Patient Preference and Adherence

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ORIGINAL RESEARCH

Preferences and Attitudes Towards Digital Communication and Symptom Reporting Methods in Clinical Trials

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Purpose: With the growing use of digital health technologies (DHT) in clinical trials, the opportunity to use technology to promote greater patient centricity and inclusivity has emerged. Current technology provides various mechanisms for communication, eg, through voice or text, however, participant familiarity and preference for them is poorly understood. The purpose of this study was to understand participants' communication preferences, their comfort with and use of messaging methods and their attitudes towards different communication and technology-driven symptom reporting methods in clinical trials.

Participants and Methods: Fifty-five participants, with any form of chronic health condition or recent intervention causing daily pain or discomfort were recruited by way of convenience sample for a single-centre, non-interventional, single-visit study, conducted in Ireland. Participants completed a questionnaire on communications preferences via an app on the participants' own electronic device.

Results: In communication with friends and family, 69.6% of participants most preferred to use a messaging service. In communication with their healthcare provider, 72.7% preferred phone calls. Respondents preferred to communicate with friends/family via text messages (80.4%) over other methods. In clinical trial settings, participants are willing to use messaging methods to communicate with their physician. When reporting symptoms, most preferred a phone/video call to physicians (50.9%) and touch screen on device/smartphone (47.3%). 72.7% preferred to report symptoms using their own phone. Some respondents were interested in having the device read the questions/answers aloud (36.4%) and answer questions verbally (41.8%).

Conclusion: Participants were familiar with various communication methods but showed different preferences to communicate with friends and family versus healthcare professionals. For reporting symptoms in a clinical trial while at home, split results suggested a preference for independent reporting as well as live communication with physician, perhaps reflecting the rising use of telehealth. Further exploration is needed for the use of questions read aloud or answered verbally when reporting symptoms in a clinical trial.

Keywords: eCOA, electronic clinical outcome assessments, PRO, patient reported outcome, digital health technology, DHT

Introduction

Effective communication between clinical trial participants and healthcare providers is important for adherence to the clinical trial protocol for which they are enrolled. Patient-physician communication can impact the patient's compliance to treatment, their level of satisfaction and decisions.[1] Bamigbola and Warwick's study comparing clinical trial patients with non-clinical trial patients found that patients with clinical trial experience were more confident in getting information from their physician, felt as involved in their treatment as they wanted to be and were twice as likely to discuss treatment side effects with their physician.[2] A study by Zhou et al (2019) discovered that participants thinking of dropping out of a clinical trial rate their communication with their physician lower, while those who intend to remain in the trial score more positively on relational communication and feel more informed.[3] If patients do not feel comfortable enough to report important lifestyle issues, insufficient communication between patient and physician could lead to maltreatment.[4] An example of this is patient reporting of suicidal ideation and behavior symptoms. A study by

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Yamamoto et al found that younger participants and females were significantly more likely to be honest about their symptoms if reporting electronically rather than in a face-to-face interview.[5]

However, physician-participant communication does not need to be conducted face-to-face. Rather than being "hindered by technology", one study shows how the use of text messaging led to "digital intimacy"; a relationship built on "knowing about the patient" which did not exist with regular face-to-face encounters.[6]

In clinical trials, the move away from face-to-face/in-person to electronic approaches to trial conduct greatly increased during the COVID-19 pandemic to enable trial continuity.[7] The use of Digital Health Technologies (DHTs), such as mobile health, telehealth, wearable devices and electronic patient reported outcomes (ePROs) made this possible. It has been estimated that the use of DHTs in clinical trials has increased by 97% since 2018.[8] An advantage of DHTs is the potential to increase participation of underrepresented groups. Increased accessibility to clinical trials is advocated by the FDA to ensure the trial population is more representative of the population for whom the drug is intended.[9,10] However, user practices and preferences must be considered and affect how they are implemented in a trial.[11,12] Participants have indicated a preference to take part in clinical trials that use mobile technologies such as a smartphone, tablet, or a wearable health monitor.[4] As for participating in a trial, 75% said they preferred to respond "to a digital ad in social media and completing a pre-screening form online".[13]

Consumer smartphones and tablets contain a wide array of options to communicate, such as through phone call, text messaging, video messaging, and voice memos. Providing patients with various communication options promotes greater inclusivity, accessibility, and patient centricity in clinical trials. For example, voice memos could potentially benefit participants with vision impairment. However, participant familiarity, usage, and preference for these features remain poorly understood. Therefore, the focus of this study is to understand patient communication preferences and usage in social and clinical situations, and attitudes towards using these features in clinical trials.

