VICTORIAN INSTITUTE OF FORENSIC MEDICINE

MONASH University

RECOMMENDATIONS FOR PREVENTION OF DEATHS OF YOUNG PEOPLE IN RESIDENTIAL AGED CARE SERVICES

Health Law & Ageing Research Unit

Department of Forensic Medicine

Monash University

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Title Page

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Conflict of Interest

The authors have no conflicts to declare.

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Disclaimer

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Glossary

ABI	Acquired Brain Injury
ACFI	Aged Care Funding Instrument
GP	General Practitioner
IRS	Reporting System
MS	Multiple Sclerosis
NACA	National Aged Care Alliance
NCIS	National Coronial Information System
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NGT	Nominal Group Technique
RAC	Residential Aged Care
RACS	Residential Aged Care Services
SDA	Specialist Disability Accommodation
VIFM	Victorian Institute of Forensic Medicine

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Contents

Table of Contents

Executive Summary

In Australia there are over 6000 people under the age of 65 years in Residential Aged Care Services (RACS) each year. This situation is widely regarded as inappropriate as the system in general does not provide an environment suitable for the provision of high-quality care and life for younger people in RACS.

Improving the quality of care for younger people living in RACS in Australia requires a better understanding of the subject matter as a whole. The information from our research contributes to reducing the risk of injury-related deaths among younger people in RACS by developing evidence-based information for prevention strategies.

Three methods were applied to develop evidence for this report: 1) a literature review 2) a retrospective review of deaths among young people in RACS reported to Australian coroners and 3) expert consultation forums. From this analysis 10 recommendations to reduce the risk of harm among young people in RACS were formulated for consideration by RACS providers, government, agencies and professionals working in the field.

Principles of Recommendations

These recommendations should be considered as a way for improving the care of all people in RACS. Furthermore, these recommendations are underpinned by an aged care sector which embodies a philosophy that ensures that the care of all people in RACS is focused on individualised care needs and wishes, regardless of the resident's characteristics such as age, race or creed.

Principle 1: That each person is an individual and should receive tailored care

This notion is deemed as the ideal situation for aged care providers. Though younger people as a cohort have differing characteristics to older counterparts, the individualism of each person

cannot be ignored. Despite researching the cohort of younger people in RACS, each resident's care should be reflective of their individual needs and desires.

Principle 2: That safety is just one element of quality of life

These recommendations should be about enhancing the quality of life of which safety is just one element. Being an injury prevention study, these recommendations are skewed towards people's safety.

Summary of Recommendations

1. That educational resources and specific training programs to address cultural and condition-specific needs of younger people are developed and made available to RACS staff who are regularly involved in care of younger people.

2. That a proactive, multidisciplinary and collaborative approach be taken to assist younger people in RACS their family and staff to understand and be aware of their rights and choices to access services and equipment funded through the NDIS and other community services.

3. That primary care health professionals (including; GPs, allied health professionals and specialists) and RACS staff are educated and supported to provide individualised and coordinated care to improve access and delivery of required general medical assessments and condition specific care of younger people in RACS.

4. That a national collaborative support and advocacy network incorporating consumers, disability advocates, RAC providers, medical, nursing, allied health and other stakeholders be developed and implemented to improve the care and lives of younger people in RACS.

5. That better Specialist Disability Accommodation (SDA) and more housing stock is created for people with disability, especially for young people living in aged

care allowing for the appropriate housing stock and supports to promote alternative models of care. Although NDIA and government sector are currently addressing an increase in funding would expedite the progress of this initiative.

6. That RACS apply the supported decision-making model for younger people in RACS, specifically to empower younger residents' decision making surrounding their quality of life and respecting the principle of 'dignity of risk'.

7. That the health, law and ageing research unit's recommendations from 2017 for prevention of injury related deaths in residential aged care services be reviewed by the original research team, medical, nursing and allied health professionals to determine their outcomes to date and to identify those pertinent to younger people in RACS.

8. That the national disability and health care systems better support the provision of rehabilitation programs and access to health professionals to ensure that all younger people in RACS have access to the appropriate therapy, promote reablement and capacity building for their condition.

