

## APPENDIX 12: Privacy obligations regulating the use & disclosure of health information

Organisations and applicable privacy law	Use & Disclosure Privacy principle(s)	Possible lawful pathways for the use or disclosure of health information
<p><i>Privacy Act 1988</i> (Cth)</p> <p>Commonwealth government agencies</p> <p>Private sector organisations (including private universities; private sector health organisations), with some exemptions</p> <p>Non-government organisations</p>	<p>APP 6</p> <p>(Cth)</p>	<p>Organisations can only use or disclose health information for limited purposes, including:</p> <ul style="list-style-type: none"> <li>• for the primary purpose it was collected (APP 6.1), or</li> <li>• <b>for a directly related secondary purpose within the patient's reasonable expectations (APP 6.2(a)(i))</b>, or</li> <li>• with the individual's consent (APP 6.1(a)), or</li> <li>• if the use or disclosure is required or authorised under another law (APP 6.2(b)), or</li> <li>• where the use or disclosure is necessary for research, or the compilation or analysis of statistics, relevant to public health or public safety (s 16B(3)), and: <ul style="list-style-type: none"> <li>○ it is impracticable to obtain the individual's consent to the use or disclosure</li> <li>○ the use or disclosure is conducted in accordance with NHMRC's guidelines issued and approved under s 95A of the Privacy Act<sup>64</sup> (which may require HREC approval), and</li> <li>○ in the case of a disclosure, the organisation reasonably believes that the recipient of the information will not disclose the information (or personal information derived from the information), or</li> </ul> </li> </ul>

<sup>64</sup> See: <https://www.nhmrc.gov.au/about-us/publications/guidelines-approved-under-section-95a-privacy-act-1988>

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		<ul style="list-style-type: none"> <li>• where the Privacy Commissioner makes a Public Interest Determination (PID) that provides the organisation is not required to comply with the privacy principle requirements that usually apply (Part VI, Div 1), or</li> <li>• where another exemption applies.</li> </ul>
<p><i>Health Records (Privacy and Access) Act 1997 (ACT)</i></p> <p>ACT government agencies (including ACT public universities)</p> <p>Public and private health organisations in the ACT</p>	<p>PP 9, PP 10 (ACT)</p>	<p>Organisations in the ACT can only <u>use</u> health information in limited circumstances, including:</p> <ul style="list-style-type: none"> <li>• for the primary purpose it was collected (PP 9(1)), or</li> <li>• where the information is being shared between members of the individual's treating team for health treatment purposes (PP 9(1)), or</li> <li>• where the individual has consented to the use (PP 9(1)(a)), or</li> <li>• where the use is required or authorised under another law (PP 9(1)(c)), or</li> <li>• <b>where purpose for the use is directly related to the primary purpose of collection (PP 9(1)(d)), or</b></li> <li>• the use of the information is related to the management, funding or quality of the health service received by the individual (PP 9(1)(e)), or</li> <li>• where another exemption applies.</li> </ul> <p>Where health information will be used for the management, funding or quality of the health service received by the individual, there is no obligation for the treating team leader to notify the individual about the identity of persons, or of classes of persons, who will handle their information for this purpose (PP 9(3)).</p> <p>Organisations in the ACT can only <u>disclose</u> health information to another entity in limited circumstances, including:</p> <ul style="list-style-type: none"> <li>• where the information is being shared between members of the individual's treating team for health treatment purposes (PP 10(2)(a)), or</li> </ul>

