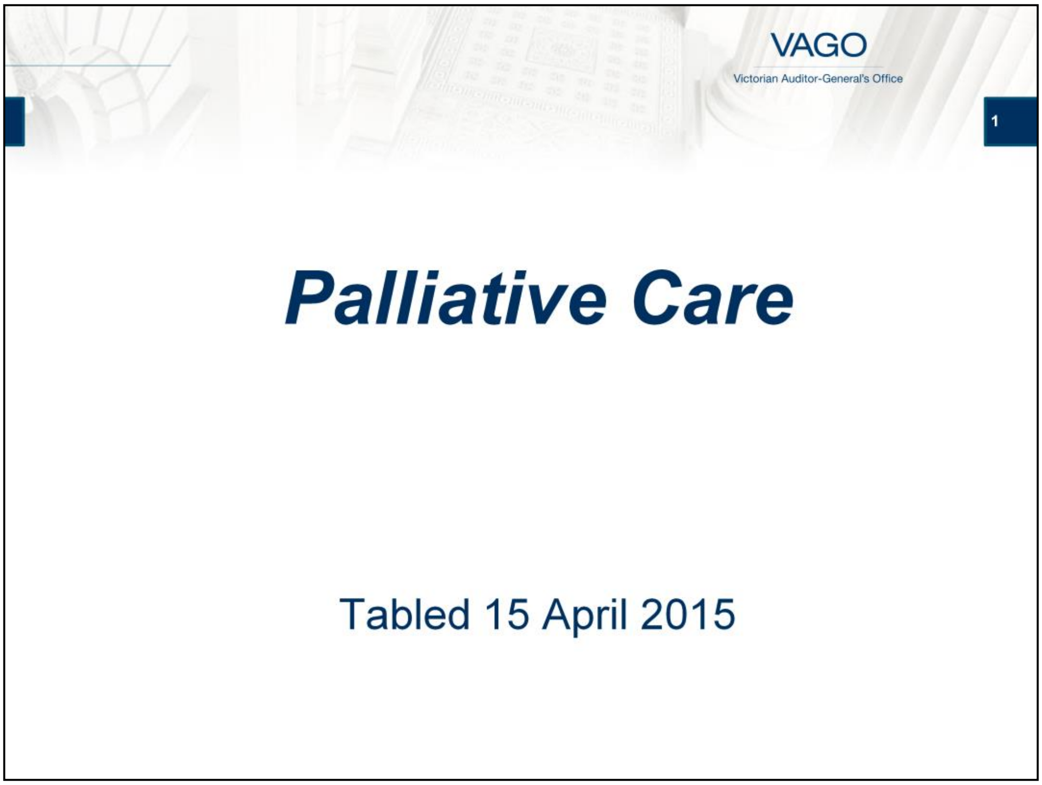


VAGO

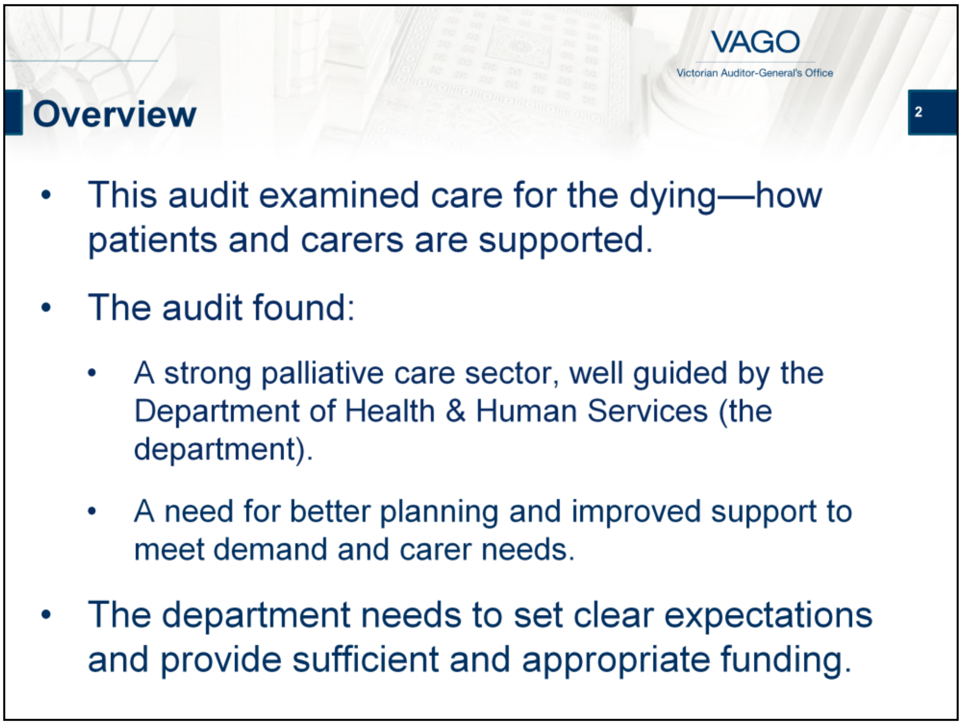
Victorian Auditor-General's Office

Palliative Care

Tabled 15 April 2015

The Auditor-General provides assurance to Parliament on the accountability and performance of the Victorian Public Sector. The Auditor-General conducts financial audits and performance audits, and reports on the results of these audits to Parliament.

