Making videogames more inclusive for people living with MND: protocol for a scoping review

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ABSTRACT

People living with motor neurone disease (MND) in Australia experience increasing physical disability, often accompanied by a lack of choice and control in daily activities, isolation, boredom, stress and similar mental health issues that are all associated with a reduced quality of life. Yet, people living with MND also face major technological, social and economic barriers to participating in recreational activities and online environments that can help with overall wellbeing, including playing videogames, a past time growing in popularity. The aim of this protocol is to clearly articulate and document the objectives, methods, and reporting of a scoping review that maps the evidence base of what helps make videogames more inclusive for people living with MND. We developed the protocol as the first stage of our research. The protocol describes a framework for guiding the research, including how the academic and grey literature databases will be systematically searched, the ways in which studies are to be assessed for inclusion and their data summarised, and the overall review's findings reported. The protocol, and findings of the review, are expected to help guide future research into establishing what may or may not work best

when developing more inclusive videogames for people living with MND, and how research may inform policy development, clinical practice, technological work and awareness raising activities. Sharing the protocol at this stage also offers an opportunity for other researchers and practitioners to provide feedback on our decision-making process, learn from our work and use the protocol as a basis for their own scoping reviews to help reduce barriers to videogames for those experiencing health, social, education, economic and similar issues. We presented significant parts of this protocol at the Games for Change Asia-Pacific 2021 conference.

INTRODUCTION

Motor neurone disease (MND) is a neurodegenerative condition in which the muscles enabling movement, speech, swallowing and breathing progressively weaken and waste, causing increasing physical disability and with typical life expectancy of two to three years (Dharmadasa et al., 2017). In Australia, people living with MND face major challenges to accessing and using the internet, smartphones and other information technology for playing videogames and enjoying similar recreational activities (Mackenzie et al., 2016). For those people living with MND who may enjoy videogames, the challenges can reduce quality of life.

A lack of physical ability and technological, economic and social barriers can all lead to difficulty with independent operation of videogame technology and enjoying playing them alone and with others. Limitations in hand function make it hard to press buttons on keyboards, a mouse and other controllers, while compromised speech affects capacity to use microphones and engage with voice activated software (Mackenzie et al., 2016) (James et al., 2019). There is a need for training and support to use technology, software, hardware and/or assistive technology and equipment (Mackenzie et al., 2016) (Hobson et al., 2017). Cost is an issue, with apps being reported as expensive, as are a lack of interest and low levels of computer literacy and confidence for some people living with MND (Mackenzie et al., 2016) (Hobson et al., 2017). Internet speeds may be slow and related technical problems can limit access to videogames, too (Helleman et al., 2020).

Limited access to and difficulty playing videogames, like a lack of access to online information, can reinforce the exclusion felt by some people living with MND. In turn, exclusion from information technology can reduce a sense of choice and control, which has been found to be important when living with MND. Supporting choice and control with MND can help to facilitate better care and reduce stress by better meeting a person's needs, shared decision making and improved communication (Maunsell et al., 2019). Simply having an opportunity to enjoy the fun and pleasure of hobbies like playing videogames has also been found to be important for reducing the worry of what lies ahead when living with a terminal illness, and for creating memories and spending quality time with family and loved ones (MND Australia, 2021).

This protocol paper seeks to describe the process and methods we are using to conduct a scoping review for mapping relevant areas of research into what may or may not work best when making videogames more inclusive for people living with MND. Our description includes the framework used to conduct the scoping review, including its major stages and activities, major research questions, databases to be searched, how studies will be included or excluded and how we will present the findings of our scoping review. In line with previous research recommendations, the development of this scoping review protocol can also help to support the implementation of a scoping review. We argue that protocol papers are able to clearly define the objectives, methods, and reporting of the review, and encourage transparency of the process and ways to reduce bias (Tricco et al., 2016). In turn, with a transparent and well developed process, it is possible to conduct a higher quality scoping review that better explains the areas of research that may or may not work best for making videogames more inclusive for people living with MND. We also hope this paper helps to build a community of practice with other researchers and practitioners and for providing an opportunity to discuss our decision-making process and improve our approach, as well providing an example for others to use in scoping reviews about videogames.

