Submission
No 719

INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO HEALTH AND HOSPITAL SERVICES IN RURAL, REGIONAL AND REMOTE NEW SOUTH WALES

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Date Received:	17 January 2022

Submission to the New South Wales Legislative Council

Portfolio Committee No. 2 – (Health)

Inquiry into health outcomes and access to health and hospital services in rural, regional and remote New South Wales.

Trevor Rowe

January 2022

Contents

List of recommendations

I recommend that:

The Committee consider recommending the New South Wales Government establish a Royal Commission to examine the health care of older Australians resident in New South Wales and in particular, rural, regional and remote areas of the State. **(Recommendation 1, page 10)**

The Committee request the New South Wales Auditor-General, to undertake a performance audit into the effectiveness of death certificate as used in New South Wales and in particular how accurately death certificates record factors contributing to a death in any hospital. **(Recommendation 2, page 21)**

The Committee hear evidence from an independent patient advocate to gain a full appreciation of what independent patient advocates can do to improve the healthcare and hospital experience of people living in rural, regional and remote New South Wales. **(Recommendation 3, page 35)**

All hospitals, medical centres and GP surgeries in New South Wales have well displayed notices and leaflets for patients, their families and caregivers that provide information on:

(a) patient advocates generally;

(b) Independent or private patient advocates; and

(c) how they can be contacted. **(Recommendation 4, page 35)**

Steps be taken to deliver a patient advocacy training course for suitably qualified medical personal. Completion of such a course would be a prerequisite for practising as a patient advocate. **(Recommendation 5, page 35)**

Introduction

Background

1. I commend the Legislative Council Portfolio Committee No. 2 (the Committee) for its *Inquiry into health outcomes and access to health and hospital services in rural, regional and remote New South Wales* (the Inquiry). The Inquiry has already brought attention to the fact that there are serious deficiencies in the current health care of those Australians, particularly those older Australians, who live in rural, regional and remote areas of New South Wales (NSW).

2. The catalyst for this submission is the segment of the 14 September 2020 *60 Minutes* Program titled, *The greatest loss,* which was hosted by *60 Minutes* Reporter, Liz Hayes.[1] As you know, *The greatest loss* provides accounts of what happened to Ms Hayes' father Brian Ryan in NSW country hospitals and what happened to Allan Wells, the father of ABC journalist Jamelle Wells. I note that Liz Hayes and Jamelle Wells have made submissions to the Committee and given evidence at public hearings.

3. The stories of Brian Ryan and Allan Wells make one wonder if things could have been different for both men and their families. My conclusion is yes – different outcomes were possible. Their stories reminded me of what happened to my own parents, Ross and Gwyneth Rowe, both of whom died after unsatisfactory experiences in hospitals. In my mother's case, one of the hospitals, The Canberra Hospital (TCH), is a destination for patients from rural and regional NSW.

Submission structure

4. This submission has four main sections:

    1. **Sins of omission** - This section comments on things missing with the recent Royal Commission into Aged Care Quality and Safety. The Royal Commission did not examine the experience of older Australians in hospitals nor did it publish all the 'public submissions' that it received. Older Australians in rural, regional and remote New South Wales deserve to have this work completed.

    2. **Iatrogenic events and death** – This section examines the concept of iatrogenesis which is defined as any injury or illness that occurs as a result of

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[1] The 60 Minutes program was broadcast on 14 September 2020. It can be viewed on YouTube at: https://youtu.be/0aQD98ABziE

medical care. It is evident that people in regional New South Wales have suffered injury and/or died due to their medical treatment. Some estimates of the numbers are provided – each week an estimated 26 people experience harm or death due to medical treatment in hospitals in regional NSW.

There is an anomaly in the way statistics on mortality are collected and published. Australian Bureau of Statistics (ABS) data does not include deaths due to medical errors and yet the World Health Organisation views unsafe care as one of the 10 leading causes of death and disability.

3. **Causes of medical errors** – while lack of funding, funding allocations, lack of staff and the quality of staff are the 'usual suspects', it appears that poor case management is a significant and growing problem. Patients can literally die waiting for a treatment.

4. **Going forward** – This section looks at ways of mitigating problems in medical treatment. Patient centred care is the current buzz phrase but what people in regional New South Wales experience is very different. They experience the old fashioned systems approach in which patients are subjected to a variety of treatment systems with less than satisfactory co-ordination and poor case management.

   The Australian Commission on Safety and Quality in Health Care and the NSW Clinical Excellence Commission promote patient centred care but evidence presented to the Committee suggests cultural change is very slow.

   Patient advocacy is an effective means of achieving better outcomes for patients, their families and caregivers. Very well trained and experienced nurses are ideal candidates to be patient advocates and increasingly hospitals are employing patient advocates and patient navigators. But there are two problems: (1) medical hierarchies and (2) employer loyalty, which is summed up in the saying, 'Who pays the piper, calls the tune'.

   Independent or private patient advocates are effective in other jurisdictions and there is a compelling case to use them in Australia. They offer independence, better health outcomes and savings in health budgets. Use of independent patient advocates has the potential to be a game changer in the healthcare of people in rural, regional and remote areas of New South Wales.

Sins of omission

5. Short-comings in hospital and health care systems impact on people of all ages but I observe that it is older Australians who are most at risk of poor medical treatment. The percentage of people in Sydney aged 60 and over is 20%. The percentage in regional NSW aged 60 and over is 28%.[2]

6. The recent Royal Commission into Aged Care Quality and Safety (the Royal Commission) was heralded as bringing about much needed reform in aged care but the Royal Commission's Terms of Reference did not cover what happens to older Australians when they are in hospital.[3] (See Reference A). So, despite what people may think, there has not been any investigation into what happens to older Australians when they are in hospital. This is a serious omission.

7. Older Australians often encounter age discrimination and, as with most age discrimination, it is subtle but sometimes it is quite blatant. Hospitals and medical staff too often express views that people who have reached the age of 80 or older have had a good life and are somehow less worthy of medical treatment.

8. I made a submission to the Royal Commission and was told by Royal Commission staff that the Royal Commission's *Terms of Reference* did not extend to treatment provided in hospitals. However, I argued that an examination of aged care should by definition include the medical treatment of older Australians in hospitals.

9. My submission to the Royal Commission was published in late February 2021 just before the conclusion of the Royal Commission and transmittal of its Final Report to the Governor-General.[4] I was keen for people to know the story of my parents and in particular, that of my mother. Equally I wanted to know the stories of other older Australians and their families. Regrettably the Royal Commission's policy was to publish only a limited selection of 'public submissions', that is, submissions where the authors were content for the submissions to be made public. This is in stark contrast to the public inquiry process of parliamentary committees. The Royal Commission's policy means that all too many stories will never be accessible to the general public unless of course they wish to seek access via Freedom of Information requests. This can be viewed as second 'sin of omission'.

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[2] Australian Bureau of Statistics, *Regional population by age and sex*, Release date 28 August 2021.

[3] Royal Commission into Aged Care Quality and Safety – Terms of Reference can be found at: https://agedcare.royalcommission.gov.au/about/terms-reference

[4] Australia. Royal Commission into Aged Care Quality and Safety. Submission by Trevor Rowe. See: https://agedcare.royalcommission.gov.au/system/files/2021-02/AWF.600.02345.0001.pdf

Recommendation

10. I recommend that:

> The Committee consider recommending the New South Wales Government establish a Royal Commission to examine the health care of older Australians resident in New South Wales and in particular, rural, regional and remote areas of the State. **(Recommendation 1)**

Iatrogenic events and death

Definition

11. The adjective 'iatrogenic' refers to 'health events' that result in a person suffering adverse effects or death from medical treatments and/or treatment errors. An iatrogenic condition is a state of ill health or an adverse effect, which may include death caused by medical treatment. It is usually the result of a mistake made in treatment, and can also be the fault of a doctor, nurse, therapist, pharmacist or health care worker or simply the system in which they work.

12. Many people believe doctors, nurses and other health professionals can do no wrong. They believe medical professionals to be people with good motives, professional ethics and a caring nature. I think most medical professionals are just like this but the reality is that there are some who are not.

