

A data-based aged care system

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Summary

This is a submission to the Royal Commission into Aged Care Quality and Safety, made on behalf of consumers. It addresses part 13 of the submissions by Peter Gray QC on 4 March 2020.

We propose a data-based aged care system allowing for

- rapid detection of individual health problems, and prompt help to individuals
- prompt help to providers, and well-based regulatory action where needed
- rapid detection of system health threats
- quality of care measurements to help consumers, providers and regulators
- appropriate Commonwealth subsidies for each care recipient
- well-timed transitions between care levels
- research on the cost-effectiveness of different monitoring systems
- research on the needs for different levels of care staff
- data access for treating professionals
- data access for researchers.

Automatically monitored care data are transmitted to a central agency and the provider, together with automatically-generated messages to the provider where help to a person seems needed.

The data generated in a year would fit into about 10 mobile phones. This is about 10,000 times the data generated by the present system.

1. Introduction

1.1 Purpose of this submission

This submission addresses part 13 of the submissions made on 4 March 2020 by Peter Gray QC [1 p70-74]. He proposed that

“The Australian Government should implement a standardised data collection program designed on the ‘collect once, use many times’ principle”.

The program must be designed to inform longitudinal evaluation at the user, provider, and system levels.”

We strongly support this proposal, and we suggest ways in which it could be implemented.

Our submission builds on suggestions made by Cumpston and Bail in a submission to the Commission [2 p13-15].

1.2 Sharing all the data

It would be a big step forward to have all the data in one place, with regulators, providers, consumers, treating professionals and researchers having access to data relevant to them. This would have helped avoid the regulatory failure with PeopleCare [1 p72]. Going forward, it should allow better quality control, more effective care and better research.

1.3 Using modern technology to provide better care to the aged

One of the Commission’s terms of reference is

“how best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure”

Modern technology has made it possible to automatically collect large volumes of data on individuals, store the data indefinitely, and analyse it for commercial gain. We suggest that these techniques be applied to provide better care to the aged.

1.4 Automatic monitoring in aged care

Some automatic monitoring occurs within individual aged care facilities, alerting staff to resident care needs. As far as we know, no resident data are automatically transmitted to a central agency. The types of data that might be automatically generated for aged care residents, and any automatically-generated responses, are thus very uncertain. In 7.2 we suggest that large-scale tests of any proposed monitoring device be based on expert medical advice and technological availability, and be followed by evaluation of the test results.

1.5 Advantages of automatic monitoring

Potential advantages of automatic monitoring are speed, accuracy, fraud-resistance and staff safety. The error rates of different monitoring devices can be established by trial, and matched to the accuracy required for their proposed purposes. Automatic data should be less vulnerable to provider fraud than manually entered data. Automatic monitoring could also reduce staff times and safety risks.

1.6 Automatically-generated messages where help may be needed

Given multiple data flows for each resident, artificial intelligence should allow useful messages to be sent to providers, alerting them to persons who may need prompt help.

