



National Screening Advisory Committee

**National Screening Advisory Committee (NSAC)  
Note of the meeting held on 21 October 2021**

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**Members present:**

- Professor Niall O’Higgins (Chair)
- Professor Sheelagh McGuinness
- Dr James O’Mahony
- Martina Fitzgerald
- Irene Regan
- Dr Ellen Crushell
- Dr Paul Kavanagh
- Jillian van Turnhout
- Professor Michael Rigby
- Professor Keelin O’Donoghue
- John Gleeson
- Dr Abigail Collins
- Dr Susan Kent
- Dr Jenny Mc Sharry
- Dr Mary Codd
- Dr Velma Harkins

**Observers:**

- Fiona Murphy, CEO, National Screening Service
- Louise Loughlin, National Manager, National Advocacy Service for People with Disabilities, Observer

**Secretariat:**

- Evette Wade, Population Health Screening Unit
- Jane Hannon, Population Health Screening Unit
- Luke Kearney, Population Health Screening Unit

**Department of Health:**

- Kate O’Flaherty, Population Health Screening Unit

**Health Information and Quality Authority (HIQA):**

- Dr Patricia Harrington, Deputy Director of Health Technology Assessment (HTA)
- Dr Susan Spillane, Head of Assessment, Health Technology Assessment (HTA)
- Dr Laura Comber, Senior Health Technology Assessment (HTA) Analyst

**Member Apologies:**

- Professor Andrew Green
- Dr John Ward
- Professor Ciaran O’Neill

**Observer Apologies:**

- Dr Mary Rose Sweeney, Irish Universities Association (IUA), Heads of School of Nursing and Midwifery Group

**1. Welcome & Introductions**

The Chair welcomed everyone to the meeting.

**a) Conflict of Interest**

There were no new conflicts of interests declared.

**b) Apologies**

Apologies were received from Professor O'Neill, Professor Green and Dr Ward.

**c) Observers attending**

Fiona Murphy and Louise Loughlin were in attendance. Apologies were received from Dr Sweeney.

**d) Chair's update on recent developments**

The Chair informed the Committee that Anne Burke's term of membership has come to an end. Anne joined the Committee on its establishment, as one of the Public Voice representatives. Her valuable input and contribution was acknowledged by the Chair.

The Chair also noted that Dr Alan Smith, DCMO has moved on to a new role within the Health Service. His valuable work in supporting the establishment of the Committee and laying the foundations for how the Committee carries out its work was acknowledged.

**e) Minutes of the 20 May 2021 meeting**

The minutes of the 20 May 2021 meeting were agreed and signed by the Chair.

**f) Matters arising**

There were no matters arising.

**2. NSAC Ethics Framework**

**a) HIQA Draft Review of international ethics frameworks used in policy-making in the context of screening**

The Chair welcomed and thanked members of the dedicated HIQA support team for their work in producing the document '[DRAFT Review of international ethics frameworks used in policy-making in the context of screening](#)'.

The purpose of the HIQA report is to describe their review to outline ethics frameworks used internationally for policy-making around screening, with the goal of informing the development of the NSAC ethics framework.

This document was provided to members in advance of the meeting where HIQA delivered a presentation on its contents. The presentation referred to the research questions and objectives of the review and then covered the methodology and sources of information used in production of the document. Sources used were websites and surveys of bodies with responsibility for screening such as public health agencies, national ethics bodies and other relevant international agencies.

An ethics framework will provide an important structure to support evaluations and deliberations of the Committee in relation to population-based screening programmes. It is envisaged that the framework will detail both substantive values for the assessment of screening policy and procedural values to guide the deliberations.

#### **b) Professor Sheelagh McGuinness – NSAC Ethics Framework**

Professor McGuinness presented to the members regarding progress made so far in the development of the NSAC Ethics Framework and the next steps in the process.