Material and Methods

Study Design

The study was a single-centre, non-interventional, single-visit study, conducted in Ireland, and was part of a larger equivalency study (published separately) which determined the sample size.[14] Participant prequalification was performed by telephone consultation with patient recruitment staff. Fifty-five participants were recruited with any form of chronic health condition or recent intervention causing daily pain or discomfort (Table 1) through convenience sampling. There were no exclusion criteria. To the degree possible, sample diversity was sought with respect to age, gender and education level. The recruitment plan included the following targets: Male/Female: Min 20 each, Android/Apple: Min 20 each; Age (>40, 40–59, 60+): Min 10 each; Education: Min 5 each. All participants

Table 1 Participant Demographics (N=55)

Characteristic		**N = 55**
Age		
	28–39	14 (25%)
	40–49	6 (11%)
	50–59	18 (33%)
	60–69	13 (24%)
	70–80	4 (7%)
	Range	28–80
	Mean ± Standard Deviation	51.9 ± 13.7
	Median	54

(*Continued*)

Table 1 (Continued).

Characteristic		N = 55
Gender		
	Female	35 (63.6%)
	Male	20 (36.4%)
Education		
	Left school with no qualification	6 (10.9%)
	Leaving Certificate or equivalent	9 (16.4%)
	College/Technical College (eg Certificate, Advanced diploma)	13 (23.6%)
	University Undergraduate level (eg BA, BSc)	15 (27.3%)
	University Postgraduate level (eg PhD, MSc)	11 (20.0%)
	Prefer not to share	1 (1.8%)
Mobile Device		
	Android Smartphone (Samsung, OnePlus, Motorola, Google Pixel etc.)	34 (61.8%)
	Apple Smartphone (iPhone)	21 (38.2%)

were recruited using internet and newspaper advertising. The questionnaire was developed by Clario and completed via an app on participants' own electronic devices. Ethical approval for this study was obtained from the Dublin City University Research Ethics Committee in accordance with standard research practices. This approval required that all participants provided informed consent and were provided with a plain language description of the study. The study population included participants that were 18 years or older. There were no specific exclusion criteria. Respondents had to be willing to complete a questionnaire and be able to read and write English fluently. The questionnaire asked about participants' use of different digital methods when communicating with friends and family, to rank order their preference for each and to indicate their frequency of use and level of comfort with each method. Participants were then asked about communication methods with their physician or healthcare provider, ranking each method, and their attitudes towards communication and symptom reporting methods if they were participating in clinical trials. Interviews took place between 16 February and 23 March 2023.

Statistical Analysis

Frequency and percentage tables were produced for the full data sample. The frequency of each response was calculated and presented as percentage of all respondents. The use and preference of each communication technology and patient interest in electronic communication with their physician was calculated and presented in the same way, as were communication preferences during clinical trials, such as reporting symptoms and receiving reminders. The level of comfort with each technology was measured on a 5-point Likert scale. All analyses were performed using Microsoft Excel.

Results

Fifty-five participants were aged between 28 and 80, with a mean of 51.9 years of age and a median of 54. 63.6% of participants were female, 30.4% male (Table 1). Education levels varied, with 70.9% having attained college or higher level and 29.1% having no qualification, a school leaving certificate or preferred not to share their educational level.

Communication Differences Between Family and Friends, and Clinicians and Healthcare Providers

When communicating with friends and family, participants showed a preference for using WhatsApp – a messaging and calling platform – (69.6%, Figure 1) over other methods. Phone calls were the next preferred option, at 21.4%. When compared with the preferred communication method with physicians or healthcare providers, preferences were found to be very different. With physicians or healthcare providers, a phone call is most preferred (72.7%), followed by Email at 20.0%. Only 3.6% of participants preferred using WhatsApp to communicate with their physician or healthcare provider.

