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Expanding eligibility and improving quality of cervical cancer screening in Estonia: The 2021 reforms

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ABSTRACT

Estonia has one of the highest death rates from cervical cancer in the European Union despite having had a population-based screening programme for over 15 years.

In 2021, this high disease burden, alongside a new national cancer prevention plan, prompted a series of cervical cancer screening programme reforms to address low screening uptake and evidence of variable screening test quality.

The reforms had three main elements: expansion of eligibility to all women aged 30–65 regardless of insurance status; increasing test provision by enabling family physicians to take screening samples and introducing self-sampling; and improving testing procedures, replacing cytology with HPV testing as the primary screening test.

Although the impact of these changes is yet to be seen, early signs suggest increased programme participation. However, at 51 %, further action to address barriers to uptake will likely be necessary.

If Estonia is to avoid another period of policy dormancy, as happened between 2006 and 2021, greater clarity on screening programme accountability is required. The establishment of the National Cancer Screening Group may enable this. The first test will be the delivery of an end–to-end evaluation of the reformed programme, with an emphasis on equity of access. The next step will be to develop and deliver solutions that respond to these needs.

The purpose of the reform

Estonia has among the highest death rates from cervical cancer in the European Union, even though both screening and HPV vaccination are available across the country [1]. Its poor outcomes reflect several factors. Estonia was the last EU country to implement a HPV vaccination programme, in 2018, a decade later than in countries such as Spain and France, and, although organised cervical cancer screening has been available for 15 years, uptake has been poor and highly unequal [2–4].

Something had to be done, and in 2021, the health authorities sought to modernise and expand cervical cancer screening by reforming elements of the existing programme. This health policy reform monitor describes what prompted these changes, what they comprise, and how they are progressing. It has been produced as part of a more extensive study working with disadvantaged women in Estonia and two other countries with poor cervical cancer outcomes, Romania and Bulgaria. It seeks to identify possible lessons for countries elsewhere facing similar problems.

The 2021 reforms had three main elements. First, eligibility was expanded to all women aged 30–65 years. In the original scheme only those covered by the Estonian Health Insurance Fund (EHIF) were eligible. Enrolment in the EHIF is based on employment-related contributions by those of working age; thus, the initial form of the programme excluded, by design, the approximately 9 % of otherwise

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eligible women due to insurance status [5,6]. The reforms also increased the upper age limit to 65.

Second, the number of service providers delivering screening was increased and routes to access screening expanded. From 2021, processes required for potential providers to deliver screening were simplified, and family physicians were permitted to take screening samples, which had previously been limited to gynaecologists and midwives [7,8]. Additionally, self-sampling, an approach increasingly popular in Europe and piloted over recent years in Estonia, is now being rolled out in multiple regions across the country [9,10,11].

Third, the testing regime was changed, moving away from traditional cytology-based Pap smear to testing for HPV, coupled with enhanced quality control. While this change to HPV testing reflected changes taking place internationally, it also addressed a specific issue in Estonia whereby smaller laboratories had been found to have high rates of false negatives [12]. The new system provided for five-yearly screenings for HPV, with samples stored in a preservative that allows for subsequent cytology, should the HPV test be positive. Those with atypical squamous cells of undetermined significance or negative for intra-epithelial lesions are retested at 12 months. Those with low-grade squamous intra-epithelial lesions undergo colposcopy. [13] This element was expected to reduce the number of missed opportunities for early diagnosis and treatment [8].

The Estonian health system context

Overall health policy in Estonia is the responsibility of the Ministry of Social Affairs (MoSA), which oversees the work of three agencies: the State Agency of Medicines (SAM), the National Institute for Health Development (NIHD), which undertakes a range of public health functions [14], and the Centre of Health and Welfare Information Systems (CeHWIS). There is a single payer, the EHIF, an independent public body formed in 2001 following the merger of previous national and regional sickness funds, which is funded by a combination of income-related contributions, from those in employment, and budget transfers from the government, to cover pensioners and some other groups [15]. The EHIF purchases services from a range of providers, including hospitals, laboratories and primary care clinics, which may be owned by the MoSA, county governments, local municipalities, or the private sector [16]. There is an Estonian Cancer Screening Registry¸ managed by the NIHD, which in turn reports to the MoSA. It collates data on those eligible for screening and their participation by demographic and geographic characteristics. This makes it possible to incorporate additional data, such as that needed to identify those who have undergone hysterectomies or are transgender, through sharing agreements with the EHIF and others [17].

