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## A dashboard of predictive analytics and decision support to drive care quality and client outcomes in aged care: A mixed-methods study protocol

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Complete List of Authors:	Ludlow, Kristiana; Macquarie University, Centre for Health Systems and Safety Research, Australian Institute of Health Innovation Westbrook, Johanna; Macquarie University, Centre for Health Systems and Safety Research, Australian Institute of Health Innovation Jorgensen, Mikaela; Macquarie University, Centre for Health Systems and Safety Research, Australian Institute of Health Innovation Lind, Kimberly ; The University of Arizona, Department of Health Promotion Sciences, Mel & Enid Zuckerman College of Public Health Baysari, Melissa; The University of Sydney Faculty of Medicine and Health, Discipline of Biomedical Informatics and Digital Health, Charles Perkins Centre Gray, Len; The University of Queensland, Centre for Research in Geriatric Medicine Day, Richard; University of New South Wales, St Vincent's Clinical School Ratcliffe, Julie; Flinders University of South Australia; University of New South Wales, School of Public health and Community Medicine Georgiou, A; Macquarie University, Centre for Health Systems and Safety Research, Australian Institute of Health Innovation Braithwaite, Jeffrey; Macquarie University, Centre for HealthCare Resilience and Implementation Science, Australian Institute of Health Innovation; ISQua Raban, Magdalena; Macquarie University, Centre for Health Systems and Safety Research, Australian Institute of Health Innovation Close, Jacqueline; Neuroscience Research Australia Beattie, Elizabeth; Queensland University of Technology, School of Nursing Zheng, Wu Yi; Black Dog Institute Debono, Deborah; University of Technology Sydney, School of Public Health, Faculty of Health Nguyen, A; Macquarie University, Centre for Health Systems and Safety Research, Australian Institute of Health Innovation Siette, Joyce; Macquarie University, Centre for Health Systems and Safety Research, Australian Institute of Health Innovation Siette, Joyce; Macquarie University, Centre for Health Systems and Safety Research, Australian Institute of Health Innovation Siette, Joyce; Macquarie University, Cent

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A dashboard of predictive analytics and decision support to drive care quality and client outcomes in aged care: A mixed-methods study protocol

Kristiana Ludlow<sup>\*1</sup>, Johanna Westbrook<sup>1</sup>, Mikaela Jorgensen<sup>1</sup>, Kimberly E. Lind<sup>2</sup>, Melissa Baysari<sup>3</sup>, Leonard C. Gray<sup>4</sup>, Richard Day<sup>5</sup>, Julie Ratcliffe<sup>6</sup>, Stephen R. Lord<sup>7,8</sup>, Andrew Georgiou<sup>1</sup>, Jeffrey Braithwaite<sup>9,10</sup>, Magdalena Z. Raban<sup>1</sup>, Jacqueline Close<sup>7</sup>, Elizabeth Beattie<sup>11</sup>, Wu Yi Zheng<sup>12</sup>, Deborah Debono<sup>13</sup>, Amy D. Nguyen<sup>1</sup>, Joyce Siette<sup>1</sup>, Karla Seaman<sup>1</sup>, Melissa Miao<sup>14</sup>, Jo Root<sup>15</sup>, David Roffe<sup>16</sup>, Libby O'Toole<sup>17</sup>, Marcela Carrasco<sup>18</sup>, Alex Thompson<sup>18</sup>, Javed Shaikh<sup>18</sup>, Jeffrey Wong<sup>18</sup>, Cynthia Stanton<sup>19</sup>, Rebecca Haddock<sup>20</sup>

<sup>1</sup>Centre for Health Systems and Safety Research, Australian Institute of Health Innovation, Macquarie University, Sydney, Australia

<sup>2</sup> Department of Health Promotion Sciences, Mel & Enid Zuckerman College of Public Health, The University of Arizona, Tucson, AZ, United States of America

<sup>3</sup> Discipline of Biomedical Informatics and Digital Health, Charles Perkins Centre, Faculty of Medicine and Health, The University of Sydney

<sup>4</sup> Centre for Health Services Research, University of Queensland, Brisbane, Australia

<sup>5</sup> St Vincent's Clinical School, University of New South Wales, Sydney, Australia

<sup>6</sup>College of Nursing and Health Sciences, Flinders University, Adelaide, Australia

<sup>7</sup>Neuroscience Research Australia, Sydney, Australia

<sup>8</sup> School of Public health and Community Medicine, University of New South Wales, Sydney, Australia

<sup>9</sup>Centre for Healthcare Resilience and Implementation Science, Australian Institute of Health Innovation, Macquarie University, Sydney, Australia

<sup>10</sup> The International Society for Quality in Health Care, Dublin, Ireland

<sup>11</sup> School of Nursing, Queensland University of Technology, Brisbane, Australia

<sup>12</sup> Black Dog Institute, Sydney, Australia

<sup>13</sup> School of Public Health, Faculty of Health, University of Technology Sydney, Sydney,

Australia

<sup>14</sup> Graduate School of Health, University of Technology Sydney, Sydney, Australia

<sup>15</sup> Consumers Health Forum of Australia, Deakin, Australia

<sup>16</sup> IT consultant

<sup>17</sup> Aged Care Quality and Safety Commission, Sydney, Australia

<sup>18</sup> Anglicare, Sydney, Australia

<sup>19</sup> Sydney North Health Network, Sydney, Australia

<sup>20</sup> Deeble Institute for Health Policy Research, Australian Healthcare and Hospitals

Association, Canberra, Australia

\* Corresponding author details:

Address: Level 6, 75 Talavera Road, Macquarie University, NSW 2109, Australia; email: kristiana.ludlow@mq.edu.au

#### **KEYWORDS**

Health informatics; Information technology; Health & Safety; Quality in Health care; Risk Management; Geriatric Medicine

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#### ABSTRACT

### Introduction

There is a clear need for improved care quality and quality monitoring in aged care. Aged care providers collect an abundance of data, yet rarely are these data integrated and transformed in real-time into actionable information to support the provision of evidence-based care, nor shared with older people and their informal caregivers. This protocol describes the design and testing of a dashboard, for both residential and community-based aged care settings, comprising integrated information to provide an 'at-a-glance' overview of individuals receiving care, indicators to identify clients at risk of fall-related hospitalisations and poor quality of life, and evidence-based decision support to minimise these risks. Longer-term plans for dashboard implementation and evaluation are also outlined.

#### Methods

This mixed-methods study will involve (i) co-designing dashboard features with users including aged care staff, clients, informal caregivers and general practitioners (GPs), (ii) integrating aged care data silos and developing risk models, and (iii) testing a dashboard prototype with users. The dashboard features will be informed by direct observations of routine work, interviews and focus groups with users, and a community forum. Multivariable discrete time survival models will be used to develop risk indicators, using predictors from linked historical aged care and hospital data. Dashboard prototype testing will comprise interviews, focus groups and walk-through scenarios using a think-aloud approach with staff members, clients and informal caregivers, and a GP workshop.

## Ethics and dissemination

This study has received ethical approval from the NSW Population & Health Services Research Ethics Committee and [University name blinded for peer-review] The findings of this research project will be presented to the aged care provider who will share results with staff members, clients and their informal caregivers. Findings will also be disseminated as peer-reviewed journal articles, policy briefs, conference presentations, and discussions with policymakers and advocacy networks.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- The linkage of multiple data sources will allow for comprehensive information about aged care clients' health conditions, psychosocial characteristics, care management, hospitalisations, and quality of life.
- The dashboard's use of existing routinely collected data will enable the prediction of risk, and provide evidence-based guidance, in real-time.
- To ensure that the dashboard is fit-for-purpose, intended users (staff, aged care clients, informal caregivers, general practitioners) will be involved in the co-design and testing of the dashboard.
- The dashboard will be designed to have generic characteristics which will allow it to be embedded into existing aged care information technology to facilitate its transferability and sustainability.
- Most aged care services in this study will be located in major cities, therefore, findings will be limited in regional and remote areas, where client profiles and staff workflows could be different.

#### INTRODUCTION

Good quality care relies upon the availability of good quality data and real-time analytics to support decision-making. This is particularly the case for older people with complex health needs who are supported by a wide-range of people in different settings. Aged care services have not been well served by information systems that support everyday care provision. Internationally, there is consistent evidence that aged care systems are struggling to provide high quality services for older adults, with shortcomings highlighted by many recent reviews, reports and research.<sup>1-5</sup> The delivery of optimal care is hindered by a lack of integration between aged care and other healthcare services, fragmented funding systems, inadequate infrastructure, insufficient workforce training and support, and a widening gap between supply and demand of services.<sup>6</sup>

In Australia, concerns about suboptimal care and escalating pressure on aged care services has led to more than 40 major inquires and reviews over the past 40 years,<sup>7</sup> the latest being the Royal Commission into Aged Care Quality and Safety (2018-20). The purpose of the Royal Commission is to examine the current state of the aged care system and determine what is needed to improve it for those receiving care now and into the future.<sup>18</sup> Interim findings have made it clear that the community is demanding better quality aged care and greater transparency: a system that meets older peoples' needs, identifies when they are at risk, and responds in effective and compassionate ways.<sup>19</sup>

Despite enormous amounts of data collected in the sector, there continues to be considerable problems for informal caregivers, providers, and governments to obtain meaningful information to allow the monitoring of care delivery and outcomes, and to guide effective decision-making.<sup>1</sup> The increasing use of electronic systems provides an opportunity to address some of these shortcomings. The World Health Organization's World Report on Ageing and Health identified information and communication technologies (ICT) as a

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"critical tool for transforming health systems and services to deliver person-centred and integrated care that is appropriate to older people".<sup>6(p. 109)</sup> The report outlines some of the anticipated and demonstrated benefits of utilising ICT in terms of access to services, quality and safety of care, cost effectiveness of services, accessibility of information and knowledge, social care and connectedness, and the provision of evidence-based care.<sup>6</sup>

#### Data rich but information poor

While the last decade has seen substantial uptake of ICT by aged care sectors internationally,<sup>10</sup> the potential of these systems to transform care quality by increasing the usability and transparency of aged care information remains largely unrealised.<sup>10</sup> Health and aged care systems are often characterised as *'data rich but information poor'*,<sup>11 12</sup> meaning that although providers collect vast amounts of clinical and care management data, these data frequently exist within silos that are rarely integrated to create meaningful information or knowledge to support care staff to coordinate, monitor and enhance care delivery. In Australia, these information silos are often driven by variations in funding and ownership of data (e.g., between aged care and healthcare, or between State and Federal governments). Furthermore, these data are not often shared with the people who are the subject of data collection (i.e., those receiving services and their informal caregivers) or with the general public who largely fund aged care services through tax contributions.

Data have traditionally been used for reporting purposes rather than quality improvement activities or driving care processes. Several countries have mandated systems for collecting and reporting aged care information,<sup>13</sup> for example, the Home Care Reporting System and Continuing Care Reporting System in Canada, the United States' MDS 3.0 and Nursing Home Compare, Sweden's Open Comparisons national quality monitoring system, and the International Resident Assessment Instrument Long-Term Care Facility (interRAI-

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LTCF) Assessment System in New Zealand. Australia's aged care system lags behind other Organisation for Economic Co-operation and Development (OECD) countries in terms of measuring and reporting on aged care quality.<sup>14</sup> For example, Australia's National Aged Care Mandatory Quality Indicator Program,<sup>15</sup> operating since 2019, collects information on three quality indicators (physical restraint use, pressure ulcers and weight loss) in residential aged care settings (also known as assisted living facilities, nursing homes, long-term care facilities, and skilled nursing facilities). The aggregated data that are publicly reported for this program allow comparisons to be made between providers at this time. Additional quality indicators for falls and major injury, and medication management are being introduced to the program in 2021. Currently, there is no system for mandatory reporting of quality indicators in community care settings (i.e., formal aged care services provided in the home and community). Limited and disparate information on the quality of aged care in Australia reduces the capacity for older adults and their caregivers to make informed decisions about their care. Without this information, providers are limited in their ability to monitor and benchmark key quality indicators across services, initiate improvement activities, and systematically and iteratively assess the effectiveness and cost-effectiveness of services and interventions.