On 15 April 2015, the Auditor-General tabled his performance audit report, *Palliative Care*.



VAGO

Victorian Auditor-General's Office

Overview

- This audit examined care for the dying—how patients and carers are supported.
- The audit found:
  - A strong palliative care sector, well guided by the Department of Health & Human Services (the department).
  - A need for better planning and improved support to meet demand and carer needs.
- The department needs to set clear expectations and provide sufficient and appropriate funding.

Death and dying can be a confronting prospect for anyone with a terminal illness.

Understanding your prognosis, finding out what options exist, and deciding what kind of care you would prefer can be complex and emotional.

Making this process as straightforward and responsive to a patient’s needs and symptoms as possible is what good palliative care is about.

This audit examined how patients, their families, friends and carers are supported through the palliative health care system in Victoria.

The audit found that:

- Victoria has a strong palliative care sector, and the Department of Health & Human Services, which we will refer to as the department, has set a clear and ambitious agenda.
- Palliative care in Victoria is delivered by skilled and

dedicated staff who specialise in caring for people with a terminal illness.

- However, a number of areas for further improvement remain including better planning and improved support to meet demand and carer needs.

Going forward, it is imperative that the department sets clear expectations for service delivery across the state and provides sufficient and appropriate funding to health services and community organisations.

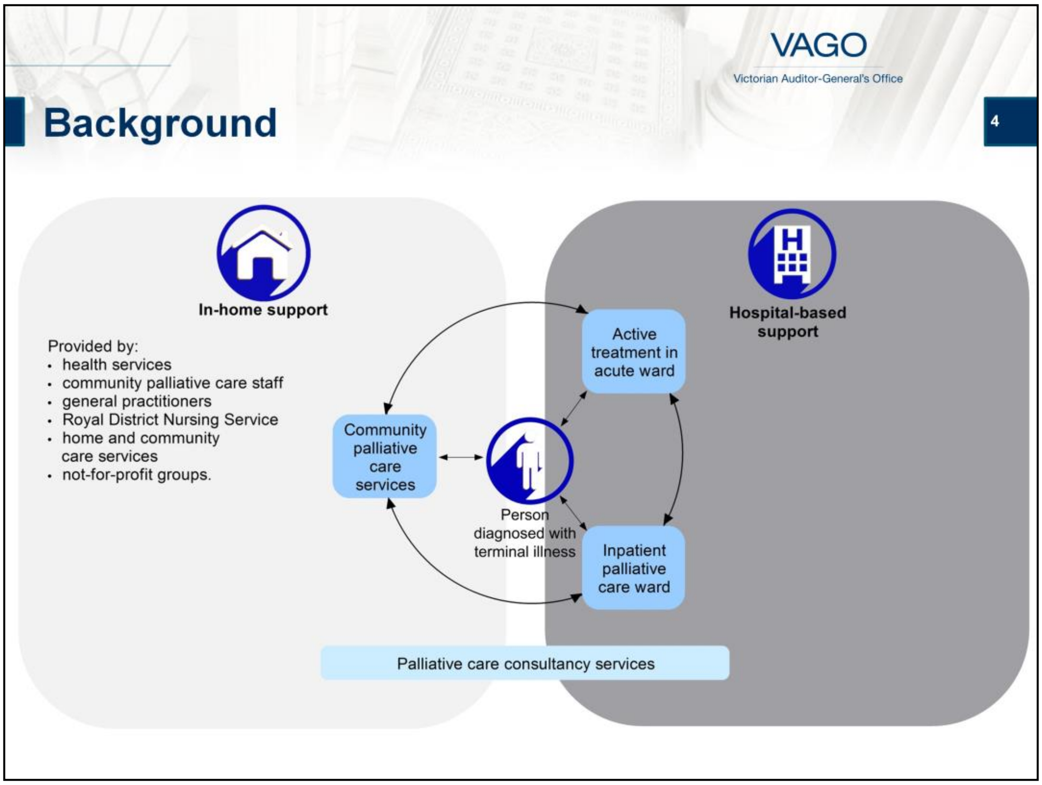
Background

- Population is growing and ageing.
- Around half of all Victorians who die each year would benefit from palliative care.
- Most people prefer to die in their home.
- Traditionally accessed in hospital by people with terminal cancer—profile is changing.
- The majority of palliative care takes place in the home—supported by community-based palliative care services.

