



*UK National  
Screening Committee*

# **Guidance for the development, production and review of information to support UK population screening programmes**

# About the UK National Screening Committee

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or better informed decisions. National population screening programmes are implemented in the NHS on the advice of the UK National Screening Committee (UK NSC), which makes independent, evidence-based recommendations to ministers in the four UK countries.

The UK NSC secretariat is hosted by Public Health England (PHE).

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# Background

The [2014 Parliamentary Science and Technology Committee Report on national health screening](#) noted that although national population screening programmes promoted the concept of those eligible making an ‘informed choice’ to enter a programme, the UK NSC did not have a clear definition of ‘informed choice’ that was consistently applied.

The report also expressed concerns about “inconsistencies in the method of developing public information, both within and across programmes” and “that there was no mechanism to share best practice across all programmes and that there was no UK-wide oversight of all NHS screening information materials”.

To address these points, a 4 country UK NSC public information task and finish group was established in 2016. The group undertook to agree a definition of ‘informed choice’ to be applied to all screening programmes and to develop guidelines for a process for producing information to share best practice and avoid duplication across the 4 nations.

## Informed choice

The group carried out a review of relevant literature around informed choice in screening published since the UK NSC last undertook a major review in 2011.

It proposed that in the context of population screening, all programmes should aim to facilitate a ‘**personal informed choice**’. The addition of ‘personal’ emphasises that all programmes seek to ensure that a decision to have screening or not is the right one for the individual involved and fits with their values and unique circumstances. All screening information should be produced with this in mind. As well as having access to information, people offered screening must also be able to discuss their screening options with an appropriately trained member of the screening team.

Our definition of a **personal informed choice** is:

A decision made to accept or decline a screening test based on access to accessible, accurate, evidence-based information covering:

- the condition being screened for
- the testing process
- the risks, limitations, benefits and uncertainties
- the potential outcomes and ensuing decisions

There should also be the opportunity to reflect on what the test and its results might mean to the individual. Support must be available to potential participants to help them

make a decision based on their individual context (which may include discussion of some aspects of the information as relevant to that person).

## 1. Introduction

This document provides guidance to all 4 UK countries on the development or revision of screening publications for UK NSC recommended programmes, including public information, online content, guidance and training publications for health professionals and staff involved in screening. The 4 UK countries differ in their organisational and governance arrangements for national screening programmes, so this guidance avoids a prescriptive approach.

It is important that high quality information products are shared across all 4 countries, to promote best practice, ensure consistency and avoid unnecessary duplication. This will require keeping a database of the screening information produced in each country. Dedicated funds will be essential to ensure this can be properly maintained and updated.

There will be a necessary difference in approach to the content on information pertaining to those programmes where participation is recommended (such as bowel cancer screening and antenatal screening for infectious diseases) and those antenatal screening programmes aiming to enable reproductive choice. In all public information, it must be clear that individual decisions to accept or decline the offer of screening will be equally respected.

It is important to note that there can be a discrepancy between the information individual users might want and the information required to present all aspects of the screening programme. A careful balance must be struck between providing the requisite information most individuals will need to help them decide about entering a screening programme and providing so much information that many are discouraged to read it. In view of this all users should be made aware that more information is available through national screening programme websites and other trusted sources.

## 2. Principles for information development

### 2.1. Best principles

In order that users and commissioners can be confident that screening programmes are adhering to the principle of promoting personal informed choice, the public information to support programmes must be fit for purpose. This means it should follow the principles of best practice:

1. Information should be balanced and include accurate, evidence-based information on the condition being screened for, potential benefits, risks, limitations and uncertainties of taking the test and the possible outcomes and decisions that may ensue.
2. Information should be based on the best available scientific evidence regarding incidence and prevalence of the condition being screened for and test performance (sensitivity, specificity and positive/negative predictive value).
3. Information should make it clear that it is a personal choice to accept or decline screening and both choices will be fully supported.
4. Information should follow the principles of plain English, while recognising the need to use correct technical and medical terminology.
5. Public information should be suitable for the UK average reading age of 11.
6. Information should make use of techniques that are known to aid comprehensibility and engagement such as providing essential information early in the document using images, infographics and videos.
7. First line information should be proportionate but more detailed information should be available and accessible to those who want it. Internet access must not be assumed.
8. Stakeholders should be involved in the process of developing the information.
9. Information should be tested by, and as far as possible be deemed acceptable to, users.
10. Information for the public should be supported by any necessary training for frontline providers, including training in effective communication.
11. Information should be subject to an agreed evaluation and review process.

All public-facing information must present an accurate, evidence-based description of the condition being screened for. When the screening programme aims to enable reproductive choice, the condition screened for must be described in a fair and

balanced way. As stated earlier, it must always be made clear that decisions to accept or decline the offer of screening will be equally respected and fully supported by health professionals. The potential consequences of each decision should be explained. The sensitivity, specificity and positive/negative predictive value of a screening test along with risks and probability are difficult concepts to communicate effectively but a good understanding by both staff and individuals offered screening is necessary if a personal informed choice is to be made. Careful thought should be given how to approach this and training materials made available to staff. Equally challenging but necessary is to ensure that an individual understands potential harms in a realistic and personally applicable way. Guidelines and training materials should be readily available to all staff involved in screening discussions.