## Predictive risk models

Very little attention has been placed on the power of new analytic models to exploit the increasing volume of data that are stored in aged care IT systems. Initial research to capitalise on this valuable information source has focused on retrospective and descriptive analyses.<sup>16 17</sup> This foundational research has demonstrated the potential value of these data to better understand quality of care issues.<sup>18-20</sup> Further, this work has shown that it is possible to create automated risk-adjusted indicators of client care and outcomes by linking existing

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administrative, clinical and care management datasets routinely collected by providers.<sup>21 22</sup> A number of studies in the acute care sector have shown the possibilities of leveraging electronic data systems to implement real-time predictive risk models.<sup>23-26</sup> These models have been used to identify clients who are at risk of adverse events earlier and facilitate the uptake of tailored evidence-based strategies by time-poor staff.<sup>27-30</sup>

## Dashboards

Dashboards offer promise in integrating multiple data sources and supporting the use of predictive analytics to improve client care. They allow for a single-view summary of an individual's information and can provide decision-related information using text and visual features. These summaries can be dynamic; reflecting changes in clinical environments and a person's information in real-time. Dashboards typically utilise graphical information displays and colour, allowing users to easily interact with and explore important information. Dashboards may include features that alert users to areas requiring attention, such as deteriorating patients or those at high risk of injury or harm and provide support tools to guide staff members' responses to alerts. These features allow for the quick and targeted communication of information, helping reduce the cognitive effort of the user and enabling them to make informed decisions effectively and efficiently (Figure 1).

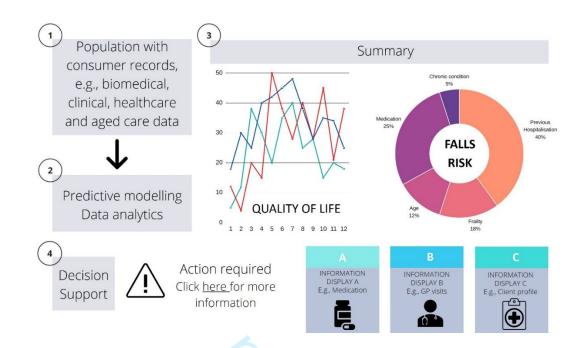


Figure 1: Example of a dashboard to predict risk and deliver actionable information

Dashboards have predominantly been implemented and evaluated in primary, acute and mental health care.<sup>31-33</sup> In these settings, dashboards have been shown to improve clinician situational awareness, decision-making, and guideline adherence, positively affecting outcomes such as mortality.<sup>31 34</sup> At an organisational-level, dashboards can improve the detection of overdue tasks, procedural bottlenecks, and support better resource allocation.<sup>34</sup> At the client-level, they have the potential to make meaningful information accessible to clients and their families, placing individuals at the centre of their own information and care.

Dashboards are less commonly used in aged care settings, and this setting may encounter specific challenges with uptake and use due to poor ICT infrastructure and support services, and a workforce with lower computer experience and digital literacy skills than found in acute care settings.<sup>35 36</sup> Co-design is an important strategy to deliver interventions which take account of contextual factors and to facilitate ownership of interventions, and motivate uptake and user satisfaction.<sup>31 36</sup> To ensure that dashboards are tailored to the skills,

needs and preferences of their users, as well as available resources, rigorous assessment and evaluation of dashboard design, use and work-integration are necessary.

#### Rationale

[Organisation name blinded for peer-review], a large non-profit aged care provider located in New South Wales (NSW), Australia, identified the critical need for leveraging their electronic systems to support evidence-based practice across their services. [Organisation name blinded for peer-review] is partnering with [Organisations' names blinded for peerreview] to design, develop, implement and evaluate an interactive dashboard comprising integrated client information, risk indicators and decision support. This dashboard is intended to be used by [Organisation name blinded for peer-review] staff (e.g., registered nurses, care workers, care advisors, managers), clients, informal caregivers, and general practitioners (GPs) providing services to [Organisation name blinded for peer-review] clients, collectively referred to as 'users'. It is expected that the dashboard will be used to identify and support older adults at risk of poor outcomes in residential aged care facilities and community-based aged care. The dashboard will be iteratively co-designed and evaluated with stakeholders to (i) allow care managers to monitor robust real-time indicators of care quality, (ii) support staff members and GPs to obtain a client overview 'at-a-glance' and make evidence-based decisions about their care, and (iii) provide timely, meaningful information to older persons and their families.

#### Priority aged care challenges

Risk indicators will initially target two priority aged care challenges relevant to both residential- and community-based care populations: (i) hospital-related falls; and (ii) Quality of Life (QoL).

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(i) Falls are a major cause of harm to older Australians, experienced by more than a third of adults aged  $\geq 65$  every year.<sup>37</sup> In 2014-15 in Australia, over 1.4 million hospital days were attributable to fall-related injuries among older adults,<sup>38</sup> costing >\$500 million AUD.<sup>39</sup> Falls are the cause of 92% of injury hospitalisations among aged care residents.<sup>40</sup> Identifying those at risk is the starting point to improve falls management. However, falls risk tools currently in use are stand-alone assessments that are rarely integrated with dynamic information about an individual's risk, such as changes in medications or health following a hospitalisation.<sup>41</sup>

(ii) QoL has been recognised by international peak health and healthcare organisations as an important aspect of active ageing and quality care in long-term care settings.<sup>6 42 43</sup> Older Australians report QoL as a central goal for aged care.<sup>44</sup> While research on the relationships between QoL and clinical outcomes in aged care settings is sparse, some evidence suggests that lower QoL scores are associated with poorer clinical outcomes in residential aged care clients.<sup>45-47</sup> Alongside the increased recognition of the importance of QoL for older adults, valid and reliable QoL tools have recently been developed, including those suitable for use by people with dementia.<sup>45 48-53</sup> Currently, reporting on QoL in Australian aged care is not mandatory, and while recent national policy requires community care providers to report on client wellness,<sup>54</sup> relatively little is known about modifiable factors contributing to QoL in aged care.

These two exemplar indicators will serve as an initial model to test embedding risk indicators in an electronic dashboard within aged care settings. Other indicators may be added during the study in response to feedback from users.

# Study aim

The aim of this study is to describe the design and testing of a dashboard in residential and community-based aged care settings, and to outline longer-term plans for dashboard implementation and evaluation.

# METHODS AND ANALYSIS

# Study design

The research comprises three components: 1. Co-design of the digital dashboard with users; 2. Integration of data sources and development of risk models; and 3. Dashboard prototype testing with users. The processes and data sources for each component are summarised in Figure 2. The study gained ethics approval in December 2019, with data collection commencing April 2020.

	1. Dashboard co-design	2. Data integration and risk models	3. Prototype testing
Processes	<ul> <li>Investigate users' needs and preferences</li> <li>Receive feedback from users on dashboard prototype</li> </ul>	<ul> <li>Integrate siloed aged care data sources</li> <li>Develop and validate risk models using linked health and aged care data</li> </ul>	• Conduct usability testing with users
Data sources	<ul> <li>Observations of routine work</li> <li>Interviews</li> <li>Focus groups</li> <li>Workshop</li> <li>Community forum</li> </ul>	<ul> <li>[Blinded for review] client records</li> <li>NSW EDDC</li> <li>NSW APDC</li> <li>NSW RBDM</li> </ul>	<ul> <li>Think-aloud task- based scenario walkthroughs</li> <li>Follow-up interviews/focus groups</li> </ul>

NSW=New South Wales; EDDC=Emergency Department Data Collection; APDC=Admitted Patient Data

Collection; RBDM=Registry of Births, Deaths and Marriages registries

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#### Figure 2: Overview of study design: components, processes, and data sources

## **Study population**

[Organisation name blinded for peer-review] provides a variety of support services across the life span, including aged care, mental health services, palliative care, and family support. This study involves [Organisation name blinded for peer-review] 23 residential aged care facilities, and their community-based aged care service outlets which provide services to older people in their homes. The risk modelling and data integration component of this study will include data about all of [Organisation name blinded for peer-review] residential and community care clients over the previous five years (1 July 2014 - 31 December 2019, n=~14,800). The co-design and prototype testing components will involve samples drawn from [Organisation name blinded for peer-review] staff members (registered nurses, care workers, care managers), clients, informal caregivers and GPs.

#### Methods and analysis

#### Component 1: Co-design of the digital dashboard with users

The design of the dashboard will draw on existing literature in human factors design and evaluation, evidence of features of effective dashboards, and input from users. A multi-method approach will be taken to investigate users' needs and preferences, and to examine how the dashboard could be integrated into everyday practices. This will include:

- Direct observations of staff members' routine work interactions including type, location and duration of activities. Observations will be conducted unobtrusively (e.g., at a distance).
- Interviews and focus groups with staff members to elicit their perspectives on core

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information to be included in the dashboard, dashboard features (e.g., presentation of information and inclusion of decision support tools), how decision-making guidance for the target priority areas (hospital-related falls and QoL) could be of value, and work processes or challenges garnered from the direct observations.

- Interviews and focus groups with aged care clients and informal caregivers to explore their preferences and experiences relating to access to medical and aged care information, involvement in decision-making, and use of technology. To better understand how clients and their informal caregivers would like healthcare and aged care information communicated, they will also be asked for their opinions on potential dashboard features, information to be included in the dashboard, and the dashboard's presentation of client information.
- Interviews with GPs focusing on how the dashboard could support improved communication between aged care and primary care. This will include, for example, discussion of current processes and difficulties experienced in the transfer of information between aged care facilities and GP practice records. Exploration of GP use of decision support tools will also occur.
- Working groups with users (staff members, GPs, clients and informal caregivers) to develop the decision support for the risk indicators will be established. The decision support will comprise evidence-based information on actions to be taken when clients are identified as at risk.
- Mock-ups of the dashboard prototype will be presented to staff members, clients and informal caregivers during focus groups and a community forum, to seek feedback that will guide revisions of the dashboard. GPs feedback on the mock-ups will be sought though a working group. As the dashboard is intended for different users, the presentation of information, dashboard features and evidence-based decision support

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will be tailored towards each user group and therefore, mock-ups will be user-specific. Users' feedback will provide insights into their perspectives of the prototype design, functionality and modifications needed.

Qualitative data from the focus groups, interviews and workshop will be analysed using a structured content analysis approach.<sup>55 56</sup> A critical realist approach, a structured method for examining for whom and under what circumstances interventions work, will be applied. The influence of subjectivity and the social context on data collection and analysis will be acknowledged. Data analysis will be conducted in NVivo version 12.<sup>57</sup> Two researchers will perform the initial coding of these data, producing a list of codes which will then be reviewed by the research team. Any discrepancies in coding will be discussed and used to modify the list of codes until the research team agrees on code application. The codes will then be sorted into preliminary domains and themes, which will be repeatedly reviewed and refined to maximise homogeneity prior to developing an analytic narrative. Data from the observation sessions will be descriptively analysed for time spent on different activities, interactions with people, tools and other methods used to complete tasks, and rate of interruptions.

## Component 2: Integration of data sources and development of risk models

Building upon the feedback from users in component 1, we will develop a list of information items that will be used to populate the dashboard, based on the data available from [Organisation name blinded for peer-review] sources (Table 1). Two exemplar risk models, one for each priority area, will be developed through the linkage of available historical [Organisation name blinded for peer-review] client records with data from the NSW Emergency Department Data Collection (EDDC), the NSW Admitted Patient Data Collection (APDC) and the NSW Registry of Births, Deaths and Marriages (RBDM) registries (see Table 1 for descriptions of data sources). Data will be extracted for all [Organisation name blinded

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for peer-review] residential and community care clients over the previous 5 years. Hospital data for these clients will be requested from the data custodians of the NSW EDDC, the NSW APDC and the NSW RBDM death registrations. The Centre for Health Record Linkage (CHeReL) will conduct the data linkage in order to allow preservation of individual confidentiality as data custodians supply only personal identifiers to CHeReL without clinical data. Only clinical data without personal identifiers will be supplied to researchers.

