Review of the National Cervical Screening Programme's Population Based Register

Te Kāwanatanga o Aotearoa
New Zealand Government

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Te Whatu Ora

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The review panel thanks the people who made time to share their knowledge and experience to inform this review. It would also like to thank those that helped to shape and guide the preparation of this review report.

We wish to acknowledge the hard work, dedication, and aroha that so many individuals have contributed to the development and delivery of cervical screening in Aotearoa New Zealand, over many years. These efforts have improved the lives of the programme's participants and their whānau. The review panel also acknowledges the teams that have worked hard to implement the change to Human Papillomavirus (HPV) primary screening and institute the new register, including the National Cervical Screening Programme (NCSP) team and the HPV Project team.

It is also acknowledged that the development and delivery of the population-based Cervical Screening Register (which is the subject of this review), took place during a period of significant change. This included the establishment of Health New Zealand | Te Whatu Ora (Health NZ) and transition to a new health system. This was the largest change to the health system in recent times and followed a period of unprecedented impact on health services due to the COVID-19 pandemic.

This report's findings and recommendations are offered in the spirit of continuous improvement of services to ensure consistent provision of safe, high-quality care to those eligible for screening.

Ngā mihi nui

The Review Panel

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Glossary

Term	Definition
Carcinoma in situ	A precancerous condition where abnormal cells are found at the site where they formed but have not yet spread to any surrounding tissue.

Cohorting	A process of introducing notifications for the Primary HPV screening programme in phases, prioritising the groups at highest need first. The three cohorts identified were:
	• Cohort 1, which includes those who are either
	  ○ unscreened or under-screened Māori or Pacific over 30 years of age not enrolled in primary care, or,
	  ○ newly eligible and either 25-30 years of age and/or a new National Health Index (NHI) (enrolled or not)
	• Cohort 2, which includes those who are unscreened, under-screened, or overdue and enrolled in primary care.
	• Cohort 3, which includes those who are either,
	  ○ regularly screened and enrolled, or,
	  ○ unscreened or under-screened individuals who are not recorded as either Māori or Pacific and who are not enrolled with a primary care provider.

Colposcopy	A procedure where a doctor uses an instrument called a colposcope to examine the cervix, vagina, and vulva for any abnormal cells or signs of cancer.
Failsafe process/reporting	A backup system to identify and respond to a failure in the planned functioning of the Register.
H-codes	Prescribed recommendation codes for laboratory results. The H-codes are checked by the H-code flows to ensure that laboratory recommendations match the correct pathway.
Human Papillomavirus (HPV)	A group of viruses spread by skin-to-skin contact that infect the genital tract and causes >95% of cervical cancers.
Liquid Based Cytology (LBC)	Also called a ‘cervical smear test’, the main cervical screening test used from 1991-2023, before HPV Primary Screening was introduced in 2023. Involves collection of cells from the cervix and viewing the cells under a microscope in a laboratory for abnormal changes to the cells.
Mortality Rate	A measure of the number of deaths in a specific population, scaled to the size of that population.
Next Expected Event	What the Register calculates will be the next event in an individual’s journey through the cervical screening pathway, such as a colposcopy referral or appointment, or the next screening test due.
Notification	Communication initiated by the Register from the NCSP to an individual. To date, notifications have mainly been sent by post as letters. Definitions of notifications discussed in this report are given below. For a full list of notifications, see figure 1 in appendix 4.

• Eligibility notification • Enrolment notification • Recall notification • Reminder notification	Invites participants to take part in cervical screening for the first time. This has been sent to people turning 25, and some groups older than this who have already 'aged in' to the programme but never had a screening test done. Sent once an individual's first cervical screening test result is received to let them know they have been enrolled. Tells an individual that their next screening test is due. Reminds individuals their next screening test has not been done and is now overdue.
Pathway Status	A description of an individual's current place in the cervical screening pathway.
Population Based Register	A comprehensive, centralised database that records and tracks information about individuals within a specific population.
Primary Health Organisation (PHO)	Health New Zealand contracts Primary Health Organisations to provide primary health services, managing contracts to general practice providers that provide subsidised health care for those people enrolled with them. PHOs also provide other health services to support primary healthcare provision in their communities to ensure seamless care is provided.
Recommendation Mismatch (RMM)	Occurs when a recommendation code entered by a screening laboratory is identified by the Register as being incompatible with the individual's screening information.
Regional Co-ordinators	Staff in regional teams who receive tasks raised by The Register to follow up on local participants with abnormal screening results who have not progressed to the next stage of the screening pathway as expected, based on the data the Register holds for the individual.
Register Central Team (RCT)	Sometimes referred to as The National Coordination Centre (NCC), the RCT is delivered by Whakarongorau Aotearoa. It makes sure register data in the Register is correct, so participants are on the right screening pathway with the right information held about them. Works with the screening laboratories and colposcopy clinics to ensure any Register tasks are addressed. Also processes returned letters and paper-based colposcopy forms.
Under-screened	The status of an individual who has not been screened regularly and on time.
Unscreened	The status of an individual who has never had a cervical screening test.
Whakarongorau Aotearoa/New Zealand Telehealth Services	Whakarongorau Aotearoa has held the contract to support operation of the NCSP Register since April 2019, acting as the Register Central Team (RCT), sometimes referred to as the National Coordination Centre (NCC).
Withdrawal notifications	Communications sent to acknowledge a request to be withdrawn and later to confirm when withdrawal has been completed or acknowledge when a withdrawal request has been cancelled.

1. Executive Summary

Introduction and purpose

This report sets out the findings of a review of the NCSP's population-based register ("the Register"). This review was initiated by Health NZ in response to a range of quality and safety issues with the Register's functionality identified by the National Public Health Service (NPHS) following its launch in September 2023. This included incomplete sending of communications to invite, recall, and remind participants to screen, and other issues outside the notification functionality. These issues were considered a risk to the safe and equitable operation of the screening programme. As the responsible body for delivering the NCSP, the NPHS sought a clinical quality and safety review to:

- assess the remedial work done to date to fix the identified issues
- identify other risks and issues, and
- provide recommendations to operate a safe and high-quality Register to best support the NCSP.

Health NZ's Executive Leadership Team (ELT) commissioned the National Service Review Team in the (then) Service Improvement and Innovation Directorate, to coordinate the review.

A terms of reference for the review was developed (set out in **Appendix One**) and a multidisciplinary expert review panel was appointed to undertake the review, with the support of the National Service Review Team.

Scope

This review was conducted between November 2024 and June 2025.

As stated in the Terms of Reference, the purpose of this review was to assess the clinical safety and quality of the Register. This includes reviewing:

- whether implementation meets the intended design and what can be learned from the implementation process
- current functionality, including ensuring participants receive effective and timely notifications, and that screen detected abnormalities are managed
- monitoring, audit, and reporting capabilities
- ability to adapt to future requirements.

The clinical safety and quality of the Register across each of these aspects directly contributes to the ability of the NCSP to deliver an equitable screening programme and meet its Te Tiriti o Waitangi responsibilities.

The appropriate coordination and oversight of screen-detected abnormalities by the Register in the context of complex clinical pathways, is a key clinical safety focus for the panel.

This review included discussion and assessment of the functionality of the Register, including its interaction/interface with Information and Communications Technology (ICT) systems and supporting business processes, such as the sending of notifications, raising

and actioning tasks; and the manual review of cases unable to be automated by the Register.

The review did not cover every aspect of the NCSP, and does not include assessment of wider sector issues, such as colposcopy clinic capacity and waiting times, other than where this was a relevant consideration to issues related directly to the Register.

Method

Background documentation was collected to inform the review panel about the service under review. A list of documents reviewed by the review panel is set out in **Appendix Two**. All data was stored on a confidential Microsoft SharePoint site, which was accessible only to the review panel.

Interviews were conducted online using Microsoft Teams with a range of staff involved in the development of the Register and the delivery of cervical screening, and other key stakeholders. Interviews were semi-structured, with questions asked following the terms of reference as relevant to each interviewee. Notes were taken during interviews by members of the review panel. A list of the roles of the individuals who were interviewed is set out in **Appendix Three**.

Key individuals who were not available to be interviewed, or who wished to contribute further following their interview, were invited to make a submission in writing. Following the interviews, additional documentation identified by the review panel was requested and reviewed.

Background

Cervical cancer screening is a key preventative health measure, which reduces the number of people developing, and dying from, cervical cancer each year. Screening and subsequent follow-up increases the chances of detecting pre-cancerous changes to the cervix, or early cancer, for which treatment is likely to be more effective.

A change in primary[1] cervical cancer screening testing from Liquid Based Cytology (LBC) ('smear test') to HPV Primary Screening was first signalled in 2016 with funding recommended by a Parliamentary Review Committee in 2018. In May 2021, Cabinet approved funding, and a business case was later approved by Cabinet's Social Wellbeing Committee. This included funding for the adoption of HPV screening and the building of a new ICT system.

The HPV Primary Screening Implementation project and the build of the Register commenced in July 2022. The Register was launched on 12 September 2023 and the switch of the screening test from LBC screening to HPV Primary Screening occurred on the same date. The eligible population for the NCSP is 25- to 69-year-old people with a cervix[2]. This

[1] Primary Screening refers to the main (and first) screening test for most participants. Depending on the result, LBC may follow a first HPV primary screen. Based on some participants' clinical history, the first screening test may be/also be LBC.

[2] This is the eligible age range for those being invited to screen for the first time. Section 2 of the clinical guidelines set out specific transitional screening scenarios for individuals previously screened in the old programme, including some individuals aged 70 to 74. The NHI does not hold whether a person is eligible for publicly funded healthcare as there is no current means of easily determining this.

includes wāhine/women, transgender, and non-binary individuals with a cervix. Routine HPV screening frequency is every five years, or every three years for immunosuppressed people. Screening test type and frequency may differ based on clinical history.

One of the NCSP's aims of introducing HPV Primary Screening and a new population-based register was to increase screening rates. Overall, the proportion of the population screened had dropped in the preceding eight years prior to go-live. There had also been consistently lower and decreasing rates of screening for Māori and Pacific people. HPV primary screening was considered a more accessible screening test due to it offering a self-test option, being less invasive and more culturally acceptable.

Summary of the NCSP screening pathway

The diagram below is a high-level summary of the NCSP screening pathway.

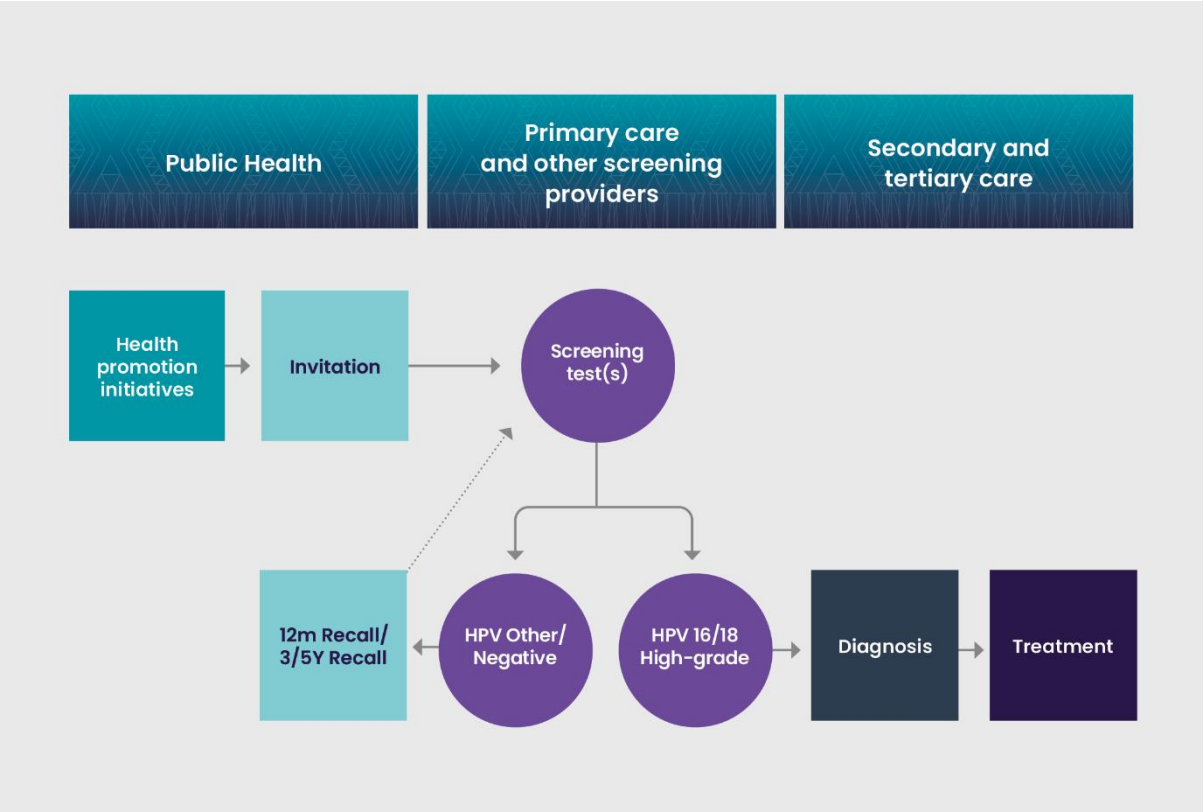
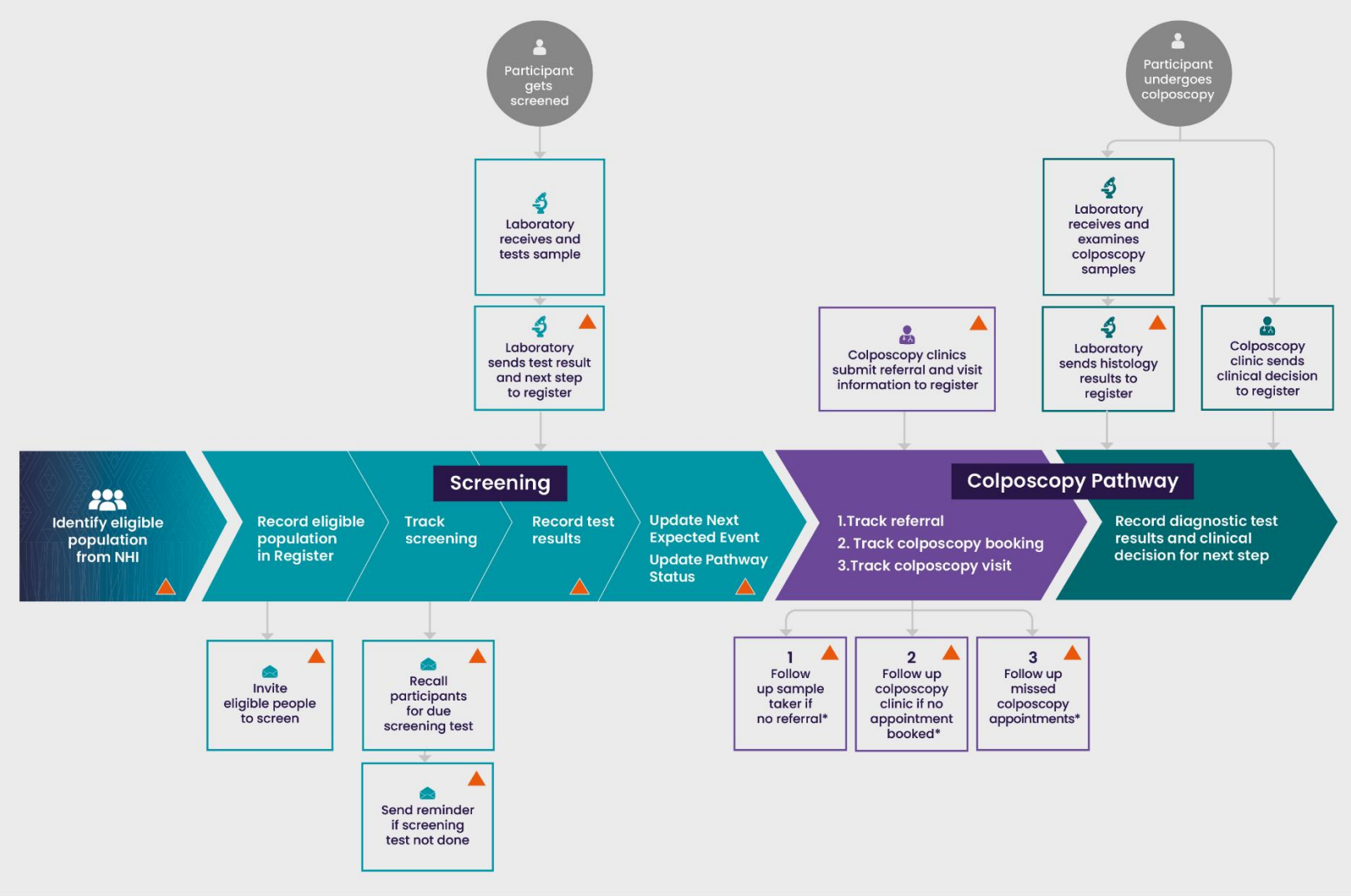


Figure 1. Summary of the NCSP screening pathway

Overview of the Register's role in the NCSP pathway

Figure 2 below is a summary of the Register's function within the screening pathway for an individual, and some of the supporting manual processes triggered by The Register. The red flags represent gaps at the indicated stage of the pathway that were identified during the review. Monitoring and programme reporting issues are not represented in full but are discussed in the report below.



