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Research Article
Insights from ARCOS-V's Transition to Remote Data Collection During the COVID-19 Pandemic: A Descriptive Study

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Short Title: Insights from ARCOS-V's Transition to Remote Data Collection During COVID-19

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Abstract
Introduction: The ARCOS-V study, an epidemiological study on stroke and transient ischemic attack (TIA), faced the challenge of continuing data collection amidst the COVID-19 pandemic. This study aims to describe the methodological changes and challenges encountered during the transition from paper-based methods to digital data collection for the ARCOS-V study, and to provide insights into the potential of using digital tools to transform epidemiological research.
Methods: The study adapted to remote data collection using REDCap and Zoom, involving daily health record reviews, direct data entry by trained researchers, and remote follow-up assessments. The process was secured with encryption and role-based access controls. The transition period was analyzed to evaluate the effectiveness and challenges of the new approach.
Results: The digital transition allowed for uninterrupted monitoring of stroke and TIA cases during lockdowns. Using REDCap and Zoom improved data reach, accuracy, and security. However, it also revealed issues such as the potential for systematic data entry errors and the need for robust security measures to protect sensitive health information.
Conclusion: The ARCOS-V study's digital transformation exemplifies the resilience of epidemiological research in the face of a global crisis. The successful adaptation to digital data collection methods highlights the potential benefits of such tools, particularly as we enter a new age of Artificial Intelligence (AI).

Introduction

Impact of COVID-19 on stroke and TIA research

Stroke is a major public health problem. It is the second leading cause of death and disability worldwide [1], contributing to 6.55 million deaths and 143.23 million disability-adjusted life years (DALYs) in 2019 [2]. Due to increasing and ageing populations, the absolute numbers of stroke cases in New Zealand (NZ) and worldwide is increasing. In NZ, there are about 9000 new strokes and 3000 new TIAs annually [3]. Patients with transient ischaemic attack (TIA) have an increased risk of secondary vascular events including myocardial infarction (MI), cognitive deficits and major stroke, with incidence of adverse outcomes being reported as high as 25% within 90 days [4].

The COVID-19 pandemic has posed severe challenges to the healthcare sector and the research community worldwide. The rapid spread of the virus and its severe consequences have disrupted the delivery of essential health services and the conduct of epidemiological studies [5,6]. Among the various fields of research affected by the pandemic, stroke and TIA research has faced significant difficulties in maintaining its activities and ensuring the quality and validity of its data. The pandemic hastened the adoption of digital data collection methods in epidemiological research, particularly in NZ, where lockdowns were particularly stringent, hindering traditional approaches like face-to-face interviews and surveys. With research facilities closed and social distancing enforced, many researchers pivoted to remote online data gathering. This transition has proven largely effective and is expected to expand further in future years. Therefore, it is crucial to examine how the pandemic has impacted stroke and TIA care and research, and in particular, the tools that have been used to mitigate these challenges.

An example of this transformation occurred in the Auckland Regional Community of Stroke (ARCOS) epidemiological study of stroke and TIA that has been conducted in Auckland, NZ since 1980. ARCOS has provided valuable information on the epidemiology, risk factors, management, and outcomes of stroke and TIA in the Auckland region, and has been used to inform stroke prevention and management strategies [7]. ARCOS V is the latest iteration of the study, which aims to determine trends in stroke and TIA incidence, prevalence, and outcomes, and how these have changed over the past 40 years, using both the old World Health Organization (WHO) and new American Heart Association (AHA) classifications of stroke and TIA [8].

Rationale for evaluation

Due to New Zealand's COVID-19 lockdowns, the ARCOS V steering committee opted for remote data collection methods, ensuring compliance with both the government-mandated lockdowns and data privacy standards. This approach mirrored strategies adopted in other stroke research studies globally. The UK's Sentinel Stroke National Audit Programme (SSNAP), the Australian Stroke Clinical Registry (AuSCR), and the New Zealand National Stroke Reperfusion Register are notable examples [9–11]. All are comprehensive, prospective longitudinal studies that shifted to digital data collection in 2009, 2012, and 2018 respectively. Their prior digital infrastructure proved invaluable during the pandemic, enabling uninterrupted data collection when traditional methods were impractical. Similarly, ARCOS V's use of remote tools reflects a broader trend in stroke and other epidemiological research towards leveraging digital tools (including Artificial Intelligence, or AI) for resilient data collection amid challenging circumstances [12,13].