Following the presentation, the Committee discussed the next steps in the development of the NSAC Ethics Framework. The first phase is now complete, and it is expected that HIQA will publish the above-mentioned report on their website in the coming weeks.

The next phase will be progressed by Professor McGuinness working with the Department of Health and other stakeholders. This will likely involve the establishment of an expert advisory group and case study analysis and discussions, as well as wider stakeholder engagement. It is envisaged that a draft NSAC Ethics Framework based on the recommendations of the HIQA report will be available for the Committee to consider in early 2022.

#### **c) Approval of next phase of the development of the NSAC Ethics Framework**

The Committee commended HIQA on an excellent and valuable report, formally endorsed the HIQA report and its conclusions, and agreed to move onto the next phase of the process.

The importance of ensuring that stakeholder engagement for the next phase of the work is inclusive, diverse, and representative of the population was noted. In addition, a suggestion was made to reach out to HRB and UK NSC colleagues who may be in a position to provide their expertise in the development of the NSAC Ethics Framework.

**Action – Professor McGuinness to work with the Department of Health and other stakeholders to develop a draft NSAC Ethics Framework based on the recommendations of the HIQA report for consideration early in 2022.**

### **3. Expansion of the Newborn Bloodspot Screening Programme**

#### **a) Update from Department**

- Kate O’Flaherty provided a verbal update to the Committee regarding progress since the last meeting: HIQA published their evidence review document ‘[Review of processes in use to inform the expansion of newborn bloodspot screening programmes](#)’ in July 2021.
- Officials from the Department of Health met with members of the HSE National Newborn Bloodspot Screening Programme Governance Group to discuss the provision of a list of conditions which may be considered by the Committee.
- Following on from the NSAC recommendation for the addition of ADA SCID (Adenosine Deaminase Deficiency – Severe Combined Immunodeficiency) to the National Newborn Bloodspot Screening Programme, HIQA have now begun preparatory work on an evidence review in respect of the addition of other SCID types. This follows a reaffirmation of the recommendation from the National Newborn Bloodspot Screening Programme Governance Group.

It is proposed that HIQA will follow a stepwise (two-phase) process. In the first phase, evidence supporting screening for SCID based on the technology known as TREC (T cell receptor excision circles) will be conducted. A second phase may then be undertaken to assess the economic, organisational, social, ethical and legal implications of introducing TREC-based screening for SCID in Ireland.

A multidisciplinary expert advisory group (EAG) will also be convened by HIQA to advise the Evaluation Team during the course of the review.

It is envisaged that draft reports relating to this piece of work will be available for the Committee to consider in early 2022.

#### **b) Clinical recommendations from the HSE National Newborn Bloodspot Screening Programme Governance Group (NNBSPGG)**

The HSE National Newborn Bloodspot Screening Programme Governance Group wrote to the Chair about the request to provide a list of conditions which may be considered by the Committee. This correspondence was circulated to the Committee members and discussed at the meeting.

Dr Abbey Collins, who in addition to being a member of the Committee is currently the Interim Chair of the HSE National Newborn Bloodspot Screening Programme Governance Group, provided explanation and clarification on the contents of the correspondence.

The list of conditions is based on expert opinion from knowledge of cases, and high level of broad understanding of whether something could be screened for and the impact earlier screening is likely to have on outcomes for children with these conditions.

It was highlighted that a significant amount of work would be required to research and produce a comprehensive prioritised list of conditions that may be included on the National Newborn Bloodspot Screening Programme, and that the conditions listed in the letter is neither an exhaustive nor a prioritised list.

Following discussion, it was agreed that the next stage is the development of a methodology for prioritisation of conditions for consideration by the Committee for evidence assessment and evaluation by HIQA. The Department of Health will engage with a working group containing some members of the NSAC and the specialist team in HIQA who support the work of the Committee to develop this methodology.

