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Healthier Lives, Digitally Enabled

Selected Papers from the Digital Health Institute Summit 2020

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Preface

2020 has been an unprecedented year in many ways. On top of an already evolving healthcare landscape, nationally and internationally, we have been met with the public and societal health challenge of the COVID-19 pandemic. Not only has this stressed individuals and healthcare systems to their limits but it has also driven an urgent and rapid need to mobilise digital health technology, as well as pressure test digital health in ways and under timeframes not previously imagined. This has its obvious challenges, but it has also created the opportunity for the digital health and informatics community to stand-up and lead. For many, this has meant dealing with digital health projects, such as major electronic medical record (EMR) system implementations at the same time as managing human health. All under very challenging circumstances, while continuing to ensure the safe, effective, and efficient delivery of care in a patient-centred manner. For some others, we have also seen the rapid deployment and uptake of telehealth services, both out of necessity to maintain continuity of care but also to ensure those who need healthcare are still able to access it no matter what the situation or where they are located. Again, it is here that the clinical informatics community has led.

Nationally, the Australasian Institute of Digital Health (AIDH) was launched this year, while all these massive shifts have been occurring all around it. We have continued to be guided under the directives of Australia's National Digital Health Strategy, and recently observed the release of the Australian Digital Health Agency's (ADHA) Workforce and Education Roadmap. This signposts the need to support and deliver on upskilling our health workforce in digital health and informatics. Three key 'horizons' underpin the roadmap, which describes: the use of health record and consumer data, new ways of working with technology, and transformation. There has perhaps been no better time to advocate for our workforce in digital health.

With the workforce in mind, the annual Australian Health Informatics Conference (HIC) represents the coming together of the nation's digital health community to shape the agenda, network, learn, share, and showcase current and future initiatives that support the progression of digital health. Under normal circumstances, HIC provides the place to discuss innovation, digital models of care, data driven decision making, and more. However, and perhaps poetically, this will not look the same in 2020. Considering the COVID-19 pandemic, we will see the emergence of State-led satellite events, coming together with an online feature showcase under the umbrella of the 'Digital Health Institute Summit'. Disruption often drives innovation and having seen the way that the AIDH and the informatics community have embraced digital remote meetings, learning, and social gatherings this year, we have no doubt that the Digital Health Institute Summit will still bring the usual (if not more) vigour, liveliness, and passion for change amongst attendees.

The number of submissions and expressions of interest to present at this year's Summit has been reflective of the passion to continue to drive the digital agenda. We saw overwhelming interest in the form of academic and scientific paper publications. This is reflected in the calibre and breadth that this year's publications demonstrate. This volume of papers reflect highly topical themes across various areas and disciplines. Examples include (but are not limited to): digital health in aged care, mental health,

COVID-19, public health, and workforce. From the digital perspective, we note familiar topics, such as: wearables, mobile health and remote monitoring, interoperability, and data privacy. As well as an increasing appetite for telehealth, automation, bots, and other applications of artificial intelligence.

Like previous years, this year's academic program maintains the same high standard of papers that we know and expect from this conference. All submissions were double blind-peer reviewed by three health informatics experts. We continue to acknowledge the tireless efforts of our volunteer reviewers, without whom, this would not be possible. This thanks extends to the spectacular team at the AIDH, who have been instrumental in supporting this process. 37 papers underwent the initial review. Authors then addressed reviewer feedback and were confirmed by the Scientific Program Committee. What you have here is the culmination of 17 included in this volume. Our sincere congratulations and commendations to the authors of these papers for their contributions to digital health.

