

Digital Health Interventions for Adults with Acquired Brain Injury and Their Close Others: Implementation, Scalability, and Sustainability in the COVID-19 Context

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Abstract. The Social Brain Toolkit is a novel suite of web-based interventions to support people with acquired brain injury and their close others with communication difficulties post-injury. The aim of this study was to investigate potential impacts of the Toolkit's wider political, economic, regulatory, professional, and sociocultural context on its implementation, scalability, and sustainability. Nine people with academic, healthcare or industry experience implementing digital health interventions prior to and during COVID-19 were individually interviewed. Data were deductively analysed according to the Non-adoption, Abandonment, Scaleup, Spread and Sustainability framework, with a focus on the domain of the 'Wider system'. Results indicated that COVID-19 facilitated a pivot to virtual care models which was timely for the implementation of the Social Brain Toolkit; political and economic changes were entwined; and risk management, data compliance and governance were key considerations for healthcare professionals and organisations.

Keywords. brain injury, complexity, digital health, implementation science

1. Introduction

Acquired brain injuries (ABI) such as stroke and traumatic brain injury commonly cause a range of communication difficulties [1,2] with short and long-term psychosocial impacts on both the person with ABI [3–6] and their close others [7]. Clinical guidelines for the management of ABI [8,9] therefore recommend that speech pathologists provide evidence-based communication support to both people with ABI and their close others.

Meeting this rehabilitation need may require alternative service delivery models that supplement traditional face-to-face care, as people living with ABI are estimated to surpass 135 million globally, with medical and psychosocial needs that exceed current face-to-face healthcare capacities [10,11]. To this end, the Social Brain Toolkit [12] was developed as a suite of web-based interventions which enable adults with ABI and their close others to access evidence-based communication support via the internet from 2021.

'Wider system' changes can be pivotal to determining the implementation, scalability, and sustainability of digital health interventions [13]. However, there are

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currently limited implementation data describing the organisational or wider contexts of digital health interventions for ABI, or the interactions of these contexts over time [14]. This knowledge gap is especially pronounced given dramatic and global political, economic, regulatory, professional, and sociocultural changes during the 2019 Coronavirus Disease (COVID-19) pandemic. Therefore, the aim of this study was to investigate potential considerations for the implementation, scalability, and sustainability of the Social Brain Toolkit within the COVID-19 context and beyond.

2. Methods

2.1. Theoretical Framework

This study was theoretically underpinned by the Non-adoption, Abandonment, Scaleup, Spread and Sustainability (NASSS) framework [13]. The seven-domain framework was selected to examine the complexity of digital health implementation, scalability, and sustainability [14] as opposed to general implementation [15]. The present study focussed on the sixth domain of the NASSS framework concerning the ‘Wider system’; namely, the political, economic, regulatory, professional, and sociocultural context.

2.2. Setting and Participants

This study was completed as part of a larger coproduction of implementation knowledge with stakeholders with living experience of ABI, close others, clinicians, and leaders in digital health implementation [16,17]. It presents the contemporaneous perspective of nine individuals with direct experience implementing digital health interventions for any health condition within healthcare, industry, and academic contexts prior to and during the COVID-19 pandemic. Participants were identified through either public track records of relevant publications in digital health implementation, or equivalent healthcare or industry experience, as identified through public industry profiles, researcher networks, or snowball recruitment. Due to the specialised nature of this expertise, participant demographic details are aggregated to preserve anonymity: six participants were male and three were female; eight participants were Australian, and one was Danish; one had additional living experience of ABI; all were qualified with a PhD.

2.3. Data Collection and Analysis

The study was completed with human research ethics approval from the University of Technology Sydney (ETH20-5466) and informed written consent from all participants. Between the 13th of April and the 6th of August 2021, participants responded to semi-structured individual interview questions concerning each of the seven domains of the NASSS framework, published as Multimedia Appendix 2 of the study protocol [16]. Each videocall interview (range 1-2.5 hours, mean 70 minutes) was transcribed verbatim and deductively analysed [18] against the seven domains of the framework [13] by the first author (MM), with 25% of the coding of the first interview confirmed by a second author (DD). Data pertaining to the sixth domain of the ‘Wider system’ were extracted for reporting, with participants numbered P1-9 to protect their anonymity. Two thirds of participants (6/9, 66%) confirmed the interpretation of their data with no changes.

3. Results

In the COVID-19 context, participants repeatedly suggested “*striking while the iron is hot in a time like now*” (P6); “*everything is about timing*” (P3); and “*this is the time to go with [telehealth and virtual care interventions], because they’re really starting to gain some traction*” (P8). The political, economic, regulatory, professional, and sociocultural context of this timing is reported.

