



National Screening Advisory Committee

**National Screening Advisory Committee (NSAC)
Note of the meeting held on 20 May 2021**

Members present:

- Professor Niall O’Higgins (Chair)
- Dr Sheelagh McGuinness
- Dr James O’Mahony
- Ms Martina Fitzgerald
- Ms Irene Regan
- Dr Ellen Crushell
- Dr Paul Kavanagh
- Ms Jillian van Turnhout
- Professor Michael Rigby
- Professor Keelin O’Donoghue
- Mr John Gleeson
- Professor Ciaran O’Neill
- Dr Abigail Collins
- Ms Anne Burke
- Dr Susan Kent
- Dr Jenny Mc Sharry

Observers:

- Ms Fiona Murphy, CEO, National Screening Service
- Dr Mary Rose Sweeney, Irish Universities Association (IUA), Heads of School of Nursing and Midwifery Group

Secretariat:

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

Department of Health:

- Kate O’Flaherty, Population Health Screening Unit
- Dr Alan Smith, DCMO
- Emma Craven, Population Health Screening Unit

Health Information and Quality Authority (HIQA):

- Dr Máirín Ryan, Deputy Chief Executive and Director of Health Technology Assessment (HTA)
- 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

Apologies:

- Dr Mary Codd
- Professor Andrew Green
- Dr John Ward
- Dr Velma Harkins
- Ms Louise Loughlin, National Manager, National Advocacy Service for People with Disabilities, Observer

1. Welcome & Introductions

The Chair opened the meeting and welcomed Dr Mc Jenny Sharry who has been appointed to the Committee by the Minister for Health in order to fill the psychology vacancy. Apologies were noted and the Chair also welcomed the observers. No new conflicts of interest were identified by the members or observers of the Committee.

The Committee approved the minutes of the previous meeting which took place on 18 February 2021, which will be published on the NSAC website.

Under matters arising, Dr O'Mahony asked that the NSAC consider requesting information from the Department of Health regarding the cost effectiveness threshold concerning population-based screening programmes. The Chair agreed to consider the request and revert to Dr O'Mahony.

Action: Secretariat to publish the minutes of the 18 February 2021 meeting on the NSAC website

Action: Chair to consider the request from Dr O'Mahony

2. Process for approval and adoption

a) NSAC Application Process - modification to existing programmes

Dr Alan Smith presented the Committee with the draft process for receiving applications for modifications to existing population screening programmes. This was followed by discussion noting that:

- it is intended to open applications for both new screening proposals and modifications to existing programmes, at an 'Annual Call' process which would be open to the HSE, professional bodies and the public;
- while applications for new screening programmes will be sought under the 'Annual Call' process, applications for modifications to existing programmes can be made at any time should new relevant evidence become available;
- the Committee noted the importance of having a transparent prioritisation process to manage the resources within HIQA and maintain public trust in the process, and
- if the modification application route is successful, the NSAC will make a recommendation to the Minister for Health for a formal policy change for an existing programme.



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The Committee approved the NSAC Application Process and the Secretariat will publish the process on the NSAC website.

Action: Secretariat to publish the NSAC Modifications to Existing population screening programmes application process on the NSAC website.

3. HIQA Evidence Review (Newborn Bloodspot Screening)

a) Review of processes in use to inform the expansion of newborn bloodspot screening programmes

The Chair welcomed members of the dedicated team from HIQA which is in place to support the work of the NSAC.

In order to inform the expansion of Newborn Bloodspot Screening (NBS) programme, which is an important priority for the Committee, at the request of the Committee, HIQA produced the evidence review document: **DRAFT Review of processes in use to inform the expansion of newborn bloodspot screening programmes.**

This document was provided to members in advance of the 18 May meeting where HIQA delivered a presentation on its contents.

This document provides a comprehensive review of the experience and approaches of other countries in expanding NBS, in addition to the scientific and technological information, ethical, legal and societal issues arise when planning an enduring population-based programme of this nature.