13. People have strengths and weaknesses and any person can make errors even when they have the best of intentions. A few years ago I was employed by a major health regulator in the United Kingdom, the Nursing and Midwifery Council (NMC). The NMC regulates the UK nursing profession which is approximately 750,000 nurses. A large part of the NMC is focussed on what is called 'fitness to practise', which involves assessing complaints about nurses. The vast majority of nurses are caring professionals but some are found guilty of causing harm to patients and even the death of patients.[5]

14. Hospitals are invariably very hierarchical organisations. My first job after graduating with a Degree in Economics was as a trainee hospital administrator in an in-service training program run by a group of Sydney and NSW healthcare providers.[6] If nothing else the program opened my eyes to the hierarchical nature of hospitals and the healthcare system. In any hospital there are power structures with vested interests in maintaining the status quo and avoiding criticism. Jamelle Wells experienced this in seeking the truth about what happened to her father Allan Wells. It is a situation replicated throughout NSW, Australia and in fact the world.

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[5] NMC – What is fitness to practice? See: https://www.nmc.org.uk/concerns-nurses-midwives/dealing-concerns/what-is-fitness-to-practise/

[6] A similar program today is the *Health Management Internship Program* (HMIP) which is run by the College of Health Service Management.

US experience

15. In a 2016 study published in *The BMJ*[7], patient safety experts at John Hopkins University calculated that in the United States more than 250,000 deaths per year are due to medical error. This figure is greater than the 150,000 deaths due to respiratory disease estimated by the US Center for Disease Control and Prevention (the CDC) and which is said to be the third highest cause of death. (See Reference B).

16. A 2018 CNBC report referred to the John Hopkins study and claimed that other reports suggested the annual number of people dying in the United States due to medical treatment to be as high 440,000. It stated medical errors are the third-leading cause of death after heart disease and cancer and reported that, 'Advocates are fighting back, pushing for greater legislation for patient safety.[8]

17. The Johns Hopkins team was led by Professor Martin Makary, Professor of Surgery at the Johns Hopkins University School of Medicine. He said that the CDC's way of collecting national health statistics fails to classify medical errors separately on the death certificate. The researchers are advocating for updated criteria for classifying deaths on death certificates.

18. Professor Makary, an authority on health reform, is quoted as saying:

> Incidence rates for deaths directly attributable to medical care gone awry haven't been recognized in any standardized method for collecting national statistics. … The medical coding system was designed to maximize billing for physician services, not to collect national health statistics, as it is currently being used.

19. Professor Makary says that in 1949, the US adopted an international form that used International Classification of Diseases billing codes to tally causes of death:

> At that time, it was under-recognized that diagnostic errors, medical mistakes, and the absence of safety nets could result in someone's death, … and because of that, medical errors were unintentionally excluded from national health statistics.

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[7] The BMJ is the British Medical Journal. The article was published on 3 May 2016.

[8] https://www.cnbc.com/2018/02/22/medical-errors-third-leading-cause-of-death-in-america.html

Iatrogenic deaths in Australia and NSW

20. In 1995 Sydney-based researchers published the *Quality in Australian Health Care Study,* which was a ground-breaking examination of the adverse events in healthcare in Australia. Published in The Medical Journal of Australia, the landmark study reported that 16% of patients in hospitals experienced some form of adverse event during their admission and approximately 50% of these were preventable. The Study dramatically raised the profile of patient safety and stimulated a major review of safety of patient care.[9]

21. Other significant reports followed the 1995 Australian study. In 2000 a report titled, *To Err is Human* in 2000, revealed that in the United States as many as one in 10 hospital patients were harmed unnecessarily, and that a substantial proportion of patients died as a direct result of medical care.

22. The Australian Commission on Safety and Quality in Health Care states:

> Increasingly, patient harm was understood to be not just a result of human fallibility, but the result of system failures in the way care was organised and coordinated, and potentially preventable through improvement efforts targeted at clinical practice, health service organisations and systems. Clinical risk, once regarded primarily as a professional indemnity issue for clinicians, became a priority for healthcare policymakers and providers, and a focus for consumers.
>
> Knowledge gaps were identified, the healthcare sector began to draw on safety lessons from other high-risk industries and the role of clinical governance and organisational culture to support patient safety was accepted.[10]

23. Three more recent estimates of patient safety and iatrogenic deaths in Australia are:

    1. A study by Professor Libby Roughead at the University of South Australia estimates that the number of iatrogenic deaths due to medication errors to be 11,000 per year.[11]

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[9] Wilson, R M, et al., *The quality in Australian Health Care Study*, Medical Journal of Australia, 6 November 1995, Vol 163(9), pp. 458-71

[10] Australian Commission on Safety and Quality in Health Care, *The state of patient safety and quality in Australian hospitals 2019.* See: https://www.safetyandquality.gov.au/sites/default/files/2019-07/the-state-of-patient-safety-and-quality-in-australian-hospitals-2019.pdf

[11] [add footnote]

2. University of Technology (Sydney) law lecturer Dr David J Carter has written that the number of iatrogenic deaths is 27,000 per year.[12]

3. The Medical Error Action Group (MEAG) estimates that iatrogenic deaths range from 18,000 up to 54,000 per year.[13]

24. Using population data published by the Australian Bureau of Statistics (the ABS) it is possible to show what these iatrogenic death estimates look like Australia-wide. Table 1 shows this.

Table 1`- Iatrogenic deaths in Australia by State and Territory

			Annual iatrogenic death estimates		
	Population as at 31/3/21 ('000)	**percentage (%)**	**11,000 deaths**	**27,000 deaths**	**54,000 deaths**
New South Wales	8,176.40	32%	3,499	8,589	17,177
Victoria	6,648.60	26%	2,845	6,984	13,967
Queensland	5,206.40	20%	2,228	5,469	10,938
South Australia	1,771.70	7%	758	1,861	3,722
Western Australia	2,675.80	10%	1,145	2,811	5,621
Tasmania	542.00	2%	232	569	1,139
Northern Territory	247.00	1%	106	259	519
Australian Capital Territory	431.80	2%	185	454	907
Australia (a)	25704.3	100%	11,000	27,000	54,000

25. Using population data for Greater Sydney and Regional NSW enables estimates to be made of iatrogenic deaths for Greater Sydney and Regional NSW.[14] Table 2 shows these estimates.

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[12] Carter, David J., *Responsibility for iatrogenic death in Australian criminal law – Thesis abstract*., Journal & Proceedings of the Royal Society fo New South Wales, vol. 152, part 1, 2019, pp. 140-142.

[13] See: website of the Medical Error Action Group: https://www.medicalerroraustralia.com/

[14] Source of regional population data: Chris Angus, *Regional NSW: A demographic and economic snapshot*. NSW Parliamentary Library, Briefing Paper No. 1/2020.

Table 2 - Estimates of iatrogenic deaths for NSW: Greater Sydney and Regional NSW

		Iatrogenic death estimates based on Australia-wide estimates:		
		11,000 deaths	27,000 deaths	54,000 deaths
Per year				
Regional NSW	38%	1,340	3,289	6,579
Greater Sydney	62%	2,159	5,299	10,598
	100%	3,499	8,589	17,177
Per month				
Regional NSW	38%	112	274	548
Greater Sydney	62%	180	442	883
	100%	292	716	1,431

26. These estimates are disturbing. Even using the lowest estimate, this means that each month there are 112 people harmed or dying in regional NSW due to medical treatments and medical errors. That is nearly 26 people per week. The evidence of Liz Hayes and Jamelle Wells puts a human face to these estimates.

27. In a 2011 article in the Australian Family Physician titled, ‘How to complete a death certificate’, Dr Sarah Bird wrote:

> The Medical Certificate of Cause of Death (the ‘death certificate’) is an important legal document. The completion of a death certificate by a medical practitioner is a vital part of the notification process of a death to the Registrar of Births, Deaths and Marriages in the relevant state or territory in which the death occurred and enables an authority to be provided to the funeral director to arrange disposal of the body. Medical practitioners have a professional responsibility to ensure the accurate completion of death certificates. Accurate cause of death information is important:
>
> - for legal purposes – for example, the information may be relevant to the determination of the validity of a will, or life insurance payment;
>
> - for statistical and public health purposes – the information recorded on death certificates is coded by the Australian Bureau of Statistics and is the major source of Australia’s mortality statistics, which enable the evaluation and development of measures to improve the health of Australians;

- for family members – to know what caused the death and to be aware of conditions that may occur in other family members.[15]

28. Dr Bird is Director of Medico-Legal and Advisory Services for at MDA National, which provides medical indemnity insurance for doctors. The mere existence of MDA National is evidence that things go wrong in hospitals and with medical treatments.

