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Newborn bloodspot screening policy framework for Australia

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REVIEW

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ABSTRACT

Background

The aim of newborn bloodspot screening (NBS) is to identify rare genetic and non-genetic conditions in children soon after birth in order to commence therapies that prevent the development of progressive, serious, and irreversible disabilities. Universal NBS programmes have been implemented in most countries, with minor adaptations to target conditions most relevant to the local healthcare environment.

Aims

In this article, we describe the initiatives of international and Australian governments to develop policies to address the expansion of NBS in their healthcare systems.

Methods

We have reviewed published public policies and literature to formulate recommendations based on clinical, social, legal, and ethical principles to inform a national governance and policy framework for Australia.

Results

Australian policy makers have been slow to develop a coordinated plan. While the experience from other governments can guide our national policy, there are specific areas that require further consideration by Australian health experts. Key reforms involve the separation of policy and operational activities, multidisciplinary decision-making and oversight by the Australian Health Ministers' Advisory Council for policy direction.

Conclusion

A formal national policy framework will guide the coordination of NBS services that can adapt to the needs of Australian children and families.

Key Words

Newborn screening, policy, genetics, health technology assessment

What this study adds:

1. What is known about this subject?

Australian programmes began screening for phenylketonuria in 1967 and since then have expanded to cover 29 conditions within a voluntary, government-funded public health service.

2. What new information is offered in this study?

We propose a policy framework to guide policy and evaluate evidence to select appropriate disorders to include in the Australian NBS panel.

3. What are the implications for research, policy, or practice?

It is essential that Australia develop a unified, national policy framework to guide the governance and delivery of expanded NBS services.

Background

Newborn bloodspot screening (NBS) is a successful population health programme to detect children born with a range of rare genetic conditions that can lead to progressive intellectual disability and developmental

disability.[1,2] In the early 1960s, Robert Guthrie described a simple screening test for phenylketonuria, a genetic defect of phenylalanine metabolism which, left untreated, causes irreversible brain damage.[3] The development of children with phenylketonuria (PKU) will be relatively normal if dietary phenylalanine can be restricted from early in the neonatal period. At this time in the United States of America (USA), the success of universal polio vaccinations enabled organisations such as the March of Dimes Foundation to shift focus onto the prevention of birth defects and infant mortality. The benefits of newborn blood screening in children quickly attracted community support as early dietary modification for phenylketonuria could prevent progression of intellectual and developmental disability.[2]

Universal NBS for PKU commenced in Massachusetts in 1963 and many countries quickly established universal NBS programmes. Over the next 30 years these screening services expanded to include other neonatal-onset disorders, such as congenital hypothyroidism, galactosaemia, and cystic fibrosis. With advances in new technology such as tandem mass spectrometry in the late 1990s, some jurisdictions in the USA began NBS for up to 37 different disorders. Australia followed and expanded the scope of NBS disorders to include rare defects of organic, amino, and fatty-acid metabolism.[4] NBS panels were also being revised in other countries. In the European Union, individual countries screen for between 1–29 disorders,[5] between five and 29 disorders in Canada,[6] while the United Kingdom (UK) maintained a conservative core NBS panel screening of nine disorders.[7]

The recent trend to expand the public health goals of NBS has coincided with a shift in public attitudes away from a public health initiative towards individual benefits. Many families now recognise that the early diagnosis of a child with an inherited condition like cystic fibrosis can be used to adjust future reproductive decisions.[8] Thus, the value of NBS is beginning to be redefined in terms of the value of knowledge to parents about their child's condition and the avoidance of a "diagnostic odyssey".[9,10] In some cases, this has led to implementation of NBS for rare disorders, even when the prospect of altering quality of life or life expectancy is remote.[9,11] Screening has been proposed for many more conditions, including some that are benign or might not emerge until later in life.

Any consideration to expand a NBS panel should involve a rigorous process of decision-making that balances benefits against the risks of harm.[12] In 2007, Raffle and Gray identified that policy makers, public health practitioners, managers, and clinicians share collective responsibility for managing population screening services. They succinctly observed: "*All screening programmes do harm. Some do good as well and, of these, some do more good than harm at reasonable cost*".[13]

Even within current NBS services there is the potential for harm. For some children, the clinical implications of screen-positive results and the value of treatments are unclear. At worst, false-positive results expose children to further investigations and therapeutic interventions that consume health resources for little to no benefit. Furthermore, NBS services may risk losing public support if they are absorbed into a de facto population biobanks[14] by retaining blood samples for unspecified or unconsented purposes.

