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

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Acknowledgement of Country

Our team would like to begin by acknowledging and paying our respect to this nation's past, present and future Traditional Custodians and Elders. I would also like to express my support for integrating their cultural, spiritual and knowledge-based practices in every aspect of our Australian society.

Our team for this study



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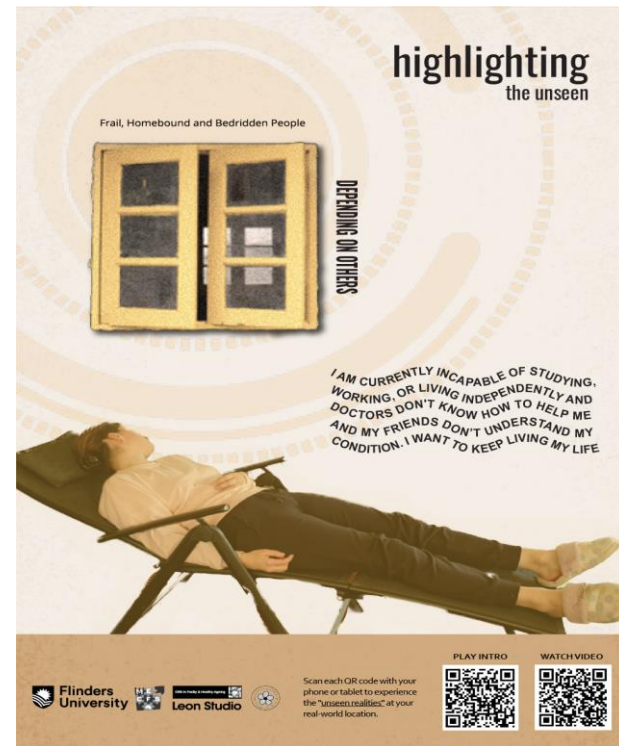
Professor (Full) at Instituto Tecnológico Metropolitano
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Why piloting a Big Data Epidemiology Approach to Support Frail, Homebound, and Bedridden People?



- More than **600,000 Australians** may be classifiable as Frail, homebound, and bedridden people (FHBP) – An invisible sector of our population
- FHBP are Australians living at home whose daily life is physically limited to the boundary of their houses because of their ongoing health, energy, and psychosocial or socio-functional impairments.





Some of the most prominent survey results



Younger adults, with the largest group identified being 41-45 years old.



81% self-identifying as female and 9% as male.



Identified as People with disabilities (72%); (LGBTIQ+) people (20%).



One-third of the surveyed FHBP live alone, while two-thirds do not.



The most common marital status: single (42%).



Do not have children aged 18 or younger living with them (78%).



The largest group completed a bachelor's degree (38%).



Physical, neurological, and sensory impairments.



Three or more chronic conditions.



The most diagnosed condition: ME/CFS (78%), other not specified (45%) and Fibromyalgia (38%).



Difficulty getting around at home or outside their home (85%).



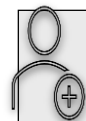
Nearly half are using mobility assistance devices to move around their homes, while 53% indicated not using such devices.



About 40% need help to move around.



More than three-quarters could not leave the house most or all the time (78%), while 53% indicated having to stay in bed most or all the time.



Respondents' most common type of health support was an unpaid family member or friend assistance (37%).



Other types of health support: the National Disability Insurance Scheme (27%), self-funded assistance (19%), aged care package (5%), and other forms of support.



What did we do?

- Multiple Correspondence Analysis (MCA), which can be seen as a generalisation of principal component analysis.
- We used the *FactoMineR* and *factoextra* packages of R software for the visualisation of possible distribution and components of health-related states and adverse events experienced by FHBP

Variables included from reported survey data

- Difficulty getting around at home or outside your home.
- Mobility assistance device to move around at home or outside your home
- Help from another person to move around, inside or outside your home
- Unable to leave the house most or all of the time.
- Stay in bed most or all of the time
- Are you permanently unable to leave your home
- Do you permanently need to stay in your bed
- Filter question
- People description (free text)
- Describe the situation (free text)
- Have you experienced
- Free text
- Consider it important to help you or other Australians.
- Relevant experience concerning the ambulance and hospital services
- Do you struggle to
- How many chronic conditions do you have
- Different prescription drugs you need to take each day
- The number of hospital admissions and unplanned re-admissions
- You have serious memory loss
- Compared to people your age, what do you think of your health?
- How confident are you in filling out medical forms by yourself?
- Do you live alone?
- You have children/stepchildren aged 18 and younger who live with you.
- Current marital status?
- Are you currently...?
- Describe your living location.
- What type of health support do you receive?
- Need the help of another person for
- Best describes your current situation or impairments.
- What is your age?
- Gender
- Highest degree or level of education