Information for professionals will need to be accessible to and appropriate for staff with varying levels of knowledge. Therefore, it is important that clinicians and front-line providers are involved in its production. Messaging must be consistent between professional and public information.

To help ensure that all information is written in plain English, a member of the development team should be experienced in communicating in plain English and have knowledge of health literacy.

## 2.2. Promoting equity

Each of the UK countries commits to making reasonable provision to meet the needs of those who may face barriers to accessing information. Broadly, people who have a learning disability or sensory loss need information about screening they can access and understand. People with a learning disability or sensory loss should also receive appropriate support to help them to communicate.

Equity in screening includes accommodating potential participants who do not speak or read English. This will require screening service providers to have access to professional interpreting services and translated materials. National programmes will provide key information in the most widely spoken languages and make this easily available online for providers.

## 3. User need

Establishing user need is the first step in the development process. The user need should be defined as clearly as possible in order that the development process succeeds in producing information that fulfils it. To do this it helps to consider the perspective of the user:

**As a...** [who is the user?]

**I need to...** [what does the user want to do?]

**So that...** [why does the user want to do this?]

In relation to screening an example user need could be:

**As a** person being offered a screening test

**I need to** understand the potential benefits risks, limitations uncertainties, potential outcomes and ensuing decisions involved in the testing

**So that** I can decide whether it is right for me to have the test or not

The Government Digital Service has more detailed [guidance on user needs](#).

### 3.1. Project team

Once the user need has been agreed by screening leads, setting up a project team will ensure good oversight of the development process. The team should include members with knowledge of screening and the condition being screened for, along with someone with expertise in public information and engagement who will lead on the content development. Not all information products will require a large team.

More substantial publications will usually require additional input from clinical experts and stakeholders to help inform content. It may be necessary to establish an editorial board. In this case, appropriate terms of reference should be agreed at the first meeting.

## 4. Research

The UK NSC will have gathered the requisite research evidence to support the implementation of a population screening programme and some of this will provide evidence to underpin information content. However, some specific research prior to information development may be necessary. This might be in order to determine the implications or practicalities of local administration of the programme or may be qualitative research to establish the particular information needs of the target population. The latter may be important in relation to those target groups who have more specific access needs. Such research should always be proportionate.

Publication of new or revised information will sometimes require the updating of related public facing health information. Discussions should start with providers of any related information in good time so updates go live at the same time as new information is published.

## 5. Development

The information development process should be no longer or more complex than is absolutely necessary to meet the user need. For more substantial publications it is likely to be an iterative process which will include input from external stakeholders and users

### 5.1. Engaging with users

It is worth considering focus groups when developing new public information materials as this is a productive way of obtaining the user view. Professional publications may also benefit, so this should be considered on a case by case basis. Input from users must be proportionate. However, it is vital that a range of user views is sought to include those who accepted and declined screening and made different decisions based on the results.

There may also be scope for 'user testing'. This involves individual user interviews where people are observed as they read information and are asked specific questions about what they understand.

### 5.2. Surveys

Surveys of existing information users may be required, depending on the publication type. When reviewing an existing publication, an online survey can be useful in generating evidence to inform changes. The project team should work together to ensure that surveys are fit for purpose. Stakeholders such as charities may be able to help disseminate surveys.

### 5.3. Consultations

For some major projects an open consultation period of up to 3 months may be considered. For such projects, an online consultation process will generally be the most viable approach. In most cases the consultation period will be significantly shorter and may not be open to all. Again, the principles of proportionality and practicality should apply.

### 5.4. Documenting the process

There should be a mechanism to document the development process, including evidence used to develop publications and any consultation undertaken. A record should be retained.

## 6. Approval

There should be a formalised and transparent process to agree and 'sign off' that the information meets the user need brief and is ready for distribution.

## 7. Publication

For public information, versions should be available to meet the needs of those with sensory loss or learning disability. This could include braille, audio and easy read. Translated versions will be needed in the most prevalent minority languages (see 2.2).

## 8. Distribution

It is important that:

- service providers know how to access the information quickly and easily
- information can be provided to users in a timely fashion

Each country will have communication channels to alert service providers to the publication of any new material. In some circumstances, it may be necessary to extend such communication to relevant stakeholder organisations.

## 9. Evaluation and review

All new public information materials should be evaluated post-implementation. This will include user feedback.

Review of existing publications should normally take place every 3 years. In some cases, a shorter timeframe may be required – for example, due to a policy change or new evidence.

It is important to ensure that the evaluation process seeks to check that the public facing information achieved its purpose to encourage an individual to consider the offer of a screening test and make a personal informed choice to accept or decline. The approach should be proportionate, but is likely to include a questionnaire for users and providers and may involve focus groups.