29. The Committee will be interested to know that MDA National Insurance has entered into an agreement with the Department of Health and Medicare Australia to administer the *Premium Support Scheme* (PSS) on behalf of the Australian Government. The PSS is an Australian Government Scheme introduced to assist eligible doctors meet the costs of their medical indemnity insurance.[16]

Mortality statistics in Australia

30. In Australia, the Australian Bureau of Statistics publishes data on the number of deaths and the causes of deaths. Relevant publications are:

    1. *The National Mortality Database*;
    2. *Causes of Death, Australia methodology*;
    3. *Information Paper: Cause of Death Certification Australia, 2018*;
    4. *Causes of Death, Australia* (Released 29/09/2021);
    5. *Causes of Death, Australia: Doctor Certified Deaths, Summary Tables – Statistics on doctor certified death registrations.*

31. The ABS uses the relevant version of the *International Statistical Classification of Diseases and Related Health Problems* (ICD) which is produced by the World Health Organisation (WHO).[17] However, the ICD does not include causes of death due to medical treatment.

32. While the ICD does not include deaths due to the medical treatment, the WHO recognises the importance of patient safety and in 2019 published *10 facts on patient safety.* (See Reference C). The preface states:

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[15] Bird, Sarah, *How to complete a death certificate – a guide for GPs*. Reprinted from Australian Family Physician, Vol. 40 No. 6., June 2011.

[16] Information on the Premium Support Scheme is at: https://www.mdanational.com.au/insurance-products/professional-indemnity-insurance/premium-support-scheme

[17] World Health Organisation, International Statistical Classification of Diseases and Related Health Problems (ICD) https://www.who.int/standards/classifications/classification-of-diseases

> Patient safety is a serious global public health concern. It is estimated that there is a 1 in 3 million risk of dying while travelling by airplane. In comparison, the risk of patient death occurring due to a preventable medical accident, while receiving health care, is estimated to be 1 in 300. Industries with a perceived higher risk, such as the aviation and nuclear industries, have a much better safety record than health care does.[18]

33. One of the 10 facts is:

> The occurrence of adverse events due to unsafe care is likely one of the 10 leading causes of death and disability in the world'.[19]

34. In Australia, the Australian Commission on Safety and Quality in Health Care (the Commission) has developed the National Safety and Quality Health Standards (the NSQHS Standards) in collaboration with the Australian Government, States and Territories, the private sector, clinical experts, patients and carers. The primary aims of the NSQHS Standards are to protect the public from harm and to improve the quality of health service provision.

35. The Commission has also produced The Australian Charter of Healthcare Rights. (See Reference D). A revised version of the Charter was launched on 8 August 2019. Dr Grant Davies, then the South Australia's Health and Community Services Complaints Commissioner, explained the Charter:

> In practical terms, the Charter provides a set of clear directions to consumers of how they can participate in the health care they receive. It encourages consumers to be equal partners in that healthcare delivery and it also makes health service providers aware of what their obligations are with consumers …
>
> We want people to really engage in their health care and have legitimate expectations about what that health care looks like and how they experience it. With many of the complaints we receive, things have gone wrong due to poor communication. A Charter of Healthcare Rights sets an expectation for

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[18] World Health Organisation, 10 facts on patient safety. See: https://www.who.int/news-room/photo-story/photo-story-detail/10-facts-on-patient-safety

[19] World Health Organisation, 10 facts on patient safety. See: https://www.who.int/news-room/photo-story/photo-story-detail/10-facts-on-patient-safety

> consumers that they have a right to be informed about their health care, services and treatment in a way that they understand. [20]

36. This sounds good but the experience of people in rural, regional and remote NSW seems to be very different. I discovered the existence of the Australian Charter of Health Care Rights months after the death of my mother. It is a particularly good document and provides a basis for patients, their families and carers to understand and assess medical treatment. However, is there any evidence that the vast majority of people in regional NSW have never heard of the Charter? They need to know about it and how to use it.

37. Hospitals are required to report sentinel events (deaths) and the Australian Commission on Safety and Quality in Health Care has produced its *Incident management guide.*[21] In NSW the Clinical Excellence Commission is responsible for managing sentinel event data.[22]

38. Is there any evidence that the people in regional NSW have heard about sentinel event reporting?

39. When one looks at ABS publications on mortality statistics there is no reference to sentinel event reporting and those organisations responsible for it. This raises fundamental questions about transparency and accountability.

40. The ABS provides a process chart of what happens when a death occurs. This is shown below in Figure 1.

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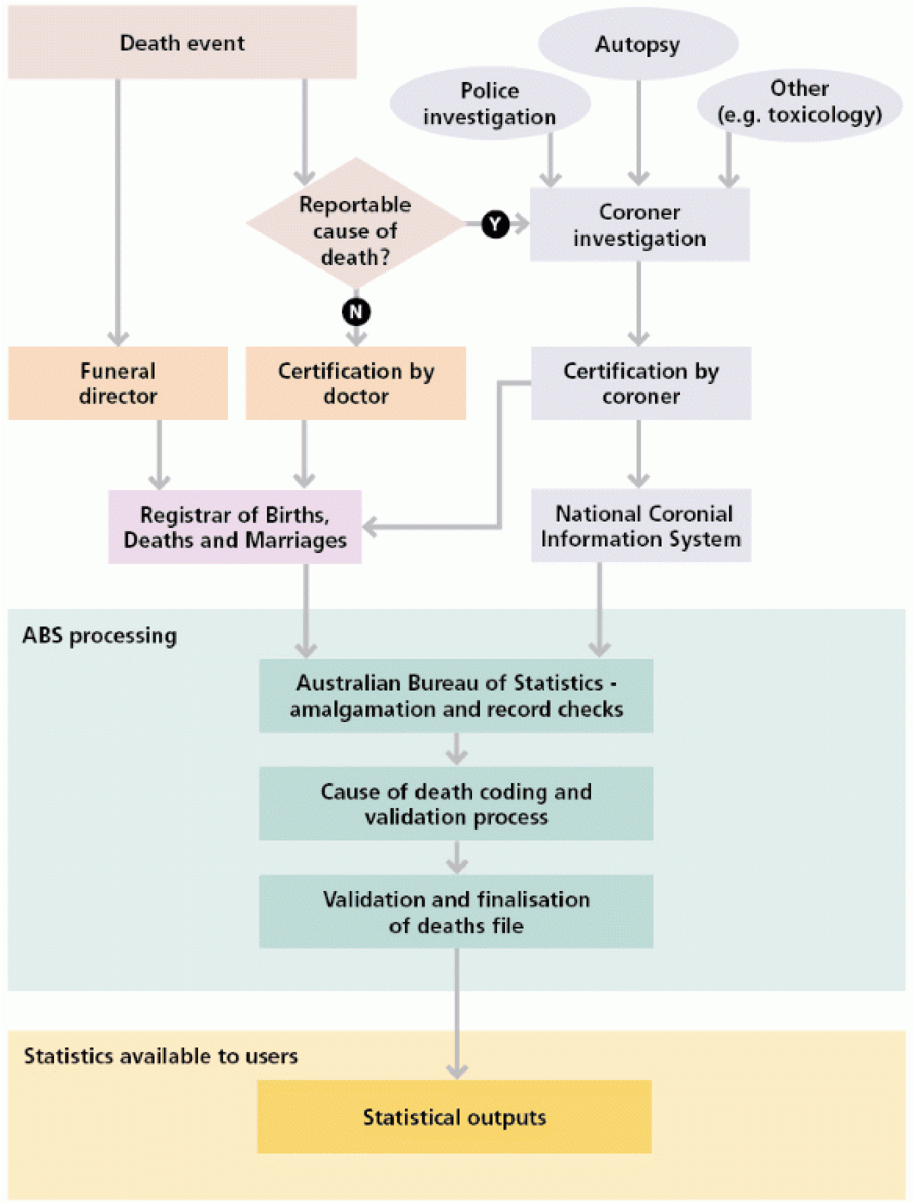
[20] Australian Commission on Safety and Quality in Health Care, *The Australian Charter of Healthcare Rights - New Australian Charter of Healthcare Rights empowers patients as partners,* Media release, 8 August 2019. See: https://www.safetyandquality.gov.au/about-us/latest-news/media-releases/new-australian-charter-healthcare-rights-empowers-patients-partners

[21] Australian Commission on Safety and Quality in Health Care, *Incident management guide,* November 2021.