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		<ul style="list-style-type: none"> <li>• where the individual is reasonably likely to have been made aware that their information will be disclosed to the particular entity (PP 10(2)(b)), or</li> <li>• with the individual's written and signed consent (PP 10(2)(c) &amp; PP 10(7)), or</li> <li>• the disclosure is required or authorised under another law (PP 10(2)(e), or</li> <li>• where the disclosure of the information is necessary for the management, funding or quality of the health service received, or being received, by the individual (PP 10(2)(f)), or</li> <li>• where the disclosure is necessary for the purpose of research or the compilation or analysis of statistics, in the public interest (PP 10(3)), and: <ul style="list-style-type: none"> <li>○ it is impracticable to seek the individual's consent before disclosure, and</li> <li>○ the purpose of the research or the compilation or analysis of statistics cannot be achieved by disclosing de-identified data, and</li> <li>○ the receiving entity is required: <ul style="list-style-type: none"> <li>▪ to protect the health information it receives to at least the same standard set out under the HRP Act (ACT) and that prevents any further disclosure, and</li> <li>▪ to take reasonable steps to de-identify or destroy the health information at the earliest possible opportunity, and</li> <li>▪ to ensure that identifiable health information is not made publicly available, and</li> </ul> </li> <li>○ the disclosure is made in accordance with any relevant guidelines issued under the HRP Act (which may require HREC approval), or</li> </ul> </li> <li>• where another exemption applies.</li> </ul>

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		Where the disclosure of health information is allowed under any of these exceptions, the recipient entity must not use or disclose the information for a purpose other than the purpose for which the information was provided (PP 10(8)).
<p><i>Health Records and Information Privacy Act 2002 (NSW)</i></p> <p>NSW government agencies (including NSW public universities)</p> <p>Public and private health organisations in NSW</p>	<p>HPP 10, HPP 11, HPP 14</p> <p>(NSW)</p>	<p>Organisations in NSW can only use or disclose health information in limited circumstances, including:</p> <ul style="list-style-type: none"> <li>• for the primary purpose it was collected (HPP 10(1); (HPP 11(1)), or</li> <li>• with the individual's consent (HPP 10(1)(a); HPP 11(1)(a)), or</li> <li>• <b>for a directly related secondary purpose within the individual's reasonable expectations (HPP 10(1)(b); HPP 11(1)(b)), or</b></li> <li>• if the use or disclosure is required or authorised under another law (HPP 10(2); HPP 11(2)), or</li> <li>• for the funding, management, planning or evaluation of health services (HPP 10(1)(d); HPP 11(1)(d)), and <ul style="list-style-type: none"> <li>○ either this purpose cannot be achieved with de-identified data <i>and</i> it is impracticable to seek the individual's consent for the use or disclosure OR reasonable steps have been taken to de-identify the information, and</li> <li>○ identifiable health information will not be published in a generally available publication, and</li> <li>○ the use or disclosure is in accordance with NSW Privacy Commissioner's statutory guidelines on the management of health services (which may require HREC approval),<sup>65</sup> or</li> </ul> </li> <li>• for research, or the compilation or analysis of statistics, in the public interest (HPP 10(1)(f); HPP 11(1)(f)) and:</li> </ul>

<sup>65</sup> See: [https://www.ipc.nsw.gov.au/sites/default/files/file\\_manager/statutory\\_guidelines\\_health\\_issue\\_management.pdf](https://www.ipc.nsw.gov.au/sites/default/files/file_manager/statutory_guidelines_health_issue_management.pdf)

Organisations and applicable privacy law	Use & Disclosure Privacy principle(s)	Possible lawful pathways for the use or disclosure of health information
		<ul style="list-style-type: none"> <li>○ either this purpose cannot be achieved with de-identified data, and it is impracticable to seek the individual's consent for the use, or disclosure OR reasonable steps have been taken to de-identify the information, and</li> <li>○ identifiable health information will not be published in a generally available publication, and</li> <li>○ the use or disclosure is in accordance with NSW Privacy Commissioner's statutory guidelines on research (which may require HREC approval), or</li> <li>• where a Health Privacy Code (prepared in consultation with the NSW Privacy Commissioner and approved by the NSW Health Minister) modifies the HPPs to authorise the use or disclosure of health information by organisations in the circumstances (or otherwise provides an exemption from compliance with the HPPs) (ss 38 – 40), or</li> <li>• where the NSW Privacy Commissioner makes a Public Interest Direction (PID) that provides organisations are not required to comply with the HPPs in the circumstances (s 62), or</li> </ul> <p>where another exemption applies.</p> <p>In addition to the above requirements, organisations are not permitted to transfer health information outside of NSW or to a Commonwealth agency unless:</p> <ul style="list-style-type: none"> <li>• they reasonably believe the recipient of the information is subject to a law, scheme or contract that provide substantially similar privacy protection to the HPPs (HPP 14(a)), or</li> <li>• the individual consents to the transfer (HPP 14(b)), or</li> <li>• the transfer is necessary for the performance of a contract that is in the interest of the patient, between the organisation and the recipient (HPP 14(d)), or</li> </ul>

