Research into Frail, Homebound, and Bedridden People (#FHBP): collecting experiences and developing advocacy tools



Severe ME Month 2025 Webinar Event Dr Maria Alejandra Piñero de Plaza Research Fellow College of Nursing and Health Sciences Flinders University



https://researchnow.flinders.edu.au/en/persons/maria-alejandra-pinero-de-plaza

Penelope McMillan Spokesperson ME/CFS Australia Lived experience of Severe ME











Acknowledgement of Country

Meso level

We acknowledge the traditional owners and custodians of the land from which Alejandra and Penelope present today: The Kaurna People. We pay respect to their Elders, past and present, and emerging leaders.

We also acknowledge traditional owners and custodians across Australia, wherever people are watching today, and extend our respect to Aboriginal and Torres Strait Islander peoples here today.

Health System Enablers and Barriers to Continuity of Care for First Nations Peoples Living with Chronic Disease

2. Limited health and social care pathways

1. Scarce community initiatives 1. Siloed teams' approach 2. Inadequate clinical pathways 2. Inadequate collocation of services 3. Sparse points of access 3. Insufficient transitional care services. **Organisational integration points** Macro level 3. Scattered managed care **Professional integration points System integration points Clinical integration points** A lack of Micro level culturally adapted personcentred and 1. Limited coaching and peer support integrated care 2. Inadequate case management **Functional integration points** 3. A lack of holistic assessment and care planning 1. Limited continuity of information 1. Insufficient health and social care networks 2. Partial decision support



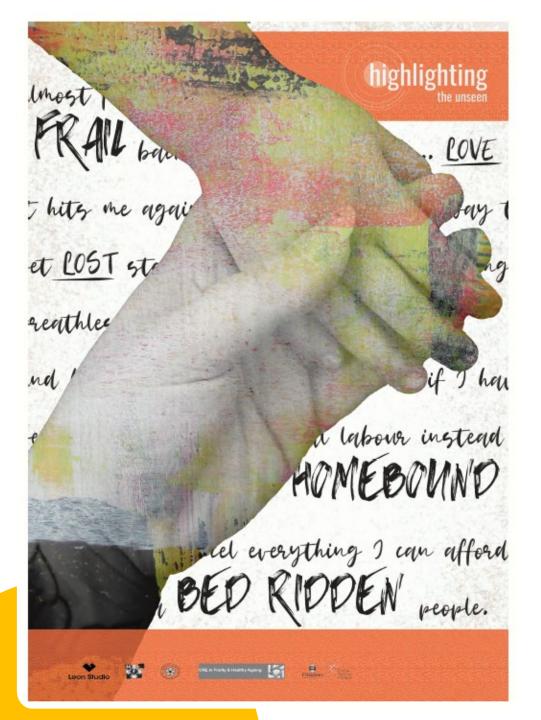
https://ijic.org/articles/10.5334/ijic.7643







3. Restricted technology-to enable care



Content

- The origins of the project: community need
- The academic need
- Key outputs/outcomes
- Medicare/Telehealth
- New evidence and advocacy tools













The community need

- L. Invisibility
- 2. Marginalisation
- B. Health and quality of life deterioration
- 4. Barrier to accessing disability, welfare and other supports

Ricky Buchanan, author of:

"Just Invisible"

Medical Access Issues For Homebound/
Bedridden Persons



Approximately **596,800** Australians aged 5 and over do not leave home as often as they would like due to their disability or condition. Of these, **383,500** are aged 5-64, and **212,800** are aged 65 or older (**2018, ABS**). A significant portion of these are people with Severe ME.

Alejandra, Penelope and Ricky - Transformation of healthcare delivery for Homebound patients



https://www.facebook.com/watch/?v=572189996766243

The academic need

- Video evaluation on Frailty.
- 2. Knowledge translation research.
- 3. Previous experience as a consumer advocate and an interest in engaging with stakeholders as co-researchers.

Videos :



Frailty: Every Step You Take Matters!

YouTube · Mandy Archibald 15 Mar 2019

Frailty is a continuum, not a label. It can be prevented or reduced by adopting healthy habits and seeking support.



The University of Adelaide

https://health.adelaide.edu.au > media > cre_speci... PDF

CRE in Frailty & Healthy Ageing

A short film on Frailty and Forgotten. Australians is also in production.