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Acknowledgements

Contents

Not Well Enough to Attend Appointments: Telehealth Versus Health Marginalisation

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Abstract. Temporary telehealth initiatives during COVID-19 have been life-changing for many people in Australia; for the first time Frail, Homebound, and Bedridden Persons (FHBP) equitably received primary healthcare services, like Australians without a disability. However, government changes to telehealth funding mean that since July 2020 telehealth is only available for those who have attended a face-to-face appointment in the last 12 months, thus excluding FHBP. This paper illustrates the reported health exclusion and marginalisation of FHBP. We reviewed the literature and surveyed 164 Australian adults (27% homebound people and 73% affiliated persons) to ascertain their opinions and thoughts on potential strategies to tackle issues associated with FHBP's current circumstances. Results demonstrate that digital technologies and telehealth services are ethical imperatives. Policymakers, clinicians, and health researchers must work with end-users (community-based participation) to create an inclusive healthcare service.

Keywords. telehealth, participatory research, homebound, bedridden, frailty, marginalisation, COVID-19

1. Introduction

Frail, Homebound and Bedridden Persons (FHBP) live with complex, incapacitating, and debilitating illnesses. In addition to functional issues, FHBP can experience financial hardship and social isolation, which puts them at a higher risk of depression (1). Social isolation refers to a state of having minimal contact with other people. It is commonly associated with loneliness, the feeling of missing connections, affection, and proximity in relationships (2). People living with complex chronic conditions, such as older FHBP, require connections, care, and support to maintain their relationships, social activities, psychological health, and activities linked to self-care, mobility, and domestic life (3). This can be facilitated using digital technologies (DT), such as mobile phones, tablets, and computers, which enable remote healthcare delivery (i.e. telehealth) (4).

Ongoing support and guidance with medications and self-care are necessary for FHBP; helping them is a critical public health concern globally (5, 6). An American feasibility study on the use of telehealth for FHBP demonstrated its perceived benefits for homebound people and a reduction in costs associated with their health administration processes and care (5). These findings are important given that many FHBP experience social exclusion, health disparities, and marginalisation from health services because of the Australian healthcare system being devised mostly around physical (i.e., in-person) attendance (7).

As an emergency response to COVID-19, Australia activated a National Health Plan, which rapidly expanded the use of telehealth technologies. This plan included increased practice incentive payments and benefits to allow doctors, nurses, midwives, and allied health professionals (including mental health) to deliver telehealth services to all Australian citizens (4). The response demonstrated that Australia is capable of rapidly overcoming critical barriers to the expansion of telehealth, including well described regulatory, financial, cultural, technological, and workforce impediments (8). As described by Ms Penelope Macmillan, Chair of ME/CFS South Australia (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) – a disease turning many Australians into FHBP: "*In the past, clinicians only met clients when the person was well enough to attend an appointment. With the introduction of telehealth for GP services, we could meet with them when our symptoms were too severe to allow us to leave home. The understanding of our illness severity and the nature of our impairments was dramatically improved.*" (9).

However, on 20 July 2020, without consideration of consumer feedback or needs, access to General Practitioner (GP) telehealth services was terminated for people who had not attended a face-to-face appointment in the last 12 months. The rationale behind the GP-telehealth cut was based on concerns about "*the rise in low-value pop-up telehealth services*" (10). In situations where cuts to services are being considered, decisionmakers must use evidence to determine the risks and benefits of such choices for consumers and consider how these choices might conflict with matters of ethics and values (11).

For socio-technological change and public health policy to be most useful and supportive of the needs of the public, it is necessary to involve consumers in creating and informing such change or policy (8, 11, 12). These participatory research (PR) strategies are required in the system-level change and knowledge creation process (e.g., co-design), in which consumers are included in offering their perspectives and interpretations concerning studies and resulting policies (7, 8, 11, 12). Therefore, with an emphasis on a PR approach, this paper aims to explore the key strategies to tackle the pressing issues associated with FHBPs' described circumstances. The study has two objectives: 1) Provide evidence to inform decision making, health practice, and health research in this field, and 2) Explore consumer-centric solutions that address the problems of social isolation, marginalisation, and needs of FHBP.

