nsac

National Screening Advisory Committee

ANNUAL REPORT 2020

Table of Contents

1. Foreword/Chairperson's Report (Prof Niall O'Higgins) 4

2. Introduction 6

3. Membership of the Committee 7

4. Development of the Committee 7

5. Committee Governance 8

6. Terms of Reference 9

7. Activity Report November 2019 – December 2020 10

8. Recommendations made to the Minister for Health in 2020 15

8a. Adenosine Deaminase Deficiency - Severe Combined Immunodeficiency Disease (ADA-SCID) 15

8b. Diabetic Retinopathy 16

9. Planning for 2021 and beyond 18

10. References 19

Appendices 20

Appendix A: Organised Population-Based Screening Programmes in Ireland 21

Appendix B: List of 8 Conditions Currently Screened for Under the NNBSP 22

Appendix C: NSAC Chair & Membership 23

Appendix D: NSAC Observers 24

Appendix E: NSAC International Honorary Advisory Faculty 24

Appendix F: Glossary of Terms 25

1. Foreword/Chairperson's Report

In the short time since it was inaugurated, despite the difficulties and constraints caused by COVID-19, the progress of the National Screening Advisory Committee (NSAC) has been remarkable. The enthusiasm of the members of the Committee has motivated everyone involved and it is very satisfying for me to acknowledge in public the advice and guidance provided by so many of them.

This first Annual Report describes the work carried out by the NSAC to date and indicates the plans for the year ahead. This includes details for the processing of new applications for population-based screening, requiring the input of those who are professional experts both in analysing the quality of evidence and assessing developments in technology as applied to health services.

To draw up specific details relating to terms of reference, standing orders and a system for appraisal of proposals is rarely easy and often tricky but these have been completed with attention and skill within a short time. I gladly pay tribute to those in the Department of Health who have pushed through with the development of these processes, even though much of their time has been devoted by necessity to the pandemic. Under the guidance of Ms Kate O'Flaherty and Dr Alan Smith, an expert team is now in place and it is a pleasure to acknowledge the work of Ms Evette Wade, Ms Inese Freimane and Mr Luke Kearney.

Although initiated and supported by the Department of Health, the Committee was established as an independent group and in its deliberations and advice it will remain so. Its recommendations will continue to be based on science in accordance with best contemporary practice.

The Health Information and Quality Authority (HIQA) and its Health Technology Assessment section have excellent systems in place for assessing the quality of scientific medical evidence. A team of HIQA experts devoted specifically to the work of the NSAC has now been appointed. Funded by the Department of Health, these skilled individuals are crucial to our continuing work and we are very pleased to welcome them.

We are fortunate to be able to draw on much national experience in screening for diseases in children and adults and also to have access to the range and depth of expertise available through the UK National Screening Committee to whose meetings we have been warmly invited as observers.

The Beating Cancer Plan of the European Commission, launched in February 2021, proposes a new EU-supported Cancer Screening Scheme to help Member States ensure that 90% of the EU population who qualify for breast, cervical and colorectal cancer screenings are offered screening by 2025. The scheme will be supported by EU funding and focus on making improvements in three key areas: access, quality and diagnostics.

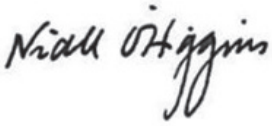
The Beating Cancer Plan aims to eliminate cervical cancer and other cancers caused by the human papillomaviruses. These cancers can be prevented by vaccination. The intention in the Plan is to vaccinate at least 90% of the EU target population of girls and to significantly increase the vaccination of boys by 2030. The NSAC adds its strong support for all efforts to encourage the uptake of the vaccine so that the scourge of HPV-associated cancer can be eradicated from society.

Abundant and convincing evidence exists from around the globe that screening for many diseases by prevention, early diagnosis and treatment can reduce death rates, prevent illness and improve the quality of life for people. The Committee will endeavour, in whatever way it can, to assist in providing accurate information and explanation surrounding the value and limitations of population-based screening for disease. Public confidence in cancer screening must be improved. An important objective for the NSAC is to play a strong role in redeveloping public trust in existing screening programmes and it is hoped that it will, by its Communications Strategy now under development, become a dependable source of information in its advocacy for evidence-based screening.

The impact of COVID-19 will endure after the pandemic has been overcome. Reappraisal of the systems and arrangements for delivering health services will be necessary. Reframing of structures will require fresh thinking and planning.