▲ Issues were identified in the review

*Tasks should be raised in register for Register Central Team and Regional Co-ordinators to follow up

Figure 2. Overview of the Register's role in the NCSP pathway

Key findings

The review panel's key findings are presented below, with more detailed information addressing each part of the terms of reference in sections three to seven.

Overview

The Register was developed in 2022 and 2023 as part of a plan to redevelop the National Cervical Screening Programme. These planned changes included a change of primary screening method, implementing updated clinical guidelines, and replacing the existing screening register. The new, population-based register was planned to function as a more comprehensive screening management tool than previously, with more central notification functionality.

The Register's development experienced challenges, including changing technical requirements while screening clinical guidelines were developed, instability in staffing (including in governance roles), and a compressed timeframe in the run-up to launch.

The Register launched in September 2023, with limited functionality and several known issues including incomplete data migration from the previous register. While remedial work has been undertaken over an 18-month period to address these issues, some key items of planned functionality are still to be delivered. These include:

- ability to directly refer support to screening services
- integration of screening histories with General Practice (GP) systems[3]
- ability to 'flag' historically under-screened participants in the register
- functionality to invite, remind and recall participants
- ability to automatically account for complex patient scenarios (currently must be set manually)
- improved review of patient screening histories (currently impacted by resourcing)

The review also identified related issues that have impacted effective delivery and management of the register. These include:

- human resourcing challenges have placed significant added workload on current staff, resulting in delays in ensuring people are on the correct screening pathway
- lack of adequate user acceptance testing prior to launch, and inadequate post go-live monitoring
- Other gaps identified in manual and automated processes.

These issues mean the Register is not yet functioning as a comprehensive clinical safety net. As such, there may be other ongoing, unidentified issues which pose a clinical risk. There is also the possibility of undetected harm that has occurred because of these issues. Therefore, ongoing monitoring for harm will be required and has been recommended by this review.

There is also more work needed to ensure the level of monitoring and reporting required is in place and to publish a monitoring report to assess the safety and effectiveness of the programme. The review panel was also concerned that the Register may not have the necessary flexibility to implement the new clinical guidelines which will be finalised soon and

[3] At the time of the review this was in the process of being implemented.

other anticipated changes beyond this. The review panel considered that governance processes to manage risk are insufficient.

Overall, the review panel concluded that although the Register is working satisfactorily in many ways, there remain processes that are not working as intended. As such, the Register is not yet able to support fully the goals of the NCSP to equitably eliminate cervical cancer in Aotearoa New Zealand. In addition, there are some situations detailed below in which the clinical safety of the register cannot be assured and there may be other issues of clinical safety that have not yet been identified. The register is also not yet well positioned to incorporate evidence-based changes in the clinical pathway, some of which have already been identified. The lack of a monitoring report also means that the public are unable to be assured that the NCSP is providing safe and effective cervical screening for Aotearoa New Zealand.

The review panel considers that a clinically safe and effective register must:

- Hold accurate records of a participant's screening and diagnostic test results to ensure they can be managed according to their individual risk as per the clinical guidelines. That the Register does not hold a complete screening history for all participants suggests that this requirement is not being met fully.
- Ensure that any participant with an abnormal screening result is appropriately referred and followed up, including alerting a responsible person to act when off-track. There are significant numbers of individuals for whom laboratory recommendation mismatches occur, which can delay their further progress through the screening pathway, as well as individuals for whom a lack of progress through assessment in colposcopy clinics is not identified as intended.
- Alert participants and follow up when they are overdue for their next screening event. Decisions around who receives notifications, including 'cohorting' and the three-year National Health Index (NHI) active rule, as well as a recent incident affecting reminder notifications, means that not all participants have received recall and reminder notifications when required.
- Be well designed, intuitive, and easy to use to increase efficiency in the system and relieve administrative work burden on the screening health workforce. The current implementation of the Register involves large quantities of tasks, to resolve data issues and mismatches, which adds to workloads and would benefit from streamlining.

The review panel considers these are core aspects of clinical safety and concluded that while these are functioning for most participants, there are still some participants for whom clinically safe progression through the screening pathway is not certain. The panel also considered that the Register is not yet functioning as an equity-enhancing tool as envisaged, due to incomplete functionality and incomplete implementation of the NCSP's Equity and Notification Strategies. Overall, therefore, the review panel considers that the Register is not yet able to support fully the goals of the NCSP to eliminate cervical cancer in Aotearoa New Zealand.

Register issues affecting the cervical screening pathway

Below are the review panel's key findings about Register issues that affect the different stages in a participant's cervical screening journey. This is not an assessment of every step in the pathway, but a summary of the issues that came to light during this review. These are presented in pathway order, rather than in order of significance of clinical risk:

Identifying the eligible population

- The Register utilises NHI information which may mis-identify transgender and non-binary individuals with a cervix, and not capture other important participant demographics correctly, including ethnicity.
- Transgender and non-binary individuals with a cervix are not invited if their gender is recorded as male in the NHI, as there is no NHI field to identify their sex at birth. This means they will not be offered the opportunity to participate in cervical screening.
- Māori are under-counted in the NHI data, which is the primary source of ethnicity information in the Register. This prevents people receiving enhanced outreach and additional follow up.

Inviting and recalling eligible participants

- The Register is not initiating contact with all eligible people about screening due to the way it was designed as well as unintentional flaws in the way it was built.
- Postal address quality issues in NHI data prevent some participants' from being invited to, recalled for, and reminded to screen. These can also cause privacy issues if personal information is sent to the wrong address and requires staff time to follow up. Register functionality using email and text messaging is not yet implemented.
- An 'NHI active rule' was designed so that someone who hasn't accessed health services for six years is not sent cervical screening eligibility information. Instead, this was implemented for those not active for three years, meaning fewer people than intended are being contacted.
- 'Cohorting' was a transition measure planned to be discontinued by March 2024, but as of May 2025 was still in effect, preventing some individuals from being contacted. Ongoing 'cohorting[4]' means eligibility and recall notifications are only sent to those in cohort one: who are those aging into the programme as well as unscreened or under-screened Māori or Pacific people who are not enrolled in primary care. Other individuals[5] are not being sent these notifications, including:
    - those who are unscreened or under-screened of any ethnicity and enrolled in primary care
    - unscreened or under-screened non-Māori/non-Pacific individuals not enrolled in primary care
- As of June 2025, there were almost 160,000[6] notifications recorded as triggered but unsent, including about 108,000 eligibility notifications not sent to 'inactive' individuals and about 51,000 recall and reminder notifications not sent due to 'cohorting'. In addition, almost 808,000 notifications were not triggered, including about 656,000 eligibility notifications not triggered, of which about 495,000 were due to the individual being 'inactive'. There were also 101,000 reminder notifications not triggered due to 'case closure issues' (1). Attending to unsent notifications appeared to be on hold, while email contact was being piloted.

Reminding and following up participants overdue for screening

- Technical flaws in reminder notification logic have been identified and there are process gaps limiting follow up of priority overdue participants.

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[4] See the glossary above for explanations of the terms cohorting, eligibility and recall notifications, unscreened and under-screened.
[5] Cohorts 2 and 3.
[6] This figure does not include approx. 50,000 notifications not sent to participants who requested not to receive communications.

- There have been technical issues with various Register processes to initiate notifications and, as of 2025, there is at least one outstanding technical issue preventing some reminder notifications being sent.
- Some parts of the country do not have Support to Screening services to follow up on individuals overdue for screening. The Register was designed to assist Support to Screening services by creating tasks to identify which individuals need support, but these tasks have been turned off due to a lack of Support to Screening service capacity. The Register was also meant to notify Support to Screening services to undertake early screening reminders for priority populations. This functionality was also turned off because reminders were inadvertently being sent later for priority populations due to the way the functionality worked when Support to Screening follow up did not take place.
- The Register lacks the functionality to 'look back' at previous screening results and so cannot determine, and flag, when an individual is unscreened or under-screened. This was intended to be a key piece of Register functionality to bring visibility to these individuals to facilitate better outreach to improve screening rates.
- The Register is not yet integrated with primary care systems, so GPs and practice nurses don't have live access to centralised screening history records to use when they see patients. This makes it less likely a GP or nurse will discuss the benefits of screening with their patients and to screen people opportunistically.

Cervical screening tests and assigning participants to the correct clinical pathway

- Some participants' pathway status in the Register is incorrect or outdated, which could prevent or delay the required clinical follow up such as referral to colposcopy. This can occur when there is an unresolved recommendation mismatch task or where the patient's clinical history is complex and therefore their case requires manual review to set the correct pathway status.
- When a participant's sample is tested by a screening laboratory, the Register is designed to identify recommendation mismatches, and where these are genuine the tasks raised help these to be resolved. A variety of issues, including incomplete data migration and problems with how the Register has been built can also cause recommendation mismatches to occur. This can mean that a patient's screening pathway could change after the mismatch has been resolved, which could delay clinical follow up and could be distressing for the individual. These additional mismatches may also delay the resolution of genuine mismatch tasks, causing further delays.
- Due to the Register lacking the functionality to 'look back' at previous screening results, individuals have at times been placed on the wrong pathway or given the wrong pathway status. This is particularly problematic for individuals who are at higher risk given their screening history as they may not be recalled in line with clinical guidelines, for example, individuals who have suffered from persistent HPV infection over a long period of time, with no previous examination of the cervix. In trying to mitigate this risk, the pathway status for a lot of people has needed to be checked manually. This creates a lot of additional work and potentially delays some people's progress in the screening pathway. In a small number of individuals who have extensive pre-cancer or cancer, a delayed diagnosis by many months is likely to impact prognosis. For the smaller number of patients with HPV 16/18, requiring colposcopy, the risk to individual patients of any delay is greater.

Clinical follow up following abnormal screening tests

- Recall notifications not being sent due to 'cohorting' include those sent to participants who previously tested positive for 'HPV other' when they are recalled for their next screening test. These individuals have been screening positive and may have had their HPV infection for some time, so they are at higher risk, and so there is a significant risk to these notifications not being sent.
- The Register's function as a clinical safety net relies on staff manually following up individuals or healthcare providers via 'tasks' raised by The Register. These tasks are not always prioritised by clinical urgency and numbers of tasks currently exceed volumes that can be completed within a reasonable time.
- The Register raises tasks when it interprets that a participant is not following the correct pathway, such as when a colposcopy referral has not been accepted, or a clinic appointment has not been held. Several issues[7] can cause the Register to hold out of date information, which means that some Register tasks are redundant while some tasks which should be raised are not. This can lead to delays in resolving these issues, which slow down a participant's journey through the pathway and may mean follow up tests take place later than they should. This is particularly problematic for individuals who are at higher risk due to their clinical history, including previous significant cervical screening test results.
- Some participants may be discharged without a colposcopy visit[8], which requires follow up by the screen taker. This job is made more difficult and could therefore be delayed by the fact that the reason for no visit is not visible, making it difficult for the Register Central Team and Regional Coordinators[9] to prioritise.

Safety nets to identify individuals who are not progressing through the screening pathway

- Current monitoring is not sufficient to identify if all clinically significant follow up tasks have been raised by the Register as required, and to monitor progress in "catching up" with unresolved tasks.
- Reports are run to act as an additional safety net by identifying individuals who have not progressed through the screening pathway correctly or have not been followed up as required. There may still be gaps in pathway safety nets because the Register does not have complete screening history information. Reports therefore may lack the ability to determine which individuals have significant screening histories, which put them at higher risk.

Other key findings

The following are other key findings identified by the review panel, which relate to wider Register issues:

[7] These include out of data gynaecology plus software leading to the Register rejecting messages, paper colposcopy forms which are late to be entered, the Register's lack of compatibility with SNOMED CT codes meaning incomplete information can be submitted to the Register, and the outstanding data migration e.g. history of some forms of gynaecological cancer or a hysterectomy.
[8] This could be because they have not been able to be contacted, have declined to be seen, or have chosen to be seen in private practice.
[9] Please refer to the glossary for explanations of the Register Central Team and Regional Coordinators.

- Difficulty obtaining access to, and limitations in the available functionality of, Whaihua[10] has prevented some Whaihua users from carrying out their roles effectively.
- No monitoring report has yet been produced. The publication of this report is important to ensure that the sector has visibility of the impact of the introduction of HPV primary screening and of the safety and effectiveness of the cervical screening programme.
- The review panel is not confident that quality reporting for screening laboratory messaging was effective, considering issues were detected in October 2024, which may have been ongoing since go-live. Screen taker and colposcopy clinic quality monitoring is also not yet in place.
- Although several Register defects have been fixed, other important improvements to functionality, such as flags for under-screened participants, are still outstanding. This calls in to question the Register's flexibility/adaptability. Limitations to the Register's flexibility/adaptability are significant given substantial changes will soon need to be made to implement new clinical guidelines.
- Governance roles and responsibilities and processes for the Register are not unified across the NCSP and Digital Services. This includes processes for identifying and documenting risks and issues, and escalation of, and decision making for, key issues. This may have contributed to some key decisions not being made.
- Processes for documenting and communicating some prioritised Register issues have improved, but this has not included outstanding notifications issues. As a result, these issues have not had the same level of visibility and may therefore have been deprioritised, given a lack of capacity to address all issues at once.
- The review panel saw updates on incident investigations in progress suggesting incident management processes are in place, however, these could be better supported with dedicated resources. Incident investigations are time consuming and better resourcing would help ensure they are timely and explore deeper learning from incidents, by further exploring root causes. This will help to determine if there remain undetected systematic deficiencies in the Register.
- There has been limited implementation of the draft Te Tiriti o Waitangi and equity strategy and seemingly limited consideration of equity for groups identified in this strategy (including those living in rural areas, those with disabilities or with a severe mental illness, LGBTQI+ individuals, and people in correctional facilities). This has had implications for acting on the evidence to best engage these groups and understanding how these groups have been affected by Register issues.

Recommendations

The following recommendations, which are organised by priority of implementation, are made by the review panel based on the information that it received during the review.

Priority recommendations provided on 19 February 2025

On 19 February 2025, a memo titled, 'Priority Actions from Review of National Cervical Screening Programme population-based register' was submitted for discussion at the

[10] Whaihua is a digital interface, launched in December 2023, that allows health providers to view information held in Health New Zealand registers.

Clinical Quality and Safety Committee. This provided the following priority recommendations for immediate attention:

I. An action plan is developed that documents issues that need to be addressed, prioritises these issues, identifies appropriate actions to mitigate/fix, an accountable role, and a timetable for completion of each action.
II. Increase staffing resources allocated to individual case reviews, to expedite their resolution.
III. Priortise the pathway status safety work being initiated and supplement it with additional resources to ensure it can be completed as quickly and effectively as possible.
IV. Consider how staffing resources can be protected and strengthened to support the NCSP to operate and maintain a safe population-based register.

The review panel wishes to restate the importance of urgently progressing these recommendations. Additionally, it should be noted that there is likely to be an even greater need for additional staffing resources, to develop and action plan and implement this report's recommendations, including for the:

- NCSP clinical team
- NCSP operational team
- Register Central Team
- Screening intelligence team

The review panel recommends that additional resourcing for the NCSP includes a dedicated Business Analyst (BA) resource, based within the NCSP, to help support the translation of NCSP clinical requirements into technical requirements.

High priority recommendations

The following recommendations are of high priority and work to implement them should begin immediately.

1. **Register functionality to flag unscreened and under-screened individuals needs to be built.** This will allow for appropriate clinical prioritisation of individuals overdue for screening and to meet reporting requirements. The first step should be for the NCSP clinical team and Digital Services to review definitions and then develop technical requirements. The NCSP clinical team should review these to ensure they will meet clinical requirements. If the ICT vendor advises this functionality cannot be developed quickly, an interim workaround should be explored. Use of screening data warehouse information to identify unscreened and under-screened individuals should be considered, and for this designation to then be uploaded to the Register to allow for flags to be created.
2. **Ensure there is appropriate follow-up for screen detected abnormalities.** Given the Register does not have access to complete screening histories for all participants and so may not always be able to determine the appropriate next expected event, additional work is required to review participants with complex histories, including previous high-grade results or other persistent HPV infections, to ensure they are on the correct clinical pathway. This will require reporting outside of the Register to identify relevant individuals based on their screening history. Failure to do so poses a significant risk to affected individuals, potentially leading to delayed diagnosis or treatment and so proactive measures must be taken to safeguard patient outcomes.