Candidate variables to be evaluated as predictors will be based on existing literature and the extracted data from [Organisation name blinded for peer-review] client records (see Table 1). Multivariable discrete time survival (DTS) modelling will be used.<sup>58 59</sup> A rounded score for each risk factor in the final model will be calculated by dividing the regression coefficient of each covariate by the lowest coefficient in the model. This allows for total risk scores to be calculated for each person by summing the scores for each present risk factor. Risk models will be internally validated using bootstrap resampling.

Data source	Description
Aged care client	This electronic health and care management information system
records	includes client demographic information, clinical data, client needs
	data, service and activity data, medications administered, social
	factors, and QoL measures.
EDDC	This collection provides information about patient presentations to the
	emergency departments of public hospitals in NSW, such as admission
	and separation dates, mode of separation, referral source, triage
	category and diagnoses.

Table 1: Data sources for project component 1 risk models

APDC	This collection records all admitted patient services provided by NSW
	public hospitals, public psychiatric hospitals, public multi-purpose
	services, private hospitals, and private day procedures centres. Data
	includes admission and separation dates, demographics, mode of
	separation, diagnosis and procedures.
RBDM	This dataset contains date and cause of death information for deaths

registrations occurring in NSW.

NSW=New South Wales; EDDC= NSW Emergency Department Data Collection; APDC= Admitted Patient Data Collection; RBDM=Registry of Births, Deaths and Marriages registries

## Component 3: Dashboard prototype testing

User-specific prototypes of the dashboard will be created by a specialist IT programmer and [Organisation name blinded for peer-review] IT staff using and adapting modifiable modules within [Organisation name blinded for peer-review] existing infrastructure. Client health and care information, along with the risk models, will be integrated into the dashboard to a) provide an overview of clients' information (e.g., current medications) and b) alert users to changes in clients' risk levels for the two priority risk indicators in real-time. Each indicator will be accompanied by evidence-based decision guidance to direct actions in response the level of risk identified.

To test the dashboard prototype, staff members will be guided through task-based scenario 'walk-throughs' with a think-aloud approach.<sup>60</sup> Subsequent follow-up interviews or focus groups will be conducted to explore staff members' perceptions of the dashboard and alignment with workflow. Clients and informal caregivers will also engage in scenario walk-throughs, along with follow-up interviews or focus groups to elicit their views on their use of the dashboard. Qualitative data from the think-aloud activity and interviews will be analysed

using the same methods as Component 2.

#### Longer-term plans for dashboard implementation and evaluation

While the wide-spread implementation and evaluation of the dashboard are not the focus of this protocol, a broad overview of an anticipated large-scale trial to investigate the scalability and effectiveness is outlined below. Once the dashboard has been revised in line with the findings from prototype testing, a hybrid stepped-wedge cluster randomised controlled trial will be carried out. This will involve implementing the dashboard in 12 [Organisation name blinded for peer-review] residential facilities and 12 community care units, with two residential aged care facilities and two community care units randomly selected for dashboard implementation each month for six months. The remaining facilities and community units will continue with usual care until the end of the trial. Implementation processes will utilise [Organisation name blinded for peer-review] staff training mechanisms and provide workshops for staff and clients/informal caregivers on dashboard purpose and use, using practical examples and incorporating behaviour change principles to support both intervention fidelity and effectiveness. As part of the randomised controlled trial, process evaluation will be conducted to identify barriers and facilitators to dashboard use, and economic evaluations to assess resource use and costs associated with the development and implementation of the dashboard will be undertaken.

#### Patient and public involvement

This research centres on the philosophy that users are *co-creators of* the research rather than *participants in* the research.<sup>61 62</sup> The project proposal was co-designed from inception with key [Organisation name blinded for peer-review] staff in a series of workshops starting in

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December 2017. In order to ensure that the research will have meaningful and real-world applications, users (staff, aged care clients, informal caregivers, and GPs) will continue to have strong engagement across the various stages of the research.<sup>61</sup> We aim to elicit users' expert knowledge, preferences and experiences through a range of methods, namely, interviews, observations, focus groups, workshops and forums. This feedback will be used to guide development of the dashboard, facilitate its implementation, and inform future evaluations of the intervention. Relevant stakeholders including [Organisation name blinded for peer-review] representatives and users will be included in publications arising from this research to ensure appropriate interpretation of findings.<sup>61</sup>

## ETHICS AND DISSEMINATION

This study has received ethical approval from the NSW Population & Health Services Research Ethics Committee [Details blinded for peer-review] and the [University name and details blinded for peer-review]. The findings of this research project will be disseminated as peer-reviewed journal articles and as presentations at national and international conferences, seminars and workshops. [Organisation name blinded for peer-review], will play a valuable role to support policy translation using their extensive advocacy networks across health policy portfolios. Research findings will be disseminated though policy briefs and regular meetings with parliamentary staff and policy-makers. Utilising the partnership with [Organisation name blinded for peer-review], findings will be relayed back to [Organisation name blinded for peer-review] to inform decisions, and their networks will be used to present findings to clients and their informal caregivers in newsletters.

#### CONCLUSIONS

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> This protocol outlines the design and testing of a predictive analytic dashboard for use in residential- and community-based aged care settings. The dashboard will allow care providers to detect changes in clients' risk levels and will deliver actionable evidence-based information through the decision support function. Identifying at-risk clients earlier is expected to reduce hospital-related falls and improve QoL, two key priority areas for aged care. The dashboard will also allow for the provision of timely and meaningful information to aged care clients and their informal caregivers. It is anticipated that the dashboard will serve as a model for both Australian and international aged care organisations wanting to integrate siloed data and use informatics to facilitate real-time quality monitoring and management of client outcomes. Lessons learned from this project may be applied more broadly to the co-. utilis design of interventions with users, as well as the utilisation of data and IT systems in aged care settings.

## LIST OF ABBREVIATIONS

**AUD** Australian dollars

**APDC** Admitted Patient Data Collection

CHeReL Centre for Health Record Linkage

**EDDC** Emergency Department Data Collection

**GP** General Practitioners

**ICT** Information and communication technologies

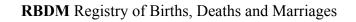
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## NHMRC National Health and Medical Research Council

**NSW** New South Wales

## QoL Quality of Life

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[Blinded for peer-review]

SW-CRCT Stepped-wedge cluster randomised controlled trial

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## DECLARATIONS

## **Competing interests**

The authors declare that they have no competing interests.

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## Authors' contributions

This protocol was based on a successful funding application prepared by the chief investigators JW, MB, LCG, RD, JR, SRL, AG and JB with input from the associate investigators (MZR, JC, EB, WYZ, DD, JR, DR), staff from the aged care partner organisation (MC, AT, JS, JW), research partners (LO, CS, RH) and members of the project team working on the research (KL, MJ, KEL, AND, JS, KS, MM). KL drafted the protocol and all authors contributed to reviewing and approving the final version.

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# **BMJ Open**

## Co-designing a dashboard of predictive analytics and decision support to drive care quality and client outcomes in aged care: A mixed-methods study protocol

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#### **BMJ** Open

Co-designing a dashboard of predictive analytics and decision support to drive care quality and client outcomes in aged care: A mixed-methods study protocol

Kristiana Ludlow<sup>\*1</sup>, Johanna Westbrook<sup>1</sup>, Mikaela Jorgensen<sup>1</sup>, Kimberly E. Lind<sup>2</sup>, Melissa Baysari<sup>3</sup>, Leonard C. Gray<sup>4</sup>, Richard Day<sup>5</sup>, Julie Ratcliffe<sup>6</sup>, Stephen R. Lord<sup>7,8</sup>, Andrew Georgiou<sup>1</sup>, Jeffrey Braithwaite<sup>9,10</sup>, Magdalena Z. Raban<sup>1</sup>, Jacqueline Close<sup>7</sup>, Elizabeth Beattie<sup>11</sup>, Wu Yi Zheng<sup>12</sup>, Deborah Debono<sup>13</sup>, Amy D. Nguyen<sup>1,5</sup>, Joyce Siette<sup>1</sup>, Karla Seaman<sup>1</sup>, Melissa Miao<sup>14</sup>, Jo Root<sup>15</sup>, David Roffe<sup>16</sup>, Libby O'Toole<sup>17</sup>, Marcela Carrasco<sup>18</sup>, Alex Thompson<sup>18</sup>, Javed Shaikh<sup>18</sup>, Jeffrey Wong<sup>18</sup>, Cynthia Stanton<sup>19</sup>, Rebecca Haddock<sup>20</sup>

<sup>1</sup>Centre for Health Systems and Safety Research, Australian Institute of Health Innovation, Macquarie University, Sydney, Australia

<sup>2</sup> Department of Health Promotion Sciences, Mel & Enid Zuckerman College of Public Health, The University of Arizona, Tucson, AZ, United States of America

<sup>3</sup> Discipline of Biomedical Informatics and Digital Health, Charles Perkins Centre, Faculty of Medicine and Health, The University of Sydney

<sup>4</sup> Centre for Health Services Research, University of Queensland, Brisbane, Australia

<sup>5</sup> St Vincent's Clinical School, University of New South Wales, Sydney, Australia

<sup>6</sup>College of Nursing and Health Sciences, Flinders University, Adelaide, Australia

<sup>7</sup>Neuroscience Research Australia, Sydney, Australia

<sup>8</sup> School of Public health and Community Medicine, University of New South Wales, Sydney, Australia

<sup>9</sup>Centre for Healthcare Resilience and Implementation Science, Australian Institute of Health Innovation, Macquarie University, Sydney, Australia

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<sup>10</sup> The International Society for Quality in Health Care, Dublin, Ireland

<sup>11</sup> School of Nursing, Queensland University of Technology, Brisbane, Australia

<sup>12</sup> Black Dog Institute, Sydney, Australia

<sup>13</sup> School of Public Health, Faculty of Health, University of Technology Sydney, Sydney,

Australia

<sup>14</sup> Graduate School of Health, Faculty of Health, University of Technology Sydney, Sydney,

Australia

<sup>15</sup> Consumers Health Forum of Australia, Deakin, Australia

<sup>16</sup> IT consultant

<sup>17</sup> Aged Care Quality and Safety Commission, Sydney, Australia

<sup>18</sup> Anglicare, Sydney, Australia

<sup>19</sup> Sydney North Health Network, Sydney, Australia

<sup>20</sup> Deeble Institute for Health Policy Research, Australian Healthcare and Hospitals

Association, Canberra, Australia

\* Corresponding author details:

Address: Level 6, 75 Talavera Road, Macquarie University, NSW 2109, Australia; email:

kristiana.ludlow@mq.edu.au

## **KEYWORDS**

Health informatics; Information technology; Health & Safety; Quality in Health care; Risk Management; Geriatric Medicine

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#### ABSTRACT

#### Introduction

There is a clear need for improved care quality and quality monitoring in aged care. Aged care providers collect an abundance of data, yet rarely are these data integrated and transformed in real-time into actionable information to support the provision of evidence-based care, nor shared with older people and their informal caregivers. This protocol describes the co-design and testing of a dashboard, for both residential and community-based aged care settings, comprising integrated information to provide an 'at-a-glance' overview of individuals receiving care, indicators to identify clients at risk of fall-related hospitalisations and poor quality of life, and evidence-based decision support to minimise these risks. Longer-term plans for dashboard implementation and evaluation are also outlined.

## Methods

This mixed-methods study will involve (i) co-designing dashboard features with users including aged care staff, clients, informal caregivers and general practitioners (GPs), (ii) integrating aged care data silos and developing risk models, and (iii) testing a dashboard prototype with users. The dashboard features will be informed by direct observations of routine work, interviews and focus groups with users, and a community forum. Multivariable discrete time survival models will be used to develop risk indicators, using predictors from linked historical aged care and hospital data. Dashboard prototype testing will comprise interviews, focus groups and walk-through scenarios using a think-aloud approach with staff members, clients and informal caregivers, and a GP workshop.