2. Method

This paper reports on the first part of a program of research concerning FHBP in Australia: '*Making the invisible visible: Exploring the experiences of frail, homebound and bedridden people'*. The study is approved by the Flinders University Social and Behavioural Research Ethics Committee (Project No. 8557). This paper presents a mixed-method, consumer-centric approach (co-designed with one health consumer as a co-researcher at a peer level with the academic investigators and her FHBP peer-reference networks). The method involves two steps:

First step: A rapid scoping review with the aims of identifying existing interventions enhanced by technologies that target social isolation reduction for older adults. The search is focused on previous reviews (Pubmed/Medline), and grey literature (Google/Google Scholar). The results were presented narratively and classified according to the main risk factor addressed by each intervention as per the Framework

for Isolation for adults over 50 of the AARP Foundation (34), published between April 2014 and April 2020.

Second step: Two questions from a larger online survey (Project No. 8557) were selected to explore the needs of FHBP and solutions/actions to the pressing issues they routinely experience (e.g. social isolation and telehealth; the GP-telehealth cut occurred near the end of data collection). The survey was shared via social media as a press release across different universities platforms and consumers advocate groups.

The first question of the survey: *"Excluding an accident or temporary illness, are you permanently unable to leave your home?"* distinguished homebound people (using the American Medicare classification for homebound persons as those whose absences from home are infrequent, or for periods of relatively short duration, or to receive medical treatment, 13) from their affiliates (e.g. people experiencing similar conditions, people caring for FHBP or people invested in the issues of FHBP). The second question: "*Please, check the boxes that you consider important to help you or other Australians who are facing similar problems to your*s" involved multiple selection options about issues with healthcare access. This question facilitated problem identification without demanding much writing from respondents. The list of co-designed options (presented in the survey as potential needs or required solutions or actions) is presented in Table 2. Data were collected from 02/07/2020 until 05/07/2020. Basic descriptive statistics and crosstabulation of variables were used to analyse the data.

3. Results

Rapid review: our search retrieved five reviews. The content of reviews is synthesised in Table 1, which outlines risk factors for social isolation, the strategy and technology utilised to overcome these risks, and the examples or comments concerning each publication (as per 34). The evidence in Table 1 demonstrates that current practices and knowledge can be effectively operationalised using digital and similar technologies (e.g. wearables, systems mapping, social media and robots) to mitigate and prevent loneliness and social isolation in older adults with complex health issues. Such knowledge can arguably be adapted to support FHBP living in Australia.

Table 1. Examples of technologies used to mitigate and prevent loneliness and social isolation in older adults.

Risk factor	*Strategy*	*Technology*	*Examples/Comments*
Living alone	Informational social support (Education/empowerment)	Telehealth (14, 15)	Videoconference groups mediated by health providers focusing on education about health issues led to an improvement in social isolation.
	Increasing social network	Telehealth (16)	Videoconference delivered by lay providers during meals.
	An increasing sense of presence/companionship	Embodied conversational agent (17)	Virtual pet therapy
	The increasing frequency of social contacts	An online platform (18)	A platform that matches people who want to donate meals to ones who are

Risk factor	Strategy	Technology	Examples/Comments
			searching for companionship during meals
	Detecting loneliness and activating family support	Wearable/telemonitoring (19)	Monitoring of conversations and word count throughout the day then prompting social contact when levels drop too low.
Small social network and/or inadequate social support	Promoting integration within local communities	Online platforms/websites (20, 21, 22)	Information-based intervention that provides personalised information and referral service to increase older adults' awareness and knowledge of the services and activities available to them.
			Advice on community events. Focused on older adults.
			Focused on culturally and linguistically diverse people
	Promoting integration within local communities	Geographic information system mapping (23)	Simple map to find community organisations. Focused on older adults
	Promoting integration within local communities	Telephone-based (24)	A resource that provides older men with opportunities for mateship, and the chance to re-connect with the community
	Facilitating integration within families	Home telehealth and telemonitoring combined with social media (25)	Home telehealth system from the provision of health care to enhancing older adults' interpersonal communication and social participation
	Peer support	Online social network/social media (26)	Social media moderated by health professionals
	Promoting structured social support (social network with volunteers rather than acquaintances/friends)	Telehealth (27)	Health provider train volunteers for conversation facilitation. Once trained volunteers facilitate group discussion utilising teleconferencing.
	Increase opportunities for social contact	Digital games (28)	Opportunities for meeting friends online through games communities for older adults
Major life transitions	Emotional support	Telehealth/telephone-based (29)	Online/telephone advice on how to cope positively with life after loss.
Mobility or sensory impairment	Increase sense of presence/companionship	Embodied conversational agents/avatars (30)	Full-bodied gesture-based interactions and avatars can be used to create a sense of virtual presence between older people who are unable to meet face-to-face.
	Increase sense of social participation	Virtual and augmented reality (31)	Overcoming social isolation through the power

