



Media release

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## A new national digital collaborative to improve child health

Australia's states and territories have joined forces in a unique and transformative partnership that harnesses technology to improve the health and wellbeing of Australian children.

In one of the first initiatives of *Australia's National Digital Health Strategy – Safe, Seamless, and Secure*, the Australian Digital Health Agency is partnering with eHealth NSW and the Sydney Children's Hospitals Network (SCHN) to establish the National Children's Digital Health Collaborative.

SCHN Chief Executive Dr Michael Brydon said that records on a child's health and development are currently captured in multiple paper and digital systems, meaning they are not always available when they are needed.

"The Collaborative is exploring how every child in Australia can have the option of a comprehensive digital health record from the time they are conceived, through those critical first years and adolescence; readily accessible by parents and healthcare providers and ultimately for that individual throughout their life.

"This will be of enormous value – not only to healthcare professionals providing care to those children – but to the children themselves as they become young adults and start making decisions about their own health and care," Dr Brydon said.

The Collaborative comprises around 400 clinicians, consumers, IT experts, and researchers from across Australia and is aimed at making a positive impact on children's health and wellbeing.

Agency CEO Tim Kelsey said the Collaborative is a momentous opportunity to make a lasting difference to the long-term health of all young Australians, given that many predictors of adult disease have their origins in childhood.

"This work will enable the establishment of lifetime digital health records for all Australian children, wherever they live or present for treatment," Mr Kelsey said.

The Collaborative comprises a wide variety of experts, including clinicians, consumers, governments, researchers, providers and industry representatives, who will co-design and test a way for parents and healthcare providers to easily access standardised information on a child's health and development.

This initiative will test how information can be captured not only through a child's interaction with the health system and other services such as school immunisation programs, but also through their mother's relevant interactions during her pregnancy.

eHealth NSW Chief Executive Dr Zoran Bolevich said the aim is to create a holistic digital view of a child's health for families who choose to have one. The Collaborative will also test the ways in which parents, carers and healthcare providers want to access this information, including through systems such as My Health Record. This work will then provide a base of evidence and experience with a view to rolling out solutions nationally.

"We want to engage and empower children and their families by providing them with consumer-friendly digital access to their health information and evidence-based health resources," Dr Bolevich said.

The initiatives identified in the Collaborative align with the National Digital Health Strategy's models of care to improve accessibility, quality, safety, and efficiency in improving child health.



“In 2016 more than 311,000 babies were born in Australia.\* When these initiatives are implemented, Australian children will have a lifelong digital health record their healthcare providers can refer and contribute to. How powerful a treatment aid will that be?” Mr Kelsey said.

Mr Kelsey said this is a platform for innovation for industry to develop new tools and digital health services.

The National Digital Health Strategy outlines a test bed for children’s health that will examine how every child in Australia can have access to a comprehensive digital health record. This record will be readily accessible by parents and healthcare providers, to track key childhood healthcare interventions such as immunisations and to ensure that healthcare providers are able to offer safe, high-quality care.

In October 2017, the Agency’s Board approved funding to design, build, and evaluate proofs of concept for five nationally focused initiatives that include:

- 1. A National Child Digital Health Record** – Currently a child’s health and development information is captured in hard copy baby books, such as the Red Book in Queensland, Blue Book in NSW and Green Book in Victoria. These books must be carried between healthcare appointments by a child’s parents and carers, and are often forgotten or misplaced. This initiative will capture this information digitally so it is easily accessible by a child’s parents and families and available to healthcare providers where and when it is needed. *New South Wales and Victoria are leading this work.*
- 2. Upload of school immunisation records to the Australian Immunisation Register (AIR)** – The AIR does not currently capture and record all of the vaccinations adolescents receive through the school immunisation programs. Adolescents may be given a paper record of a vaccine they received in school, which is often lost or misplaced, meaning they have an incomplete knowledge of their vaccination history. This results in potentially missed vaccinations or duplicate vaccinations being given. This initiative will support the upload of school vaccination records to the AIR so a full history of a young person’s vaccinations from birth through to early adulthood is stored securely in one place and accessible to them, their parents, and their healthcare providers. *Australian Capital Territory and Tasmania are leading this work.*
- 3. A National Digital Pregnancy Health Record** – Currently, women’s antenatal or pregnancy records are mostly captured on paper, with women needing to carry them between their healthcare providers and appointments. These handwritten records are often difficult to read and providers need to double-enter the handwritten information into separate paper and digital systems, and this important information is often not brought to hospital when the woman goes into labour. This initiative will develop a digital shared care pregnancy plan accessible by pregnant women and their healthcare providers. *Queensland and South Australia are leading this work.*
- 4. National Digital Child Health Checks** – Child health checks such as the Medicare Health Assessment for Aboriginal and/or Torres Strait Islander People (MBS Item 715) are conducted by GPs and Aboriginal Medical Services (AMS). However, the information often stays within the GP or AMS software, it is not shared electronically, and it is not readily accessible to other care providers. This may limit the opportunities for early detection, diagnosis, and intervention for common and treatable conditions by a child’s wider care team, and reduces the ability to offer integrated care and to better identify any services a child may require. This initiative will digitise child health checks to help support the early identification of a child’s health and wellbeing needs. *Northern Territory and Western Australia are leading this work.*
- 5. Research into the Longitudinal Digital Child Health Record** – The implementation of the above four initiatives will help to build a longitudinal child digital health record. This will create a national repository of high quality, commonly understood, and structured child development information contributed by young people, their families and carers, primary care and jurisdictions. This will be a valuable national asset that, following all required legalisation, policy and privacy protocols, could help researchers and policy-makers better understand children’s health and wellbeing needs, and ensure that policies and programs aimed at



improving health outcomes for children and young people are evidence-based and informed by robust health research and data systems.

Some of the identified research themes this information could support include:

- (i) Quality Use of Medicines in pregnant women and children
- (ii) Prenatal and early childhood influences into obesity's developmental origins and
- (iii) Research into early childhood development across developmental domains.

\*3301.0 - Births, Australia, 2016, Australian Bureau of Statistics at:

<http://www.abs.gov.au/AUSSTATS/abs@.nsf/mf/3301.0>

#### Further information

[Australia's National Digital Health Strategy – Safe, Seamless, and Secure](#) is available on the Agency website.

#### ENDS

#### Notes for Editors

- The Australian Digital Health Agency commenced operations on 1 July 2016.
- The Agency is tasked with improving health outcomes for all Australians through the delivery of digital healthcare systems and the National Digital Health Strategy.
- The Agency's focus is on putting data and technology safely to work for patients, consumers and the healthcare professionals who look after them.
- More than 3,000 people participated in the consultation on the *National Digital Health Strategy* between October 2016 and January 2017. Public meetings were held in more than 103 locations across Australia. More than 1,000 formal submissions and survey responses were received. These submissions are published at <https://conversation.digitalhealth.gov.au>.
- Australian consumers, carers, healthcare providers, and other health stakeholders informed the consultation.
- Health consumers and carers expressed a strong desire to be increasingly empowered – to take control of decisions regarding their own health, and to be provided with access to their own personal health information.
- The National Children's Digital Health Collaborative is a good example of the Agency addressing health consumer's needs with practical solutions.

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#### About the Australian Digital Health Agency

The Agency is tasked with improving health outcomes for all Australians through the delivery of digital healthcare systems, and implementing [Australia's National Digital Health Strategy – Safe, Seamless, and Secure](#) in collaboration with partners across the community. The Agency is the System Operator of the [My Health Record](#), and provides leadership, coordination, and delivery of a collaborative and innovative approach to utilising technology to support and enhance a clinically safe and connected national health system. These improvements will give individuals more control of their health and their health information, and support healthcare professionals to provide informed healthcare through access to current clinical and treatment information. Further information: [www.digitalhealth.gov.au](http://www.digitalhealth.gov.au).

#### About eHealth NSW

A dedicated agency of NSW Health, eHealth NSW partners with NSW Health organisations in the planning, adoption, and ongoing development of digital technologies and capabilities that deliver value. It plans and



manages ICT investments, maintains standards, designs and procures systems, manages implementations and commissions or provides ICT support services.

[www.ehealth.nsw.gov.au](http://www.ehealth.nsw.gov.au)

#### **About the Sydney Children's Hospitals Network**

Sydney Children's Hospitals Network cares for thousands of children each year in our hospitals and in their homes — with one purpose in mind — to help young people live their healthiest lives.

[www.schn.health.nsw.gov.au](http://www.schn.health.nsw.gov.au)