**Action – Department of Health to progress the development of a methodology for prioritisation of conditions for consideration by the Committee.**

#### **4. NSAC Annual Call 2021 - NSAC Annual Call 2021 launch plan**

Kate O’Flaherty gave a presentation to the Committee regarding the progress of the first NSAC Annual Call and the plan for its launch on 1<sup>st</sup> November 2021. The Committee will be seeking proposals for new population-based screening programmes or changes to existing programmes.

Both the Chair of the Committee, Prof Niall O’Higgins, and the Public Voice representative, Jillian van Turnhout will be available for media interviews on behalf of the Committee to ensure that the Annual Call is publicised as much as possible.

#### **5. Member discussion proposal - Cost-effectiveness threshold for screening interventions**

Dr O’Mahony provided the Committee with a note on cost-effectiveness thresholds for screening interventions. It was agreed that Dr O’Mahony would write a letter to the Department in this regard.

**Action – Dr O’Mahony to write to the Department in relation to cost-effectiveness thresholds.**

#### **6. Updates on impact of COVID-19**

Fiona Murphy, CEO of the National Screening Service, gave a presentation to the Committee regarding the impact of the COVID-19 pandemic on screening services. The Committee were informed that despite the disruption caused by COVID-19 and the recent Cyber Attack on the HSE, all NSS screening programmes have resumed.

## 7. NSAC Work Programme

The Secretariat provided an update on progress achieved in 2021 and an overview of the 2022 work programme. The proposed Draft 2022 NSAC Work Programme might include:

- A substantial element of the Committee's work programme for 2022 will be the consideration of proposals submitted to the Annual Call 2021, and development of processes for management of proposals including prioritisation and selection for further assessment by HIQA.
- Development and adoption of the NSAC Ethics Framework early in 2022.
- The NSAC Annual Report 2021 will be published in quarter one of 2022.
- The Secretariat will plan for the launch of the 2022 Annual call in quarter four of 2022.
- Consideration of antenatal screening for foetal anomaly.
- Consideration of international developments in relation to the use of AI in population-based screening.

Members were asked to email the Secretariat with any further suggestions for additions to the 2022 work programme.

**Action: The Secretariat will collate responses from members in relation to the suggested work programme for 2022 and present to the Committee at its first meeting in 2022.**

## 8. NSAC Membership update - NSAC Membership extension and vacancies

There are currently 2 vacant positions on the Committee in the areas of Pathology & Public Voice. The Secretariat is working on plans to fill these positions.

**Action: Secretariat to progress with the process for filling the vacant roles.**

## 9. Observers Comments

It was suggested that providing the Observers with confidential access to meeting papers would allow them to be more effective in their role. The Chair agreed to this request going forward.

It was suggested to review the role of Observers and to reflect that in the Committee's standing orders.

**Action: The Secretariat will review the NSAC Standing Orders to reflect the role of Observers.**

**10. Administrative**

**a) Correspondence received**

Correspondence received was noted by the Committee.

**b) 2022 meeting schedule**

Proposed dates for the Committee's 2022 were suggested by the Chair:

- Thursday 17 February 2022
- Thursday 26 May 2022
- Thursday 22 September 2022
- Thursday 17 November 2022

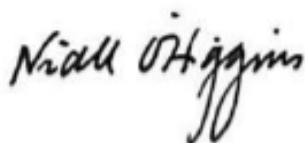
**c) National Screening Advisory Committee Bill 2020 – Second Stage Bill raised in Seanad Éireann on 30 September 2020**

Kate O'Flaherty gave a verbal update on the National Screening Advisory Committee Bill 2020 which is currently before Seanad Éireann at Second Stage.

The Chair thanked the members and observers of the Committee for attending and concluded the meeting.

**National Screening Advisory Committee (NSAC)  
Chair's Action  
Following the 21 October 2021 meeting  
Notification of Chair's action on behalf of the NSAC**

Action Number	Item to be addressed	Initial status	Reason for action	Decision
1	No Chair actions recorded			



Professor Niall O'Higgins

**Date:** 17 February 2022