Demand for palliative care is growing as the population ages and people endure increasingly lengthy periods of chronic illness.

Further, as awareness of palliative care options grows, the number of those who elect to die at home or in home-like settings—such as aged care facilities and disability group homes—is increasing.

These trends are shifting pressure from the palliative inpatient care system on to community-based palliative care services.



Background

In-home support

Provided by:
- health services
- community palliative care staff
- general practitioners
- Royal District Nursing Service
- home and community care services
- not-for-profit groups.

Hospital-based support

Active treatment in acute ward

Community palliative care services

Person diagnosed with terminal illness

Inpatient palliative care ward

Palliative care consultancy services

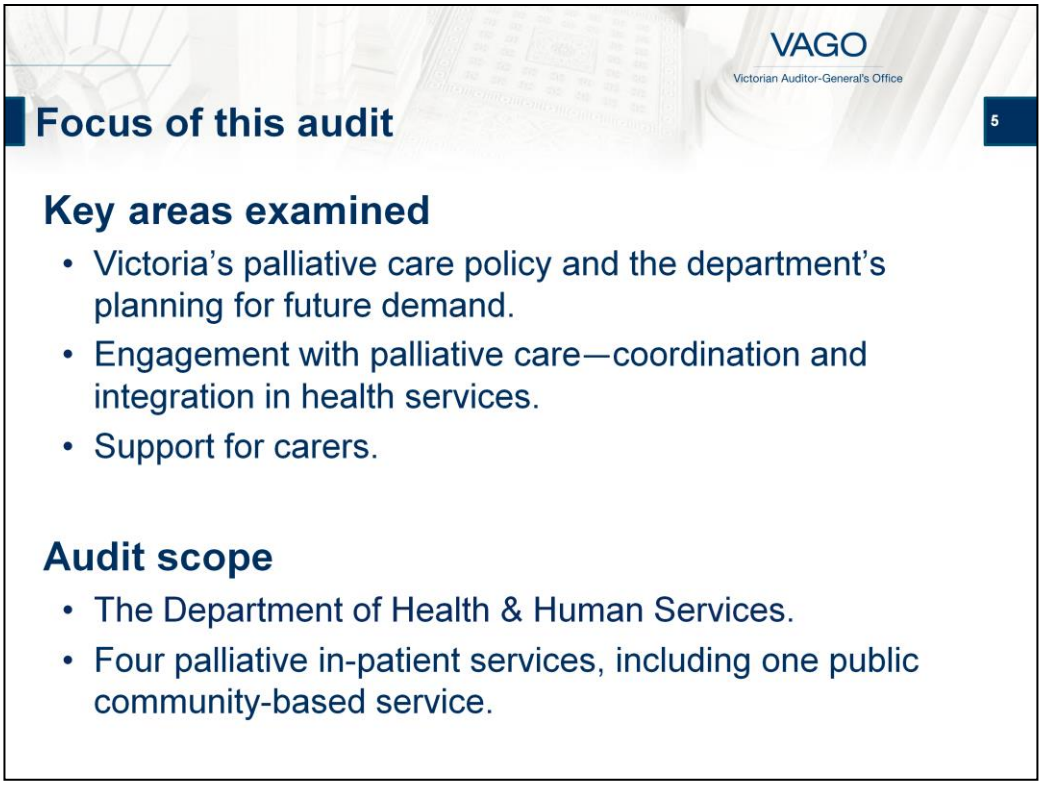
Palliative patients can be supported in their own home, another home-like setting, or in a public hospital.

In-home support is provided by a range of service providers including public health services and not-for-profit groups.

Hospital support can be provided in acute wards or in specialist palliative care wards.

The cost to the state for patients dying in hospitals and aged care facilities far exceeds the cost of dying at home, supported by community palliative care services.

However, currently, only 35 per cent of Victorian palliative care funding goes to community palliative care.



Focus of this audit

Key areas examined

- Victoria's palliative care policy and the department's planning for future demand.
- Engagement with palliative care—coordination and integration in health services.
- Support for carers.