3. **The NCSP and Digital Services should develop an action plan to address all the issues identified by the notification review, which have not yet been resolved.** This should record all ongoing remediation, actions identified in the notification review action tracker, actions to address the relevant recommendations in this report, and any other actions identified as being required. Actions should be prioritised according to clinical risk and thereafter impact on the effectiveness of the programme. This action plan should incorporate advice from the ICT vendor on timeframes to implement solutions. This action plan should be presented regularly to a relevant governance group and a summary should be included in weekly remediation email updates to ensure visibility.
4. **'Cohorting' functionality should be phased out to ensure all eligible individuals receive cervical screening notifications.** While cohorting was an appropriate transition measure to protect cervical screening services and promote equity, it should not be continued indefinitely, in line with the original intentions of the notification strategy. The review panel recommends that the first step should be disabling cohorting for high priority recall notifications[11], followed by other recall notifications and finally any eligibility notifications not currently being sent.
5. **The Register's notification functionality needs to include being able to initiate text message and email communication.** The Register should include a record of individual communication preferences. Small scale pilots being carried out should inform the development of full-scale functionality, with implementation as soon as possible.
6. **Support to Screening task management functionality should be built to allow for follow up tasks to be centrally coordinated and overseen.** The volume of tasks likely to require management needs to be assessed and Support to Screening services capacity match this expected level of demand (see recommendation 12). It may make sense to trial task functionality with one Support to Screening service first, to ensure the functionality is working as intended and gather feedback from users about whether usability functionality needs to be improved prior to wider rollout.
7. **Early reminder for priority population functionality should be rebuilt**. Early reminder tasks should be created for Support to Screening services at two months with a routine reminder sent at three months if screening has not taken place. This should be deployed once Support to Screening capacity has been addressed, and tasks are in place.
8. **The design of solutions to address ongoing Register issues and implement new clinical guidelines should incorporate lessons from the implementation of the Register.** A formal reflective exercise incorporating all relevant perspectives (clinical, technical, and operational teams) should be undertaken (if it has not already been conducted). This reflective learning exercise may also provide valuable lessons which would benefit other Prevention initiatives including other screening Programmes. The exercise should include exploring:
    - Improving the capture of clinical requirements and communication to the design of technical solutions.
    - Those designing technical solutions must have a firm understanding of the intention of clinical guidelines, as well as the documented requirements, to ensure solutions meet these intentions.
    - Feedback and collaboration to address requirements not considered to be technically or operationally feasible.
    - Ongoing clinical input in the design and development of technical solutions.
    - Joint clinical, technical, and operational sign-off of designed solutions before they are finalised, to confirm that the intended result has been achieved.

[11] I.e., 'REC0 CR2'.

- Robust testing, by the ICT vendor, Digital Services, and by end users of the solutions prior to deployment to prevent issues from arising.
- A robust safety-net, including operational monitoring, being designed and prepared with clinical input to be put in place at go-live to ensure the solutions implemented are safe, effective, and meet requirements.

9. **Catch-up batches of unsent notifications must be sent as soon as possible.** To inform how these notifications are sent, the NCSP and Digital Services must carry out a realistic appraisal of how soon email and text message notification functionality can send large volumes of notifications. If this will not be possible soon, funds should be found to ensure notifications are sent by mail without any further delay. The NCSP should consider whether an explanation about the delay of these notifications should be included when they are sent. These notifications should be prioritised based on a clinical risk assessment considering:
    - individuals' history of abnormal results and those on a higher risk pathway
    - the screening history of those affected
    - which types of notifications are most significant
    - how long the notifications have been overdue
    - whether individuals are members of priority populations.
10. **The NCSP should conduct a root cause analysis of samples of recent laboratory recommendation mismatches and colposcopy clinic rejection messages.** This will help to determine what the major contributing factors of these issues are. This should be supported by Prevention quality resources to bring additional expertise and capacity.
11. **The pathway safety net project should include the root cause analysis of individuals identified by reporting as having fallen through existing safety nets.** This should explore the reasons why this has occurred, whether the underlying issue may have affected other individuals not yet identified, and what can be done to strengthen safety nets to prevent similar issues from occurring. As new safety net processes are designed and implemented, ongoing reporting will be required to demonstrate that safety is being improved and the need for root cause analysis is decreasing.
12. **The NCSP should publish an independently peer reviewed monitoring report as soon as possible.** The publication of an independent peer reviewed monitoring report is important to ensure sector visibility of the impact of the new HPV programme. It is likely that, to ensure this deadline is met, dedicated screening intelligence resources are required. The review panel recommends monitoring report indicators are analysed by prioritised ethnicity, rural/urban status[12], and sex assigned at birth. The NCSP should also explore how to report on indicators for other prioritised groups identified in its equity strategy, i.e., based on LGBTQI+ and disability status. Preparation of this report should involve consultation with the National Kaitiaki Group (NKG).
13. **The NCSP should progress Support to Screening service contract arrangements**. This process should ensure that adequate services are available across the country and that contracts are long enough to allow for permanent staff to be recruited. It is acknowledged that these services are shared with BreastScreen Aotearoa and Hauora Māori Services and therefore joint discussions are required to progress this action.
14. **Participants should only be classified as 'under specialist care' in appropriate circumstances with tasks monitored to ensure they are actioned.** The review panel would suggest that a clear definition of this term, perhaps limited to where a sample is taken in a colposcopy clinic, is provided in standard operating procedure (SOP)

[12] i.e., using the Geographic Classification for Health.

documents and shared through clinical education. The Register should not allow these tasks to be closed without appropriate reason and there should be monitoring of whether tasks are managed appropriately.

15. **The NCSP should document and communicate who has clinical responsibility for each stage of participants' screening journey.** This should include different scenarios for processes including invitation and recall for screening and management of positive results. Consideration should also be given to how these lines of responsibility may change if the Register is to take a more central role in invitation, recall and reminder, and potentially direct referral to colposcopy, in the future.
16. **The NCSP's operational and clinical teams and Digital Services should work collaboratively to develop and document a shared Register governance process.** This should include defined roles and responsibilities related to the Register, escalation pathways, and decision-making processes, which should include all three parties. There should be clinical input to all key decisions about Register functionality, including prioritisation and production planning of functionality development.
17. **There should be a single, unified process for identifying, documenting, and assessing risks and issues.** If the current Prevention level template for documenting Register risks and issues is used, there should be Digital Services input into this to ensure all risks and issues are visible in one place. There should also be shared processes for planning actions to mitigate/resolve risks and issues, prioritisation of actions, and monitoring and holding accountability for progress in implementing these actions. There must be clinical oversight of actions to address issues that pose clinical risk.
18. **Quality monitoring for laboratory messages, screen takers, and colposcopy clinics should be developed, to ensure that the programme is operating as expected**. Recently implemented Health Provider Index (HPI) information should facilitate this to be done.
19. **There should be ongoing monitoring for harms associated with the NCSP.** This is particularly important given the issues associated with the implementation of the new Register. If it is determined that individuals have come to harm and that deficiencies in the way that screening has been offered or provided, including related to the Register, may have contributed to this, appropriate disclosure, apology, and explanation should be provided. Monitoring should include identifying if individuals with cervical cancer were:
    - not invited to be screened,
    - not recalled or reminded,
    - not followed up when reminded to be screened,
    - delayed in receiving a cancer diagnosis after an abnormality was detected,
    - screened, but abnormalities were not detected.
20. **Unnecessary barriers to clinical staff gaining access to Whaihua should be removed.** This should include removing the requirement for specialist gynaecologists to do online HPV training prior to being given access.

Secondary priority recommendations

The following recommendations should be prioritised next in order following implementation of the above higher priority actions:

21. **The interface between laboratory information systems and the Register should be re-thought.** Any solution should ensure the information laboratories hold is also considered when assessing potential mismatches. Given there are a small number of laboratories undertaking this testing and their staff are subject matter experts, if there is

a mismatch then a pathway to harmonise the information and recommendation is needed. Developing a solution that provides laboratories with clinical guideline-driven suggested recommendations or rapid and direct feedback on recommendations mismatches should be explored.

22. **The NHI active rule should be amended or eliminated to ensure notifications are sent appropriately.** This rule should either be amended to the six-year timeframe originally intended, to match the cervical screening interval, or eliminated and catch-up notifications sent. The review panel noted that once email notifications can be sent, the NHI active rule may no longer be required. Using email eliminates the cost and privacy implications of sending letters to individuals who may no longer be in the country or living at the recorded address. Sending email notifications to inactive individuals may help to determine if they need screening or if they would wish to opt out of screening either temporarily while they are away, or indefinitely.
23. **Upgrade all districts to the latest version of Gynaecology Plus**. This will help eliminate rejection messages and thereby reduce the number of colposcopy clinic tasks. This will have an up-front cost but should produce savings in the form of reduced Register Central Team and colposcopy clinic staff time. To make the case for funding to be allocated to upgrades, a cost-benefit analysis could be undertaken to quantify potential savings.
24. **A technical solution should be found to ensure immunocompromised status is communicated to the Register from laboratory information systems, where this information is available on the laboratory form.**
25. **Implementing primary care access to screening histories needs to incorporate lessons learned from the implementation of the Register.** This includes:
    - Performing robust testing by the ICT vendor, Health NZ Digital Services, and by selected end-users of the solution prior to deployment to prevent serious issues, such as the out of sequence histories that affected the Register post-implementation, which could undermine primary care confidence in the NCSP.
    - Listening to feedback from pilot practices and acting on this to ensure that the solution implemented meets the needs of users.
26. **The NCSP should issue updated guidance to screening providers on how to effectively capture details of individuals' ethnicity, gender, and sex assigned at birth and have these recorded in the Register.** This should include an explanation of why this is important to cervical screening. The NCSP should ensure that the process for having updated information recorded in the Register is easy for providers to follow to encourage this to be done consistently.
27. **The Register test plan should be reviewed and improved as required.** This should take account of learning from the recent HPI incident and why the underlying issue was not identified in testing.
28. **The NCSP should revisit its decision to not include negative results from HPV studies that used a test that was not validated at the time but is now validated for use in New Zealand.** Both positive and negative tests from these studies should be used to inform pathways and the study results displayed in the Register. This is important because the World Health Organisation (WHO) recommends screening no more frequently than every five years because HPV infections detected so soon after a negative test are very unlikely to be associated with significant disease and in this scenario, the harms of screening are likely to outweigh the much lower benefits associated with early rescreening. They will also have a systemic impact through unnecessary referral to colposcopy at a time where these services are already stretched.
29. **Develop operational reporting of the rates of completed notifications, which can identify if there are significant gaps.** This will help to identify any lasting or new

technical issues preventing notifications from being sent. This reporting should be managed by the Register Central Team and shared with the NCSP's clinical and operational teams to ensure they have the necessary oversight of the programme. This reporting should include a breakdown by priority groups identified in the equity strategy.

30. **Operational Register reporting that is contingent on previous screening history needs to be supplemented with reporting from the screening data warehouse.** This includes any reporting that needs to identify high risk individuals who are overdue for screening or a next expected event. This additional reporting may necessitate additional screening intelligence resources. In the long term, it may be more efficient to migrate screening histories to the Register, to allow for this reporting to be done within the Register, and this should be considered.
31. **The NPHS and Digital Services must critically assess the long-term viability of the Register and the underlying National Screening Solution (NSS) to support the NCSP.** This should be informed by feedback from the ICT vendor about the possibility, timeframes for, and costs of implementing the functionality these recommendations call for. This assessment should also include consideration of whether the Register can effectively and efficiently implement clinical guidelines changes. If this assessment determines that the required functionality cannot be implemented, a risk-assessment should be undertaken of procuring a new software solution in the long term rather than continuing with the Register and NSS. This assessment should also include reviewing the contract in place with the ICT vendor to determine what of the outstanding functionality that requires further development is covered by the work that was contracted and what work will require additional funding. Advice from Health NZ legal should be sought as required.
32. **Once notification functionality is working as intended, the NCSP should clearly communicate the role of primary care in notifying enrolled participants.** This should be informed by discussion with the primary care sector to ensure there is a unified vision of the best way to achieve the NCSP's goals of eliminating cervical cancer. There should be ongoing discussion with the primary care sector to determine a long-term vision for the role of central invitation, engagement, and self-testing (including the sending of self-testing kits). This will help to guide the long-term planning of the requirements for a cervical screening population-based register.
33. **Adverse event management processes should explore if there are root causes that include deficiencies in the Register's functionality and/or supporting processes.** Adverse event management should be supported by a dedicated quality resource that brings additional capacity and expertise to ensure that investigations are comprehensive.
34. **The NCSP should work with NKG to investigate the decrease in applications for data to the NKG.** The groups should explore whether there are any systemic barriers contributing to this that need to be addressed.
35. **NCSP education materials should be revised and/or developed to improve the accuracy of pathway management.** This should include revising screen taker education materials to ensure they provide clear instructions on capturing immunosuppressed status. The need for additional education materials, e.g., for laboratory or colposcopy clinic staff, should be informed by the findings of the root cause analysis of recent laboratory recommendation mismatches and colposcopy clinic rejection messages (see recommendation 9).
36. **The NCSP should develop policies and procedures for follow-up of individuals overdue for screening or subsequent clinical assessment and testing**. These should set out responsibilities and expectations any follow up to be conducted by the Register Central Team, Regional Coordinators, and Support to Screening services.

37. **The NCSP should finalise and publish its Te Tiriti o Waitangi and Equity Strategy.** Once finalised, NCSP leaders should consider whether the programme is currently in alignment with this strategy. If any gaps are identified, outside of those already identified by this review, actions to address these gaps should be developed.
38. **Rules for sending unenrolment communications should be reviewed.** It should be ensured that anyone being unenrolled is sent this communication, including any transgender and non-binary individuals being unenrolled due to their sex at birth.
39. **The NCSP should confirm if Whaihua users have access to the necessary functionality to undertake their roles.** This includes laboratory, colposcopy clinic, and Support to Screening service users. Functionality available should include updating demographic and contact information and reporting participants with an incorrect pathway status. Changes to levels of access, permission to edit fields, and/or user education may be required to address issues. If Whaihua users cannot complete necessary tasks, and this functionality cannot be added to Whaihua, direct Register access may be necessary for some types of users.
40. **There should be a regular venue for discussion of long-term requirements of a cervical screening population-based register.** This should involve clinical, technical and operational perspectives. This should lead to a multi-year plan including forward planning for future clinical guideline changes and other new functionality requirements.
41. **Consult with private colposcopy clinics on the clinics moving to the use of a software-based process to submit data to the Register.** The NCSP may wish to consider making this a requirement of being a screening provider in the long term.
42. **The NPHS and Digital Services should review how key product documents are stored.** The review panel was concerned that some key documents may only be stored in an environment controlled by the ICT vendor. This may have implications for Health NZ's access to this documentation and its ability to meet requirements such as fulfilling Official Information Act requests. The learning from this may have wider implications for other Health NZ digital products.
43. **The NCSP should work towards gathering data to meet the requirements of, and submit data to, the World Health Organisation's Cancer Screening in Five Continents (CanScreen5) project.**
44. **The NPHS should communicate with the Cervical Screening Parliamentary Review Committee and the Ministry of Health's Public Health Agency about implementing these recommendations in line with wider action plans for cervical screening.**

2. Background and Context

Introduction

Cancer screening is a key preventative health measure. Access to cervical screening reduces the number of people developing, and dying from, cervical cancer each year in Aotearoa New Zealand. Screening and subsequent follow-up increases the chances of detecting pre-cancerous changes to the cervix, or early cancer, for which treatment is likely to be more effective. Of people in Aotearoa New Zealand who develop cervical cancer, around 85% are unscreened (have never had a cervical screening test) or are under-screened (have not been screened regularly and on-time) (2). Access to appropriate follow up and treatment following an abnormal screening test result is crucial, as the initial screening test in and off itself will not change the development of cervical cancer.

History of the National Cervical Screening Programme

The Cartwright Inquiry

The NCSP has important historic origins. The decision to create the screening programme was as a result of a recommendation from the 1988 government Inquiry report: *Allegations Concerning The Treatment of Cervical Cancer At National Women's Hospital* ('the Cartwright Inquiry'[13]). (3) This inquiry investigated an unethical research experiment conducted by a gynaecologist at the National Women's Hospital from 1966. This resulted in Cancer In Situ progressing to cancers, delays in treatment, and ultimately the deaths of some women (3) .

As well as providing the impetus to act on the evidence for an organised, population-based cervical screening programme, the Cartwright Inquiry changed the landscape for patient safety, patient rights and health research ethics in New Zealand. Other positive patient safety initiatives resulted from the inquiry recommendations[14].

