Royal Commission
into Aged Care Quality and Safety

Supplementary Statement of Johanna Irene Mary Westbrook

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1. This statement made by me accurately sets out the evidence that I am prepared to give to the Royal Commission into Aged Care Quality and Safety. This statement is true and correct to the best of my knowledge and belief.
2. The views I express in this statement are my own based on my education, training and experience. They are not intended to represent any views of my employer.
3. This statement is supplementary to my previous statement (**WIT.0196.0001 .0001**) dated 3 June 2019, which was made in response to the Royal Commission's notice NTG-0196 dated 16 May 2019 (**first statement**).

The application of quality of life tools in older populations

4. In my first statement (**WIT.0196.0001 .0001**) at paragraph 75 I mention the research of Professor Julie Ratcliffe at Flinders University. I have considered some further articles and their relevance to the matters addressed in my first statement for the purposes of making this second statement. (See Bulamu et al (2015)[1] [RCD.9999.0094.0031], Ratcliffe et al (2017)[2] [RCD.9999.0097.0007], Ratcliffe et al (2010)[3] [RCD.9999.0094.0073], Bulamu et al (2018)[4] [RCD.9999.0094.0018].
5. This previous work includes research which highlights the importance of utilising preference-based quality of life measures which are specific for use in older populations.

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1 Bulamu N, Kaamwa B, Ratcliffe J. A systematic review of instruments for measuring outcomes in economic evaluation within aged care, *Health and Quality of Life Outcomes* (2015) 13:179.

2 Ratcliffe J, Lancsar E, Flint T, Kaambwa B et al, Does one size fit all? Assessing the preferences of older and younger people for attributes of quality of life, *Qual Life Res* (2017) 26:299.

3 Ratcliffe J, Laver K, Couzner L et al, Not just about costs: the role of health economics in facilitating decision making in aged care, *Age and Ageing* (2010), 39:426

4 Bulamu N, Kaambwa B, Ratcliffe J (2018), Economic evaluations in community aged care: a systematic review *BMC Health Services Research* (2018) 18:967.

Such measures have scoring algorithms based upon research consulting older people about what they value. This is in contrast to generic-preference based quality of life tools which have scoring algorithms based upon the views from a general population sample.

6. Ratcliffe et al 's 2017 study[2] demonstrated that: the ability to be independent; physically mobile; and have control over their daily lives; were the most important determinants of older people's quality of lives. For people aged 18-64 years these factors were less valued in terms of quality of life. Thus, generic preference-based quality of life tools may not be ideal for use in aged and community care settings.

7. Scores from preference-based quality of life tools can be used in economic evaluation studies to calculate Quality Adjusted Life Years (QALYS) and the costs per QALY associated with an intervention/program. Economic evaluation studies which measure the relationship between the costs of an intervention and the benefits that it provides can assist providers, clients and policy-makers in determining which types of services and interventions we should invest in given there are scarce resources. The systematic review[4] by Professor Ratcliffe's group show the paucity of such studies to date in the aged care sector.

8. As outlined in my original witness statement (points 64-7) in our research we selected the ICEpop CAPability (ICECAP-O) which is an older-person specific preference based quality of life tool. Other benefits of the ICECAP-O include that there is some evidence that proxy reports by health care providers and carers (i.e. where these people fill out the survey on behalf of an older person) show good agreement with self-reports of the older person. Also, ICECAP-O has been shown to be reliable among those with mild cognitive impairment and it is short to complete, increasing the likelihood that it will be acceptable and used.

9. In our project, the use of the ICECAP-O, along with a social participation survey tool, were incorporated as part of the standard assessment process for community age care clients by a large service provider. Case-workers and clients completed the surveys together in an interview format which has shown to be helpful with older people.[1]

10. An unexpected, and important result from our research was that this process of completing the surveys became an intervention in itself as it changed the nature of discussions between community care workers and their clients.

11. Case workers indicated they could use information gained to better target their advice and services with a shift in focus to activities which might support clients pursue their interests and enhance their social participation. One case work reported *"I found it quite exhilarating, at times very emotional. Very helpful, it gave me a great insight into how I can help my clients or attempt to help my clients. It definitely helped in the care plan, in planning our care plans.*

12. Clients also reported benefits in just being asked about their lives and letting someone know, for example, that they were lonely or depressed about what they could no longer do. These are often hard conversations to have with family members.

13. A qualitative study lead by Dr Joyce Siette in our team investigated what clients' thought about completing the surveys. These are some of the responses they gave.