Analysis showed that the frequency of using a specific messaging method followed a similar trajectory to participants' comfort level with using each messaging method ie, as usage frequency increased, so would the comfort level (see supplementary Figure 1). For example, typing text messages, which has the highest usage frequency (52.7% use it very often) also has the highest level of comfort (60% are very comfortable with it). A similar pattern could be seen in all forms of messaging. Participants' use of video messaging was lowest (70.9% never use it), which is reflected in participants' lowest level of comfort using it (5.5% is very comfortable).

Participants were then asked to rank their preferred method for messaging friends and family. Choices were typing text messages, speech-to-text messages (eg, dictating and sending text messages using a voice assistant such as Siri, Alexa, or Google), voice memos (eg, sending a pre-recorded voice recording via text or voice note via WhatsApp) and voice messages (eg, leaving a message after being prompted by an answering service). Typing text messages was most preferred by participants (80.4%, Figure 2A), followed by voice messages (8.9%). The least preferred options were voice memos (32.1% of participants' least preferred option) and speech-to-text (39.3% of participants' least preferred option).

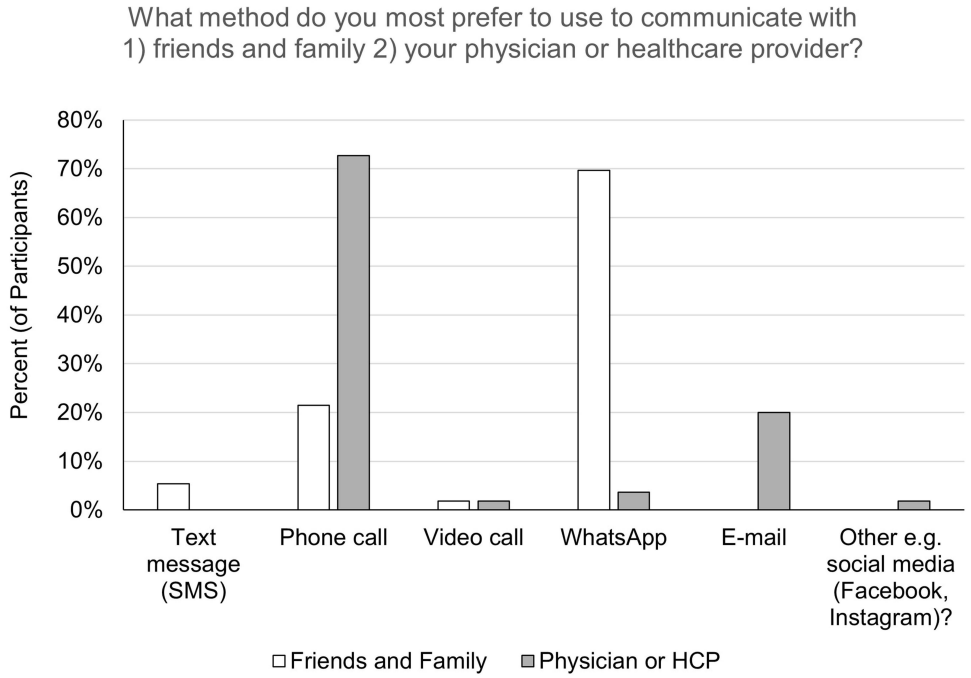

Figure 1 Subject responses related to communication preferences with friends and family versus physician or healthcare provider.