Introduction of the National Cervical Screening Programme

A National Cervical Screening Programme was introduced in Aotearoa New Zealand in 1991. Prior to this, cervical screening was available 'opportunistically' to a minority of women rather than as a formalised national programme. Cervical screening coverage in 1990 was less than 10% of the total population. (4)

Over the next decade, the overall rate of cervical cancer decreased by about 40% and deaths from cervical cancer reduced by over 60%. Most of the decrease in rates of cervical cancer following the introduction of the NCSP has been attributed to the introduction of an organised screening programme. Some, but not all the increase in survival from cervical cancer has also been attributed to screening (4)

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[13] Often referred to as 'the Cartwright Inquiry', the inquiry having been chaired by Judge (Dame) Silvia Cartwright.

[14] Including, the creation of The Health and Disability Commissioner, a focus on medical school ethics teaching, and the development of medical research ethics committees. The National Kaitiaki Regulations and The National Kaitiaki Group were also established, to safeguard Māori participant cervical screening data and associated research on this data.

Gisborne Cervical Smear Inquiry

Following the introduction of the screening programme, a laboratory quality monitoring issue was detected in the next decade when a group of women in Gisborne developed cervical cancer despite having been screened regularly with reportedly normal cervical smear test results. It was discovered their abnormal smears had been missed, having been misread as normal by the local laboratory pathologist[15]. This led to an inquiry commencing in 1999 and a subsequent report was published: The *"Report of the Ministerial Inquiry into the under-reporting of cervical smear abnormalities in the Gisborne Region"* (5). This led to a number of recommendations and subsequent improvements in the quality and safety standards of the laboratories assessing cervical screening tests, and improvements in the quality and safety monitoring for the NCSP.

These historic events, having had devasting effects on individuals and their families, emphasise the need for a maintained focus on delivering a high quality, safe, person and whānau-centred cervical screening programme today.

Epidemiology of Cervical Cancer in Aotearoa New Zealand

Over the past two decades there have been further decreases in incidence of and deaths due to cervical cancer. The most recent data available suggests that overall rates have dropped from 12 cases per 100,000 in 1990 (4) to 5.6/100,000 in 2022 (6) . Some population groups have benefitted more over time from the introduction of the cervical screening programme than others, meaning they have had greater access to cervical screening, follow up assessment and care, and to the wider health system. Population sub-groups also have different rates of risk factors which can influence the development of cervical cancer, for example, smoking (7), and lower access to HPV vaccination (8).

These factors have contributed to persistent, avoidable differences (inequities) in rates of, and deaths from, cervical cancer between different population groups. This includes between Māori and non-Māori, and Pacific people and non-Pacific people (9) (10)

Rates of cervical cancer

In 2022[16], the overall Incidence Rate of cervical cancer for the female total population was5.6/100,000 (6). However, the incidence varies between ethnic groups with the Māori and Pacific ethnic groups having the highest cervical cancer rates (Incidence Rates). Across the period 2018-2022, The Incidence Rate for Māori was 8.7/100,000, and for Pacific peoples was 8.6/100,000, compared to 4.9/100,000 for Asian and 6.1/100,00 for European/Other (9). (Figure 3).

[15] When individuals develop cervical cancer who have been screened, 'lookback' is undertaken to check the screening history, and their screening samples may be re-read to check for missed abnormalities. In the case of The Gisborne Inquiry, an overseas laboratory re-read the participants' cervical smear tests, and they were found to be abnormal.

[16] The most recent cancer registrations and cancer deaths data is for 2022 at the time of writing.

Figure 3. Rate of Female Cervix (C53) Cancer Registrations in 2018-2022 by Prioritised Ethnicity (per 100,000 age-standardised)

Rates of death from cervical cancer

Rates of deaths from cervical cancer also vary between ethnic groups. The Māori and Pacific ethnic groups are more likely to die from cervical cancer than other ethnic groups. Rates of deaths from cervical cancer from 2018-2022 were highest in Māori at 2.9/100,000; Māori were over twice as likely to die from cervical cancer than the European/ Other grouping (rate of cervical cancer deaths 1.4/100,000), and three times more likely than in the Asian ethnic group (rate of cervical cancer deaths 0.8/100,000) (10). The rate in Pacific peoples was 2.2/100,000 (10) (Figure 4).

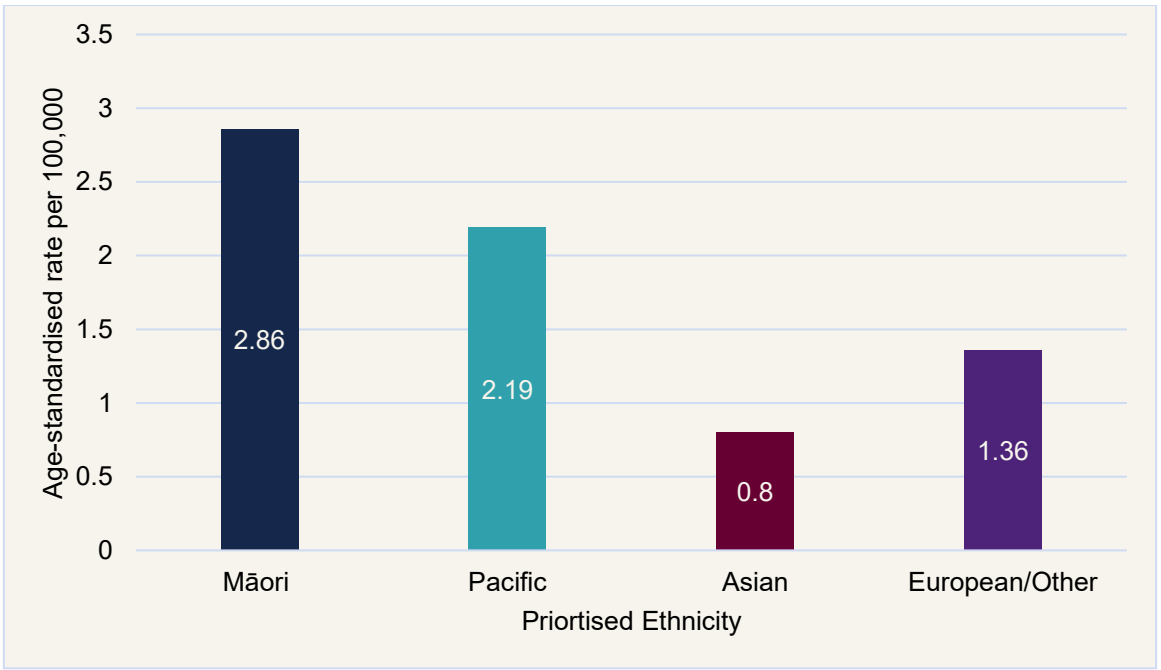

Figure 4. Rate of Female Cervix (C53) Cancer Deaths in 2018-2022 by Prioritised Ethnicity (per 100,000, age-standardised)

Eligible Screening Population: Primary Care Enrolment and Screening Status

The programme has historically predominantly been delivered through primary care (i.e., in General Practices/GPs), as well as through Screening Support Service providers and Family Planning clinics, now called Sexual Wellbeing Aotearoa clinics.

As at April 2023 1.38 million people with a cervix aged 25-69 in New Zealand were eligible for cervical screening (11). There were a significant number of those who were enrolled in primary care but were still unscreened or under-screened. The following data was stated by the National Public Health Service in May 2023:

For those enrolled in primary care[17]:

- 190,000 participants were enrolled but un-screened (13,091 Māori and 12,969 Pacific)
- 163,300 participants were enrolled and under-screened (42,877 Māori and 21,293 Pacific)

For those not enrolled in primary care[18], >30 years old, Māori or Pacific:

- 2,820 Māori and Pacific who were not enrolled in primary care and unscreened
- 3,264 Māori and Pacific who were not enrolled in primary care and were under-screened

In addition, more than 12,000 participants were regularly being screened by Support to Screening Service providers or Family Planning clinics, now called Sexual Wellbeing Aotearoa.

Screening Coverage

There has been an increase in rates of screening in all ethnic groups since the switch to HPV Primary Screening in September 2023. This includes for eligible people who are Māori, where the percentage of people up to date for cervical screening had been dropping since 2013. However, significant differences in access to screening between different ethnic groups is still evident. As at March 2025, screening coverage (screening 'up to date') rates were: 66.8% for Māori, 71.7% for Pacific people, 59.6% for Asian and 81.6% for Other (NZ European and all other ethnicities) The percentage of those up to date for cervical screening overall was 73.6% (12) (Figure 5).

[17] based on 2021 PHO enrolment status.

[18] based on 2021 PHO enrolment status.

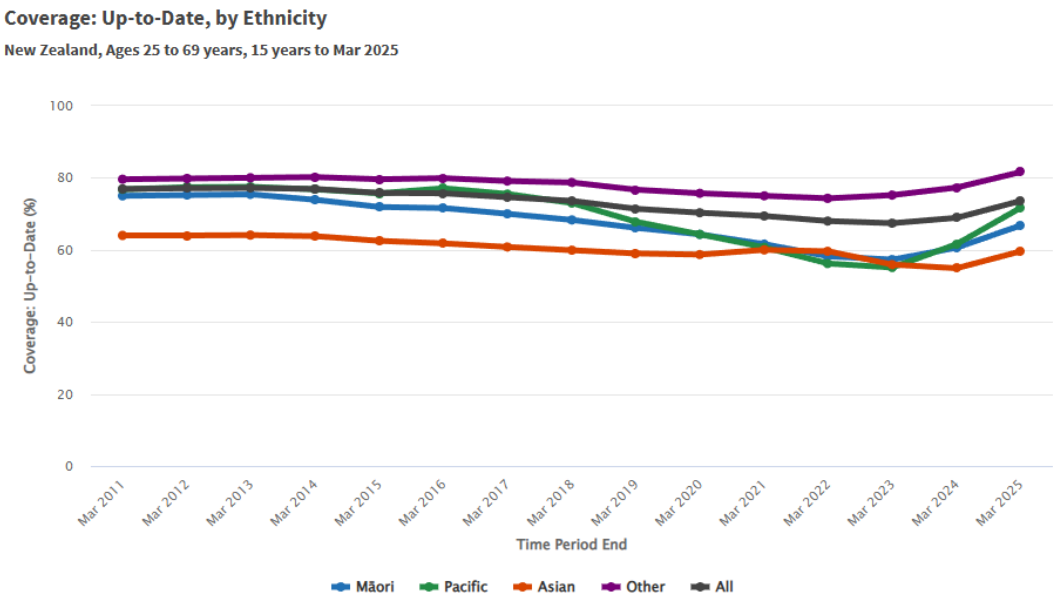

Figure 5. Yearly screening coverage (screening up to date) Mar 2011-March 2025, by prioritised ethnicity

History of the switch to HPV Primary Screening

A change in primary cervical cancer screening test from LBC ('smear test') to HPV Primary Screening was first signalled in 2016 by the then Minister of Health. This followed recommendations from the former National Screening Unit (NSU), the National Screening Advisory Committee, the 2021 Parliamentary Review Committee Report into the National Cervical Screening Programme, and with international evidence of best practice supporting HPV Primary Screening. HPV Primary Screening had already been implemented in several high-income comparable countries, including Australia in 2017 (13).

Liquid Based Cytology involves collection of a sample of cells from the cervix which are then tested for the presence of cervical cancer or abnormal changes to the cervix which can lead to cervical cancer (pre-cancerous changes). An LBC sample must be collected by a trained health professional via a vaginal speculum examination.

HPV Screening instead tests for the presence of HPV, a virus which causes over 95% of cervical cancers, making an HPV test an effective cervical screening test. HPV infects the genital tract and is usually able to be cleared by the human body, but in some people the infection can be persistent and lead to cancerous changes in the cervix over time.

There are many types of HPV, only a small number of which cause problematic changes to the cells of the cervix that can lead to cancer, including 'HPV 16 and 18'. Among Aotearoa New Zealand cervical cancer cases who test positive for HPV, approximately 65% have HPV 16 or 18 (14). This proportion is similar between Māori and non-Māori (15).

HPV primary screening involves testing a sample collected either with a self-collected vaginal swab ('self-test') or by a trained health professional via a vaginal speculum examination. HPV self-testing is less invasive than other sample collection methods, and access to this test was hoped to make screening more acceptable and hence accessible to more people. Introducing HPV testing was therefore expected to improve screening rates, particularly in groups who had low rates of screening. As a result of increased screening, cervical cancer rates and deaths from cervical cancers were expected to decrease in these groups. HPV Screening is also a higher 'sensitivity' screening test, meaning it detects a

greater proportion who have cancerous or pre-cancerous changes in their cervix, compared with the LBC test.

This was to be the first national HPV programme to go live with the universal option of the vaginal self-test and as such it introduced several unknowns regarding the optimal clinical pathways.

Funding and procurement

In 2018, the Parliamentary Review Committee recommended funding for HPV primary screening, including self-testing be provided urgently. A strategic assessment for investment to ensure the "Sustainability of the NCSP" was approved in the same year. This included both the move to HPV primary screening, and a replacement of the existing cervical screening register.

The existing cervical screening register was deemed an ageing "legacy" ICT system that needed updating. Not replacing the register was stated to pose a quality and safety risk. The new register was proposed to be a population-based register, in contrast to the existing register, which held records only for those who had been screened, or who had had cervical histology (tissue sample) reported.

The Ministry of Health published an open tender on the Government Electronic Tenders Service for a suitable supplier to deliver first the platform for the National Bowel Screening Programme's (NBSP) Bowel Screening Register (BSR), then other screening programme registers, subject to funding. In Jan 2019, Deloitte was selected as the ICT vendor to deliver the NSS utilising the 'Salesforce[19]' software platform. Delivering the new Register for the NCSP was also in the scope of this initial NSS procurement.

In May 2021, Budget 2021 was published and cabinet approved funding for "NCSP programme sustainability", which had been outlined in the strategic assessment. The Implementation Business Case commenced in June 2022, with a business case approved by the Cabinet Social Wellbeing Committee.

This business case was for "urgent investment to ensure the sustainability of the NCSP, through the implementation of HPV Primary Screening with the option for participants to administer the test themselves with clinical supervision (self-testing) and the upgrade of the supporting ICT" (16). It outlined the options, recommendations, and costs for project implementation. The first work by the ICT vendor commenced in early 2022.

The final version of the implementation business case was produced in March 2023 (17). A briefing was sent to the Ministers of Health and Finance seeking approval of drawdown of funding (18). This outlined the need to invest in the "sustainability of the NCSP", meaning both HPV primary screening and the register replacement. It noted the immediate imminent risks to the delivery of the screening programme and how introducing HPV primary screening and a population-based register would "provide a foundation for the programme to address persistent equity gaps" (18). Modelled benefits included:

- lower incidence and mortality from cervical cancer,
- improved equity in cancer outcomes across groups,
- improved screening participation in the groups with least access to screening, and

[19] Salesforce is a Customer Relationship Management platform.

- long term health system and NCSP fiscal savings following the initial investment.

The business case acknowledged the tight project delivery timeline and stated that register implementation would commence following approval of the funding.

It also signalled the development of a Notification Strategy based on centralised register screening invitation, recall, and overdue reminders from the NCSP. This was intended to better engage priority unscreened and under-screened groups, which in turn would address differences in cervical cancer and mortality rates between different groups.

The business case noted, however, that this investment would not be enough to completely address the issue of equity gaps between population groups even if the modelled benefits were realised. It stated that other opportunities to remove remaining barriers in the service delivery model were being explored.

Implementation project

The HPV Primary Screening Implementation project commenced in October 2021, with a planned go-live date for HPV Primary Screening and the Register of 28 July 2023. An HPV Primary Screening Implementation project team (hereafter, the project team) was assembled. Its role was to co-ordinate the implementation of both HPV primary screening and the Register. The ICT build began in July 2022.

A "Notification Strategy" was developed[20] alongside the Register, to specify when notifications should be sent, based on clinical history and screening status, demographic characteristics, and primary care enrolment status. It also specified when referrals should be made to Regional Coordinators and Support to Screening services and the actions they should take. The Notification Strategy was designed to include a phased approach, aiming to prioritise with the highest need groups to receive eligibility notifications first.

At the end of 2022, in response to project management and senior project stakeholder uncertainty, a series of leadership and governance changes were made, which took effect from January 2023.

In early 2023, challenges were noted in defining the essential requirements of the Register necessary for go live, referred to by some as a 'Minimum Viable Product' (MVP). In late March, the risk of the planned July go-live date slipping was noted as part of creating a formal project Risk Register. In mid-June 2023, Health NZ was informed by the ICT vendor that the July go-live date was not possible, as several components of the Register build were still incomplete.