9. That the clinical response to an adverse incident involving younger people in RACS is appropriate and aligned with the residents' advanced care plan.

10. That all incidents with a severe or fatal outcome (IRS grade 1 and 2) involving a younger person in RACS are externally investigated, the findings collated, analysed and stored in a single nation-wide database. Incidents of lesser severity should be internally reviewed and subjectable to audit by the Australian Aged Care Quality Agency.

These recommendations complement our team's previous work.

http://www.vifmcommuniques.org/wp-content/uploads/2017/12/Recommendations-for-Prevention-of-Injury.pdf

Background to improving Quality of Care and Safety for Young People in Residential Aged Care

ANNA CARTWRIGHT, ALEXANDRA HOPKINS, JOSHUA ZAIL, JOSEPH E IBRAHIM

Introduction

Each year in Australia, 2000 young people (defined as being under 65 years old) with disabilities are admitted to Residential Aged Care Services (RACS).[1] This situation is considered to be an inappropriate approach to providing care and housing for this population. The majority (58%) of the young people in RACS in Australia have an acquired brain injury (ABI), while approximately 31% have degenerative neurological conditions such as Multiple Sclerosis (MS) and Huntington's Disease.[2] [3] [4] These conditions can lead to difficulties in swallowing that may result in an increased risk of choking.[5] One study noted that 42% of people under 50 years of age living in RACS in Victoria, Australia had swallowing difficulties.[6] Similarly, these conditions can cause difficulties with balance, thus increasing the risk of injury through falls.[7]

Morbidity and Mortality of Young People in RACS

The paucity of information about the health and welfare of young people in RACS extends to a virtual absence of empirical research into the extent of injury and death among this population and potential interventions that might reduce these issues.

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[1] Parliament of Australia. Answers to Estimates Questions on Notice Social Services Portfolio (Official Hansard), S.C.A. Committee, Editor. 2017.
[2] Winkler D, Farnworth L, Sloan S. People under 60 living in aged care facilities in Victoria. Aust Health Rev. 2006;30(1):100-8
[3] Winkler D, Sloan S, Callaway L. Younger people in residential aged care: Support needs, preferences and future directions: Summer Foundation; 2007: 1-132. Available from: https://www.summerfoundation.org.au/wp-content/uploads/SF-YPIRAC-Support-Needs-2007.pdf
[4] Australian Institute of Health and Welfare (AIHW). Younger people with disability in residential aged care program final report on the 2007–08 Minimum Data Set. 2009:1-74. Available at: https://www.aihw.gov.au/reports/aged-care/younger-people-disability-aged-care-2007-08-final/contents/table-of-contents
[5] Reference 3
[6] Reference 3
[7] White LJ, Dressendorfer RH. Exercise and multiple sclerosis. Sports Med. 2004;34(15):1077-100.

However, the little research into the physical risks of RACS for young people indicates that younger people are at risk of being injured and dying from preventable incidents.[8] [9]

Injury among Young People in RACS

One study observed that in a 12-month period 67% of participants consisting of people under the age of 50 years in RACS had an illness or infection and 36% had an injury.[10] The study indicated that choking and aspiration were the leading causes of injury (both fatal and non-fatal) in this cohort.[11] Young people in RACS are also susceptible to secondary conditions (including respiratory infections, falls and other injuries) due to their high care needs.[12] These secondary conditions and the risks posed to young people in RACS can lead to deterioration in health and sometimes result in death.[13] However, it has been noted that many of the risks posed to young people in RACS are preventable.[14]

Deaths among Young People in RACS

Death is the most extreme outcome of an incident or injury event and is the most common reason for permanent discharge of young people from RACS [15]; however, there has been little reporting on the causes of death of young people in RACS. The majority of deaths among younger residents in RACS occur within the first two years following admission.[16]