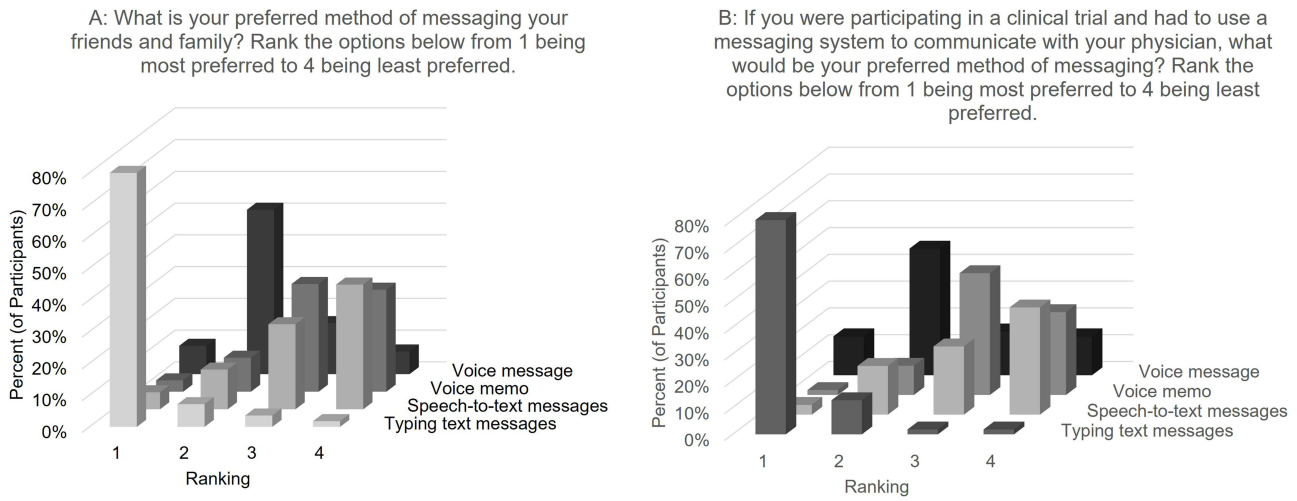

Figure 2 Subjects' responses to questions related to preferred method of messaging friends and family (**A**) and preferred method of messaging during a clinical trial (**B**). Subjects were asked to rank the options.

Communication in a Clinical Trial Setting

The next part of the questionnaire was focused on understanding communication preferences during clinical trials. First, participants were asked whether they had ever participated in a clinical trial, to which 74.5% answered "No", 21.8% answered "Yes" and 3.6% did not know whether or not they had participated.

Subsequently, participants were asked which messaging method they preferred to use to communicate with their physician, when asked to use a messaging system during a clinical trial. Figure 2B shows that typing text messages was the most preferred option (80.0%), followed by voice message (14.5%). The least preferred methods were voice memos (30.9% of participants' least preferred option) and speech-to-text messages (40% of participants' least preferred option).

Reporting Symptoms and Receiving Reminders Away From Site

To understand how trial participants prefer to communicate their symptoms from home during a clinical trial, participants were given the following options: Touch screen to select an answer on a device or smartphone, voice to select an answer on a device or smartphone, voice recording of your answers using a device or smartphone and via phone or video call with your physician. Figure 3A demonstrates that, given the choice, participants slightly prefer a phone or video call with their physician (50.9%) over a touch screen (47.3%), although 91% of participants chose the touch screen as either their first or second option, versus 74.5% of participants who chose the phone or video call as either option one or two (see Supplementary Figure 2a).

When asked what their most preferred electronic device would be to report their symptoms on (Figure 3B), 72.7% of participants chose their own smartphone, followed by their own laptop or desktop computer (12.7%, Figure 3B). Using a provisioned device (a device provided to them for trial purposes only) was less popular, 7.3% and 5.5% respectively for smartphone and tablet. The provisioned tablet was the least preferred option overall (see Supplementary Figure 2b).

Clinical study participants are reminded to report their symptoms on a regular basis depending on the indication and assessment. These reminders may improve engagement and compliance and reduce dropout. Therefore, participants were asked how often they check their cell phone for notifications or text messages, and their preferred method for receiving reminders. More than 56% check their cell phone twice or more every hour (Figure 4A). Over 83% of participants check their cell phone at least every 2–3 hours.

In terms of the preferred method for receiving reminders, participants' preferences were divided (Figure 4B). Most preferred receiving text messages (29.1%) followed by audible alarms (25.5%). Responses on audible alarms were polarized. Although 25.5% most preferred this option, for 25.5% of participants this was the least preferred option (see Supplementary Figure 3). The Email option was least preferred overall.