Opportunities will arise for redesigning many relevant activities, for example, (i) equitable access to services (ii) timely appointments for consultations, procedures and treatments (iii) continual measurement of high quality of care (iv) effective application of technologies to improve accuracy and minimise error (v) structured integration of community, hospital and specialist services (vi) more purposeful specialist medical training programmes (vii) enhanced professional dialogue with organisations within the European Union and (vii) efficient communications at every level.

These considerations will apply not only to screening but to all aspects of the health services.



Professor Niall O'Higgins
March 2021

2. Introduction

The National Screening Advisory Committee (NSAC) provides independent expert advice to the Minister for Health concerning population-based health screening. Its main function is to advise about new proposals for screening and revisions or changes to existing programmes.

The NSAC was established in 2019 by the Department of Health following recommendations made in the Scoping Inquiry into the CervicalCheck Screening Programme (Dr Gabriel Scally, September 2018). Dr Scally identified that such a Committee would be advantageous where the 'aim of the Committee is to recommend population-based screening programmes, using the best available evidence, to reduce the incidence of and mortality from disease'. [1]

The NSAC has a strategic role in the development of population screening programmes in Ireland. By adopting proactive and transparent engagement with stakeholders it aims to enhance public trust and confidence in health screening.

Ireland has several population-based screening programmes, including those for breast, cervical and colon cancers, diabetic retinopathy and newborn screening (a list of screening programmes is available in **Appendices A & B**). The purpose of these is to reduce morbidity and mortality through early detection and treatment of disease. The Health Service Executive (HSE) and the National Screening Service (NSS) have responsibility for the implementation and operation of these programmes.

This first annual report of the NSAC (hereafter referred to as the "Committee") sets out detail on the establishment of the Committee, its governance and its activities during the first year of operation.

3. Membership of the Committee

Professor Niall O'Higgins was appointed by the Minister for Health as Chair of the Committee in July 2019. Following the appointment of Prof. O'Higgins, expressions of interest for membership of the Committee were sought by way of public advertisement from the following fields of expertise: Cancer; Diagnostic Imaging; Epidemiology; Ethics; General Practice; Genetics; Health Economics; Journalism; Laboratory Services; Medico-Legal; Nursing and Midwifery; Obstetrics; Paediatrics and Child Health; Psychology; Public Health; Public Voice; Social Science and Pathology.

Members were selected by an independent, international selection panel (which included a patient advocate) in September 2019 and appointed by the Minister for Health in October 2019 for a term of two years. The Chair and members are appointed as individuals to fulfil the Terms of Reference of the Committee, based on knowledge, experience and skills and not on institutional affiliation.

As the Committee deals with many different social, ethical, and legal issues associated with population screening programmes, the wide variety of expertise and experience ensures the provision of independent advice, enables the Committee to be agile, responsive and well-informed, and be in a position to respond to and advise on new developments and scientific research in relation to population-based screening.

The Department of Health strives to involve the voice of the public in developing and implementing its policies. It was considered important to include public voice representatives in this Committee and two such members have been appointed.

Further details on membership is at **Appendix C**.

4. Development of the Committee

The inaugural meeting of the Committee was held on 18 November 2019. From end 2019 and throughout 2020, the Committee has developed and published documents related to its governance and processes, including formal Terms of Reference and Standing Orders.

The NSAC Secretariat, which is provided by the Department of Health, supports the administration and operational business of the Committee, which generally meets three to four times a year.

5. Committee Governance

On establishment, a priority for the Committee was to set out its role and adopt clear structures, operational policies and procedures to underpin good governance.

In order to set out the way the Committee will work and make its decisions (i) Terms of Reference (ii) Standing Orders and (iii) Criteria for appraising the viability, effectiveness and appropriateness of a screening programme were developed, adopted and published.

The Committee places a high value on transparency of its deliberations and decisions, and on effective communication with its stakeholders. All relevant documents, including the minutes of each meeting and details of recommendations made by the Committee, are published on the Committee's webpage on the Department of Health website at the following link: **www.nsacommittee.gov.ie**

After each Committee meeting, a note from the Chair, intended as a brief communication of the topics discussed at the meeting, is published on the webpage within 10 working days. Formal minutes of each meeting are agreed at the subsequent meeting and published along with any finalised documents.