## Ethics and dissemination

This study has received ethical approval from the NSW Population & Health Services

Research Ethics Committee and Macquarie University's Human Research Ethics Committee. The findings of this research project will be presented to the aged care provider who will share results with staff members, clients and their informal caregivers. Findings will also be disseminated as peer-reviewed journal articles, policy briefs, conference presentations, and discussions with policymakers and advocacy networks.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- The linkage of multiple data sources will allow for comprehensive information about aged care clients' health conditions, psychosocial characteristics, care management, hospitalisations, and quality of life.
- The dashboard's use of existing routinely collected data will enable the prediction of risk, and provide evidence-based guidance, in real-time.
- To ensure that the dashboard is fit-for-purpose, the dashboard will be co-designed and tested with intended users (staff, aged care clients, informal caregivers, general practitioners).
- The dashboard will be designed to have generic characteristics which will allow it to be embedded into existing aged care information technology to facilitate its transferability and sustainability.
- Most aged care services in this study will be located in major cities, therefore, findings will be limited in regional and remote areas, where client profiles and staff workflows could be different.

#### **INTRODUCTION**

Good quality care relies upon the availability of good quality data and real-time analytics to support decision-making. This is particularly the case for older people with complex health needs who are supported by a wide-range of people in different settings. Aged care services have not been well served by information systems that support everyday care provision. Internationally, there is consistent evidence that aged care systems are struggling to provide high quality services for older adults, with shortcomings highlighted by many recent reviews, reports and research.<sup>1-5</sup> The delivery of optimal care is hindered by a lack of integration between aged care and other healthcare services, fragmented funding systems, inadequate infrastructure, insufficient workforce training and support, and a widening gap between supply and demand of services.<sup>6</sup>

In Australia, concerns about suboptimal care and escalating pressure on aged care services has led to more than 40 major inquires and reviews over the past 40 years,<sup>7</sup> the latest being the Royal Commission into Aged Care Quality and Safety (2018-20). The purpose of the Royal Commission is to examine the current state of the aged care system and determine what is needed to improve it for those receiving care now and into the future.<sup>18</sup> Interim findings have made it clear that the community is demanding better quality aged care and greater transparency: a system that meets older peoples' needs, identifies when they are at risk, and responds in effective and compassionate ways.<sup>19</sup>

Despite enormous amounts of data collected in the sector, there continues to be considerable problems for informal caregivers, providers, and governments to obtain meaningful information to allow the monitoring of care delivery and outcomes, and to guide effective decision-making.<sup>1</sup> The increasing use of electronic systems provides an opportunity to address some of these shortcomings. The World Health Organization's World Report on

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Ageing and Health identified information and communication technologies (ICT) as a "critical tool for transforming health systems and services to deliver person-centred and integrated care that is appropriate to older people".<sup>6(p. 109)</sup> The report outlines some of the anticipated and demonstrated benefits of utilising ICT in terms of access to services, quality and safety of care, cost effectiveness of services, accessibility of information and knowledge, social care and connectedness, and the provision of evidence-based care.<sup>6</sup>

## Data rich but information poor

While the last decade has seen substantial uptake of ICT by aged care sectors internationally,<sup>10</sup> the potential of these systems to transform care quality by increasing the usability and transparency of aged care information remains largely unrealised.<sup>10</sup> Health and aged care systems are often characterised as *'data rich but information poor'*,<sup>11 12</sup> meaning that although providers collect vast amounts of clinical and care management data, these data frequently exist within silos that are rarely integrated to create meaningful information or knowledge to support care staff to coordinate, monitor and enhance care delivery. In Australia, these information silos are often driven by variations in funding and ownership of data (e.g., between aged care and healthcare, or between State and Federal governments). Furthermore, these data are not often shared with the people who are the subject of data collection (i.e., those receiving services and their informal caregivers) or with the general public who largely fund aged care services through tax contributions.

Data have traditionally been used for reporting purposes rather than quality improvement activities or driving care processes. Several countries have mandated systems for collecting and reporting aged care information,<sup>13</sup> for example, the Home Care Reporting System and Continuing Care Reporting System in Canada, the United States' MDS 3.0 and Nursing Home Compare, Sweden's Open Comparisons national quality monitoring system,

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and the International Resident Assessment Instrument Long-Term Care Facility (interRAI-LTCF) Assessment System in New Zealand. Australia's aged care system lags behind other Organisation for Economic Co-operation and Development (OECD) countries in terms of measuring and reporting on aged care quality.<sup>14</sup> For example, Australia's National Aged Care Mandatory Quality Indicator Program,<sup>15</sup> operating since 2019, collects information on three quality indicators (physical restraint use, pressure ulcers and weight loss) in residential aged care settings (also known as assisted living facilities, nursing homes, long-term care facilities, and skilled nursing facilities). The aggregated data that are publicly reported for this program allow comparisons to be made between providers at this time. Additional quality indicators for falls and major injury, and medication management are being introduced to the program in 2021. Currently, there is no system for mandatory reporting of quality indicators in community aged care settings (i.e., formal aged care services provided in the home and community). Limited and disparate information on the quality of aged care in Australia reduces the capacity for older adults and their caregivers to make informed decisions about their care. Without this information, providers are limited in their ability to monitor and benchmark key quality indicators across services, initiate improvement activities, and systematically and iteratively assess the effectiveness and cost-effectiveness of services and interventions.

## **Predictive risk models**

Very little attention has been placed on the power of new analytic models to exploit the increasing volume of data that are stored in aged care IT systems. Initial research to capitalise on this valuable information source has focused on retrospective and descriptive analyses.<sup>16 17</sup> This foundational research has demonstrated the potential value of these data to better understand quality of care issues.<sup>18-20</sup> Further, this work has shown that it is possible to create

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automated risk-adjusted indicators of client care and outcomes by linking existing administrative, clinical and care management datasets routinely collected by providers.<sup>21 22</sup> A number of studies in the acute care sector have shown the possibilities of leveraging electronic data systems to implement real-time predictive risk models.<sup>23-26</sup> These models have been used to identify clients who are at risk of adverse events earlier and facilitate the uptake of tailored evidence-based strategies by time-poor staff.<sup>27-30</sup>

## Dashboards

 Dashboards offer promise in integrating multiple data sources and supporting the use of predictive analytics to improve client care. They allow for a single-view summary of an individual's information and can provide decision-related information using text and visual features. These summaries can be dynamic; reflecting changes in clinical environments and a person's information in real-time. Dashboards typically utilise graphical information displays and colour, allowing users to easily interact with and explore important information. Dashboards may include features that alert users to areas requiring attention, such as deteriorating patients or those at high risk of injury or harm and provide support tools to guide staff members' responses to alerts. These features allow for the quick and targeted communication of information, helping reduce the cognitive effort of the user and enabling them to make informed decisions effectively and efficiently (Figure 1).

#### <Insert Figure 1 here>

Dashboards have predominantly been implemented and evaluated in primary, acute and mental health care.<sup>31-33</sup> In these settings, dashboards have been shown to improve

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clinician situational awareness, decision-making, and guideline adherence, positively affecting outcomes such as mortality.<sup>31 34</sup> At an organisational-level, dashboards can improve the detection of overdue tasks, procedural bottlenecks, and support better resource allocation.<sup>34</sup> At the client-level, they have the potential to make meaningful information accessible to clients and their families, placing individuals at the centre of their own information and care. Dashboards are less commonly used in aged care settings, and this setting may encounter specific challenges with uptake and use due to poor ICT infrastructure and support services, and a workforce with lower computer experience and digital literacy skills than found in acute care settings.<sup>35 36</sup>

#### Rationale

Anglicare, a large non-profit aged care provider located in New South Wales (NSW), Australia, identified the critical need for leveraging their electronic systems to support evidence-based practice across their services. The Australian Institute of Health Innovation, Macquarie University, is partnering with Anglicare; the Sydney North Health Network (SNHN); the Northern Sydney Local Health District (NSLHD); the Deeble Institute for Health Policy Research, Australian Healthcare and Hospitals Association (AHHA); and the Australian Aged Care Quality and Safety Commission, to design, develop, implement and evaluate an interactive dashboard comprising integrated client information, risk indicators and decision support. This dashboard is intended to be used by Anglicare staff (e.g., registered nurses, care workers, care advisors, managers), clients, informal caregivers, and general practitioners (GPs) providing services to Anglicare clients, collectively referred to as 'users'. It is expected that the dashboard will be used to identify and support older adults at risk of poor outcomes in residential aged care facilities and community-based aged care. The dashboard will be iteratively co-designed and evaluated with stakeholders to (i) allow care managers to monitor robust real-time indicators of care quality, (ii) support staff members and GPs to obtain a client overview 'at-a-glance' and make evidence-based decisions about their care, and (iii) provide timely, meaningful information to older persons and their families.

## Priority aged care challenges

Risk indicators will initially target two priority aged care challenges relevant to both residential- and community-based care populations: (i) hospital-related falls; and (ii) Quality of Life (QoL).

- (i) Falls are a major cause of harm to older Australians, experienced by more than a third of adults aged  $\geq$  65 every year.<sup>37</sup> In 2014-15 in Australia, over 1.4 million hospital days were attributable to fall-related injuries among older adults,<sup>38</sup> costing >\$500 million AUD.<sup>39</sup> Falls are the cause of 92% of injury hospitalisations among aged care residents.<sup>40</sup> Identifying those at risk is the starting point to improve falls management. However, falls risk tools currently in use are stand-alone assessments that are rarely integrated with dynamic information about an individual's risk, such as changes in medications or health following a hospitalisation.<sup>41</sup>
- (ii) QoL has been recognised by international peak health and healthcare organisations as an important aspect of active ageing and quality care in long-term care settings.<sup>6 42 43</sup> Older Australians report QoL as a central goal for aged care.<sup>44</sup> While research on the relationships between QoL and clinical outcomes in aged care settings is sparse, some evidence suggests that lower QoL scores are associated with poorer clinical outcomes in residential aged care clients.<sup>45-47</sup> Alongside the increased recognition of the importance of QoL for older adults, valid and reliable QoL tools have recently been developed, including those

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suitable for use by people with dementia.<sup>45 48-53</sup> Currently, reporting on QoL in Australian aged care is not mandatory, and while recent national policy requires community care providers to report on client wellness,<sup>54</sup> relatively little is known about modifiable factors contributing to QoL in aged care.

These two exemplar indicators will serve as an initial model to test embedding risk indicators in an electronic dashboard within aged care settings. Other indicators may be added during the study in response to feedback from users.

#### **Study aim**

The aim of this study is to describe the co-design and testing of a dashboard in residential and community-based aged care settings, and to outline longer-term plans for dashboard implementation and evaluation. elien

#### **METHODS AND ANALYSIS**

#### **Study design**

The research comprises three components: 1. Co-design of the digital dashboard with users; 2. Integration of data sources and development of risk models; and 3. Dashboard prototype testing with users. The processes and data sources for each component are summarised in Figure 2. The study gained ethics approval in December 2019, with data collection commencing April 2020.

## <Insert figure 2 here>

## **Co-design** principles

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Co-design is a methodology used to design and deliver interventions which take account of contextual factors, facilitate ownership of interventions, and motivate uptake and user satisfaction.<sup>31 36</sup> It is an approach that seeks out the meaningful involvement of potential user groups in designing tools and interventions, drawing on their lived experiences to ensure that outputs are tailored to their expressed needs and preferences, and align with workflows and available resources. Our research processes and methodology choices are guided by the following co-design principles outlined by Blomkamp,<sup>55</sup> adapted from New South Wales Council of Social Services<sup>56</sup>: Outcomes-focused, inclusive, participative, respective, and adaptive. The overarching goal of our research is to achieve positive change in aged care by improving outcomes for older adults. We plan to involve a range of participants in the design process and will be seeking out their unique knowledge, opinions, and experiences. We acknowledge that each user group has equal standing and are experts in their own right. Our study will involve users at different stages throughout the co-design process to ensure that the dashboard is appropriate, useful, and relevant. Participants' input with be sought throughout an iterative process to help refine the dashboard.