Risk factor	*Strategy*	*Technology*	*Examples/Comments*
			of virtual reality and shared experiences. Focused on older adults.
Mental health condition	Peer support	Online chat forum/social media (32)	Focused on people with alcohol and drugs addiction
Cognitive impairment	Facilitate communication with carers	Telepresence robots (33)	Focused on people with dementia

Survey: According to the responses from 164 Australians adults, 27% of whom are homebound and 73% representing their affiliates, the five most important needs/actions to help them or other Australians who are facing similar problems are:

- Education for all health professionals and service providers about people with their needs (96%)
- Educating Centrelink, NDIS, and government services about paperwork difficulties (e.g. providing more time or accepting GP reports rather than specialist paperwork only) (93%)
- Access to community care services (e.g. NDIS, Aged Care packages) (93%)
- Adequate Medicare rebates for home visits (93%)
- Extending the existing telephone or online consults (Telehealth) for rural and remote patients to also cover patients who are housebound or bedbound (93%).

The responses from FHBP affiliates were consistent with the importance rankings of homebound respondents. The relevancy of the needs/action list was validated, with most options checked by homebound adults and their affiliates in high percentages (above 64%).

Table 2. Important actions to help FHBP according to homebound/affiliates.

Important actions (needs) to help you or other Australians who are facing similar problems to yours	*Homebound*	*Affiliates*	*Total*
Education for all health professionals and service providers about people with your needs	43	89	132
Educating Centrelink, NDIS, and government services about paperwork difficulties, e.g. providing more time or accepting GP reports rather than specialist paperwork only	42	86	128
Access to community care services, for example, NDIS, Aged Care packages	42	82	124
Adequate Medicare rebates for home visits	42	81	123
Extending the existing telephone or online consults (Telehealth) for rural and remote patients to also cover patients who are housebound or bedbound	42	79	121
Telephone consults	40	72	112
Ability to fund the testing and medical reports required to access benefits	39	80	119
Regular home access to a general practitioner	39	71	110
Access to advocacy services (including legal) to assist with the day to day issues (e.g. NDIS access, DSP access, discrimination, access to insurance policies, domestic violence, etc.)	37	80	117
Home access to psychology (or psychological) services	37	72	109
Find out about how many Australians are living with similar problems to yours to generate faster solutions	37	67	104
Services to enable you to keep living in the community	35	75	110
Access to housing or accommodation arrangements	35	53	88
Access to food services (e.g. Meals on Wheels)	33	66	99

Important actions (needs) to help you or other Australians who are facing similar problems to yours	Homebound	Affiliates	Total
Access to services that are equivalent to the help provided by home palliative care services, for example, regular home visits by a nurse or GP	32	63	95
Streamlining easier access to patient transport	29	53	82
Other	12	27	39
Total Count	45	119	164

4. Discussion and Conclusion

Our rapid review found sufficient evidence to support the use of effective technological, social and health interventions to mitigate some of the negative experiences of FHBP (i.e. concerning health, technology, social isolation, and loneliness). Technology enables strategies to increase informational/educational support, connection/network or social contact, family contact, emotional assistance, and patient-carers communication. These findings are backed and complemented by our survey findings, in which is evident that technology must be combined with a person-centred approach and a culture of care service that gives visibility to the needs and voices of marginalised FHBP in Australia.

