HSC Public Health Agency

Equality and Human Rights Screening Template

The PHA is required to address the 4 questions below in relation to all its policies. This template sets out a proforma to document consideration of each question.

What is the likely impact on equality of opportunity for those affected by this policy, for each of the Section 75 equality categories? (Minor/major/none)

Are there opportunities to better promote equality of opportunity for people within the Section 75 equality categories?

To what extent is the policy likely to impact on good relations between people of a different religious belief, political opinion or racial group? (Minor/major/none)

Are there opportunities to better promote good relations between people of a different religious belief, political opinion or racial group?

For advice & support on screening contact:

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SCREENING TEMPLATE

See Guidance Notes for further information on the 'why' 'what' 'when', and 'who' in relation to screening, for background information on the relevant legislation and for help in answering the questions on this template.

(1) INFORMATION ABOUT THE POLICY OR DECISION

The Northern Ireland Newborn Blood Spot Programme (NBSP) offers all newborn babies (aged up to 364 days old) a blood spot screening test to identify if they are at increased risk of rare, but serious, inherited conditions. The aim of the programme is to improve the outcomes for babies born with one of these conditions, by achieving early diagnosis and treatment. As part of the programme, in the first week after birth, ideally on day 5 of life, all babies are offered blood spot screening. Currently in Northern Ireland the programme offers screening for:

- Phenylketonuria (PKU)
- Congenital hypothyroidism (CHT)
- Cystic fibrosis (CF)
- Medium-chain acyl- coA dehydrogenase deficiency (MCADD)
- Sickle cell disorders (SCD)

The UK National Screening Committee (UKNSC) has advised that additional screening of selected Inherited Metabolic Disorders (IMD) is added to the NBSP. This so-called 'expanded programme' will test for the following additional conditions:

- Glutaric aciduria type 1 (GA1)
- Isovaleric acidaemia (IVA)
- Maple syrup urine disease (MSUD)
- Homocystinuria (pyridoxine unresponsive) (HCU)

The Department of Health (DoH) in Northern Ireland has directed Trusts and the Public Health Agency to make arrangements for the implementation of the expanded programme in Northern Ireland (HSS (MD) 13/2016).

1.2 Description of policy or decision

- **What is it trying to achieve? (aims and objectives)**

  The aim is to expand the existing NBSP testing to include screening for maple syrup urine disease (MSUD), homocystinuria (HCU), glutaric aciduria type 1 (GA1), and isovaleric acidaemia (IVA), in line with the national Newborn Blood Spot Screening Programme Standards and Guidance. Whilst those eligible for newborn blood spot screening will be offered testing for these additional conditions there will be no change to how the screening tests are accessed (how, where or when), or how the sample is taken, or other delivery of the screening programme. As is the case for current conditions screened for, pathways (based on national guidance) will be developed to ensure follow up of those identified as screen positive for each of the additional conditions.

- **How will this be achieved? (Key elements)**

  To take this work forward a Regional Project Board and Project Team have been established by the Public Health Agency (PHA). A draft Project Plan has been agreed with the aim of introducing the expanded programme in March 2020.

- **What are the key constraints? (for example financial, legislative or other)**

- Staff capacity in regard to the Public Health Agency (PHA), the Regional Laboratory, Child Health Systems (CHS), Business Services Organisation (BSO) and the Trusts Metabolic Clinical Team's and services
- Laboratory risks, for example a delay in receipt of essential equipment
- Timescales for tasks including training and education of various stakeholders

1.3 Main stakeholders affected (internal and external)

For example staff, actual or potential service users, other public sector organisations, voluntary and community groups, trade unions or professional organisations or private sector organisations or others

- Service users (newborn infants and families)
- Health and Social Care Trusts (impact on staff is minimal) those who are currently involved in the existing NBS programme: midwifery, neonatal, paediatric and health visiting staff.
- Regional newborn screening laboratory, Belfast Health and Social Care Trust
- NBSP Staff at Public Health Agency (PHA)
- Child Health Systems (CHS)

1.4 Other policies or decisions with a bearing on this policy or decision

Making Life Better, DHSSPS (2012-2023).

The UK National Screening Committee (UKNSC) has advised that additional screening for Inherited Metabolic Disorders (IMDs) is added to the existing Newborn Blood Spot Screening Programme (NBSP). This 'expanded programme' will offer additional screening for the following conditions:

- Glutaric aciduria type 1 (GA1)
- Isovaleric acidaemia (IVA)
- Maple syrup urine disease (MSUD)
- Homocystinuria (pyridoxine unresponsive) (HCU)

Newborn Blood Spot screening for these conditions is currently offered in England and Wales and has been from 2015. The Department of Health (DoH) in Northern Ireland has directed Trusts and the Public Health Agency to make arrangements for the implementation of the expanded programme in Northern Ireland. (HSS (MD)13/2016).

