

**National Screening Advisory Committee (NSAC)
Note of the meeting held on 25 May 2023**

Members present:

- Professor Niall O'Higgins (Chair)
- Dr Ellen Crushell
- Professor Michael Rigby
- Professor Keelin O'Donoghue
- Professor Andrew Green
- Ms Dolores Keane
- Dr Paul Kavanagh
- Ms Jillian van Turnhout
- Dr James O'Mahony
- Dr Velma Harkins
- Dr Alissa Connors
- Ms Irene Regan
- Ms Hilary McGouran
- Dr Mary Codd
- Dr Deirdre Murray
- Professor Sheelagh McGuinness

Observers:

- Ms Fiona Murphy, CEO, National Screening Service

Secretariat:

- Evette Wade, Population Health Screening Unit
- Luke Crealy, 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

Health Information and Quality Authority (HIQA):

- Dr Susan Spillane, Head of Assessment, Health Technology Assessment (HTA)
- Dr Laura Comber, Senior Health Technology Assessment (HTA) Analyst in attendance for agenda item 4 & 5
- Dr Helen O'Donnell, Senior Health Technology Assessment (HTA) Analyst in attendance for agenda item 5

Member Apologies:

- Dr Aoife Doyle
- Dr Jennifer McSharry
- Professor Ciaran O'Neill
- Ms Lora Ruth Wogu
- Dr Susan Kent

1. Welcome & Introductions

The Chair welcomed everyone to the meeting, the first meeting of the Committee in person since 2020. The Chair also introduced four new members of the Committee, recently appointed by the Minister, Ms Hilary McGouran, Prof Deirdre Murray, Ms Dolores Keane, and Dr Alissa Connors.

The Chair noted that this meeting marked Professor Keelin O'Donoghue's last as a member of the Committee. He was joined by the members in expressing his gratitude for Prof O'Donoghue's invaluable service to the Committee.

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.

Minutes of the 23 February 2023 meeting

The minutes of the 23 February 2023 meeting were circulated by the Secretariat to Committee members prior to the meeting. The Chair sought any matters of accuracy on the draft document. No matters of accuracy were identified, and the minutes were approved for publishing.

Matters arising

The Chair noted the successful publication of the National Screening Advisory Committee's Annual Report 2022 on 19 May 2023.

2. NSAC Annual Call 2021/2022

The Chair gave a brief overview of the proposals received in both the Annual Call 2021 and 2022 for the new members of the Committee.

The Secretariat provided a progress update on the NSAC Annual Call 2021 and 2022. The NSAC Work Programme has been updated accordingly on the Committee's website.

Age expansion in BowelScreen and BreastCheck

Proposals were received in Annual Calls 2021 and 2022 for the expansion of the age range eligibility in BowelScreen (50 to 74 years – in addition to the 55 to 74 already committed to in the Programme for Government) and BreastCheck (45 to 49 and 70 to 74 years – including consideration of breast density as it applies to the younger cohort).

The Chair has written to HIQA to reaffirm the Committee's decision to proceed to full HTA for both proposals in sequence and asked that the team commence the BowelScreen HTA initially. The submission on Breast Density from Annual Call 2022 has been sent to HIQA.

Abdominal Aortic Aneurysm

The submission to Annual Call 2022 proposed an age range of males aged 60+ and women 65 + who have associated risk factors.

The Chair has now written to HIQA to ask that the team include males aged 60 + and women 65 + who have associated risk factors when examining the evidence for this proposal. The submission from Annual Call 2022 has been sent to HIQA.

Developmental Dysplasia of the Hip

The proposal made to Annual Call 2022, was to introduce a new screening programme to expand the current selective, standardised programme whereby all babies would be routinely referred for ultrasound examination at birth, to be performed by 6 weeks of age, for Developmental Dysplasia of the Hip.

The Chair has written to HIQA to ask that the team look at the evidence in other jurisdictions in relation to ultrasound screening of all newborns for Developmental Dysplasia of the Hip. The submission from Annual Call 2022 has been sent to HIQA.

Familial Hypercholesterolaemia

Two submissions for the introduction of a population-based screening programme for Familial Hypercholesterolaemia (FH) were received in response to Annual Call 2021.

The Secretariat continues to collate information from Europe (Netherlands and Slovenia) on FH and plan to bring a paper to the Committee for consideration at a future meeting.

Genetic Haemochromatosis

Proposal to introduce screening for genetic haemochromatosis in adults in Ireland aged 25 + in primary and hospital settings was received in Annual Call 2022. A second element of the proposal is the introduction of a registry of hereditary haemochromatosis patients to help develop clinical research in the field and improve patient care and healthcare planning.