Cervical cancer screening was entirely opportunistic at first, but, in 2003, this was supplemented by an organised, population-based programme that followed the EU recommendations prevailing at the time [18,19]. The programme, led jointly by the EHIF and MoSA, and paid for by EHIF, was piloted, trialling differing approaches to eligibility, before being extended nationally in 2006, offering five-yearly screenings to women aged 30–55 [7]. Mass media campaigns promoted it, and those eligible were invited by post to book an appointment with a gynaecologist or midwife who would administer the test [20]. The programme remained unchanged between 2006 and the reforms in 2021, aside from occasional updates to clinical guidelines delivered by the Cancer Society, the Estonian Gynaecologists Society, and the Estonian Cancer Screening Registry in 2015 [20–22].

Several developments drew attention to cervical cancer screening in the build-up to the 2021 reforms. In 2019, an OECD report highlighted high levels of preventable disease in Estonia, singling out the limited access to preventive services for those uninsured and the overall low uptake of cervical cancer screening. It also documented wide inequalities in health and major barriers to accessing care [23]. This is apparent from the wide disparity in examinations undergone by women with and without health insurance invited for screening (Figs. 1 and 2).

The high burden of cervical cancer in Estonia, compared to other European countries, was evident in a report using 2020 data, when the age-standardised (new European standard population) incidence was 27.4 per 100,000, compared with the EU-27 average of 12.8 per 100,000 [24]. However, other data provide lower figures, although still above the EU average, of 17.4 per 100,000 in all age groups and 25.3 per 100,000 amongst those aged 60–64 years, a group then excluded from screening [25]. The incidence is even higher amongst those aged 70–74, at 33.6 per 100,000, [26]. Shortly after the OECD report was published, Estonia signed up for the European Cancer Mission, committing it to supporting scientific activity and implementing evidence-based clinical solutions [27,28].

Beyond these concerns specific to cervical cancer, several domestic developments in the health system at this time focused attention on the need to expand coverage by health services and disease prevention. Like many countries with health coverage linked to employment, changes in the labour patterns meant that Estonia was experiencing a growing number of people falling through the gaps. To this end, in 2021, the government increased EHIF funding, providing an additional €300 million [15,29]. This coincided with the transfer of vaccine procurement to the EHIF from MoSA, expanding the former's role in disease prevention activities [23]. Although not directly linked to these changes, the following year, a nationwide HPV vaccination scheme for girls aged 12–14 years was established, another manifestation of an increased policy focus on cervical cancer.

In addition to these factors, internal pressure from clinicians, transmitted through the Estonian Gynaecologists Society, was growing. Clinicians were especially concerned that Estonia was missing out on innovations in screening elsewhere, such as in HPV testing. They were also unhappy about the quality of the screening programme overall. They and others noted the failure to increase screening uptake since the mid-2010s (Table 1). [2] Note that these figures are lower than those shown in Figs. 1 and 2 because of the different denominators. There were also concerns about the growing evidence of inequality in access, going beyond that shown in Figs. 1 and 2 to include those of non-Estonian nationality, single women, those who are unemployed, and those with only basic education among the groups less likely to participate in screening [3]. As elsewhere, people at greatest risk of developing cervical cancer, such as those who smoke or those living with HIV, were overrepresented amongst those under-screened [3,30], an example of the inverse care law [31].

Research examining access barriers identified the inconvenience of services as a particular challenge [32–34]. There was also growing concern about quality, owing to evidence of low accuracy of cytology testing, with a worryingly high number of patients with cervical cancer having had a test processed in rural laboratories in the previous five years that had reported no abnormalities [12]. These were clear challenges to achieving equal treatment, one of two principles guiding the work of the EHIF [35].

The health policy process

In 2020, a working group, led by the NIHD, was established to develop proposals for reform to the cervical cancer screening programme, part of a broader initiative covering cancer at several sites. Its members were mostly representatives of the EHIF, MoSA, and relevant professional bodies, but it also reached out to engage with various other stakeholders. Members of the public, and in particular women, were a notable omission. Some commentators have sought to justify this, arguing that changes to screening were largely a technical issue and low on the public agenda, the latter perhaps because of low awareness of screening among those most at risk and most distant from the health system [32].

