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Psychosocial Applications of Technology for Health and Wellness Coaching of Older Adults with Dementia and Mild Cognitive Impairment and their Carers in Rural Areas

Aplicaciones Psicosociales de la Tecnología para la Capacitación en Salud y Bienestar de Adultos Mayores con Demencia y Deterioro Cognitivo Leve y sus Cuidadores en Zonas Rurales

Doctoral Thesis/Tesis Doctoral

Mauricio Molinari Ulate

Supervisors/Directores
Dr. Manuel Ángel Franco Martín
Dra. Henriëtte Van Der Roest

MEDUSA NEGRA

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Negra / Luis Felipe
Campos Thompson

DOCTORAL THESIS

TESIS DOCTORAL

PSYCHOSOCIAL APPLICATIONS OF TECHNOLOGY FOR HEALTH AND WELLNESS COACHING OF OLDER ADULTS WITH DEMENTIA AND MILD COGNITIVE IMPAIRMENT AND THEIR CARERS IN RURAL AREAS

APLICACIONES PSICOSOCIALES DE LA TECNOLOGÍA PARA LA CAPACITACIÓN EN SALUD Y BIENESTAR DE ADULTOS MAYORES CON DEMENCIA Y DETERIORO COGNITIVO LEVE Y SUS CUIDADORES EN ZONAS RURALES

THESIS BY COMPENDIUM OF PUBLICATIONS

TESIS POR COMPENDIO DE PUBLICACIONES

PRESENTED BY/PRESENTADA POR: MAURICIO MOLINARI ULATE

SUPERVISORS/DIRECTORES

Dr. MANUEL ÁNGEL FRANCO MARTÍN

Dra. HENRIËTTE VAN DER ROEST

SALAMANCA

SEPTIEMBRE

2023

Manuel Ángel Franco Martín, Doctor of Medicine and Surgery, Chief of the Psychiatry and Mental Health Department, Zamora Health Care Complex, Associate Professor University of Salamanca

y Henriëtte van der Roest, PhD. In Psychology, Director of the Department on Aging, Netherlands Institute of Mental Health and Addiction (Trimbos Institute):

CERTIFY THAT:

Mr. Mauricio Molinari Ulate has completed under supervision the Doctoral Thesis: "Psychosocial Applications Of Technology For Health And Wellness Coaching Of Older Adults With Dementia And Mild Cognitive Impairment And Their Carers In Rural Areas" to opt for the degree of Doctor with international mention from the University of Salamanca. This Doctoral Thesis is presented in the modality of Thesis by Compendium of Publications.

Salamanca, on July 21st, 2023.

FRANCO MARTIN MANUEL ANGEL - 09278225W

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Fdo. Manuel Ángel Franco Martín

Fdo. Henriëtte van der Roest

Nadie llega a nada sin la ayuda de alguien más

(Franklin Chang-Díaz)

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Thanks to all the friends I made throughout all these years. You made my stay in Valladolid and Zamora very special. Your company gave me the strength to carry on with the project. I want to make a special mentioned to Hugo, Claudia, Natalia, Cristina, Rodri, Sandra, Javi, Gabe and Becky, you always were in touched to know how I was doing and that is something I will never forget. Also, thanks to my Latin America group of PhDs, Leslie, Alejandra, and Andrea, it was such a pleasure to meet you.

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Thanks to my best friends, Carlos, Beto, Ricardo and Viquez. You have been by my side before I even consider the possibility to pursue a PhD. You were also there for my Master and you are still with me for my PhD. You already know how deeply grateful I am with your friendship. And thanks to my new best friend, Milo you came at the end of the process but you gave me the daily strength to finish and to enjoy life. You shared with me every day and you have always given me your love.

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Lastly, I made it Papi and Mami! This is my way of thanking you for all your effort of raising me. I want you to feel proud because this achievement is completely yours. Thanks for always been there, for your love and support throughout all my life, but particularly throughout this stage. I love you!

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DISTINCT: Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology. H2020 Marie Skłodowska Curie Actions – Innovative Training Networks (MSC-ITN).

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ABSTRACT

Introduction: The transition to an ageing population has brought several challenges to societies and healthcare systems around the world. The need for new healthcare approaches and interventions to adjust to the new situation is one of the most relevant issues worldwide. This project particularly targets three of these challenges: the complexity of older adult care, the increase of people living with dementia and their caregivers, and the poor accessibility of rural populations to access healthcare services to face these challenges.

Aims: To develop a proof of concept of a technological platform integrating several innovative digital tools for health and wellness coaching of older adults with dementia and cognitive impairment and their carers, and to study the effects of utilisation of the platform on physical health, mental and emotional wellbeing, activities of daily living, social and cognitive functioning and professional care use. To involve older adults with dementia and their carers in the design and development of the platform, assessing their satisfaction, the impact of the system in realistic settings, acceptability and usability, to enable them to manage the system autonomously in daily life.

Methodologies: Two systematic reviews were conducted in July 2021 and April 2023 in PubMed, CINAHL, and Web of Science. A qualitative appraisal/risk of bias was performed for the studies included. Three qualitative studies were conducted, implementing online and face-to-face workshops, semi-structured interviews, focus groups, and co-design and co-production processes with Patient and Public Involvement (PPI). Thematic analysis was the chosen approach for the analysis of the results. A mixed-methods usability and user experience study and a pilot study of an online training and support programme for caregivers of people living with dementia are being carried out, implementing semi-structured interviews and questionnaires targeting usability, dementia knowledge and caregiver burden.

Results: A series of steps necessary to create the foundations of a technological platform were identified: a) the interRAI LTFC and the interRAI HC were recommended as the CGAs to be used for the assessment and monitoring of potential users in long-term care facilities and home care, respectively; b) the barriers for the usability and implementation of DHTs to assist and to help to reach the full potential of CGAs are described, as well as a series of recommendations to improve its usability and implementation by healthcare professionals and clinical settings; c) a framework to study the pros and cons of developing digital patient and public involvement and suggestions to improve the implementation of e-PPI were developed and identified; d) the facilitators and barriers to implementing the socio-community intervention of the Meeting Centre Support Programme were identified and several recommendations were described to overcome the limitations for a successful implementation; and e) as an attempt to offer a support service alternative for caregivers of PLwD in remote rural areas, the cultural adaptation of the iSupport training and support programme for carers of PLwD was developed, and its usability and user-experience, and impact on dementia knowledge and caregiver burden are under study.

Conclusions: This project described a series of steps necessary to create the foundations of a technological platform for health and wellness coaching of older adults with dementia and cognitive impairment and their carers. By embedding the findings in this project and

including novel technologies such as AI, robotics, wearable technologies, and monitoring devices, the idea of the technological platform could be feasible. Further projects could implement these initiatives to generate an impact on facing the current challenges of the ageing population.

RESUMEN

Introducción: La transición hacia una población que envejece ha planteado varios retos a las sociedades y los sistemas sanitarios de todo el mundo. La necesidad de nuevos enfoques e intervenciones sanitarias para adaptarse a la nueva situación es una de las cuestiones más relevantes en todo el mundo. Este proyecto se centra especialmente en tres de estos retos: la complejidad de la atención a los adultos mayores, el aumento del número de personas que viven con demencia y de sus cuidadores, y la escasa accesibilidad de las poblaciones rurales a los servicios sanitarios para hacer frente a estos retos.

Objetivos: Desarrollar una prueba de concepto de una plataforma tecnológica que integre varias herramientas digitales innovadoras para la capacitación en salud y bienestar de adultos mayores con demencia y deterioro cognitivo y sus cuidadores, y estudiar los efectos de la utilización de la plataforma en la salud física, el bienestar mental y emocional, las actividades de la vida diaria, el funcionamiento social y cognitivo y el uso para los cuidados profesionales. Involucrar a los adultos mayores con demencia y a sus cuidadores en el diseño y desarrollo de la plataforma, evaluando su satisfacción, el impacto del sistema en entornos realistas, su aceptabilidad y usabilidad, para permitirles manejar el sistema de forma autónoma en la vida diaria.

Métodos: Se realizaron dos revisiones sistemáticas en julio de 2021 y abril de 2023 en PubMed, CINAHL y Web of Science. Se realizó una valoración cualitativa/riesgo de sesgo de los estudios incluidos. Se realizaron tres estudios cualitativos, implementando talleres online y presenciales, entrevistas semiestructuradas, grupos focales y procesos de codiseño y coproducción con Participación de Pacientes y Público (PPI). El análisis temático fue el enfoque elegido para el análisis de los resultados. Se está llevando a cabo un estudio de usabilidad y experiencia de usuario con métodos mixtos y un estudio piloto de un programa en línea para la capacitación y formación de cuidadores de personas que viven con demencia, en los que se aplicarán entrevistas semiestructuradas y cuestionarios sobre usabilidad, conocimiento de la demencia y sobrecarga de los cuidadores.

Resultados: Se identificaron una serie de pasos necesarios para crear las bases de una plataforma tecnológica: a) se recomendaron el interRAI LTFC y el interRAI HC como las Evaluaciones Geriátricas Integrales (EGI) que se utilizarán para la evaluación y el seguimiento de los usuarios potenciales en los centros de larga estancia y en la atención domiciliaria, respectivamente; b) se describen las barreras para la usabilidad y la implementación de las Tecnologías de Salud Digital (TSD) para asistir y ayudar a alcanzar todo el potencial de las EGI, así como una serie de recomendaciones para mejorar su usabilidad e implementación por parte de los profesionales sanitarios y los entornos clínicos; c) se desarrolló e identificó un marco para estudiar los pros y los contras del desarrollo de la participación digital de pacientes y público (e-PPI, por sus siglas en inglés) y sugerencias para mejorar la implementación de e-PPI; d) se identificaron los factores que facilitan y dificultan la aplicación de la intervención sociocomunitaria del Programa de Atención de Centros de Encuentro (MCSP, por sus siglas en inglés) y se describieron varias recomendaciones para superar las limitaciones y lograr una aplicación satisfactoria; y e) como intento de ofrecer una alternativa de servicio de apoyo a los cuidadores de personas que viven con demencia en zonas rurales remotas, se desarrolló la adaptación cultural del programa de formación y apoyo iSupport para cuidadores de personas que viven con demencia, y se está estudiando su usabilidad y experiencia de usuario, así como su impacto en los conocimientos sobre la demencia y la sobrecarga en los cuidadores.

Conclusión: Este proyecto describe una serie de pasos necesarios para crear los cimientos de una plataforma tecnológica para la capacitación en salud y bienestar de los adultos mayores con demencia y deterioro cognitivo y sus cuidadores. La idea de la plataforma tecnológica podría ser factible si se incorporan los resultados de este proyecto y se incluyen tecnologías novedosas como la inteligencia artificial, la robótica, las tecnologías ponibles y los dispositivos de monitorización. Otros proyectos podrían poner en práctica estas iniciativas para generar un impacto a la hora de afrontar los retos actuales del envejecimiento de la población.

ORGANIZATION OF THE THESIS

The RD 99/2011, of January 28th regulates the official doctoral programs. Likewise, the Doctoral and Postgraduate Commission, through article 17 of the Doctoral Regulations of the University of Salamanca, establishes and accepts as a possible doctoral thesis format, the modality by compendium of articles and/or publications in specialized journals. Therefore, this Doctoral Thesis is presented under this modality.

Articles

1. **Molinari Ulate, M.**, Mahmoudi Asl, A., Franco Martin, M., & van der Roest, H. (2022). Psychometric Characteristics of Comprehensive Geriatric Assessments (CGAs) for long-term care facilities and community care: A Systematic Review. Ageing Research Reviews, 81. doi: https://doi.org/10.1016/j.arr.2022.101742

Ageing Research Reviews – Journal Citation Reports (2022)

Impact factor: 13.1

Category: Geriatrics & Gerontology

Ranking by Journal Citation Indicator: 1/54

Journal Citation Indicator Quartile: Q1

2. **Molinari-Ulate, M.**, Woodcock, R., Smith, I. et al. Insights on conducting digital patient and public involvement in dementia research during the COVID-19 pandemic: supporting the development of an “E-nabling digital co-production” framework. Res Involv Engagem 8, 33 (2022). https://doi.org/10.1186/s40900-022-00371-9

BMC Research Involvement and Engagement – CiteScore (2022)

CiteScore: 5.2

Category: Social Sciences. Health (social science)

Ranking: 52/344

Percentile: 85th

3. **Molinari-Ulate M,** Guirado-Sánchez Y, Platón L, van der Roest HG, Bahillo A, Franco-Martín M. Cultural adaptation of the iSupport online training and support programme for caregivers of people with dementia in Castilla y León, Spain. Dementia. 2023;0(0). doi:10.1177/14713012231165578

Dementia (London) – Journal Citation Reports (2022)

Impact factor: 2.4

Category: Gerontology

Ranking by Journal Citation Indicator: 21/48

Journal Citation Indicator Quartile: Q2

4. **Molinari Ulate, M.**, Mahmoudi Asl, A., Parra-Vidales, E., Muñoz-Sánchez, J. L., Franco Martin, M., & van der Roest, H. (in press). Digital Health Interventions (DHIs) supporting the application of Comprehensive Geriatric Assessments (CGAs) in long-term care settings and community care: Systematic Review. *Digital Health.*

Digital Health Sage Journals – Journal Citation Reports (2022)

Impact factor: 3.9

Category: Health Policy & Services

Ranking by Journal Citation Indicator: 17/87

Journal Citation Indicator Quartile: Q1

5. **Molinari Ulate, M.**, Vallejos, C., van der Roest, H., Franco Martin, M., & Dröes, R. M. (under review). Facilitadores y Barreras de la Implementación Adaptada del Meeting Centre Support Programme en Países de Habla Hispana. El Caso de España y Ecuador (Under Review).

Acción Psicológica – Journal Citation Reports (2022)

Impact factor: 0.09

Category: Psychology, Multidisciplinary

Ranking by Journal Citation Indicator: 195/211

Journal Citation Indicator Quartile: Q4

Collaborations & Grants

The PhD candidate contributed to different research projects and grants during his PhD. Nonetheless, these collaborations and grants won’t be an object of the thesis defence. The following publication was part of the collaborations with Early Stage Researchers of the DISTINCT project:

- Mahmoudi Asl, A., **Molinari Ulate, M.**, Franco Martin, M., & van der Roest, H. (2022). Methodologies Used to Study the Feasibility, Usability, Efficacy, and

Effectiveness of Social Robots For Elderly Adults: Scoping Review. J Med Internet Res, 24(8), e37434. doi:10.2196/37434 (Supplementary Material #12)

The following publications are part of the updated Best Practice Guidelines: Human Interaction with technology in Dementia (Supplementary Material #10). This guidance results from the literature and field research conducted within INDUCT project (2016-2020) and DISTINCT project (2019-2023). The PhD candidate collaborated in the update of this guidance.

- **Molinari Ulate, M.** (2023). E-learning interventions, such as the iSupport-Sp, should be considered as alternative support services to reach caregivers of people with dementia living in remote areas, thus increasing service coverage [3.3.4.3]. In R. M. Dröes, et al. Best Practice Guidance: Human Interaction with Technology in Dementia. Recommendations based on the research conducted in the Marie Sklodowska Curie International Training Network INDUCT and the Marie Sklodowska Curie Innovative Training Network DISTINCT. Retrieved from https://www.dementiainduct.eu/guidance/
- **Molinari Ulate, M.** (2023). Adaptive implementation processes are required to successfully implement psychosocial applications of technology in dementia care [3.3.6.13]. In R. M. Dröes, et al. Best Practice Guidance: Human Interaction with Technology in Dementia. Recommendations based on the research conducted in the Marie Sklodowska Curie International Training Network INDUCT and the Marie Sklodowska Curie Innovative Training Network DISTINCT. Retrieved from https://www.dementiainduct.eu/guidance/
- **Molinari Ulate, M.** (2023). Digital Health Technologies are recommended to support fully Comprehensive Geriatric Assessments, because they improve communication and data transfer of patient medical data, health decision-making, and sharing of assessment responsibility between different professionals, thereby reducing the psychological burden of individual healthcare professionals [3.3.3.12]. In R. M. Dröes, et al. Best Practice Guidance: Human Interaction with Technology in Dementia. Recommendations based on the research conducted in the Marie Sklodowska Curie International Training Network INDUCT and the Marie Sklodowska Curie Innovative Training Network DISTINCT. Retrieved from https://www.dementiainduct.eu/guidance/
- **Molinari Ulate, M.** (2022). Use of the E-nabling Co-production Framework is recommended to improve digital Patient and Public Involvement in dementia research [3.1.4.3]. In R. M. Dröes, et al. Best Practice Guidance: Human Interaction with Technology in Dementia. Recommendations based on the research conducted in the Marie Sklodowska Curie International Training Network INDUCT and the Marie Sklodowska Curie Innovative Training Network DISTINCT. Retrieved from https://www.dementiainduct.eu/guidance/
- **Molinari Ulate, M.** (2022). The application of digital Patient and Public Involvement in dementia research should take into account technological, involvementability, resources and ethical and welfare conditions [3.1.4.4]. In R. M. Dröes, et al. Best Practice Guidance: Human Interaction with Technology in Dementia. Recommendations based on the research conducted in the Marie Sklodowska Curie International Training Network INDUCT and the Marie Sklodowska Curie Innovative

Training Network DISTINCT. Retrieved from https://www.dementiainduct.eu/guidance/

The PhD candidate contributed to obtaining the following grants during his doctoral thesis:

- Current Research
  - Bangor University Innovation and Impact Awards 2023 (Dr. Patricia Masterson-Algar, PI)
  - Amount Awarded: £33,956.00
  - Period of Grant Award: 01/08/23 to 31/07/24
  - Title of Project: *iSupport Young Carers* as a driver of change in how we support young people living in families affected by dementia.
  - Role on Project: Co-Investigator (CI)
- Current Research
  - NHMRC 2022 TCR Cultural Ethnic and Linguistic Diversity in Dementia Research (Dr. Lily Xiao, PI)
  - Amount Awarded: $1,555,078.05
  - Period of Grant Award: 5 years (starting 2024)
  - Title Project: A ‘culturally tailored iSupport model’ for carers of people with dementia.
  - Role on Project: Assistant Investigator (AI)

Other publications:

The following are short publications that were part of the doctoral student’s work in DISTINCT (Supplementary Material #11). Due to their nature, they won’t be an object of the thesis defence.

- Spring DISTINCT Newsletter #2. June 2021. Available at https://www.dementiadistinct.com/wp-content/uploads/2021/06/DISTINCT-Newsletter-Spring-2021-Final-version-1.pdf
- Cycling through the Netherlands… Developing the road to the Spanish version of the Meeting Centres Support Programme. DISTINCT Newsletter #3. March 2022. Available at https://www.dementiadistinct.com/wp-content/uploads/2022/03/3rd-DISTINCT-Newsletter-Winter-2022_final-3.3.22.pdf
- Spanish Online course for pioneers of Meeting Centres available in Spring 2022. MeetingDem Newsletter. December 2021. Available at https://meetingdem.eu/wp-content/uploads/2021/12/MeetingDem-Newsletter-December-2021_v1.0.doc.pdf
- A new start for the Meeting Centre in Spain. MeetingDem Newsletter. December 2022. Available at https://meetingdem.eu/wp-content/uploads/2023/03/MeetingDem-Newsletter-December-2022_v1.2.pdf

Conference Contributions:

The following publications were part of the dissemination of the PhD project. These publications won’t be an object of the thesis defence.

Oral Presentations

2022

- **Molinari Ulate, M.** (2022, October 17 – October 19). Technology for health and wellness coaching for PLwD and carers in rural areas [oral presentation]. 32nd Alzheimer Europe Conference. Bucharest, Romania.
- **Molinari Ulate, M.** (2022, September 29 – October 1). Use and Usefulness of Comprehensive Geriatric Assessments (CGAs) for long-term and community care settings: Cognition and Behavior Assessment [oral presentation]. XIX Congreso de la Sociedad Española de Psicogeriatría. Valladolid, Spain.
- **Molinari Ulate, M.**, Woodcock, R., & Smith, I. (2022, May 13). Enabling Digital Co-production: a framework to assess the differing impacts of digital PPI [oral presentation]. Advancing PPIE in the Midlands: Sharing Best Practice. Virtual, Midlands Health Alliance.
- **Molinari Ulate, M.** & Franco Martín, M. A. (2022, February 10). iSupport Program for caregivers of PLwD, Spanish adaptation and implementation plan [oral presentation]. International iSupport Research Meeting. Virtual, World Health Organization.

2021

- **Molinari Ulate, M.**, Woodcock, R., & Smith, I. (2021, December). Have you been listening online? Moving to digital co-production for dementia [webinar oral presentation]. NIHR MindTech 2021 Mental Health Technology Symposium. Virtual, NIHR.
- **Molinari Ulate, M.**, Mahmoudi, A., van der Roest, H. G. & Franco Martín, M. A. (2021, November/December). Psychometric features of Comprehensive Geriatric Assessments (CGAs) in long-term and community care settings: A Systematic Review [oral presentation]. 2021 IPA Virtual Congress. Virtual, International Psychogeriatric Association.
- **Molinari Ulate, M.**, Mahmoudi, A., Parra Vidales, E., Muñoz Sánchez, J. L., van der Roest, H. G. & Franco Martín, M. A. (2021, November/December). A systematic review of Digital Health Interventions (DHIs) supporting the application of Comprehensive Geriatric Assessments (CGAs) in long-term and community care [oral presentation]. 2021 IPA Virtual Congress. Virtual, International Psychogeriatric Association.
- **Molinari Ulate, M.** & Franco Martín, M. A. (2021, November 26-27). The World Health Organization (WHO) iSupport Program for caregivers of people living with dementia [oral presentation]. Multiplier Event SIDECAR Project. Virtual, SIDECAR Project.
- Kohl, G.*, **Molinari Ulate, M.**, Bhatt, J., Lynch, J., Scior, K., & Charlesworth, G. (2021, November 10-13). Individuals' decision to disclose a diagnosis of dementia and the development of an online empowerment intervention [oral presentation]. 2021 Annual Meeting of the Gerontological Society of America. Virtual. (*presenting author)

- **Molinari Ulate, M.**, Woodcock, R., & Smith, I. (2021, July 14). ePPI and Dementia [webinar oral presentation]. Centre for Dementia lunchtime seminars (online), Institute of Mental Health, University of Nottingham.
- **Molinari Ulate, M.** (2021, May 17). Technology and Mental Health [oral presentation]. 2021 Pint of Science Costa Rica. Virtual, San José, Costa Rica.

Poster Presentations

2022

- **Molinari Ulate, M.**, Vallejos León, C. P., Alvarado Rodas, A., Franco Martín, M. & Dröes, R. M. (2022, September 29 – October 1). Implementación adaptada del Meeting Centre Support Programme en países de habla hispana. Facilitadores y barreras en España y Ecuador. Proyecto piloto en España [poster presentation]. XIX Congreso de la Sociedad Española de Psicogeriatría. Valladolid, España.
- **Molinari Ulate, M.**, Woodcock, R., Smith, I., van der Roest, H.G., Franco Martín, M., & Craven, M.P., (2022, July 31 – August 4). Experiencing the Digital Working Transition in Patient and Public Involvement in Dementia Research During the COVID-19 Pandemic [poster presentation]. 2022 Alzheimer's Association International Conference. Virtual, California, USA.
- **Molinari Ulate, M.**, Vallejos León, C. P., Franco Martin, M.A., & Dröes, R. M. (2022, April 25-26). Adaptative Implementation of the Meeting Centre Support Programme in Spanish Speaking Countries. Facilitators and Barriers in Ecuador and Spain [poster presentation]. 3rd Latinos and Alzheimer's Symposium. Virtual, Bonita Springs, Florida, USA.

2021

- **Molinari Ulate, M.**, Mahmoudi, A., Parra Vidales, E., Muñoz Sánchez, J.L., Franco Martín, M.A., & van der Roest, H.G. (2021, July 26-30). Comprehensive Geriatric Assessments for long-term and home care settings and digital platforms available to support their applicability: A Systematic Review [poster presentation]. 2021 Alzheimer's Association International Conference. Virtual, Denver, USA
- Kohl, G.*, **Molinari Ulate, M.**, Bhatt, J., Scior, K., & Charlesworth, G. (2021, July 26-30). Factors associated with disclosing a diagnosis of dementia to one's social network: A systematic review [poster presentation]. 2021 Alzheimer's Association International Conference. Virtual, San Diego, USA. (*presenting author)
- Mahmoudi, A.*, van der Roest, H.G., **Molinari Ulate, M.**, & Franco Martín, M.A. (2021, July 26-30). Methodologies used to study the effectiveness of social robots in long-term and community care settings [poster presentation]. 2021 Alzheimer's Association International Conference. Virtual, Denver, USA. (*presenting author)

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CHAPTER I.
INTRODUCTION

The rapidly demographic transition to ageing populations is bringing new challenges to societies and public health systems (WHO, 2015, 2018), confronting them with the need for new adjustments and responses from all sectors (WHO, 2018). The proportion of people over 60 years of age worldwide is expected to double by 2050 (from 12% to 22%) and the rate at which this proportion is increasing seems to be faster than before, triggering the need to readjust public health systems (WHO, 2018). This transition has been also reflected in Spanish society, where this project has been implemented. It is expected that by 2050 one of every three Spaniards will be over 65 years old (Sánchez Sánchez, 2006) and that by 2068 a 29,4% (around 14 million people) of the total Spanish population will be older adults (Pérez Diaz, Abellán García, Aceituno Nieto, & Ramiro Fariñas, 2020). This situation will modified the Spanish population pyramid, as it is expected that by 2050 the older adults population will be duplicated and will double the number of children, increasing the pressure over the social protection systems mainly by 2040 (Pérez Diaz et al., 2020).

As ageing occurs, care systems are facing and struggling with the widely diverse and complex panorama of older adult care, as their physical and mental capacities tend to decline, at the same time their health difficulties become more chronic and complex (WHO, 2018). Some of these complexities are associated with comorbidities, polypharmacy, multiple treatments and interventions from different healthcare providers, and the risk of developing functional and cognitive impairment, which have profound implications on the quality of life and independence and autonomy capacity of the older adult population (Bernabei, Landi, Onder, Liperoti, & Gambassi, 2008; Molinari-Ulate, Mahmoudi, Franco-Martín, & van der Roest, 2022; WHO, 2015). Additionally, healthcare systems mismatch the current older populations needs as they were designed for a relatively younger population, emphasizing curative care and structured around the diagnosis and cure of acute health issues (WHO, 2018). Currently, the clinical focus should be on geriatric problems associated with chronic pain, frailty, urinary incontinence, and management of ongoing difficulties with hearing, seeing, walking or activities of daily living (ADL), to prevent, reverse or delay the potential decline of the older adult health (WHO, 2018). This situation increases the need for high degree of coordination between healthcare providers and clinical interventions, involving multiple healthcare and social care settings and interventions (WHO, 2018).

Another challenge faced as people age is the rise on the prevalence of dementia which duplicates every 5 years after the ages between 65 and 69 (Villarejo Galende et al., 2021). According to the World Alzheimer Report 2018, around 50 million people are living with dementia around the world, and these numbers are expected to increase to 78 million by 2023 and to triple to 152 million people by 2050 (Gauthier, Rosa-Neto, Morais, & Webster, 2021; Patterson, 2018). This phenomenon is not indifferent to the Spanish society in which more than 700 thousand people are estimated to be living with dementia, with predictions that by 2050 these numbers will increase to around two million people (Ministerio de Sanidad, Consumo y Bienestar Social, 2019; Ministerio de Sanidad, Servicios Sociales e Igualdad, 2016). These data confirm the growth of one of the most disabling and loss of autonomy diagnoses of older adults, which is estimated to have a cost of approximately US$ 2 trillion by 2030 (Patterson, 2018).

As the disease progresses, an increase in the need for supervision and personal care for a person with dementia is expected, estimating that 80 to 83% of this care is provided by family members, friends or unpaid caregivers (Alzheimer's Association, 2016; Coduras et al., 2010) and that 85% of the costs are attributed to the family and social care (Gauthier et al., 2021; Ministerio de Sanidad, Consumo y Bienestar Social, 2019). Whether it is a family member or another external person who assumes the role of caregiver, it has been evidenced that this task can lead to negative consequences on physical and mental health, quality of life, and occupational, socioeconomic and family domains (Casal Rodriguez, Rivera Castineira, & Currais Nunes, 2019; Oliva-Moreno, Trapero-Bertran, Peña-Longobardo, & Del Pozo-Rubio, 2017; Waligora, Bahouth, & Han, 2018), which has led to consider informal caregivers as the silent victims of this diagnosis (Hazzan, Ploeg, Shannon, Raina, & Oremus, 2013).

Considering that care is assumed more than half of the time by family members, mainly by women (Pérez Diaz et al., 2020), the high costs of caring for the disease for the social and healthcare systems, the deficits in the training of professionals for an adequate approach and intervention and in medical-health care programs, both for PLwD and for their relatives and caregivers, and the lack of information, training, counselling and support for relatives and informal caregivers (Ministerio de Sanidad, Consumo y Bienestar Social, 2019), highlight the complexities of dementia care.

This situation led us to an extra challenge particularly for the Spanish society. In Spain, care for people with dementia falls mainly on middle-aged women (45 to 64 years), with the spouse and daughters tending more often to assume this role (Pérez Diaz et al., 2020). However, the current sociodemographic context in Spain, known as “emptied Spain”, might be affecting the availability of informal care, specifically in rural and remote regions. This context is characterized by a relatively higher percentage of ageing and depopulation in rural areas and an increasing rural-urban migration. Most of the depopulation occurs in young adult population and mostly in women (de la Torre, 2018), precisely the population that tends to assume the caregiving role of PLwD in Spain (Pérez Diaz et al., 2020). This situation particularly affects the rural areas of Asturias, Castilla y León, Galicia, País Vasco, Cantabria and Aragón, where the proportion of elderly people is much higher (Pérez Diaz et al., 2020). The low density and smaller demographic size of these regions has led to a demographic vulnerability that affects the provision and efficiency of basic services in these municipalities (de la Torre, 2018; López González, 2021), such as those focus on providing dementia care.

This demographic vulnerability is even more relevant if we consider that age is one of the factors that have the greatest impact on the prevalence of dementia (Villarejo Galende et al., 2021), so the demographic transition to an older population, coupled with depopulation and limitations in the provision and efficiency of basic services in rural areas, could increase the risk of developing dementia and not having access to resources to face its challenges.

Integrated care and Comprehensive Geriatric Assessments (CGAs)

For facing this panorama, healthcare professionals and public health policymakers must pursue the development of alternative healthcare approaches to the traditional and standard service delivery that place older people’s needs and preferences in the centre of service delivery (WHO, 2015, 2018). One such an alternative approach is integrated care, a person-centred type of care in which different care levels and services are integrated across healthcare and long-term care settings (including home care) covering the needs and preferences of older adults along their life course (WHO, 2015, 2018). It has shown to be an effective approach to implement in the complex spectrum of older adult care (WHO, 2018), improving the quality of life and positively impacting rates of institutionalization and costs (Johri, Beland, & Bergman, 2003; McDonald, Schultz, & Chang, 2013; WHO, 2015).

Integrated care comprises three key features, a case-management system that assess the individual’s needs according to a person-centred perspective, a comprehensive care plan and assessment which aim to assist people on their treatment and care decisions, and an effective transfer of information among caregivers and settings aiming to improve coordination and integration of care (WHO, 2015, 2018). To deliver a more integrated care, healthcare professionals could take the following recommended steps: a) use case management strategies that include comprehensive assessments, care plans and proactive follow-up; b) implement evidence-based interventions targeting the level of intrinsic capacity of the older adults; and c) collaborate with other healthcare providers (WHO, 2018).

Following these recommendations, Comprehensive Geriatric Assessments (CGAs) have become important interventions in older adults care (Ellis, Whitehead, Robinson, O'Neill, & Langhorne, 2011; Pilotto et al., 2017), as they capture multiple domains and focus on the variety of complex problems experienced in frail older people (Bernabei et al., 2008; Ellis et al., 2011; Pilotto et al., 2017; Scanlan, 2005). CGAs are considered multidimensional assessments that support multidisciplinary care teams in clinical decision-making and personalized care planning to address the needs of older people and their families and carers, emphasizing functional status and quality of life using quantitative assessment scales (BGS, 2019; Parker et al., 2018; Pilotto et al., 2017; WHO, 2015). A wide range of benefits of the utilization of CGAs in older adult care has been documented, such as reductions in hospitalizations, admissions to long-term care facilities, functional decline and mortality (BGS, 2019; Martínez et al., 2018; Pilotto et al., 2017); prevention of negative health outcomes, such as shortened survival times and care dependency (WHO, 2015); or by supporting improvements in care planning and quality of care (Bernabei et al., 2008). However, as this care process approach considers multiple areas of an individual, care professionals and policy makers must be aware of CGA’s psychometric flaws and fortes to be able to take reliable decisions on care planning and health policy outcomes, aiming to optimize care quality.

Digital Health Technologies

As a result of the higher percentage of transitions between care settings in older populations, associated with the complexities of an ageing population and the shift from institutional care to home care delivery (Arai et al., 2012; LaMantia, Scheunemann, Viera, Busby-Whitehead, & Hanson, 2010; Vanneste, Vermeulen, & Declercq, 2013), accurate communication of medical information and treatment plans have become fundamental to provide quality older adult integrated care (LaMantia et al., 2010). Several initiatives have been developed to target and support integrated care, such as the development of technological systems that allow the assessment and clinical data transfer around clinical settings (e.g. home, nursing homes, long-term care facilities, hospitals, etc.) (Devriendt et al., 2013; Gray & Wootton, 2008; Vanneste et al., 2013). These systems could facilitate sharing and monitoring clinical data, integrating and coordinating assessments, improving communication among health environments, continuity of care, identifying people at risk or coordinating better person-centred interventions (Devriendt et al., 2013; Gray & Wootton, 2008; Vanneste et al., 2013).

Digital Health refers to the general use of a variety of information and communication technologies (ICTs), big data, genomics, and artificial intelligence to address health needs and to improve the health, well-being, and care of people (Fatehi, Samadbeik, & Kazemi, 2020; Seckman & Van de Castle, 2021; WHO, 2016, 2019c). Digital Health Technologies (DHTs) are intended to enhance people's health and well-being, and to improve health and social care systems (Lehoux & Grimard, 2018; NIHR, 2022). The variety of digital tools include, among others, the adoption and use of computer platforms, software, mobile apps (mHealth), wearable devices, electronic health records, telemedicine or telehealth, robotics, and monitoring and sensors devices (Center for Devices and Readiological Health, 2020; Lehoux & Grimard, 2018; Seckman & Van de Castle, 2021).

The employment of DHTs can potentially assist in reaching the full capacity of CGAs and overcome the constraints of data transfer between settings and stakeholders (Chadwell, 2001; Gray et al., 2009) facilitating the implementation of integrated care in healthcare systems. Involving DHTs in healthcare systems has been shown to improve the availability, quality, and use of data for healthcare decision-making and offer opportunities for the sustainability of healthcare systems by providing better insight into the quality and efficiency of care delivery (Common Road Map Steering Committee, 2015; WHO, 2019c). However, concerns have been raised regarding the overwhelming diversity of available digital health tools and the limited evidence on their impact on health systems and person's well-being (WHO, 2019c).

Evidence-based interventions to deliver integrated care

This project contributes to the search for better healthcare systems tools that could face the above-mentioned challenges, specifically the complexity of older adult care, the increase on the prevalence of people living with dementia (PLwD) and their caregivers, and the accessibility of the rural population to healthcare services to face the ageing population difficulties. For this reason, this project aimed to implement evidence-based interventions to support the delivery of more integrated care services (WHO, 2018). The following interventions were studied in this project:

The Meeting Centres Support Programme

The MCSP consists of a combined care in a socio-community context for PLwD and their informal caregivers, offering practical, emotional, and social support (Dröes, Meiland, Schmitz, & van Tilburg, 2004). It is based on psychomotor therapy and cognitive stimulation for PLwD, and psychoeducation and emotional peer support for informal caregivers. It also offers meetings and social activities for both target populations (PLwD and informal caregivers). The Meeting Centre is held three days a week and the support group for informal caregivers is held once a month, additionally, information sessions and individual counselling are offered (Dröes, Meiland, et al., 2004).The MCSP has been successfully implemented in several European countries (e.g., United Kingdom, Italy, The Netherlands, Poland) and has shown to improve the quality of life and mental health of PLwD and their caregivers, decreasing caregiver burden and showing a higher cost-benefit than other care modalities (Brooker et al., 2018; Dröes, Breebaart, Meiland, Van Tilburg, & Mellenbergh, 2004; Dröes, Meiland, et al., 2004; Henderson et al., 2021; Mangiaracina et al., 2017).

iSupport: training and support program for caregivers of PLwD

The iSupport is an evidence-based training and support program developed by the World Health Organization. It includes components of psychoeducation, relaxation, behavioural activation, cognitive reframing, and problem-solving (https://accesswho.campusvirtualsp.org/isupport-virtualcourse-skills-and-knowledge-training-carers-people-dementia) (Pot et al., 2019; WHO, 2019a). It includes five modules: 1) introduction to dementia (1 lesson); 2) being a carer (4 lessons); 3) caring for me (3 lessons); 4) providing everyday care (5 lessons); and 5) dealing with behaviour changes (10 lessons). The primarily target audience are family members, relatives, friends, and other informal carers of PLwD, however, it also targets other stakeholders such as nongovernmental organizations, health and social care workers, and private sector service delivery or healthcare insurance (WHO, 2019a). iSupport has already been culturally adapted in several countries and languages (e.g., Greek, Portuguese, or Chinese) and some of these projects have been published in the scientific literature (Baruah, Loganathan, et al., 2021; Efthymiou et al., 2022; Teles, Napolskij, Paul, Ferreira, & Seeher, 2021; Xiao, Ye, et al., 2022).

Patient and Public Involvement

Lastly, this project recognized the importance of involving *'experts by experience'* through the different stages that were developed. Patient and Public Involvement (PPI) has gained more attention in recent years across all areas of health research (NIHR, 2018) and it has been considered as a cornerstone for governmental and ethical policies in health research (Charlesworth, 2018; Gove et al., 2018; INVOLVE, 2012). It has been defined as a research project or public policy development carried out with or by patients or members of the public that is beyond their engagement as research subjects (Burton, Ogden, & Cooper, 2019; Dogba, Dossa, Breton, & Gandonou-Migan, 2019; INVOLVE, 2012). With practical benefits in enhancing the quality of the research (Charlesworth, 2018; INVOLVE, 2012; Miah et al., 2019) and as part of an accepted discourse (Beresford, 2019), PPI occupies at minimum a stipulated requirement, rather than an option, including funding applications for health research (INVOLVE, 2012). Whilst democratic rationales (Ives, Damery, & Redwod, 2013; Williams et al., 2020) may receive less attention than technocratic or transactional motivations, patient involvement has the potential to either address or exacerbate existing inequalities within health outcomes (Madden & Speed, 2017). Indeed, these existing inequalities risk being further compounded through the COVID-19 pandemic (Bambra, Riordan, Ford, & Matthews, 2020).

CHAPTER II.
OBJECTIVES

General Objectives

The main aims of this project were:

1. To develop a proof of concept of a technological platform integrating several innovative digital tools to remotely assess and monitor and offer health and wellness coaching to older adults with dementia and cognitive impairment and their carers.
2. To study the effects of utilisation of the platform on physical health, mental and emotional well-being, activities of daily living, social and cognitive functioning and professional care use.
3. To involve older adults with dementia and their carers in the design and development of the platform, assessing their satisfaction, the impact of the system in realistic settings, acceptability, and usability, to enable them to manage the system autonomously in daily life.

Specific objectives by study

To achieve the main aims of the project, it was needed to conduct several studies with specific objectives which are described as follows:

Systematic reviews

1. *Literature search on the content and psychometric characteristics of Comprehensive Geriatric Assessments (CGAS) used in long-term care settings and community care*

This systematic review aimed to provide insight into the content and psychometric characteristics of CGAs used in long-term care settings and community care.

2. *Literature search on the evidence and technical features of Digital Health Technologies (DHTs) developed to facilitate the administration of CGAs for long-term care settings and community care*

This systematic review aimed to describe the evidence on DHTs that have been developed to facilitate the administration of CGAs and describe their technical features and components, address the feasibility and usability, efficacy and effectiveness, and implementation outcomes, and report on the maturity of the DHTs.

Digital Patient and Public Involvement in dementia research

This study aimed to explore the experiences of e-PPI within a dementia-specific context during the COVID-19 pandemic and intended to use the findings to refine an existing ‘Overview of Digital Considerations’ originally developed by a PPI group, resulting in the ‘E-nabling Digital Coproduction’ Framework.

Adaptive implementation of the Meeting Centres Support Programme

This project aimed to identify the facilitators and barriers that could facilitate an adaptive implementation of the programme by understanding the cultural, care and social context of two regions of Spain and Ecuador.

Cultural adaptation of the iSupport online training and support programme

This project aimed to culturally adapt the iSupport, an evidence-based training and support programme for caregivers of PLwD developed by the World Health Organization, and co-design an online platform with PLwD, informal carers, and people from rural regions in Castilla y León, Spain.

Usability, user experience, and pilot study of the efficacy of the iSupport-Sp

This project aimed to study the usability and user experience of the iSupport-Sp in informal and formal caregivers of PLwD and explore whether its use has an effect on the level of dementia knowledge and the self-perceived caregiver burden.

CHAPTER III. METHODOLOGY

This project comprises five different studies that were aligned to target the aims presented in the previous chapter. Each of them was developed with a specific methodology that is described in this section.

Systematic Reviews

1. Literature search on the content and psychometric characteristics of CGAs used in long-term care settings and community care

Literature Search

A search strategy was conducted in three databases, PubMed, CINAHL and Web of Science Core Collection for studies up to July 13, 2021. See Table 1 for the inclusion and exclusion criteria. The reference lists of selected studies and systematic reviews that were relevant for the aims of this review, were scanned for potentially eligible primary studies.

Table 1. Inclusion and exclusion criteria for the Literature Review of CGAs

Inclusion Criteria	Exclusion Criteria
The Comprehensive Geriatric Assessment instrument must be one single test or assessment tool	An assessment that consists of a collection of single domain measures, tests or assessments, or stand-alone instruments assessing one domain (e.g, depression)
The study should report on the validation or reliability of the instrument	Studies published in languages other than English or Spanish Publications such as conference abstracts, case studies, protocols, dissertations, books and systematic reviews (however, references from selected SRs were checked)
The instrument must target specifically people of 55 years and older	
	If the entire instrument is self-report.
	Instruments developed for acute care, mental health care, palliative care, primary care or hospitalized settings. Also, those instruments that assessed transfer from or to any of the aforementioned care setting.

Search Strategy

Two authors developed the search strategy comprising free text keywords and Medical Subject Headings (MeSH). The search strategy was translated to the databases' correspondent-controlled vocabulary headings and appropriate syntax, when necessary. The following search strategy was used:

("geriatric assessment" (MeSH Major Topic) OR "geriatric assessment/methods" (MeSH Major Topic) OR "geriatric assessment" OR "geriatric evaluation" OR "geriatric instrument" OR GA OR "comprehensive geriatric assessment" OR CGA OR "multidimensional geriatric assessment") AND

("residential facilities" (MeSH Major Topic) OR "Community Health Centers" (MeSH Major Topic) OR "Community health services" (MeSH Major Topic) OR "long term care" (MeSH Major Topic) OR "elderly care" OR "residential facilit*" OR "long-term care facilit*" OR "LTCF" OR "geriatric care" OR "aged care" OR "home care" OR "senior center*" OR "residential care" OR "community care") AND

("reproducibility of results" (MeSH Major Topic) OR "validation studies as a topic" (MeSH Major Topic) OR "valid*" OR "reliab*")

Studies Selection Procedure

Duplicates from the initial search were identified and removed. Two author independently screened titles and abstracts of the records identified. The full-text review was performed by two reviewers independently. Final records were considered for the analysis. A third reviewer was involved to solve any discrepancies.

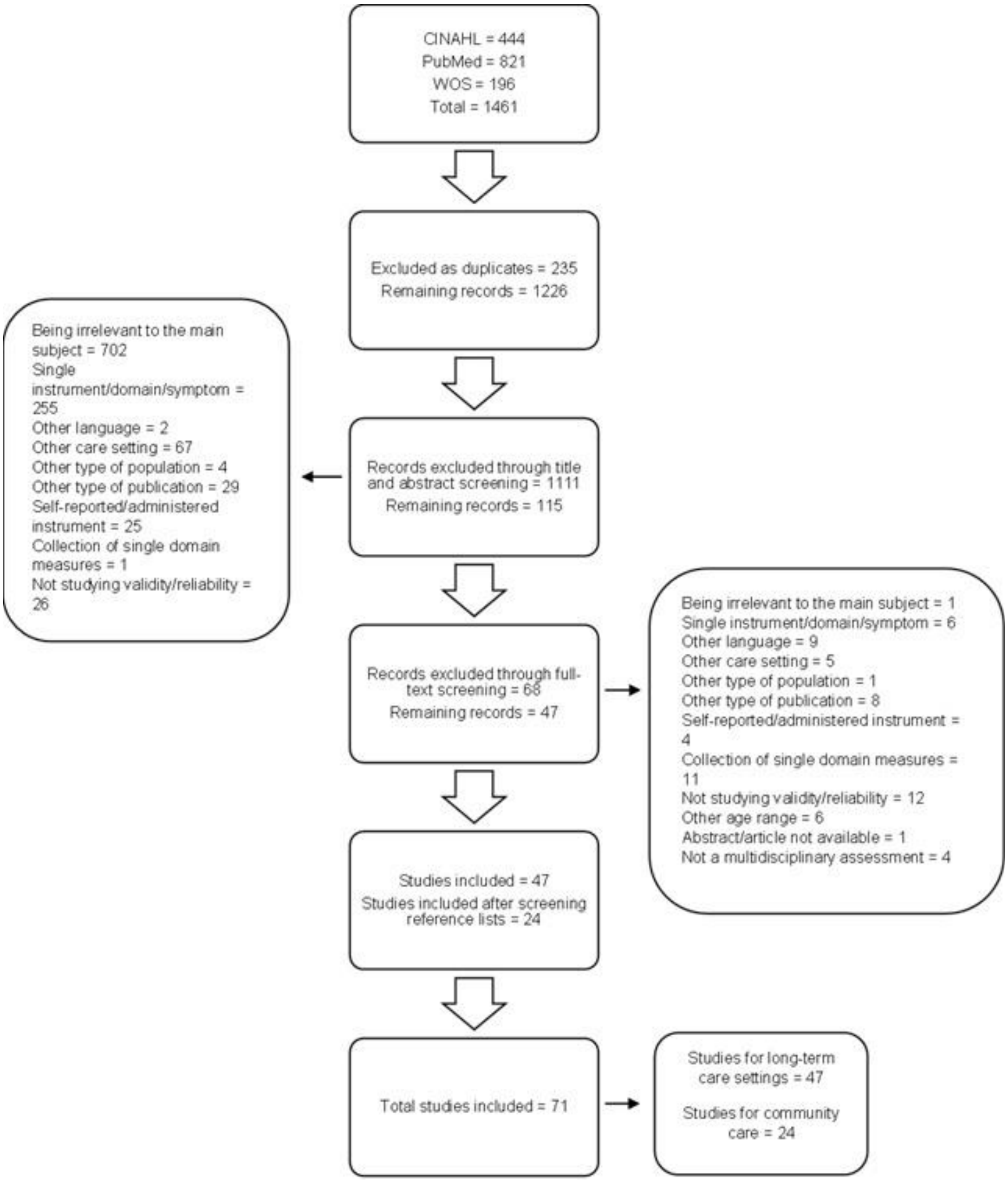

Figure 1. Prisma Flow Diagram for the Literature Review of CGAs

Data Extraction

Data was extracted by one of the authors from the final records identified. The data gathered was: a) name of CGA; b) authors/year; d) description of sample; e) country; f) study setting; g) study design; h) aim of the study; i) type of validity/reliability; and j) main findings. Scale, items, indices, or domains were also extracted from the relevant studies.

The domains covered by the CGAs were also reported, followed by the results on the evaluation of the reliability/validity of 1) complete CGAs; 2) specific domains and items; 3) scales and indexes; and 4) outcomes relevant for organization of care and clinical decision making. The domains of the CGAs were extracted from the description of the areas assessed in the papers, and from the forms or questionnaires, when available. The areas related to demographic or administrative data (e.g., Identification, Background or Assessment information) were excluded from this analysis to avoid bias, as they might not be reported in the papers but included in the forms, which were not all available.

Interpretation of Scores

The following standardized criterion based on the literature was used for the interpretation of test scores: a) for effect sizes, results were interpreted according to Cohen's definition, which an r of 0.1 is consider as a small effect, an r of 0.3 as a medium effect, and an r of 0.5 would be a large effect (Clark-Carter, 2004); b) for inter-rater reliability a Kappa value in the range of 0.4 to 0.6 is considered fair, from 0.6 to 0.75 is good and more than 0.75 is considered as excellent (Clark-Carter, 2004); c) for test-retest reliability a minimum r of 0.8 is expected. It can also be analysed by using the standards for correlations previously mentioned (Clark-Carter, 2004); d) for Cronbach's Alpha, mainly internal consistency reliability, results should be around 0.9 and not below 0.7 (Clark-Carter, 2004); e) Intraclass Correlation coefficients (ICC) less than 0.5 are indicative of poor reliability, values between 0.5 and 0.75 indicate moderate reliability, values between 0.75 and 0.9 indicate good reliability, and values greater than 0.90 indicate excellent reliability (Koo & Li, 2016); f) Areas Under the Curve (AUC) are excellent between 0.9 and 1, good from 0.8 to 0.9, worthless from 0.7 to 0.8, and not good from 0.6 to 0.7 (Hosmes & Lemeshow, 2005; Zhu, Zeng, & Wang, 2010); g) for sensitivity and specificity, the sum between both measures should be at least 1.5 for a test to be consider useful (Power, Fell, & Wright, 2013); and h) factor loadings above 0.5 will be considered as acceptable (Hair, Black, Babin, & Anderson, 2014).

Risk of Bias

The checklist is formed by 14 items which are scored according to the degree in which they meet the criteria (0 = no, 1 = partial, 2 = yes). Four of the original items of the scale were "not applicable" according to the characteristics of the papers analysed in this review (items 5, 6, 7, and 13). An extra item was included identifying the "type of validity/reliability" and was scored using the same score range for the rest of the items (0-2). Total score was obtained using the same formula explained in the checklist guide (Kmet, Lee, & Cook, 2004), including the extra item added for this review.

2. Literature search on the evidence and technical features of DHTs developed to facilitate the administration of CGAs for long-term care settings and community care

Literature Search

A literature search was conducted for studies up to April 5, 2023, in PubMed, CINAHL and Web of Science. See Table 2 for the inclusion and exclusion criteria.

Table 2. Inclusion and exclusion criteria for the Literature Review of DHTs

Inclusion Criteria	Exclusion Criteria
The CGA must be one single multidisciplinary test or assessment tool	An assessment that consists of a collection of, tests or assessments, or stand-alone instruments assessing one domain (e.g., depression)
Studies describing and/or assessing the feasibility, usability, efficacy, effectiveness, or implementation of DHTs use for the applicability or for performing a CGA	Studies published in languages other than English or Spanish
The DHT is developed for use in clinical practice.	DHTs that support entirely self-report instruments.
Any DHT supporting the application of a CGA in long-term care settings or community care	Publications such as conference abstracts, case studies, protocols, dissertations, books, and systematic reviews.
The instrument supported by the DHT targets people 55 years old or above	DHTs that support instruments for acute care, mental health care, palliative care, hospitalized settings, or transfer between any of the aforementioned settings.

Search Strategy

Two authors developed a search strategy through a list of free text keywords and MeSH. The list was translated to the databases' correspondent-controlled vocabulary headings and appropriate syntax, when required. The following search strategy was used:

CGA: “geriatric assessment” (MeSH Major Topic) OR “geriatric assessment/methods” (MeSH Major Topic) OR “geriatric assessment” OR “geriatric evaluation” OR “geriatric instrument” OR GA OR “comprehensive geriatric assessment” OR CGA OR “multidimensional geriatric assessment” AND

Setting: “residential facilities” (MeSH Major Topic) OR “Community Health Centers” (MeSH Major Topic) OR “Community health services” (MeSH Major Topic) OR “long-term care” (MeSH Major Topic) OR “elderly care” OR “residential facilit*” OR “long-term care facilit*” OR “LTCF” OR “geriatric care” OR “aged care” OR “home care” OR “primary care” OR “senior center*” OR “residential care” OR “community care” AND

DHT: "internet" (MeSH Major Topic) OR "telemedicine" (MeSH Major Topic) OR "software" (MeSH Major Topic) OR “digital*” OR “internet” OR “electronic*” OR “computer*” OR “automat*” OR “software” OR “web” OR “web-based” OR “mHealth” OR “telehealth” OR “mobile” OR “eHealth” OR “online” OR “app*"

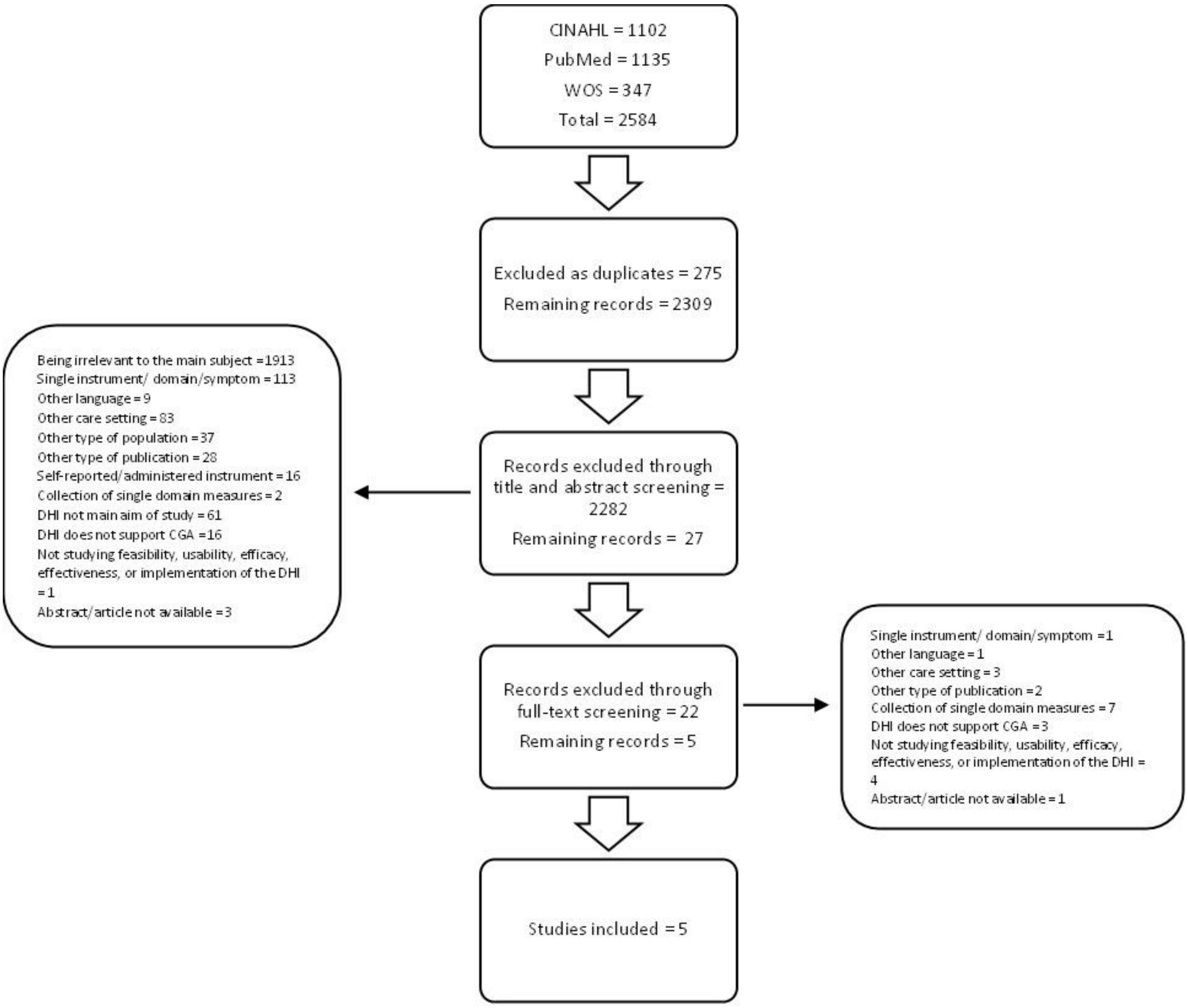

Figure 2. PRISMA Flow Diagram for the Literature Review of DHTs

Studies Selection Procedure

Duplicates were identified and removed. The remaining records were divided amongst three pairs of reviewers (six reviewers in total) who screened the titles independently. Deviations were discussed and agreements were sought within each pair. The potentially eligible records remain were screened by two authors, leading to the final full-text review. This final stage was performed by the same two authors independently. Discrepancies were solved by involving a third reviewer.

Data Extraction

The data extracted from the final studies was done by one author. The following data was gathered: a) author and year of publication; b) name of the DHT, c) name of the CGA; d) technical features; e) stage of maturity; f) aim of the study; g) study design; h) country; i) care setting; j) description of the study sample (size, female percentage, mean age, and standard deviation); k) outcomes; l) main findings.

State of evaluation (outcome variables):

The state of evaluation aims to determine whether the DHT under evaluation functions, is effective, or is ready to scale-up (WHO, 2016). In other words, if the DHT is feasible, usable, effective, or if it can be implemented on larger scales. According to the WHO (2016), the definitions of these outcomes are as follows: a) the feasibility assess whether the DHT works as intended in a given context; b) the usability assess if the DHT can be used as intended by the users; c) the efficacy assess if the DHT can achieve the intended results in a controlled research setting; d) the effectiveness assess whether the DHT can achieve the intended results in an uncontrolled (non-research) setting; and e) the implementation assess the uptake, integration and sustainability of the DHT for a specific context (includes policies and practices).

Stage of maturity and state of evaluation

The maturity life cycle of DHTs ranges from a concept to a fully developed and functioning platform that is ready for up-scaling, providing insight regarding if the DHT has been developed and evaluated for the first time, or if it is mature to undergo scale-up (WHO, 2016). In brief, the different stages of maturity as described by WHO (2016) are:

Pre-prototype: includes hypothesis building, needs/context assessment, and testing of usability/feasibility and technical stability.

Prototype: the user-focused designs are created and tested, as well as the functionality, technical stability, and usability. Improvements are examined.

Pilot: examines the digital intervention in controlled research settings to assess if it produces the expected effect.