[8] Dearn L. "Permanent discharge": deaths of people under 50 years of age in residential aged care in Victoria. J Law Med. 2011;19(1):53-68.
[9] Reference 3
[10] Reference 3
[11] Reference 3
[12] Kinne S, Patrick DL, Doyle DL. Prevalence of secondary conditions among people with disabilities. Am J Public Health. 2004;94(3):443-5.
[13] Department of Health Services, Victoria. Creating new opportunities: responding to the needs of younger people in Victoria's residential aged care services 2005.
[14] Sutton JP, DeJong G. Managed care and people with disabilities: framing the issues. Arch Phys Med Rehabil. 1998;79(10):1312-6.
[15] Reference 8
[16] Reference 13

Despite many of these deaths being accounted for by residents with poor prognoses being admitted, it is unlikely that their underlying degenerative conditions account for all deaths.[17] [18] The rate of death of young people in RACS was reported to be 21.4 per year from 1999 to 2005.[19]

Development Expert Consultation Forums

The production of 104 recommendations for injury prevention in the aged care system by Monash University shows the potential of stakeholder and expert consultation using the Nominal Group Technique (NGT).[20] The research in this thesis follows the same procedures as those studies.

This study forms the 8th component to this research program and followed the same methods. A detailed account of such methods can be found in the *Recommendations for Prevention of Injury-Related Deaths In Residential Aged Care Services* by the Health Law and Aging Research Unit, Department of Forensic Medicine at Monash University (Ibrahim, 2017).[21]

Conclusion

There is relatively little research on young people in RACS. More research is required to truly understand the intricacies of this issue and to develop sustainable and effective solutions.

There is a tremendous opportunity for Australia to improve the lives of young people.

[17] Reference 13
[18] Reference 3
[19] Reference 13
[20] Ibrahim J. Recommendations for prevention of injury-related deaths in residential aged care services. Southbank: Monash University; 2017. [cited 2018 Aug 5]. Available from: http://www.vifmcommuniques.org/wp-content/uploads/2017/12/Recommendations-for-Prevention-of-Injury.pdf
[21] Reference 20

Detailed overview of recommendations

Recommendation 1

That educational resources and specific training programs to address cultural and condition specific needs of younger people are developed and made available to RACS staff who are regularly involved in care of younger people.

Aim:

To increase staff capacity to prevent injury and premature death of young people in RACS and enhance quality of life.

Rationale:

Younger people suffer from different disabilities, such as ABI, MS and Huntington's compared to the older cohort in RACS.[22] These conditions have been shown to pose an increased risk of incidents such as choking and aspiration which may lead to injury or death. Choking has been described as a leading cause of death in younger people in RACS, this contrasts with the leading cause of death in older residents, which is falls.[23] This highlights the differences in complex care needs for younger people in RACS, the accommodation of which has been shown to be unmet.[24]

Actions:

This can be achieved by:

- Production of pertinent educational resources through consultation with experts in the field and evidence-based research.
- Providers offering access to the resources developed as part of the staff members' professional development.
- Policy makers working with Universities and TAFE to develop and implement a national mandatory program incorporating young people education and training into the aged care qualification into the aged care qualification curriculum.

Limitations:

Potential limitations of this recommendation and barriers to implementation include funding, resources, and time. This initiative requires investment to implement on a nation-wide scale and would require resources such as trainers and educational materials. The effort would need to be directed to supporting staff to attend and access this training with incentives.

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[22] Reference 3

[23] Ibrahim J. Recommendations for prevention of injury-related deaths in residential aged care services. Southbank: Monash University; 2017. [cited 2018 Aug 6]. Available from: http://www.vifmcommuniques.org/wp-content/uploads/2017/12/Recommendations-for-Prevention-of-Injury.pdf

[24] Winkler D, Sloan S, Callaway L. People under 50 with acquired brain injury living in residential aged care. Brain Impair. 2010;11(3):299-312.

Recommendation 2

That a proactive, multidisciplinary and collaborative approach be taken to assist younger people in RACS their family and staff to understand and be aware of their rights and choices to access services and equipment funded through the NDIS and other community services.

Aim:

To ensure that every young person in RACS can easily access the services they wish to access and that no young person is involuntarily omitted from access to such services.