(2) CONSIDERATION OF EQUALITY AND GOOD RELATIONS ISSUES AND EVIDENCE USED

2.1 Data gathering

What information did you use to inform this equality screening? For example, previous consultations, statistics, research, Equality Impact Assessments (EQIAs), complaints. Provide details of how you involved stakeholders, views of colleagues, service users, staff side or other stakeholders.

- PHA Staff data June 19
- (https://www.gov.uk/government/publications/health-professional-handbook-newborn-blood-spot-screening/appendix-a-incidence-and-positive-predictive-values)
- The Northern Ireland Statistics and Research Agency mid-year population estimates http://www.nisra.gov.uk/demography/default.asp17.htm
- CENSUS DATA 2011
- The Northern Ireland Neighbourhood Information Service (NINIS), NISRA http://www.ninis2.nisra.gov.uk/public/Home.aspx
- https://www.publichealth.hscni.net/about-us/making-life-better
- Electoral Office NI, (2017)

2.2 Quantitative Data

Who is affected by the policy or decision? Please provide a statistical profile. Note if policy affects both staff and service users, please provide profile for both.

Table 1 outlines the incidence and impact of each of the additional conditions that will be screened for:

Condition	UK incidence	PPV%	Without early treatment, the condition can result in
MSUD	1 in 150,000	50%	coma, permanent brain damage and possible death
IVA	1 in 150,000	50%	coma, permanent brain damage and possible death
GA1	1 in 300,000	50%	coma and brain damage which affects muscle movement
HCU	1 in 300,000	50%	learning difficulties, eye problems, osteoporosis, blood clots or strokes

In 2016-17, 31 out of 668,668 babies tested in England and Wales were identified as screen positive for one of these four conditions. This equates to a condition specific screen positive rate of 0.1-0.2 per 10,000. In Northern Ireland there are approximately 24,000 babies screened per year, it is estimated that there could be 1-2 babies identified as screen positive per year across all four conditions.

(https://www.gov.uk/government/publications/health-professional-handbook-newborn-blood-spot-screening/appendix-a-incidence-and-positive-predictive-values)

Category	What is the makeup of the affected group? (%) Are there any issues or problems? For example, a lower uptake that needs to be addressed or greater involvement of a particular group?
Gender	**Total births in Northern Ireland (NINIS/NISRA, 2017):** • Total: 23,075 • Male: 11,898 • Female: 11,177 **Potential Users:** The size of the resident population in Northern Ireland is estimated to be 1.862 million people. Just over half (50.9 per cent) of the population were female, with 946,900 females compared to 915,200 males. (Mid-year population estimate 2016; published June 2017) **PHA Staff Data:** Male: 20.00% Female: 80.00%
Age	**Potential Users:** It is recognised that most service users will be women of child-bearing age and their respective partners/ spouses/ family members. Mother's age for infants born 2016/17 (NI Residents): 174 births to women aged 17 years or under; 586 births to women aged 18-19; 3060 births to women aged 20-24; 6584 births to women aged 25-29; 8267 births to women aged 30-34; 4492 births to women aged 35-39 and; 914 births to women aged 40 years and over (NIMATS).

PHA Staff Data:

16-24	0.32%
25-29	4.84%
30-34	9.35%
35-39	11.94%
40-44	16.77%
45-49	23.23%
50-54	15.81%
55-59	12.58%
60-64	4.52%
>=65	0.65%

Screening will be offered to all babies in the first week after birth, ideally on day 5 of life. NBS screening may be offered up to day 364 of life in some cases.

Religion	The religious make-up of the population of Northern Ireland, according to the 2011 census is as follows:

Protestant	40.8%
Catholic	41.6%
No religion	10.1%
Other	0.8%
Not stated	6.8%

PHA Staff Data:

Perceived Protestant	4.84%
Protestant	32.58%
Perceived Roman Catholic	1.94%
Roman Catholic	31.61%
Neither	1.61%
Perceived Neither	0%
Not assigned	27.42%

Political Opinion	First preference votes per party in Northern Ireland Assembly Elections 2017 (Source: Electoral Office NI, 2017)

First preference votes per party in Northern Ireland Assembly Elections 2017
(Source: Electoral Office NI, 2017)

Party	Votes
Democratic Unionist Party	225,413
Sinn Fein	224,245
Social Democratic and Labour Party	95,958
Ulster Unionist Party	103, 314
Alliance	72,717
Other	81,668