Our survey indicates that prompt action is required to educate all health professionals and service providers about FHBP; educate Centrelink, NDIS, and government services about the difficulties FHBP are facing; facilitate access to community care services (e.g., NDIS, aged care packages); provide adequate Medicare rebates for home visits, and extend the existing telephone or online consults (Telehealth) for rural and remote patients to also cover FHBP in city locations (as it was done for everyone temporarily because of the first wave of COVID-19).

The academic literature, the communities we surveyed, and public opinion (e.g. news media reports), all points to the same direction: telehealth and digital technologies are effective and needed tools to combat the health marginalisation of Australia's FHBP. The task now is to educate several service providers and policymakers about the devastating consequences of maintaining a healthcare system working around the exclusory and impractical requirement of physical attendance. The negative health and psychosocial impacts of COVID-19 are highlighting the relevancy of our findings particularly concerning the groups comprising a greater proportion of FHBP, such as older people with co-morbidities and individuals living with disabilities.

References

[1] Choi, N. G., Teeters, M., Perez, L., Farar, B. and Thompson, D. (2010). Severity and correlates of depressive symptoms among recipients of Meals on Wheels: Age, gender, racial/ethnic difference. Aging & Mental Health 14(2): 145–154.
[2] J. De Jong Gierveld, T.G. Van Tilburg, P.A. Dykstra. Loneliness and social isolation. D. Perlman, A. Vangelisti (Eds.), The Cambridge Handbook of Personal Relationships, Cambridge University Press, Cambridge (2006), pp. 485-500.
[3] Abdi, S., Spann, A., Borilovic, J., de Witte, L., & Hawley, M. (2019). Understanding the care and support needs of older people: a scoping review and categorisation using the WHO international classification of functioning, disability and health framework (ICF). BMC geriatrics, 19(1), 195.
[4] Commonwealth of Australia | Department of Health. (2020). COVID-19 National Health Plan – Primary Care Package – MBS Telehealth Services and Increased Practice Incentive Payments. Accessed 16.04.2020.