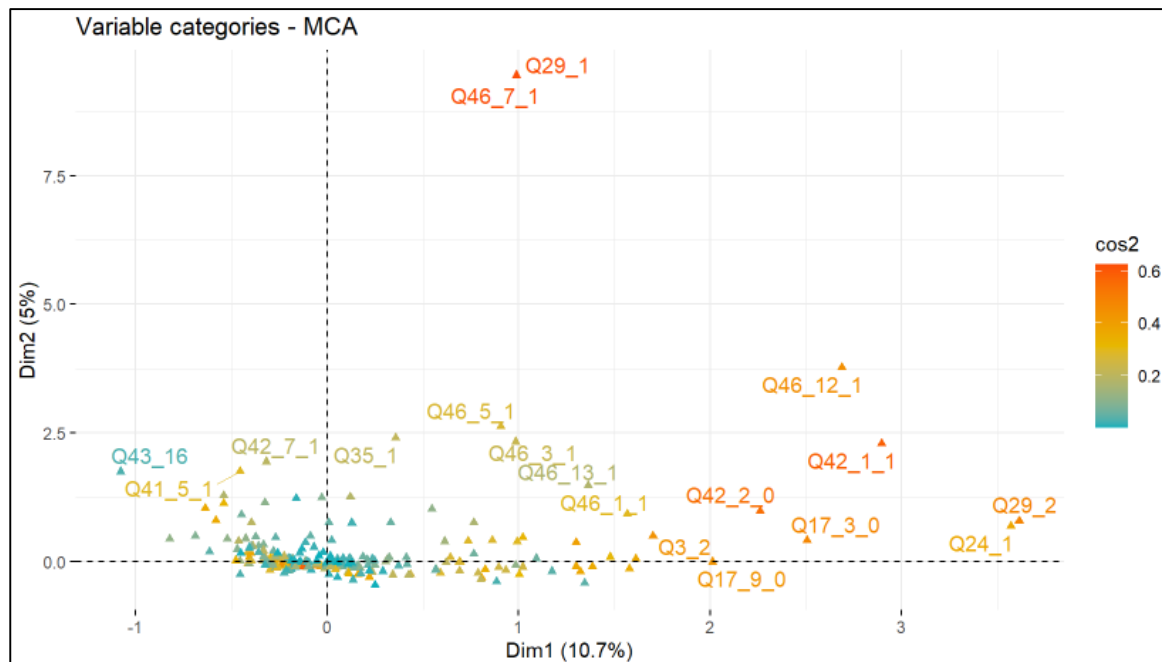
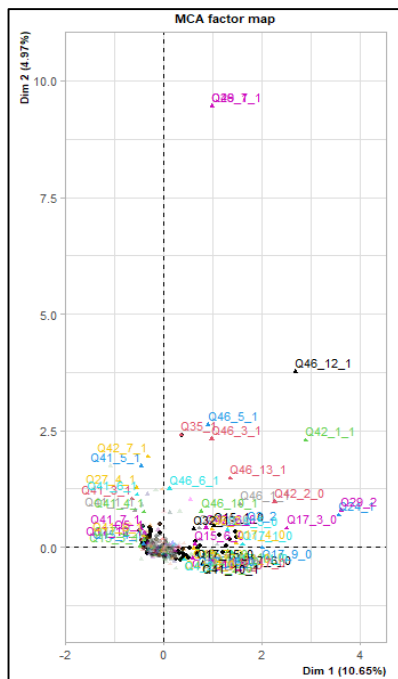


Figure 1. Biplot of individuals and variable categories: Individuals are represented by points and variable categories by triangles; colours present the quality of representation.

Figure 2. Quality on the factor map presents the associations between the considered variables/categories.

Report with survey data



Goodman and Kruskal's tau correlations plot for some of the considered variables in the study; it shows that the current situation or impairments that best describe people's situation (Q42) positively correlate with how they compare their health status with people their age (Q29).