BACKGROUND

Videogames for people living with MND, like other forms of technology, are a part of daily life, and an opportunity for enjoyment and connection with others (Harley & Willis, 2020). Recent survey work conducted by the MND Association of Victoria in Australia with people living with MND found that while connecting with family and friends online was the most common reason for using iPads, playing videogames was also a common reason (McEvoy et al., 2020). Similarly, other people living with MND report using technology such as NeuroNode (Harley, 2019) to play videogames or the potential of eye gaze tracking for helping with their technology needs (Microsoft, 2019) (Connors et al., 2019), and people living with MND, family, friends and loved ones play videogames competitively to help raise funds for MND (MND Association of England, Wales and Northern Ireland, 2021).

Evidence suggests that making videogames more inclusive for people living with MND could help to reduce stress, and improve quality of life and social connection. Yet, making videogames more inclusive for MND it is a complex and challenging area of work. Past research, while quite limited in scope and applicability to the Australian context, suggests that there is great potential to find ways of develop videogames and related information technology so that they are easier to interact with and enjoy for people living with MND. Changes to information about decision making on online platforms, software and algorithms, virtual reality systems, touch screens, motion capture and feedback devices, voice recognition, controllers and peripherals, wheelchairs and similar equipment used for accessing videogames, wireless internet connections, and other forms of technological modification and re-design can encourage choice and participation, and reduce the burden and limitations of physical disability from muscle weakness (Maunsell et al., 2019) (Marston & Smith, 2012) (Hobson et al., 2018) (Pinto et al., 2020).

For example, re-designing touch-screen layouts has been found to help reduce the amount of hand movement required for interaction by people living with MND, reducing time taken and enabling participation despite moderate arm weakness or fatigue (Hobson et al., 2018). Voice recognition and eye gaze software have also been reported as helping to overcome arm weakness for those with MND (Hobson et al., 2017) (Trevizan et al., 2018). Significantly, involving people living with MND in both the design and development of information technology used by videogames, and in the selection of information technology that best suits their needs, can better support them to improve and maintain functionality (Pousada García et al., 2021). More broadly, improvements in mood and wellbeing are also possible when playing videogames (Weber et al., 2009) (Soundy & Condon, 2015) (Belchior et al., 2019) (Villani et al., 2018).

However, the research has also found significant challenges in developing videogames and associated information technology to meet the needs of people living with MND and experiencing physical disability. Health professionals need to have the appropriate knowledge about use of information technology to support people with MND to select the best technology options as early as possible after diagnosis (Mackenzie et al., 2016). A lack of confidence, skills and understanding in how to use information technology, and upper limb dysfunction, continue to make it hard for people living with MND to easily enjoy online platforms (Mackenzie et al., 2016) (Hobson et al., 2017). Language and cognitive difficulties, such as difficulties with reading and concentration, have prevented some people with MND from learning to use new devices (Hobson et al., 2017). Slow internet connections and technical issues have limited participation (Helleman et al., 2020). The need for "multiple changes" in the design of a digital product like a videogame is also a major issue. Time pressures, financial constraints and rapid advances in technology development, combined with the involvement of users at each stage of the process, can make it much harder to implement changes to code and other aspects of a product (Hobson et al., 2018).

Structural barriers also play a major role in limiting how people living with MND access information technology used for videogames. More training and support programs are required to increase ability and confidence in using information technology for a range of needs, including recreation (Mackenzie et al., 2016) (Hobson et al., 2017). The cost of the internet and specific forms of information technology, such as new and emerging kinds like eye tracking and brain-computer interfaces, is too high for some people living with MND (Mackenzie et al., 2016) (Helleman et al., 2020). Poor or unstable access to the physical infrastructure that provides high quality broadband internet, including the National Broadband Network and fiber optic cabling, can interrupt and stop the playing of software like videogames online (Jang-Jaccard et al., 2014). Health professionals also need to have an in depth understanding of how to best support people living with MND to use information technology in ways that suit their needs (Mackenzie et al., 2016).

Furthermore, there is a major gap in research about MND and videogames. No in-depth study exists in Australia that explores the opportunities and challenges in developing more inclusive videogames for people living with MND. Beyond Australia, groups of researchers have begun piloting work exploring the potential of videogames for people living with MND and others experiencing disability, such as researchers associated with Microsoft's game accessibility program and X-Box Adaptive Controller (Sanchez, 2021). Yet, these studies are limited in applicability due to their relatively small size, and lack of particular focus on the experiences of people living with MND.

