Business processes and system requirements for an Advance Health Directive Register

FINAL REPORT

WA Department of Health

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1 Executive summary

Advance Health Directives (AHDs) are an important output of advance care planning. AHDs provide legally binding direction on the type of care a person wishes to receive at the point they lose the capacity or competency to make or communicate contemporaneous decisions for themselves. Increasing the uptake of AHDs is an emerging priority for both the Western Australian (WA), and Australian Governments.

AHDs remain significantly underutilised in WA, with prevalence studies finding that as low as 2.1 per cent of people in a WA hospital or residential aged care facility have an AHD, the lowest of any Australian state or territory. Their use – along with the systems, processes and legislative framework underpinning them - have been the subject of two major inquiries, one by the Joint Select Committee on End-of-Life Choices in 2018 (JSC), and the subsequent Ministerial Expert Panel on AHDs in 2019 (MEP). The final reports of each body recommended, among other reforms, the establishment of a state-based electronic AHD Register as a critical step in increasing the uptake and application of AHDs.

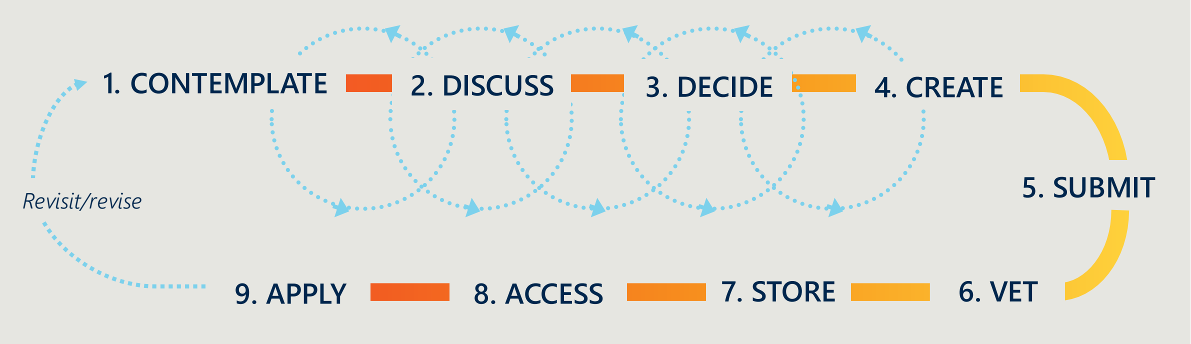
In line with the recommendations of the JSC and MEP, Nous Group (Nous) has been engaged by the WA Department of Health (the Department) to support the design of business processes and system requirements for an AHD Register (the Register). This work is being led by the Department's Advance Care Planning/AHD project team, as part of its broader End of Life Care Program.

This report is the culmination of a three-month design process that commenced in November 2020 and concluded in January 2021.

The Register should be underpinned by a comprehensive understanding of how AHDs are created and applied

The design process has reinforced the life cycle of an AHD can be conceived as a linear (albeit iterative) process, as shown in Figure 1.

Figure 1 | Life cycle of an AHD



Through the life cycle, there are six distinct 'end user' groups who will use the Register, and who have informed its design:

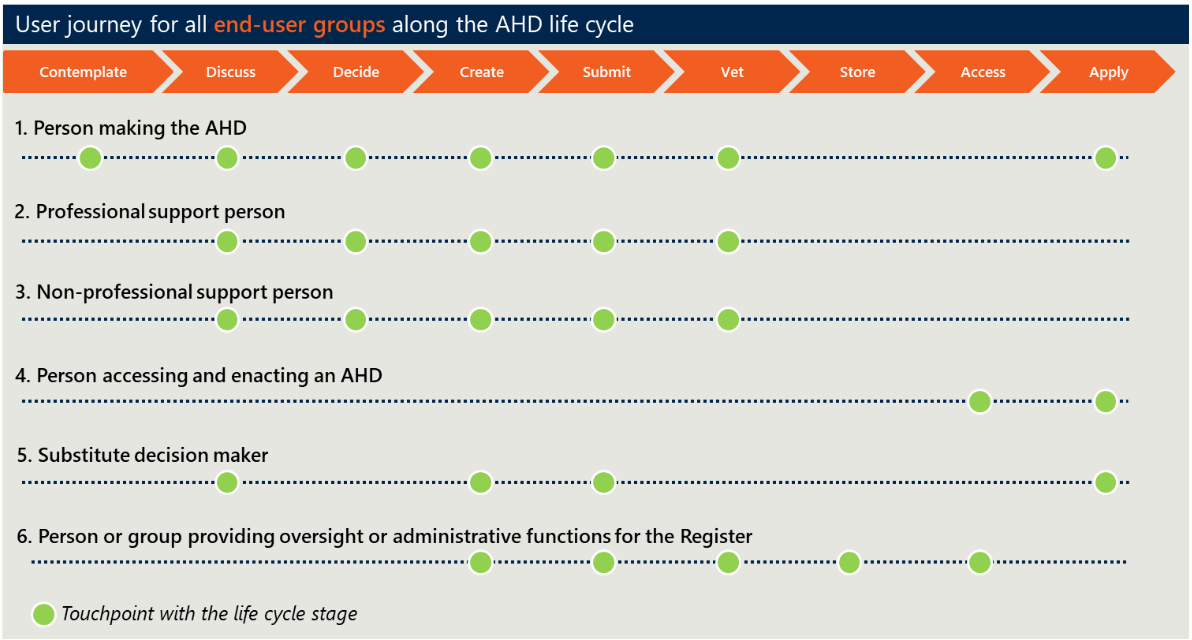
- **The person making the AHD**. An individual may be making their AHD for the first time or creating a new AHD to replace their existing AHD.
- **Individuals or groups supporting others to make an AHD as part of their profession or employment (professional support person).** This may include but are not limited to General Practitioners (GPs), legal practitioners, aged care workers, nurses, peer support workers, paid carers, advocates and Aboriginal health workers.

- **Individuals or groups supporting others to make an AHD outside of their professional role (non-professional support person)**. This group includes friends, family or others who have little prior experience supporting an individual to make an AHD.
- **Individuals accessing and enacting an AHD**. This group includes those charged with putting into effect an AHD, which may include clinicians, paramedics, GPs, aged care workers, and other health care workers caring for an individual who has lost capacity.
- **The Substitute Decision Maker (SDM).** A SDM is the person who is legally appointed or legally entitled to make health care decisions for a person who has lost capacity. The SDM may be legally appointed, either through a guardianship order made by the State Administrative Tribunal or an Enduring Power of Guardianship (EPG), or is the person legally entitled to make health care decisions for a person who has lost capacity as per the hierarchy of authorised people prescribed within the *Guardianship and Administration Act 1990 (WA)*. The SDM may use the values and preferences expressed in an AHD to guide their decision-making when making decisions that aren't captured specific treatment decisions in the AHD.
- **Individuals or groups providing oversight or administrative functions for the Register**. The Department will be the administrator of the Register. As part of its role, the Department will be responsible for maintaining the Register, ensuring appropriate integration with WA Health and non-WA Health systems, and managing the 'vetting' process for AHDs submitted to the Register.

People may also play multiple roles, such as a SDM and non-professional support person; or professional support person and individual accessing and enacting the AHD.

Each end user will interact with the Register at different stages of the AHD life cycle (see Figure 2).

Figure 2 | Touchpoints of each end user in a future AHD life cycle



User journey for all end-user groups along the AHD life cycle

	Contemplate	Discuss	Decide	Create	Submit	Vet	Store	Access	Apply
1. Person making the AHD	●	●	●	●	●	●			●
2. Professional support person		●	●	●	●	●			
3. Non-professional support person		●	●	●	●	●			
4. Person accessing and enacting an AHD								●	●
5. Substitute decision maker		●		●	●				●
6. Person or group providing oversight or administrative functions for the Register				●	●	●	●	●	

● *Touchpoint with the life cycle stage*

The ideal actions and experiences of each end user across each stage of the AHD life cycle have been identified through the focus groups and desktop research, and in turn informed the development of the business processes, service and operating model, and system requirements detailed in this report.

The Register should function as both a public-facing website, and a central repository for advance care planning documents

The Register should not be considered only as a repository for AHDs. The Register should be developed and implemented as a holistic solution that guides all end users through the AHD life cycle – supporting advance care planning conversations, the creation of an AHD, and the easy access and application of an AHD when required. For this reason, the Register, as used in this report, is defined as having:

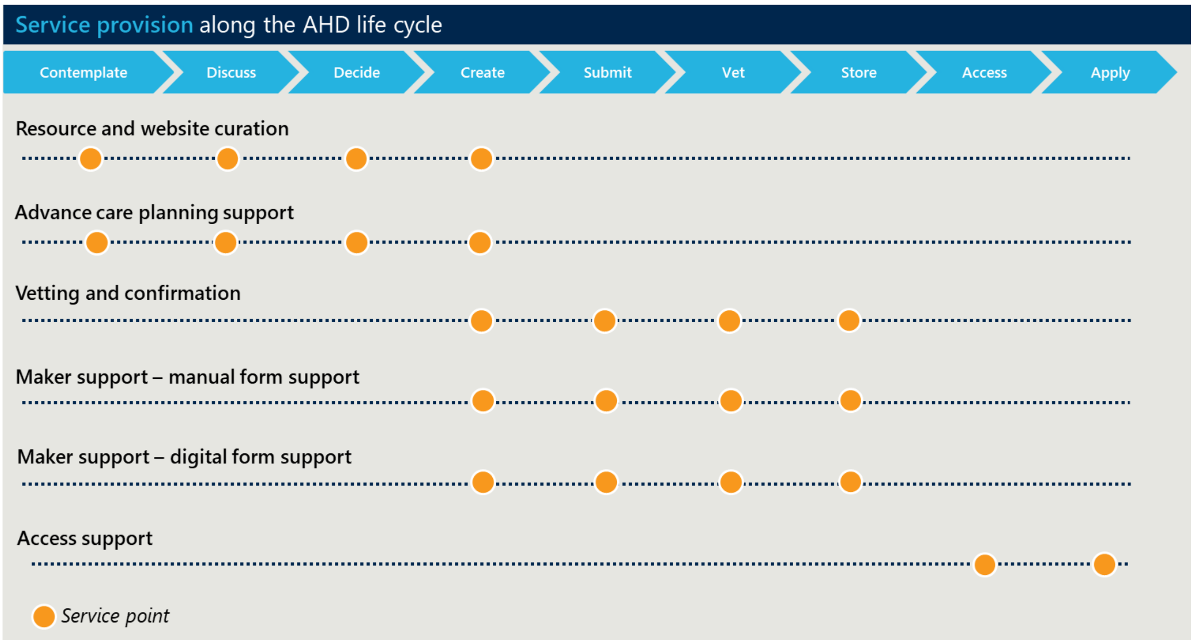
- **Public-facing website**: The Register should have a comprehensive front-end website or portal that provides those that access it with detailed and interactive resources to guide advance care planning conversations, and the process of deciding to create, and creating an AHD. Consultation revealed a broad range of resources that end users may want access to, including but not limited to, testimonials by those who have completed an AHD, detailed how-to guides, frequently asked questions, example AHDs, animated how-to videos, and 'contact us' information.
- **Secure storage**: The Register will necessarily need to enable AHDs to be securely stored. The 'repository' function of the Register will not be seen by end users, but should provide sufficient information to all end users to assure them of the privacy and confidentiality of their personal information.
- **Integrated access pathways**: In addition to the storage function of the Register, it should be well integrated with the broader systems of WA Health, and the Australian Digital Health Agency (ADHA). The Register should be seamlessly integrated with these systems so that there is no inconsistency or contradiction in the advance care planning information contained in each system. As a priority, the Register should be integrated with My Health Record, WebPAS, BossNet and other WA Health patient administration systems.

To enable the Register to function in this way, it will need to be underpinned by a service delivery model (the 'functions' or 'service' experienced by end users), and an operating model (the 'functions' or roles carried out by the Department to support end users in using the Register).

The Register should be supported by a clear service and operating model

Figure 3 summarises a high-level service delivery model for the Register. It was informed by the inputs of consumers, carers and service providers through consultations, and the recommendations of the JSC and MEP. The service model should be read concurrently with the detailed process maps for the Register (provided separately to the Department). These process maps describe the specific steps and actions to be taken by each end user in interacting with the Register through the AHD life cycle.

Figure 3 | Proposed service model



The service model of the Register should be enabled by an operating model that articulates the roles and functions that the Department will need to establish, as custodian of the Register, to meet the needs of the end users. Figure 4 captures the four recommended functions of the Department as custodian of the Register.

Figure 4 | Suggested roles to enable the Register

RESOURCES AND EDUCATION

This team will be responsible for creating and maintaining content (online and paper-based) to guide individuals, non-professional and professional support persons through the advance care planning process, and the process of creating, submitting, accessing and implementing an AHD.

VETTING AND SUPPORT

This team will be responsible for providing support (e.g. via telephone or email) to individuals requiring advice in creating an AHD. Once in receipt of a submitted AHD, the team will be responsible for vetting the AHD, and working with the maker to address any concerns prior to finalisation and storage.

SECTOR ENGAGEMENT AND CHANGE MANAGEMENT

This team will be responsible for change management and sector engagement. This includes proactive engagement with the health and aged care sector, including St Johns Ambulance, to support the transition of their internal practices to using the AHD Register.

ANALYSIS AND SYSTEM ADMINISTRATION

This team will be responsible for audit, oversight, system maintenance and administration for the AHD Register. This should include engagement with IT and data teams in HSPs, health care providers, health service providers, and the Australian Digital Health Agency. This role should also include a monitoring and assurance function to ensure only authorised persons are accessing an individuals AHD.

These roles require expertise and, accordingly, it is recommended certain aspects of the roles be managed by established functions within the Department, or within Health Service Providers (HSPs). Where such expertise does not yet exist, such as the vetting and support role, this may be a new function within the Department established as part of implementation and change management processes.

There is a compelling case for the scope of the Register to be expanded to include other advance care planning documents

AHDs have clear precedence in the hierarchy of advance care planning instruments. They provide direction for treatment decisions in specific circumstances, which health professionals are legally bound to follow. As part of the design process, the case for expanding the scope of the Register beyond AHD has been assessed. This included consideration of limitations with the current AHD form, stakeholder feedback from clinicians and decision-makers, and the inter-dependence between AHDs and EPGs. In line with these considerations, and informed by feedback garnered through consultations with consumers and consumer advocates, carers, and health care workers, Nous recommends that the scope of the Register be expanded to include functionality to, at minimum, store other advance care planning, and decision-making documents, particularly EPGs and Advance Care Plans (ACPs).

The success of the Register will be dependent on key implementation considerations

Nous has identified five key implementation considerations that should guide the Department as it progresses the detailed design, development, and implementation of the Register. These are:

- **System integration**. The Register will need to 'speak to' and be interoperable with the range of existing health information systems administrated by WA Health, and more broadly, the ADHA. Integration with these systems will be particularly critical to clinicians and health care workers in public and private hospitals, aged care and emergency response settings in accessing and affecting an AHD, and GPs in supporting individuals to create, review and revoke their AHDs. In particular, the Register should be integrated with WA Health's patient administration systems, specifically WebPAS. It should also explore in the short-term, integration with My Health Record, to allow AHDs to be visible by health care workers in other Australian jurisdictions.
- **Risk management.** The development and implementation of the Register is a key step for the WA Government to increase the awareness of, and uptake of AHDs. However, the transition to a standalone electronic system comes with several risks that will each need to be carefully monitored and managed. Specifically, the move to an electronic system will come with risks associated with system outages/failures, cyber-attacks and breaches, and intentional and unintentional privacy breaches of personal information. Each of these risks should be managed, with safeguards put in place to prevent the risk and mitigate the impact of the risks eventuating.
- **Change management**. The implementation of the Register represents a broad and complex change for health care workers, legal practitioners, and most importantly, the public. As part of managing this change, the Department should consider the levers available to implement and manage this change. These levers include leadership, engagement, education and policy/process change. It will be important to effectively utilise these levers to not only guide stakeholders through the change, but to also communicate and instil the case for change to bring stakeholders along the journey of 'why' the change must occur. The case for change will be articulated in the business case and subsequent communications and will provide the footing for future change management.
- **Concept, business case and funding approvals**. A robust business case to secure funding for the development, implementation and operation of the Register could possibly be ready for submission to the 2021/22 budget process, based on an expectation of the budget being brought down in early August 2021. The business case should include the detailed design and costing for the Register, and seek full funding for its development and implementation, change management, and ongoing funding for operation, support and system maintenance, including the costs of full-time equivalent employees to provide the necessary functions around and within the Register and system 'evergreening' costs.
- **Costs**. The detailed design, development, implementation, and change management associated with the Register represents a not insubstantial investment for the WA Government. Nous has estimated

that the development, implementation, and ongoing operation of the Register represents a one-off cost of between $6.75m and $7.75m, with an estimated recurrent cost of $1.5m.

The findings set out in this report will inform the detailed design, business case development, and implementation and operation of the Register

The purpose of this report is to summarise the findings of the design process for the Register. It will inform the detailed design of the Register, as well as the business case to secure funding for its implementation.

2 Key terms used in this report

AHDs exist within a broad and complex landscape of advance care planning tools and instruments – some enshrined in legislation and common law, and others in practice. The definition of each tool and instrument can vary significantly across jurisdictions.

Nous recently completed a project to revise the National Framework for Advance Care Planning Documents. While this framework has not yet been formally endorsed and released publicly, it was developed through extensive consultation, including with WA stakeholders. A major focus of this work was to establish a common 'intent of key terms' across jurisdictions. WA currently uses the term 'advance care plans' to refer to documents that are set out values and preferences rather than instructional directives. However, as the AHD template is currently under revision and is likely to provide for more general statements of choice, the distinction between the contents of the two instruments will become less clear. The definition of ACPs used in this report aligns with that in the draft National Framework document and uses competency as a major differentiator between AHDs and ACPs.

To guide the reader, Table 1 provides a list of definitions for the advance care planning terms used in this report. The hierarchy of advance care planning documents is included in Figure 5.