## **Study population**

Anglicare provides a variety of support services across the life span, including aged care, mental health services, palliative care, and family support. This study involves Anglicare's 23 residential aged care facilities, and their community-based aged care service outlets which provide services to older people in their homes. The risk modelling and data integration component of this study will include data about all of Anglicare's residential and community care clients over the previous five years (1 July 2014 - 31 December 2019, n=~14,800). The co-design and prototype testing components will involve samples drawn from Anglicare staff members (registered nurses, care workers, care managers), clients, informal caregivers and

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GPs. These groups represent the anticipated users of the dashboard, and are the people most likely to access client information and make decisions about care. Anglicare staff members will be recruited during management meetings and via emails from executive Anglicare staff, where information about the study and participation requirements are presented. Information of interested staff members will be provided to researchers for follow-up for focus groups. Clients and informal caregivers who meet the following inclusion criteria: currently receiving Anglicare residential or community care services, or their informal caregiver; ability to participate in an English-language interview; and ability to provide informed consent, will be invited to participate in the study. Clients will be provided with information and consent sheets by members of Anglicare staff. Those who are interested in participating in the study will be asked if they consent to their contact details being shared with the research team, who will then contact them to provide more information about the study, answer any questions and schedule an interview time if appropriate. General practitioners will be recruited via the Sydney North PHN networks through email or flyers. All participants will be required to provided written of verbal consent before engaging in the study.

#### Methods and analysis

## *Component 1: Co-design of the digital dashboard with users*

The design of the dashboard will draw on existing literature in human factors design and evaluation, evidence of features of effective dashboards, and input from users, guided by codesign principles. A multi-method approach will be taken to investigate users' needs and preferences, design the dashboard and to examine how the dashboard could be integrated into everyday practices. This will include:

Direct observations of staff members' routine work interactions including type, location and duration of activities. Observations will be conducted unobtrusively (e.g., at a distance of approximately 3 metres) using a validated time and motion tool (e.g., Work Observation Method By Activity Timing.<sup>57 58</sup>

- Interviews and focus groups with staff members about the design of the dashboard, including their perspectives on core information to be included in the dashboard, dashboard features (e.g., presentation of information and inclusion of decision support tools). They will also be asked about how decision-making guidance for the target priority areas (hospital-related falls and QoL) could be of value, and work processes or challenges garnered from the direct observations.
- Interviews and focus groups with aged care clients and informal caregivers to explore their preferences and experiences relating to access to medical and aged care information, involvement in decision-making, and use of technology. The interviews will also focus on design features of the dashboard including functions (what clients would like the dashboard to do, and how), appearance (e.g., colours, fonts, layout), and information to be included in the dashboard.
- Interviews with GPs focusing on how the dashboard could support improved communication between aged care and primary care. This will include, for example, discussion of current processes and difficulties experienced in the transfer of information between aged care facilities and GP practice records. Exploration of GP use of decision support tools will also occur.
- Co-design groups with users (staff members, GPs, clients and informal caregivers) to design and develop the decision support for the risk indicators will be established. The decision support will comprise evidence-based information on actions to be taken when clients are identified as at risk.

#### Analysis

Interviews, focus groups and working groups will be audio recorded and transcribed verbatim.

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Qualitative data from the focus groups, interviews and workshop will be analysed using a structured content analysis approach.<sup>59 60</sup> This approach allows for major domains and themes from participant responses to be categorised in order to understand participant needs and preferences related to dashboard appearance and functionality. A critical realist approach, as described by Pawson and Tilley,<sup>61</sup> will be applied. This a structured method for examining not only whether an intervention works, but also for whom and under what circumstances interventions work. Understanding the actors and drivers underlying appropriate utilisation of the dashboard will provide insight into what is required to tailor the dashboard for each user to ensure effectiveness within their work practices. The influence of subjectivity and the social context on data collection and analysis will be acknowledged. Data analysis will be conducted in NVivo version 12, a program that will support categorising of the qualitative data into domains and themes.<sup>62</sup> Two researchers will perform the initial coding of these data, producing a list of codes which will then be reviewed by the research team. Any discrepancies in coding will be discussed and used to modify the list of codes until the research team agrees on code application. The codes will then be sorted into preliminary domains and themes, which will be repeatedly reviewed and refined to maximise homogeneity prior to developing an analytic narrative. Data from the observation sessions will be descriptively analysed for time spent on different activities, interactions with people, tools and other methods used to complete tasks, and rate of interruptions.

## Refinement of prototypes

The findings from the co-design activities will be used to create mock-ups of the dashboard prototypes that will be presented to staff members, clients and informal caregivers during focus groups and a community forum, as we as GPs during a working group. As the dashboard is intended for different users, the presentation of information, dashboard features and evidence-based decision support will be tailored towards each user group and therefore, mock-ups will

be user-specific. Users' feedback will provide insights into their perspectives of the prototype design, functionality and modifications needed, and guide revisions to the dashboard prototype. The qualitative data obtained through prototype feedback sessions will be analysed using the same strategies outlined above.

#### Component 2: Integration of data sources and development of risk models

Building upon the feedback from users in component 1, we will develop a list of information items that will be used to populate the dashboard, based on the data available from Anglicare sources (Table 1). Two exemplar risk models, one for each priority area, will be developed through the linkage of available historical Anglicare client records with data from the NSW Emergency Department Data Collection (EDDC), the NSW Admitted Patient Data Collection (APDC) and the NSW Registry of Births, Deaths and Marriages (RBDM) registries (see Table 1 for descriptions of data sources). Data will be extracted for all Anglicare's residential and community care clients over the previous 5 years. Hospital data for these clients will be requested from the data custodians of the NSW EDDC, the NSW APDC and the NSW RBDM death registrations. The Centre for Health Record Linkage (CHeReL) will conduct the data linkage in order to allow preservation of individual confidentiality as data custodians supply only personal identifiers to CHeReL without clinical data. Only clinical data without personal identifiers will be supplied to researchers.

Candidate variables to be evaluated as predictors will be based on existing literature and the extracted data from Anglicare client records (see Table 1). Multivariable discrete time survival (DTS) modelling will be used.<sup>63 64</sup> A rounded score for each risk factor in the final model will be calculated by dividing the regression coefficient of each covariate by the lowest coefficient in the model. This allows for total risk scores to be calculated for each person by summing the scores for each present risk factor. Risk models will be internally validated using

bootstrap resampling. We have presented the approach to DTS modelling, however other modelling will be explored to ensure the most appropriate method is used. STATA will be used to conduct the statistical analysis.

## Table 1: Data sources for project component 1 risk models

Data source	Description
Aged care client	This electronic health and care management information system
records	includes client demographic information, clinical data, client needs
	data, service and activity data, medications administered, social
	factors, and QoL measures.
EDDC	This collection provides information about patient presentations to the
	emergency departments of public hospitals in NSW, such as admission
	and separation dates, mode of separation, referral source, triage
	category and diagnoses.
APDC	This collection records all admitted patient services provided by NSW
	public hospitals, public psychiatric hospitals, public multi-purpose
	services, private hospitals, and private day procedures centres. Data
	includes admission and separation dates, demographics, mode of
	separation, diagnosis and procedures.
RBDM	This dataset contains date and cause of death information for deaths
registrations	occurring in NSW.
NSW=New South Wale	es; EDDC= NSW Emergency Department Data Collection; APDC= Admitted Patient
Data Collection; RBDN	M=Registry of Births, Deaths and Marriages registries

## Component 3: Dashboard prototype testing

Informed by the findings from component 1, and the outputs of component 2, user-specific prototypes of the dashboard will be created by a specialist IT programmer and Anglicare IT staff using and adapting modifiable modules within Anglicare's existing infrastructure. Client health and care information, along with the risk models, will be integrated into the dashboard to a) provide an overview of clients' information (e.g., current medications) and b) alert users to changes in clients' risk levels for the two priority risk indicators in real-time. Each indicator will be accompanied by evidence-based decision guidance to direct actions in response the level of risk identified.

To test the dashboard prototype, staff members will be guided through task-based scenario 'walk-throughs' with a think-aloud approach.<sup>65</sup> Subsequent follow-up interviews or focus groups will be conducted to explore staff members' perceptions of the dashboard and alignment with workflow. Clients and informal caregivers will also engage in scenario walk-throughs, along with follow-up interviews or focus groups to elicit their views on their use of the dashboard. Qualitative data from the think-aloud activity and interviews will be analysed using the same methods as Component 2. The prototype testing phase will inform refinements of the dashboard, driven by users' feedback.

## Longer-term plans for dashboard implementation and evaluation

While the wide-spread implementation and evaluation of the dashboard are not the focus of this protocol, a broad overview of an anticipated large-scale trial to investigate the scalability and effectiveness is outlined below. Once the dashboard has been revised in line with the findings from prototype testing, a hybrid stepped-wedge cluster randomised controlled trial will be carried out. This will involve implementing the dashboard in 12 Anglicare residential facilities and 12 community care units, with two residential aged care facilities and two

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community care units randomly selected for dashboard implementation each month for six months. The remaining facilities and community units will continue with usual care until the end of the trial. Implementation processes will utilise Anglicare's staff training mechanisms and provide workshops for staff and clients/informal caregivers on dashboard purpose and use, using practical examples and incorporating behaviour change principles to support both intervention fidelity and effectiveness. As part of the randomised controlled trial, process evaluation will be conducted to identify barriers and facilitators to dashboard use, and economic evaluations to assess resource use and costs associated with the development and implementation of the dashboard will be undertaken.

It is anticipated that the dashboard will serve as a model for both Australian and international aged care organisations wanting to integrate siloed data and use informatics to facilitate real-time quality monitoring and management of client outcomes. Lessons learned from this project may be applied more broadly to the co-design of interventions with users, as well as the utilisation of data and IT systems in aged care settings.

#### Patient and public involvement

This research centres on the philosophy that users are *co-creators of* the research rather than *participants in* the research.<sup>66 67</sup> The project proposal was co-designed from inception with key Anglicare staff in a series of workshops starting in December 2017. In order to ensure that the research will have meaningful and real-world applications, users (staff, aged care clients, informal caregivers, and GPs) will continue to have strong engagement across the various stages of the research.<sup>66</sup> We aim to elicit users' expert knowledge, preferences and experiences through a range of methods, namely, interviews, observations, focus groups, workshops and forums. This information will be used to guide development of the dashboard, facilitate its implementation, and inform future evaluations of the intervention. Relevant stakeholders

including Anglicare representatives and users will be included in publications arising from this research to ensure appropriate interpretation of findings.<sup>66</sup>

## **ETHICS AND DISSEMINATION**

This study has received ethical approval from the NSW Population & Health Services Research Ethics Committee (Ref: 2020/ETH00166) and the Macquarie University Human Research Ethics Committee (Ref: 6144). Data will be managed and stored in line with Macquarie University policies. The findings of this research project will be disseminated as peer-reviewed journal articles and as presentations at national and international conferences, seminars and workshops. The Deeble Institute for Health Policy Research, AHHA, will play a valuable role to support policy translation using their extensive advocacy networks across health policy portfolios. Research findings will be disseminated though policy briefs and regular meetings with parliamentary staff and policy-makers. Findings will be relayed back to Anglicare to inform decisions, and their networks will be used to present findings to clients and their informal caregivers in newsletters.

#### LIST OF ABBREVIATIONS

- **AUD** Australian dollars
- **APDC** Admitted Patient Data Collection
- CHeReL Centre for Health Record Linkage
- **EDDC** Emergency Department Data Collection
- **GP** General Practitioners
- ICT Information and communication technologies

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NSLHD Northern Sydney Local Health District

NHMRC National Health and Medical Research Council

**NSW** New South Wales

QoL Quality of Life

**RBDM** Registry of Births, Deaths and Marriages

SNPHN Sydney North Primary Health Network

SW-CRCT Stepped-wedge cluster randomised controlled trial

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#### **DECLARATIONS**

#### **Competing interests**

The authors declare that they have no competing interests.