Health NZ commissioned a rapid independent review of the project and the revised proposed September go-live date, by an external independent consulting company. The output of this independent review was the 'HPV Primary Screening Performance Assessment Report ". The report concluded that the revised go-live date of September was feasible, however many specific actions were recommended to "de-risk" the implementation. Multiple challenges with project management, governance and human resourcing during the project were also noted.

The ICT build of the Register was deemed complete by the ICT vendor on June 30. The Register went live on 12 September 2023. Some functionality was planned to follow shortly

[20] An 'MVP version' was signed off in February 2023 and version two in April 2024.

after go-live (a ‘fast-follow’). This included the roll-out of the Register’s notification functionality, which commenced in November 2023, and data migration of some participant screening records with screening history scenarios deemed too complex to migrate automatically.

Notification Review

Issues with Register notifications were identified by the NCSP’s clinical and operational teams shortly after the notification functionality was introduced in November 2023. The review panel was told that monitoring of the number of notifications sent identified far fewer being sent than was expected. This was characterised as, “only a couple of hundred” of notifications being sent out weekly, rather than “a few thousand” as would have been expected.

A ‘notification review’ was conducted, with a report produced on 5 April (v1.0) and updated on 23 April 2024 (19) (v1.1) with additional information. The report identified:

- technical problems where the Register’s logic was not built as intended by the NCSP
- problems with the design of the Register functionality not meeting the expectations of the NCSP
- business processes that were not in place to support the intentions of the Notification Strategy
- lack of manual processes required to ensure safe Register functioning.

The notification review included an assessment of the absolute volumes and proportions of notifications triggered that had been sent successfully and those not sent as of 5 April 2024, approximately seven months since go-live. Figure 2 in Appendix 4 is taken from the notification review and shows the proportions of higher volume notifications[21] triggered that were sent successfully and those not sent. In addition, it was identified that some notifications had not been triggered but should have been as they did meet the criteria for sending. Figure 3 in Appendix 4 shows the number notifications triggered that were sent or not and those not triggered.

The notification review described issues arising because of functionality ‘gaps’, including notifications that were:

- untriggered and so were unsent
- triggered but not sent
- delayed outside of timeframes specified by the notification strategy
- sent incorrectly, in place of the correct notification
- sent inappropriately, such as enrolment letters for those who had opted out

NHI data quality issues were also apparent shortly following go-live, with the ICT vendor providing information on this to the NCSP in December 2023. It was recommended that the data quality issues were investigated separately from the notification review.

Decision for National Service Review

[21] Withdrawal notifications were excluded because of the low volumes involved, but a numerical breakdown was included in a data table within the Notification Review.

Additional issues beyond the scope of the Notifications function of the Register, and therefore beyond the scope of the Notifications Review, were identified by operational and clinical teams in the months following go live. Examples of these issues include:

- inaccuracy of screening histories
- incomplete primary care enrolment information
- lack of identification of ‘unscreened’ or ‘under-screened’ status based on previous screening history
- higher than anticipated numbers of recommendation mismatches (RMMs) between lab recommendations and those expected by the register, requiring individual manual review
- issues related to data migration from the previous register, including for patients with a history of gynaecological cancer or a hysterectomy, requiring individual manual review to determine screening and follow up requirements
- follow up tasks for overdue ‘next expected event’ not being completed, including for participants identified as overdue for a colposcopy referral or visit.

In view of these issues, the Clinical Director Screening advocated for an external review of the Register. A memo from the National Director (Acting), National Public Health Service (NPHS) was presented to the ELT on 21 May 2024.This memo recommended that ELT endorse a national clinical safety review, led by Service Improvement & Innovation, now called Planning, Funding and Outcomes.

A further memo was presented to the (then) Board’s Clinical Quality Assurance Committee on 20 June 2024, outlining the proposed scope of the review. This described that the review would assess the register issues and associated remediation to date, describe any other identified clinical and quality safety risks, and make recommendations to help the NPHS operate a safe and high-quality register that enables delivering the highest quality cervical screening programme.

A multidisciplinary expert panel was appointed, including members external to Health NZ and with experience of operational cervical screening registers outside Aotearoa New Zealand. Review panel expertise included cervical screening register operation, pathology, gynaecology, screening register data management, clinical informatics, public health medicine, primary care and Hauora Māori expertise. A list of the review panel members and roles is listed in the beginning of this report.

The scope of this review is outlined in detail in the Terms of Reference, which is included as Appendix 1 of this report.

3. Implementation of the Register

3.1 Implementation approach

The process of implementing the Register was described by interviewees as a complex project, due to the scale of change, and a hectic period of 18 months. The Register's launch coincided with:

- A switch to HPV testing as the primary cervical screening test
- the development of new clinical guidelines to support this change
- a new notification strategy to support the move to a population-based register that was no longer dependent on enrolment discussions with a health care provider.

Some interviewees felt that making these changes all at once was necessary, as new clinical guidelines and a new register were necessary to support the new approach to HPV screening. Others, however, said they had been surprised that the changes had been made all at once, and that the resulting issues were predictable.

Interviewees described that moving between registers gradually, such as one region at a time, would have been very difficult or impossible. It was commented that a gradual introduction of the Register would only have worked if there had been a new cohort of participants, not already on the old register.

Several interviewees commented they had hoped the rollout of the Register would benefit from lessons learned during the implementation of the NBSP's BSR. The BSR was built on the same Salesforce software contracted under the NSS agreement with the ICT vendor. The BSR and the Register, however, use different Salesforce environments and add-ons.

It was noted, however, that the NCSP's clinical pathways are much more complex than the NBSP's, due to having more clinical scenarios and test, treatment, and referral pathways, and therefore more difficult to build into a technology platform. Some commented that the underlying technology may not be suitable for such a complex programme.

3.2 Staffing continuity during implementation

The review panel heard from several interviewees there had been a lack of continuity in the personnel involved in the build and implementation of the Register and that this high rate of staff turnover had continued following the launch.

The issue of turnover was identified by the independent assessment of the implementation project, conducted in 2023. This noted, "There had been considerable turn-over of key resources resulting in loss of institutional knowledge, which in the context of the commentary above related to key project documentation and controls is concerning."(20)

A contributory factor to programme team staff turnover was said to be the transition of the NCSP from within the former NSU structure within the Ministry of Health, to within the Prevention directorate of the newly formed NPHS on 1 July 2022.

The panel was also told there was a lot of instability in the HPV implementation project team, most of whom were fixed-term contractors. This high-level of project staff turnover was said to have led to insufficient capacity, a lack of institutional knowledge about both the NCSP and the Register, and key documents becoming lost. The review panel heard this led to new

staff being brought in and trained ‘on the fly’. This was said to be particularly problematic due to the high level of complexity of the project.

It was said that there was under-staffing following launch, given the scale of the changes introduced and the further work needed. It was noted that less funding was available once implementation was completed as the project funding ran out.

Staff turnover was also said to have caused disruption to relationships with key stakeholders, including Register users. This was said to have led to issues raised by stakeholders not being followed up, and stakeholders not knowing who to approach to resolve issues or get updates.

At the time of this review, the NCSP’s staffing situation was said to still be ‘fragile’, with several vacancies unable to be filled due to a Health NZ ‘recruitment freeze’. The panel also heard some key personnel had been on fixed term contracts which had recently ended. Furthermore, the panel was told other key contracts were soon to end, and it was unclear if they would be renewed. Concern was expressed that staff could become ‘burnt out’ if they were not supported. Interviewees noted that, due to the complexity of the programme, the established head count of the NCSP should be increased.

Prior to the publication of this report, the review panel provided interim recommendations that included advice that staffing resources be strengthened to support the safe functioning of the Register.

3.3 Implementing clinical guidelines

Interviewees said there had been too much ‘fluidity’ in the Register’s build requirements. This was said to partly be due to delays in the finalisation of updated clinical guidelines, which were published in June 2023, by which time the original go-live date of July 2023 had been delayed until September 2023. According to some interviewees the development of the updated clinical guidelines had been under-resourced.

It was noted by interviewees that the new clinical guidelines were complex and that the Register ‘rules’ that needed to be developed to implement the guidelines would always have exceptions in nuanced treatment scenarios. It was said that it was known in advance of go-live that there would be a lot of participants for whom pathway status could not be automated because of the number of variables.

The review panel heard that translating clinical principles to technical processes was not easy, as there were complex definitions of principles like under-screened and that there were different definitions for different purposes. It was also commented that things like using the term ‘recall’ for several different situations could be confusing for those not familiar with screening principles.

Despite the high level of complexity, the review panel heard that the translation of the clinical practice guidelines into Register business rules was significantly under-resourced. The translation work was also said to have been affected by the level of turnover of the Business Analyst roles supporting it.

3.4 Defining a ‘Minimum Viable Product’

During the development of the Register, stakeholders who would use the register were consulted to define their requirements. The review panel heard that requirements were

'RAG' (red, amber, or green) rated, and the feasibility of implementation assessed. As development progressed it became clear that not all requirements could be delivered.

The 'HPV Primary Screening Implementation Performance Assessment' (20) review report stated that, "In December 2022 the Minimum Viable Product (MVP) was first defined and this informed the business and technology changes (the project reset) necessary by the planned go live of July 2023". Many initial requirements did not make it into the 'MVP', including:

- link to the National Immunisation Register[22], to check HPV vaccination status
- interface with hospital IT systems
- compatibility with SNOMED CT[23] clinical coding
- email and text message notifications initiated by the Register.

Some interviewees commented the Register had been a 'working prototype' at launch, with known issues and missing functionality to be delivered as a 'fast follow'. The 'HPV Technical Delivery Plan' (21), describes that a version 1.1 release was planned for two weeks following launch. This added functionality was not ready at go-live, including some notifications, integration with the New Zealand Cancer Registry[24], the NHI active business rule[25], screening history views, non-critical reports and tasks, and updates to some code governing the flow of information from other systems.

Interviewees said that one of the most significant functions not delivered was the ability of the Register to flag someone as being 'unscreened' or 'under-screened', thought to be essential to implementing the Notification Strategy. This issue is discussed in more detail in the subsequent section of this report on the current functionality of the Register.

The review panel was told that the NCSP's clinical team did not have direct involvement in some of the Register's functionality during development. It was said the implementation had lacked a 'translator' who could act as a go-between for the clinical and 'technology' teams within Health NZ and with the ICT vendor.

An example cited was the design of the notification functionality to implement the notification strategy. This was said to have been led by the NCSP clinical team, with input from other teams, with a member of the HPV implementation project team translating the requirements for the ICT vendor. The review panel heard there had been no 'feedback loop' and that nobody came back to the NCSP clinical team to ask for further input. The review panel was told that the NCSP clinical team would not have knowingly agreed to the Register going live without the functionality for identifying 'unscreened' or 'under-screened' individuals.

The review panel heard different opinions as to whether the agreed 'MVP' had been delivered, or whether MVP functionality had been defined in detail. Some felt the MVP had been delivered as HPV primary screening was being provided with support from the new Register, and a 'like for like' with the old Register had been delivered. Others said that the Register was not yet an MVP.

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[22] The National Immunisation Register has been replaced by the Aotearoa Immunisation Register.
[23] SNOMED CT is a comprehensive system of clinical terminology that comprises over 350,000 concepts and 1,200,000 terms in health and social care. It was developed by a global team of clinicians, researchers and content authors.
[24] The New Zealand Cancer Registry is a population-based register of all primary malignant diseases diagnosed in New Zealand.
[25] This business rule tells the Register whether to notify a participant based on how recently they have accessed healthcare services.

3.5 Timing of 'go-live'

During the 'project reset', the ICT Vendor highlighted what was required to achieve the July 2023 deadline, commenting:

- "Scope - The scope of the business case does not adequately describe the scope of the work to achieve the outcomes."
- "Requirements – While many have started the high-level requirements are not complete."
- "Resourcing – Due to funding delays the team is not at full complement and the NSU [National Screening Unit] has "made do"."
- "Technology – There is no overall solution architecture, and the required components have not yet been identified."
- "Delivery team – A group of individuals with varying skills, capabilities, and experiences operating in silos without clear responsibilities."

The review panel was advised that, in late March 2023 the first formal project Risk Register was created (see section 3.8). This identified there was a risk the Register's planned July launch date would not be met. On 14 June, the ICT vendor informed Health NZ that development of the Register had taken longer than planned, several components of the Register were still incomplete, and the planned 28 July 2023 go-live date could not be achieved. On 3 July, a briefing was sent to the Associate Minister of Health advising the July go-live date would not be met and recommending a revised go-live date of 12 September.

Interviewees described that, as the launch date approached, things became increasingly 'intense' and 'pressured'. It was noted that the development and testing became 'compressed' and that there was a concern of 'cut corners'.

During interviews, there were differing views about whether the go-live date should have been delayed further. Some believed the Register had been launched too soon and that more preparation and more 'failsafe' processes had been required. Others felt that, although the Register was not fully featured at launch, it was important that go-live was not further delayed due to the interdependence with switching to HPV primary screening. It was suggested that a further delay to the implementation of HPV screening would have negatively impacted on the screening eligible population.

3.6 Testing

It was reported that 'system testing[26]' was done by the ICT vendor, while Health NZ undertook 'functional end to end testing[27]'. The review panel was told there had also been hands-on testing by Register end-users.

The Health NZ test team was said to have designed a risk-based testing approach in consultation with the NCSP clinical team. 25 discreet business process flows were identified

[26] System testing is a term usually used to described testing that focuses on verifying that a system meets its specified requirements, while testing all its components together, in a controlled 'test environment'.
[27] End to end Testing typically describes the process of testing the system's entire workflow from start to finish, simulating real world user scenarios, to ensure that functionality meets what is intended.

for testing, focusing mostly on the rules[28] governing transfer of information from laboratory information systems to the Register. The testing approach required the ICT vendor to commit to development delivery dates, which were met except for one deviation that was reportedly mitigated.

The period in which testing was undertaken, between May and September 2023, was described as an intense period for those involved. Some interviewees commented they felt testing had been too rushed, and that more extensive testing over a longer period would have identified more issues. It was also suggested there should have been more clinical input to testing, and representatives of an end-user group reported feedback given during the testing process was not acted on.

The review panel heard from interviewees that, following testing, there were known defects, which were risk-assessed from clinical, technical, and business perspectives prior to go-live. Interviewees commented that the Register was perhaps '60-70% ready at go live' and that the last 12 months has been like a 'warranty period'.

A copy of 'Test Summary and Exit Report Release 1.0' (22), with a 'date test completed' of 12 September 2023, was shared with the review panel. This states that, "User Acceptance Testing was performed with Labs and Whakarongorau (the Register Central Team) participants." The report states that 546 defect and 73 'end to end defect' issues were found. Each issue was given a 'Bug Severity Rating, from 1 ('blocker') to 4 ('acceptable workaround').

One of the report's 'Acceptance Measures' was, "Severity 1 or 2 unresolved defects. Any remaining unresolved defects/issues have an agreed documented remediation plan." The report states that, "All acceptance criteria has been met for go live." The report shared did not include a complete list of defects, but the review panel noted that one of the 'Severity 2' defects listed, described as, "Pathway statuses not updated for aging in person" had a status of 'Won't do'.

3.7 User experience of implementation

The review panel heard from several groups who use the Register, or access information from the Register via another system, on their experience of the implementation process.

It was reported that there had been no engagement from the Register implementation project team with the Register Central Team (RCT) until about four weeks before go-live and requirements had not been gathered from the RCT. Consequently, the RCT asked for the Register's implementation to be delayed.

For the screening laboratories, the launch was said to have been 'fraught' because of the delays getting the Register up and running. The review panel heard that the laboratories had needed to set themselves up for a new screening test, including making workforce changes. The laboratories were said to have only been given a two-week notification of the delay to go-live. It was said that this late change caused a problem, as the cytologist workforce had already been reduced in anticipation of the move to HPV testing but, because of the delay,

[28] The rules use 'Health Level Seven' (HL7), which is a range of global standards for the transfer of clinical and administrative health data between applications. These are sometimes referred to by the NPHS as H flow codes or H flows.

the demand for cytology testing continued at the previous, higher level. As a result, it was said that there was already a backlog at go-live and the labs 'hit the ground behind'.

Interviewees described that some colposcopy clinics had offered their assistance during implementation but that this was not taken up until about six weeks before go-live. The review panel also heard that there had been a 'lack of understanding' of the workflow of colposcopy clinics that had led to a 'last minute scramble' to set up clinics' access to screening history information, through another software platform, Whaihua.

Regional Coordinators were said to have been consulted as part of the register working group, contributing considerable time and energy, but felt that their advice was not heeded. In the lead up to and following go-live, Regional Coordinators were said not to have been supported with user-guides or training and therefore felt they were "flying solo" and had to teach themselves how to use the Register. It was noted that it had taken about six months for communication to improve, with Standard Operating Procedures (SOPs) eventually being provided.