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		<ul style="list-style-type: none"> <li>the transfer is for the benefit of the individual <u>and</u> it is impracticable to obtain the individual's consent <u>and</u> if it were practicable, the individual would likely give their consent (HPP 14(e)), or</li> <li>the organisation has taken reasonable steps to ensure the health information being transferred outside of NSW or to a Commonwealth agency will not be held, used or disclosed by the recipient inconsistently with the HPPs (HPP 14(g)), or</li> </ul> <p>the transfer is authorised or required by another law (HPP 14(h)).</p>
<p><i>Information Act 2002</i> (NT)</p> <p>NT government agencies (including NT public universities)</p>	<p>IPP 2, IPP 9 (NT)</p>	<p>Organisations in the NT can only use or disclose health information in limited circumstances, including:</p> <ul style="list-style-type: none"> <li>for the primary purpose it was collected (IPP 2.1), or</li> <li><b>for a directly related secondary purpose within the individual's reasonable expectations (IPP 2.1(a))</b>, or</li> <li>with the individual's consent (IPP 2.1(c)), or</li> <li>if the use or disclosure is required or authorised under another law (IPP 2.1(f)), or</li> <li>where the use or disclosure is necessary for research, or the compilation or analysis of statistics, in the public interest (IPP 2.1(ca)), and: <ul style="list-style-type: none"> <li>it is impracticable to obtain the individual's consent to the use or disclosure, and</li> <li>the research, compilation or analysis will not be published in a form that identifies the individual, and</li> <li>the use or disclosure is conducted in accordance with the guidelines issued by the NT Information Commissioner (which may require HREC approval),<sup>66</sup> and</li> </ul> </li> </ul>


<sup>66</sup> See: [https://infocomm.nt.gov.au/data/assets/pdf\\_file/0008/184643/s86-Useanddisclosureofhealthinformationforwebsite.pdf](https://infocomm.nt.gov.au/data/assets/pdf_file/0008/184643/s86-Useanddisclosureofhealthinformationforwebsite.pdf)

Organisations and applicable privacy law	Use & Disclosure Privacy principle(s)	Possible lawful pathways for the use or disclosure of health information
		<ul style="list-style-type: none"> <li>○ in the case of a disclosure, the organisation reasonably believes that the recipient of the information will not disclose the information, or</li> <li>• the organisation is subject to a Code of Practice approved by the NT Information Commissioner that modifies the IPPs to allow limited non-compliance (conditions must be met to support such modifications and the approval of a Code of Practice) (ss 72 – 80), or</li> <li>• the NT Information Commissioner has granted a public interest authorisation to allow the organisation to use or disclose health information in a manner that would otherwise be inconsistent with the IPPs (s 81), or</li> <li>• another exemption applies.</li> </ul> <p>In addition to the above requirements, organisations are not permitted to transfer health information outside of the NT unless:</p> <ul style="list-style-type: none"> <li>• the transfer is authorised or required by another law (specifically a Territory or Commonwealth law) (IPP 9.1(a)), or</li> <li>• they reasonably believe the recipient of the information is subject to a law, scheme or contract that provide substantially similar privacy protection to the IPPs (IPP 9.1(b)), or</li> <li>• the individual consents to the transfer (IPP 9.1(c)), or</li> <li>• the transfer is necessary for the performance of a contract that is in the interest of the individual, between the organisation and the recipient (IPP 9.1(e)), or</li> <li>• the transfer is for the benefit of the individual <u>and</u> it is impracticable to obtain the individual's consent <u>and</u> if it were practicable, the individual would likely give their consent (IPP 9.1(f)), or</li> <li>• the organisation has taken reasonable steps to ensure the health information being transferred outside of the NT will not be held, used or disclosed by the recipient inconsistently with the IPPs, or</li> </ul>