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#### Authors' contributions

This protocol was based on a successful funding application prepared by the chief investigators JW, MB, LCG, RD, JR, SRL, AG and JB with input from the associate investigators (MZR, JC, EB, WYZ, DD, JR, DR), staff from the aged care partner organisation (MC, AT, JS, JW), research partners (LO, CS, RH) and members of the project team working on the research (KL, MJ, KEL, ADN, JS, KS, MM). KL drafted the protocol and all authors contributed to reviewing and approving the final version.

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#### **FIGURE LEGEND**

Figure 1: Example of a dashboard to predict risk and deliver actionable information Figure 2: Overview of study design: components, processes, and data sources

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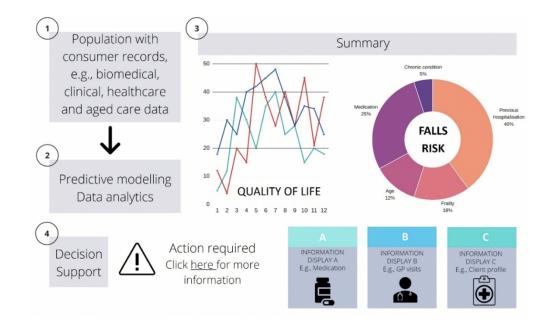
	1. Dashboard co-design	2. Data integration and risk models	3. Prototype testing
Processes	<ul> <li>Investigate end- users' needs and preferences</li> <li>Design dashboard features, functions, and presentation with users</li> <li>Seek user feedback on dashboard prototypes to guide refinements</li> </ul>	<ul> <li>Integrate siloed aged care data sources</li> <li>Develop and validate risk models using linked health and aged care data</li> </ul>	Conduct usability testing with users
Data sources	<ul> <li>Observations of routine work</li> <li>Interviews</li> <li>Focus groups</li> <li>Workshop</li> <li>Community forum</li> </ul>	<ul> <li>Anglicare's client records</li> <li>NSW EDDC</li> <li>NSW APDC</li> <li>NSW RBDM</li> </ul>	<ul> <li>Think-aloud task- based scenario walkthroughs</li> <li>Follow-up interviews/focus groups</li> </ul>

NSW=New South Wales; EDDC=Emergency Department Data Collection; APDC=Admitted Patient Data

Collection; RBDM=Registry of Births, Deaths and Marriages registries

Overview of study design: components, processes, and data sources

609x521mm (57 x 57 DPI)



Example of a dashboard to predict risk and deliver actionable information

532x327mm (57 x 57 DPI)

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## Co-designing a dashboard of predictive analytics and decision support to drive care quality and client outcomes in aged care: A mixed-methods study protocol

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	Miao, Melissa; University of Technology Sydney, Graduate School of Health, Faculty of Health Root, Jo; Consumers Health Forum of Australia Roffe, David; IT Consultant O'Toole, Libby; Aged Care Quality and Safety Commission Carrasco, Marcela; Anglicare Sydney Thompson, Alex; Anglicare Sydney Shaikh, Javed; Anglicare Sydney Wong, Jeffrey; Anglicare Sydney Stanton, Cynthia; Sydney North Health Network Haddock, Rebecca; Australian Healthcare and Hospitals Association, Deeble Institute for Health Policy Research
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Co-designing a dashboard of predictive analytics and decision support to drive care quality and client outcomes in aged care: A mixed-methods study protocol

Kristiana Ludlow<sup>\*1,2</sup>, Johanna Westbrook<sup>1</sup>, Mikaela Jorgensen<sup>1</sup>, Kimberly E. Lind<sup>3</sup>, Melissa Baysari<sup>4</sup>, Len C. Gray<sup>5</sup>, Richard Day<sup>6</sup>, Julie Ratcliffe<sup>7</sup>, Stephen R. Lord<sup>8,9</sup>, Andrew Georgiou<sup>1</sup>, Jeffrey Braithwaite<sup>10,11</sup>, Magdalena Z. Raban<sup>1</sup>, Jacqueline Close<sup>8</sup>, Elizabeth Beattie<sup>12</sup>, Wu Yi Zheng<sup>13</sup>, Deborah Debono<sup>14</sup>, Amy D. Nguyen<sup>1,6</sup>, Joyce Siette<sup>1</sup>, Karla Seaman<sup>1</sup>, Melissa Miao<sup>15</sup>, Jo Root<sup>16</sup>, David Roffe<sup>17</sup>, Libby O'Toole<sup>18</sup>, Marcela Carrasco<sup>19</sup>, Alex Thompson<sup>19</sup>, Javed Shaikh<sup>19</sup>, Jeffrey Wong<sup>19</sup>, Cynthia Stanton<sup>20</sup>, Rebecca Haddock<sup>21</sup>

<sup>1</sup>Centre for Health Systems and Safety Research, Australian Institute of Health Innovation, Macquarie University, Sydney, Australia

<sup>2</sup> School of Psychology, University of Queensland, Brisbane, Australia

<sup>3</sup> Department of Health Promotion Sciences, Mel & Enid Zuckerman College of Public

Health, The University of Arizona, Tucson, AZ, United States of America

<sup>4</sup> Discipline of Biomedical Informatics and Digital Health, Charles Perkins Centre, Faculty of Medicine and Health, The University of Sydney

<sup>5</sup> Centre for Health Services Research, University of Queensland, Brisbane, Australia

<sup>6</sup> St Vincent's Clinical School, University of New South Wales, Sydney, Australia

<sup>7</sup>College of Nursing and Health Sciences, Flinders University, Adelaide, Australia

<sup>8</sup>Neuroscience Research Australia, Sydney, Australia

<sup>9</sup> School of Public health and Community Medicine, University of New South Wales, Sydney, Australia

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<sup>10</sup>Centre for Healthcare Resilience and Implementation Science, Australian Institute of Health Innovation, Macquarie University, Sydney, Australia <sup>11</sup> The International Society for Quality in Health Care, Dublin, Ireland <sup>12</sup> School of Nursing, Queensland University of Technology, Brisbane, Australia <sup>13</sup> Black Dog Institute, Sydney, Australia <sup>14</sup> School of Public Health, Faculty of Health, University of Technology Sydney, Sydney, Australia <sup>15</sup> Graduate School of Health, Faculty of Health, University of Technology Sydney, Sydney, Australia <sup>16</sup> Consumers Health Forum of Australia, Deakin, Australia <sup>17</sup> IT consultant <sup>18</sup> Aged Care Quality and Safety Commission, Sydney, Australia <sup>19</sup> Anglicare, Sydney, Australia <sup>20</sup> Sydney North Health Network, Sydney, Australia <sup>21</sup> Deeble Institute for Health Policy Research, Australian Healthcare and Hospitals Association, Canberra, Australia \* Corresponding author details:

Address: Level 6, 75 Talavera Road, Macquarie University, NSW 2109, Australia; email: kristiana.ludlow@mq.edu.au

## **KEYWORDS**

Health informatics; Information technology; Health & Safety; Quality in Health care; Risk

 Management; Geriatric Medicine

Word count: 4,651

## ABSTRACT

#### Introduction

There is a clear need for improved care quality and quality monitoring in aged care. Aged care providers collect an abundance of data, yet rarely are these data integrated and transformed in real-time into actionable information to support evidence-based care, nor are they shared with older people and informal caregivers. This protocol describes the co-design and testing of a dashboard in residential aged care facilities (nursing or care homes) and community-based aged care settings (formal care provided at home or in the community). The dashboard will comprise integrated data to provide an 'at-a-glance' overview of aged care clients, indicators to identify clients at risk of fall-related hospitalisations and poor quality of life, and evidence-based decision support to minimise these risks. Longer-term plans for dashboard implementation and evaluation are also outlined.

## Methods

This mixed-methods study will involve (i) co-designing dashboard features with aged care staff, clients, informal caregivers and general practitioners (GPs), (ii) integrating aged care data silos and developing risk models, and (iii) testing dashboard prototypes with users. The dashboard features will be informed by direct observations of routine work, interviews and focus groups with users, and a community forum. Multivariable discrete time survival models will be used to develop risk indicators, using predictors from linked historical aged care and hospital data. Dashboard prototype testing will comprise interviews, focus groups and walk-through scenarios using a think-aloud approach with staff members, clients and informal

caregivers, and a GP workshop.

# Ethics and dissemination

This study has received ethical approval from the NSW Population & Health Services Research Ethics Committee and Macquarie University's Human Research Ethics Committee. The research findings will be presented to the aged care provider who will share results with staff members, clients and informal caregivers. Findings will be disseminated as peerreviewed journal articles, policy briefs and conference presentations.

# STRENGTHS AND LIMITATIONS OF THIS STUDY

- The linkage of multiple data sources will allow for comprehensive information about aged care clients' health conditions, psychosocial characteristics, care management, hospitalisations, and quality of life.
- The dashboard's use of existing routinely collected data will enable the prediction of risk, and provide evidence-based guidance, in real-time.
- To ensure that the dashboard is fit-for-purpose, the dashboard will be co-designed and tested with intended users (staff, aged care clients, informal caregivers, and general practitioners).
- The dashboard will be designed to have generic characteristics which will allow it to be embedded into existing aged care information technology to facilitate its transferability and sustainability.
- Most aged care services in this study will be located in major cities, therefore, findings will be limited in regional and remote areas, where client profiles and staff workflows could be different.

## INTRODUCTION

Good quality care relies upon the availability of good quality data and real-time analytics to support decision-making. This is particularly the case for older people with complex health needs who are supported by a wide-range of people in different settings. Aged care services have not been well served by information systems that support everyday care provision. Internationally, there is consistent evidence that aged care systems are struggling to provide high quality services for older adults, with shortcomings highlighted by many recent reviews, reports and research.<sup>1-5</sup> The delivery of optimal care is hindered by a lack of integration between aged care and other healthcare services, fragmented funding systems, inadequate infrastructure, insufficient workforce training and support, and a widening gap between supply and demand of services.<sup>6</sup>

In Australia, concerns about suboptimal care and escalating pressure on aged care services has led to more than 40 major inquires and reviews over the past 40 years,<sup>7</sup> the latest being the Royal Commission into Aged Care Quality and Safety (2018-20). The purpose of the Royal Commission is to examine the current state of the aged care system and determine what is needed to improve it for those receiving care now and into the future.<sup>18</sup> The Commission's findings have made it clear that the community is demanding better quality aged care and greater transparency: a system that meets older peoples' needs, identifies when they are at risk, and responds in effective and compassionate ways.<sup>19 10</sup>

Despite enormous amounts of data collected in the sector, there continues to be considerable problems for informal caregivers, providers, and governments to obtain

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meaningful information to allow the monitoring of care delivery and outcomes, and to guide effective decision-making.<sup>1</sup> The increasing use of electronic systems provides an opportunity to address some of these shortcomings. The World Health Organization's World Report on Ageing and Health identified information and communication technologies (ICT) as a "critical tool for transforming health systems and services to deliver person-centred and integrated care that is appropriate to older people".<sup>6(p. 109)</sup> The report outlines some of the anticipated and demonstrated benefits of utilising ICT in terms of access to services, quality and safety of care, cost effectiveness of services, accessibility of information and knowledge, social care and connectedness, and the provision of evidence-based care.<sup>6</sup>

# Data rich but information poor

While the last decade has seen substantial uptake of ICT by aged care sectors internationally,<sup>11</sup> the potential of these systems to transform care quality by increasing the usability and transparency of aged care information remains largely unrealised.<sup>11</sup> Health and aged care systems are often characterised as '*data rich but information poor*',<sup>12,13</sup> meaning that although providers collect vast amounts of clinical and care management data, these data frequently exist within silos that are rarely integrated to create meaningful information to support care staff to coordinate, monitor and enhance care delivery. In Australia, these information silos are often driven by variations in funding and ownership of data (e.g., between aged care and healthcare, or between State and Federal governments). Furthermore, these data are not often shared with the people who are the subject of data collection (i.e., those receiving services and their informal caregivers) or with the general public who largely fund aged care services through tax contributions.