1.7 Commonwealth should pay for equipment and computer programs

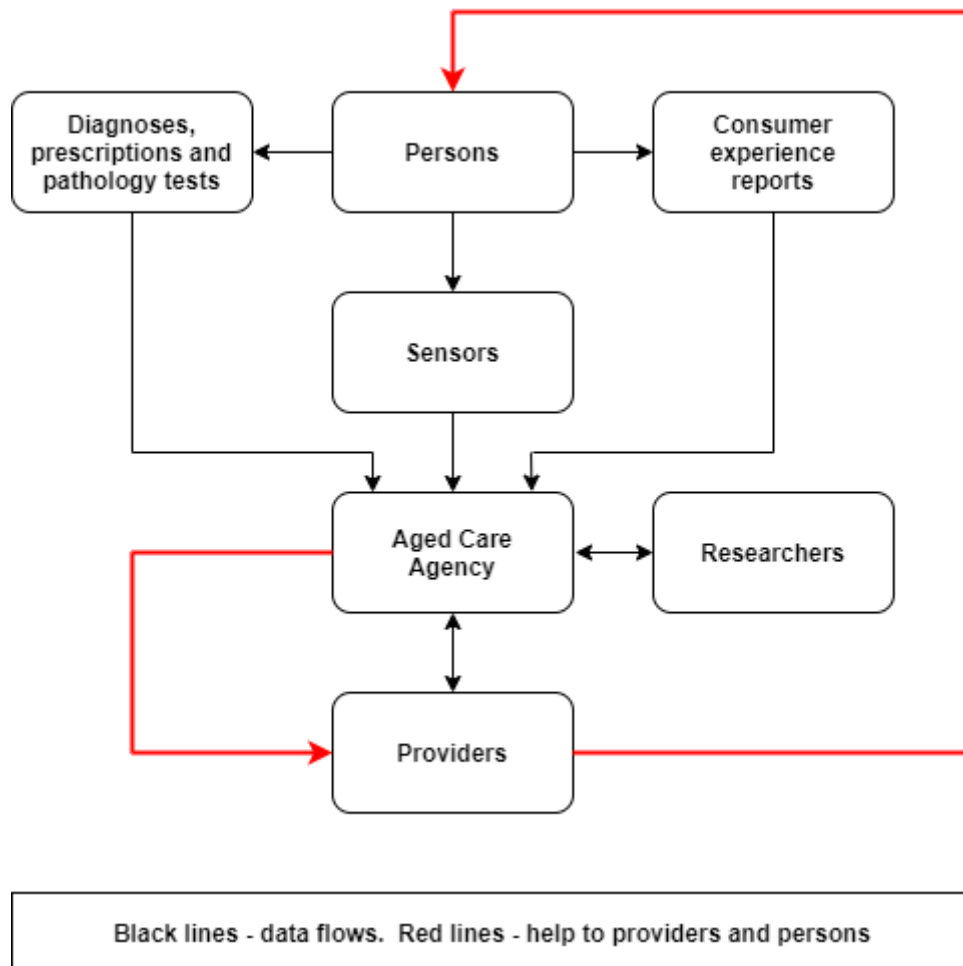
Gray submitted that

“The Australian Government should fund and support the development of the Information Communication and Technology systems ...” [1 p70]

We believe that the Commonwealth should pay for the design, testing and manufacture of any monitoring and communication devices. It is important that these devices be sufficiently accurate for their intended purposes, fraud-proof, robust and identical for all providers. Allowing individual providers to develop their own monitoring and communication systems seems a costly pathway to chaos.

2. A data-based aged care system

2.1 Data and help flows in a data-based aged care system



2.2 Prompt help to persons by providers

The flow chart in 2.1 shows data about persons flowing through multiple paths to the Aged Care Agency. No such agency exists at present, but there are many reasons why there should be a single holding point for all aged care data. The Aged Care Agency would immediately transmit individual data to the providers responsible for those individuals, together with automatically-generated warnings where help to the person seemed needed.

Help to persons could take many forms. A fall might require immediate attention. Changes to temperature and pulse rate might indicate an infection. Rises in odour levels would signal incontinence. An unexpectedly vacant room might prompt a search for a wandering resident. A lack of movement in bed might suggest over-medication or a cardiovascular event. Weight loss soon after admission might reflect an unsatisfactory mealtime environment, or unsuitable food.

2.3 Help to providers, and regulatory action where needed

Australia's aged care system exists to provide care to the aged. But providers are a vital part of the system, and also need help. Automatically-generated warnings where help to a person seems needed would assist providers provide better care. Continuing high levels of warning messages could provide strong evidence in regulatory actions against non-complying providers.

The data flows direct from providers to the Aged Care Agency should include financial data, in more standardised formats than at present. This would allow providers in financial trouble, and those potentially heading into financial trouble, to be identified. Regulatory action could include improving the adequacy of the Commonwealth subsidy systems for particular regions or persons with particular care needs, as well as grants to some providers meeting unusual needs.

