



National Screening Advisory Committee

National Screening Advisory Committee (NSAC)

Note of the meeting held on 17 February 2022

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
- Dr Susan Kent
- Dr Jenny Mc Sharry
- Dr Velma Harkins
- Professor Andrew Green
- Dr John Ward
- Professor Ciaran O’Neill
- Dr Aoife Doyle

Observers:

- Fiona Murphy, CEO, National Screening Service
- Louise Loughlin, National Manager, National Advocacy Service for People with Disabilities, Observer
- Dr Mary Rose Sweeney, Irish Universities Association (IUA), Heads of School of Nursing and Midwifery Group

Secretariat:

- Evette Wade, Population Health Screening Unit
- Jane Hannon, Population Health Screening Unit
- Inese Freimane, 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 Susan Spillane, Head of Assessment, Health Technology Assessment (HTA) in attendance for the full meeting.
- Dr Patricia Harrington, Deputy Director of Health Technology Assessment (HTA) in attendance for agenda item three.

- Dr Laura Comber, Senior Health Technology Assessment (HTA) Analyst in attendance for agenda item three.

Member Apologies:

- Dr Mary Codd
- Dr Abigail Collins
- John Gleeson

1. Welcome & Introductions

The Chair welcomed everyone to the meeting.

a) Conflict of Interest

The Chair reminded members of the need to declare any potential conflicts of interest. There were no new conflicts of interests declared. It was noted that if any applications made to the Annual Call that are being considered by the Committee presented a conflict of interest, members should absent themselves from the discussions and decisions in relation to those items.

b) Apologies

Apologies were received from Dr Mary Codd, Dr Abigail Collins and John Gleeson.

c) Observers attending

Fiona Murphy, CEO, National Screening Service, Louise Loughlin, National Manager, National Advocacy Service for People with Disabilities, Observer and Mary Rose Sweeney, Irish Universities Association (IUA), Heads of School of Nursing and Midwifery Group were in attendance at the meeting.

d) Minutes of the 21 October 2021 meeting

The minutes of the 21 October 2021 meeting were discussed and approved with some minor amendments to be made by the Secretariat prior to publishing.

e) Matters arising

The Chair welcomed new member Dr Aoife Doyle who has recently been appointed by the Minister for Health to the Committee as a member with expertise in the area of Pathology.

An action from the last meeting was to update the Standing Orders to reflect the role of the Observers. As the Committee intends to review its Standing Orders later in 2022, in line with its Terms of Reference (ToR), the role of observers will be included as part of that review.

Arising from the last meeting Dr James O'Mahony had indicated that he would write to the Department of Health in relation to the cost effectiveness threshold. Dr O'Mahony advised that there have been some developments concerning the industry agreement about cost-effectiveness thresholds and that he has therefore deferred writing the letter.

The Secretariat proposed that meetings of the Committee might be recorded to aid with minute taking. Members raised some concerns about this and asked that they be provided with the Department of Health's policy on recording meetings. This matter will be brought back to the Committee at the May meeting for further consideration.

2. NSAC Annual Call

Kate O'Flaherty updated the Committee on the response to the first Annual Call for new population-based screening programmes or changes to existing programmes. The Annual Call was launched on 1 November 2021 with a closing date of 23 December 2021 and was supported by a communications and stakeholder engagement plan.

The Committee received 53 applications from a variety of sources which included members of the public, patient advocates, the HSE and health professionals. It was also noted that a number of different submissions came in from various sources for the same conditions.

a) Overview of NSAC Annual Call 2021 and high-level process for assessing proposals

The Chair proposed that, due to the volume of proposals received, the Committee consider the 27 proposals that were received for changes to existing programmes (BowelScreen, BreastCheck, CervicalCheck and the National Newborn Bloodspot Screening (NBS) Programme) at the meeting today and the Committee were in agreement with this approach.