Demonstration: the evaluation is done under some restricted population/region conditions but does not take place in controlled settings.

Scaled-up: at this step, the intervention is ready to be implemented widely, across multiple settings or at the population level.

Integration and sustainability: is the final stage where the intervention is already being used in a broader system, and other supporting features to enhance the impact of the intervention at a large scale are assessed (such as policies, financing, human resources, interoperability, etc.).

Risk of Bias

The quality of the studies was evaluated by two raters through the "mERA Methodological Criteria" (WHO, 2016). This tool contains two sections: a) essential items that must be evaluated for all studies, independent of study type (23 items), and b) items specifically for qualitative (3 items) or quantitative (3 items) research. In the case of mixed method studies, items from both categories (quantitative and qualitative) were used.

For this study, each item was rated according to the degree to which the study met the criteria (0 = no, 1 = partial, 2 = fully). When an item was not applicable, the item was not considered in the calculation of the summary score. The summary score was calculated for each study by summing the total score obtained from the relevant items and dividing it by the total possible score. According to this scoring system, results are between 0 and 1, closer to 0 the methodology is considered poor, and scores closer to 1 indicate a stronger methodology.

Digital Patient and Public Involvement in dementia research

The MindTech Involvement Team was involved during all the steps of this study. The MindTech Involvement Team is a group of people and carers bringing their own lived experiences of mental health conditions, as well as expertise in the processes of patient and public involvement, aiming to involve patients and public in all aspects of research. It occupies a strategic and advisory role in MindTech, a national centre established in 2013 and funded by the National Institute for Health and Care Research (NIHR) focussing on the development, adoption, and evaluation of new technologies for mental healthcare and dementia.

Developing a Co-produced Dementia e-PPI project

One representative member of the MindTech Involvement Team was a co-lead at the different sessions of the project and was involved as a facilitator of the online workshops. The project lead ran three types of sessions: a) a project design and development session, b) project delivery sessions (workshops), and c) meetings to analyse and synthesis the outcomes.

Online workshops

Workshops were selected as opposed to other alternatives such as semi-structured interviews, considering it as the most pragmatic approach to working online with PPI groups. Workshops allow to exchange ideas within a scaffolded structure, inclusion of potential challenges or allow for a range of positions expressed within a supported environment, thereby enabling to identify various positions within a group forum. Also, by providing online workshops, it is possible to use the chat function as a mean to share comments in parallel with the panel discussion, allowing to share thoughts without having to speak to the rest of the group.

A project information sheet and a semi-structured guide of possible topics and questions to cover at the discussions was shared with all the participants before the sessions (Supplementary Material #3). A one-minute pre-recorded video was also shown at the beginning of each session, aiming to introduce the project and to invite the individuals to participate. It was also helpful as an “ice-breaking” strategy to initiate the activity. The time for the sessions varied from 25 min to approximately an hour.

Two roles were provided by the project co-leads: (a) facilitation of the workshops and discussion; and (b) administrative and inclusion role, with a person in charge of taking field notes and checking the chat box. Field notes were chosen to gather the information as they have been previously implemented in similar public engagement projects (Craven et al., 2019; Harrington, Craven, Wilson, & Landowska, 2020) and because sessions were not recorded to maintain the policies of the PPI groups involved and as this project was targeted as a PPI activity rather than a research activity. For this reason, verbatim transcripts of the workshops were not obtained. Microsoft Teams (MS Teams) was the chosen tool as it was available by the institutions involved.

Groups participating in the workshops

Two online workshops and one individual interview were performed. Workshop 1 involved four researchers and two PPI coordinators (either staff or public contributors that have a role in facilitating PPI). An individual interview was held with one of the researchers as could not attend the workshop. Workshop 2 involved an existing PPI group, the 'Dementia, Frail Older People and Palliative Care Patient and Public Involvement Advisory Group' from the University of Nottingham. This group is made up of members who have experience of caring for PLwD, are carers themselves, who provide advice and guidance at all stages of research projects. The workshop strategy was brought to one of its existing virtual meetings and 11 members were part of the session. Using an existing PPI group provided a safe and structured settings for working with PLwD carers, recognising the need for increased attention to ethical and welfare issues as described in the literature (Gove et al., 2018).

The groups involved in the workshops only participated in their respective workshop sessions and were not involved in any other stages of the project.

Qualitative analysis method

The analysis of results was performed through a thematic analysis approach. As it was a co-produced project, a collaborative data analysis (CDA) was performed with members of the MindTech Involvement Team (Jennings, Slade, Bates, Munday, & Toney, 2018). An online meeting was held between two of the co-leads and other members of the MindTech Involvement Team to start coding the information, identifying the potential to utilise the Overview of Digital Considerations document (Supplementary Material #4) to support this endeavour. Co-production continued with the public contributor project co-lead and the other project leads, consolidating the coding into four key themes, including the addition of the concept of ‘involvementability’ as identified within the researchers and PPI coordinators Workshop. This resulted in the ‘E-nabling Digital Co-production’ Framework (see Fig. 3). Ambiguities and final coding were brought back to the MindTech Involvement Team for discussion and final inputs.

Figure 3. 'E-nabling Digital Co-production' Framework

Adaptive implementation of the Meeting Centre Support Programme

Cultural adaptation of the iSupport online training and support programme

The WHO Adaptation and Implementation Guide of iSupport (available upon request from whodementia@who.int) (WHO, 2019b) guided the translation and adaptation process for this iSupport Spanish version. The instructions of this guide aims to ensure that the adaptations are accurate in order to the generic version without modifying the core components, however, that an appropriate local version can be provided (WHO, 2019b). The process followed in this study is provided in Figure 5 and embedded three stages: a) translation by the authors, b) cultural adaptation, and c) co-design of the online platform.

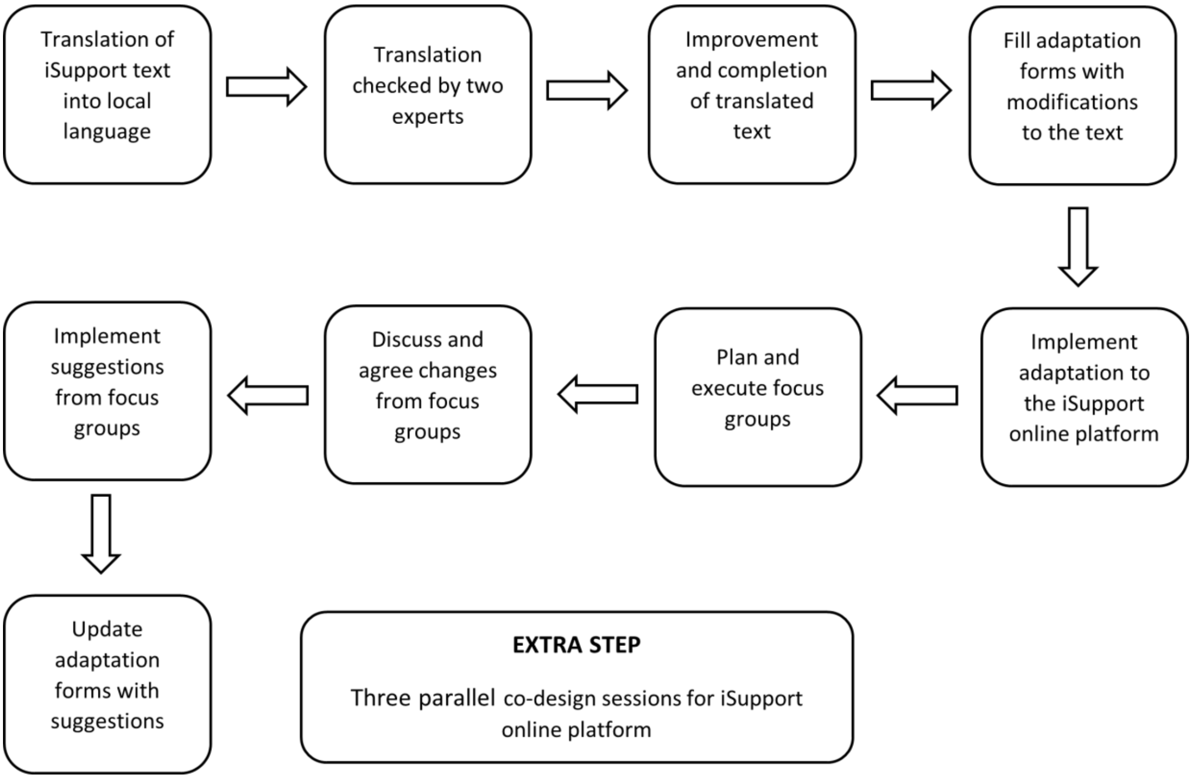

Figure 5. Translation and adaptation process (WHO, 2019b) and co-design parallel sessions

Translation by the authors

The translation was performed by two of the authors with experience in working with people living with dementia and their caregivers. This approach was chosen as it facilitated the translation of technical vocabulary and as both of the authors are native Spanish speakers with good English level and familiar with the context of Castilla y León, Spain.

Cultural adaptation

Following the WHO guidelines (WHO, 2019b), a preliminary adaptation of the iSupport translated content was conducted by the same two authors. This first adaptation targets changes on words, names, links, and resources embedded in the iSupport generic version which are recommended to be modified according to the local culture and habits. These modifications were recorded in the adaptation forms provided by the WHO and were included by the engineers into the online version.

The resulting text was review by three focus groups independently, involving a) informal caregivers; b) formal/professional caregivers; and c) a group of experts on cognitive impairment and dementia. This third group was involved despite it was not included in the recommendations of the WHO guide as it was considered by the authors that it would give an extra value on the adaptation of the technical vocabulary to a more common use language for the target population. This step was performed by one of the authors at the State Reference Centre for the Care of People with Alzheimer's Disease and Other Dementias, where the formal and informal caregivers were recruited. The groups of experts were recruited from the master's program of Dementia and Neuropsychology of the University of Salamanca, Spain (postgraduate fellows).

The focus groups lasted 90 minutes each session (two sessions in total) for the informal and formal caregivers' groups. The first session consisted of an explanation of the project and how to register the suggestions in the adaptation forms; during the second session, the information collected was discuss. The methodology for the groups of experts differed slightly as the data was collected by e-mail and only received one session explaining the purpose of the project and how to register the suggestions. All individuals participating in the focus groups had two weeks to go through the iSupport content (hardcopy manuals) and to register their feedback in the adaptation forms.

The final results from the focus groups discussions were collected in a single adaptation form to compare the results of the three samples. The data analysis was performed through thematic analysis, which was supported by an initial coding extracted from previous published iSupport cultural adaptations (Baruah, Loganathan, et al., 2021; Efthymiou et al., 2022; Teles et al., 2021; Xiao, Ye, et al., 2022). Data was coded by two of the authors, when new codes were identified they were included in the final analysis. Disagreements were discussed and a third reviewer was involved for a final decision, when required. All modifications were updated in the platform by the engineers. Suggestions regarding additional content or altering the original meaning of the text were not added to the final adaptation, however, they were reported in the results. Decisions were made by consensus between two of the authors who were familiar with the iSupport content and based in their clinical experience.

Co-design

This step was included in addition to the ones proposed in the adaptation guide aiming to increase the quality of the design and adaptation of the iSuppor online platform to the context and culture of interest. A PPI activity was performed through three separate sessions with: a) the European Working Group of People with Dementia (EWGPWD), a group of people living with dementia and their carers with experience in research engagement; b) the Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology (DISTINCT), a group of researchers aiming to improve the lives of people living with dementia and their carers through technology; and c) a group of people living in a rural area in Salamanca, Spain, which eight of them were or used to be caregivers of people living with dementia at the moment of the meeting. The EWGPWD meeting was performed online through Zoom, and with the DISTINCT Network and the rural population meetings were in-person. Sessions varied from 20 to 40 minutes. For the EWGPWD, the iSupport generic version was shown, and through a group discussion, participants gave feedback on how to improve the platform for adapted versions. For the DISTINCT Network and the rural area population, a prototype of the iSupport Spanish adapted version (iSupport-Sp) was shown and feedback from the participants was obtained and registered. The final remarks obtained from the three sessions were discussed between the project leaders and engineers to consider its inclusion. The final decisions were made according to the technological viability and the adaptation guidelines from the WHO.

Usability, user experience, and pilot study of the efficacy of the iSupport-Sp

The following methodology is presented as it is important for the context of the thesis, however, this study is being conducted at the moment this thesis has been written. For this reason, the steps describe as follows are based on the protocol proposed to the Ethics Committee (Supplementary Material #8).

Study design

A mixed methods study of human-online platform interaction was the chosen design. Mixed methods research is a methodology for conducting research that involves collecting, analysing, and integrating quantitative and qualitative research. This approach to research is used when this integration provides a better understanding of the research problem than either alone. The design is being conducted in a single phase: a usability and user experience study (questionnaires and semi-structured interview) and an exploratory pilot efficacy study on dementia knowledge and level of caregiver burden (pre-test evaluation, intervention and post-test evaluation). The primary outcomes are "Knowledge about Dementia" (assessed by the

DKAT2-SP questionnaire), "Level of caregiver burden" (assessed by the Zarit Questionnaire), "User Experience" and "Usability" (assessed by the Computer System Usability Questionnaire and a survey).

Participants

The sample consists of 50 participants who can be either informal caregivers or formal caregivers of people with cognitive impairment or dementia. The inclusion criteria is: a) be over 18 years of age; b) be an informal caregiver (family member, friend or other who do not receive a salary for their caregiving role) or formal caregiver (health professionals or people with professional caregiver training, salaried, who care for people with cognitive impairment or dementia); c) that the person being cared for presents a formal diagnosis of mild cognitive impairment or dementia; d) be able to read, write and speak Spanish; and e) not have loss of any sense that hinders the use of electronic devices (e.g., blindness or deafness); f) signature of the consent form. Participants are being recruited through Memory Clinics, Alzheimer’s Associations and the Zamora Residence Network.

In addition, seminars are being held to explain the project to primary care and social network professionals so that they themselves can refer potential participants to the study as long as they meet the inclusion criteria.

Procedure

Participants can access the iSupport-Sp online platform through the following link https://learning.bluece.eu/. After registering by filling the sociodemographic questionnaire and accepting the privacy policy, the participants’ information sheet and the consent form, the pre-test questionnaires on knowledge of dementia (DKAT2-Sp) and self-perceived caregiver burden (Zarit Questionnaire) are enabled to be self-completed.

When participants have completed both questionnaires, they have access to the iSupport content and navigate the platform. After the participant completes all modules and lessons, the platform enables the post-test questionnaires on dementia knowledge (DKAT2-Sp), self-perceived caregiver burden (Zarit Questionnaire), usability (CSUQ) and a user experience survey. Once all questionnaires have been completed, the participant can download a certification of completion of the iSupport-Sp.

Materials and Measures

The following materials and measures are being used:

Sociodemographic Data Questionnaire: the following relevant sociodemographic data is being collected: a) gender (e.g., male, female, other), b) age, c) type of caregiver (e.g., formal or informal caregiver), d) years of experience as a caregiver, e) municipality of residence (e.g., less than 10,000 inhabitants, greater than 10,000 inhabitants), f) level of education, and g) level of use of technologies.

Dementia Knowledge Assessment Tool 2. Spanish version (DKAT2-Sp): consists of a questionnaire that measures knowledge about dementia in the Spanish-speaking population. It consists of 21 items with three response options for each: "yes", "no" and "do not know". Thus, the higher the score, the greater the knowledge about dementia. The maximum score obtained can be transformed into a knowledge index.

Zarit questionnaire: consists of an instrument used to quantify the degree of burden presented by informal caregivers of dependent persons. It consists of 22 items with five response options: "never", "almost never", "sometimes", "quite often" and "almost always".

Computer System Usability Questionnaire (CSUQ): it is composed of 16 items on a Likert scale from 1 to 7, where 1 is strongly disagree and 7 is strongly agree. CSUQ is suitable for use in field tests, i.e., where the participant can answer the questionnaire without having to perform any specific task with the interface, it is only required that the participant has interacted with the interface previously. The CSUQ items produce four scores: one overall and three subscales about system quality, information quality and interface quality. It requires little time to answer.

User Experience Survey: it consists of a series of open questions focused on the users' experience with the platform, aimed at knowing different aspects such as expectations, usability, content, design, etc. The following questions are being asked:

- Have the expectations you had about this website been met?
- How would you describe the overall experience with this site?
- What is your overall impression of the design?
- What features are most useful and valuable to you, and why?

- What do you think of the website content?
- What did you like the least and most?
- Approximately how many days did it take you to learn how to use this website?
- Briefly describe the benefits you see from this website
- Briefly describe the disadvantages you see from this website
- Please write down any suggestions you would like to make on how to make the site easier to use.

Data on platform usage: the following data related to the use of the platform is being obtained for each participant: a) session start time, b) session end time, c) time the participant has been connected in the session, and d) number of lessons and modules completed.

Data analysis

Quantitative data: statistical analysis of the data will be performed using IBM SPSS v.26. Descriptive statistics of the sociodemographic data will be presented. Comparative tests for related samples will be performed to analyse the results obtained through the questionnaires. In case parametric assumptions are not met, non-parametric statistical tests will be applied (Mann-Whitney U test, Wilcoxon signed ranks test, calculation of Spearman's correlation coefficient, etc.).

Qualitative data: thematic analysis will be conducted through NVivo 12 using Braun and Clarke (2006) six-step approach as follows; 1) become familiar with the data, 2) generate initial codes, 3) search for themes, 4) review themes, 5) define themes, 6) write up.

CHAPTER IV. COMPENDIUM OF PUBLICATIONS

This section presents the compendium of publications that make up this project. The original publication is presented and, additionally, a Spanish translation of the title and abstract is included. Only for publication #4 an English translation of the abstract is included, as it was written in Spanish. Each publication is presented according to the scientific journal guidelines where they were published.

Publication #1. Psychometric characteristics of comprehensive geriatric assessments (CGAs) for long-term care facilities and community care: A systematic review

Publicación #1. Características psicométricas de las evaluaciones geriátricas integrales (EGI) para residencias de largan estancia y atención domiciliaria: Una revisión sistemática

Mauricio Molinari-Ulate, Aysan Mahmoudi, Manuel A. Franco-Martín, Henriëtte G. van der Roest

Resumen en español

Antecedentes: Las Evaluaciones Geriátricas Integrales (EGC) se han incorporado como un enfoque de atención integrada eficaz para enfrentar los desafíos asociados a la atención descoordinada, el riesgo de hospitalización, las necesidades insatisfechas y la planificación de los cuidados experimentados en la atención a los adultos mayores. Dado que evalúan diferentes dimensiones, es importante informar sobre el contenido y las propiedades psicométricas para orientar las decisiones a la hora de seleccionarlos e implementarlos en la práctica. Esta revisión sistemática proporciona una visión exhaustiva de los puntos fuertes y débiles de las EGI utilizadas en las residencias de larga estancia y en la atención domiciliaria.

Métodos: Se realizó una búsqueda sistemática en PubMed, CINAHL y Web of Science Core Collection. Se consideraron los estudios publicados hasta el 13 de julio de 2021. Se realizó una evaluación de la calidad de los estudios incluidos.

Resultados: Se identificaron un total de 10 EGI diferentes en 71 estudios incluidos. Se describieron tres instrumentos para residencias de larga estancia y siete para la atención domiciliaria. El contenido no era homogéneo y difería en cuanto al detalle y la claridad de las áreas evaluadas. La validez y la fiabilidad de algunas de las EGI se mantuvieron en un rango de bueno a excelente.

Conclusiones: El establecimiento de dominios más específicos y claros, asociados a las necesidades especiales del entorno asistencial, podría mejorar las decisiones informadas a la hora de seleccionar e implementar una EGI. Teniendo en cuenta la cantidad y calidad de la evidencia, la trayectoria de desarrollo de los instrumentos, la validación en diferentes idiomas y la disponibilidad en diferentes entornos asistenciales, recomendamos el uso del interRAI LTCF y el interRAI HC para las residencias de larga estancia y la atención domiciliaria.

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Review

Psychometric characteristics of comprehensive geriatric assessments (CGAs) for long-term care facilities and community care: A systematic review

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ABSTRACT

Background: Comprehensive Geriatric Assessments (CGAs) have been incorporated as an integrated care approach effective to face the challenges associated to uncoordinated care, risk of hospitalization, unmet needs, and care planning experienced in older adult care. As they assessed different dimensions, is important to inform about the content and psychometric properties to guide the decisions when selecting and implementing them in practice. This systematic review provides a comprehensive insight on the strengths and weaknesses of the CGAs used in long-term care settings and community care.
Methods: A systematic search was conducted in PubMed, CINAHL, and Web of Science Core Collection. Studies published up to July 13, 2021, were considered. Quality appraisal was performed for the included studies.
Results: A total of 10 different CGAs were identified from 71 studies included. Three instruments were reported for long-term care settings, and seven for community care. The content was not homogenous and differed in terms of the detail and clearness of the areas being evaluated. Evidence for good to excellent validity and reliability was reported for various instruments.
Conclusions: Setting more specific and clear domains, associated to the special needs of the care setting, could improve informed decisions at the time of selecting and implementing a CGA. Considering the amount and quality of the evidence, the instrument development trajectory, the validation in different languages, and availability in different care settings, we recommend the interRAI LTCF and interRAI HC to be used for long-term facilities and community care.

1. Background

Societies and health systems are being challenged by the current demographic transition to ageing populations, arising the need for adjustments and responses from all sectors, including public health (WHO, 2015, 2018). The complexity of older adult care associated to comorbidities, polypharmacy, multiple treatments and interventions from different health care providers, socioeconomic status, and the risk of developing functional and cognitive impairment, have implications on the quality of life and capacity for independence and autonomy of the older adult population (Bernabei et al., 2008; World Health Organization, 2015). For facing this panorama, health care professionals and public health policymakers must pursue the development of healthcare approaches that place older people's needs and preferences in the centre of service delivery (WHO, 2015).

Integrated care has been considered as an effective alternative approach to the traditional and standard service delivery, improving the quality of older adult care and positively impacting rates of institutionalization and costs (Johri et al., 2003; McDonald et al., 2013; World Health Organization, 2015). A method in which different care levels and

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services are integrated across health care and long-term care settings covering the needs and preferences of older adults along their life course (World Health Organization, 2015). It comprises three key features, a case-management system that assess the individual's needs according to a person-centred perspective, a comprehensive care plan which aim to assist people on their treatment and care decisions, and an effective transfer of information among caregivers and settings aiming to improve coordination and integration of care (World Health Organization, 2015).

Following this approach, Comprehensive Geriatric Assessments (CGAs) became important interventions in geriatric care (Ellis et al., 2011; Pilotto et al., 2017). CGAs incorporate the main pillars of an integrated care approach and are being defined as a process of care including a coordinated multidimensional and multidisciplinary assessment, facilitating the clinical decision for the formulation of a personalized care plan to address the needs and concerns of the older person (and their family and carers) (Pilotto et al., 2017; British Geriatrics Society, 2019).

The interdisciplinary and integrated care process approach, centres its attention on the person and relatives, leading to a holistic evaluation of core domains. As this care process approach considers multiple areas of an individual, care professionals and policy makers must be aware of CGA's psychometric flaws and fortes to be able to take reliable decisions on care planning and health policy outcomes, aiming to optimize care quality. For this reason, the aim of this systematic review is to provide insight into the content and psychometric characteristics of CGAs used in long-term care settings and community care.

2. Methods

2.1. Literature search

A systematic literature search was conducted in three databases, PubMed, CINAHL and Web of Science Core Collection for studies up to July 13, 2021 (search strategy and studies selection procedure are available in Methods A.1). See Table 1 for inclusion and exclusion criteria. Reference lists of selected studies and relevant systematic reviews were scanned for potentially eligible primary studies.

2.2. Data extraction

One author (MMU) extracted the data from the final selection of papers. The following information was gathered: a) name of CGA; b) authors/year; d) description of sample; e) country; f) study setting; g) study design; h) aim of the study; i) type of validity/reliability; and j) main findings. Scale, items, indices, or domains were also extracted from the relevant studies.

Results on the domains covered by the CGAs were reported, followed by results on the evaluation of the reliability/validity of 1) complete CGAs; 2) specific domains and items; 3) scales and indexes; and 4) outcomes relevant for organization of care and clinical decision making. The domains of the CGAs were obtained from the description of the areas assessed in the papers, and from the forms or questionnaires, when available. To avoid bias on the domains' description, those areas related to demographic or administrative data (e.g., Identification, Background or Assessment information) were excluded from this analysis, as they might not be reported in the papers but included in the forms.

Table 1
Inclusion and exclusion criteria used for the study selection.

Inclusion Criteria	Exclusion Criteria
The Comprehensive Geriatric Assessment instrument must be one single test or assessment tool	An assessment that consists of a collection of single domain measures, tests or assessments, or stand-alone instruments assessing one domain (e.g, depression)
The study should report on the validation or reliability of the instrument	Studies published in languages other than English or Spanish
The instrument must target specifically people of 55 years and older	Publications such as conference abstracts, case studies, protocols, dissertations, books and systematic reviews (however, references from selected SRs were checked) If the entire instrument is self-report. Instruments developed for acute care, mental health care, palliative care, primary care or hospitalized settings. Also, those instruments that assessed transfer from or to any of the aforementioned care setting.

2.3. Risk of bias

The quality of the studies was assessed independently by two authors (MM and AM) using the "STANDARD QUALITY ASSESSMENT CRITERIA" for quantitative studies (Kmet et al., 2004) and percentage of agreement was calculated. Subsequently, the same two raters discussed the disagreements and came with a final consent agreement. Further detailed regarding the risk of bias methodology is provided in Methods A.1.

2.4. Interpretation of test scores

The validity and reliability outcomes were obtained according to the aims of the studies and the primary outcomes identified. When outcomes were unclear or multiple outcomes were reported, the researcher selected the one that best reflected the main result of the study (e.g., main scales outcomes rather than subscales). To avoid differences on the interpretation of the psychometric outcomes between the studies, the reviewers decided to use a standardized criterion based on the literature (available in Methods A.1).

3. Results

3.1. Literature search

After duplicates were removed, the titles and abstracts of 1226 records were screened, of which 115 records were analysed in detail by full text. Finally, 47 records were included in the review. After scanning the reference lists of selected studies, 24 additional studies were considered as eligible primary studies. In total, 71 papers were included in the final results (Fig. 1. PRISMA flow diagram).

3.2. Risk of bias

Two raters (MM and AM) scored the quality of the 71 papers, obtaining a 78.97% of agreement. The scores ranged from 0.50 to 1 (1 maximum score), with an average score of 0.83 (Table A.1).

3.3. CGA characteristics

Ten different CGAs were identified: three focused on long-term care settings and seven focused on community care (see Table 2). Table 3 shows the number of domains assessed by each CGA and the number of studies that used criterion measures and the number of criterion measures used to validate some of their domains. The areas validated and the criterion measures used for their validation are available in Table A.2.

3.4. Psychometric characteristics of the CGAs

The following section describes the reliability and validity results. The first subsection describes the results of the long-term care facilities instruments, followed by the community care. Each subsection starts with the reliability results followed by validity findings. Results are

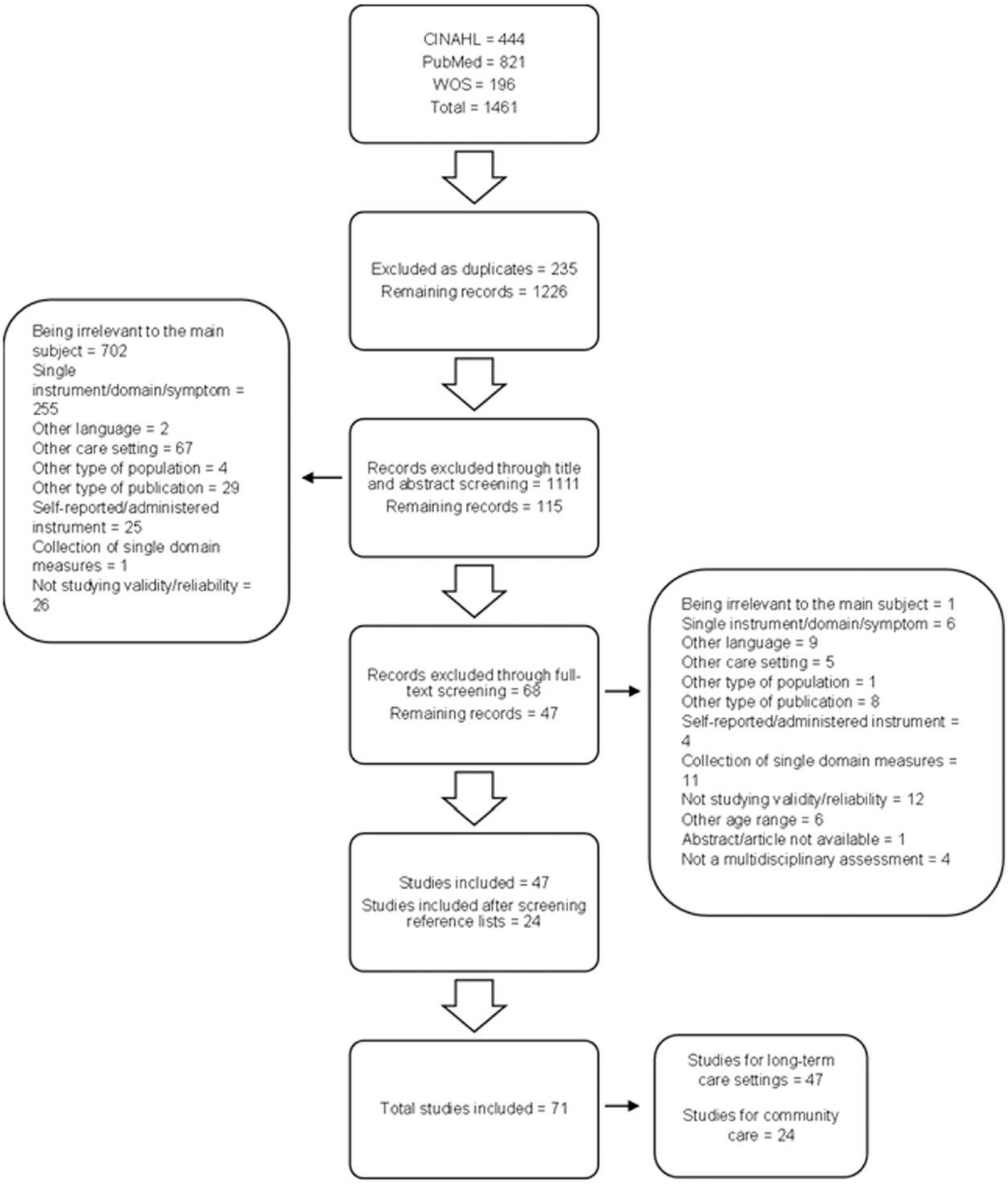

Fig. 1. PRISMA flow diagram.

described according to the four approaches identified to study the psychometric characteristics: a) complete CGAs; b) specific domains or items; c) specific scales or indices; and d) outcomes relevant for clinical decision making and organization of care. The psychometric evidence for outcomes relevant for organization of care and clinical decision making are described in a separate subsection.

3.5. *CGAs for long-term care settings*

3.5.1. *Reliability results*

The reliability of the complete CGA RAI-MDS and subsequent updated versions (n = 8), and CPAT (n = 1), was studied (Table A.3). Good to excellent inter-rater reliability was reported for more than 91.7% of the

Table 2
CGAs identified in the review, according to their care setting.

Long-term care setting	Community care
Resident Assessment Instrument-Minimum Data Set (RAI-MDS) (Morris et al., 1990) [a]RAI-MDS 2.0 (Morris et al., 1997b) [a]RAI-MDS 2.1 Chinese version (Chou et al., 2001) [ab]MDS 3.0 (Saliba and Buchanan, 2012) [a]interRAI Long-term Care Facilities (LTCF) v.9.1 (Hirdes et al., 2008) [a]interRAI LTCF Korean Version (Kim et al., 2015)	Comprehensive Assessment and Referral Evaluation (CARE) (Gurland et al., 1977)
VALutazione GRAFica (ValGraf) Residential version (Gigantesco et al., 1995)	Older American's Resources and Services (OARS) Multidimensional Functional Assessment Questionnaire (OMFAQ) (Fillenbaum and Smyer, 1981) [a]OARS-OMFAQ Spanish version (Fibla et al., 1996)
Care Planning Assessment Tool (CPAT) (Fleming, 2008) [a]J-CPAT Japanese version (Kanegae et al., 2010)	Philadelphia Geriatric Center Multilevel Assessment Instrument (MAI) (Lawton et al., 1982)
	Popovich Scale (Grubba et al., 1990) Outcome and Assessment Instrument Set (OASIS) (Shaughnessy et al., 1994) RAI-MDS Home Care (HC) (Morris et al., 1997a) [a]RAI-MDS HC Chinese version (Kwan et al., 2000) [a]RAI-MDS HC Swiss version (Ludwig and Busnel, 2017) [a]interRAI HC (Hirdes et al., 2008) [a]interRAI HC Korean version (Kim et al., 2015) Community Assessment of Risk Instrument (CARI) (Clarnette et al., 2015)

[a] Are considered as subsequent versions of the original instrument.
[b] The MDS 3.0 is an updated version of RAI-MDS and RAI-MDS 2.0, however, it was not developed by the interRAI network.

Table 3
Number of domains included in the CGAs, number of studies using criterion measures, and number of criterion measures used for validation.

Care setting	Name of CGA	# of domains assessed by the CGA	# of studies that included criterion measures	# of criterion measures or gold standards used for validation
Long-term Care	RAI-MDS	15	14	37
	RAI-MDS 2.0	16	7	11
	MDS 3.0	16	2	2
	ValGraf	8	1	2
	CPAT	8	2	4
	interRAI LTCF	17	0	0
Community Care	CARE	3	0	0
	OARS-OMFAQ	5	1	4
	MAI	7	0	0
	Popovich Scale	4	1	2
	OASIS	4	2	5
	RAI-MDS HC	16	5	7
	interRAI HC	18	3	5
	CARI	3	0	0

Note: RAI = Resident Assessment Instrument; MDS = Minimum Data Set; ValGraf = Valutazione Grafica; CPAT = Care Planning Assessment Tool; LTCF = Long Term Care Facilities; CARE = Comprehensive Assessment and Referral Evaluation; OARS-OMFAQ = Older American's Resources and Services Multidimensional Functional Assessment Questionnaire; MAI = Philadelphia Geriatric Center Multilevel Assessment Instrument; OASIS = Outcome and Assessment Instrument Set; HC = Home Care; CARI = Community Assessment of Risk Instrument.

items for the CPAT (Fleming, 2008).

The RAI-MDS inter-rater reliability improved with every updated version. Originally, reliability was reported to be fair to moderate for more than half of the items (Hawes et al., 1995; Morris et al., 1990), and for the core set of items of the RAI-MDS in several countries (Sgadari et al., 1997). For the revised items and 83% of the new items in version 2.0, good to excellent inter-rater reliability was reported (Morris et al., 1997b); for version 3.0, good to excellent inter-rater reliability was found for the majority of the new and modified items (Saliba and Buchanan, 2012). The latest version, the interRAI LTCF and its Korean version (Hirdes et al., 2008; Kim et al., 2015), reported good to excellent inter-rater reliability for more than 90% of the items, and an international study reported excellent average test-retest reliability and good average inter-rater reliability (Onder et al., 2012).

The reliability of domains was reported for the RAI-MDS (n = 1), and the J-CPAT (n = 1), and *for the items* of RAI-MDS and its subsequent version 2.0 (n = 3) (Table A.4). For the 16 studied domains of the RAI-MDS, inter-rater reliability was moderate for 11, good for one, and poor for four (Hawes et al., 1995). The inter-rater and test-retest reliability for the eight J-CPAT domains were reported to be in the adequate range (Kanegae et al., 2010).

For specific RAI-MDS items related to urinary incontinence, moderate to good inter-rater reliability was reported, except for one item that was reported as poor; excellent inter-rater reliability was found for identifying different gradations of incontinence (Resnick et al., 1996). Oral/dental items reported poor or none inter-rater reliability between nursing staff and dental assessment, except for one item reporting good inter-rater reliability (Jockusch et al., 2021). Excellent test-retest reliability was found for all RAI-MDS 2.0 pain items (Fisher et al., 2002).

The reliability of scales from the RAI-MDS and subsequent versions (n = 8), and the CPAT (n = 1), *and for the indices* derived from the RAI-MDS (n = 2), was reported (Table A.5). From the eight scales of the CPAT, internal consistency was adequate for all, except for the Psychiatric Symptom Scale (Fleming, 2008).

Internal consistency was in the acceptable range for the following RAI-MDS and subsequent versions 2.0 and Korean interRAI LTCF scales: CPS, MDS-Cognition Scale (MDS-COGS), Challenging Behaviour Profile Scale (CBP) (except for one subscale), Communication, Pain and ADL (Gerritsen et al., 2008; Gruber-Baldini et al., 2000; Kim et al., 2015; Mor et al., 2011). The scales for Social Engagement, Mood, Behaviour, and Pain Scale did not reach acceptable levels for internal consistency (Mor et al., 2011). Internal consistency of the depression scales were reported as follow: insufficient for the DRS in the RAI-MDS 2.0, but acceptable in the RAI-MDS (Anderson et al., 2003; Hsiao et al., 2015), acceptable for the Depression Scale in the Korean interRAI LTCF (Kim et al., 2015), and for the composite depression measure (sum of all items in section E1, E1SUM) in version 2.0 (Koehler et al., 2005).

Inter-rater reliability was reported as excellent for all eight scales from the CPAT (Fleming, 2008). To screen dementia, the cut-off point 2 or higher of the MDS-COGS of the RAI-MDS showed high specificity, but lower sensitivity than cut-off point 1. For the cut-off point of 2, interrater and test-retest reliability for a negative screen was found to be high, but moderate for a positive screen (Zimmerman et al., 2007). For the CBP from the RAI-MDS 2.0, overall inter-rater reliability was reported as fair (Gerritsen et al., 2008). Poor to moderate test-retest reliability was shown for the DRS of RAI-MDS 2.0 (Anderson et al., 2003).

Only the reliability of indices from the RAI-MDS was studied, reporting good to excellent inter-rater reliability for seven indices (Casten et al., 1998), and an acceptable internal consistency for the Social Engagement Index (Mor et al., 1995).

3.5.2. Validity results

The validity of the complete CGA was only reported for the construct validity of the ValGraf, indicating that 52.9% of the variance was explained by 13 factors (Pascazio et al., 2009) (Table A.3).

The validity of domains was assessed for the RAI-MDS (n = 2), the CPAT (n = 1), and the ValGraf (n = 1), and *for the items* from the RAI-MDS and subsequent updated versions (n = 10) (Table A.4). Three studies of RAI-MDS and version 2.0 included samples with individuals with the characteristics of the conditions that were being validated, two of them determining the condition through previous medical diagnoses (Hendrix et al., 2003; Liang et al., 2011). Even though this was not specifically reported for the CPAT, the study sample included people from dementia and rehabilitation care settings (Kanegae et al., 2010). For the ValGraf this was not described.

The criterion validity for the RAI-MDS Behaviour and ADL domains reported medium to large effect sizes, also poor to fair agreement between RAI-MDS ADL assessments and the criterion measure (Lum et al., 2005; Snowden et al., 1999). For the CPAT Japanese version, the domains of Confusion, Self-help, Physical Problems, and Care dependency reported large effect sizes when compared against criterion scales (Kanegae et al., 2010). The concurrent validity for the Functional and Cognitive domains of the ValGraf reported large effect sizes (Pascazio et al., 2009).

Results from the validation of items from the RAI-MDS and subsequent updated versions reported difficulties on identifying their specific conditions. Risk of undernutrition and mood anxiety symptoms items from the RAI-MDS were found to underreport these conditions (Liang et al., 2011; Simmons et al., 2002). The same results have been reported for the mood indicators items from the RAI-MDS 2.0 (Hendrix et al., 2003). However, improvements in the validity of items on cognition, mood, behaviour and depression in version 3.0, and higher agreement with criterion measures as compared to the RAI-MDS 2.0 items, was reported (Saliba and Buchanan, 2012). Validity problems have been also reported for the oral/dental (Hoben et al., 2016; Jockusch et al., 2021), fall (Hill-Westmoreland and Gruber-Baldini, 2005), and pain items (Fisher et al., 2002) of the RAI-MDS 2.0.

Diagnostic accuracy for falls was in the acceptable range for only one of the two fall items (Hill-Westmoreland and Gruber-Baldini, 2005). Similar difficulties were described for the urinary tract infection (UTI) items (Stevenson et al., 2004).

Test content validity for the oral health section of the interRAI LTCF and interRAI HC was considered incomplete and items not clearly worded. Four items were considered as relevant, and two items were considered as feasible (Krausch-Hofmann et al., 2019).

The validity of scales was assessed for the CPAT (n = 1), and for the RAI-MDS and subsequent versions (n = 15), and *for the indices* from the RAI-MDS (n = 4) (Table A.5). The CPAT sample was selected from specific dementia care units, while for nine studies of the RAI-MDS and version 2.0 samples included individuals with the conditions determined before the study, four of them established by medical diagnoses (Anderson et al., 2003; Liang et al., 2011; Morris et al., 1994; Zimmerman et al., 2007).

The CPAT scales validated against criterion measures were Confusion and Self-help, which reported large effect sizes (Fleming, 2008). In the case of RAI-MDS and subsequent versions, all Cognition Scales (MDS-COGS, CPS, and Brief Interview for Mental Status), the Pain Scale, and two subscales of the CBP reported large effect sizes and good/-excellent agreement against criterion measures (Fries et al., 2001; Gerritsen et al., 2008; Gruber-Baldini et al., 2000; Hartmaier et al., 1994, 1995; Morris et al., 1994; Saliba et al., 2012). However, a medium effect size between the CPS and the Mini-Mental State Examination (MMSE) (Snowden et al., 1999), and a fair agreement between the CPS and the 7-item Global Deterioration Scale were described (Hartmaier et al., 1994). Small to medium effect sizes were found for the divergent validity from the MDS-COGS and the CPS (Gruber-Baldini et al., 2000).

The criterion validity for the DRS reported inconsistencies. One study reported a large correlation against the Geriatric Depression Scale-Short From (GDS-SF) (Hsiao et al., 2015), however, another study found some contradictory results using the same criterion measure (Liang et al., 2011). Also, the DRS did not correlate with standard measures or small to medium effect sizes as shown in two studies (Anderson et al., 2003),(Koehler et al., 2005).

Construct validity for the DRS and the CPS reported acceptable factor loadings, and the CPS also met the criteria for simplicity and face validity (Hsiao et al., 2015),(Morris et al., 1994). For the CBP, construct validity reported that it is formed by four subscales, and it was also identified as strong predictor of one year mortality (Gerritsen et al., 2008; Hsiao et al., 2015; Mor et al., 2011).

Regarding the diagnostic accuracy, AUC was excellent for CPS, MDS-COGS, and the Brief Interview for Mental Status (BIMS) (Hartmaier et al., 1994, 1995; Saliba et al., 2012), with the exception of one study that reported an insufficient AUC for the MDS-COGS (Zimmerman et al., 2007). The AUC for the DRS was also insufficient and for the Fracture Risk Scale not good (Hsiao et al., 2015; Ioannidis et al., 2017). These results are related to the Sensitivity and Specificity values reported for the different scales, which described high values for all Cognition Scales (Hartmaier et al., 1994, 1995; Morris et al., 1994; Saliba et al., 2012; Zimmerman et al., 2007), but inconsistencies and low values for the DRS that did not reach the expected minimum (Anderson et al., 2003; Hsiao et al., 2015). Also, it was identified that the DRS under detects the prevalence of depression compared to the GDS-SF (Hsiao et al., 2015).

For the RAI-MDS indices, large effect sizes were demonstrated for Cognition, ADL, Time Use and Social Engagement (Lawton et al., 1998; Mor et al., 1995), while medium and small correlations for Problem Behaviours and Depression when compared against criterion measures (Lawton et al., 1998). Discriminant validity was also demonstrated for all these indices (Lawton et al., 1998). Construct validity for Social engagement, Cognition, ADL and Time Use reported acceptable factor loadings, however, most factors failed to be replicated within a cognitive impaired sample (Casten et al., 1998; Mor et al., 1995). Lastly, Depression and Cognition were associated with the psychiatric diagnosis of depression and strongly with a dementia diagnosis, respectively (Lawton et al., 1998). Four models of mortality risk indices were validated, reporting that the Flacker models were more reliable predictors and better discriminators of mortality risk than the MDS-Mortality Risk indices (Kruse et al., 2010).

3.6. CGAs for community care

3.6.1. Reliability results

The reliability of the complete CGA was studied for the OASIS (n = 3), RAI-MDS HC and subsequent interRAI HC version (n = 5), and CARI (n = 1) (Table A.3). Two studies reported good to excellent inter-rater reliability for the OASIS (Hittle et al., 2004; Madigan and Fortinsky, 2004), nonetheless, in another study was reported poor to moderate inter-rater reliability for more than 60% of its items (Kinatukara et al., 2005).

Good to excellent inter-rater reliability has been reported for the RAI-MDS HC and interRAI HC in several countries (Hirdes et al., 2008; Kim et al., 2015; Kwan et al., 2000; Morris et al., 1997a). Data reliability reported inaccurate records in demographic and height or weight variables of the interRAI HC (Schluter et al., 2016).

Lastly, the majority of the items included in the CARI reported poor to fair inter-rater reliability (Clarnette et al., 2015).

The reliability of domains of the CARE, OASIS and CARI was targeted by three studies (Table A.4). For CARE domains, poor to excellent reliability was found, with the Psychiatric Dimension performing the best of the three domains (Gurland et al., 1977). OASIS domains internal consistency was within the acceptable range only for the functional domain (Madigan and Fortinsky, 2000), while intra-rater reliability was good to excellent for the affect and behavioural domains, and fair to good for the clinical and functional domains (Madigan and Fortinsky, 2000).

Inter-rater reliability of the CARI was poor to fair for their three domains and low agreement was reported for risk outcomes (Clarnette et al., 2015).

The reliability of scales or indices from the RAI-MDS HC and interRAI HC (n = 5), Popovich Scale (n = 1), OARS-OMFAQ (n = 1), and MAI (n = 1), were reported (Table A.5).

Internal consistency was studied for eight scales of the RAI-MDS HC Chinese version and six scales of the interRAI HC Korean version. Of the tested scales, the Pain, Communication, and Instrumental Activities of Daily Living (IADL) involvement and capacity Scales of both CGAs, and the Activities of Daily Living (ADL) and Depression Scales of the interRAI HC Korean version, reported internal consistency reliability withing acceptable ranges (Kim et al., 2015; Kwan et al., 2000; Leung et al., 2011, 2012). For all the scales of the Popovich Scale, inter-rater reliability reported large effect sizes (Grubba et al., 1990), while for the OARS-OMFAQ, it was good for the majority of the scales except for the Physical Health scale (Fillenbaum and Smyer, 1981).

Regarding the reliability of the indices, the Frailty Index of the RAI-MDS HC (Mor et al., 1995) and all indices of the MAI reported acceptable internal consistency (Lawton et al., 1982; Ludwig and Busnel, 2017)). Large effect sizes for test-retest reliability and moderate to good inter-rater reliability was also described for all scales of the MAI (Lawton et al., 1982).

3.6.2. Validity results

The validity of the complete CGA was reported only for the convergent validity of the OASIS (n = 1), indicating several inconsistencies between the OASIS and the criterion measure (Kinatukara et al., 2005) (Table A.3).

The validity of domains was studied for the OASIS (n = 2), and for the mortality data of the interRAI HC (n = 1), *and for the items* of the oral health section of the interRAI HC (n = 1) (Table A.4). When compared against gold standards, functional items of the OASIS reported medium to large effect sizes for the composite scores of ADL and IADL, large effect sizes were described for the cognitive functioning items, and moderate for the depressive symptoms items (Tullai-McGuinness et al., 2009). Regarding construct validity, only the functional domain reported adequate performance (Madigan and Fortinsky, 2000).

The criterion validity of the mortality data of the interRAI HC was reported to be consistent (Schluter et al., 2016). The test content validity of the oral health section was considered as incomplete and items not clearly worded; only four items were considered as relevant, and only two items were considered as feasible (Krausch-Hofmann et al., 2019).

The validity of scales was studied for the RAI-MDS HC and interRAI HC subsequent version (n = 7), OARS-OMFAQ (n = 2), and Popovich Scale (n = 1), and *for the indices* from the RAI-MDS HC (n = 3), and the MAI (n = 1) (Table A.5). The two studies validating the interRAI HC scales included samples with individuals diagnosed by the condition being assessed (Gee et al., 2021; Penny et al., 2016); for the other CGAs, this condition was not identified in their studies.

The criterion validity of the ADL, IADL, and Cognition Scales of the RAI-MDS HC reported large effect sizes (Carpenter et al., 2005; Landi et al., 2000). However, for the RAI-MDS HC Mood scale and the interRAI HC Depression Rating Scale (DRS), no correlation and a medium effect size were reported against the criterion measure, respectively (Carpenter et al., 2005; Penny et al., 2016). For the Economic, Mental Health, Physical Health, and Self-care capacity Scales of the OARS-OMFAQ and the Cognitive, Physical health and Social resources Subscales of the Popovich Scale, large effect sizes were reported (Fillenbaum and Smyer, 1981; Grubba et al., 1990).

Regarding content validity, RAI-MDS HC was reported to have higher data completion and better domain coverage compared to current used assessment instruments (Carpenter et al., 2005). Concerning construct validity, a good factorial structure was reported for the IADL involvement and capacity Scale and Negative Mood Scale of the RAI-MDS HC Chinese version (Leung et al., 2011, 2012). The OARS-OMFAQ Spanish version revealed a similar factor structure to the original English version, with some differences in the Self-care and Mental Health Scales (Fibla et al., 1996). For the Popovich Scale, the Economic Subscale construct validity was demonstrated (Grubba et al., 1990).

The diagnostic accuracy revealed excellent and inadequate Areas Under the Curve (AUCs) for the Cognitive Performance Scale (CPS) and the DRS of the interRAI HC, respectively (Gee et al., 2021; Penny et al., 2016). The sum between sensitivity and specificity reached the minimum expected value for the CPS but not for the DRS (Gee et al., 2021; Penny et al., 2016). In the case of the Changes in Health, End-stage disease, and Signs and Symptoms scale (CHESS), results showed it to be a strong predictor for hospitalization (Campitelli et al., 2016).

The Frailty Index of the RAI-MDS HC, was found as a strong predictor of mortality risk, admission to a long-term care facility, hospitalizations, and falls (Burn et al., 2018; Campitelli et al., 2016; Ludwig and Busnel, 2017). The studies on the seven indices from the MAI described large effect sizes for internal validity and concurrent validity, while small to large effect sizes for criterion validity for all indices with exception for the Cognition and Perceived Environment indices (Lawton et al., 1982).

3.7. Outcomes relevant for clinical decision making and organization of care

The RAI-MDS and subsequent version 2.0, interRAI-LTCF, and RAI-MDS HC and subsequent version also generate outcomes relevant for clinical decision making and organization of care. None of the other identified CGAs validated similar outcomes.

For *clinical decision making*, the Resident Assessment Protocols (RAPs) from the RAI-MDS reported reliable detection of two different urodynamic diagnosis (Resnick et al., 1996). In its Chinese version, four RAPs, Cognitive loss, ADL, Communication and Mood Symptoms, reported good concurrent validity and inter-rater and test-retest reliability (Chou et al., 2001). For the new version of the RAPs, the Clinical Assessment Protocols (CAPs) from the RAI-MDS HC, four of the 30 CAPs reported good to excellent validity, the remaining CAPs reported slight and fair agreements (Kwan et al., 2000).

RAI-MDS triggers for the detection of undernutrition were validated (Beck et al., 2001). They reported those triggers to be able to identify relevant characteristics of this condition in comparisons with those participants with no triggers (Beck et al., 2001).

For *organization of care*, the Resource Utilization Groups (RUG-III) from the RAI-MDS reported to be able to differentiate between residents according to intensity of care needs, validating RUGs with the level of Registered General Nurses care time (Carpenter et al., 2003). The Finish version of the RUG-III for version 2.0, explained 38.2% of the variance of total patient cost per diem; also, they found an ambiguity in terms of the inter-rater reliability as it varied from fair to good according to the type of professionals, agreement was slightly better when assessors were personal nurses, as compared to personal nurse and outsider evaluator (Björkgren et al., 1999). For the interRAI HC version, good convergent validity with the Resource Utilization in Dementia instrument (RUD-Lite) (Wimo et al., 1998) for the estimations of societal costs of care (including healthcare and nursing, welfare and informal care) derived from interRAI-HC data was reported (van Lier et al., 2016).

Applicable for quality improvement and benchmarking purposes, the 22 Quality Indicators (QIs) from the RAI-MDS 2.0 reported fair to excellent inter-rater reliability, except for two (Mor et al., 2003). Except for three of the 100 single items used for measuring the quality indicators, good to excellent inter-rater reliability was reported for all (Mor et al., 2003). In addition, the content validity of the QIs reported pressure ulcers as the most practice sensitive QI; variations were found between the QIs considered as most sensitive for physician and nursing care, while none of them were considered to be most sensitive for policy/decision makers (Estabrooks et al., 2013).

Lastly, the accuracy of the RAI-MDS in identifying hospitalization events and payment sources was evaluated, reporting that the RAI-MDS is not ideal for the identification of these elements without the support of supplemental information from claims data (Cai et al., 2011).

4. Discussion

This systematic review aimed to provide insight into the content and psychometric characteristics of CGAs to enable potential users to make an informed decision when a CGA is considered to be implemented.

We found that some of the CGAs included broad domains which makes it difficult to identify what they are specifically assessing. On the contrary, other assessments were more specific or clearer by referring and evaluating the domains in more detail. We consider it necessary to be more specific on the domains as these are screening tools that could identify risk factors for potential deterioration and take into account the complexity associated with older adult care, which is associated with comorbidity, polypharmacy, multiple treatments, etc., and could guide clinical decision making and interventions (Bernabei et al., 2008; World Health Organization, 2015; Scanlan, 2005), so if the information is clear, and the dimensions and warnings are well defined, the relevant clinical information will be gathered by the clinicians. This approach also allows to compare how comprehensive a CGA is against proposed lists of domains that are considered relevant to be evaluated by a CGA (Pilotto et al., 2017; British Geriatrics Society, 2019) and could facilitate the clinicians and policy makers decision on which instruments are more suitable for their specific situation and aim.

By acknowledging the comprehensiveness of the CGAs, a big amount of data could be gathered supporting improvements and developments of algorithms that could be used to incorporate automatic learning to extract and identify useful information through large databases (Dipnall et al., 2016). Consequently, this could guide the development of decision models for medical and care procedures, such as prognosis, diagnosis, and treatment planning, which should be embedded into CGAs as systematic support components (Góngora et al., 2018), optimizing personalized treatments and improving evidence-based decisions making among clinicians and scientists, identifying the causes of unmet care of older adults and more effective treatment approaches (Góngora et al., 2018).

The most studied instruments for long term care were the RAI-MDS and its subsequent versions, and for community care were the RAI-MDS HC and subsequent version, and OASIS. The RAI-MDS and RAI-MDS HC and their subsequent versions have been studied, validated, and adapted globally. Only the CPAT and OARS-OMFAQ were adapted for other non-English speaking countries, but not reaching the global covering of the interRAI network instruments. Another distinguishing feature was that interRAI instruments used specific population samples clinical characteristics (e.g., depression, cognition, dementia) necessarily to validate the outcomes of interest.

Although the number of studies and psychometric results positively support the RAI-MDS and subsequent versions for its used in long-term care facilities as compared to the other identified CGAs, some considerations must be made. Its reliability improved along the evolution to the next versions, reporting good to excellent results in the later stages. Overall, the main strengths rely on the psychometric characteristics of the Cognition, ADL, Time Use, and CBP items, and the outcomes relevant for clinical decision making and organization of care (e.g., RAPs and RUG III); however, flaws remain on items such as oral/dental problems, risk of undernutrition, urinary tract infection, and depression and mood.

For community care, the difference on the number of studies validating the CGAs was not as vast as for long-term care settings, and the psychometric characteristics appear to achieve high standards for all, except for the CARI and the CARE. However, some considerations must be contemplated: a) The CARE, the CARI, the MAI and the OARS-OMFAQ were not reported to be validated against gold standards or criterion measures; b) the CARE, the CARI, the Popovich Scale, the OASIS, and the OARS-OMFAQ were studied with suboptimal study designs, using small samples; c) items of the scales of the Popovich Scale and OASIS were validated against OARS-OMFAQ scales as the criterion measure, for which strong psychometric evidence is not available; d) inconsistency was revealed on the validation and reliability of the OASIS, some studies reported high values but this was not confirmed by other studies; and e) the RAI-MDS HC and subsequent version reported similar flaws to the aforementioned for the RAI-MDS and subsequent versions on areas such as mood and depression and the oral health section.

In this review mainly studies performed in high income countries have been included. Studies on CGAs performed in low to middle income countries, such as African, Southeast Asian, and Latin-American countries have not been found, despite Spanish language was one of the inclusion criteria. This might imply that in these regions, where health systems are not optimally developed, an integrated care approach towards ageing has not been implemented yet, despite that these regions are also confronted with an ageing population (Prina et al., 2019).

4.1. *Strengths and limitations*

The strength of this review relies on reporting on a comprehensive panorama of the CGAs available for long-term and community care, with insights on the psychometric properties, the content, and the variety of instruments. The results presented here support reliable decision-making on care planning and health policy outcomes, impacting the vulnerable older adult population that live in these care settings.

Several limitations regarding this systematic review must be considered. First, our definition of a CGA encompassed single multidisciplinary assessment instruments targeting different domains, not a conglomerate of single domain instruments assessing each area individually or those developed for being used for one single discipline. Therefore, a number of CGAs used in practice might not be included in our results. This definition of a CGA might be closer to the integrated care approach proposed at the introduction (Johri et al., 2003; McDonald et al., 2013; World Health Organization, 2015), which focusses on the facilitation of data sharing across care settings, offering a core set of items avoiding different score systems, and thereby facilitating an easy transfer between care settings. Second, several statistical methods and strategies were used to assess the psychometric characteristics, however we proposed a single criterion to report, compare and analyse these results. Also, we only used specificity, sensitivity, and AUC regarding diagnostic accuracy. Third, CGAs in other languages than English and Spanish were not considered. Finally, some of the study designs and types of validity and reliability presented at the tables are according to the researchers' judgements as they were underreported by some of the studies.

5. Conclusion

The timely detection of clinical problems, side effects or comorbidity is strategic for a good quality care, so, it is highly relevant to considered reliable tools with clear and specific domains to support clinical decisions.