2.4 Rapid detection of system health threats

Automated monitoring of all persons in residential care could provide strong early evidence of system health threats. For example, rising temperatures and mobility changes amongst residents in different locations could reflect a new antibiotic-resistant infection. Of the seven COVID-19 deaths confirmed in Australia up to 22 March 2020, three were from an aged care facility [3]. Aged care residents may be like canaries in a coal mine, detecting threats.

2.5 Quality of care measurements

The Productivity Commission recommended in 2011 that

“The quality assurance framework for aged care should be expanded to include published quality indicators at the service provider level to help care recipients and their families make informed choices about care and to enhance transparency and accountability about funds spent on care.” [4 p1xxi]

Mandatory quality indicators were not introduced until 1 July 2019 [5], and substantial criticisms about the reporting process have been made by Cumpston, Sarjeant & Service [6]. Automatic monitoring, together with statistical research, should be able to provide objective indicators of quality of care, valuable to consumers, providers and regulators.

2.6 Appropriate Commonwealth subsidies for each care recipient

Eagar et al [7 p8] have proposed a funding model based on resident assessments made by independent assessors. In trials, assessors were able to draw on observation of the resident, interviews with the resident, family and staff, and notes and documents [8 p24]. No information is available on the relative importance of these sources, or on variations between independent assessments of the same resident. Automatically recorded health data would surely assist the reliability of these assessments.

As data become available, the role of the assessors could be modified to forming opinions about particular aspects of an individual's needs. For example, a key aspect of the proposed classification is mobility, and this can be measured by a range of monitoring techniques. Behavioural issues are much harder to measure, and this might be where the

assessors could add most value. The final rating should rest on a combination of automatic measurements and expert assessments.

2.7 Well-timed transitions between care levels

The Commonwealth funds aged care through home support, four levels of home care package, respite and permanent residential care, transition care and other specialized care (see 3.1). Assessment teams are asked to make recommendations about entry into care, and about transitions between care levels. These recommendations might be more reliable if partly based on automatically measured data on the person.

It will be more difficult to monitor persons in their own homes, rather than residential care. It may not be economically feasible to set up equipment to monitor and transmit a range of health variables. Some measurements, such as weight, might have to be recorded manually, and sent to the Aged Care Agency by the provider. It may be possible to record falls and movement data using a wearable device, with periodic downloads to the Agency. The types of service used, and prescriptions, would also be a guide to care needs.

2.8 Research on the cost-effectiveness of different monitoring systems

Monitoring systems are widely used, for example by hospitals and exercise participants. Given the great variations between different aged care recipients, and their complex health needs, some monitoring systems may not be feasible, and others may need considerable adaptation. Large-scale tests should be made, before choosing systems for system-wide use.

Some of the relevant questions will be

- can measurements be made by devices acceptable to the care recipient?
- how often should the measurement be recorded?
- is the measurement sufficiently reliable for practical use?
- will the measurement add predictive power?
- is the measurement cost-effective?

2.9 Research on the needs for different levels of care staff

The data flows from providers to the Aged Care Agency could include each employee's start and stop times each day, together with the employee's level of training. This would allow quality of care and quality of life measurements to be analysed against staff resources, and provide a sound basis for any minimum staff requirements.

2.10 Data access for treating professionals

In evidence to the Commission, Dr Bartone referred to the need for better communication between residential care staff and treating doctors [9 p548]. The Commission has heard evidence regarding issues with information exchange between residential aged care facilities and primary and allied health providers [1 p71]. Information transfer may also be a problem when aged care residents transfer to or from hospitals. The proposed data-based aged care system could reduce these problems.

2.11 Data access for researchers

The much greater volumes of data in the proposed system would allow much better research into ways to help aged care recipients. The Australian Institute of Health and Welfare is a very effective way to distribute aged care data to researchers, while observing privacy requirements. It would be valuable if aged care data could be provided to the Institute at monthly rather than yearly intervals, as this would allow quicker detection of emerging trends. Cost issues have caused some important data to be not supplied. For example, the Institute has not received any ACAP assessments since June 2015.