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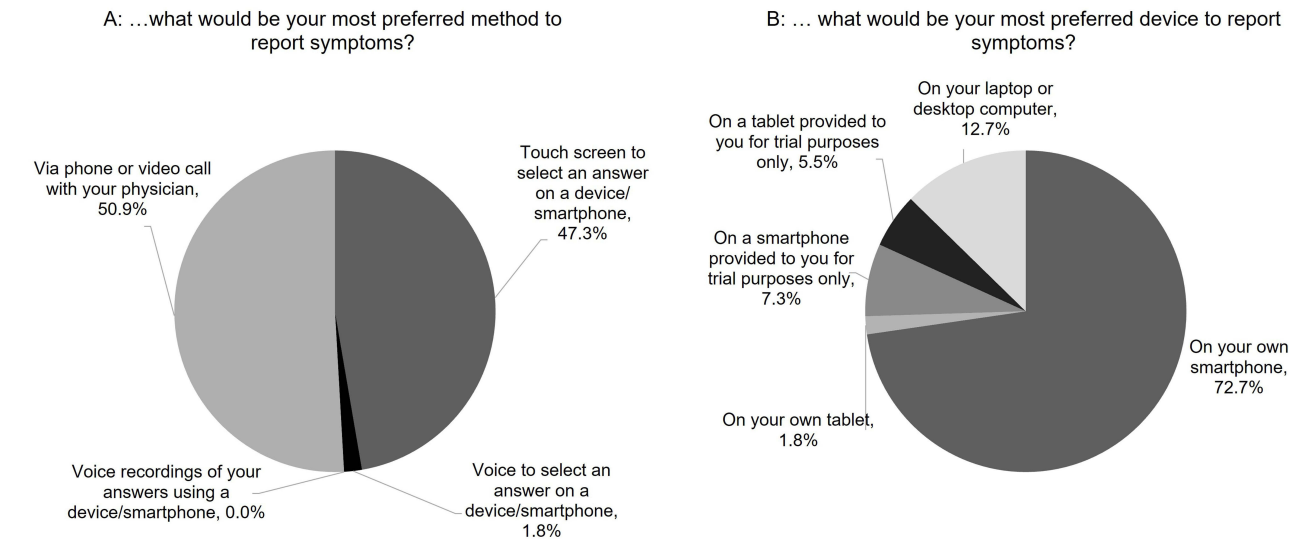

Figure 3 Subjects' most preferred method for reporting symptoms (**A**) and most preferred device for reporting symptoms (**B**).

