



**An Bille fá Choiste Comhairleach Náisiúnta um
Braitheoireacht, 2020**
National Screening Advisory Committee Bill 2020

Meabhrán Mínitheach
Explanatory Memorandum



**AN BILLE FÁ CHOISTE COMHAIRLEACH NÁISIÚNTA UM
BRAITHEOIREACHT, 2020
NATIONAL SCREENING ADVISORY COMMITTEE BILL 2020**

EXPLANATORY MEMORANDUM

Introduction

The objective of this Bill is to expand the National Newborn Bloodspot Screening Programme in Ireland which has the potential to allow for life-saving treatment for at least one child per week.

Such a proposal represents a considerable saving to the Exchequer in terms of obviating lengthy, expensive and ultimately ineffective treatment.

The Bill also implements the recommendations of the Scally report by placing the National Screening Advisory Committee on a statutory footing and requiring open disclosure, as well as accountability in respect of all screening programmes in the State.

The National Newborn Bloodspot Screening Programme

Newborn bloodspot screening ascertains whether a child, who may look healthy and well, is suffering from certain biochemical or metabolic disorders which can be extremely serious but are also treatable if identified at an early stage.

The newborn screening programme for the condition phenylketonuria (PKU), known colloquially as ‘the PKU test’, was started in Ireland on behalf of the Department of Health by Drs Seamus Cahalane and Doreen Murphy at the Children’s University Hospital, Temple Street in February 1966. A number of other conditions have since been added, with all babies born in Ireland on or after December 2018 now offered screening for 8 conditions through the National Newborn Bloodspot Screening Programme (hereinafter referred to as the NNBSP). All the conditions tested cause either mental handicap or life-threatening illness unless they are detected early.

There is no specific legislative act providing for the NNBSP.

The National Rare Disease Plan for Ireland¹ published in 2014 recognised the need to support the further development of the NNBSP. Bar the addition of two new conditions to the test in 2018, there has been no further development of the screening programme.

¹ *National Rare Disease Plan for Ireland 2014 – 2018*, Department of Health (2014) (<https://health.gov.ie/wp-content/uploads/2014/07/EditedFile.pdf>).

National Screening Advisory Committee (NSAC)

The Scally Report² in 2018 recommended the establishment of a National Screening Committee as an independent expert advisory committee responsible for considering population screening programmes in Ireland against internationally accepted criteria.

The National Screening Advisory Committee (NSAC) had its inaugural meeting on the 18th November 2019. The NSAC is an independent advisory committee and will advise the Minister and Department of Health on all new proposals for population-based screening programmes and revisions to existing programmes. The Minister for Health has asked that this Committee prioritise a review of the National Newborn Bloodspot Screening Programme (NNBSP) and specifically how to progress its expansion.

Section 1 – Definitions

This is a standard provision. It defines certain terms for the purposes of the Bill.

Section 2 - Establishment of National Screening Advisory Committee

Subsection (1) establishes the National Screening Advisory Committee on a statutory footing.

Subsection (2) provides that the NSAC will be independent.

Subsection (3) sets out that the HSE will provide the NSAC with any administrative services that it may need in order to conduct its meetings.

Subsection (4) applies the procedural details as set out in the Schedule to the NSAC.

The National Screening Advisory Committee (NSAC) has been in existence since its inaugural meeting on the 18th November 2019. The NSAC is to provide independent expert advice to the Minister for Health on screening programmes in Ireland. The Committee was a key recommendation of the Scally Report in 2018. However, a persistent recommendation of the Scally Report was the need for greater openness and transparency in the provision of our health services. The establishment of the National Screening Advisory Committee on a statutory footing accords with the recommendations of the Scally Report.

Section 3 – Functions of Advisory Committee

Subsection (1) sets out that the functions of the NSAC in the first instance is to advise and make recommendations to the Minister in relation to any screening programme in Ireland. Secondly the NSAC must report to the Minister under *section 5* of this Bill.

Subsection (2) provides that the NSAC may gather information and consult with whomever it may need to in order to perform its functions.