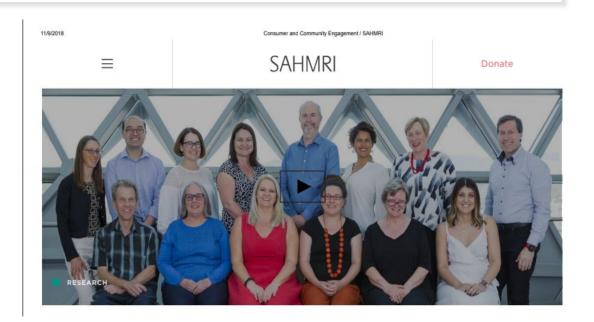


Flinders University

https://www.flinders.edu.au > research-projects > knowl...

Knowledge Translation Program

23 June 2021 — **To promote the effective transfer of research findings** about frailty screening and management into practice and policy.



Consumer and Community Engagement

A COMMITMENT TO IMPROVING CONSUMER AND COMMUNITY ENGAGEMENT IN HEALTH AND MEDICAL RESEARCH

Key outputs/outcomes

MAKING THE INVISIBLE VISIBLE EXPLORING THE EXPERIENCES OF FRAIL HOMEBOUND AND BEDRIDDEN PEOPLE PRELIMINARY RESEARCH REPORT FOR THE COMMUNITY



3. Consumer-Led and Community-Oriented **Examples: Figshare Report**: *Making the Invisible Visible* — lived experiences of

- **Highlighting the Invisible Video**: Co-produced media to amplify the voices of #FHBP, ME/CFS and others.
- **Other dissemination**: Facebook page, videos, presentations, lectures.









Selected survey outcomes: things that are important to me

















Selected survey outcomes: things that I have lost







Selected survey outcomes: what do households look like?



Do you live alone?

Two thirds of the people surveyed do not live alone, 67%.

However, about 33% of the FHBP surveyed live alone.

What is your current marital status?

Most FHBP surveyed were single, 42%. The second-largest group of respondents were married, 26%. The third-largest group was constituted by divorced people, 13%.

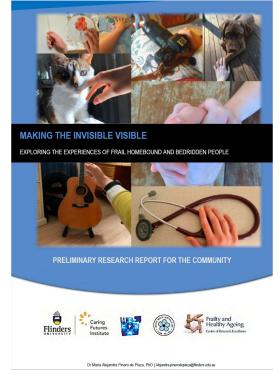
Do you have children/stepchildren aged 18 and younger who do live with you?

Most FHBP respondents indicated that they do not have children living with them, 78%. However, 22% indicated that they have children aged 18 and younger living with them

In the last year, have you experienced...

Most FHBP reported social isolation, 88%. A reduction of their capacity to participate in family and community life, 87%. A reduction in their overall health of 84%.

Selected survey outcomes: diagnoses, bedridden



How many chronic conditions do you have?

More than half of respondents indicated that they have three or more chronic conditions, 66%. The following group indicated they have two or more, 16%. The third-largest group indicated that they have one condition, 14%.

Have you been diagnosed with any of these conditions?

Most respondents identified Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (includes CFS, ME or ME/CFS diagnoses) as one of their conditions, 78%. Other conditions not tabled represented the second largest group of responses, 45%. The third group identified Fibromyalgia with 38% of responses.

Do you need to stay in bed most or all of the time?

Nearly more than half of the respondents indicated that they have to stay in bed most or all of the time, 53%. The rest of the FHBP surveyed indicated that they do not have to stay in bed most of their time.

Selected survey outcomes: most important needs



Many Frail, Homebound, and Bedridden People receive no support to access clinical services and may not have a regular primary care provider, such as a GP, because the Australian health system has been designed around patients' physical attendance (as COVID-19, consumers, and these responses have demonstrated).^{1,2,3,6,7,8,9}









Dr Maria Ale

Education for all health professionals and service providers about people with your needs

Educating Centrelink, NDIS, and government services about paperwork difficulties, e.g. providing more time or accepting GP reports rather than specialist paperwork only

Access to community care services, for example, NDIS, Aged Care packages

Adequate Medicare rebates for home visits

Extending the existing telephone or online consults (Telehealth) for rural and remote patients to also cover patients who are housebound or bedbound

Medicare-subsidised telehealth in Australia, August 2025

GP telehealth consultations

To be eligible for GP telehealth services, patients must have had a face-to-face consultation with their GP (or another GP in the same practice) in the 12 months before the telehealth service. There are some limited exceptions.