There is a small evidence base in Australia and some relevant studies internationally that have helped to establish what may or may not support people living with MND to better use information technology in a general sense, which, while important, do not directly address experiences with videogames. MND Victoria's recent survey does find that videogames are a common reason for using an iPad by people living with MND (McEvoy et al., 2020), but it does not explore what may or may not help in their access and use. Similarly, other studies about developing more inclusive approaches to use of information technology for videogames and other platforms with people experiencing physical and other forms of disability show relevance to MND, but are not focused on the experiences of those with MND. Currently, the limitations of the evidence base suggest a need for, and valuable opportunity to, scope and bring together existing studies to better determine what areas of future research could best support the needs of people living with MND.

A scoping review can help to address issues with the evidence base, and map studies of what may help make videogames more inclusive for people living with MND. The mapping provides an "overview" of past research conducted on a topic and identifies the range of available studies, summarizes results of studies and highlights evidence gaps (Wickremasinghe et al., 2016) (Pollock et al., 2021). Scoping reviews are an established approach to mapping existing research for helping to manage the physical symptoms and psychological conditions associated with MND (Waito et al., 2017) (Zarotti et al., 2021). Scoping reviews have also helped to identify areas for future research into videogames and physical health (Baranowski & Lyons, 2020), and health and information technology generally (Pradhan et al., 2019).

There are two major ways in which a scoping review is valuable for providing an overview of research into videogames and MND. In the first instance, a scoping review can help to widen understanding of the research available in order to develop a comprehensive approach, particularly when it is difficult to imagine the range of studies available (Arksey & O'Malley, 2005). While scoping reviews do not aim to critically assess individual studies (Arksey & O'Malley, 2005), a comprehensive approach to gathering existing evidence is particularly relevant to this study given the intersection of relevant fields, including health, disability, technology and education.

In the second instance, scoping reviews can help to balance the academic literature and more effectively map the evidence by identifying relevant work in grey literature outside the academy (Douma et al., 2020), such as evaluations and other studies in government, non-profit, technology development and commercial databases. The lack of published academic literature on videogames and MND suggests exploring grey literature is important for maintaining a comprehensive approach.

To help address the need to better understand what research is most relevant for developing videogames that are more inclusive for people living with MND, in this scoping review protocol we present an approach based on Arksey and O'Malley's framework for conducting a scoping review (Arksey & O'Malley, 2005) and recent updates to the framework to help improve methodological clarity (Levac et al., 2010) (Joanna Briggs Institute, 2015) (Pollock et al., 2021). The framework provides the stages required for organising and conducting the review.

METHODS AND ANALYSIS

Building on past research into the effectiveness of scoping reviews, this scoping review will be conducted in five main stages (Arksey & O'Malley, 2005) (Pollock et al., 2021):

- Stage 1. Identifying the research question
- Stage 2. Identifying relevant studies
- Stage 3. Study selection.
- Stage 4. Chart, present and/or narratively summarize the data.
- Stage 5. Collating, summarizing and reporting the results.

A limited consultation was undertaken with a small number of relevant key stakeholders, including a librarian, videogame researchers and practitioners, a person living with MND and health and non-profit workers with a background in MND. Stakeholder consultation is an optional part of a scoping review (Arksey & O'Malley, 2005). The consultation for this review helped to identify appropriate ways to practically manage the project, relevant databases and areas relevant to research questions and fields of study. However, while a more robust stakeholder consultation may be beneficial, due to financial and time restraints, the scoping review will not include further stakeholder engagement.

The research team formed during the consultation. Comprising of four researchers, the team bring together expertise in health communication and information technology, health sociology and history of sociology, videogame development and games-based learning, and user experience (UX) design and digital trust. All the team have worked on projects that have explored, or were highly relevant to, barriers and opportunities in the access and use of online platforms. One researcher was diagnosed with MND in 2013 and continues to write and publish academically about lived experience of the disease.