Audit scope

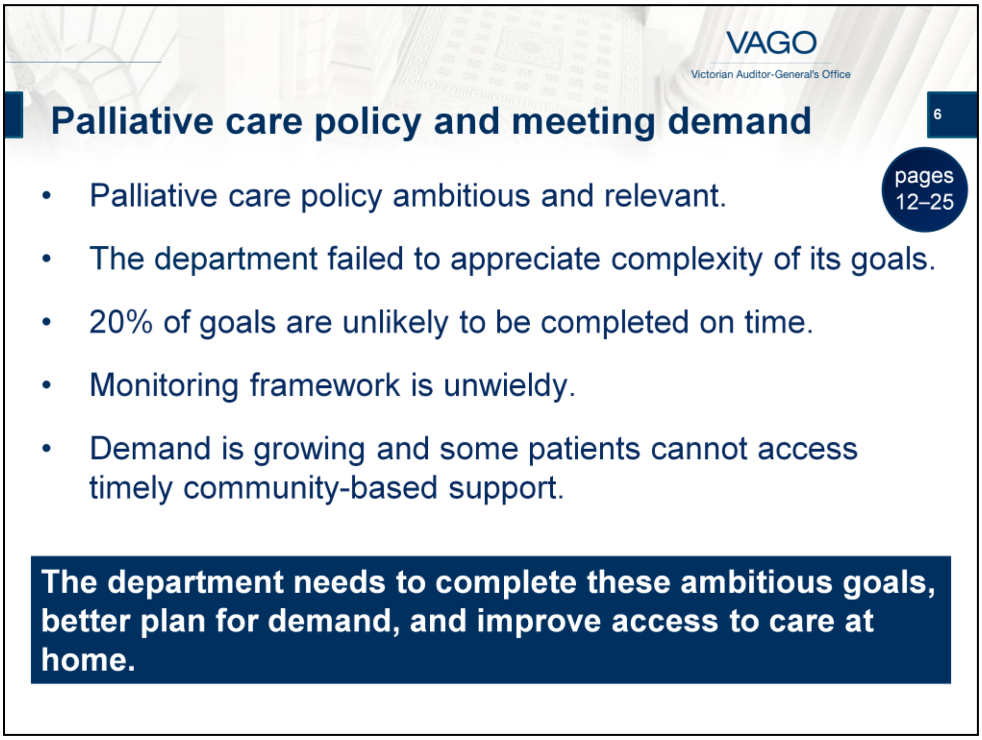
- The Department of Health & Human Services.
- Four palliative in-patient services, including one public community-based service.

The audit examined:

- The implementation of Victoria's palliative care policy and the department's planning for future demand.
- How health services coordinate internally and with the community.
- And, support for carers, looking at respite, psychosocial and bereavement support options for carers.

The scope included the department and four in-patient services. One of the in-patient services also had a public community palliative health service.

The provisions of the *Audit Act 1994* limited the extent to which we could assess non-government community provision.



VAGO
Victorian Auditor-General's Office

Palliative care policy and meeting demand

pages
12–25

- Palliative care policy ambitious and relevant.
- The department failed to appreciate complexity of its goals.
- 20% of goals are unlikely to be completed on time.
- Monitoring framework is unwieldy.
- Demand is growing and some patients cannot access timely community-based support.

The department needs to complete these ambitious goals, better plan for demand, and improve access to care at home.

We looked at Victoria's palliative care policy, *Strengthening palliative care: Policy and strategic directions 2011-2015.* Its goals were relevant and its implementation strategy set out clear steps needed to achieve the intended outcome.

However, the goals targeting improved carer support and community engagement will not be fully realised in 2015.

Internal monitoring of progress towards reaching the goals is hampered by a monitoring system that is flawed and complex and may mask both good performance and gaps.

Demand for palliative care is growing, and to ensure Victoria continues to be a leader in palliative care, the department needs to better plan for existing and future demand for services.

Looking ahead to its new end-of-life framework, the department needs to continue to work on these ambitious goals and assess resourcing for community palliative care services to improve access to care at home.


VAGO
Victorian Auditor-General's Office

Engagement with palliative care

pages 23–30

- Little improvement in community awareness.
- Community awareness projects have started but too early to determine impact.
- Consultancy teams advise and coordinate with staff in hospitals, disability group homes and aged care facilities.
- Advance care planning:
  - allows palliative care teams to understand what is important for a patient at the end of their life
  - is essential, but use is low and inconsistent.

The department needs to do more to promote discussions on dying in diverse communities.

We found that there has been little improvement in community awareness about palliative care.

Work has begun—albeit belatedly—to improve awareness of palliative care in communities who do not typically access these services. These include culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander communities and others who do not routinely access palliative care. However, it is difficult to determine the impact of this work just yet.

One positive step is that palliative care consultancy teams have been established to advise other hospital ward staff on palliative care treatment and plan for discharge home. They, along with other palliative care staff and regional nurses, also advise and coordinate with staff at disability group homes and aged care facilities.