Subsection (3) provides the NSAC with all powers necessary for or incidental to the performance of its functions.

Section 4 - Conferral of additional functions

This is a standard provision. It allows the Minister for Health to draft an order which must be laid before Houses conferring the NSAC with any additional functions it may need to perform effectively.

² Scally G, 'Scoping Inquiry into the CervicalCheck Screening Programme', page 145 (<http://scallyreview.ie/wp-content/uploads/2018/09/Scoping-Inquiry-into-CervicalCheck-Final-Report.pdf>).

Section 5 - Reports of Advisory Committee

Subsection (1) requires the NSAC to report and make recommendations to the Minister for Health in relation to the expansion of the conditions tested for by the National Newborn Bloodspot Screening Programme within 6 months of this bill being enacted. The Minister must also cause copies of that report to be laid before each House of the Oireachtas.

Subsection (2) requires the NSAC to provide the Minister with an annual report in writing to the Minister of its activities during that year and the Minister must also cause copies of those reports to be laid before each House of the Oireachtas.

Subsection (3) sets out the information that the NSAC should detail in its annual report. In particular, the NSAC should advise and make recommendations to the Minister in relation to the expansion of the list of conditions tested for by the National Newborn Bloodspot Screening Programme on an annual basis.

Subsection (4) provides that, where the Minister decides not to accept a recommendation of the NSAC, the Minister must, within 1 month of being given a copy of the NSAC reports containing their recommendations, prepare and lay a statement of the Minister's reasons for not accepting the NSAC's recommendations.

Subsection (5) defines the National Newborn Bloodspot Screening Programme.

This section is where the objective of this legislation is met. The section requires the NSAC to report and make recommendations to the Minister within 6 months of this Bill being enacted on the conditions tested by the Newborn Bloodspot Screening Programme. It acknowledges that work is being done by the already established NSAC but puts a deadline on that initial piece of work.

The section requires that the NSAC reports annually on the conditions tested by the Newborn Bloodspot Screening Programme, so that the programme and the addition of conditions to be tested always remains a central part of the Committee's work and focus.

The section also makes the Minister answerable to the Houses in circumstances where he does not accept the recommendations of the NSAC. This encourages open disclosure, a central recommendation of the Scally Report in 2018.

Section 6 - Short title and commencement

This is a standard provision. It also provides that the Bill will commence within 3 months of being enacted.

Schedule - Procedural Issues relating to Advisory Committee

The Schedule contains the standard provisions that must accompany the establishment of a body such as the NSAC on a statutory footing.

The Schedule sets out the *membership* of the Committee which closely mirrors the career track records of the current 20 members of the NSAC. It specifically provides for a patient advocate member of the Committee at paragraph (2)(a)(iii). It also requires gender balance amongst the Committee members.

The Schedule provides that the *term of office* for members of the NSAC is 7 years, which can be held consecutively for a total of no more than 14 years.

The Schedule provides that the members of the non-statutory NSAC will become members of the statutory NSAC and that the 7-year term will commence on enactment of this Bill. (*Appointment of Initial Members*)

The Schedule provides that *remuneration* (if any) and other terms and conditions of the office will be set by the Minister for Health, in consultation with the Minister for Public Expenditure and Reform.

The Schedule provides the detail on the resignation, removal, disqualification etc. of members of the NSAC.

The Schedule requires members to *disclose interests* in any material matter to be considered by the NSAC and that the Minister may, if he or she deems fit, disqualify a member of the NSAC for failing to disclose such interests.

The Schedule prohibits the *unauthorised disclosure of confidential information* obtained a person in any capacity that engages with the NSAC and makes it a criminal offence to do so.

A member of the NSAC cannot be a *member of either House of the Oireachtas or European Parliament*.

The Schedule obliges the chairperson of the NSAC to *appear before Oireachtas Committees* whenever requested to do so.

The Schedule allows the NSAC to set its own *procedure and quorum* for meetings.

*Senator David P.B. Norris,
Senator Victor Boyhan,
Senator Gerard P. Craughwell,
Meán Fómhair, 2020.*