The process of deciding which disorders are suitable for NBS involves the assessment of epidemiological and clinical evidence of benefit, as well as clinical utility and cost effectiveness. Conceptual frameworks informing discussions around future planning of NBS services have been published and provide useful guidance on the use of evidence in health service planning.[15] The process of evaluating evidence on whether or not to add a new condition into a NBS panel includes pilot population-based research trials as well as financial, regulatory, and logistical assessments. The investigation of increasingly rare conditions proposed for NBS is beyond the capacity of most state-based NBS services.[16] In the US particularly, high profile and influential families and their supporters pressured NBS programmes to expand their scope to include some disorders that occur infrequently. However, parents or legal guardians have responsibilities for the health of their children, and should be involved in the discussion of NBS priorities.[16]

There has been considerable international interest in planning for expanded NBS and the impact on resource allocation, programme standardisation, and the consideration of the ethical issues. Many governments have strategically invested in expert networks to develop policy, governance principles, and processes for monitoring and evaluation of NBS programmes.[17–20]

Method

Inevitably, variations between international NBS services will reflect differences in disease prevalence and the influence of political and community priorities. Nevertheless, they all share the common goal of developing mechanisms for effective, consistent, evidence-based delivery of NBS services. In the following section, we review the policy deliberations and research that have led to

different approaches being taken by the US, Canada, the UK, Europe, and New Zealand.

Results

International NBS policy frameworks

United States of America

NBS programmes in the USA are unique in that most regions of the country have legislatively mandated screening within public health programmes and parents are required to bear the cost of screening.

In response to a lack of national uniformity in the USA, the Newborn Screening Task Force of the American Academy of Paediatrics recommended the development of a national system to coordinate NBS standards and policies.[19] In 2003, the Secretary of Health and Human Services convened a committee (now called the Discretionary Advisory Committee) to provide recommendations on screening tests, technologies, policies, guidelines, and standards.[21] The Committee recommended screening for a panel of 29 core disorders and 25 secondary target disorders. The Committee also proposed mechanisms to evaluate evidence for new candidate disorders and technologies.[19] There followed a period of intense debate that eventually led to a systematic and transparent evaluation process to review and select candidate disorders, which are included in the Recommended Uniform Screening Panel (RUSP). Since then, the Committee has evaluated a further 12 disorders and three have been added to the recommended NBS panel.[21]

The Discretionary Advisory Committee has US federal government authority to assess and recommend NBS tests.[21] However, there have been instances where local and political advocacy has overturned the evidence-based expert decisions on candidate disorders. One example concerns Krabbe disease, which is a rare form of lysosomal storage disease, occurring in 1 in 100,000 births. A former high profile football player whose son died from the disease persuaded the New York State legislature to mandate NBS for Krabbe disease despite the lack of a definitive diagnostic test, poor prognosis following bone marrow transplantation, and no long-term follow-up data. As a result, the high false-positive rate has generated further intensive monitoring of asymptomatic children. So, despite a specific recommendation against NBS for Krabbe disease, patient support groups have influenced several local state legislatures to implement screening for Krabbe disease and other metabolic disorders.[22]

On the other hand, the decision-making model in the USA has demonstrated flexibility in reviewing new evidence and adjusting its recommendations. In 2010, the Discretionary Advisory Committee reversed an earlier recommendation against screening for severe combined immunodeficiency (SCID). The condition was initially not recommended for NBS and ranked 57 out of 66 disorders evaluated.[19] A subsequent review of a two-tiered screening strategy could identify SCID cases and human stem cell transplantation was associated with almost 95 per cent survival of affected children.[23] Based on the new evidence, SCID was added to the Recommended Uniform Screening Panel and within a year pilot studies were testing 25 per cent of newborns in the United States.

Canada

Universal NBS in Canada is managed by the provincial/territorial jurisdictions. Each province determines the disorders for screening and the technologies, procedures for consent, treatment, and monitoring activities.[24] The provinces screen between five and 29 disorders.[6] Variations in health service delivery models led to the Canadian federal government to sponsor the Garrod Association as a permanent national body for the coordination and management of inherited metabolic disorders and in 2005, proposals were adopted for the national NBS agenda to include a nationally consistent NBS strategies, minimum standards for services based on ethical and social consensus agreements.[25] Since that time, the Canadian provinces have begun to standardise NBS services through financial and cooperative agreements. In turn, this has led to harmonisation of policies, screening panels, treatment, and monitoring practices.[6]

United Kingdom (UK)