The Secretariat continues to compile information on Genetic Haemochromatosis and plan to bring a paper to the Committee for consideration at a future meeting.

Fetal Aneuploidy

Submissions for the introduction of a population-based screening programme for first Trimester fetal chromosomal abnormalities/congenital anomaly, also known as Fetal Aneuploidy, were received in response to Annual Calls 2021 and 2022.

As agreed at the last meeting in February 2023, the Chair wrote to the Department of Health and the HSE noting that proposals on Fetal Aneuploidy were received and considered by the Committee.

During the meeting the Committee discussed the suggested revision to wording in the Work Programme and felt more consideration was required to accurately reflect the status of this proposal on its Work Programme.

Action: The Secretariat will revise and update wording of this proposal on the Work Programme.

Lichen Sclerosus

The Chair has written to the National Screening Service (NSS) to seek their views on the Annual Call 2022 proposal on this condition. It was noted in the response from the NSS that no randomised control trials were identified from a rapid scoping review of the literature and that there was no evidence to show that screening for Lichen Sclerosus is effective in reducing mortality or morbidity.

Decision: The Committee decided to change the current status on the Work Programme from 'Under consideration by NSAC' to 'Not approved for screening: Further consideration deferred pending significant new evidence emerging'. The Secretariat will update the proposer on the status of their submission.

Action: The Secretariat to update the NSAC Work Programme based on the Committee's decision which will reflect the proposals current status. The Secretariat will update the proposer on the status of their submission.

3. Cancer Screening

The NSAC Secretariat updated the Committee on the three pilot projects in Ireland on lung, prostate, and gastric cancer.

At the 23 February 2023 meeting the Committee asked the National Cancer Registry of Ireland (NCRI) for data on the incidence and mortality of gastric cancer in Ireland over the past 20 years which were circulated to members ahead of the meeting.

Committee member and Director of NCRI, Prof Deirdre Murray, presented the Committee with an update on the Epidemiology of Gastric Cancer in Ireland.

Implementation of the updated recommendation will be a collaborative process between the Committee, the Department of Health, and national and European stakeholders. The Secretariat will liaise with Departmental colleagues to develop a process to support consideration of the implementation of the updated recommendation in Ireland.

4. Expansion of the Newborn Bloodspot Screening (NBS) Programme

The meeting was paused to welcome Minister Hildegard Naughton, with responsibility for Public Health, Well Being and the National Drugs Strategy, to discuss the work of the Committee and convey good wishes to the Chair on his last meeting.

a) Update from HIQA on the Spinal Muscular Atrophy (SMA) HTA process

Dr Laura Comber, Senior Health Technology Assessment (HTA) Analyst, HIQA, updated the Committee on the work carried out so far on the HTA for the addition of Spinal Muscular Atrophy (SMA) to the NBS Programme.

Dr Comber advised that the Expert Advisory Group (EAG) met in May 2023 and reviewed four draft chapters: Description of technology; Systematic review of clinical effectiveness of screening; Overview and availability of disease-modifying treatment options in Ireland; and Systematic review of cost effectiveness.

HIQA is working on the second group of chapters to be considered at the next EAG meeting which will take place in August 2023. These chapters will cover the Epidemiology and burden of disease; Budget impact and resource implications; Organisational implications; and Ethical and social considerations.

The Committee expects to receive the completed HTA report for consideration in Q4 2023.

b) Update on Expansion of Newborn Bloodspot Screening Programme

The Committee was provided with a paper on the progress of the development of a methodology to inform prioritisation and selection of the next condition(s) for HTA. A group comprising of clinical and testing expertise, representatives from the NBS Programme as well as NSAC members, was convened

to provide expert advice and additional clinical information into this process. This group has met three times, most recently on Friday 12 May 2023.

Evette Wade, NSAC Secretariat, Dr James O'Mahony and Dr Ellen Crushell, members of the Committee, updated the Committee on the recent meeting.

The group discussed the three highest ranking conditions which are the same as previously noted by the Committee: Sickle Cell Disease, Tyrosinaemia Type I, and Biotinidase deficiency.

The NBS Programme and clinicians will provide inputs to the process regarding the possible clustering of metabolic conditions and will reconvene later in the year to discuss the prioritisation and advise Committee accordingly.

The Committee endorsed the ongoing work and the approach to further refine the process.

5. HIQA Work Programme

Dr Susan Spillane, Dr Laura Comber, and Dr Helen O'Donnell gave a presentation to the Committee on the HIQA work programme and progress to date. The Committee considered the preliminary review to inform a HTA of screening for Abdominal Aortic Aneurysm (AAA), and the advice outlined in HIQA's report on Health Technology Assessment of the addition of SMA to the National Newborn Bloodspot Screening Programme. After some discussion the Committee agreed that HIQA should begin the HTA on age range expansion in the BowelScreen programme first, and then commence the HTA on AAA after completion of the final HTA on Spinal Muscular Atrophy.