The Committee agreed that it would consider the remaining 26 proposals in relation to new screening programmes and new testing procedures at the May meeting. These submissions have been broadly categorised as follows:

- New Antenatal/Prenatal proposals
- New Adult Cancer proposals
- New Adult non-Cancer proposals
- New testing procedures

The Committee endorsed this approach and considered the proposals for changes to existing programmes one by one.

The CEO of the National Screening Service (NSS), who was in attendance as Observer, absented from the discussions regarding proposals relating to NSS programmes.

b) NSAC Annual Call 2021 – review of proposals to modify existing programmes

BowelScreen

Two proposals for modifications to the BowelScreen programme were received.

Proposal 1: Proposal received from the Irish Cancer Society (ICS) for age eligibility expansion of the BowelScreen programme.

The proposal is for the Committee to consider the expansion of the age range of the BowelScreen programme to those aged 50 to 74 years. The relevance of factors that may have an impact on uptake and overall pathway capacity are also highlighted as important areas.

The Committee discussed the proposal and noted that the current Programme for Government commits to expand the BowelScreen Programme to all aged 55 to 74 years, in line with the National Cancer Strategy 2017-2026. The discussion then focused on the proposal to consider expansion of the programme from 50 to 54 years.

Members noted that consideration needs to be given to capacity in the entire pathway when considering expansion of the age range, which includes endoscopy capacity, surgery, histopathology and treatment. It was also raised whether consideration should be given to the frequency of screening in the BowelScreen Programme.

Decision:

The Committee decided to ask HIQA to look at the evidence for further extending the programme from age 50 to 54 years (i.e., in addition to the expansion to 55 to 74 already committed to in the Programme for Government).

In reviewing the evidence for this extension to the age range, HIQA should also consider the evidence relevant to the following factors:

- The impact of such a change on the pathway and capacity
- The impact of such a change on uptake
- Any other relevant factors

The Committee noted that the evidence review by HIQA might also need to consider the frequency of screening. The Committee also noted that HIQA might consider modelling an overall approach to age expansion that might apply to all our cancer screening programmes.

Action – Chair to write to HIQA to ask that they look at the evidence for extending the BowelScreen programme from 50 to 54 years.

Proposal 2: Proposal received from the BowelScreen Programme for the adoption of a new clinical guideline.

The proposal is that the BowelScreen programme adopts the British Society of Gastroenterology/Association of Coloproctology of Great Britain and Ireland/Public Health England post-polypectomy and post-colorectal cancer resection surveillance guidelines to ensure that BowelScreen is aligned with current clinical practice across the symptomatic service in Ireland (HSE).

Decision:

The Committee decided to recommend to the Minister for Health that this change to the programme can be made due to the extent of evidence provided in the submission.

Action – Chair to write to the Minister for Health to recommend that this change can be made to the BowelScreen programme.

BreastCheck

Proposals were received for modifications to the age range eligibility for the BreastCheck programme from five separate submissions.

Proposal 1: Proposals received for age eligibility expansion of the BreastCheck programme were received from the following:

- Irish Cancer Society (ICS)
- National Screening Service/BreastCheck Programme
- The Cancer Patient Advisory Committee
- Lobular Breast Cancer Ireland
- Patient Advocates

The proposals are for the Committee to consider the expansion of the age range for participation in the BreastCheck programme from age 40 to 49 and age 70 to 74 years, with some variation between the individual submissions on the specific age extension proposed. One submission also proposes consideration of additional surveillance of high-risk cohorts.

Decision:

The Committee decided to ask HIQA to look at the evidence for extending the BreastCheck programme from age 45 to 49 and 70 to 74 years, in line with European Commission Initiative on Breast Cancer (ECIBC) guidelines which have been referenced in some of the submissions.