Table 1 | Definitions of advance care planning terms

Advance Health Directive (AHD)	An AHD enables individuals to consent or refuse consent to future health care treatments in a prescribed form. Due to its status as a legally binding document, an AHD can only be completed while a person has the ability – or 'full legal capacity' – to make and communicate decisions as per the *Guardianship and Administration Act 1990* (WA). Full legal capacity means the capacity to make a formal agreement and to understand the implications of statements contained in that agreement. When a person loses capacity and requires treatment, their AHD comes into legal effect, to the extent that the health circumstances and treatment decisions contained within it are applicable. Health professionals are required to comply with a person's treatment decisions as contained in their AHD. An AHD must also be witnessed when it is being created. The current prescribed form for an AHD focuses only on treatment decisions, that is, specific and unambiguous instructions that must be followed in specified circumstances (for example, 'If my heart stops, I do not want to be artificially resuscitated'). However, this form is currently being re-designed, and is expected to provide more scope for individuals to document their wishes, values, and preferences for their future health care to guide decision-making by a substitute decision maker, if their AHD does not cover the circumstances they face or treatment options available.
Common Law Directive	A Common Law Directive is created and governed under common law. Like statutory AHDs, an individual must have capacity to make a Common Law Directive, and it applies at the time the individual no longer has capacity to make or communicate decisions. However, unlike statutory AHDs, there are no formal requirements for a Common Law Directive to be valid, other than that the individual must have capacity at the time of making the directive and must have made the directive voluntarily. A Common Law Directive can be made in writing or orally. However, if made orally, or without signatures and witnessing, it may be difficult for the directive to be followed and implemented.
Advance Care Plan (ACP)	An ACP is a document which captures an individual's beliefs, values and preferences in relation to future health care decisions, but which does not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient

	decision-making capacity or lack of formalities (such as inadequate person identification, signature and date, or witnessing). While not legally binding, the values and preferences set out in an ACP can be used to inform health care decisions.
Enduring Power of Guardianship (EPG)	An EPG is a legal document which enables an adult with capacity to appoint a person of their choice to make personal, lifestyle and treatment decisions on their behalf if they lose the ability to make these decisions for themselves because of an illness or injury. This person becomes their enduring guardian[1]. AHDs and EPGs are mutually exclusive instruments – individuals may make one, or both, or neither of these documents. If a person has made an AHD and appointed an enduring guardian (with authority to make treatment decisions) and the person loses capacity and requires treatment which is covered in their AHD, the treatment decision is made in line with their AHD. If the AHD does not cover the treatment decision required, the health professional will seek a treatment decision from the enduring guardian (with authority to make treatment decisions).
Goals of Patient Care (GoPC)	GoPC are a set of clinical and other goals that relate to an individual during a specific episode of care. The goals are determined in the context of a shared decision-making process between the individual and their clinician. GoPC documents are different to AHDs as GoPC are completed by health care professionals, and should align with the preferred health outcomes and treatment decisions made by the individual (to the extent that they have the capacity to participate in shared decision-making) and are generally specific to a finite treatment period. GoPC may also be informed by AHDs, Common Law Directives, ACPs and undocumented verbal instructions.
Substitute Decision Maker (SDM)	A SDM is the person who must make a decision about the care provided to an individual, in circumstances where the individual lacks capacity to make a decision for themselves, and there is no relevant treatment decision listed in an AHD. A SDM may be someone who has been formally appointed either as a guardian by the State Administrative Tribunal, or as an enduring guardian by the person themselves by making an EPG before they lost capacity, or they may be the person at the top of someone's 'hierarchy of treatment decision makers' which is a list of people prescribed in the *Guardianship and Administration Act 1990* (WA), who are authorised to make treatment decisions for a person who has lost capacity.

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[1] Office of the Public Advocate, Enduring Power of Guardianship Information Kit, Government of Western Australia Department of Justice, Western Australia, pg. 2. https://www.publicadvocate.wa.gov.au/_files/epg_kit.pdf

Figure 5 | Advance care planning documentation

Advanced care planning instruments

BINDING INSTRUMENTS

- Completed by competent people
- Minimum requirements – such as name, DOB, persons signature and date
- Binding

Advance Health Directives

Statutory documents, created under the *Guardianship and Administration Act 1990 (WA)*

Common law directives

Documents not recognised by specific legislation but by courts through case law

Enduring Power of Guardianship

Statutory document which enables an adult to appoint another person to make treatment decisions

NON-BINDING DOCUMENTS

- Documents completed by people with reduced capacity
- Documents which do not meet minimum legal requirements such as signatures and witnessing

Advance care plans

Documents written by people with reduced or insufficient capacity that articulate their values, beliefs and preferences for their future care.

3 The case for change

More than ever before, Australians are taking steps to consider and plan for their future health care, which includes thinking about their beliefs, values and preferences about their health and wellbeing.

Many individuals will go through periods – some short and episodic, and others enduring – where they are unable to make informed, contemporaneous care decisions for themselves. This may be due to chronic illness, a sudden injury, cognitive decline, periods of acute mental illness, or other times where competency levels are fluctuating.

Advance care planning is a voluntary process in which individuals can think and plan for their future health care; that is, care that is required during periods where they cannot make or communicate contemporaneous decisions for themselves. There are several different outputs of advance care planning conversations – some legally binding, and others not.

An AHD is one potential outcome of advance care planning conversations – one where individuals wishing to record their decisions about their future health care can do so in a formalised, and legally binding manner. Other outcomes of the advance care planning process may include a decision to not record ones wishes in any way, or decisions to make a Common Law Directive or an ACP. These instruments are collectively known as 'advance care planning' documents.

In WA, the uptake of AHDs is very low relative to other jurisdictions. A recent study by Advance Care Planning Australia[2] into the prevalence of advance care planning documentation in Australian health and residential aged care services found only 2.1 per cent of individuals in a sample of WA hospitals and residential aged care facilities had an AHD[3]. This issue was reaffirmed by the findings and recommendations of the JSC and the subsequent MEP. The final reports from each body reinforced that the very low uptake of AHDs and other advance care planning instruments in WA is due to a variety of factors, including, but not limited to, poor awareness amongst health professionals and the general community of the existence of, and processes underpinning AHDs, limitations of the AHD form, and difficulties accessing AHDs at the appropriate time to direct care.

The recommendations of the JSC and MEP included, among other things, the establishment of a standalone Register. Moreover, the MEP identified that a one-stop-shop register or portal, that supports individuals through the entire process of advance care planning, and the creation, storage and access of AHDs, is the optimal solution to ensure increased uptake of AHDs, and increased confidence by individuals and health care professionals that AHDs will be valid, accessed and applied to direct care.

AHDs, however, exist within a complex landscape of legal and health policy. The design, development and implementation of a Register will be dependent on a range of factors to ensure its success in achieving the outcomes envisioned by the JSC and MEP.

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[2] Buck K, Detering KM, Sellars M, Sinclair C, White B, Kelly H and Nolte L. 2019. Prevalence of advance care planning documentation in Australian health and residential aged care services. Advance Care Planning Australia, Austin Health, Melbourne.

[3] The sample size of WA services was relatively low, and included two hospitals, and two residential aged care facilities, and a total of 145 individuals surveyed.

3.1 Establishing a state-based Register is an important next step for the WA Government

An electronic register of AHDs presents an important and timely opportunity to increase the uptake and implementation of AHDs in WA, resulting in more people receiving health care that aligns with their values and preferences.

The current WA Government's commitment to providing respect and dignity through end-of-life choices commenced with the establishment of the JSC. The final report of the JSC, "My Life, My Choice", was released in August 2018. The JSCs final report contained several recommendations related to advance care planning, and three specific recommendations on AHDs, specifically:

- **Recommendation 1:** The establishment of a purpose-built central electronic register for AHDs, and related recommendations.
- **Recommendation 2:** The broad education of health professionals on the nature, effect and use of AHDs.
- **Recommendation 3:** Community education and awareness-raising about AHDs.

In response to these recommendations, the Attorney General appointed an expert panel (the MEP) to review the relevant law, health policy and practice relating to AHDs and provide recommendations to address Recommendations 1-3 of the JSC.

The MEP handed down its final report to the Attorney General in August 2019. The final report contained 23 recommendations and associated findings relating to its terms of reference and guiding principles. Recommendations 14 – 21 were targeted at the justification for, and scope, functionality and implementation of a purpose-built central electronic register for AHDs in WA.[4] Additionally, Recommendations 8 – 13 concerned the content of the AHD template, which is presently being re-designed by the Department and will inform the design of the Register. A summary of recommendations is provided at Appendix B.

In recommending the design of a dedicated Register, the MEP found there is no existing online platform, nationally or in WA which can effectively serve as a register for AHDs while also meeting the scope and functionality requirements the panel recommended. In coming to this view, the MEP considered several existing models for the making of and storage of AHDs, including the Queensland Health state-wide electronic storage system for AHDs, My Health Record, and existing systems in WA Health. Ultimately, in assessing the strengths and weaknesses of each option, the MEP recommended the design and development of a standalone platform that supports individuals and organisations through considering, planning, making, witnessing and sharing an AHD. An analysis of each option is detailed in Appendix C.

At a broader state and national level, the development of a centralised Register aligns closely with the findings and priorities of several reviews and inquiries of significance, including but not limited to the Royal Commission into Aged Care Quality and Safety,[5] the Sustainable Health Review,[6] WA Health Digital Strategy 2020-2030[7], and Actions 2.4, 2.5, 2.6, 5.3 and 6.3 of the National Safety and Quality Health Service

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[4] Government of Western Australia, Ministerial Expert Panel on Advance Health Directives Final Report August 2019.

[5] The Royal Commission into Aged Care Quality and Safety is a royal commission established on 8 October 2018. The Honourable Richard Tracey AM RFD QC and Ms Lynelle Briggs AO were appointed as Royal Commissioners

[6] In June 2017, the Government of Western Australia announced the Sustainable Health Review to prioritise the delivery of patient-centred, high quality and financially sustainable healthcare across the State. The Sustainable Health Review Final Report was published in April 2019and outlined eight Enduring Strategies and 30 Recommendations. The final report can be found here: https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Sustainable%20Health%20Review/Final%20report/sustainable-health-review-final-report.pdf#page=74

[7] The WA Health Digital Strategy 2020–2030 aims to take advantage of the innovations transforming healthcare to drive better health outcomes for all Western Australians. The strategy can be found here https://ww2.health.wa.gov.au/~/media/Files/Corporate/Reports%20and%20publications/Digital%20strategy/Digital-Strategy-2020-2030.pdf#page=6

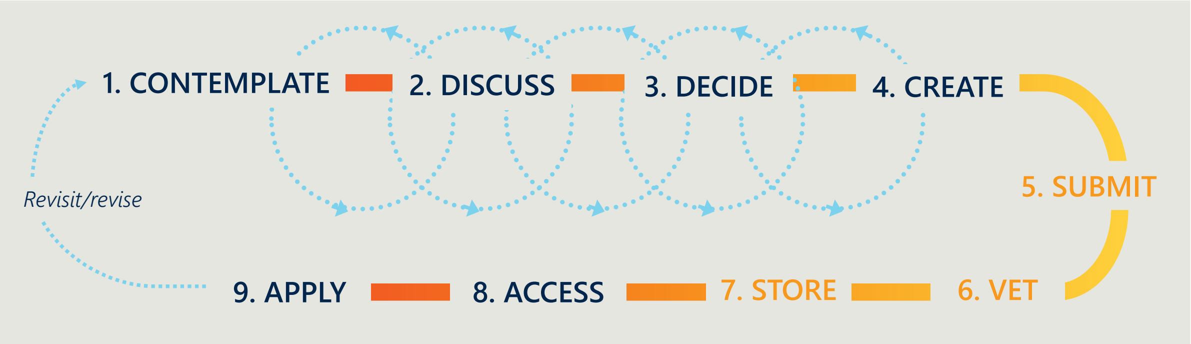
(NSQHS) Standards. These reports and reviews are all consistent in their findings about the opportunities to improve patient agency to make informed decisions about future care, and the enhanced role of health care professionals in supporting the creation and utilisation of advance care planning instruments, and providing safe, quality and respectful treatment that is consistent with the patient's wishes.

3.2 The current process of creating, storing and applying AHDs has several limitations which have prompted its re-design

AHDs, as defined in WA, are legally binding documents made under the *Guardianship and Administration Act 1990* (WA). They allow individuals who have legal capacity to record their 'treatment decisions' in a prescribed form. An AHD will only apply where the individual making the AHD (the 'maker') loses their mental capacity or is unable to communicate to make and/or convey their own treatment decisions.

The current process of considering, creating, storing and applying an AHD in WA broadly encompasses six iterative, and non-linear stages (the stages which appear in **navy** text in Figure 6 below). Stages five, six and seven do not currently take place and accordingly are distinguished in **orange** text. Throughout this report, this process has been referred to as the 'AHD life cycle'. The 'future' life cycle which includes all nine stages is further explored in Section 4.2.

Figure 6 | Life cycle of an AHD



1. **Contemplate.** Advance care planning is an opportunity for individuals to think about their future health care and consider what is important to them. It follows the creation of an AHD, which is a process, not a single event, which starts with an individual beginning to think about what is important to them, and the decisions they would like to make about their future care.
2. **Discuss.** An AHD is the end-output of a culmination of conversations between an individual, and their family, carers, friends, and others. However, the decision to make an AHD does not necessarily need to follow these discussions. Some individuals may wish to make an AHD without speaking with loved ones, or health and legal practitioners.
3. **Decide.** The outcome of advance care planning discussions may not necessarily result in a decision to make an AHD. It may see an individual make a conscious decision to not make decisions about their future health care, or to create an alternative advance care planning instrument (i.e. an EPG or ACP).
4. **Create.** A person decides to make an AHD. While individuals are encouraged to seek advice and/or assistance from a medical and/or legal practitioner, they are not required to do so. An AHD is rarely completed in one sitting and a maker may draft sections and revisit it over a period of time before validating the document formally by signing and having it witnessed. An individual may also revisit an

AHD at a later date and choose to revoke their AHD and make a new AHD by going through the same validation process[8].

The processes of 'submit', 'vet' and 'store' do not currently exist. The proposed processes are detailed in Section 4.2.

8. **Access.** An AHD is located and reviewed to inform a treatment decision. This could occur in various settings, including in residential aged care facilities, in community settings such as General Practice, the maker's home, an emergency department, by paramedics, or when a maker is admitted to hospital as an inpatient.
9. **Apply.** At the point the maker loses capacity or ability to communicate, their AHD comes into effect if they require treatment. Should, for any reason, the AHD be deemed to not apply in the circumstances, its content should help inform the person's SDM to make treatment decisions.

While there is a growing appreciation of the value of advance care planning and AHDs in delivering person-centred care, AHDs remain underutilised in WA. There are several reasons for this, including limited awareness and understanding of the purpose and value of AHDs, difficulty in accessing support to create the document, as well as challenges in using the current prescribed format to detail preferences and values for future specific treatment decisions.[9]

AHDs are made under various circumstances, including where an individual seeks help or advice from a health or legal professional, creates a document with a family or friend, or completes the form without assistance. The act of creating an AHD is significant, however its value is inherently tied to how available and instructive it is at a time when it is required.

Currently, there is no consistent process for storing and accessing AHDs: some individuals keep hard copy versions in their files at home; others in the trust of a solicitor, a GP or with a family member or friend. My Health Record currently stores GoPC documents uploaded from WA clinical systems, and has the folder structure in place to facilitate upload of AHDs, however there are challenges around how these can be integrated with electronic patient records and accessed when they are needed, and not everyone has opted to have a My Health Record.

The lack of a consistent process to create, store and apply AHDs has given rise to several potential points of process failure

The lack of a consistent and secure process for the creation, storage and access of AHDs in WA has created several potential 'failure points' across the AHD life cycle, which act as barriers to them being used effectively to guide health care decisions. Examples of such potential process failures are listed in Table 2.

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[8] Under the *Guardianship and Administration Act 1990* (WA), and individual may make multiple, concurrent AHDs, if those AHDs contain different and unrelated Treatment Decisions. However, stakeholder input strongly supported the AHD Register only including one AHD at a time. Nous has reflected the guidance provided through consultations, however, under legislation, it remains that an individual may legally have more than one AHD at a time.

[9] The current form of the AHD template is currently being reviewed by the Department of Health End of Life Care Program

Table 2 | Potential failure points in the AHD life cycle

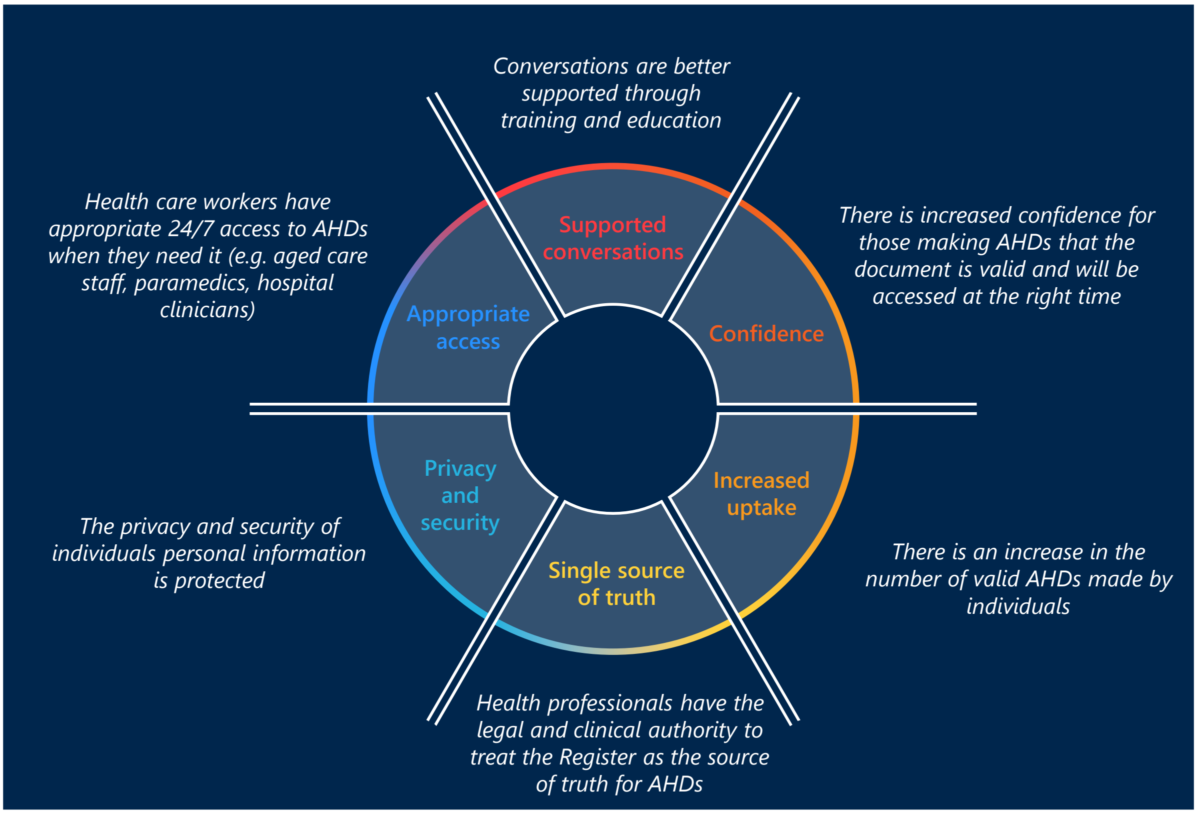
Stage of AHD life cycle	Failure point	Description
CONTEMPLATE, DISCUSS, DECIDE, CREATE	**An AHD does not exist**	Advance care planning is a voluntary process and it is acceptable if an individual chooses not to make an AHD or is ineligible to do so, for example, because of competency issues. However, a failure point arises where individuals may like to make an AHD, but do not. This may be because they do not know about AHDs, lack understanding about how an AHD can be used to guide future care, or because the process to make one is unclear and/or confusing.
EXECUTE	**The AHD is not validly executed**	If an AHD is not signed and witnessed correctly, it does not meet the requirements of a valid statutory instrument. While an unsigned or unwitnessed AHD may still be considered a Common Law Directive, this is reported to create uncertainty among clinicians and health care practitioners about if and/or how it should be followed.
ACCESS	**The existence or location of an AHD is unknown**	An individual may have an AHD, but its existence may not be known to the maker's family, SDM, carers or treating team. Additionally, if efforts are not made to enquire about an AHD, its existence may not be revealed and therefore not applied. This includes because it is stored in a location not known to others, it cannot be found in time to direct or influence treatment decisions by the treating team or because there are multiple versions of an AHD and the most recent version is not apparent.
APPLY	**The AHD could not be understood**	An AHD may be difficult to apply for many reasons. It may be illegible, written in poor English, written in a language other than English, exorbitantly lengthy, or lacking clear direction. Additionally, an AHD may not anticipate the circumstance in which the maker finds themselves in.
	The AHD is internally inconsistent	The content of an AHD may contain conflicting instructions on an individual's treatment preferences. If the AHD provides conflicting guidance regarding treatment wishes, it can be challenging to implement.
	The AHD is externally inconsistent	An AHD may be inconsistent with other care planning documents made by an individual or may be inconsistent with laws governing medical treatment.
	The AHD does not apply	An AHD may not apply to a health care decision because the maker may not have been prompted or guided to anticipate the range of treatment decisions and/or circumstances that needed to be considered.