Due to the study characteristics such as the sample size, number of studies, instrument development trajectory, validation in several countries, and availability in different care settings, we recommend the interRAI LTCF and interRAI HC to be used for long-term care facilities and community care, respectively. Also, it has been demonstrated their potential for predicting mortality, hospitalizations, admission, urinary infections, and detecting cognitive problems, falls, and nutritional risk factors. Nonetheless, health care professionals must be aware of the flaws reported for mood, depression, oral health, risk of undernutrition, and urinary tract infection.

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CRediT authorship contribution statement

MMU, HR, and MF conceptualized and designed the review. MMU and AM screened the titles and abstracts of the records resulted from the search. MMU and AM evaluated the records for risk of bias. MMU extracted the data from the included studies, and it was verified by HR. MMU, HR, and MF drafted and critically revised the manuscript. HR and MF provided overall study supervision. All authors authorized the final version of the manuscript that was submitted. All authors read and approved the final manuscript.

Conflict of interest

MF and HR are fellows of interRAI Network (www.interRAI.org). HR is a co-author in one of the studies included in this review, however, she was not involved in the risk of bias assessment, which was performed independently by MMU and AM.

Data availability

No data was used for the research described in the article.

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Not applicable.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.arr.2022.101742.

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Publication #2. Digital Health Technologies (DHTs) supporting the application of Comprehensive Geriatric Assessments (CGAs) in long-term care settings or community care: A systematic review (In Press)

Publicación #2. Tecnologías de Salud Digital (TSD) para asistir la administración de Evaluaciones Geriátricas Integrales (EGI) en residencias de larga estancia o atención domiciliaria: Una revisión sistemática (En Prensa)

Mauricio Molinari-Ulate, Aysan Mahmoudi, Esther Parra-Vidales, Juan-Luis Muñoz-Sánchez, Manuel A. Franco-Martín, and Henriëtte G. van der Roest.

Resumen en español

Antecedentes: Para proporcionar una atención de alta calidad a las personas adultas mayores, las Tecnologías de Salud Digital (TSD) pueden ayudar potencialmente a alcanzar la plena capacidad de las Evaluaciones Geriátricas Integrales (EGI) para mejorar la comunicación y la transferencia de datos sobre la información médica y el plan de tratamiento de los pacientes, y la toma de decisiones sanitarias. Por este motivo, el objetivo de esta revisión sistemática fue describir la evidencia sobre la factibilidad y usabilidad, la eficacia y la efectividad, y los resultados de la implementación de las TSD desarrolladas para facilitar la administración de las EGI en residencias de larga estancia o atención domiciliaria, y describir sus características técnicas y componentes.

Métodos: Se realizó una estrategia de búsqueda en tres bases de datos, dirigida a estudios que evaluaran los TSD que facilitan la administración de EGIs utilizadas en residencias de larga estancia o atención domiciliaria. Se consideraron los estudios en inglés y español publicados hasta el 5 de abril de 2023.

Resultados: Se identificaron cuatro TSD que facilitan la administración de las EGI. Se encontró información limitada sobre las características técnicas y el hardware necesario. Algunas de las barreras identificadas respecto a la usabilidad pueden superarse con tecnologías novedosas, sin embargo, la formación de los profesionales sanitarios sobre las

evaluaciones y el conocimiento del personal respecto a la finalidad de los datos recogidos, no están relacionados con la tecnología y deben ser abordados.

Conclusiones: Los obstáculos relativos a la usabilidad estaban relacionados con las dificultades experimentadas para navegar por el software, la conectividad inestable a la red y la duración de la evaluación. Los obstáculos relativos a la factibilidad estaban relacionados con la falta de formación para utilizar la TSD, la disponibilidad y accesibilidad al hardware (ej., ordenadores portátiles) y la falta de conocimiento de los beneficios clínicos de los datos recopilados. La investigación futura debe centrarse en estas áreas para mejorar la implementación y la utilidad de estas TSD.

Digital Health Technologies (DHTs) supporting the application of Comprehensive Geriatric Assessments (CGAs) in long-term care settings or community care: A systematic review

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Abstract

Objective: To provide high-quality elderly care, Digital Health Technologies (DHTs) can potentially assist in reaching the full capacity of Comprehensive Geriatric Assessments (CGAs) to improve communication and data transfer on patients' medical and treatment plan information, and health decision-making. For this reason, this systematic review aimed to describe the evidence on the feasibility and usability, efficacy and effectiveness, and implementation outcomes of DHTs developed to facilitate the administration of CGAs for long-term care settings or community care and to describe their technical features and components.

Methods: A search strategy was conducted in three databases, targeting studies evaluating the DHTs facilitating the administration of CGAs used in long-term care settings or community care. Studies in English and Spanish published up to April 5, 2023, were considered.

Results: Four DHTs supporting the administration of the CGAs were identified. Limited information was found on the technical features and required hardware. Some of the barriers identified regarding usability can be overcome with novel technologies, however, training of health professionals on the assessments and staff knowledge regarding the purpose of the data collected, are not technology-related and need to be addressed.

Conclusions: Barriers regarding usability were related to experienced difficulties navigating the software, unstable network connectivity, and length of the assessment. Feasibility obstacles were associated with the lack of training to use the DHT, availability and accessibility to hardware (e.g., laptops), and lack of insight into the clinical benefits of collected data. Further research must focus on these areas to improve the implementation and usefulness of these DHTs.

Keywords:

Digital Health Technology; Comprehensive Geriatric Assessment; long-term care; community care; ageing; multidisciplinary assessment.

Introduction

Ageing is associated with comorbidity, polypharmacy, declining physical and cognitive functioning, causing frail elderly people to receive multiple treatments and interventions from healthcare providers with different specialisms, working in different sectors (e.g., community care, acute care, long-term care). Declining health and the risk of developing functional and cognitive impairment, have implications on the quality of life and capacity for independence and autonomy of the older adult population [1, 2]. This complex interplay between factors related to clients, care professionals and care sectors, yields comprehensive information on elderly persons' health status, highlighting the need for a high degree of coordination and accurate communication between healthcare providers and clinical interventions to provide quality older adult integrated care [3]. This could improve the early identification of individuals at risk of (further) decline, facilitating adequate and timely treatment, care plans and clinical decision-making [4, 5].

To tackle the aforementioned complexities, Comprehensive Geriatric Assessments (CGAs) have become an important assessment tool in elderly care, as they capture multiple domains and focus on the variety of complex problems experienced in frail older people[1, 4, 6, 7]. CGAs are considered multidimensional assessments that support multidisciplinary care teams in clinical decision-making and personalized care planning to address the needs of older people and their families and carers, emphasizing functional status and quality of life[2, 4, 8, 9].

A wide range of benefits of the utilization of CGAs in elderly care has been documented, such as reductions in hospitalizations, admissions to long-term care facilities, functional decline and mortality[4, 8, 10]; prevention of negative health outcomes, such as shortened survival times and care dependency[2]; or by supporting improvements in care planning and quality of care[1]. However, as a result of the higher percentage of transitions between care settings in older populations, associated with the complexities of an ageing population and the shift from institutional care to home care delivery[3, 11, 12], accurate communication of medical information and treatment plans have become fundamental to provide quality elderly care[3]. For this reason, to reach the full potential of CGAs, their implementation should be supported by electronic data systems, that provide relevant output and enable information sharing within multidisciplinary teams of care professionals and multiple care settings in a timely manner, thereby optimizing the coordination of care and avoiding potential discrepancies in terms of the completeness and reliability of data collection[13-15].

Digital Health refers to the general use of a variety of information and communication technologies (ICTs), big data, genomics, and artificial intelligence to address health needs and to improve the health, well-being, and care of people[16-19]. Digital Health Technologies (DHTs) are intended to enhance people's health and well-being, and to improve health and social care systems[20, 21]. The variety of digital tools include, among others, the adoption and use of computer platforms, software, mobile apps (mHealth), wearable devices, electronic health records, telemedicine or telehealth, robotics, and monitoring and sensors devices[19, 20, 22]. The employment of DHTs can potentially assist in reaching the full capacity of CGAs and overcome the constraints of data transfer between settings and stakeholders[14, 15]. Involving DHTs in healthcare systems has been shown to improve the availability, quality, and use of data for healthcare decision-making and offer opportunities for the sustainability of healthcare systems by providing better insight into the quality and efficiency of care delivery[16, 23]. However, concerns have been raised regarding the overwhelming diversity of available digital health tools and the limited evidence on their impact on health systems and person's well-being[16].

A previous scoping review identified a lack of publications on web-based applications for frailty assessments in older adults and limited data regarding their time efficiency, security, algorithm efficiency, environmental requirements, and browser requirements [24]. Also, the lack of comprehensive instructions, training materials, and materials to support the interpretation of the results, was also highlighted[24]. Nonetheless, the web-based assessment tools showed several advantages such as their convenience and ease of completing the assessments, the implementation of highly friendly user interfaces by most tools identified, and the high-cost efficiency of most of the applications[24].

Despite this initial attempt to identify the challenges and opportunities of web-based applications for the assessment of older adults, the scoping review excluded the diversity of digital tools comprised under the term DHTs. Additionally, it focused exclusively on frailty, excluding other potential DHTs covering a wider range of functional domains such as those provided by CGAs, where frailty scales are also embedded[24]. For this reason, we aimed to describe the evidence on DHTs that have been developed to facilitate the administration of CGAs and describe their technical features and components, and address the feasibility and usability, efficacy and effectiveness, and implementation outcomes of the DHTs.

Methods

Eligibility criteria

Studies considered eligible for inclusion in this review focused on the feasibility, usability, efficacy, effectiveness, or implementation of DHTs supporting CGAs for long-term care settings or community care. Searches were conducted up to April 5, 2023, in the following databases: PubMed, CINAHL and Web of Science. Only studies in English and Spanish were considered eligible. See Table 1 for inclusion and exclusion criteria.

Table 1. Inclusion/Exclusion Criteria for the search strategy

Inclusion Criteria	Exclusion Criteria
The CGA must be one single multidisciplinary test or assessment tool	An assessment that consists of a collection of, tests or assessments, or stand-alone instruments assessing one domain (e.g., depression)
Studies describing and/or assessing the feasibility, usability, efficacy, effectiveness, or implementation of DHTs use for the applicability or for performing a CGA	Studies published in languages other than English or Spanish
The DHT is developed for use in clinical practice.	DHTs that support entirely self-report instruments.
Any DHT supporting the application of a CGA in long-term care settings or community care	Publications such as conference abstracts, case studies, protocols, dissertations, books, and systematic reviews.
The instrument supported by the DHT targets people 55 years old or above	DHTs that support instruments for acute care, mental health care, palliative care, hospitalized settings, or transfer between any of the aforementioned settings.

Search Strategy

A list of free text keywords and Medical Subject Headings (MeSH) was developed by two authors (MMU & HvR) for PubMed. Subsequently, the list was translated to the correspondent-controlled vocabulary headings and appropriate syntax of the other databases. The following search strategy was used:

CGA: “geriatric assessment” (MeSH Major Topic) OR “geriatric assessment/methods” (MeSH Major Topic) OR “geriatric assessment” OR “geriatric evaluation” OR “geriatric instrument” OR GA OR “comprehensive geriatric assessment” OR CGA OR “multidimensional geriatric assessment” AND

Setting: “residential facilities” (MeSH Major Topic) OR “Community Health Centers” (MeSH Major Topic) OR “Community health services” (MeSH Major Topic) OR “long-term care” (MeSH Major Topic) OR “elderly care” OR “residential facilit*” OR “long-term care facilit*” OR “LTCF” OR “geriatric care” OR “aged care” OR “home care” OR “primary care” OR “senior center*” OR “residential care” OR “community care” AND

DHT: "internet" (MeSH Major Topic) OR "telemedicine" (MeSH Major Topic) OR "software" (MeSH Major Topic) OR “digital*” OR “internet” OR “electronic*” OR “computer*” OR “automat*” OR “software” OR “web” OR “web-based” OR “mHealth” OR “telehealth” OR “mobile” OR “eHealth” OR “online” OR “app*"

Selection Procedure

After duplicate removal, the remaining publications were divided amongst three pairs of authors (six reviewers in total), who screened the titles independently according to the inclusion and exclusion criteria. Within each pair the screening was compared, deviations were discussed, and agreement was sought. The abstracts of potentially eligible publications were screened by two authors independently (MMU & AM), leading to the final full-text review stage. As the last step, the same authors checked the full texts for eligibility (see Figure 1). In case of discrepancies, a third author (HvR) made the final decision to include or exclude the study.

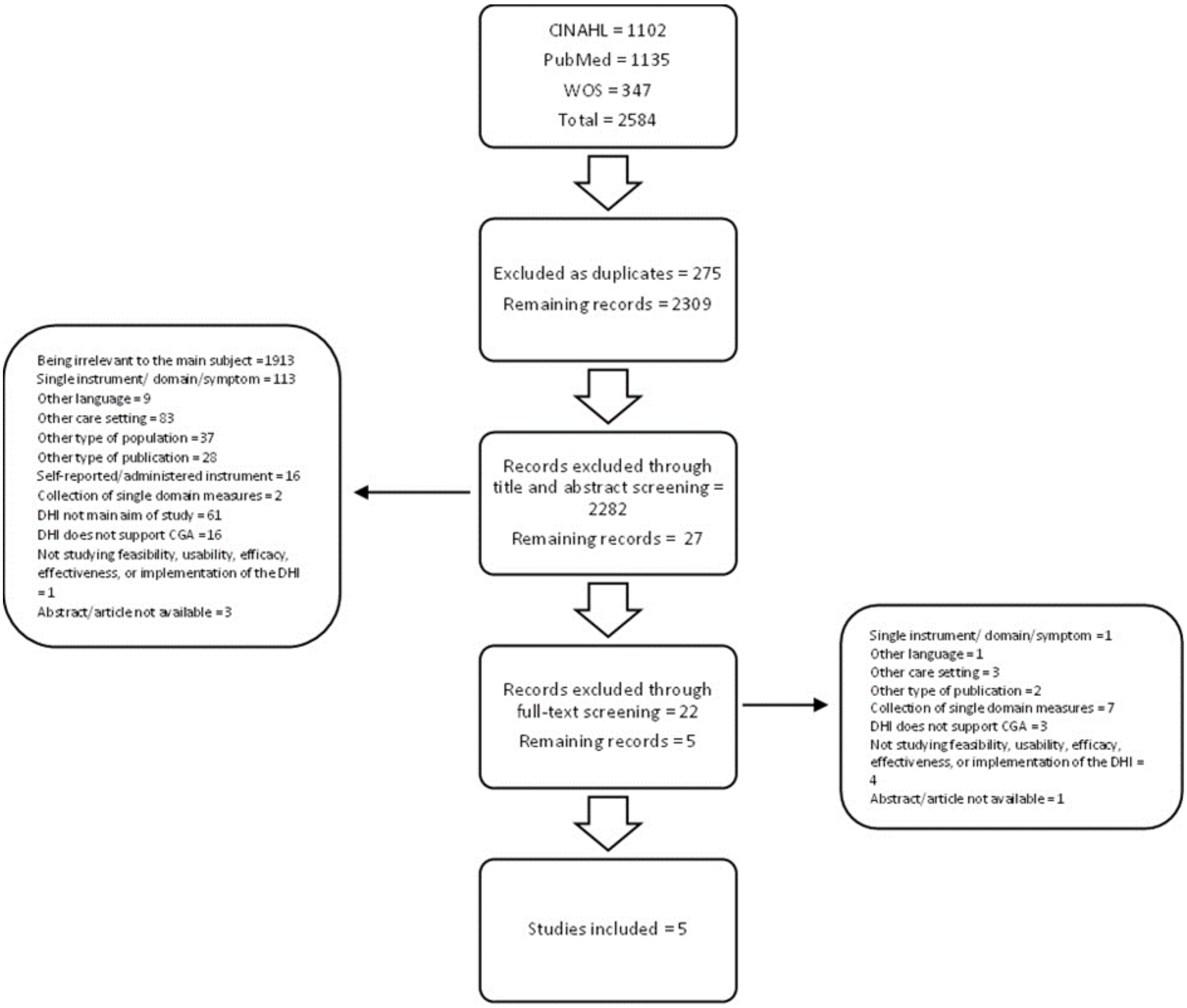

Figure 1. PRISMA Flow Diagram

The data extracted from the studies were performed by one author (MMU). The following data were extracted from the final selection: a) author and year of publication; b) name of the DHT, c) name of the CGA; d) technical features; e) stage of maturity; f) aim of the study; g) study design; h) country; i) care setting; j) description of the study sample (size, female percentage, mean age, and standard deviation); k) outcomes; l) main findings.

State of evaluation (outcome variables):

The state of evaluation aims to determine whether the DHT under evaluation functions, is effective, or is ready to scale-up[17]. In other words, if the DHT is feasible, usable, effective, or if it can be implemented on larger scales. According to the WHO[17], the definitions of these outcomes are as follows: a) the feasibility assess whether the DHT works as intended in a given context; b) the usability assess if the DHT can be used as intended by the users; c) the efficacy assess if the DHT can achieve the intended results in a controlled research setting; d) the effectiveness assess whether the DHT can achieve the intended results in an uncontrolled (non-research) setting; and e) the implementation assess the uptake, integration and sustainability of the DHT for a specific context (includes policies and practices).

Stage of maturity

The maturity life cycle of DHTs ranges from a concept to a fully developed and functioning platform that is ready for up-scaling, providing insight regarding if the DHT has been developed and evaluated for the first time, or if it is mature to undergo scale-up[17]. In brief, the different stages of maturity as described by WHO[17] are:

Pre-prototype: includes hypothesis building, needs/context assessment, and testing of usability/feasibility and technical stability.

Prototype: the user-focused designs are created and tested, as well as the functionality, technical stability, and usability. Improvements are examined.

Pilot: examines the digital intervention in controlled research settings to assess if it produces the expected effect.

Demonstration: the evaluation is done under some restricted population/region conditions but does not take place in controlled settings.

Scaled-up: at this step, the intervention is ready to be implemented widely, across multiple settings or at the population level.

Integration and sustainability: is the final stage where the intervention is already being used in a broader system, and other supporting features to enhance the impact of the intervention at a large scale are assessed (such as policies, financing, human resources, interoperability, etc.).

Risk of bias (quality assessment)

The quality of the studies was evaluated by two raters (MMU & AM) through the “mERA Methodological Criteria”[17]. This tool contains two sections: a) essential items that must be evaluated for all studies, independent of study type (23 items), and b) items specifically for qualitative (3 items) or quantitative (3 items) research. In the case of mixed method studies, items from both categories (quantitative and qualitative) were used.

For this study, each item was rated according to the degree to which the study met the criteria (0 = no, 1 = partial, 2 = fully). When an item was not applicable to a particular study, the item was not considered in the calculation of the summary score. The summary score was calculated for each study by summing the total score obtained from the relevant items and dividing it by the total possible score. According to this scoring system, results are between 0 and 1, closer to 0 the methodology is considered poor, and scores closer to 1 indicate a stronger methodology.

Results

After duplication removal, the titles and abstracts of 2723 records were screened, of which 2696 records were excluded. The remaining 27 studies were analysed through a final full-text review. After the final screening, five papers were included for analysis (see Figure 1. PRISMA flowchart).

The feasibility and usability of the MDS-HC© Electronic web-based interface and the interRAI electronic assessment tools was assessed by one study each[25, 26]. Kim et al.[27] studied the effectiveness of the System for Person-centered Elder Care (SPEC). Vanneste et al.[28] and Vanneste et al.[29] focused on studying the implementation of the BelRAI (Table 2).

Table 2. Characteristics and data extracted from the studies

Authors/ Year	Duyver et al. (2010)[25]	Smith et al. (2013)[26]	Vanneste et al. (2015)[28]	Vanneste et al. (2016)[29]	Kim et al. (2020)[27]
Name of DHT	MDS-HC© Electronic web-based interface	interRAI electronic assessment tools	BelRAI	BelRAI	System for Person-centered Elder Care (SPEC)
Name of CGA	Minimum Data Set Home Care (MDS-HC)	Minimum Data Set Home Care (MDS-HC)	interRAI Home Care (HC)	interRAI Home Care (HC)	interRAI Long-Term Care Facilities (LTCF)
Technical Features	- Web-based interface - Login and password required - Possible to add data from other caregivers - Automatic results calculation	- Software (unspecified) - Data synchronizes with national data warehouses - Automatic calculation of risk triggers	- Web-based application - Available in Belgium's official languages - Possible to invite caregivers to assess related their areas of expertise - Reveals conflicting and dubious answers - System to prevent erroneous completion - Software obliged to answer all items - Offers an online support platform to facilitate assessment and enhance multidisciplinarity and training of professionals	-Web-based application -Available in Belgium's official languages - Possible to invite caregivers to assess related their areas of expertise - Reveals conflicting and dubious answers - System to prevent erroneous completion - Software obliged to answer all items - Offers an online support platform to facilitate assessment and enhance multidisciplinarity and training of professionals	- Information and communication technology (ICT) - Enhanced integrated care model - A computerized care management software - It uses a cloud-based information system - Offer an individualized need/risk profile report, a profile-based care plan, and a care plan checklist - Allow interdisciplinary case conferences and multidisciplinary and integrated care management
Stage of maturity	Prototype	Scaled-up	Integration/ sustainability	Integration/ sustainability	Demonstration
Aim of the study	To examine the feasibility and added value of the MDS HC© and explore barriers	To identify the barriers and the organisational support required for the adoption of the	To examine the assessment completion using the BelRAI and possible causes for the	To study the characteristics of the missing data prevalence at 6-month follow-up and	To examine the impact of the Systems for Person-centered Elder Care (SPEC) on the quality of care of

	and facilitators for its implementation in the community.	platform through unit/service managers and end users.	incomplete assessments and their consequences on care quality	the profile differences between individuals with and without missing data	older residents in Korean nursing homes
Study design	Mixed methods study design	Phenomenology study design	Cross-sectional study design	Observational study of data	Stepped-wedge crossover clustered randomized controlled trial study design
Country	Belgium	New Zealand	Belgium	Belgium	South Korea
Care setting	Community health care	Healthcare services	Home Care	Home Care	Nursing Home
Study Sample (N, female %, mean age, SD)	41 first-year general practitioner trainees	Five nursing and allied health professionals (all females; ages ranged from 30 to 69)	Nurses, occupational therapists, social workers, psychologists, physiotherapists, speech therapists, and physicians, caring for frail, community-dwelling elderly 65 years and older.	Nurses, occupational therapists, social workers, psychologists, physiotherapists, speech therapists, and physicians, caring for frail, community-dwelling elderly 65 years and older.	Control period sample: 482 older nursing home residents (80.3% female; mean age 82.7y ± 7.3y) Intervention period sample: 431 older nursing home residents (80.9% female; mean age 83.1y ± 7.5y)
Outcomes	Feasibility and added value: Technical acceptability Clinical relevance of the tool Management and optimization of healthcare planning Valorisation of the role of the GP	Performance expectancy Effort expectancy Social influence Facilitating condition	Completeness of items Health professionals responsible for the completeness of the assessment	Institutionalization Death Scales performance Trigger Clinical Assessment Protocols (CAPs)	Primary outcome: quality of care (reported via a composite score of quality indicators, QIs) Secondary outcomes: A set of individual quality indicators (QIs) variables All QIs represent care problems
Main findings	37 participants completed the study. Participants agreed that items are presented clearly and coherently and logically. Difficulties regarding the steps to take in the software were experienced. Clinical Assessment Protocols (CAPs) were considered as clinically relevant when activated.	Platform was perceived as useful and beneficial as several considered that it improves their performance, however, the assessment was considered too long. Practice makes it easier to use. Constant connectivity and lighter hardware technology were seen as potentials for improvement Main barriers were related to lack of access to hardware	Lower completion scores were seen in items of Functional Status (Section G), Disease diagnoses (Section I), Oral and Nutritional Status (Section K), Medications (Section M), Treatment and procedures (Section N), Responsibility (Section O) and Discharge potential and overall status (Section R). The proportion of responsibility for ensuring the completion of the assessments by professionals was nurses (62,1%);	Missing data at follow-up was related to more impairment and depressive symptoms at baseline, higher likelihood of declining, increased likelihood of improving when problem was addressed, higher chance of dying and being admitted into residential care.	Quality of care significantly change as the composite QI score decreased either in the unadjusted and confounder-adjusted models (8.1% and 11.1% decrease, respectively). Regarding the secondary outcomes, intervention significantly decreased ADL late-loss worsening (-31.1%), cognitive decline (-32.5%), communication decline (-39.4%), delirium new or persistent (-44.7%), and behaviour

	In terms of management and empowerment of the GPs, the platform was not considered as adding any value.	and consistent network connectivity; the need for ongoing training in the use of interRAI systems, and not knowing the purpose of the data collected.	occupational therapists (21,5%); social workers (9,9%); psychologists (4,8%); physiotherapists (1,4%); speech therapists (0,3%); and physicians (<0.1%)		problem worsening (-33.4%). Significant similar values were identified at the 3 and 6-month time-specific intervention effects. Intervention effect was larger for moderate and severe cognitive impairment and severe ADL limitations.

Study outcomes (feasibility, usability, efficacy and effectiveness, and implementation)

Five studies on four different DHTs developed to support the implementation of CGAs for long-term care settings or community care were identified: a) MDS-HC© Electronic Web-based Interface[25]; b) interRAI electronic assessment tools[26]; c) System for Person-centered Elder Care (SPEC)[27]; and d) BelRAI[28, 29]. The SPEC was studied in long-term care facilities and the four other DHTs in community care. The DHTs support three CGAs, the Minimum Data Set Home Care (MDS-HC), the interRAI Long-Term Care Facilities (interRAI LTCF), and the interRAI Home Care (interRAI HC) (Table 3). Two platforms were studied in Belgium (the MDS-HC© and the BelRAI), one in New Zealand (the interRAI electronic assessment tools), and one in South Korea (SPEC) (see Table 2).

Table 3. CGAs supported by the DHTs identified.

Digital Health Technology	Comprehensive Geriatric Assessment supported
MDS-HC© Electronic web-based interface	Minimum Data Set Home Care (MDS-HC)
System for Person-centered Elder Care (SPEC)	interRAI Long-Term Care Facilities (LTCF)
interRAI electronic assessment tools	Minimum Data Set Home Care (MDS-HC)
BelRAI	interRAI Home Care (HC)

The MDS-HC© and the interRAI electronic assessment tools were at the feasibility and usability stage of evaluation and were in the prototype and scaled-up state of maturity, respectively. The other two platforms, SPEC and BelRAI, have been studied in uncontrolled settings. The SPEC was investigated at the stage of maturity of demonstration and the effectiveness state of evaluation. The BelRAI was in the integration/sustainability stage of maturity and at the implementation state of evaluation.

Regarding how feasible and useful professionals perceived the DHTs, Duyver et al.[25] and Smith et al.[26] found mixed results. Regarding usability, nurses and other health care professionals found the interRAI electronic assessment tools software useful and beneficial, as it improved their performance. The DHT helped them gain a broader perspective of the individual's situation and needs and supported in gathering the relevant information for professionals to provide good care. However, the assessment was considered too long and tiresome[26]. The MDS-HC© was tested amongst general practitioners, who did not report added value regarding their management and empowerment, but they considered activated triggers that warn of clinical risks in clients in the MDS-HC© (Clinical Assessment Protocols (CAPs)), as clinically relevant[25].

Reported facilitators for implementing a DHT were familiarity with the DHT and ease of use[26], and clear and coherent presentation of the items[25]. Usability barriers were related to experienced difficulties navigating the software[25], unstable network connectivity, and length of the assessment[26]. Feasibility obstacles were associated to the lack of training to use the DHT, availability and accessibility to hardware (e.g., laptops), and lack of insight into the clinical benefits of collected data[26].

The effectiveness of a DHT was only studied for the SPEC by Kim et al.[27]. The use of SPEC showed to have a significant positive impact on the quality of care in nursing homes. This was measured via a composite score of quality indicators, showing reductions in care problems of 8.1% and 11.1% for an unadjusted and confounder-adjusted model respectively[27]. Decreases were also observed in secondary health and functional outcomes, such as ADL late-loss worsening, cognitive decline, communication decline, new or persistent delirium, and worsening of behavioural problems[27].

In terms of implementation, the BelRAI was the only DHT that was studied. Analyses showed that seven out of the 18 domains reported lower completion rates[28] (see Table 2 for the specific domains). The authors attributed this amongst others to the incapability of the assessors due to insufficient training, insufficient information required by other caregivers, and lack of time to complete the assessment during the first house visit. Missing data at follow-up assessments was related to worse health status at baseline, higher risks of decline, admission to long-term care facilities, and mortality[29]. The authors point out that missing data could be an indicator of poor quality of care. The responsibility for data collection was not adequately distributed amongst health professionals involved in the care of a client and relied mainly on nurses[28].

Technical features and components of the DHTs

The MDS-HC© and BelRAI were web-based interface applications, while the interRAI electronic assessment tools and SPEC were software. The used hardware for the interRAI electronic assessment tools were laptops. For the other DHTs, information about required hardware was not reported. Only for the SPEC, it was mentioned to be computerized. Multiple access for data collection, allowing access to multiple health professionals and caregivers to single assessments for data entry, was reported for the MDS-HC© and the BelRAI. The SPEC was reported to allow multidisciplinary and integrated care management, however, multiple access for data collection was not reported. No information regarding user access was obtained for the interRAI electronic assessment tools. The data of the interRAI electronic assessment tools was stored in national data warehouses and SPEC reported to use cloud-based data storage. For the MDS-HC© and BelRAI, no information on data storage was reported. All DHTs enabled the calculation of composite outcomes and scales, reflecting clinical outcomes and risk of decline.

Other technical characteristics were described for the BelRAI, such as revealing conflicting and dubious answers, preventing erroneous completion, the obligation to answer all items, and it has an online support platform for assessors. In the case of the SPEC, it offers an individualized needs/risk profile report, a profile-based care plan, and a care plan checklist.

Quality of the studies

An initial inter-rater agreement of 86.2% was reached by two reviewers (MMU & AM) for the quality appraisal of included studies. The total quality score for the studies ranged between 0.62 and 1.00 (Table 4). The main weaknesses in the quality of identified studies were found in the participant eligibility and sampling, which was only mentioned in Kim et al.[27]; participant recruitment, reported in Kim et al.[27] and Smith et al.[26]; and enrolment, described in Duyver et al.[25] and Kim et al.[27]. See Table 4, for a detailed overview of the quality appraisal.

Table 4. Results of quality assessment

Study		Duyver et al.[25]	Smith et al.[26]	Vanneste et al.[28]	Vanneste et al.[29]	Kim et al.[27]
Introduction	Rationale	2	2	2	2	2
	Objectives	2	2	2	2	2
	Logic model	2	2	2	2	2
Methods	Study design	0	2	0	2	2
	Outcomes	2	2	2	2	2
	Data collection methods	2	2	2	2	2
	Participant eligibility	0	0	0	2	0
	Recruitment	0	2	0	2	0
	Bias	2	1	1	2	0
	Sampling	0	0	0	2	0
	Setting and locations	0	0	1	2	1
	Comparator	N/A	N/A	N/A	2	2
	Data sources	2	2	2	2	2
Results	Enrolment	2	0	0	2	0
	Description of study population	0	2	1	2	1
	Reporting on outcomes	2	2	2	2	2
Discussion	Summary of evidence	2	1	2	2	2
	Limitations	2	2	2	2	2
	Generalizability	2	2	0	2	0
	Conclusions	2	2	2	2	2
Conflicts	Funding	2	0	2	2	2
	Ethical considerations	2	2	2	2	2
	Competing interests	2	0	2	2	2
Quantitative study	Confounding	0	N/A	0	2	2
	Statistical methods	2	N/A	2	2	2
	Missing data	0	N/A	0	2	2
Qualitative study	Analytical methods	N/A	2	N/A	N/A	N/A
	Data validation	N/A	2	N/A	N/A	N/A
	Reflexivity of account provided	N/A	2	N/A	N/A	N/A
Sum		34	36	31	38	52
Score		0.68	0.72	0.62	0.73	1

Discussion

To provide high-quality elderly care, accurate communication of the patients' medical and treatment plan information has been identified as fundamental[3, 30]. For this reason, we aimed to describe the evidence on the feasibility and usability, efficacy and effectiveness, and implementation outcomes of DHTs developed to facilitate the administration of CGAs for long-term care settings or community care, and to describe their technical features and components.

Little information regarding technical features and hardware characteristics that could provide insight into the functioning of the platforms was reported. Only Smith et al.[26] reported using laptops, however, the used software was not specified. In terms of the description of the platform, more features were identified for the BelRAI and the SPEC as compared to the other two DHTs.

Three of the four platforms were studied in community care settings, supporting two CGAs, the MDS-HC and the interRAI HC. Only the SPEC was studied for long-term care facilities and supports the interRAI LTCF. These results raise a concern in terms of how many CGAs are being supported by DHTs, as in this study only the interRAI family of CGAs was identified, even when a previous systematic review reported a total of three CGAs for long-term care and seven for community care[31]. According to Molinari-Ulate et al.[31], the interRAI family of instruments are the most studied CGAs in the scientific literature in both settings, which could explain why there is evidence of the DHTs supporting them. Nonetheless, we cannot conclude if the lack of scientific literature reporting on DHTs supporting the remaining CGAs is because they are not being supported by DHTs or because of a lack of studies and evidence on their feasibility and usability, efficacy and effectiveness, and implementation. The limited research publications in this area have been also highlighted in a previous scoping review studying the web-based applications for the assessment of frailty in older adults[24].

A lack of studies in this regard could lead to poorly designed systems jeopardising patients' safety and contributing to psychological stress for users, including burnout and low morale[30, 32, 33]. Two of the studies included in this review identified outcomes associated with this problem. Vanneste et al.[28] identified that several sections were less completed than others, which might lead to concerns regarding decision-making, quality of care, interventions and care planning, as they are supported by the assessments' results. Also, Vanneste et al.[29] considered that missing data could be related to lower quality of care, as they identified that the group with missing data at follow-up had worse health status at baseline, were more functionally impaired, showed more depressive symptoms, had a higher risk of health problems (such as cardio-respiratory conditions, undernutrition, dehydration, etc.), and reported an increased risk of mortality and institutionalization when missing data was found in 6-months follow-ups. Additionally, the identified high responsibility of nurses for the completion of assessments[28], associated with the perception of lengthy and time-consuming assessments[25, 26] could lead to overloading the workload of health care professionals and contradicts one of the basic premises of a CGA, the multidisciplinary cooperation to achieve high-quality care.

The results gathered from the studies of feasibility and usability reported some important barriers that could affect the implementation of these DHTs in care practice. Regarding usability, the following barriers were reported: a) difficulties navigating the software; b) length of the assessments; and c) inconsistent network connectivity. In terms of feasibility, d) availability and accessibility to appropriate hardware; e) the need for ongoing training to perform the assessment correctly; and f) the lack of staff knowledge regarding the information collected and its purpose, were identified as potential obstacles. Some of these barriers might be overcome nowadays as the DHTs could include novel technologies that have evolved since their publication; for example, there are multiple and novel wearable and lighter devices that can be carried around instead of laptops; network connectivity is constantly evolving in terms of coverage, speed, and consistency; novel software and apps might be able to perform offline assessments; technology can support multiple access for data entry and breakdown long assessment instruments facilitating a more efficient and multidisciplinary administration; and guidelines and recommendations on the assessment and development of DHTs have been developed[16, 34, 35]. Nonetheless, there are some barriers that are associated with the training of the healthcare workforce, such as the training of health professionals on assessments and staff knowledge regarding the purpose of the data collected. These barriers were also highlighted by Chang, et al.[24] who described a lack of comprehensive instructions, training materials, and materials to support the interpretation of the results in web-based applications used for the assessment of frailty in older populations. As these obstacles are not technology related, they need to be addressed by the healthcare systems and policymakers.

Some of these barriers can be tackled by considering the major priorities for strengthening DHTs identified by Sheikh et al.[30]. For example, the lack of staff understanding of the information collected and its purpose could be approached by building capacity for managing and analysing data through investing in data science, quality improvement and health informatics training for the workforce and by incorporating new professionals such as data scientists and clinical informaticists that jointly work with health care professionals and patients[30]. Also, engaging the health care taskforce and patients in DHTs design and development, research and implementation process will inform developers on design and evaluation issues, which could translate into early amendments, reducing costs before releasing the system[30, 36]. This also could lead to more engaging and user-friendly systems[37] that could be more aligned with the needs of the different stakeholders and the context of their healthcare systems.

Identified features that reinforced the usability, effectiveness, and implementation of DHTs supporting the application of CGAs were: a) utilization of a safe data storage warehouse, such as clouds; b) inclusion of automatic alerts, notifications, or a continuous check for item completion in the DHTs; c) access allowance for multiple health care professionals on individual assessments in the DHT, avoiding to rely on one professional to complete the CGA but using the expertise of each team member; d) provisioning of individualized profile reports of needs and risks, and personalised care plans; and d) automatic calculation of the composite outcomes and scales. Assuring the security and privacy of the data and improving the exchange of information between healthcare organisations have been also identified as major priorities for enhancing the implementation of DHTs in healthcare systems[30].

By embedding novel technologies into DHTs supporting the administration of CGAs, such as AI and robotics, the accuracy and efficacy of these identified features could be increased. For example, by including a graphical representation of the person’s health profile and status or by providing real-time people’s information and feedback from large databases that can facilitate the development of machine-learning algorithms[38]. Through this learning health systems, clinically relevant information regarding the progression or deterioration of the person can be obtained and could improve timely decision-making and quality and personalisation of care[30, 38, 39].

Limitations and Future Research

The results presented in this review describe the state of the art of the DHTs supporting the administration of CGAs for long-term care settings or community care. The oldest study was published in 2010 and technology has evolved since then. Some of the limitations reported in this review might have been solved, however, information on potential updates or increased maturity of these DHTs not published in selected databases were not taken into account in this review.

We identified limited information regarding technical features and hardware characteristics needed for the proper functioning of the DHTs. The reported characteristics are based on the information available in the articles. Descriptions are often incomplete, missing relevant information that can lead to better insight regarding factors contributing to the usability, feasibility, and effectiveness of the DHTs in care practice, such as devices needed for the administration of the assessments, which functions the platform performs (e.g., automatic calculation of outcomes, alerts, notifications, notes) or the possibility to involve different disciplines in the assessment. Similarly, there is a lack of studies targeting the implementation of these DHTs on a large scale. Further investigation is required to dig into the technological features of these DHTs and how to fit them into general information systems of health or social care. The relevance of using these tools for improving the quality of care makes it necessary to prove their usability, implementation, and usefulness in clinical settings, which will become relevant for clinical decisions and policymakers.

The scope of this review did not cover any costing implementation analysis of the DHTs. None of the studies included were reviewing this area, however, we consider it very important for future studies to include cost-effectiveness as a relevant outcome as it could improve health and policy decision-making regarding the available platforms. Similarly, due to the limited information and the number of studies identified, is very difficult to provide a comparison between the DHTs reported. Only one platform was developed for long-term care, and the other three for community care, and the description in terms of technological features, hardware characteristics, and other relevant data to provide a helpful comparison is very limited. Additionally, the healthcare systems where the DHTs have been studied might differ substantially as the studies were performed in three different countries on three different continents (Belgium, New Zealand, and South Korea). For this reason, this review provides recommendations and describes different barriers identified from the DHTs included in an attempt to offer some guidelines for future developers and policymakers.

Only studies in English and Spanish were considered, omitting other possible DHTs developed that have been reported in different languages. Also, our definition of a CGA excludes those DHTs that support multidimensional assessments that consist of a collection of single-domain measures, tests, or assessments. For example, digitized frailty assessments or indices were not addressed and not included in the search terms as we considered that they do not cover the whole spectrum of domains included in the CGAs. Insights on these DHTs that might contribute to improvements of DHTs for CGAs are lacking in this study.

To the best of our knowledge, there are other commercial platforms available. However, studies on usability, feasibility, efficacy, effectiveness or implementation were not identified. One of the authors (MMU) contacted several companies that developed and deployed these platforms, to inquire about performed studies on these topics. According to the responses received, no studies have been performed on these DHTs.

Even though DHTs are considered essential in collecting, processing, and reporting outcomes relevant to daily care practice, we only identified studies of DHTs supporting the interRAI suite of instruments from all the CGAs identified in Molinari-Ulate et al.[31]. For further development of DHTs for this goal and to support optimal utilization of valuable CGAs to improve the quality of care, more insight is required into how care professionals use DHTs and their outputs efficiently, in such a way it supports daily care practice.

Considering the barriers and limitations reported in this review, there is still a lot of room for improvement regarding the development and implementation of DHTs supporting the application of CGAs in long-term care facilities or community care. Further research should focus on solving the barriers reported in this review, study the functionality of the platforms in up-to-date devices (such as tablets, mobiles, smartwatches, etc.), and focus on the integration of data from CGAs with monitoring data acquired via novel technologies such as wearable technology devices and Artificial Intelligence (AI) within the DHT.

Conclusions

Data on DHTs supporting the application of CGAs in long-term care facilities or community care is limited, with only five studies and only the interRAI family of CGAs being supported. These studies reported on barriers regarding usability mainly concerning inconsistency in network connectivity; technical issues leading to inappropriate, inconsistent, and missing data; duration of the assessment; and feasibility obstacles such as the availability and accessibility to appropriate devices; and lack of training and knowledge regarding the information collected and its purpose.

Regarding effectiveness, the results of one study reported a significant impact on the quality of care in long-term care settings and a decrease in ADL late-loss worsening, cognitive decline, communication decline, new or persistent delirium, and worsening of behavioural problems. In terms of implementation, the incompleteness of some sections was attributed to insufficient training, insufficient information required by other caregivers, and lack of time to complete the assessment. Responsibility for data collection was identified as not adequately distributed among health professionals, relying mainly on nurses.

Recommendations that might enhance the usability, effectiveness and implementation of these platforms are accessibility to the individual's assessment by multiple health care professionals and allowance to break down the sections according to the professional expertise to share the assessments' responsibility; the use of safe data storage, such as clouds; automatization of a real-time calculation of the scales and outcomes with a graphical representation of the person's profile and health status; automatic alerts, notifications and continuous monitoring for item completion; and provisioning of personalized care plans according to the data collected.

Limited information reporting on the technical features, required hardware, and lack of implementation studies of DHTs, limits the conclusions of this review. Further research must focus on these areas to improve the implementation and usefulness of these DHTs to support the application of CGAs in the healthcare system.

Declarations

Conflicting interests

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: MF and HR are fellows of interRAI Network.

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Ethical Approval and patient consent

Not applicable. No human subjects were involved in this research. Ethical approval was not sought.

Guarantor

MMU

Contributorship

MMU, HR, and MF conceptualized and designed the review. MMU, AM, EPV, JMS, MFM, and HR screened the titles of the records resulting from the search. MMU and AM screened the abstracts and full text of the records remained after title screening. MMU and AM evaluated the records for risk of bias. MMU extracted the data from the included studies, and it was verified by HR. MMU, HR, and MF drafted and critically revised the manuscript. HR and MF provided overall study supervision. All authors authorized the final version of the manuscript that was submitted. All authors read and approved the final manuscript.

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Not applicable

Abbreviations

CAP: Clinical Assessment Protocol

CGA: Comprehensive geriatric assessment

DHT: Digital health technology

ICT: Information and communication technology

interRAI LTCF: interRAI long-term care facilities

interRAI HC: interRAI home care

MDS-HC: Minimum data set-Home care

MeSH: Medical subject headings

SPEC: System for person-centered elder care

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Publication #3. Insights on conducting digital patient and public involvement in dementia research during the COVID-19 pandemic: supporting the development of an ‘E-nabling digital co-production’ framework

Publicación #3. Reflexiones sobre la participación digital de pacientes y el público en la investigación de la demencia durante la pandemia COVID-19: apoyo al desarrollo de un marco de ‘Habilitación a la Coproducción Digital’.

Mauricio Molinari-Ulate, Rebecca Woodcock, Isabelle Smith, Henriëtte G. van der Roest, Manuel A. Franco-Martín and Michael P. Craven

Resumen en español

Antecedentes: La rápida transición al trabajo digital, acelerada debido a la respuesta a la pandemia de COVID-19 ha repercutido en la participación de los pacientes y el público en la investigación. Este artículo presenta las experiencias de participación digital de pacientes y público (e-PPI) en la investigación de la demencia desde los confinamientos y ofrece recomendaciones sobre el futuro trabajo digital e híbrido. Además, presenta un marco de coproducción para que investigadores, coordinadores de PPI y colaboradores públicos identifiquen y debatan los retos y las oportunidades que ofrece la e-PPI.

Métodos: Se realizaron dos talleres en línea y una entrevista individual con un grupo de investigadores y coordinadores de PPI con experiencia en PPI en la investigación de la demencia, y con un grupo existente de PPI que trabaja temas de demencia y con alguna experiencia de trabajo en línea durante la pandemia. El proyecto se construyó como una actividad de PPI, con MindTech (un grupo de PPI) implicado en todo el proceso, y se adoptó un proceso de análisis de datos colaborativo.

Resultados: Tras afinar la estructura de codificación, el MindTech Involvement Team y los coordinadores del proyecto identificaron cuatro temas principales, lo que dio lugar al marco de ‘Habilitación a la Coproducción Digital’. Durante el desarrollo de este marco se expresaron diferentes posturas asociadas a la transición al trabajo digital. Dos temas

principales fueron compartidos por los grupos participantes en relación con e-PPI: un mayor alcance potencial sin limitaciones geográficas y la percepción de sesiones más comerciales con menos oportunidades de interacción social y comunicación. En el caso concreto de investigación sobre la demencia, mientras que e-PPI puede permitir a los colaboradores públicos asistir a más reuniones, los entornos potencialmente de apoyo mutuo proporcionados por las reuniones cara a cara podrían disminuir, con la posible reducción de las oportunidades de respiro informal.

Conclusiones: Gracias a la participación de colaboradores públicos, investigadores y coordinadores de PPI centrada en PPI digital en la investigación de la demencia, pudimos perfeccionar y coproducir el marco de ‘Habilitación a la Coproducción Digital’. Demostrando su potencial para el análisis de los beneficios y las limitaciones dentro de e-PPI, fue posible identificar tanto las ideas generales como las específicas de la investigación de la demencia. Sin embargo, la contribución más significativa del marco es su potencial para apoyar los procesos locales de coproducción en las actividades digitales e híbridas de participación pública en curso.

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Research Involvement
and Engagement

RESEARCH **Open Access**

Insights on conducting digital patient and public involvement in dementia research during the COVID-19 pandemic: supporting the development of an "E-nabling digital co-production" framework

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Abstract

Background: The rapid transition to digital working, accelerated due to the response to the COVID-19 pandemic, has impacted the involvement of patients and public in research. This paper presents experiences of engaging in digital Patient and Public Involvement (e-PPI) in dementia research since the lockdowns, offering recommendations regarding future digital and hybrid working. Furthermore, it introduces a co-produced framework for researchers, PPI coordinators and public contributors to identify and discuss challenges and opportunities provided by e-PPI.

Methods: Two online workshops and one individual interview were performed with a group of researchers and PPI coordinators with experience in PPI in dementia research, and with an existing dementia PPI group having some experience of working online during the pandemic. The project was constructed as a PPI activity, with the MindTech Involvement Team (PPI group) involved in the entire process, and a collaborative data analysis process was adopted.

Results: After refinement of the coding structure, the MindTech Involvement Team and Project Leaders identified four main themes, resulting in the 'E-nabling Digital Co-production' Framework. During this framework development, different positions were expressed, associated with the transition to digital working. Two main themes were shared by the participating groups regarding e-PPI: wider potential reach without geographical constraints, and the perception of more business-like sessions with reduced opportunities for social interactions and communication. Specifically for dementia research, whilst e-PPI may allow public contributors to attend more meetings, potentially mutually supportive environments provided by face-to-face meetings could be diminished, with carers experiencing a possible reduction in informal respite opportunities.

Conclusions: Through involving public contributors, researchers, and PPI coordinators with a focus on digital PPI in dementia research, we were able to further refine and co-produce the 'E-nabling Digital Co-production' Framework. Demonstrating potential for analysis of benefits and limitations within e-PPI, it was possible to identify both general

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insights and those specific to dementia research. However, the most significant contribution of the framework is the potential to support local journeys of co-production in ongoing digital and hybrid public involvement activities.

Keywords: Dementia, COVID-19, Patient and public involvement, PPI, Dementia research, Co-production

Plain English Summary

The COVID-19 pandemic has impacted the engagement of patients and the public in research. Lockdowns, social distancing, and reduced physical contact have affected the involvement of public contributors in research studies. In particular, the pandemic triggered a rapid transition to digital working, increasing the use of Information and Communication Technologies such as video conferencing on computers and mobile devices. With little time to reflect on the consequences of digital working in PPI and with a continuing legacy of hybrid or blended approaches to involvement, this project highlights the challenges and potential for e-PPI approaches (electronic/digital PPI) within the context of dementia research. In addition to examining the transition to digital working in this area, we present a co-produced framework for researchers, PPI coordinators and public contributors.

Background

Patient and Public Involvement (PPI) has gained more attention in recent years across all areas of health research [1], including dementia [2, 3]. Considered as a cornerstone for governmental and ethical policies in health research along with the development of PPI best practice guidelines [2, 4, 5] it has been defined as a research project or public policy development carried out with or by patients or members of the public that is beyond their engagement as subjects [5–7].

With practical benefits in enhancing the quality of the research [3–5] and as part of an accepted discourse [8], PPI occupies at minimum a stipulated requirement, rather than an option, including funding applications for health research [5]. Whilst democratic rationales [9, 10] may receive less attention than technocratic or transactional motivations, patient involvement has the potential to either address or exacerbate existing inequalities within health outcomes [11]. Indeed, these existing inequalities risk being further compounded through the COVID-19 pandemic [12].

Since the beginning of the pandemic, declared by the World Health Organization in March 2020, the involvement of patients and the public in research has been challenged because of social distancing, lockdowns, and other reduced physical contact [13]. Therefore, quick responses and adjustments have been needed, which have been accompanied by increased use of Information and Communication Technologies (ICT) [14, 15]. With the definition, breadth and theoretical underpinning of PPI already conceptually challenged and contested [9] alongside a range of practices and values underpinning its delivery [16], the move to digital represents a further domain in which complicated dynamics exist.

Previous literature on conducting digital PPI (referred to henceforth as e-PPI) is scarce [7, 17], however, it highlights several challenges that differ from those found in face-to-face meetings such as: (a) less spontaneous interactions between the individuals (e.g., more direction from the meeting chairs, breaks taken individually), (b) lack of non-verbal cues (e.g., difficult to observe non-verbal communication such as gestures), (c) difficulties in turn-taking (e.g., less spontaneous change of speaker), (d) changes in the meeting chair role (e.g., a more active and directive role), (e) linguistic barriers (e.g., less participation in discussions), or (f) limited view of each participant's face [17]. Also, a scoping review looking at the role of ICT to involve patients and the public identified limitations of internet use as being impersonal, expensive, or stressful, and it was considered that weblogs cannot be a replacement for in-person meetings [7]. Wider consideration of approaches to understand Working From Home (WFH), whilst not focused on PPI, may also serve to highlight relevant factors [18].

As COVID restrictions have gradually eased in some countries this has led to more hybrid approaches such as blended meetings (online contributions and face-to-face attendance). With such a legacy, the importance of getting e-PPI right will remain a topical and evolving issue.

Co-producing an immediate local response

MindTech (https://www.mindtech.org.uk) is a national centre established in 2013 and funded by the National Institute for Health and Care Research (NIHR) focussing on the development, adoption, and evaluation of new technologies for mental healthcare and dementia. The MindTech Involvement Team, a group of people and carers bringing their own lived experiences of mental health conditions, as well as expertise in the processes of patient and public involvement, occupies a strategic and advisory role in the organisation, aiming to involve patients and public in all aspects of research.

Experiencing an immediate and instrumental shift to e-PPI in March 2020, the MindTech Involvement Team continued to meet regularly through virtual meetings despite not previously operating online involvement methods. Although public contributors, staff (employed as PPI coordinators) and researchers acknowledged inherent challenges and opportunities that this brought to ensuring continued meaningful involvement, there was a recognition that these would differ at individual, group, and research level. As a localised response, the MindTech Involvement Team and PPI staff co-produced an overview of the primary areas that were impacted by the shift to e-PPI. Presented at the MindTech Symposium in December 2020, these considerations were accompanied by a set of local actions taken to both mitigate challenges and harness the potential from these new ways of working (Additional file 1: Overview of Digital Considerations).

From developing an initial generic set of considerations regarding e-PPI, the work continued with a project conceived in November 2020 as part of the first author's (MMU) training programme placement for the European DISTINCT network (https://www.dementiadistinct.com). Working remotely in collaboration with the local academic supervisor from MindTech and the Centre for Dementia at the Institute of Mental Health (MPC), MindTech Involvement Team staff PPI co-ordinator (RW) and with a designated public contributor from within the team as project co-lead (IS), this afforded the opportunity for further involvement and application of these considerations within the context of dementia-specific PPI.

Whilst PPI groups nationally grappled with many similar elements, systematic consideration and understanding of the relative successes of different PPI groups within the transition to e-PPI remained elusive. It was proposed that although there remained a set of shared considerations, success may be predicated on both the area of health research and significantly on the type of group experiencing the transition to online involvement.

People Living with Dementia (PLwD) and carers represent one such group. Although far from homogenous, PPI groups working with PLwD may share a set of challenges and opportunities with respect to this digital transition and which are additional to considerations already well articulated [2]. With telephone or e-mail already identified as valuable tools for PPI representatives' engagement in dementia research [6], further insights may be made through exploring the experiences of using ICT, with a view to identifying better approaches for public involvement and making the most of *experts by experience*.

We therefore decided to explore the experiences of e-PPI within a dementia-specific context during the COVID-19 pandemic and intended to use the findings to refine the existing 'Overview of Digital Considerations' (Additional file 1) originally developed by the MindTech Involvement Team, resulting in an 'E-nabling Digital Co-production' Framework. The framework is introduced as a tool for researchers, PPI coordinators and vitally public contributors themselves to identify and discuss challenges and opportunities provided by e-PPI and future blended and hybrid approaches.

Methods

Developing a Co-produced Dementia e-PPI project

Continuing the focus on co-production, the project leads ran three types of session: (a) a project design and development session, (b) project delivery sessions (workshops), and (c) meetings to analyse and synthesis the outcomes. One representative member of the Involvement Team was a co-lead of the project and was involved as a facilitator of the online workshops (IS).

Online workshops

The project co-leads selected by preference a workshop approach as opposed to alternatives such as semi-structured interviews with individual PPI members, considering it the most pragmatic strategy to working online with PPI groups. Workshop formats allow an exchange of ideas within a scaffolded structure, inclusion of potential challenges or allow for a range of positions expressed within a supported environment, thereby enabling various positions within a group forum to be identified. By undertaking workshops online, it is also possible to share comments through the chat function, where a parallel discussion can be facilitated, allowing people to share their thoughts without having to speak to the rest of the group.

Before each of the sessions, participants were provided with a project information sheet and a semi-structured guide of possible topics and questions to cover at the discussions (Additional files 2 and 3, respectively). A one-minute pre-recorded pitch was shown at the beginning of each of the sessions by way of introducing the project, inviting individuals to participate, and as an "ice-breaking" strategy to initiate the activity. The time for the sessions varied from 25 min to approximately an hour.

Two online workshops and one individual interview (the latter for one academic researcher who could not attend the workshops) were conducted. Two roles were provided by the project co-leads: (a) facilitation of the workshops and discussion (MMU and IS); and (b) administrative and inclusion role, with a person in charge of taking field notes and checking the chat box (RW and IS). Field notes were chosen to gather the information as they have been previously implemented in similar public engagement projects [19, 20] and because verbatim

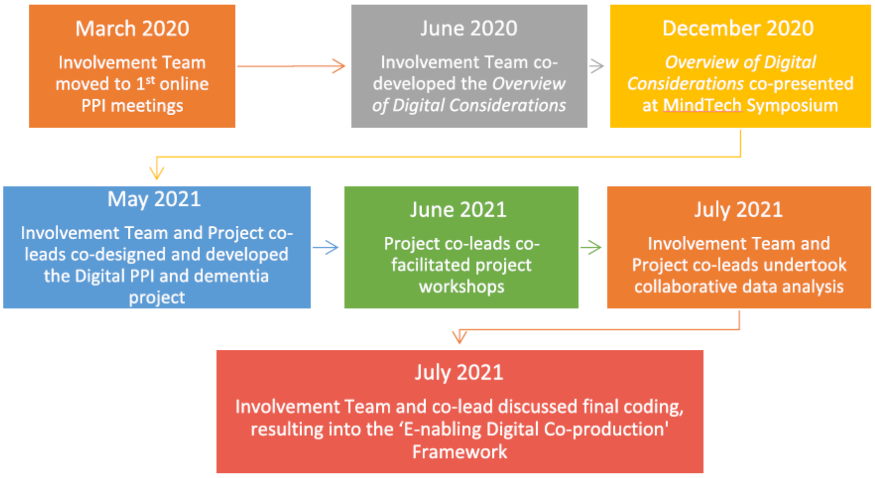


Fig. 1 The co-production journey of the "E-nabling Digital Co-production" Framework

transcripts would not be available, since the sessions were not recorded to maintain the policies of the PPI groups involved and as this project was organised as a PPI rather than a research activity (see ethical approval statement). The online platform used was Microsoft Teams (MS Teams) as this was the tool facilitated by the institutions involved.

Groups participating in the workshops

To develop a broader perspective on the challenges and experiences related to the transition to e-PPI in dementia research, we contacted researchers and PPI coordinators (either staff or public contributors that has a role in facilitating PPI) for one of the workshops. Four researchers and two PPI coordinators accepted the invitation and were invited to a group session (Workshop 1). An individual interview was held with one of the researchers as accepted the invitation but could not attend the workshop.

A second workshop was performed with an existing PPI group, the 'Dementia, Frail Older People and Palliative Care Patient and Public Involvement Advisory Group' (the Advisory Group from now on) from the University of Nottingham (Workshop 2). The Advisory Group is made up of members who have experience of caring for PLwD, are carers themselves, who provide advice and guidance at all stages of research projects. The group was meeting regularly once a month and a request to participate in one of their sessions was sent by MMU. The workshop strategy was brought to one of the Advisory Group's existing virtual meetings and a total of 11 members were part of this session. Using an existing PPI group provided a safe and structured settings for working with PLwD carers, recognising the need for increased attention to ethical and welfare issues as described in the literature [2].

These two groups participated only in their respective workshop sessions and were not involved in any other stage of the project.