In the UK, a National Screening Committee (UKNSC) was established in 1996 to advise ministers and the National Health Service about screening and to support the implementation of new screening programmes.[17] A subgroup of the UKNSC, known as the Fetal, Maternal, and Child Health Coordinating Group, was directed to formulate a policy framework for NBS. The subgroup coordinated consultations that led to the development of NBS practice standards as well as policies for which disorders to include in screening, informed by independent systematic reviews and economic evaluation.[17] The recommended screening panel was initially conservative with just five conditions identified. Following a pilot-screening project involving more than 700,000 children, the NBS Programme in England has recently adopted a recommendation to expand the number of disorders to be screened in 2015 to nine disorders.[26]

European Union (EU)

In 2009, the European Commission initiated a review of current NBS services and a network of experts (EUNENBS) to assess and recommend a core panel of disorders to be screened.[20] The membership of EUNENBS consisted of experts in paediatrics, genetics, public health, health technology assessment, epidemiology, economics, and ethics.[5] A key element was a systematic decision-making matrix to be used by member states to evaluate their screening protocols. The report provided a framework for discussions on European NBS screening policies around the assessment of evidence and the delivery of future health services.[20] The EUNENBS made 70 recommendations on areas identified for improvement, including programme governance, evaluation, communication of results, diagnostic criteria, and quality assurance.[20] They also recognised the need for a process to consider disorders for an expanded NBS service.[20] With great foresight, they also recommended a decision-making matrix that could be used by member states to systematically expand (or contract) screening mandates. The report provided a framework to start the debate on NBS screening policies. Among the outcomes identified were that further work was required to develop case definitions for all disorders screened and an examination of the relevance of the ethical framework to current knowledge of disease, treatment, test, and costs.

The experts recognised that the interests of the child should be paramount in the development of NBS policy and that guidelines should not dictate how states operate services or the disorders that are screened. They accepted that diversity between populations and different funding scenarios should determine how each NBS service is structured. However, they did recognise the benefits of a centralised expert and authoritative body and recommended that it should provide guidelines for local health systems.[27]

New Zealand

In 2005, the New Zealand Ministry of Health's National Screening Unit (NSU) assumed leadership of the National Newborn Screening Programme. Between 2007–2009 the NSU undertook consultations with community groups, clinical and scientific stakeholders, and government policy advisors to develop a national NBS policy.[28] A comprehensive framework, released in 2011, outlined the governance structure of the national NBS service and specified the roles and responsibilities of health service providers with reference to the relevant national legislation and regulations.[28] The framework also describes a process for consultation between the NSU and NBS experts to determine the appropriate screening panel and strategic directions of the national NBS service.[28] The process for review of each condition nominated for NBS requires a cost-benefit analysis, stakeholder consultation, literature review, and international expert advice.

Common challenges for NBS

All national NBS programmes face similar policy issues (Table 1). Many new disorders being proposed for NBS have low incidence and for some screen-positive cases. However, for many, the natural history of the condition is unpredictable. These ambiguities create unique issues when planning NBS services for rare genetic disorders. In order to define the clinical and biochemical phenotypes of disorders that are suitable targets for NBS with appropriate clinical validation of cut-off values, multi-centre collaborations across several countries are essential to secure sufficient evidence.[29]

Table 1: Common goals for national NBS

1. Coordination of national standardised NBS services.
2. Processes to evaluate new technologies and tests.
3. Mechanisms to recommend amendments to NBS panel using evidence-based criteria.
4. National reporting, monitoring, and evaluation of NBS services.
5. Protocols for consent, retention, storage, or return and further use of residual bloodspots.
6. Education of parents and healthcare personnel involved in NBS services.
7. Harmonisation of a national legal and regulatory framework.
8. Deliberation on economic, ethical, and clinical issues with community and multidisciplinary specialist stakeholders.
9. Defined roles of funding bodies to support and maintain national NBS standards.