Following the presentation, the Committee took part in a wide ranging facilitated discussion. The purpose of the facilitated discussion was to obtain the input of the NSAC members on a number of key considerations outlined within the document:

- What balance should be given to the different potential beneficiaries of screening (that is, the child, the family, society)
- What is the appropriate balance between (i) rigour of policy-making and (ii) timeliness of additions to NBS?
- To what extent should consideration be given to wider ethical, legal and societal implications, and what weight should these carry?
- How should the prioritisation and selection process operate (for example, informal process, ranking against criteria, formal prioritisation process)
- Within the assessment of conditions for possible expansion of the NBS programme, what forms of evidence should be considered?
- What support tools, if any, should be used to guide decision-making (for example, numerical-based ranking methods, use of frameworks or checklists)?
- Should recommendations on conditions for the expansion of the NBS programme be categorical/conditional in nature, or binary?

The Committee concluded that there are several potential conditions that could be selected for consideration for addition to the NBS programme in Ireland and could therefore be subjected to formal assessment by HIQA in the coming months.



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HIQA will produce a statement of outcomes resulting from the discussion for the Committee which will inform the next steps in consideration of the expansion of the Newborn Bloodspot Screening Programme.

Action: HIQA to produce Statement of Outcomes for the Committee

Action: Chair to write to the Minister for Health to provide an update on progress following the Committee's discussion of the HIQA report on the processes in use to inform the expansion of newborn bloodspot screening programmes.

4. Updates from Members

a) Antenatal screening for fetal anomaly in Ireland - Prof Keelin O'Donoghue,

Prof O'Donoghue updated the Committee on the current situation in Ireland in regard to antenatal screening for fetal anomalies.

b) NSAC Ethics Framework - Dr Sheelagh McGuinness

Dr McGuinness provided the Committee with an update on her work in developing an Ethics Framework for the NSAC, highlighting that ethical considerations should be integrated into the work of the Committee. It was agreed that the support team in HIQA would be engaged in order to produce a scoping review on best ethical practice by screening committees internationally and also within national bodies.

Action: HIQA to produce a report on their review of international ethics frameworks used in policy-making in the context of screening for the Committee.

5. Updates

a) Communications Update

Kate O'Flaherty provided the Committee with an overview of activity since the last meeting, particularly surrounding the publication and reception of the NSAC Annual Report 2020.

It is anticipated that the next communications opportunity for the Committee will be the launch of the 'Annual Call' for new screening proposals.

The Secretariat will continue to keep the Committee up to date in relation to the NSAC Communications Plan.

Action: Secretariat to keep the Committee up to date in relation to the NSAC Communications Plan.

b) NSS paper on COVID-19 impact on screening

Kate O’Flaherty provided the Committee with an update on the current situation within the National Screening Service, informing them that all screening services had resumed following disruptions caused by COVID-19. It was agreed to have a further substantive discussion on the topic at the October meeting.

Action: Secretariat to add this topic to the agenda for the October 2021 NSAC meeting

7. Administrative

a) Correspondence received

Correspondence received by the Committee in relation to applications for new population-based screening programmes were noted. The Chair noted that responses were provided informing of the upcoming ‘Annual Call’ process and that the senders will be notified when it is live.

b) NSAC members Term of Office

The Chair reminded members to return their Term of Office form to the Secretariat, indicating if they wish to continue with the Committee.

Action: Secretariat to liaise with members in relation to their Term of Office on the Committee

c) Date of next meeting via Microsoft Teams: Thursday 21 October 2021 11am - 2pm

The next meeting is scheduled for Thursday 21 October 2021 from 11am to 2pm.

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



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Chair's Action

Following the 20 May 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	Chair to consider the request from Dr O'Mahony	In progress	Chair will add this item to the Agenda of the next meeting	Complete
2	Chair to write to the Minister for Health to provide an update on progress following the Committee's discussion of the HIQA report on the processes in use to inform the expansion of newborn bloodspot screening programmes	In progress	To keep the Minister updated on progress	Complete

I confirm that I have taken the Chairs action in relation to the decisions recorded above.

Professor Niall O'Higgins

Date: 21 October 2021