[22] The role of the CEC, detailed in a determination of functions in 2012, is to lead, support and promote improved safety and quality in clinical care across the NSW health system through consultation and collaboration with clinicians, health consumers, other pillars and the NSW Ministry of Health.
The agency has two broad areas of responsibility: setting standards for safety, and monitoring clinical safety and quality processes and improving performance of individuals, teams and systems in prioritising safety.

Figure 1 – Australian cause of death statistics system[23]



41. The Committee’s Inquiry raises doubts about the initial steps in the above cause of death reporting process in regional NSW hospitals. Evidence presented to the Committee by Liz Hayes, details that her father Brian Ryan was over medicated and then undermedicated for a week, not receiving medicine to prevent a stroke.
Ms Hayes says in her submission states, ‘A Root Cause Analysis cited human error.’[24]

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[23] Australian Bureau of Statistics, *Causes of death, Australia methodology*, Canberra. Released 29 September 2020.

[24] Submission No. 613 by Elizabeth Hayes. 14 January 2021.

42. The Committee may wish to investigate what was recorded on Mr Ryan's Medical Certificate of Cause of Death. It would be a pleasant surprise if there were mention of human error as a contributing factor.[25]

43. In the case of my late mother, she was denied surgery for a damaged and painful artificial hip, a pain management plan was never developed and in the midst of this, in early January 2020, she suffered a catastrophic fall at the hands of hospital physiotherapist which was followed by a cocktail of opioid and nerve drugs administered by her hospital geriatrician. The trauma of the fall and the medications left her in a state of deep delirium. The combination of the lack of a pain management plan, the catastrophic fall and the medications destroyed her. These factors did not rate a mention in her discharge letter, which failed to spell my mother's name correctly. When in February 2020 it was agreed my mother could return home, her GP said it was end of life. My mother died a few weeks later. Her death certificate made no mention of the iatrogenic events in hospital.[26]

44. I would add that in mid-January 2020 my mother experienced prolonged periods of deep delirium and sleep. I hoped and prayed that she would come out of it and get well enough to return home. One day a geriatrician visited my mother. He was doing his rounds, filling in for my mother's allocated geriatrician. My mother was receiving an IV antibiotic for treatment of an infection. Out of nowhere, the doctor in question turned to me and said, 'If you or the family like, I can remove the IV drip.' I was shocked and lost for words. I understood the subtext – he was offering to precipitate my mother's death. I raised this with the Ward social worker. Her response was that there was a difference of opinion amongst doctors about euthanasia. You can be sure that if my mother's family had agreed to the doctor's suggestion that the death certificate would have been in part a work of fiction.[27]

45. There is a need to examine how accurately death certificates record all the contributing causes of death in New South Wales regional hospitals and to examine how iatrogenic events are recorded if at all on death certificates. ABS mortality data reports make no reference to iatrogenic deaths and one could conclude from the mortality data that there are no iatrogenic deaths but the evidence before the Committee suggests otherwise. People in regional NSW need to know that being in hospital could be a cause of harm or worse, death.

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[25] Submission No. 613 by Elizabeth Hayes. 14 January 2021.

[26] Rowe, T., *Submission to the Royal Commission into Aged Care Quality and Safety*. Section 3.28 – GP: Get home ASAP., page 48.

[27] Rowe, T., *Submission to the Royal Commission into Aged Care Quality and Safety*, Section 3.29 – Surprise offer of euthanasia, page 48.

46. My experience, and my observation of others, is that when someone dies, the person's family are often consumed with grief. As such they are at a major disadvantage if they have concerns about the cause of death and their grief makes it exceedingly difficult to raise the death with the coroner and/or to make a complaint against a hospital or a medical service provider. Even if a family manages to make a complaint, they will find they are outgunned by institutional power and a good supply of hospital lawyers.

47. The NSW Auditor-General is empowered to conduct independent management reviews (performance audits). When requests are made under section 27B(3) of the *Government Sector Audit Act 1983* the Auditor-General is generally required to act on the request. Engagements may be requested as a one-off arrangement, or as an annually recurring service.[28]

48. There is a compelling case for the Auditor-General to examine how accurately deaths in rural and regional hospitals are recorded on death certificates and to assess whether death certificates are fit for purpose. In particular, do they contain specific questions as to whether patients have experienced any adverse health events as part of their medical treatment.

Recommendation

49. I recommend that:

> The Committee request the New South Wales Auditor-General, to undertake a performance audit into the effectiveness of death certificate as used in New South Wales and in particular how accurately death certificates record factors contributing to a death in any hospital. **(Recommendation 2)**

50. I note that any issues found in New South Wales will most likely be replicated in other States and the two Territories.

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[28] New South Wales. Auditor-General, *Requests for audit*. See: https://www.audit.nsw.gov.au/our-work/requests-for-audit

Causes of medical errors

The usual suspects

51. Other witnesses have already given evidence about causes of health events in NSW hospitals and community health care. The usually identified causes include lack of funding and/or the allocation of funds and/or staffing issues. Staffing issues are not just about the number of staff but are also about the quality of staff.

52. I have observed that there is an increasing number of doctors and nurses and other staff who do not have satisfactory English language skills. The result of this is less than satisfactory communication between patients (particularly older Australians) and medical and other staff.

Poor case management

53. There is growing appreciation both in Australia and in other jurisdictions that while there are ongoing general improvements in medical science and technology and medical treatments and medical expertise, there is a decline in case management. In part this is due to the growing complexity of medical treatments and the fact that many patients have what is termed co-morbidity.

54. Poor case management means patients do not receive appropriate treatment. This could be simply a question of timing: patients and their families and/or carers often wait long times for appointments with medical and other staff and in a hospital context the relevant people may fail to appear. Poor case management creates situations which are conducive to medication errors. You can have well-funded and well-staffed hospitals but if you do not have good case management things will go wrong. Patients will suffer. Some patients will die.

Going forward

World Health Organisation's *Patient Safety Plan 2021-30*

55. At a global level, the World Health Organisation has published the *Global patient safety action plan 2021-2030, 'Toward eliminating avoidable harm in health care*. The Plan explains the emergence of patient safety thinking:

> The paradigm shifts in thinking about safety in health care came with the realization that it was not completely different from other high-risk industries and when things went wrong, it was seldom due to an error by a single individual. Rather, the true cause of an accident in aviation or an adverse event in health care was due to human error embedded in a complex amalgam of actions and interactions, processes, team relationships, communications, human behaviour, technology, organizational culture, rules and policies, as well as the nature of the operating environment. With this realization, came a deeper understanding that the design and operation of systems could provoke human error or worsen its impact when it occurred.
>
> In this system thinking view of the risks of health care, the term 'medical error' became something of a misnomer, since error in itself was not the primary problem. Indeed, harm to patients cannot be corrected solely by urging health workers to be more careful. The use of the term 'patient safety', a more holistic concept, to describe the safety risks in health care and the measures to address these risks and patient harm came into being at the beginning of the 21st century. It recognized the scale of the problem of inadvertent harm in the delivery of health care, the common causes that allowed similar kinds of adverse events to occur in all countries worldwide, the need to see human error as something to be mitigated and prevented rather than eliminated entirely, and the strong parallels with the experience of other high-risk industries, thus creating opportunities for transfer learning. An alternative emerging approach in patient safety (Safety II) focuses on proactively making health care safer through an emphasis on the conditions under which people succeed rather than fail. This perspective views patient safety in terms of intended and acceptable outcomes as high as possible.[29]

