Executive summary

Well-organized cervical screening programmes have been shown to reduce the incidence of and mortality from cervical cancer at the population level. This document describes current best practices in the following aspects of a cervical screening programme:

- conducting an audit of cervical cancers;
- establishing legal and ethical frameworks to safeguard the interests of screening participants, health professionals, and programme managers associated with cervical screening;
- developing a strategy for effective and transparent communication with target populations and other stakeholders about the benefits, risks, and limitations of cervical screening; and
- establishing a framework for developing workforce competencies in communication.

This document is based on a review of the scientific literature and on the opinions of technical experts who were convened through three Technical Working Groups. A summary of the current best practices as noted by the members of the Technical Working Groups is given below.

Audit of cervical cancers in a screening programme

- The purpose of programmatic audit of cancers in a cervical screening programme is to discover discrepancies between actual practice and recommended standards in order to identify any changes needed in the process or the system to improve the quality of care. Audit findings are expected to direct further investigations of screening practice that target improvement rather than blaming an individual professional or an organizational entity for perceived lapses.
- There is variation between countries with regard to the need for, the implementation of, and the communication of audit of cervical cancers. No legal or ethical consensus prevails internationally.
- It is not possible to achieve zero-error screening in standard practice, no matter how high the quality of cancer screening is.
- Audit planning and the engagement of stakeholders are key to the success of the entire audit process.
- An individual case review should be distinguished from a programmatic audit and should be planned and implemented differently, because the two processes have different objectives.
- The public good and the responsibility to provide a high-quality screening programme outweigh the possible risks to an individual from participating in the audit. Thus, not obtaining individual informed consent at the time of

a programmatic audit is justified. However, this means that the women who undergo screening must be informed at the time of the screening of the possibility of an audit.

- The European guidelines recommend that all cervical cancers should be investigated, whether detected in screened women or in unscreened women.
- An interval cervical cancer is defined as any cancer (including microinvasive cancer [stage IA]) diagnosed in a woman between her most recent screening episode and her next screening round, at an interval stipulated by the programme, who had either (i) no abnormal screening test result or (ii) an abnormal screening test result but a negative triage test result or a negative diagnostic test result. It is important to distinguish between these two different types of interval cancers.

Legal and ethical frameworks associated with cervical screening programmes

- A screening-eligible woman who is invited to participate in cervical cancer screening should be informed about the nature and purpose of cervical screening and of the tests, the possible results, and the benefits, risks, and limitations. The woman's right to decline to undergo a test and the possible consequences of opting out should also be explained.
- Operators of cervical cancer screening programmes have an ethical obligation to carry out programmatic audits that seek to improve patient care and outcomes through systematic review of care against explicit criteria and to take action to improve care when standards are not met.
- Confidentiality and the protection of privacy are essential in cervical screening. Information about a cervical screening test is highly sensitive, given that it may include the results of the test and information about the participant's cancer or precancer status.
- Programmatic audit should preferably be conducted using anonymized or de-identified data, whereby consent from each screening participant is not necessary and disclosure of findings is not possible.
- Consent to undergo a cervical screening test as a health-care intervention is not the same as consent for the processing of data related to that screening test for audit. Even where consent is not relied upon as the basis for data processing, the data controller should ensure that privacy notices are prominently displayed that inform the screening participants about how their data will be processed.
- Screening programmes may offer an individual case review to participants after obtaining informed consent. When consent is obtained for an individual case review, participants should be asked whether they wish to be informed of a discrepancy if one is detected in the future.
- Regarding legal liability for errors in screening, it should be possible to make a claim for negligence with respect to cervical screening, but the standards applied by courts in assessing such claims should accommodate and reflect the reality of cervical screening, including hindsight bias in an audit of cancers. The determination of whether the particular screening error was serious enough to be categorized as negligent and/or serious enough to entitle the participant to compensation needs to consider the inherent limitations of cervical screening.

Effective and transparent communication about cervical screening

- Because of the heterogeneity of the target population for screening, the approaches to screening and downstream management are variable across settings, and so are the access barriers encountered. These differences need to be considered when developing messages and designing communication strategies to promote uptake of cervical screening.
- The screening information conveyed should highlight that screening is a personal choice and should include clear statements on the benefits, risks, and limitations of screening. The information needs to provide a clear statement on the estimates of probabilities of the condition and potential positive and negative outcomes from screening. It also needs to highlight that the programmeprovides screening because of the significant burden of disease and because the benefits of undergoing the tests outweigh their risks and limitations.
- Acknowledging that screening has risks and describing the benefit-to-risk balance through a pragmatic communication strategy is likely to build long- lasting trust in the programme and ensure autonomy in decision-making by every potential screening participant.
- When developing screening information materials, the information should be provided using a tiered approach, starting from basic concepts and building up to more complex information, supported by visual aids and using behavioural science support.
- A multipronged delivery strategy and obtaining feedback from all relevant stakeholders on the appropriateness of the content and the acceptability of the delivery modes are important.

- Communication with all other stakeholders is essential to build relationships of trust that will facilitate the implementation and operation of the screening programme. Stakeholder analysis helps to define various audiences, their level of sophistication, and their willingness to hear the messages that are communicated. The content and delivery mode of the messages must be tailored to the intended audience and must consider cultural norms and sensitivities.
- Once the stakeholder analysis is complete, a documented stakeholder engagement strategy needs to be developed. Such a strategy improves trust in the screening policies, increases buy-in, and may help to mitigate any short- and long-term issues with the programme.
- Screening programmes should be prepared by having a communication strategy in place for events that may evolve into a crisis. Such incidents may be related to risks of screening, a change in the screening criteria or the interval of screening, or any occurrences after screening, which may not be directly related to the screening programme itself.

Workforce competencies in communication about cervical screening

- Health professionals involved in the screening pathways need to acquire appropriate knowledge and should be able to demonstrate skills that include:
  - being able to foster a relationship of mutual trust, understanding, and commitment;
  - being able to exchange information that recognizes the individual's information needs and overcomes any barriers related to low health literacy and poor understanding of statistical information and considers cultural contexts;
  - being able to manage uncertainty by acknowledging it and providing further information, support, and cognitive strategies;
  - supporting shared decision-making through active involvement of the potential participants and their family members in the information-exchange and deliberation stages of the decision-making process; and
  - enabling people to navigate the health system by providing appropriate guidance on seeking appropriate care and finding further information.