In addition to appointed members, Observers from various backgrounds have been invited to attend Committee meetings. Their role is to add a quality assurance perspective and they may be invited to comment on the quality of the discussion and provide an external review of the functioning of the Committee. The current Observers include representation from the National Screening Service (NSS), the National Advocacy Service for People with Disabilities (which provides the Patient Advocacy Service), and School of Nursing, Psychotherapy and Community Health at Dublin City University. Further details on the current list of Observers is set out in **Appendix D**.

An International Honorary Advisory Faculty was also established to offer consultation and advice to the Chair of the Committee when required. The current Faculty are listed in **Appendix E**.

6. Terms of Reference

Terms of Reference were formally adopted and published by the Committee in July 2020 and are set out below. They will be reviewed at least every three years and the Committee will adopt a continuous quality improvement approach to its work:-

1.1 Effectively implement an agreed methodology for accepting applications to consider new or revisions to existing population-based screening programmes in Ireland;

1.2 Develop and implement a robust, inclusive and transparent evidence-review process to evaluate the case for new or revisions to existing population-based screening programmes in Ireland;

1.3 Communicate advice directly to the Minister for Health, through the Office of the Chief Medical Officer;

1.4 Publish and communicate the advice issued by the Committee to the Department of Health, HSE, relevant stakeholders and the public, with a focus on increasing public understanding and confidence in screening programmes;

1.5 Review any advice issued routinely every three years, or sooner if significant new evidence becomes available;

1.6 Periodic review of the appropriateness of the existing national screening programmes with the HSE;

1.7 Maintain close working relationships with the UK National Screening Committee, EU Member States and relevant EU institutions and work programmes;

7. Activity Report November 2019 – December 2020

The Committee held its inaugural meeting on 18 November 2019. The meeting was opened by the Minister of Health who welcomed the members and thanked them for joining the Committee.

Despite the impacts from the COVID-19 pandemic on work priorities within the health sector throughout 2020, the Committee held three meetings during the year - on 5 March, 17 July and 15 October. Due to public health restrictions, the July and October meetings were held in a virtual format.

In addition to setting up its governance and operational processes, the Committee submitted two formal recommendations to the Minister for Health in 2020:

1. The addition of Adenosine Deaminase Deficiency - Severe Combined Immunodeficiency (ADA -SCID) in the list of conditions to be screened for as part of the National Newborn Bloodspot Screening Programme (NNBSP).
2. The modification of the Diabetic RetinaScreen - the National Diabetic Retinal Screening Programme, to extend the interval between screens from one to two years for people with diabetes who are at low risk of retinopathy.

Further details of these recommendations are in the following **Section 8** of this report.

Standardised Application Process

During 2020, the Committee progressed the development of a standardised application process and methodology for assessing new applications for a population-based screening programme in Ireland, using methodologies based on international best practice. A process to facilitate an annual public call for proposals for new screening programmes is also under development. It is hoped to finalise and adopt these procedures early in 2021.

NSAC support team in the Health Information and Quality Authority (HIQA)

A critical development in 2020 was the appointment by HIQA of a specialist team to support the work of the Committee. Funded by the Department of Health, these specialists in Evidence Synthesis and Health Technology Assessment provide essential expertise in fulfilling the role of the Committee in providing evidence-based information. Formal evidence reviews, evidence-mapping, objective stratification of levels and quality of evidence and detailed Health Technology Assessments based on updated international information all form part of the remit of this specialist team.

Members of the HIQA team attended Committee meetings in 2020 and work began to develop a systematic approach to the evidence review function and a programme of work for the Committee. In addition, HIQA conducted work to support the recommendations made by the Committee in 2020.

The prioritisation of work within HIQA to contribute to the national response to COVID-19, and in particular the significant and urgent demands for ongoing evidence support to the COVID-19 NPHET, impacted on the NSAC support resource, as the team was temporarily redeployed to the COVID-19 work for much of 2020.

Prioritisation of the National Newborn Bloodspot Screening Programme

In 2019, the Minster for Health, requested that the Committee consider the expansion of the National Newborn Bloodspot Screening Programme (NNBSP) as a priority and the Chair agreed to this request. Under the NNBSP, all newborn babies are currently offered screening for eight rare, but serious, conditions. Further information is available at https://www2.hse.ie/heel-prick-screening/.