Qualitative analysis method

A thematic analysis was the chosen approach for the analysis of the results. In keeping with a methodological approach based on co-production, a collaborative data analysis (CDA) was performed with members of the MindTech Involvement Team [21]. The co-leads (IS and RW) and other members of the Involvement Team held an online meeting session to start coding the information, identifying the potential to utilise the Overview of Digital Considerations document (Additional file 1) to support this endeavour. After initially reviewing the initial coding co-production continued with our public contributor project co-lead (IS) and the other project leads (MMU and RW) working together, leading to consolidation into four key themes. This included addition of the concept of 'involvementability' as identified within the researchers and PPI coordinators Workshop. This resulted in the 'E-nabling Digital Co-production' Framework (see Fig. 1). MMU, RW and IS continued with the final coding before ambiguities and final coding was brought back to the Involvement Team for discussion and final inputs.

Fig. 2 "E-nabling Digital Co-production" Framework

An overview of the 'E-nabling Digital Co-production' Framework can be seen in Fig. 2, with descriptions of each of the four areas of the framework available in Table 1.

Results

The workshops were held in June 2021 and 14 pages of notes resulted from a total meeting time of 2 h.

To explore the move to e-PPI for dementia research during the pandemic, the insights from the workshops were mapped against the four areas of the 'E-nabling Digital Co-production' Framework, as it was refined following the co-production journey described previously. This approach also allowed for the opportunity to identify and highlight specific insights for dementia research.

The following section demonstrates how insights were then categorised according to the co-produced framework themes. Both positive and negative aspects of e-PPI were expressed by the participants and recorded accordingly. Dementia specific remarks were highlighted separately for each theme.

Technological

All remarks about technology aspects came from the researchers and coordinators group. Three main technical issues were highlighted: online platform alternatives, technical support, and accessibility. Concerning access to different platforms, researchers and coordinators commented on restrictions due to institutional rules or policies which determine the platform options, such as requiring use of MS Teams rather than a broader choice. Other platforms were identified as having potential to solve various barriers or constraints to participation, while some individuals were more familiar with or preferred different platforms.

Other reflections emphasised the need for technical or administrative support having responsibility during virtual meetings to help resolve technical issues, and the concern about difficulties identified in giving full access to other participants.

Resources

A diversity of topics arose about resources. On the positive side, there was time saved on not travelling to meetings, with implications particularly for public contributors who are most often asked to attend meetings in research settings away from their homes. For researchers and PPI coordinators, facilitating arrangements in terms of venues, catering, or other coordination, such as transportation for PPI representatives was identified as resource intensive. However, it was understood that other resource requirements may be needed instead, such as the time for additional support staff to facilitate online delivery, or the practice of providing additional reimbursement to recompense costs incurred through online working. Another positive was the reflection that virtual meetings were more "straight to the point" although this may itself contribute to some of the perceived lack of informal communication and connections that face-to-face PPI may create. Also mentioned was that online meetings allowed members to attend more meetings. Finally, both researchers and coordinators, and the members of the Advisory Group, considered that e-PPI had a wider potential reach, with virtual meetings enabling connections with researchers or participants that are geographically dispersed. On the negative side, attendees underlined that planning e-PPI is more time consuming, and others mentioned that controlling time and contributions could be harder.

Particularly for carers of PLwD, it was considered that virtual meetings helped to overcome some of the limitations related to their role as carers, such as concerns around time away, finding an alternative carer, or other time constraints, as they could attend the PPI sessions from home.

Involvementability

Three main barriers for e-PPI involvement stood out regarding this area: virtual meeting limitations, communication, and social interaction.

Virtual meeting limitations: researchers and coordinators emphasised the limitations of the type of activities that could be done; some of the insights referred to the difficulties in involving individuals when different devices are required. One example was the need for multiple devices

Table 1 Description of the four key areas of the "E-nabling Digital Co-production" Framework

The 'E-nabling Digital Co-production' Framework	
Key area	**Description**
Technological	Technological considerations include assessment of the constraints, preferences, and opportunities that technology can provide **Preferences:** ● How are preferences and any support needs identified by public contributors communicated with researchers? **Power:** ● What is the potential for shared decision-making regarding the use of technology, including functional and operational components? ● To what extent are technological considerations revisited regularly with public contributors recognising the fast pace of developments in online collaborative platforms? ● What potential exists for supporting researchers, PPI staff and public contributors to develop confidence in using online methods?
Resources	Resources were considered at a personal or a more mechanistic level **Personal:** ● Consideration of increased emotional toll with online involvement, with recognition of increasing fatigue and additional personal resilience often required for negotiating challenging work within a virtual context **Professional resources:** ● Both payment for lived experience input and increased demands on those delivering PPI online **Preparation:** ● Are additional requirements planned from the outset? These could include additional facilitation roles, onboarding sessions, costs of coproduction platforms, phone credit/printing etc./software, budgeting for an increased frequency but shorter meetings ● Wider resources may include additional training for researchers, PPI staff and public contributors to support the use of new technology
Involvementability	'Involvementability' is offered as an example of a non-functional requirement, a concept that aims to describe requirements that are related to the success of a design task or process but are not integral to its content [22] **Process:** ● How does the nature of involvement method or process itself impact on the extent that meaningful involvement can be achieved? ● How do codesign methods differ in a digital space? **Product:** ● How does the area of health research itself impact on the extent that involvement can easily translate to a digital space, such as exploring digital health interventions may be facilitated or made more complex through online involvement? **Population:** ● How easily will 'involvement' translate online for different populations?
Ethical and Welfare	How does digital PPI interact with a range of areas including: ● Welfare of public contributors ● Digital exclusion ● Impact of digital engagement on social communication ● Power ● Safeguarding ● Privacy, confidentiality, and data security

as in the case of using a laptop for ICT while the research was to evaluate another device or software, such as an app on a phone or tablet. Another issue arising from the use of video communications, mentioned by researchers, is the limited view of physical prompts or other non-verbal communication.

Communication: both groups considered that communication is less effective during virtual meetings. Reflections that reinforced this idea related to feedback mechanisms and interchanges between attendees and researchers that were missing or diminished in an online exchange. It was proposed that this was affected by the reduced non-verbal communication, resulting in less fluid discussion (e.g., more formal turn-taking) and not being able to see all participants on the screen at the same time. However, a positive reflection from researchers and coordinators was that virtual meetings served to encourage reflection about communication methods, particularly the role of raising hands and waiting for an opportunity to participate.

One area of potential ambiguity was whether e-PPI served to increase the inclusion of those less confident in participating. Whilst participation could be more easily regulated with facilitation leading to greater inclusion, it was also highlighted that online interactions may create or reinforce additional barriers to engagement.

Specifically for dementia research, participants underlined the need to consider cognitive abilities as the level of attention or concentration needed for virtual meetings could affect the discussion and engagement, for example, someone may forget their contribution by the time they have an opportunity to talk.

Social interaction: overall participants had experienced less social interaction through virtual meetings. They mentioned a decrease of informal social interaction, such as breaks during the sessions that allow for spontaneous conversations and interchange between attendees, and lack of opportunities to share and meet with others, leading to a more "business-like" meetings.

In terms of positive contributions, researchers and coordinators considered that e-PPI could be less threatening concerning the physical social interaction and that, normally, the individual will be participating in a safe environment (e.g., their home). Additionally, they mentioned that people wishing to isolate for any reason (e.g., COVID) can be included, and that close and strong relationships could be developed.

Regarding dementia specific remarks, it was considered that meeting online may diminish the opportunity of a respite and supportive space for members providing care, which seems to be accomplished in face-to-face meetings.

Ethical and welfare

The following three main topics were identified in this area:

Diversity and inclusion: as a negative perception, researchers and coordinators considered that e-PPI could be a barrier for inclusion as the group of individuals attending virtual meetings may stay the same without new members coming along. Also, they considered that the group does not represent all sectors of the community.

On the contrary, virtual environments could offer the opportunity to include those that have not been considered for several circumstances. However, it was noted that to achieve this, recruitment methods would need to be improved with further recognition that this is compounded, with increased difficulties in recruiting PLwD in an online context.

Digital inclusion: several barriers were identified by members from the Advisory Group, including that with e-PPI, some individuals could feel that they are not part of the research team as the sense of group is missing, and that difficulties with the technology or the dislike for virtual meetings was a factor in losing participants. A similar barrier was considered by researchers and coordinators as they mentioned that e-PPI could be excluding individuals that lack the skills and confidence needed to use the technology, which might be exacerbated in vulnerable populations, and that even those familiar with the platforms struggled when technical issues occurred.

Furthermore, equity arose as a concern in terms of the technology use and support, particularly because some individuals could have better access while others do not (e.g., good bandwidth) and those in need of support or living alone might not be able to join (e.g., PLwD).

Regarding dementia specific remarks, the participation and presence of the caregiver is harder to distinguish in virtual meetings, with more sophisticated facilitation skills needed to support meaningful participation of PLwD and carers.

Ethical issues: some of the barriers mentioned by researchers and coordinators related to the need for clarity regarding reimbursement of public contributors participating remotely, gaining informed consent to record virtual meetings, and providing emotional support when people get distressed or frustrated.

Specifically for dementia, the severity of cognitive impairment arose as a consideration. As cognitive function determined the level of support needed at the virtual meetings, this was not always straightforward to assess or address. Furthermore, it was identified that there was an increased difficulty in determining levels of caregiver support and input, with potential to diminish participation from the individual living with dementia.

Tips to improve e-PPI

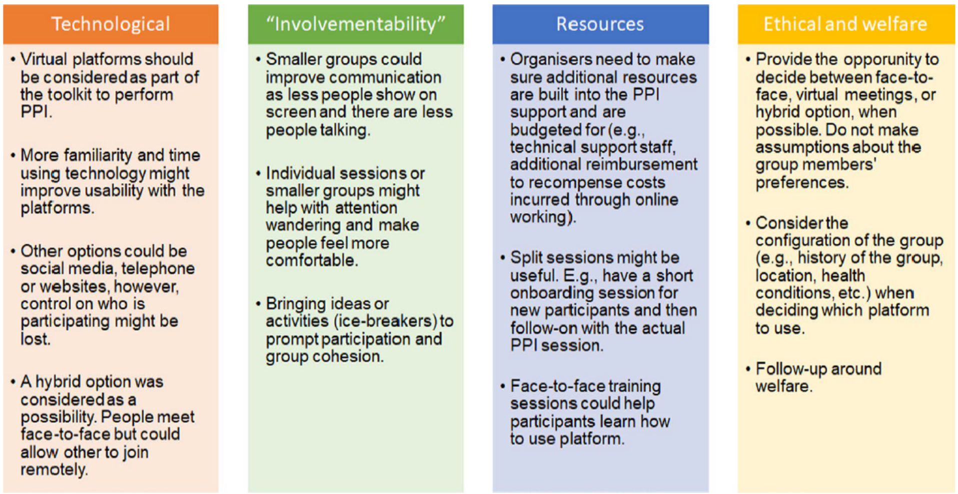
By using the 'E-nabling Digital Co-production' Framework, several recommendations were obtained from the workshops' discussions and mapped according to the areas of the framework. These recommendations were discussed with the MindTech Involvement Team during the data analysis and the final outcome is presented in Fig. 3.

Discussion

A new framework

The project aimed to consider e-PPI in a dementia-specific context and as a by-product led to refining existing guidance and co-producing the MindTech *'E-nabling Digital Co-production'* Framework which is introduced here as a tool for researchers and PPI coordinators to help them identify and discuss challenges and opportunities provided by e-PPI.

Offering a step forward for thematic analysis, its four themes served well as the top-level codes, with insights from the participating groups mapped accordingly. We believe that the development process of the final framework (Fig. 1) is a good example of collaborative data analysis [21].



Technological	"Involvementability"	Resources	Ethical and welfare
• Virtual platforms should be considered as part of the toolkit to perform PPI. • More familiarity and time using technology might improve usability with the platforms. • Other options could be social media, telephone or websites, however, control on who is participating might be lost. • A hybrid option was considered as a possibility. People meet face-to-face but could allow other to join remotely.	• Smaller groups could improve communication as less people show on screen and there are less people talking. • Individual sessions or smaller groups might help with attention wandering and make people feel more comfortable. • Bringing ideas or activities (ice-breakers) to prompt participation and group cohesion.	• Organisers need to make sure additional resources are built into the PPI support and are budgeted for (e.g., technical support staff, additional reimbursement to recompense costs incurred through online working). • Split sessions might be useful. E.g., have a short onboarding session for new participants and then follow-on with the actual PPI session. • Face-to-face training sessions could help participants learn how to use platform.	• Provide the opporunity to decide between face-to-face, virtual meetings, or hybrid option, when possible. Do not make assumptions about the group members' preferences. • Consider the configuration of the group (e.g., history of the group, location, health conditions, etc.) when deciding which platform to use. • Follow-up around welfare.

Fig. 3 Tips to improve e-PPI meetings

The framework development has adopted the term 'co-production', one described in terms of *Cobiquity'* by Williams, et al. [10], referring to the extent that it is frequently co-opted and potentially rendered meaningless. We have attempted to address issues of power and structural inequalities within the different categories and hope that the framework can be used by members of PPI groups and a journey, worthy of the term co-production, can be continued at a local level.

Although the four existing themes were used as the final codes, the framework is flexible enough to allow the inclusion of subcategories without modifying its content, meaning, and structure. For example, under the Ethical and Welfare code, three relevant subcodes were identified (Diversity and Inclusion, Digital Inclusion, Ethical Issues).

Although it was developed as a broad response to the transition to digital co-production (e-PPI) due to the pandemic this project shows that the framework is useful for specific populations and contexts, in this case for dementia research. We hope this means it will be readily used with other populations. Also, its adaptability to other situations makes it a suitable tool to study how e-PPI, and going forward, the complexities of blended meetings, will impact the involvement of the public in research, even more so in the COVID-19 context that is still evolving.

Likewise, the framework is not exclusive to e-PPI, but is rather a tool with the potential to consider how PPI is approached, both considering the current pandemic conditions, and going forward. It may help groups to explore their own preferences and the implications of different models of PPI within the post-pandemic transition. The experience of online meetings and increased familiarisation with digital platforms is likely to be built upon.

A previous systematic review reported 65 published frameworks for supporting, evaluating, and reporting PPI [23], however, none of them were targeting the digitalization of PPI. Although the authors of this review grouped those frameworks in five categories: (a) power-focused, (b) priority-setting, (c) study-focused, (d) report-focused, and (e) partnership-focused, we could not identify areas such as 'technological' or 'resources' that are included in our proposed framework. Furthermore, none of them included specific consideration of e-PPI or the move to e-PPI as part of a blended approach. For this reason, we consider that an extra category should be included in the proposed framework's categorization associated to the approach on how to perform PPI (e.g., in-person or digital meetings) that could be termed 'approach-focused'.

Regarding our findings in terms of the challenges and approaches of e-PPI, it is possible to identify both positive and negative opinions concerning digital co-production. However, ambiguities were also highlighted between the participants that opened deeper discussions, where a clear outcome from the assessment pros and cons is not obvious. For example, e-PPI was considered in one respect as a barrier in terms of the diversity and inclusion of the PPI groups if the same members are always attending the sessions, however, it was also mentioned that the virtuality could offer the opportunity to include others who have not engaged in

PPI before. Within the dementia context, e-PPI offers carers the capacity to attend more meetings but simultaneously they may lose time away care responsibility.

Both workshop groups agreed that e-PPI acts as a barrier for communication and social interaction compared to experiences of meeting face-to-face but nonetheless offered an opportunity to re-evaluate the importance of meeting etiquette and communication styles which might provide a way into conversations for those who are less confident.

Therefore, e-PPI has a variety of pros and cons that must be evaluated as part of a context specific and co-produced response, to find the right solutions. Even with a retreat from the pandemic, e-PPI will remain embedded as a potential method to add value to existing approaches or to be considered as part of an evolving hybrid toolkit to perform PPI in research.

In addition to the differing opinions, two remarks were shared by the participating workshop groups. Firstly, that the removal of geographical constraints are useful to widen participation. Secondly that it saves resources. However, from an ethical perspective, these could still exacerbate existing inequalities. The transition to digital e-PPI has not occurred in a vacuum, with other external drivers and the recognition that diversity and inclusion within research is an area that requires multi-stakeholder action and commitment [1, 14]. Such topical debate dissects discussion around digital exclusion and wider inclusion in PPI and so practitioners need to explore the nuances of how e-PPI impacts this debate.

To increase social interaction, e-PPI methods could be adapted to include other approaches, potentially offering increased opportunity for this social interchange between public contributors and researchers and coordinators. This can be promoted by raising the awareness of the meeting chair to facilitate a more social atmosphere, taking an active role in focusing on inclusion of all meeting participants [17]. Also, other initiatives, such as online forums, could be more conducive to recreating the informal spaces of face-to-face meetings and overcome this vision of business-like sessions. This may further uncover ambiguities surrounding the purpose of PPI and the role of reciprocity in establishing relationships, where it is accepted that public contributors engage in health research with numerous and varying motivations [24]. As the literature on volunteering explores this phenomenon [25] it should be both recognised and reflected in efforts to reframe digital e-PPI that can mitigate the perception of a reduction to a transactional exchange, that has been highlighted.

New ethical challenges are ushered in within the digital domain, particularly the digital divide in populations, as the familiarity and access to the technologies remains inequitable, leading to an exclusion of vulnerable populations and some sectors of the society [14, 26]. Also, administrative considerations such as the consent form for recording or the reimbursement for public contributors, are topics warranting further discussion. This resonates with other considerations that whilst not arising during these workshops aspects such as internet security and data management are also important concerns.

The framework also offered recommendations to improve e-PPI, shown earlier in Fig. 3, and with some of these aligned with those suggested previously by Lampa, et al. [17].

Most of the insights overlapped between both workshops' groups, suggesting that the results presented in this project are shared by the different populations involved. However, with the opportunity for both public contributors and organisers of e-PPI to consider these areas collaboratively or independently, it may serve to identify where there are different priorities and interpretations of costs and benefits associated with e-PPI. It is anticipated that this process itself could uncover both further areas to improve PPI and highlight power imbalances with regards how decisions on digital working are made.

Dementia specific

We were interested to see if the framework could target specific insights for e-PPI in dementia research. Some of the remarks seem to be relevant for carers in general, regardless of the condition of the person being cared for, such as the pros and cons of convenience versus time away from caring as mentioned above. For example, on the positive side e-PPI seems to allow attending more sessions without being worried or stop attending due to their care role. However, by meeting online, virtual public contributors are missing a respite and supportive space that is present in face-to-face meetings, also they might be excluding those living alone or needing more support, and potentially more challenging to distinguish impacts that having a caregiver present may have on the level of participation of the person they are supporting.

For the dementia context, enabling those with cognitive impairment to take part is a more specific concern, hopefully leading to choices in the format of e-PPI to optimise involvement whether this is about being mindful abilities of participants to remember joining instructions, being mindful of levels of attention and concentration, or providing explicit cues to speaker. Degree of impairment will determine the level of support required, which may leads to the need for specialised training for facilitators, having additional supporters in the meeting, or other relevant potential solutions.

Limitations and further projects

The project was conceived as a public involvement activity and for this reason, we did not explicitly collected demographic information, which is quite normal practice in PPI [27]. The workshops were biased to the views of those who were already engaged in remote communications, by necessity due to the pandemic. Results should therefore be used as an insight to improve future approaches to e-PPI in dementia research and other related contexts, rather than for their generalisability.

Due to the COVID-19 pandemic, difficulties were experienced with finding active PPI groups of PLwD, including those struggling to meet online. This led us to contact PPI groups known by the project team to be currently active. However, the Advisory group that participated in Workshop 2 was made of informal caregivers of PLwD, so a strong voice of PLwD for this project is missing. Furthermore, the time to perform the workshop with this group was shorter than the workshop with researchers and coordinators due to constraints of fitting within an existing meeting structure, which could have affected the volume and depth of insights identified from its members.

Only one digital platform was used (MS Teams), as it was the only one available to the institutions involved. Future studies could contribute by controlling the familiarity with online tools and by adding and comparing different digital platforms.

Future public involvement activities or research projects could test, use, and revise the framework to improve its usefulness. The flexibility that it affords, encourages individual groups to explore their own journey and co-produce a bespoke response, with the potential to adapt to an increasing body of involvement methods, including blended approaches that include a digital element. As such it could be beneficial for researchers, organisations and individuals undertaking future PPI activities.

Regarding dementia digital PPI, it would be beneficial to undertake further research on a larger scale and possibly incorporate comparisons between types of dementia to explore if this has an impact on preferences. This framework could be used on a micro level such as a PPI group with particular social and health needs to better understand the digital preferences of the group and consequently have better outcomes for sessions. On the other hand, the framework could be utilised on a macro level to undertake national studies to understand the PPI digital working needs of those with different health conditions. As the stages of the pandemic change and restrictions are lifted and face-to-face working is fully or partly resumed, it is imperative that those facilitating PPI activity are aware of the impact that e-PPI working has had upon the preferences among public contributors and the potential impact on power dynamics. Finally, with potentially increased ability to facilitate face-to-face PPI activity, future research regarding e-PPI could include those not currently involved in digital working for a broader understanding. It would be recommended future research continues to explore e-PPI (and blended approaches) in both dementia and other conditions to gain a clearer understanding of how we can better facilitate future e-PPI working in these ever-changing times.

Conclusion

The 'E-nabling Digital Co-production' Framework that was developed through this public involvement activity was useful in advancing understanding of the issues and opportunities regarding e-PPI. It also helped identify specific insights for facilitating PPI in dementia research. The framework and approach to e-PPI described here could be generalised to further projects. This project also provides an example of a journey of co-production in developing PPI practice.

Abbreviations

COVID-19: Coronavirus disease 2019; PPI: Patient and public involvement; e-PPI: Electronic/digital patient and public involvement; ICT: Information and communication technologies; DISTINCT: Dementia: intersectorial strategy for training and innovation for current technology; PLwD: People living with dementia; MS Teams: Microsoft teams; DHIs: Digital health interventions; WFH: Working From Home; NIHR: National Institute for Health and Care Research.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s40900-022-00371-9.

Additional file1: **Table S1.** Overview of digital considerations. It shows the MindTech Involvement Team's first overview of the primary areas that were impacted by the shift to e-PPI and the local actions taken to mitigate challenges and harness the potential from working digitally.

Additional file2: **Project Information Sheet.** It describes the project and includes the contact information of the Project Leads given to the participants before their involvement in the project.

Additional file3: **Semi structured Questions Guide.** It shows the questions that were used to guide the workshops, this document was given beforehand to the participants.

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Author contributions

MMU, executive researcher of the project wrote the first draft of the manuscript. MMU, RW, IS and MPC substantially contributed to the study design. MMU, RW and IS substantially contributed to the acquisition, analysis, and interpretation of data. All authors substantially contributed to the conception of the work and the final revised version of the manuscript. All authors have approved the submitted version that involved the author's contribution to the study and have agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature. All authors read and approved the final manuscript.

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Availability of data and materials
Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

Declarations

Ethics approval and consent to participate
Advice was sought from the Chair of the University of Nottingham Faculty of Medicine and Health Science Research Ethics Committee (REC). It was considered that REC approval to conduct this project was not required as it is a public engagement activity with all participants contributing as experts (REC correspondence reference no. 255–0521).

Consent for publication
Not applicable.

Competing interests
The authors declared that they have no competing interests.

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Publisher's Note

Publication #4. Facilitators and Barriers of the Adaptive Implementation of the Meeting Centre Support Programme in Spanish Speaking Countries. The Case of Spain and Ecuador (Under Review).

Publicación #4. Facilitadores y Barreras de la Implementación Adaptada del Meeting Centre Support Programme en Países de Habla Hispana. El Caso de España y Ecuador (En Revisión).

Mauricio Molinari-Ulate, Cinthia Vallejos†, Henriëtte G. van der Roest, Manuel Franco-Martín, Rose-Marie Dröes

CONFLICT OF INTEREST
TEXT AVAILABLE UPON
REQUEST

CONFLICT OF INTEREST
TEXT AVAILABLE UPON
REQUEST

Publication #5. Cultural adaptation of the iSupport online training and support programme for caregivers of people with dementia in Castilla y León, Spain

Publicación #5. Adaptación cultural del programa de formación y apoyo en línea iSupport para cuidadores de personas con demencia en Castilla y León, España

Mauricio Molinari-Ulate, Yolanda Guirado-Sánchez, Luis Platón, Henriëtte G. van der Roest, Alfonso Bahillo and Manuel A. Franco-Martín.

Resumen en español

Antecedentes: El e-learning ha demostrado ser una intervención eficaz para ayudar a los cuidadores informales de personas con demencia. Tiene el potencial de llegar a personas que viven en zonas remotas, aumentando la cobertura de los servicios. Como respuesta al contexto demográfico en España asociado a un mayor porcentaje de envejecimiento, la despoblación y las complejidades de la prestación de servicios sanitarios en zonas rurales, esta publicación describe la adaptación cultural y el co-diseño del programa de formación y apoyo en línea iSupport para Castilla y León, España, como una posible intervención de e-salud para mitigar estas limitaciones.

Métodos: La traducción y la adaptación cultural se realizaron siguiendo las directrices de la OMS, con algunas adaptaciones debidas al contexto cultural de España. Se realizaron tres grupos focales con cuidadores informales, profesionales sanitarios y un grupo de expertos en deterioro cognitivo y demencia. El proceso de co-diseño se llevó a cabo como una actividad de Participación de Pacientes y Público (PPI) con tres grupos formados por personas con demencia, cuidadores informales, población rural y expertos en tecnología y demencia.

Resultados: Se propusieron 435 sugerencias de adaptación relacionadas con terminología errónea, reformulación del texto/escritura, errores gramaticales o de signos de puntuación e información repetida o necesidad de contenido adicional. Durante el proceso de co-diseño se expusieron varias recomendaciones: preferencia por material interactivo como vídeos o imágenes, un foro para retroalimentación de profesionales sanitarios y dejar comentarios de satisfacción, disponibilidad en múltiples plataformas (por ejemplo, tableta, portátil, móvil),

formato de diapositivas para la presentación de la información, y disponibilidad para editar el tamaño de letra y los colores de fondo.

Conclusiones: Se desarrolló una versión culturalmente adaptada del iSupport para Castilla y León, España. La necesidad de modificar palabras y expresiones, enlaces de información a sitios web de recursos locales, y ajustes de los nombres de los personajes y los escenarios de los cuidadores fueron recomendadas. Las sugerencias sobre el diseño deberían tenerse en cuenta para futuras versiones adaptadas y desarrollos de la plataforma.

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Cultural adaptation of the iSupport online training and support programme for caregivers of people with dementia in Castilla y León, Spain

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Abstract

Background: E-learning has shown to be an effective intervention in helping informal caregivers of people living with dementia. It has the potential to reach people living in remote areas, increasing service coverage. As a response to the demographic context in Spain associated with a higher percentage of ageing, depopulation, and the complexities of health service delivery in rural areas, this paper describes the cultural adaptation and co-design of the iSupport online training and support programme for Castilla y León, Spain, as a potential e-health intervention to mitigate these constraints.

Methods: The translation and cultural adaptation were performed following the WHO guidelines, with some adaptation due to the cultural context of Spain. Three focus groups were conducted with informal caregivers, health professionals, and a group of experts on cognitive impairment and dementia. The co-design process was performed as a Patient and Public Involvement activity with three groups consisting of people living with dementia, informal caregivers, rural population and experts on technology and dementia.

Results: A total of 435 suggestions were proposed for adaptation associated with erroneous terminology, rewording text/writing, grammatical or punctuation marks errors, and repeated information or need for additional content. Several recommendations were exposed during the co-design process: preference for interactive material such as videos or images, a forum to receive feedback from health care professionals and to leave satisfaction comments, availability in multiple platforms (e.g., tablet, laptop, mobile), slide format for information presentation, and availability to edit letter size and background colours.

Conclusions: A culturally adapted version of the iSupport was developed for Castilla y León, Spain. The need for modification of words and expressions, information links to local resources websites, adjustments of characters' names and caregivers' scenarios, and additional content to some sections were recommended. Suggestions for the design should be taken into account for further adapted versions and platform developments.

Keywords

psychoeducation, cultural adaptation, dementia, informal caregivers, people with dementia, online interventions, training and support, iSupport, e-learning, eHealth

Background

Around 50 million people are living with dementia around the world and it is expected to increase to triple to 152 million by 2050 (Gauthier, Rosa-Neto, Morais, & Webster, 2021; Patterson, 2018). With an increase in the population living with dementia, which exponentially increases with ageing, duplicating the prevalence every five years after the ages between 65 and 69 (Villarejo Galende et al., 2021), it is to be expected a raise in the number of informal caregivers (Waligora et al., 2018).

It is estimated that 80–83% of the care is provided by family members, friends or unpaid caregivers (Alzheimer's Association, 2016; Coduras et al., 2010), a role that often falls to women (Alzheimer's Association, 2016; Pérez Diaz et al., 2020), and that 85% of the costs are related to the family (Gauthier et al., 2021; Ministerio de Sanidad, 2019). As the disease progresses, caring for a person with dementia becomes more challenging due to an increasing need for supervision and personal care (Alzheimer's Association, 2016), which can lead to adverse health and financial effects and lower quality of life (Alzheimer's Association, 2016; Casal Rodriguez et al., 2019; Waligora et al., 2018).

Supporting interventions for informal caregivers have shown improvements in quality of life and care (Dickinson et al., 2017; Naunton Morgan et al., 2022), reduction in caregiver burden, improve care service delivery or helping to cope with care responsibilities (Alzheimer's Association, 2016) and have the potential to delay nursing and residential care (Alzheimer's Association, 2016; Dickinson et al., 2017). E-learning has shown to be an effective intervention in helping informal caregivers of people living with dementia (Naunton Morgan et al., 2022), demonstrating some benefits on dementia knowledge and social support (Murray et al., 2005; Sitges-Maciá et al., 2021). It has the potential to overcome some constraints from in-person interventions, such as costs and transportation for assisting the sessions (e.g., people living in remote areas), inability to leave home because of caregiving role (Hattink et al., 2015; O'Connor et al., 2014; Wasilewski et al., 2017) and might help to increased service coverage (Pot et al., 2019).

The current demographic context in Spain, known as *"emptied Spain"*, refers to a relatively higher percentage of ageing and depopulation in rural areas and an increasing rural-urban migration, particularly of the youth. Service delivery in rural areas have been diminished and posed increasingly challenges (López González, 2021; Pérez Diaz et al., 2020). One of them is the access to support for informal caregivers of these regions. For this reason, considering the aforementioned benefits from e-learning and its significantly lower cost than other in-person and print modalities (Mitchell, 2011), we considered the adaptation and development of the iSupport online platform for the Spanish population as a potential asset to support and train informal caregivers of people living with dementia living in remote rural areas but also able to support any other regions with access to internet.

The iSupport is an evidence-based training and support program developed by the World Health Organization. It includes components of psychoeducation, relaxation, behavioural activation, cognitive reframing, and problem-solving (https://accesswho.campusvirtualsp.org/isupport-virtual-course-skills-and-knowledge-training-carers-people-dementia) (Pot et al., 2019; WHO, 2019a). It includes five modules: 1) introduction to dementia (1 lesson); 2) being a carer (4 lessons); 3) caring for me (3 lessons); 4) providing everyday care (5 lessons); and 5) dealing with behaviour changes (10 lessons). The primarily target audience are family members, relatives, friends, and other informal carers of people living with dementia (WHO, 2019a).

iSupport has already been culturally adapted in several countries and languages (e.g., Greek, Portuguese, or Chinese) and some of these projects have been published in the scientific literature (Baruah et al., 2021; Efthymiou et al., 2022; Teles et al., 2021; Xiao et al., 2022). This project aimed to culturally adapt the iSupport and co-design an online platform with people living with dementia, informal carers, and people from the target rural region of Castilla y León, Spain.

Methods

The translation and adaptation methodology was performed following the World Health Organization (WHO) Adaptation and Implementation Guide (available upon request from whodementia@who.int) (WHO, 2019b). The guide offers standardised instructions for the translation and adaptation to ensure that the adapted version is accurate and in order to the generic version without modifying its core components, but aiming to obtain an appropriate local version (WHO, 2019b). Figure 1 shows step by step the procedure followed by the authors. The process can be divided into three stages: a) translation by the authors, b) cultural adaptation, and c) co-design of the online platform.

Translation by the authors

The translation was performed by MMU and MFM who have experience in the field of dementia and have previously worked with caregivers, which facilitates the translation of the technical vocabulary.

Both authors are native Spanish speakers with a good level of English and familiar with the context of Castilla y León, Spain.

Cultural adaptation

A preliminary adaptation of the content was conducted by MMU and MFM following the Part B of the Adaptation and Implementation Guide, which describes suggestions to actual changes needed in the text or design of the online programme. This first step focused on modifying the words, names, links, and resources included in the iSupport generic version which are recommended by the Guide to be changed according to the local culture and habits. Changes to the text were included in the adaptation forms developed by WHO. Modifications to the content and text were included by the engineers LP and AB into the online version.

The next step was conducted to review the translated and adapted version and involved three focus groups with three different populations: a) informal caregivers; b) formal/professional caregivers; and c) a group of experts on cognitive impairment and dementia. We decided to involve this third group of experts as we consider they would give an extra value on how to adapt the content and the technical vocabulary to a more common use language targeting the population of interest. This step was performed by YGS who was a psychologist and local contact from the State Reference Centre for the Care of People with Alzheimer's Disease and Other Dementias.

Formal/professional and informal caregivers were recruited from the State Reference Center for the Care of People with Alzheimer's Disease and Other Dementias (Salamanca, Spain), while the group of experts were recruited from the master's program of Dementia and Neuropsychology of the

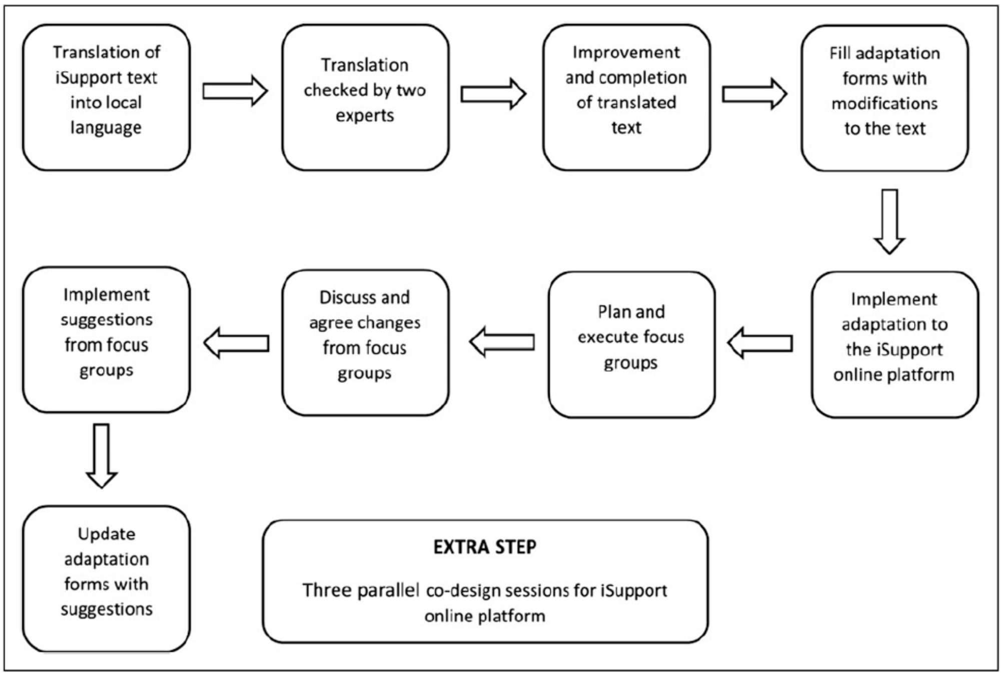

Figure 1. Translation and adaptation process (WHO, 2019b) and co-design parallel sessions.

University of Salamanca, Spain (postgraduate fellows). The experts' sample included 28 participants with an age range between 24 to 30 years.

The group of formal/professional caregivers consisted of two occupational therapists, a speech therapist, a neuropsychologist, two nurses, and a nursing assistant. The group of informal caregivers consisted of three daughters, a sister, and a spouse. Table 1 shows the characteristics of the sample of formal/professional and informal caregivers.

For the groups of informal caregivers and formal/professional caregivers, two sessions of 90 minutes were performed. The first session included an explanation of the project and how to register the modifications in the adaptation forms; the second session was performed to collect the data from each of the participants and discuss the modifications suggested. For the group of experts, the methodology was slightly different as the data was collected by e-mail after a first session where MFM explained the purpose of the project and how to register the feedback. All participants had a two-week period to go through the iSupport content and fill the adaptation forms with their suggested modifications.

All modifications and changes registered through each participant adaptation form were collected and discussed in the focus groups. The final remarks from each group were collected and included in an adaptation form to compare all the results from the three samples. A thematic analysis approach was chosen for the analysis of the data. Codes were initially obtained according to the results of previously published iSupport cultural adaptations (Baruah et al., 2021; Efthymiou et al., 2022; Teles et al., 2021; Xiao et al., 2022). When new codes were identified, they were included in the analysis. Data were coded by YGS and MMU. When disagreements were identified, a third researcher (MFM) was involved in a final decision. Engineers were once again involved to update the platform according to the final modifications obtained from the focus groups.

All suggestions were analysed and are reported in the results, however, those that were identified as altering the meaning of the text or adding content beyond the original version were not added to the final adapted version. Decisions were made through consensus between MFM and MMU who were familiar with the iSupport content and based on their clinical experience.

Co-design

An additional step to increase the quality level of the design and adaptation process of the iSupport online platform was done in parallel to the translation and adaptation process. Three Patient and Public Involvement (PPI) extra sessions were performed with: a) the European Working Group of People with Dementia (EWGPWD), a group of people living with dementia and their carers with experience in research engagement (n = 3 caregivers; n = 5 people living with dementia); b) the Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology (DISTINCT), a group of researchers aiming to improve the lives of people living with dementia and their carers through technology (n = 25); and c) a group of

Table 1. Sociodemographic data of the formal/professional and informal caregivers' sample.

	Formal caregivers	Informal caregivers
Total	7	5
Gender	85,7% (n = 6) women	100% women
Age range	26–45 years	46y and above
Age of caregiver experience	Mean 6.43 years ± 4.32 years	Mean 8.8 years ± 9 years

people living in a rural area in Salamanca, Spain (n = 16), which eight of them were or used to be caregivers of people living with dementia at the moment of the meeting. Sessions were done individually with each group. The EWGPWD meeting was performed online through Zoom, with the DISTINCT Network and the rural population meetings were in-person. The time for the sessions varied from 20 to 40 minutes.

For the EWGPWD, the iSupport generic version was shown, and through a group discussion, participants gave feedback on how to improve the platform for adapted versions. For the DISTINCT Network and the rural area population, a prototype of the iSupport Spanish adapted version (iSupport-Sp) was shown and feedback from the participants was obtained and registered. All feedback was discussed between the project leaders and engineers to consider its inclusion. Decision for the inclusion of the recommendations were done according to the technological viability and the adaptation guidelines from WHO.

Ethics

This study was not subject to the Medical Research Involving Human Subjects Act. Advice was sought from the Chair of the Research Ethics Committee of Zamora Healthcare Complex. It was considered that REC approval to conduct this project was not required as no patients and vulnerable populations were intervened and because it was approached as a public engagement activity with all participants contributing as experts.

Results

Focus groups

The focus groups were held from March to June 2022. A summary of the number of suggestions according to the categories identified is presented in Table 2.

The following categories were used to organize the modifications or recommendations identified by the participants:

Erroneous terminology refers to words, terms, concepts, that when translated might not be the most recommended in the translated language. Some of the examples identified were the use of the word *"compassion"* or *"approach"* which had to be modified from the original translation for a more appropriate terminology:

"Delete the word compassion. Substitute for understanding" (FC2, FC4, FC5, FC6) (Lesson 2, Module 2).

"Delete 'person with memory difficulties'. Substitute for 'person with dementia/living with dementia'" (FC2, FC5, FC6) (Lesson 3, Module 2).

"Use the word understanding instead of compassion" (IC4)(Lesson 2, Module 2).

"Delete the word limitations. Substitute for 'difficulties'" (FC5, FC7) (Lesson 3, Module 3).

"Change the word 'condition' for 'situation'" (FC5) (Let's look at an example, Lesson 3, Module 2).

"Delete the word miserable, it is not appropriate" (IC4) (Jo's unhelpful and helpful thoughts, Lesson 3, Module 3).

"Delete the word 'unhelpful', shouldn't be used" (FC1) (Lesson 3, Module 3).

Rewording of the text/writing included those sections where the participants considered that the translation is not correct, and writing must be changed for a better understanding. For example, some expressions that needed to be reworded according to the Spanish cultural context or changing the person's name in the examples (e.g., *Jonathan* into *Juan*):

Table 2. Total suggestions to the content of iSupport, by sample group.

	Erroneous terminology	Rewording of the text/writing	Grammatical or punctuation marks errors	Repeated information or add content	Total
Formal caregivers	40	73	57	74	244
Informal caregivers	8	6	—	7	21
Experts	16	51	11	92	170
Total	64	130	68	173	435

"Delete 'let know your friends'. Substitute for 'communicate to your friends/inform when you need to rest" (FC4, FC5, FC6) (Lesson 1, Module 2).

"Change the name Jessica for Juana" (FC5, FC6) (Lesson 1, Module 2).

"Change the name Jonathan for Juan" (FC4, FC2) (Check your understanding, Lesson 2, Module 2).

"Check the verb tenses. Questions have been formulated in a very complex way and are hard to understand" (FC6)(Lesson 1, Module 2).

"Change the time to the Spanish one. Around 10 at night" (FC5) (Activity, Lesson 5, Module 5).

Grammatical or punctuation marks errors are associated with all grammatical errors or erroneous use of the punctuation marks coming from the translation or a different used between English and Spanish. This was first checked during the translation process; however, participants identified some sections that needed to be fixed, such as:

"Check punctuation marks at the end of the first phrase" (FC3) (Check your understanding, Lesson 2, Module 2)

"Delete the commas after the word 'father'" (FC5) (Check your understanding, Lesson 2, Module 2)

"Check punctuation marks. Some commas are in the wrong position and others are not needed) (FC6) (General remark to Lesson 2, Module 2)

"Use bullet points or dashes for better understanding" (FC1, FC3) (Check your understanding, Lesson 3, Module 3)

Repeated information or add content refers to the feedback associated to a perceived repetition of the information along the text and the modules, and the perceived lack of information in several sections of the modules or the need to include relevant information according to the Spanish context or another presentation modality of the information (e.g., video or image instead of text), for example the use of links to the local public health services or associations working with people living with dementia. Another example was to include videos and audio material to help the users with the relaxation activities. In terms of additional information for clarification of the section, an example is the need for more information explaining the section of *"repetitive behaviours". Some examples are:*

"Write an introduction about relaxation in the section (relaxation section) before reading the example directly, to put the reader in context" (FC2) (The importance of relaxing, Lesson 1, Module 3)

"Add more information to this section, it is incomplete" (FC3) (Which of your activities can you do today, Lesson 2, Module 3)

"The design could be presented through audio, videos or illustrations that facilitate the understanding and execution (relaxation exercise) of the person who will implement the activity" (Expert 1) (Relaxation Exercises, Lesson 1, Module 3)

Most of the suggestions were made by formal caregivers and experts. Rewording the text/writing and highlighting repeated information or the need for additional content or further explanation to certain sections were the most mentioned suggestions. The inclusion of visual and audio material was also suggested in several sections, particularly by the experts' group, which were counted under the repeated information or add a content category. No records regarding the structure of modules and lessons were mentioned, for this reason, it was kept in line with the generic version of the programme (see Table 3).

For all the modules, repeated information and the need for additional content was the most prominent suggestion. Module 2 received the most comments. For Modules 4 and 5, no comments were recorded from informal caregivers.

Co-design

Three sessions were performed from April to May 2022. Suggestions from the sessions were collected and are presented in Table 4.

Experts, people living with dementia and caregivers suggested to include the ability to change the colours and font, allowing the users to select the best combination to their own preferences. They mentioned that a standard black and white combination might not be the best selection for everyone. Additionally, they considered that information can be offered in video format besides the written material or just video instead of text, as some carers mentioned to prefer videos over reading. Similarly, the experts and the rural area group considered, as an added value, if the information can be accessed also by audio.

Additional recommended features were the possibility to exchange feedback with health care professionals or a peer support group, to leave satisfaction comments regarding the use and content of the online platform, and to make it available for multiple platforms (e.g., mobile, tablet, laptop) as it was difficult to navigate in other devices other than a laptop. Also, experts considered important to keep the slide format presentation of the generic version instead of the continuous text to avoid an overload presentation of information.

Two recommendations, one from the experts and the other one from the EWGPWD, were considered as relevant for future implementations due to other technological requirements or because it depends particularly on the region it will be implemented. The use of a personal link, instead of username and password, could facilitate the access to the content and avoid difficulties remembering the required information. In terms of making the platform accessible in community facilities (e.g., libraries, hall) it came as suggestion for those lacking access to technological devices or Wi-Fi, which can be implemented according to each community.

iSupport-Sp online platform

Considering the previous results, we came up with the iSupport Spanish online version (iSupport-Sp). The platform is provided by a Learning Management System which allows creating and integrating course materials, articulate learning goals, align content and assessments, get users feedback, and track studying progress to make it easier for the learner and facilitator. It also incorporates dashboards to track users' progress. Therefore, it can then report on key items such as completion rates, attendance data and success likelihood. Utilizing these metrics can help facilitators better understand gaps in user knowledge.

iSupport-Sp is carried out via the consumption of text in slideshows format with customized activities in the form of a variety of different question types such as: one/multi-line answer; multiple choice answer; ordering; free text; matching; essay; true or false/yes or no; fill in the gaps; and agreement scale; and it also includes links to videos for better understand the content

Table 3. Modules and lessons of iSupport-Sp (in Spanish).

	Modules				
Lessons	Introducción a la demencia	Ser un cuidador	Cuidándome	Proporcionando cuidado diario	Afrontar los cambios conductuales
	Introducción a la demencia	El viaje juntos	Reducir el estrés en la vida cotidiana	Comer y beber - comidas más agradables	Introducción a los cambios conductuales
		Mejorando la comunicación	Hacer tiempo para actividades placenteras	Comer y beber - prevenir problemas de salud	Pérdida de memoria
		Apoyo en la toma de decisiones	Pensar de forma diferente	Cuidados en el baño y de la incontinencia	Agresión
		Involucrando a otros		Cuidado personal	Depresión, ansiedad y apatía
				Un día agradable	Dificultad para dormir
					Delirios y alucinaciones
					Comportamiento repetitivo/estereotipado
					Perderse dando un paseo
					Cambios en la capacidad de razonamiento
					Cómo ponerlo todo en orden…

of the courses. Thanks to the availability of these resources, it facilitates a self-paced learning process.

iSupport-Sp was developed in WordPress using the online training plugin LearnDash and the Enfold theme. It is hosted in a cloud system (isupport.bluece.eu) following a software as a service model. All data is stored by the facilitator's own resources and accessed by users through the internet connection. It can be accessed via most electronic devices including a computer, laptop, tablet, or smartphone, making it a versatile and easy way for users to learn wherever they are. iSupport-Sp is available upon request to the authors as it will be under study for its feasibility and usability.

Discussion

As an attempt to offer a support service alternative for informal caregivers of people living with dementia in remote rural areas in Spain, this project aimed to present the cultural adaptation of the iSupport training and support programme for carers of people living with dementia for the region of Castilla y León, Spain. Additionally, it describes the co-design process of the online iSupport platform with people living with dementia, informal carers, and people from the target rural region.

Table 4. Summary of suggestions made during the Co-design step.

	Group		
Suggestions	EWGPWD	DISTINCT	Rural area
Access to the information by audio		[b]	[b]
Feedback from health care professionals or peer support groups			
A section for satisfaction comments		[a]	
Letter size/Background colours	[a]	[a]	
Include images and videos next to the text	[a]	[a]	
Slide format (similar to the generic version)		[a]	
Multiplatform format		[a]	
A personal link to access the platform instead of a username and password		[a]	
Easy language/Avoid technical words	[a]		
Make it available in public spaces for those without access to wifi or technological devices, e.g. community libraries, town hall	[c]		

[a] represent the suggestions included in the platform.
[b] are suggestions that are planned to be included.
[c] are considered as recommendations.

A total of 435 suggestions for modification were done by the experts on cognitive impairment and dementia and the formal and informal caregivers, who provided approximately 5% of all remarks. Most of the adjustments were associated to a) repeated information (e.g., repetitive vocabulary throughout the text) or the need to add more content to introduce some sections, and the lack of information for specific topics; and b) the need for rephrasing the text or the writing to adjust it to the cultural context. Other considerations were related to grammatical or punctuation mark errors and the use of erroneous terminology (e.g., exact translation needed to be modified to a more common term to the culture). Not all suggestions could be added to the final adapted version because some of them would change the text meaning or add more information that differs from the original version. For this reason, it was necessary to filter the suggestions, especially those identified under the code "Repeated information or add content". Nonetheless, we consider it important to report all suggestions as this could be relevant for further development and improvement of the iSupport lessons and modules.

Similar remarks were provided in previous adaptations to Greek, Portuguese, Chinese-Australian and the Indian culture (Baruah et al., 2021; Efthymiou et al., 2022; Teles et al., 2021; Xiao et al., 2022). Changes associated with definitions, semantic and conceptual expressions, cultural adaptation of caregivers' scenarios, resources according to the local context (e.g., link to local institutions and websites), characters with common names according to the culture, clarity and precision of concepts and titles, and additional content regarding severe stages of dementia and more scenarios for the behavioural disorders sections, are some of the remarks identified across the previous studies that might account for all (future) adaptations. Even when the implementation is done in the same language (e.g., the English generic version to Indian culture, or the Spanish generic version to Spain culture), it has been recognized the need for several modifications on this regard (Baruah et al., 2021).

Even though WHO provides an adaptation guideline (WHO, 2019b), the adaptation processes have differed slightly between India, Portugal, Greece, Chinese-Australians and the one reported in here (Spain). According to the literature, the Greek and Chinese version (Efthymiou et al., 2022; Xiao et al., 2022) and our adaptation process have followed the recommended step of conducting two focus groups, one with informal caregivers and one with health or social care professionals caring for people living with dementia. This step aims to review the translated and adapted first attempt to obtain a better result according to the local context. For the Indian version, they performed face to face interviews and an online test run with caregivers (feedback was sent to the research team through emails) (Baruah et al., 2021) and in Portugal, this step was performed only by a group of experts on ageing, dementia and psychosocial and/or psychological support for informal caregivers of people living with dementia (Teles et al., 2021). These slight diversion between the adaptation processes is something to consider for better results on the new adapted versions. The differences might not be relevant in terms of the core components of the iSupport generic version. However, they might have an impact on the adequate process to obtain an appropriate local version. For example, the absence of either a focus group of local informal caregivers or health and social care professionals could omit the view from the important stakeholders to whom the intervention is addressed, that could improve the cultural adaptation and make the content of the iSupport more valuable for the target users. This limitation was already mentioned by Teles et al. (2021) as they lack from the informal caregivers' perspective during the review of the first cultural adapted attempt of the Portuguese version.

Consequently, for providing a more standardized version of the iSupport across countries, aiming to perform a cross-cultural study on its efficacy and effectiveness on several outcomes of informal caregivers, it is important to follow the adaptation guide provided by WHO. Nonetheless, the counterpart of this suggestion is the lack of flexibility if one of the steps is not feasible in a specific region because of lack of resources or cultural reasons. In this project, for example, the representation of male informal caregivers did not follow the recommendation of the Guide (50/50 male to female ratio) as the care responsibility mainly falls on women according to the context of caregivers in Spain (Pérez Diaz et al., 2020).

Regarding the co-design of the online iSupport platform for Spain, several recommendations not included in the generic version were exposed (Table 4). Some of them are aligned to the suggestions proposed by the focus groups in the Greek and Chinese-Australians version, such as a preference for interactive versions that include videos and a forum to receive feedback from health care professionals or a peer support group (Efthymiou et al., 2022; Xiao et al., 2022) or for satisfaction comments (according to our results), changes to the navigation style, which associates to our recommendation on keeping a slide format style to present the content instead of scrolling down the text (Efthymiou et al., 2022), the possibility to develop an alternative audio format, or facilitating the access to the platform by using voice recognition or key words search (Xiao et al., 2022), similar to our suggestion of using a personal link without the need of a password. No other recommendations were identified in other studies regarding the design of the platform.

The iSupport-Sp introduced by this project is provided via e-learning which has numerous advantages in terms of enhancing the health care service provision and enabling remote areas to access them, as otherwise it would be needed to incurred in travel costs or leave aside, in this case, caregiver responsibilities (Klimova et al., 2019; Ritterband & Tate, 2009). Also, they have shown to be cost-effective in comparison to other modalities (Dickinson et al., 2017; Mitchell, 2011) and they have the potential to offer multimedia information delivery (e.g., videos and links to access relevant websites), which has been considered relevant to potentiate learning and making more engaging content (Ruiz et al., 2006).

These advantages are especially beneficial for informal caregivers as often they are limited and restricted in time, cannot leave caregiver responsibilities or undertake other several daily duties such as employment, caring for other family members (e.g., children) or housework (Serafini et al., 2007). The only requirement is an internet connection to be able to access iSupport learning materials through a web browser and in a slide-based format at any place and time removing the geographical obstacles often associated with traditional classrooms and education.

Despite of these benefits, we are also aware of some limitations that must be considered for future versions. The most effective interventions in supporting caregivers consist of multiple components, such as cognitive behavioural therapy and relaxation strategies, educational resources, online peer support groups, and also sessions with person tailored elements (e.g., telephone contact) (Naunton Morgan et al., 2022) and interaction with health professionals (Sitges-Maciá et al., 2021). This mixture of interventions and methods delivery seems to be a key for better results, however, the iSupport-Sp is lacking elements such as online peer support, contact with health care and more personal elements. These considerations should be taking into account to incorporate in future adapted versions of the iSupport.

Strengths, limitations, and further research

The strength of this project relies on the diverse populations included during the different stages which enriches the suggestions and recommendations either for the cultural adaptation or the co-design of the online platform. Along the process, the views, and insights from people living with dementia, informal caregivers, health professionals, experts on cognitive impairment and dementia, caregivers and residents from a rural population in Spain, and experts on novel technologies to improve quality of life of people living with dementia and informal caregivers, were considered for the final adapted version of the iSupport-Sp. We hope that this diversity of perspectives offers a more feasible and user-friendly training and support programme to informal caregivers in Spain.

Regarding the population involved in the project, there are three remarks to notice. First, informal caregivers were least represented in the cultural adaptation (n = 5). This underrepresentation may have affected the inclusion of the perspectives of informal caregivers during the review of the first translated and culturally adapted content. In fact, Table 2 shows that informal caregivers' suggestions were far fewer than the other stakeholder groups, leading to an imbalance between the perspective of the three groups involved in this adaptation. Second, the same group was not representative for a rural population, which is the main target group for this adaptation. Nonetheless, the participants were residents of the region where this iSupport version has been adapted for. A rural representation was involved in the co-design of the platform. Third, the representation of male caregivers during the focus groups for the cultural adaptation was very limited (n = 1). However, this is very much representative for the context of caregivers in Spain, where the care responsibility falls mainly on women (Pérez Diaz et al., 2020).

The adaptation guide provided by WHO (2019b) includes an adaptation template to register all suggestions and modifications that must been delivered once the process is finalized for a fidelity check by the responsible of WHO. Despite the usefulness of these templates, it is difficult to manage and train participants in the focus groups to register the feedback in the templates, while also checking the content of the iSupport. For this reason, we provided a printed version of the iSupport and the templates, considering that filling the registrations by hand might be easier for some subgroups than digitally. We assumed that digitally filling the forms might especially burdensome for informal caregivers, and care professionals with lower computer literacy. It is important to notice that by the time this project is published, a Spanish generic version of the iSupport was developed by WHO (https://www.campusvirtualsp.org/es/curso/isupport-capacitacion-sobre-aptitudes-y-conocimientos-para-quienes-cuidan-de-personas-con). This version was not used for this adaptation as was not available at the time this project started. Considering this, the whole process of translation was required and the adaptation to the context of Spain, specifically for Castilla y León, is unique for the version presented in this project.

The culturally adapted iSupport-Sp on the new online platform will be tested in a usability/feasibility study with informal and formal and professional caregivers. Subsequently, a pilot study with pre- post-test assessments will be executed. The results of this pre-experimental design will serve the design of a future randomized controlled trial.

Conclusion

This study describes the Spanish cultural adaptation process of the online iSupport training and support programme. A diverse group of stakeholders was involved in the adaptation and co-design process, which impacts the quality of the adaptation to the local standards.

The cultural adaptations published in the literature in other countries and the one provided here converge on the need for modification of words and expressions, information links to relevant websites, characters' names and adjustments of caregivers' scenarios, and additional content is recommended for some sections. Some deviations were identified from the methodologies advised for the cultural adaptation. It is recommended to stick to the adaptation guideline provided by WHO for a more standardized version of the iSupport across countries.

Relevant recommendations for the design of the online platform were identified. More interactive sessions including videos and audio, a forum to receive feedback from health professionals, the option to leave satisfaction comments, availability on multiple devices (e.g., tablet, laptop, mobile), slide format for information presentation, and the option to change letter size and background colours, were some of the suggestions recorded.

Further research should study the usability and feasibility, and efficacy and effectiveness of the iSupport-Sp platform in informal caregivers.

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Authors' contribution

MMU, the executive researcher of the project wrote the first draft of the manuscript. MMU, MFM and YGS substantially contributed to the study design and to the acquisition, analysis, and interpretation of data. LP and AB contributed to the development and improvement of the iSupport online platform according to the suggestions from the results. All authors substantially contributed to the conception of the work and the final revised version of the manuscript. All authors have approved the submitted version that involved the author's contribution to the study and have agreed on both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

Declaration of conflicting interests

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Ethical approval

This study was not subject to the Medical Research Involving Human Subjects Act. Advice was sought from the Chair of the Research Ethics Committee of Zamora Healthcare Complex. It was considered that REC approval to conduct this project was not required as no patients and vulnerable populations were intervened and because it was approached as a public engagement activity with all participants contributing as experts.

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Yolanda Guirado Sánchez graduated in Occupational Therapy in 2021 from the Miguel Hernández University of Elche, Alicante, Spain. During the academic year 2021/2022 she completed a Master in Intervention in people with Alzheimer's disease and other dementias at the University of Salamanca, and in turn she joined the company Gerhogar, day care center for people in a situation of dependence in the city of Salamanca, Spain, as an occupational therapist until June 2022. She is currently taking an official course in neurorehabilitation methods and is an occupational therapist at Grupo ICOT, an integral centre for neurological specialities, on the island of Tenerife. Her interests are based on neurology and neurological diseases and increasing functionality in people with acquired brain injury and dementia.