PHA Staff Data:

Political opinion	%
Broadly Nationalist	0.97%
Other	5.48%
Broadly Unionist	1.94%
Not assigned	88.06%
Do not wish to answer	3.55%

Marital Status	The marital status of the population of NI according to the 2011 Census are as follows:

Married	47.6% (680,840)
single	36.1% (517,359)
Registered in same sex civil partnership	0.1% (1,288)
Divorced, separated or previously in a same-sex partnership	9.4% (134, 994)
Widowed or a surviving partner	6.8% (97,058)

PHA Staff Data:

Divorced	1.61%
Mar/CP	54.19%
Other	0.97%
Separated	0.97%
Single	17.10%
Unknown	24.19%
Widow/R	0.65%
Not assigned	0.32%

Dependent Status	**PHA Staff Data:**

Yes	8.06%
Not assigned	86.13%
No	5.81%

Disability	According to the 2011 Census, 17 – 21% of the NI population report having a disability. 21% percent of the ordinarily resident population are living with a long term health problem or disability which limits their day to day activities. The table below shows the percentage of people in Northern Ireland population, by type of long term condition or disability:

Type of long – term condition	Percentage of population with condition %
Deafness or partial hearing loss	5.14%
Blindness or partial sight loss	1.7%
Communication Difficulty	1.65%
Mobility of Dexterity Difficulty	11.44%
Learning, intellectual, social or behavioural difficulty.	2.22%
Emotional, psychological or mental health condition	5.83%
Long – term pain or discomfort	10.10%
Shortness of breath or difficulty breathing	8.72%
Frequent confusion or memory loss	1.97%
A chronic illness (such as cancer, HIV, diabetes, heart disease or epilepsy).	6.55%
Other condition	5.22%

PHA Staff Data:

No	65.48%
Not assigned	33.23%
Yes	1.29%

Ethnicity	The 2011 Census suggests that 1.8 per cent (32,400) of the usual resident population of Northern Ireland belonged to minority ethnic groups. The main minority ethnic groups were:

Chinese	6,300
Indian	6,200
Mixed	6,000
Other Asian	5,000

Each accounting for around 0.3% of the population. Irish Travellers comprised 0.1% of the population.

PHA Staff Data:

Not assigned	75.81%
White	24.19%
Other	0%
Black African	0%
Indian	0%
Chinese	0%

Sexual Orientation	**PHA Staff Data:**

Do not wish to answer	1.29%
Not assigned	87.10%
Opposite sex	10.00%
same sex	1.61%

2.3 Qualitative Data

What are the different needs, experiences and priorities of each of the categories in relation to this policy or decision and what equality issues emerge from this? Note if policy affects both staff and service users, please discuss issues for both

Category	*Needs and Experiences*
Gender	There is no data to suggest that the needs and experiences of service users differ on the basis of Gender.
Age	There is no data to suggest that the needs and experiences of service users differ on the basis of age.
Religion	There is no data to suggest that the needs and experiences of service users differ on the basis of religion.
Political Opinion	There is no data to suggest that the needs and experiences of service users differ on the basis of political opinion.
Marital Status	There is no data to suggest that the needs and experiences of service users differ on the basis of marital status, however, it should be considered that the needs and experiences of a baby testing positive for any of these conditions may be exacerbated for single parents, or parents with little or no family support.
Dependent Status	The needs and experiences of a baby testing positive for any of these conditions may be exacerbated for families with multiple dependants.
Disability	The needs and experiences of a baby testing positive for any of these conditions may be exacerbated for parents or families living with disability.
Ethnicity	There is data to suggest that sickle cell disorders are more prevalent among people of African Caribbean descent. There is also data to suggest that Cystic Fibrosis is more prevalent among people of Caucasian descent.
Sexual Orientation	There is no data to suggest that the needs and experiences of service users differ on the basis of sexual orientation.

2.4 Multiple Identities

Are there any potential impacts of the policy or decision on people with multiple identities? For example; disabled minority ethnic people; disabled women; young Protestant men; and young lesbians, gay and bisexual people.

N/A

2.5 Making Changes

Based on the equality issues you identified in 2.2 and 2.3, what changes did you make or do you intend to make in relation to the policy or decision in order to promote equality of opportunity?

In developing the policy or decision what did you do or change to address the equality issues you identified?	***What do you intend to do in future to address the equality issues you identified?***
All staff involved in the NBSP are aware of the complex health and social care needs of their local populations. Stakeholders, have been, and will continue to be, included at each step of the expansion project.	Review of Annual Reports and the implementation of new status codes will aid future learning. Ensure equal access to services and information.