Australian NBS policy

Australian NBS services are supported by health departments in each state as voluntary, universal, and free public health initiatives. Each state provides additional diagnostic testing, education, clinical follow-up, monitoring, and quality assurance. A Joint Newborn Screening Committee of the Human Genetics Society of Australasia (HGSA) and the Division of Paediatrics of the Royal Australasian College of Physicians (RACP) has published a screening policy for health professionals[30] and recommended a structure for organisation and operation of NBS programmes to screen disorders that are almost

entirely metabolic in nature. Over the past decade, Australian NBS services have maintained a relatively consistent approach to the use of technology and the number and type of disorders screened,[30] although differences have begun to emerge. For example, there are differences in the number of mutations tested in the cystic fibrosis gene[31,32] and Victoria has implemented a written protocol requiring parental consent to collect blood for NBS with an additional option to make the excess blood available for de-identified health research.[33]

The current NBS model has served Australia well for 50 years, but a different paradigm is needed to guide Australian NBS services into the future. Advances in genetic diagnoses and therapies challenge current practices and bring greater opportunities.[11,22] Until recently, neither state nor federal governments have engaged with issues related to the scope, risks, and benefits of deciding what disorders to screen and how to manage the complex ethical, regulatory and technical context on NBS services.[2,34–36] In 2003, the Australian Law Reform Commission recommended that Australian states adopt nationally consistent rules in relation to the collection, storage, use and disclosure of, and access to newborn screening cards and standards in relation to the development and implementation of such services. In response, the Australian Health Minister's Advisory Council (AHMAC) established a group to develop guidelines for a national policy framework in consultation with clinical and community stakeholders. The work of that group floundered when the Joint Newborn Screening Committee withdrew support. A second initiative led by the Office of Population Health Genomics in the Western Australia (WA) Health Department has begun to develop a national policy framework for newborn bloodspot screening for the Health Ministers Advisory Council. This is a welcome development but so far, progress has been slow and the issues of planning, resourcing, and implementing national screening standards remain unresolved.[34,36]

A national framework would provide a mechanism to recommend those disorders considered suitable for inclusion in a universal NBS panel and evaluate national performance against agreed standards. State NBS services lack a process to coordinate an expansion of NBS services for rare disorders nationally. Rational policy decisions on the future of NBS services require formal mechanisms involving government and stakeholders to review and implement decisions. This is illustrated by the failed attempts to find a forum to consider NBS for congenital adrenal hyperplasia (CAH) in Australia. Despite strong clinical support and affirmative systematic evaluations of risks and benefits, all attempts to promote national NBS for CAH have failed.[37] Neither state nor federal governments have been able to agree how to share responsibility for providing the coordination of public health NBS services[36] and state-based NBS services have been left on their own to resolve legal, technical, and regulatory issues.[34]

Multidisciplinary contribution to decision making

In the future, decisions about evaluating evidence for which other disorders to expand NBS will require input from experts in disciplines currently outside the composition of the current HGSA/RACP Joint Committee. Expanded screening for CAH and severe combined immunodeficiency syndrome (SCID) are just two disorders that are currently being promoted for inclusion into NBS. If adopted, implementation of screening for these disorders would require increased capacity for paediatric endocrine and immunology services and additional technical resources for gene-based assays.

Separation of policy and operational responsibility

Muir Gray proposed that the purpose of evidence-based policy making is to set the context in which evidence-based clinical practice can take place.[38] The organisational structure required to plan expanded NBS services should require policy, priority setting, and national monitoring activities be separated from the day-to-day operational activities of the multi-specialist team responsible for service delivery. The public policy responsibilities of government for legislative, financial, and administrative mechanisms provide the structure to define and coordinate NBS services. State governments play an important role in the operational delivery of NBS services, monitoring, education, and coordination of medical specialities and nursing staff employed by public and private organisations.

Formal advisory role to the Australian Health Ministers' Advisory Council

National population screening programmes share a common governance structure: major policy decisions are determined by AHMAC, through a Standing Committee on Screening. The overall role is to coordinate the development and implementation of national strategies relating to primary and secondary prevention.[38] AHMAC plays a central coordination role in the development of national policies and the implementation of national strategies relating to primary and secondary prevention. In the past, Australian governments have established healthcare agreements to support national population screening programmes for mammography, cervical cancer, bowel cancer, and the Australian childhood immunisation

programme. NBS services require government input to maintain universal access, uniform testing protocols, and centralised evaluation and monitoring. A national NBS framework delivers a national, uniform, public health service, economies of scale, and transparent evaluation of programme performance. Together, these would sustain NBS services to deliver the best evidence-based healthcare available to children with rare genetic disorders.[6]

Conclusion

Australia lags behind international experience in the development of a national health policy agenda for NBS and remains ill-prepared to address the challenges of expanding services for our population.[34,36] A national NBS framework is essential for stakeholders to determine priorities for standardised NBS services, expanded NBS services, and operating NBS services within a formal ethical, legal, and policy construct. The outcomes will enable states to establish accords that define responsibility for managing NBS services within harmonised national guidelines endorsed by AHMAC.

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