2.12 Estimated data volumes in a year for a data-based system

Data type	Collection cycle	Bytes of data per collection	Data pa gigabytes
Weight	Minutes	8	841
Movement	Minutes	8	841
Geographic co-ordinates	Minutes	16	1682
Falls	Minutes	8	841
Pulse rate	Minutes	8	841
Body temperature	Minutes	8	841
Odours	Minutes	16	1682
Staff logons & logoffs	Daily	24	1.8
Diagnoses	Monthly	256	0.6
Prescriptions	Monthly	256	0.6
Pathology tests	Quarterly	256	0.2
Total			7572

The above table is incomplete, and based on some very uncertain assumptions. It suggests that the data collected in a year might be of the order of 10,000 gigabytes. Mobile phones can be bought with up to 1000 gigabytes of storage. These rough estimates suggest that the data collected in a year might fit into about 10 mobile phones.

3. The present aged care system

3.1 Persons receiving care in 2018-19, and sources of funds

Type of care	Persons receiving care	Commonwealth funds \$m	Personal funds \$m	Funds per person \$
Permanent residential	243,561	12,642	5,043	72,611
Respite residential	66,327	392		5,910
Home care packages	135,404	2,469	128	19,180
Home support	840,984	3,333	230	4,237
Transition care	28,834	177		6,139
Other		869		
Total	1,315,110	19,882	5,401	19,225

Persons receiving care at any time in 2018-19, and Commonwealth funds, are from [10]. The figures available for transition care are admissions, and the numbers receiving transition care at any time in 2018-19 were estimated by adding 20%. The split between permanent and respite expenditure was obtained from [11]. Personal funds were estimated from [12], allowing for 5% growth between 2017-18 and 2018-19.

Persons can receive more than one type of aged care in a year, so the total of 1.315 million persons receiving care in 2018-19 is misleading. Counting only the permanent residentials and home support cases suggests about 1.1 million received at least one form of aged care.

3.2 Data volumes in present aged care system

Data type	Source	Period	Size megabytes	% data included	Data pa megabytes
ACAP	AIHW	1/7/12-30/6/15	314	80%	131
ACFI	AIHW	1/7/15-30/6/16	177	80%	221
HCP	AIHW	1/7/18-30/6/19	6.8	20%	34
Service list	AIHW	30/6/19	0.7	80%	0.8
Complaints	ACQSC	1/1/14-31/3/19	6.4	20%	6.1
Sanctions	DoH	2018	0.1	80%	0.1
Notices of non-compliance	DoH	2018	0.2	80%	0.3
Consumer experience reports	ACQSC	3/9/18-18/6/19	0.2	5%	5.6
Financial statements	DoH	1/7/18-30/6/19	0.3	50%	0.7
Mandatory quality indicators	Estimate	1/7/19-30/6/20	0.2	100%	0.2
Total					400

The table shows the sizes of nine data samples received for different purposes, together with very approximate estimates of the sizes of the files needed to hold all the data collected in a year. The sample file of consumer experience reports had only totals for each residential care service, rather than the responses of each individual, so may only have been about 5% of the data collected. The data files were all comma separated variable files, not a particularly efficient form of storage.

From these very approximate estimates, it seems likely that all the data collected for aged care purposes in 2018-19 was less than one gigabyte (1000 megabytes). A mobile phone could thus hold about 1000 years of present aged care data.

4. Data principles

4.1 Keep all the data

Stephenson [13 p5] noted that, as a result of the plummeting cost of disk storage,

“It became cheaper to store useless data rather than filter and discard it ... we exchanged the challenge of managing scarcity for the challenge of managing over-abundant data.”

An example of false economy was provided by the Aged Care Funding Instrument (ACFI), introduced in March 2008, which allowed only three fields for recording physical health conditions. As providers increasingly recorded conditions that increased their Commonwealth subsidies, reported numbers of clinically important conditions dropped.