Following working group activity, programme adaptations began to be implemented on 1st February 2021. In contrast to the earlier changes,

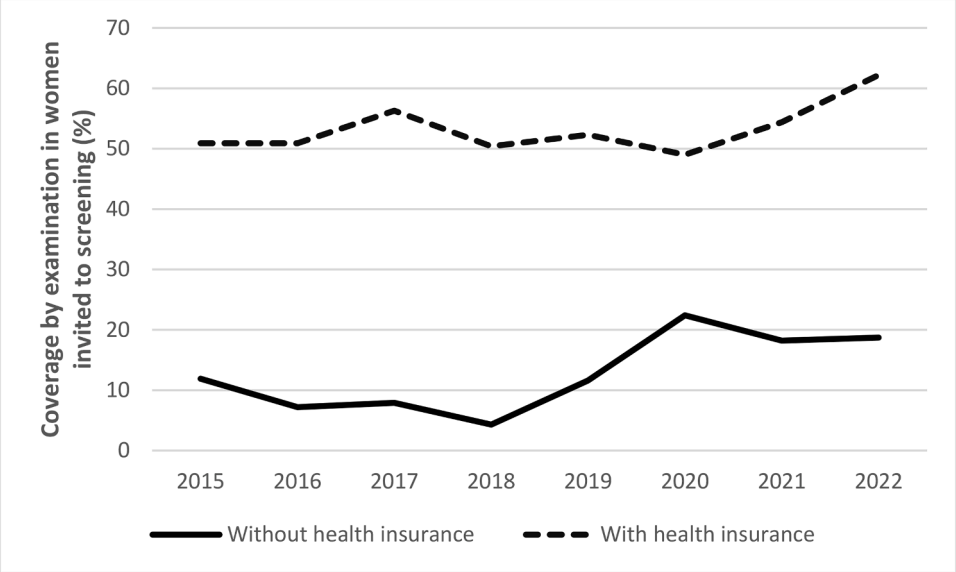

Fig. 1. Percentage of women with and without health insurance invited for screening who receive examinations over time Source: https://statistika.tai.ee/pxweb/en/Andmebaas/Andmebaas_02Haigestumus_07Soeluuringud/VSR15.px/table/tableViewLayout2/.

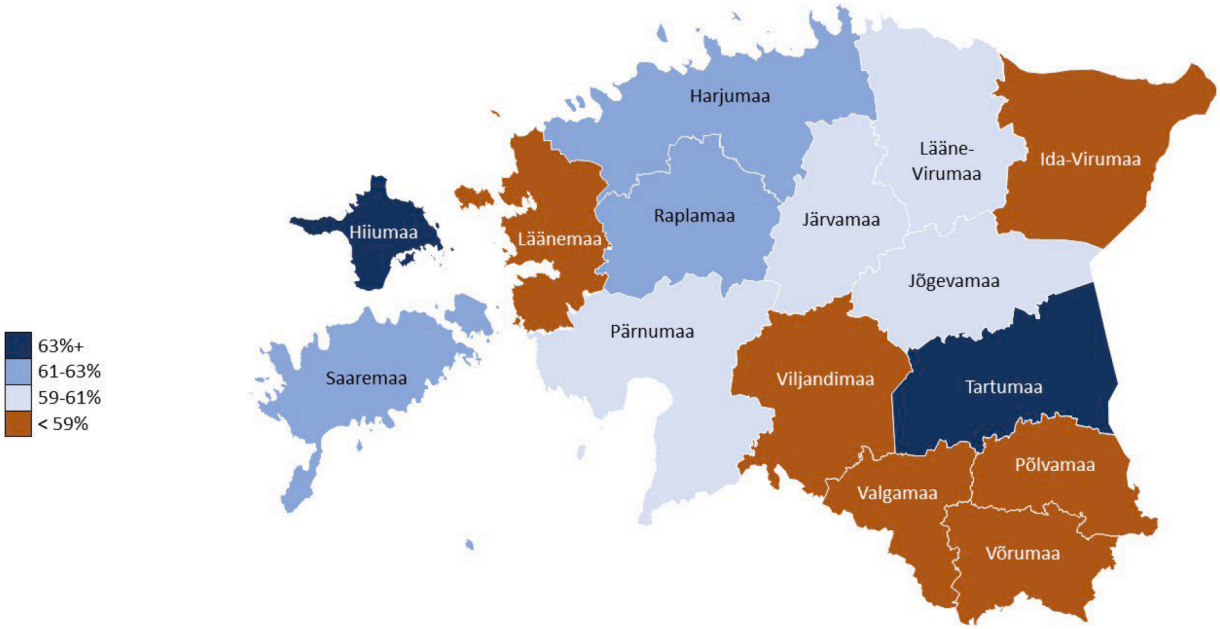

Fig. 2. Percentage of women invited for screening who receive examinations in Estonian counties in 2022 Source: https://statistika.tai.ee/pxweb/en/Andmebaas/Andmebaas_02Haigestumus_07Soeluuringud/VSR15.px/table/tableViewLayout2/.

