

Rachel Stephen-Smith MLA

Minister for Health

Minister for Children, Youth and Family Services

Minister for Disability

Minister for Aboriginal and Torres Strait Islander Affairs

Member for Kurrajong

RESPONSE TO QUESTION ON NOTICE**Questions on Notice Paper No 41****12 APRIL 2024****Question No. 1748****MS LEANNE CASTLEY MLA:** To ask the Minister for Health —

Is it the case that (a) up until the age of 14, parents have full access to a child's medical test results on MyDHR, (b) between the ages of 14 and 15 parents require a power of attorney from the child, (c) from the age of 15 a child can grant larger access to test results to their parents on myDHR; if so, what is the legal or regulatory basis for each contingency and (d) has consideration been given to simplifying the differing access arrangements from age 14 onwards; if so, what consideration.

MS RACHEL STEPHEN-SMITH MLA - The answer to the Member's question is as follows:

- a) A parent can request full Child Adult Proxy Access to their child's MyDHR account from birth to 14 years.
- b) From 14 years of age a young person can have their own MyDHR account. All Child Adult Proxy Access will automatically be updated to Teen Proxy Access from 14 – 15 years of age. Teen Proxy Access is limited to protect the privacy of the young adult, therefore a parent will not be able to see any clinical information including upcoming appointments or test results.
- c) From 15 years of age, all previous proxy access will cease, and the patient can instigate any proxy access they feel is needed, and to what level of access should be provisioned. This can be revoked at any time through MyDHR or by contacting the health service or Digital Solutions Support.

The decision around what age a consumer should have access to their own MyDHR account and the provision of proxy access was discussed at length during the Digital Health Record (DHR) Project. This included through the Consumer Experience Steering Committee (CESC) and the decisions below were recommended. These were then supported by the Clinical Steering Committee (CSC), DHR Board and sent for legal advice.



The CESC is made up of representatives from:

- Project Officer - Health Care Consumers' Association (HCCA) (Chair)
- Carers ACT
- Meridian
- ACT Mental Health Consumer Network
- Chronic Conditions Network Coordinator - HCCA
- Health Literacy Officer - HCCA
- Youth Coalition
- Patient and Safety Canberra Health Services
- Health Information Services Canberra Health Services

The decision regarding age of access to MyDHR and proxy access also took into account the age of access to Medicare Statements, My Health Record and Immunisation History Statements and young people's capacity to obtain their own Medicare Card.

The recommendation by the CESC was:

- From 14 years of age a young person can have their own MyDHR account. From 15 years of age, all previous proxy access will cease, and the patient can instigate any proxy access they feel is needed, and to what level of access should be provisioned. This can be revoked easily at any time through MyDHR or by contacting the health service or Digital Solutions Support.

This recommendation was reviewed by the Government Solicitor's Office to ensure it met the requirements of the *Health Records (Privacy & Access) Act 1997* as well as the *Children and Young People Act 2008*. To ensure consent was provided without duress or coercion, the restrictions for teen proxy access were recommended and approved.

Any information not currently available to parents/carers due to these restrictions can still follow pre-DHR workflows for accessing a person's health record which are governed by the *Health Records (Privacy & Access) Act 1997*.

The CESC was also asked to make a recommendation of what diagnosis and results should be shared to MyDHR. The recommendation was that all diagnosis and results should be shared, although they recommended some results should be held to allow time for a clinician to have appropriate discussions with a consumer when the results could be life changing – for example, anatomical pathology results which could be diagnostic of cancer are held for 10 days. This decision was taken noting the CESC did not feel they had the appropriate clinical knowledge to make recommendations of what the time delays should be associated with each result.

These recommendations were again supported by the CSC and the DHR Board. The CSC made the recommendations for the appropriate time delays associated with medical imaging and pathology results. In consultation with mental health clinicians, decisions were also made to not show visit diagnosis on an After Visit Summary (AVS) for mental health outpatient appointments and the AVS for eating disorders does not show the patient's BMI/height/weight.

d) MyDHR Proxy Access was again discussed at the CESC on 17 April 2024, where the decision to maintain the current access was unanimously supported. The primary rationale for this decision included:

- MyDHR is not personally controlled like My Health Record (that is, the consumer cannot decide what is included/released), therefore providing parents full access may limit young people getting the help they need (for example, sexual health care or emergency contraception) if there is a risk that test results would be available to parents.
- When a patient is an inpatient there are other avenues to protect the young person and the clinician can make the decision to share with the parent or not (therefore providing support to the young person).
- The custodian of the Health Record is the health service, not the patient.
- Parents will always have the ability to request records through the Health Information Management Team or their General Practitioner (as per pre-DHR guidelines), where the information released can be monitored and as the access is a manual release, reasonable effort is undertaken by the Health Information Management Team to ensure the patient has consented without duress before information is released. By contrast, the release of information on MyDHR is an automated process.

Comparison				
MyDHR	Access to own Medicare Statements	Access to own Immunisation History Statement	Access to own My Health Record and allocate proxy access	Able to obtain own Medicare Card
Age 14 With parent as Teen Proxy. Age 15 can determine who and what level Proxy will be approved.	Age 14 <i>Medicare Australia has a policy that requires young person aged 14 and over to consent before their parents can access their medical records.</i>	Age 14	Age 14 <i>The Australian Parliament passed the My Health Records Amendment (Strengthening Privacy) Bill 2018, to create greater privacy for teenagers aged 14 and over.</i>	Age 15

Approved for circulation to the Member and incorporation into Hansard.



Rachel Stephen-Smith MLA
Minister for Health

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This response required 3hrs 10mins to complete, at an approximate cost of \$274.79.