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		another exemption applies (IPP 9.1(g)).
<p><i>Health Records Act 2011</i> (Vic)</p> <p>Victorian government agencies (including Victorian public universities)</p> <p>Public and private health organisations in Victoria</p>	HPP 2, HPP 9 (Vic)	<p>Organisations in Victoria can only use or disclose health information in limited circumstances, including:</p> <ul style="list-style-type: none"> <li>• for the primary purpose it was collected (HPP 2.1), or</li> <li>• with the individual's consent (HPP 2.2(b)), or</li> <li>• <b>for a directly related secondary purpose within the individual's reasonable expectations (HPP 2.2(b))</b>, or</li> <li>• if the use or disclosure is required or authorised under another law (HPP 2.2(c)), or</li> <li>• where the use or disclosure is necessary for the provision of a health service to the individual (HPP 2.2(e)), including where the individual is incapable of giving consent (HPP 2.2(d)), or</li> <li>• where the use or disclosure is for the purpose of funding, management, planning, monitoring, improvement or evaluation of health services (HPP 2.2(f)(i)), and: <ul style="list-style-type: none"> <li>○ either this purpose cannot be achieved with de-identified data <i>and</i> it is impracticable to seek the individual's consent for the use OR reasonable steps have been taken to de-identify the information, and</li> <li>○ identifiable health information will not be published in a generally available publication, and</li> <li>○ the use or disclosure is in accordance with any guidelines issued by the Victorian Health Complaints Commissioner on the management of health services,<sup>67</sup> or</li> </ul> </li> </ul>

<sup>67</sup> To date, no statutory guidelines have been issued by the Victorian Health Services Commissioner on the management of health services.



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		<div data-bbox="1108 300 1153 351" style="text-align: center;">  </div> <ul style="list-style-type: none"> <li>• where the use or disclosure is necessary for research, or the compilation or analysis of statistics, in the public interest (HPP 2.2(g)), and:             <ul style="list-style-type: none"> <li>○ is impracticable to seek the individual's consent for the use or disclosure, and</li> <li>○ this purpose cannot be achieved with de-identified data, and</li> <li>○ the use or disclosure is in accordance with the statutory guidelines on research issued by the Victorian Health Complaints Commissioner (which may require HREC approval), and</li> <li>○ identifiable health information will not be published in a generally available publication, or</li> </ul> </li> </ul> <p>where another exemption applies.</p> <p>In addition to the above requirements, organisations are not permitted to transfer health information outside of Victoria unless:</p> <ul style="list-style-type: none"> <li>• they reasonably believe the recipient of the information is subject to a law, scheme or contract that provide substantially similar privacy protection to the HPPs (HPP 9.1(a)), or</li> <li>• the individual consents to the transfer (HPP 9.1(b)), or</li> <li>• the transfer is necessary for the performance of a contract that is in the interest of the individual, between the organisation and the recipient (HPP 9.1(d)), or</li> <li>• the transfer is for the benefit of the individual and it is impracticable to obtain the individual's consent and if it were practicable, the individual would likely give their consent (HPP 9.1(e)), or</li> <li>• the organisation has taken reasonable steps to ensure the health information being transferred outside of Victoria will not be held, used or disclosed by the recipient inconsistently with the HPPs (HPP 9.1(f)), or</li> </ul>

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		the transfer is authorised or required by another law (HPP 9.1(g)).
<p><i>Information Privacy Act 2009</i> (QLD)</p> <p>Queensland government agencies (including Queensland public universities)</p>	QPP 6 (QLD)	<p>A Queensland organisation can only use or disclose health information in limited circumstances, including:</p> <ul style="list-style-type: none"> <li>• for the primary purpose it was collected (QPP 6.1), or</li> <li>• <b>for a directly related secondary purpose within the individual's reasonable expectations (QPP 6.2(a)(i))</b>, or</li> <li>• with the individual's consent (QPP 6.1(a)), or</li> <li>• if the use or disclosure is required or authorised under another law (QPP 6.2(b)), or</li> <li>• where the organisation is a health agency and the use or disclosure is necessary for research, or the compilation or analysis of statistics, relevant to public health or public safety (Sch 4, Part 2: Permitted Health Situation 4), and: <ul style="list-style-type: none"> <li>○ it is impracticable to obtain the individual's consent to the use or disclosure, and</li> <li>○ the use or disclosure is conducted in accordance guidelines approved by the chief executive of the health department (which may require HREC approval),<sup>68</sup> and</li> <li>○ in the case of a disclosure, the organisation reasonably believes that the recipient of the information will not disclose the information (or personal information derived from the information), or</li> </ul> </li> <li>• where the use or disclosure is necessary for research, or the compilation or analysis of statistics, in the public interest (QPP 6.2(g)), and:</li> </ul>