" It helped bring things out in the open too. You know, it's, you don't talk with other people because you think they don't want to listen to you anyway.

"I remember that I did [complete the survey]. *Yes. It was good. It makes you realise that everybody is the same but it's not something you talk about it really to someone."*

" That somebody cares, so, it's very, knowing that because as when you were working so, you're not contributing anything so, you think people have forgotten all about you, but when you have these surveys it makes us feel like, yes, people are still interested in us. Well, that's how I felt."

"I think about the questions, I found they are really properly questions because it's important our private life, our participation with this Centre, our participation in the Church and for me I think the questions are really good."

14. Nearly 200 of the 1300 clients who completed these surveys have been re-surveyed 12 months later. Preliminary results indicate that approximately 36% of clients' quality of life score improved, 21% remained the same and 44% declined. Clients with a greater number of of community care service hours were more likely to be in the group who maintained or increased their quality of life.

15. As these data are embedded in the clients' records they can be tracked over time and linked with other data to be able to answer questions such as which programs of services may be most helpful among specific groups. They can also be used in economic evaluation studies.

16. Our team are working with the provider to apply versions translated in Turkish, Korean and Mandarin.

17. I am strongly of the view that the integration of quality of life tools should be a core element of data collected for both residential and community care clients. These should not be anonymous, stand-alone surveys, but seen as of equal importance to clinical assessments which are central to providing appropriate and effective care for clients.

National Residential Medication Chart

18. In my first statement at paragraph 23 I discuss the National Residential Medication Chart. A report from the Australian Commission on Safety and Quality in Health Care called *Phased implementation of the national residential medication chart in NSW residential aged care facilities: Evaluation report 2014* (April 2014) is attached to this statement [RCD.9999.0114.0071].

19. The trial of the electronic (eNRMC) is the only tripartite (GP-Pharmacy-RACF) system that I have been able to identify (following several discussions with colleagues and aged care providers).

20. KPMG has been successful in their application to undertake the evaluation of the e-NRMC pilot for the Commonwealth Department of Health. KPMG are sub-contracting my research centre to conduct the clinical assessment component of this evaluation. In essence this task is to determine how the e-NRMC has impacted upon medication safety in residential aged care facilities. This evaluation is about to commence and will be completed before the end of the year. KPMG will be evaluating other elements such as the impact of the e-NRMC on workflows, data security etc.

21. My initial investigations indicate that there are potentially large positive changes to workflows from use of the eNRMC. In the trial sites, an electronic prescribing function has been incorporated to allow GPs to directly prescribe medications on the electronic chart at the aged care facility. In conjunction with legislative changes introduced as part of the trial a paper version of the chart with ink signatures is no longer required. I have provided two diagrams attached to this statement to illustrate the changes in workflows.

22. Diagram 1 [RCD.9999.0114.0054] illustrates a slightly updated version of the workflow contained in my original article. This represents the current situation among many RACFs that have implemented an electronic medication administration system. In such situations there is an electronic version of the NRMC produced BUT there is no electronic prescribing capacity. There are still legislative barriers in that ink signed charts are required and these must be sighted by RNs when they administer medications to residents. Hence the need to print the charts and have them all signed by a GP.

23. Diagram 2 [RCD.9999.0114.0055] shows how the workflow would change when an electronic-NRMC with an e-prescribing system is implemented. My understanding is that this is the model that has been included in all the pilot sites.

24. In 2018 legislative changes occurred (see the *National Health (Electronic National Residential Medication Chart Trial) Special Arrangement 2018* attached to this statement [RCD.9999.0114.0056]. which removed the need to have any medication charts printed and signed on paper during the trial.

25. As can be seen from comparing the two diagrams, many steps are removed in this model, potentially significantly reducing the risk of medication errors, miss-communication about medications and providing a more efficient process. However until the evaluation is completed we cannot be clear about these outcomes.

26. It should be noted that the GPs in this scenario are not using their practice software to prescribe, but they are able to log into the RACF prescribing system from their practice to view and prescribe. The longer term goal would be for the GP system to directly interface with the RACF system. This step is dependent upon the IT vendors of both types of systems to allow their systems to 'talk to each other'. I would also mention that some facility staff has voiced concerns that when GPs no longer need to visit a facility to prescribe medications, they may receive many fewer visits from GPs, which would be concerning.

US and Canadian indicators

27. At paragraph 80 of my first statement I mention standardised reporting of national quality indicators. The United States and Canada use Quality Indicators and data in regulation. My colleague Dr Kim Lind at Macquarie University has conducted an assessment of US and Canadian indicators to see whether they can be measured using existing data stored in Australian RACFs that use a clinical information system such as iCare, using a data analytics approach to manipulate that data. Attached to this statement is that feasibility assessment [RCD.9999.0114.0120].

