

# National Screening Advisory Committee (NSAC) Note of the meeting held on 26 May 2022

# Members present:

- Professor Niall O'Higgins (Chair)
- Professor Sheelagh McGuinness
- Dr James O'Mahony
- Martina Fitzgerald
- Irene Regan
- Dr Ellen Crushell
- Jillian van Turnhout
- Professor Michael Rigby
- Professor Keelin O'Donoghue
- Dr Susan Kent
- Dr Jenny Mc Sharry
- Dr Velma Harkins
- Professor Andrew Green
- Dr Aoife Doyle
- Lora Ruth Wogu
- Dr Mary Codd
- Dr Abigail Collins
- John Gleeson

#### **Observers:**

• Fiona Murphy, CEO, National Screening Service

#### **Secretariat:**

- Evette Wade, Population Health Screening Unit
- Jane Hannon, Population Health Screening Unit
- Inese Freimane, 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 3
- Dr Laura Comber, Senior Health Technology Assessment (HTA) Analyst in attendance for agenda item 3
- Mairin Ryan Director of Health Technology Assessment & Deputy CEO in attendance for agenda item 3



# **Member Apologies:**

- Dr Paul Kavanagh
- Dr John Ward
- Professor Ciaran O'Neill

# **Observer Apologies:**

- Louise Loughlin, National Manager, National Advocacy Service for People with Disabilities
- 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

The Chair reminded members of the need to declare any potential conflicts of interest. There were no new conflicts of interests declared.

# b) Minutes of the 17 February 2022 meeting

The Minutes of the 17 February 2022 meeting were discussed and approved for publication.

# d) Matters arising

The Chair welcomed new member Lora Ruth Wogu who has recently been appointed by the Minister for Health to the Committee as the second Public Voice member.

The Committee again noted an action from the October 2021 meeting which 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 <u>Terms of Reference</u> (ToR), the role of observers will be included as part of that review and ahead of the next meeting in September 2022.

At the February 2022 meeting, the Secretariat had proposed that meetings of the Committee might be recorded to aid with minute taking. This matter was further discussed, and it was decided not to pursue this further at this time.

It was suggested that membership of the NSAC International Honorary Advisory Faculty should be reviewed and updated. Members were asked to send suggestions for membership of the faculty to the Secretariat, noting to keep the importance of gender balance in mind.

Action – Secretariat to follow up with members for suggestions for membership of the NSAC International Honorary Advisory Faculty.



#### 2. NSAC Annual Call

# a) Update on decisions made at February 2022 meeting re changes to existing population-based screening programmes

The NSAC Secretariat circulated a brief paper before the meeting and the Committee received a verbal update on progress on the decisions made since the February 2022 meeting.

The Committee noted that:

The Minister has approved the recommendation made by the Committee for the BowelScreen programme to adopt a British Society of Gastroenterology/Association of Coloproctology of Great Britain and Ireland/Public Health England post-polypectomy and post-colorectal cancer resection surveillance guideline.

The Chair had written to HIQA regarding the Committee's decision to request that they look at the evidence for extending the age range eligibility for breast screening and bowel screening.

The Chair had also written to the National Screening Service (NSS) in relation to two proposals which were considered at the February meeting. The Chair requested information and views about breast density from the BreastCheck programme and self-sampling from the CervicalCheck programme.

A response has since been provided by the NSS on these matters, which was shared with the Members ahead of the meeting. The CEO of the NSS, who was in attendance as an Observer, absented herself from the discussions regarding this correspondence.

The Chair also wrote to the National Newborn Bloodspot Screening Programme Governance Group (NNBSPGG) about proposals received on newborn screening. The Committee noted the initial correspondence received from the NNBSPGG and asked the NSAC Secretariat to engage further with them and explore the option of establishing a subgroup of the Committee comprising some NSAC members and other relevant expertise. It was agreed that this subgroup would support the programme of work already underway on the expansion of the NBS programme and the proposals received as part of Annual Call 2022.

