

A nationally consistent scheme for access to digital records upon death or loss of decisionmaking capacity

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Submitted to:

The NSW Department of Communities and Justice policy@justice.nsw.gov.au

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1. Introduction

Lived Experience Australia (LEA) is a national representative organisation for Australian mental health consumers and carers, formed in 2002 with a focus on the private sector, and recognised by government as the mental health lived experience peak for consumers who use the private sector.

Our core business is to advocate for systemic change to improve mental health care across the whole Australian health system. This includes input to important initiatives within state and territory jurisdictions, from time to time, as they relate to mental health communities. It includes advocating for empowerment of consumers in their own care, promoting engagement and inclusion of consumers and carers within system design, planning and evaluation and most importantly, advocating for consumer choice and family and carer inclusion and wellbeing in the broader community.

We welcome the opportunity to provide our responses to the Consultation Paper that has been prepared for the NSW Department of Communities and Justice which is leading this interjurisdictional work program, endorsed by the Meeting of Attorneys-General (MAG), to develop a nationally consistent scheme to access to digital records upon death or loss of decision-making capacity.

Our Submission comes from the perspectives and experiences of people with lived experience of mental health challenges, their families, and carers. Our responses are provided in the template below.

2. Contact

We thank the NSW Department of Communities and Justice for this work and wish you every success with the next steps in its development. We would be keen to discuss further, any clarification or issues raised with you.

Please contact us on:

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Stakeholder feedback questions

Stakeholders are invited to provide feedback on the recommendations made by the NSWLRC in *Report 147 – Access to digital records upon death or incapacity* and related issues using the table below. Where appropriate, the questions seek feedback on how such recommendations could or should operate if there was to be a nationally consistent scheme.

Consultation question	Relevant NSWLRC recommendation	Comment
A statutory scheme for access		
 Should Australian jurisdictions introduce a statutory scheme that enables an authorised person to access a deceased or incapacitated person's digital records in limited circumstances? In particular: (a) What, if any, legislative and non-legislative options currently facilitate access to such records? (b) What other legislative or non-legislative options might be available as an alternative to the scheme recommended by the NSWLRC? (c) Should a scheme apply equally to records of deceased people and people who have lost decision-making capacity? (d) How might a nationally consistent scheme be achieved (for example, a Commonwealth scheme; enactment of uniform state and territory laws or adopting agreed national principles)? 	2.1: A statutory scheme for NSW NSW should enact a statutory scheme that enables an authorised person to access a deceased or incapacitated person's digital records in limited circumstances.	We agree that a statutory scheme would offer a high level of protections and accountabilities, to ensure the proper conduct or authorized persons with regard to access to the person's digital records. We are unsure whether such a scheme should apply equally to records of deceased people and people who have lost decision-making capacity. However, we believe that there may well be circumstances and potential consequences unique to each scenario, particularly as options that are then enacted during a period of temporary loss of decision-making capacity (eg. Due to extended hospitalization as a result of a significant physical trauma) might understandability require added considerations for if and when the person emerges from that state and circumstance. Proof that the person is deceased would also likely be determined through existing formal processes, though this may be complicated by mental health challenges. For example, each year in Australia, there are individuals who become unwell, homeless and lose contact with their family and friends. This can include people from all 'walks of life'; it can involve significant trauma, and it may involve issues of abuse and other circumstances. Where a person may have mental health challenges and, for whatever reason, may have 'disappeared', there are likely to be other requirements to consider regarding who the most appropriate

