

## Implementation of organized cervical cancer screening in Slovenia



In the 1990s an increase in cervical cancer incidence was observed in data from the Slovenian cancer registry (one of the oldest population-based cancer registries in Europe).

The **desired aim was to reduce cervical cancer incidence** (1) by implementing an **organized cervical cancer screening programme** with a care pathway linking timely follow-up services; and (2) by **introducing quality assurance mechanisms** to improve the quality of screening services.

A way forward was proposed by public health experts working in collaboration with health-care providers, the Ministry of Health and insurance providers to achieve the desired change and implement an organized, population-based cervical cancer screening programme for the defined target population. Following European guidelines and WHO recommendations, guidelines were developed, a central registry was established, and quality assurance mechanisms were put in place.

It was challenging given the different interests involved. Some gynaecologists and women were sceptical that the incidence of cervical cancer would be lowered by moving from opportunistic to organized screening, limiting the screening age, and prolonging the screening interval. Changing these perceptions was only possible thanks to the high level of trust that existed between public health experts and the public health directorate and between women and their gynaecologists. Trust was also built over time between screening providers and public health experts.

"When we switched from annual screening examinations to three-yearly ones, I wasn't scared at all because I trusted my gynaecologist completely. I am very grateful that Slovenia has ZORA, and I highly recommend that all women, mothers and grandmothers accept an invitation for screening, because it may save your life. I am also grateful to my gynaecologists, who have done a very good job."



Nevenka, patient.

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Increased screening coverage among the target population, linked to follow-up care and quality improvement, meant that cervical cancer incidence dropped to record low levels. At the same time, the recall rate for positive screening results dropped from 15% to 5%. Having previously had one of the highest cervical cancer burdens in Europe, Slovenia now had one of the lowest.

Achieving change. As the first results of the shift from opportunistic to organized screening were observed in the pilot, initial doubts about its safety – and the suspicion that it was financially motivated – gradually dissipated. Within a few years, trust of health professionals in the new programme was secured, and from them it spread to their female patients.

But trust does not spring up overnight and must be constantly nurtured. Decision-making must be anchored in evidence and a values framework. There must be transparency in communication and practice, and personal commitment on the part of leaders, whose belief and energy inspire others. However, believing is not enough: a plan is also needed, and for that, clear organizational and governance structures must be in place.

"In Slovenia, patient organizations in the field of oncology have certainly played a pioneering role, leading to patient representatives being involved in different decision-making processes. As an association and patient representatives, we have been included in the screening steering programme for more than 10 years. It started with three separate screening programmes – DORA, ZORA and SVITt – which subsequently merged into one steering committee, so all patient representatives now sit together in a single steering committee in Slovenia."

Dr Tanja Spanic, Patient Representative and President, Europa Donna Slovenia.



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A shared vision. An important moment on this journey was the WHO announcement that cervical cancer could be eliminated. In 2019 the Association of Slovenian Cancer Societies held a press conference at which it was announced that "Slovenian experts believe that with HPV vaccination and cervical screening we can prevent almost every case of cervical cancer in Slovenia". Since that date, the Association has informally led the cervical cancer elimination initiative in Slovenia, connecting and mobilizing all relevant stakeholders. Allied with other professional bodies, they hold an annual press conference, and on 17 November important Slovenian landmarks are lit up in teal – the colour of cervical cancer awareness.



## The Association of Slovenian Cancer Societies' landmark press conference, held in Ljubljana in January 2019.

Specific training was needed to ensure that all key stakeholders were pulling in the same direction. Since 2011 the coordination centre for the screening programme, ZORA, has organized education days, increasing health literacy concerning cervical cancer and motivating health professionals in the screening pathway. Thanks to regular engagement, the media too are now health-literate and fully supportive of the current screening policy.

More details on ZORA's shared vision are available here.

A new challenge – the switch from cytology to HPV screening. During the preparation phase for the switch from cytology to HPV-based screening, a modelling exercise was conducted to determine the optimal HPV-based screening and triage strategy for Slovenia, in terms of cost-effectiveness, benefits and harms. What was acceptable to women was also modelled – for example, all screening intervals longer than six years were ruled out because they might be seen as unsafe and lead women to seek alternative solutions. The optimal yet socially acceptable screening scenario, as revealed by the modelling, is described in a published article (Jansen et al., 2021). **Implementation of quality assurance measures required standardization and digitalization** – a shift from paper to a digital registry where high-quality data could be structured for use and analysis. Clinicians initially feared the change might be used to penalize them, but in time they came to see the value of the data and feedback.