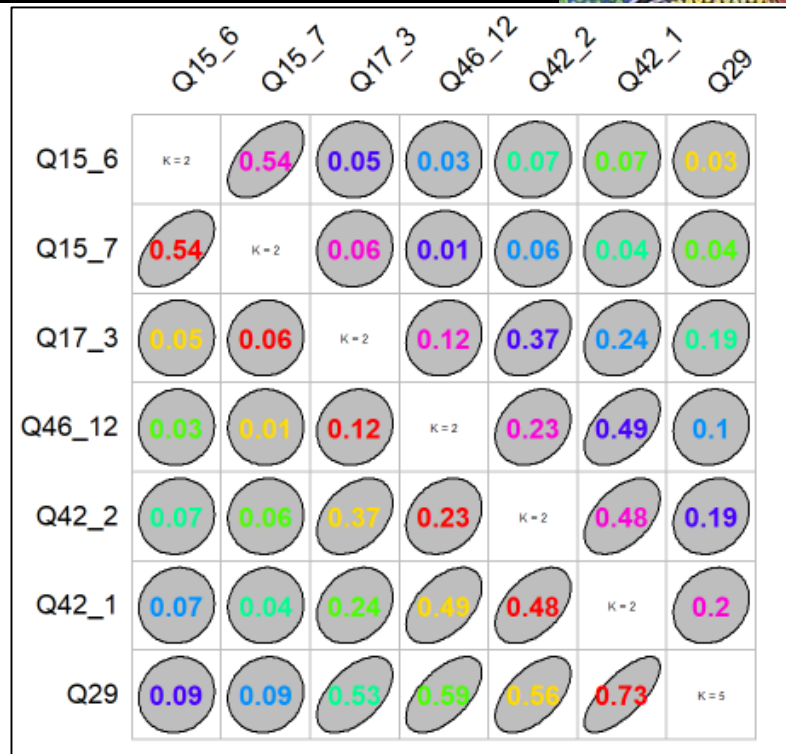


Figure 3. Goodman and Kruskal's tau correlations. K values represent the number of levels for each variable, and values inside of ovals represent correlations between variables. Note that this correlation is not symmetric.



What is the innovation of this pilot?

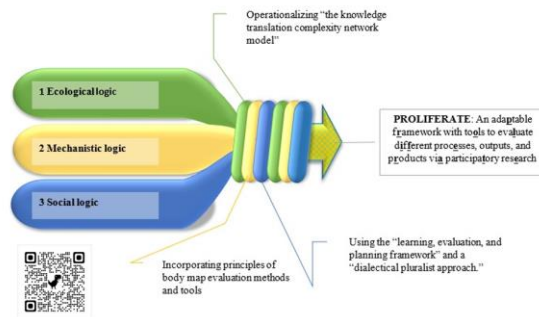


Our co-design approach

- Demonstrating that we must investigate further big-data epidemiology approaches in collaboration (co-design) with experts from different socio-medical areas and consumers.
- Triggering change by recognising the person's feedback to group them by their reported experiences and sociodemographic characteristics/networks, not just by their most symptomatic disease.
- Bringing a different perspective towards creating potential tools to solve complex public health problems from a more holistic and person-centred position.



Conclusion



#FHBP



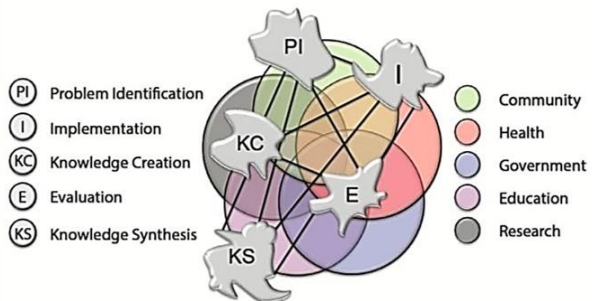
Submitted to and acknowledged by The Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability
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Thank you for your attention and questions

Some of our current knowledge translation and complexity science approaches



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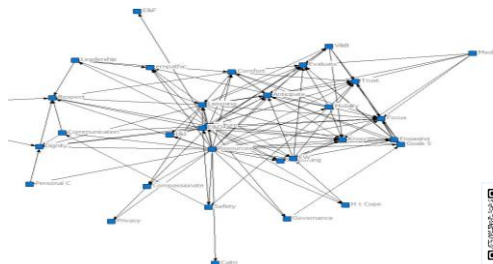
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Wicked problems in a post-truth political economy: a dilemma for knowledge translation

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