Scope and key terms		authorized person will be and to enable an authorized person to access the person's digital records. We do not have a set view regarding a preference for uniform laws or adopting national principles. Of importance, is that the system adopted has minimal burden on families and kin of the person and does not get bogged down in its interpretation across jurisdictions. Uniform State and Territory laws are likely to provide the most consistent approach. We do not believe that there should be a varied approach to this issue, especially given people and their networks and digital activities may cross jurisdictional borders.
2. Should a nationally consistent scheme apply to a custodian, regardless of where the custodian is located, if the user is domiciled in an Australian jurisdiction or was domiciled in an Australian jurisdiction at the time of their death?		Yes. We believe there are core moral, ethical and legal principles and codes of conduct that should apply to custodians regardless of where they are located.
Consultation question	Relevant NSWLRC recommendation	Comment
3. How would a scheme regulate access to joint user accounts where one person is domiciled in Australia and the other overseas? Output Description:		Where possible, we believe that there should be equity in access regardless of where the person is domiciled. There may be significant reasons why the persons are domiciled in different places (eg. Family ties, access to support networks, kin and cultural networks, family violence, etc). A clear understanding of why this is the case may well help to determine how to proceed. Risks of misuse may be greater where the person is located overseas given Australian authorities are more likely to have greater and more timely access to information about persons located in Australia. Effective communication with overseas authorities such as banks and relevant bodies would be important.

- Please comment on the key terms of the statutory scheme recommended by the NSWLRC. In particular, stakeholder comment is invited on:
 - The proposed scope of the scheme, including the scope of the definitions of 'digital record' and 'custodian' (noting that this definition would include records held by both private entities and government entities).
 - Whether the definition of 'digital record' is sufficiently technology neutral to enable new or emerging technologies to be covered by the scheme.
 - Whether any records should be excluded from the scope of the scheme.

3.2: Key terms of the statutory scheme

The scheme should include the following definitions:

- (1) "Authorised person" means the person with the right, under this scheme, to access particular digital records of the user.
- (2) "Custodian" means a person or service that has, or had at the time of the user's death, a service agreement with the user to store or maintain particular digital records of the user.
- (3) "Custodian policy" means a statement of policy by the custodian, not otherwise incorporated in a service agreement, which relates to the digital records of the user stored or maintained by that custodian, and applies whether or not the user is alive or has capacity.
- (4) "Digital record" means a record that:
 - (a) exists in digital or other electronic machine-readable form, and
 - (i) was created by or on behalf of the user, in whole or in part, or
 - (ii) relates to the user, and the user had access to it while the user was alive. or
 - (iii) relates to the user, and their representative had access to it during any period of incapacity, but

The key terms appear to be clear and unambiguous.

- (b) does not include an underlying asset (such as money in a bank account or the copyright in a literary work) or liability, unless the asset or liability is itself a digital record.
- (5) "Incapacitated user" means an adult user who requires or chooses to have assistance with decision-making in relation to particular digital records of the user.
- (6) "Online tool" means a tool provided by a custodian online that allows the user to give directions or permissions to a third party for managing the digital records of the user stored or maintained by that custodian.
- (7) "Service agreement" means an agreement between a user and a custodian that relates to the digital records of the user stored or maintained by that custodian.
- (8) "User" means a natural person who has entered into a service agreement with a custodian to store or maintain particular digital records of the user.

The authorised person and the extent of their access

5. Would the statutory hierarchy of authorised persons entitled to access digital records of both a 'deceased user' and 'incapacitated user', as recommended by the NSWLRC, be appropriate for a nationally consistent scheme? What, if any, changes are necessary? For example, should the hierarchy allow for more than one authorised person? How should conflict between different authorised persons be addressed under the scheme?

4.1: Authorised person entitled to access a user's digital records

The scheme should provide that:

- (1) The authorised person entitled to access particular digital records of a deceased user is:
 - (a) the person specifically appointed by the user's will to manage those digital records:
 - (i) in the case of a formal will, whether or not there has been a grant of representation of the will. or
 - (ii) in the case of an informal will, only if there has been a grant of representation
 - (b) if there is no person specifically appointed by the user's will to manage those digital records, the person

We know that families can be complex, and members can have complicated relationships with each other that may be longstanding or may arise in the context of the person becoming incapacitated or upon their death. Whilst having more than one authorized person may seem like a straightforward solution to any potential family conflict or disagreement, on the assumption that individuals will come together to make decisions that all are happy with, this is not always the case. Even in families where they may not have been apparent division of conflict, we know that a change in circumstances such as death or incapacity) can bring a range of unhelpful and sometimes unpredicted emotions to the surface.