3.8 Governance during implementation

The 'HPV Primary Screening Implementation Performance Assessment' (20) review report stated that, in January 2023 as part of a project reset, a new governance structure was put in place (see figure 18 in appendix four). The report also gave recommendations to address challenges with governance of the project. These included:

- Formalising clinical safety risk raised by clinical leadership and developing actions.
- Establishing a 'control tower' to ensure clear decision-making processes were in place to address any incidents that occurred.
- Active management of dependencies, supported by clear accountability for leadership, to strengthen ways of working between the "Product Manager/Owners, the HPV Project Business Owner, and the HPV Project Manager(s)".
- Identify and actively manage any 'key person risk' to prevent further turn-over of key staff.

Regarding equity and project implementation, the report also noted the following risk, "There is an underlying concern that the implementation plan will not sufficiently address equity. As this is one of the key investment objectives the risk of not delivering against the proposed benefits in this area should be addressed as part of formal benefits realisation planning and management".

The review panel was told the 'control tower' recommended by the review was established, with meetings held once or twice per week, with input from relevant stakeholders including communications, business change, Digital Services, and the ICT vendor.

The review panel was shown an implementation phase 1 risk register from 2023 (23), which described 163 risks, although there were noted be several duplicates. 17 were rated as critical, including the risk of the go-live date being missed. Another 65 risks were rated 'high priority', including, 'Minimum Viable Product not clear' for which the action 'define the MVP' and 'communicate the MVP' were identified.

A phase 2 risk register from 2024 (24) was also seen, which included 48 risks of which six were rated 'critical', including:

- "Prioritisation of letters before emails / SMS [text messages] is not equitable and goes against advice from our advisory groups".

- “If we don't include the correct stakeholders in meetings or discussions, we will make poor decisions that may require rework or result in wasted work, and if those stakeholders are BAU [business as usual] stakeholders we will harm our ability to continue to deliver a strong programme after the project team rolls off”.

The phase 2 risk register also includes 16 risks rated at high priority, including:

- “Lack of ownership of the implementation of the notification strategy will invalidate the operational capability of the notifications.”
- “Lack of visibility for remediation issues for notifications.”
- “Scope and capacity around the notification Delivery Lead.”

Findings

- The process to identify, precisely define, document, and communicate the technical requirements of the Register appears to have fallen short. This may in part be because updates to the clinical guidelines were completed later than would have been ideal. Another contributing factor appears to be the disrupted staffing environment that occurred during the planning and implementation of the register, leading to a lack of consistency including in the key translational function between clinical and technical teams. There also appears to have been poor and/or delayed communication between different groups with roles in the screening pathway.
- There appears to have been a lack of effective, early consultation with prospective Register users, including amongst the RCT, labs, colposcopy clinics, and Support to Screening services. This means that functional requirements were not captured as early as they might have been, contributing to the fraught nature of the run up to launch.
- A lack of well-defined and documented requirements appears to have led to a lack of shared understanding by all parties involved as to the direction the Register’s development should and was taking and what the functionality would be at launch.
- Delays to clinical guidelines and functionality requirements being defined were identified early on as risks and ultimate there was less time available to build and test all the Register’s desired functionality than was required. This led to the scope being cut back to a reduced ‘MVP’ and may also have contributed to the issues with the Register’s functionality that have since been identified.
- It was unclear to the review panel how decisions were made about what functionality was and was not considered to be essential for go-live. It appears that there was a lack of clinical input to some of these decisions, and that some may have been made by technical or operational staff instead of clinicians. This is demonstrated by the fact that clinical staff were then and remain unclear exactly what functionality was being delivered.
- Given that it was known that the Register was to launch without full functionality and with known ‘defects’ requiring resolution following go-live, robust failsafe processes and reporting were necessary to ensure the Register was operating safely or to detect where it was not. Failsafe processes were not sufficiently robust at launch and have had to be developed since, and at the time of review still needed to be developed further given the Register’s ongoing issues.

See recommendations 8, 25, and 27, which address these issues.

4.Register functionality

4.1 Eligible population identification and implementation

The review panel heard during interviews that the Register was initially loaded with the details of participants who had been screened before from the old register. It was commented that this included some participants who were last engaged 20+ years ago some of which may have since moved overseas.

The review panel was also told those invited to screen can include recent visitors to Aotearoa New Zealand who accessed healthcare and so had been allocated an NHI number. There are no data sharing agreements with other agencies to identify individuals going overseas.

Duplicate NHI profiles[29] identified during implementation, were said to remain unresolved and access to the archive of the legacy register is required to investigate and resolve. It was also stated that there is a Register Central Team Standard Operating Procedure for the ongoing management of new duplicate NHI profiles as they are advised by the NHI team.

Transgender and non-binary individuals with a cervix

The NHI records gender only (female, male, another gender, or unspecified or unknown[30]) and does not separately record biological sex/sex assigned at birth. Individuals can have their gender assignment in the NHI changed if their historically assigned gender (e.g., that assigned at their birth) does not reflect how they identify. By default, the Register extracts the apparent eligible population from the NHI listed gender (females).

The NCSP was asked to provide information about how the programme accommodates transgender and non-binary individuals. The review panel was provided with an SOP for transgender participants dated 12 April 2024 (25). This states, “The register pulls peoples “Gender” from HealthUI[31], and this gender only relates to how the person identifies. This means that for participants that don’t identify as their sex at birth, the gender may not accurately represent if the person is eligible for Cervical Screening. To ensure we know who is eligible and who is not, we need to update a person’s “Sex” if it is different to their “Gender”.

The SOP also describes the process for recording in the Register, if:

- A female participant on the Register was “male at birth” – a sex of male is added to their profile on the Register and that their tracking is blanked so they do not appear in reports for PHOs thereby avoiding incorrect follow-up as eligible, due, or overdue for screening.

[29] It can occur that individuals have more than one NHI number, often because an existing NHI number is not known when the individual accesses healthcare and so a new NHI number is created to ensure the healthcare event is recorded, or because individuals have multiple names or aliases.
[30] HISO 10046:2024 Consumer Health Identity Standard - https://www.tewhatuora.govt.nz/publications/hiso-100462024-consumer-health-identity-standard
[31] Health User Interface (HealthUI) enables healthcare providers to connect to the NHI database to search for and view patient identity information as well as other identity related functions.

- A male participant on the Register was “female at birth” - a sex of female is added to their profile on the Register. Relevant details, including age, immune status, and screening history are checked to inform the tracking status which must be updated.

The NCSP’s Policies and Standards Section 3: Cervical Screening Services (26) states, “People should be encouraged to participate in the NCSP if they are a woman, or anyone who has a cervix, aged 25 to 69. This includes people who… are transgender, gender diverse, or non-binary and has a cervix”. The programme’s draft Te Tiriti o Waitangi and Equity Strategy (27) states, “The HPV self-test will maximise autonomy and the NCSP must clearly communicate that cervical screening is advised for all people with a cervix.”

The review panel was provided with a copy of a leaflet titled, ‘Cervical Screening – Your test, your choice!’ (28). This leaflet provides information about HPV, the options for HPV screening, who is eligible for the NCSP, and how frequently screening is required. It also explains, “It makes no difference what your sexuality or gender identity is, or if you have not been sexually active for a long time. If you have a cervix, it’s best to get tested.”

Participant ethnicity

The NCSP’s draft ‘Te Tiriti o Waitangi and Equity Strategy’ states that, "The NCSP Register will obtain information on eligible participants via National Enrolment Service (NES) and NHI data. These data sources are known to undercount Māori[32] when compared with National Census data. NCSP will engage with ongoing Health NZ work to improve data quality."

The review panel was informed that:

- Ethnicity information in the Register is the NHI recorded ethnicity. Any changes made in the NHI database are updated daily and visible in the Register.
- The NHI data includes up to six ethnicity fields[33].
- Changes to ethnicity information can be initiated at the point of care.
- Primary Care providers can, through their practice management system (PMS), update the ethnicity data but would need to ask for this to be changed at NHI level by the NHI central team for it to be updated in the Register.
- The RCT and Regional Coordinators can also send requests to the NHI central team to update NHI ethnicity information.

The review panel was provided with a copy of the NCSP’s Policies and Standards Section 3: Cervical Screening Services, V1.2 November 2023. Standard 3.5.7 states, “The NCSP requires accurate ethnicity data to monitor outcomes for different ethnic groups. Documentation of ethnicity must follow Health NZ Ethnicity Data protocols:

- The participant must identify their own ethnicity.
- The standard ethnicity question for the health and disability sector must be used, that is the Stats NZ 2018 Census ethnicity question.
- The sample taker must not guess ethnicity on behalf of the respondent or limit the number of ethnicities given.”

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[32] Audits showed one in five Māori were not identified as Māori on the NHI when compared to their self-identified census data, Harris & McLeod: https://www.tewhatuora.govt.nz/assets/Publications/Maori-health/Ethnicity-Data-Action-Plan.pdf

[33] As per the minimum required via HISO 10001:2017 Ethnicity Data protocols: https://www.tewhatuora.govt.nz/assets/Our-health-system/Digital-health/Health-information-standards/HISO-10001-2017-Ethnicity-Data-Protocols.pdf

It was noted by the NCSP that there is a gap between the standards and what happens in practice and the NCSP's expectations regarding the documentation of ethnicity described by the standards, is not likely routine practice. The review panel was told that the NCSP did not have a specific strategy to overcome ethnicity data quality limitations but that it took account of the undercount of Māori when interpreting and presenting data.

Participant postal addresses

At the time of the Review, notifications were routinely being sent by postal letter only. Use of email and text message to contact some unscreened individuals had not yet been fully implemented but was being trialled.

The review panel was informed the Register generates a 'mail file' each day, detailing the items of correspondence to be sent and the address to send each one to. This is sent to the mail house for letter printing and posting. The mail house performs an address check and rejects some addresses in the mail file. It was noted that the Register is updated daily, including any changes to addresses.

Address quality issues were identified in interviews. These included COVID-19 related issues such as addresses recorded as a flight number or a managed isolation facility (hotel). The panel were told these issues have mostly been resolved but the mail house still reject some addresses on the mail file for these reasons.

When a letter is returned, the NCSP's Gone No Contact (GNC) SOP (29) states that the RCT should record the individual's details in a spreadsheet shared with Regional Coordinators. The Regional Coordinator is then asked to:

- refresh NES status for Participants
- check if recent contact details are recorded in Health NZ Patient Management System
- call or email the participant's GP to confirm their postal address
- contact the participant by phone, text message, or email to ask for their current address if no GP update is available.

The review panel was told that, if correspondence is turned off but a test result comes in, the Register will create a task to check if correspondence should be turned back on. There is not yet a process to do the same when a new address is added, and so manual action to trigger correspondence is needed. It was said that a workplan to improve/expand these processes was underway.

Currently, if a new address is provided, it should then be updated in the Register by the Regional Coordinator and a new letter triggered. It was reported that periodic review by of programme specific addresses were carried out by the Register Central Team, comparing them to the NHI address of the participant. If the two addresses are found to now be the same, the programme specific address is removed, otherwise no change is made, and the programme specific address remains as the address used for notifications.

If no new address is available, the participant will remain marked as to 'receive no further correspondence'. The GNC SOP, states, "GNC tasks will be assigned to Regional Coordinators to investigate and action and refer to Screening Support Services where appropriate and as applicable". "Following investigation, if no new address can be found, the Register User will mark the Participant as No Further Correspondence".

The review panel heard that Support to Screening services do not have access to the Register and so cannot add or update addresses. It was commented that instead they contact a participant's GP (for those that have one), to update the individual's details in their system and share this information with the NHI team.

The review panel was told that there had been an issue of address changes in the Register being over-written when the NHI data was refreshed. It was said that this has since been fixed, and an individual can now have a programme specific 'mailing' address in addition to their NHI derived 'residential' address. The NCSP's GNC SOP states, "Mailing address is prioritised over residential address when sending correspondence and notification letters."

Findings

- The NHI data the Register utilises as the basis for understanding the eligible screening population has limitations, which impact on the Register's ability to correctly identify and implement the screening eligible population.
- The review panel highlighted that the NCSP's Te Tiriti o Waitangi and Equity Strategy remains in draft and that a final version has not yet been published on the public-facing website.
- The Register's functionality does not yet include the ability to send notifications by text message and/or email. As identified by the notification strategy, this would have given more options to reach participants and may have helped reach higher risk individuals, including those without a stable place of residence where postal address is out of date. The panel noted the draft NCSP Te Tiriti o Waitangi Equity Strategy stated text and emails are "preferred [communication] methods for many Māori and Pacific participants. This functionality is now being trialled and hopefully will soon be available for the NCSP to use.
- The review panel asked to see, but did not receive, any NCSP analysis of the relative completion/correctness of postal vs email addresses vs mobile telephone numbers to inform which is the better default communication method(s).
- Māori are at higher risk of cervical cancer because of poorer reach by the NCSP to eligible Māori people. Other system-related factors that need to be addressed include
    - Māori have lower enrolment with primary care
    - The NHI significantly under-counts Māori.
- Both these factors affect the NCSP's ability to identify under-screened Māori, who are a priority population due to being at increased risk of developing and of dying from cervical cancer.
- Transgender and non-binary individuals with a cervix may also not be invited if they are recorded as male in the NHI. If they do not interact with a healthcare provider or that provider does not record that their 'sex' as female they will likely not be identifiable as eligible for cervical screening. There are multiple barriers to this occurring, which makes the transgender and non-binary populations at risk of being unscreened or under-screened.
- For transgender and non-binary individuals not eligible for screening, the NCSP's SOP describes that their pathway tracking is blanked. The individual is not unenrolled from the programme and the reason for this is not communicated to the participant, and hence this process lacks transparency. PHOs may also have difficulty crossmatching against their own enrolled populations.
- The review panel received conflicting information about whether ethnicity can be recorded in the Register separately from the information loaded from the NHI. The panel notes, given the known, long-standing undercounting of Māori in the NHI, the

collection of ethnicity data according to best practice recommendations is important to ensure accurate, high-quality monitoring of programme outcomes for all population groups.

- The NCSP's Gone No Correspondence SOP describes the use of spreadsheets to share information with Regional Coordinators. The review panel expected that the Register would be used to send these tasks, allowing for central tracking.
- The review panel supports work underway to improve/expand Register processes that would automatically create a task to check if correspondence should be enabled after a new address is added.

See recommendations 26 and 37, which address these issues.

4.2 Notification strategy design and implementation

A notification strategy (30) was developed alongside the Register. It states that, "The new Register will enable information to be sent to participants that they are due for routine screening and their options (known as a notification) and send reminders to those who have not attended for screening or follow-up and routine recalls. In addition, the Register will send reminders to participants or relevant services when the expected clinical follow-up has not occurred." The notification strategy was designed to include a phased launch, aiming to prioritise the highest need groups to receive eligibility notifications first.

The notification strategy contains (as appendix 2) a 'Framework for notification for first round of screening'. This describes what eligibility, follow up, reminder, and recall notifications should be sent to ten different groups of participants based on their enrolment status and if they were newly eligible (such as ageing into the screening programme), unscreened or under-screened, overdue or had been regularly screened.

Several interviewees commented on the Register's role in initiating contact with participants about screening. It was noted that the old register was primarily a store of information but also acted as a safety net by identifying people overdue for screening. The smear taker was responsible for recall, but the register identified if that was unsuccessful or did not occur. Some interviewees felt that it was now less clear who has responsibility for contacting participants given that the Register now initiates the sending of letters to tell some people if they are eligible for screening.

It was commented that, leading up to launch, there were split opinions from the primary care consultation, on the role of the NCSP in inviting and recalling those individuals who are enrolled with a primary care provider. Some GP practices preferred the Register to take over responsibility of contacting all participants, while others wanted to retain this responsibility for all their patients. It was said that there was ongoing need for clarity around this issue.

During interviews the review panel was told that the implementation of notifications was not complete at go live and there was a need for this work to be a "fast follow". About half were introduced between 3-23 November and the rest on 11 December 2023. The period between the launch of the Register on 12 September and the completion of the notification functionality on 11 December is referred to as the 'transition period'. Figure 1 in appendix 4 describes each of the notifications the Register initiates, and when they went live.

NHI profile activity

The review panel was provided with a copy of a document titled 'National Simple NHI Data Extract Specification for the HPV Screening Programme' dated October 2023. This states

that an NHI population data extract is updated weekly and includes records where the "Client has had a last date of contact (see appendix 5 for details) with the NZ Health system in the previous three years". Interviewees stated the purpose of this check was to identify individuals active in the health system and therefore likely to engage in screening.

The notification review report states, "The programme acknowledged that ideally the data would include active dates within the last six years to align with the five-year screening period + one additional year. However, this data/change could not be completed prior to NHI simple being implemented or before the change freeze. Decision was made to accept the 3-year data period".