Action – Secretariat to facilitate engagement with the National Newborn Bloodspot Screening Programme Governance Group (NNBSPGG).

# b) NSAC Annual Call 2021 – review of proposals for new population-based screening programmes:

As noted in the Minutes of the 17 February 2022 meeting, the Committee had decided to consider the 26 proposals that were received for new population-based screening programmes and new testing procedures at its 26 May 2022 meeting.

The submissions have been broadly categorised as follows:

- Antenatal/Prenatal
- Adult Cancer
- Adult and Child Non-Cancer



New testing procedures

#### Antenatal/Prenatal

Six (6) submissions for the establishment of antenatal/prenatal screening for four (4) conditions were received.

#### Proposal 1:

Two (2) submissions for the introduction of a population-based screening programmes for Fetal Alcohol Spectrum Disorder (FASD) were received.

The proposal is for the introduction of screening of antenatal patients for alcohol consumption. The Committee noted that it was not clear that the tests could specifically screen for or diagnose FASD.

Neither submission refers to a population-based screening programme internationally, however WHO communications regarding awareness of FASD and public health measures to reduce alcohol consumption during pregnancy are referenced.

The remaining submissions were proposals for ultrasound screening in pregnancy:

# Proposal 2:

Two (2) submissions for the introduction of a population-based ultrasound screening programme for first trimester fetal chromosomal abnormalities/congenital anomaly were received.

# **Proposal 3:**

One (1) submission for the introduction of a population-based ultrasound screening programme for critical congenital heart disease (CCHD) was received.

#### **Proposal 4:**

One (1) submission for the introduction of a population-based ultrasound screening programme for Vasa Previa was received.

## **Decision:**

During a wide-ranging discussion, a previous presentation from Prof Keelin O'Donoghue on antenatal screening for fetal anomaly in Ireland was referenced and the Committee noted that, while antenatal/prenatal routine monitoring is taking place in Ireland currently, there are no organised screening programmes in place. There appears to be a variation of practice clinically and the Committee raised the question as to whether these proposals fall under the remit of population-based screening or if they would more appropriately be considered routine clinical care in pregnancy.



The Committee noted that it would be beneficial to seek the views of the National Women and Infants Health Programme (NWIHP) to assist them in considering all of these proposals further. The Committee decided to ask the NSAC Secretariat engage with the NWIHP to request a formal meeting to discuss antenatal/prenatal screening in Ireland to assist the Committee in considering these proposals further.

Action – Secretariat to seek a meeting with the National Women and Infants Health Programme (NWIHP) to assist them in considering these proposals.

#### **Adult Cancer**

Nine (9) submissions for three (3) new population-based cancer screening programmes were received. The proposals were for the introduction of national population-based screening programmes for Anal, Lung and Prostate cancers.

The Committee considered the proposals and noted that the European Commission are expected to publish updated Council recommendations on cancer screening later in the year.

#### **Decision:**

The Committee decided to defer further consideration of these proposals pending the publication of the updated Council recommendations on cancer screening. In relation to the proposal for Anal Cancer the Committee asked the Secretariat to liaise with the Sexual Health and Crisis Pregnancy Programme (SHCPP) as to current practice and plans around HPV testing for this high-risk cohort.

Action – Secretariat to update the Committee when the European Commission updated Council recommendations on cancer screening are published later this year. The Secretariat will also liaise with the SHCPP in the HSE to seek further information.

#### **Adult and Child Non Cancer**

Eight (8) submissions for five new non-cancer population-based screening programmes were received.

#### Proposal 1:

Two (2) submissions for the introduction of a population-based screening programme for Abdominal Aortic Aneurysm (AAA) were received.

The proposal is for the introduction of screening for Abdominal Aortic Aneurysm (AAA) using ultrasound tests on men aged over 65 years. It is noted that population-based AAA screening is available in other countries, including the UK.