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[29] World Health Organisation has published *Global patient safety action plan 2021-2030, 'Toward eliminating avoidable harm in health care*

56. The Plan talks about the global burden of unsafe care:

> The magnitude of the problem of unsafe care attracted greater public attention with the release of the landmark report *To err is human: building a safer health system* by the United States (US) Institute of Medicine in 1999. The Institute of Medicine extrapolated a death rate of the incidence of adverse events in US hospitals from two earlier studies and estimated that at least 44,000, and perhaps as many as 98,000 people, die in hospitals each year as a result of medical errors. In 2002, the United Kingdom (UK) government's Chief Medical Adviser published *An organisation with a memory.* Both reports scoped the subject of safety and harm in health care, drew parallels with other high-risk industries, and also provided the first estimates of the burden of patient harm for what was to become a new health priority and a new field of health services' research.
>
> In more recent years, the focus has also been on economic losses and access problems due to unsafe care that have the potential to become major barriers in achieving UHC. Research studies have shown that an average of one in 10 patients is subject to an adverse event while receiving hospital care in high-income countries. The estimate for low- and middle-income countries (LMICs) suggests that up to one in four patients is harmed, with 134 million adverse events occurring annually due to unsafe care in hospitals, contributing to around 2.6 million deaths. Overall, 60% of deaths in LMICs from conditions amenable to health care are due to unsafe and poor-quality care. People mostly link patient safety with hospital-based care, although unsafe care is a system-wide problem. Half of the global disease burden arising from patient harm originates in primary and ambulatory care. The economic cost of unsafe care can be understood in two ways: the direct cost due to resource wastage and the indirect costs in loss of productivity in the population. In high-income countries, up to 15% of hospital expenditure can be attributed to wastage due to safety failures.[30]

57. The Plan's vision is, 'A world in which no one is harmed in health care and every patient receives safe and respectful care, every time, everywhere.'[31]

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[30] World Health Organisation has published *Global patient safety action plan 2021-2030, 'Toward eliminating avoidable harm in health care*

[31] World Health Organisation has published *Global patient safety action plan 2021-2030, 'Toward eliminating avoidable harm in health care*

58. The Plan's Guiding Principles are:

- Engage patients and families as partners in safe care;
- Achieve results through collaborative working
- Analyse data to generate learning
- Translate evidence into measurable improvement
- Base policies and action on the nature of the care setting
- Use both scientific expertise and patient experience to improve safety
- Instil safety culture in the design and delivery of health care.

59. While governments in Australia are signed up to this systems improvement approach, there is scope for more to be done by patients and civil society organisations.

Patient centred care.

60. There is a growing consensus that consumers of health care (patients, their families and their carers) need to be involved in determining their medical treatment and that such an approach can serve to reduce the occurrence of iatrogenic events. The Australian Commission on Safety and Quality in Health Care,[32] the NSW Excellence Commission[33] and NSW Health[34] endorse and promote patient centred care and it is an integral part of their respective strategic plans. I think patient centred care is the new buzz phrase but the evidence before the Committee suggests it is early days in changing medical and hospital cultures which still embrace systems-based treatments where patients fit into long established ways of being treated which involve long queues and token acknowledgement that patients are important.

Patient advocacy

61. Patient advocacy is an area of specialisation in health care concerned with advocacy for patients, their families and caregivers. Patient advocacy recognises that in the healthcare and hospital context there is a power imbalance which leaves patients in a position of vulnerability.

62. A patient advocate may be an individual - a family member, caregiver and/or trusted friend. A patient advocate may be an organisation often concerned with a

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[32] Australia. Australian Commission on Safety and Quality in Health Care. Website: https://www.safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care

[33] New South Wales. Clinical Excellence Commission. Website: https://www.cec.health.nsw.gov.au/improve-quality/teamwork-culture-pcc/person-centred-care

[34] New South Wales. Health NSW

specific medical condition or group of consumers. An example is the Cancer Council, which advocates for people with cancer and their families. The Cancer Council receives little government funding instead relying on donations and its own fundraising.

63. The Older Persons Advocacy Network (OPAN) is a network of publicly funded advocacy organisations for older Australians. Member organisations focus on helping older Australians navigate the aged care system and in some jurisdictions this may extend to assisting people receiving healthcare and people in hospital. OPAN manages the Australian Government's National Aged Care Advocacy Program (NACAP). In 2021 the Government increased funding from $ 52.6 million to $151.1 million over four years.[35] It is not evident how much funding is directed to regional NSW.

Patient navigators

64. As healthcare becomes more complex, larger hospitals are employing their own patient advocates and/or patient navigators although the latter are more like administrative coordinators. Leading consumer organisations such as the Consumers Health Forum of Australia (CHF) are supporting the introduction of a network of care coordinators and health system navigators.[36]

65. While the existence of advocates and navigators in hospitals is a welcome step towards patient centred care, any patient advocate employed by a hospital will in the end have loyalty to their employer rather than a patient. The is an important issue and is summed up by the saying, 'Who pays the piper, call the tune.'

Hospital nurses as patient advocates

66. The role of patient advocacy is not new in the nursing profession. Historically, patient advocacy has been a moral obligation for nurses. In recent years, nursing literature has focused on the advocacy role and the nursing profession has adopted the term 'patient advocacy' to denote an ideal of the practice.

67. Well qualified and experienced nurses are the ideally placed to be patient advocates but the problem for nurses employed in hospitals is that they are

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[35] Australia. Department of Health. Ministers, National aged care advocacy expanded as reforms gain momentum. Media release, 1 December 2021. See: https://www.health.gov.au/ministers/senator-the-hon-richard-colbeck/media/national-aged-care-advocacy-expanded-as-reforms-gain-momentum

[36] Consumers Health Forum of Australia, Consumer Commission Report – Marking Health Better Together, Canberra, 2020, page 4.

employed in hierarchical organisations and their effectiveness as patient advocates will all too often be mitigated by the medical hierarchy.[37]

68. Although multiple factors influence the need for advocacy, it is generally true that someone in the healthcare environment must assume the role of client advocate, particularly for the client whose self-advocacy is impaired. Generally, advocacy aims to promote or reinforce a change in one's life or environment, in program or service, and in policy or legislation. In healthcare delivery, these activities focus on health conditions, healthcare resources, and the needs of patients and the public.

Independent (private) patient advocates

69. As health systems and treatment options grow ever more complex, a new kind of support role is becoming increasingly popular in the United States, the United Kingdom and Europe – the private patient advocate. In the United States independent or private patient advocates have been a common part of patient-centred care since the mid-2000s.[38]

70. Like many other people, I learnt about independent patients advocates the hard way. A full account is at Reference E. In summary, when there were issues with my mother's treatment in hospital, a friend suggested I get an independent patient advocate. I had never heard of patient advocates. Several times I went to call an independent patient advocate but was deterred by the prospect of having to pay for something I did not understand. After my mother had died I was left with one regret and that was that I never engaged an independent patient advocate.

71. Some months after my mother's death, I witnessed an independent patient advocate in action and realised how such a professional could help patients, their families and caregivers when contending with less than satisfactory treatment in hospital. When I watched the September 2020 *60 Minutes* report, *The greatest loss,* I thought if only the people in the report had known about independent patient advocates! Better to have someone stand in your corner during treatment or when you are in hospital than to be complaining when it is too late.