In reviewing the evidence for this extension to the age range, HIQA should also consider the evidence relevant to the following factors:

- The impact of such a change on the pathway, capacity and resourcing
- Any other relevant factors

The Committee noted that work in relation to surveillance of high-risk cohorts is underway by the National Cancer Control Programme (NCCP). The Committee also noted its Terms of Reference around population-based screening and felt that it was not appropriate for them to consider policy decisions concerning high-risk cohorts at this point.

Action - Chair to write to HIQA to ask that they look at the evidence for extending the BreastCheck programme from age 45 to 49 and 70 to 74 years.

Proposal 2: Proposal received in relation to breast density from Lobular Breast Cancer Ireland and patient advocates.

The proposal from Lobular Breast Cancer Ireland asks that the Committee consider the introduction of standardised breast density notification for all participants in the BreastCheck programme.

The proposal from the patient advocates suggests the establishment of a category of breast density at 40 years so they can be offered mammography and be aware of the need to self-screen under the guidance of their GP.

The Committee noted that breast density may be a relevant factor when considering expanding screening to younger women; however, it was also noted it had limited information about this and noted that reference to breast density was not included in the proposal from the BreastCheck programme.

Decision:

The Committee decided to write to the National Screening Service (NSS) and request information and views from the BreastCheck Programme in relation to this issue. This information may be taken into consideration by HIQA when assessing the evidence for age extension to the programme.

Action - Chair to write to the National Screening Service and request information and views from the BreastCheck Programme on this issue.

CervicalCheck

The Committee received two proposals for modifications to the programme.

Proposal 1: Proposal received from the Irish Cancer Society (ICS) for the addition of a self-sampling HPV test to the CervicalCheck programme.

As this proposal relates to the CervicalCheck programme, Dr Aoife Doyle absented herself from the discussions and decision due to her continuing work with the programme.

The proposal is for the introduction of a self-sampling HPV test to the CervicalCheck programme to increase uptake.

The Committee noted that some early policy scoping regarding self-sampling in the programme is being developed by the National Screening Service and the Department of Health and that further information would be required to feed into considerations.

Decision:

The Committee decided to write to the National Screening Service (NSS) and request information and views from the CervicalCheck Programme on this issue.

Action - Chair to write to the National Screening Service and request information and views from the CervicalCheck Programme on self-sampling in the programme.

Proposal 2: Proposal received from a health professional for the introduction of an HPV vaccination programme to run in tandem with the CervicalCheck programme.

The proposal is for the introduction of a dedicated catch-up HPV vaccination programme, including specifically for those who have had CIN2+ detected in tandem with the CervicalCheck Programme. The Committee notes this proposal refers to a recommendation of the National Immunisation

Advisory Committee (NIAC) and that these policy questions are under consideration by the appropriate policy areas within the Department of Health.

Decision:

The Committee decided that this proposal is outside of the remit of the Committee and asked that the Secretariat correspond with the proposer to that effect. The Secretariat will give guidance to the proposer in terms of other relevant parts of the health system to where they might direct their proposal.

Action – Secretariat to correspond with the proposer to inform them of the Committee’s decision in relation to the proposal for the introduction of a dedicated catch-up HPV vaccination programme.

c) NSAC Annual Call 2021 – review of proposals to modify the National Newborn Bloodspot Screening Programme

As part of the Annual Call 2021, 18 submissions for seven conditions have been submitted in relation to the newborn bloodspot screening (NBS Programme).

The Committee noted that further to their meeting in October 2021, a number of conditions are currently undergoing a preliminary evidence review by HIQA, and that some of these conditions were the subject of submissions.

Five other conditions, which are not included in the preliminary evidence review were also the subject of submissions, and these were as follows:

- Duchenne Muscular Dystrophy
- Hunter Syndrome (mucopolysaccharide type II or MPS II)
- Infantile Nephropathic Cystinosis (known as Cystinosis)
- Spinal Muscular Atrophy
- 22q11.2 deletion syndrome

The Committee were asked to make a decision as to whether these conditions be included in the HIQA preliminary evidence review.