Rationale:

Parts of the aged care system also sit within the broader Australian Health Care System. This contributes to concerns that young people in residential aged care are getting caught between multiple systems.[25] This is exemplified by the recent implementation of the National Disability Insurance Scheme (NDIS). Young people living in RACS are eligible to receive assistance from the NDIS including planning and assessment, assistance with care-related costs (excluding daily living expenses or accommodation), support to age-appropriate networks, therapy and allied health support and specialist equipment.[26] However, there is still general confusion about how the NDIS fits into the existing aged care sector (National Aged Care Alliance, 2016).[27] The Senate Standing Committee on Community Affairs found that there was a lack of clarity and contradicting evidence surrounding the role of the NDIS and that this uncertainty extended to individuals, families and service providers (Community Affairs References Committee, 2015).[28]

Actions:

This can be achieved by:

- RACS staff being encouraged to seek and be receptive to consultation with NDIS support coordinators.
- RACS staff and managers are made fully aware of the benefits that they are eligible for through the NDIS and how this differs through funding via the ACFI.
- Younger residents and significant others continue to be made aware of their entitlements under the scheme.

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[25] National Aged Care Alliance. Improving the interface between the aged care and disability sectors. 2016. [cited 2018 Aug 6]. Available from: http://www.naca.asn.au/Publications/Improving%20the%20Interface%20Between%20the%20Aged%20Care%20and%20Disability%20Sectors.pdf

[26] National Disability Insurance Scheme (NDIS). Younger people in residential aged care. Supports the NDIS will fund for younger participants in residential aged care [press release]. 2013. [cited 2018 Jun 15] Available from: https://www.ndis.gov.au/document/supports-ndis-will-fund-younger 45

[27] Reference 25

[28] The Senate Community Affairs References Committee. Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia. Canberra, Australian Capital Territory: Commonwealth of Australia; 2015.

Limitations:

Potential limitations of this recommendation and barriers to implementation include coordinating and navigating this suggestion with the rollout of this scheme. The implementation of this recommendation would also require changing perceptions of workers within the sector to overcome institutional and systemic barriers.

Recommendation 3

That primary care health professionals (including; GPs, allied health professionals and specialists) and RACS staff are educated and supported to provide individualised and coordinated care to improve access and delivery of required general medical assessments and condition specific care of younger people in RACS.

Aim:

To improve the identification, treatment and management of preventable conditions and deterioration among young people in RACS.

Rationale:

Difficulties experienced by primary carers to provide coordinated care for people in RACS has been documented.[29] Common obstacles to providing such care are organisational barriers, low levels of reimbursement, the time-consuming nature of appointments.[30] Moreover, GPs often do not have formal links with the RACS, further obstructing the provisions of care.[31] The current political landscape has also been reported not to support GPs visiting RACS leading to unnecessary barriers to quality medical services in RACS.[32] Thus, educating and supporting the primary health providers in the care of younger people in RACS is supported by the current understanding of this interface.

Actions:

This can be achieved by:

- Increased awareness among providers about the access issues of health care professionals in aged care.
- Development and distribution of educational material to health care professionals around the medical assessments relevant to young people in RACS.

Limitations:

Potential limitations of this recommendation and barriers to implementation include changing perceptions of workers within the sector to overcome institutional and systemic barriers.

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[29] Dwyer D. Experiences of registered nurses as managers and leaders in residential aged care facilities: a systematic review. Melbourne, Australia:2011;388-402.

[30] Gadzhanova S, Reed R. Medical services provided by general practitioners in residential aged-care facilities in Australia. Med J Aust. 2007;187(2):92-5

[31] Reference 30

[32] Australian Medical Association. AMA submission to the Aged Care Workforce Strategy Taskforce – the aged care workforce strategy. Australian Capital Territory Australian Medical Association; 2018. [cited 2018 Aug 9] Available from: https://ama.com.au/system/tdf/documents/AMA%20submission%20to%20the%20Aged%20Care%20Workforce%20Strategy%20Taskforce.pdf?file=1&type=node&id=48123

Recommendation 4

That a national collaborative support and advocacy network incorporating consumers, disability advocates, RAC providers, medical, nursing, allied health and other stakeholders be developed and implemented to improve the care and lives of younger people in RACS.

