Who owns our blood?

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The absence of specific laws which define the ownership, storage and use of blood drops taken from every Australian baby since 1971 could threaten public trust in newborn screening (NBS) programs in Australia, a University of Melbourne academic has warned.

For the past 40 years, the heel of nearly every baby born in Australia has been pricked to collect several drops of blood. These drops – which are then tested for a variety of genetic conditions, such as cystic fibrosis - are effective health checks. But according to Dr. Diana Bowman, from the Melbourne School of Population Health , the tests and what is done with the blood afterwards, raises many legal questions.

“The main problem is that there is no focused set of laws governing NBS programs in Australia. This means that questions like ‘who owns the cards?’, ‘who can access them?’ and ‘under what conditions’ don’t have clear answers,” she said.

“Australia, the US and Europe have had similar experiences in recent times– namely, a series of controversial incidents regarding NBS cards that have caused public outcry and eventually led to the destruction of card archives.”

Research by Dr. Bowman and Professor David Studdert, from the University of Melbourne – published in the *Medical Journal of Australia* today – calls for a dedicated regulatory regime for NBS programs to be established.

"We urge governments in Australia to develop a coherent legal framework for NBS programs. That framework should reflect a considered balance between the rights of parents and children, community attitudes to the storage and use of biospecimens and the interests of all Australians in maintaining high-quality care at birth," Dr. Bowman said.

"New rules would probably mean stricter requirements for informed consent than has been the norm to date. But when it comes to research, it might actually open up more opportunities. Above all, what a sensible legal structure would do is protect against the possibility that some future controversy over use of the cards would threaten these very valuable public health programs."

Provided by University of Melbourne

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