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[37] Ford, Steve (Editor), Patient advocacy: breaking down barriers and challenging decisions, Nursing Times, 3 January 2017. See: https://www.nursingtimes.net/clinical-archive/holistic-care/patient-advocacy-breaking-down-barriers-and-challenging-decisions-03-01-2017/

[38] Stockton, Shelley, *Patient advocates: a private affair*, The Medical Republic, 10 March 2017. See: https://medicalrepublic.com.au/patient-advocates-private-affair/7790

The case for independent patient advocates

72. The website for Patient Advocates Australia presents the case for using an independent patient advocate:

> The average healthcare ‘incident’ will involve 3+ doctors, 5+ healthcare providers and 3-7 different locations. This can be confusing, overwhelming and is often characterised by stress, poor communication and a lack of co-ordination. An experienced health professional helping you manage your care knows how to navigate all this and achieve the best results.
>
> The health system works best when patients are well informed, speak up and fend for themselves. When something goes wrong with our health care, we are not as likely to complain as we would if we got bad service in a store or restaurant. We may worry that speaking up will undermine our care, offend our health care providers, or interrupt our treatment.
>
> We may be too angry or too intimidated to confront a health care provider, especially if we are still receiving medical care from him or her. We may think, ‘What difference does it make? The problem has already happened. It’s too late to do anything now.’ Or we may not have the communication skills or medical knowledge to assert ourselves effectively.
>
> Those concerns are valid and underpin the logic in recruiting an independent expert to assist you. An advocate negotiates and mediates to achieve the required outcome. Where appropriate, they will intercede and have your management reviewed.
>
> Speaking up is important because:
>
> - It can prevent problems from occurring;
> - action can still be taken to improve the situation;
> - providers and health care professionals respect and respond best to well informed and well supported patients;
> - action can prevent the problem from escalating (becoming worse);
> - assertion and self-advocacy becomes a lifelong skill that strengthens future involvement in health care encounters.[39]

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[39] www.patientadvocatesaustralia.com.au/faqs

73. Patient Advocates Australia says:

> Being a patient can be isolating and daunting: examinations, medications, diagnosis, treatment options. Even just managing chronic illness.
>
> All of these things can easily overwhelm a person, no matter how old, educated or stoic they are. We imagine ourselves to be the masters of our bodies, but sometimes we are dealt an uneasy hand and suddenly everything changes.
>
> How do you make decisions? Who can you turn to? A qualified health professional and [independent] patient advocate …
>
> There is a growing trend worldwide of the expectation that healthcare should be evidence based, patient centred and collaborative. However, most patients do not have the knowledge, skills or confidence to look after their own best interests in this area.
>
> Additionally, when someone is unwell they are least able to fend for themselves.
>
> Patient Advocates are trained health professionals who accompany patients to medical appointments in order to ask questions, explain disease concepts and treatment options and provide patients with confidence that they are getting good care.
>
> In NSW, the system has struggled in recent decades to the point where access to services is difficult, standards have declined, health management is fragmented and care is less focused on the individual patient. Stress, frustration, expense and poor hospital or medical care and substandard care and outcomes result. An independent advocate assists patients to effectively use specialist consultations, meetings and advice and navigates them through the sometimes overwhelming health system maze.
>
> Whereas healthcare facilities (hospitals, medical centres, pharmaceutical companies) and insurers often provide advocates, discharge planners or social workers to work with patients, those employees owe their allegiance to their employers and seldom achieve genuine patient centred care.

> [Independent] patient advocates are independent of any employer constraints and are typically medically savvy and health literate. Support provided can be short term and specific to an acute issue or of an ongoing nature.[40]

74. Independent patient advocates provide:

Practical support:

- Asking relevant medical questions on behalf of the patient or other supporting persons
- Ensuring the patient and their support network understand the advice and information provided by healthcare providers
- Facilitating an ongoing relationship with a medical practitioner
- Educating the patient and family members on the available medical resources
- Alleviating confusion or conflict between the patient and the physician, or between practitioners
- Arranging a second opinion when the patient is concerned about the information provided by the treating professional
- Arranging specialist appointments
- Liaising with private health insurers to settle disputes or clarify misunderstandings
- Negotiating or intervening when care standards are sub optimal
- Exploring access for relevant clinical trials
- Compiling and submitting a complaint about care.

Emotional support:

- Accompanying the patient and other supporting persons to medical appointments
- Providing regular contact with carers, practitioners, nurses, as well as the patients, to ensure satisfactory medical support is being provided consistently over a period of time
- Monitoring the patient's sense of wellbeing, including while travelling or during changed circumstances
- Tailoring care to individual needs: whether in person, by telephone, text message or email.[41]

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[40] https://www.patientadvocates.com.au/what-is-a-patient-advocate.html

[41] https://www.patientadvocates.com.au/what-is-a-patient-advocate.html

75. What are the responsibilities of an independent patient advocate? The Patient Advocate Australia website says:

> An advocate is not there to make decisions for the patient or their support persons. They provide guidance, clarify confusing or overwhelming information, help the affected person through a trying time, suggest alternative options of care, or explore various ways to manage chronic pain or disease. They co-ordinate care, source specialist doctors and second opinions, ensure communication between doctors and between family members and eliminate duplication or omission of services.
>
> An advocate does provide legal advice. They do not supplant a Medical Power of Attorney, give financial advice, nor do they replace a next-of-kin.42

76. Older Australians, their families and caregivers need to know about independent patient advocates. When I reflect on my years as a carer and the health and aged care experiences of my parents, I am convinced better outcomes could have been achieved if I had known about independent patient advocates and engaged one.

77. My understanding is that at present there is no health fund rebate for using the services of a patient advocate. This should change. It could be a game changer for the quality of health and aged care services. There could be significant savings to the overall cost of health care and aged care if people used independent patient advocates. People can get health cover for the pets today and so why not have cover that enables the best possible health outcomes for older Australians ... in fact, all Australians.

78. With just a handful of private advocates operating in Australia to date, their introduction raises many questions, and it remains to be seen how this emerging industry will streamline patient care but the potential is there. Studies in other countries provide evidence that patient advocates contributed to better outcomes in terms of patient health and save money in the health system. With the percentage of the population who are single increasing there is surely an ever increasing need for single people not to experience hospital and health treatments alone.

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[42] https://www.patientadvocates.com.au/what-is-a-patient-advocate.html

Developing the profession

79. From my own research I conclude that the number of independent patient advocates in Australia is small. I have been fortunate to find one outstandingly good independent patient advocate in the person Dorothy Kamaker. She is a highly experienced Intensive care and Emergency nurse, having taught a university master's degree course in nursing and, importantly, she is trained in patient advocacy.

80. I seek to create awareness of independent patient advocacy for two reasons. First, it is a legacy of my mother's experience – I would like other people to be spared a similar experience. I would like people in regional NSW not to go through the experiences of Brian Ryan and Allan Wells and their families.

81. Secondly, from a pure self-interest perspective, I would like there to be an army of independent patient advocates like Dorothy Kamaker for when I am a patient in hospital. I envisage the advocates being well qualified nurses with nursing experience and with training in advocacy. I do not want just anyone deciding they will be an advocate. The emerging profession of independent patient advocates needs to be regulated with professional standards and have a code of practice.

82. In recent years an effective training course on patient advocacy was run in Melbourne by health psychologist Liz Crocker but at present training options are limited to online courses from providers based in the United States. Liz Crocker and her daughter Claire Crocker converted their training course into a book titled, *The patient advocate handbook*.[43]

83. I note that Craig Gear, the CEO of OPAN is planning the development of standards and regulation of advocates for older Australians operating in the aged care context.[44] While OPAN advocates are publicly funded it should be possible to include those who operate privately. In the longer term, patient advocates including independent patient advocates, should be regulated by the Australian Health Practitioner Regulation Agency (AHPRA) in the same way the nursing profession is regulated by AHPRA.[45]

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[43] See also: Crocker, L and Crocker C., *The patient advocate handbook – How to find and use your voice in health care*, Balboa Press, Australia, 2019.

[44] Conversation with Craig Gear on 30 November 2021.

[45] The Australian Health Practitioner Regulation Agency (AHPRA works with the 15 National Boards to help protect the public by regulating Australia's registered health practitioners. Together, their primary role is to protect the public and set standards and policies that all registered health

84. I urge the Committee to consider how the people in rural, regional and remote NSW may benefit from being aware of independent patient advocates.