Aim:

To promote communication, education, training and sharing of learnings between RACS with young residents.

Rationale:

Community based health-related content websites provide a single point for multiple stakeholders to interact and contribute. Such E-communities to share experiences, ask questions or provide support have been implemented across a variety of topics in the healthcare sector.[33] This may provide an opportunity for collaboration among stakeholders such as; aged care providers, agencies, professionals and consumers in the issue of young people in RACS. However, research into peer-peer support networks and communities related to health rarely detail the effect these groups have on consumers.[34]

Actions:

This can be achieved by:

- Identification of key participants to involve in the network.
- Research into the identification of the optimal platform to use for this support network.
- Collaboration with key stakeholders and experts surrounding the issue of young people in RACS.
- Promotion the use of this network to users.

Limitations:

Potential limitations of this recommendation and barriers to implementation include issues with uptake and utilisation of forums. It may also prove difficult to determine an effective form for this network.

[33] Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. BMJ. 2004;328(7449):1166.

[34] Reference 33

Recommendation 5

That better Specialist Disability Accommodation (SDA) and more housing stock is created for people with disability, especially for young people living in aged care allowing for the appropriate housing stock and supports to promote alternative models of care. Although NDIA and government sector are currently addressing an increase in funding would expedite the progress of this initiative.

Aim:

To reduce the number of young people forced to live in RACS and increase the availability of appropriate alternatives that they may wish to pursue.

Rationale:

Currently, the disability accommodation market is fragmented with limited housing stock available. As of July 2016, the NDIS introduced the Specialist Disability Accommodation (SDA) payment policy which budgets $700 million to SDA annually.[35] The Summer Foundation estimates that $2.5 billion is needed to create housing for the ~6,000 young people currently living in RACS in Australia.[36] Additional funding is also needed to develop housing for the 2,000 young people entering RACS annually in Australia (Parliament of Australia, 2017).[37]

Actions:

This can be achieved by:

- Identify the amount and type of accommodation needed to supply young people at risk of and currently living in RACS.
- Increase national budget allocated to the development of SDA.
- Develop specified SDA.

Limitations:

Potential limitations of this recommendation and barriers to implementation include limited financial resources. Additionally, a commitment by government across all jurisdictions to work with funders of new RACS. Finally, the new housing stock would need to cater for the individual needs of residents.

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[35] Wilkie R, Winkler D. NDIS Specialist Disability Accommodation: Pathway to a mature market. 2017;1-22. [cited 2018 Aug 2]. Available from: https://www.pwc.com.au/pdf/ndis-specialist-disability-accommodation-aug17-v2.pdf

[36] Winkler D, Taleporos G, Bo'sher L. How the NDIS is using the market to create housing for people with disability. The Conversation 2017. [cited 2018 Aug 2] Available from: https://theconversation.com/how-the-ndis-is-using-the-market-to-create-housing-for-people-with-disability-83144

[37] Reference 1

Recommendation 6

That RACS apply the supported decision-making model for younger people in RACS, specifically to empower younger residents' decision making surrounding their quality of life and respecting the principle of 'dignity of risk'.

Aim:

To improve the ability of young people in RACS and significant others to make risk-informed decisions about their quality of life. This requires describing the activity, the potential hazards and associated risks which are explained to the resident and significant others.

Rationale:

Supported decision making is a model for supporting people with disabilities to make significant decisions and exercise their legal capacity. Specific decisions are addressed, weighed and concluded by the individual, whilst drawing on the support of significant others. Dignity of risk allows an individual to have the dignity afforded by risk-taking, enhancing personal growth and quality of life.[38] Previous research describes the role that dignity of risk plays in determining whether harm or deaths are preventable and highlights that informed autonomous actions may override prevention strategies.[39]

Actions:

This can be achieved by:

- Formal facilitation of the process by creating a written supported decision-making agreement.
- Develop educational materials to increase the awareness of supported decision-making process and the principle of dignity of risk.
- Providers encourage the use of this material through incentives for the staff.

Limitations:

Potential limitations of this recommendation and barriers to implementation include the implementation of this recommendation increasing the potential risks posed to a young person in RACS, this may limit the uptake of this recommendation.

