Public attitudes to the use of remote data collection in clinical research

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Abstract

Background/Aims

Coronavirus Disease 2019 (COVID-19) has presented an unprecedented challenge for delivering clinical research. The use of technology-assisted data collection for clinical research is desirable for many practitioners, but the acceptability of use in the general population has not been assessed. The aim of the study was to assess attitudes towards using technology-assisted remote methods in the delivery of clinical research in the UK and to understand the barriers to taking part in research with respect to both remote assessments and traditional research methods across different age ranges.

Methods

The study was conducted as an online anonymous survey with a 4-part questionnaire, between August 2020 and December 2020. Participants living in the UK aged 18 years and above were eligible to take part.

Results

A total 351 completed the survey and are included in the data analysis. In all age groups, participants identified that use of online assignments, video calls and telephone calls would make them more likely to take part in clinical research. Overall, the largest barrier to taking part in research was time commitments and timing of the appointment. COVID-19 has had a small, positive influence on the confidence of using technology in the general population.

Conclusions

The study found that there is a large interest in taking part in research using online, telephone and video call appointments, which could facilitate research delivery in light of ongoing COVID-19-related restrictions and also improve the accessibility and inclusivity of research.

Keywords

Clinical Trials, clinical research, telemedicine, Methodology, eTrials, Remote assessments, online trials, digital trials, trial designs

Background

Coronavirus Disease 2019 (COVID-19) has presented an unprecedented challenge for delivering clinical research. Modelling data suggest that restrictions such as social distancing and community containment may be needed for an extended period of time (1). This is likely to have significant negative effects on participation in clinical research where participant assessments are invariably delivered in the traditional face-to-face manner in research centres, hospitals and clinics (2). Unless alternative methods are found, poorer participation in research may lead to a slow-down of important research which will disproportionately affect certain populations of people, such as those with underlying conditions who need to shield, from participating.

The use of communication technology and innovative approaches in the delivery of clinical research in the home and in community settings may allow the avoidance of unnecessary attendance at appointments in the healthcare setting. The use of telephone calls and videocalls to provide clinical care, also known as telemedicine or eHealth appointments, have gained extensive momentum during the pandemic (3–5). Using these approaches in the research setting has the potential to allow individuals, for whom the physical journey to a research site would be a limiting factor such as the frailest, physically and socially disadvantaged individuals, to participate; this may encourage these traditionally under-represented groups to participate in research (6–9).

At present, most remote clinical trials have taken place in the US (e.g. Jacobs et al., 2005; Orri et al., 2014), with little to no research carried out in the UK (or European setting)

regarding the acceptability and attitudes towards the use of technology-assisted remote clinical research methods.

Methods

The aim of this study was to assess attitudes towards using technology-assisted remote methods in the delivery of clinical research in the UK and to understand the barriers to taking part in research with respect to both remote assessments and traditional research methods.

Study design

The study was approved by the University of Bristol Faculty of Health Sciences Ethics Committee (reference 104202). The study was conducted as an online anonymous survey with a 4-part questionnaire, between August 2020 and December 2020 and used an inclusive approach open to participants aged 18 years and above. Participants provided written electronic consent, and were asked to fill in each of the 4 parts comprising 1) demographic information, 2) information about their use and ability to use communication technology, 3) their experience with the use of telehealth, and 4) their experience and opinions on the use of communication technologies in clinical research. With the exception of consent, the participants could choose not to answer any question or part of the survey. All questions were multiple choice, with an option to provide a free text answer when selecting 'other' as an answer option. Participants who did not wish to fill in the survey online had the option to complete it over the telephone with a member of the research team.

Participants

The survey was open online to all UK residents aged 18 years and above. The survey was advertised on social media (Facebook and Twitter) and in a large selection of electronic newsletters, including Parkinson's UK, NIHR supported Patient & Public Involvement Groups, University staff and student newsletters, NHS volunteer and staff newsletters. The channels of advertisement were chosen to sample a broad range of individuals, with and without chronic health problems.