“...many websites are now storing all data from each online visit, allowing them to look back and ask detailed questions. The scale of this customer journey is typically several gigabytes per day for smaller websites and several terabytes per day for larger sites.” [13 p9]

This suggests that e-commerce websites generate between a thousand and a million gigabytes of data a year. In 1.12, a data-based aged care system was estimated to generate about ten thousand gigabytes a year.

4.2 Don't aggregate data

We get great value from tables and charts, based on aggregates of data. But aggregation is a very poor way to store data, as it prevents many useful analyses. For example, insurers are required to make provisions for late-reported claims, but such claims are usually of a different nature to promptly reported claims. An actuary supplied only with aggregate data about claims will not be able to make useful estimates of late-reported claims. What is needed are data on individual claims, including their incidence and report dates. This is an example of “unit record” data.

An extreme example of aggregation is required by the mandated quality indicators [5], introduced on 1 July 2019. For example, weight loss is defined to have occurred if monthly weight measurements in a quarter fit either of two criteria. No data on actual weight are reported. No identity details are provided for the persons reported as losing weight, preventing cross-analyses against other physical and mental conditions. Longitudinal analyses of ongoing weight changes by individuals are impossible in such a system.

4.3 Keep all the data from an individual linked

Persons needing aged care are likely to have complex health conditions, evolving over time. It is important that all the data for a person be linked, allowing longitudinal and multivariable analyses.

Analyses of the consumer experience reports introduced in May 2017 have been severely restricted by the absence of links with the health conditions of the sampled residents. Apparent improvements in reported satisfaction may reflect increasingly biased sampling, rather than real improvements.

4.4 Data: the more the better

“More data generally enables better analysis. It improves some analysis and completely transforms others. It’s like adding power tools to a set of hand tools. Some jobs you can do better, and some that were previously not feasible suddenly become feasible.” [13 p39]

Additional data types may show new dependencies within the data. For example, Wells & Solly [14] found much higher probabilities that residents at smaller aged care homes would report positive satisfaction. By adding additional variables, Cumpston [15] showed that ownership (for-profit or not-for-profit) and location (city versus regional) were also important, and that the size effects were smaller than those found by Wells & Solly.

Increasing the volume of data is likely to reduce the uncertainty in coefficient estimates, and thus allow more reliable projections.

4.5 Use a range of data analysis tools

Many computerised data analysis tools, using statistical methods, have been available for many years. In the last 20 years, other tools, not based on statistical models, have been developed to help use big data. Some of the many tools now available are

- Multivariate regression
- Principal component analysis
- Functional data analysis
- Decision trees
- Random forests
- Support vector machines
- Artificial neural networks.

A common approach is to apply several different tools, and select the one giving the best results.

The funding model for residential care proposed by Eager et al [7 p33] used a classification and regression tree model, which subdivided data on 1655 residents into 13 classifications. Splits into classifications were done by removing those in palliative care, and then using a mobility index to split into independent, mobility assisted and not mobile groups. The independent group was split into two classifications, using regression analysis, with independent variables including “RUG-ADL, AM-FIM cognition, AKPS, daily injections and behaviour”. In all, 5 regression equations were used to create 10 of the 13 classes, using at least 15 independent variables. This classification and regression tree model was partly chosen on the basis that an additive model would have ignored the interactions between concurrent problems experienced by residents [8 p6].

4.6 Use sufficiently transparent models

*“...we sometimes use the term **model transparency** to indicate the ease with which a model can be explained and understood intuitively, particularly for a non-technical audience ... Model transparency is particularly important for applications where outcomes must be explained to healthcare patients, government regulators or consumers.” [13 p129-130]*

The details of the 5 regression equations underling the Eagar et al funding model have not been made public. But it is clear that the model is unintelligible to anyone without statistical training. More data might have allowed the fitting of a model with more classifications but no regression equations. Experiments could have been made with a multivariate regression approach, as used in ACFI, to see if comparable or better statistical fits occurred.

