data could fall into the hands of criminals. They worry about the expected difficulty in accessing health information using digital media going forward.

Furthermore, they anticipate an increase in social isolation; a lack of 'real life' contact will increase their stress, anxiety and depression or other forms of mental illness as, according to the group consulted: 'humans are social beings'.

Recommendations

Ethnic minority older people **need support** rather than be overlooked, now more than ever with the introduction of technology to access health services.

- Appoint bi-lingual **health and social care workers** to work with ethnic minority older people, removing the burden of doing so from community workers.

- Provide information and guidance in their **own language** (either written or video link).

- GPs don't have sufficient data on patients' additional support needs, e.g. communication barriers (language or otherwise). We discovered through these consultations that some surgeries do, but several others don't. Social workers should identify patients' needs and link with GP and Health Practitioners; through adopting **a triangular approach**, the patient's needs receive effective attention and can be more comprehensively understood.

- There is a need for a nation-wide programme to address the issue of **digital accessibility** [digital poverty], i.e. provision of devices and Wi-Fi connectivity for the elderly, particularly those who live alone without family support.

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