Advance care planning allows palliative care teams to understand what is important for a patient at the end of their life, and brings comfort to the patient, their family and carers that their final wishes are known and will be considered.

Given that it has been an accepted model of practice for many years, it is disappointing that greater progress has not been made, as it is a central pillar to effective palliative care.

The department needs to continue to promote advance care planning across all health settings and better promote discussions about dying in settings and communities that are not accessing palliative care.

Support for carers

pages
12–27

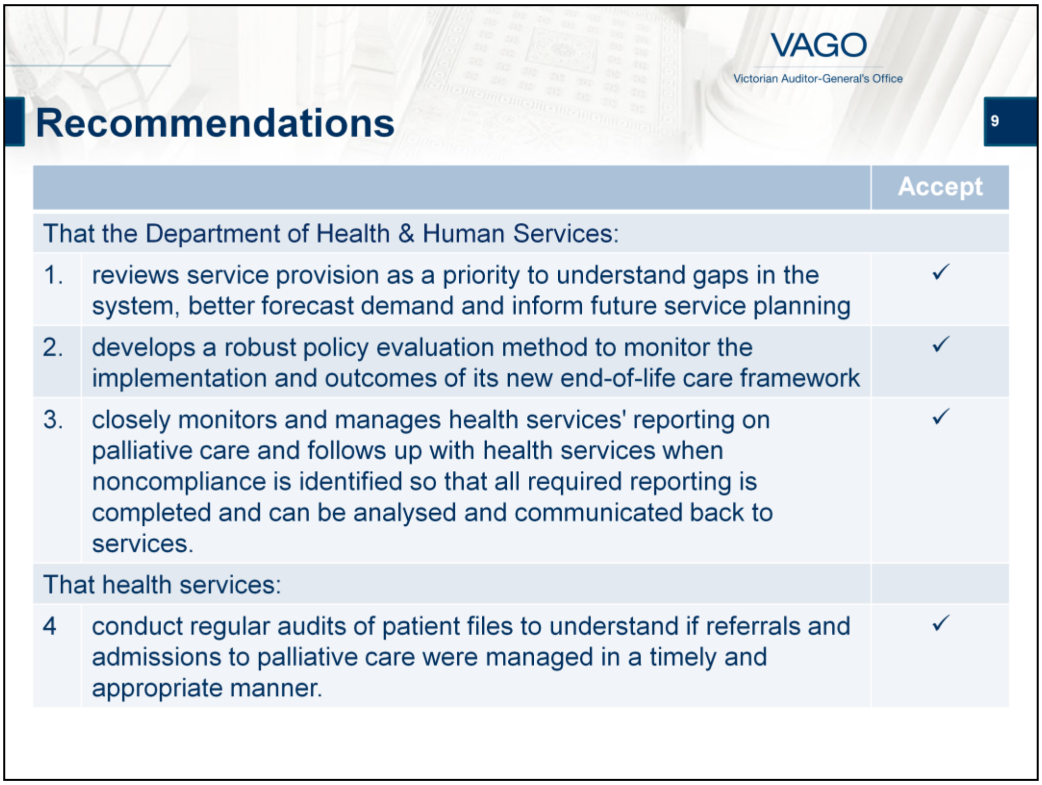
- Support for carers remains inadequate.
- Improving access to supports remains a priority.
- Better screening and referring of carers at risk of stress and complicated grief is needed.
- Performance measures need to be patient and carer centred and after-hours support reviewed.

The department needs to work closely with carers and the palliative care sector to provide better support options for carers.

While a range of support options are available to carers, these are not always sufficient or responsive to their needs. In particular, there has been little improvement in respite since 2011.

The department has developed bereavement support standards for use in specialist palliative care services. While these would enable better screening and referring of carers at risk of stress and complicated grief, many services do not use them. The department also needs to improve the quality of reporting on these matters.

The department needs to work closely with carers and the palliative care sector to provide better support options for carers.