STAGE 1. IDENTIFYING THE RESEARCH QUESTION

This protocol and the initial development of the scoping review were based on an exploration of relevant studies in MND and videogame research. The exploration resulted in a decision to use search criteria that included the lived experience of MND wherever possible, including from grey literature, as evidence suggests that user participation is an important part of health, MND and technology research (Maunsell et al., 2019) (Hobson et al., 2018) (Darcy et al., 2017) (Ghanouni et al., 2020).

The exploration of relevant studies identified the following research questions for the scoping review:

- What is the existing evidence base about use of video games by people with MND, and opportunities for and barriers to making them more inclusive?
- What kinds of software, hardware aids and assistive technology are available to enable people living with MND to play video games?
- What are the barriers and opportunities for improving use of videogames for people living with MND?
- What role do videogames play for people living with MND and what adjustments can people living with MND make to enable game playing?
- How can future research address the evidence base, including for exploring barriers and opportunities, policy development, advocacy, education, and awareness raising activities, clinical practice and games technology development?

STAGE 2. IDENTIFYING RELEVANT STUDIES

The second stage of the scoping review focused on developing search criteria for identifying studies to be included in the review, using recommendations from Arksey and O'Malley (Arksey & O'Malley, 2005) and Pollock et. al (Pollock et al., 2021). Development of the criteria aimed to reinforce a comprehensive approach and yet also direct the search to the most relevant studies and research.

The scoping review will include studies that can be found in the following databases:

- MEDLINE/ PubMed, Cochrane Library, Scopus, SocIndex, Web of

Science, Google Scholar, Joanna Briggs Library, ACM Digital Library, Sports Medicine & Education Index, Humanities Index, Computer Science Database.

A full list of databases is available in the Supplemental Materials. Studies will also be included from the following “grey literature” databases:

- MND Associations of Australia: MND New South Wales, MND Victoria, MND Queensland, MND Tasmania, MND Western Australia, MND South Australia
- Australian Federal Government: Department of Health; Department of Infrastructure, Transport, Regional Development and Communications; Australian Communication and Media Authority; National Disability Insurance Scheme; Department of Social Services
- Australian State and Territory Governments
- Peak bodies: Home Modifications Australia, Assistive Technology Australia, Cerebral Palsy Australia, Neurological Alliance Australia, Muscular Dystrophy Australia, Media Access Australia, Infoxchange, eSafety Commissioner, Occupational Therapy Australia, Speech Pathology Australia, Australian Centre for the Moving Image, Australian Communications Consumer Action Network, Australian, Interactive Games and Entertainment Association of Australia
- International: International Alliance of ALS/MND, MND Association (England, Wales and Northern Ireland), ALS Association, ALS Society of Canada, World Wide Web Consortium (W3C), Microsoft, Apple, Google, International Game Developers Association

Based on the exploration of relevant studies, we agreed on the following eligibility criteria:

- Type of publication: journal articles and conference presentations
- Time frame: any
- Language: English

- Study population: people living with or affected by MND, including family, carers, MND Association staff and health, technology and disability professionals.
- Types of interventions: studies aiming at increasing use and access of information technology for playing videogames by people living with MND.
- Types of articles: quantitative (e.g. surveys); qualitative (e.g. semi-structured interviews); prototype development; iterative, user-centered digital technology development; pilots; rapid, narrative, systematic and other reviews; evaluation reports.

After initial scoping of the evidence base, we agreed to exclude studies that were: conference abstracts; book reviews; and, not published in English.

We used an iterative process to develop search terms for the scoping review, in line with past recommendations (Arksey & O'Malley, 2005) (Levac, Colquhoun, & O'Brien, 2010) (Pollock et al., 2021). The following keywords are to be used:

- "motor neurone disease" OR "motor neuron disease" OR "amyotrophic lateral sclerosis" OR "frontotemporal degeneration" OR "nervous system diseases" OR "muscular atrophy" OR "muscle wasting" OR "muscular dystrophy" OR "hand weakness" OR paralysis OR palsy OR ("fine motor" AND (weak* OR degenerat* OR regres*)
- "educational technology" OR console* OR (hand* N/5 device*) OR "technology uses in education" OR (comput* N/5 mice) OR joystick* OR (point* N/5 device*) OR "virtual reality" OR "machine learning")
- esport* OR e-sport* OR "electronic sport" OR gaming OR gamification OR video-gam* OR videogam*
- inclusion OR inclusive OR adjust* OR accommodation OR intervention OR adapt* OR support* OR responsive* OR management
- "videogames" OR "online games" OR "internet games" OR "mobile

games" OR "computer games" OR "gaming" OR gaming OR gamification OR video-gam* OR videogam* OR "online game" OR "internet game OR "mobile game" OR "computer game"