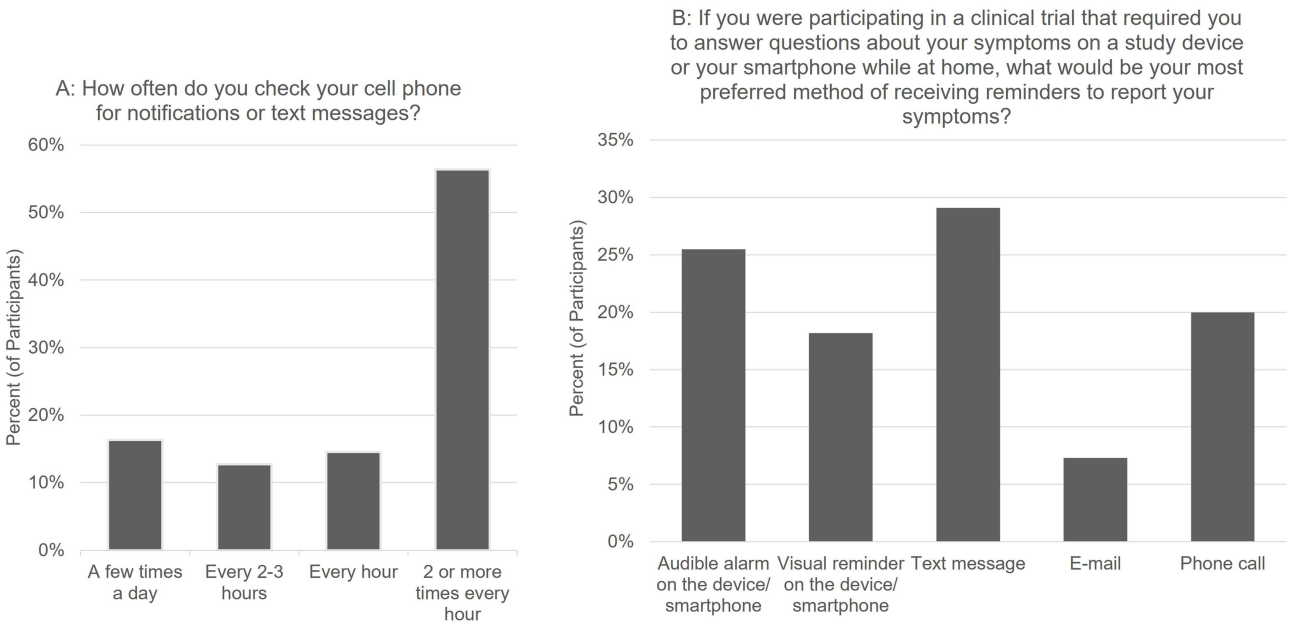

Figure 4 Subjects' responses to questions related to frequency of checking cell phone for notifications or texts (**A**) and most preferred method to receive reminders for symptom reporting (**B**).

The final questions looked into accessibility feature preferences. Participants were asked whether they would be interested in having the device read the questions and answer options aloud and whether they would want to answer the questions verbally. Figure 5A shows that 50.9% said no to having questions and answer options read aloud, 36.4% said yes, and 12.7% said they did not know.

When asked about answering questions verbally, 41.8% of participants said yes, they would be interested, 32.7% said no, and 25.5% said they did not know (Figure 5B).

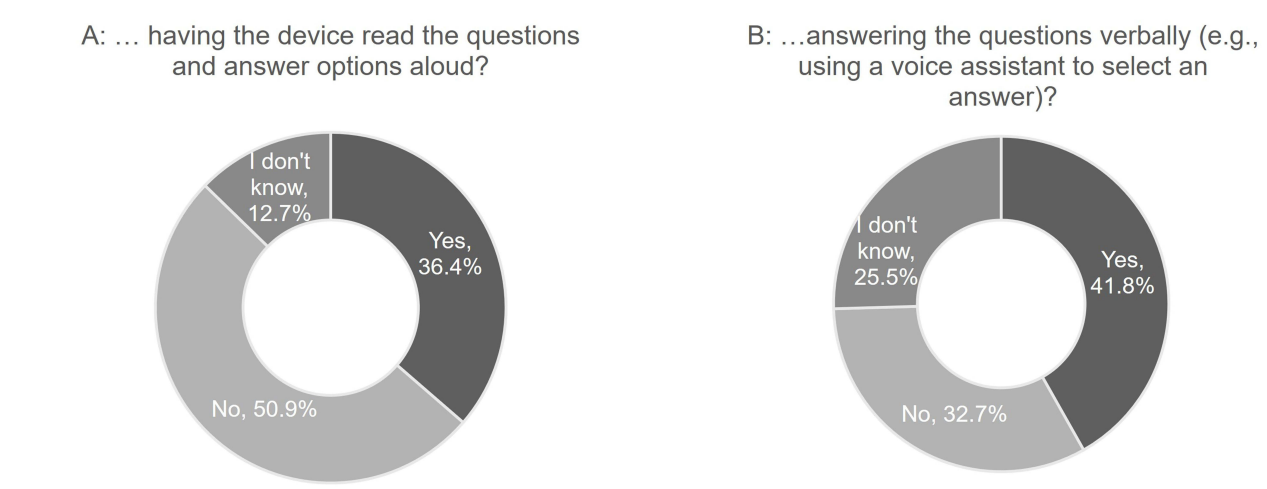

Figure 5 Subject interest in having questions and answer options read aloud (**A**) and interest in answering questions verbally (**B**).

Discussion

The difference in method preference between communicating with friends and family on the one hand and physicians and healthcare providers on the other is quite pronounced. It is unclear whether this difference is due to WhatsApp/Text Messaging not being available or not being offered as a communication method by physicians and healthcare providers. A study by Campbell et al found that where offered, text messages helped patients feel connected and reduced calls into the doctor's office.[15]

The similarity in trajectory of frequency of usage and level of comfort using each method was not in itself surprising. It does suggest however that if participants use a particular method less, their comfort level may be less, which could result in participants having difficulty reporting their symptoms via the method requested in a clinical trial. Participant training can help bridge this confidence gap. Hill, Betts and Gardner[16] found discomfort being one of the barriers to using technology. However, the study concluded that once patients' fears were overcome, technology became an enabler.