Like SSNAP and AuSCR, the ARCOS V study is a sizable, prospective research effort that is assessing local incidence and burden of stroke. However, it carries the added challenge of having performed a digital transformation *during* the pandemic [14]. This specifically positions ARCOS V as a crucial example for assessing pandemic-related changes in stroke research and informing digital strategies to enhance research both during and post-pandemic. As such, our aim in this descriptive study was to evaluate the impact and efficacy of performing a digital transformation of the ARCOS V study, moving from primarily paper-based to electronic survey collection methods under significant constraints.

Methods

Digital transformation of ARCOS V methodology

The transition period occurred between March 2020 and August 2021. Due to the COVID-19 pandemic's impact on healthcare services, the ARCOS Steering Committee decided on April 3, 2020, to delay recruitment for the ARCOS stroke and TIA study. The recruitment was rescheduled from September 1, 2020, to August 31, 2021, which included a 6-month extension due to an approximately 30% decrease in enrolment rates during this period. However, ongoing case registration, which began on March 1, 2020, continued to monitor stroke and TIA impacts during the pandemic.

From March 1 to August 31, 2020, residents in Auckland aged 16 and above, who experienced new stroke and TIA cases were identified. This involved daily reviews of records from public hospitals, emergency departments, and General Practitioner (GP) clinics. Between September 1, 2020, and August 31, 2021, comprehensive identification of stroke and TIA cases in Auckland residents was carried out. This encompassed daily reviews of public hospitals and emergency departments; Computed Tomography (CT) and Magnetic Resonance Imaging (MRI) records; hospital discharges; weekly reviews of private hospitals, rest homes, and community health services; monthly reviews of coroner and autopsy records; and quarterly reviews of death certificates. Data from hospitalization records provided by the study's research nurseswere used to determine stroke and TIA incidence rates per 100,000 people annually.

The research leadership decided to switch from paper-based collection methods to using Research Electronic Data Capture (REDCap), a globally recognized cloud-based application for survey-based research that is widely used for longitudinal epidemiological studies [15]. Developed by Vanderbilt University, REDCap empowers researchers to create customizable online surveys and databases, supporting features like data validation, automated export procedures, and real-time data entry with audit trails. The data management capabilities of REDCap streamline the data collection process and help to improve data accuracy. Moreover, REDCap is highly customizable, and provides an Application Programming Interface (API) that allows researchers to write (or employ) custom external modules and integrate with other software tools, enabling researchers to tailor the data collection process to their specific needs. This flexibility extends to the types of data that can be collected, encompassing a wide range of formats from text to images, audio, and video files. In addition to switching to REDCap, face to face interactions were replaced by telephone or video assessments.

Trained hospital researchers gathered baseline data from relevant medical records, and sought consent from patients and families for a one-month follow-up after discharge. Patients received information sheets, and verbal consent was obtained for further contact. One-month outcomes, including the level of disability using the modified Rankin Scale, were recorded. Teleconference interviews with stroke patients were transcribed into REDCap via iPad. Data protection and security measures, such as daily backups and anonymization of identifiers, were in place. Clinical information was accessed through the hospital's inpatient management system platform 'Clinical Portal', requiring two-factor authentication (2FA). Clinical Portal access was performed remotely via Citrix Receiver, but required researchers to sign a confidentiality agreement and undergo training before having access to the data.

During the Alert Level 4 Lockdown, certain modifications were implemented until August 31, 2020: in-person interactions for consent or follow-up were halted, except for essential service staff; TIA cases were registered, but one-month follow-ups were suspended due to lockdown constraints; and interviews in languages other than English were postponed.

Results

Data collection architecture

The data collection architecture for the ARCOS V project following the digital transformation is detailed in Figure 1. In-person communications with patients were replaced with teleconference calls, using Zoom or Microsoft Teams software. Informed consent from potential participants was obtained through secure communication channels within REDCap. Study information, along with an e-Consent form featuring e-Signature capabilities, was securely delivered to participants via text messages or emails. Participants were also given the option to download forms for their records.