These failure points have informed the design of an overarching service and operating model, detailed business processes, and system requirements for a future Register. The findings of the design process are detailed in Section 4.

3.3 A state-based Register will overcome process failures and better support person-centred care

While the need for a state-based Register had been previously highlighted by the JSC and MEP (as summarised in section 3.1), there was previously not a shared understanding of what a good outcome of this work might look like. Through a process of desktop research and stakeholder consultation, Nous identified six key outcomes which characterise the desired future state in Figure 7.

Figure 7 | The Register will contribute towards six outcomes



Conversations are better supported through training and education

There is increased confidence for those making AHDs that the document is valid and will be accessed at the right time

There is an increase in the number of valid AHDs made by individuals

Health professionals have the legal and clinical authority to treat the Register as the source of truth for AHDs

The privacy and security of individuals personal information is protected

Health care workers have appropriate 24/7 access to AHDs when they need it (e.g. aged care staff, paramedics, hospital clinicians)

There are inherent tensions between some of these outcomes. In developing the Register, trade-offs between these outcomes will inevitably be required. For example, there could be tension between developing a Register that provides ‘appropriate’ universal access to search AHDs and developing a Register which ensures the privacy and security of individuals’ personal information.

Consultations saw stakeholders express different views as to how the Register should balance competing outcomes. Stakeholders agreed that concessions on matters such as privacy, for example, could be tempered with full and transparent disclosure of who and when personal information would be accessed as well as auditing of access records. Ultimately, as the MEP outlined, the Register is not mandatory, and individuals have the ability to enter as much or as little information as they prefer onto the Register, including to record only the existence and location of the AHD, recognising this may compromise the ability of health professionals to obtain their AHD in a timely manner.

3.4 There are legislative and operational factors which impact the success of a future Register

The ability of the Register to achieve the outcomes set out above will be dependent on several factors that exist outside the scope of this work, and the development of the Register itself. Some of these factors relate to current policy settings and the legislative framework in relation to end-of-life care, while others relate to current practice around advance care planning.

These factors have informed parts of the design of the processes and system requirements of the Register. However, the success of the Register may be dependent on the factors below being revised or reformed, to the extent possible, to enable the MEP's vision for the Register to be realised.

These factors include:

- **The design and format of the new AHD form**. Under Workstream 1 of the End of Life Care Program's Advance Care Planning and Advance Health Directive Project, the template for AHDs (which is prescribed in the *Guardianship and Administration Act 1990* (WA)) is being redesigned. The redesign has included desktop research of best practice examples as well as consultation and collaboration with relevant stakeholders. The success of the Register will be dependent on the extent to which the form is able to address the concerns identified by stakeholders consulted and the MEP, including but not limited to the 'lack of guidance for people completing it'.[10] The MEP also noted the lack of opportunity for a person to record information about their underlying values and preferences and that consideration should be given to the format by which a person can express their values (such as through tick-boxes and free text).[11]
- **Requirement for wet signatures**. Under the *Guardianship and Administration Act 1990* (WA) s110Q an AHD is not valid unless it is signed by the maker (or by someone on the direction and in the presence of the maker) and signed and witnessed by two people. Simultaneously, electronic transactions such as signatures are governed by the *Electronic Transactions Act 2011* (WA) (ETA). The ETA provides a transaction is not invalid if it has taken place wholly or partially by way of electronic communication with certain exceptions. An exception under the ETA includes documents which require verification, authentication, attestation or witnessing under the signature of a person other than the author of the document.[12]

  Accordingly, documents such as wills, codicils and AHDs may be interpreted as falling outside of the remit of the ETA and still requiring wet signatures of the maker and witnesses. This has consequences for the Register particularly in the ability for efficient creation and submission of an AHD digitally. Accordingly, a necessary requirement of the Register is to allow for generation of AHD contents into a printable format for completion and upload of a scanned copy to validate the entry.
- **Financial support or rebates for time with professional support.** A concern raised throughout consultations was the ability by a maker to access medical and/or legal advice during the contemplation, discussion, decision and creation stages of the AHD life cycle. Given the nature of AHD creation, it is often the case that a maker will seek to discuss their preferences, values, concerns and questions over several, extended sessions with a legal and/or medical practitioner. Time with wills and estates lawyers, and GPs, however, can incur substantial costs. Stakeholders were concerned at the limited resources available to subsidise these discussions through Medicare rebates, and the absence of any financial assistance for those seeking legal advice.

  The ability to address this barrier lies outside of the scope of this project. However, a clear output of consultation is the requirement for the Register to host resources, training and education materials

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[10] Government of Western Australia, Ministerial Expert Panel on Advance Health Directives Final Report August 2019, pg. 30.

[11] Government of Western Australia, Ministerial Expert Panel on Advance Health Directives Final Report August 2019, pg. 31.

[12] Regulation 3(1) of the *Electronic Transactions Regulations 2012* (WA)

catered to a range of end-users which are free and easily accessible. These resources would be available without a ‘login’ and would seek to answer common questions, provide testimonials, how-to guides and referrals to support individuals in a range of languages and accessibility preferences

- **Training and outreach to community and professionals**. The success of the Register will be dependent on the extent to which there is sufficient investment in changing the behaviour of those that would interact with it – including makers, professional and non-professional support people, and health care practitioners. Under Workstreams 2 and 3 of the Advance Care Planning and Advance Health Directive Project respectively, a broad education program is being developed to improve the understanding and awareness of AHDs amongst health care workers and the community. Either through that workstream or the implementation of the Register itself, there will need to be substantial investment in change management across the AHD life cycle to build the awareness and capability of all end users to use the Register.

The requirements and supporting business processes will seek to address these factors to the extent possible. Ultimately, however, most of these factors will be subject to broader changes in law and policy.

4 Key findings

The findings of this report centre around the 'current state' factors influencing the creation of the Register, as well as projections of what the 'future state' of an AHD life cycle may look like. Specifically discussed are:

- The **existing policy context and structures of the WA Health and legal system**. This includes an exploration of the impetus for the Register's creation as the result of the JSC and MEP reports as well as the health and legal infrastructure which the Register would operate within.
- The **'life cycle' of an AHD** as designed based on MEP recommendations, consultations, desktop research and existing processes.
- The **'end users' of the Register**. These hypothetical people represent the key groups who may use and/or access the Register in the future. These representations are based on ideas and feedback developed during consultations and the existing 'users' of AHDs extrapolated to accommodate for future needs.
- The suggested **operational framework** to support and maintain the Register and those who access it. This includes a consideration of the types of human 'services' which may be provided in order to maintain the Register itself as well as provide ongoing support to end users. It also includes a high level 'operating model' which seeks to explain the different areas of expertise required to provide those services and how those areas of expertise may work together.
- The **functional and non-functional requirements** of the Register. These requirements have been extrapolated primarily from the anticipated needs of end users as well as consultation with internal Nous expertise in system design. This includes:
    - **Functional requirements**, which define what behaviours or functions that the Register must, or must not perform, when certain conditions are met. For example, a functional requirement of the Register will be to allow makers to create a new account, or to allow a member of the vetting team to generate audit reports.
    - **Non-functional requirements**, which define how the end user will experience the Register, by describing how the Register will perform its functions. For example, a non-functional requirement will be the interoperability of the Register with a range of other WA Health patient management systems, or the security of the storage database.
- **Features or requirements explored during consultations** but currently unavailable due to legislative or structural limitations.

Each of these are explored in further detail below.

4.1 The scope of the Register should be expanded

An AHD is one of many legal and non-legal instruments which can be used by individuals and health professionals in planning for and making decisions about future health care. In determining the potential scope of a Register, the MEP considered whether an online register for AHDs should be extended to incorporate other relevant advance care planning instruments, including ACPs and EPGs.

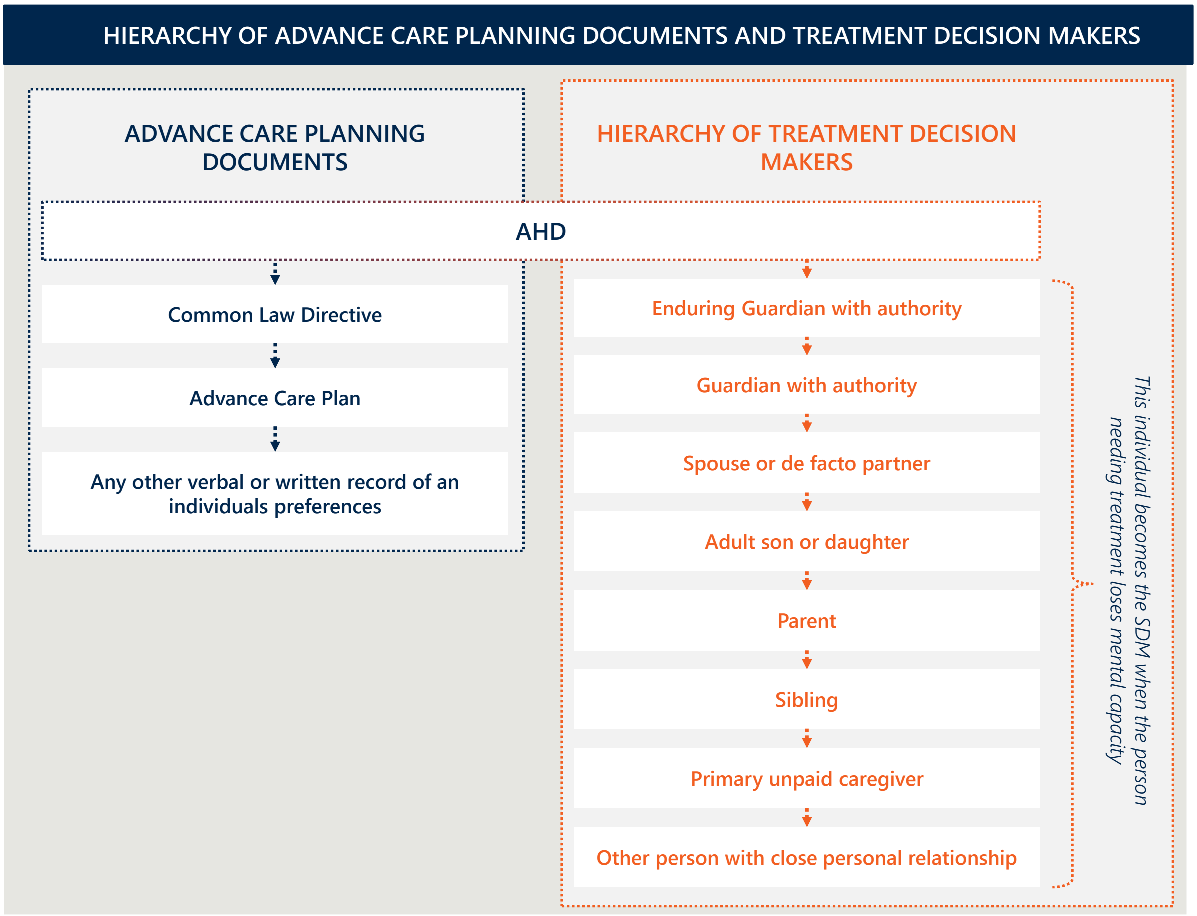
Ultimately, the MEP recommended the Register should be confined only to AHDs. In coming to this recommendation, the MEP considered three factors:

- ACPs are non-binding documents which reflect an individual's values, beliefs and care preferences. The MEP cautioned ACPs may potentially create confusion in terms of the interpretation and application of a person's wishes as compared to AHDs.
- With the expected overhaul of the AHD template to include values statements, the MEP noted this would enable an individual to record their personal preferences, religious beliefs, cultural requirements and other statements within the AHD.
- EPGs and Enduring Powers of Attorney were deemed out of scope due to their complexity, and broad coverage of matters not including health care. It was noted the new AHD form should retain a checkbox indicating whether the individual has an enduring guardian.

Acknowledging the MEPs guidance, Nous recommends the scope of the Register be expanded to include other relevant advance care planning instruments in the future based on feedback from stakeholders and synergies between documents such as AHDs and EPGs.

Figure 8 shows the hierarchy of documents that inform health care decisions as well as those who make those decisions, as set out in the *Guardianship and Administration Act 1990* (WA).

Figure 8 | Hierarchy of advance care planning documents and treatment decision-makers



AHDs have clear precedence in this hierarchy and provide unequivocal direction about treatment decisions in very specific circumstances. Health professionals are legally bound to follow these directions.

However, AHDs – particularly in the current statutory form that is limited to treatment decisions – may only represent a small portion of all documentation about individuals' values and preferences. Stakeholder feedback has strongly indicated that clinicians and decision makers will readily consider any record of a person's wishes and use these to inform a treatment decision. An example includes Common Law

Directives, which are still legally binding, as well as cases where a person who did not meet the competency threshold required to make an AHD has still stated their values and preferences in an ACP, which is not legally binding. There are therefore clear advantages to including such information, binding or not binding, in the Register.

Additionally, as per the MEP's recommendation, the proposed AHD template includes more general information about an individual's values and preferences, which brings the AHD closer into line with documents such as the ACP which traditionally have focused more on values. The question of inclusion of Common Law Directives and ACPs was not specifically tested with stakeholders during consultation due to the MEP recommendations, though it was nonetheless raised by some stakeholders.

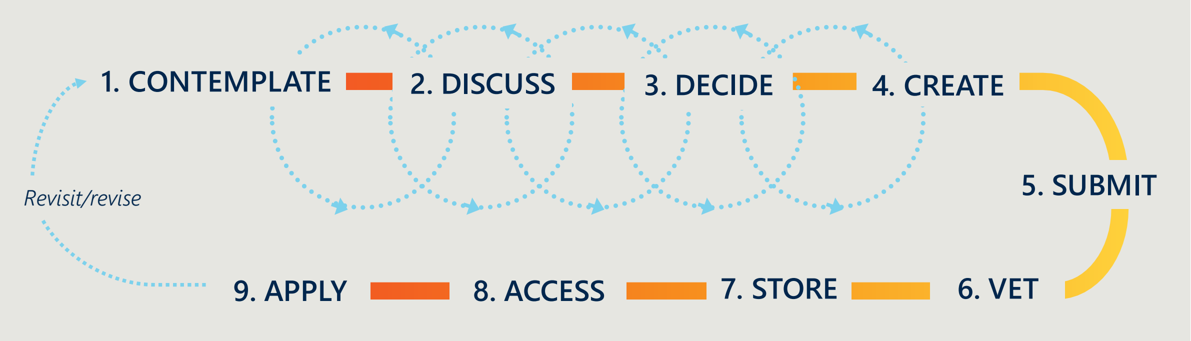
In addition to inclusion of alternative planning documents on the Register, stakeholders felt the inclusion of contact details about SDMs was another piece of critical information which should be included on the Register. With the proposed reform of the statutory AHD template, it is hypothesised that it will fall more often to an SDM to interpret 'values' rather than specific care instructions as part of their decision-making role. Co-locating information about appointed SDMs (such as enduring guardians) is likely to result in faster identification of the SDM if appointed.

In line with these considerations, and informed by feedback garnered through consultations, Nous recommends that the scope of the Register be expanded to include functionality to, at minimum, store other advance care planning, and decision-making documents, particularly EPGs and ACPs. There should further be consideration for including a 'notification' for decisions made by the State Administrative Tribunal, including the appointment of a guardian, revocation of an AHD or EPG, and directions made in relation an AHD or EPG.

4.2 There are nine key steps to the AHD life cycle

The process of advanced care planning and generation, and application of an AHD is not necessarily linear, and stages can be revisited and repeated. Figure 9 shows the projected life cycle of an AHD that interacts with the Register. It builds on the life cycle shown in Figure 6 and explained on page 12 but provides additional detail about how the Register would facilitate the process. It also includes the additional steps - 'submit', 'vet' and 'store'. This AHD life cycle is the recommended overarching framework that should guide the detailed design, development, implementation and change management of the Register.

Figure 9 | Life cycle of an AHD



The nine steps of the AHD life cycle are as follows:

1. **Contemplate.** Advance care planning is an opportunity for individuals to think about their future care and consider what is important to them. Contemplating the creation of an AHD is a process, not a single event. To assist in this step, individuals may access resources online via the Register website or through a health or aged care service. Educational materials might cover the role of an AHD, the steps

in creating one, the availability and utility of other advance care planning documents, and what happens to an AHD once it is submitted.