Data have traditionally been used for reporting purposes rather than quality improvement activities or driving care processes. Several countries have mandated systems

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for collecting and reporting aged care information,<sup>14</sup> for example, the Home Care Reporting System and Continuing Care Reporting System in Canada, the United States' MDS 3.0 and Nursing Home Compare, Sweden's Open Comparisons national quality monitoring system, and the International Resident Assessment Instrument Long-Term Care Facility (interRAI-LTCF) Assessment System in New Zealand. Australia's aged care system lags behind other Organisation for Economic Co-operation and Development (OECD) countries in terms of measuring and reporting on aged care quality.<sup>15</sup> For example, Australia's National Aged Care Mandatory Quality Indicator Program,<sup>16</sup> operating since 2019, collects information on three quality indicators (physical restraint use, pressure ulcers and weight loss) in residential aged care settings (also known as assisted living facilities, nursing homes, care homes, long-term care facilities, and skilled nursing facilities). The aggregated data that are publicly reported for this program allow comparisons to be made between providers. Additional quality indicators for falls and major injury, and medication management are being introduced to the program in 2021. Currently, there is no system for mandatory reporting of quality indicators in community aged care settings (i.e., formal aged care services provided in the home and community, such as domestic assistance, social support, gardening, transport). Limited and disparate information on the quality of aged care in Australia reduces the capacity for older adults and their caregivers to make informed decisions about their care. Without this information, providers are limited in their ability to monitor and benchmark key quality indicators across services, initiate improvement activities, and systematically and iteratively assess the effectiveness and cost-effectiveness of services and interventions.

## Predictive risk models

Very little attention has been placed on the power of new analytic models to exploit the increasing volume of data that are stored in aged care IT systems. Initial research to capitalise

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on this valuable information source has focused on retrospective and descriptive analyses.<sup>17 18</sup> This foundational research has demonstrated the potential value of these data to better understand quality of care issues.<sup>19-21</sup> Further, this work has shown that it is possible to create automated risk-adjusted indicators of client care and outcomes by linking existing administrative, clinical and care management datasets routinely collected by providers.<sup>22 23</sup> A number of studies in the acute care sector have shown the possibilities of leveraging electronic data systems to implement real-time predictive risk models.<sup>24-27</sup> These models have been used to identify clients who are at risk of adverse events earlier and facilitate the uptake of tailored evidence-based strategies by time-poor staff.<sup>28-31</sup>

#### **Dashboards**

Dashboards offer promise in integrating multiple data sources and supporting the use of predictive analytics to improve client care. They allow for a single-view summary of an individual's information and can provide decision-related information using text and visual features. These summaries can be dynamic; reflecting changes in clinical environments and a person's information in real-time. Dashboards typically utilise graphical information displays and colour, allowing users to easily interact with and explore important information. Dashboards may include features that alert users to areas requiring attention, such as deteriorating patients or those at high risk of injury or harm. They may also provide support tools to guide staff members' responses to alerts. These features allow for the quick and targeted communication of information, helping reduce the cognitive effort of users and enabling them to make informed decisions effectively and efficiently (Figure 1).

## <Insert Figure 1 here>

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Dashboards have predominantly been implemented and evaluated in primary, acute and mental health care.<sup>32-34</sup> In these settings, dashboards have been shown to improve clinician situational awareness, decision-making, and guideline adherence, positively affecting outcomes such as mortality.<sup>32 35</sup> At an organisational-level, dashboards can improve the detection of overdue tasks, procedural bottlenecks, and support better resource allocation.<sup>35</sup> At the client-level, they have the potential to make meaningful information accessible to clients and their families, placing individuals at the centre of their own information and care. Dashboards are less commonly used in aged care settings, which may encounter specific challenges with uptake and use due to poor ICT infrastructure and support services, and a workforce with lower computer experience and digital literacy skills than found in acute care settings.<sup>36 37</sup>

## Rationale

Anglicare, a large non-profit aged care provider located in New South Wales (NSW), Australia, identified the critical need for leveraging their electronic systems to support evidence-based practice across their services. The Australian Institute of Health Innovation, Macquarie University, is partnering with Anglicare; the Sydney North Health Network (SNHN); the Northern Sydney Local Health District (NSLHD); the Deeble Institute for Health Policy Research, Australian Healthcare and Hospitals Association (AHHA); and the Australian Aged Care Quality and Safety Commission, to design, develop, implement and evaluate an interactive dashboard comprising integrated client information, risk indicators and decision support. This dashboard is intended to be used by Anglicare staff (e.g., registered nurses, care workers, care advisors, managers), clients, informal caregivers, and general practitioners (GPs) providing services to Anglicare clients, collectively referred to as

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'users'. It is expected that the dashboard will be used to identify and support older adults at risk of poor outcomes in residential aged care facilities and community-based aged care. The dashboard will be iteratively co-designed and evaluated with stakeholders to (i) allow care managers to monitor robust real-time indicators of care quality, (ii) support staff members and GPs to obtain a client overview 'at-a-glance' and make evidence-based decisions about their care, and (iii) provide timely, meaningful information to older persons and their families.

## Priority aged care challenges

Risk indicators will initially target two priority aged care challenges relevant to both residential- and community-based care populations: (i) hospital-related falls; and (ii) Quality of Life (QoL).

- (i) Falls are a major cause of harm to older Australians, experienced by more than a third of adults aged  $\geq 65$  every year.<sup>38</sup> In 2014-15 in Australia, over 1.4 million hospital days were attributable to fall-related injuries among older adults,<sup>39</sup> costing >\$500 million AUD.<sup>40</sup> Falls are the cause of 92% of injury hospitalisations among aged care residents.<sup>41</sup> Identifying those at risk is the starting point to improve falls management. However, falls risk tools currently in use are stand-alone assessments that are rarely integrated with dynamic information about an individual's risk, such as changes in medications or health following a hospitalisation.<sup>42</sup>
- QoL has been recognised by international peak health and healthcare
   organisations as an important aspect of active ageing and quality care in long-term
   care settings.<sup>6 43 44</sup> Older Australians report QoL as a central goal for aged care.<sup>45</sup>
   While research on the relationships between QoL and clinical outcomes in aged
   care settings is sparse, some evidence suggests that lower QoL scores are

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associated with poorer clinical outcomes in residential aged care clients.<sup>46-48</sup> Alongside the increased recognition of the importance of QoL for older adults, valid and reliable QoL tools have recently been developed, including those suitable for use by people with dementia.<sup>46 49-54</sup> Currently, reporting on QoL in Australian aged care is not mandatory, and while recent national policy requires community care providers to report on client wellness,<sup>55</sup> relatively little is known about modifiable factors contributing to QoL in aged care.

These two exemplar indicators will serve as an initial model to test embedding risk indicators in an electronic dashboard within aged care settings. Other indicators may be added during the study in response to feedback from users.

#### Study aim

The aim of this study is to describe the co-design and testing of a dashboard in residential and community-based aged care settings, and to outline longer-term plans for dashboard implementation and evaluation.

## **METHODS AND ANALYSIS**

## Study design

The research comprises three components: 1. (a) Co-design of the digital dashboard with users and (b) Refinement of prototypes; 2. Integration of data sources and development of risk models; and 3. Dashboard prototype testing with users. Figure 2 provides an overview of the study design. The study gained ethics approval in December 2019, with data collection commencing April 2020.

#### <Insert figure 2 here>

## **Co-design** principles

Co-design is a methodology used to design and deliver interventions which take account of contextual factors, facilitate ownership of interventions, and motivate uptake and user satisfaction.<sup>32 37</sup> It is an approach that seeks out the meaningful involvement of potential user groups in designing tools and interventions, drawing on their lived experiences to ensure that outputs are tailored to their expressed needs and preferences, and align with workflows and available resources. Our research processes and methodology choices are guided by the following co-design principles outlined by Blomkamp,<sup>56</sup> adapted from New South Wales Council of Social Services<sup>57</sup>: Outcomes-focused, inclusive, participative, respective, and adaptive. The overarching goal of our research is to achieve positive change in aged care by improving outcomes for older adults. We plan to involve a range of stakeholders in the design process and will be seeking out their unique knowledge, opinions, and experiences. We acknowledge that each user group has equal standing and are experts in their own right. Our study will involve users at different stages throughout the co-design process to ensure that the dashboard is appropriate, useful, and relevant. Stakeholders' input with be sought throughout an iterative process to help refine the dashboard.

#### **Study population**

Anglicare provides a variety of support services across the life span, including aged care, mental health services, palliative care, and family support. This study involves Anglicare's 23 residential aged care facilities, and their community-based aged care service outlets which provide services to older people in their homes. The risk modelling and data integration Page 15 of 33

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component of this study will include data about all of Anglicare's residential and community care clients over the previous five years (1 July 2014 - 31 December 2019, n=~14,800). The co-design and prototype testing components will involve samples drawn from Anglicare staff members (registered nurses, care workers, care managers), clients, informal caregivers and GPs. These groups represent the anticipated users of the dashboard, and are the people most likely to access client information and make decisions about care. Anglicare staff members will be recruited during management meetings and via emails from executive Anglicare staff, where information about the study and participation requirements will be presented. Contact details of interested staff members will be provided to researchers for recruitment. Clients and informal caregivers who meet the following inclusion criteria will be invited to participate in the study: currently receiving Anglicare residential or community care services; ability to participate in an English-language interview; and ability to provide informed consent. Clients will be provided with information and consent sheets by members of Anglicare staff. Those who are interested in participating in the study will be asked if they consent to their contact details being shared with the research team, who will then contact them to provide more information about the study, answer any questions and schedule an interview time if appropriate. General practitioners will be recruited via the Sydney North PHN networks through email or flyers. All participants will be required to provide written or verbal consent before engaging in the study.

## Methods and analysis

#### Component 1a: Co-design of the digital dashboard with users

The design of the dashboard will draw on existing literature in human factors design and evaluation, evidence of features of effective dashboards, and input from users, guided by codesign principles. A multi-method approach will be taken to investigate users' needs and

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preferences, design the dashboard and to examine how the dashboard could be integrated into everyday practices. This will include:

- Direct observations of staff members' routine work interactions including type, location
  and duration of activities. Non-participant observations will be conducted
  unobtrusively (e.g., at a distance of approximately 3 metres) using a validated time and
  motion tool (e.g., Work Observation Method By Activity Timing.<sup>58 59</sup>
- Interviews and focus groups with staff members about the design of the dashboard. Staff members will be asked about their perspectives on core information to be included in the dashboard and dashboard features (e.g., presentation of information and inclusion of decision support tools). They will also be asked about how decision-making guidance for the target priority areas (hospital-related falls and QoL) could be of value, and work processes or challenges garnered from the direct observations.
- Interviews and focus groups with aged care clients and informal caregivers to explore their preferences and experiences relating to access to medical and aged care information, involvement in decision-making, and use of technology. The interviews will also focus on design features of the dashboard including functions (what clients would like the dashboard to do, and how), appearance (e.g., colours, fonts, layout), and information to be included in the dashboard.
- Interviews with GPs focusing on how the dashboard could support improved communication between aged care and primary care. This will include, for example, discussion of current processes and difficulties experienced in the transfer of information between aged care facilities and GP practice records. Exploration of GP use of decision support tools will also occur.
- Co-design groups with users (staff members, GPs, clients and informal caregivers) to design and develop decision support for the risk indicators. The decision support will

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comprise evidence-based information on actions to be taken when clients are identified as at risk.