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Henriëtte van der Roest, PhD, is a social psychologist and gained her PhD in Psychiatry in 2009 at the VU University medical center/GGZ Buitenamstel.The topic of her PhD was care needs of community dwelling people with dementia and their carers and the development and evaluation of a digital social chart. Since 2009 until 2018 she worked as a researcher and project manager on several European projects at the Department of General Practice and Elderly Care Medicine of the Amsterdam UMC (former VU University medical center). Currently, she is Head of the Department on Aging of the Netherlands Institute of Mental Health and Addiction (Trimbos Institute). Her research focus is on elderly psychiatry, dementia, informal care, person centered care, quality, organization, and policy of long-term care and community care for elderly, and assistive technology. Henriëtte has (co-)authored over 65 international peer reviewed papers, is member of INTERDEM (Early detection and Timely INTERvention in DEMentia) and an interRAI fellow.

Alfonso Bahillo received a degree in telecommunications engineering in 2006 and the Ph.D. degree in 2010 from the University of Valladolid, Spain, and the PMP Certification with PMI, in 2014. From 2006 to 2010, he joined CEDETEL as a Research Engineer. From 2006 to 2011, he was an Assistant Professor at the University of Valladolid. From 2013 to 2017, he held a Postdoctoral position and was the Project Manager of DeustoTech-Fundación Deusto, Bilbao. From 2017 to 2020 he was the Director of DeustoTech-Fundación Deusto, University of Deusto. Currently, he is Associate Professor at the University of Valladolid. He has coauthored more than 35 research papers published in international journals, more than 40 communications in international conferences, and four national patents. He has worked (leading some of them) in more than 25 regional, national, and international research projects and contracts. His interests include local and global positioning techniques, biomedical and health informatics, ambient assisted living and wireless networking.

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Appendix

Abbreviations

DISTINCT	Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology
EWGPWD	European Working Group of People With Dementia
PPI	Patient and Public Involvement
WHO	World Health Organization

CHAPTER V. DISCUSSION

Six studies comprised this project, one of which is still underway, and the others are described in the previous chapter. Each of the studies included its own discussion section in their respective publication (see Chapter IV), for this reason, this section will focus on discussing the results of the six studies in accordance with the general context of the whole project and the objectives initially stated.

This project delved deeper into potential innovative and technological solutions to equip healthcare systems with tools that could face the challenges associated to the ageing population, particularly the complexity and diversity of older adult care, the rise on the prevalence of people living with dementia and their caregivers, and the accessibility of the rural population to healthcare services to face these challenges. To pursue this objective, it intended to develop a proof of concept of a technological platform integrating several innovative digital tools to remotely assess and monitor and offer health and wellness coaching to older adults with dementia and cognitive impairment and their carers, and to study its utilisation effects on physical health, mental and emotional well-being, activities of daily living, social and cognitive functioning, and professional care use. This procedure would be accompanied by the involvement of older adults with dementia and their carers in the development and design of the platform, assessing their satisfaction, acceptability and usability, the impact of the system in realistic settings, and to enable them to manage the system autonomously in daily life.

If by "proof of concept" it is considered an "evidence (usually deriving from an experiment or pilot project) demonstrating that a design concept, business idea, etc., is feasible; a piece of such evidence" (Oxford Dictionary) or a kind of research aiming to provide justification in practice of the potential transferability of knowledge acquired through experimental testing (Kendig, 2016), then this project partially accomplished its main purpose. The six studies and their methodologies and objectives described in the previous chapters were aiming to study innovative digital tools for health and wellness coaching of older adults with dementia and cognitive impairment and their carers, however, their final results haven't been yet integrated in a single technological platform. Nonetheless, this project main outcomes can be considered as the foundations required for the development of such technological platform.

As a first step, the need to identify reliable assessment and monitoring tools matching the current older adult care needs and complexities was pinpoint. These complexities are associated with comorbidities, polypharmacy, multiple treatments and interventions from different healthcare providers, uncoordinated care, the risk of developing functional and cognitive impairment (Bernabei et al., 2008; Molinari-Ulate, Mahmoudi, Franco-Martín, & van der Roest, 2022; WHO, 2015), and the prevalence of geriatric conditions associated with chronic pain, frailty, urinary incontinence, and management of ongoing difficulties with hearing, seeing, walking or activities of daily living (ADL) (WHO, 2018). According to this panorama, the assessment and monitoring tools sought must be developed according to the principles of the integrated care approach and must assess a wide range of health domains to come up with an integrated profile of the older adult.

Reliable comprehensive assessments and monitoring tools to support clinical decisions

Such kind of assessment tools can be found in CGAs, which have demonstrated evidence that could help to face the complexity of older adult care by improving the communication and clinical data transfer between healthcare settings and stakeholders to take more reliable decisions on care planning and health policies, optimizing the quality of care (Chadwell, 2001; Common Road Map Steering Committee, 2015; Gray et al., 2009; WHO, 2019c). However, due to the diversity of domains identified in the CGAs, it is important to consider when making the decision on which CGA to use, those that are more specific on the areas under assessed, as they are screening tools that could identify potential risk factors for deterioration and take into account the complexity of older adult care (e.g., comorbidities, polypharmacy, multiple treatments, etc.), which could improve clinical decision making and personalized treatment and care plans (Bernabei et al., 2008; Molinari-Ulate, Mahmoudi, et al., 2022; Scanlan, 2005; WHO, 2015). By gathering clearer information through well-defined domains and warnings, clinicians could obtained more relevant clinical data to make more reliable decisions (Molinari-Ulate, Mahmoudi, et al., 2022). It will also be possible to develop and improve algorithms obtained from large databases, to incorporate automatic learning that can extract and identify useful information to guide the development of clinical decision models, facilitating the prognosis, diagnosis, and treatment planning, and optimizing the quality of care by identifying unmet needs of older adult care (Dipnall, et al., 2016; Góngora et al., 2018).

From the CGAs identified in the scientific literature, the interRAI LTCF and interRAI HC were considered to have better psychometric characteristics and to have been studied under higher quality methodologies than their peer CGAs (Molinari-Ulate, Mahmoudi, et al., 2022).

However, it is important to be aware of their psychometric flaws associated to the domains of mood, depression, oral health, risk of undernutrition, and urinary tract infection, as the evidence did not support the validation of these items (Molinari-Ulate, Mahmoudi, et al., 2022). Despite of this, the interRAI LTCF and interRAI HC are recommended to be used for long-term care facilities and community care, respectively, as they have also demonstrated their potential for predicting mortality, hospitalizations, admission, urinary infections, and detecting cognitive problems, falls, and nutritional risk factors (Molinari-Ulate, Mahmoudi, et al., 2022). For instance, these CGAs were the selected assessment and monitoring tools to be included in the targeted technological platform and were translated an adapted to the Spanish healthcare context (Supplementary Material #7).

DHTs to support the healthcare workforce in reaching the full capacity of CGAs

To reach the full capacity of the CGAs, it is necessary to employ DHTs that could assist on been more reliable at the completion of the items (due to the length of these assessments) and to distribute the workload of this completion between several healthcare professionals, and then support in the data management and data analysis. However, the lack of scientific literature reporting on DHTs supporting these assessment tools (Molinari-Ulate, Mahmoudi, Parra-Vidales, Muñoz-Sánchez, Martin, & van der Roest, in press), can put at risk the reliability of the outcomes obtained from the CGAs, the usability and implementation of these assessment tools in the healthcare services, and their acceptability by the healthcare workforce. In fact, this lack of evidence has been associated with poorly designed systems that could threaten the safety of patients and contributing to users' burnout and low morale (Committee on Patient Safety and Health Information Technology, Institue of Medicine, 2011; Kroth et al., 2019; Sheikh et al., 2021), leading to concerns regarding decision-making, quality of care, interventions and care planning, as these are supported by the assessments' results (Vanneste, De Almeida Mello, Macq, Van Audenhove, & Declercq, 2015).

To reinforced the usability, effectiveness, and implementation of DHTs in healthcare settings, the following features were identified: a) utilization of a safe data storage warehouse, such as clouds; b) inclusion of automatic alerts, notifications, or a continuous check for item completion; c) access allowance for multiple health care professionals on individual assessments, avoiding to rely on one professional to complete the assessment but using the expertise of each team member; d) provisioning of individualized profile reports of needs and risks, and personalised care plans; and d) automatic calculation of the composite outcomes and scales. Additionally, assuring the security and privacy of the data and improving the exchange of information between healthcare organisations have been also targeted as major priorities for enhancing the implementation of DHTs in healthcare systems (Sheikh et al., 2021).

Some important barriers identified that could affect the implementation of these DHTs in care practice were a) technical difficulties using the software; b) length of the assessments; c) inconsistent network connectivity; d) carrying around the hardware, mainly laptops; e) need of ongoing training to perform the assessment correctly; and f) the lack of staff knowledge regarding the information collected and its purpose (Duyver, Van Houdt, De Lepeleire, Dory, & Degryse, 2010; Smith, Whiddett, & Hunter, 2013). However, current technologies can be implemented to overcome these complexities; for example, multiple and novel wearable and lighter devices are now available in the market that can be carried around instead of laptops; network connectivity has and is progressively improving in terms of service coverage, speed, and consistency; novel software and apps might be able to perform offline assessments; technology can support multiple access for data entry and breakdown long assessment instruments facilitating a more efficient and multidisciplinary administration; and guidelines and recommendations on the assessment and development of DHTs have been developed (Dröes et al., 2020; ISO, 2021; WHO, 2019c). Nonetheless, other barriers such as the training of health professionals on the assessments and staff knowledge regarding the purpose of the data collected are not technology related and need to be addressed. To avoid these specific problems, it will be necessary to invest in data science, quality improvement and health informatics training for the healthcare workforce, and to incorporate data scientists and clinical informaticists in the clinical teams (Sheikh et al., 2021). Also, by engaging the healthcare professionals and the patients in the design and development, research and implementation process of the DHTs, leading to more engaging and user-friendly systems aligned to the stakeholders' needs (Thabrew, Fleming, Hetrick, & Merry, 2018) and to identify early amendments, reducing the costs of the systems (Kushniruk, Hall, Baylis, Borycki, & Kannry, 2019; Sheikh et al., 2021).

Considering both, the features reinforcing the usability, effectiveness and implementation of DHTs and the identified barriers that prevent it, the last recommendation associated to the engagement of the stakeholders and the patients in the design, development, research, and implementation process to develop more engaging and user-friendly systems, became more relevant for this project. For this reason, it was necessary to study how to involve the potential users in the design and development of the targeted technological platform during a particular situation that changed the world, the COVID-19 pandemic.

Digital involvement of the patients and the public under the COVID-19 pandemic circumstances

Three months after this project started (December 2019), the World Health Organization declared in March 2020 the COVID-19 pandemic, challenging any kind of human activity, including the involvement of patients and the public in research mainly because of social distancing, lockdowns, and other reduced physical contact restrictions (NHS, 2021). Therefore, quick responses and adjustments were needed, increasing the use of Information and Communication Technologies (ICT) (Cadel et al., 2021; Johnson, 2020). Additionally, the target population of this project are PLwD and their carers living in rural areas, some of them located in remote areas, so the possibility of involving them in the development process may involve offering them remotely digital participation. For this reason, it was required to study how to perform digital PPI.

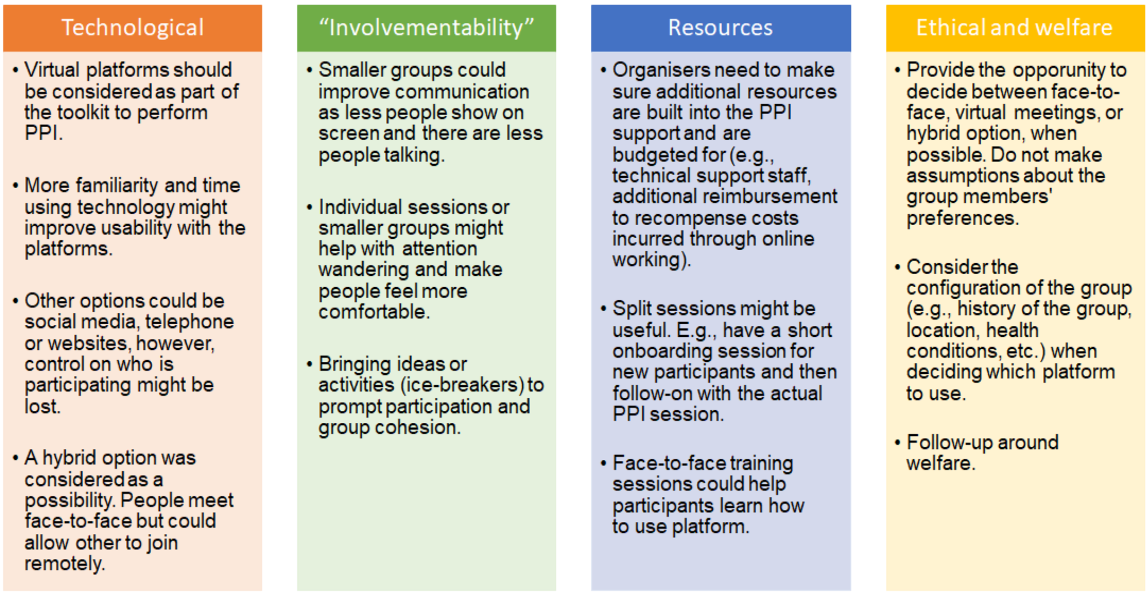
Previous literature on conducting e-PPI highlighted several challenges that differ from those found in face-to-face meetings such as: a) less spontaneous interactions between the individuals (e.g., more direction from the meeting chairs, breaks taken individually), b) lack of non-verbal cues (e.g., difficult to observe nonverbal communication such as gestures), c) difficulties in turn-taking (e.g., less spontaneous change of speaker), d) changes in the meeting chair role (e.g., a more active and directive role), e) linguistic barriers (e.g., less participation in discussions), or f) limited view of each participant’s face (Lampa, Sonnentheil, Tökés, & Warner, 2021). Also, limitations of internet use as being impersonal, expensive, or stressful, and alternatives such as weblogs not considered to be a replacement for in-person meetings (Dogba et al., 2019), spotlight the importance of getting e-PPI right.

The development of the ‘E-nabling Digital Co-production’ Framework was a response to this rapid transition to digital co-production, however, it is not exclusive to e-PPI as it was also consider as a tool with the potential to examine how PPI is approached in different contexts and conditions (Molinari-Ulate, Woodcock, et al., 2022). The framework also explores the preferences and implications of different modalities of conducting PPI within the post-pandemic transition (Molinari-Ulate, Woodcock, et al., 2022). To the best of our knowledge, this framework is the first one targeting the digitalization of PPI and to consider it as a part of a blended approach (Molinari-Ulate, ReWoodcock, et al., 2022), as in a previous systematic review reporting on 65 frameworks for supporting, evaluating, and reporting PPI, this was not considered (Greenhalgh et al., 2019).

Regarding the challenges and approaches of e-PPI identified through the framework, some of the challenges previously described by other studies were confirmed (Dogba et al., 2019; Lampa et al., 2021). e-PPI was considered to act as a barrier for communication and social interaction compared to experiences of meeting face-to-face (Molinari-Ulate, Woodcock, et al., 2022). Nonetheless, it offers an opportunity to re-evaluate the importance of meeting etiquette and communication styles which might provide a way into conversations for those who are less confident (Molinari-Ulate, Woodcock, et al., 2022). Also, e-PPI was considered in one respect as a barrier in terms of the diversity and inclusion of the PPI groups if the same members are always attending the sessions, however, it was also mentioned that the virtuality could offer the opportunity to include others who have not engaged in PPI before (Molinari-Ulate, Woodcock, et al., 2022).

Therefore, e-PPI has a variety of pros and cons that must be evaluated as part of a context specific and coproduced response, to find the right solutions. For example, within the dementia context, e-PPI offers carers the capacity to attend more meetings but simultaneously they may lose time away care responsibility, also they might be excluding those living alone or needing more support, and potentially more challenging to distinguish impacts that having a caregiver present may have on the level of participation of the person they are supporting (Molinari-Ulate, Woodcock, et al., 2022). For those with cognitive impairment, enabling them to take part is a more specific concern, as the facilitators must be mindful of the participants' cognitive abilities to remember joining instructions, consider their levels of attention and concentration, or provision of explicit cues to the speaker (Molinari-Ulate, Woodcock, et al., 2022). These special characteristics of this specific context may lead to the need for specialised training for facilitators, having additional supporters in the meeting, or other relevant potential solutions.

As an attempt to improve the implementation of e-PPI, several recommendations were identified by using the ‘E-nabling Digital Co-production’ Framework which were aligned to those suggested previously by Lampa et al. (2021) (see Figure 6).



Technological

- Virtual platforms should be considered as part of the toolkit to perform PPI.
- More familiarity and time using technology might improve usability with the platforms.
- Other options could be social media, telephone or websites, however, control on who is participating might be lost.
- A hybrid option was considered as a possibility. People meet face-to-face but could allow other to join remotely.

“Involvementability”

- Smaller groups could improve communication as less people show on screen and there are less people talking.
- Individual sessions or smaller groups might help with attention wandering and make people feel more comfortable.
- Bringing ideas or activities (ice-breakers) to prompt participation and group cohesion.

Resources

- Organisers need to make sure additional resources are built into the PPI support and are budgeted for (e.g., technical support staff, additional reimbursement to recompense costs incurred through online working).
- Split sessions might be useful. E.g., have a short onboarding session for new participants and then follow-on with the actual PPI session.
- Face-to-face training sessions could help participants learn how to use platform.

Ethical and welfare

- Provide the opportunity to decide between face-to-face, virtual meetings, or hybrid option, when possible. Do not make assumptions about the group members' preferences.
- Consider the configuration of the group (e.g., history of the group, location, health conditions, etc.) when deciding which platform to use.
- Follow-up around welfare.

Figure 6. Tips to improve e-PPI meetings

Adaptation of evidence-based interventions to deliver integrated care

The lessons learned from the digital engagement of the stakeholders and patients, were necessary to move to the next and final steps of the project. Due to the lack of resources in healthcare systems to address the challenges associated with dementia, such as insufficient healthcare workforce trained, lack of dementia knowledge and lack of funding for long-term care (Fam, Mahendran, & Kua, 2019; Prince et al., 2008; Richly et al., 2019), and the changing role of caregiving because of the reduction of young population and a more active role of women in the workplace (Fam et al., 2019; Prina, Mayston, Wu, & Prince, 2019; Prince et al., 2008), there is a growing need for socio-community programs that take into account the local resources in search of more sustainable and effective interventions (Fam et al., 2019; Prina et al., 2019; Prince et al., 2008).

The Meeting Centres Support Programme in Spanish Speaking countries

Such socio-community program could be the MCSP, which has demonstrated to be an intervention with greater socio-community integration and a better cost-benefit ratio, improving the quality of life and the mental health of PLwD and their carers (Brooker et al., 2018; Dröes, Breebaart, et al., 2004; Dröes, Meiland, et al., 2004; Henderson et al., 2021; Mangiaracina et al., 2017). However, these results and its implementation have been successfully demonstrated in non-Spanish Speaking European countries, such as The Netherlands, United Kingdom, Poland and Italy.

Therefore, stakeholders from Spain and Ecuador were interviewed online to identify the facilitators and barriers of the implementation of the MCSP in two regions, Zamora and Cotacachi, respectively. The facilitators and barriers identified differed according to the cultural context, the access to training resources and the geographic distribution of these populations (Molinari-Ulate, Vallejos, van der Roest, Franco-Martín, & Dröes, under review). Also, some of the facilitators and barriers differed from the ones identified in non-Spanish speaking countries. For example, the access to rural areas and the need for transportation were identified as the main barriers to implement this programme in the Spanish-speaking countries (Molinari-Ulate, Vallejos, under review). Other barriers were identified that were not evident in previous research (Mangiaracina et al., 2017; Meiland et al., 2005). In Ecuador, the administrative process to create collaborations or obtain funding was considered as a possible barrier because it could slow down the process (Molinari-Ulate, Vallejos, et al., under review). In Spain, the program was perceived as an additional burden as it was not fully adjusted to the needs of informal caregivers, who expected a traditional day care centre methodology (Molinari-Ulate, Vallejos, et al., under review).

Additionally, in Ecuador, the enthusiasm of all parties involved, including project promoters, was identified as a facilitator as in other studies in Europe (Mangiaracina et al., 2017; Meiland et al., 2005), and similarly to the UK and Poland (Mangiaracina et al., 2017), in Ecuador the coordination between social welfare and health organizations or departments to obtain funding and create collaborations was highlighted as a barrier. The latter arises because the MCSP pertains to both areas, so it could benefit from support from both sectors (Meiland et al., 2004). Also, contrary to the perception of Ecuador and other Northern European countries, the availability of staff and volunteers trained and skilled in MCSP and finding a sufficient number of participants were identified as facilitators in Spain (Mangiaracina et al., 2017; Meiland et al., 2005).

This shows the need to develop strategic adaptation plans for the implementation of socio-community programs, such as the MCSP, taking into account the cultural contexts and geographic distributions of the regions of interest. It is recommended that this adaption includes the socio-cultural adaptation of training materials, in addition to the development of actions to overcome specific barriers, such as the development of resources to offer the service remotely to provide access to rural populations (Molinari-Ulate, Vallejos, et al., under review).

For example, due to lack of adapted training material identified as a barrier in this study, the ‘Guide to setting up Meeting Centres for people with dementia and their caregivers’ was translated and adapted to Spanish, and thanks to the collaboration between the MeetingDem network and the Institute of Biomedical Research of Salamanca (IBSAL), through a subproject of the DISTINCT program, the course in Spanish for the Implementation of Meeting Centers was developed, available free of charge and online at the following link https://e4you.org/es/moocs/implementacion-de-centros-de-encuentro-para-personas-con-demencia-y-sus-cuidadores (Supplementary Material #5). It is expected that this material have an impact in the implementation of Meeting Centres in Spain and Latin America.

iSupport-Sp: an attempt to provide training and support for caregivers of PLwD living in remote rural areas in Castilla y León, Spain.

As a response to the rural barrier identified in the implementation of the MCSP and considering the sociodemographic situation of the ‘Emptied Spain’, the final step of the project targeted how to deliver remotely and accessible healthcare services for PLwD and their caregivers living in remote rural areas. Due to the financial and time constraints of this project, the focus was solely on developing an intervention for caregivers of PLwD.

As an attempt to reach the caregivers of PLwD living in remote rural areas of Castilla y León, Spain, and to provide them with a support service alternative for training and support, the iSupport-Sp was developed. This training and support program is based on its original version developed by the WHO, and it includes the same five modules and number of lessons, with the difference that includes several modifications suggested during the cultural adaptation according to the Spanish context of Castilla y León, and the recommendations identified during the co-design process of the online platform (Molinari-Ulate et al., 2023).

The iSupport-Sp includes similar changes and recommendations to those identified in previous cultural adaptions (Baruah, Loganathan, et al., 2021; Efthymiou et al., 2022; Teles et al., 2021; Xiao, Ye, et al., 2022). For example, changes associated with definitions, semantic and conceptual expressions, cultural adaptation of caregivers' scenarios, resources according to the local context (e.g., link to local institutions and websites), characters with common names according to the culture, clarity and precision of concepts and titles. However, not all suggestions were added to the final adapted version because some of them would change the text meaning or add more information that differs from the original version, especially those identified under the code "Repeated information or add content". Nonetheless, it was considered important to report all suggestions as this could be relevant for further development and improvement of the iSupport lessons and modules, and to support other future adaptations (Molinari-Ulate et al., 2023).

For providing more standardized versions of the iSupport across countries, it is important to follow the adaptation guide provided by WHO. This will bring the opportunity to conduct more reliable cross-cultural studies on its efficacy and effectiveness on informal caregivers. Nonetheless, the counterpart of this suggestion is the lack of flexibility if one of the steps is not feasible in a specific region because of lack of resources or cultural reasons (Molinari-Ulate et al., 2023). For example, for the iSupport-Sp adaptation, the representation of male informal caregivers did not follow the recommendation of the Guide (50/50 male to female ratio) as the care responsibility mainly falls on women, which represents the context of caregivers in Spain (Pérez Diaz et al., 2020).

Regarding the co-design of the online iSupport-Sp platform, several recommendations were included, aligned to the suggestions identified in the Greek and Chinese-Australians version. A preference for interactive versions that include videos and a forum to receive feedback from healthcare professionals or a peer support group (Efthymiou et al., 2022; Xiao, Ye, et al., 2022) or for satisfaction comments (Molinari-Ulate et al., 2023), changes to the navigation style, such as keeping a slide format style to present the content instead of scrolling down the text (Efthymiou et al., 2022; Molinari-Ulate et al., 2023), the possibility to develop an alternative audio format (Molinari-Ulate et al., 2023), or facilitating the access to the platform by using voice recognition or key words search (Xiao, Ye, et al., 2022) or by using a personal link without the need of a password (Molinari-Ulate et al., 2023).

The iSupport-Sp online platform is provided via e-learning as it aims to enhance the healthcare service provision and to enable remote areas to access its content and resources, otherwise, these remote populations would incurred in travel costs or leave aside caregiver responsibilities to access these resources (Klimova, Valis, Kuca, & Masopust, 2019;

Ritterband & Tate, 2009). E-learning tools have demonstrated to be cost-effective compare to other modalities (Dickinson et al., 2017; Mitchell, 2011) and to have the potential of delivering multimedia information, which has been considered relevant to offer more engaging content and to potentiate learning (Ruiz, Mintzer, & Leipzig, 2006). The only requirement to access the iSupport-Sp is to have internet connection, then, its learning materials could be accessed at any place and time removing any geographical obstacles and the limitation associated to the caregiving role, such as restricted time or undertake daily duties such as employment, caring for other family members or housework (Serafini, Damianakis, & Marziali, 2007).

Despite of these benefits and all the recommendations identified during the co-design process, the current iSupport-Sp has several limitations that needs to be improve in future versions. According to the scientific literature, the most effective interventions in supporting caregivers consist of multiple components, such as cognitive behavioural therapy (CBT) and relaxation strategies, educational resources, online peer support groups, and sessions with person tailored elements (e.g., telephone contact) (Naunton Morgan, Windle, Sharp, & Lamers, 2022) and interaction with healthcare professionals (Sitges-Maciá, Bonete-López, Sánchez-Cabaco, & Oltra-Cucarella, 2021). The iSupport-Sp current version includes the multiple component therapeutic features (e.g., CBT, relaxation, problem-solving, etc.), however, it lacks from elements such as online peer support, contact with healthcare professionals and more person tailored elements (Molinari-Ulate et al., 2023).

There is no evidence on the efficacy and effectiveness of the use of the iSupport on any caregivers' outcomes (e.g., caregiver burden, dementia knowledge, mental health). However, several randomized controlled trials are being conducted to identify its potential as a caregivers' intervention (Baruah, Varghese, et al., 2021; Nguyen et al., 2021; Teles, Ferreira, Seeher, Fréel, & Paúl, 2020; Xiao, Wang, et al., 2022). The iSupport-Sp is currently being under study for its usability and user-friendliness, additionally, a pilot efficacy study is underway to identify preliminary data of its impact on caregiver burden and dementia knowledge level of caregivers of PLwD.

In summary…

By putting together all the results obtained in this project, it becomes clear that it is potentially feasible to develop a technological platform for health and wellness coaching of older adults with dementia and mild cognitive impairment and their carers in rural areas. For the assessment and monitoring, the interRAI LTCF and HC were the selected CGAs to be embedded in the platform, demonstrating high psychometric standards and potential for predicting mortality, hospitalizations, admissions, urinary infections and cognitive, falls, and nutritional risk factors, and also provide the clinicians with warnings and personalized care plans (Molinari-Ulate, Mahmoudi, et al., 2022). Additionally, they were translated and adapted according to the Spanish healthcare context. However, to take advantage of its full potential, they must be supported by a DHT that could produce automatic alerts and notifications, allowing multiple healthcare professionals to be involved in the assessment, and providing them with individualized profile reports of needs and risks and care plans (Molinari-Ulate, Mahmoudi, et al., in press). These features should be part of the targeted technological platform. Once the clinicians received the clinical data of warnings and personalized care needs in a simple and user-friendly manner (e.g., graphical representation of the person's health profile and status), they could offer an immediate response through digital and remote interventions that must be integrated in the technological platform. According to what it has been identified in this project, difficulties on accessing rural populations is a barrier to implement socio-community programmes such as the MCSP (Molinari-Ulate, Vallejos, et al., under review). The technological platform must include a remote access modality to some of the activities perform in the Meeting Centres, making them available to the rural populations through telepresence, facilitating the potential user with the same activities that are performed in-person and in real-time. Also, family members and caregivers could be supported through e-learning technologies, such as the iSupport-Sp, without requiring moving to physical facilities and leaving their caregivers' responsibilities (Molinari-Ulate et al., 2023). However, to potentiate the implementation and usability of the technological platform, it must be developed according to the stakeholders' needs. To do this, the development should integrate co-design and co-development sessions through Patient and Public Involvement, including the lessons learned from performing digital PPI as it might be the key to involve people living in remote rural areas (Molinari-Ulate, Woodcock, et al., 2022; Thabrew et al., 2018).

To make this technological platform feasible and possible, additional to all the work done in this project, it is still needed to integrate and prove several novel technologies that could facilitate all the technological requirements. To remotely assess and monitor, several devices must be installed in the potential users houses such as wearable technologies, monitoring devices, smart houses, social robots, and telepresence technologies. Then, the data obtained from the devices should help on filling the CGAs information and should be cross validated with the data obtained from the healthcare professionals. This will produce a big amount of data that could support the improvement and development of algorithms that could be used to incorporate automatic learning to extract and identify useful clinical information through machine learning and AI (Dipnall et al., 2016; Góngora et al., 2018; Sheikh et al., 2021). This could guide the development of decision models for medical and care procedures, such as prognosis, diagnosis, and treatment planning, optimizing personalized treatments and improving evidence-based decisions making among clinicians and scientists, identifying the causes of unmet care of older adults and more effective treatment approaches (Góngora et al., 2018). Then, according to the personalized care treatment plans, several remote interventions integrated in the platform could be offer to the healthcare professionals and potential users such as caregivers, older adults, and PLwD.

Strengths, limitations, and future research

Each study describes its own strengths and limitations in their respective publications (see Chapter IV). In this section, the strengths and limitations of the entire project are described, and some recommendations to continue this line of research are also provided.

The strength of this project relies mainly in two specific rationales: multidisciplinarity and the engagement of the patients and the public. Throughout the entire process, these two rationales are very well reflected and were the main pillars on which the basis of this project was built. First, a wide range of disciplines were involved during the different studies, from healthcare professionals (e.g., psychiatrists, gerontologists, psychologists, neuropsychologists, nurses), social workers, occupational therapists, administrative staff, to engineering professionals (e.g., computer engineers, telecommunication engineers, industrial engineers). The diversity of opinions, methodologies, and knowledge coming from all these disciplines, made it possible to cover the vast majority of aspects of a subject as complex and diverse as Digital Health and older adult care. When delving deeper into this topic, the importance and necessity of multidisciplinary work becomes much more evident, since no professional or discipline has the knowledge and skills to be able to develop this type of initiatives. For this reason, it becomes clearer the need to address the complexity of older adult care and dementia care from an integral and holistic perspective, not only because of the characteristics of the target population, but also because the solutions to face these challenges can only be developed in a collective and interdisciplinary manner. Second, the engagement of the public, patients and any other stakeholders in the entire process since the development to the implementation and continuation assessment of a new DHT, becomes crucial to develop user-friendly systems that targets the real needs of the population of interest. Their contributions are essential to avoid higher costs for technologies that are not used, outdated or forgotten, and to really have an impact on the issues under discussion. As it was described in the previous chapters, this project made an effort to involve different stakeholders during the entire process, from PLwD and their carers, healthcare professionals, and researchers, to politicians, PPI contributors and rural populations.

The main obstacle this project faced were the restrictions imposed because of the COVID-19 pandemic. This situation not only stopped and delayed any progress since the beginning (the project started in December 2019) but also impeded the access to the main stakeholders of the project: older adults, PLwD, caregivers of PLwD, and healthcare professionals. All these populations were the most restricted to have any face-to-face contact due to their vulnerability if getting infected. To face this situation, the whole research plan needed to be restructure and adapted, and the progress was done according to the uncertainty of the pandemic evolution. As any other field during the lockdowns, the rapid transition to digital working came with several challenges for which no preparation was done and whose answers were given right on the spot. For this project, the first face-to-face meeting with the target population started at the end of 2021, almost two years after the start in 2019.

Another relevant limitation was to depend on the development of the technology on the technical side. The pace and challenges from developing a DHT from scratch are diverse and range from technical difficulties such as the availability of the technological devices, software, internet access and connection, or details on the programming, to accessing the target population to get feedback on the technology, adapt the materials to cultural context of interest, or getting the funding for the maintenance. It clearly reflects that time and patience are needed while waiting for the first prototype.

Other obstacles that had to be faced were the lack of evidence-based material offer in the Spanish language. This not only implies the translation of the content, but also its cultural adaptation to the region in which it will be implemented. This requires devoting time to a number of tasks that are not necessarily related to obtaining the scientific evidence of the tools or interventions that want to be implemented. Apart from that, this study targeted people living in rural areas, so the adaptation was not only necessary in terms of the culture, but also regarding the specific complexities of accessing these regions and how to deliver the adapted interventions in such a way that it would not increase their costs and take time away from their daily responsibilities.

To continue this line of research, either academic institutions, industry, and healthcare systems, should integrate in their departments multidisciplinary groups including disciplines such as engineering, healthcare professionals with expertise on the topic of interest, and the target stakeholders for whom the developed technology is intended. This will provide an environment enriched by different knowledge and perspectives and could speed out the development of initiatives and prevent errors, saving potential costs. Also, this will increase the chances to develop more user-friendly technologies that target the specific needs of those for whom it is intended.

By considering the lessons learned and outcomes obtained from this study, future research can take advantage of the information described in this project and integrate it with novel technologies or already developed technological platforms to improve the healthcare services for people living in remote rural areas. Nonetheless, it is still necessary to focus on studying the feasibility, usability, efficacy and effectiveness of some of the tools elaborated for this project, and if it is feasible and effective to deliver them remotely.

CHAPTER VI.

CONCLUSIONS (ENGLISH & SPANISH)

Conclusions in English

This project described a series of steps necessary to create the foundations of a technological platform for health and wellness coaching of older adults with dementia and cognitive impairment and their carers. The studies comprised in the project aimed to contribute to the search for solutions to face the challenges that come with the ageing population, particularly the complexity of older adult care, the increase of people living with dementia and their caregivers, and the poor accessibility of rural populations to access healthcare services to face these challenges.

First, the timely detection of clinical problems, side effects or comorbidity is strategic for a good quality care, so, it is highly relevant to considered reliable assessment tools with clear and specific domains to support clinical decisions. This project recommends the use of the interRAI LTCF and interRAI HC for long-term care facilities and community care, respectively, as the scientific literature has evidence high standards in the studies validating them, associated to the sample size, number of studies, instrument development trajectory, validation in several countries, and availability in different care settings. Also, their validity and reliability results have been improving since their initial versions, reaching high standards for most of the domains assessed. Additionally, they have demonstrated potential for predicting mortality, hospitalizations, admission, urinary infections, and detecting cognitive problems, falls, and nutritional risk factors. Nonetheless, it is important to be aware and raise the concern regarding their flaws in assessing aspects such as mood, depression, oral health, risk of undernutrition, and urinary tract infection. Both the manual and form for both CGAs have been translated and adapted to the Spanish context and are available upon request to the author of this project.

Second, the evidence on the feasibility and usability, efficacy and effectiveness, implementation outcomes, and technical features of DHTs supporting the administration of CGAs were identified, as they are necessary to reach the full capacity of the CGAs. The scientific literature on this topic was scarce, describing limited information on the technical features, required hardware, and lack of implementation studies of DHTs. On one side, the barriers identified regarding their usability and feasibility were a) the availability and accessibility to appropriate devices; b) inconsistency in network connectivity; c) technical issues leading to inappropriate, inconsistent, and missing data; d) duration of the assessment;

and e) lack of training and knowledge regarding the information collected and its purpose. On the other side, the recommendations that might improve their usability and implementation were a) the accessibility to the individual's assessment by multiple health care professionals and allowance to break down the sections according to the professional expertise to share the assessments' responsibility; b) the use of safe data storage, such as clouds; automatization of a real-time calculation of the scales and outcomes with a graphical representation of the person's profile and health status; c) automatic alerts, notifications and continuous monitoring for item completion; and d) provisioning of personalized care plans according to the data collected.

Third, the digital engagement of stakeholders and patients on the design, development, research and implementation, was studied to face the challenges caused by the COVID-19 pandemic on developing this research methodology and to engage people living in remote rural areas. The 'E-nabling Digital Co-production' Framework was useful in advancing understanding of the issues and opportunities regarding e-PPI. It was identified as a useful tool for researchers, PPI coordinators and vitally public contributors to identify and discuss pros and cons provided by e-PPI and blended and hybrid approaches. The two main advantages identified from e-PPI were the removal of geographical constraints which is useful to widen participation, and that it saves resources in terms of time saved on not travelling to meetings, and facilitating arrangements associated to venues, catering, or other coordination, such as transportation. The framework was also useful to identify several recommendations to improve the implementation of e-PPI.

Four, the facilitators and barriers of implementing a socio-community care approach that has demonstrated better cost-benefit ratio compared to other methodologies, the MCSP, were identified. The main obstacles identified were the project funding and the coordination and collaboration between institutions. Additionally, the difficulty to involve rural populations and the need to access training materials and training for personnel were relevant topics for the cultural context of Spain. Enthusiasm among stakeholders and interinstitutional collaboration have been identified as key enablers. The need for an adapted implementation process to the context of interest, and the development of actions to overcome specific barriers, such as the development of tools to offer this care approach remotely to involve rural populations, was considered as the major finding. As part of the results of this project, the 'Guide to setting up Meeting Centres for people with dementia and their caregivers' is available in Spanish, and the Spanish Course for the Implementation of Meeting Centres is available at https://e4you.org/es/moocs/implementacion-de-centros-de-encuentro-para-personas-con-demencia-y-sus-cuidadores.

Five, as an attempt to offer a support service alternative for caregivers of PLwD in remote rural areas of Spain, the cultural adaptation of the iSupport training and support programme for carers of PLwD was developed. The iSupport-Sp platform is provided via e-learning, enhancing the health care service provision, and enabling remote areas to access it with the only requirement of having access to internet connection. This will be especially beneficial for caregivers often limited from their restricted time due to caregiver responsibilities and other daily duties. Relevant recommendations for the design of the online platform were identified, such as more interactive sessions including videos and audio, a forum to receive feedback from health professionals, the option to leave satisfaction comments, availability on multiple devices (e.g., tablet, laptop, mobile), slide format for information presentation, and the option to change letter size and background colours, were some of the suggestions recorded. The current iSupport-Sp has several limitations that needs to be improve in future versions, as it lacks from elements such as online peer support, contact with healthcare professionals and more person tailored elements. Currently, the iSupport-Sp usability and user-experience, and its impact on dementia knowledge and caregiver burden, are being currently studied to obtain some evidence of its efficacy and improve the service to target the stakeholders' needs. Through the following link it is possible to access the iSupport-Sp usability and pilot study https://learning.bluece.eu/.

Lastly, by embedding the findings from these five steps and by including novel technologies such as AI, robotics, wearable technologies, and monitoring devices, the idea of the technological platform could be feasible. This integration of technologies is needed to guide the development of decision models for medical and care procedures, such as prognosis, diagnosis, and treatment planning, to optimize the development of personalized treatments and improve decisions making among clinicians and scientists, to identify the unmet needs of older adults and to offer more effective treatment approaches. Further projects can learn from the lessons obtained in this project and could implement the initiatives described here, to generate an impact on potential solutions for challenges currently faced by the ageing population.

Conclusions in Spanish/Conclusiones en Español

Este proyecto describió una serie de pasos necesarios para crear las bases de una plataforma tecnológica para la capacitación en salud y bienestar de los adultos mayores que viven con demencia y deterioro cognitivo y sus cuidadores. Los estudios incluidos en el proyecto pretendían contribuir a la búsqueda de soluciones para hacer frente a los retos que plantea el envejecimiento de la población, en particular la complejidad de la atención a los adultos mayores, el aumento de las personas que viven con demencia y de sus cuidadores, y la escasa accesibilidad de las poblaciones rurales a los servicios sanitarios para afrontar estos retos.

En primer lugar, la detección oportuna de problemas clínicos, efectos secundarios o comorbilidad es estratégica para una atención de buena calidad, por lo que es de gran relevancia considerar herramientas de evaluación confiables con dominios claros y específicos para apoyar las decisiones clínicas. En este proyecto se recomienda el uso del interRAI LTCF e interRAI HC para residencias de larga estancia y atención domiciliaria, respectivamente, ya que la literatura científica ha evidenciado altos estándares en los estudios que los validan, asociados al tamaño de la muestra, número de estudios, trayectoria de desarrollo de los instrumentos, validación en varios países y disponibilidad en diferentes entornos de atención. Asimismo, sus resultados de validez y confiabilidad han ido mejorando desde sus versiones iniciales, alcanzando altos estándares para la mayoría de los dominios evaluados. Además, han demostrado potencial para predecir mortalidad, hospitalizaciones, ingresos, infecciones urinarias y detectar problemas cognitivos, caídas y factores de riesgo nutricional. No obstante, es importante ser conscientes y plantear la preocupación sobre sus defectos en la evaluación de aspectos como el estado de ánimo, la depresión, la salud bucodental, el riesgo de desnutrición y la infección urinaria. Tanto el manual como el formulario de ambas EGI han sido traducidos y adaptados al contexto español y están disponibles previa solicitud al autor de este proyecto.

En segundo lugar, se identificaron las pruebas sobre la viabilidad y la usabilidad, la eficacia y la efectividad, los resultados de la implementación y las características técnicas de las TSD que apoyan la administración de EGI, ya que son necesarias para alcanzar la plena capacidad de estas. La literatura científica sobre este tema es escasa con información limitada sobre las características técnicas, el hardware necesario y la falta de estudios de implementación de las TSD. Por un lado, las barreras identificadas en relación con su usabilidad y viabilidad fueron a) la disponibilidad y accesibilidad a los dispositivos apropiados; b) la inconsistencia en la conectividad de red; c) los problemas técnicos que conducen a datos inapropiados, inconsistentes y faltantes; d) la duración de la evaluación; y e) la falta de formación y conocimiento sobre la información recogida y su propósito. Por otro lado, las recomendaciones que podrían mejorar su usabilidad e implementación fueron a) la accesibilidad a la evaluación por parte de varios profesionales sanitarios y la posibilidad de dividir las secciones según la experiencia profesional para compartir la responsabilidad de las evaluaciones; b) el uso de almacenamiento de datos seguro, como las nubes; la automatización de un cálculo en tiempo real de las escalas y los resultados con una representación gráfica del perfil y el estado de salud de la persona; c) alertas automáticas, notificaciones y supervisión continua de la cumplimentación de los ítems; y d) la provisión de planes de atención personalizados según los datos recopilados.

En tercer lugar, se estudió la participación digital de las partes interesadas y los pacientes en el diseño, el desarrollo, la investigación y la aplicación, para hacer frente a los retos causados por la pandemia COVID-19 en el desarrollo de esta metodología de investigación y para involucrar a las personas que viven en zonas rurales remotas. El marco "E-nabling Digital Co-production" resultó útil para avanzar en la comprensión de los problemas y oportunidades relacionados con la e-PPI. Se consideró una herramienta útil para que los investigadores, los coordinadores de la PPI y, sobre todo, los colaboradores públicos identificaran y debatieran los pros y los contras de la PPI electrónica y los enfoques mixtos e híbridos. Las dos principales ventajas identificadas de la e-PPI fueron la eliminación de las limitaciones geográficas, lo que resulta útil para ampliar la participación, y el ahorro de recursos en términos de ahorro de tiempo al no tener que desplazarse a las reuniones, y la facilitación de los preparativos asociados a los lugares de reunión, el catering u otras coordinaciones, como el transporte. El marco también fue útil para identificar varias recomendaciones para mejorar la aplicación del e-PPI.

En cuarto lugar, se identificaron los facilitadores y barreras de la aplicación de un enfoque de atención sociocomunitaria que ha demostrado una mejor relación coste-beneficio en comparación con otras metodologías, el MCSP. Los principales obstáculos identificados fueron la financiación del proyecto y la coordinación y colaboración entre instituciones. Además, la dificultad para involucrar a las poblaciones rurales y la necesidad de acceder a materiales de formación y capacitación del personal fueron temas relevantes para el contexto cultural de España. El entusiasmo de las partes interesadas y la colaboración interinstitucional se identificaron como elementos facilitadores clave. La necesidad de un proceso de implementación adaptado al contexto de interés, y el desarrollo de acciones para superar barreras específicas, como el desarrollo de herramientas para ofrecer este enfoque asistencial de forma remota para involucrar a las poblaciones rurales, fue considerada como el principal hallazgo. Como parte de los resultados de este proyecto, la "Guía para la puesta en marcha de Centros de Encuentro para personas con demencia y sus cuidadores" está disponible en español, y el Curso en Español para la Implementación de Centros de Encuentro está disponible en https://e4you.org/es/moocs/implementacion-de-centros-de-encuentro-para-personas-con-demencia-y-sus-cuidadores.

En quinto lugar, en un intento de ofrecer una alternativa de servicio de apoyo a los cuidadores de personas que viven con demencia en zonas rurales remotas de España, se desarrolló la adaptación cultural del programa de capacitación y formación iSupport para cuidadores de personas que viven con demencia. La plataforma iSupport-Sp se proporciona a través de aprendizaje en-línea, mejorando la prestación de servicios de atención sanitaria, y permitiendo que las zonas remotas puedan acceder a ella con el único requisito de tener acceso a conexión a Internet. Esto será especialmente beneficioso para los cuidadores, a menudo limitados por su escaso tiempo debido a sus responsabilidades como cuidadores y otras obligaciones diarias. Se identificaron recomendaciones relevantes para el diseño de la plataforma en-línea, como sesiones más interactivas que incluyan vídeos y audio, un foro para recibir comentarios de los profesionales sanitarios, la opción de dejar comentarios de satisfacción, disponibilidad en múltiples dispositivos (por ejemplo, tableta, ordenador portátil, móvil), formato de diapositivas para la presentación de la información y la opción de cambiar el tamaño de letra y los colores de fondo, fueron algunas de las sugerencias registradas. El iSupport-Sp actual tiene varias limitaciones que deben mejorarse en futuras versiones, ya que carece de elementos como el apoyo en-línea entre pares, el contacto con profesionales sanitarios y más elementos adaptados a la persona. A través del siguiente enlace es posible acceder al estudio piloto y de usabilidad de iSupport-Sp https://learning.bluece.eu/.

Por último, integrando los resultados de estos cinco pasos e incluyendo tecnologías novedosas como la IA, la robótica, las tecnologías ponibles y los dispositivos de monitorización, la idea de la plataforma tecnológica podría ser factible. Esta integración de tecnologías es necesaria para guiar el desarrollo de modelos de decisión para procedimientos médicos y asistenciales, como el pronóstico, el diagnóstico y la planificación del tratamiento, para optimizar el desarrollo de tratamientos personalizados y mejorar la toma de decisiones entre médicos y científicos, para identificar las necesidades no cubiertas de los adultos mayores y para ofrecer enfoques de tratamiento más eficaces. Otros proyectos pueden aprender de las lecciones obtenidas en este y podrían poner en práctica las iniciativas aquí descritas, para generar un impacto en las posibles soluciones a los retos a los que se enfrenta actualmente la población que envejece.

ABBREVIATIONS

AI: Artificial Intelligence

CGA: Comprehensive Geriatric Assessment

CBT: Cognitive Behavioural Therapy

DHT: Digital Health Technology

e-PPI: digital Patient and Public Involvement

ICT: Information and Communication Technologies

interRAI HC: interRAI Home Care

interRAI LTCF: interRAI Long Term Care Facilities

iSupport-Sp: iSupport Spanish Version

MCSP: Meeting Centres Support Programme

PLwD: People Living with Dementia

PPI: Patient and Public Involvement

WHO: World Health Organization

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SUPPLEMENTARY MATERIAL

Supplementary Material 1. Extended Spanish Summary/Resumen Extendido en Español

1. Introducción

La transición demográfica hacia el envejecimiento de la población está planteando nuevos desafíos a las sociedades y los sistemas de salud pública (OMS, 2015), enfrentándolos a la necesidad de nuevos ajustes y respuestas de todos los sectores (OMS, 2018). Los sistemas de atención sanitaria han estado enfrentando y luchando con el panorama ampliamente diverso y complejo de la atención del adulto mayor, principalmente asociado a comorbilidades, polifarmacia, múltiples tratamientos e intervenciones de diferentes proveedores de salud, y el riesgo de desarrollar deterioro funcional y cognitivo, que tienen profundas implicaciones en la calidad de vida y la capacidad de independencia y autonomía de la población adulta mayor (Roberto Bernabei, Francesco Landi, Graziano Onder, Rosa Liperoti, & Giovanni Gambassi, 2008; Molinari-Ulate, Mahmoudi, Franco-Martín, & van der Roest, 2022; OMS, 2015).

A medida que se produce el envejecimiento, la prevalencia de la demencia aumenta y se duplica cada 5 años después de las edades comprendidas entre 65 y 69 años (Villarejo Galende et al., 2021). Según el Informe Mundial sobre el Alzheimer 2018, alrededor de 50 millones de personas viven con demencia en todo el mundo y se espera que se triplique hasta alcanzar los 152 millones de personas en 2050 (Gauthier, Rosa-Neto, Morais, & Webster, 2021; Patterson, 2018). A medida que la enfermedad progresa, se espera un aumento de la necesidad de supervisión y cuidado personal de una persona con demencia (Alzheimer, 2016), lo que afecta a la salud y la calidad de vida de los cuidadores y repercute en su salud financiera (Alzheimer, 2016; Casal Rodríguez, Rivera Castineira, & Currais Nunes, 2019; Waligora, Bahouth, & Han, 2018). Se estima que alrededor del 80% de los cuidados son proporcionados por cuidadores informales (por ejemplo, familiares, amigos, cuidadores no remunerados) (Alzheimer, 2016; Coduras et al., 2010) y que el 85% de los costes son atribuidos a la familia (Gauthier et al., 2021; Ministerio de Sanidad, 2019).

La transición hacia una población envejecida también se ha reflejado en la sociedad española, donde se ha puesto en marcha este proyecto. Se prevé que en 2050 uno de cada tres españoles tenga más de 65 años y que la población con demencia aumente en cerca de un millón (Sánchez Sánchez, 2006). Esta situación ha modificado la pirámide poblacional española y ha desarrollado nuevos retos sociodemográficos (Pérez Diaz, Abellán García, Aceituno Nieto, & Ramiro Fariñas, 2020), afectando principalmente a las zonas rurales de Asturias, Castilla y León, Galicia, País Vasco, Cantabria y Aragón, donde la proporción de adultos mayores es mayor (Pérez Díaz, Abellán García, Aceituno Nieto, & Ramiro Fariñas, 2020). Este contexto demográfico actual en España se conoce como "España vaciada" y se refiere a un porcentaje relativamente mayor de envejecimiento y despoblación en las zonas rurales y a una creciente migración del campo a la ciudad, particularmente de los jóvenes, lo que ha disminuido la prestación de servicios en las zonas rurales y ha planteado cada vez más desafíos (de la Torre, 2018; López González, 2021; Pérez Díaz et al., 2020).

Para enfrentar este panorama, se ha sugerido desarrollar enfoques de atención médica que coloquen las necesidades y preferencias de las personas mayores en el centro de la prestación de servicios (OMS, 2015, 2018). Uno de estos enfoques es la atención integral, que ha demostrado ser un enfoque alternativo eficaz para implementar en el complejo espectro de la atención de adultos mayores (OMS, 2018), mejorando la calidad de vida e impactando positivamente en las tasas de institucionalización y costos (Johri, Beland, & Bergman, 2003; McDonald, Schultz, & Chang, 2013; OMS, 2015). En los últimos diez años se han desarrollado varias iniciativas para orientar y apoyar las propuestas de atención integral, como el desarrollo de sistemas tecnológicos que permiten la evaluación y la transferencia de datos clínicos en distintos entornos clínicos (por ejemplo, el hogar, residencias de ancianos, centros de atención a largo plazo, hospitales, etc.) (Devriendt et al., 2013; L. Gray & Wootton, 2008; Vanneste, Vermeulen, & Declercq, 2013). Estos sistemas podrían facilitar el intercambio y seguimiento de datos clínicos, la integración y coordinación de evaluaciones, la mejora de la comunicación entre entornos sanitarios, la continuidad de la atención, la identificación de personas en situación de riesgo o la coordinación de mejores intervenciones centradas en la persona (Devriendt et al., 2013; L. Gray & Wootton, 2008; Vanneste et al., 2013).

Este proyecto contribuye a la búsqueda de mejores herramientas para los sistemas sanitarios que puedan hacer frente a los retos mencionados, en concreto la complejidad de la atención a los adultos mayores, el aumento de las personas que viven con demencia (PvD) y sus cuidadores, y la accesibilidad de la población rural a los servicios sanitarios para hacer frente a las dificultades del envejecimiento de la población. En las siguientes secciones se explica cómo se abordaron estas complejidades y qué se hizo específicamente para contribuir a la solución de este panorama.

1.1. Objetivos generales

Los principales objetivos de este proyecto eran

a) Desarrollar una prueba de concepto de una plataforma tecnológica que integre varias herramientas digitales innovadoras para la formación en salud y bienestar de personas mayores con demencia y deterioro cognitivo y sus cuidadores.

b) Estudiar los efectos de la utilización de la plataforma sobre la salud física, el bienestar mental y emocional, las actividades de la vida diaria, el funcionamiento social y cognitivo y el uso para los cuidados profesionales.

c) Involucrar a los adultos mayores con demencia y a sus cuidadores en el diseño y desarrollo de la plataforma, evaluando su satisfacción, el impacto del sistema en entornos realistas, la aceptabilidad y la usabilidad, para permitirles manejar el sistema de forma autónoma en la vida diaria.

1.2. Objetivos de los estudios

Para alcanzar los objetivos principales del proyecto, fue necesario realizar varios estudios con objetivos específicos. En este subapartado se explica y justifica brevemente qué estudios se realizaron y sus objetivos que ayudaron a acercarse al objetivo principal:

i. Revisiones sistemáticas

a. Búsqueda bibliográfica sobre el contenido y las características psicométricas de las Evaluaciones Geriátricas Integrales (EGIs) utilizadas en entornos de centros de larga estancia y atención domiciliaria (Molinari-Ulate, et al., 2022)

Dado que la plataforma tecnológica se dirige a múltiples dominios de PvD (por ejemplo, salud física, bienestar mental y emocional, actividades de la vida diaria, funcionamiento social y cognitivo y calidad de la atención), era necesario identificar las herramientas de evaluación disponibles en la literatura científica que cubren estos dominios y comparar sus características psicométricas para tomar una decisión informada sobre qué herramienta implementar. Por este motivo, esta revisión sistemática tenía como objetivo proporcionar información sobre el contenido y las características psicométricas de las EGIs utilizadas en los entornos de centros de larga estancia y en la atención domiciliaria. Las EGIs se consideran como un proceso de atención que integra una evaluación multidimensional y multidisciplinaria coordinada facilitando las decisiones clínicas para el desarrollo de planes de atención personalizados para abordar, a través de un enfoque centrado en la persona, las necesidades y preocupaciones de los adultos mayores y sus familias y cuidadores (BGS, 2019; Pilotto et al., 2017). Incorporan los principales pilares de la atención integral y se han convertido en intervenciones importantes en la atención geriátrica (Ellis, Whitehead, Robinson, O'Neill y Langhorne, 2011; Pilotto et al., 2017).

b. Búsqueda bibliográfica sobre la evidencia y las características técnicas de las Tecnologías de Salud Digital (TSD) desarrolladas para facilitar la administración de EGIs para entornos de centros de larga estancia o atención domiciliaria

Tras la primera búsqueda bibliográfica, se identificó que, para alcanzar todo el potencial de las EGIs, estas deben estar respaldadas por sistemas de datos electrónicos que proporcionen a los equipos multidisciplinares de profesionales asistenciales resultados relevantes y que permitan compartir información entre múltiples entornos asistenciales de manera oportuna (Chadwell, 2001; Devriendt et al., 2013; L. C. Gray et al., 2009). Esto podría optimizar la coordinación de la atención y evitar posibles contratiempos asociados a la exhaustividad y fiabilidad de los datos recopilados. En consecuencia, esta revisión sistemática tuvo como objetivo describir la evidencia sobre las TSDs que se han desarrollado para facilitar la administración de EGIs y describir sus características técnicas y componentes, abordar la viabilidad y usabilidad, la eficacia y efectividad, y los resultados de la implementación, e informar sobre la madurez de las TSD.

ii. Participación digital de Paciente y Público en la investigación sobre la demencia (Molinari-Ulate, et al., 2022)

Para conseguir la implicación de las PvD y sus cuidadores en el diseño y desarrollo, era necesario estudiar la metodología para llevar a cabo esta iniciativa. La Participación del Paciente y el Público (PPI, por sus siglas en inglés) se ha considerado un proyecto de investigación o desarrollo de políticas públicas de piedra angular llevado a cabo con o por pacientes y miembros del público para las políticas gubernamentales y éticas en la investigación en salud (Burton, Ogden, & Cooper, 2019; Charlesworth, 2018; Dogba, Dossa, Breton, & Gandonou-Migan, 2019; Gove et al., 2018; INVOLVE, 2012; Miah et al., 2019). Sin embargo, en marzo de 2020 la Organización Mundial de la Salud (OMS) declaró la pandemia de COVID-19 y la participación de los pacientes y el público en la investigación se vio afectada por el distanciamiento social, los confinamientos y la reducción del contacto físico (NHS, 2021), lo que aceleró la rápida transición al trabajo digital. Debido a esta situación y a la escasa literatura sobre cómo llevar a cabo la PPI digital (e-PPI), este estudio pretendía explorar las experiencias de e-PPI dentro de un contexto específico de demencia durante la pandemia COVID-19 y pretendía utilizar los resultados para refinar una "Visión general de las consideraciones digitales" (Overview of Digital Considerations) existente, desarrollada originalmente por un grupo de PPI, que dio lugar al Marco de "Habilitación a la Co-producción Digital" (“E-nabling Digital Coproduction” Framework).

iii. Implementación adaptativa del Programa de Atención de Centros de Encuentro (MCSP, por sus siglas en inglés)

La falta de recursos en los sistemas sanitarios para afrontar los retos de la demencia y los cambios sociodemográficos que afectan al rol del cuidador han llevado a una creciente necesidad de programas sociocomunitarios en busca de intervenciones más sostenibles y eficaces (Fam, Mahendran, & Kua, 2019; Prina, Mayston, Wu, & Prince, 2019; Prince et al., 2008). Uno de estos enfoques es el Programa de Atención de Centros de Encuentro (MCSP), ya que se ha identificado como un enfoque de atención alternativa con una mayor integración sociocomunitaria y una mejor relación coste-beneficio que mejora la calidad de vida y la salud mental de las PvD y sus cuidadores (Brooker et al., 2018; Dröes, Breebaart, Meiland, Van Tilburg, & Mellenbergh, 2004; Dröes, Meiland, Schmitz, & van Tilburg, 2004; Henderson et al., 2021; Mangiaracina et al., 2017). Por este motivo, este proyecto pretendía identificar los facilitadores y barreras que podrían facilitar una implementación adaptativa del programa mediante la comprensión del contexto cultural, asistencial y social de dos regiones de España y Ecuador. Una implementación adaptativa del programa podría facilitar su integración en el contexto rural de Zamora, España, y su implementación podría apoyarse con la plataforma digital para llegar de forma remota a las poblaciones rurales.

iv. Adaptación cultural del programa de formación y apoyo en línea iSupport (Molinari-Ulate et al., 2023)

Siguiendo el objetivo de integrar herramientas digitales para el entrenamiento en salud y bienestar para las PvD y sus cuidadores, particularmente aquellos que viven en áreas rurales, el aprendizaje en línea ha sido identificado como un enfoque efectivo que beneficia el conocimiento de la demencia y el apoyo social de los cuidadores de PvD (Murray, Burns, See Tai, Lai, & Nazareth, 2005; Sitges-Maciá, Bonete-López, Sánchez-Cabaco, & Oltra-Cucarella, 2021). También tiene el potencial de superar algunas limitaciones de las intervenciones presenciales, como los costes y el transporte, la imposibilidad de salir de casa debido al rol de cuidador, y podría ayudar a aumentar la cobertura del servicio (Hattink et al., 2015; O'Connor, Arizmendi, & Kaszniak, 2014; Pot et al., 2019; Wasilewski, Stinson, & Cameron, 2017). Por lo tanto, este proyecto tuvo como objetivo adaptar culturalmente el iSupport, un programa de capacitación y apoyo basado en la evidencia para cuidadores de PvD desarrollado por la Organización Mundial de la Salud, y co-diseñar una plataforma en línea con PvD, cuidadores informales y personas de regiones rurales en Castilla y León, España. Esta plataforma se desarrolló como parte de las herramientas digitales que se integrarían en la plataforma tecnológica principal, apoyando su implementación remota.

v. Usabilidad, experiencia de usuario y estudio piloto de la eficacia del iSupport-Sp

Asociado al estudio de adaptación cultural del iSupport, este proyecto tiene como objetivo estudiar la usabilidad y experiencia de usuario del iSupport-Sp en cuidadores informales y formales de PvD. Además, el estudio explora si el uso del iSupport-Sp influye en el nivel de conocimiento de la demencia y la sobrecarga autopercibida del cuidador. Los resultados de este estudio piloto pre-experimental servirán para diseñar un futuro ensayo controlado aleatorizado para determinar la eficacia del iSupport-Sp e incluirlo en la plataforma tecnológica si demuestra ser una herramienta digital eficaz para los cuidadores de PvD.