Statistical analysis

Simple statistical summaries of the closed form responses to each survey item were generated using GraphPad Prism (GraphPad v8.0). For comparisons, the participants were grouped by age as follows: 18-45 years, 46-65 years and 66+ years. These groups were based on the age distribution of the participants. Responses were compared using the Chi-squared test and the p-value reported.

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Results

A total of 375 people agreed to take part in the study, 24 people completed only consent and/or demographics data so were excluded from the analysis. A total 351 completed the survey and are included in the data analysis. All participants took part using the online survey. The demographics of the participants are summarised in Table 1 below.

Table 1: Demographics

	(n)	(%)
Region of residence (UK) (n=351)		
East of England	12	3
East Midlands	17	5
London	21	6
North East	6	2
North West	31	9
Northern Ireland	17	5
Scotland	16	5
South East	47	13
Southwest	149	42
Wales	16	5
West Midlands	8	2
Yorkshire and The Humber	11	3
Accommodation (n=350)		
Living alone	80	23
Living with spouse, partner, family or friends	270	77
Age Group (n=328)		
18 – 25 years	17	5
26 – 35 years	52	15
36 – 45 years	53	15
46 – 55 years	55	16
56 – 65 years	57	16
66 – 75 years	86	25
76 – 85 years	25	7
86 – 95 years	6	2
Gender (n=350)		
Female	217	62
Male	130	37
Other	1	0
Prefer not to say	2	1
Ethnicity (n=350)		
Asian or Asian British	14	4
Black, Black British or Caribbean	3	1
Mixed or multiple ethnic groups	7	2
White	322	92
Any other background	1	0
Prefer not to say	3	1
Highest level of education (n=351)		
No qualifications	8	2
Completed GCSEs	22	6
Completed post-16 vocational course	19	5
A-levels or equivalent (at school until age 18 years)	23	7
Undergraduate or professional qualification	139	40
Postgraduate degree	92	26

Doctorate	48	14
Long term health conditions (n=351)		
Yes	208	59
No	141	40
Prefer not to say	2	1

Clinical trial participation

More than half of respondents (n=195 (58%)) had previously taken part in clinical research. The remaining 15 participants chose not to respond to this question. Of the 195 who had taken part in clinical research, 41 (21%) had taken part in research which included taking a medication as part of the research.

The majority of respondents (n=284 (85%)) said they would be interested in taking part in clinical research in the future. Those who would be interested in taking part in research were asked how a range of common research practices would influence their choice to participate.

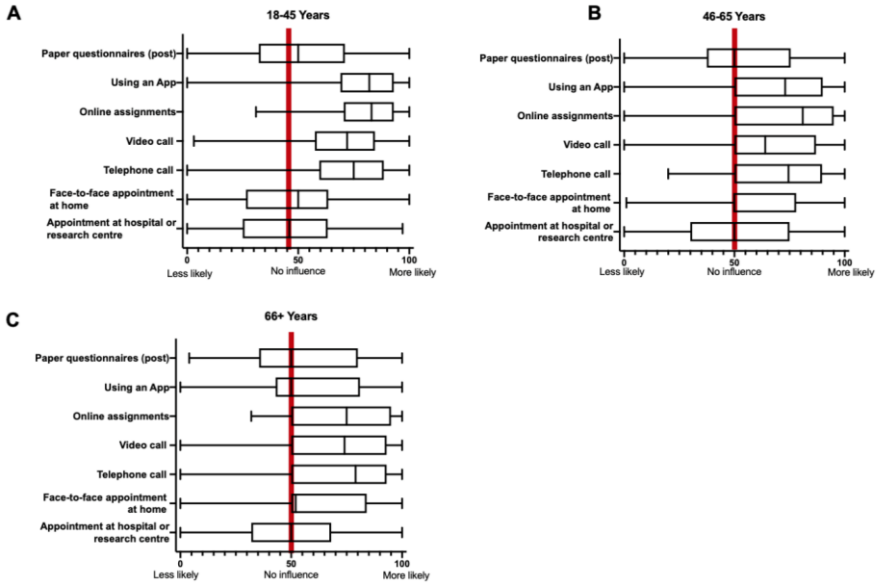

Figure 1 Research activities and their influence on willingness to participate in A) 18-45 years (n=85), B) 46-65 years (n=88), C) 66+ years (n=80). Columns represent the mean with 95% CI. Error bars present minimum-maximum range. Red line indicates no influence on willingness to participate.