In considering an expansion of the current programme, the Committee noted that the number of conditions screened for in similar programmes varies across Europe. The UK screens for nine conditions while other countries such as France screen for fewer (five conditions) and a number of countries screen for more conditions (Netherlands 19), while some regions of Italy screen for over 40.

Rapid expansion of newborn bloodspot screening has become a possibility (and a reality in some jurisdictions) thanks to a powerful laboratory analytical technique called Tandem Mass Spectrometry (TMS). This analytical technology can identify and quantify compounds/metabolites in the dried blood spots collected for newborn bloodspot screening that could be indicative of an inherited metabolic disease.

With such technological developments there are two clear approaches for policy-makers to consider with regard to the expansion of bloodspot screening, an epidemiological approach and a technology-driven approach.

An epidemiological approach

With this approach the likely achievable benefits, harms and costs of the entire screening programme pathway (from invitation to screening test to diagnosis and treatment options) for each individual condition are comprehensively investigated, assessed, and considered against internationally recommended screening criteria, informed by Irish epidemiology for that disease. This strategy is reflected in the Committee's approach to the evaluation of the evidence for a new programme.

Technology driven approach

This approach means that because TMS is capable of testing for a metabolite it should be utilised routinely as a first-round test. However, this policy is not without difficulty. For example, some metabolites detected are not specific for a particular disease. Therefore, a technology-driven approach does not always provide a clear-cut disease diagnosis. In addition, the routine screening of all babies for a metabolite/condition for which there may be no known or acceptable treatment raises genuine ethical questions and concerns. How such a technological approach would adhere to internationally recognised screening criteria would also have to be examined.

Although some countries have taken a technological approach, not all this experience is directly transferable to Ireland for several reasons including (i) population differences (ii) prevalence of rare diseases (iii) the effects of founder mutations in DNA that may occur in the population in Ireland (iv) variable sampling timings in blood spot programmes (v) variations in follow-on analytic approaches and (vi) differences in technological capabilities.

In considering the most suitable approach in Ireland, the Committee emphasised the need to be robust and consistent in evaluating the expansion of the programme in line with its adopted NSAC Criteria for Appraising the Viability, Effectiveness and Appropriateness of a Screening Programme.

Work has already commenced with HIQA on developing the protocol that will underpin a review of the evidence to support the expansion of the programme in Ireland, including consideration of the relevant epidemiological evidence.

The Committee acknowledged that, prior to its establishment, considerable work was undertaken by the HSE National Newborn Bloodspot Screening Governance Group, including an evaluation of the evidence-base for the addition of a condition known as ADA-SCID to the NNBSP. The Committee agreed to consider inclusion of this condition in the national newborn bloodspot screening programme (See Section 8 for further details).

Building National and International Stakeholder Engagement and Profile of the Committee

The invitation to attend meetings of the UK National Screening Committee (UK NSC) and its main Subcommittees, the Adult Reference Group (ARG) and the Fetal Maternal and Child Health Group (FMCHG), has allowed the Committee to have access to the decisions and recommendations and to participate in discussions of the UK NSC and its constituent area in England and Wales, Scotland and Northern Ireland. Since its establishment over 25 years ago, the UK NSC has acquired extensive and deep knowledge, skill and experience in the scientific evaluation of proposals and submissions related to health screening. To have such a resource so readily available has been and remains of major benefit to the Committee.

Access to the conferences and published documents of the European Cancer Organisation (ECCO) which represents 31 Member Societies and a Patient Advisory Committee (comprised of 20 European patient groups) allows rapid access to developments in all aspects of oncology, including cancer screening so that new information across the European Union is made available rapidly.

The EU Beating Cancer Plan of the European Commission, recently published in February 2021, places emphasis on cancer prevention and early diagnosis and is given priority by the President of the European Commission.

Building international linkages with similar bodies of expertise is an important aspect of the Committee's work to fully establish its programme in accordance with its terms of reference. In addition to the establishment of an International Honorary Advisory Faculty, the Committee and its Chair have several important and valuable international connections.

The Committee intends to continue to build relationships and to communicate effectively and widely with stakeholders. In addition to inviting relevant national bodies to act as Observers at Committee meetings, the Chair regularly engages with key stakeholders, including the Department of Health.