The web-based interface of REDCap was utilized by trained Research Assistants (RAs) who each had their own individual REDCap accounts. To ensure additional security, RAs were required to re-authenticate using 2FA methods such as Google Authenticator or email verification. To guarantee a secure and smooth transition to remote data collection, RAs received training in the safe use of Clinical Portal, data privacy, and access rights. We implemented comprehensive user rights modules to prevent unauthorized access to identifiable participant data, ensuring the protection of sensitive information, such as date of birth (DoB) and National Health Index (NHI) identifiers.

An advantage of implementing REDCap was its emphasis on data security. REDCap instances are deployed by partner institutions behind secure firewalls, and data is encrypted in transit via Secure Socket Layer (SSL) encryption [16]. Furthermore, it allows for role-based access control, meaning that each team member can only access the data necessary for their role in the study. This feature not only enhanced data security but also facilitated efficient, secure collaboration among members of the ARCOS research team. REDCap also includes a comprehensive user rights module, enabling us to define specific user roles with designated access to forms and functionalities. This restricted unauthorized users from accessing identifiable participant information, such as the NHI number and DoB. Only users with appropriate training and permissions were able to export variables from REDCap marked as direct identifiers of patient information.

In terms of data security and integrity, any data alterations or form changes required REDCap administrator approval. Moreover, only de-identified data was shared in password-protected files, ensuring participant privacy. All project-related documents were stored on secure data servers managed by the institution, and no physical copies of data were retained.

Transformation outcomes

Overall, the digital transformation of the ARCOS V study was successful, leveraging tools like REDCap and teleconferencing for remote data collection on stroke and TIA cases in Auckland during the COVID-19 lockdowns. There were some minor adjustment challenges in transitioning to remote systems, but the research team eventually adapted well. For example, telephone assessments were difficult for participants with hearing or speech/language difficulties. However, the assessments were generally less time-consuming since they were limited to those that could be done over the phone. Additionally, the enrolment of participants in terms of consenting them into the study would have normally occurred in the community as a home visit, followed by a baseline assessment. Switching to e-consenting and online assessments saved the costs associated with these visits in terms of mileage and researcher time. However, these savings were offset by the extended recruitment period.

The research team have adopted the new processes well, and they are now being used for other studies, including projects interfacing with external hospital contractors. The transformation is now being applied to the larger ARCOS project, with all data collection and storage moving online. The digital transformation of the ARCOS project is expected to enhance service delivery and lead to improved research outcomes. One of the key outcomes of the ARCOS study is to identify service gaps and unmet needs in evidence-based policy, resource allocation, prevention planning, management services, and evaluation of service performance. As such, this transformation has improved the efficiency of service delivery and health outcomes of ARCOS.

Discussion

Remote data collection offers distinct advantages and challenges in a post-pandemic world. On the positive side, these tools reduce the need for face-to-face interactions, thereby lowering the risk of COVID-19 transmission. They also streamline data collection and analysis, freeing up valuable time for other research tasks. However, these tools are not immune to errors; data entry mistakes or technical issues can compromise the integrity of the collected data, particularly if they are systematic errors.

Digital survey tools, such as REDCap [15] or Qualtrics [17], offer several advantages for epidemiological studies, particularly during pandemics. They facilitate data collection from a wider range of diverse participants, including those in remote areas, and streamline the collection process by reducing physical travel requirements, saving both time and resources [18,19]. They can also be

used to collect data in real time, which can be helpful for tracking the spread of disease or monitoring the effectiveness of interventions [18].

The pandemic also led to a surge in the use of telehealth video conferencing tools like Zoom and Microsoft Teams [20,21], which have proved to be invaluable for epidemiology research. These tools facilitated global collaboration, enabling researchers to share findings, discuss hypotheses, and conduct virtual patient consultations in real-time, thereby accelerating the pace of research and response to the pandemic. However, they have also been associated with increased feelings of anxiety, stress, and burnout, a phenomenon known as 'Zoom fatigue' [20].