Decision:

It was agreed that the Committee would write to the National Newborn Bloodspot Screening Governance Group to seek information and their views on the five conditions and their view as to their inclusion in the preliminary evidence review that is underway.

Action - Chair to write to the National Newborn Bloodspot Screening Governance Group to seek their views on the five conditions and their view as to their inclusion in the preliminary evidence review.

3. Expansion of the Newborn Bloodspot Screening Programme

a) Prioritisation process: Expansion of the NBS Programme

Kate O’Flaherty updated the Committee on the progress made in developing the methodology for a prioritisation process for expansion of the NBS Programme.

At October 2021 meeting, it was agreed that the Department would engage with HIQA, and some members of Committee to progress this with a view to supporting the Committee in selecting and prioritising the next condition to be considered once the HIQA team complete the HTA for SCID.

In progressing the development of the methodology, it was agreed that an amount of preliminary evidence first needs to be collated, reviewed and considered.

The HIQA team has completed work to gather information for each condition on:

- (a) international practice in screening for the condition, based on HIQA’s previous work for the NSAC on international approaches to expansion of NBS, and
- (b) recent/planned assessments in other key international areas.

Further preliminary data will be gathered on other key criteria such as ‘effective treatment’ and additional Irish clinical/population/trend data which will be helpful in informing the design of the methodology.

b) Update on work ongoing with SCID Health Technology Assessment (HTA)

Dr Laura Comber and Dr Susan Spillane from HIQA presented to the Committee on the work in relation to the consideration of the addition of other SCID types to the NBS Programme (following on from the recommendation in 2020 that ADA-SCID should be added to the Programme). The presentation covered the domains of Health Technology Assessment (HTA), the HIQA process flow for NSAC topics, an overview of HIQA processes and an update on the progress and milestones for the HIQA SCID assessment.

The Secretariat had circulated the ‘Protocol for the Health Technology Assessment of the addition of severe combined immunodeficiency (SCID) to the National Newborn Bloodspot Screening Programme’ to the members prior to the meeting; it was noted that HIQA will publish this in the coming weeks.

The HIQA team will produce the draft report on Phase One of the HTA by the end of March 2022 which will be considered by the Expert Advisory Group (EAG) that has been convened by HIQA in April 2022.

Following input from the EAG, a finalised Phase One report will be submitted to the Committee with a view to the Committee making a decision regarding progression to Phase Two of the HTA process.

The Committee look forward to receiving the Phase One report.

4. Work Programme 2022

The Chair presented to the Committee proposals for the resources required to support the expanded work programme of the Committee in 2022.

The Chair proposed writing to the Minister for Health to outline the situation and the Committee endorsed this approach.

Action – Chair to write to the Minister for Health on behalf of the Committee to outline the resource requirements to support the NSAC work programme.

5. NSAC Ethics Framework

Kate O’Flaherty updated the Committee on the progress on developing the NSAC Ethics Framework.

In line with the approach agreed at the NSAC meetings, the work is progressing through the next phase. The Population Health Screening Unit in the Department has been liaising with the Chief Bioethics Officer in the Department of Health, Dr. Siobhan O’Sullivan, on the development of a high-level project plan.

The work will take a step-wise approach to developing and agreeing; (a) the set of specific values and principles which will underpin the NSAC framework (and which will be based on the findings of the [HIQA report](#)); and (b) an initial draft Framework based on these agreed, specific values.

A Reference Group, comprising Prof McGuinness and a number of experts in this area, is being convened to support the process, and NSAC members will also be consulted during the development process.

Once a draft Framework has been developed with the NSAC and expert Reference Group, it will undergo wider stakeholder consultation before finalisation. A key element of these later stages of the process will be using relevant questions and examples to test the applicability and utility of the draft Framework in supporting the types of decisions that will likely come to NSAC for consideration.