[5]   Choi, Namkee G, Hegel, Mark T, Marti, C Nathan, Marinucci, Mary Lynn, Sirrianni, Leslie, & Bruce, Martha L. (2014). Telehealth Problem-Solving Therapy for Depressed Low-Income Homebound Older Adults. American Journal of Geriatric Psychiatry., 22(3), 263-271.
[6]   Lee, JuHee and Suh, Yujin and Kim, Yielin, Multidimensional Factors Affecting Homebound Older Adults: A Systematic Review (2020). Preprint with The Lancet. Accessed 16.04.2020.
[7]   Buchanan, R. (2018). "Just Invisible" Medical Access Issues For Homebound/Bedridden Persons. Accessed on the 20/06/2019.
[8]   Jang-Jaccard, J., Nepal, S., Alem, L., & Li, J. (2014). Barriers for delivering telehealth in rural Australia: a review based on Australian trials and studies. Telemedicine and e-Health, 20(5), 496-504.
[9]   Disability Insider. Telehealth cuts see services withdrawn to Australians with disabilities (2020). Coronavirus Pandemic, Disability Insider. Accessed 29/07/2020.
[10] Tsirtsakis, A. Government restricts telehealth MBS access to a patient's regular GP. NewsGP -The Royal Australian College of General Practitioners. Accessed 10/07/2020.
[11] Solomon, M. Z., Gusmano, M. K., & Maschke, K. J. (2016). The ethical imperative and moral challenges of engaging patients and the public with evidence. Health Affairs, 35(4), 583-589.
[12] Slattery, P., Saeri, A. K., & Bragge, P. (2020). Research co-design in health: a rapid overview of reviews. Health Research Policy and Systems, 18(1), 17.
[13] Talaga, S. R. (2013). Medicare home health benefit primer: Benefit basics and issues. Library of Congress, Congressional Research Service. March (accessed on the 20 of July 2019).
[14] Banbury A, Chamberlain D, Nancarrow S, Dart J, Gray L, Parkinson L. Can videoconferencing affect older people's engagement and perception of their social support in long-term conditions management: a social network analysis from the Telehealth Literacy Project. Health Soc Care Community. 2017;25(3):938-950. doi:10.1111/hsc.12382.
[15] Banbury A, Nancarrow S, Dart J, et al. Adding value to remote monitoring: Co-design of a health literacy intervention for older people with chronic disease delivered by telehealth - The telehealth literacy project. Patient Educ Couns. 2020;103(3):597-606. doi:10.1016/j.pec.2019.10.005.
[16] Banbury A, Nancarrow S, Dart J, et al. Adding value to remote monitoring: Co-design of a health literacy intervention for older people with chronic disease delivered by telehealth - The telehealth literacy project. Patient Educ Couns. 2020;103(3):597-606. doi:10.1016/j.pec.2019.10.005.
[17] Machesney D, Wexler SS, Chen T, Coppola JF. Gerontechnology Companion: Virtual pets for dementia patients: IEEE; 2014 Presented at Systems, Applications and Technology Conference (LISAT), 2014 IEEE Long Island; 2-2 May 2014; New York p. 1-3.
[18] Casserole Club. Available at https://www.casseroleclub.com/. Accessed on 13th July, 2020.
[19] Wearable tech lends an ear to lonely elderly. Available at: https://www.rmit.edu.au/news/all-news/2019/feb/wearable-tech-lonely-elderly. Accessed on 13th July, 2020.
[20] Seniors Enquiry Line. Available at: https://seniorsenquiryline.com.au/. Accessed on 13th July, 2020.
[21] Connect to new possibilities without leaving home. Available at: https://www.mather.com/neighborhood-programs/telephone-topics Accessed on 13th July, 2020.
[22] Mosaic Seniors. Available at: https://www.mosaicbc.org/services/settlement/seniors/ Accessed on 13th July, 2020.
[23] Be Connected Partner Map. Available at: https://beconnected.esafety.gov.au/find-local-help Accessed on 13th July, 2020.
[24] TomNet – The older men network. Available at: Tomnet.org.au Accessed on 13th July, 2020.
[25] Yu-Chen Huang, Yeh-Liang Hsu, Social networking-based personal home telehealth system: A pilot study, Journal of Clinical Gerontology and Geriatrics, Volume 5, Issue 4, 2014, Pages 132-139, ISSN 2210-8335, https://doi.org/10.1016/j.jcgg.2014.05.004.
[26] Beyond Blue. Online social community. Available at https://www.beyondblue.org.au/get-support/online-forums/community-rules. Accessed on 13th July, 2020.
[27] Brotherhood of St Laurence. Available at: https://www.bsl.org.au/ Accessed on 13th July, 2020.
[28] Australian Government. Be Connected. Games centre for mouse and keyboard. Available at https://beconnected.esafety.gov.au/games/games-centre Accessed on 13th July, 2020.
[29] TomNet – The older men network. Available at: Tomnet.org.au Accessed on 13th July, 2020.
[30] The University of Melbourne. Ageing and Avatars. Available at: https://socialnui.unimelb.edu.au/research/ageing-avatars/ Accessed on 13th July, 2020.
[31] Rendever. Available at: https://rendever.com/ Accessed on 13th July, 2020.
[32] Alcohol and Drugs. Counselling online forums. Available at: https://forum.counsellingonline.org.au/index.php Accessed on 13th July, 2020.
[33] Moyle W, Arnautovska U, Ownsworth T, Jones C. Potential of telepresence robots to enhance social connectedness in older adults with dementia: an integrative review of feasibility. Int Psychogeriatr. 2017;29(12):1951-1964. doi:10.1017/S1041610217001776.

[34] AARP Foundation Frameworks for Isolation in adults over 50. Available at https://www.aarp.org/content/dam/aarp/aarp_foundation/2012_PDFs/AARP-Foundation-Isolation-Framework-Report.pdf [Acessed on 17th April, 2020].