To be eligible for the MyMedicare service items, you must have seen your GP twice in the previous 24 months.

- in isolation or quarantine for COVID-19 due to a state or territory public health order
- experiencing homelessness
- under 12 months of age
- treated at an AMS or an Aboriginal Community Controlled Health Service (ACCHS)
- in a natural disaster area
- needing mental health support
- requiring urgent after hours service in unsociable hours
- undergoing eating disorder support or pregnancy counselling
- receiving blood borne viruses, sexual or reproductive health consultations
- getting MyMedicare attendance service items 91900, 91903, 91906, 91910, 91913 or 91916
- getting an eligible service from an eligible urgent care clinic.

Systematic Review & Meta-Analysis

New evidence and advocacy tools



https://doi.org/10.1155/hsc/7224151

Research Question & Methods

Research Question:



for Is telehealth an effective care solution for homebound people compared to in-person care?

PICO

- •Population (P): Homebound individuals with severe health or psychosocial conditions in community settings (n = 2,245)
- •Intervention (I): Telehealth interventions (video, phone, digital platforms, nurse-assisted virtual visits, etc.)
- •Comparator (C): Standard in-person care
- •Outcomes (O): Healthcare utilisation, health-related quality of life (HRQOL), well-being

Systematic Review & Meta-Analysis

- •Databases searched: MEDLINE, Embase, PsycINFO, CINAHL, Cochrane CENTRAL, Scopus, LILACS, Web of Science
- •Timeframe: All years to August 2023 (no language restrictions)
- •Articles screened: $3,289 \rightarrow 10$ studies included (8 meta-analysed)
- •Study types: RCTs + quasi-experimental
- •Follow-up: 3 months \rightarrow 2 years
- •Codesign: 21 co-researchers (consumer co-researchers + multidisciplinary team)



WILEY

Research Article

Telehealth as a Care Solution for Homebound People: Systematic Review and Meta-Analysis of Healthcare Utilization, Quality of Life, and Well-Being Outcomes

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Received 4 September 2024; Accepted 21 Ma

Academic Editor: Hannah Wesley

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Systematic Review & Meta-Analysis

New evidence and advocacy tools



https://doi.org/10.1155/hsc/7224151

Findings & Meaning

Key Results (Telehealth vs In-Person Care):

- •Healthcare utilisation: ↓ significantly (SMD –0.49; low certainty)
- •**HRQOL:** ↑ significantly (SMD +0.18; *moderate certainty*)
- •Well-being: ↑ significantly (SMD –0.31; moderate certainty)

What this means:

- •SMD (Standardised Mean Difference): a way to compare results across different scales;
 - -0.49 = moderate reduction in service use (fewer hospital days/ED visits).
 - +0.18 = small but real improvement in quality of life.
 - −0.31 = moderate improvement in well-being (less depression, anxiety, loneliness).

•GRADE certainty:

- Low = further studies may change the effect (healthcare use).
- Moderate = reasonably confident the effect is real (HRQOL, well-being).

This evidence must be shared so that policies change their **restrictive telehealth access for homebound people**

Wiley Health & Social Care in the Community Volume 2025, Article ID 7224151, 32 pages https://doi.org/10.1155/bs/2722415 WILEY

Research Article

Telehealth as a Care Solution for Homebound People: Systematic Review and Meta-Analysis of Healthcare Utilization, Quality of Life, and Well-Being Outcomes

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Received 4 September 2024; Accepted 21 May 200

Academic Editor: Hannah Wesley

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application **Awarded:** @SafeHome Telemonitoring

1. Health System Transformation:

- Systematic Review & Meta-Analysis: Telehealth reduces hospital use and improves outcomes for homebound people
- Big Data Epidemiology Pilot: Supporting visibility and inclusion of FHBP in national datasets

Effectiveness of telehealth versus standard care on health care utilization, health-related quality of life, and well-being in homebound populations: a systematic review protocol

Maria Alejandra Pinero de Plaza 1:2:3 - Alline Beleigoli 1 - Shannon Brown 1 - Lemma N. Bulto 1:3 -Lemlem G. Gebremichael^{1,3} · Katie Nesbitt^{1,3} · Matthew Tieu¹ · Vincent Pearson¹ · Sara Noonan¹ · Penelope McMillan4 · Robyn A. Clark 1/3 · Sonia Hines3 · Alison Kitson 1/2 · Stephanie Champion 1 · Hila Dafny1-3 - Jeroen M. Hendriks1-3-5