In an ideal world, the person would be best placed to nominate who they would want as their nominated person whilst they have capacity – similar to the process of appointing executors and power of attorney processes regarding wills.

The relevant layers, as described in the Recommendation column here appear to provide sufficient clarity about 'who and how' according to each potential scenario pertaining to the person and their circumstances.

- nominated through an online tool to manage those records
- (c) if there is no person specifically appointed by the user's will or nominated through an online tool to manage those digital records, the executor of the user's will:
 - (i) in the case of a formal will, whether or not there has been a grant of representation of the will. or
 - (ii) in the case of an informal will, only if there has been a grant of representation
 - (d) if there is no will or no executor willing or able to act, and no person nominated through an online tool to manage those digital records, the administrator of the user's estate
 - (e) if no provision or order has been made, a person to whom the deceased user has communicated the access information for those digital records, but not where that person holds the access information as part of an employment or other contractual relationship involving remuneration for the activity, unless the user has indicated that the arrangement is to have effect after their death.

- (2) The authorised person entitled to access particular digital records of an incapacitated user is:(a) any person appointed under:
 - (i) an enduring guardianship arrangement that has effect, or
 - (ii) an enduring power of attorney that has effect,

but only in relation to those records that are:

- (iii) specified in the enduring guardianship arrangement or enduring power of attorney, or
- (iv) otherwise relevant to the person's role either as enduring guardian or attorney
- (b) if there is no person appointed under an enduring guardianship or enduring power of attorney, any person appointed under:
 - (i) a guardianship order, or
 - (ii) a financial management order,

but only in relation to those records that are:

Consultation question	Relevant NSWLRC recommendation	Comment
	(iii) specified in the guardianship order or financial management order, or	
	(iv) otherwise relevant to the person's role as guardian or financial manager	
	(c) if there is no person appointed under an enduring guardianship, enduring power of attorney, guardianship order or financial management order, the person nominated through an online tool to manage those digital records	
	(d) if no provision or order has been made, the person with access information for those digital records, either because:	
	(i) the incapacitated user has communicated the access information for those digital records to the person, or	
	(ii) the person created those digital records on the incapacitated user's behalf	
	but not where the person holds the access information as part of an employment or other contractual relationship involving remuneration for the activity, unless that relationship is a paid carer relationship.	

6. If there were to be a nationally consistent scheme governing access to digital records on death or loss of decision-making capacity, what should be the appropriate	4.2: A person can apply to the Supreme Court of NSW for an order that they are the authorised person	
Consultation question	Relevant NSWLRC recommendation	Comment
forum for a person to apply for an order that they are the authorised person?	The scheme should provide that a person can apply to the Supreme Court of NSW for an order that they are the authorised person entitled to access particular digital records of the deceased or incapacitated user under Recommendation 4.1.	We agree that this option seems sound. Our main concern would be that there is adequate informational, practical and financial support for the person to make this application, that it is not so burdensome that it creates unnecessary distress and burden, particularly where the authorized person may themselves experience social, literacy, and other challenges in understanding and navigating complicated bureaucracies. They may because they are themselves managing a disability, have literacy concerns, are elderly, do not have English as their first language, etc. Where the person may have been a parent with enduring mental health issues and were 'cared for' by their child who is still under 18 years and without other family, there may need to be some particular consideration of support provision to the young person. Young carers are stoic and often quite isolated, and can fall through gaps in support once the adult dies or loses capacity. If an authorized person is appointed outside the family in this circumstance, we would hope that they respect and work closely with the young carer.

- 7. Would the extent of the authorised person's access right, as recommended by the NSWLRC, be appropriate for a nationally consistent scheme? What, if any, changes are necessary? For example, are further safeguards required to ensure that access is provided only to those limited records which are strictly necessary? What safeguards are required to protect the rights and interests of the deceased person or adult with impaired capacity?
- 8. To what extent should a nationally consistent scheme prescribe how an authorised person should be able to deal with the digital records of a deceased person or person who has lost decision-making capacity?