3.1. Political and Economic

A major facilitator of sustaining change was financial; “*[The] investment that we’re seeing around virtual care at the state level, but also within local health districts as a result of COVID, that’s infrastructure that will stay with us into the future.*” (P6). Participants observed that “*From a rules/government/policy [perspective], the shift over the last 12 months has been enormously favourable to what you’re doing. I don’t think that’s going away.*” (P5). Of note was the relationship between legislation and healthcare billing; “*in Denmark it also has to do with the economic incentives because [clinicians] are actually paid better for face-to-face than they are on the other services. I think they have to change also the structure of the payment. In the beginning, in 2009, they doubled the amount of money they got for an email and then suddenly they started. So, they were pushed by the Danish Government, that they were paid better in a period of time to run it, to get it running and going.*” (P2). By contrast, in Australia, “*Five years ago, [...] the legislation banned [clinicians] from billing for a virtual consultation.*” (P5).

3.2. Regulatory

Irrespective of COVID-19, participants noted that a digital health intervention “*has to be wrapped up in a very secure IT [Information Technology] governance framework, which ensures the security, privacy, confidentiality, the back-ups, and so on.*” (P1), including timely reporting of data security incidents, and to whom (P9). Therefore, an identified facilitator of sustainability was compliance with data privacy and security regulations, particularly in public health systems; “*[State service agency] compliance is almost like, you know, the magic bean. If you’ve got that, health districts go ‘Well, [state service agency] has reviewed, approved,’ [...] So having all of those checks done and going through that process makes life a lot easier down the track.*” (P6). This was also true for international regulations such as Health Insurance Portability and Accountability (HIPAA) compliance in the United States (US); “*The benefits [of HIPAA compliance] for your product, in my opinion, would outweigh the effort. You ultimately being non-HIPAA-compliant might reduce the pathways that you could follow down the line.*” (P5).

For international interventions, variations in regulations between countries had to be managed. For example, “*what country the server is hosted in makes a difference from where it’s uploaded, because if you’ve got a YouTube one that’s hosted in America, the rules are very different. The Australian ones are quite restrictive, that you can’t upload content that’s in copyright on an Australian server, but you can in the US, and [built-in] privacy stuff in Australia is high. It [is in Europe] too, but not in the US.*” (P3).

Internet accessibility standards also needed to be met; “*if you end up going down a line where you are [...] presented through [Australian] government channels, whether Federal or State, you’ll be expected to demonstrate WCAG [Web Content Accessibility Guideline] [19] 2.0 compliance.*” (P5).

3.3. Professional

Participants identified that professional acceptance of digital health interventions required the establishment of sound clinical governance for risk management. This included complaints management and reporting and obtaining “*emergency contacts and information and an address [...] in case you do a teleconsult and something happens during the consult.*” (P9). Otherwise; “[*Clinicians*]’ll start to challenge the safety profile [*evidence*].” (P1). Clinician acceptance may also benefit from professional training; “*in Denmark, they are not trained in any digital solution. They don't even write an email to a patient. They don't train. They have face-to-face training [...] so I have argued for many years now, that, 'Why don't they have a module about digital telecare?'*” (P2). In the interim, COVID-19 was described as having increased providers’ proficiency and capacity in digital health service delivery; “[*The COVID-19 context*] improves the likelihood of [*implementation*] success significantly. I think a lot of care providers have learnt to provide virtual care over the last 12-18 months now.” (P8).

3.4. Sociocultural

Societally, “*whether that be online banking, online shopping, online healthcare, whatever it is, there's a definite shift towards services being delivered online. So, there's going to be some early adopters of this sort of technology in healthcare that people will get on board with it straight away, and fantastic. Conversely, you've got the conservative-type people who might take a little bit longer [...] you'll 100% get people on board and you'll 100% get people that don't as well.*” (P8). For example, an industry expert recalled the positive impact of COVID on the acceptability of web-based care; “*We've done a market research [study] recently, and about 40% [of 1000] people will not go online for their online care. They just don't want to do - they want to see their clinician in person. [...] that was an online questionnaire. So, 40%, even of people that are online, don't want to get online telehealth or technology to support their healthcare. [...] So, you can imagine of those that are not online. [...] It has shifted [due to COVID]. As I said, five years ago, you would've seen that number more at 60% or 70%.*” (P7).

4. Discussion and Conclusions

According to the NASSS framework, the national establishment of financial requirements, and increased professional and civil support of digital health, have reduced ‘Wider system’ complexities relative to the years prior to COVID-19, facilitating the Social Brain Toolkit’s implementation, scalability, and sustainability [13]. Recently identified interest in using the Toolkit within the tertiary education sector [20] may further facilitate professional acceptance. Although study data were well-suited to inform the initial Australian development of the Toolkit, future studies may seek more diverse international perspectives. Nevertheless, the findings offer unique insight into the ‘Wider system’ context from individuals with direct experience implementing digital health, complementing the condition-specific expertise of people with ABI, their close others, and clinicians [17]. The findings of this study may also be informative for the implementation, scalability, and sustainability of other digital health initiatives for people with ABI and their close others, as well as the implementation of digital healthcare for people with other health conditions.