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Objective: The objective of the review is to determine the effectiveness of telehealth versus in-person care or health care utilization, health-related quality of life, and well-being in homebound population

Introduction: Globally, an increasing number of people are becoming homebound. These individuals experience high levels of social isolation and deterioration of their well-being. Reports from homebound people and recen publications suggest that this cohort may benefit from accessing telehealth solutions from their homes to treat and prevent serious issues affecting their health and well-being. This review will synthesize the evidence on the effectiveness of telehealth compared to standard care (in-person care) on health care utilization, health-rela

Inclusion criteria: Studies including people living in community settings, whose daily life is physically limited to the boundary of their homes because of their ongoing health, energy, and psychosocial or socio-functional impairments will be considered for inclusion.

Methods: This review will consider relevant, peer-reviewed primary experimental and quasi-experimental studie with no limit on language or date. Databases to be searched include MEDUNE, Embase, PsycINFO, CINAHL, the Cochrane Central Register of Controlled Trials (CENTRAL), Scopus, LILACS, JBI Evidence Synthesis (hand-searched for further studies), and Web of Science. Two independent reviewers will be involved in study selection and data extraction. Eligible studies will be critically appraised for methodological quality using the relevant JBI critical appraisal checklists, and statistical meta-analysis will be done (where possible). Findings will be presented in

Keywords: bedridden: health care utilization; homebound; quality of life; telehealth JBI Evid Synth 2022; 20(11):2734-2742.

DOI: 10.11124/JBIES-21-00410

G lobally, an increasing number of people are diag-nosed with health issues, including disabilities, Correspondence: Maria Alejandra Pinero de Plaza,

SH is a senior associate editor of JBI Evidence Synthesis, but had no The other authors declare no conflict of interest

defined as homebound: people whose daily lives a physically limited to the boundary of their hom because of their ongoing health, energy levels, functional impairments.^{1,2}

homebound persons and their affiliated communiti

> Stud Health Technol Inform. 2024 Jan 25:310:1292-1296. doi: 10.3233/SHTI231173.

Piloting a Big Data Epidemiology Approach to Support Frail, Homebound, and Bedridden People

Maria Alejandra Pinero De Plaza ¹, Alline Beleigoli ¹, Alison Kitson ¹, Penelope McMillan ², Carlos Javier Barrera Causil 3

PMID: 38270023 DOI: 10.3233/SHTI231173

Abstract

Frail, homebound, and bedridden people (FHBP) are people living at physically limited to the boundary of their houses because of their c psychosocial or socio-functional impairments. This definition needs driven view of the distribution (frequency, pattern) and determinant related states and adverse events experienced by FHBP. Thus, we pil approach (Multiple Correspondence Analysis and data visualization) FHBP experiences and identified a positive correlation between perc

Keywords: Big data epidemiology; bedridden; frail; homebound; public health.

Affiliations + expand

☑ Full text links









Health & Social Care in the Community Volume 2025, Article ID 7224151, 32 pages https://doi.org/10.1155/hsc/7224151

Research Article

Telehealth as a Care Solution for Homebound People: Systematic Review and Meta-Analysis of Healthcare Utilization, Quality of Life, and Well-Being Outcomes

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Received 4 September 2024; Accepted 21 May 2025

Academic Editor: Hannah Wesley

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2. Policy Change:

- CHF 2021 Poster: Exclusion from primary care and implications for disability strategy (Prize)
- Policy Submissions & Presentations: Digital Health Institute Summit (2020) Disseminated by WHO during COVID-19, Research submitted and cited in the Royal Commission and AU Parliament, Referenced by Queensland Government on their approach to homebound, AAG

ENLIGHTEN ONLINE Exhibition: Presented at AAG 2022; art-science submission to the Royal

Commission (more than 4000+ views)





#FHBP

Submitted to and acknowledged by The Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability SUB.001.02754 & SUB.001.02754

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Winner of CHF Big Ideas 2021



3. Consumer-Led and Community-Oriented Interventions:

- Figshare Report: Making the Invisible Visible lived experiences of FHBP.
- Highlighting the Invisible Video: Co-produced media to amplify the voices of #FHBP, ME/CFS and others.
- Other dissemination: Facebook page, videos, presentations, lectures.