Across all ages, participants identified that use of online assignments, video calls and telephone calls in the delivery of a trial would make them more likely to take part. Interestingly, face-to-face appointments, whether at home or at a research centre or hospital, had a slight negative effect on the willingness to participate. These data are summarised in Figure 1.

Barriers to taking part in research

The participants were asked which factors they perceive as barriers to taking part in research. Overall, timing of the appointment (n=340, 40%), transport (n=340, 38%), parking (n=340, 38%) and awareness of research available (n=340, 37%) were most consistently

identified, although appointment time was relatively less important in the older age group, whilst time commitment was as well as the time of the appointment was more important to the youngest age group. These data are shown in Table 2.

Table 2: Barriers to research; percentage of the respondents for each age group identifying each factor as a barrier to taking part in research.

	All Groups	**18-45 years**	**46-65 years**	**66+ years**
Timing of the appointment (e.g. 9-5pm Monday to Friday)	40%	66%	39%	14%
Transport to the hospital or research centre	38%	41%	35%	38%
Parking near the hospital or research centre	38%	26%	38%	50%
I don't know about research available in my area	37%	49%	29%	32%
Time (I am too busy)	32%	57%	29%	8%
Distance to my nearest hospital or research centre	29%	23%	26%	37%
The number of assessments and/or visits may be too much	23%	24%	24%	21%
Potential negative effects on my health	23%	25%	16%	27%
The assessments may be too invasive (e.g. physical tests that I might find uncomfortable)	18%	18%	15%	22%
Physical ability (e.g. fatigue, anxiety, pain, etc.)	11%	5%	14%	15%
Interest (there is no interesting research in my local area)	11%	8%	10%	14%
Lack of remuneration (payment)	10%	16%	9%	4%
Other	8%	4%	8%	12%
I don't think clinical research is relevant to me	2%	5%	1%	1%
I don't know what research is	0.9%	1%	0%	2%
Language barrier	0.6%	0%	1%	1%
I don't trust health research	0.3%	0%	1%	0%

Attitudes to technology in clinical research

Participants were asked to select which methods they would find acceptable for obtaining consent, medical and medication history, questionnaires, collection of data using equipment such as blood pressure monitors and attending regular classes (e.g. exercise interventions). There was little difference between age groups in term of the methods of data collection identified as acceptable to them. Overall, the modality of delivery noted as acceptable by the highest proportion of survey participants was online research.

Clinical research involving a medicine

Lastly, the participants were asked '*If you had agreed to take part in a clinical trial which is testing a medicine for a condition that you have, would you be happy to take the medication* ***without*** *a face-to-face discussion with the doctor?*'. Overall, a small proportion (n=81, 23%) answered they would only take a medication following a face-to-face consultation with their doctor. Interestingly, 75% responded they would be happy to take a medication without a face-to-face consultation; 24% (n=81) would do so with written instructions from their doctor, 30% (n=101) following a telephone consultation with their doctor and 21% (n=71) would take the medication following a video call with their doctor.

The participants were also asked which option they would find acceptable for receiving a medicine, whether this would be delivered to their home address or for collection from the pharmacy. The participants were able to choose both options if they found both to be acceptable. Overall, 86% (n=292) responded that they would find home delivery acceptable, whilst 61% (n=209) would be prepared to collect the medication from the pharmacy. Interestingly, with respect to collecting the medication from the pharmacy, the acceptability decreased with age ($p<0.0001$). The data are shown in Figure 2.