A dedicated webpage (**www.nsacommittee.gov.ie**) on the Government website was created to ensure that relevant information about the Committee and its work is publicly accessible and available.

Ireland, through the Department of Health, has observer status membership of the UK NSC which allows Ireland to attend, engage and interact with its colleagues in Northern Ireland, Scotland, England and Wales. Since it was established in 1996, the UK NSC has established itself as a world leading body with extensive expertise in science, medicine, public health, psychology, ethics, epidemiology, health economics, biostatistics, public administration and law. The Committee Chair and Department of Health representatives regularly attend meetings of the UK NSC and the briefings, documents and recommendations of that committee are available to the Committee.

The Chair engages regularly with colleagues and institutions from other parts of Europe and attends international conferences and meetings to ensure the Committee is aware of emerging topical issues internationally.

In Ireland there is a high level of public, media and political interest in population-based screening issues, and the Committee aims to take a proactive approach to engaging in the national dialogue on screening.

Following the issues that emerged in Ireland in 2018 in relation to the national cervical cancer screening programme, CervicalCheck, the restoration and maintenance of public confidence, understanding and trust in screening is a particularly significant and relevant issue of public, media and political discourse and focus.

In 2020, issues relevant to the Committee's remit were raised and discussed in the Oireachtas, including by way of Parliamentary Questions. In late September 2020, a Private Member's Bill entitled *The National Screening Advisory Committee Bill 2020* was introduced by a number of Senators and debated at its Second Stage in the Seanad on 30 September. The Seanad agreed a timed amendment proposed by the Government to defer further consideration of the Bill for a 12-month period.

Further developments in communications, stakeholder engagement and networking are planned for 2021 and beyond so the Committee can fulfil its important role in improving public confidence in population-based screening.

8. Recommendations made to the Minister for Health in 2020

8a. Adenosine Deaminase Deficiency - Severe Combined Immunodeficiency Disease (ADA-SCID)

Severe Combined Immunodeficiency Disease (SCID) is a group of inherited disorders of the human immune system and, unless treated, is fatal in infancy. ADA-SCID is the leading cause of SCID in Ireland. Infants appear healthy at birth and signs of immunodeficiency appear some weeks or months later. SCID is curable via haematopoietic stem cell transplant (HSCT) or gene therapy (GT) that enable reconstitution of the immune system in affected individuals. If diagnosed early and treated in a timely manner, the survival rate is approximately 94%. [8]

The HSE National Newborn Bloodspot Screening Programme Governance Group gave a presentation on the case to expand the NNBSP to include ADA-SCID at the Committee meeting on 5 March 2020. A significant amount of work had already been completed by the NNBSP over the course of the preceding two years. This had included an evaluation of the case for screening for ADA-SCID against the internationally accepted Wilson and Jungner criteria. The programme governance group recommended the addition of ADA-SCID to the list of conditions screened for in Ireland. [6]

Having regard to the work already undertaken and completed by the HSE, the Committee considered it unreasonable to request the HSE to restart an application using the new Committee application process. Instead, given the unique circumstances, the Committee undertook a process to satisfy itself of the scientific merits and robustness of the work undertaken to date. The application made by the HSE was further considered and approved on an exceptional basis at the Committee meeting on 17 July 2020

The Chair of the Committee wrote to the Minister for Health recommending that ADA-SCID be added to the NNBSP. The Minister considered and approved the recommendation and informed the HSE of the decision. Provision for the addition of ADA-SCID to the NNBSP has been included in the HSE's 2021 National Service Plan. [7]

8b. Diabetic Retinopathy

Diabetic RetinaScreen (DRS) is one of four national screening programmes operated by the HSE NSS (see **Appendix A**).

The HSE NSS submitted an application to the Committee in early 2020 to introduce a revised screening frequency for people with diabetes at low risk of sight loss from yearly screening to a screening frequency of every two years. People at low risk are defined as those who have no retinopathy at two consecutive annual screening examinations.

Diabetic retinopathy is a common cause of vision impairment and sight loss. It is estimated that approximately one-third of all people with diabetes worldwide have signs of diabetic retinopathy and a further one-third of these have sight-threatening diabetic retinopathy. Diabetic retinal screening programmes can prevent sight-threatening diabetic retinopathy by timely detection and treatment of cases.