2. Métodos

2.1. Revisiones sistemáticas

2.1.1. Búsqueda bibliográfica sobre el contenido y las características psicométricas de las EGIs utilizadas en entornos de centros de larga estancia y atención domiciliaria (Molinari-Ulate, Mahmoudi, et al., 2022).

Se realizó una estrategia de búsqueda en tres bases de datos, PubMed, CINAHL y Web of Science Core Collection de estudios hasta el 13 de julio de 2021. Se examinaron las listas de referencias de los estudios seleccionados y las revisiones sistemáticas pertinentes en busca de estudios primarios potencialmente elegibles. Se excluyeron los estudios si a) la EGI era una evaluación que consistía en una colección de medidas, pruebas o evaluaciones de un solo dominio o instrumentos independientes que evaluaban un dominio (ej., depresión); b) estudios publicados en idiomas distintos del inglés o el español; c) publicaciones como resúmenes de congresos, estudios de casos, protocolos, disertaciones, libros y revisiones sistemáticas; d) si toda la EGI era de autoinforme; e) EGIs desarrolladas para entornos de cuidados intensivos, atención de salud mental, cuidados paliativos, atención primaria u hospitalización; f) aquellas EGIs que evaluaban la transferencia desde o hacia cualquiera de los entornos de atención mencionados.

Dos autores construyeron la estrategia de búsqueda a partir de palabras clave de texto libre y Medical Subject Headings (MeSH). La estrategia de búsqueda se tradujo a los correspondientes encabezamientos de vocabulario controlado de la base de datos y a la sintaxis apropiada, cuando fue necesario. Se eliminaron los duplicados identificados en la búsqueda inicial. Dos autores revisaron de forma independiente los títulos y resúmenes de los registros identificados. La revisión del texto completo de los artículos fue realizada de forma independiente por dos revisores, que obtuvieron los registros finales para el análisis. Las discrepancias se resolvieron mediante discusión o incorporando un tercer revisor.

De los estudios finales seleccionados se extrajeron los siguientes datos: a) nombre de la EGI; b) autores/año; d) descripción de la muestra; e) país; f) ámbito del estudio; g) diseño del estudio; h) objetivo del estudio; i) tipo de validez/fiabilidad; y j) principales conclusiones. También se extrajeron escalas, ítems, índices o dominios de los estudios pertinentes. La calidad de los estudios/riesgo de sesgo fue evaluada de forma independiente por dos de los autores mediante el "STANDARD QUALITY ASSESSMENT CRITERIA for Evaluating Primary Research Papers from a Variety of Fields"(Kmet, Lee, & Cook, 2004).

2.1.2. Búsqueda bibliográfica sobre la evidencia y las características técnicas de las TSD desarrolladas para facilitar la administración de EGI para entornos de centros de larga estancia o atención domiciliaria.

Se realizaron búsquedas hasta el 5 de abril de 2023 en PubMed, CINAHL y Web of Science. Los criterios de inclusión de los estudios fueron a) el estudio se centró en la viabilidad, usabilidad, eficacia, efectividad o implementación de TSDs que apoyen la administración de EGIs para entornos de centros de larga estancia y atención domiciliaria; b) la EGI fue una única prueba multidisciplinar o herramienta de evaluación; c) la TSD fue desarrollada para su uso en la práctica clínica, d) la EGI apoyada por la TSD debe estar dirigida a personas de 55 años o más. Sólo se consideraron los estudios en inglés y español.

La estrategia de búsqueda fue desarrollada por dos autores utilizando palabras clave de texto libre y MeSH. La estrategia se tradujo a los correspondientes encabezamientos de vocabulario controlado y a la sintaxis adecuada de las otras bases de datos. Tras la eliminación de duplicados, los registros restantes se dividieron entre tres parejas de revisores (seis en total) que examinaron los títulos de forma independiente. Dentro de cada pareja, se discutieron las desviaciones y se buscó un acuerdo. Los resúmenes de los registros restantes potencialmente elegibles fueron revisados por dos autores. Los mismos autores revisaron el texto completo de los artículos elegibles. Las discrepancias se resolvieron con la participación de un tercer autor.

Los datos extraídos de los estudios finalmente seleccionados fueron: a) autor y año de publicación; b) nombre de la TSD, c) características técnicas; d) estadio de maduración; e) nombre de la EGI; f) objetivo del estudio; g) diseño del estudio; h) país; i) ámbito asistencial; j) descripción de la muestra del estudio (tamaño, porcentaje de mujeres, edad media y desviación estándar); k) resultados; l) conclusiones principales. El riesgo de sesgo fue evaluado por dos calificadores mediante los " mERA Methodological Criteria" (OMS, 2016).

2.2. Participación digital de Pacientes y Público en la investigación sobre la demencia (Molinari-Ulate, et al., 2022)

El proyecto se coprodujo con el MindTech Involvement Team, un grupo de personas y cuidadores que aportan sus propias experiencias vividas en relación con las afecciones de salud mental, así como experiencia en los procesos de Participación de Pacientes y Público (PPI, por sus siglaes en inglés). Se realizaron tres tipos de sesiones: a) una sesión de diseño y desarrollo del proyecto, b) sesiones de ejecución del proyecto (talleres), y c) reuniones para analizar y sintetizar los resultados.

Se realizaron dos talleres en línea y una entrevista individual. En el taller 1 participaron cuatro investigadores y dos coordinadores de PPI. Se realizó una entrevista individual con uno de los investigadores que no pudo asistir al taller. El taller 2 se realizó con el " Dementia, Frail Older People and Palliative Care Patient and Public Involvement Advisory Group", un grupo de PPI ya existente de la Universidad de Nottingham, formado por miembros con experiencia en el cuidado de personas mayores con demencia y algunos eran ellos mismos cuidadores.

Siguiendo con el enfoque de la coproducción, se llevó a cabo un análisis de datos en colaboración con miembros del MindTech Involvement Team. Se eligió el análisis temático para analizar los resultados. La codificación fue realizada por los responsables del proyecto y la codificación final se presentó al MindTech Involvement Team para su debate y aportaciones finales. Los temas identificados se compararon con el marco de "Habilitación a la Coproducción Digital" que se perfeccionó durante el análisis de los datos de este proyecto.

2.5. Implementación adaptativa del Programa de Atención de Centros de Encuentro

En octubre de 2021 se realizaron dos entrevistas en línea semiestructuradas con actores de Ecuador y España. En Ecuador, los actores entrevistados representaban a los sectores público, de servicios sociales y académico. En España, la entrevista se realizó a la coordinadora y a la facilitadora del programa del Centro de Encuentro de Zamora, España.

Las entrevistas se realizaron a través de Microsoft Teams y se transcribieron literalmente para su análisis. Las partes interesadas recibieron una lista de facilitadores y obstáculos identificados a partir de estudios previos de implantación que se utilizó para familiarizar a los participantes con ejemplos de procesos de implementación. El enfoque elegido para el análisis de los datos fue el análisis temático, realizado de forma independiente por dos revisores. Los facilitadores y las barreras identificados se compararon con el modelo teórico para identificar facilitadores y barreras en la implementación adaptativa (Meiland, Dröes, De Lange y Vernooij-Dassen, 2004). Se utilizó una lista de facilitadores y barreras identificados en estudios anteriores como marco para el proceso de codificación.

2.6. Adaptación cultural del programa de formación y apoyo en línea iSupport (Molinari-Ulate et al., 2023)

Se llevaron a cabo tres pasos principales, cada uno con sus propios métodos: a) traducción, b) adaptación cultural y c) codiseño de la plataforma en línea. La traducción fue realizada por dos autores nativos españoles familiarizados con el contexto de Castilla y León, España, y con experiencia en demencia y cuidadores.

La adaptación cultural se realizó según la Guía de Adaptación e Implementación proporcionada por la OMS (OMS, 2019a). En primer lugar, se modificaron las palabras, nombres, enlaces y recursos incluidos en la versión genérica original del iSupport y que la Guía recomienda cambiar, de acuerdo con la cultura y los hábitos locales. En segundo lugar, se realizaron tres grupos focales para revisar la versión traducida y adaptada con a) cuidadores informales, b) cuidadores formales/profesionales y c) un grupo de expertos en deterioro cognitivo y demencia. Para los dos primeros grupos, los grupos focales consistieron en dos sesiones de 90 minutos cada una; para el grupo de expertos, los datos se recogieron por correo electrónico tras una primera sesión presencial para explicar la finalidad del proyecto y cómo registrar los datos. En tercer lugar, se recogieron todas las modificaciones y se debatieron en los grupos de discusión; las observaciones finales se incluyeron en un formulario de adaptación para comparar las tres muestras. El análisis temático fue el enfoque elegido para codificar los datos; los códigos se obtuvieron inicialmente de adaptaciones culturales de iSupport publicadas anteriormente y se incluyeron los nuevos códigos identificados. Los datos fueron codificados por dos de los autores y los desacuerdos se resolvieron con la participación de un tercer investigador.

Se llevó a cabo un proceso adicional de codiseño para aumentar la calidad del diseño y la adaptación de la plataforma en línea. Este paso se planteó como una actividad de PPI y se llevó a cabo con a) el Grupo de Trabajo Europeo de Personas con Demencia (EWGPWD, por sus siglas en inglés), un grupo de personas que viven con demencia y sus cuidadores con experiencia en el compromiso con la investigación; b) la Demencia: Estrategia Intersectorial de Formación e Innovación en Red para la Tecnología Actual (DISTINCT, por sus siglas en inglés), un grupo de investigadores cuyo objetivo es mejorar la vida de las personas que viven con demencia y sus cuidadores a través de la tecnología; y c) un grupo de personas que viven en una zona rural de Salamanca, de las cuales ocho eran o solían ser cuidadores de personas que viven con demencia. La reunión de EWGPWD se realizó en línea a través de Zoom, con la Red DISTINCT y las reuniones de la población rural fueron presenciales. El tiempo de las sesiones varió de 20 a 40 minutos. La decisión para la inclusión de las recomendaciones se realizó en función de la viabilidad tecnológica y las directrices de adaptación de la OMS.

3.5. Usabilidad, experiencia del usuario y estudio piloto de la eficacia del iSupport-Sp

Se está llevando a cabo un estudio de métodos mixtos sobre la interacción entre el ser humano y la plataforma en línea. El estudio se ha realizado en una única fase con dos vertientes: a) un estudio de usabilidad y experiencia de usuario, y b) un estudio piloto exploratorio de la eficacia del iSupport-Sp sobre el conocimiento de la demencia y la sobrecarga del cuidador. Para la primera vertiente, se está administrando una vez finalizado el programa de formación iSupport-Sp, el Cuestionario de Usabilidad de Sistemas Informáticos (CSUQ, por sus siglas en inglés) y una entrevista semiestructurada de experiencia de usuario. Para el estudio piloto de eficacia, se están administrando dos cuestionarios antes y después de la finalización del iSupport-Sp, la Herramienta de Evaluación del Conocimiento de la Demencia 2 Versión Española (DKAT2-Sp, por sus siglas en inglés) y la Entrevista de Sobrecarga de Zarit (ZBI, por sus siglas en inglés).

La muestra objetivo son 50 personas identificadas como cuidadores informales o formales de PvD que están siendo reclutados de Clínicas de Memoria, Asociaciones Españolas de Alzheimer y centros de larga estancia en Castilla y León, España. Los criterios de inclusión son: a) ser mayor de 18 años, b) ser cuidador informal o formal, c) que la persona cuidada tenga un diagnóstico de demencia, d) saber leer, escribir y ser hispanohablante fluido, y e) no tener pérdida de ningún sentido que dificulte el uso de dispositivos electrónicos.

Una vez identificados los participantes, tendrán acceso al enlace iSupport-Sp donde deberán registrarse y crear un nombre de usuario y una contraseña. A partir del registro se recogerán datos sociodemográficos. Tras el registro, los participantes completarán el DKAT2-Sp y el ZBI, y a continuación tendrán acceso a los módulos y lecciones. Una vez que los participantes hayan completado todos los módulos y lecciones, completarán el DKAT2-Sp y el ZBI post-test, y el CSUQ y la entrevista semi-estructurada de experiencia de usuario. Al final, tendrán la opción de descargar un certificado de finalización del iSupport-Sp.

3. Resultados

3.1. Revisiones sistemáticas

3.1.1. Búsqueda bibliográfica sobre el contenido y las características psicométricas de las EGI utilizadas en entornos de centros de larga estancia y en la atención domiciliaria (Molinari-Ulate, et al., 2022).

Se identificaron un total de 10 EGI diferentes en 71 estudios revisados. El Resident Assessment Instrument-Minimun Data Set (RAI-MDS) y sus versiones posteriores, la versión residencial de VALutaziones GRAFica (ValGraf) y la Care Planning Assessment Tool (CPAT) se centraron en los entornos de centros de larga estancia. Para la atención domiciliaria, se identificaron el Comprehensive Assessment and Referral Evaluation (CARE), el Older American's Resources and Services (OARS) Multidimensional Functional Assessment Questionnaire (OMFAQ), el Philadelphia Geriatric Center Multilevel Assessment Instrument (MAI), la Popovich Scale, el Outcome and Assessment Instrument Set (OASIS), el RAI-MDS Home Care (HC) y sus versiones posteriores, y el Community Assessment of Risk Instrument (CARI).

Los instrumentos más estudiados para los centros de larga estancia fueron el RAI-MDS y sus versiones posteriores, mientras que para la atención domiciliaria fueron el RAI-MDS HC y su versión posterior y el OASIS. Se identificaron inconsistencias en cuanto a la especificidad de los dominios evaluados entre las EGI. Mientras que algunas EGIs incluían dominios amplios que dificultaban la comprensión de lo que se estaba evaluando específicamente, otras eran más específicas o más claras al referirse y evaluar los dominios con más detalle.

El número de estudios y las características psicométricas apoyan positivamente el uso de la RAI-MDS y las versiones posteriores en centros de larga estancia en comparación con las otras EGIs. Sin embargo, muestra algunos fallos en ítems como problemas bucodentales, riesgo de desnutrición, infección urinaria y depresión y estado de ánimo. En el caso de la atención domiciliaria, el número de estudios que validan las EGI no difiere tanto como en los centros de larga estancia, y las características psicométricas parecen alcanzar niveles elevados para todas las EGI, excepto para el CARI y el CARE. Existen algunas consideraciones relevantes sobre la psicometría de las EGI para la atención domciliaria (Molinari-Ulate, et al., 2022).

Teniendo en cuenta las características del estudio, las características psicométricas, la trayectoria de desarrollo del instrumento y la adaptación y validación global, se recomienda el uso del interRAI LTCF y del interRAI HC en los centros de larga estancia y en la atención domiciliaria. No obstante, los profesionales sanitarios deben ser conscientes de los fallos que presentan estos instrumentos.

Debido a esta recomendación, el interRAI LTCF y el interRAI HC fueron traducidos y adaptados culturalmente con profesionales sanitarios de Zamora y Barcelona, España. Se espera que los manuales y formularios de estos instrumentos se publiquen y estén disponibles tras la aprobación de interRAI. Asimismo, dado que el conjunto de instrumentos interRAI comparte ítems centrales, el interRAI Salud Mental (MH, por sus siglas en inglés), el interRAI Salud Mental Comunitaria (CMH, por sus siglas en inglés) y el interRAI Detección Urgente de Problemas Mentales (ESP, por sus siglas en inglés) también fueron traducidos y adaptados para la población española.

3.1.2. Búsqueda bibliográfica sobre la evidencia y características técnicas de las TSD desarrolladas para facilitar la administración de EGIs para entornos de centros de larga estancia o atención domiciliaria

A pesar de que en la búsqueda bibliográfica previa se identificaron tres EGIs para centros de larga estancia y siete para la atención domiciliaria (Molinari-Ulate, et al., 2022), en esta revisión de la literatura científica sólo se identificaron cuatro TSDs compatibles con dos de esas EGIs, el MDS-HC y el interRAI HC. Se incluyeron cinco estudios en el análisis, dirigidos a las siguientes TSDs: a) MDS-HC© Electronic Web-based Interface; b) interRAI electronic assessment tools; c) System for Person-centered Elder Care (SPEC); y d) BelRAI. El MDS-HC© y la interRAI electronic assessment tools se encontraban en la fase de evaluación de viabilidad y usabilidad y estaban en el estado de madurez de prototipo y escalado, respectivamente. El SPEC se investigó en la fase de madurez de demostración y en el estado de evaluación de eficacia. El BelRAI se encontraba en la fase de madurez de integración/sostenibilidad y en el estado de evaluación de implementación.

La información relativa a las características técnicas y de hardware de las TSD era limitada. Sólo se informó en el caso de la interRAI electronic assessment tools, en el que se describía el uso de ordenadores portátiles; sin embargo, no se especificaba el software utilizado. A partir de los datos de viabilidad y usabilidad recopilados, se identificaron las siguientes barreras que afectan a la implementación de las TSD en la práctica asistencial: a) dificultades técnicas para utilizar el software; b) duración de las evaluaciones; c) conectividad de red inconsistente; d) transporte del hardware, principalmente ordenadores portátiles; e) necesidad de formación continua para realizar la evaluación correctamente; y f) falta de conocimiento del personal sobre la información recopilada y su finalidad. Algunos de estos obstáculos pueden superarse con nuevas tecnologías, pero la formación de los profesionales sanitarios sobre las evaluaciones y los conocimientos del personal sobre la finalidad de los datos recopilados no están relacionados con la tecnología y deben abordarse.

Además, los resultados mostraron algunas características que podrían reforzar la usabilidad, la eficacia y la implementación de las TSD que apoyan la aplicación de las EGI, tales como: a) utilización de un almacén seguro de almacenamiento de datos, como las nubes; b) inclusión de alertas automáticas, notificaciones o una comprobación continua de la cumplimentación de ítems en las TSD; c) posibilidad de acceso de múltiples profesionales sanitarios a las evaluaciones individuales en la TSD, evitando depender de un solo profesional para cumplimentar la EGI pero utilizando la experiencia de cada miembro del equipo; d) provisión de informes de perfiles individualizados de necesidades y riesgos, y planes de cuidados personalizados; y d) cálculo automático de los resultados y escalas compuestas.

3.2. Participación digital de Pacientes y Público en la investigación de la demencia (Molinari-Ulate, Woodcock, et al., 2022)

En cuanto a los retos y enfoques de la e-PPI, los grupos participantes compartieron dos temas principales a) el mayor alcance potencial sin limitaciones geográficas, que podría ser útil para ampliar la participación, y b) la percepción de sesiones más empresariales con menos oportunidades para las interacciones sociales y la comunicación. También se identificaron opiniones tanto positivas como negativas en relación con la transición a la coproducción digital. Por ejemplo, en cuanto a la diversidad y la inclusión de los grupos de PPI, se consideró que la e-PPI suponía un obstáculo si siempre asistían a las sesiones los mismos miembros; sin embargo, también podía ofrecer la oportunidad de incluir a otras personas que no hubieran participado antes en la PPI. En el contexto de la demencia, el e-PPI ofrece a los cuidadores la posibilidad de asistir a más reuniones (ya que no necesitan abandonar la responsabilidad de cuidar al asistir virtualmente), pero al mismo tiempo pueden perder tiempo fuera de la responsabilidad de cuidar (oportunidades de descanso y espacio de apoyo).

Tras el perfeccionamiento de la guía existente 'Overview of Digital Considerations' desarrollada por el MindTech Involvement Team, que se utilizó para iniciar la codificación de los resultados, se identificaron y coprodujeron cuatro áreas que dieron lugar al marco “Habilitación a la Coproducción Digital”: Tecnológica, Recursos, Implicabilidad y Ética y Bienestar. El proceso de desarrollo del marco es un buen ejemplo de colaboración en el análisis de datos y la coproducción. También se identificó que el marco es una herramienta para que los investigadores, los coordinadores de la PPI y los colaboradores públicos identifiquen y debatan los retos y las oportunidades que ofrecen la e-PPI y los enfoques mixtos/híbridos. Tiene el potencial de ser utilizado con poblaciones y contextos específicos, como se demostró a través del objetivo del contexto de la demencia en este proyecto. El marco debe considerarse una oportunidad para estudiar cómo se aborda la PPI y explorar las preferencias e implicaciones de las diferentes metodologías de enfoque de la PPI.

3.5. Implementación adaptativa del Programa de Atención de Centros de Encuentro

Las barreras identificadas tanto en Ecuador como en España, también compartidas por otros países europeos (Países Bajos, Reino Unido, Polonia e Italia), fueron la colaboración y coordinación entre instituciones y la financiación del proyecto. Los principales facilitadores fueron el entusiasmo de las partes interesadas y la colaboración entre socios e instituciones. Se identificaron nuevos facilitadores y barreras, no evidentes en estudios anteriores, específicamente en España y Ecuador. Por ejemplo, la diferencia entre las zonas urbanas y rurales, en particular las dificultades para acceder a las poblaciones rurales, y la necesidad de transporte se identificaron como barreras en ambos países hispanohablantes. La disponibilidad de personal y voluntarios formados y capacitados en MCSP y encontrar un número suficiente de participantes se identificaron como facilitadores en España, sin embargo, se consideraron barreras en Ecuador. Se identificaron otras barreras como el proceso administrativo para crear colaboraciones u obtener financiación, que en Ecuador se consideró que ralentizaba el proceso. En España, el programa se percibió como una carga adicional para los cuidadores informales, ya que no se ajustaba plenamente a sus necesidades.

El proyecto también demostró que el modelo de trazabilidad y el proceso de implementación por fases, implementados previamente en países europeos, podían aplicarse en países hispanohablantes. Además, el estudio abre la puerta a llevar a cabo procesos de implementación adaptados del MCSP en Latinoamérica. En este sentido, estos resultados motivaron el desarrollo del 'Curso Introductorio en Español para la Implementación de Centros de Encuentro para Personas con Demencia y sus Cuidadores' que incluye ejemplos de los facilitadores y barreras identificados en este estudio y fue desarrollado específicamente para países de habla hispana. Este curso fue desarrollado con el apoyo de la red MeetingDem, el Instituto de Investigación Biomédica de Salamanca (IBSAL), y Amsterdam University Medical Centres, sede Vrije Universiteit. Ya está disponible en https://e4you.org/es/moocs/implementacion-de-centros-de-encuentro-para-personas-con-demencia-y-sus-cuidadores.

3.6. Adaptación cultural del programa de formación y apoyo en línea iSupport (Molinari-Ulate et al., 2023)

Se propusieron un total de 435 sugerencias de adaptación asociadas a terminología errónea, reformulación del texto/escritura, errores gramaticales o de signos de puntuación, e información repetida o necesidad de contenido adicional. La mayoría de las sugerencias fueron propuestas por los cuidadores formales (n=244), seguidos por el grupo de expertos (n=170) y por los cuidadores informales (n=21). Como se ha demostrado, las sugerencias de los cuidadores informales fueron mucho menos numerosas que las del otro grupo de partes interesadas, lo que provocó un desequilibrio entre la perspectiva de los tres grupos que componían la muestra.

En cuanto al proceso de codiseño, se expusieron varias recomendaciones: a) preferencia por material interactivo como vídeos o imágenes, b) un foro para recibir opiniones de los profesionales sanitarios y dejar comentarios de satisfacción, c) disponibilidad en múltiples plataformas (ej., tablet, portátil, móvil), d) formato de diapositivas para la presentación de la información, e) acceso a la información mediante audio, f) un enlace personal para acceder a la plataforma en lugar de un nombre de usuario y contraseña, g) lenguaje sencillo evitando vocabulario técnico, h) que esté disponible para quienes no tienen acceso a Wi-Fi o dispositivos tecnológicos, y e) disponibilidad para editar el tamaño de letra y los colores de fondo.

Teniendo en cuenta los resultados anteriores, se desarrolló la versión online de iSupport en español (iSupport-Sp). iSupport-Sp se desarrolló en WordPress utilizando el plugin de formación online LearnDash y el tema Enfold. Está alojado en un sistema en la nube (isupport.bluece.eu) y los usuarios pueden acceder a él a través de la conexión a Internet. La plataforma puede ejecutarse desde un ordenador, portátil, tableta o smartphone. Incorpora cuadros de mando para seguir el progreso de los usuarios. Por lo tanto, puede informar sobre las tasas de finalización, los datos de asistencia y la probabilidad de éxito. iSupport-Sp está disponible previa solicitud a los autores, ya que se está estudiando su viabilidad y usabilidad.

3.7. Usabilidad, experiencia del usuario y estudio piloto de la eficacia del iSupport-Sp

Este estudio está en curso y no se dispone de datos preliminares al momento de redactar este resumen. Se espera que la coproducción y el codiseño del iSupport-Sp se reflejen en la usabilidad y la experiencia de usuario de los participantes. Además, se espera que el uso del iSupport-Sp mejore el conocimiento de la demencia y disminuya la sobrecarga de los cuidadores de las personas con demencia que participan en el estudio.

4. Discusión

Este proyecto pretendía contribuir a la búsqueda de soluciones innovadoras y tecnológicas para dotar a los sistemas sanitarios de herramientas que pudieran hacer frente a los nuevos retos que plantea el envejecimiento de la población. En particular, se centró en la complejidad y diversidad de la atención a los adultos mayores, el aumento de las personas que viven con demencia y sus cuidadores, y la accesibilidad de la población rural a los servicios sanitarios para hacer frente a estos retos. Para perseguir este objetivo, se pretendía desarrollar una prueba de concepto de una plataforma tecnológica que integrase varias herramientas digitales innovadoras para la formación en salud y bienestar de adultos mayores con demencia y deterioro cognitivo y sus cuidadores, y estudiar sus efectos de utilización sobre la salud física, el bienestar mental y emocional, las actividades de la vida diaria, el funcionamiento social y cognitivo, y su uso para cuidados profesionales. Este procedimiento iría acompañado de la participación de los adultos mayores con demencia y sus cuidadores en el desarrollo y diseño de la plataforma, evaluando su satisfacción, aceptabilidad y usabilidad, el impacto del sistema en entornos realistas, y capacitarles para manejar el sistema de forma autónoma en la vida diaria.

Como primer paso, el objetivo era identificar qué EGIs estaban disponibles en la literatura científica que incorporaran los principales pilares de un enfoque de atención integral, e identificar la evidencia de las TSD que se han desarrollado para ayudar a estas herramientas de evaluación. Las EGIs, y las TSDs que las asisten, podrían ayudar a afrontar la complejidad de la atención a los adultos mayores mejorando la comunicación y la transferencia de datos clínicos entre los entornos sanitarios y las partes interesadas para tomar decisiones más fiables sobre la planificación de la atención y las políticas sanitarias, optimizando la calidad de la atención (Chadwell, 2001; Comité, 2015; L. C. Gray et al., 2009; OMS, 2019b). Debido a la diversidad de dominios identificados en las EGI, se considera necesario ser más específicos sobre qué áreas se evalúan, ya que se trata de herramientas de cribado que podrían identificar posibles factores de riesgo de deterioro y tener en cuenta la complejidad de la atención del adulto mayor (ej., comorbilidades, polifarmacia, tratamientos múltiples, etc.), lo que podría mejorar la toma de decisiones clínicas y los planes de tratamiento y atención personalizados (R. Bernabei, F. Landi, G. Onder, R. Liperoti y G. Gambassi, 2008; Molinari-Ulate, Woodcock y otros, 2022; Scanlan, 2005; OMS, 2015). Mediante la recopilación de información más clara a través de dominios y advertencias bien definidos, los clínicos podrían obtener datos clínicos más relevantes para tomar decisiones más fiables (Molinari-Ulate, Woodcock, et al., 2022). También será posible desarrollar y mejorar algoritmos obtenidos a partir de grandes bases de datos, para incorporar el aprendizaje automático que permita extraer e identificar información útil para guiar el desarrollo de modelos de decisión clínica, facilitando el pronóstico, el diagnóstico y la planificación del tratamiento, y optimizando la calidad de la atención mediante la identificación de necesidades insatisfechas de atención al adulto mayor (Dipnall et al., 2016; Góngora et al., 2018).

Para alcanzar esta plena capacidad de las EGI, es necesario emplear TSDs que puedan ayudar en la gestión de estos datos. Sin embargo, se identificó una falta de literatura científica que informe sobre TSDs que apoyen estas herramientas de evaluación. Esta falta de evidencia podría causar sistemas mal diseñados que amenazan la seguridad de los pacientes y contribuyen al agotamiento y la baja moral de los usuarios (Committee on Patient, Health Information, & Institute of, 2011; Kroth et al., 2019; Sheikh et al., 2021), y llevar a preocupaciones con respecto a la toma de decisiones, la calidad de la atención, las intervenciones y la planificación de la atención, ya que estos son apoyados por los resultados de las evaluaciones (Vanneste, De Almeida Mello, Macq, Van Audenhove, & Declercq, 2015). Para evitar algunos de estos problemas y las barreras que podrían afectar a la implementación de las TSD en entornos clínicos, mencionadas anteriormente en las sección de resultados, será necesario invertir en formación en ciencia de datos, mejora de la calidad e informática sanitaria para el personal sanitario, e incorporar científicos de datos e informáticos clínicos en los equipos clínicos (Sheikh et al., 2021). Asimismo, involucrar a los profesionales sanitarios y a los pacientes en el proceso de diseño y desarrollo, investigación e implementación de las TSD, podría conducir a sistemas más atractivos y fáciles de usar, más alineados con las necesidades de las partes interesadas (Thabrew, Fleming, Hetrick, & Merry, 2018) y a identificar enmiendas tempranas, reduciendo los costes del sistema (Kushniruk, Hall, Baylis, Borycki, & Kannry, 2019; Sheikh et al., 2021).

La última recomendación asociada a la implicación de las partes interesadas y los pacientes en el proceso de diseño, desarrollo, investigación e implementación, nos guió hacia nuestro segundo paso de este proyecto: estudiar cómo abordar la PPI digitalmente, en particular a causa de la pandemia COVID-19. El desarrollo del marco "Habilitación a la Coproducción Digital" fue una respuesta a la rápida transición a la coproducción digital como consecuencia de la pandemia, sin embargo, no es exclusivo de la e-PPI, ya que también debe considerarse como una herramienta con potencial para examinar cómo se aborda la PPI en diferentes contextos y condiciones (Molinari-Ulate, Woodcock, et al., 2022). También podría utilizarse como herramienta para explorar las preferencias e implicaciones de las diferentes modalidades de realización de la PPI dentro de la transición pospandémica (Molinari-Ulate, Woodcock, et al., 2022). Hasta donde sabemos, este marco es el primero que se centra en la digitalización de la PPI y que considera la PPI electrónica como parte de un enfoque mixto (Molinari-Ulate, Woodcock, et al., 2022), ya que en una revisión sistemática anterior que informaba sobre 65 marcos para apoyar, evaluar e informar sobre la PPI, esto no se tuvo en cuenta (Greenhalgh et al., 2019). El marco permitió identificar una variedad de pros y contras en un contexto específico de demencia, no obstante, debe considerarse como parte de un conjunto de herramientas híbridas en evolución para realizar PPI en otros contextos de investigación (Molinari-Ulate, Woodcock, et al., 2022). También se identificaron una serie de recomendaciones para mejorar la e-PPI que coincidían con las sugerencias descritas en estudios anteriores (Lampa, Sonnentheil, Tökés, & Warner, 2021; Molinari-Ulate, Woodcock, et al., 2022).

Las lecciones aprendidas de la participación digital de las partes interesadas y los pacientes en el proceso de diseño, desarrollo, investigación e implementación fueron necesarias para pasar a los siguientes y últimos pasos del proyecto. Debido a la falta de recursos en los sistemas sanitarios para abordar los retos asociados a la demencia, como la insuficiente formación del personal sanitario, la falta de conocimientos sobre la demencia y la falta de financiación para los cuidados a largo plazo (Fam et al., 2019; Prince et al., 2008; Richly et al., 2019) y el papel cambiante de los cuidadores debido a la reducción de la población joven y un papel más activo de las mujeres en el lugar de trabajo (Fam et al., 2019; Prina et al., 2019; Prince et al., 2008) existe una necesidad creciente de programas sociocomunitarios que tengan en cuenta los recursos locales en busca de intervenciones más sostenibles y eficaces (Fam et al., 2019; Prina et al., 2019; Prince et al., 2008). Por este motivo, se entrevistó en línea a partes interesadas de España y Ecuador para identificar los facilitadores y las barreras de la implementación de un enfoque de atención alternativa que ha demostrado una mayor integración sociocomunitaria y una mejor relación coste-beneficio, el MCSP (Brooker et al., 2018; Dröes, Breebaart, et al., 2004; Dröes, Meiland, et al., 2004; Henderson et al., 2021; Mangiaracina et al., 2017).

Los facilitadores y barreras identificados difieren según el contexto cultural, el acceso a los recursos de formación y la distribución geográfica de la población. Asimismo, algunos de los facilitadores y barreras diferían de los identificados en países no hispanohablantes. Por ejemplo, el acceso a las zonas rurales y la necesidad de transporte se identificaron como la principal barrera para implemenntar este programa en los países hispanohablantes. Esto muestra la necesidad de desarrollar un plan estratégico de adaptación para la implementación de programas socio-comunitarios, como el MCSP, teniendo en cuenta las diferentes condiciones de cada país. Se recomienda que esta adaptación incluya la adaptación sociocultural de los materiales de formación, además del desarrollo de acciones para superar barreras específicas, como el desarrollo de recursos para ofrecer el servicio a distancia para facilitar el acceso a las poblaciones rurales.

Como respuesta a la barrera rural identificada en la aplicación del MCSP y teniendo en cuenta la situación sociodemográfica de la "España vaciada", el último paso del proyecto se centró en cómo prestar a distancia algunos servicios sanitarios para las PvD y sus cuidadores que viven en zonas rurales. En un intento de ofrecer una alternativa de servicio de apoyo, se adaptó culturalmente un programa de formación y apoyo para cuidadores de PvD y se diseñó conjuntamente con las partes interesadas y las PvD. El iSupport-Sp fue el resultado final, siguiendo cambios y recomendaciones similares a los identificados en adaptaciones culturales anteriores (Baruah et al., 2021; Efthymiou et al., 2022; Teles, Napolskij, Paul, Ferreira, & Seeher, 2021; Xiao et al., 2022). Esta plataforma digital se proporciona a través del aprendizaje en línea, ya que su objetivo es mejorar la prestación de servicios sanitarios y permitir que las zonas remotas accedan a sus contenidos y recursos; de lo contrario, estas poblaciones remotas incurrirían en gastos de viaje o dejarían de lado las responsabilidades del cuidador para acceder a estos recursos (Klimova, Valis, Kuca, & Masopust, 2019; Ritterband & Tate, 2009).

Las herramientas de aprendizaje en línea han demostrado ser rentables en comparación con otras modalidades (Dickinson et al., 2017; Mitchell, 2011) y tener el potencial de ofrecer información multimedia, que se ha considerado relevante para ofrecer contenidos más atractivos y potenciar el aprendizaje (Ruiz, Mintzer, & Leipzig, 2006). El único requisito para acceder al iSupport-Sp es disponer de conexión a Internet, por lo que se podría acceder a sus materiales de aprendizaje en cualquier lugar y momento, eliminando cualquier obstáculo geográfico y la limitación asociada a la función de cuidador, como la restricción de tiempo o la realización de tareas cotidianas como el empleo, el cuidado de otros miembros de la familia o las tareas domésticas (Serafini, Damianakis, & Marziali, 2007). En el momento de redactar este informe, se están probando la usabilidad y la facilidad de uso del iSupport-Sp, así como su potencial para reducir la sobrecarga de los cuidadores y mejorar los conocimientos sobre la demencia. Se espera que los resultados de este estudio refuercen el interés de las partes interesadas y los responsables políticos y que puedan contribuir a la mejora de la plataforma.

Este proyecto profundizó en las posibles soluciones a los retos asociados al envejecimiento de la población. El objetivo principal era desarrollar una prueba de concepto de una plataforma tecnológica que integrara diferentes tecnologías innovadoras para mejorar la salud y el bienestar de las personas que viven con demencia y sus cuidadores. Si se considera la "prueba de concepto" como un tipo de investigación cuyo objetivo es proporcionar una justificación en la práctica de la transferibilidad potencial de los conocimientos adquiridos a través de pruebas experimentales (Kendig, 2016), se puede considerar que este proyecto cumplió parcialmente su objetivo principal. Se han descrito varios estudios cuyos resultados pueden considerarse los cimientos necesarios para el desarrollo de la plataforma tecnológica prevista. Si los resultados presentados anteriormente pudieran combinarse en una única TSD, integrando tecnologías novedosas como la Inteligencia Artificial (IA), la robótica, las tecnologías ponibles y los dispositivos de monitorización, la idea de la plataforma tecnológica podría ser factible.

Sin embargo, sin los conocimientos adquiridos a través de este proyecto, sería más difícil que esta idea se hiciera realidad. Por ejemplo, las evaluaciones interRAI Long-term care y Home Care se identificaron como las herramientas recomendadas para el seguimiento y la evaluación de los usuarios potenciales, que demostraron su potencial para predecir la mortalidad, las hospitalizaciones, los ingresos, las infecciones urinarias y los factores de riesgo cognitivos, de caídas y nutricionales, además de proporcionar a los clínicos alertas y planes de atención personalizados (Molinari-Ulate, Mahmoudi, et al., 2022). Sin embargo, para aprovechar todo su potencial, se identificó su necesidad de ser apoyado por una TSD que pudiera producir alertas y notificaciones automáticas, permitiendo que múltiples profesionales sanitarios participaran en la evaluación, y proporcionándoles informes de perfil individualizados de necesidades y riesgos y planes de cuidados. Una vez que los médicos recibieran los datos clínicos de alertas y necesidades de cuidados personalizados de forma sencilla y fácil de usar (por ejemplo, representación gráfica del perfil y estado de salud de la persona), podrían ofrecer una respuesta inmediata mediante intervenciones digitales y a distancia. En este caso, las dificultades de acceso a la población rural se identificaron como una barrera para implementar un programa socio-comunitario como el MCSP, sin embargo, la plataforma podría ofrecer acceso remoto a algunas de sus actividades a través de la telepresencia, facilitando al usuario potencial las mismas actividades que se realizan en persona y en tiempo real en una región diferente. Asimismo, los familiares y cuidadores podrían recibir apoyo a través de tecnologías de aprendizaje en línea, como el iSupport-Sp, sin necesidad de desplazarse a instalaciones físicas y abandonando las responsabilidades de sus cuidadores (Molinari-Ulate et al., 2023). No obstante, el desarrollo de este tipo de iniciativas debe contar con la participación de las partes interesadas y los pacientes para lograr sistemas más atractivos y fáciles de usar que se ajusten a las necesidades reales (Molinari-Ulate, Woodcock, et al., 2022; Thabrew et al., 2018).

5. Conclusión

Este proyecto describió una serie de pasos necesarios para crear las bases de una plataforma tecnológica para la formación en salud y bienestar de adultos mayores con demencia y deterioro cognitivo y sus cuidadores. Los estudios comprendidos en el proyecto pretendían contribuir a la búsqueda de soluciones para hacer frente a los retos que plantea el envejecimiento de la población, en particular la complejidad de la atención a los adultos mayores, el aumento de las personas que viven con demencia y de sus cuidadores, y la escasa accesibilidad de las poblaciones rurales a los servicios sanitarios para hacer frente a estos retos.

En primer lugar, se identificaron las herramientas de evaluación alineadas con un enfoque de atención integral que podrían utilizarse para monitorizar y evaluar múltiples dominios de una persona, y proporcionar a los médicos datos relevantes, alertas y planes de atención personalizados. El interRAI LTCF y el interRAI HC se recomiendan para su uso en centros de larga estancia y atención domiciliaria, respectivamente, debido al número de estudios, la trayectoria de desarrollo del instrumento, la validación en varios países y sus características psicométricas.

En segundo lugar, se identificaron las pruebas y características de las TSD que apoyan la administración de los EGI, ya que son necesarias para alcanzar su plena capacidad. La literatura científica sobre este tema fue escasa, sin embargo, se reportaron barreras relacionadas con su usabilidad y factibilidad, tales como la disponibilidad y accesibilidad a dispositivos apropiados; inconsistencia en la conectividad de la red; problemas técnicos que llevan a datos inapropiados, inconsistentes y faltantes; duración de la evaluación; y falta de entrenamiento y conocimiento sobre la información recolectada y su propósito. Asimismo, se describieron algunas recomendaciones que podrían mejorar su usabilidad e implementación, por ejemplo, la accesibilidad a la evaluación del individuo por parte de múltiples profesionales sanitarios y la posibilidad de desglosar las secciones en función de la experiencia profesional para compartir la responsabilidad de las evaluaciones; el uso de almacenamiento de datos seguro, como las nubes; la automatización de un cálculo en tiempo real de las escalas y los resultados con una representación gráfica del perfil y el estado de salud de la persona; alertas automáticas, notificaciones y seguimiento continuo para la finalización de los ítems; y la provisión de planes de atención personalizados en función de los datos recopilados.

En tercer lugar, se estudió la participación digital de las partes interesadas y los pacientes en el diseño, el desarrollo, la investigación y la aplicación, para hacer frente a los retos causados por la pandemia COVID-19 en el desarrollo de esta metodología de investigación. El principal resultado fue el marco de "Habilitación a la Coproducción Digital", que se identificó como una herramienta útil para que los investigadores, los coordinadores de la PPI y, sobre todo, para que identificaran y debatieran los pros y los contras de la PPI electrónica y los enfoques mixtos e híbridos. El marco también fue útil para identificar varias recomendaciones para mejorar la aplicación de la e-PPI.

En cuarto lugar, se identificaron los facilitadores y obstáculos de la aplicación de un enfoque de atención sociocomunitaria que ha demostrado una mejor relación coste-beneficio en comparación con otras metodologías, el MCSP. Los principales obstáculos identificados fueron la financiación del proyecto y la coordinación y colaboración entre instituciones. Además, la dificultad para involucrar a las poblaciones rurales y la necesidad de acceder a materiales de formación y capacitación del personal fueron temas relevantes para el contexto cultural de España. La necesidad de un proceso de implementación adaptado al contexto de interés, y el desarrollo de acciones para superar barreras específicas, como el desarrollo de herramientas para ofrecer este enfoque asistencial de forma remota para involucrar a las poblaciones rurales, se consideró como el principal hallazgo.

En quinto lugar, en un intento de ofrecer una alternativa de servicio de apoyo a los cuidadores de personas que viven con demencia en zonas rurales remotas de España, se desarrolló la adaptación cultural del programa de formación y apoyo iSupport para cuidadores de PvD. La plataforma iSupport-Sp se proporciona a través del aprendizaje en línea, mejorando la prestación de servicios de atención sanitaria, y permitiendo que las zonas remotas puedan acceder a ella con el único requisito de tener acceso a conexión a Internet. Esto será especialmente beneficioso para los cuidadores, a menudo limitados de tiempo debido a sus responsabilidades como cuidadores y otras obligaciones diarias. Además, se están estudiando la usabilidad y la experiencia del usuario de iSupport-Sp, así como su impacto en el conocimiento de la demencia y la sobrecarga de los cuidadores, con el fin de obtener pruebas de su eficacia y mejorar el servicio para adaptarlo a las necesidades de las partes interesadas.

Si se incorporan los resultados de estas cinco fases y se incluyen tecnologías novedosas como la IA, la robótica, las tecnologías ponibles y los dispositivos de monitorización, la idea de la plataforma tecnológica podría ser viable. Otros proyectos pueden aprender de las lecciones obtenidas en este proyecto y podrían poner en práctica las iniciativas aquí descritas, para generar un impacto en las posibles soluciones a los retos a los que se enfrenta actualmente la población que envejece.

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Supplementary Material 2. Extended English Summary

1. Introduction

The demographic transition to ageing populations is bringing new challenges to societies and public health systems (WHO, 2015), confronting them with the need for new adjustments and responses from all sectors (WHO, 2018). Care systems have been facing and struggling with the widely diverse and complex panorama of older adult care, mainly associated with comorbidities, polypharmacy, multiple treatments and interventions from different healthcare providers, and the risk of developing functional and cognitive impairment, which have profound implications on the quality of life and independence and autonomy capacity of the older adult population (Roberto Bernabei, Francesco Landi, Graziano Onder, Rosa Liperoti, & Giovanni Gambassi, 2008; Molinari-Ulate, Mahmoudi, Franco-Martín, & van der Roest, 2022; WHO, 2015).

As ageing occurs, the prevalence of dementia rises and it duplicates every 5 years after the ages between 65 and 69 (Villarejo Galende et al., 2021). According to the World Alzheimer Report 2018, around 50 million people are living with dementia around the world and it is expected to triple to 152 million people by 2050 (Gauthier, Rosa-Neto, Morais, & Webster, 2021; Patterson, 2018). As the disease progresses, an increase in the need for supervision and personal care for a person with dementia is expected (Alzheimer's, 2016), affecting the caregivers' health and quality of life, and impacting their financial health (Alzheimer's, 2016; Casal Rodriguez, Rivera Castineira, & Currais Nunes, 2019; Waligora, Bahouth, & Han, 2018). It is estimated that around 80% of the care is provided by informal caregivers (e.g., family members, friends, unpaid caregivers) (Alzheimer's, 2016; Coduras et al., 2010) and that 85% of the costs are attributed to the family (Gauthier et al., 2021; Ministerio de Sanidad, 2019).

The transition to an ageing population has been also reflected in Spanish society, where this project has been implemented. It is expected that by 2050 one of every three Spaniards will be over 65 years old and that the population with dementia will increase by close to one million (Sánchez Sánchez, 2006). This situation has modified the Spanish population pyramid and has developed new sociodemographic challenges (Pérez Diaz, Abellán García, Aceituno Nieto, & Ramiro Fariñas, 2020), principally affecting the rural areas of Asturias, Castilla y León, Galicia, País Vasco, Cantabria, and Aragón, where the proportion of older adults is higher (Pérez Díaz, Abellán García, Aceituno Nieto, & Ramiro Fariñas, 2020). This current demographic context in Spain is known as "Emptied Spain" and refers to a relatively higher percentage of ageing and depopulation in rural areas and an increasing rural-urban migration, particularly of the youth, which has diminished service delivery in rural areas and posed increasingly challenges (de la Torre, 2018; López González, 2021; Pérez Diaz et al., 2020).

For facing this panorama, it has been suggested to develop healthcare approaches that place older people's needs and preferences in the centre of service delivery (WHO, 2015, 2018). One such an approach is the integrated care, which has shown to be an effective alternative approach to implement in the complex spectrum of older adult care (WHO, 2018), improving the quality of life and positively impacting rates of institutionalization and costs (Johri, Beland, & Bergman, 2003; McDonald, Schultz, & Chang, 2013; WHO, 2015). Several initiatives have been developed in the last ten years to target and support the integrated care proposals, such as the development of technological systems that allow the assessment and clinical data transfer around clinical settings (e.g. home, nursing homes, long-term care facilities, hospitals, etc.) (Devriendt et al., 2013; L. Gray & Wootton, 2008; Vanneste, Vermeulen, & Declercq, 2013). These systems could facilitate sharing and monitoring clinical data, integrating and coordinating assessments, improving communication among health environments, continuity of care, identifying people at risk or coordinating better person centred interventions (Devriendt et al., 2013; L. Gray & Wootton, 2008; Vanneste et al., 2013).

This project contributes to the search for better healthcare systems tools that could face the above-mentioned challenges, specifically the complexity of older adult care, the rise on people living with dementia (PLwD) and their caregivers, and the accessibility of the rural population to healthcare services to face the ageing population difficulties. In the next subsections, it is explained how these complexities were approached and what was specifically done to contribute to the solution of this panorama.

1.1. General aims

The main aims of this project were:

a) To develop a proof of concept of a technological platform integrating several innovative digital tools for health and wellness coaching of older adults with dementia and cognitive impairment and their carers

b) To study the effects of utilisation of the platform on physical health, mental and emotional well-being, activities of daily living, social and cognitive functioning and professional care use.

c) To involve older adults with dementia and their carers in the design and development of the platform, assessing their satisfaction, the impact of the system in realistic settings, acceptability, and usability, to enable them to manage the system autonomously in daily life.

1.2. Studies objectives

To achieve the main aims of the project, it was needed to conduct several studies with specific objectives. In this subsection, it is briefly explained and justified what studies were conducted and their objectives that helped to get closer to the main goal:

i. Systematic reviews

a. Literature search on the content and psychometric characteristics of Comprehensive Geriatric Assessments (CGAS) used in long-term care settings and community care (Molinari-Ulate, Mahmoudi, et al., 2022)

As the technological platform is targeting multiple domains of PLwD (e.g., physical health, mental and emotional well-being, activities of daily living, social and cognitive functioning and quality of care), it was necessary to identify the assessment tools available in the scientific literature that cover these domains and to compare their psychometric characteristics to make an informed decision on which tool to implement. For this reason, this systematic review aimed to provide insight into the content and psychometric characteristics of CGAs used in long-term care settings and community care. CGAs are considered as a care process embedding a coordinated multidimensional and multidisciplinary assessment that facilitates clinical decisions for the development of personalized care plans to address, through a person-centred approach, the needs and concerns of older adults and their families and carers (BGS, 2019; Pilotto et al., 2017). They incorporate the main pillars of integrated care and have become important interventions in geriatric care (Ellis, Whitehead, Robinson, O'Neill, & Langhorne, 2011; Pilotto et al., 2017).

b. Literature search on the evidence and technical features of Digital Health Technologies (DHTs) developed to facilitate the administration of CGAs for long-term care settings or community care

After the first literature search, it was identified that to reach the full potential of CGAs, they must be supported by electronic data systems that provide the multidisciplinary teams of care professionals with relevant outputs and that enable sharing of information between multiple care settings in a timely manner (Chadwell, 2001; Devriendt et al., 2013; L. C. Gray et al., 2009). This could optimize the coordination of care and avoid potential setbacks associated with the completeness and reliability of the data collected. Consequently, this systematic review aimed to describe the evidence on DHTs that have been developed to facilitate the administration of CGAs and describe their technical features and components, address the feasibility and usability, efficacy and effectiveness, and implementation outcomes, and report on the maturity of the DHTs.

ii. Digital Patient and Public Involvement in dementia research (Molinari-Ulate, Woodcock, et al., 2022)

To achieve the involvement of PLwD and their carers in the design and development, it was needed to study the methodology to conduct this involvement. Patient and Public Involvement (PPI) has been considered a cornerstone research project or public policy development carried out with or by patients and members of the public for governmental and ethical policies in health research (Burton, Ogden, & Cooper, 2019; Charlesworth, 2018; Dogba, Dossa, Breton, & Gandonou-Migan, 2019; Gove et al., 2018; INVOLVE, 2012; Miah et al., 2019). However, in March 2020 the World Health Organization (WHO) declared the COVID-19 pandemic and the involvement of patients and the public in research was challenged by social distancing, lockdowns and reduced physical contact (NHS, 2021), accelerating the rapid transition to digital working. Due to this situation and the scarce literature on how to conduct digital PPI (e-PPI), this study aimed to explore the experiences of e-PPI within a dementia-specific context during the COVID-19 pandemic and intended to use the findings to refine an existing ‘Overview of Digital Considerations’ originally developed by a PPI group, resulting in the ‘E-nabling Digital Coproduction’ Framework.

iii. Adaptive implementation of the Meeting Centres Support Programme

The lack of resources in health care systems to face the challenges of dementia and the sociodemographic changes affecting the caregiver role have led to a growing need for socio-community programs in search of more sustainable and effective interventions (Fam, Mahendran, & Kua, 2019; Prina, Mayston, Wu, & Prince, 2019; Prince et al., 2008). One such approach is the Meeting Centres Support Programme (MCSP) as it has been identified as an alternative care approach with greater socio-community integration and a better cost-benefit ratio that improves the quality of life and mental health of PLwD and their caregivers

(Brooker et al., 2018; Dröes, Breebaart, Meiland, Van Tilburg, & Mellenbergh, 2004; Dröes, Meiland, Schmitz, & van Tilburg, 2004; Henderson et al., 2021; Mangiaracina et al., 2017). For this reason, this project aimed to identify the facilitators and barriers that could facilitate an adaptive implementation of the programme by understanding the cultural, care and social context of two regions of Spain and Ecuador. An adaptive implementation of the programme could facilitate its integration in the rural context of Zamora, Spain, and its implementation could be supported by the digital platform to reach remotely the rural populations.

iv. Cultural adaptation of the iSupport online training and support programme (Molinari-Ulate et al., 2023)

Following the aim of integrating digital tools for health and wellness coaching for PLwD and their carers, particularly those living in rural areas, e-learning has been identified as an effective approach that benefits the dementia knowledge and social support of caregivers of PLwD (Murray, Burns, See Tai, Lai, & Nazareth, 2005; Sitges-Maciá, Bonete-López, Sánchez-Cabaco, & Oltra-Cucarella, 2021). It has also the potential to overcome some constraints of in-person interventions, such as costs and transportation, inability to leave home due to the caregiving role, and might help to increase the service coverage (Hattink et al., 2015; O'Connor, Arizmendi, & Kaszniak, 2014; Pot et al., 2019; Wasilewski, Stinson, & Cameron, 2017). Therefore, this project aimed to culturally adapt the iSupport, an evidence-based training and support programme for caregivers of PLwD developed by the World Health Organization, and co-design an online platform with PLwD, informal carers, and people from rural regions in Castilla y León, Spain. This platform was developed as part of the digital tools to be integrated into the main technological platform, supporting its remote implementation.

v. Usability, user experience, and pilot study of the efficacy of the iSupport-Sp

Associated with the cultural adaptation study of iSupport, this project aimed to study the usability and user experience of the iSupport-Sp in informal and formal caregivers of PLwD. Additionally, the study explores whether the use of the iSupport-Sp influences the level of dementia knowledge and the self-perceived caregiver burden. The results of this pre-experimental pilot study will serve to design a future randomized controlled trial to determine the efficacy of the iSupport-Sp and to include it in the technological platform if it shows to be an effective digital tool for caregivers of PLwD.

2. Methods

2.3. Systematic Reviews

2.1.1. Literature search on the content and psychometric characteristics of CGAs used in long-term care settings and community care (Molinari-Ulate, Mahmoudi, et al., 2022)

A search strategy was conducted in three databases, PubMed, CINAHL and Web of Science Core Collection for studies up to July 13, 2021. Reference lists of selected studies and relevant systematic reviews were scanned for potentially eligible primary studies. Studies were excluded if a) the CGA was an assessment that consists of a collection of single domain measures, tests or assessments, or stand-alone instruments assessing one domain (e.g, depression); b) studies published in languages other than English or Spanish; c) Publications such as conference abstracts, case studies, protocols, dissertations, books and systematic reviews; d) if the entire CGA was self-report; e) CGAs developed for acute care, mental health care, palliative care, primary care or hospitalized settings; f) those CGAs that assessed transfer from or to any of the aforementioned care settings.

Two authors constructed the search strategy from free text keywords and Medical Subject Headings (MeSH). Search strategy was translated to the database’s correspondent-controlled vocabulary headings and appropriate syntax, when necessary. Duplicates identified from the initial search were removed. Two authors independently screened titles and abstracts of the records identified. Full-text article review was conducted independently by two reviewers, obtaining the final records for the analysis. Discrepancies were solved through discussion or by incorporating a third reviewer.