4.3: Extent of the authorised person's access right

The scheme should provide that:

- (1) For the purposes of determining the extent of the authorised person's right:
 - (a) "administering the deceased user's estate" includes informal administration of the deceased user's estate
 - (b) "managing the incapacitated user's affairs" includes informal management of the incapacitated user's affairs, and
 - (c) "deal" or "dealing" includes transferring digital records to the person entitled to them, but does not include editing the content of digital records.
- (2) The authorised person entitled to access particular digital records of a deceased user may access and deal with those digital records:
 - (a) subject to applicable fiduciary duties, and
 - (b) subject to other applicable laws, and
 - (c) subject to any terms of the following, as applicable:
 - (iii) the will (even where the authorised person is not the person named in the will), or
 - (iv) the online tool, or
 - (d) if there are no such terms, only for the

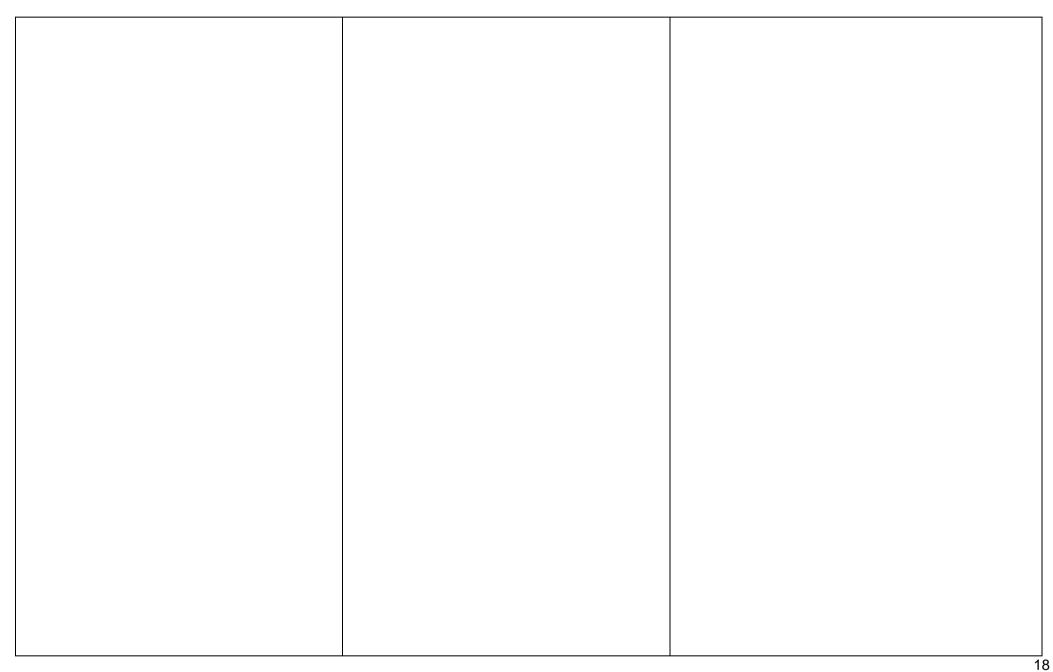
We know that assessments of capacity and incapacity are fraught and not as straightforward as is often assumed, particularly for people with mental health diagnoses. Stigma and discrimination is a significant concern and has shaped many adverse responses within the mental health sector and outside of it towards people with mental health challenges. In our field, supported decision-making and viewing people from a Strengths perspective is an important human rights issue. A person may have incapacity in many aspects of life but they may still exercise capacity in some aspects such as who they trust, where they live, who they live with, what they eat, who they vote for, what they wear each day, etc. Incapacity does not preclude individuals from having their preferences and basic rights to choose removed.

purpose of administering the deceased user's estate.	