There are approximately 190,000 people in Ireland with diabetes and it is estimated that 19,000 of them are at risk of developing sight loss due to retinopathy. The DRS Programme is responsible for the screening and treatment of sight-threatening diabetic retinopathy in all individuals aged 12 years and older with either type 1 or type 2 diabetes. [9] [10] [11]

After reviewing the application from the HSE NSS at its 17 July 2020 meeting, the Committee engaged with HIQA and requested them to complete a scoping report on the relevant evidence. The HIQA team produced a report entitled '*Extended Interval Screening of the Diabetic RetinaScreen Programme in Ireland*'. The HIQA report was submitted and presented to the Committee for consideration at the 15 October 2020 meeting.

The aim of this report was to provide an overview of the evidence pertaining to extending the screening interval for diabetic retinopathy from one to two years for those at low risk of diabetic retinopathy progression. The report found that extending diabetic retinopathy screening intervals from one to two years in those at low risk appears to be safe, and in line with international best practice. It also recommended that any planned changes to the national programme would need to be accompanied by a significant communications campaign including all relevant stakeholders, in order to address any concerns. Additionally, ongoing audit of coverage and tracking of non-responders would be essential to identify any changes in adherence to screening intervals in a timely fashion.

The application from the HSE NSS for the modification in the screening interval was approved by the Committee at the October 2020 meeting. The Chair of the Committee then wrote to the Minister for Health recommending a revised screening interval for people with diabetes at low risk of sight loss from yearly screening, to a screening frequency of every two years. All others will continue to be invited for annual screening.

The Minister considered and approved the application and wrote to the DRS Programme to inform them of his decision.

The HSE has committed to the implementation of this recommendation in the 2021 National Service Plan.

9. Planning for 2021 and beyond

Building on the progress and achievements of 2020, the Committee is setting an ambitious work programme for 2021, which will address and finalise (i) recommendations on the National Bloodspot Screening Programme (ii) a framework for Ethics in Screening Programmes, (iii) activation of the Application Process for new proposals including planning for the first annual call for submissions and (iv) the development of a Communications Strategy focused on engagement with the public and all stakeholders in order to underpin priorities in accordance with its Terms of Reference.

NSAC Meetings in 2021

The Committee has scheduled three regular meetings in 2021 and will continue to manage the risk that the COVID-19 pandemic presents to its operations by continuing to hold its meetings in a virtual format in line with the prevailing public health advice.

Conclusion

With scientific development, guidelines and standards around screening and early detection must be kept under frequent and continual review. Issues concerning quality control will require constant surveillance. Newer systems such as Digital Health and Artificial Intelligence (AI) may have an impact on the conduct of screening and the long-term consequences of COVID-19 may present additional difficulties in the implementation of screening systems. Inequalities in access continue to affect uptake of screening invitations and newer methods of communication must be sought to improve compliance. Better tools are needed to validate the benefits and the harms of screening.

It is necessary for the Committee to base its activities and recommendations on science and to continue to appoint members on the basis of their expertise and not on institutional affiliation. The need for international co-operation and collaboration will increase in importance as new information becomes available. By being aware of the advances in prevention, diagnosis and treatment the Committee can thrive and become a valuable resource to citizens and health policy-makers.