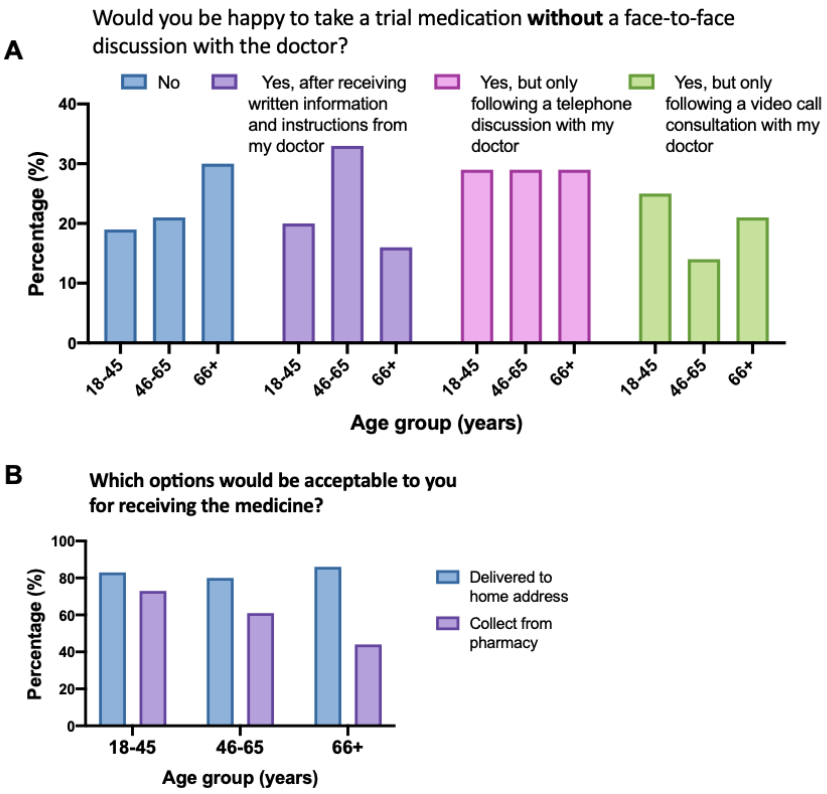

Figure 2: Prescription and delivery of trial medication. A) Responses to 'would you be happy to take a trial medication without a face-to-face discussion with a doctor?' presented as the percentage response by age group (n=337), B) Acceptable options for delivery of trial medication (n=340).

Impact of COVID-19 on the use of technology

Participants were asked to rate their overall ability to use technology for video calls, messaging, and emailing for communicating with others. The majority rated their ability as very good (n=174, 50%) or good (n=121, 35%). The perceived ability was lower in the older

population (see Supplemental Figure S2), but more than half of the older population surveyed reported good or very good ability (74% of those aged 66+ years).

The participants were asked to rate how their overall ability to use technology had changed after the government COVID-19 related lockdown in the UK in March 2020. Most reported no change in ability (n=216, 62%), whilst about a third reported their ability was better than before (n=126, 36%) and only 6 (2%) reported their ability as worse than before the lockdown. Reports of improved ability was similar between the age groups with 35% of 18-45 year olds, 36% in the 46-65 year olds and 37% in the 66+ year group perceiving an improved ability, respectively.

When asked about the amount of time spent using digital technologies (such as mobile phone, computer, laptop, tablet or smart device) following the first government lockdown in March 2020, most participants suggested that they spend more time than before (slightly more time n=153, 44%; a lot more time n=138, 40%), whilst 14% spend the same as before (n=50), and 1% spend slightly less (n=5) or a lot less than before (n=3).

Further data on the access and ability to use technology at home is presented in the supplemental materials (Table S2 and Figure S3).

Barriers to the use of technology

To better understand the potential barriers to using technology for research, participants were asked to identify one or more factors which may limit their use of technology. The most frequently reported barrier was internet speed and/or quality (n=88, 25%), followed by confidence (n=75, 21%), familiarity (n=61, 17%), tremor/shaking (n=40, 11%), dexterity (n=39, 11%), problems with thinking/memory (n=20, 6%), hard of hearing (n=18, 5%), vision

(n=15, 4%), devices being hard to use (n=5, <1%) and other reasons not listed (n=26, 7%). Of those that chose 'other' the most common reason supplied were lack of interest in technology, privacy concerns and costs. Interestingly, confidence was cited more often with increasing age bands. The data are shown by age group in Figure 3.