4.7 Avoid undesirable consequences to individuals

Data models are usually fitted by maximising some performance indicator. The residential aged care funding model proposed by Eagar et al was fitted by maximising the “reduction in variance”, giving an overall reduction of 52% [7 p40]. This is an overall measure of how well the model fits the data.

Even though a fitted model may give good overall performance, the form of the model may have undesirable consequences for individuals. For example, behavioural problems appear only in the regression equations of the Eagar et al model. As a result, aged care facilities may have little certainty about the funding available for behavioural problems, and be reluctant to admit persons with dementia. A similar risk of exclusion may arise for obese persons.

4.8 Get independent confirmation

In 1989 Fleischmann and Pons reported anomalous heat, which they ascribed to cold fusion. Independent replications of their work quickly suggested experimental error. Many scientific and economic journals require source data to be available, so that independent analyses can be made. Individual researchers may be biased towards particular tools, or miss important issues. Duplication of research is very cheap in relation to the cost of the aged care system.

5. Transparency issues

An application under the Freedom of Information Act 1982 for a copy of the five regression equations fitted by Eagar et al [7] was refused. An internal review [16] confirming the refusal said in part

“I am satisfied from the advice provided by the subject matter experts and third party submissions that disclosure of the algorithm is reasonably likely to open the system to manipulation.

I am satisfied that even with robust measures to reduce vulnerability to fraud, that this would not eliminate the possibility of fraud occurring if the algorithm was released.

I am also satisfied that the release of the classification systems would, or could reasonably be expected, to have a substantial adverse effect on the department’s operations in managing a new funding model for the residential aged care sector.”

These reasons imply that the Department is concerned about manipulation and fraud within the ACFI system. The Department appears to believe that fraud risks will continue, even with external assessors. But it is hard to see how disclosing the details of a draft funding

model would affect the risks in the final model, which should be based on much more data, and have a different structure.

The Department clearly intends to keep the details of the final funding model confidential. Care providers will be asked to accept or reject applicants, without any clear idea of their care needs or likely Commonwealth subsidies. This will not be an environment encouraging co-operation between providers and the Department. The legality and practicality of such a secretive approach must be suspect.

6. Privacy issues

6.1 Unavailability of financial data on aged care providers

Confidentialised financial reports for each aged care provider were published by the Department from 2006-07 to 2014-15, and since then have been available through FOI requests [20]. The actual reports have never been published, for reasons that are not known. By contrast, financial data for each general insurer have been published by the Australian Prudential Regulatory Authority since 1999 [21].

As aged care providers receive the bulk of their funding from the Commonwealth, it seems reasonable that their financial positions should be publicly known. This is important for consumers choosing between providers, but it is also important for researchers looking at links between quality of care and financial positions.

6.2 Privacy restrictions on present quality data

Under the mandatory quality of care indicators introduced on 1 July 2019, residents have to consent to their data being recorded. As noted in 4.3, analysis of consumer experience reports has been restricted by the lack of links to the health conditions of the respondents.

6.3 Privacy restrictions on data-based aged care systems

Australia has long-established personal privacy legislation. Automatic collection of personal health data, as proposed here, may require personal consents. But most aged people are used to providing personal data to doctors and nurses, and understand that the data are needed for their care. Extensive health data on all persons in permanent residential care have been routinely collected since 2008. Provided the bulk of aged care recipients provide data, very valuable analyses should be possible to help all those in aged care.

Public attitudes about personal data may be changing. We are used to very large amounts of personal data being stored by companies such as Google, Amazon and Facebook. We record large amounts of physical data about ourselves, using devices such as Fitbits. It is more common for the illnesses of politicians and celebrities to be publicly discussed.