10.References

1. Scally, G., 2018. Scoping Inquiry into the CervicalCheck Screening Programme. [online] Dublin. Available at: <**https://www.gov.ie/en/publication/aa6159-dr-gabriel-scallys-scoping-inquiry-into-cervicalcheck/>** [Accessed 15 January 2021].
2. Health Service Executive (HSE). 2021. Heel Prick Screening. [online] Available at: <**https://www2.hse.ie/heel-prick-screening/**> [Accessed 15 January 2021].
3. Health Service Executive (HSE). 2018. A Practical Guide to Newborn Bloodspot Screening In Ireland. [online] Dublin. Available at: <**https://www.hse.ie/eng/health/child/newbornscreening/newbornbloodspotscreening/information-for-professionals/a-practical-guide-to-newborn-bloodspot-screening-in-ireland.pdf**> [Accessed 15 January 2021].
4. Health Service Executive (HSE). 2017. Framework for The National Healthy Childhood Programme. [online] Dublin. Available at: <**https://hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/child-health-and-wellbeing/nhcp%20framework.pdf**> [Accessed 15 January 2021].
5. Health Service Executive (HSE). 2019. Newborn Hearing Screening. [online] Available at: <**https://www2.hse.ie/screening-and-vaccinations/newborn-hearing/**> [Accessed 15 January 2021].
6. Wilson, J. and Jungner, G., 1968. PRINCIPLES AND PRACTICE OF SCREENING FOR DISEASE. [online] Geneva. Available at: <**https://apps.who.int/iris/bitstream/handle/10665/37650/WHO_PHP_34.pdf?sequence=17&isAllowed=y**> [Accessed 15 January 2021].
7. Health Service Executive (HSE). 2021, National Service Plan 2021 [online] Available at <**https://www.hse.ie/eng/services/publications/serviceplans/national-service-plan-2021.pdf**> [Accessed 24 February 2021].
8. Kwan, A. and Puck, J., 2015. History and current status of newborn screening for severe combined immunodeficiency. *Seminars in Perinatology*, [online] 39(3), pp.194-205. Available at: <**https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4433840/**> [Accessed 15 January 2021].
9. World Health Organization (WHO), 2020. Diabetic retinopathy screening: a short guide. [online] Copenhagen. Available at: <**https://apps.who.int/iris/handle/10665/336660**> [Accessed 15 January 2021].
10. Health Service Executive (HSE). 2021. About Diabetic RetinaScreen. [online] Available at: <**https://www2.hse.ie/screening-and-vaccinations/diabetic-retina-screening/diabetic-retina-screening.html**> [Accessed 15 January 2021].
11. Health Information and Quality Authority (HIQA). 2021. Extended Interval Screening of the Diabetic RetinaScreen Programme in Ireland. <**https://www.hiqa.ie/reports-and-publications/health-technology-assessment/extended-interval-screening-diabetic**> [Accessed 16 February 2021].

Appendices

Appendix A	Organised Population-Based Screening Programmes in Ireland
Appendix B	List of 8 Conditions Currently Screened for Under the NNBSP
Appendix C	NSAC Chair & Membership
Appendix D	NSAC Observers
Appendix E	NSAC International Advisory Faculty
Appendix F	Glossary of Terms

Appendix A: Organised Population-Based Screening Programmes in Ireland

1. **BowelScreen** – The National Bowel Screening Programme (**www.BowelScreen.ie**)

   Bowel screening aims to detect signs of bowel cancer at an early stage, when there are no symptoms. Over 2,700 people are diagnosed with bowel cancer in Ireland every year. Bowel cancer is the third most common cancer in men and the fifth most common cancer in women in Ireland. People aged between 60 and 69 are invited to take part in Bowel Screen every two years.

2. **BreastCheck** – The National Breast Screening Programme (**www.BreastCheck.ie**)

   BreastCheck aims to reduce deaths from breast cancer by finding and treating the disease at an early stage. Breast cancer is one of the most common cancers among women in Ireland and about 1 in 8 women will develop breast cancer in their lifetime. BreastCheck screening is offered to women between the ages of 50 and 69.

3. **CervicalCheck** – The National Cervical Screening Programme (**www.CervicalCheck.ie**)

   CervicalCheck aims to reduce the incidence and mortality of cervical cancer through the identification and treatment of precancerous stages of cervical cancer. In cervical screening, the target group is women and people with a cervix who have been sexually active and are aged 25 to 65 years old. There are approximately 300 cases of cervical cancer diagnosed in Ireland each year.

4. **Diabetic RetinaScreen** – The National Diabetic Retinal Screening Programme (**www.DiabeticRetinaScreen.ie**)

   Diabetic RetinaScreen aims to reduce the risk of sight loss for people with diabetes through the early detection, appropriate monitoring and treatment of diabetic retinopathy, which is one the biggest causes of blindness among people of working age. There are about 190,000 people in Ireland with diabetes, 19,000 of them are at risk of developing vision loss due to retinopathy.

Appendix B: List of 8 Conditions Currently Screened for Under the NNBSP

Newborn bloodspot screening is performed to identify treatable inborn errors of metabolism or other inherited disorders in infants. Screening is performed so that disorders may be identified before the development of symptoms, thereby facilitating the use of interventions to prevent or mitigate adverse outcomes associated with these conditions. This is commonly known as the 'heel prick test', it involves taking a small amount of blood from a baby's heel onto a screening card for testing in the National Newborn Screening laboratory for 8* rare conditions:

1. cystic fibrosis (CF)
2. congenital hypothyroidism (CHT)
3. phenylketonuria (PKU)
4. classical galactosaemia (C Gal)
5. glutaric aciduria type 1 (GA1)
6. medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
7. homocystinuria (HCU)
8. maple syrup urine disease (MSUD)

*the list of conditions screened for will increase to 9 when ADA SCID is added to the programme.