A winner of the Big Ideas video competition to improve the Australian health system. Consumer Health Forum of Australia, 2021.











https://doi.org/10.6084/m9.figshare.14417987.v3

Nursing Philosophy

TOP CITED

ARTICLE 20222023

The trouble with personhood and person-centred care

Matthew Tieu PhD 🔀 Alexandra Mudd LLB, BN(Hons), RN, Tiffany Conroy PhD, MNSc, BN, RN, FACN, Alejandra Pinero de Plaza PhD, Alison Kitson DPhil, BSc(Hons), RN, FRCN, FAAN, FAHMS

First published: 13 April 2022 | https://doi.org/10.1111/nup.12381 | Citations: 11

> Stud Health Technol Inform, 2024 Jan 25:310:389-393, doi: 10.3233/SHTI230993.

A Human-Centered Approach to Measuring the Impact of Evidence-Based Online Resources

Maria Alejandra Pinero De Plaza ¹, Mandy Archibald ², Michael Lawless ¹, Rachel Ambagtsheer ³, Penelope McMillan ⁴, Alexandra Mudd ¹, Michaelle Freeling ¹, Alison Kitson ¹

Affiliations + expand PMID: 38269831 DOI: 10.3233/SHTI230993



Nursing

Philosophy



Abstract

Evidence-based online resources aim to combat vulnerabilities associated with health misinformation, evidence misalignment, and science illiteracy. Yet, it is a challenge to measure and demonstrate their impacts beyond looking at proxies for success (e.g., numbers of followers and likes). Addressing this gap, we introduce an emerging evaluation and verify its functionality in delivering optimal impact and sustainability measures for an evidence-based video resource on frailty.

Keywords: Evaluation; digital health; knowledge translation; science communication.

4. Knowledge Translation & Co-design for impact:

- KT in Transdisciplinary Teams
- Human-Centred Implementation Science Evaluation

PROLIFERATE & PROLIFERATE_AI: Frameworks to evaluate real-world impact

The VicePresident &
Executive Dean's
Research Awards
2022

Check for updates

Northumbria University, United Kingdo

University of Glasgow, United Kingdom

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This article was submitted to implementation

Pinero de Plaza MA Vadavil and Broon A (2023)

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Co-designing measuring and optimizing

innovations and solutions within complex

Science, a section of the journal Frontiers in

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CORRESPONDENCE

SPECIALTY SECTION

RECEIVED 30 January 2023

accromm 27 Fabruary 2023

PUBLISHED 31 March 2023

adaptive health systems.

Front, Health Serv. 3:1154614

doi: 10.3389/frts.2023.1154614

Per Niben, Linköping University Sweden CSIRO
On Prime
Innovation
Pulmator 31 March 2023
DOI 10.3389/91th. 2023 1154614

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Award 2024

International Journal of Medical Informatics 196 (2025) 105810

Contents lists available at ScienceDirect International Journal of Medical Informatics

journal homepage: www.elsevier.com/locate/ijmedinf



Co-designing, measuring, and optimizing innovations and solutions within complex adaptive health systems

Maria Alejandra Pinero de Plaza*, Lalit Yadav and Alison Kitson The Ceiro Futures Institute, Colege of Nusing and Health Sciences, Finders University, Adelaide, SA

Objective: To introduce, describe, and demonstrate the emergence and testing of an evaluation method that combines different logics for co-designing, measuring. and optimizing innovations and solutions within complex adaptive health systems. Method: We describe the development and preliminary testing of a framework to evaluate new ways of using and implementing knowledge (innovations) and technological solutions to solve problems via co-design methods and measurable approaches such as data science. The framework is called PROLIFERATE: it is initially located within the ecological logic: complexity science, by investigating the evolving and emergent properties of systems, but also embraces the mechanistic logic of implementation science (IS) (i.e., getting evidence-based interventions into practice); and the social logic, as the study of individuals, groups, and organizations. Integral to this logic mixture is measuring person-centered parameters (i.e., comprehension, emotional responses, barriers motivations, and optimization strategies) concerning any evaluated matter across the micro, meso, and macro levels of systems. We embrace the principles of Nilsen's taxonomy to demonstrate its adaptability by comparing and encompassing the normalization process theory, the 2×2 conceptual map of influence on behaviors, and PROLIFERATE.