2. **Discuss.** An AHD is the end-output of a culmination of conversations between an individual, and some of their family, carers, kin, friends, medical and legal professional support and non-professional support. However, the decision to make an AHD does not necessarily need to follow these discussions. Some individuals may wish to make an AHD without speaking with loved ones, or health and legal practitioners. Any person may access resources online via the Register website or through a service to deepen their understanding of AHDs, their role in its creation, and the process.
3. **Decide.** The outcome of advance care planning discussions may not necessarily result in a decision to make an AHD. It may see an individual make a conscious decision to not make decisions about their future health care, or to create an alternative advance care planning instrument (i.e. an EPG). The decision to proceed with any option may be informed by resources and information accessed via the Register or through a service.
4. **Create.** A person decides to make an AHD. While individuals are strongly encouraged to seek advice assistance from a health and/or legal practitioner in the current AHD form, it is not required to create a legally binding AHD. An AHD is rarely completed in one sitting and a maker may draft sections and revisit it over a period of time before validating the document formally by signing it and having it witnessed. An individual may also revisit an AHD at a later date and choose to revoke their AHD and create a new AHD by going through the same validation process. The processes of revocation and re-creation can be done online or on a paper-based form.
5. **Submit.** Once the AHD is completed and validated, it should be submitted to the Register. This may occur through one of several means, including through a Register-specific website or portal, through the My Health Record website, or submitted in-person at an accessible location (e.g. a local post office). Submission to the Register means an AHD is centrally stored. Due to legislative requirements for validation, the AHD must be signed and witnessed on a hard copy document with 'wet' signatures. This hard copy document can then be scanned, uploaded or copied and submitted. For documents that are submitted to a local post office in hardcopy, the process should mirror the current process for submitting an Enduring Power of Attorney at Landgate. This process would see an individual submit two, executed hardcopy AHDs in person. Upon vetting and approval by the Department's vetting team, one version would be returned to the individual, and the other submitted to the Register.
6. **Vet**. Once the AHD has been submitted, it will be vetted by appropriate personnel identified by the Department as having that role. The vetting process should ensure, at a minimum, that the AHD is legally valid, and clear enough to ensure the individuals wishes can be implemented. This process should not assess the advisability of the individuals preferences, wishes or treatment decisions.
7. **Store.** Once an AHD has been reviewed and deemed valid, the AHD would be stored in the Register and the maker notified. The maker and any nominated parties would be notified of the outcome of the submission, including the SDM if specified to be notified. The storage of the AHD in the Register would also then trigger a flag in My Health Record or a clinical alert in WebPAS that an AHD exists, rather than the AHD being 'stored' on My Health Record or WebPAS to ensure a 'single source of truth'.
8. **Access.** An AHD is stored on the Register and may link through to external platforms (such as My Health Record, or WebPAS) and its contents reviewed to provide a treatment decision. This could occur in various settings, including in residential aged care facilities, in community settings such as in general practices, the maker's home, an emergency department, by paramedics, or when a maker is admitted as an inpatient at a public or private hospital. This requires carers/clinicians in these settings to need access to the Register. There are also resources available which are relevant to appliers of an AHD on the Register to assist.

9. **Apply.** At the point the maker loses capacity or ability to communicate their wishes, their AHD comes in to force and provides their treatment decisions to health professionals if treatment decisions are required. Where the instructions within an AHD do not apply to the circumstances which have presented themselves, its content, including values and preferences should be used to inform the decision-making of the SDM.

4.3 The Register will have six distinct ‘end users’

The process of creating and implementing an AHD involves several individuals, groups, and organisations, in addition to the maker of the AHD. These are referred to as the ‘end users’ of a Register. These individuals may be involved at only one stage in the process, several stages or all stages. The involvement of each end user is non-linear. Each end user may be involved at different stages, to different extents, subject to the needs and wants of the individual who has made an AHD.

In mapping and designing the potential future processes of a Register – Nous identified six distinct ‘end user’ groups who will use a Register:

- **The person making the AHD**. An individual may be making their AHD for the first time, reviewing their AHD to check if they still stand by their decisions, or revoking their AHD and creating a new AHD in its place.
- **Individuals or groups supporting others to make an AHD as part of their profession or employment (professional support person).** This may include, but are not limited to GPs, legal practitioners, aged care workers, nurses, peer workers, paid carers, advocates and Aboriginal health workers.
- **Individuals or groups supporting others to make an AHD outside of their professional role (non-professional support person)**. This group includes friends, family or others who have little prior experience supporting an individual to make an AHD.
- **Individuals accessing and enacting an AHD**. This group includes those charged with implementing an AHD, which may include clinicians, paramedics, GPs, aged care workers, and other health care workers caring for an individual who has lost capacity or is unable to communicate their wishes.
- **The SDM.** A SDM is the person who must make a decision about the care provided to an individual, in circumstances where the individual lacks capacity to make a decision for themselves, and there is no relevant treatment decision listed in an AHD. A SDM may be someone who has been formally appointed either as a guardian by the State Administrative Tribunal, or as an enduring guardian by the person themselves by making an EPG before they lost capacity, or they may be the person at the top of someone’s ‘hierarchy of treatment decision makers’ which is a list of people prescribed in the *Guardianship and Administration Act 1990* (WA).
- **Individuals or groups providing oversight or administrative functions for the Register**. The Department will be the administrator of the Register. As part of its role, the Department will be responsible for maintaining the Register, ensuring appropriate integration with WA Health and non-WA Health systems, and managing the ‘vetting’ process for AHDs submitted to the Register.

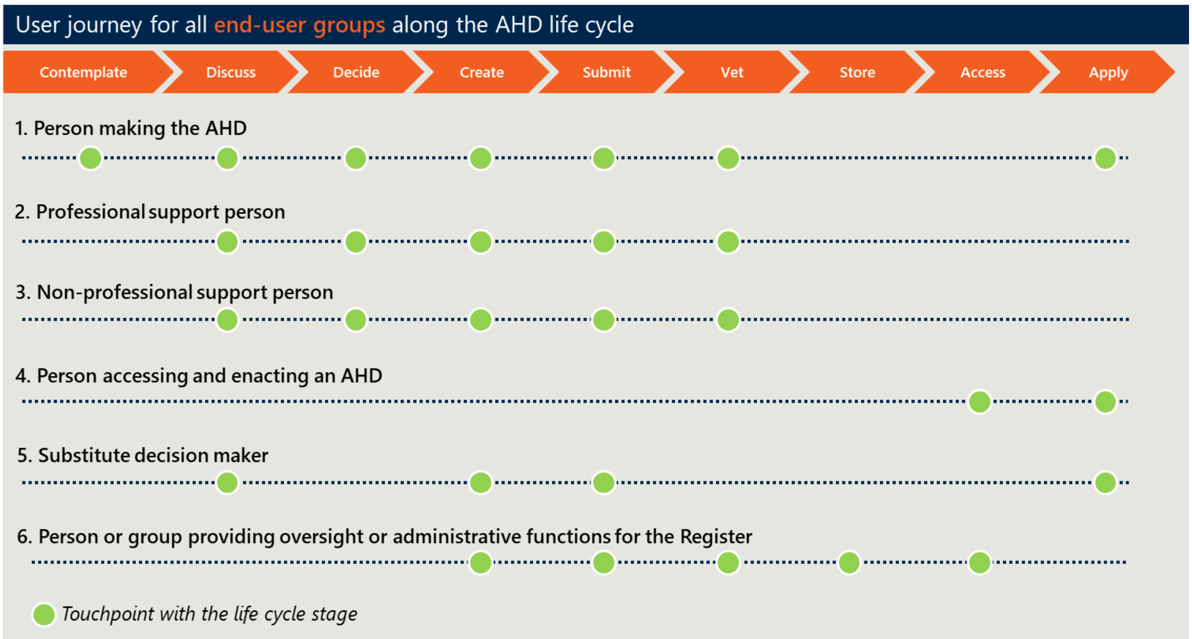
People may also play multiple roles, such as a SDM and non-professional support person; or professional support person and individual accessing and enacting the AHD.

The ideal actions and experiences of each end user across each stage of the AHD life cycle have been identified through the focus groups and desktop research, and in turn informed the development of high-level future state end user journeys. These user journeys are detailed in the section that follows.

Each end user may have several touchpoints with the Register through the AHD life cycle

Each end user will interact with the Register at different stages of the AHD life cycle (see Figure 10).

Figure 10 | Touchpoints of each end user in a future AHD life cycle



User journey for all end-user groups along the AHD life cycle

	Contemplate	Discuss	Decide	Create	Submit	Vet	Store	Access	Apply
1. Person making the AHD	●	●	●	●	●	●			●
2. Professional support person		●	●	●	●	●			
3. Non-professional support person		●	●	●	●	●			
4. Person accessing and enacting an AHD								●	●
5. Substitute decision maker		●		●	●				●
6. Person or group providing oversight or administrative functions for the Register				●	●	●	●	●	

● *Touchpoint with the life cycle stage*

User journeys have been developed which outline what activities and experiences would make up an ‘ideal’ interaction with the Register. Hypothesised pain points along the user journey have also been highlighted to identify design solutions for the Register. These user journeys and pain points were informed by extensive consultation – both as part of this engagement and other processes undertaken at a state- and national-level, and findings and recommendations of the JSC and MEP. The consultations centred around the use of ‘personas’ which are hypothetical individuals who sit within each group and are given context and a ‘story’. These personas are then tested with participants to understand their process and functionality requirements. The personas used during consultations are included in Appendix D. The user journeys and pain points are included in Appendix E.

4.4 The Register will be enabled by a robust service and operating model

As envisioned by the MEP, and informed through extensive consultation, the Register should not be considered only as a repository for AHDs. The Register should be developed and implemented as a holistic solution that guides all end users through the AHD life cycle – supporting advance care planning conversations, the creation of an AHD, and the easy access and application of an AHD at the time of care.

To enable the Register to function in this way, it will need to be underpinned by a service delivery model (i.e. the scope and scale of services that will be provided to end users), and operating model (the roles carried out by the Department to support end users in using the Register).

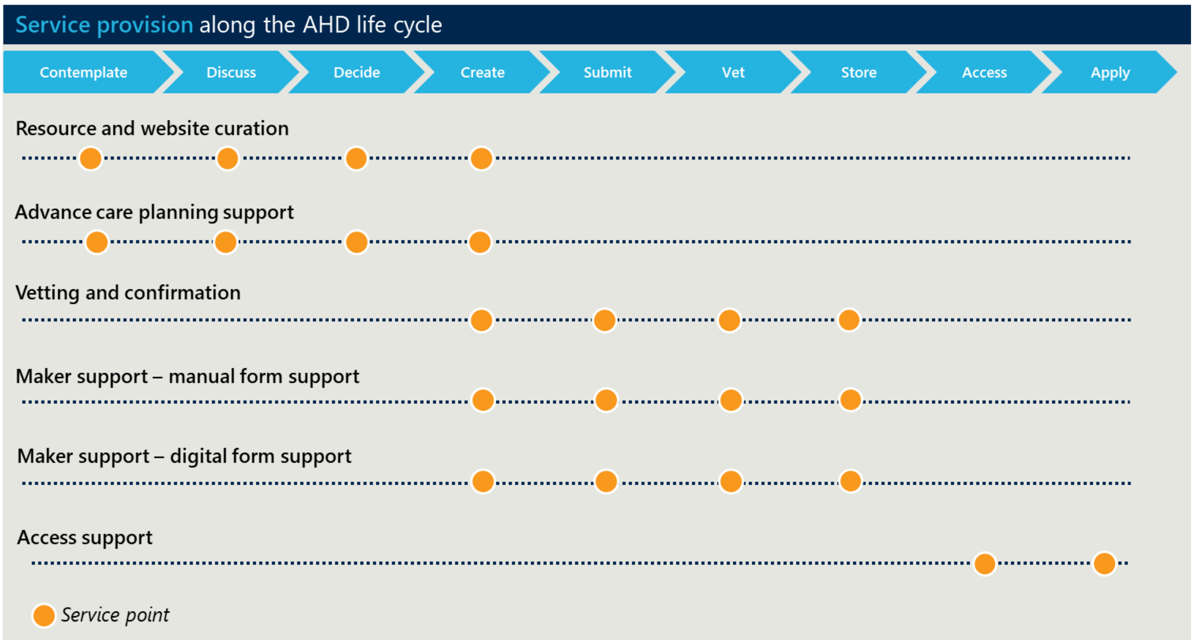
The recommended service delivery model and operating model for the Register, as informed by consultations, is detailed in the sections that follow.

4.4.1 Service delivery model

A service delivery model defines the conceptual framework by which an organisation designs its services to its defined ‘customer segments’ or, in this case, end users. An organisation’s service delivery model must execute a defined purpose or strategy as well as achieve customer value for minimal resource input.

Figure 11 summarises a high-level service delivery model for the Register. It has been informed by the inputs of consumers, carers and service providers through consultations, and the recommendations of the JSC and MEP. The service model should be read concurrently with the detailed process maps for the Register[13]. These process maps describe the specific steps and actions to be taken by each end user in interacting with the Register through the AHD life cycle.

Figure 11 | Proposed service model



The core services that will be delivered as part of the service delivery model are:

- **Resource and website curation**. The Register will be accessed through a comprehensive website which provides tailored resources and support to end users. This may include downloadable brochures, illustrative videos, written guidance, video testimonials, and exemplars of completed AHDs.[14] The Department should be responsible for the development and ongoing curation of these resources to ensure the information reflects contemporary best practice information or triage to other appropriate providers/resources, such as Advance Care Planning Australia, and ensure end users are able to access the information they require when they require it.
- **Advance care planning support**. As part of supporting end users through the first four stages of the AHD life cycle, the Department should ensure that all end users, if required, are able to receive support to access information, have an advance care planning discussion, and use the Register to create an AHD. This service would cater to makers and non-professional support users predominantly, but also professional support users, and provide each with telephone or email support in navigating the Register and the AHD form. It should provide end users with a triage service to external organisations that can provide expert advice and guidance to end users, such as Palliative Care WA and Advance Care Planning Australia.
- **Vetting and confirmation**. The Department should be responsible for vetting completed AHDs for legal validity and actionability. As part of this service, the Department should engage with makers, and if required, their supports, to address any concerns which arise through the vetting process, prior to the finalisation of the AHD through to upload to the Register. The minimum viable service should

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[13] These process maps are being provided separately to the Department in Microsoft Visio format.

[14] Any exemplar content will be caveated with the fact an AHD maker is not bound to include any specific content or decision and example content is provided for the purpose of providing guidance on the type of language which may be used, length of a document and format.

include reviewing AHDs for completeness and compliance with legislative requirements. However, as informed by consultations, there is broad support for the vetting service to also assess the logic and length of the AHD's contents in order to provide guidance on how 'implementable' the AHD will be in a clinical context.

- **Maker support – manual form support**. This service would cater to makers who chose to submit a paper-based form (e.g. at a local post office). As part of this service, the Department will support makers (e.g. with a telephone support service) to create an account, securely store the AHD, and provide ongoing communication to the maker (and other individuals, as stipulated by the maker) in relation to the AHD. This service would provide information on the different ways to submit a form offline. As noted earlier in this report, this process should mirror the current process for submitting an Enduring Power of Attorney at Landgate. This process would see an individual submit two, executed hardcopy AHDs in person to a GP or local post office. Upon vetting and approval by the Department's vetting team, one version would be returned to the individual, and the other submitted to the Register.
- **Maker support – digital form support**. This service would cater to makers who chose to submit a digital form by providing step-by-step guidance on the Register website and technical support such as assistance with website/register navigation and entering details, and account troubleshooting (e.g. forgotten passwords).
- **Access support**. This service would cater to those accessing and applying an AHD and the parties supporting them. For example, this service would seek to provide governance and integration support to organisations with patient management systems which are integrated with the Register. It would also provide services to authorise access to the Register for persons or parties who may need to access and put into effect an AHD where access has not been granted, such as to the Office of the Public Advocate or State Administrative Tribunal, for example.

4.4.2 Operating model

An operating model is how an organisation is set up to meet the needs of its customers and deliver on its purpose and outcomes. In this case, the operating model articulates, at a high level, the roles and functions that the Department will need to establish, as custodian of the Register, to meet the needs of the end users.

Figure 12 captures the four recommended functions of the Department as custodian of the Register.

Figure 12 | Suggested roles to enable the Register

RESOURCES AND EDUCATION

This team will be responsible for creating and maintaining content (online and paper-based) to guide individuals, non-professional and professional support persons, and SDMs through the advance care planning process, and the process of creating, submitting, accessing and implementing an AHD.

VETTING AND SUPPORT

This team will be responsible for providing support (e.g. via telephone or email) to individuals requiring advice in creating an AHD. Once in receipt of a submitted AHD, the team will be responsible for vetting the AHD, and working with the maker to address any concerns prior to finalisation and storage.

SECTOR ENGAGEMENT AND CHANGE MANAGEMENT

This team will be responsible for change management and sector engagement. This includes proactive engagement with the health and aged care sector, including St Johns Ambulance, to support the transition of their internal practices to using the AHD Register.

ANALYSIS AND SYSTEM ADMINISTRATION

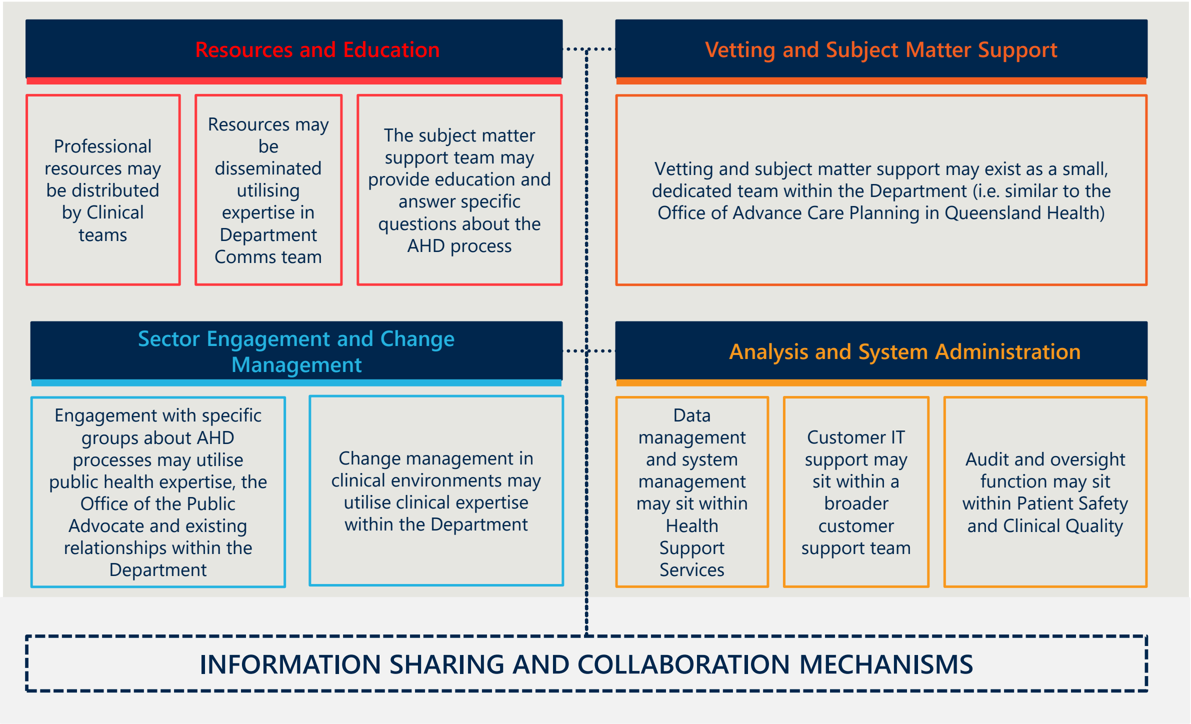
This team will be responsible for audit, oversight, system maintenance and administration for the AHD Register. This should include engagement with IT and data teams in HSPs, health care providers, HSS and the ADHA. This role should also include a monitoring and assurance function to ensure only authorised persons are accessing an individuals AHD.