Confidence and familiarity were recognised as limiting factors in a larger percentage of the older age groups (46-65 years and 66+ years) compared to the youngest groups (18-45years). Health related factors such as tremor, dexterity, vision and hearing were reported mostly in the oldest age group.

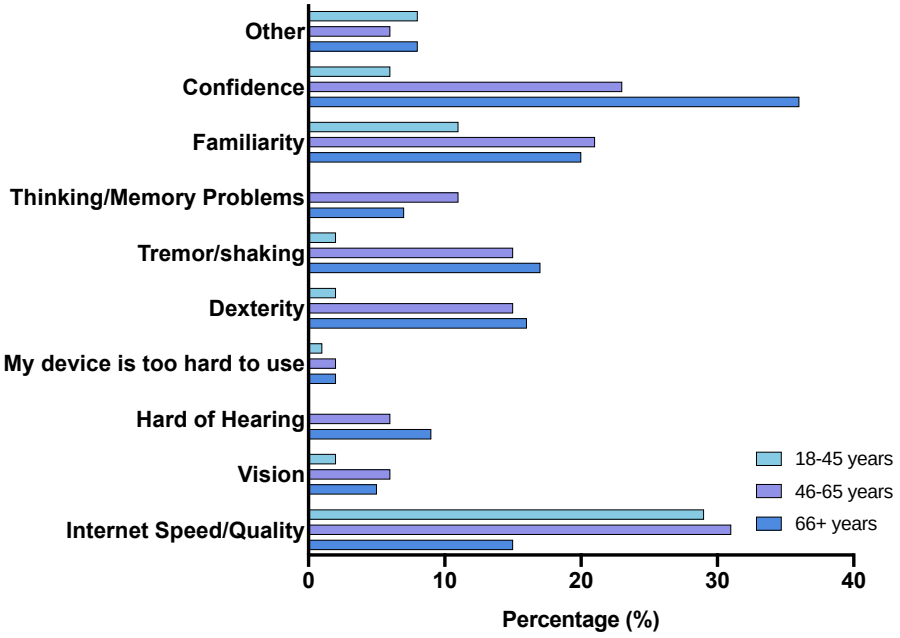

Figure 3: Barriers to the use of technology by age group, 18-45 years (n=122), 46-65 years (n=112), and 66+ years (n=117). Data shown are percentage of participants responding that the item listed is a barrier.

Use of telehealth

Participants were asked whether they had ever had an interactive appointment with a doctor or other healthcare professional that was delivered online, for example via videocall. Thirty percent (30%, n=103) of the participants responded that they had, whilst 70% (n=245) had not, and 0.3% responded that they preferred not to say (n=1). Of those who had used a telehealth appointment, 71% (n=73) had a chronic health condition whilst 21% (n=30) of the participants who attended a telehealth appointment did not have a chronic health condition (p=0.005).

Participants were also asked whether they use any wearable health technologies such as a smartwatch, fitness tracker or an exercise app. 43% (n=148) of the participants responded that they had, 43% (n=149) responded that they have never used such technology and 15% (n=51) responded that they had tried, but no longer use such technologies. There was no difference across the age groups with respect to the use of telehealth appointments (p=0.58), or health technologies (p=0.047).

Discussion

This study assessed attitudes to the use of technology-assisted remote research methods which could be used in clinical research. The study found a positive attitude towards the use of remote technologies in healthcare research, including the use of video calls, online research assessments and telephone appointments. Interestingly, traditional research methods, such as research appointments at a hospital or research centre, were seen as a

limiting factor to taking part in research, suggesting that the move to remote assessment methods and/or a hybrid model should be encouraged. Other studies have found support for the use of virtual assessments in clinical care including equivalence for usual care with the added benefit of saving time and mileage for the patient, and may increase access to care (12,13). With the challenges brought forth by COVID-19, clinical research is finding new ways to answer research questions. The challenge has brought about an exciting opportunity for innovation and increased inclusivity, by allowing barriers to research to be explored and addressed.