VAGO
Victorian Auditor-General's Office

Recommendations

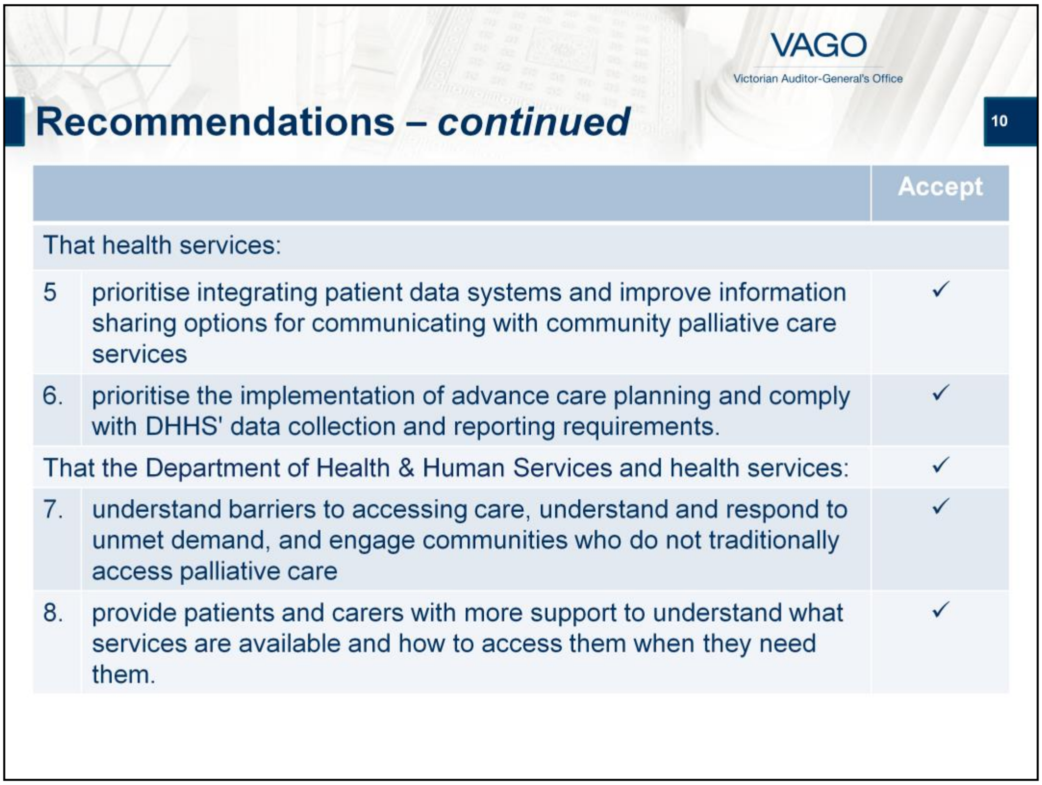
		Accept
That the Department of Health & Human Services:		
1.	reviews service provision as a priority to understand gaps in the system, better forecast demand and inform future service planning	✓
2.	develops a robust policy evaluation method to monitor the implementation and outcomes of its new end-of-life care framework	✓
3.	closely monitors and manages health services' reporting on palliative care and follows up with health services when noncompliance is identified so that all required reporting is completed and can be analysed and communicated back to services.	✓
That health services:		
4	conduct regular audits of patient files to understand if referrals and admissions to palliative care were managed in a timely and appropriate manner.	✓

We made 12 recommendations.

Seven of these are directed to the department to address issues around performance monitoring, planning for growth and responding to patient and carer needs.

Three recommendations are for health services—to focus on improving referrals and coordinating patient information.

Two recommendations require the department and health services to work together to address how they inform patients and carers about palliative care and respond to unmet demand.