- (3) If the authorised person entitled to access particular digital records of a deceased user also has authority over the user's tangible personal property that is capable of holding, maintaining, receiving, storing, processing or transmitting a digital record, they are authorised to access and deal with the property and digital records of the user stored on it:
 - (a) subject to applicable fiduciary duties, and
 - (b) subject to applicable laws, and
 - (c) subject to the terms of the following, as applicable:
 - (i) the will (even where the authorised person is not the person named in the will), or
 - (ii) the online tool, or
 - (d) if there are no such terms, only for the purpose of administering the deceased user's estate.
- (4) The authorised person entitled to access particular digital records of an incapacitated user may access and deal with those digital records:
 - (a) subject to applicable fiduciary duties, and
 - (b) subject to applicable laws, and
 - (c) subject to the terms of the following, as

applicable:	

- a. the online tool, or
- b. an enduring guardianship or enduring power of attorney, which has effect, or
- c. the guardianship or financial management order, or
- (d) if there are no such terms, only for the purpose of managing the incapacitated user's affairs
- (5) If the authorised person entitled to access particular digital records of an incapacitated user also has authority over the user's tangible personal property that is capable of holding, maintaining, receiving, storing, processing or transmitting a digital record, they are authorised to access and deal with the property and digital records of the user stored on it:
 - (a) subject to applicable fiduciary duties, and
 - (b) subject to applicable laws, and
 - (c) subject to the terms of the following, as applicable:
 - (i) the online tool, or
 - (ii) the enduring guardianship or enduring power of attorney, which has effect, or
 - (iii) the guardianship or financial management order, or



Consultation question	Relevant NSWLRC recommendation	Comment
	 (d) if there are no such terms, only for the purpose of managing the incapacitated user's affairs. In all such cases, the authorised person is deemed to have the consent of the deceased or incapacitated user for the custodian to disclose the content of the digital records to the authorised person. 	
9. Are the other obligations of the authorised person as recommended by the NSWLRC appropriate for a nationally consistent scheme? What, if any, changes are necessary?	4.4: Other obligations of the authorised person The scheme should provide that: (1) Where the authorised person entitled to access particular digital records of a deceased user is not the executor or the administrator of the user's estate, they must do all things reasonably necessary to provide relevant information to the executor or administrator for the purposes of administering the user's estate.	Yes
	(2) Where the authorised person entitled to access particular digital records of an incapacitated user is not appointed under:	
	(a) an enduring guardianship, or	
	(b) an enduring power of attorney, or	
	(c) a guardianship order, or	
	(d) under a financial management order,	
	they must do all things reasonably necessary to	

	provide relevant information to a person so appointed for the purpose of managing the user's affairs.	
Consultation question	Relevant NSWLRC recommendation	Comment

4.5: Improper disclosure of information

The scheme should provide that:

- (1) It is an offence for an authorised person entitled to access particular digital records of the deceased user to disclose information about the deceased user, or another person, obtained in accessing those records, unless the disclosure is:
 - (a) in accordance with the relevant instrument or order appointing the authorised person
 - (b) for the purpose of administering the deceased user's estate
 - (c) necessary for legal proceedings
 - (d) authorised by law
 - (e) authorised by a court or tribunal in the interests of justice, or
 - (f) disclosed to authorities as necessary to prevent serious risk to life, health or safety or to report a suspected serious indictable offence.
- (2) It is an offence for an authorised person entitled to access particular digital records of the incapacitated user to disclose information about the deceased user, or another person, obtained in accessing those records, unless the disclosure is:
 - (a) in accordance with the relevant instrument or order appointing the authorised person

 (b) for the purpose of managing the incapacitated user's affairs (c) necessary for legal proceedings authorised by law (d) authorised by a court or tribunal in the interests of justice, or (e) disclosed to authorities as necessary to prevent serious risk to life, health or safety or to report a suspected serious indictable offence. 	

Access procedures, liability limits and conflicting terms in custodian agreements and policies

11. Are the procedural requirements for access requests as recommended by the NSWLRC appropriate for a nationally consistent scheme? What, if any, changes are necessary? For example, what consequences, if any, should there be for failure to provide access within the prescribed timeframe?