Encouragingly, the current study found that there was little discrepancy between age groups in terms of access to, and ability to use, communication technologies (see supplemental information). This is in line with the report from the Office for National Statistics (14) which suggests that the technology gap is narrowing across age groups. The most frequent barrier was internet speed/quality, along with confidence and familiarity which affected the older age group more.

Trialists should consider barriers including internet upload/download speed and quality are sufficient to support the chosen web applications, video call platform and other online activities. Further, cost and access to technology, especially where particular standards (e.g. specific operating systems or hardware models may be needed to run some applications) are required, will be an important consideration for the future of clinical research. Simplifying study design and adapting the delivery, for example by providing verbal instructions or costing for adaptive technologies, could ensure that older adults including those with visual impairment or dexterity issues are able to participate.

Our findings show that the COVID-19 pandemic led to an increase in the time spent using technology and, one third reported that their ability in using technology had improved. The use of health technology and telehealth appointments may be of particular interest to obtain physiological measures and healthcare information in the home setting in both clinical and research settings. Although the number of telehealth appointments have increased due to COVID-19 (15), only about one third of the participants had utilised this method of appointment and there was no difference in the use of telehealth appointments across age groups. Similarly, there were no age-related trends with respect to current or prior use of health technologies, such as FitBits or other health Apps and technology.

Across all age groups, telephone calls, video calls and online assignments, improved willingness to participate. App use was preferred by younger people (aged 18-45 years). Interestingly, the type of trial data collected (consent, health data (including medical and medication history) didn't seem to influence people's choice.

Whilst the pandemic is almost certainly a factor in the preference towards online and app-based research over face-to-face appointments in the hospital setting (16), when asked about the barriers to taking part in research (table 2), a main obstacle across all age groups was the transport, distance and parking at hospitals and research centres. In addition, time required, and timing of the appointment were limiting factors for a large proportion of the participants. Taken together, this may suggest that the preference for data collection using online methods, as well as telephone/video calls over the traditional face-to-face visit could be due to the logistical factors of taking part more so than the consideration of the current pandemic.

Regarding Clinical Trial of Investigational Medicinal Products (CTIMPs), the participants were asked whether they would find it acceptable to take a medication without a prior face-to-face discussion with a doctor. The majority (~75%) were happy to do so, with little difference in the proportions who would prefer to do so with a previous telephone call versus video call versus written instruction from their doctors. The majority of participants would find it acceptable to have the medicine delivered to their home. During the pandemic, UK-based CTIMPs were quick to implement ways of delivering medicines to participants' homes in order to complete ongoing trials (17). The current study supports the initiative in that the delivery of medicine to people's homes was considered acceptable by the majority of the participants.

Limitations

The survey was opened in July 2020 and therefore does not capture the attitude of the population at the height of the first wave of the pandemic in the UK. The majority of the questions asked of the participants do not specify whether the participant should consider their response in general or in relation to the ongoing urgent public health crisis. Therefore, the results could be biased by a mixed interpretation of the question base. However, it is important to note that a variable level of the perceived threat, resolution and future outlook at the time of the survey would need to be captured in an accurate manner to correct for such bias. Importantly, the alert levels have remained variable throughout the UK in 2020.

As the survey was provided online, a pre-requisite for taking part was access to a device with internet access. Attempts were made to widen the participation through assisted surveys (e.g. using care home volunteers/staff). However, due to COVID-19, in-person recruitment and supported completion of the survey, was not appropriate at the time the study was undertaken. Potential participants also had the option to take part via telephone. However due to the national COVID-19 guidelines in place at the time of the survey, no face-to-face interviews or paper copies were administered. It would be beneficial to repeat the survey as face-to-face appointments return to pre-pandemic levels. We therefore recognise that our sample is likely to be biased towards those who are more technologically literate already.

The authors of the work has a special interest in Parkinson's disease which may have influenced the advertising and consequently population recruited (e.g. advertisement was undertaken through Parkinson's UK). However, the study was advertised widely and 40% of the participants reported no long term health conditions.