## Analysis

Interviews, focus groups and co-design groups will be audio recorded and transcribed verbatim. Qualitative data will be analysed using a structured content analysis approach.<sup>60 61</sup> This approach allows for major domains and themes from users' responses to be categorised in order to understand users' needs and preferences related to dashboard appearance and functionality. Data analysis will be conducted in NVivo version 12, a program that will support the categorisation of qualitative data into domains and themes.<sup>62</sup> Two researchers will perform the initial coding of these data, producing a list of codes which will then be reviewed by the research team. Any discrepancies in coding will be discussed and used to modify the list of codes until the research team agrees on code application. The codes will then be sorted into preliminary domains and themes, which will be repeatedly reviewed and refined to maximise homogeneity prior to developing an analytic narrative. Data from the observation sessions will be descriptively analysed for time spent on different activities, interactions with people, tools and other methods used to complete tasks, as well as the rate of interruptions.

# Component 1b: Refinement of prototypes

The findings from the co-design activities will be used to create mock-ups of the dashboard prototypes that will be presented to staff members, clients and informal caregivers during focus groups and a community forum, as well as GPs during a workshop. As the dashboard is intended for different users, the presentation of information, dashboard features and evidence-based decision support will be tailored towards each user group and therefore, mock-ups will be user-specific. Users' feedback will provide insights into their perspectives of the prototype design, functionality and modifications needed, and guide revisions to the dashboard prototype. The qualitative data obtained through prototype feedback sessions will be analysed using the

same strategies outlined above.

#### Component 2: Integration of data sources and development of risk models

Building upon the feedback from users in component 1a, we will develop a list of information items that will be used to populate the dashboard, based on the data available from Anglicare sources (Table 1). Two exemplar risk models, one for each priority area, will be developed through the linkage of available historical Anglicare client records with data from the NSW Emergency Department Data Collection (EDDC), the NSW Admitted Patient Data Collection (APDC) and the NSW Registry of Births, Deaths and Marriages (RBDM) registries (see Table 1 for descriptions of data sources). Data will be extracted for all Anglicare's residential and community care clients over the previous 5 years. Hospital data for these clients will be requested from the data custodians of the NSW EDDC, the NSW APDC and the NSW RBDM death registrations. The Centre for Health Record Linkage (CHeReL) will conduct the data linkage in order to allow preservation of individual confidentiality as data custodians supply only personal identifiers to CHeReL without clinical data. Only clinical data without personal identifiers will be supplied to researchers.

Candidate variables to be evaluated as predictors will be based on existing literature and the extracted data from Anglicare client records (see Table 1). The variables will be used in the development of the two independent risk models, one for falls and one for quality of life. Multivariable discrete time survival (DTS) modelling will be used to develop each model.<sup>63 64</sup> A rounded score for each risk factor in the final models will be calculated by dividing the regression coefficient of each covariate by the lowest coefficient in the model. This allows for total risk scores to be calculated for each person by summing the scores for each present risk factor. Risk models will be internally validated using bootstrap resampling. We have presented the approach to DTS modelling, however other modelling will be explored, for example joint

regression<sup>65</sup> and landmark models.<sup>66</sup> To inform decision-making about the most appropriate model to use, statistical model performance techniques, such as the concordance index, will be performed. STATA will be used to conduct the statistical analysis.

# Table 1: Data sources for project component 2: Risk models

Data source	Description
Aged care client	This electronic health and care management information system
records	includes client demographic information, clinical data, client needs
	data, service and activity data, medications administered, social
	factors, and QoL measures.
EDDC	This collection provides information about patient presentations to th
	emergency departments of public hospitals in NSW, such as admission
	and separation dates, mode of separation, referral source, triage
	category and diagnoses.
APDC	This collection records all admitted patient services provided by NSV
	public hospitals, public psychiatric hospitals, public multi-purpose
	services, private hospitals, and private day procedures centres. Data
	includes admission and separation dates, demographics, mode of
	separation, diagnosis and procedures.
RBDM registries	This dataset contains date and cause of death information for deaths
	occurring in NSW.
JSW=New South Wale	s; EDDC= NSW Emergency Department Data Collection; APDC= Admitted Patient
Data Collection; RBDN	I=Registry of Births, Deaths and Marriages registries

# Component 3: Dashboard prototype testing

Informed by the findings from component 1, and the outputs of component 2, user-specific prototypes of the dashboard will be created by a specialist IT programmer and Anglicare IT staff using and adapting modifiable modules within Anglicare's existing infrastructure. Client health and care information, along with the risk models, will be integrated into the dashboard to a) provide an overview of clients' information (e.g., current medications) and b) alert users to changes in clients' risk levels for the two priority risk indicators in real-time. Each indicator will be accompanied by evidence-based decision guidance to direct actions in response the level of risk identified.

To test the dashboard prototype, staff members will be guided through task-based scenario 'walk-throughs' with a think-aloud approach.<sup>67</sup> Subsequent follow-up interviews or focus groups will be conducted to explore staff members' perceptions of the dashboard and alignment with workflow. Clients and informal caregivers will also engage in scenario walk-throughs, along with follow-up interviews or focus groups to elicit their views on their use of the dashboard. Qualitative data from the think-aloud activity and interviews will be analysed using the same methods as Component 2. The prototype testing phase will inform refinements of the dashboard, driven by users' feedback.

## Longer-term plans for dashboard implementation and evaluation

While the wide-spread implementation and evaluation of the dashboard are not the focus of this protocol, a broad overview of an anticipated large-scale trial to investigate the scalability and effectiveness is outlined. Once the dashboard has been revised in line with the findings from prototype testing, a hybrid stepped-wedge cluster randomised controlled trial will be carried out. This will involve implementing the dashboard in 12 Anglicare residential facilities and 12 community care units, with two residential aged care facilities and two community care

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units randomly selected for dashboard implementation each month for six months. The remaining facilities and community units will continue with usual care until the end of the trial. Implementation processes will utilise Anglicare's staff training mechanisms and provide workshops for staff and clients/informal caregivers on dashboard purpose and use, using practical examples and incorporating behaviour change principles to support both intervention fidelity and effectiveness. As part of the randomised controlled trial, process evaluations will be conducted to identify barriers and facilitators to dashboard use, and economic evaluations to assess resource use and costs associated with the development and implementation of the dashboard will be undertaken.

It is anticipated that the dashboard will serve as a model for both Australian and international aged care organisations wanting to integrate siloed data and use informatics to facilitate real-time quality monitoring and management of client outcomes. Lessons learned from this project may be applied more broadly to the co-design of interventions with users, as well as the utilisation of data and IT systems in aged care settings.

## Patient and public involvement

This research centres on the philosophy that users are *co-creators of* the research rather than *participants in* the research.<sup>68 69</sup> The project proposal was co-designed from inception with key Anglicare staff in a series of workshops starting in December 2017. In order to ensure that the research will have meaningful and real-world applications, users (staff, aged care clients, informal caregivers, and GPs) will continue to have strong engagement across the various stages of the research.<sup>68</sup> We aim to elicit users' expert knowledge, preferences and experiences through a range of methods, namely, interviews, observations, focus groups, co-design groups, workshops and forums. This information will be used to guide development of the dashboard, facilitate its implementation, and inform future evaluations of the intervention. Relevant

stakeholders including Anglicare representatives and users will be included in publications arising from this research to ensure appropriate interpretation of findings.<sup>68</sup>

# ETHICS AND DISSEMINATION

This study has received ethical approval from the NSW Population & Health Services Research Ethics Committee (Ref: 2020/ETH00166) and the Macquarie University Human Research Ethics Committee (Ref: 6144). Data will be managed and stored in line with Macquarie University policies. The findings of this research project will be disseminated as peer-reviewed journal articles and as presentations at national and international conferences, seminars and workshops. The Deeble Institute for Health Policy Research, AHHA, will play a valuable role to support policy translation using their extensive advocacy networks across health policy portfolios. Research findings will be disseminated though policy briefs and regular meetings with parliamentary staff and policy-makers. Findings will be relayed back to Anglicare to inform decisions, and their networks will be used to present findings to clients and their informal caregivers.

# LIST OF ABBREVIATIONS

- AUD Australian dollars
- APDC Admitted Patient Data Collection
- CHeReL Centre for Health Record Linkage
- EDDC Emergency Department Data Collection
- GP General Practitioners
- ICT Information and communication technologies

NSLHD Northern Sydney Local Health District

NHMRC National Health and Medical Research Council

**NSW** New South Wales

QoL Quality of Life

**RBDM** Registry of Births, Deaths and Marriages

SNPHN Sydney North Primary Health Network

SW-CRCT Stepped-wedge cluster randomised controlled trial

#### DECLARATIONS

#### **Competing interests**

The authors declare that they have no competing interests.

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## Authors' contributions

This protocol was based on a successful funding application prepared by the chief investigators JW, MB, LCG, RD, JR, SRL, AG and JB with input from the associate

investigators (MZR, JC, EB, WYZ, DD, JR, DR), staff from the aged care partner organisation (MC, AT, JS, JW), research partners (LO, CS, RH) and members of the project team working on the research (KL, MJ, KEL, ADN, JS, KS, MM). KL drafted the protocol and all authors contributed to reviewing and approving the final version.

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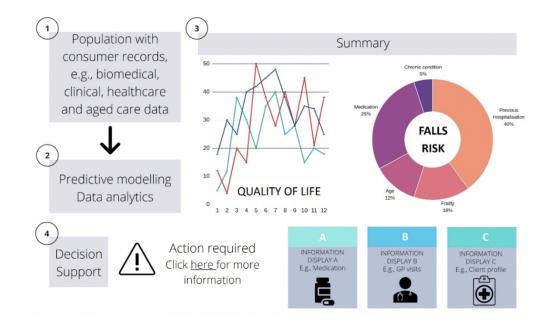
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# FIGURE LEGEND

Figure 1: Example of a dashboard to predict risk and deliver actionable information

Figure 2: Overview of study design

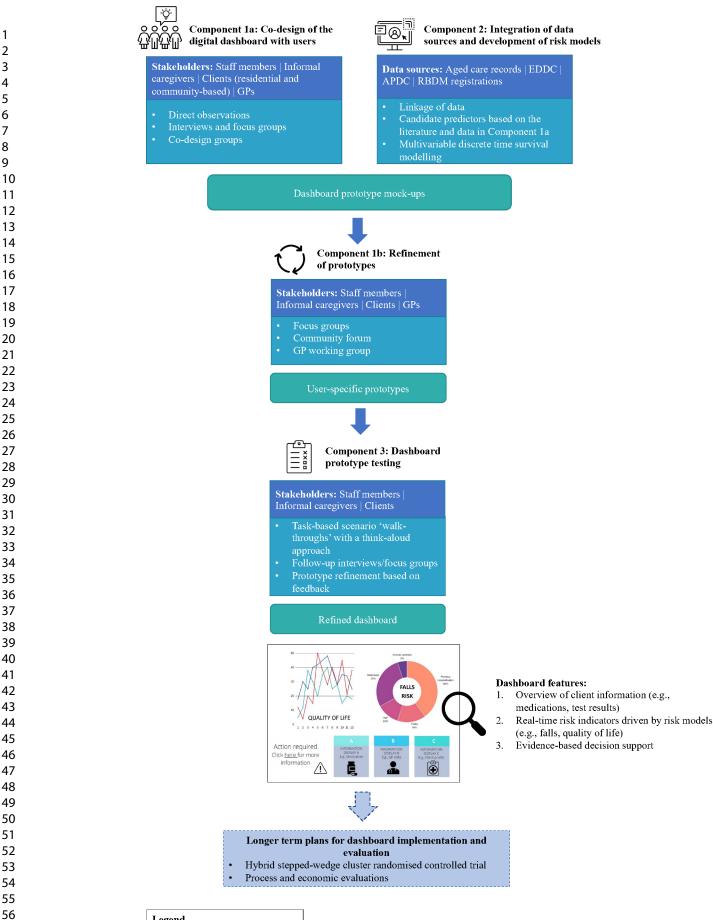
EDDC=Emergency Department Data Collection; APDC=Admitted Patient Data Collection; RBDM=Registry of Births, Deaths and Marriages



Example of a dashboard to predict risk and deliver actionable information

532x327mm (57 x 57 DPI)

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