Navigating the digital transformation in epidemiological research requires a balance between embracing innovation and ensuring data security. In particular, the vulnerability of digital data to breaches or unauthorized access risks exposing sensitive personal health information at a greater scale than previously possible, since a successful hack can expose the entire database. Furthermore, the potential for data manipulation or falsification threatens the integrity of research outcomes. To mitigate these risks, several protective measures can be employed, such as robust encryption, stringent access controls, regular data monitoring, and educating researchers on security protocols [22]. However, despite these safeguards, the inherent risk of data compromise remains. Thus, the decision to use digital data in epidemiological studies requires a thoughtful evaluation of its risks and benefits. In particular, individuals must take steps to safeguard their digital security and be cautious when sharing data online, as human error continues to be one of the main issues with security of digital databases [23].

Data sharing, transparency, and ethics

The COVID-19 pandemic underscored the critical role of data sharing in facilitating rapid clinical response times to evolving healthcare needs [24]. In this context, digital tools emerged as indispensable assets, enabling seamless and secure data sharing among research communities. These tools not only expedited the dissemination of crucial information but also ensured that data was exchanged in a confidential and protected environment. Thus, the pandemic has illuminated the transformative potential of online data-sharing mechanisms in enhancing collaborative research efforts during global health emergencies.

Despite the recognized benefits of data sharing, numerous challenges persist, leading to the continued isolation or "siloing" of data, preventing the equitable distribution of data and findings [25]. One primary concern is the need to maintain privacy and confidentiality, particularly when dealing with sensitive or personal information. Regulatory frameworks and ethical considerations often necessitate stringent data access controls, limiting the extent to which data can be freely shared or integrated across different platforms or research initiatives. Additionally, a lack of transparency in institutional data collection, management, or usage practices can contribute to data siloing. Organizations may hoard data due to proprietary interests, competitive advantages, or simply a reluctance to disclose methodologies and findings. This lack of openness inhibits collaborative efforts and hampers the collective progress of the research community. Moreover, technical barriers, such as incompatible data formats, disparate systems, or inadequate infrastructure, can further exacerbate data siloing. These technical constraints hinder seamless data integration, making it challenging to aggregate or synthesize information from various sources effectively [26].

Addressing these challenges requires researchers to balance privacy protections with the need for collaborative and transparent research environments. Implementing standardized protocols, investing in interoperable technologies, and promoting a culture of data sharing can help dismantle silos and unlock the full potential of collective data resources [27]. Much work needs to be done to develop and improve awareness of data sharing frameworks [28], such as the Open Science Framework (OSF) [27], in the hope that this will influence data sharing policy at the start of research projects.

Ethical considerations in data sharing are paramount, especially in the context of epidemiological research where sensitive personal health information is involved. Despite the comfort shown by people in performing online interviews post-COVID [29], the limited understanding of data sharing among the general public raises concerns about informed consent and the protection of individual

privacy. Researchers need to use clear, simple language to inform participants of how their data is being used, the measures taken to safeguard their data, and their data rights.

Not all patients are able or willing to access remote care options [30], which may introduce some bias into the results of a remotely conducted study. Potential inequities in access to technology can lead to disparities in who is able to participate in digital health research [31]. This digital divide may disproportionately affect groups such as older adults, those in rural areas, and individuals from lower socioeconomic backgrounds [32,33]. To address these issues, researchers must consider alternative methods of data collection that can accommodate individuals without reliable internet access or digital literacy. This may involve the use of phone interviews, paper surveys, or community-based data collection assistants.

Security

Advancements in biometric authentication methods, such as online signatures, fingerprint scanning, and even face or eyeball recognition [34], are transforming online security and the validation of survey participants. Ethical authorities are recognizing the need for improved security for remote technologies to facilitate all parts of data collection, including consent. The widespread acceptance of these technologies as reliable forms of identity verification also reflects society's growing comfort with online tools. This may have some benefits, as there is increasing concern over the growing danger of automated 'bots' targeted at online surveys, particularly those that offer financial compensation [35,36]. With malicious actors constantly innovating new attack vectors, it is only a matter of time before large language models (LLMs) like ChatGPT are integrated into these methods, making security an even greater concern.