<sup>68</sup> We cannot see that any such guidelines have been approved to date under the QLD NPPs; however, guidelines relevant to this pathway may be issued after the QPPs become effective.

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		<ul style="list-style-type: none"> <li>○ the use or disclosure does not involve the publication of all or any of the personal information in a form that identifies any individual, and</li> <li>○ it is not practicable to obtain the consent of the individual before the use or disclosure, and</li> <li>○ in the case of a disclosure, the organisation is satisfied on reasonable grounds the recipient of the information will not disclose the information, or</li> <li>• The Queensland Information Commissioner approves a public interest waiver or modification of a privacy principle requirement that applies to the organisation (s 157), or</li> </ul> <p>where another exemption applies.</p> <p>If the health information was originally collected under Permitted Health Situation 3(1)), the organisation must take reasonable steps to ensure that the information is de-identified before the organisation discloses it under QPP 6.1 or QPP 6.2 (QPP 6.4).</p>
<p><i>Premier and Cabinet Circular 12 - Information Privacy Principles Instruction*</i></p> <p>South Australian government agencies</p> <p>*This instruction is a piece of binding policy on South Australian</p>	<p>IPPs 7-8, IPP 10 (SA)</p>	<p>A South Australian organisation can only use or disclose personal information in limited circumstances, including:</p> <ul style="list-style-type: none"> <li>• for the primary purpose it was collected (IPP 8; IPP 10), or</li> <li>• <b>for a related secondary purpose within the individual's reasonable expectations (IPP 8(a); IPP 10(a))</b>, or</li> <li>• with the individual's consent (IPP 8(b); IPP 10(b)), or</li> <li>• if the use or disclosure is required or authorised under another law (IPP 8(d); IPP 10(d)), or</li> <li>• where another exemption applies.</li> </ul>

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government agencies. It is not law.		The Privacy Committee of South Australia may also exempt an organisation from compliance with one or more of the IPPs (Proclamation of the Privacy Committee of South Australia, s 4(1)).
<p><i>Personal Information Protection Act 2004</i> (Tas)</p> <p>Tasmanian government agencies (including Tasmanian public universities)</p>	PIP 2, PIP 9 (Tas)	<p>Organisations in Tasmania can only use or disclose health information in limited circumstances, including:</p> <ul style="list-style-type: none"> <li>• for the primary purpose it was collected (PIP 2.1), or</li> <li>• <b>for a directly related secondary purpose within the individual's reasonable expectations</b> (PIP 2.1(a)), or</li> <li>• with the individual's consent (PIP 2.1(b)), or</li> <li>• if the use or disclosure is required or authorised under another law (PIP 2.1(f)), or</li> <li>• where the use or disclosure is necessary for research, or the compilation or analysis of statistics, in the public interest (other than for publication in a form that identifies any particular individual) (PIP 2.1(c)), and: <ul style="list-style-type: none"> <li>○ it is impracticable to obtain the individual's consent before the use or disclosure, and</li> <li>○ in the case of a disclosure, the organisation reasonably believes that the recipient of the information is not likely to disclose the information, or</li> </ul> </li> <li>• where the Minister for Justice has approved a public interest exemption from compliance with the PIP requirements (ss 13 – 15), or</li> </ul> <p>another exemption applies.</p> <p>Where the health information was originally <i>collected</i> under PIP 10.4 (i.e. for research or the compilation or analysis of statistics relevant to public health or public safety, or the management, funding or monitoring of a health service), the organisation must take reasonable steps to permanently de-identify the health information before disclosing it (PIP 10.5).</p>