5.1: Procedural requirements for access requests

The scheme should provide that:

- (1) The authorised person entitled to access particular digital records of a deceased or incapacitated user may request access to those records stored or maintained by a custodian by contacting the custodian and providing proof of their authority.
- (2) In relation to a deceased user's digital records, the authorised person will prove their authority by providing the custodian with a copy of the following, as applicable:
 - (a) proof of the user's death
 - (b) the formal will
 - (c) in the case of a formal will that has not been proved, a statutory declaration establishing that the will is the user's last valid will
 - (d) the grant of representation
 - (e) proof of the authorised person's identity
- (3) In relation to an incapacitated user's digital records, the authorised person will prove their authority by providing the custodian with a copy of the following, as applicable:
 - (a) the enduring guardianship or enduring power of attorney
 - (b) the guardianship or financial management order

Yes, we believe these requirements are appropriate and sufficient

Consultation question	Relevant NSWLRC recommendation	Comment
	(c) proof of the authorised person's identity.	
	(4) For the purposes of Recommendation 5.1(2) and 5.1(3), a "copy" includes a copy in digital or other electronic machine-readable form.	
	(5) If, and only if, the authorised person is unable to provide proof of authority in accordance with Recommendation 5.1(2) or 5.1(3), authority will be proved by an order from the Supreme Court of NSW that states that they are the authorised person.	
	(6) A custodian may choose not to require the particular proof of authority set out in Recommendation 5.1(2) or 5.1(3). If the custodian chooses to require proof of authority, the custodian can only require a Supreme Court order where the authorised person does not provide proof in accordance with Recommendation 5.1(2) or 5.1(3).	
	(7) A custodian who receives a request from an authorised person, in accordance with Recommendation 5.1, must provide access to the authorised person within 30 days of receipt of the request, unless the custodian can show that access is not technically feasible.	

12. Should a nationally consistent scheme protect custodians from liability for acts or omissions done in good faith in compliance with the scheme?	5.2: Protecting custodians from liability The scheme should protect custodians from liability for acts or omissions done in good faith to comply with the scheme.	Yes, so long as they then comply with the scheme and not leave the person's family, kin of significant others in limbo. Ie. resolution is important because navigating bureaucratic layers can be frustrating at least and traumatizing at worst for some individuals.
Consultation question	Relevant NSWLRC recommendation	Comment
 13. Should a nationally consistent scheme protect persons who purport to act as an authorised person and in good faith? 14. What amendments to criminal laws would be needed to enable a nationally consistent scheme? 	5.3: Protecting the authorised person from liability The scheme should provide that: (1) A person who: (a) purports to act as an authorised person under the scheme, and (b) does so in good faith, and without knowing that another person is entitled to be the authorised person in accordance with the scheme, is not liable for so acting. For the purposes of s 308H of the Crimes Act 1900 (NSW), access to or modification of restricted data held in a computer is authorised if it is done in accordance with the scheme.	Yes, though there should be clear checks and processes established for that person to demonstrate that they had acted in good faith.

15. Are the NSWLRC recommendations in relation to conflicting provisions in custodian service agreements and policies appropriate for a nationally consistent scheme? What, if any changes are necessary?	 5.4: Conflicting provisions in service agreements and policies The scheme should provide that: (1) Despite any other applicable law or a choice of law provision in a relevant service agreement or custodian policy, a provision in that service agreement or custodian policy that limits the authorised person's access to particular digital records of the deceased or incapacitated user, contrary to the scheme, is unenforceable. Despite any provision, including a choice of law provision, in a relevant service agreement or custodian policy, the authorised person's 	Policies and agreements are notoriously difficult for many people to fully understand. We know this from the nature of information about insurance, for example, that is often convoluted and other paperwork that is not user friendly. We would hope that any such information about service agreements and policies is understandable to the widest range of community members as possible. We also have concern about the general digital literacy of the community, particularly groups that may experience more marginalization and disadvantage in their access to knowledge and digital technology.
Consultation question	Relevant NSWLRC recommendation	Comment
16. What should be the proper forum to resolve disputes in a nationally consistent scheme?	access to particular digital records of a deceased or incapacitated user, in accordance with the scheme, does not require the consent of the custodian and is not a violation or breach of any provision of the service agreement or relevant custodian policy. 5.5: NSW as the proper forum for disputes	We agree with this recommendation, though would hope that a mediation-type process or similar that is
	The scheme should provide that, despite any forum selection term in the relevant service agreement, the courts of NSW with the relevant jurisdiction are the proper forum for disputes concerning the access to particular digital records of a deceased or incapacitated user, where the user is domiciled in NSW or was domiciled in NSW at the time of their death.	more humane and user-friendly, and less adversarial, is available.
Changes to existing laws and other issues related to the scheme		