The representation of the South West comprised nearly half of the population sampled. This was largely due to the success of identifying local advertisement space and outlets. Efforts were made to balance the participants across all regions of the UK by advertising the study to local groups and charities across all areas. Furthermore, our sample were largely educated and research active. Approximately 70% of the sampled population had higher degrees (undergraduate or above). This is not representative of the general population, but calls to a bias often disregarded in relation to health research and public engagement with science in which there is a skew towards people with higher degrees (18). Conscious efforts

should be focused to ensure that research is accessible and advertised more widely to reach communities outside this level of education.

Lastly, the study population comprised 92% identifying as white, whilst the UK population is estimated to be ~86% white (ONS census 2011). Therefore, the study presents with undersampling people of sample under-represents people of other ethnicities. Whilst we sought to identify barriers to taking part in clinical research, which may lead to under-representation of certain groups, no data was collected on the reasons why individuals may have chosen not to participate in this survey. This research question is important and should be considered in future research. Caution should be exercised in extrapolating these findings more widely to other groups.

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Conclusions

This study provides anonymous opinions on the use of technology in the delivery of clinical research. The study identifies the main obstacles in using technology in trials within the context of barriers to taking part in research. Encouragingly, the study substantiated that there is appetite for participation in research that utilises online, telephone and video call appointments. As such, given the limitations of the study mentioned above, the results should be taken with some caution as to the generalisability of the findings. Such an approach will partially mitigate some of the negative impact of COVID-19-related restrictions on research delivery. Such approaches have huge potential to improve the accessibility and inclusivity of research affording more people the opportunity to benefit from research study inclusion.

List of abbreviations

COVID-19 – Coronavirus Disease 2019

Declarations

Ethics approval and consent to participate
The study was approved by the University of Bristol Faculty of Health Sciences Ethics Committee (reference 104202). All participants signed the consent form online before entering the survey. Contact information for questions prior to consent was provided.

Availability of data and materials
The datasets generated and/or analysed during the current study are available in the University of Bristol data.bris repository [*PERSISTENT WEB LINK TO DATASETS*]

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Authors' contributions
SN, design, data collection, data analysis, writing of manuscript
AB, design, data collection, data analysis, writing of manuscript
FL, design, data collection, data analysis, writing of manuscript
ET, design, data collection, data analysis, writing of manuscript
EH, design, data collection, writing of manuscript

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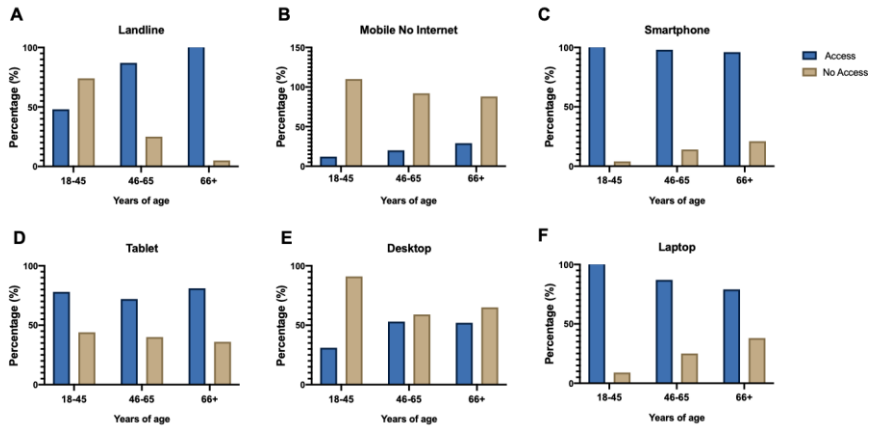
Supplemental Material

Access to Technology at Home

The participants were asked which device(s) they have access to at home. The majority of the 351 participants reported access to a smartphone (with internet access and camera functionality) (n=312, 89%), laptop computer (n=279, 79%), tablet device (for example iPad) (n=231, 66%) and/or to a landline phone (n=247, 70%). Less than half of the participants had access to digital camera (n=158, 45%), mobile phone (no internet access or camera) (n=61, 17%), desktop computer (n=136, 39%), and no respondents reported access to none of the mentioned devices (n=0, 0.0%).