The review panel was informed that, currently, whether an individual has any activity recorded on their NHI in the previous three years only determines whether they are sent an eligibility notification letter and does not affect if reminder letters are sent. It was stated that reminder letters will be sent to anyone who:

- had at least one screen in the old programme, or
- has received an eligibility notification, or
- is not now recorded as deceased in the NHI.

In addition, it was explained a 'day one batch' of eligibility notifications were sent to individuals who had not previously been screened, were not enrolled in primary care, were recorded as being in a priority ethnicity (Māori and Pacific Peoples) group, aged over 30 and who had an active NHI profile.

It was acknowledged there can be a considerable lag in NHI activity data, which it was suggested comes either from the NHI team or the data sources such as hospitals, primary care providers, etc. The review panel was informed that if an individual does subsequently have a touchpoint with the health system, then their eligibility letter would be re-triggered.

Cohorting

The notification strategy describes that notifications were to be implemented in phases, for different 'cohorts', to:

- spread out any potential increases in demand for cervical screening services
- allow time for discussion with primary care of centralised notifications, and
- allow time for expanding Support to Screening services.

The notification review describes the three cohorts of individuals as follows:

- Cohort 1 includes those who are either
    - unscreened or under-screened Māori or Pacific over 30 years of age not enrolled in primary care, or,
    - newly eligible and either 25-30 years of age and/or a new NHI (enrolled or not)
- Cohort 2 includes those who are unscreened, under-screened, or overdue and enrolled (in primary care).
- Cohort 3 includes those who are either,
    - regularly screened and enrolled, or,
    - unscreened or under-screened individuals who are not recorded as either Māori or Pacific and who are not enrolled with a primary care provider.

The notification strategy states that the three cohorts were planned to go live as follows:

- Cohort 1 – October to December 2023 (as notifications implemented)
- Cohort 2 – January 2024
- Cohort 3 – March 2024

It notes those in cohort 3 did not fall within the scope of referral to Support to Screening providers. Therefore, the NCSP needed to find a referral pathway for follow up of these individuals before setting up their notifications.

As of the time of this review, cohorts 2 and 3 were not yet live for receiving eligibility or recall notifications. The review panel saw a draft memo dated 25 October 2024 (31) , which highlighted clinical risks associated with cohorting. The highest risk was said to be the application of cohorting to the recall of individuals to screening after an LBC test result didn't arrive within three months. The memo notes that reminders were sent at three and 12 months, providing mitigation of the risk of recall notifications not being sent to cohorts 2 and 3. The draft memo made several recommendations, including:

- cohorting should be removed for these recall letters, as a priority, as well as for eligibility letters
- unsent eligibility letters should now be sent, where reminders have not been sent
- enabling recall letters for those not enrolled in primary care and regularly screened.

The notification review (19), (undertaken shortly after launch in response to concerns about notification functionality) also commented that, as the roll-out period had passed, "consideration should be given as to whether cohorting is still relevant".

Identifying under-screened participants

During interviews the review panel heard that the Register did not have the functionality to 'flag' an individual if they were under-screened. It was said the Register could not look back and could only categorise participants based on their current screening status, such as their most recent screening episode or result. It was clarified that someone looking at the Register could 'manually' view an individual's screening history but that the 'pathway status' did not always accurately reflect all past events.

It was explained there had been an issue in translating what was meant by 'unscreened or under-screened' to technical requirements. It was said that these terms had been defined in 'clinical language' but not in 'technical language'. The review panel was told it was possible to systematically identify unscreened or under-screened individuals in the 'data warehouse', outside of the Register, such as for reporting on the programme.

Interviewees commented the intention of building a population-based register was to enable providing support to individuals who were missing out on screening. The inability of the Register to identify who was under-screened was described as a 'missed opportunity'.

Technical issues affecting notifications

The notification review identified seven 'gaps' where notifications were not triggered. These are summarised in appendix 6. Several involved participants with a pathway status for which the necessary notification 'logic' had not been built, meaning no notifications were triggered.

The notification review also identified three other 'gaps' where notification functionality was not working as planned:

- 3,000 participants who were previously unenrolled were re-enrolled, which triggered an enrolment letter. The notification review commented that the Register was, "working as designed to re-enrol participants, however the current letter may not be applicable for all re-enrolment scenarios."
- GP enrolment information in the Register was not up to date, leading to individuals incorrectly identified as unenrolled receiving recall notifications earlier than planned. Enrolment data has since been updated in the Register.
- The Register was intended to initiate follow up action by Support to Screening services at two months overdue for priority ethnicity participants, one month ahead of the default automated three-month reminder sent to other participants. If no screening test was done three months following the referral to Support to Screening services at two months overdue, a Register reminder letter would then be sent. Due to a lack of Support to Screening service capacity, and latterly Support to Screening tasks being turned off, priority populations were not receiving reminders until they were five months overdue (see figure 2 in appendix four for a diagrammatic representation of this workflow issue). This issue was reported to have affected approximately 17,000 people receiving 'reminder letters. During interviews it was commented that this issue had occurred due to a gap in understanding between the clinical and technical teams.

The review panel was provided with a copy of a document produced by the ICT vendor titled, 'NCSP Notification Review Action Tracker on Key Findings', dated 25 November 2024. This provided an overview of work completed to address the 'gaps' identified in the notification review.

There were, however, other issues identified by the notification review that the review panel has seen no update on. These include:

- Whether data remediation to activate the status of participants over 70 who require a test to close out their screening was undertaken.
- If notification logic for participants moving from a blank or 'unregistered' status to 'enrolled' has been fixed. If not, it wasn't clear if this group would be sent recall and reminder notifications and if Register tasks would be raised.
- If high-priority unsent reminders for follow-up co-tests following colposcopy have been sent and if Register tasks are raised where these reminders are outstanding.
- Individuals sent multiple enrolment notifications due to a historical or corrected clinical event or a syncing issue triggering a second notification.
- Notifications are not sent (and tracking is turned off) if there is an outstanding recommendation mismatch task (see section 4.4 below).

March 2025 reminder notification incident

During this review, after interviews had been conducted, the review panel was made aware of a newly identified incident. On 6 March 2025 it was identified that 182,598 HPV screening reminder letters had not been sent. The cause of this was documented in the Prevention Adverse Event Register (32) as follows,

> "When sending the reminder letters there is system logic that checks to see if there is an open Case for the participant, if there isn't then the reminder letter is not triggered in the system.
>
> Since go-live we don't believe there has been the functionality in CSR to open new Cases when the participant is on a routine screening pathway. This has meant that

many Reminder letters have not been sent for participants that are on a H1 or H2 (regularly screened) pathway."

It was subsequently clarified that 'H1' relates to the five-year recall HPV screening test pathway and 'H2' is the three-year recall HPV screening test pathway for individuals with an immunocompromised clinical history.

In response to this, it was reported that the NCSP was planning to catch up with these missed notifications through normal daily letter production and was looking at options to prioritise the order in which they would be sent. It was also stated that it was looking at options for sending a large catch-up batch, including emailing letters where possible.

Catch up-batches

The 'NCSP Notification Review Action Tracker on Key Findings' (33), dated 25 November 2024, provided recommendations from the ICT vendor to address priority 'gaps'. These issues are summarised in appendix 6. This includes numbers of overdue notifications, due to various Register issues. For some it was suggested notifications could wait, e.g., for the next scheduled reminder at 12 months, following a missed reminder at 3 months. For others it was suggested that notification should be sent, when possible, either by post once address remediation had been completed, or by email.

As described earlier in section 2 of this report, the notification review report produced in April 2024 (19) included an assessment of the numbers of notifications triggered that had not been sent and the number not triggered (see figure 3 in appendix 4).The review panel was provided with an updated table of figures of unsent and untriggered notifications dated June 2025 (1). These updated figures are included as figure 5 in appendix 4. In summary, as of June 2025:

- 160,000[34] notifications that were triggered but not sent, including
  - 108,000 eligibility notifications not sent to 'inactive' individuals
  - 51,000 recall and reminder notifications not sent due to 'cohorting'
- 808,000 notifications that were not triggered, including
  - 656,000 eligibility notifications not triggered, of which about 495,000 were due to the individual being 'inactive'
  - 101,000 reminder notifications not triggered due to 'case closure issues'.

It was noted that, "The volumes displayed are dynamic and change frequently as participants progress through the pathway, make contact with health care system etc." It was also noted that, "Not all unsent notifications need to be sent", such as where individuals have since been screened.

It was commented during interviews that it would cost several hundred thousand dollars to send 'catch-up' batches of notifications to all of these individuals. It was noted that it some of these notifications had not been budgeted for, such as the individuals who had not been sent eligibility notification as their NHI profile was inactive, and so there was no funding available. It was also said that, as only about 20% of recipients were likely to act, this would not be an efficient use of funding.

[34] This figure does not include approx. 50,000 notifications not sent to participants who requested not to receive communications.

Findings

- As noted by some interviewees, the now more central approach to notifying participants means there is a risk of less clear lines of responsibility for initiating contact. Therefore, it is important to maintain engagement with the primary care sector and for future decisions about contacting participants to be informed by research.
- Several notifications logic flaws have been fixed, but the review panel did not see a comprehensive assessment of all faults identified by the notification review describing how each had been addressed, suggested some may yet remain. The March 2025 reminders incident suggests there could also be more technical faults which have not yet been identified.
- The review panel was concerned that the NHI active rule may be inappropriately preventing some individuals from being invited to screening by the NCSP. For example, healthy individuals ageing into screening who have had no need to interact with the health system. This also affects those who, despite need, have not interacted with the health system due to systemic and structural barriers. They may also therefore be at higher risk for developing cervical cancer, and unlikely to be engaged by primary care.
- The three-year NHI active timeframe is half of the intended six-year timeframe originally recommended, to align with the screening interval. This appears to have been dictated by technical limitations rather than a clinically driven decision.
- The review panel was also concerned that poor quality data may be limiting the accuracy of 'NHI active' statuses and that some clinical events, such as casual primary care appointments, may not be counted. This would be particularly problematic given the greater likelihood of priority populations accessing healthcare through these means.
- The review panel was told reminder notifications would be sent regardless of 'NHI active' status. However, as the review panel understands it, reminder notifications are only sent to individuals tested in the old programme, sent an eligibility notification, or tested in the new programme. A 'day one batch' of eligibility notifications was sent to a subset of priority unscreened groups, but anyone not included in this batch would miss out on reminders.
- 'Cohorting' was designed as a transition measure, but as of March 2025 only cohort one is being sent notifications. This means that those individuals in cohorts two and three are not being sent eligibility or recall notifications by the Register. Given the issue, which was identified in March 2025, that was preventing the sending of large volumes of reminder notifications, the ongoing use of cohorting is particularly problematic.
- It is significant that cohort three includes individuals who are unenrolled in primary care and unscreened or under-screened from the 'Other' ethnicity group. The ongoing use of cohorting is a risk for this group as it is likely no one is inviting them to screen. It is noted that there may be priority population individuals, who are incorrectly identified in NHI ethnicity data, that are affected by ongoing cohorting.
- It was stated that it was never intended that cohorting be applied to pathways for abnormal results. It is noted, however, that cohorting is being applied to recall notifications sent when a participant who previously tested positive for 'HPV other' is recalled for their next screening test. Although this issue was stated to be somewhat mitigated by the fact that reminder notifications should subsequently be sent, the potential for delay is problematic given that this cohort is at heightened risk given

their history and so the review panel was concerned that these notifications were not being sent. The review panel saw an internal draft document that recommended that this rule should be disabled for this notification type to remove this risk, but it appears as though this proposal was never taken forward for consideration.

- Due to a combination of issues, there are individuals who may not be sent eligibility, recall, and/or reminder notifications and as a result are unlikely to engage in screening. These issues disproportionately affect the most at-risk populations who are not enrolled in primary care as they are less likely to be invited outside of Register generated notifications.
- There are outstanding volumes of notifications that were not sent for due to the delayed introduction of notification functionality, technical flaws in how the notifications were first built, or because of NHI activity and cohorting rules. As of June 2025, there were more than 972,000 unsent or untriggered notifications, some of which have been held since late 2023. The review panel was told that there are significant financial considerations involved given the cost of sending letters and as a result email and/or text messages are being considered and trialled as an alternative. While the review panel supports developing this functionality (which is explored further in section six of this report below) and agrees it may be appropriate to send some notifications by these means in the future, the currently unsent notifications should not be delayed indefinitely.
- As was noted in the implementation business case (17), even if the Register's notification functionality was operating optimally, this alone would not be sufficient to eliminate the differences in cervical cancer incidence and mortality between population groups and ultimately achieve the WHO elimination target[35]. Outreach from trusted providers is needed and for this reason the notification strategy was designed around having Support to Screening services in place to provide outreach with direct referrals from raising tasks in the Register using the eligible population data held in the Register. Unfortunately, several issues have meant that these services are not able to fulfil this role to the full extent envisaged and are essentially operating in the same capacity as prior to the launch of the Register.
- Some parts of the country have no access to these services, and of those that do, some have better access than others. The NCSP's contracting and funding of these services are outside of the remit of this review. The review panel notes, however, that implementing the notification strategy successfully requires a well-developed network of Support to Screening services.
- Beyond the issue of resourcing, Support to Screening services were further impacted by technical flaws in the implementation of the Register. At launch incorrect implementation of enrolment data led to Support to Screening services being sent too many tasks, which could not be managed and so were switched off. As of the time of this review, these tasks were still disabled.
- The Register lacks the functionality to look back at a participant's screening history and generate a flag when the participant is unscreened or under-screened. These flags were intended to be a key tool to identify at risk individuals who would benefit from outreach to support them to screen. This is a significant deficiency as it inhibits the ability of Register users to identifying individuals at heightened risk, which is particularly important in the context of large volumes of Register tasks.

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[35] The WHO has advised, "To eliminate cervical cancer, all countries must reach and maintain an incidence rate of below 4 per 100 000 women." - https://www.who.int/initiatives/cervical-cancer-elimination-initiative

- There may also be other clinical implications of the Register lacking the functionality to 'look back' at previous screening results, which could result in individuals being placed on the wrong pathway or given the wrong pathway status. If it is not possible to deliver this functionality at all, it would suggest the Register may not be a suitable solution in the long-term.
- Unsent notifications, a lack of Support to Screening service resources, referral tasks to Support to Screening having been disabled, no early reminders for priority populations, and no functionality to flag under-screened individuals means the notification functionality of the Register is not currently able to deliver the benefits intended. It is therefore not contributing to closing the cervical screening (and therefore cervical cancer) equity gaps. The potential advantages of having a population-based register with data for all the eligible population including demographic information, primary care enrolment status, and screening records in one place is likely therefore being underutilised.
- The panel viewed limited analysis only on how unsent notifications have affected different ethnic groups. It is unaware of any analysis of how other groups identified as being at higher risk of not being able to access screening in the (draft) NCSP Te Tiriti o Waitangi and Equity Strategy have been affected. This includes those living in rural areas, those with disabilities or with a severe mental illness, LGBTQI+ individuals, and people in correctional facilities. This information is important to support informing how best to communicate with members of these groups going forward. There are also implications for monitoring equity for these groups if data identifying individuals is not in the Register.

See recommendations 1, 3-7, 9, 13, 15, 18, 22, 29, 232, and 36-38, which address these issues.

4.3 Flow of information from and to other systems

The review panel was provided with a high-level overview of the architecture of the Register (see figure six in appendix four), and the other information systems that the Register interacts with. The review panel heard interviewee's perspectives on some of these information flows as described below.

For a discussion of how information flows to and from HPV laboratory information management systems, see the section 4.4. Perspectives on using the 'Whaihua' digital interface are in section 4.7.

Flow of information from the National Enrolment Service

The NES can provide up to date national primary care enrolment, identity, and address data[36]. At launch, enrolment data had not been successfully loaded into the Register and so it appeared as though some people who were enrolled in primary care were instead unenrolled. This issue affected the Support to Screening services' ability to manage Register tasks assigned to them. This issue has since been resolved, and manual bulk updates have improved the enrolment data quality in the Register. Integration of the Register with the NEMS, to enable frequent automated updates to enrolment data, was deployed on 25 February 2025.

[36] Address data for the Register is not retrieved from NES, the NHI is the source of address data for the Register.

One limitation noted was that the Register doesn't identify who holds a community services card. This is relevant as cervical screening is free to those aged 25 to 69 and hold a Community Services Card. As a result, manual checks of other systems are necessary to confirm this information. It was suggested that this could be part of the information gathered by the Register from the NES.