It was raised by a member that a pilot study on AAA was run between 2008 and 2012 in a Dublin hospital. The NSAC Secretariat will endeavour to find out more information on behalf of the Committee.



#### **Decision:**

The Committee decided to ask the Secretariat to source and circulate the UK NSC evidence summary in relation to the UK NSC decision on AAA in advance of the next meeting for further consideration, and to include any useful information from the Irish pilot study. The Committee will then consider the proposal further.

Action - Secretariat to circulate documentation to the Committee to support further consideration.

# **Proposal 2:**

One (1) submission for the introduction of a population-based screening programme for Chronic Kidney Disease (CKD) was received.

The proposal is for the introduction of screening for Chronic Kidney Disease (CKD). The submission proposed that screening could be carried out in primary care through blood and urine testing for adults aged over 55 and at higher risk. The submission did not refer to any organised population-based screening programme internationally.

#### **Decision:**

The Committee concluded that it was not clear if this proposal was within their remit and also decided that there was insufficient information to fully consider it. The Committee suggested that the NSAC Secretariat seek any available information from the relevant HSE clinical programmes and international examples mentioned in the submissions.

Action - Secretariat to seek available information to support further consideration.

#### Proposal 3:

Two (2) submissions for the introduction of a population-based screening programme for Familial Hypercholesterolaemia (FH) were received.

The proposal is for the introduction of screening for Familial Hypercholesterolaemia (FH). Both proposals note that screening for FH would involve testing of children using a blood test for lipid profile, and cascade screening of family members. The Committee noted that opportunistic testing occurs at present where there is a diagnosis in a family.

It was noted that in 2020 the UK NSC did not recommend screening for FH in children. The UK NSC considered screening for FH in adults in 2011 and also decided not to recommend screening. The Committee also noted that the submissions mentioned a pilot FH programme in Australia, and the NSAC Secretariat was requested to seek further information on this pilot.

# **Decision:**

The Committee concluded that screening for this condition may be more appropriate as a targeted screening programme for high-risk populations. The NSAC Secretariat will seek information from the



Australian FH pilot, which was published in February 2022, for the Committee's further consideration as well as the documentation about the UK NSC decision. The Committee will consider the proposal further in light of this information.

Action - Secretariat to seek and collate information to support further consideration.

#### **Proposal 4:**

Two (2) submissions for the introduction of a population-based screening programme for Osteoporosis were received.

The proposal is for the introduction of screening for Osteoporosis in primary care annually in men and women aged 65 years and over, using a DEXA bone density scan following a risk assessment. The submissions do not refer to any organised population-based screening programme internationally.

#### **Decision:**

The Committee noted that the effectiveness of testing patients for osteoporosis is not clear. The Committee concluded that it was also not clear if this proposal was within their remit and also decided that there was insufficient information to fully consider it.

#### **Proposal 5:**

One (1) submission for the introduction of a population-based screening programme for Structural Heart Disease (SHD) was received.

The proposal is for the introduction of screening for Structural Heart Disease (SHD) through heart health checks for people aged 65 years and over. The submission does not refer to any organised population-based screening programme internationally.

#### **Decision:**

The Committee noted that this proposal could fall under routine care in General Practice as opposed to population-based screening. The Committee concluded that it was not clear if this proposal was within their remit and also decided that there was insufficient information to fully consider it.

At this point of the meeting the Committee acknowledged the many learning opportunities which had arisen as it considered the proposals received as part of Annual Call 2021. The discussion led to the decision to carry out a review of the Annual Call documentation and processes by the NSAC Secretariat. The Secretariat will develop a preliminary review of submissions before bringing them to the full Committee and also assess what further guidance and supports for applicants can be built into the process in 2022.



#### **New Testing Procedures**

Three (3) submissions for new testing procedures were received, however, due to time constraints these submissions were deferred for consideration by the Committee at the next meeting in September 2022.

# 3. Expansion of the Newborn Bloodspot Screening Programme

Decision on proceeding to Phase 2 of the SCID HTA process following HIQA presentation on the Phase 1 report.