17. What changes to succession and estate laws, and assisted decision-making laws in Australian jurisdictions would be necessary or desirable in association with a nationally consistent scheme?	 6.1: Clarify that NSW succession and estate laws, and assisted decision-making laws, extend to property in digital form (1) The definition of "property" in s 3 of the Succession Act 2006 (NSW) should be amended to include "property in digital or other electronic machine-readable form". (2) The definition of "personal estate" in s 3 of the Probate and Administration Act 1898 (NSW) should be amended to include "property in digital or other electronic machine-readable form". (3) The definition of "property" in s 3(1) of the Powers of Attorney Act 2003 (NSW) should 	We agree with these suggested changes.
Consultation question	Relevant NSWLRC recommendation	Comment
	be amended to include "property in digital or other electronic machine-readable form".	
18. What changes to privacy laws in Australian jurisdictions would be necessary or desirable in association with a nationally consistent scheme?19. What other legislative amendments would be required to allow lawful access to digital records subject to an access scheme?	6.2: Amendments to NSW privacy laws to allow for the operation of the scheme Amendments should be made to NSW privacy laws about accessing and managing personal information, to allow for the operation of the scheme.	We agree with these suggested changes.

20. What educational programs and materials would be appropriate for a nationally consistent scheme, and what institutions and organisations are best placed to provide these? 21. What information should custodians be	6.3: Education about digital records and their management Institutions and organisations already educating the community and legal practitioners about succession law, administration of estates, and assisted decision-making laws, should incorporate into their education programs information about digital records, and how they can be managed following a person's death or incapacity. 6.4: Custodian procedures for access	We agree strongly with this recommendation. We stress that such education should be accessible and in a format that is understandable to the widest possible community of people, regardless of their levels of literacy and digital literacy. As stated above, this should be in language that is
required to make available about how access requests are handled under a nationally consistent scheme? Crypto accets	requests Custodians should have transparent processes for handling access requests.	clearly understood by lay individuals.
Crypto assets		
Consultation question	Relevant NSWLRC recommendation	Comment
22. Should crypto assets such as Bitcoin and NFTs be considered digital records under the NSWLRC Scheme? If so, would the proposed definition of digital assets need to be revised to accommodate this?		We have no comments to make regarding Bitcoin assets.

23. Would the NSWLRC Scheme enable access to the crypto assets of a deceased or person who has lost decision-making	
···	
or person who has lost decision-making	
capacity? Is there an identifiable custodian	
who may provide access to an authorised	
person as proposed under the scheme?	
24. If not, what other models or schemes can	
be applicable to enable an authorised	
person to access a deceased person or	
person who has lost decision-making	
capacity's crypto assets?	
25. Would the extent of the authorised person's	
access right, as recommended by the	
NSWLRC, be appropriate for crypto assets?	
What other safeguards and limitations	
should be imposed on an authorised	
person's access to crypto assets?	
26. Are there other issues regarding accessing	
crypto assets should be considered?	
Other comments	

Consultation question	Relevant NSWLRC recommendation	Comment
27. What, if any, other considerations are relevant to assessing options for a nationally consistent scheme for access to digital records? For example, what human rights considerations (including privacy) are relevant to considering a digital records access scheme?		
28. Stakeholders are invited to provide case studies or examples of current approaches to accessing digital records on death or loss of decision-making ability, as well as an assessment of their adequacy.		