7. Transitioning to a data-based aged care system

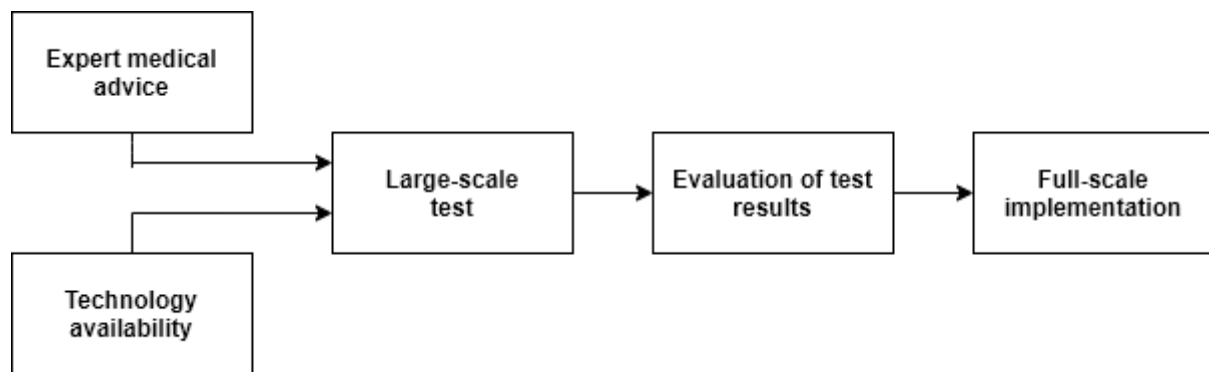
7.1 Develop in parallel paths

Agile project management is an approach

“in which small, multi-functional teams deliver incremental products, which eventually grow into the full solution... It is especially helpful in big data analytics projects, where challenges and benefits are less clearly understood, and more difficult to anticipate” [13 p140-141]

A version of this approach, using parallel paths, seems appropriate for the development of a data-based aged care system. There are many uncertainties about the types of data that may prove cost-effective, and the best ways to measure them. As paths progress, they are likely to provide insights on ways to develop other paths.

7.2 A path flow chart for a proposed monitoring device



Much of the relevant technology and software is likely to have been developed for other purposes, such as hospital monitoring or personal use. Considerable adaption may be needed to fit the needs of a data-based aged care system. Large-scale tests, possibly of the order of 10,000 devices, will be needed.

7.3 Include staff-time measurements early

The Australian Nursing and Midwifery Federation’s call for legislated minimum staffing ratios for aged care has been supported by the Australian Medical Association, the Royal Australian College of General Practitioners, the Australian and New Zealand Society of Geriatric Medicine [22]. But it may be premature to introduce minimum staffing ratios until there is evidence about staff levels needed to give good quality. Automated staff-time measurements should be introduced for residential care as soon as possible, so that analyses can be made of the associations between staff levels and quality of care.

7.4 Improve mandated quality indicators

The present mandated indicators use valuable staff time, are error-prone and vulnerable to fraud. Urgent consideration should be given to using automatic sensors to measure and report more detailed data for central analysis. For example, the estimates in 2.12 assume automatic recording of resident weight each minute, rather than manual weighing each month. The capital costs of data capture, transmission and analysis may be less than the costs of manual weighing and data collation by providers.

7.5 Record diagnoses, prescriptions and pathology tests

Gray submitted that

“The Australian Government should fund and support the development of the Information Communication and Technology systems, linkages with the Pharmaceutical Benefits Scheme and Medicare Benefits Schedule information systems, and linkages with other datasets available to the Australian Institute of Health and Welfare and other government bodies...” [1 p70]

This proposal may create an endless series of inter-agency consultations about procedures to standardise and share data. In the meantime, the aged care data system should capture whatever data it can, in any format, and use intelligent processing to derive value from it.

7.6 Investigate other quality measures

Recipients of aged care have a wide range of health conditions and care needs. Health professionals and care providers should be consulted about ways to measure quality that use little labour, are fraud-resistant, and may be relevant for specific types of care-recipients.

Glossary

ACAP	Aged Care Assessment Process
ACFI	Aged Care Funding Instrument
FOI	Freedom of Information
Gigabyte	10 ⁹ bytes
Megabyte	10 ⁶ bytes
Terabyte	10 ¹² bytes

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