HIQA circulated and presented to the Committee on the Phase 1 Health Technology Assessment (HTA) report - 'Interim report - Health Technology Assessment of the addition of severe combined immunodeficiency (SCID) to the National Newborn Bloodspot Screening Programme'.

The Phase 1 report of the HTA covered the domains of description of the technology used internationally to screen for SCID, the epidemiology of the condition in Ireland, and the clinical effectiveness of screening (including reviews of test accuracy and the clinical benefit of early versus late diagnosis or treatment).

The Committee commended HIQA on the report and decided to progress to Phase 2 of the HTA, which will focus on the other domains relating to economic, organisational, social and ethical issues relevant to the broader implications of adding TREC-based screening for SCID to the NBS programme.

The Committee expects to receive the final HTA report from HIQA, following completion of Phase 2 of the HTA, before the end of the year. It was noted that the timing of the 17 November 2022 meeting may need to be considered in line with internal HIQA processes for the production of the Phase 2 report.

Action – Chair to write to HIQA to formally request that the HTA proceed to Phase Two.

# 4. Work Programme 2022

It was noted that the Chair had corresponded with the Minister for Health on the NSAC work programme and the additional requirements needed to ensure its success. Kate O'Flaherty advised that the Minister has indicated that he is supportive, and correspondence will issue to the Chair shortly. The Committee will be updated further at the September meeting.

#### 5. NSAC Ethics Framework

The Committee were provided with a paper ahead of the meeting on the progress on developing the NSAC Ethics Framework. The update noted that a Reference Group, comprising Prof McGuinness and other NSAC members along with a number of experts in this area, has been convened to support and feed into the process. The Reference Group plan to meet in June 2022.

# 6. Communications and Engagement Update

Kate O'Flaherty updated the Committee on NSAC Communications and Engagement since the February 2022 meeting.



The Committee published the <u>NSAC Annual Report 2021</u> in May 2022. This was supported by a communications plan which included use of social media and direct distribution of the report to the NSAC stakeholder list of 130+ individuals and organisations.

The Committee also discussed upcoming communications plans for the remainder of the year which will include publication of the Committee's Work Programme later in 2022.

The Secretariat will soon begin planning for the launch of Annual Call 2022 and planning for the filling of two vacancies which will arise in October 2022 for members with expertise in the Ethics and Medico-Legal areas.

# 7. Progress update on NSAC Recommendations

The Committee was pleased to receive updates from the HSE on the implementation of two (2) previous recommendations made by the Committee which were approved by the Minister for Health.

#### **Diabetic RetinaScreen**

The Diabetic RetinaScreen (DRS) programme provided an update on the implementation of the modification to the programme which prolongs the interval between screens from one to two years for people with diabetes who are at low risk of retinopathy. The Committee was pleased to see the progress made by the Programme in the successful implementation of its recommendation.

# **National Newborn Bloodspot Screening programme**

The Committee received an update from the National Newborn Bloodspot Screening Programme Governance Group on the addition of Adenosine Deaminase Deficiency Severe Combined Immunodeficiency (ADA-SCID) to the NBS programme, which commenced on 23 May 2022. The Committee extended its congratulations to all involved in this considerable achievement and noted the positive media coverage this week.

#### 8. Administrative

The next meeting of the Committee is on 22 September and the format of the meeting was discussed. It was agreed that the NSAC Secretariat will contact members to ask their preference to meet either online, in person or if a hybrid option would be preferable. The Committee also noted that the timing of the 17 November meeting may be reviewed to align with HIQA internal processes.

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

Action – Secretariat to contact members and ask them to indicate their preference for either an online, hybrid or in-person meeting later in the year.



# **National Screening Advisory Committee (NSAC)**

# Chair's Actions Following the 26 May 2022 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 HTA on Severe	Yes
	Combined Immunodeficiency (SCID) proceed to Phase Two.	

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

Professor Niall O'Higgins

Date: 22 September 2022