Recommendations

85. I recommend that:

> The Committee hear evidence from an independent patient advocate to gain a full appreciation of what independent patient advocates can do to improve the healthcare and hospital experience of people living in rural, regional and remote New South Wales. **(Recommendation 3)**
>
> All hospitals, medical centres and GP surgeries in New South Wales have well displayed notices and leaflets for patients, their families and caregivers that provide information on:
>
> (a) patient advocates generally;
>
> (b) independent or private patient advocates; and
>
> (c) how they can be contacted. **(Recommendation 4)**
>
> Steps be taken to deliver a patient advocacy training course for suitably qualified medical personal. Completion of such a course would be a prerequisite for practising as a patient advocate. **(Recommendation 5)**

Game changer

86. Some people react to the idea of independent patient advocates by saying not everyone can afford the fees. I would make the following comments:

- the reality is that the need for an independent patient advocate is most likely to be for a brief period;
- my research is that the fees are modest. You are likely to pay more for a tradesperson;
- there are studies showing patient benefits and benefits to the health system from using patient advocates – better health outcomes and shorter hospital

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practitioners must meet. Each Board has a health profession agreement with AHPA that sets out fees, budget and the services provided by AHPRA. See www.ahpra.gov.au stays. Research in other jurisdictions suggests significant savings can be made from reducing medication errors.[46] I believe independent patient advocates can play a significant role in improving case management, reducing medication errors and reducing the duration of hospital stays; and

- fees being claimable items for those people with health insurance may ensure benefits to all parties. This requires a proper cost-benefit analysis which is beyond the scope of this submission.

87. For Medicare patients, there is a case for mirroring the current government funding for people with disability who face complex challenges or are unable to advocate for themselves, and do not have family, friends or peers who can support them as informal advocates, to access advocacy support.[47]

88. When you look at hospitals and the healthcare system in rural, regional and remote areas of NSW it is clear there are major problems; there are funding issues and staff shortages. Things have to change. One definition of insanity is to keep doing the same things and expect different outcomes. More funding and more staff should help make things better but the nature of healthcare has fundamentally changed. Medical treatment is increasingly complex and driven by the need to achieve performance targets. Doctors and nurses are forced to operate in a system that encourages an environment of speed.

89. American independent RN (registered nurse) patient advocate Karen Marcerau says:

> Everything is related to how many patients you can see, or how many procedures you can do … patients are in awe or afraid. They do not have time to gather their thoughts and they don’t know what to tell the doctor. People don’t know what is important to discuss.[48]

90. Marcerau thinks patients are effectively opting out of their medical treatment. Everything is rushed and healthcare workers do not have time to probe, to listen and to ask careful questions.

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[46] Walsh, E. K., et al*., Economic impact of medication error: a systematic review*, IPSE (Official Journal of the International Society of Pharmacoepidemiology, 13 March 2017.

[47] Australia. Department of Social Security, Disability Advocacy Fact Sheet, 5 December 2018. See: https://www.dss.gov.au/disability-advocacy-fact-sheet

[48] Gustafson, Craig, *[Interview with] Karen Mercereau, RN: Patient advocacy – Filling the gaps to prevent medical errors, improve outcomes and reduce costs*. Intergrative Medicine Clinical Journal. 15 March 2016

91. Independent patient advocates have an education role and part of that entails helping people to be better patients, helping them understand how to interact with the increasingly complex healthcare system.

92. People need independent patient advocates to stand in their corner. Independent patient advocates offer a new way doing things. They can be a game changer for healthcare in rural, regional and remote areas of New South Wales.

References

Reference A. Royal Commission into Aged Care Quality and Safety – Terms of Reference

The terms of reference for the Royal Commission are included in the Letters Patent, which the Administrator of the Government of the Commonwealth of Australia signed on 6 December 2018, and which the Governor-General amended by Letters Patent on 13 September 2019. The Letters Patent were further amended by the Governor-General on 25 June 2020.

- Letters Patent 6 December 2018
- Letters Patent 13 September 2019
- Letters Patent 25 June 2020

The Commissioners were appointed to be a Commission of inquiry, and required and authorised to inquire into the following matters:

a. the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;
b. how best to deliver aged care services to:
    i. people with disabilities residing in aged care facilities, including younger people; and
    ii. the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;
c. the future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:
    i. in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
    ii. in remote, rural and regional Australia;
d. what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;
e. how to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters;

f. 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;
g. any matter reasonably incidental to a matter referred to in paragraphs (a) to (f) or that [the Commissioners] believe is reasonably relevant to the inquiry.

Published on 6 December 2018.

Reference B. John Hopkins Study: Physicians advocate for changes in how deaths are reported

Extract of article from The Hub (Internet magazine published by John Hopkins University) - Johns Hopkins study suggests medical errors are third-leading cause of death in US: Physicians advocate for changes in how deaths are reported

1. In their study, the researchers examined four separate studies that analysed medical death rate data from 2000 to 2008. Then, using hospital admission rates from 2013, they extrapolated that based on a total of 35,416,020 hospitalizations, 251,454 deaths stemmed from a medical error, which the researchers say now translates to 9.5 percent of all deaths each year in the U.S.

2. According to the CDC, in 2013, 611,105 people died of heart disease, 584,881 died of cancer, and 149,205 died of chronic respiratory disease - the top three causes of death in the U.S. The newly calculated figure for medical errors puts this cause of death behind cancer but ahead of respiratory disease.

3. "Top-ranked causes of death as reported by the CDC inform our country's research funding and public health priorities," Makary says. "Right now, cancer and heart disease get a ton of attention, but since medical errors don't appear on the list, the problem doesn't get the funding and attention it deserves."

4. The researchers caution that most medical errors are not due to inherently bad doctors, and that reporting these errors shouldn't be addressed by punishment or legal action. Rather, they say, most errors represent systemic problems, including poorly coordinated care, fragmented insurance networks, the absence or underuse of safety nets, and other protocols, in addition to unwarranted variation in physician practice patterns that lack accountability.

5. "Unwarranted variation is endemic in health care," Makary says. "Developing consensus protocols that streamline the delivery of medicine and reduce variability can improve quality and lower costs in health care. More research on preventing medical errors from occurring is needed to address the problem."

Reference C. World Health Organisation, *10 facts on patient safety*

https://www.who.int/news-room/photo-story/photo-story-detail/10-facts-on-patient-safety

Patient safety is a serious global public health concern. It is estimated that there is a 1 in 3 million risk of dying while travelling by airplane. In comparison, the risk of patient death occurring due to a preventable medical accident, while receiving health care, is estimated to be 1 in 300. Industries with a perceived higher risk, such as the aviation and nuclear industries, have a much better safety record than health care does.

Fact 1: One in every 10 patients is harmed while receiving hospital care

Estimates show that in high-income countries, as many as one in 10 patients is harmed while receiving hospital care. The harm can be caused by a range of adverse events, with nearly 50% of them considered preventable.

A study on the frequency and preventability of adverse events across 26 hospitals in eight low-and middle-income countries, showed the adverse event rate to be around 8%. Of these events, 83% were preventable, while about 30% were associated with death of the patient.

Fact 2: The occurrence of adverse events due to unsafe care is likely one of the 10 leading causes of death and disability across the world

The occurrence of adverse events, resulting from unsafe care, is likely to be one of the 10 leading causes of death and disability worldwide. Recent evidence suggests that 134 million adverse events occur each year due to unsafe care in hospitals in low- and middle-income countries (LMICs), resulting in 2.6 million deaths annually.

Another study has estimated that around two-thirds of all adverse events resulting from unsafe care, and the years lost to disability and death (known as disability adjusted life years, or DALYs), occur in LMICs.

Fact 3: The occurrence of adverse events due to unsafe care is likely one of the 10 leading causes of death and disability across the world

The provision of safe services is extremely important across all levels of health care, including in primary and outpatient (ambulatory) care, where the bulk of services are offered. Globally, as many as four out of 10 patients are harmed while receiving health care in these settings, with up to 80% of the harm considered to have been preventable. The most detrimental errors are related to diagnosis, prescription and the use of medicines.

Harm in primary and ambulatory care often results in hospitalization. It has been found, that across Organisation for Economic Co-operation and Development (OECD) countries, patient harm may account for more than 6% of hospital bed days and more than 7 million admissions.