These roles require expertise and, accordingly, it is recommended certain aspects of the roles be managed by established functions within the Department, or its partner agencies. Where such expertise does not yet exist, such as the vetting and support role, this may be a new function within the Department, established as part of the implementation and change management plan (discussed further in Section 5 below).

A proposed division of roles may be as shown in Figure 13 based on expertise or appropriateness. While roles may be divided as the Department sees fit, the operating model also acknowledges the need for information sharing and collaboration between teams to ensure a shared focus on end user success. Cross-functional delivery will be supported by clear end-to-end ownership, open and collaborative two-way dialogue, and co-location of teams where needed:

- **End-to-end ownership with clear responsibilities**. Teams must work together across shared processes, with a single and clear process owner, and clear roles and responsibilities across teams.
- **Co-location to reinforce collaboration**. Where teams across functions are required to work closely together to deliver on shared processes, co-location is recommended to reinforce expectations of effective teamwork, enhance communication and collaboration, and facilitate timely decision-making and action.

Figure 13 | Potential role distribution



A Data Steward will be required to support the Department in the governance of the register

It is envisaged that the Department will act as the custodian of the Register as per the roles in Figure 12. Custodianship is primarily concerned with ensuring and maintaining the technical and operational environment in which the Register exists. In addition to this, a ‘Data Steward’ is required to provide oversight of the data assets, and to implement appropriate business rules. It is recommended that this function sits within the Information and System Performance branch of the Department.

4.5 The Register will comprise a repository and publicly facing website

The following sections describe the functional and non-functional requirements for the Register (referred to in this section as the ‘system’) which includes:

- **Public-facing website**: The Register should have a comprehensive front-end website or portal that provides those that access it with detailed and interactive resources to guide advance care planning conversations, and the process of deciding to create, and creating an AHD. Consultation revealed a broad range of resources that end users may want access to, including but not limited to, testimonials by those who have completed an AHD, detailed how-to guides, frequently asked questions, example completed AHDs, how-to videos, links to external information resources, and ‘contact us’ information.
- **Secure repository**: The Register will need to enable AHDs to be securely stored. The ‘repository’ function of the Register will not be seen by end users but should provide sufficient information to all end users to assure them of the privacy and confidentiality of their personal information.
- **Integrated access pathways**: The Register should be well integrated with the broader systems of WA Health, and the ADHA. The Register should be seamlessly integrated with these systems so that there is no inconsistency or contradiction in the advance care planning information contained in each

system. As a priority, the Register should be integrated with My Health Record, WebPAS and WA Health's patient administration system. The nature of this integration is detailed further in Section 5.

Addressing end user pain points informs the functional and non-functional requirements of the system

User journeys and pain points were synthesised into a set of design opportunities that reflect a minimum viable product Register. These design opportunities then informed the development of the 'system requirements' of the Register, comprising:

- **Functional requirements**, which will define what functions a user must or must not experience from the Register, when certain conditions are met. For example, a functional requirement of the Register will be to enable 'makers' to create a new account, or to allow a member of the administration team to generate audit reports.
- **Non-functional requirements** describe the behaviours or performance of the Register that are not apparent or not important to an individual user. For example, a non-functional requirement will be the interoperability of the Register with a range of other patient management systems, or the security of the storage database.

The requirement for 'wet signatures' in WA has significant bearing on the functionality of the Register

At the time of writing, the witnessing requirements for AHD's necessitate the use of 'wet signatures' and therefore the submission process has been assumed to require printing, scanning and uploading of a physical AHD form, either by the maker or support person, or by an authorised individual, including the Department's AHD support team. The solution described below also assumes that the AHD image will not be processed using text recognition or other technologies to interpret and validate the AHD. Instead when and if the requirement for wet signatures is removed, it is anticipated the Register will be updated to include an online form with inbuilt validation.

4.5.1 Functional business requirements

The primary users of the Register fall into three main categories based on the analysis of feedback, and user expectations from the various consultations conducted as part of this project. These categories and roles are suggested based on the grouping of their needs from the Register and their involvement in each stage of the AHD life cycle. The user categories and suggested roles are presented in Table 3 below.

Table 3 | User groups and their specific end-users

User groups	Specific end-users and roles
Makers and supports – Those principally involved in the process of contemplating, discussing and deciding on the need for an AHD, and, possibly, then creating and submitting an AHD. This includes the individual creating an AHD for themselves, and any other person – professional or non-professional – who supports them or submits on their behalf.	• Person making an AHD • Professional support person • Non-professional support person
Accessors – Those principally involved in accessing, interpreting and enacting the directions within an AHD at the point of care, including the SDM.	• Person accessing and enacting an AHD • The SDM

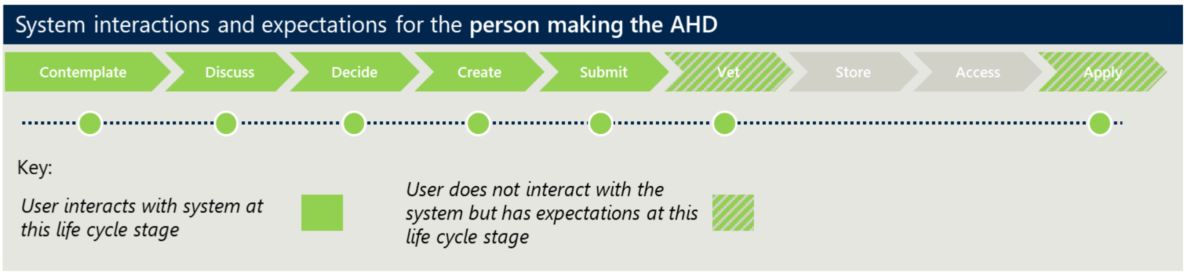
User groups	Specific end-users and roles
Administrators and vetting personnel – Those involved in performing administrative and oversight functions for the Register, including vetting, user management, and monitoring and evaluation.	• Individuals or groups providing oversight or administrative functions • AHD vetting team or personnel

Functional business requirements have been developed considering the expectations of each user category. To ensure the requirements are comprehensive and practical, the requirements have been structured according to the journey that the user is likely to undertake when using the Register.

4.5.2 Makers and supporters

Makers and supporters are those involved in activities surrounding the creation and management of an AHD. They could include members of the public creating and managing their own AHD's, or the professional or non-professional support persons assisting them through the process. They represent a broad group with diverse needs, including those with low levels of computer literacy, and those that are culturally and linguistically diverse. Figure 14 shows the indicative user journey for makers and supporters along the AHD life cycle.

Figure 14 | Indicative user journey and system interactions for makers and supporters



Contemplate, Discuss, Decide

It is important that members of the public can access relevant and curated information about various advanced care planning documents, including but not limited to AHDs.

1. The system must be hosted on a domain that is easily discovered through a web search.
2. The system should provide comprehensive and easily accessible informational and educational resources, including illustrative videos, downloadable guides, and text testimonials, exemplars, and frequently asked questions, and in accessible forms for culturally and linguistically diverse groups, and Aboriginal and Torres Strait Islander peoples.
3. The system must provide sufficient information and clarity regarding alternative advance care planning documents such as ACPs, and EPGs.
4. The system website must link to websites of organisations that provide advance care planning support, including Advance Care Planning Australia and Palliative Care WA.
5. The system must provide 'contact us' details so that a user can contact the Department for assistance.

Create

Those wanting to create or manage their AHD need to establish their identity with the Register, enabling them to manage the creation of an account linked to their unique identifier, and to manage the creation, review, deletion and replacement of their AHD.

Create account

6. The system must allow a person to create an account that uniquely identifies them as a resident of WA, from which they are able to create and manage an AHD in perpetuity.
7. The system must provide the ability for an authorised person[15] to create an account on behalf of someone else.
8. See user management in Section 4.5.4 below for requirements pertaining to the cancellation of an account.

Create AHD

9. The system must enable creation of an AHD though completion of an online form.
10. The system must allow a person to start a draft AHD and come back to the draft at any time. This should include an edit and autosave drafting environment and a resubmit/replace function so that the maker can save a draft of changes whilst a previously submitted AHD remains active.
11. The system should enable deletion of an AHD once it has been revoked and uploading of a new AHD which replaces a revoked AHD[16].
12. The system should only be able to store one AHD in finalised form but may contain versions in a 'draft environment' that would be superseded by the binding AHD upon execution, vetting and finalisation.
13. The system should provide auto-reminders via SMS or email to review a previously completed and valid AHD after a period of time.

Submit

After creating or managing an AHD, the user will need to submit their completed forms to the Register for vetting, either in paper-based or electronic form.

14. The system must allow individuals who do not wish to upload their AHD to the Register on account of privacy concerns, to have the option of using the system to record only the existence and location of the AHD.
15. The system must allow for a mechanism to upload a scanned document containing paper-based signatures.
16. The system must allow for a mechanism for an authorised individual to upload a scanned document containing paper-based signatures on behalf of the maker.
17. The system must allow the maker of an AHD to provide consent for their AHD to be linked to or flagged in their My Health Record.

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[15] An authorised person someone that the department has granted permission for creating an AHD for a member of the public who instructs them to do so. For example, this could be a GP assisting a person with the creation of their AHD or someone in the department who receives a paper-based form.

[16] Under the *Guardianship and Administration Act 1990* (WA), and individual may make multiple, concurrent AHDs, if those AHDs contain different and unrelated Treatment Decisions. However, stakeholder input strongly supported the AHD Register only including on AHD at a time. Nous has reflected the guidance provided through consultations, however, under legislation, it remains that an individual may legally have more than one AHD at a time.

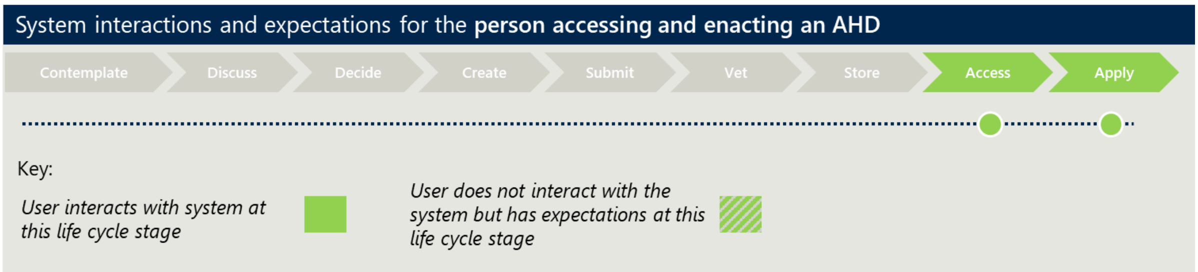
18. The system must allow the maker of an AHD to provide consent that their AHD be linked with WA clinical systems, public and private, aged care, and emergency response systems.
19. The system must provide the ability to view the status and outcome of a vetting process (see below for vetting process).

4.5.3 Accessors

Accessors represent users that are responsible for accessing an AHD at the point of care, and for making treatment decisions based on the contents of an AHD. Appendix E shows the indicative user journey for accessors along the AHD life cycle.

System access for these users is covered under the user management requirements described under the administrator section below.

Figure 15 | Indicative user journey and system interactions for accessors



Access

Accessors need to be able to identify that an AHD exists for a person, retrieve it, and make it available, in a timely manner, to the treating health professional who seeks the treatment decision.

20. The system must provide a means for the accessor to access the Register through a web-based user interface.
21. The system must have a mechanism for searching for an individual's AHD, by using the individual's personal information, including (but not limited to) their name and date of birth.
22. The system must enable accessors with Level 2 Permissions to request access to a specific persons AHD (see Section 4.5.4 for requirements regarding permission levels).
23. The system must link to patient administration systems (for example WebPAS, BossNet) with patient information indicating the existence of an AHD and providing a hyperlink to the AHD.
24. The system must indicate whether the maker also appointed an enduring guardian, or since they have lost capacity if a guardian has been appointed by the State Administrative Tribunal.
25. The system must allow GoPC to be accessed through the Register.
26. The system must allow for the accessor to identify when the AHD was created.
27. The system must allow for the accessor to open and read the AHD.
28. The system must record a decision made by the State Administrative Tribunal that an AHD is invalid, or whether the State Administrative Tribunal has given direction about the terms of the AHD.

4.5.4 Administrators and vetting personnel

Administrators are responsible for two main functions. These are user management, and monitoring and evaluation; defined as:

- **User management**, including the management of user accounts, including and allowing or denying access for viewing the contents of an AHD based on the defined permission levels outlined in Table 4.
- **Monitoring and evaluation**, including activities that: (1) analyse and report on the efficacy and impact of the overall solution (i.e. whether the system is used by the public and by clinicians); (2) detect and report malicious behaviour on the system (i.e. unauthorised, unnecessary and inappropriate access or attempts at access).

The Register will also be supported by vetting personnel, whose role is defined as:

- **Vetting**, the process which ensures that a submitted AHD is valid. During this process, in the minimum viable product, AHDs are checked for validation by signature and witness signature, and in the preferred processes, assessed for legibility, internal consistency, and legal and medical applicability.

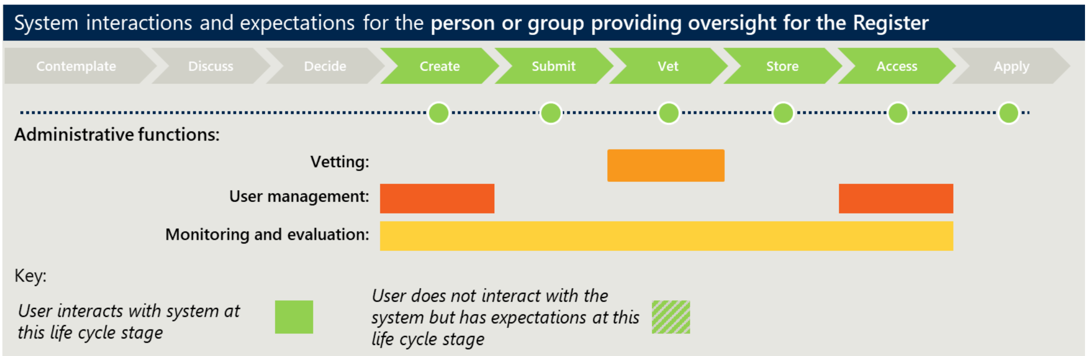
Table 4 | Suggested permission levels for accessing the contents of an AHD

Permission levels	Examples of specific end-users within each user group		
	Makers and supporters	Accessors	Administrators and vetting personnel
Level 0: No access to the contents of any AHD			Administrators performing user management, and monitoring, audit and evaluation functions
Level 1: Access to a person's own AHD only (in all forms)	Person who is making or managing their AHD (with or without a support person)		
Level 2: Timed access on request to an individual's AHD that is not their own		• Residential aged care facilities • GPs • Office of the Public Advocate • State Administrative Tribunal	
Level 3: Access to an individual's AHD in draft form, and assigned to them, to 'vet'			Persons performing vetting functions
Level 4: Universal access to any individual's AHD		• Registered clinicians and nurses authorised to access patient records in public and private hospitals	

Permission levels	Examples of specific end-users within each user group		
	Makers and supporters	Accessors	Administrators and vetting personnel
		- St John Ambulance	

Figure 16 shows the administrative functions mapped to the stages of the AHD life cycle.

Figure 16 | Indicative user journey and system interactions for administrators



User management

Administrators need to be able to log and report on the number and nature of AHD's created, updated, deleted or superseded, as well as create and manage user accounts with appropriate permissions.

29. The system must allow the administrator to create new user accounts synchronised to a departmental active directory.
30. The system must allow the administrator to assign users to roles which in turn will set access permissions as per the suggestions in Table 4.
31. The system must allow the administrator to suspend or reactivate users.
32. The system must enable an administrator to grant access to an AHD, subject to permissions described in Table 4.
33. The system must allow an administrator to lock, suspend or unlock a user's account.
34. The system must allow an administrator to de-activate or delete a user's account.
35. The system must log whenever an AHD is created, reviewed, or revoked.
36. The system should enable the administrator to close an account and inactivate an AHD if notified the person has deceased.
37. The system must allow an administrator to monitor the accessing or attempted accessing of accounts.

Vet

The vetting team may consist of a centralised vetting personnel who will perform vetting of individual AHDs.

38. The system must show a backlog of draft AHD's for vetting according to the date submitted.
39. The system must enable vetting team leader to assign a draft AHD to a team member.

40. The system must allow a vetting team member to view an AHD if assigned to them.
41. The system must allow a vetting team member to record feedback against an AHD for the maker and support to consider and address. This feedback should be attached to the relevant section of the AHD, not bundled in a separate document.
42. The system must enable a vetting team member to flag an AHD as final.

4.5.5 Non-functional requirements

The non-functional business requirements for the online portal are set out below.

Security and privacy

The system must ensure privacy of consumers' data by restricting access to authenticated users and following all applicable data privacy laws.

43. The system must only allow access to an AHD within the Register to authorised users with appropriate permissions, such as those described in Table 4.
44. The system must process and store all data in line with the Australian Privacy Principles and the *Privacy Act 1988* (Cth).

Logging, reporting and auditability

The system will enable the administrator's monitoring, auditing and evaluation function by logging all user actions on the system throughout the AHD life cycle.

45. The system must log the following user actions on the portal:
    a. log-on and log-off, including attempted access of an account
    b. account creation
    c. AHD creation (including creation of a draft)
    d. deletion or revocation of an AHD
    e. searching for the existence of an AHD
    f. accessing an AHD.
46. The system must log all administrator and administrator actions.
47. The system must enable the administrator to review all user actions in the log.
48. The system must enable the administrator and auditors to review all administrator actions in the log.