References

- [1] Norman RS, Swan AA, Jenkins A, Ballard M, Amuan M, Pugh MJ. Updating and refining prevalence rates of traumatic brain injury–related communication disorders among post-9/11 veterans: a chronic effects of neurotrauma consortium study. *Perspect ASHA Special Interest Groups*. 2021;6(5):1060-72.
- [2] Cock ED, Batens K, Hemelsoet D, Boon P, Oostra K, Herdt VD. Dysphagia, dysarthria and aphasia following a first acute ischemic stroke: incidence and associated factors. *Euro J Neuro*. 2020;27(10):2014-21.
- [3] Ponsford JL, Downing MG, Olver J, Ponsford M, Acher R, Carty M, et al. Longitudinal follow-up of patients with traumatic brain injury: outcome at two, five, and ten years post-injury. *J Neurotrauma*. 2013 Jul;31(1):64-77.
- [4] Douglas JM, Bracy CA, Snow PC. Return to work and social communication ability following severe traumatic brain injury. *J Speech Lang Hear Res*. 2016 Jun;59(3):511-20.
- [5] Langhammer B, Sunnerhagen KS, Sällström S, Becker F, Stanghelle JK. Return to work after specialized rehabilitation—an explorative longitudinal study in a cohort of severely disabled persons with stroke in seven countries. *Brain Behav*. 2018 Jul;8(8):e01055.
- [6] Hewetson R, Cornwell P, Shum D. Social participation following right hemisphere stroke: influence of a cognitive-communication disorder. *Aphasiology*. 2018 Feb;32(2):164-82.
- [7] Kjeldgaard A, Soendergaard PL, Wolffbrandt MM, Norup A. Predictors of caregiver burden in caregivers of individuals with traumatic or non-traumatic brain injury: a scoping review. *NeuroRehabilitation*. 2022 Jan;52(1):9-28.
- [8] Stroke Foundation. Living guidelines updates [Internet]. InformMe. 2023. Available: <https://informme.org.au/guidelines/living-guidelines-updates>
- [9] Togher L, Douglas J, Turkstra LS, Welch-West P, Janzen S, Harnett A, et al. INCOG 2.0 guidelines for cognitive rehabilitation following traumatic brain injury, part IV: cognitive-communication and social cognition disorders. *J Head Trauma Rehabil*. 2023 Feb;38(1):65.
- [10] James SL, Theadom A, Ellenbogen RG, Bannick MS, Montjoy-Venning W, Lucchesi LR, et al. Global, regional, and national burden of traumatic brain injury and spinal cord injury, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neuro*. 2019 Jan;18(1):56-87.
- [11] Cieza A, Causey K, Kamenov K, Hanson SW, Chatterji S, Vos T. Global estimates of the need for rehabilitation based on the Global Burden of Disease study 2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet*. 2020 Dec;396(10267):2006-17.
- [12] Acquired Brain Injury Communication Lab. The social brain toolkit [Internet]. 2023. Available: <https://abi-communication-lab.sydney.edu.au/social-brain-toolkit/>
- [13] Greenhalgh T, Wherton J, Papoutsi C, Lynch J, Hughes G, A'Court C, et al. Beyond adoption: a new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies. *J Med Internet Res*. 2017 Nov;19(11):e367.
- [14] Miao M, Rietdijk R, Brunner M, Debono D, Togher L, Power E. Implementation of web-based psychosocial interventions for adults with acquired brain injury and their caregivers: systematic Review. *J Med Internet Res*. 2022 Jul;24(7):e38100.
- [15] Christie HL, Bartels SL, Boots LMM, Tange HJ, Verhey FRJ, de Vugt ME. A systematic review on the implementation of eHealth interventions for informal caregivers of people with dementia. *Internet Interv*. 2018 Sep;13:51-9.
- [16] Miao M, Power E, Rietdijk R, Debono D, Brunner M, Salomon A, et al. Coproducing knowledge of the implementation of complex digital health interventions for adults with acquired brain injury and their communication partners: protocol for a mixed methods study. *JMIR Res Protoc*. 2022 Jan;11(1):e35080.
- [17] Miao M, Morrow R, Salomon A, Mcculloch B, Evain JC, Wright MR, et al. Digital health implementation strategies coproduced with adults with acquired brain injury, their close others and clinicians: mixed methods study with collaborative autoethnography and network analysis. *JMIR Preprints*. 2023. Available: <https://preprints.jmir.org/preprint/46396>
- [18] Kyngäs H, Kaakinen P. Deductive Content Analysis. In: Kyngäs H, Mikkonen K, Kääriäinen M, editors. *The application of content analysis in nursing science research*. Cham: Springer International Publishing; 2020. p.23-30.
- [19] Web Content Accessibility Guidelines (WCAG) 2.1. Available: <https://www.w3.org/TR/WCAG21/#dfn-supplementary-content>
- [20] Miao M, Rietdijk R, Power E, Brunner M, Debono D, Togher L. Self-Guided, Web-based training for communication partners of adults with acquired brain injury: a 12-month prospective, mixed methods, hybrid type 2 implementation-effectiveness study of 'interact-ABI-lity'. *JMIR Preprints*. Available: <https://preprints.jmir.org/preprint/46400>