- "information technology" OR "internet" OR "computer" OR "mobile" OR "technology" OR "assistive technology" OR "communication" OR "aids" OR "equipment" OR "phone" OR "tablet" OR "device" OR "screen" OR "smart phone" OR smartphone* OR tablet* OR ipad*

Articles are to be retrieved and then screened for their titles, abstracts and index terms. An academic librarian was consulted to help enhance medical and other search terms, and ways to improve searching of academic and grey literature databases (Supplemental Information). Once retrieved, articles from each database will be imported into Zotero reference management software.

STAGE 3: STUDY SELECTION

In the third stage of our scoping review, we will identify studies to be included in the review. The results from searches of all databases will be consolidated and all duplicates removed. Following consolidation, one team member will screen titles and abstracts of the articles to exclude those that do not meet the review's eligibility criteria. Studies meeting eligibility criteria will be retrieved.

Another team member will conduct a screening on a sample of retrieved articles. The screening will help to maintain consistency with regards to application of review eligibility criteria. As part of the screening, studies that remain unclear as to whether they are eligible for inclusion will be reviewed. Team member disagreements about study eligibility of the sampled articles will be discussed by the two reviewers until there is agreement. A third reviewer will arbitrate, if required. We will report on study selection using the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2016).

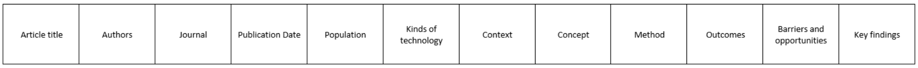
STAGE 4: CHART, PRESENT AND/OR NARRATIVELY SUMMARIZE THE DATA.

A data extraction framework was developed using past recommendations for the conduct of scoping reviews and our exploration of relevant studies (Hobson et al., 2017) (Pollock et al., 2021). The framework includes 12 categories (Table 1). Categories will be used to assess articles included in the scoping review. Piloting of data extraction will be performed with 2 reviewers on 2 to 3 studies to help with consistency and to identify any need for adjustments.

In addition to standard article information, the framework will extract information about kinds of technology used to improve use and access by people living with MND, as well as barriers to technology and the types of contexts, methods, concepts and key findings explored by researchers.

The framework will be piloted by two team members. The pilot will be performed on a sample of included studies to help make sure that coding of the framework is consistent. The framework categories will be revised where required and disagreements addressed through team member discussions.

The two team members will also use the framework to independently chart the data from each study included in the review. Afterwards, a sample of the articles independently reviewed will be compared by the two team members. Issues or a lack of compatibility between data extractions will be discussed and resolved, and where required, a third team member will arbitrate.



Article title	Authors	Journal	Publication Date	Population	Kinds of technology	Context	Concept	Method	Outcomes	Barriers and opportunities	Key findings

Table 1: Data Extraction Framework

STAGE 5: COLLATING, SUMMARISING AND REPORTING THE RESULTS

The analysis of the data will provide information on the existing evidence base about use of video games by people with MND, and opportunities for and barriers to making them more inclusive. We anticipate that the evidence base will show what areas of future research are likely to help determine what may or may not work best when developing more inclusive videogames for MND. We also hope that it will be possible to highlight the ways in which research can contribute to policy development, clinical practice, awareness raising and related initiatives. Results will be presented as a whole and in visual form (e.g. tables, graphs), where required.

ETHICS AND DISSEMINATION

This study is being completed in line with university ethics protocols and processes, and therefore does not require an ethics application for approval. The article and its results will be disseminated via submissions to academic journals and presentations at relevant conferences and events, including those held by the MND Network in Australia. We hope to complete knowledge translation based on the article findings, including written and spoken appearances in media outlets. We also plan to share findings from this article in meetings and workshops involving health professionals, people living with MND and others supporting those living with MND to encourage evidence-based planning, evaluation, funding submissions and related activities.

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