Availability and performance

The system ordinarily will be accessed by the public in private homes and health care settings in WA, including general practice, hospitals, community health and aged care settings.

49. The system availability must at least be consistent with existing patient administration systems.
50. The system must comply with the WA Accessibility and Inclusivity Standard 2019.

Storage

AHDs will be stored in electronic format within the Register. At the time of writing the requirement for 'wet signatures' for the verification process means that AHD forms will need to be scanned and uploaded into the Register as PDFs or image formats.

51. The system must store the draft contents of an incomplete AHD form within the Register.

52. The system must be able to store a submitted AHD form either as an electronic document or an image.

53. The system must be able to maintain up to 5,000,000[17] distinct user accounts.

54. The system must be able to store up to 50,000,000[18] AHDs and other advance care planning documents within the Register.

55. The system must comply with relevant record keeping and management protocols including but not limited to Records Management Advice published by the State Records Office of WA, the *WA State Records Act 2000* (WA), or others otherwise specified by the Department.

Integration

To simplify the discovery and access of AHDs by treating clinicians and health administrators, in addition to the Register the AHDs also need to be accessible through WA Health patient administration systems.

The following requirements are conditional on whether an individual has elected to make their AHD visible through My Health Record and clinical systems.

56. The system must be integrated with WA clinical systems, signalling to system users whether an AHD exists for an individual.

57. The system must enable clinical system users to 'click through' to the Register and access the AHD for the individual.

58. The system should be integrated with My Health Record, signalling to My Health Record users whether an AHD exists for an individual.

59. The system should enable My Health Record users to 'click through' to the Register and access the AHD for the individual.

4.6 Some features cannot be accommodated through the recommended functionality of the Register

Throughout consultations, some features or system requirements were raised as being important for the Register. However, due to limitations that currently exist, or inherent conflicts with priority system requirements, these features cannot be accommodated through functionality. These are:

- **Searching content within an AHD**. A core system requirement for the Register is the ability for individuals to print, or access a hard-copy AHD form for signing and witnessing, and then upload a scanned copy of that form to the Register for vetting and submission. By virtue of this requirement, the Register will provide those that access an AHD with the ability to 'search' an AHD for a key word. While this requirement was raised in consultations, it is both not functionally viable (i.e. it would require advanced document scanning) and would not represent best practice in advance care planning, as individuals making an AHD will have varying vocabulary, and understandings of clinical terminology.
- **Interjurisdictional access**. By virtue of the Register being a state-based system, it will not enable clinicians and health care practitioners in other Australian jurisdictions to access an AHD if a WA resident is admitted to a hospital in another state or territory. It is recommended that in future

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[17] Assuming one account per person in WA (2020 population of approximately 2.7 million persons), and accounting for future population growth.

[18] Assuming one person may have up to 10 advance care planning documents per account.

releases the Register be comprehensively integrated with My Health Record. This integration should ensure that an AHD that is created through the Register is automatically uploaded to My Health Record, with the consent of the maker. It is worth noting that integration of advanced care documentation with My Health Record has already been successfully implemented with the GoPC, and a similar approach for AHDs could be easily demonstrated. While this requirement will go some way toward addressing the issue of interjurisdictional access, it will not ensure the AHD is either legally valid or applied in those jurisdictions.

5 Implementation considerations

The success of the Register is dependent on the approach taken by the Department in progressing its detailed design, development and implementation, including change management. This report recognises that the Register is being designed in a complex legal, policy and clinical landscape, and that its design and implementation will be progressed contemporaneous with other reforms as part of the Departments End of Life Care Program.

This section details four key considerations for the Department in progressing the implementation of the Register. It includes:

- The investment required in a comprehensive change management program for consumers, carers, clinicians and health and aged care workers.
- A proposed approach for the procurement of the platform.
- The provision of a comprehensive business case, including indicative costs for the design, development and implementation of the Register.
- Planning for and eventual integration with existing WA Health patient administration systems, and the My Health Record platform.

5.1 System integration

The success of the Register in achieving its objectives will be heavily dependent on its ability to 'speak to' and be interoperable with the range of existing health information systems administrated by WA Health, and more broadly, the ADHA. Integration with these systems will be particularly critical to clinicians and health care workers in public and private hospitals, aged care and emergency response settings in accessing and affecting an AHD, and GPs in supporting individuals to create, review and revoke their AHDs.

Across WA Health, the efficient and effective use of the Register will require integration with patient administration systems, specifically WebPAS. This integration may take the form of a 'flag' in WebPAS that notifies a nurse or clinician of the existence of a patients AHD. This would then act as the 'prompt' for a clinician, nurse, or administrator to access the AHD via the Register for application. This functionality should also be able to extend to systems used in private hospitals which rely on a variety of systems to manage patient records and information.

On a national level, in subsequent iterations of the Register, the integration with My Health Record would allow AHDs to be visible by health care workers in other Australian jurisdictions. This would provide some assurance to individuals that create an AHD in WA, that should they become unwell and lose capacity in another Australian jurisdiction, that their AHD can be accessed and implemented (albeit not legally binding). It is further recommended that the Department proactively engage with the ADHA to understand the extent to which system integration can be achieved. For example, the Department may wish to explore opportunities for AHD records on the Register to seamlessly 'flow' to My Health Record, with the consent of the maker, or for the existence of an AHD being 'flagged' in an individual's My Health Record.

5.2 Risk management

The development and implementation of a Register is a key step for the WA Government in increase the awareness of, and uptake of AHDs. However, the transition to a standalone electronic system comes with several risks that will each need to be monitored and mitigated against. Nous has identified the following risks that carefully managed by the Department as it progresses the detailed design, development, and implementation of the Register. These risks do not represent an exhaustive summary of possible risks, but rather a starting point for the Department's risk management approach moving forward.

- **System outages or failures**. In moving to an online system, the Department will need to ensure it has policies and procedures in place to manage system outages or failures. This will be particularly important for emergency settings like emergency departments and for paramedics, who may require access to the Register in the moment.
- **Cyber-attacks and breaches**. In the health care sector features a range of cyber-security issues that may compromise the integrity of systems, and the privacy of individuals. This may include malware, distributed denial of service (DDoS) attacks, and email and fraud scams, among other threats. It is expected that the Department, and Health Support Services has in place mechanisms to protect against these threats. It is recommended that the responsible team proactively engage with the areas of the Department and Health Support Services responsible for cyber security through the Register's detailed design and development process.
- **Intentional and unintentional privacy breaches of personal information**. Throughout consultations, stakeholders stressed the importance of putting in place robust mechanisms to protect the privacy and confidentiality of individuals personal information that is stored on the Register. These mechanisms should protect against both indirect privacy breaches (i.e. where an individual with universal access accidentally accesses an AHD without purpose) and direct privacy breaches (i.e. where an individual misuses their access privileges to access an AHD without purpose). As noted in the non-functional requirements section above, the Register system must process and store all data in line with the Australian Privacy Principles and the *Privacy Act 1988* (Cth). This includes having a clear process in place for managing notifiable data breaches as defined in the *Privacy Act 1988* (Cth), and mechanisms for monitoring the account activity for individuals accessing an AHD, and revoking permissions when access privileges are abused.

5.3 Change management

The implementation of the Register represents a broad and complex change for health care workers, legal practitioners, and most importantly, the public. As part of managing this change, the Department should consider the levers available to them to implement and manage this change. These levers include leadership, engagement, education and policy/process change. Table 5 below outlines some proposed change levers which may be relied upon to ensure smooth implementation and uptake of the Register.

It will be important to effectively utilise these levers to not only guide stakeholders through the change, but to also communicate and instil the case for change to bring stakeholders along the journey of 'why' the change must occur. The case for change will be articulated in the business case and subsequent communications, and will provide the footing for future change management.

Knowing what levers are best suited for the change will allow the Department to plan and deliver successes using these levers early.

Table 5 | Potential change levers

Change lever	Description	Desired impact
Leadership		
Clinical leaders model and drive the change	Department leadership have shared their thoughts on the requirements the Register requires. They may communicate, facilitate, model and expect change in their teams and more broadly to leadership in HSPs, public hospitals, private hospitals, and clinical leadership.	Staff know what is expected and make the effort to understand and embrace the change.
Engagement and involvement		
Stakeholder engagement	Internal: The right staff are involved in the development, implementation and sustainment of the Register. Right staff are those whose work will impact or will be impacted by the Register. External: The Department utilises its working relationship with the clinical institutions, health services, aged care providers, paramedic services and community groups to discuss the design and implementation of the Register. If possible, a reference group with key end users should be established to perform validation exercises of proof of concept and user acceptance testing of the Register in its development phase and environment. This will ensure the Register meets the needs of end users.	The involvement in creating the change makes the change fit-for-purpose and more likely to stick.
Communications	The Department develops fit-for-purpose communications for its internal and external stakeholders to ensure that they understand what the change contains, how it impacts them, what is expected of them and the outcomes it will achieve for consumers.	Stakeholders know what is happening, what is expected of them and what the outcome will be.
Quick wins to demonstrate success	The Department utilises a minimum viable product scheme to demonstrate the impact and potential successes of the register and ensure the design is fit-for-purpose. The learnings of the minimum viable product may be incorporated in the plans for further roll-outs.	Stakeholders recognise the value of the Register and what is required to deliver the intended outcomes of AHDs.
Learning and development		
Learning and development (L&D)	The Department assesses the knowledge, skills and capability needs for future end users including makers, appliers and vetting team. It subsequently develops a L&D plan to address potential gaps. The Department should work with HSPs and other stakeholders (including private hospital providers and aged care services) to implement this plan.	Clinical and health provider staff have the capability to support incorporation of AHDs and the use of the Register as business-as-usual. Community stakeholders are empowered to encourage use of the Register.
Structural changes to embed the change		
Changes to structures or job roles	The Department creates or adjusts team structures and job roles (to follow the service model) to maximise support for	The Department's organisation structure supports the transition

	the release and sustainment of the Register in the most efficient way.	to managing the Register in business-as-usual.
Changes to systems, processes and policies	The Department changes its own and encourages external organisations to update their systems, processes, information governance and policies to integrate the Register.	The Department and health organisations' systems, processes and policies support the transition to business-as-usual.

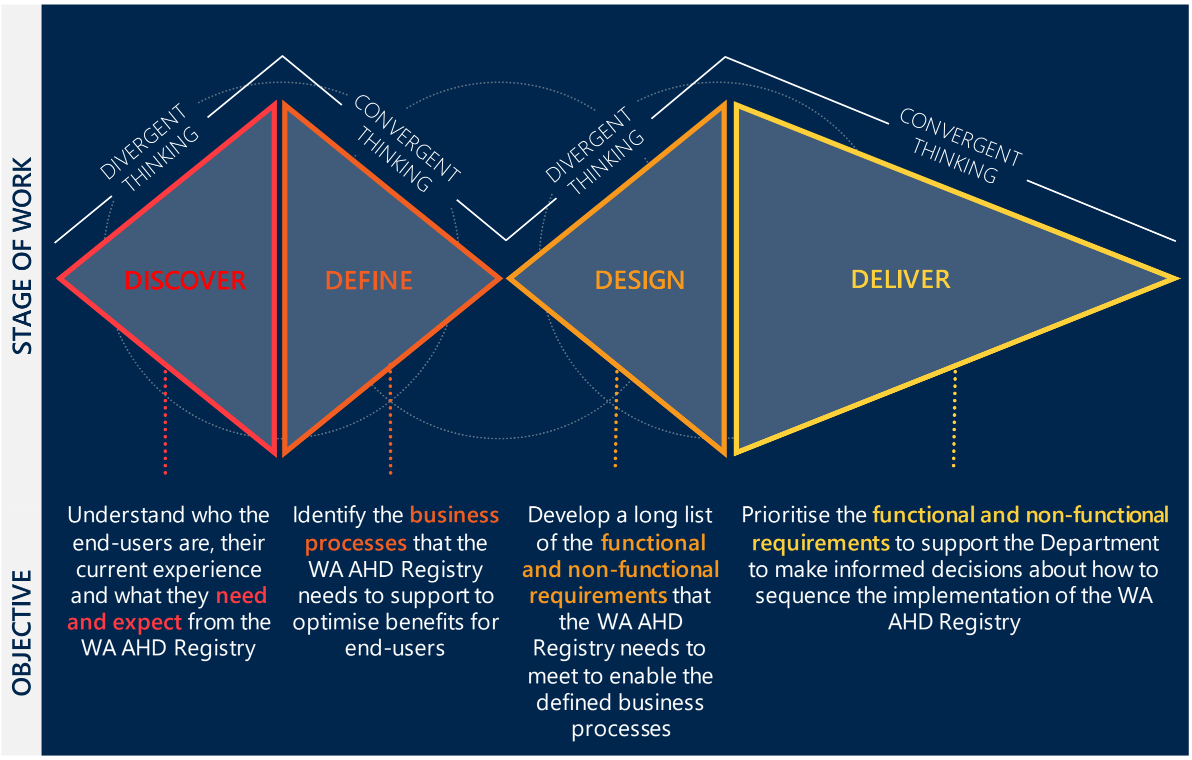
Appendix A Approach and method

Nous has been engaged by the Department to support the design of business processes and system requirements for an AHD Register, in line with the recommendations of the JSC and MEP. This work is being led by the Department's ACP/AHD project team, as part of its broader End of Life Care Program.

To ensure the AHD Register meets the needs of and optimises benefits to end-users, the project has been informed by human-centred design approaches and has involved engagement and input from lived-experience stakeholders such as consumers, families and carers, as well as service-delivery stakeholders, including clinicians and other aged care and health workers. This places end-users at the centre of the development process and ensure their lived experience and professional expertise are reflected in this report, as well as the final deliverable.

The Double Diamond set out in Figure 17 below is the overarching framework for human-centred design processes, and this interim report represents the findings of the first segment, 'discover'.

Figure 17 | Double Diamond approach to the design of the AHD Register



Understand who the end-users are, their current experience and what they **need and expect** from the WA AHD Registry

Identify the **business processes** that the WA AHD Registry needs to support to optimise benefits for end-users

Develop a long list of the **functional and non-functional requirements** that the WA AHD Registry needs to meet to enable the defined business processes

Prioritise the **functional and non-functional requirements** to support the Department to make informed decisions about how to sequence the implementation of the WA AHD Registry

Our methodology was characterised by several key processes and stages, listed below and explored in further detail in the subsequent sections:

- Focus groups, workshops and interviews with lived-experience stakeholders including consumers and carers, health and aged care workers, and clinical and technical experts.
- Analysis of internal documents provided by the ACP/AHD project team and external, publicly available documents.
- Testing and validation of findings with workshop participants, Department stakeholders, Nous internal experts and the ACP/AHD project team.

Discover focus groups and interviews

In order to develop an accurate and nuanced understanding of who the end-users of the AHD Register were and what they would need and want from the AHD Register the *Discover* focus groups and interviews consulted over 50 lived-experience and service-delivery stakeholders.

Nous undertook six focus groups and five interviews with a number of key representatives across stakeholder groups. We used these consultations to build on our understanding of the current AHD-related processes and structures, identify how end-users experience these processes and structures, and explore opportunities for the Register.

Preparing end-user personas and journeys

We consolidated our findings from the environmental scan and *Discover* focus groups and interviews on who the end-users are and what their current experiences are into a set of personas and journeys. These outputs were delivered as part of the Interim Report and the Final Report.

The purpose of these personas was to ground the *Define and Design* workshop participants in the perspectives of end-users, to ensure that the business processes, and functional and non-functional requirements developed meet their needs.

Define and *Design* workshops

To ensure the AHD Register meets the needs of end-users, we developed and tested business processes and functional and non-functional requirements with 75 stakeholders.

We conducted two half-day workshops with a combination of lived-experience and service-delivery stakeholders. The purpose of the workshops was to further explore the current experience of end-users, test and validate the end-user personas, high-level process map and develop user stories to inform the functional and non-functional requirements for the AHD Register. Following the workshop, these end user stories were translated into functional and non-functional requirements for the Register.

Testing interviews with key Department stakeholders

The content of this Final Report will be tested and validated with key system stakeholders prior to being finalised and delivered to the Department.

Appendix B Relevant MEP recommendations

Table 6 | Relevant recommendations MEP report on AHDs

#	Recommendations of MEP
16	Accessible by health professionals and consumers 24 hours a day, seven days a week. • Enable more individualised, restricted access for other parties including restricted access to specific access where permitted. For example, relevant allied health practitioners and community service providers may have restricted access. • Distinguish access between 24/7 access to ambulance services, Royal Flying Doctor Service, aged care providers, public and private hospital staff, GPs, enduring guardians, Office of Public Advocate and State Administrative Tribunal. • Distinguish between searchable access to all records (such as for emergency medical services) and the right to access a specific individual's information (such as for an enduring guardian), as well as the right for an individual to have permission to their own information.
17.1, 17.2	• Encourage the upload of completed AHDs and use of the Register by the public rather than mandate AHD completion. • Individuals who do not wish to upload their AHD to the Register on the account of privacy should have the option of using the Register to record only the existence and location of the AHD recognising this may compromise the ability of health professionals to obtain their AHD in a timely manner.
18.1	Enable for some form of vetting of uploaded AHDs to occur either through a manual or automated process.
19.2	The Register should accommodate all aspects of the AHD template, including whether a person has nominated an enduring guardian.
20.1	Individuals should be able to use the Register to flag the existence and location of advance care planning documents including ACPs , Common Law Directives or pre-existing AHDs.
21.1	Health professionals should be legally required to search the Register for an AHD prior to treating an individual.

#	Principles identified by MEP[19]
-	The Register must facilitate annual reporting to Parliament on the number of AHDs currently active in the WA community.
1	Enable individuals to have control over, and be accountable for, their own personal information.
2	Allow individuals to engage with the Register knowing their AHD and personal information can and will be accessed and applied in accordance with the law (where valid).

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[19] Government of Western Australia, Ministerial Expert Panel on Advance Health Directives Final Report August 2019, pg. 40.

#	Principles identified by MEP[19]
3	Health professional should have the legal and clinical authority to treat the register as the ‘source of truth’ for AHDs in WA. • The Register must have the ability to store multiple entries and archive superseded documents. • The Register must support a simple means by which AHDs can be deleted or superseded as required. • The Register ideally should have the capacity to flag entries to indicate where an AHD, or specific treatment decision with an AHD, is the subject of proceedings in the State Administrative Tribunal or has been declared invalid by the State Administrative Tribunal.

Appendix C Analysis of AHD storage options

The MEP considered the available platforms to store AHDs in response to Finding 8 of the JSP: 'Lawful advance health directives are not stored centrally and are not readily accessible to health professionals when required.'[20] In doing so, the MEP considered the information management systems within WA Health, as well as looking nationally to the only Australian jurisdiction which operates an analogous register as contemplated by the JSC, Queensland.