The research showed that participants' preferences in communicating with their physician during a clinical trial reflected their preferences for communicating with friends and family. Although participants' preference in communicating with their physician may be a phone call, participants' answers indicate their willingness to use messaging in a clinical trial setting, if required. For reporting symptoms in a clinical trial while at home, participants were split between phone/video call and using a smartphone touchscreen. This may suggest a preference for both independent reporting as well as live communication with their physicians, which may reflect the rising use of telehealth. Research by Gordon et al concluded that some patients found the use of a video call to be a barrier to "speaking up" and felt that their physician paid less attention to them.[17] However, a systematic review by Leonardsen et al found that technology facilitated patient empowerment, including participation, control and knowledge.[18]

Furthermore, participants indicated a clear preference for using their own devices to report their symptoms during a clinical trial, rather than a provisioned device. Studies by Shahraz et al and Byrom et al confirm this finding, also in older participants.[19–21] These results support the inclusion of Bring-Your-Own-Device (BYOD) options in clinical trials. Sponsors should take into consideration that while most preferred their own smartphone device, a good portion of participants preferred a provisioned smartphone or tablet for the purposes of the trial, highlighting the importance of providing participants a choice to either use their own device or a provisioned device.

A large proportion of participants check their phone very regularly, making this a natural choice to receive reminders on. This is in line with a recent Deloitte study in Ireland, which reported that "36% of respondents check their phone at least 50 times a day".[22] An American study found that people check their phone 144 times a day, on average.[23]

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Participants were divided in their preferences, although a text message was most preferred. Only 7.3% of participants ranked e-mail as their most preferred choice. This appears to depend more on people's personal preferences, meaning that more than one reminder option might be offered to participants.

As mentioned initially, accessibility to clinical trials is important to ensure the clinical trial population is representative. Electronic devices that capture clinical data can increase accessibility by including functionality that improves or enables a positive trial experience for participants with visual or other impairments. While many participants showed interest in having the clinical trial device read the questions and answers aloud or answering verbally, the proportion was still less than half. It is possible that the reduced interest is related to a concern for privacy, even if the assessment is completed at home. This is reflected in studies by Shen et al, Small, Hohl and Balka and Young et al, which found that privacy is a patient concern to using digital tools.[24–26]

It is also possible that the reduced interest could be due to a lack of need for these accessibility features, or a lack of familiarity with them. Further research could examine the preferences for these accessibility features with those who rely on them, such as due to vision impairment or other disability.

Potential limitations of the study include the single research location as the source for participants. A future study could be conducted in other (non-Western) countries to better understand the impact of culture on communication preferences. Furthermore, it could examine differences in communication preferences across age groups using a larger, more diverse group of participants.

In addition, the patient communication preference study was part of a larger equivalence study, for which the sampling method and size was chosen. This may have impacted the results of this research. Finally, the study's questionnaire was not validated.

Conclusion

This research study provided an overview of communication preferences with friends and family and physicians and healthcare providers. Participants preferred "direct" contact with physicians and healthcare providers and "indirect" contact with friends and family. In a clinical trial setting, participants chose text messages to communicate with their physician or healthcare provider and selected to report symptoms both via phone/video call and via a touchscreen device/smartphone. Participants' comfort and usage levels with digital communication methods vary. Consequently, depending on the method chosen, participant training is recommended to ensure participants can complete the assessments. Participants prefer their own devices to report symptoms and receive reminders by audible alarm, although other options might be offered.

In summary, this research underscores the importance of understanding and respecting individuals' diverse communication preferences, particularly in the clinical setting, where tailored approaches and training can enhance the effectiveness of communication methods and result in better clinical trial outcomes.

Ethics Statement

The study complies with the Declaration of Helsinki.

Acknowledgments

The data used in the research are proprietary to Clario. Funding for this research was provided by Clario. The publication of study results was not contingent on the sponsor's (Clario's) approval or censorship of the manuscript.

Disclosure

Sarah Gary reports being an employee of Clario. The authors report no other conflicts of interest in this work.

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