Utilisation of electronic health records in aged care

28. There is a need for greater understanding as to the take-up of electronic health records systems in aged care in Australia, from which data for data analytics of the kinds I have outlined in my statements could be drawn.

29. In 2018 Professor Greg Alexander (while visiting from the US as a Fulbright scholar) conducted a survey of RACFs to determine the level of IT system use.[5] He sent a survey to 876 RACFs in NSW. 130 responded (a response rate of 14.8%). This is not a high response rate and it is possible that those Facilities that did respond may not be representative of the overall population of RACFs in NSW. Some of his key results were:

    a. 90% of facilities indicated that they used an IT system for administrative functions such as recording admission details of clients.

    b. 84% of facilities indicated that they entered their incident data into an IT system.

    c. 56% of facilities reported using an electronic medication administration system (NB, not prescribing).

    d. Not-for-profit facilities tended to have greater IT system coverage compared to other providers

30. In discussion with some IT vendors, it would seem reasonable to estimate that around 40-50% of RACF beds would be covered by some form of electronic clinical system which includes medication administration functions. For example, staff from Telstra Health, (personal communication June 2019), one of the largest IT system vendors in the sector indicated that their iCare system covers around 60,000 beds, which is ~30% of aged care beds. Of these, 70% (42,000 – i.e. 22% of all aged care beds) use Telstra Health's electronic medication administration system. There are 4-6 other reasonably large IT vendors offering similar systems.

31. In May 2019, The Australian Commission on Safety and Quality in Healthcare put out a Request for tender –"Clinical Safety Review 17: My Health Record in Aged Care" to conduct a project with the purpose to "establish a contemporary baseline understanding of current electronic health record (EHR) systems across Australian residential aged

5 Alexander Gregory L., Georgiou Andrew, Siette Joyce, Madsen Richard, Livingstone Anne, Westbrook Johanna, Deroche Chelsea (2019) Exploring information technology (IT) sophistication in New South Wales residential aged care facilities. *Australian Health Review*: https://doi.org/10.1071/AH18260.

care facilities (RACFs), including My Health Record (MHR) functionality and workflow related insights". No information appears to have yet been made publicly available from this project.

Some Overall Key Messages to the Royal Commission

1. **Implement electronic information systems which integrate administrative, financial and clinical information, by all aged care providers *(residential and community care providers)***

32. Paper record systems are no longer fit for purpose and cannot meet future needs. Paper systems prevent the re-use of information for multiple purposes and lock up valuable information. The aged care sector requires access to timely, quality data to manage clients, to monitor quality and safety, to identify if interventions and policy reforms are effective in driving improvements, and to provide the community and individual clients with access to meaningful information to guide decision-making.

33. Creating a quality standard mandating the use of electronic information systems which captures a national minimum dataset would drive substantial change.

2. ***Improve the functionality of aged information systems and the exchange of electronic information between the aged care sector and other providers including GPs, community pharmacists, hospitals, and specialists***

34. The aged care sector currently relies heavily on faxing, scanning, emailing and in some instances mailing information between external care and service providers. This system increases the risk of error, is resource intensive and inefficient.

35. The functionality of existing aged care information systems could be vastly improved to support the information needs of the sector. This requires a collaborative approach between IT vendors, aged care clients, providers, government and researchers to design system features which support improved quality and safety of services.

36. Multiple strategies and partners are required. There are pockets of advancement underway e.g. The Australian Digital Health Agency's work on secure messaging could be leveraged; The Commonwealth Department of Health trial of the e-NRMC (following evaluation results) presents as a possible model in relation to medication information exchange. Creating incentives and drivers for IT vendors to facilitate greater information exchange and make substantial improvements to their clinical information systems are vital.

37. There are some models for achieving greater industry buy-in. For example, the Australian Digital Health Agency made an 'Industry Offer' to the core (~7) IT vendors providing IT systems to community pharmacies. The Agency provided modest funding to IT vendors to make software upgrades to allow community pharmacy systems to be able to access My Health Record. Currently around 82% of pharmacies can access My Health Record. Of ~ 900 aged care providers approximately 236 have access to My Health Record (personal communication with the Australian Digital Health Agency, June 2019).

3. Decide upon a national standard aged care dataset (which includes a quality of life measure) which all aged care providers collect, and store electronically

38. This dataset should support multiple functions (i.e. information required to support: funding models, day-to-day care of clients, monitoring of quality and safety, assessment of the impact of interventions, services and policy reforms on clinical and quality of life outcomes and transparent reporting to the community).