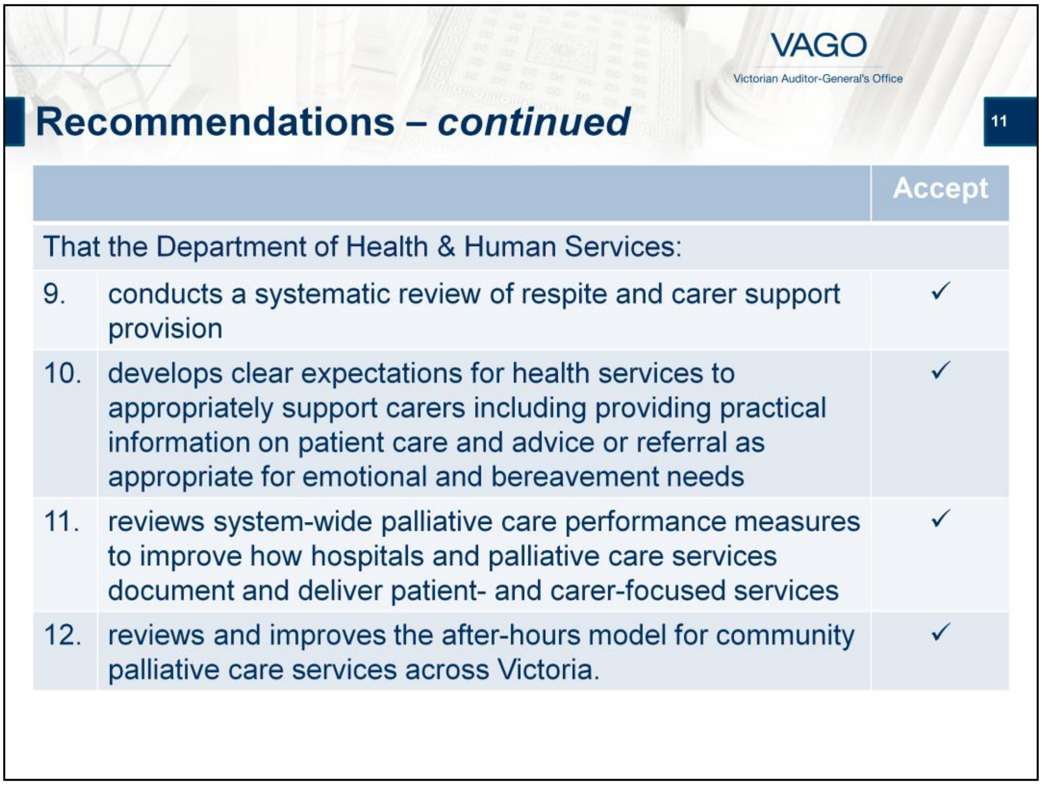
VAGO
Victorian Auditor-General's Office

Recommendations – *continued*

		Accept
That health services:		
5	prioritise integrating patient data systems and improve information sharing options for communicating with community palliative care services	✓
6.	prioritise the implementation of advance care planning and comply with DHHS' data collection and reporting requirements.	✓
That the Department of Health & Human Services and health services:		✓
7.	understand barriers to accessing care, understand and respond to unmet demand, and engage communities who do not traditionally access palliative care	✓
8.	provide patients and carers with more support to understand what services are available and how to access them when they need them.	✓

The department has accepted all recommendations and included an action plan detailing how it intends to address them over the next two years. This is contained in Appendix A of the report.

Two audited health services also provided a formal response to the audit and both indicated that they accept the recommendations and outlined how they will address them.



VAGO
Victorian Auditor-General's Office

Recommendations – *continued*

		Accept
That the Department of Health & Human Services:		
9.	conducts a systematic review of respite and carer support provision	✓
10.	develops clear expectations for health services to appropriately support carers including providing practical information on patient care and advice or referral as appropriate for emotional and bereavement needs	✓
11.	reviews system-wide palliative care performance measures to improve how hospitals and palliative care services document and deliver patient- and carer-focused services	✓
12.	reviews and improves the after-hours model for community palliative care services across Victoria.	✓

The Auditor-General will monitor this progress over time and will also look to see how other health services have acted to address the recommendations.

VAGO

Victorian Auditor-General's Office

Key messages

The department needs to complete its ambitious goals, better plan for demand, and improve access to care at home.

The department needs to do more to promote discussions on dying in diverse communities.

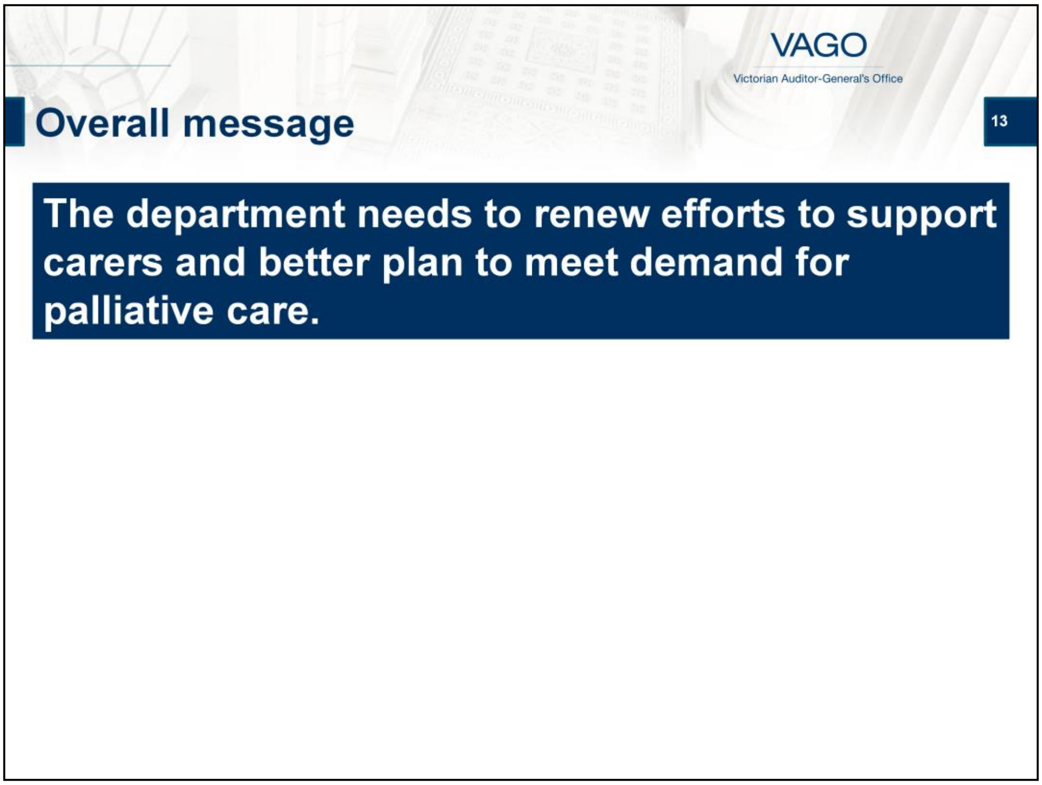
The department needs to work closely with carers and the palliative care sector to provide better support options for carers.