Table 1
Coverage and uptake of the population-based cervical screening programme in Estonia: 2015–2021.

Year	Population eligible (n)	Screened through pop. based programme (n)	Target group coverage through pop. based programme (%)
2015	56737	26087	46.0
2016	56606	26030	46.0
2017	56300	28604	50.8
2018	56132	25445	45.3
2019	56921	26234	46.1
2020	55735	23508	42.2
2021	74265	37587	50.6

Source: NIHD, 2022 [2].

in 2003, no piloting was undertaken, reflecting the perceived urgency to do something. This urgency stemmed from not only the longstanding and growing concerns about access and quality noted above but also an immediate need to adapt to maintain screening during the COVID-19 pandemic.

Despite the relative lack of consultation with the public, there was little resistance to change. There was now a strong political momentum for action to tackle the high burden of cancer, exemplified by the publication of a national cancer prevention action strategy for 2021–2030. As noted above, there was also concern among health professionals that Estonia had to catch up with the rest of the EU, where most member states were already offering screening to all women aged 30–65 years, and an increasing number were replacing Pap smears with primary HPV testing [36], consistent with EU guidance [37].

While this support was reassuring, it was always possible that there would have been opposition to changes to the programme. Pathologists and other laboratory staff might have been expected to oppose it, given the threat to their employment due to reduced cytology examinations. However, resistance was limited, perhaps because of a recognition that Estonia faced a severe shortage of medical and scientific staff, in part a consequence of migration following EU accession. Another potential focus for resistance was amongst family physicians, given the potential for increased workload associated with screening. This was assuaged by making their participation voluntary. The number of family practice lists (of about 780) offering cervical screening increased from 253 in 2021 to 341 in 2022 and 318 in 2023, an overall increase of 26 %. At the same time, the number of samples taken by midwives in primary care increased from 982 in 2021 to 1826 in 2023, an 86 % increase. This is, however, still much lower than desirable, and the limited engagement of primary care remains a barrier to the success of the programme. The one group who did express concerns were gynaecologists, anxious that they would struggle with the increased demand for colposcopy. However, their concerns were allayed by implementing a system of triage, requiring initial cytology in those who tested positive for HPV before proceeding to colposcopy [8].

Other factors also eased implementation. Estonia has invested heavily in digital technology, and much government activity is now online, enabling rapid communications with partners and the public using established platforms. Additionally, a national population registry, which includes data on Estonian citizens and others registered as residents in Estonia, meant that many of those newly eligible could quickly be identified and invited to participate in screening. However, this is not a panacea as many of those eligible are not accessible with the information in the registry, such as those who have recently changed their residence or who lack official documentation. Another facilitating factor is the extent of pre-existing contractual and other relationships managed by the EHIF as the single major healthcare insurer, enabling swift adjustment to payment arrangements. This makes it possible to include payments through the existing systems for HPV testing, cytology, and colposcopy, subject to certain rules, such as the tests being undertaken for the purpose of screening and according to the prevailing guidelines and in authorised laboratories [38]. Of the approximately 780 family practices in Estonia, about 370 have midwives, who mostly take the samples for screening. Of these practices, most provide services only for registered patients, but 21 are open to all eligible.

Policy impact

The goal of the reforms was to reduce cervical cancer incidence and related mortality by increasing screening uptake and quality, preventing cancer, and improving early detection and treatment [8]. It is too early to measure success in these terms, and, anyway, this will be complicated by trends in incidence, reflecting, potentially, changes in sexual behaviour and the impact of HPV vaccination, which has reduced the incidence of pre-cancerous lesions dramatically elsewhere.

At this early stage, it is useful instead to consider logically what the impact of changes might be and reflect on early programme data where available. Taking this approach, three areas stand out. The first relates to coverage and uptake. Expanding eligibility to include older women and those uninsured will improve programme accessibility. Indeed, the number screened through the programme increased by 60 % following eligibility expansion (see Table 1) [2]. While this may represent a shift from opportunistic screening, earlier reforms in 2006 were not associated with a reduction in opportunistic screening. Even if this were the case, it is positive as participation in organised, rather than opportunistic, screening leads to better outcomes [39]. However, the issue of low programme participation still needs to be solved, as 51 % uptake is far from satisfactory. The EHIF plays a major role in supporting participation and raising awareness regarding eligibility. Current efforts to boost awareness involve working with professionals and disseminating messaging to the public through various media, including social media, television, and radio.