Research data sovereignty is a concept that is gaining importance worldwide. In New Zealand, the Māori Data Sovereignty Network, Te Mana Raraunga, advocates for Māori rights and interests in data to be protected, with data being subject to the laws of the nation from which it is collected [37]. This presents certain challenges from a data management standpoint. For example, platforms like REDCap and Qualtrics comply with the requirement to keep indigenous data stored locally within the country of origin, but researchers should be aware that many platforms are cloud-hosted, and store data in overseas servers, which goes against the principles of data sovereignty [37]. Hence, researchers should make themselves aware of these principles, and be prepared to apply necessary changes to their data architectures.

Limitations and future research

Despite the promising benefits of digital tools, it is crucial for researchers to be aware of potential difficulties and drawbacks. Technical glitches such as errors in data entry, system breakdowns, or interruptions in network connectivity can affect the reliability and accuracy of the data collected (although data entry risks are also present in paper-based data collection) [38]. Yet more crucially, risks related to data security, including data breaches, unauthorized access, or manipulation of data, can lead to widespread exposure of confidential personal information on a greater scale than previously possible, which can impact research credibility. Barriers to participant access, such as disparities in internet access, digital literacy, or availability of devices, can introduce bias or exclusion in the data, thereby limiting the applicability of the findings to some population subgroups.

Different survey tools provide varying levels of security and practicality. However, little research has been done to compare the efficacy of different online survey tools for performing epidemiological research. This is made difficult by the rapid development of these tools; however, certain platforms are more stable by design due to their heightened security and quality requirements, such as REDCap or Qualtrics. Future research should focus on conducting comparative studies to evaluate the efficacy and security of these platforms. This could involve designing and implementing similar epidemiological studies across different platforms and comparing the quality of data collected, the ease of data management, and the overall user experience. Additionally, research should explore how these platforms can be customized or adapted to meet the specific needs of different types of epidemiological studies. By doing so, researchers can make more informed decisions about which online survey tool to use, ultimately improving the quality and efficiency of epidemiological research.

One of the next big steps in the evolution of digital technology is the development of AI. Recently, the pace of development of AI tools has increased, with some AI algorithms being demonstrated to match or even exceed human performance on many tasks [39]. This raises the question of whethersuch tools should be integrated into epidemiological study pathways, both as a means of increasing data collection efficiency and as a method of analyzing larger, more complex datasets. Future research should evaluate the potential of AI tools in epidemiological studies, from automating data collection to identifying patterns and trends in large datasets [40]. This could involve developing machine learning algorithms tailored to epidemiological research, testing their performance against traditional methods, and assessing their impact on study outcomes. Additionally, ethical and privacy considerations related to the use of AI in health research need to be thoroughly explored, particularly if these tools are to be safely integrated with online survey tools. Yet AI tools have the potential to revolutionize epidemiological research, making it more efficient, accurate, and insightful.

Conclusion

The COVID-19 crisis has hastened the digital evolution of epidemiological research, compelling the healthcare sector to use innovative technologies to sustain service delivery. Utilizing tools like REDCap and Zoom for remote data collection, the ARCOS V study maintained its case registration activities while upholding stringent data privacy standards during pandemic-related lockdowns. This successful transition has influenced the broader ARCOS initiative to also embrace remote data gathering via digital survey and teleconference tools, enhancing overall research efficiency. Given these benefits and growing concerns over digital security, we encourage researchers to keep abreast of evolving digital technologies, such as the latest AI and biometric authentication methods, and to integrate them into their research designs.

Statements

Statement of Ethics

Ethical approval was obtained from the New Zealand Northern Y Regional Ethics Committee (NTX/10/90/090). Written informed consent was obtained from all participants (or their parent/legal guardian/next of kin) to participate in the study.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

N.H. and B.N. conceived of the idea for the manuscript. N.H. was the primary author of the manuscript. All authors contributed to the design and implementation of the research, and to the writing of the manuscript.

Data Availability Statement

Data is available on requirement.

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Figure Legends

Fig. 1. Data architecture for modified ARCOS V project following digital transformation.