2.6 Good Relations

What changes to the policy or decision – if any – or what additional measures would you suggest to ensure that it promotes good relations? (refer to guidance notes for guidance on impact)

Group	***Impact***	***Suggestions***
Religion		
Political Opinion		
Ethnicity		

(3) SHOULD THE POLICY OR DECISION BE SUBJECT TO A FULL EQUALITY IMPACT ASSESSMENT?

A full equality impact assessment (EQIA) is usually confined to those policies or decisions considered to have major implications for equality of opportunity.

How would you categorise the impacts of this decision or policy? (refer to guidance notes for guidance on impact)

Please tick:

Major impact	
Minor impact	x
No further impact	

Do you consider that this policy or decision needs to be subjected to a full equality impact assessment?

Please tick:

Yes	
No	x

Please give reasons for your decisions.

Mitigation has been put in place to address any equality issues identified in the screening of this policy. It is not thought that subjecting this policy to EQIA will present further opportunities to promote equality of opportunity.

(4) CONSIDERATION OF DISABILITY DUTIES

4.1 In what ways does the policy or decision encourage disabled people to participate in public life and what else could you do to do so?

How does the policy or decision currently encourage disabled people to participate in public life?	*What else could you do to encourage disabled people to participate in public life?*
The NBS programme offers screening to every baby born in NI as well as 'movers in'. The programme ensures that every parent/guardian has access to this service and that they are given the relevant information surrounding NBS screening to enable informed consent irrespective of disability.	Ensuring equal access to services and information.

4.2 In what ways does the policy or decision promote positive attitudes towards disabled people and what else could you do to do so?

How does the policy or decision currently promote positive attitudes towards disabled people?	*What else could you do to promote positive attitudes towards disabled people?*
The NBS programme offers screening to every baby born in NI as well as 'movers in'. The programme ensures that every parent/guardian has access to this service and that they are given the relevant information surrounding NBS screening to enable informed consent irrespective of disability.	Ensuring Equal access to services and information.

(5) CONSIDERATION OF HUMAN RIGHTS

5.1 Does the policy or decision affect anyone's Human Rights? Complete for each of the articles

ARTICLE	Yes/No
Article 2 – Right to life	No
Article 3 – Right to freedom from torture, inhuman or degrading treatment or punishment	No
Article 4 – Right to freedom from slavery, servitude & forced or compulsory labour	No
Article 5 – Right to liberty & security of person	No
Article 6 – Right to a fair & public trial within a reasonable time	No
Article 7 – Right to freedom from retrospective criminal law & no punishment without law	No
Article 8 – Right to respect for private & family life, home and correspondence.	No
Article 9 – Right to freedom of thought, conscience & religion	No
Article 10 – Right to freedom of expression	No
Article 11 – Right to freedom of assembly & association	No
Article 12 – Right to marry & found a family	No
Article 14 – Prohibition of discrimination in the enjoyment of the convention rights	No
1st protocol Article 1 – Right to a peaceful enjoyment of possessions & protection of property	No
1st protocol Article 2 – Right of access to education	No

*If you have answered no to all of the above please move on to **Question 6** on monitoring*

5.2 If you have answered yes to any of the Articles in 5.1, does the policy or decision interfere with any of these rights? If so, what is the interference and who does it impact upon?

List the Article Number	Interfered with? Yes/No	What is the interference and who does it impact upon?	Does this raise legal issues?* Yes/No

** It is important to speak to your line manager on this and if necessary seek legal opinion to clarify this*

5.3 Outline any actions which could be taken to promote or raise awareness of human rights or to ensure compliance with the legislation in relation to the policy or decision.

(6) MONITORING

6.1 What data will you collect in the future in order to monitor the effect of the policy or decision on any of the categories (for equality of opportunity and good relations, disability duties and human rights)?

Equality & Good Relations	Disability Duties	Human Rights
Number of babies born in NI Number of babies screened (uptake of screening)		

Approved Lead Officer: Rachel Doherty

Position: Consultant Lead, NI NBSP

Date: 19.11.2019

Policy/Decision Screened by: Annie McGeown

Business Unit and contact details: PHA, Linenhall St, Belfast 02895360346

Please note that having completed the screening you are required by statute to publish the completed screening template, as per your organisation's equality scheme. If a consultee, including the Equality Commission, raises a concern about a screening decision based on supporting evidence, you will need to review the screening decision.

Please forward completed template to: Equality.Unit@hscni.net

Template updated January 2015

Any request for this document in another format or language will be considered. Please contact us (see contact details provided above).