Appendix C: NSAC Chair & Membership

Appointments have been based on knowledge and skills rather than on institutional affiliation.

The initial appointment will be for a period of 2 years (21 October 2019 - 20 October 2021), renewable for a further 2 years up to a maximum of 4 years

Prof Niall O'Higgins	**Chair** - Professor Emeritus of Surgery, University College Dublin
Dr Abigail Collins	Consultant in Public Health Medicine, National Cancer Control Programme
Dr John Ward	Consultant Radiologist, University Hospital Galway
Dr Mary Codd	Associate Professor of Epidemiology and Biostatistics, UCD
Dr Sheelagh McGuinness	Reader in Law, University of Bristol Law School
Dr Velma Harkins	General Practitioner, Offaly
Prof Andrew Green	Consultant in Clinical Genetics and Professor of Medical Genetics, Our Lady's Children's Hospital
Dr James O'Mahony	Assistant Research Professor, Centre for Health Policy and Management, School of Medicine, Trinity College
Martina Fitzgerald	Journalist
Irene Regan	Chief Medical Scientist, Our Lady's Children's Hospital
John Gleeson	Solicitor and former partner in Mason Hayes and Curran Solicitors
Dr Susan Kent	Professor Associate - Nursing, Midwifery, Community and Public Health, School of Nursing, Psychotherapy and Community Health, Dublin City University
Dr Keelin O'Donoghue	Consultant Obstetrician and Gynaecologist, Cork University Maternity Hospital
Dr Ellen Crushell	Consultant Paediatrician with a special interest in Inherited Metabolic Disorders
Dr Paul D'Alton	Associate Professor Principal Clinical Psychologist, St Vincent's University Hospital
Dr Paul Kavanagh	Consultant in Public Health Medicine, HSE
Anne Burke	Public Voice
Jillian van Turnhout	Public Voice
Prof Michael Rigby	Professor Emeritus of Health Information Strategy, Keele University
Prof Ciaran O'Neill	Professor of Health Economics, Queens University Belfast
Vacancy	Pathology

Appendix D: NSAC Observers

Ms 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
Ms Fiona Murphy	CEO, National Screening Service

Appendix E: NSAC International Honorary Advisory Faculty

Prof Robert Steele CBE	Chair of the UK National Screening Committee; Professor of Surgery, University of Dundee
Professor H.J. de Koning MD, PhD	Professor of Public Health & Screening Evaluation, Public Health, Erasmus MC, University Medical Center Rotterdam
Professor Peter Boyle	President, International Prevention Research Institute, Lyon; Executive Director, Strathclyde Institute for Global Public Health at iPRI, Lyon (France) and Glasgow (Scotland)

Appendix F: Glossary of Terms

ADA-SCID	Adenosine Deaminase Deficiency-Severe Combined Immunodeficiency
ARG	Adult Reference Group
C Gal	Classical Galactosaemia
CF	Cystic Fibrosis
CHT	Congenital Hypothyroidism
DRS	Diabetic RetinaScreen
ECCO	European Cancer Organisation
FMCHG	Fetal Maternal and Child Health Group
GA1	Glutaric Aciduria type 1
GT	Gene Therapy
HCU	Homocystinuria
HIQA	Health Information and Quality Authority
HPV	Human papillomavirus
HSCT	Haematopoietic Stem Cell Transplant
HSE	Health Service Executive
HTA	Health Technology Assessment
MCADD	Medium chain Acyl CoA Dehydrogenase Deficiency
MSUD	Maple Syrup Urine Disease
NNBSP	National Newborn Bloodspot Screening Programme
NSAC	National Screening Advisory Committee
NSC	National Screening Committee
NSS	National Screening Service
PKU	Phenylketonuria
SLA	Service Level Agreement
STDR	Sight-Threatening Diabetic Retinopathy
TMS	Tandem Mass Spectrometry
UK NSC	UK National Screening Committee
WHO	World Health Organization

nsac

National Screening Advisory Committee