From the final studies selected, the following data were extracted: a) name of CGA; b) authors/year; d) description of sample; e) country; f) study setting; g) study design; h) aim of the study; i) type of validity/reliability; and j) main findings. Scale, items, indices, or domains were also extracted from the relevant studies. The quality of the studies/risk of bias was assessed independently by two of the authors through the “STANDARD QUALITY ASSESSMENT CRITERIA for Evaluating Primary Research Papers from a Variety of Fields”(Kmet, Lee, & Cook, 2004).

2.1.2. Literature search on the evidence and technical features of DHTs developed to facilitate the administration of CGAs for long-term care settings or community care

Searches were conducted up to April 5, 2023, in PubMed, CINAHL and Web of Science. The studies inclusion criteria were a) the study focused on the feasibility, usability, efficacy, effectiveness, or implementation of DHTs supporting the administration of CGAs for long-term care settings and community care; b) the CGA was a single multidisciplinary test or assessment tool; c) the DHT was developed for use in clinical practice, d) the CGA supported by the DHT must be targeting people 55 years old or above. Only studies in English and Spanish were considered.

The search strategy was developed by two authors using free text keyword and MeSH. The strategy was translated to the correspondent-controlled vocabulary headings and appropriate syntax of the other databases. After duplicate removal, the remaining records were divided amongst three pairs of reviewers (six in total) who screened the titles independently. Within each pair, deviations were discussed and agreement was sought. The abstracts of the potentially eligible remaining records were screened by two authors. The same authors checked the full-text of the eligible papers. Discrepancies were solved by involving a third author.

The data extracted from the studies finally selected were: a) author and year of publication; b) name of the DHT, c) technical features; d) stage of maturity; e) name of the CGA; f) aim of the study; g) study design; h) country; i) care setting; j) description of the study sample (size, female percentage, mean age, and standard deviation); k) outcomes; l) main findings. Risk of bias was evaluated by two raters through the “mERA Methodological Criteria” (WHO, 2016).

2.4. Digital Patient and Public Involvement in dementia research (Molinari-Ulate, Woodcock, et al., 2022)

The project was co-produced with the MindTech Involvement Team, a group of people and carers bringing their own lived experiences of mental health conditions, as well as expertise in the processes of patient and public involvement (PPI). Three types of sessions were performed a) a project design and development session, b) project delivery sessions (workshops), and c) meetings to analyse and synthesize the outcomes.

Two online workshops and one individual interview were conducted. Four researchers and two PPI coordinators participated in Workshop 1. An individual interview was held with one of the researchers as could not attend the workshop. Workshop 2 was performed with the 'Dementia, Frail Older People and Palliative Care Patient and Public Involvement Advisory Group', an existing PPI group from the University of Nottingham, made up of members who have experience of caring for PLwD and some were carers themselves.

Continuing the focus on co-production, a collaborative data analysis was performed with members of the MindTech Involvement Team. Thematic analysis was chosen for the analysis of results. Coding was performed by the project leads and final coding was brought back to the Involvement Team for discussion and final inputs. Themes identified were mapped against the 'E-nabling Digital Co-production' Framework, which was refined during the data analysis of this project.

2.5. Adaptive implementation of the Meeting Centre Support Programme

Two online semi structured interviews were conducted in October 2021 with stakeholders of Ecuador and Spain. In Ecuador, the stakeholders interviewed were representing the public, social services, and academic sectors. In Spain, the interviewed was conducted with the coordinator and the programme facilitator of the Meeting Centre in Zamora, Spain.

Interviews were conducted through Microsoft Teams and were transcribed verbatim for analysis. Stakeholders received a list of facilitators and barriers identified from previous studies of implementation was used to familiarize the participants with implementation process examples. Thematic analysis was the chosen approach for data analysis, and it was conducted independently by two reviewers. The facilitators and barriers identified were mapped against the theoretical model for tracing facilitators and barriers in adaptive implementation (Meiland, Dröes, De Lange, & Vernooij-Dassen, 2004). A list of facilitators and barriers identified in previous studies was used as the framework for the coding process.

2.6. Cultural adaptation of the iSupport online training and support programme (Molinari-Ulate et al., 2023)

Three main steps were conducted, each with its own methods: a) translation, b) cultural adaptation, and c) online platform co-design. The translation was performed by two native Spanish speakers' authors familiar with the context of Castilla y León, Spain, and with experience in dementia and caregivers.

The cultural adaptation was conducted according to the Adaptation and Implementation Guide provided by the WHO (WHO, 2019a). First, the words, names, links, and resources included in the original generic version of the iSupport and recommended by the Guide to be changed, were modified according to the local culture and habits. Second, three focus groups were conducted to review the translated and adapted version with a) informal caregivers, b) formal/professional caregivers, and c) a group of experts on cognitive impairment and dementia. For the first two groups, the focus groups consisted of two sessions of 90 minutes each; for the group of experts, the data was collected by e-mail after a first face-to-face session to explain the purpose of the project and how to register the data. Third, all modifications were collected and discuss in the focus groups, the final remarks were included in an adaptation form to compare the three samples. Thematic analysis was the chosen approach to code the data; codes were initially obtained from previous published iSupport cultural adaptations and new codes identified were included. Data was coded by two of the authors and disagreements were solved by involving a third researcher.

An additional co-design process was performed to increase the quality of the design and adaptation of the online platform. This step was targeted as a PPI activity and performed with a) the European Working Group of People with Dementia (EWGPWD), a group of people living with dementia and their carers with experience in research engagement; b) the Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology (DISTINCT), a group of researchers aiming to improve the lives of people living with dementia and their carers through technology; and c) a group of people living in a rural area in Salamanca, which eight of them were or used to be caregivers of people living with dementia. The EWGPWD meeting was performed online through Zoom, with the DISTINCT Network and the rural population meetings were in-person. The time for the sessions varied from 20 to 40 minutes. Decision for the inclusion of the recommendations were done according to the technological viability and the adaptation guidelines from the WHO.

2.7. Usability, user experience, and pilot study of the efficacy of the iSupport-Sp

A mixed methods study of human-online platform interaction is being conducted. The study has been done in one single phase with two slopes: a) a usability and user experience study, and b) a exploratory pilot study of the efficacy of the iSupport-Sp on dementia knowledge and caregiver burden. For the first slope, the Computer System Usability Questionnaire (CSUQ) and a semi structured interview of user-experience are being administered after the iSupport-Sp training program has been completed. For the efficacy pilot study, two questionnaires are being administered pre- and post- the completion of the iSupport-Sp, the Dementia Knowledge Assessment Tool 2. Spanish Version (DKAT2-Sp) and the Zarit Burden Interview (ZBI).

The targeted sample are 50 individuals identified as informal or formal caregivers of PLwD which are being recruited from Memory Clinics, Spanish Alzheimer Associations and Long-term care settings in Castilla y León, Spain. The inclusion criteria is: a) being 18 year and older, b) being an informal or formal caregiver, c) the person being care should have a dementia diagnosis, d) know how to read, write and being a fluent Spanish-speaker, and e) not have loss of any sense that makes it difficult to use electronic devices.

Once the participants are identified, they have access to the iSupport-Sp link where they must register and create a username and password. Sociodemographic data will be gathered from the registration. Following the registration, participants will complete the DKAT2-Sp and the ZBI, and then they will have access to the modules and lessons. Once the participants have completed all modules and lessons, they will complete the DKAT2-Sp and the ZBI post-test, and the CSUQ and user-experience semi structured interview. At the end, they will have the option to download a certificate of completion of the iSupport-Sp.

3. Results

3.3. Systematic Reviews

3.1.1. Literature search on the content and psychometric characteristics of CGAs used in long-term care settings and community care (Molinari-Ulate, Mahmoudi, et al., 2022)

A total of 10 different CGAs were identified from 71 studies reviewed. The Resident Assessment Instrument-Minimun Data Set (RAI-MDS) and its subsequent versions, the VALutaziones GRAFica (ValGraf) Residential version, and the Care Planning Assessment Tool (CPAT) were focused on long-term care settings. For community care, the Comprehensive Assessment and Referral Evaluation (CARE), the Older American’s Resources and Services (OARS) Multidimensional Functional Assessment Questionnaire (OMFAQ), the Philadelphia Geriatric Center Multilevel Assessment Instrument (MAI), the Popovich Scale, the Outcome and Assessment Instrument Set (OASIS), the RAI-MDS Home Care (HC) and its subsequent versions, and the Community Assessment of Risk Instrument (CARI), were identified.

The most studied instruments for long-term care were the RAI-MDS and its subsequent versions, while for community care were the RAI-MDS HC and its subsequent version and the OASIS. Inconsistencies in terms of how specific the domains assessed were between the CGAs were identified. Whilst some CGAs included broad domains which makes it difficult to understand what were specifically assessing, others were more specific or clearer by referring and evaluating the domains in more detail.

The number of studies and the psychometric characteristics positively support the use of the RAI-MDS and subsequent versions in long-term care settings as compared to the other CGAs. However, it shows some flaws on items such as oral/dental problems, risk of undernutrition, urinary tract infection, and depression and mood. For community care, the number of studies validating the CGAs did not differ as much as in long-term care, and the psychometric characteristics appear to achieve high standards for all CGAs, except for the CARI and the CARE. Some relevant considerations regarding the psychometrics of community care CGAs are available (Molinari-Ulate, Mahmoudi, et al., 2022).

Considering the study characteristics, the psychometric features, the instrument development trajectory, and the global adaptation and validation, the interRAI LTCF and interRAI HC are recommended to be used for long-term care facilities and community care. Nonetheless, health care professionals must be aware of the flaws reported for these instruments.

Due to this recommendation, the interRAI LTCF and the interRAI HC were translated and culturally adapted with health care professionals of Zamora and Barcelona, Spain. The manuals and forms of these instruments are expected to be published and available after interRAI approval. Also, as the interRAI suite of instruments share core items, the interRAI Mental Health (MH), the interRAI Community Mental Health (CMH), and the interRAI Emergency Screener for Pyschiatry (ESP) were also translated and adapted for the Spanish population.

3.1.2. Literature search on the evidence and technical features of DHTs developed to facilitate the administration of CGAs for long-term care settings or community care

Despite that the previous literature search identified three CGAs for long-term care settings and seven for community care (Molinari-Ulate, Mahmoudi, et al., 2022), this scientific literature review only identified four DHTs supporting two of those CGAs, the MDS-HC and the interRAI HC. Five studies were included in the analysis, targeting the following DHTs: a) MDS-HC© Electronic Web-based Interface; b) interRAI electronic assessment tools; c) System for Person-centered Elder Care (SPEC); and d) BelRAI. The MDS-HC© and the interRAI electronic assessment tools were at the feasibility/usability stage of evaluation and were in the prototype and scaled-up state of maturity, respectively. The SPEC was investigated at the stage of maturity of demonstration and the effectiveness state of evaluation. The BelRAI was in the integration/sustainability stage of maturity and at the implementation state of evaluation.

Information regarding the technical features and hardware characteristics of the DHTs was limited. Only reported for the interRAI electronic assessment tools, which described the use of laptops, however, the used software was not specified. From the feasibility and usability data gathered, the following barriers affecting the implementation of the DHTs in care practice were identified: a) technical difficulties using the software; b) length of the assessments; c) inconsistent network connectivity; d) carrying around the hardware, mainly laptops; e) need of ongoing training to perform the assessment correctly; and f) lack of staff knowledge regarding the information collected and its purpose. Some of these barriers can be overcome with novel technologies, however, training of health professionals on the assessments and staff knowledge regarding the purpose of the data collected, are not technology-related and need to be addressed.

Also, the results showed some features that could reinforced the usability, effectiveness, and implementation of DHTs supporting the application of CGAs, such as: a) utilization of a safe data storage warehouse, such as clouds; b) inclusion of automatic alerts, notifications, or a continuous check for item completion in the DHTs; c) access allowance for multiple health care professionals on individual assessments in the DHT, avoiding to rely on one professional to complete the CGA but using the expertise of each team member; d) provisioning of individualized profile reports of needs and risks, and personalised care plans; and d) automatic calculation of the composite outcomes and scales.

3.4. Digital Patient and Public Involvement in dementia research (Molinari-Ulate, Woodcock, et al., 2022)

Regarding the challenges and approaches of e-PPI, two main themes were shared by the participating groups a) the wider potential reach without geographical constraints, which could be useful to widen participation, and b) the perception of more business-like sessions with reduced opportunities for social interactions and communication. It was also identified both positive and negative opinions concerning the transition to digital co-production. For example, in terms of the diversity and inclusion of the PPI groups, e-PPI was considered as a barrier if the same members are always attending the sessions, however, it could also offer the opportunity to include others who have not engaged in PPI before. Within the dementia context, e-PPI offers carers the capacity to attend more meetings (as they do not need to leave care responsibility by attending virtually) but simultaneously they may lose time away from care responsibility (respite and supportive space opportunities).

After the refinement of the existing guidance ‘Overview of Digital Considerations’ developed by the MindTech Involvement Teams, which was used to start the coding of the results, it was identified and co-produced four areas that resulted in the ‘E-nabling Digital Co-production’: Technological, Resources, Involvementability, and Ethical and Welfare. The development process of the framework is a good example of collaborative data analysis and co-production. It was also identified that the framework is a tool for researchers, PPI coordinators and public contributors to identify and discuss challenges and opportunities provided by e-PPI and blended/hybrid approaches. It has the potential to be used with specific populations and contexts, as it was demonstrated through the dementia context target in this project. The framework should be considered as an opportunity to study how PPI is approached and to explore the preferences and implications of different PPI approach methodologies.

3.5. Adaptive implementation of the Meeting Centre Support Programme

The barriers identified in both Ecuador and Spain, also shared by other European countries (Netherlands, United Kingdom, Poland, and Italy), were the collaboration and coordination between institutions and the project funding. The main facilitators were the stakelhoders’ enthusiasm and the collaboration between partners and institutions. New facilitators and barriers, not evident in previous studies, were identified specifically in Spain and Ecuador. For example, the urban-rural difference, particularly the difficulties accessing rural populations, and the need for transportation were identified as barriers in both Spanish-speaking countries. The availability of staff and volunteers trained and skilled in MCSP and finding a sufficient number of participants were identified as facilitators in Spain, however, they were considered as barriers in Ecuador. Other barriers were identified such as the administrative process to create collaborations or obtain funding, which in Ecuador was considered to slow down the process. In Spain, the program was perceived as an additional burden for informal caregivers as it was not fully adjusted to their needs of informal caregivers.

The project also demonstrated that the traceability model and the phased implementation process, previously implemented in European countries, could be applied in Spanish-speaking countries. In addition, the study opens the door to carry out adapted implementation processes of the MCSP in Latin American. On this regard, these results motivated the development of the ‘Spanish Introductory Course Implementation of Meeting Centres for People with Dementia and their Caregivers’ which includes examples of the facilitators and barriers identified in this study and was specifically developed for Spanish-speaking countries. This course was developed with the support of the MeetingDem network, the Institute of Biomedical Research of Salamanca (IBSAL), and the Amsterdam University Medical Centres, location Vrije Universiteit. It is now available at https://e4you.org/es/moocs/implementacion-de-centros-de-encuentro-para-personas-con-demencia-y-sus-cuidadores

3.6. Cultural adaptation of the iSupport online training and support programme (Molinari-Ulate et al., 2023)

A total of 435 suggestions were proposed for adaptation associated with erroneous terminology, rewording text/writing, grammatical or punctuation marks errors, and repeated information or need for additional content. The majority of the suggestions were proposed by the formal caregivers (n=244), followed by the experts group (n=170) and by the informal caregivers (n=21). As demonstrated, suggestions from informal caregivers were far fewer than the other stakeholders group, which led to an imbalance between the perspective of the three groups composing the sample.

Regarding the co-design process, several recommendations were exposed: a) preference for interactive material such as videos or images, b) a forum to receive feedback from health care professionals and to leave satisfaction comments, c) availability in multiple platforms (e.g., tablet, laptop, mobile), d) slide format for information presentation, e) access to the information by audio, f) a personal link to access the platform instead of a username and password, g) easy language avoiding technical vocabulary, h) make it available for those without access to Wi-Fi or technological devices, and e) availability to edit letter size and background colours.

Considering the previous results, the iSupport Spanish online version (iSupport-Sp) was developed. iSupport-Sp was developed in WordPress using the online training plugin LearnDash and the Enfold theme. It is hosted in a cloud system (isupport.bluece.eu) and it can be accessed by users through the internet connection. The platform can be run by a computer, laptop, tablet, or smartphone. It incorporates dashboards to track users’ progress. Therefore, it can report on completion rates, attendance data and success likelihood. iSupport-Sp is available upon request to the authors as it is under study for its feasibility and usability.

3.7. Usability, user experience and pilot study of the efficacy of the iSupport-Sp

This study is underway, and no preliminary data is available at the time this report has been written. It is expected that the co-production and co-design of the iSupport-Sp will be reflected in the usability and user experience of the participants. Also, it is expected that the use of the iSupport-Sp improves the dementia knowledge and decrease the caregiver burden of the caregivers of PLwD participating in the study.

4. Discussion

This project aimed to contribute to the search of innovative and technological solutions to equip healthcare systems with tools that could face the new challenges caused by the ageing population. It particularly targeted the complexity and diversity of older adult care, the rise on people living with dementia and their caregivers, and the accessibility of the rural population to healthcare services to face these challenges. To pursue this objective, it intended to develop a proof of concept of a technological platform integrating several innovative digital tools for health and wellness coaching of older adults with dementia and cognitive impairment and their carers, and to study its utilisation effects on physical health, mental and emotional well-being, activities of daily living, social and cognitive functioning, and professional care use. This procedure would be accompanied by the involvement of older adults with dementia and their carers in the development and design of the platform, assessing their satisfaction, acceptability and usability, the impact of the system in realistic settings, and to enable them to manage the system autonomously in daily life.

As a first step, the target was to identify which CGAs were available in the scientific literature that incorporate the main pillars of an integrated care approach, and to identify the evidence of the DHTs that have been developed to assist these assessment tools. CGAs, and the DHTs assisting them, could help to face the complexity of older adult care by improving the communication and clinical data transfer between healthcare settings and stakeholders to take more reliable decisions on care planning and health policies, optimizing the quality of care (Chadwell, 2001; Committee, 2015; L. C. Gray et al., 2009; WHO, 2019b). Due to the diversity of domains identified in the CGAs, it is consider necessary to be more specific on which areas are assessed, as these are screening tools that could identify potential risk factors for deterioration and take into account the complexity of older adult care (e.g., comorbidities, polypharmacy, multiple treatments, etc.), which could improve clinical decision making and personalized treatment and care plans (R. Bernabei, F. Landi, G. Onder, R. Liperoti, & G. Gambassi, 2008; Molinari-Ulate, Woodcock, et al., 2022; Scanlan, 2005; WHO, 2015). By gathering clearer information through well-defined domains and warnings, clinicians could obtained more relevant clinical data to make more reliable decisions (Molinari-Ulate, Woodcock, et al., 2022). It will also be possible to develop and improve algorithms obtained from large databases, to incorporate automatic learning that can extract and identify useful information to guide the development of clinical decision models, facilitating the prognosis, diagnosis, and treatment planning, and optimizing the quality of care by identifying unmet needs of older adult care (Dipnall et al., 2016; Góngora et al., 2018).

To reach this full capacity from the CGAs, it is necessary to employ DHTs that could assist on managing these data. However, it was identified a lack of scientific literature reporting on DHTs supporting these assessment tools. This lack of evidence could cause poorly designed systems threaten the safety of patients and contributing to users' burnout and low morale (Committee on Patient, Health Information, & Institute of, 2011; Kroth et al., 2019; Sheikh et al., 2021), and lead to concerns regarding decision-making, quality of care, interventions and care planning, as these are supported by the assessments' results (Vanneste, De Almeida Mello, Macq, Van Audenhove, & Declercq, 2015). To avoid some of these problems and the barriers that could affect the implementation of the DHTs in clinical settings, previously mentioned in the results sections, it will be necessary to invest in data science, quality improvement and health informatics training for the healthcare workforce, and to incorporate data scientists and clinical informaticists in the clinical teams (Sheikh et al., 2021). Also, by engaging the healthcare professionals and the patients in the design and development, research and implementation process of the DHTs, could lead to more engaging and user-friendly systems more aligned to the stakeholders' needs (Thabrew, Fleming, Hetrick, & Merry, 2018) and to identify early amendments, reducing the costs of the system (Kushniruk, Hall, Baylis, Borycki, & Kannry, 2019; Sheikh et al., 2021).

The last recommendation associated to the engagement of the stakeholders and the patients in the design, development, research, and implementation process, guided us to our second step of this project: to studied how to approach PPI digitally, particularly because of the COVID-19 pandemic. The development of the 'E-nabling Digital Co-production' Framework was a response to the rapid transition to digital co-production as a consequence of the pandemic, however, it is not exclusive to e-PPI as it should also be consider as a tool with the potential to examine how PPI is approached in different contexts and conditions (Molinari-Ulate, Woodcock, et al., 2022). It could be used as a tool to explore the preferences and implications of different modalities of conducting PPI within the post-pandemic transition (Molinari-Ulate, Woodcock, et al., 2022). To the best of our knowledge, this framework is the first one targeting the digitalization of PPI and to consider e-PPI as a part of a blended approach

(Molinari-Ulate, Woodcock, et al., 2022), as in a previous systematic review reporting on 65 frameworks for supporting, evaluating, and reporting PPI, this was not considered (Greenhalgh et al., 2019). The framework allowed to identified a variety of pros and cons in a dementia specific context, nonetheless, it should be considered as part of an evolving hybrid toolkit to perform PPI in other research contexts (Molinari-Ulate, Woodcock, et al., 2022). A series of recommendations to improve e-PPI were also identified and were aligned with suggestions described in previous studies (Lampa, Sonnentheil, Tökés, & Warner, 2021; Molinari-Ulate, Woodcock, et al., 2022).

The lessons learned from the digital engagement of the stakeholders and patients in the design, development, research, and implementation process, were necessary to move to the next and final steps of the project. Due to the lack of resources in healthcare systems to address the challenges associated with dementia, such as insufficient healthcare workforce trained, lack of dementia knowledge and lack of funding for long-term care (Fam et al., 2019; Prince et al., 2008; Richly et al., 2019), and the changing role of caregiving because of the reduction of young population and a more active role of women in the workplace (Fam et al., 2019; Prina et al., 2019; Prince et al., 2008), there is a growing need for socio-community programs that take into account the local resources in search of more sustainable and effective interventions (Fam et al., 2019; Prina et al., 2019; Prince et al., 2008). For this reason, stakeholders from Spain and Ecuador were interviewed online to identify the facilitators and barriers of the implementation of an alternative care approach that has demonstrated greater socio-community integration and a better cost-benefit ratio, the MCSP (Brooker et al., 2018; Dröes, Breebaart, et al., 2004; Dröes, Meiland, et al., 2004; Henderson et al., 2021; Mangiaracina et al., 2017).

The facilitators and barriers identified differed according to the cultural context, the access to training resources and the geographic distribution of the population. Also, some of the facilitators and barriers differed from the ones identified in non-Spanish speaking countries. For example, the access to rural areas and the need for transportation were identified as the main barrier to implement this programme in the Spanish-speaking countries. This shows the need to develop a strategic adaptation plan for the implementation of socio-community programs, such as the MCSP, taking into account the different conditions of each country. It is recommended that this adaption includes the socio-cultural adaptation of training materials, in addition to the development of actions to overcome specific barriers, such as the development of resources to offer the service remotely to provide access to rural populations.

As a response to the rural barrier identified in the implementation of the MCSP and considering the sociodemographic situation of the ‘Emptied Spain’, the final step of the project targeted how to deliver remotely some healthcare services for PLwD and their caregivers living in rural areas. As an attempt to offer a support service alternative, a training and support programme for caregivers of PLwD was culturally adapted and co-design with stakeholders and PLwD. The iSupport-Sp was the final outcome, following similar changes and recommendations to those identified in previous cultural adaptions (Baruah et al., 2021; Efthymiou et al., 2022; Teles, Napolskij, Paul, Ferreira, & Seeher, 2021; Xiao et al., 2022). This digital platform is provided via e-learning as it aims to enhance the healthcare service provision and to enable remote areas to access its content and resources, otherwise, these remote populations would incurred in travel costs or leave aside caregiver responsibilities to access these resources (Klimova, Valis, Kuca, & Masopust, 2019; Ritterband & Tate, 2009).

E-learning tools have demonstrated to be cost-effective compare to other modalities (Dickinson et al., 2017; Mitchell, 2011) and to have the potential of delivering multimedia information, which has been considered relevant to offer more engaging content and to potentiate learning (Ruiz, Mintzer, & Leipzig, 2006). The only requirement to access the iSupport-Sp is to have internet connection, then, its learning materials could be accessed at any place and time removing any geographical obstacles and the limitation associated to the caregiving role, such as restricted time or undertake daily duties such as employment, caring for other family members or housework (Serafini, Damianakis, & Marziali, 2007). At the moment this report has been written, the iSupport-Sp usability and user-friendliness are being tested, as well as its potential to reduce caregiver burden and improve dementia knowledge. It is expected that the results from this study reinforce the interest of stakeholders and policy makers and that they can contribute to the improvement of the platform.

This project delved deeper into potential solutions for the challenges associated to the ageing population. The main aim was to develop a proof of concept of a technological platform integrating different innovative technologies to improve health and wellness of PLwD and their caregivers. If “proof of concept” is considered as a kind of research aiming to provide justification in practice of the potential transferability of knowledge acquired through experimental testing (Kendig, 2016), it can be considered that this project partially accomplished its main purpose. Several studies have been described whose results can be considered as the foundations required for the development of the targeted technological platform. If the results presented previously could be combined in a single DHT, embedding novel technologies such as Artificial Intelligence (AI), robotics, wearable technologies, and monitoring devices, the idea of the technological platform could be feasible.

However, without the knowledge acquired through this project, it would be more difficult for this idea to become a reality. For example, the interRAI Long-term care and Home Care assessments were identified as the recommended tools for the monitoring and assessment of potential users, which demonstrated their potential for predicting mortality, hospitalizations, admissions, urinary infections and cognitive, falls, and nutritional risk factors, and also provide the clinicians with warnings and personalized care plans (Molinari-Ulate, Mahmoudi, et al., 2022). However, in order to take advantage of its full potential, it was identified their need to be supported by a DHT that could produce automatic alerts and notifications, allowing multiple healthcare professionals to be involved in the assessment, and providing them with individualized profile reports of needs and risks and care plans. Once the clinicians received the clinical data of warnings and personalized care needs in a simple and user-friendly manner (e.g. graphical representation of the person’s health profile and status), they could offer an immediate response through digital and remote interventions. In this case, difficulties in accessing rural population were identified as a barrier to implement a socio-community programme such as the MCSP, however, the platform could offer remote access to some of its activities through telepresence, facilitating the potential user with the same activities that are performed in-person and in real-time in a different region. Also, family members and caregivers could be supported through e-learning technologies, such as the iSupport-Sp, without requiring to move to physical facilities and leaving their caregivers’ responsibilities (Molinari-Ulate et al., 2023). Nonetheless, the development of this kind of initiatives needs to be supported by the involvement of stakeholders and patients to achieve more engaging and user-friendly systems aligned to the real needs (Molinari-Ulate, Woodcock, et al., 2022; Thabrew et al., 2018)

5. Conclusion

This project described a series of steps necessary to create the foundations of a technological platform for health and wellness coaching of older adults with dementia and cognitive impairment and their carers. The studies comprised in the project aimed to contribute to the search for solutions to face the challenges that come with the ageing population, particularly the complexity of older adult care, the increase of people living with dementia and their caregivers, and the poor accessibility of rural populations to access healthcare services to face these challenges.

First, the assessment tools aligned to an integrated care approach that could be used to monitored and assessed multiple domains of a person, and provide clinicians with relevant data, warnings, and personalized care plans, were identified. The interRAI LTCF and interRAI HC are recommended to be used in long-term care facilities and community care, respectively, due to the number of studies, instrument development trajectory, validation in several countries, and their psychometric characteristics.

Second, the evidence and characteristics of DHTs supporting the administration of CGAs were identified, as they are necessary to reach the full capacity of the CGAs. The scientific literature on this topic was scarce, however, barriers regarding their usability and feasibility were reported, such as the availability and accessibility to appropriate devices; inconsistency in network connectivity; technical issues leading to inappropriate, inconsistent, and missing data; duration of the assessment; and lack of training and knowledge regarding the information collected and its purpose. Also, some recommendations were described that might improve their usability and implementation, for example the accessibility to the individual's assessment by multiple health care professionals and allowance to break down the sections according to the professional expertise to share the assessments' responsibility; the use of safe data storage, such as clouds; automatization of a real-time calculation of the scales and outcomes with a graphical representation of the person's profile and health status; automatic alerts, notifications and continuous monitoring for item completion; and provisioning of personalized care plans according to the data collected.

Third, the digital engagement of stakeholders and patients on the design, development, research and implementation, was studied to face the challenges caused by the COVID-19 pandemic on developing this research methodology. The 'E-nabling Digital Co-production' Framework came as the main outcome and was identified as a useful tool for researchers, PPI coordinators and vitally public contributors to identify and discuss pros and cons provided by e-PPI and blended and hybrid approaches. The framework was also useful to identify several recommendations to improve the implementation of e-PPI.

Four, the facilitators and barriers of implementing a socio-community care approach that has demonstrated better cost-benefit ratio compared to other methodologies, the MCSP, were identified. The main obstacles identified were the project funding and the coordination and collaboration between institutions. Additionally, the difficulty to involve rural populations and the need to access training materials and training for personnel were relevant topics for the cultural context of Spain. The need for an adapted implementation process to the context of interest, and the development of actions to overcome specific barriers, such as the development of tools to offer this care approach remotely to involve rural populations, was considered as the major finding.

Five, as an attempt to offer a support service alternative for caregivers of PLwD in remote rural areas of Spain, the cultural adaptation of the iSupport training and support programme for carers of PLwD was developed. The iSupport-Sp platform is provided via e-learning, enhancing the health care service provision, and enabling remote areas to access it with the only requirement of having access to internet connection. This will be especially beneficial for caregivers often limited from their restricted time due to caregiver responsibilities and other daily duties. Also, the iSupport-Sp's usability and user-experience, and its impact on dementia knowledge and caregiver burden, are being currently studied to obtain some evidence of its efficacy and improve the service to target the stakeholders' needs.

By embedding the findings from these five steps and by including novel technologies such as AI, robotics, wearable technologies, and monitoring devices, the idea of the technological platform could be feasible. Further projects can learn from the lessons obtained in this project and could implement the initiatives described here, to generate an impact on potential solutions for challenges currently faced by the ageing population.

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Supplementary Material 3. Supplementary Material of Publication #1

Appendix A. Supplementary Material

Methods A.1 Search strategy, Studies selection procedure, and interpretation of test scores

Search strategy

Two authors (MM and HR) constructed the search strategy, which contained free text keywords and Medical Subject Headings (MeSH). For those databases different from PubMed, the search strategy was translated to their correspondent controlled vocabulary headings and appropriate syntax, when necessary. The search strategy is described below:

(“geriatric assessment” (MeSH Major Topic) OR “geriatric assessment/methods” (MeSH Major Topic) OR “geriatric assessment” OR “geriatric evaluation” OR “geriatric instrument” OR GA OR “comprehensive geriatric assessment” OR CGA OR “multidimensional geriatric assessment”) AND

(“residential facilities” (MeSH Major Topic) OR “Community Health Centers” (MeSH Major Topic) OR “Community health services” (MeSH Major Topic) OR “long term care” (MeSH Major Topic) OR “elderly care” OR “residential facilit*” OR “long-term care facilit*” OR “LTCF” OR “geriatric care” OR “aged care” OR “home care” OR “senior center*” OR “residential care” OR “community care”) AND

(“reproducibility of results” (MeSH Major Topic) OR “validation studies as a topic” (MeSH Major Topic) OR “valid*” OR “reliab*”)

Studies Selection Procedure

Duplicates from the initial searches were identified and removed. Two authors (MM and AM) independently screened titles and abstracts of the identified papers. Full-text article review was performed independently by two reviewers (MM and AM), obtaining the final records considered for the analysis. Discrepancies were solved through discussions or by involving a third reviewer (HR).

Risk of bias

The checklist is formed by 14 items which are scored according to the degree in which they meet the criteria (0 = no, 1 = partial, 2 = yes). Four of the original items of the scale were “not applicable” according to the characteristics of the papers analysed in this review (items 5, 6, 7, and 13). An extra item was included identifying the “type of validity/reliability” and was scored using the same score range for the rest of the items (0-2). Total score was obtained using the same formula explained in the checklist guide (Kmet et al., 2004), including the extra item added for this review.

Interpretation of test scores

The following standardized criterion based on the literature was used for the interpretation of test scores: a) for effect sizes, results were interpreted according to Cohen’s definition, which an r of 0.1 is consider as a small effect, an r of 0.3 as a medium effect, and an r of 0.5 would be a large effect (Clark-Carter, 2004); b) for inter-rater reliability a Kappa value in the range of 0.4 to 0.6 is considered fair, from 0.6 to 0.75 is good and more than 0.75 is considered as excellent (Clark-Carter, 2004); c) for test-retest reliability a minimum r of 0.8 is expected. It can also be analysed by using the standards for correlations previously mentioned (Clark-Carter, 2004); d) for Cronbach’s Alpha, mainly internal consistency reliability, results should be around 0.9 and not below 0.7 (Clark-Carter, 2004); e) Intraclass Correlation coefficients (ICC) less than 0.5 are indicative of poor reliability, values between 0.5 and 0.75 indicate moderate reliability, values between 0.75 and 0.9 indicate good reliability, and values greater than 0.90 indicate excellent reliability (Koo and Li, 2016); f) Areas Under the Curve (AUC) are excellent between 0.9 and 1, good from 0.8 to 0.9, worthless from 0.7 to 0.8, and not good from 0.6 to 0.7 (Hosmes and Lemeshow, 2005; Zhu et al., 2010); g) for sensitivity and specificity, the sum between both measures should be at least 1.5 for a test to be consider useful (Power et al., 2013); and h) factor loadings above 0.5 will be considered as acceptable (Hair et al., 2014).

Table A.1 Results of quality assessment.

Study	Item #1	Item #2	Item #3	Item #4	Item #5	Item #6	Item #7	Item #8	Item #9	Item #10	Item #11	Item #12	Item #13	Item #14	Item #15	Sum	Score
Anderson et al. (2003)	2	1	2	2	1	N/A	N/A	N/A	2	2	1	1	N/A	2	2	18	0.82
Beck et al. (2001)	2	1	0	2	1	N/A	N/A	N/A	1	2	2	2	N/A	2	2	17	0.77
Björkgren et al. (1999)	2	1	2	1	2	N/A	N/A	N/A	1	2	2	2	N/A	2	2	19	0.86
Burn et al. (2018)	2	1	1	2	0	N/A	N/A	N/A	2	2	1	2	N/A	2	2	17	0.77
Cai et al. (2011)	2	1	2	0	0	N/A	N/A	N/A	2	2	1	2	N/A	2	2	16	0.73
Campitelli et al. (2016)	2	2	2	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	22	1.00
Carpenter et al. (2003)	2	1	1	0	0	N/A	N/A	N/A	2	2	1	2	N/A	2	2	15	0.68
Carpenter et al. (2005)	2	2	1	0	1	N/A	N/A	N/A	2	1	1	1	N/A	1	1	13	0.59
Casten et al. (1998)	2	1	1	2	1	N/A	N/A	N/A	1	2	2	1	N/A	2	2	17	0.77
Chou et al. (2001)	2	1	1	2	2	N/A	N/A	N/A	2	2	1	1	N/A	2	2	18	0.82
Clarnette et al. (2015)	2	2	1	1	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	20	0.91
Estabrooks et al. (2013)	2	1	2	1	0	N/A	N/A	N/A	1	2	1	0	N/A	2	1	13	0.59
Fibla et al. (1996)	2	1	2	2	2	N/A	N/A	N/A	2	2	2	0	N/A	2	2	19	0.86
Fillenbaum and Smyer (1981)	2	1	2	2	2	N/A	N/A	N/A	2	1	2	1	N/A	2	1	18	0.82
Fisher et al. (2002)	2	2	1	2	2	N/A	N/A	N/A	2	1	2	1	N/A	2	2	19	0.86
Fleming (2008)	2	1	1	2	2	N/A	N/A	N/A	2	1	2	2	N/A	2	2	19	0.86
Fries et al. (2001)	2	1	2	2	1	N/A	N/A	N/A	2	1	2	1	N/A	2	2	18	0.82
Gee et al. (2021)	2	2	2	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	22	1.00
Gerritsen et al. (2008)	2	1	1	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	20	0.91
Grubba et al. (1990)	2	1	2	2	2	N/A	N/A	N/A	2	1	2	1	N/A	2	2	19	0.86

Study	Item #1	Item #2	Item #3	Item #4	Item #5	Item #6	Item #7	Item #8	Item #9	Item #10	Item #11	Item #12	Item #13	Item #14	Item #15	Sum	Score
Gruber-Baldini et al. (2000)	2	2	1	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	21	0.95
Gurland et al. (1977)	2	1	1	0	2	N/A	N/A	N/A	2	0	1	0	N/A	1	1	11	0.50
Hartmaier et al. (1994)	2	2	2	2	1	N/A	N/A	N/A	2	2	2	2	N/A	2	1	20	0.91
Hartmaier et al. (1995)	2	1	2	2	1	N/A	N/A	N/A	2	2	2	2	N/A	2	2	20	0.91
Hawes et al. (1995)	2	1	1	1	0	N/A	N/A	N/A	1	2	2	1	N/A	2	1	14	0.64
Hendrix et al. (2003)	2	1	1	2	0	N/A	N/A	N/A	2	2	2	2	N/A	2	2	18	0.82
Hill-Westmoreland and Gruber-Baldini (2005)	2	1	1	2	0	N/A	N/A	N/A	2	2	2	2	N/A	2	2	18	0.82
Hirdes et al. (2008)	2	1	0	2	2	N/A	N/A	N/A	2	2	2	1	N/A	2	2	18	0.82
Hittle et al. (2004)	1	1	1	0	2	N/A	N/A	N/A	1	1	2	0	N/A	2	2	13	0.59
Hoben et al. (2016)	2	1	2	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	21	0.95
Hsiao et al. (2015)	2	2	2	2	1	N/A	N/A	N/A	2	2	2	2	N/A	2	2	21	0.95
Ioannidis et al. (2017)	2	2	2	2	1	N/A	N/A	N/A	1	2	2	2	N/A	2	2	20	0.91
Jockusch et al. (2021)	2	2	2	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	22	1.00
Kanegae et al. (2010)	2	2	2	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	22	1.00
Kim et al. (2015)	2	2	1	2	2	N/A	N/A	N/A	2	2	2	1	N/A	2	2	20	0.91
Kinatukara et al. (2005)	2	1	1	2	0	N/A	N/A	N/A	1	2	2	1	N/A	2	2	16	0.73
Koehler et al. (2005)	2	1	1	2	2	N/A	N/A	N/A	1	2	2	1	N/A	2	2	18	0.82
Krausch-Hofmann et al. (2019)	2	1	2	1	2	N/A	N/A	N/A	2	2	2	1	N/A	2	2	19	0.86
Kruse et al. (2010)	2	2	0	2	0	N/A	N/A	N/A	2	2	2	2	N/A	2	0	16	0.73

Study	Item #1	Item #2	Item #3	Item #4	Item #5	Item #6	Item #7	Item #8	Item #9	Item #10	Item #11	Item #12	Item #13	Item #14	Item #15	Sum	Score
Kwan et al. (2000)	2	1	1	2	2	N/A	N/A	N/A	2	2	1	1	N/A	2	2	18	0.82
Landi et al. (2000)	2	2	1	2	2	N/A	N/A	N/A	2	1	2	2	N/A	2	2	20	0.91
Lawton et al. (1982)	1	1	1	2	2	N/A	N/A	N/A	1	2	1	1	N/A	2	2	16	0.73
Lawton et al. (1998)	2	1	1	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	20	0.91
Leung et al. (2011)	2	2	1	2	1	N/A	N/A	N/A	2	2	2	2	N/A	2	2	20	0.91
Leung et al. (2012)	2	2	1	2	2	N/A	N/A	N/A	2	2	2	1	N/A	2	2	20	0.91
Liang et al. (2011)	2	1	2	2	0	N/A	N/A	N/A	2	2	2	2	N/A	2	2	19	0.86
Ludwig and Busnel (2017)	2	1	2	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	21	0.95
Lum et al. (2005)	2	1	1	1	0	N/A	N/A	N/A	2	2	2	2	N/A	2	1	16	0.73
Madigan and Fortinsky (2000)	2	1	1	2	2	N/A	N/A	N/A	1	2	2	2	N/A	2	2	19	0.86
Madigan and Fortinsky (2004)	2	2	1	2	2	N/A	N/A	N/A	1	1	2	1	N/A	2	2	18	0.82
Mor et al. (1995)	2	1	1	2	2	N/A	N/A	N/A	2	2	2	1	N/A	2	2	19	0.86
Mor et al. (2003)	2	1	1	1	2	N/A	N/A	N/A	2	2	2	1	N/A	2	2	18	0.82
Mor et al. (2011)	2	1	1	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	20	0.91
Morris et al. (1990)	2	1	2	2	2	N/A	N/A	N/A	1	2	2	1	N/A	2	2	19	0.86
Morris et al. (1994)	2	1	1	1	0	N/A	N/A	N/A	2	2	1	2	N/A	2	1	15	0.68
Morris, Nonemaker, et al. (1997)	2	1	1	2	2	N/A	N/A	N/A	2	2	2	1	N/A	2	2	19	0.86
Morris, Fries, et al. (1997)	2	1	1	2	0	N/A	N/A	N/A	1	2	2	0	N/A	2	1	14	0.64
Onder et al. (2012)	2	2	1	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	21	0.95
Pascazio et al. (2009)	2	1	1	2	2	N/A	N/A	N/A	1	2	2	1	N/A	2	2	18	0.82

Study	Item #1	Item #2	Item #3	Item #4	Item #5	Item #6	Item #7	Item #8	Item #9	Item #10	Item #11	Item #12	Item #13	Item #14	Item #15	Sum	Score
Penny et al. (2016)	2	1	2	2	2	N/A	N/A	N/A	2	1	2	2	N/A	2	2	20	0.91
Resnick et al. (1996)	2	1	1	2	2	N/A	N/A	N/A	2	1	2	1	N/A	2	1	17	0.77
Saliba and Buchanan (2012)	2	1	2	0	2	N/A	N/A	N/A	1	2	2	0	N/A	1	1	14	0.64
Saliba et al. (2012)	2	1	2	1	1	N/A	N/A	N/A	2	2	2	2	N/A	2	2	19	0.86
Schluter et al. (2016)	2	2	1	2	0	N/A	N/A	N/A	2	1	2	0	N/A	1	1	14	0.64
Sgadari et al. (1997)	2	1	1	0	2	N/A	N/A	N/A	1	2	2	0	N/A	2	1	14	0.64
Simmons et al. (2002)	2	1	2	2	0	N/A	N/A	N/A	2	2	2	2	N/A	2	1	18	0.82
Snowden et al. (1999)	2	2	2	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	22	1.00
Stevenson et al. (2004)	2	2	2	2	1	N/A	N/A	N/A	2	2	2	2	N/A	1	0	18	0.82
Tullai-McGuinness et al. (2009)	2	1	1	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	20	0.91
van Lier et al. (2016)	2	1	2	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	21	0.95
Zimmerman et al. (2007)	2	2	2	2	2	N/A	N/A	N/A	2	2	2	2	N/A	2	2	22	1.00

Table A.2 Criterion measures or gold standards used for the validation of the CGAs, according to specific area or domain assessed.

	Long-term Care CGAs					
Domain or area assessed	**RAI-MDS**	**RAI-MDS 2.0**	**MDS 3.0**	**ValGraf**	**CPAT**	**interRAI LTCF**
Behavior Status	Physician Behavior checklist for Behavior Domain; Cohen's Manfield Agitation Inventory (CMAI); Irritability Scale of the Multidimensional Observation Scale for Elderly Subjects (MOSES)	Behavior Rating Scale for Psychogeriatric Inpatients (GIP)	-	-	-	-
Care Time	Time recording sheet; Care time recording	-	-	-	-	-
Cognition	Mini-Mental State Examination (MMSE); Test for Severe Impairment (TSI); Nurses judgement of resident's orientation status; Global Deterioration Scale (GDS); Blessed Information-Concentration Measure of Mental Status; Mattis Dementia Rating Scale; Reisberg Global Deterioration Scale; Short Portable Mental Status Questionnaire (SPMSQ); Neurological Diagnosis	-	Modified Mini-Mental Status (3MS); Cognitive Performance Scale (CPS)	MMSE	MMSE	-
Depression	Geriatric Depression Scale and its Short Form (GDS-SF); Center of Epidemiology Studies Depression Scale (CES-D Scale); Depression factor from the MOSES; Rasking Depression Ratings; Philadelphia Geriatric Center Negative Affect Rating Scales	Cornell Scale for Depression in Dementia (CSDD); Hamilton Depression Rating Scale; Geriatric Depression Scale	-	-	-	-
Falls	Chart documentation of fall events	Chart documentation of fall events	-	-	-	-
Functional Status	Dementia Rating Scale; In-person interviews by trained interviewers to residents, family members, and staff; Lawton and Brody Physical Self-Maintenance Scale (PSMS); Rosow-Breslau Scale; Lawton & Brody Index; Nagi Index	-	Katz Index	Katz Index	Katz Index	-
Hospitalization events	Health Insurance Claim Data	-	-	-	-	-
Nutrition	Standardized direct staff observations by trained observers; Photograph methodology of meal trays; Interview of food complaint by research staff;	-	-	-	-	-

	Dietician data collected; Self-reported food eaten records					
Oral/dental Status	-	Professional Dental Examination	-	-	-	-
Pain	-	Three-item Proxy Pain Questionnaire (PPQ); Visual Analogue Scale (VAS); Analgesic Medication Report	-	-	-	-
Payment source	Health Insurance Claim Data	-	-	-	-	-
Time Use	Behavior Rating Scale; WIthdrawal Scale of the MOSES; Philadelphia Geriatric Center Positive Affect Rating Scale	-	-	-	-	-
Urinary Tract Infection	Physician diagnosis	Prospective Surveillance Data of infections	-	-	-	-
Several domains or areas	-	Diagnoses from Medicare Health Insurance claims (diagnoses)	-	-	Care Rank of the Japanese Long-Term Care Insurance (Physical problems, Self-help skills, Confusion, Carer dependency domains)	-

Community Care CGAs

Domain or area assessed	**CARE**	**OARS-OMFAQ**	**MAI**	**Popovich Scale**	**OASIS**	**RAI-MDS HC**	**interRAI HC**	**CARI**
Cognition	-	-	-	SPMSQ	SPMSQ	MMSE	Clinical diagnosis of dementia	-
Depression	-	-	-	-	CES-D; Brief Symptom Inventory (BSI)	Geraitric Depression Scale	Clinical diagnoses of depression; Health of the Nation Outcome Scales for Elderly People (HoNOS65+)	-
Economic Status	-	6-point economic scale	-	-	-	-	-	-

Functional Status	-	-	-	-	OARS ADL and IADL Questionnaires	Barthel Index; Lawton and Brody Index; Duke OARS IADL	-	-
Mental Health Status	-	Assessments made by geropsychiatrists	-	-	-	-	-	-
Mortality	-	-	-	-	-	-	New Zealand's National Health Index	-
Nutrition	-	-	-	-	-	Dietician data collected; Self-reported food eaten records	-	-
Physical Health Status	-	10-point Karnofsky Scale	-	OARS	-	-	-	-
Resource utilization and cost estimates	-	-	-	-	-	-	Resource Utilization in Dementia Lite (RUD Lite)	-
Self-care Capacity	-	Therapist-developed 12-point scale	-	-	-	-	-	-
Social Resources	-	-	-	OARS	-	-	-	-
Several domains or areas	-	-	-	-	The Home Health Certification and Plan of Care of the Centers for Medicare and Medicaid Services (CMS 485) to compare against OASIS final results (validating the categories of enteral, senses, incontinence, psychosocial, shortness of breath, other, pain, physical therapy orders, wound, diagnosis, prognosis, medications, functional)	-	-	-

Table A.3 Characteristics of the studies assessing the complete CGA, divided by care setting.

Name of CGA	Authors/Year	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
				Long-term Care				
RAI-MDS	Morris et al. (1990)	383 residents (74% female; age not mentioned)	United States	Nursing Home	Cross-sectional design	To present the developmental process and a draft version of the MDS.	Inter-rater reliability	55% of items showed at least fair inter-rater reliability
RAI-MDS	Hawes et al. (1995)	123 residents (78% female; age not mentioned)	United States	Nursing Home	Two studies both with cross-sectional design	To present results on the reliability of (revised items of the) MDS	Inter-rater reliability	63% of the items showed moderate inter-rater reliability; and 89% of the items at least fair inter-rater reliability
RAI-MDS	Sgadari et al. (1997)	Participants per country: Denmark (n = 74) Iceland (n = 24) Italy (n = 82) Japan (n = 129) Sweden (n = 46) Switzerland (n = 87) United States (n = 123) Age not mentioned	Denmark Iceland Italy Japan Sweden Switzerland United States	Nursing Home	Cross-sectional design	To describe the results of inter-rater reliability of the core set of items of the MDS in the USA and non-English speaking countries.	Inter-rater reliability	Fair or better inter-rater reliability was found for more than 75% of the items in Denmark, Iceland, Italy, Japan, Sweden, Switzerland, and USA. Excellent inter-rater reliability was found for 84% of the items in Switzerland, for 34% to 49% in Italy, Denmark, Iceland, and USA, and for 31.3% in Sweden and 16.7% in Japan.
RAI-MDS 2.0	Morris, Nonemaker, et al. (1997)	187 residents (71.7% female; mean age 80.6y)	United States	Nursing Home	Cross-sectional design	To describe the reliability of new and revised MDS 2.0 assessment items and their clinical utility according to experienced nurse assessors	Inter-rater reliability	Except for one item, all new items showed fair to excellent reliability. 35 of 42 new items, showed good to excellent reliability. For item revised, reliability was significantly higher than items they replaced, and showed good inter-rater reliability, except for one. For items that were not modified, but changes in instructions or definitions were made, average inter-rater reliability was excellent after this revision.

Name of CGA	Authors/Year	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
MDS 3.0	Saliba and Buchanan (2012)	3822 residents (age not mentioned)	United States	Nursing Home	Mixed methods design - in a national test independent assessments between raters and validation instruments	To evaluate the MDS 3.0 reliability, validity, resident input, clinical utility and decreases of collection burden.	Inter-rater reliability	In general, good to excellent inter-rater reliability was reported for MDS 3.0 items, with few of them showing fair reliability. Often reliability was better than previous related MDS 2.0 items, including new or reformatted items. Specific details of results are not mentioned
ValGraf	Pascazio et al. (2009)	Factorial study**:** 8280 residents (78.4% female; mean age 83.2y ± 10.3y)	Italy	Nursing Home	Cohort study	To assess the acceptability, concurrent validity and factorial structure	Factorial Structure	Thirteen factors were found to account 52.9% of the total variance. The factorial structure with all loadings equal or greater than 0.30 (range from .30 to .95)
CPAT	Fleming (2008)	48 residents (81% female; mean age 82.6y)	Australia	Aged Care Facilities	Cross-sectional design	To describe the development of the CPAT	Inter-rater reliability	Inter-rater reliability was good to excellent for the majority of the items (91,7% of the items)
interRAI LTCF	Hirdes et al. (2008)	783 participants across 12 nations (65.7% female; majority older than 65y)	Canada France Italy Japan Korea Netherlands Norway United States	Long-term Care	Cross-sectional design	To cross-nationally examine the inter-rater reliability of interRAI instruments used in five different health care settings (home care, long term care, mental health, palliative care and post-acute care)	Inter-rater reliability	Inter-rater reliability was good to excellent for interRAI LTCF for the majority of items Average inter-rater reliability for common items and unique items was good.
interRAI LTCF	Onder et al. (2012)	4156 residents (73% female; mean age 83.4y ± 9.4y)	Czech Republic England Finland France Germany Italy Netherlands Israel	Nursing Home	Prospective cohort study	To present the test-retest and inter-rater reliability results of the interRAI LTCF in the participating countries	Test-retest reliability Inter-rater reliability	Average test-retest reliability for the items of each area assessed was excellent, and average inter-rater reliability was good to excellent. The average test-retest reliability for categorical items was excellent, and the average inter-rater reliability was good. Single items showed

Name of CGA	Authors/Year	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
								at least fair test-retest and inter-rater reliability, only one reported poor inter-rater reliability. For continuous variables items, correlations showed large effects for test-retest and inter-rater reliability.
interRAI LTCF	Kim et al. (2015)	621 participants (71.7% female; mean age 80y ± 7.5y)	Korea	Long-term Care	Cross-sectional design	To examine the reliability of the Korean version of the interRAI LTCF and the interRAI HC	Inter-rater reliability	For the 221 tested items, inter-rater reliability was good to excellent for 94,1% of the items. Mean kappa for overall items was excellent. For key common items, inter-rater reliability ranged from good to excellent, and ICC ranged from moderate to excellent.
				Community Care				
OASIS	Hittle et al. (2004)	Data was collected in two rounds: 41 patients from two Home Health Agencies (HHAs) 25 patients from three HHAs (mean age not mentioned for any of the samples)	United States	Home Health Agencies	Two independent cross-sectional designs	To examine the interrater reliability of individual OASIS items	Inter-rater reliability	90% of OASIS items were examined, 76% of the items showed good to excellent inter-rater reliability. Reliability results were also compared against the results from a second study (Berg, 1999). Reliability averages were compared reporting that mean percent agreement was 90% for this study and 92% for the second study (166 measures included), while mean kappas were 0.69 for this study and 0.58 for the second study (116 measures included). Difference is explained due to the longer length of time between assessments and more assessments clinicians with unknow proficiency in the second study.

Name of CGA	Authors/Year	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
OASIS	Madigan and Fortinsky (2004)	88 patients (66% female; mean age 77.7y ± 8.24y)	United States	Home Health Agencies	Prospective cohort study	To evaluate OASIS items inter-rater reliability	Inter-rater reliabiltiy	Inter-rater reliability was good to excellent for the OASIS items
OASIS	Kinatukara et al. (2005)	Phase I: 259 adults (67% female; mean age 73y ± 15.3y) Phase II: 105 adults (65% female; mean age 71y ± 14.42y) Phase III: 141 adults (age not mentioned)	United States	Home Health Agencies	Mixed method approach: Two cross-sectional designs; medical record review	To investigate the reliability and validity of OASIS in applied clinical practice	Inter-rater reliability Convergent validity	Inter-rater reliability was poor to moderate for 65% of the items when assessed simultaneously. 93% of the items showed poor to moderate inter-rater reliability when assessment was delayed 24-72hrs in between. For convergent validity, several frequently inconsistencies between OASIS and the criterion measure were identified. The most commonly inconsistencies were found in functional status, medications, prognosis, and diagnosis.
RAI-MDS HC	Morris, Fries, et al. (1997)	241 elderly residents (59.5% female; mean age 79.6y)	Japan United States Canada Australia Czech Republic	Home Care	Independent dual assessment design	To describe the results of a cross national field trial on the reliability of the home care version of the MDS	Inter-rater reliability	Items showed good to excellent inter-rater reliability, except for six that were fair and one poor. Average inter-rater reliability of MDS-HC items was good.
RAI-MDS HC	Kwan et al. (2000)	179 people (64.1% female; mean age 72.9y ± 5.9y)	Hong Kong	Outpatient Clinic	Cross-sectional design	To validate the Chinese version of the MDS-HC in Hong Kong Chinese elderly	Inter-rater reliability	Inter-rater reliability showed a proportion of consistency of 70%.
interRAI HC	[a] Hirdes et al. (2008)	783 participants across 12 nations (65.7% female; majority older than 65y)	Australia Czech Republic France Italy Korea United States	Home Care	Cross-sectional design	To cross-nationally examine the inter-rater reliability of interRAI instruments used in five different health care settings (home care, long term	Inter-rater reliability	Inter-rater reliability was good to excellent for the majority of items. Only four items showed poor reliability. Average inter-rater reliability for common items and unique items was good

Name of CGA	Authors/Year	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
						care, mental health, palliative care and post-acute care)		
interRAI HC	Schluter et al. (2016)	Data reliability sample: 49 participants 65y or above	New Zealand	Community Care	Longitudinal study design	To assess the data quality and the ability to be matched with other database, and describe the New Zeeland national interRAI-HC population	Data reliability	Regarding the data integrity, not accurate values recording was reported in areas such as demographics, and height or weight. Data reliability was compared for those with repeated assessments, reporting a 2% error rate in demographic variables. Also, for height and weight measures errors were identified.
interRAI HC	[a] Kim et al. (2015)	287 participants (59.9% female; mean age 79.3y ± 7.5y)	Korea	Home Care	Cross-sectional design	To examine the reliability of the Korean version of the interRAI LTCF and the interRAI HC	Inter-rater reliability	For the 205 tested items, inter-rater reliability was good to excellent for more than 90% of the items. Mean kappa for overall items was excellent. For key common items, inter-rater reliability ranged from good to excellent, and ICC ranged from good to excellent, except for one item which reported a moderate score.
CARI	Clarnette et al. (2015)	50 community dwelling older adults (60% female; mean age 82y)	Australia	Community Care	Cohort study	To assess the inter-rater reliability of the CARI	Inter-rater reliability	The majority of the items showed poor to fair inter-rater reliability (50% were poor, 37.5% were fair)

[a] Studies repeated in the table as they were assessing either other care setting or another approach of validation.

Table A.4 Characteristics of the studies assessing specific domains or items of the CGAs, divided by care settings.