6. Communications and Engagement Update

Kate O’Flaherty updated the Committee on communications and engagement since the last meeting in October 2021. The Committee noted that the Secretariat ran a successful communications and media engagement campaign to ensure that as many people as possible were made aware of the Annual Call and the submission process. This included radio and print interviews, an article in the winter edition of the HSE staff magazine *Health Matters*, and a series of promotional social media posts.

The NSAC website was an important tool in communicating clearly with the public about participation in the Annual Call. The Secretariat engaged with the National Adult Literacy Agency (NALA) to ensure that the information on the website, the submission forms and the accompanying guidance documents were in plain English and easy to understand. During the Annual Call the NSAC website was visited almost 4,000 times. The Secretariat utilised social media posts, including some promoted posts and videos from the Minister for Health and the Chair with 800,000 views over various platforms.

Members of the Committee commended the Secretariat on their work to support the Annual Call and remarked on the encouraging level of engagement with the process by the public.

In late 2021 the Committee launched an expression of interest process for the second Public Voice representative of the Committee which was hosted on the State Boards website. Their network of stakeholders was invaluable to the Committee, and the Committee received a good level of interest for the role.

The next communications opportunity for the Committee will be the publication of the NSAC Annual Report 2021 which is planned for April 2022. The Secretariat have an advanced draft of the NSAC Annual Report 2021 in development that will be circulated to members in the coming weeks ahead of publication.

Action – Secretariat to circulate the draft NSAC Annual Report 2021 to members in the coming weeks for high level comments.

7. Public Voice Vacancy

Jillian van Turnhout updated the Committee on the process that has been followed in the consideration of applications received by the Secretariat for the vacancy of the second Public Voice member.

The selection panel was chaired by Jillian van Turnhout and she was joined by Prof Michael Rigby (NSAC) and Maggie Powell (UK NSC Public Patient Voice member). The panel ensured each application was reviewed and duly considered. Following the deliberations, the panel agreed on a preferred candidate and the Chair was informed. The Secretariat will assist the Chair in completing the process for appointment of the candidate by the Minister for Health.

8. Administrative

The Secretariat noted that correspondence received was primarily related to the first Annual Call and all correspondence has been responded to as part of that process.

The Committee discussed member's preference for remote, in-person or hybrid meetings in 2022. It was agreed that the Committee would plan for a remote meeting in May 2022 and give consideration for an in-person meeting later in the year.

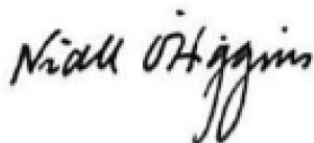
The next meeting of the Committee is on Thursday 26 May 2022.

The Chair thanked everyone for their attendance and careful consideration of the decision topics at the meeting.

**National Screening Advisory Committee (NSAC)
Chair's Actions
Following the 17 February 2022 meeting
Notification of Chair's action on behalf of the NSAC**

| Action Number | Chair's action | Complete yes/no |
|----------------------|---|------------------------|
| 1 | Write to HIQA to ask that (1) to look at the evidence for extending the BowelScreen programme from 50 to 54 years and (2) to look at the evidence for extending the BreastCheck programme from age 45 to 49 and 70 to 74 years. | Yes |
| 2 | Write to the Minister for Health to recommend that this change can be made to the BowelScreen programme. | Yes |
| 3 | Write to the National Screening Service and request information and views from the BreastCheck Programme on breast density and to seek views from CervicalCheck on HPV self-sampling | Yes |
| 4 | Write to the National Newborn Bloodspot Screening Governance Group to seek their views in relation to the five conditions and their view as to their inclusion in the preliminary evidence review. | Yes |
| 5 | Write to the Minister for Health on behalf of the Committee to outline the resource requirements to support the NSAC work programme. | Yes |

I confirm that I have taken the Chairs actions recorded above.



Professor Niall O'Higgins

Date: 26 May 2022