Supplemental Figure 1: Access to Technology at Home.

Use of Technology at Home

The participants were asked which activities they would be able to do, with or without help, on a mobile phone, tablet device or computer. Overall, only one participant felt they were

unable to do any of the proposed activities on a mobile phone, tablet or computer (<1%; age group 18-45 years). The most apparent difference in perceived ability was observed for social media use, playing games, as well as recording of videos and pictures and sending these via text or messaging. Overall, the participants reported being able to call relatives or friends via video calls (n=332, 95%), send emails (n=348, 99%), receive emails (n=348, 99%), send/receive pictures or video recordings via email (n=326, 93%), use text messaging (n=338, 96%), send pictures or video recordings via text messaging or messaging App(s) (e.g. WhatsApp, Messenger or iMessage) (n=305, 87%), record own videos or take photos (n=309, 88%), browse websites (using the internet) (n=341, 97%), use social media Apps (e.g. Facebook, WhatsApp, Instagram, TikTok, etc.) (n=308, 88%), playing games (n=261, 74%), read the news or a book (n=318, 91%), listen to music/watching films (n=302, 86%), use other Apps (e.g. weather, maps, etc.) (n=313, 89%), none of the above listed (n=1, 0.3%).

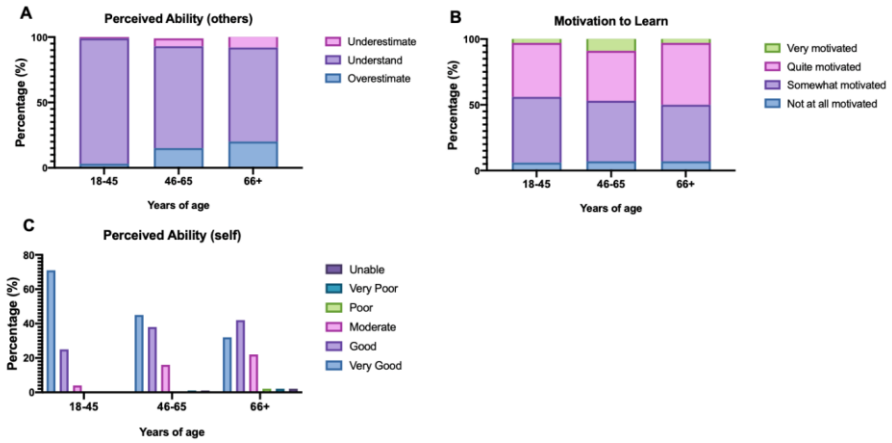
Supplemental Table 1: Perceived ability to undertake activities on mobile phone, tablet or computer by age group (% responding that they are able to).

	18-45 years	45-65 years	66 + years
Calling using videocall	99%	97%	87%
Sending Emails	100%	98%	99%
Receiving Emails	100%	99%	98%
Sending/receiving pictures or video recordings via email	98%	92%	88%
Text messaging	100%	96%	93%

Sending Pictures or video recordings over text messaging or messaging app	98%	87%	75%
Recording your own videos or taking photos	98%	88%	77%
Browsing websites (using the internet)	99%	95%	97%
Using social media Apps	99%	92%	72%
Playing Games	93%	76%	54%
Reading the news or a book	98%	89%	84%
Listening to music/watching films	98%	86%	74%
Using other Apps (e.g. weather, maps, etc)	98%	87%	82%

When asked how the participants felt others perceived ability to use technology for communication, most felt others understand their ability. However, with increasing age, a larger percentage (29% in the 66+ years compared to 4% in the 18-45 year group) of the

respondents felt their ability was underestimated or overestimated by others. The motivation to learn to use new technology was similar across all age groups (Chi-squared p=0.93, n=350). The data are shown in Supplemental Figure S below.



Supplemental Figure S2: A) Self-reported perception of others perceiving your ability (n=350), B) motivation to learn to use new technology or apps (n=350), C) Self-reported ability to use technology for video calls, messenger and emails for communicating with others (n=350).