[38] Ibrahim JE, Davis MC. Impediments to applying the 'dignity of risk' principle in residential aged care services. Australas J Ageing. 2013;32(3):188-93.

[39] Hitchen T, Ibrahim JE, Woolford M, Bugeja L, Ranson D. Premature and preventable deaths in frail, older people: a new perspective. Ageing & Society.

Recommendation 7

That the health, law and ageing research unit's recommendations from 2017 for prevention of injury related deaths in residential aged care services be reviewed by the original research team, medical, nursing and allied health professionals to determine their outcomes to date and to identify those pertinent to younger people in RACS.

Aim:

To identify and apply previous injury prevention recommendations that are applicable to young people in RACS.

Rationale:

The Victorian Institute of Forensic Medicine conducted seven research projects into the prevention of injury-related deaths in RAC.[40] This group of work focused on recommendations for deaths related to choking, medications, physical restraint, respite, resident-to-resident aggression, suicide and unexplained absences. These mechanism specific recommendations may be applicable to and lead to the reduction in injury-related deaths in young people in RACS in addition to the older cohorts they were developed for.

Actions:

This can be achieved by:

- Form a committee consisting of members of the original research team, experts/stakeholders from the initial eight forums and well as the injury prevention for young people in RACS forums.
- Review the recommendations in terms of outcomes to date.
- Review the recommendations in terms of identifying those relevant to young people in RACS.
- Communicate findings through existing networks.

Limitations:

Potential limitations of this recommendation and barriers to implementation include the dissemination and implementation of the findings. Furthermore, time and funding would be required to enable the review of these recommendations.

[40] Reference 20

Recommendation 8

That the national disability and health care systems better support the provision of rehabilitation programs and access to health professionals to ensure that all younger people in RACS have access to the appropriate therapy, promote re-ablement and capacity building for their condition.

Aim:

To ensure that all young people in RACS can receive the required rehabilitation to allow for improvement or stabilisation of the afflicting condition(s).

Rationale:

Many young people in RACS have conditions that can benefit from rehabilitation services. For conditions such as ABI, slow improvements can be made over time with access to appropriate rehabilitation.[41] Programs delivered in RACS such as ABI: Slow to Recover have shown success, however, are the exception rather than the norm.[42] Rehabilitation for the purpose of regaining function is provided by the health system, whereas the NDIS will support the on-going allied health or other therapies to enable the participant to maintain their level of functioning.[43] However, there have been many recounts that aged care facilities are often ill-equipped to provide appropriate rehabilitation services.[44]

Actions:

This can be achieved by:

- Aged care providers encouraged to identify residents for whom rehabilitation is appropriate through consultation with rehabilitation providers.
- Aged care providers incentivised to seek opportunities for rehabilitation for their younger residents.
- Rehabilitation services incentivised to provide services to young people in RACS.

Limitations:

Potential limitations of this recommendation and barriers to implementation include the access to resources such as time and financing to enable this change. The implementation of this recommendation would also require a change in attitudes by many surrounding the purpose and appropriateness of rehabilitation for young people in RACS.

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[41] The Senate Community Affairs References Committee. Quality and equity in aged care. Canberra, Australian Capital Territory: Commonwealth of Australia; 2005

[42] Reference 41

[43] National Disability Insurance Scheme (NDIS). Supports the NDIS will Fund in Relation to Healthcare 2014. [cited 2018 Aug 6] Available: https://www.ndis.gov.au/document/supports-ndis-will-fund-relation.html

[44] Reference 28

Recommendation 9

That the clinical response to an adverse incident involving younger people in RACS is appropriate and aligned with the residents' advanced care plan.

Aim:

To reduce the impact should an incident (e.g. choking) involving a young person in a RACS occur.