Fact 4: At least 1 out of every 7 Canadian dollars is spent treating the effects of patient harm in hospital care

A minimum of 1 out of every 7 Canadian dollars is spent treating the effects of patient harm in hospital care. Recent evidence shows that 15% of total hospital expenditure and activities in Organisation of Economic Co-operation and Development (OECD) countries is a direct result of adverse events, with the most burdensome events being blood clots (venous thromboembolism), bed sores (pressure ulcers) and infections.

It is estimated that the total cost of harm in these countries alone amounts to trillions of US dollars every year.

Fact 5: Investment in patient safety can lead to significant financial savings

Investment in improving patient safety can lead to significant financial savings and more importantly better patient outcomes. This is because the cost of prevention is typically much lower than the cost of treatment due to harm. As an example, in the United States alone, focused safety improvements led to an estimated US$ 28 billion in savings in Medicare hospitals between 2010 and 2015.

Greater patient involvement is the key to safer care. Engaging patients is not expensive and represents a good value. If done well, it can reduce the burden of harm by up to 15%, saving billions of dollars each year– a very good return on investment.

Fact 6: Unsafe medication practices and medication errors harm millions of patients and costs billions of US dollars every year

Unsafe medication practices and errors – such as incorrect dosages or infusions, unclear instructions, use of abbreviations and inappropriate prescriptions – are a leading cause of avoidable harm in health care around the world. Globally, the cost associated with medication errors has been estimated at US$ 42 billion annually, not counting lost wages, productivity, or health care costs. This represents almost 1% of global expenditure on health.

Medication errors may occur when weak medication systems and/or human factors such as fatigue, poor working conditions, or staff shortages affect prescribing, storage, preparation, dispensing, administration and monitoring practices. Any one or a combination of these can result in severe patient harm, disability and even death.

Fact 7: Inaccurate or delayed diagnosis is one of the most common causes of patient harm and affects millions of patients

Diagnostic error, that is the failure to identify the nature of an illness in an accurate and timely manner, occurs in about 5% of adults in the United States outpatient care settings. About half of these errors have the potential to cause severe harm. A study of primary care clinics in Malaysia established the occurrence of diagnostic errors at 3.6%.

In the United States, extensive autopsy research performed in the past decades has shown that diagnostic errors contribute to approximately 10% of patient deaths. Furthermore, medical record reviews demonstrate that diagnostic errors account for 6–17% of all harmful events in hospitals.

Evidence from low- and middle-income countries is limited, however, it is estimated that the rate is higher than in high-income countries as the diagnostic process is negatively impacted by factors such as limited access to care and diagnostic testing resources.

Fact 8: Hospital infections affect up to 10 out of every 100 hospitalized patients

Out of every 100 hospitalized patients, at any given time, seven in high-income countries and 10 in low- and middle-income countries will acquire one or more health care-associated infections (HAIs). Hundreds of millions of patients worldwide are affected by HAIs each year. People with methicillin-resistant Staphylococcus aureus (MRSA), a bacterium increasingly found in hospital settings that is resistant to most antibiotics, are estimated to be 64% more likely to die than people with a non-resistant form of the infection.

Regardless of a country’s income level, different types of interventions, including appropriate hand hygiene, can reduce HAI rates by up to 55%.

Fact 9: More than 1 million patients die annually from complications due to surgery

Findings by WHO suggest that, globally, surgery still results in high rates of illness, disease and death. Unsafe surgical care procedures cause complications in up to 25% of patients. Almost 7 million surgical patients suffer significant complications annually, 1 million of whom die during or immediately following surgery.

As a result of improved patient safety measures, deaths related to complications from surgery have decreased in the past 50 years. Nevertheless, they remain two to three times higher in low- and middle-income countries than in high-income countries.

Fact 10: Medical exposure to radiation is a public health and patient safety concern

Worldwide, there are more than 3.6 billion x-ray examinations performed every year, with around 10% of them occurring in children. Additionally, there are over 37 million nuclear medicine and 7.5 million radiotherapy procedures annually. Inappropriate or unskilled use of medical radiation can lead to health hazards, both for patients and staff.

Radiation errors involve overexposure to radiation and cases of wrong-patient or wrong-site identification. A review of 30 years of published data on safety in radiotherapy estimates that the overall incidence of errors is around 15 per 10 000 treatment courses.

Reference D. Australian Charter of Health Care Rights

Australian Commission on Safety and Quality in Healthcare, *Australian Charter of Healthcare Rights*. Second edition.

These rights apply to all people in all places where health care is provided in Australia. The Charter describes what you, or someone you care for, can expect when receiving health care.

I have a right to:

Access

- Healthcare services and treatment that meets my needs

Safety

- Receive safe and high quality health care that meets national standards
- Be cared for in an environment that makes me feel safe

Respect

- Be treated as an individual, and with dignity and respect
- Have my culture, identity, beliefs and choices recognised and respected

Partnership

- Ask questions and be involved in open and honest communication
- Make decisions with my healthcare provider, to the extent that I choose and am able to Include the people that I want in planning and decision-making

Information

- Clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent
- Receive information about services, waiting times and costs
- Be given assistance, when I need it, to help me to understand and use health information
- Request access to my health information
- Be told if something has gone wrong during my healthcare, how it happened, how it may affect me and what is being done to make care safe

Privacy

- Have my personal privacy respected
- Have information about me and my health kept secure and confidential

Give feedback

- Provide feedback or make a complaint without it affecting the way that I am treated
- Have my concerns addressed in a transparent and timely way
- Share my experience and participate to improve the quality of care and health services

Reference E. Learning the hard way

Edited extract from Submission to the Royal Commission into Aged Care Quality and Safety by Trevor Rowe. Section 3.24 – An independent patient advocate

In December 2019 I talked to a friend, who was visiting her father-in-law, who was a patient in Geriatric Ward. She observed that getting the best care for my mother in the Ward was problematic and suggested I consider engaging an independent patient advocate to get the best care for my mother. She told me that she had used one when one of her daughters was extremely ill and she did not know what to do. I searched the Internet and found Patient Advocates Australia, but somehow I never got around to making the call. I regret this.

I knew I needed someone to help me and my family make good decisions for my mother but at the time I did not comprehend what a patient advocate may be able to do. I would have consulted my mother's GP but she was on sick leave. I was weary from being a full-time carer and with my mother in hospital I just kept going one day at a time. It was emotionally draining see my mother in pain and suffering delirium and to be dealing with the idiosyncrasies of Geriatric Ward and Hospital staff. Initially we trusted doctors and other staff but soon enough I had misgivings about what they said, their decisions and the way things progressed. I questioned their competence to bring about a good outcome for my mother.

I had discovered the hard way that doctors made decisions about medications without explaining the benefits and disadvantages or sometimes without reference to family and carers. Only after my mother fell into a deep delirium did the geriatrician responsible for her care explain that some opioid and nerve drugs can overload the body and brain and bring on delirium. Once the delirium was evident, his first reaction was to dramatically decrease my mother's pain medication. He said he would put a chart with medications on the wall so that we could know what medications were being given. Days and weeks passed but there was no list of medications. (Charter Right 5).

I would be with my mother in the Ward from when she woke each morning to respond to her needs, to help with breakfast and to be present when the Geriatrician made his daily visit. My sister-in-law would then be with my mother from lunchtime and then my middle brother would be with my mother during the late afternoon. I would return at 7:00 pm and remain with my mother until she went to sleep. When she was delirious this could mean staying the night.

Recently a friend was troubled by his treatment in Canberra Hospital. I wanted to help but was not sure what I could do. Then I remembered Patient Advocates Australia, contacted

Dorothy Kamaker for advice and then recommended to my friend that he consider engaging Dorothy as his patient advocate. He agreed to engage her and was extremely grateful for the resulting change that her involvement brought about in his treatment. I observed the patient advocate Dorothy Kamaker as singularly impressive in her medical knowledge, her understanding people and hospitals systems and health systems generally, her communication skills and her ability to advocate for my friend.

I now understand why I should have called her last when my mother was first admitted to Canberra Hospital or even when my father was alive. In fact, it would have helped me as a carer when I was frustrated by aspects of my mother's Home Care Package – issues relating to the provider and the hardship caused by not having funding commensurate with my mother's Level 4 care needs.