ZORA maintains the central registry of all cervical cytology, HPV and histopathology results. It supports and enables the invitation process (paper-based), monitoring, evaluation, and improvements in the screening programme. Cytology data (since 2003) and HPV data (since 2011) have been standardized at the national level; data are digitalized in the laboratories and then sent to ZORA. Methodological guidelines for standardization and digitalization are available on the ZORA <u>website</u>.

Annual personalized feedback on number and quality of services, including follow-up results, is prepared and sent to all screening providers. Since 2023 key performance (KPI) and activity (KAI) indicators have been included in the reports, which are now digital and available for the previous five years to allow comparison over time. This is important for engagement and commitment of stakeholders and improvement in the quality of services. Screening providers can only see their own results, but they can compare them to the Slovenian average and those of other providers. Until 2023, only feedback and interpretation of the main results were presented by the head of the programme at ZORA educational days, but review/audit of the reports by expert committees has now been introduced to allow suggestions for improvement, which are sent to screening providers.

Every year the central coordinating team prepares and sends to gynaecologists a list of women who had pathological findings but did not have the expected follow-up. At first, gynaecologists took this as a "control" on their work, but within a few years they started to see this fail-safe mechanism as a help.

When standardization and digitalization were introduced 20 years ago, it initially created extra work in laboratories (digitalization and reporting results to the screening registry) and for gynaecologists (invitations to screening) since the IT systems were not interoperable. Even though this work enhanced quality of screening (which in turn reduced workload), it was still seen as an unwanted administrative burden. However, ZORA is now developing a new centralized and interoperable system that will allow data to be entered once and available to all clinicians to facilitate treatment, to issue patient invitations, and for monitoring and evaluation.

**Finance and insurance.** When implementing HPV testing in Slovenia in 2011, the screening coordination team led the negotiations at the Ministry of Health to get the go-ahead to introduce this new method for management of women with low-grade cervical changes. Negotiations were also held with the Heathy Insurance Institute on screening providers' prices, coding and reporting system for reimbursement. A complete solution was provided, from concept to implementation, including financing. Women do not pay for any screening service on a pathway – everything is covered by their health insurance.

## Where we are now:

• ZORA's success is ultimately due to its good governance structure and strong leadership. More information on its governance domains are available <u>here</u>, and on the milestones in the development of the programme <u>here</u>.

- ZORA is fully integrated into the existing health system, and data flows are digitalized, allowing access as necessary along the screening, follow-up and care pathway.
- A quality assurance and performance management system, including guidelines, indicators and monitoring, is in place.
- Funding is ensured for the screening centre, and related services along the continuum of care are covered by the health insurance benefits package.

"We cooperate in different fields and learn from each other, especially by sharing experiences, which was especially positive during the period of COVID-19."

Dr Dominika Mlakar Novak, Head of the national colorectal screening programme SVIT.

"All three of our programmes work hand in hand. We found out that when we kind of perform together, shoulder to shoulder, we are stronger."

Dr Kristijana Hertl, head of the national breast screening programme DORA.



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## Lessons to be learned: preserving the cascade of trust

At all times, stay on the side of the evidence, listen to and engage all stakeholders, stay open to new ideas, be transparent and honest to your values.

- Build good collaboration with key professionals/societies involved in the screening pathway, foreign experts and organizations, and policy-makers

   make them advocates of the programme!
- Involve NGOs and media from the beginning.
- When the time is right, engage and commit additional stakeholders lead with your shared vision and empower others to lead too.
- Gradually build a robust organizational and governance structure that can function independently and with agility and constantly evolve and improve.
- Stick to the vision and keep politics out of it!

**The challenge ahead.** Switching to HPV screening with prolongation of screening intervals and increase in the starting age of screening (as in 2003); redistribution of work among screening providers (laboratories).

Commercial interests: the industry is pushing self-sampling; threat of the spread of non-quality-assured opportunistic screening, with validated or non-validated HPV assays.

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