39. While there is existing substantial work underway developing a clinical assessment dataset for use with a new funding model[6] there does not appear to be any measure of well-being included. Siloed projects have the potential to result in perpetuating collection of separate datasets for different purposes. Attention should be paid to ensuring a holistic view of the information required to satisfy the multiple information needs of the aged care sector.

40. Variables and measures that are important to clients and their families and which allow this information to be reported in timely and meaningful ways to the community must be included. The central principle is that data are entered once in an electronic system and re-used for multiple purposes. Investments in improving the quality of these data will therefore benefit multiple outputs. Further, these aged care data can be linked to other external data sources to support evaluation of national aged care policy and programs.

4. Use existing data in more effective ways to support care processes and improve outcomes

41. The sector should shift from a focus on detailed manual care audits to investing in improving the quality and effective use of routine data in electronic systems. These electronic data can be used to generate more sophisticated quality indicators, such as risk-adjusted pressure injury rates (as discussed in my witness statement at points 34-50). Auditing processes are resource intensive, duplicate information which currently exists in other systems and prevents the analyses of data to produce meaningful comparative outcomes.

42. Innovative ideas need to be trialled and attention needs to be placed on designing better IT systems which adopt more sophisticated ways of presenting collected information to make it useful to carers and residents themselves. Computers are excellent at bringing together seemingly disparate information to provide an overall picture of what is happening to a client. For example, a computer algorithm can bring together information about changes in a client's medication profile, incidents which have occurred such as falls, a decline in participation in social activities etc, to trigger an alert that this client is deteriorating and requires attention. While each of these components of information may currently be readily available in a client's record, it requires someone to take a holistic view to detect the emerging picture. Computer analytics, predictive analytics and electronic decision support can support this process.

6 See https://agedcare.health.gov.au/reform/resource-utilisation-and-classification-study, accessed July 2019

43. Ideas such as providing clients with tools to provide real-time input into their own records or to alert staff to problems, could be tested. A simple example could be that residents are given access to an iPad which contains a well-being scale, or allows entry of free text, whenever they want to signal to staff that things may be not going well for them. Rather than be locked on a paper form, this information can be shunted electronically to multiple channels, including to family, to increase the likelihood of action.

44. There are models from other sectors which can be considered. For example, some hospitals have systems available where patients use iPads to provide real-time feedback to hospital staff (for example if they are worried about something or want to make a complaint, etc). Complaint information is immediately sent through to management staff to address, or a message can be sent to the patient's doctor or nurse in charge of the ward. An existing system used in NSW hospitals is called patient experience & consumer engagement (PEACE).[7] There are also companies that offer the technology for these type of real-time surveys.[8]

45. The coming generations of older people seeking aged care services will be increasingly information technology savvy and have greater expectations that they contribute to, and have control over, information to guide their care plans.

Some possible considerations in terms of driving change

Potential sources of funding which may assist

46. Innovative applied aged health services research will be central in supporting more effective evidence-based approaches and supporting and evaluating the effects of reform. The Medical Research Futures Fund (**MRFF**) may assist. Government has allocated ~$20B to this new research fund and intends to allocate ~ $1.4B in the first five years.

47. The priority areas are set by the MRFF Advisory Board. Current priorities include Ageing and Aged Care. Here the outcomes of the Royal Commission into Aged Care Quality and Safety is specifically mentioned and thus recommendations which may lend themselves to large-scale collaborative applied research initiatives to support change is an opportunity.[9]

48. Incentive schemes by government could be considered for aged care providers and to the IT industry to adopt evidence-based interventions/programs, such as those reported by Professor Brodaty on person-centre care initiatives; or projects which demonstrate

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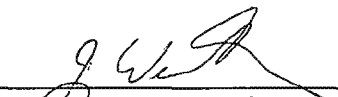
7 See https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0017/253025/Patient-Experience-Trackers-Factsheetv2.pdf

8 See for example: https://patientengagementhit.com/news/real-time-patient-experience-surveys-key-for-practice-improvement, and https://www.picker.org/case-studies/using-real-time-feedback-to-improve-patient-care/

9 See https://beta.health.gov.au/resources/publications/australian-medical-research-and-innovation-priorities-2018-2020, page 3

innovative use of electronic health record data to monitor care outcomes for residents and clients more effectively, etc. Such a program should include the requirement to evaluate and monitor outcomes.

Signed: 

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