As a result of the work of the MEP and the Department of Health WA, the available platforms have been assessed against their capacity to meet the requirements of a future AHD Register as articulated by the MEP. Below is a summary of this options analysis, with a view towards assessing available models' ability to achieve the desired requirements.

There is limited capacity of existing systems to satisfy the recommendations as outlined by the MEP

The MEP found there is no existing online platform, nationally or in WA which can effectively serve as a register for AHDs while also meeting the scope and functionality requirements the panel recommended. In coming to this view, the MEP considered several existing models for the making of and storage of AHDs, including:

- **Queensland Health model**. Queensland Health maintains a state-wide electronic storage system that can be accessed 24/7 by public hospitals, ambulance services and GPs who have registered for access[21]. The register is maintained by the Office of Advance Care Planning in the South Metropolitan Health Service. The model implemented in Queensland was not recommended by the MEP for two key reasons. Firstly, while the register is always accessible by registered health professionals, it cannot be directed and accessed by individual consumers. Secondly, the register leverages the pre-existing Queensland Health IT system that enables patient health records to be shared across the public health system and registered private providers. As WA does not presently have such a system (and one is not planned ahead of the implementation of an electronic medical record), the Queensland model cannot be replicated in WA.
- **My Health Record**. The My Health Record platform, implemented and maintained by the Australian Digital Health Agency, presented allows individuals to store advance care planning instruments (including AHDs), or provide details of the individuals who can be contacted to obtain these instruments. However, using My Health Record as the central and single source of truth is not recommended. This is for three key reasons. Firstly, while My Health Record is accessible 24/7 by authorised individuals from registered healthcare providers – it is not accessible by residential aged care and home care providers, who were identified as priority end users by the MEP. Secondly, to-date My Health Record has a 10 per cent opt out rate, which limits its accessibility to a sizeable share of the WA population. Thirdly and lastly, My Health Record is a national platform, whose custodian is the ADHA. As such, there is little to no flexibility to make changes to the platform to ensure it closely mirrors the WA landscape without broad national, state and territory agreement.
- **Existing systems in WA Health**. Under current WA Health systems, an AHD may exist in a patient's medical record where a person has presented an AHD for storage to a given health service provider. The WA Clinical Alert Policy requires the use of clinical alerts across the portfolio of WA health system

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[20] Government of Western Australia, Ministerial Expert Panel on Advance Health Directives Final Report August 2019, pg. 38

[21] Government of Western Australia, Ministerial Expert Panel on Advance Health Directives Final Report August 2019, pg. 38

applications including the Open Patient Administration System, Web-Based Patient Administration System or the Health Care Related Client Management System. Through these systems, health service staff may be alerted to the existence of a patient's AHD. The alert also stipulates when the alert was created and which hospital/health service created the alert and holds a copy of the AHD itself. The applications do not store a copy of the AHD, it is only stored in the patient's medical record. There are currently only 1,459 clinical alerts for the presence of an AHD within the applications.[22]

- The Department has dedicated significant resources to the research of best practice examples of health systems which may support an AHD Register in the form recommended by the MEP. Ultimately, in assessing the strengths and weaknesses of the Queensland model, My Health Record and existing systems the Department placed weight on the substantial strengths of developing a 'one-stop shop' platform.[23]

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[22] Government of Western Australia, Ministerial Expert Panel on Advance Health Directives Final Report August 2019, pg. 1.
[23] Government of Western Australia, Ministerial Expert Panel on Advance Health Directives Final Report August 2019, pg. 7.

Appendix D End user personas

Rose has decided to make an AHD

She is 72 years old and showing early signs of dementia

	I AM FRUSTRATED BY…	**I AM MOTIVATED BY…**
Generally…	• Having to create the form online, or trying to scan the form to be uploaded • Family and friends doubting my capacity	• Having control of my decisions and ownership of the process • Having capacity to be validated quickly, before the disease causes further degeneration
If Rose is living in an aged care facility…	• Having different treating practitioners and no one who really 'knows' me • Staff not having time to assist with drafting an AHD	• Having staff respect my wishes consistently throughout my stay
If Rose is fluent in Italian and struggles with English…	• Limited resources available in my preferred language • My family maybe not translating my wishes accurately	• Being understood by those around me, including my carers and family • Capturing my wishes orally and in writing

Peter has never heard of an Advanced Health Directive

He is 70 years old and lives at home with his partner

He has a heart condition and recently required critical care

	I AM FRUSTRATED BY...	I AM MOTIVATED BY...
Generally...	• Being asked about an AHD when under stress and not understanding what it involves • Embarrassed about not having heard about an AHD	• Having my wishes respected • Access to information prior to requiring care
If Peter lived in a rural location and had a history of depression...	• Lack of contact with accessible GP or specialist care • AHD not catering to my mental illness	• To stay at home and receive treatment and care locally • AHD to specify treatments to avoid • Use an AHD during an episode of incapacity, as well/rather than during only end-of-life care
If Peter was an Indigenous Australian...	• Difficulty with language barriers and medical concerns • Difficulty accessing information • Cultural differences inhibit ability to engage and access appropriate services	• To stay on country or in community • To be supported by indigenous workers who understand my language and cultural practices • Maintain privacy and confidentiality, if requested
If Peter identified as LGBTQAI+ and was not married to his partner...	• My partner being excluded from decision making process • Requirement to disclose my sexuality	• My partner to be recognised and included in the AHD

Dinu is 39 years old

She is supporting someone making an AHD

	I AM FRUSTRATED BY…	**I AM MOTIVATED BY…**
If Dinu was an experienced solicitor… (professional support)	• Not understanding potential medical scenarios • Navigating family dynamics and differing documents such as EPG and AHD	• Working within the scope of practice • Ensuring clarity of drafting so that my client understands the implications of the AHD and it reflects their wishes
If Dinu was a GP… (professional support)	• Limited capacity to spend time discussing and drafting an AHD • Navigating family dynamics and differing documents such as EPG and AHD	• To provide relevant and timely information so that the maker can make an informed decision • Ensuring the maker understands what medical decisions may be made in their future care
If Dinu was the primary carer for her mother… (non-professional support)	• Emotional burden of supporting an AHD with a family member • Confusing processes, jargon and acronyms • Lack of advice/support which I can understanding and explain	• My mother’s voice being heard and respected • Assurance the AHD document is valid and will be used if the time comes

Jen works as a consulting Oncologist in palliative care

A patient's condition has declined over a number of days

	I AM FRUSTRATED BY…	I AM MOTIVATED BY…
Generally…	• The time it takes to be notified of an AHD's existence and location • Having to ensure an AHD is followed by the treating time and other health care professionals in the facility • AHDs which are unclear in their representation	• Providing the care which is in the best interests of the maker • Fulfilling my legal obligations • Reducing trauma for both the maker, their family/friends and other staff • Focusing on care and not paperwork • Ability to contact a SDM in the event the AHD does not consider the circumstance at hand
She works in the Perth metropolitan area…	• The time it takes to be notified of an AHD's existence and location • Not having a personal relationship with the patient prior to treatment	• Making a decision which aligns to the AHD in a timely manner
She works in a regional hospital…	• The time it takes to be notified of an AHD's existence and location • Accessing an AHD if it is hard copy and stored elsewhere	• Making a decision which aligns to the AHD in a timely manner with the resources available

Arjun works in emergency medicine

A patient has come into his care following a car accident

	I AM FRUSTRATED BY…	I AM MOTIVATED BY…
Generally…	• Whether there is enough time to identify the patient and access an AHD whilst performing critical treatment • My team having general access to the AHD Register rather than having to look for it myself	• Providing quality critical care and making a decision in the best interests of the maker • Supporting the patient's family/next of kin
If Arjun works in a regional hospital…	• Slow connection to online Register • Lack of on-site advice/expertise	• Providing the best possible care with potentially restricted resources
If Arjun is a resident doctor and has limited experience navigating admin and patient files…	• Not knowing where to look and what is most important in time-sensitive situations • Critical time spent attempting to access AHD and next of kin • Forced to make a value judgement with limited information	• Training which prepares me to confidently access patient files • The requirements to fulfil my legal obligations and discharging my obligations

Huan is 46 years old and is the only son of his 78 year-old mother, Choon-Hee

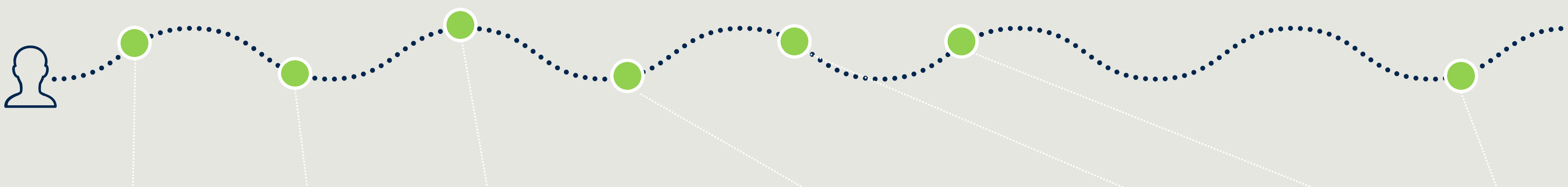
Choon-Hee is unresponsive in hospital

	I AM FRUSTRATED BY…	I AM MOTIVATED BY…
The SDM is Huan's father who is no longer in contact with the family…	• The process excludes me from speaking on behalf of my mother • My perception is my father is not aware of mothers wishes or may not act in her best interest	• Making decisions aligned to my mother's values • Making decisions aligned to the quality of life I believe my mother was comfortable with
If Huan's mother recently communicated her desire to update her AHD…	• The process of updating an AHD which is timely/complex which impacted my mother making the change	• Being able to help my mum update her AHD easily • My mother receiving timely, effective care in the manner that she wanted

Appendix E End user journey maps and pain points

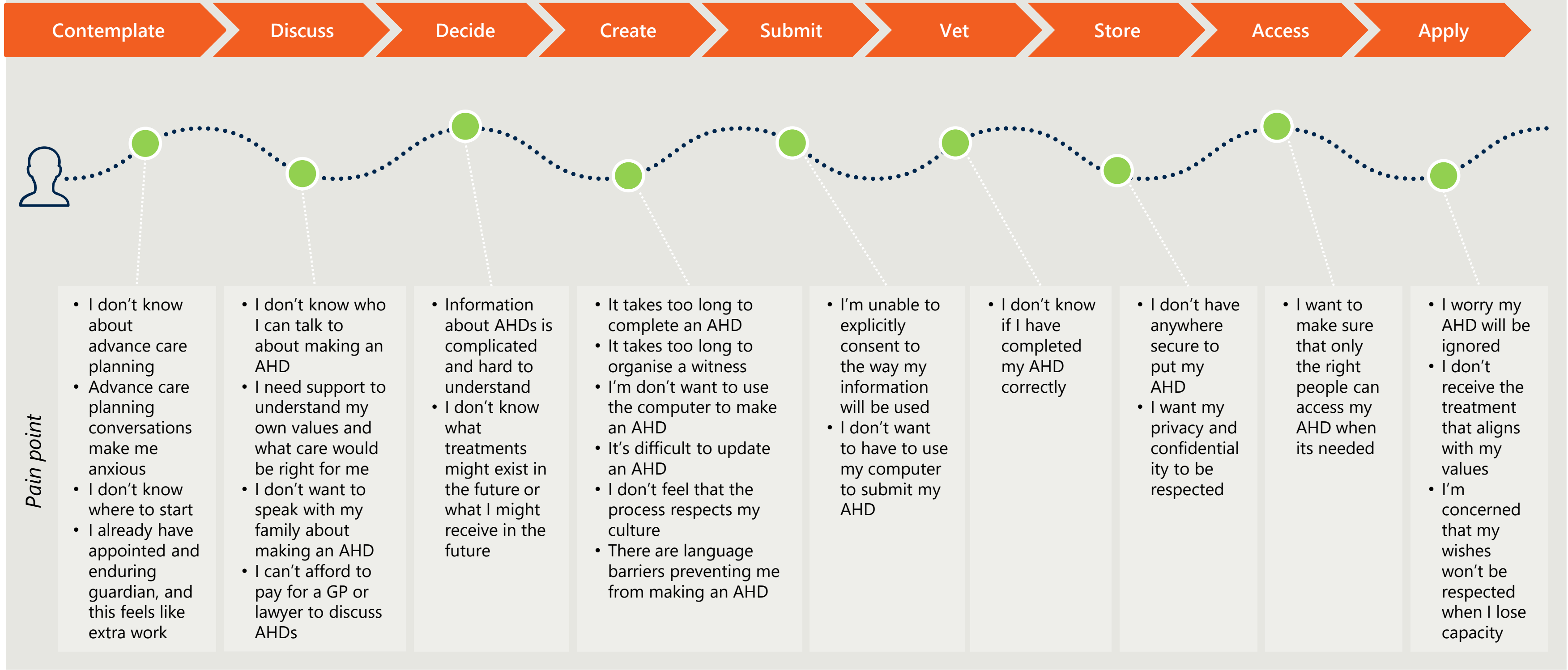
User journey for the person making an AHD

Contemplate → Discuss → Decide → Create → Submit → Vet → Store → Access → Apply



Action	• Think about current and future health, wellbeing and care	• Talk to and seek advice from others about what I value and what care I would like in the future	• Decide to create an AHD and what to include	• Locate Register online or paper-based form • Sign up for the Register • Complete the form • Sign and have form witnessed • Seek assistance to lodge form online or submit paper form	• Submit a valid document to the Register	• Wait to receive outcome of vetting process • Action required steps to validate AHD, if required	• Receive treatment in accordance with AHD
Ideal Experience	• I feel empowered to consider health, illness and dying • I have access to information and support to explore what may be important to me in plain English	• I know what kinds of things to consider with regards to future care • I know what quality of life I want after treatment • I know who I want to have access to my AHD • I have access to expert advice on areas I am unsure about	• I have considered all available options to record my wishes and decide to complete an AHD • I have sufficient time to consider options	• I can use the paper-based form if I am not good with technology or have poor literacy, English is not my first language, or have accessibility needs • I understand how to express my wishes in a way that can be understood by others and legally recognised • I can complete the process in a reasonable amount of time and I can leave and come back to it later • Getting the form witnessed is not too difficult • I know that my AHD will actually be used • I know decision makers are able to apply my instructions to a range of possible circumstances to achieve the outcomes and quality of life I want • I feel safe in expressing my beliefs as I chose to • I have sufficient access to resources and support • I have ongoing access to professional help and support if needed	• I'm confident my AHD meets legal requirements • I'm confident my privacy is protected • I'm confident my AHD will be found and used	• I'm informed in a timely matter the outcome of the vetting process • If denied, I have clear and easy to understand instructions to resolve any issues • I don't have to wait too long to have an AHD re-assessed • I am reminded of my AHD on a reoccurring basis • I can edit or supersede my AHD on the Register if and when I want to	• The care I receive aligns with my documented wishes and preferences

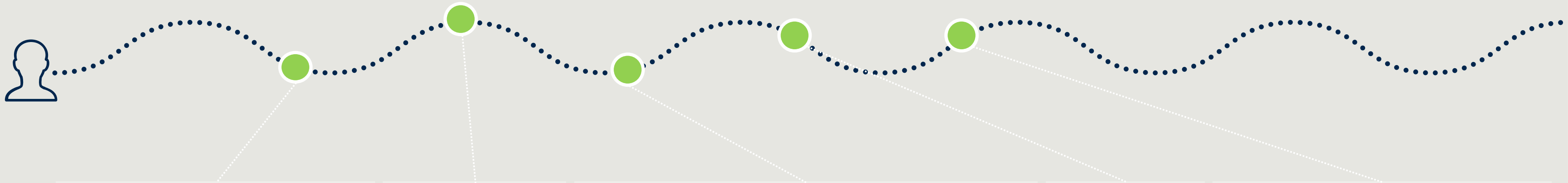
Pain points along the user journey for **the maker**



	Contemplate	Discuss	Decide	Create	Submit	Vet	Store	Access	Apply
Pain point	• I don't know about advance care planning • Advance care planning conversations make me anxious • I don't know where to start • I already have appointed and enduring guardian, and this feels like extra work	• I don't know who I can talk to about making an AHD • I need support to understand my own values and what care would be right for me • I don't want to speak with my family about making an AHD • I can't afford to pay for a GP or lawyer to discuss AHDs	• Information about AHDs is complicated and hard to understand • I don't know what treatments might exist in the future or what I might receive in the future	• It takes too long to complete an AHD • It takes too long to organise a witness • I'm don't want to use the computer to make an AHD • It's difficult to update an AHD • I don't feel that the process respects my culture • There are language barriers preventing me from making an AHD	• I'm unable to explicitly consent to the way my information will be used • I don't want to have to use my computer to submit my AHD	• I don't know if I have completed my AHD correctly	• I don't have anywhere secure to put my AHD • I want my privacy and confidentiality to be respected	• I want to make sure that only the right people can access my AHD when its needed	• I worry my AHD will be ignored • I don't receive the treatment that aligns with my values • I'm concerned that my wishes won't be respected when I lose capacity

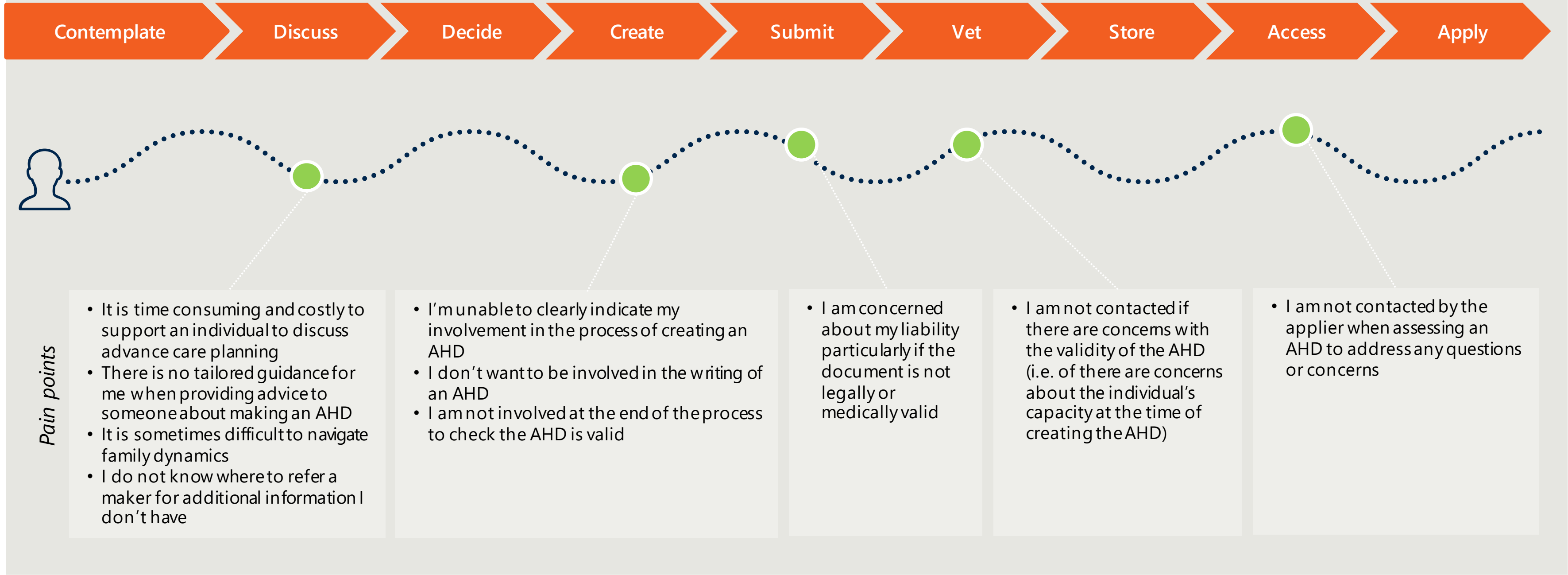
User journey for a **professional person supporting the maker of an AHD**