Name of CGA	Authors/ Year	Domains/Items	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
				Long-term Care					
RAI-MDS	[a] Hawes et al. (1995)	All RAI-MDS domains (n=16; including Identification and Background)	123 residents (78% female; age not mentioned)	United States	Nursing Home	Two studies both with cross-sectional design	To present results on the final testing of the raliability of the MDS	Inter-rater reliability	One domain showed good reliability, 11 moderate, and four poor.
RAI-MDS	Resnick et al. (1996)	13 MDS items related to urinary incontinence	Reliability sample: 123 residents (78% female; mean age 85y)	United States	Nursing Home	Cross-sectional design	To determine the reliability of the MDS items related to urinary incontinence and the diagnostic accuracy of the RAP to predict urinary incontinence	Inter-rater reliability	Excellent inter-rater reliability was found for incontinence of all grades. Reliability was better for extremes levels severity than intermediate. Of the 11 MDS items related to incontinence, inter-rater reliability was good to excellent for six items, and moderate for four. Only one item had poor scores.
RAI-MDS	Snowden et al. (1999)	Behavior and ADL domains	140 subjects (61.4% female; mean age 83.4y ± 8.2y)	United States	Nursing Home	Cross-sectional design	To describe the criterion validity and quantify the responsivenss to change over time of the MDS	Criterion validity	Medium to large effect sizes were reported for the Behavior and the ADL domains when correlated against criterion measures.
RAI-MDS	Simmons et al. (2002)	Items K4a (food complaints) and K4c (low oral intake)	75 residents (83% female; mean age 86.2y ± 10.7y)	United States	Nursing Home	Repeated measures design	To assess the accuracy of Nursing Home (NH) staff in completing the MDS items of low oral intake	Criterion validity	55 of participants were identified with low oral intake by research staff direct observations, while NH staff

Name of CGA	Authors/ Year	Domains/Items	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
							and food complaints		failed to identify 27 of them using the low oral intake MDS item. NH staff failed to identify all of the participants that expressed food complaints when standardized interviews were used. Research staff documentation and standardizes interviews significantly identified more residents at risk of undernutrition than NH staff documentation using MDS items.
RAI-MDS	Lum et al. (2005)	ADL domain	3385 residents (age not mentioned)	United States	Nursing Home	Cross-sectional design	To study the accuracy of ADL assessments in the MDS by comparing the data collected through the MDS against interview data collected with nursing home residents, family members, and staff.	Criterion validity	Poor to fair agreement was reported for ADL assessments between MDS and interview data from different sources (residents, family members and staff)

Name of CGA	Authors/ Year	Domains/Items	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
RAI-MDS	Liang et al. (2011)	MDS-Mood and Anxiety symptoms items	595 participants (all male; mean age 80.9y ± 5.3y)	Taiwan	Long-term Care	Cross-sectional design	To compare the effectiveness of the MDS-DRS Chinese Version and the GDS in screening depression among older Chinese men living in a veterans care home at Taiwan	Criterion validity	Only four (E1a, E1k, E1l, and E1m) of the Mood and Anxiety items were associated with GDS defined depression. Items, E1a (OR =12.9), E1k (OR = 15.6), and E1l (OR 22.2) were reported as independent associative factors for depression screened by the GDS. However, 48.1% of the participants defined as depressed did not score in any of the previous items, so they do not explain depression. Screening depression with a combination of these items is limited.
RAI-MDS & RAI-MDS 2.0	Hill-Westmoreland and Gruber-Baldini (2005)	Fell in the past 1 to 30 days and Fell in the past 31 to 180 days items	462 residents (75.3% female; mean age 82,8y ± 7.2y)	United States	Nursing Home	Longitudinal cohort study	To compare the data recorded in the MDS regarding falls, against a falls chart documentation of elderly nursing home residents.	Criterion validity Specificity Sensitivity	Kappa agreements between items and chart documentation of fall events were fair for the 180-day period falls and poor for the 30-day period.

Name of CGA	Authors/ Year	Domains/Items	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
									For the 180-day period, sensitivity was 53% and specificity was 97%. For the 30-day period, sensitivity was 34% and specificity 97%
RAI-MDS 2.0	Fisher et al. (2002)	Pain frequency and pain intensity items	57 residents (mean age 82.2y ± 7.98y)	United States	Nursing Home	Correlational study	To study the association between MDS pain items, Proxy Pain Questionnaire (PPQ) and analgesic medication use	Criterion validity Convergent validity Test-retest reliability	MDS pain items did not associate with the criterion pain scale. However, it showed a medium effect association with analgesic medication report. Test-retest reliability was demonstrated as MDS pain items reported large effect-sizes when correlated with each other at the two assessments.
RAI-MDS 2.0	Hendrix et al. (2003)	Section E1 Indicators of Depression, Anxiety and Sad Mood Items A-P	322 residents (72% female; 65 years and above)	United States	Nursing Home	Descriptive study	To study if mood indicators of the RAI-MDS 2.0 can identify depression in the elderly	Construct validity	The MDS mood indicators were unable to capture depressive features, whereas the CSDD was able to detect distinct features of depression in the elderly

Name of CGA	Authors/ Year	Domains/Items	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
RAI-MDS 2.0	Jockusch et al. (2021)	Oral/dental items K1a, K1c, L1a, L1b, L1c, L1d, L1e, L1f, L1g	168 participants (61.3% female; mean age 82.1y ± 9.5y)	Switzerland	Long-term care facilities	Cross-sectional design	To compare data collected by the oral/dental items of the Swiss RAI-MDS 2.0 against professional oral examinations to verify the reliability and validity of the items.	Inter-rater reliability Concurrent validity	Poor or no agreement was identified for all the items assessed with the exception of item L1b-Denture, which showed a good kappa agreement between nursing staff and dental assessment.
RAI-MDS 2.0	Stevenson et al. (2004)	Item 2j Urinary Tract Infection (UTI) the last 30 days	6947 MDS entries for the item 2j from LTCFs residents	United States	Long-term Care	Prospective surveillance	To study the validity of the MDS in detecting Urinary Tract Infection	Criterion validity Sensitivity Specificity	14% of the UTI was validated. Sensitivity of MDS was 57.9% and Specificity was 86.5% when compared with active surveillance data for urinary infection. Only 14% of residents with a positive MDS entry for UTI would actually have UTI, however, almost all (98.2%) residents with a negative MDS entry would not have this condition.

Name of CGA	Authors/ Year	Domains/Items	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
RAI-MDS 2.0	Hoben et al. (2016)	Oral health	Analysis sample: 2,711 residents with admission and follow up records (68.2% female; mean age 84.4y ± 8.9y)	Canada	Nursing Home	Retrospective, longitudinal, secondary data study	To assess criterion validity of the RAI-MDS 2.0 oral/dental items	Criterion validity	Prevalence in oral/dental problems (composite measure) did not fluctuate significantly over time but is lower than the prevalence according to clinical assessments by dental professionals, implying an under detection of oral/dental problems. Also, validity problems were indicated. Though the odds for oral/dental problems were higher in residents with lacking teeth and not wearing dentures, or with debris, and lower for denture wearers, a lack of significant association with other known contributors was found. These were amongst others a dementia diagnosis, daily cleaning, CPS, ADL-score, or DRS score.

Name of CGA	Authors/ Year	Domains/Items	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
MDS 3.0	[a]Saliba and Buchanan (2012)	Cognition, Mood, Behavior and Depression items	3822 residents (age not mentioned)	United States	Nursing Home	Mixed methods design - in a national test independent assessments between raters and validation instruments	To evaluate the MDS 3.0 reliability, validity, resident input, clinical utility and decreases of collection burden.	Criterion validity	An improvement on validity was found for the cognition, mood, and behavior items. The national validation of cognitive, depression and behavior items also reported higher agreement than MDS 2.0 items.
CPAT	Kanegae et al. (2010)	Reliability was examined for all domains. Validity was test for Physical problems, Self-help, Confusion, and Carer dependency	199 clients (70,8% female, mean age 83,4y ± 8,6)	Japan	Health facility (general and dementia specific), group home, day rehabilitation, day centre (general and dementia specific)	Cross-sectional design	To develop a Japanese version of the Care Planning Assessment Tool (J-CPAT)	Internal consistency reliability Test-retest reliability (n = 20) Criterion validity	Internal consistency and test-retest reliabilities were in the recommended range for all domains. Validation was done for confusion, physical problems, self-help skills, and care dependency domains, showing large effect sizes when compared with criterions.
ValGraf	[a] Pascazio et al. (2009)	Functional and Cognitive domains	Concurrent validity: 210 elderley subjects (81.4y ± 8.3y)	Italy	Nursing Home	Cohort study	To assess the acceptability, concurrent validity and factorial structure	Concurrent validity	Large effect sizes were found for ValGraf ADL and Cognitive Status when compared against criterion
Long-term Care & Community Care									

Name of CGA	Authors/ Year	Domains/Items	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
interRAI LTCF & interRAI HC	Krausch-Hofmann et al. (2019)	Oral-health related section Items K5a to K5f	12 experts in gerodontology, experienced dentists in LTCF, periodontologist, geriatricians, geriatric nursing care, and prosthetic dentistry	Belgium	Long-term Care & Home Care	Expert rating and focus group design	To study the content validity and reasons for inaccurate assessments wit the oral health-related section of interRAI	Test content validity	Chewing difficulty, pain, gingival inflammation and damaged teeth were considered as relevant items. None of the items were considered as clearly worded. Only prosthesis use, and pain were considered as feasible. Experts agreed that the list of items was incomplete
Community Care									
CARE	Gurland et al. (1977)	Psychiatric, Medical-Physical and Social dimensions	8 older women (age 64-80y)	United States	Community Care	Cross-sectional design	To describe the characteristics, development, reliability and validity of the CARE	Inter-rater reliability	Good to excellent reliability was shown for the Psychiatric Dimension. Poor to good reliability was found for the Medical-physical dimension, however, it was mainly poor to moderate. Poor to excellent reliability was shown for the Social dimension, however, it was mainly good to excellent. Intradisciplinary agreement in

Name of CGA	Authors/ Year	Domains/Items	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
									general was lower.
OASIS	Madigan and Fortinsky (2000)	Functional status, Behavioral, Affect, and Clinical domains	201 subjects (62.2% female; mean age 72.5y ± 13.87y) Subsample for testing reliability: Admission (n = 22) Discharge (n = 15)	United States	Home Health Agencies	Cross-sectional design	To present additional evidence on the psychometric properties of selected OASIS items	Construct validity Internal consistency reliability Intra-rater reliability	Construct validity was found adequate for the functional domain, insufficient evidence was found for the other domains. Internal consistency reliability was high for the functional domain, but poor for the other domains. Intra-rater reliability was excellent for admission and discharge items of the affect domain, and discharge items of behavioral domain. Good to excellent for the admission items of the behavioral domain, and discharge items of the Clinical and the functional domain. Fair for admission items of the functional

Name of CGA	Authors/ Year	Domains/Items	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
									and clinical domain.
OASIS	Tullai-McGuinness et al. (2009)	Functional status, cognitive functioning and depressive symptoms items	203 people (62% female; mean age 78.6y ± 9.8y)	United States	Home Health Agencies	Cross-sectional design	To study the criterion validity of specific OASIS items	Criterion validity	ADL items reported medium to large effect sizes; while IADLs items small to large. For the composite ADL items score, a large effect size was shown; while for the composite IADLs items score, the effect size was medium. Cognitive functioning reported a large effect size. Depressive symptoms reported low to moderate effect sizes.
interRAI HC	[a] Schluter et al. (2016)	Mortality data	Data reliability sample: 49 participants 65y or above	New Zealand	Community Care	Longitudinal study design (they also looked at follow up assessments	To assess the data quality and the ability to be matched with other databes, and describe the New Zeland national interRAI-HC population	Criterion validity	For criterion validity, participants records were matched against a mortality database, reporting unmatched data

Name of CGA	Authors/ Year	Domains/Items	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
									for only 0.2% of all records.
CARI	[a] Clarnette et al. (2015)	Mental State, ADL and Medical Condition domains	50 community dwelling older adults (60% female; mean age 82y)	Australia	Community Care	Cohort study	To assess the inter-rater reliability of the CARI	Internal consistency reliability Inter-rater reliability	Of the three domains, only ADL showed a desired internal consistency. Fair inter-rater reliability was reported for the Mental State and Medical Condition domains, while poor for the ADLs All Global Risk Scores demonstrated poor agreement, and particularly low for the Global Risk Score for Hospitalization.

[a]Studies repeated in the table as they were assessing either other care setting or another approach of validation.

Table A.5 Characteristics of the studies assessing specific scales or indices of the CGAs, divided by care settings.

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
Long-term Care									
RAI-MDS	Morris et al. (1994)	Cognitive Perfomance Scale (CPS)	Data collection in two independent samples of nursing home residents (n = 142 each), for model development and validation of the model. Mean age for both samples = 85y; secondary analyses on MDS data of 2,172 residents 269 nursing homes in 10 states; and 6,663 residents from 176 nursing homes in six states, for examination of distribution	United States	Long-term Care & Nursing Home	Cross-sectional design	To describe the development , item prevalence, and reliability of the Cognitive Performance Scale	Principal component Factor analysis Face validity Criterion validity Diagnostic validity	The seven items of the CPS were related in a uniform manner in the two different distribution samples. The CPS met the criteria for simplicity and face validity, and its' scores discriminate between different levels according to the TSI and MMSE. The sensitivity and specificity of the CPS with independent judgement on both orientation and disorientation was high. CPS achieved high levels of explanation of variance for both TSI and MMSE. Correlation between the neurological diagnosis and CPS reported a large effect size (r=0.59); and was similar to the 0.57 correlation between the neurological diagnosis and the MMSE.

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
RAI-MDS	Hartmaier et al. (1994)	Cognitive Perfomance Scale (CPS) and MDS-Cognition Scale (MDS-COGS)	200 residents (72% female; mean age 80.5y ± 10.92y) Two subsamples: Development sample (n=133) Validation sample (n=67)	United States	Nursing Home	Cross-sectional design	To describe the development and validity of the MDS-Cognition Scale	Concurrent validity Sensitivity Specificity	**Validation of CPS against GDS** A fair agreement was reported between the seven Global Deterioration Scales (GDS) and seven CPS levels. Agreement between the CPS and the 4-stage GDS was excellent. Percent agreement between CPS and GDS stages 5 and 7 is 50% or less. **Validation of MDS-COGS** Agreement between the MDS-COGS and the 4-stage GDS reported excellent and good weighted and unweighted kappas, respectively. Similar weighted and unweighted kappas were reported in another sample, also showing a large effect size for the correlation between MDS-COGS and GDS. MDS-COGS reported higher agreement than the CPS for GDS stages 5 and 7, but lower for GDS stages 1 and 6. In the 133 subsample, correlation between MDS COGS and MMSE reported a large effect size. **MDS-COGS Diagnostic validity:** To discriminate between cognitively impaired and cognitively intact, MDS COGS Sensitivity and

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
									Specificity were 0.95 and 0.88, respectively. An AUC of 0.96 was reported.
RAI-MDS	Hartmaier et al. (1995)	Cognitive Perfomance Scale (CPS)	200 residents (72% female; mean age 80.5y ± 10.92y)	United States	Nursing Home	Cross-sectional design	To study the validation of the MDS-CPS against the MMSE	Concurrent validity Sensitivity Specificity Area Under the Curve	A large effect size was reported for the correlation between MMSE and CPS. Adjusted for education level, agreement between CPS and MSSE was excellent. For a cut-off point of 2 or more in CPS and adjusted for education level, Sensitivity and Specificity for detecting cognitive impairment for the CPS in comparison with the MMSE were 0.94. The AUC reported was 0.96.

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
RAI-MDS	Mor et al. (1995)	Social Engagement Index	1848 residents (73.9% female; mean age 81.2y)	United States	Nursing Home	Cross-sectional design	To describe the reliability and validity of the social engagement index in the RAI-MDS	Construct validity Internal consistency reliability	Social engagement showed a large correlation with time involved in activities. Social engagement is considered as an individual domain from mood, behavior problems and conflicted relationships. Factor loadings were in the recommended range. Internal consistency for social engagement was in the recommended range.
RAI-MDS	Casten et al. (1998)	Cognition, ADL, Time Use, Social Quality, Depression, and Problem Behaviors indices	733 records from residents (75.1% female; mean age 84,50y ± 6.46y)	United States	Nursing Home	Cohort study	To determine the structure and statistical reliability of the MDS	Inter-rater reliability Construct validity	Large effect sizes were found for all indices when correlated between raters. Kappa scores were good to excellent for all indices. Confirmatory factor analysis showed that Cognition, ADL and Time Use were reasonably well measured, but the item range of psychosocial and social domains could be broader. Most factors could not be replicated in the cognitive impaired sample.
RAI-MDS	Lawton et al. (1998)	Cognition, ADL, Time Use, Problem Behaviors, and Depression indices	Two samples: - Clinical Research Center (CRC) sub-samples (N= 260): High cognition (70.3 female; mean age 86.54y ± 6.77y) & Low cognition (73.3% female; mean age 86.12 ± 6.42y) - Special Care Unit (SCU) sub-samples (N=	United States	Nursing Home	Cross-sectional design	To assess the validity of the domain indices of the MDS	Concurrent validity Discriminant validity	For the CRC sample, large effect sizes were reported for the Cognition and ADL indices, while small effect sizes were reported for the Depression index, when compared against criterions. For Time Use and Problem Behaviors, no analogous measures were determined. For the SCU sample, medium to large effect sizes were reported for the Cognition, ADL, and Time Use indices. Medium effect sizes were reported for the

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
			253): High cognition (82.8% female; mean age 87.8y ± 6.08y) & Low cognition (81.2% female; mean age 88.3 ± 5.53y)						Depression index, and small to medium for the Problem Behaviors index. All results when compared against analogous criterion measures. Discriminant validity was demonstrated as the correlation of the MDS index with the corresponding analogous measures were the highest. The Cognition and Depression indices were associated with the respective psychiatric diagnosis of dementia and depression.
RAI-MDS	[a] Snowden et al. (1999)	Cognitive Performance Scale (CPS)	140 subjects (61.4% female; mean age 83.4y ± 8.2y)	United States	Nursing Home	Cross-sectional design	To describe the criterion validity and quantify the responsiveness to change over time of the MDS	Criterion validity	A medium effect size was reported for the MDS CPS when correlated with the criterion measure
RAI-MDS	Gruber-Baldini et al. (2000)	Cognitive Perfomance Scale (CPS) and MDS-Cognition Scale (MDS-COGS)	1939 residents (72% female; mean age 81.6y)	United States	Nursing Home	Cross-sectional design	To report on the construct validity of the CPS and the MDS-COGS from the MDS	Construct validity Convergent validity Divergent validity Internal consistency reliability	Internal consistency was in the recommended range for the CPS and the MDS-COGS. Large effect sizes were reported for the correlations between the MDS cognition scales and the criterion measures. Also, a large effect size was reported between the two cognition scales. Regarding divergent validity, small to medium effect sizes were found between the MDS cognition scales and scales measuring different constructs. However, a large correlation was found

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
									between the Katz Index and the MDS-COGS.
RAI-MDS	Zimmerman et al. (2007)	MDS-Cognition Scale (MDS-COGS)	166 residents (78% female; mean age 83.6y ± 8.3y)	United States	Residential care Assisted living facilities	Cross-sectional design	The first aim was to describe the reliability and diagnostic characteristics of the MDS-COGS to detect undiagnosed dementia. The second aim was to asses the prevalence of undiagnosed dementia in the participating individuals	Test-retest reliability Inter-rater reliability Sensitivity Specificity Area Under the Curve	The ROC area under the curve was = 0.79. Diagnostic test characteristics: First cut-off point (0 vs 1 or more): Sensitivity 0.67. & Specificity 0.84 Second cut-off point (0 to 1 vs 2 or above): Specificity 0.97 & Sensitivity 0.49 Inter-rater reliability for the first cut-off point was poor, and for the second cut-off point was fair. Test-retest reliability was fair for both cut-off points.
RAI-MDS	Kruse et al. (2010)	MDS-Mortality Risk Index (MMRI) MDS-Mortality Risk Index Revised (MMRI-R) Flacker-Kiely Model (Flacker) Flacker-Kiely Model Revised (Flacker-R)	130 residents (70% female; mean age 82.8y ± 8.8y)	United States	Nursing Home	Prospective cohort study	To compare four mortality risk indices estimated through MDS data to determine 6-month mortality risk	Discrimination of risk prediction models Predictive validity	Discrimination was 0.59 (c-statistic) for both the MMRI and the MMRI-R. For the Flacker model was 0.69 for the 6 month and 6 year mortality; , and slightly higher for the Flacker-R (0.70 for the 6 month, and 0.71 for one year mortality). Indicating acceptable discrimination. Predicted 6-month mortality was 0.35 for MMRI and 0.39 for MMRI-R; while for the Flacker model and the Flacker-R model were 0.42 and 0.53, respectively (these results for the highest risk stratum). Both Flacker models were

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
									reported to better discriminators and more reliable in predicting high mortality risk than MMRI models.
RAI-MDS	[a] Liang et al. (2011)	Depression Rating Scale (DRS)	595 participants (all male; mean age 80.9y ± 5.3y)	Taiwan	Long-term Care	Cross-sectional design	To compare the effectiveness of the MDS-DRS Chinese Version and the GDS in screening depression among older Chinese men living in a veterans care home at Taiwan	Criterion validity Construct validity	Significant differences regarding the prevalence of depression were reported between the results of the MDS-DRS and the Geriatric Depression Scale-Short Form (GDS-SF) and for this reason kappa values were not calculated to evaluate the consistency of screening results. Prevalence of depression was reported to be 0.2% for the MDS-DR, while for the GDS-SF was 8.7%. The screening depression purpose of MDS-DRS failed, as it missed in identifying depression in the participants.
RAI-MDS	Hsiao et al. (2015)	Depression Rating Scale (DRS)	378 residents (27.2% female; mean age 81.9y ± 8.9y)	Taiwan	Senior Citizen Home	Cross-sectional design	To stablish the psychometric properties of the MDS-DRS Chinese version	Criterion validity Internal consistency reliability Sensitivity Specificity	The prevalence of depression for both outcomes was 23.8% for GDS-SF and 17.5% for MDS-DRS, which is much lower, indicating an under detection by the DRS. The MDS-DRS Area Under the Curve was 0.74. For the cut-off point of 3 a 43.3% sensitivity and a 90.6% specificity were reported. A large effect size was reported for the correlation

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
									between the MDS-DRS and the GDS-SF The seven items of the MDS-DRS disclose two distinct factors with factor loadings above the recommended range. The two factors were labelled as 'sadness' and 'distress'. These two factors explained the 58.1% of the variance. Internal consistency was in the recommended range
RAI-MDS 2.0	Fries et al. (2001)	Pain Scale	95 individuals (71%female; mean age 81y)	United States	Nursing Home	Retrospective design	To study the validity of a pain scale derived from the RAI-MDS and the prevalence of pain in nursing home populations	Criterion validity	Agreement between MDS and Visual Analogue Scale (VAS) on the presence of pain was good Variance explanation for predicting the VAS score for the four group MDS Pain Scale was 56%
RAI-MDS 2.0	Anderson et al. (2003)	Depression Rating Scale (DRS)	145 residents (63% female; mean age 84y)	United States	Nursing Home	Cross-sectional design	To examine the psychometric properties of the MDS-DRS for nusing home older adults	Criterion validity Sensitivity Specificity Internal consistency reliability Test-retest reliability	Small to medium effect sizes were reported for criterion validity against three criterion measures. Internal consistency was below the recommended range Sensitivity using three cut-off points range from 0.16 to 0.46, and Specificity from 0.69 to 0.92. Little difference regarding the cut-off point was reported for sensitivity, however, higher specificity was reported for the cut-off of three. Test-retest reliability was poor to moderate
RAI-MDS 2.0	Koehler et al. (2005)	Depression Rating Scale (DRS) E1SUM Section	704 individuals (77% female; mean age 86y)	United States	Nursing Home	Cross-sectional design	To examine and compare two geriatric depression measures, the RAI-MDS and the	Criterion validity Internal consistency reliability	No correlation was found between GDS and MDS Depression measures. Internal consistency was below the recommended

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
							Geriatric Depression Scale (GDS)		range for the DRS, however, it was in the recommended range for the E1SUM.
RAI-MDS 2.0	Gerritsen et al. (2008)	Challenging Behavior Profile and its Conflict, Withdrawal, Agitation, and Attention Seeking subscales	Two samples: Scale construct sample: 656 residents (74% female; mean age 81y) Reliability and validity sample: 227 residents (78% female; mean age 79,9y)	Netherlands	Nursing Home	Comparative cohort study design	To develop a challenging behavior scale based on the MDS items	Construct validity Concurrent validity Inter-rater reliability Internal consistency reliability	Principal components analysis reported four subscales: conflict, withdrawal, agitation, and attention seeking. Internal consistency for the overall items that contribute to the scale was in the recommended range. For the subscales, internal consistency was in the recommended range for all except for Conflict, which was slightly lower (0.69). Similar results were shown in the second sample. Inter-rater reliability reported fair kappa coefficients for three subscales, and good for one. Overall scale kappa was fair. Intraclass correlation was poor for one subscale, moderate for two, and good for one. Overall score for the scale was good. Correlations against the criterions measures reported large effect sizes for Conflict and Agitation, medium for Withdrawal, and small for Attention Seeking.

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
RAI-MDS 2.0	Mor et al. (2011)	ADL, Social Engagement, Mood, Behavior, Pain, CPS and Changes in Health, End-stage disease and Symptoms and Signs (CHESS) Scale	Person over 65, with a MDS assessment, or a skilled nursing facility claim. Sample characteristics by year: 2000 (n=790,227; 66.6% female; mean age 81.1y ± 7.3y) 2002 (n=790,617; 65.5% female; mean age 81.1y ± 7.3y) 2004 (n=773,746; 64.9% female; mean age 81y ± 7.3y) 2006 (n=718,555; 64.3% female; mean age 81 ± 7.4y)	United States	Skilled nursing facility mainly & Hospital	Cohort study design (2000-2007)	To summarize analyses regarding internal consistency and predictive validity of the MDS 2.0 and show geographical in time related variation	Internal consistency reliabilty Predictive validity	Internal consistency was within the recommended range for ADL Scale, not for Social Engagement, Mood, Behavior and Pain Scales. CHESS Scale appear to be a strong predictor of one year mortality Many of the diagnoses corresponded reasonably well with Medicare diagnoses. Sensitivity ranged from 0.39 to 0.93; Specificity was high for almost all diagnoses >0.86, except for any hypertension. Time and geographical variation was minimal.
RAI-MDS 2.0	Ioannidis et al. (2017)	Fracture Risk Scale	29 848 residents (66% female; mean age not mentioned)	Canada	Long-term Care	Retrospective cohort study design	To describe the development and study the validity of a Fracture Risk Scales using the RAI-MDS 2.0	Discriminative and Predictive accuracy	The AUC was consistent between the derivation and validation sample, and was borderline acceptable for the FRS. The ORs showed a stepped risk in developing a hip fracture between the eight levels. A similar pattern between the levels was found in the proportion of resident that deceased after a hip fracture. Both results for risk of developing a hip fracture as decease of it's consequences were consistent between the derivation and validation

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
									sample for the levels of the FRS.
MDS 3.0	Saliba et al. (2012)	Brief Interview for Mental Status (BIMS)	418 residents (mean age not mentioned)	United States	Nursing Home	Between group design with two groups	To examine the performance, validity and feasibility of the BIMS	Criterion validity Discriminant validity Test accuracy	Concurrent validity: a large effect size was reported for BIMS as compared with 3Ms, which was significantly higher as for the effect size between CPS and 3MS. BIMS performed significantly better in identifying any cognitive impairment (AUC = 0.930 and 0.824 respectively) and severe cognitive impairment than CPS (AUC = 0.960 and 0.857, respectively). BIMS discriminated well between any cognitive impairment and severe cognitive impairment, showing high levels of sensitivity and specificity for cut-off points.
CPAT	[a] Fleming (2008)	All CPAT subscales	48 residents (81% female; mean age 82.6y)	Australia	Aged Care Facilities	Cross-sectional design	To describe the development of the CPAT	Criterion validity Internal consistency reliability Inter-rater reliability	Large effects sizes were reported for the confusion and self-help subscales against criterion measures. Internal consistency was in the recommended range for all the scales, except for psychiatric symptom scale. Inter-rater reliability for all the scales was excellent.
interRAI LTCF	[a] Kim et al. (2015)	ADL, IADL performance, IADL capacity, Depression, Communication, and Pain Scales	908 participants (67.9% female; mean age 80y ± 7.5y)	Korea	Long-term Care	Cross-sectional design	To examine the reliability of the Korean version of the interRAI LTCF and the interRAI HC	Internal consistency reliability	Internal consistency for the scales ADL, Depression, Communication and Pain was on the recommended range

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
					Community Care				
RAI-MDS HC	[a] Kwan et al. (2000)	IADL capacity, IADL involvement, Stamina, Communication, Behavioral Symptoms, Mood, and Pain Scales	179 people (64.1% female; mean age 72.9y ± 5.9y)	Hong Kong	Outpatient Clinic	Cross-sectional design	To validate the Chinese version of the MDS-HC in Hong Kong Chinese elderly	Internal consistency reliability	Internal consistency was in the recommended range for Pain and Communication Scale (two of the seven scales assessed)
RAI-MDS HC	Landi et al. (2000)	ADL Scale IADL Scale Cognitive Performance Scale (CPS)	95 subjects (67.4% female; mean age 77.4y ± 8.9y)	Italy	Home Care	Cross-sectional design	To study the criterion validity of MDS-HC functional and cognition scales	Criterion validity	Large effect sizes were reported between the MDS-HC scales and the criterion measures: MDS-HC ADL Scale & Barthel Index *r* = 0.74 MDS-HC IADL & Lawton Index *r* = 0.81 CPS & MMSE *r* = 0.81
RAI-MDS HC	Carpenter et al. (2005)	ADL, IADL, Cognition, and Mood scales	384 people aged over 65y	United Kingdom	Social Service Departments	Pragmatic randomized controlled trial	Examine the extent to which current used assessment instrument used for elderly people in social service departments, were able to meet policy and practice goals, as compared to the MDS-HC	Criterion validity Content validity	Data completion was higher and domain coverage was better for MDS-HC as compared to current used assessment instruments. Large effect sizes were found for IADL, ADL and Cognition scales of the MDS-HC against criterion. For Mood not significant correlation was found against criterion.
RAI-MDS HC	Leung et al. (2011)	IADL Involvement Scale IADL Capacity Scale	3523 community dwellers (60% female; mean age 79.6y ± 7.5y)	Hong Kong	Community Care	Cohort design	To perform a confirmatory factor analysis to study the factor structure of the IADL Involvement and Capacity Scales of the MDS-HC Chinese version	Internal consistency reliability Factor Structure	**IADL Involvement scale:** The one-factor and two-factor models reported good fits for the data of the IADL Involvement scale. For the one factor model, all factor loadings were in the recommended criteria. Internal consistency was in the recommended range **IADL Capacity scale:** The two-factor model provides a superior fit to the one-factor model. For the one-factor model, all standardized factor loadings were in the recommended range.

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
									Internal consistency was in the recommended range.
RAI-MDS HC	Leung et al. (2012)	Negative Mood Scale	3523 community dwellers (60% female; mean age 79.6y ± 7.5y)	Hong Kong	Community Care	Cohort design	To examine the psychometric properties of factor structure, reliability and concurrent validity of the Negative Mood Scale based on the MDS-HC Chinese version Mood section	Construct validity Internal consistency reliability Concurrent validity	Exploratory Factor Analysis (EFA): Results reported a three-factor structure labelled as ‘distress’, ‘sadness’ and ‘social withdrawal’. These three factors explained the 55.2% of the total variance. Confirmatory Factor Analysis (CFA): Results confirmed the three-factor model. Also, the second order model also showed goodness-of-fit as the first-order factor model. These results suggest that a summary score can be developed for the MDS Negative Mood Scale. Internal consistency: Cronbach's Alpha values were below the recommended range There is a gender difference in older Chinese adults for the MDS Negative Mood Scale.
RAI-MDS HC	Campitelli et al. (2016)	*full* Frailty Index (FI); *modified* Frailty Index (FI) and CHESS Scale	234,552 home care clients (64.6% female; mean age 82y ± 7.42y)	Canada	Home Care	Retrospective cohort study	a) To determine the prevalence and correlates of frailty through the two versions of the	Concurrent validity Predictive validity	Agreement between the two versions of the FI was good, while between the two versions of the FI with the CHESS Scale,

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
							Frailty Index and CHESS Scale b) To study how these measure agree between each other c) To examine the predictive validity and the associations of these three measures with death, institutionalization, and hospitalization during one year follow-up		agreement was poor. For predicting death, the highest AUCs were reported for *full FI* (0.66) and the CHESS scale (0.66). For predicting LTC Admission, the strongest predictor was the *full FI* (0.70). For predicting Hospitalization, the CHESS scale reported the highest AUC (0.61) For predicting Hospitalization with Alternative Level of Care stay, strongest predictors were *full FI* (0.60) and the CHESS scale (0.60) with no significant difference between each other. All three measures were associated with increased risk of the targeted outcomes. However, incorporating the frailty measures to these models, just improved modestly the predicting validity.
RAI-MDS HC	Ludwig and Busnel (2017)	Frailty Index	3714 individuals (67.7% female; mean age 82.7y ± 7.7y)	Switzerland	Home Care	Retrospective cohort study design	To identify variables on the RAI-MDS HC Swiss version to derive a Frailty Index and study the predictive validity of the index on adverse health outcomes	Internal consistency reliability Diagnostic accuracy estimation	Internal consistency of the FI was in the recommended range. Independently from age and sex, the FI is a strong predictor of hospitalizations (OR = 3.4), falls (OR = 5.0), and mortality (OR = 9.9). The diagnostic accuracy of the FI for mortality reported an AUC of 0.59; for hospitalizations of 0.54; and for falls of 0.56.

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
RAI-MDS HC	Burn et al. (2018)	Frailty Index	5586 community dwelling people (61.3% female; mean age 82y ± 8.6y)	New Zealand	Community Care	Longitudinal study design (2008-2012)	To develop a frailty index using MDS-HC data from people living at Canterbury, New Zealand	Criterion validity Normality test	The Frailty index was significantly related to the five-year mortality rate, 25,1% of the people with a baseline frailty level, and 28.2% of the people with the highest level of frailty died after five years. The survival rate decreased with every level of the FI, as rose the admission rate for every level. The FI was significantly related to the five-year admission rate to residential care, after five year 43.7% of the people with baseline frailty still lived at home as compared to 2,6% with the highest frailty level. The Frailty index was not normally distributed.
Popovich Scale	Grubba et al. (1990)	Cognitive, Economic, Social Resources, and Physical Health subscales	30 patients 65y or older (46.7% female; mean age 73,3y)	United States	Home Health Agencies	Cross-sectional design	Examine the reliability and validity of the Popovich Scale subscales in older adults receiving home care	Criterion validity Construct validity Inter-rater reliability	Large effect sizes were shown for the Cognitive, Physical health and Social resources subscales when compared against criterion. Construct validity was demonstrated for the Economic subscale as it was able to differentiate between groups differing on their annual income report, and whether participants reported their annual income as adequate or not. Inter-rater reliability showed large effect sizes between raters for all scales.
interRAI HC	Gee et al. (2021)	Cognitive Perfomance Scale (CPS)	134 participants (51% female; mean age 78y)	New Zealand	Home Care	Retrospective diagnostic study design	To study the perfomance of the interRAI HC CPS in community settings with a sample of elderly people with	Diagnostic Accuracy	The AUC-ROC of the CPS in predicting dementia diagnosis was 0.82. An optimal cut point of 1/2 was identified with a Sensitivity of 0.90 and Specificity of

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
							know cognitive status		0.60. An alternative cut-off point of 2/3 improved the PPV value, with a Sensitivity of 0.44 and a Specificity of 0.94.
interRAI HC	[a]Kim et al. (2015)	ADL, IADL performance, IADL capacity, Depression, Communication, and Pain Scales	908 participants (67.9% female; mean age 80y ± 7.5y)	Korea	Home Care	Cross-sectional design	To examine the reliability of the Korean version of the interRAI LTCF and the interRAI HC	Internal consistency reliability	Internal consistency for the scales ADL, IADL performance and capacity, Depression, Communication and Pain was on the recommended range
interRAI HC	Penny et al. (2016)	Depression Rating Scale (DRS)	92 subjects (54% female; mean age 78.3y ± 7.5y)	New Zealand	Acute Psychogeriatric Service Wards & Memory Clinic	Cohort study	a) To examine the concurrent validity and diagnostic accuracy of the 3-day reporting period version of the DRS b) To compare its performance in no/MCI individual against people with dementia c) To study if adding other interRAI items increases its performance	Concurrent validity Diagnostic accuracy	For diagnostic accuracy for depression diagnosis an AUC of 0.68 was obtained. Using the cut-off of ≥ 3, the Sensitivity of the DRS was 0.60 and Specificity was 0.70. For the overall sample, the correlation effect size between the DRS and the criterion depression diagnosis was medium. Also, a medium effect size was reported for the correlation between the DRS and the HONOS65+.

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
MAI	Lawton et al. (1982)	Physical health, Cognition, Activities of daily living, Time Use, Social Interaction, Personal Adjustment, and Perceived Environment Indices	590 people, for subsamples mean age-band was 75,8 - 79,7y, female ranged between 16-91%	United States	Community sub-samples: independently living older people; high-intensity in-home service recipients; institutional waiting list clients	Cross-sectional design	To describe the Philadelphia Geriatric Center Multilevel Assessment Instrument (MAI) and it's psychometric properties	Inter-rater reliability (interview-reader-rater (n = 484) and interview-observer (n = 106)) Internal consistency reliability Test-retest reliability (n = 39) Criterion validity Internal validity Concurrent validity	Reliability Interview-reader-rater: 95% agreement with 0-1 point discrepancy; ICC ranged between moderate to good. Interview-observer: median correlations between interviewer and administrator (0.51) and between interviewer and clinician (0.60) were moderate. Internal consistency reliability Cronbach's alphas were in the recommended range for all scales. For the subindices, only six of them were below the recommended range. Test-retest reliability Large effect sizes were reported for all scales and subindices, except for physical self-maintenance. Internal validity Correlations between domain index items and domain summary ratings reported large effect sizes for all scales, except for perceived environment. Also, large effect sizes were reported for all subindexes, except for one subindex under Social Interaction and all subindices from Perceived Environment. Criterion validity Small to medium effect sizes were reported for all

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
									subindices between index score and a consensus summary score, except for four that were below 0.1; for all indices effect sizes range between small and large, except for Perceived Environment which was below 0.1. Concurrent validity: Except for Cognition, all indices reported large effect sizes, however, differences were identified between clinicians and administrators. Perceived environment was not assessed
OARS-OMFAQ	Fillenbaum and Smyer (1981)	Social, Economic, Mental Health, Physical Health, and Self-care Capacity scales	Two samples: Validity sample N = 33 (64% female; mean 70.24y ± 7.59y) Reliability sample N = 30 (mean 70.24 ± 7.09y)	United States	Community Care	Cross-sectional design	Report on the development, validity, and reliability of Part A of the OARS-OMFAQ	Criterion validity Inter-rater reliability	For four scales, large effect sizes were found when compared against criterions. Social scale wasn't compared against a criterion. Inter-rater reliability was good for four scales and moderate for one (physical health).

Name of CGA	Authors/ Year	Scales/Indexes	Participants (N and mean age)	Country	Study setting	Study design	Aim of the study	Type of validity/reliability studied	Main findings
OARS-OMFAQ	Fibla et al. (1996)	Social, Economic, Mental Health, Physical Health, and Self-care Capacity scales	473 elderly people (58.8% female; mean age 71.1y ± 7.96y)	Spain	Community Care	Cross-sectional design	To describe the linguistic and cultural adaptation of the OARS-OMFAQ Spanish Version	Construct validity	The factor grouping of the Spanish version coincided precisely with the original English version for the social network, economic resources, and physical health dimensions. For the self-care dimension, two factors coincided, but one item deviated from the original English version. In the mental health scale there was complete agreement, except that it was divided into two factors in this version. For all scales, Cronbach's Alpha were above 0.7, except for Social Resources scale.

[a]Studies repeated in the table as they were assessing either other care setting or another approach of validation.

Table A.6 PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Title
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Abstract
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Background
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Background
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Literature Search at Research design and methods
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Literature Search at Methods
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Appendices
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Appendices
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Data extraction at Methods
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Data extraction at Methods
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Data extraction at Methods
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Data extraction at Methods
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Data extraction at Methods
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Interpretation of test scores at Methods

Section and Topic	Item #	Checklist item	Location where item is reported
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Appendices
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Methods
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	Methods
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Methods
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Methods
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Literature search at Results
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Methods
Study characteristics	17	Cite each included study and present its characteristics.	Appendices
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Appendices
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Appendices
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Appendices
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Appendices
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Results, Appendices
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Results, Appendices
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Discussion
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Discussion
	23b	Discuss any limitations of the evidence included in the review.	Discussion
	23c	Discuss any limitations of the review processes used.	Discussion

Section and Topic	Item #	Checklist item	Location where item is reported
	23d	Discuss implications of the results for practice, policy, and future research.	Discussion
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	N/A
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Funding
Competing interests	26	Declare any competing interests of review authors.	Declaration of interest statement
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Appendices

Supplementary Material 4. Supplementary Material of Publication #3

Additional file 1: Table S1. Overview of digital considerations.

TECHNOLOGICAL CONSIDERATIONS	**Preference** • Consider other less technological options, based on individual preferences, including: One to one phone calls may work best for those with limited access to the internet, or for more in-depth discussions. • Teleconferences could also be an option, if a group discussion would be helpful but internet access is a challenge. **Access** • Does the channel, e.g. MS Teams, Zoom or MIRO etc. work where people are using different devices, e.g. smart phones, need for 2 screens etc.? • Internet connection **Aptitude** • How familiar are participants with remote communication and what are people's preferences? • Need to balance limitations on inclusivity (e.g. using people with more technological experience) against ensuring that sessions can operate smoothly and people able to contribute effectively.
ONLINE FACILATION CONSIDERATIONS	**Developing roles** • Clear roles needed from the outset • Power-dynamics and how recruiting a PPI Co-facilitator can provide supportive environment • Consider 2nd Facilitator, specifically looking at inclusion through monitoring online chat and other channels used to communicate **Online Ground Rules and Etiquette** • Establish ground rules from the offset, with clear mechanisms to enable participation from all involved • Recognise and respect that standard behavioural standards/expectations of digital meetings will differ from face-to-face, e.g. acknowledge potential interruptions due to caring responsibilities or technology, allowing people the space to respond and re-join the group **Time management** • Allowing enough time to cover agendas and topics • Importance of communicating and sharing information beforehand to maximise time gaining insight from PPI during the sessions • Recognising PPI participants may not be able or wish to stay longer than meeting end time. • Recognising PPI participants may have responsibilities and may not be able to provide involvement at short notice
CO-PRODUCTION CONSIDERATIONS	**Workshop numbers**

	•Depending on the configuration and systems used, including the ability to facilitate breakout sessions, participant numbers should reflect the additional challenges and requirements of digital PPI. **Co-Design preparation** • Preparation for a digital workshop requires additional skills and time dedicated to creating a user-friendly experience. • Issues with trying and replicate ½ day face-to-face workshop on digital • Breaking down activities into smaller segments and ensure a clear plan for the session guided by facilitator • Consider sending out documents to review beforehand if appropriate, instead of trying to present them all in the platform. **Collaborative working** • Different activities could include Synchronous (where everyone is in contact at a specific time, mimicking a typical workshop) or asynchronous input, e.g. MIRO allows you to post outside the session forum/MS Teams for specific project or hashtag where people can post at different times more suitable for them. Also providing a video tutorial of how to use the platform to help people familiarise
RESOURCE CONSIDERATIONS	**Additional resources** • As well as the cost of coproduction platforms themselves, these could include phone credit/printing etc./software/budgeting for an increased frequency but shorter meetings • Cost and time of sending equipment and resources to people who need this to partake **Workshop numbers** • Depending on the configuration and systems used, including the ability to facilitate breakout sessions, participant numbers should reflect the additional challenges and requirements of digital PPI. **Training and Opportunities** • Where a PPI Member has a role within the Research Team, time and resources should be afforded to their training and development in digital coproduction.
ETHICAL & WELFARE CONSIDERATIONS	**Impacts of digital PPI on welfare** • Change from face to face PPI impacting of wellbeing – isolated, anxiety, depression, lack of movement; On the other hand some may feel digital PPI is a better fit for them. Creating friendly space and social aspects. • Certificates and follow ups of project progress to promote wellbeing and meaning • Consider the need for additional breaks to recognise impact of working online – (consider those new to Techognoly use or health issues of the public & patient that may require adequate breaks) **Consent & Safeguarding** • Consider use of Peer Facilitator in next virtual room (or on different platform- being clear that run by separate/independent organisation • Considering how support mechanisms have been adapted for a digital environment, e.g. use of Peer Support in an alternative virtual room, or accessible by pone before, during and after a PPI session **Data security** • Asking if we are ok to have session recorded

	• Addressing concerns about privacy on platforms and where research will be shared

Additional file 2. Project Information Sheet

PROJECT INFORMATION AND INVITATION TO CONTRIBUTE

1. Title

How to approach Public and Patient Involvement (PPI) in dementia research through technologies? Feedback from *experts by experience.*

2. Invitation paragraph

Are you interested in contributing to enhance knowledge and determine better practices on the use of Information and Communication Technologies (ICTs) as an approach to involve public as part of dementia research teams? We are planning online workshop sessions to discuss about our experiences on the use of communication technologies as a facilitator tool to participate in dementia research as *experts by experience*.

No previous experience is needed regarding participation in dementia research, but at least you must have had minimum experience on using ICTs to communicate with others. However, you do not need to be an expert on ICTs, neither concerning their use to participate in research.

3. What is the purpose of the study?

Due to the COVID-19 pandemic, the involvement of patients and public in research has been challenged because of social distancing, lockdowns and reduced physical contact. Now, after more than one year since the beginning of this situation, the implementation of ICTs has been regarded the most used way to tackle these challenges, however, due to the promptness of the reaction, we might not have had the opportunity to ask the public involved how they feel using these new approaches, if the ICTs are user-friendly, or if ICTs are successful tools to get involve in shaping or guiding dementia research.

Sharing our experiences and opinions, will not only enhance how we use ICTs in dementia research during COVID-19 pandemic, but also for facing other constraints that might diminish the public engagement in regular circumstances, such as access to rural and remote areas, limited availability of services and health professionals, distance from healthcare services, poverty, PPIs Representatives' health conditions, such as fatigue, mobility restrictions, work or family commitments, limited budget for research with PPI, etc.

For this purpose, we will like you to get involve as an *expert by experience* to contribute on this discussion and propose ideas and tips on how to improve the involvement of the public on dementia research.

4. **Why have I been invited?**

We consider you as an *expert by experience* that can share your valuable opinion and knowledge about the topic being discussed. Even if you have not been part of a dementia research team before, you can provide suggestions around how ICTs can be adapted, or how we can adapt them, to have a better and more friendly experience supporting dementia research to keep public involve.

5. **Do I have to take part?**

It is up to you to decide whether or not to take part. You are free to withdraw at any time without giving a reason.

6. What will happen to me if I take part?

If you decide to take part of the workshops, you will be invited to a virtual meeting. Beforehand, you would receive information about the project, instructions to use the platform that will be used to run the workshops, general questions that will be used to start the discussion, and an opportunity to ask questions to the organizers. During the online workshops you will be sharing with other people and have the opportunity to discuss about the specific topics planned for that day. One of the organizers will be leading the discussions and will guarantee that all the participants have their chance to speak and give feedback. Meetings will not be recorded, and it is not necessary to activate the camera/video of the platform. You will also have the opportunity to share your ideas through the chat box, if you find it necessary. Feedback with the notes taken from the organizers will be sent to all the individuals involve. The aim is that together we could elaborate some tips and ideas to enhance the use of ICTs to be engage in dementia research planning and development.

7. What are the possible disadvantages and risks of taking part?

You might get exhausted during the workshops, but no other risks or disadvantages are expected. However, you are free to leave the session at any time. Also, you can take a break during the session and re-join if you consider so.

9. What are the possible benefits of taking part?

You will receive no direct benefit from taking part in this project. However, you may have the option to be included as part of the contributors in any further material or publication that could be elaborate with the information discuss during the workshops. The notes taken during the project, will enhance the knowledge on ICTs to improve public involvement in dementia research.

10. **Will my taking part in this project be kept confidential?**

Yes, your participation will be kept confidential. This is not a study, is a Public Involvement contribution. Any information gather during the project, could be presented in general terms in further publications or materials, but it will never be connected to any of the contributors participating at the workshops. We will not be asking for personal details or sociodemographic information.

11. **What will happen to the information gather from the workshops?**

One of the organizers will be taking notes, this information could be published as a report, guideline, or any other publication. Your participation will be recognized in any further material resulting from the project. You will not be identified in any of the reports or publications following the project, unless you explicitly suggest for it.

12. **Who is organising and funding the project?**

This project is part of DISTINCT: "Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology" which supports fifteen Early Stage Researchers (ESRs) across Europe, who are carrying out research projects aiming to improve the lives of people with dementia and their carers through technology. DISTINCT is funded by the Marie Skłodowska Curie Actions Innovative Training Network H2020-MSCA-ITN, under grant agreement number 813196

The project is also been organized by MindTech which is a national centre focussing on the development, adoption and evaluation of new technologies for mental healthcare and dementia and funded by the National Institute for Healthcare Research.

13. Who has reviewed the project?

Research Ethics Approval to conduct this project is not required as it is a public engagement activity. **Remember, this is not study, is a voluntary contribution to engage in a Public and Patient Involvement activity.** Faculty of Medicine and Health Science Research Ethics Committee reference no. 255-0521.

Contact for Further Information

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Note: You will be given a copy of this information sheet by email. Also, we offer the possibility to send a copy by post upon previous request.

Additional file 3. Semistructured Questions Guide

- What strengths do you identified regarding the use of online digital platforms for PPI in dementia research (e.g., platforms like Zoom, Teams, GoToMeeting)?
- Do you have the necessary equipment for the meetings?
- Do you struggle using the equipment or the online platforms?
- Do you feel these platforms are user-friendly?
- Do you prefer online or face-to-face meetings regarding PPI in dementia research?
- How confident do you feel using these technologies for PPI in dementia research?
- Do you feel included or involved in the discussion or is it less engaging or inclusive?
- How safe do you feel using the technologies for engaging in dementia research?
- How supported do you feel using online approach? Do you feel supported by the people hosting the meetings?
- Do you require any additional support by others (e.g., caregivers)?
- How emotional support could be managed during online PPI in dementia research? Or how do you feel about that and how do you think this must be managed?
- Have you been able to do more PPI, or has it been the same?

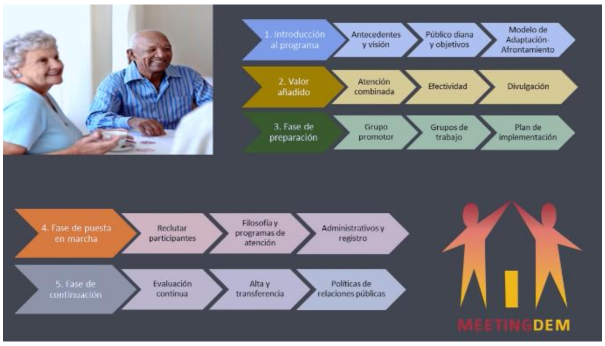
Supplementary Material 5. Screenshots of the Spanish Course for the Implementation of Meeting Centres

Personas con Demencia y sus Cuidadores

Página Principal / Mis cursos / Implementación de Centros de Encuentro para Personas con Demencia y sus Cuidadore

Implementación de Centros de Encuentro para Personas con Demencia y sus Cuidadores

- Existe una necesidad creciente de nuevas alternativas, más económicas y con mayor integración socio-comunitaria para la atención de personas con deterioro cognitivo o demencia y sus cuidadores. Una de estas alternativas, el Programa de Atención de Centros de Encuentro, se abarcará a lo largo del curso, desde su metodología de trabajo hasta su implementación.
- El curso consta de cinco módulos que abarcan la introducción al programa, su valor añadido, y sus tres fases de implementación: preparación, puesta en marcha y continuación. Está destinado a aquellas partes interesadas en implementar y adaptar la metodología a sus diferentes contextos, por lo que se incluye pasos como la identificación de facilitadores y barreras para el proceso de implementación, la descripción de las características básicas que deben presentar el programa para personas con demencia como el programa para cuidadores, videos que ejemplifican las actividades realizadas en centros de encuentro en diferentes países europeos, además de presentar una guía o manual que incluye toda la información paso a paso y por fases.


1. Introducción al programa | Antecedentes y visión | Público diana y objetivos | Modelo de Adaptación-Afrontamiento

2. Valor añadido | Atención combinada | Efectividad | Divulgación

3. Fase de preparación | Grupo promotor | Grupos de trabajo | Plan de implementación

4. Fase de puesta en marcha | Reclutar participantes | Filosofía y programas de atención | Administrativos y registro

5. Fase de continuación | Evaluación continua | Alta y transferencia | Políticas de relaciones públicas

por lo que había fragmentación de la atención,

NOMBRE APELLIDOS

con D.N.I. nº XXXXXXXX, ha superado el curso

CURSO INTRODUCTORIO A LA IMPLEMENTACIÓN DE CENTROS DE ENCUENTRO PARA PERSONAS CON DEMENCIA Y SUS CUIDADORES

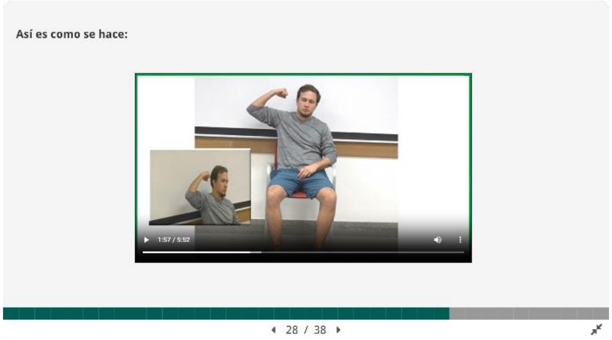
con una duración de 10 horas

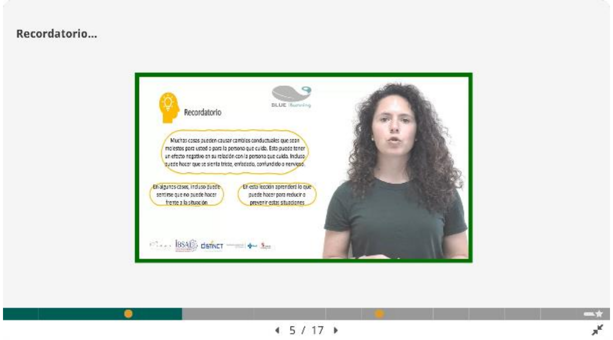
Para que conste, se expide el presente documento en Salamanca, a ....

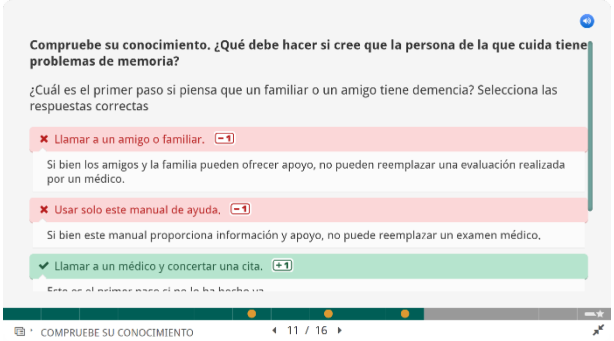
Supplementary Material 6. Screenshots of the iSupport-Sp online platform

Contenido del Curso

- CUESTIONARIOS INICIALES — Expandir
- MÓDULO 1 : INTRODUCCIÓN A LA DEMENCIA — Expandir
- MÓDULO 2: SER UN CUIDADOR — Expandir
- MÓDULO 3: CUIDÁNDOME — Expandir
- MÓDULO 4: PROPORCIONANDO CUIDADO DIARIO — Expandir







Compruebe su conocimiento. ¿Qué debe hacer si cree que la persona de la que cuida tiene problemas de memoria?

¿Cuál es el primer paso si piensa que un familiar o un amigo tiene demencia? Selecciona las respuestas correctas

✗ Llamar a un amigo o familiar. −1

Si bien los amigos y la familia pueden ofrecer apoyo, no pueden reemplazar una evaluación realizada por un médico.

✗ Usar solo este manual de ayuda. −1

Si bien este manual proporciona información y apoyo, no puede reemplazar un examen médico.

✓ Llamar a un médico y concertar una cita. +1

CERTIFICADO DE FINALIZACIÓN

Certifica que

____

ha completado con éxito el programa en-línea de formación y apoyo

para cuidadores de personas con demencia

iSupport Para Demencia

el ___(día) de ________(mes) del 20____(año).

Supplementary Material 7 to 12

The following information is available in this section:

Supplementary Material #7: Translation and Adptation of interRAI LTCF and interRAI HC

- interRAI LTCF Manual and Form Spanish version
- interRAI HC Manual and Form Spanish version

Supplementary Material #8: Protocol "Usability, user experience, and pilot study of the efficacy of the iSupport-Sp"

Supplementary Material #9: Ethics Approval for the "Usability, user experience, and pilot study of the efficacy of the iSupport-Sp"

Supplementary Material #10: Best Practice Guidance DISTINCT

Supplementary Material #11: Newsletters Publications

- Spring DISTINCT Newsletter #2. June 2021. Available at https://www.dementiadistinct.com/wp-content/uploads/2021/06/DISTINCT-Newsletter-Spring-2021-Final-version-1.pdf
- Cycling through the Netherlands… Developing the road to the Spanish version of the Meeting Centres Support Programme. DISTINCT Newsletter #3. March 2022. Available at https://www.dementiadistinct.com/wp-content/uploads/2022/03/3rd-DISTINCT-Newsletter-Winter-2022_final-3.3.22.pdf
- Spanish Online course for pioneers of Meeting Centres available in Spring 2022. MeetingDem Newsletter. December 2021. Available at https://meetingdem.eu/wp-content/uploads/2021/12/MeetingDem-Newsletter-December-2021_v1.0.doc.pdf
- A new start for the Meeting Centre in Spain. MeetingDem Newsletter. December 2022. Available at https://meetingdem.eu/wp-content/uploads/2023/03/MeetingDem-Newsletter-December-2022_v1.2.pdf

Supplementary Material #12: Collaboration in Publication

- Mahmoudi Asl A, Molinari Ulate M, Franco Martin M, van der Roest H. Methodologies Used to Study the Feasibility, Usability, Efficacy, and Effectiveness of Social Robots For Elderly Adults: Scoping Review. J Med Internet Res. 2022 Aug 1;24(8):e37434. doi: 10.2196/37434. PMID: 35916695; PMCID: PMC9379790.

These Supplementary Material is available in the pen drive enclosed with this document or available at:

https://usales-my.sharepoint.com/:f:/g/personal/maumolula_usal_es/Emz1dnAm5fNKk7E7Sj-aanYBPmoyVNI_8zJ4VhxMhz2pEA?e=jGYpe8

If there are any difficulties accessing these documents, please contact Mauricio Molinari Ulate at maumolula@usal.es or Manuel Franco Martín at mfrancom@saludcastillayleon.es