Rationale:

Many younger residents experience swallowing difficulties due to ABIs and neurodegenerative conditions. This leads to an increased risk of choking which has been shown to be the leading cause of both fatal and non-fatal injury in young people in RACS.[45] Coroner's recommendations that have followed a number of RACS resident choking deaths have emphasised the role of staff awareness of the RACS emergency procedures and the importance of ongoing staff First Aid training in response to incidents such as choking.[46]

Actions:

This can be achieved by:

- Strengthen existing programs and introducing the inclusion of Firsts Aid training of all staff in facilities.
- Aged care providers working collaboratively with First Aid training service to develop specific programs to address these particular risks and circumstances.

Limitations:

Potential limitations of this recommendation and barriers to implementation include lack of evidence for efficacy. The guidelines on the *Procedure for Choking* from the Australian Resuscitation Council state that "there is a lack of any scientific evidence for making strong clinical guideline recommendations" (Australian Resuscitation Council, 2017).[47]

[45] Reference 3
[46] Reference 20
[47] Op cit, Australian Resuscitation Council, New Zealand Resuscitation Council. ANZCOR guideline 4-airway. 2016.

Recommendation 10

That all incidents with a severe or fatal outcome (IRS grade 1 and 2) involving a younger person in RACS are externally investigated, the findings collated, analysed and stored in a single nation-wide database. Incidents of lesser severity should be internally reviewed and subjectable to audit by the Australian Aged Care Quality Agency.

Aim:

To enable learning and the identification of system failures in the event of a young residents' death in RACS. Furthermore, to improve the quality and availability of data following the death of a young person in a RACS to inform evidence-based prevention strategies.

Rationale:

The reporting and review of incidents is an established and recognised approach for the improvement of safety in a variety of industries and settings.[48] This process allows for the learnings from previous incidents and near misses which are essential for improving the quality of care.[49] Despite these objectives, underreporting remains a major issue.[50]

Actions:

This can be achieved by:

- Staff incidents to the provider or directly to health professionals as soon as possible.
- A standing committee specialising in the investigation of young people in RACS be formed.
- A nation-wide database be established for the storage of data.
- All deaths involving a young person in RACS are notified to Coroners.
- Policy makers considering introducing standardised policies and procedures of investigation of incidents of young people in RACS to gather the data that would inform future prevention strategies.

Limitations:

A potential limitation of this recommendation and barriers to implementation are that registries can be time, labour and cost intensive. Registries also collect personal information; therefore the logistics and ethics of data collation and analysis are complex. This recommendation would require the support of government, legal and regulatory authorities to implement effectively.

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[48] Kingston MJ, Evans SM, Smith BJ, Berry JG. Attitudes of doctors and nurses towards incident reporting: a qualitative analysis. Med J Aust. 2004;181(1):36-9.

[49] Reason J. Human error: models and management. BMJ. 2000;320(7237):768-170.

[50] Lawton R, Parker D. Barriers to incident reporting in a healthcare system. BMJ Qual & Saf. 2002;11(1):15-8

Appendix 1

Expert Consultation Forum Participant Organisations

Applied Aged Care Solutions

Australian and New Zealand Society for Geriatric Medicine

Australian College of Nursing

Australian Faculty of Rehabilitation Medicine

BlueCross

Dementia Australia

Department of Health

Department of Health & Human Services, Victoria

Disability Services Commissioner

La Trobe University

Melbourne University

Monash University

National Disability Insurance Agency

Office of the Public Advocate

Summer Foundation

Victorian Managed Insurance Authority

Wintringham

Women with Disabilities Victoria

Young People in Nursing Homes National Alliance

Appendix 2

Key Publications from Health Law and Ageing Research Unit

1. Ibrahim JE, Kipsaina C, Martin C, Ranson DL, Bugeja B: Variations in death notification of nursing home residents to Australian Coroners. Injury Prevention 07/2018;, DOI:10.1136/injuryprev-2017-042689

2. Ibrahim JE: Residential aged care: there is no single optimal model. *The Medical Journal of Australia* 06/2018; 208(10):431-432. , DOI:10.5694/mja18.00268

3. Jokanovic N, Ferrah N, Lovell JL, Weller C, Bugeja L, Bell S, Ibrahim JE: A review of coronial investigations into medication-related deaths in Australian residential aged care. *Research in Social and Administrative Pharmacy* 06/2018;, DOI:10.1016/j.sapharm.2018.06.007

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