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		<p>In addition to the above requirements, organisations are not permitted to transfer health information outside of Tasmania unless:</p> <ul style="list-style-type: none"> <li>• they reasonably believe the recipient of the information is subject to a law, scheme or contract that provide substantially similar privacy protection to the PIPs (PIP 9(a)), or</li> <li>• the individual consents to the transfer (PIP 9(b)), or</li> <li>• the transfer is necessary for the performance of a contract that is in the interest of the individual, between the organisation and the recipient (HPP 9(c)(ii)), or</li> <li>• the organisation has taken reasonable steps to ensure the health information being transferred outside of Tasmania will not be held, used or disclosed by the recipient inconsistently with the PIPs (PIP 9(d)), or</li> </ul> <p>the transfer is authorised or required by another law (PIP 9(e)).</p>
<p><i>Privacy and Responsible Information Sharing Act 2024 (WA)</i></p> <p>Western Australian government agencies (including Western Australian public universities)</p>	<p>IPP 2 (WA)</p>	<p>Western Australian organisations can only use or disclose health information in limited circumstances, including:</p> <ul style="list-style-type: none"> <li>• for the primary purpose it was collected (IPP 2.1), or</li> <li>• <b>for a directly related secondary purpose within the individual's reasonable expectations</b> (IPP 2.1(a)), or</li> <li>• with the individual's consent (IPP 2.1(b)), or</li> <li>• if the use or disclosure is required or authorised under another law (IPP 2.1(f)), or</li> <li>• where the use is necessary for research, or the compilation or analysis of statistics, in the public interest (IPP 2.1(c)), and: <ul style="list-style-type: none"> <li>○ the research or statistics are not to be published in a form that identifies any particular individual, and</li> </ul> </li> </ul>

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		<ul style="list-style-type: none"> <li>○ it is impracticable to obtain the individual's consent to the use or disclosure, and</li> <li>○ the organisation reasonably believes that the recipient of the information will not further disclose the information, or</li> <li>• where the WA Information Commissioner makes a Public Interest Direction (PID) that provides the organisation is not required to comply with the privacy principle requirements in the circumstances (ss 45 – 48), or</li> <li>• in the case of a disclosure, where the disclosure is to either another WA public sector entity, or to an 'external entity', for a 'permitted purpose' in accordance with a properly formed information sharing agreement (Part 3), noting: <ul style="list-style-type: none"> <li>○ an 'external entity' includes, but is not limited to: <ul style="list-style-type: none"> <li>▪ a Commonwealth, state or territory agency,</li> <li>▪ a contracted service provider,</li> <li>▪ an Aboriginal community controlled organisation, or</li> <li>▪ a body that carries out health-related research</li> </ul> </li> <li>○ a 'permitted purpose' includes, but is not limited to: <ul style="list-style-type: none"> <li>▪ to inform or enable the making or implementation of government policy,</li> <li>▪ to inform or enable the design, management, delivery or evaluation of government programs and services, or</li> <li>▪ to inform or enable research and development with clear and direct benefits to the public,</li> </ul> </li> <li>○ an information sharing agreement must be entered into which meets the requirements set out in the PRIS Act, including prior completion of any assessments required under the Act (which may include an assessment under</li> </ul> </li> </ul>

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		the responsible sharing principles, a privacy impact assessment, and an Aboriginal information assessment), or where another exemption applies.

Document Control	
<i>SynD Synthetic Health Data Governance Framework</i>	
Version Number	v1.0
Effective Date	XX/XX/XXXX
Date of last review:	XX/XX/XXXX
Owned by	Digital Heath CRC
Review Schedule	<p><i>The document should be reviewed periodically by SynD. Any changes or proposed amendments to the framework should be circulated with all SynD and participating organisations, to ensure all organisations are working from the same version of the framework.</i></p> <p><i>If the framework has not been reviewed or updated within a <b>two-year period</b>, there is a risk the laws and policy frameworks which underpin the framework may have been amended and the guidance in the framework may no longer be up to date. In these circumstances, Digital Heath CRC should initiate a review of the framework for currency and relevancy.</i></p>