

Chairperson's note of the virtual meeting of the National Screening Advisory Committee (NSAC) 20 May 2021

The National Screening Advisory Committee held its second meeting of 2021 on Thursday 20 May.

The main items on the agenda were a new formal process for receiving applications proposing modifications to existing programmes, and a discussion on the ongoing work to progress expansion of the national newborn bloodspot screening (NBS) programme.

NSAC Application Process - modifications to existing programmes

The Committee approved a new formal Standardised Application Process and procedure for modifications to existing population-based screening programmes. This builds on the progress made at our February meeting where we approved the process for applications for new population-based screening programmes.

Applications are anticipated to open later this year for both application processes with a first 'Annual Call' for proposals planned for the autumn. Further details of both application routes and information about the processes will be published on our dedicated website www.nsacommittee.gov.ie n due course.

Should individuals/groups wish to be notified when the 'Annual Call' goes live they can email the Secretariat on NSAC Secretariat@health.gov.ie and request to be added to the NSAC stakeholder list.

HIQA Evidence Review (Newborn Bloodspot Screening)

In order to inform the expansion of the national newborn bloodspot screening (NBS) programme, the Committee requested HIQA to conduct a review of processes in use internationally to inform the expansion of NBS programmes. The Committee is supported by a specialist, dedicated evidence team in HIQA. The draft report of the findings from this review was considered by the Committee at our meeting on 20th May 2021 and a wide-ranging discussion, facilitated by the HIQA team, ensued.

This draft report provided a comprehensive review of the experience and approaches of other countries in expanding NBS programmes, in addition to the scientific and technological information, ethical, legal and societal issues arise when planning an enduring population-based programme of this nature. This evidence base will greatly help to inform our future decision-making on this important topic.

The Committee also 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.

I have written to the Minister for Health following our meeting to suggest that, utilising the extensive data from the HIQA review of international experience, the Department might now engage with relevant personnel in the HSE, HIQA and the NSAC with a view to approving this formal assessment process. It is hoped that more definitive proposals and recommendations on expansion of the NBS programme can be formulated by the end of the year or early in 2022.



Development of an Ethics Framework

Dr Sheelagh McGuinness provided the Committee with an update on her work in developing a draft Ethics Framework for the NSAC. The Committee endorsed the proposed approach to progressing this work and it was agreed that the next step will be for the HIQA team to carry out a scoping review of best practice nationally and internationally.

New member appointment

The Committee welcomed its newest member, Dr Jenny Mc Sharry who was recently been appointed by the Minister for Health.

Dr Mc Sharry is a chartered Health Psychologist and a lecturer in the School of Psychology in NUI Galway. I am confident that the skills and experience that Dr Mc Sharry brings will contribute greatly to the work of the Committee.

NSAC Communications update

The Committee were updated by the Secretariat on recent communications activity, in particular the publication in April of the Committee's first Annual Report. The publication of the report, which received good stakeholder and media interest, is available on our website at this link.

Date of next meeting

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

Professor Niall O'Higgins

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Chair, National Screening Advisory Committee