In Summary:

The department needs to complete the ambitious goals outlined in its Strategic Directions, better plan for and appropriately resource demand for palliative care services, and improve access to care at home.

It also needs to do more to improve awareness of palliative care and promote discussions on dying in diverse communities.

Finally, it needs to work closely with carers and the palliative care sector to provide better support options for carers.



Overall message

The department needs to renew efforts to support carers and better plan to meet demand for palliative care.

The department has established a palliative care system in Victoria that is performing well, but it needs to set clear expectations for health services to refocus the sector and make sure that growing demand for community-based care is being met, and renew efforts to support carers.

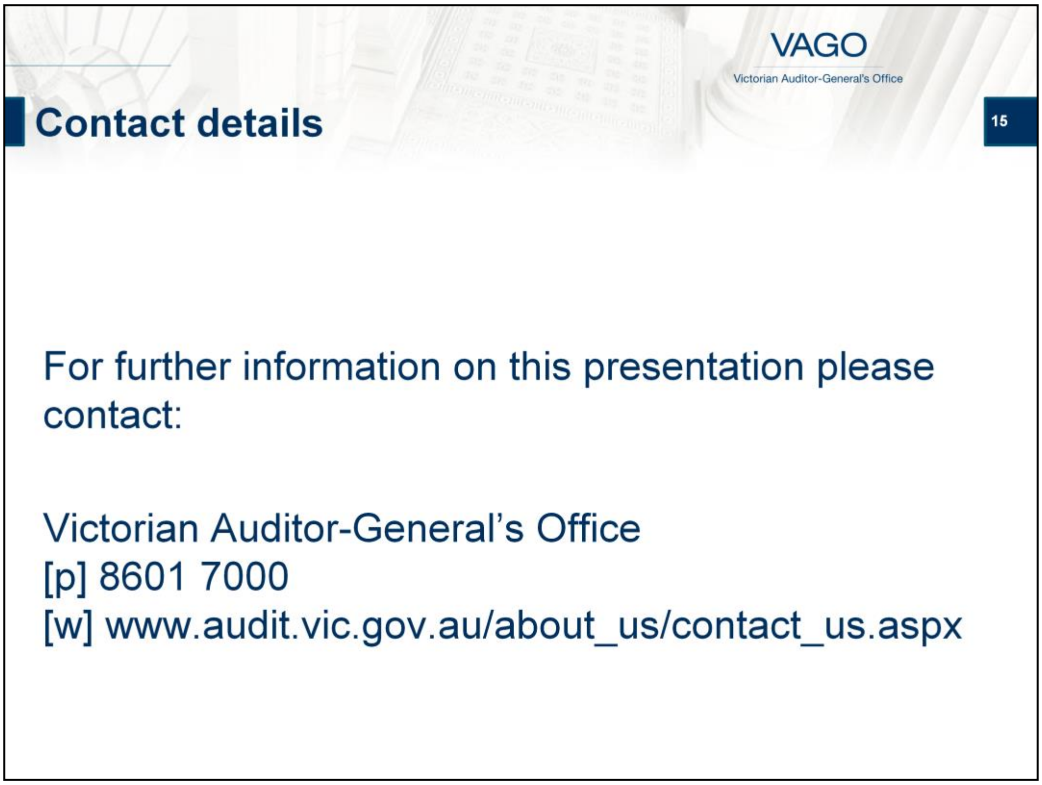
VAGO

Victorian Auditor-General's Office

Relevant audits

- *Carer Support Programs* (2012–13)

Carer Support Programs, tabled in August 2012, is a related audit.



VAGO
Victorian Auditor-General's Office

Contact details

15

For further information on this presentation please contact:

Victorian Auditor-General’s Office
[p] 8601 7000
[w] www.audit.vic.gov.au/about_us/contact_us.aspx

All our reports are available on our website.

If you have any questions about this or other reports, or if you have anything else you would like to discuss with us including ideas for future audit topics, please call us on 03 8601 7000 or contact us via our website.