Results: Snapshots of ongoing research in different healthcare settings within Australia are offered to demonstrate how PROLIFERATE can be used for codesigning innovations, tracking their optimization process, and evaluating their impacts. The exemplification involves the evaluation of HeathAGo (the design and implementation of an innovative procedure: interdisciplinary learning within an allied health service—community-based) and RAPIDx_A (an artificial intelligence randomized clinical trial being tested to improve the cardiac care of patients within emergency departments—terfary care).

Conclusion: PROLIFERNTE is one of the first firmneworks to combine ecological, mechanistic, and social logic models to co-design, track, and evaluate complex interventions while operationalizing an innovative complexity science approach: the knowledge translation complexity network model (KT-crim). It adds a novel perspective to the importance of stakeholders' agency in the system by considering their sociodemographic characteristics and experiences within different healthcare settings (e.g., procedural innovations such as further disciplinary learning' for Health2Co, and tech-enabled solutions such as RAPIDx.AI). Its structured facilitation processes engage stakeholders in dynamic and productive ways while measuring and optimizing innovation within the

Human-centred AI for emergency cardiac care: Evaluating RAPIDx AI with PROLIFERATE AI

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ARTICLEINFO

Keywords:
Artificial intelligence
Emergency medicine
Decision support
Cardiac biomarkers
Usability

Human-centred evaluation



ABSTRACT

Background: Chet pain diagnosis in emergency care is hindered by overlapping cardiac and non-acadiac symptoms, causing diagnostic uncertainty, Artificial Intelligence, such as RAPIDs Al, sims to enhance cares racy through clinical and biochemical data integration, but its adoption relies on addressing unability evaluations. The control of the contro

Objective: Evaluate RAPIDx Al's integration into clinical workflows, address usability barriers, and optimise its adoption in emergencies.

Method: The PROLIFERATE, Al framework was implemented across 12 EDG (July 2022-January 2024) with 39 participants: 15 esperts co-designed a survey via Expert Knowledge Elicitation (EKB), applied to 24 ED clinicians to ansess RAPIDx Al unability and adoption. Bayesian inference, using priors, estimated comprehension, emotional engagement, usage, and preference, while Monte Carlo simulations quantified uncertainty and variability, generating posterior means and 95% bootstrapped confidence intervals. Qualitative thematic analysis identified barriers and optimization needs, with data triangulated through the PROLIFERATE, Al scoring system to rate RAPIDx Al's performance by user roles and demographics.

Results: Registrare exhibited the highest comprehension (median: 0.466, 95 % Cl: 0.41-0.51) and preference (median: 0.456, 95 % Cl: 0.41-0.40), while residents/interns secred the lowest in comprehension (median: 0.196, 95 % Cl: 0.17-0.26) and emotional engagement (median: 0.112, 95 % Cl: 0.90-0.14). Registered nurses showed strong emotional engagement (median: 0.379, 95 % Cl: 0.35-0.45). Novice users faced usability and worldflow integration barriers, while experienced clinicians suggested automation and streamlined worldflows. RAPIDs Al scored "Good Impact," excelling with trained users but requiring targeted refinements for novice. Conclusion: RAPIDs Al enhances diagnostic accuracy and efficiency for experienced users, but usability challenges for novices highlight the need for targeted training and interface refinements. The PROLIPERATE_Alf framework offers a robust methodology for evaluating and scaling Al solutions, addressing the evolving needs of sociotechnical systems.

https://ebooks.iospress.nl/doi/10.3233/SHTI230993

Event on 18 March, 2021

Highlighting the Unseen

Conference presentation on research and innovation for people who are frail, homebound and bedridden.



People with ME/CFS are amongst those who are often excluded from primary healthcare and involvement in the community due to being homebound.

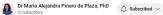
Dr Maria Alejandra Piñero de Plaza and our Chair, Penelope McMillan, are leading a research collaboration to better understand and meet the needs of people who are are frail. homebound and bedridden.

On the 18 and 19 March 2021, Alejandra and Penelope appeared in the Consumers Health Forum of Australia's Virtual Summit 2021: Shifting Gears.

On Thursday, they participated in the Big Ideas Forum, hosted by Ellen Fanning from ABC TV's *The Drum*.



Transforming Healthcare for Frail, Homebound, and Bedridden People





Takeaways and questions





https://go.nature.com/45sVD7h