Contemplate → Discuss → Decide → Create → Submit → Vet → Store → Access → Apply



Action	• Support maker to consider their future care and understand what is important to them	• Advise on creating an AHD and possible contents in area of expertise	• Login to the Register or provide paper-based form • Complete or help to complete elements of the AHD in discussion with the maker • Provide advice relating to interpretation of medical or legal terminology • Witness the form if confident in capacity	• Assist to upload signed document to the Register	• Wait to receive outcome of vetting process • Support maker with any actions to validate AHD, if required • Make any relevant notes on Register
Ideal Experience	• I have sufficient time to discuss important issues with the individual • I can easily access information that I can provide to them that is easy to understand, articulates how and why to make an AHD, and encourages them to speak about their values/decisions with their family • I am appropriately remunerated for my time and expertise in providing support	• I can articulate the difference between different advanced care documents • I am confident in the maker's capacity • I can witness the document if I choose to	• I know where to look to confirm if the maker already has an AHD and what its contents are • I know that the maker understands the implications and content of what they have included in the AHD • I review a draft version of an AHD before it is submitted so I can make sure it is implementable (internally consistent, medically sound and legal) • I am aware of other advice the maker has received, including legal or medical • I provide only advice I am experienced in providing	• My advice and decision making is recorded in the Register • I feel comfortable acting as a witness • I feel comfortable using the Register through training	• I am informed of the outcome of the vetting process • If denied, there are clear and easy to understand instructions I can use to help the maker and resolve any issues • I don't have to wait too long to hear if the AHD has been re-assessed to see if its been accepted

Pain points along the user journey for a professional support person



- It is time consuming and costly to support an individual to discuss advance care planning
- There is no tailored guidance for me when providing advice to someone about making an AHD
- It is sometimes difficult to navigate family dynamics
- I do not know where to refer a maker for additional information I don't have

- I'm unable to clearly indicate my involvement in the process of creating an AHD
- I don't want to be involved in the writing of an AHD
- I am not involved at the end of the process to check the AHD is valid

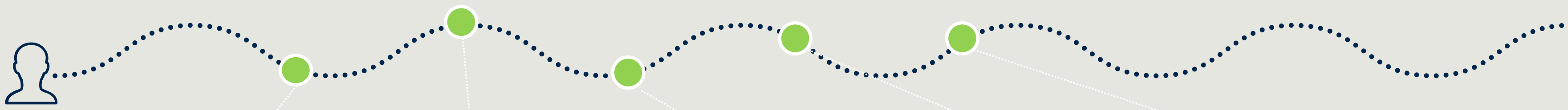
- I am concerned about my liability particularly if the document is not legally or medically valid

- I am not contacted if there are concerns with the validity of the AHD (i.e. of there are concerns about the individual's capacity at the time of creating the AHD)

- I am not contacted by the applier when assessing an AHD to address any questions or concerns

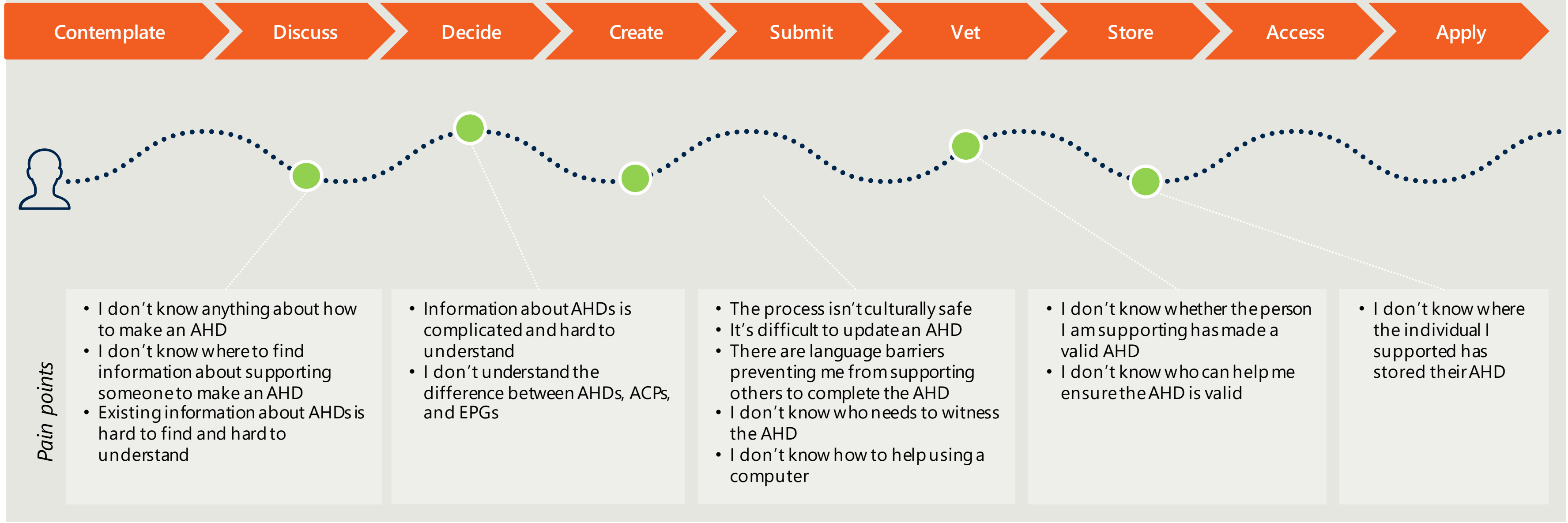
User journey for a non-professional support person

Contemplate → Discuss → Decide → Create → Submit → Vet → Store → Access → Apply



Action	• Talk to family or a friend about their future care, including making an AHD • Find out more about the AHD making process and what is included	• Help decide to create an AHD and what it may include	• Help to find the online Register or paper-based form • Support the maker in signing up for the Register • Support the maker to complete the form • Support the maker to sign and witness the form	• Assist to upload or submit a signed AHD to the Register	• Wait to receive outcome of vetting process • Support the maker with any actions to validate AHD, if required
Ideal Experience	• I understand what my role as a support maker is • I know where to find information about the AHD process to discuss with the maker • I can easily access information and materials that are easy to understand and in an appropriate language • I know who to ask if I have questions or the maker has questions	• I know the difference between different advanced care documents • I can help the maker discuss likely future treatments and their values	• I can easily interpret questions on the form and can explain them to another maker • I feel the process is culturally safe for myself and the maker that I am supporting so we can be honest • I can help complete the process in a reasonable amount of time • I have confidence the maker creating an AHD will receive care according to their intentions when the time comes • I understand what my obligations or responsibilities are in my role in supporting the maker • I understand my obligations if I choose to be a witness	• I am confident that the AHD meets legal requirements • I know the AHD is stored securely	• I am informed in a timely matter of the outcome of the vetting process • If denied, there are clear and easy to understand instructions I can use to help the maker and resolve any issues • I don't have to wait too long to hear if the AHD has been re-assessed to see if its been accepted

Pain points along the user journey for a non-professional support person



Contemplate | Discuss | Decide | Create | Submit | Vet | Store | Access | Apply

Pain points

- I don’t know anything about how to make an AHD
- I don’t know where to find information about supporting someone to make an AHD
- Existing information about AHDs is hard to find and hard to understand

- Information about AHDs is complicated and hard to understand
- I don’t understand the difference between AHDs, ACPs, and EPGs

- The process isn’t culturally safe
- It’s difficult to update an AHD
- There are language barriers preventing me from supporting others to complete the AHD
- I don’t know who needs to witness the AHD
- I don’t know how to help using a computer

- I don’t know whether the person I am supporting has made a valid AHD
- I don’t know who can help me ensure the AHD is valid

- I don’t know where the individual I supported has stored their AHD

User journey for a person accessing and enacting the AHD

Action	• Search Register for existence of a relevant AHD • Engage with and interpret contents of AHD as relevant to immediate treatment or treatment plan	• Decide on appropriate care plan taking into account AHD • Contact SDM if required • Discuss care plan with hierarchy of treatment decision makers if AHD does not consider current care • Deliver care • Update maker's medical records of decision and rationale
Ideal Experience	• I can quickly identify the existence of the AHD • I can quickly locate and retrieve the AHD • I know which AHD is the most relevant if there is more than one AHD stored • I can quickly and easily identify whether an AHD is valid • I can quickly and easily identify key information such as the presence of an EPG or SDM • I am confident that the AHD is internally consistent, legal and legible • I can easily interpret the contents of the AHD to make a treatment decision	• I can make the most appropriate clinical decision for the maker • I am confident that I have discharged my medical and legal obligations • If the AHD does not cover the treatment required, I can effectively engage with the person's guardian or enduring guardian, or if they have not been appointed or do not have authority to make treatment decisions, I can engage with the relevant person from the top of their hierarchy of treatment decision makers, as prescribed in the Guardianship and Administration Act 1990.

Pain points along the user journey for a person accessing and enacting the AHD

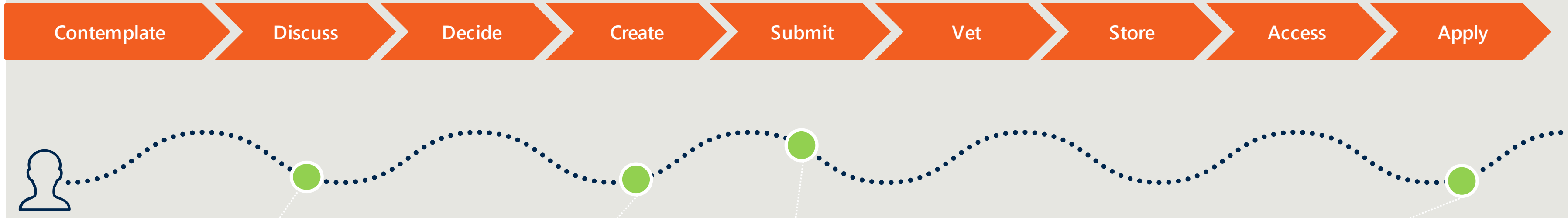
Pain points

- I don’t have time to go looking for an AHD if the individual didn’t already provide it to me
- The AHD can’t be interpreted quickly
- The AHD is not valid
- The AHD is dated and does not seem current

- The AHD provides conflicting advice about the individuals wishes
- I don’t understand what is written in the AHD
- I don’t know the AHD represents the wishes of the individual
- I don’t know the individual had capacity when making the AHD

User journey for a **Substitute Decision Maker**

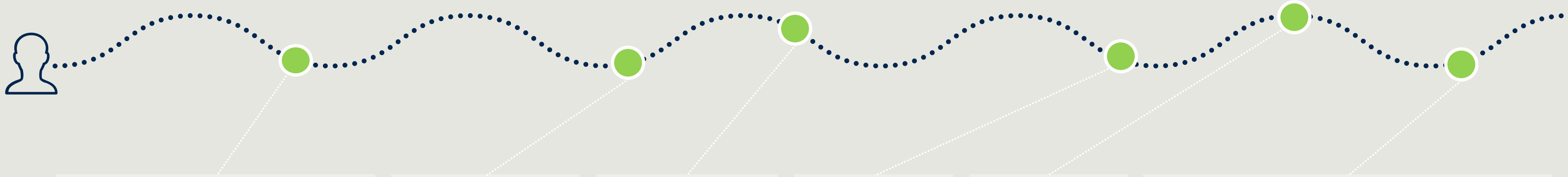
Contemplate → Discuss → Decide → Create → Submit → Vet → Store → Access → Apply



Action	• Have a discussion with the maker about their future care, including about my role as an SDM and what their expectations are	• Understand the specifics of the maker's AHD, including the values statement and quality of life preferences	• Have name and contact information submitted to Register • If I am an EPG, this is logged on Register	• Be contacted about the maker losing capacity and the need for treatment decisions • Discuss possible treatments and outcomes with treatment team to make informed decision • Decide and communicate a treatment decision • Have decision recorded on Register
Ideal Experience	• I understand my responsibilities as an SDM • I can consent to being an SDM • I can easily access information about responsibilities of an SDM that is clear and easy to understand • I know who I can contact for support advice on my role as an SDM • I understand what the AHD maker wants and what their best interests are	• I understand the rationale behind the maker's decisions and feel confident I can extrapolate their values if required • I am clearly identified in Register as an SDM • I can change my contact information on the Register easily	• I receive confirmation that an AHD has been submitted and accepted where I am the SDM	• I know which sections or versions of the maker's AHD which need to be taken into consideration in particular circumstances • I have been given clinical advice and confirmation that the maker no longer has capacity and I am able to make a decision on their behalf • I know other members on the hierarchy of decision makers are informed of my role as an SDM and what that entails (if appropriate) • I am reminded by the AHD Register of the AHD's existence and can easily change my details if they have changed

Pain points along the user journey for a **Substitute Decision Maker**

Contemplate → Discuss → Decide → Create → Submit → Vet → Store → Access → Apply



Pain points

- It's hard to find clear information about my responsibilities as an SDM
- I don't know who to talk to in order to find out more about my role as an SDM
- I don't know what my role is in relation to someone else's AHD

- The content of the AHD doesn't include a person's values and preferences – and so isn't useful to me as an SDM
- The AHD does not include the boundaries and parameters set out in the EPG

- There is no place to store an AHD and EPG so that it is accessible to those that need to access them
- I am not told when an AHD is executed by the individual

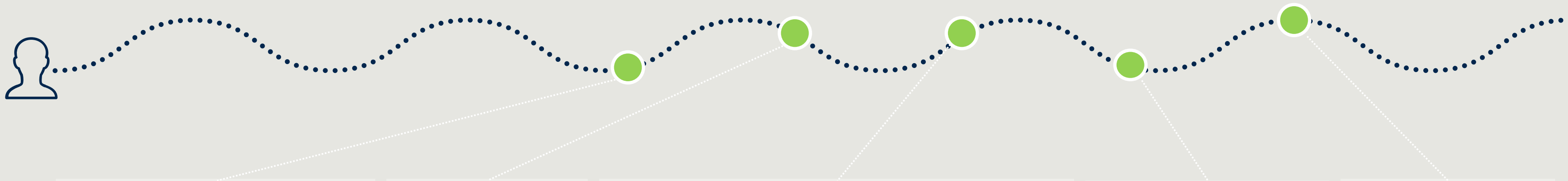
- An AHD and EPG are not stored in the same place, and so one or both may not be accessed when needed

- I may not know the individual I am the SDM for has an AHD, or where to find it (such as the public guardian)

- I am not given clear instructions on when to perform my role as an SDM
- The treating clinician does not understand my role as the SDM
- Family or friends may disagree with my decision as the SDM
- I am unsure how to remove my details from a maker's profile on the Register if I don't wish to be contacted in the future

User journey for a person or group providing oversight or administrative functions for the Register

Contemplate → Discuss → Decide → Create → Submit → Vet → Store → Access → Apply



Action	• Generate activity log on AHDs created	• Generate activity log on AHDs submitted	• Vet an AHD as per prescribed process • Notify a maker on the outcome of vetting and provide practical advice, if required • Generate activity log on AHDs vetted • Follow up on requests relating to vetting progress	• Manage access control to AHDs stored in the Register • Generate reporting on AHDs stored	• Generate activity log on AHDs accessed and requested access
Ideal Experience	• I can find out when a maker has commenced the process of creating an AHD, including their login information for troubleshooting if possible • I can easily generate a summary for reporting, auditing or analysis purposes	• I can find out when an AHD has been submitted to the Register for vetting, and by whom • I can easily generate a summary for reporting, auditing or analysis purposes	• I have a suitably qualified vetting team that can check the AHD for internal consistency, legality, and medical validity • I review an AHD form that is legible and doesn't take too long to review • I can find out the progress of AHDs through the vetting progress and the final outcomes • I am able to prioritise vetting requests based on individual circumstances • I can easily generate a summary for reporting, auditing or analysis purposes	• I can find out the number of AHDs stored in the Register at a point in time • I can easily generate a summary for reporting, auditing or analysis purposes	• I can find out when an AHD has been accessed, and by whom • I can grant access to specific personnel upon request (e.g. Office of Public Advocate) • I can easily generate a summary for reporting, auditing or analysis purposes

Pain points for a person or group providing oversight or administrative functions for the Register

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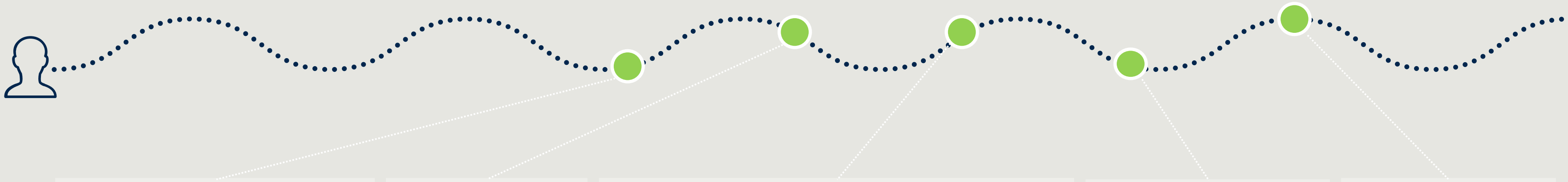

Pain points

- AHDs are not currently digitally stored or tracked

- AHDs are not currently digitally stored or tracked

- AHDs do not currently go through any independent vetting process

- AHDs are not currently digitally stored or tracked

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Appendix F Detailed process maps

Provided over page