The Committee noted the preliminary review to inform HTA of screening for AAA and decided that HIQA should focus the initial HTA on males over 65 years only.

The Committee noted HIQA's estimation that evidence review work on Developmental Dysplasia of the Hip would take approximately one to two months and therefore can be executed in tandem with the two larger HTA's and decided that HIQA should proceed on this basis.

Decision: The Committee decided the following sequencing of evidence reviews to be carried out by HIQA: evidence reviews for BowelScreen and AAA to run concurrently. Developmental Dysplasia of the Hip also to be carried out simultaneously, should resources allow.

The Committee had already asked HIQA to look at the evidence for age range extension in the BreastCheck programme (45 to 74 years) including consideration of breast density as it applies to the younger age cohorts. However, given the practicalities and already planned expansion of BowelScreen, the Committee reaffirmed its decision to proceed to full HTA for BowelScreen and BreastCheck proposals in sequence.

Action: Chair to write to HIQA to formally request that the evidence reviews be sequenced as agreed by the Committee.

6. NSAC Standing Orders

The Secretariat sought feedback from the members on the revised Standing Orders document at the previous meeting on 23 February 2023. The document was updated with the input received and

circulated again prior to this meeting. The members were asked to endorse the revised Standing Orders, excluding the section on the role of Observers which was subject to further consideration.

The Committee discussed the role of Observers and the importance of having a clear rationale for their attendance at Committee meetings. The Committee were clear that there should be a consistent approach regarding the conflict-of-interest policy for Observers and members and discussed possible alternative options to ensure Quality Assurance. The importance of transparency and communications with stakeholders and the public was also noted.

Decision: The Committee endorsed the revised Standing Orders, excluding the section regarding Observers.

Action: Secretariat to draft a section regarding Observers for the revised Standing Orders document.

To note: The Observer absented themselves from the meeting for this agenda item.

7. Member Survey

The Secretariat conducted an anonymous survey of the members prior to the meeting, to review Committee functions, and presented feedback received from the members so far. The survey remains open for a further two weeks, and the Chair encouraged members to provide any feedback and observations they may have to Secretariat before the deadline.

The feedback received will be incorporated into an information pack that the Secretariat will provide to the new Chair of the Committee.

Action: Secretariat to collate feedback from the survey and incorporate into the information pack for the new Chair of the Committee.

8. Committee Membership

The Chair noted that a number of members' terms of office will come to an end in October 2023. In the interests of ensuring continuity of the Committee, the Secretariat has been in contact with these members to gauge interest on the extension of some of the members terms to prevent a loss of corporate memory. Several members have indicated that they will leave the Committee when their term of office end in October. The Secretariat will work with members over the coming months to establish who will renew their membership and will arrange a recruitment campaign to fill the vacant positions.

Professor Niall O'Higgins has been the Chair of the Committee since its establishment in 2019 and his term is due to come to an end in June 2023. An expression of interest for the role of Chair was launched on 19 May 2023 with a closing date of Friday 9 June 2023. The Secretariat will oversee the recruitment of the new Chair and members will be kept informed of progress.

9. Communications & Engagement Update

The Secretariat provided an update on recent Communications and Engagement since the 23 February 2023 meeting, which included the publication of the NSAC Annual Report 2022, published on Friday 19 May 2023. The Secretariat has also been engaging with stakeholders in relation to submissions received during the Annual Call 2022.

10. Administrative

The Chair thanked everyone for their attendance and noted that the provisional date for the next meeting of the Committee is 19 October 2023.

11. Chair's concluding remarks

The Chair congratulated the members of the Committee, the Secretariat and Kate O'Flaherty on their enthusiasm, diligence and commitment to the work of NSAC since its inception. He thanked them for the significant achievements in establishing strong operational processes and for the expert advice in

making recommendations on health screening. He emphasised the importance of independence of the Committee and thanked the members for their courtesy and assistance help to the Chair.

**National Screening Advisory Committee (NSAC)
Chair's Actions
Following the 25 May 2023 meeting
Notification of Chair's action on behalf of the NSAC**

Action Number	Chair's action	Complete yes/no
1	Chair to write to HIQA to formally request that the evidence reviews be sequenced as agreed by the Committee. (HIQA Work Programme)	Yes

I confirm that I have taken the Chair's actions recorded above.

SUZANNE CROWE

**Dr Suzanne Crowe
Chair, National Screening Advisory Committee**

Date: 20 October 2023