Expanding the number of providers able to deliver screening could result in increased uptake, and the number of screening providers has increased by around a third since 2021. However, many in areas where service providers are not easily accessible or where family physicians have declined to participate may not benefit [7]. Moreover, increasing eligibility and routes to access screening in different parts of the health system still leaves many known obstacles needing to be solved, such as limited awareness of screening and language barriers [32,40]. It may be that the very recent introduction of the self-sampling offer serves to overcome barriers for many [10,11,41,42]. However, although initially introduced at small scale for some non-responding women in 2021, self-sampling has only been offered at scale since 2023. As such, the impact of offering self-sampling on uptake is yet to be seen. As a process of co-design with underserved women is underway, further potential solutions may be identified. However, a commitment to ongoing change will be required to realise these.

The second set of issues relates to the accuracy of testing. The move to use HPV testing, an automated process, as the primary screening test has the potential to increase accuracy, partly by reducing the human errors identified in Estonia's previous screening process [12]. However, as cytological testing is still required to determine the need for colposcopy amongst those with a positive HPV result, a residual risk remains, although this will be mitigated by actions to centralise testing and strengthen quality control [8].

Beyond the direct impact of recent programme adaptations on test uptake and accuracy, another important impact relates to programme governance. Over a period of 15 years (2006–2021), there was little change in the cervical cancer screening programme despite continued low uptake and evidence of suboptimal test quality. Estonia now has a National Cancer Screening Group, created by MoSA [27], which is well-placed to advocate for closer monitoring and policy changes and may make a meaningful impact. However, the governance landscape remains complex, with multiple bodies responsible for different areas, including the MoSA, NIHD and EHIF, all operating without a lead body with ultimate accountability and the legal authority to assert it, with no formal system in place for quality assurance. As delivering screening is a complex end-to-end process, starting with ensuring the accuracy of population registers and progressing to referring those testing positive to appropriate care, high-quality coordination is vital.

Effective governance mechanisms will be crucial over the coming years to undertake a comprehensive evaluation of the impact of recent changes, which provides a detailed understanding of residual access and quality issues and enables the formulation and delivery of equitable and timely policy responses to these issues.

Conclusion

Recent reforms to cervical cancer screening in Estonia have expanded opportunities for women to benefit and may serve as a useful case study for other countries considering screening reform. These changes in Estonia were promoted by internal and external pressure built up over the years. As a relative laggard, Estonia could draw on extensive evidence from elsewhere on both the effectiveness of the measures proposed and others' experience in implementing them. It was facilitated by a solid organisational and digital infrastructure and by a widespread consensus that change was unavoidable. There was little opposition, in part because there were no real losers and those who might have been threatened either had no realistic alternative or had their fears allayed. It is too early to know what the impact will be on cancer outcomes, although the initial signs of increased screening are positive. There are, however, many remaining challenges. Significant barriers to accessing screening remain unaddressed, and mechanisms to ensure effective programme governance, although improved, are at risk of having limited impact in a complex system with ambiguity about

ultimate accountability and leadership.

Clarity of lines of accountability and the distribution of responsibility will be necessary to create effective systems to deliver the monitoring, evaluation and policy development required to identify and respond equitably to the needs of those at risk of cervical cancer in Estonia.

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While preparing this work, the author(s) used Chat GPT v.3 to create a first draft of the paper abstract. After using this tool/service, the author (s) reviewed and extensively edited the content as needed and take(s) full responsibility for the publication's content.

CRediT authorship contribution statement

Samuel Rigby: Writing – review & editing, Writing – original draft, Conceptualization. **Rachel Greenley:** Writing – review & editing, Writing – original draft. **Anneli Uuskula:** Conceptualization, Writing – original draft, Writing – review & editing. **Anna Tisler:** Conceptualization, Writing – original draft, Writing – review & editing. **Maria Suurna:** Writing – original draft, Writing – review & editing. **Maris Jesse:** Writing – original draft, Writing – review & editing. **Marc Bardou:** Writing – original draft, Writing – review & editing. **Martin McKee:** Conceptualization, Supervision, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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