Flow of information from Gynaecology Plus

Information is sent to the Register from colposcopy clinics on referral status, visits, non-attendance, and discharges. All public hospital colposcopy clinics and some private clinics use 'Gynaecology Plus' software for collecting colposcopy data and sending it to the Register. The Register does not provide information back into Gynaecology Plus, but a summary of an individual's screening history can be viewed in Gynaecology Plus.

The review panel was told the Register rejects some information sent by Gynaecology Plus due to 'mismatches', that it was not always clear why the information had been rejected, and that it therefore took time to investigate and resolve rejections. It was estimated that, initially, about 10% of messages from Gynaecology Plus were rejected by the Register. It was said that this, "was quickly reduced and is now down to less than 0.01% of all messages" for clinics using the current version of Gynaecology Plus, and that it was intended that there would be no message rejections by June 2025. Public hospital systems were noted to still be on the previous software versions (the version launched at go-live), while private clinics were on the newer software versions.

The review panel was informed that when a visit takes place and this is recorded in Gynaecology Plus, it sends a message to the Register to delete the current (and now outdated) screening pathway status and then a second message is sent to inform the Register that the visit has taken place, so that the pathway status is updated. It was noted that if the second message is rejected then the Register would not contain the correct pathway status, and such issues are logged by Gynaecology Plus.

Another issue raised was functionality is not yet in place to send colposcopist HPI information to the Register. The HPI identifies health practitioners, health provider organisations, and facilities (the physical address where the health care takes place). It was noted that improving the quality of this data in the Register would reduce the workload of colposcopy clinics by eliminating the need for them to look this information up separately.

A release at the end of February 2025 added an enhancement to pull HPI information where it was missing by looking up against the HPI database. It was identified in March 2025 that errors were coming back from the HPI database with information not supplied as requested. While this issue was being investigated and a fix deployed, a manual process was put in place to allow messages to flow and a catch-up resending of approximately 65 missing messages was planned.

Private colposcopy clinics not using Gynaecology Plus complete a manual form to make referrals, record visit details, and discharge individuals from colposcopy. These manual forms are sent to the RCT to process. During interviews it was commented that the manual form had recently been streamlined. It was reported that the manual form was going to be replaced by an electronic form, which would eliminate manual data entry. It was, however, suggested that it should be a requirement for all clinics to use an electronic information management system to send data to the Register, as some private clinics may not be sending all information and results using the manual system.

Flow of information to primary care practice management systems

The review panel heard work was underway to interface the Register with primary care practice management systems (PMSs). It was said this approach had the advantage of primary care practices being able to see screening histories within a system they were already using and not requiring additional Register product licenses for these practices.

The review panel was told the integration being developed would allow the PMS, for example, to pop-up a screening summary window. Some interviewees commented this functionality was more limited than had originally been hoped for and that it would be ideal if messages from the Register updated the PMS to reflect the next expected event. In the current design of PMS integration, manual updates to the PMS are still required.

Work to integrate the Register with PMSs was said to have been slowed by the complexity arising from the number of different PMSs. As of the time of this review, the NCSP was planning a pilot with practices using the Indici PMS.

While this integration is being worked on, the review panel heard that monthly Primary Health Organisations (PHO) data match reports continue to be sent out by the NCSP to PHOs, from which practices can identify which of their patients are overdue, unscreened, or under-screened according to the Register. It was noted that there was a lack of clarity nationally about a definition of ‘overdue’.

The review panel heard that, if a patient is screened outside of their usual primary care practice, the practice may not know if they are not sent a copy of the result by the screen taker. The patient would come off the PHO report of overdue individuals and it may not be apparent they had been screened without looking up that individual in the data match report.

SNOMED codes

Most individuals with a history of cervical cancer will be unenrolled from screening, however those who have had superficial cancers[37] require ongoing screening under the new clinical practice guidelines. There are approximately 40-50 superficial cervical cancer cases per year. SNOMED CT is an updated coding system for cervical and vaginal histology. Te Aho o Te Kahu (the Cancer Control Agency) is running a nationwide project to get all cancer data converted to SNOMED CT.

The NCSP is the only sector that is still using the old version of SNOMED, meaning all superficial cervical cancer diagnoses cannot be identified. Until SNOMED CT is fully implemented, all cancers diagnosed since go-live require manual review and, of the 2,000 historic cases, most require/have required manual review. This is important, to ensure no distress is caused by inappropriately re-enrolling someone who is not eligible for screening due to a history of cancer. The lack of implementation of SNOMED CT has a major and ongoing impact on the capacity of the NCSP’s clinical team. These reviews were described as complex and time consuming.

The approach being taken to implementing SNOMED CT was said to be:

[37] This refers to stage 1A1 cervical cancers, which have grown 3mm or less into the tissue of the cervix.

- The SNOMED CT codes have been reviewed by Te Aho o te Kahu
- The HL7 specification needs to be updated to reflect the new SNOMED CT codes
- There needs to be an assessment of the finalised SNOMED CT codes to determine if there is any impact on Register development
- Implementing SNOMED CT requires laboratory information system development and education on the new codes. NCSP has estimated this will occur early in 2025.

Whilst the SNOMED CT approach is progressed the NCSP has republished instructions on how labs can best use existing SNOMED codes to report most accurately and reduce the need for manual reviews.

Findings

- There have been several issues with the integration of the Register with other systems and some functionality which has not yet been built.
- The issue at go-live with enrolment data not having been loaded correctly created significant issues and is something that might have been expected to have been identified with testing or quality checks. The new functionality to identify when enrolment data is updated was not implemented until February 2025 and so the review panel has not had the opportunity to assess if integration was successful.
- It was concerning that a new incident had been caused by the introduction of an 'enhancement' to improve HPI information. This suggested that testing processes may not be sufficient to detect issues, although at the time of this review the incident had not been fully investigated and so the root cause, and whether it could have been identified through more thorough testing, was not yet known.
- Initial issues with the integration of the Register and Gynaecology Plus are now said to have been largely resolved, for those on the latest version of the software. For the public hospitals still using old versions, however, there are still high rates of messages being rejected. This means the Register does not hold up to date information, which may be contributing to the large numbers of colposcopy clinic tasks (see section 4.5).
- There is an ongoing issue with the use of paper colposcopy forms by some private clinics. Although an electronic form is being developed, which will address some of these issues, the review panel considered that the ideal long-term solution would be for all clinics to use a software-based solution for sending information to the Register.
- Integration with primary care systems was initially envisaged to be in place prior to launch but was cut from the MVP and is still in development. This is a significant requirement given the importance to cervical screening of engagement with the primary care sector. As this integration is not yet in place the review panel could not assess whether it will be effective, and it was noted some interviewees expressed that they had hoped integration would be more fully featured that what is being developed.
- Histology information using the updated SNOMED CT coding system cannot be sent to the Register as the Register has not yet been set up to receive this information. This functionality is being developed but, in the interim, managing these cases can require time-consuming individual review by the NCSP clinical team.

See recommendations 23 and 25, which address these issues.

4.4 Automation of laboratory recommendations

Laboratories provide screening recommendations based on test results. Test results are sent to the sample taker and Register, along with a recommendation code set by the laboratory. These recommendations are checked to ensure they meet messaging standards and are validated against the test result and screening pathway rules, based on the clinical guidelines and the screening information the Register holds about that person. A diagrammatic representation of the Register checks/validations performed for laboratory recommendations is shown in figure seven in appendix four. The screen taker gets a full copy of the laboratory results, which includes the laboratory recommendation, even if a mismatch is identified by the Register.

Recommendation mismatches

A recommendation mismatch 'task' is created in the Register when a recommendation from the laboratory is identified by the Register as being incompatible with the screening information the Register has for that individual. The recommendation is not used to update pathway status and tracking is placed on hold pending resolution of the task raised. These mismatch tasks are designed to be a clinical safety net and require manual review, usually by the Register Central Team. While these tasks are being resolved, notifications and tracking of the individual by the Register are turned off.

Recommendation mismatches could be:

- Genuine, where the lab issued recommendation does not match the prescribed pathway for that individual, in this case the lab may have made an error.
- Redundant, because of imperfections in how information flows have been built, in this case the lab recommendations are correct.
- Raised because the information in the Register is not up-to-date, and the lab knows more than the Register does, in this case the lab recommendations are correct.

After manual review, genuine recommendation mismatches are sent back to the laboratory to be investigated and the correct recommendation code issued. The Register only updates the individual's pathway status once the issue has been resolved, and the task has been closed.

The review panel was also told that some participants end up on an incorrect pathway as both the laboratory recommendation is incorrect, and the Register holds incorrect information. It was said that the risk of this occurring was exacerbated by the fact that the Register cannot reference previous screening history.

As of 31 January 2025, there were 4,708 outstanding recommendation mismatch tasks (see figure eight in appendix four). The majority of these (76%), were for either individuals labelled as being 'under specialist care[38]' or cases under gynae oncology at the time the test was reported and were incorrectly assigned to the incorrect pathway before the NCSP gave laboratories specific instruction about how they should be reported[39]. More detail on these two categories is given below. See figure nine in appendix four for a detailed breakdown of the other open mismatch tasks as of 31 January 2025.

[38] H-code flow 13.
[39] H-code flow 17.

‘Under specialist care’

See figure 10 in appendix four for a detailed breakdown of these outstanding tasks.

The NCSP risk rated this category of tasks as ‘moderate’ and noted that, “Most will have had a sample taken by a specialist or in a hospital. In the public sector, the riskiest are those taken around the hospital but not in colposcopy or gynaecology clinics, where we can expect the specialists should have a reasonably good idea about screening. Such as ED [emergency department], in wards, other outpatient clinics where they could be lost to follow up.”

During interviews, it was commented that the designation, ‘under specialist care’ was sometimes misinterpreted. The example was given of an individual with a screen taken in hospital who was not followed up by the screen taker and the task was closed by a Regional Coordinator as the individual was ‘under specialist care’, which they inferred meant there was lower clinical risk.

Within this grouping, there are two sub-groups of individuals:

- those who are in regular screening, have a negative history, and who have had a negative result. The NCSP notes a decision is yet to be made on the approach required for these cases.
- individuals requiring review by the RCT with a new task raised for any missing clinical events (this is why the mismatch occurred in the first place).

Cases under gynae oncology

See figure 11 in appendix four for a detailed breakdown of these outstanding tasks.

The NCSP has risk rated this category of tasks as ‘medium’ and noted that, “A lot of them on the RMM [recommendation mismatch] list have had cancer in the past. The clinical risk is moderate: they are already in clinical follow-up care. We do need to align the register records with the NCSP approach to cancer that was introduced in June 2024. So that when they come in for more testing, the correct recommendation is given by the labs.”

The NCSP noted that one of the labs was unable to amend its reports retrospectively for results from before 26 June 2024.

In terms of completing the review of these cases, the NCSP notes, “A process has been agreed to update the register and send a letter via email to the practice and close the H17 Task.” “Target completion End of June”.

Individual remediation of recommendation mismatches

As noted above, recommendation mismatch tasks require manual individual review and remediation. The occurrence of some mismatches was not unexpected, and it is an intended function of the Register to check for and identify genuine mismatches as a safety net to the screening pathway. Interviewees described, however, that in January/February 2024, a few months after go-live, the number of mismatches occurring became a cause for concern, with many patients not ending up in the correct pathway.

A number of those interviewed commented that the ongoing individual remediation was taking longer than they were comfortable with. It was noted that a mismatch resolved quickly posed little risk, but that if a case was waiting for several months this was problematic due to the delay caused where clinical follow-up was required. As of 31 January 2025, 21% of open

tasks were from 2023, 64% from 2024, and 15% from 2025 with most older tasks being from the two specific issues described above.

In addition, where a change is made to a recommendation following review this is likely to be confusing for screen takers and upsetting for participants. It was noted that for a clinician to receive an amendment several months on from the initial recommendation did not occur in for other types of test results.

The review panel heard processes are in place to triage the cases requiring remediation, to identify the most high-risk individuals for urgent review. Several interviewees commented, however, that sometimes an individual's risk profile is not understood until their case is reviewed.

It was noted that significant progress has been made over the last year, but that there was still much work to be done to reach a 'steady state' and that this may take another 12 months.

Tasks are predominantly reviewed by the RCT, with some closed upon review, some sent back to the laboratory to review and amend the recommendation, and some escalated to the NCSP's clinical team. It was commented that the clinical team did not have enough capacity to progress the work outstanding more quickly. The review panel heard that the NCSP clinical team had hoped to recruit a colposcopist after the previous post holder left about six months ago. It was noted that, with additional resources, the clinical team could achieve quicker turnaround times of cases needing remediation.

It was also said that in the future, further development of SOPs may allow the RCT to resolve more tasks without the need for clinical team input.

Rebuilding information flows

As noted above, some recommendation mismatch tasks are redundant, occurring because of imperfections in how information flows have been built rather than because the recommendation is incorrect. As there are a lot of tasks to be individually remediated, redundant tasks take time away from other tasks that genuinely have a clinical impact. The review panel heard during interviews of situations where laboratories know that a recommendation is correct, but the task comes back to the lab again to resolve, which was said to be frustrating.

The review panel heard work has been commenced to rebuild some information flows to correct these issues. It was acknowledged that the Register had gone live with known defects and that it would be necessary to perform these rebuilds.

As of 31 January 2025, seven of the information flows[40] had been rebuilt. Other rebuilds have been paused because of planned changes to clinical practice guidelines, which will change some information flows. It was noted that if they were re-built now, they may need to be changed again after the clinical practice guidelines changes.

The NCSP has also noted that, "H-code flows that haven't been rebuilt may also allow recommendations to flow through when they technically should be halted and investigated further, however this is currently being mitigated through a manual process." It was acknowledged that this was inefficient and labour intensive for the RCT.

[40] H-code flows 1, 2, 5, 7, 13, 18, and 20.

Findings

- The review panel identified priority issues requiring urgent attention, which were initially communicated to the NPHS in a draft memo on 14 February (finalised on 19 February). This stated that:

  "As of 31 January 2025, there were 4,720 outstanding RMMs of which 3,639 are associated with two of the twenty lab recommendation codes.

  A recommendation issued by the lab is sent to the screen taker to act on. If the lab recommendation is for the participant to return to routine screening (e.g. three or five years) when in fact urgent follow-up is required, this creates clinical risk for the participant. While RMM [recommendation mismatch] tasks are awaiting individual review and remediation, notifications and tracking are switched off".

  "Review of the RMM [recommendation mismatch] task should identify this issue, however, as there are a large number awaiting review, this may not occur for some time. In addition, where a change is made to a recommendation following review this is likely to be confusing for screen takers and upsetting for participants. This may undermine the confidence in the NCSP of both healthcare professionals and participants, particularly when the change is made many months after the screening episode."

- The memo highlighted that the review panel was particularly concerned about the time being taken to complete these reviews, highlighting the limited capacity of the individuals undertaking them, and the impact of delays on individuals at higher risk due to their clinical history. The review panel recommended the NPHS, "Increase staffing resources allocated to individual case reviews, to expedite their resolution."
- The review panel considers the design of the Register and interface with laboratory systems was contributing to this issue. Information held by screening laboratories needs to be considered when assessing potential mismatches, to reduced erroneous recommendation mismatches being raised. Ideally, screening laboratories would be able to see clinical guideline driven suggested recommendations or rapid and direct feedback on recommendations mismatches. The current process, although acting as a safety net, appears to be overly laborious, with the RCT acting as a go-between to review and resolve mismatches. This has the potential to cause delays, which creates clinical risk. The volume of tasks means it is hard to identify the highest priority tasks, which heightens the risk of their delayed resolution.
- There is a need to understand where mismatches are coming from to inform efforts to reduce their volume, if possible. It wasn't clear what proportion of RMMs were being caused by laboratories and how many were caused by the Register. An audit of the root cause of new RMMs would help to better understand where issues lie and whether further education on clinical guidelines or more Register remediation is needed.
- Given the clinical guidelines are being revised, there is a risk that mismatch issues will get worse before they get better, if learning from past problems does not occur. This applies to the re-building and testing of information flows as well as to communicating new guidelines to the laboratories.
- The review panel noted that the terminology 'under specialist care' can be overused and/or misinterpreted. The review panel's view was that this term should be reserved to situations where a sample is taken during a colposcopy appointment as this

ensures the individuals has appropriate clinical oversight. Changing this practice is likely to require changing SOPs and clinical education.

See recommendations 10, 14, 21, 24, and 35, which address these issues.

4.5 Register pathways for abnormal results

Following an HPV test, if HPV other is detected the next step will generally be an LBC test[41]. If the LBC test detects possible or definite high-grade cell changes, then a referral to a colposcopy clinic would be made. If HPV 16/18 is detected, the screen taker will typically make a direct referral to colposcopy without first performing an LBC test under-screened. See figure 12 in appendix four for an overview of the HPV pathway.

The review panel heard the Register did not identify explicitly whether HPV and LBC test results were for a primary screen or a follow up test. It was said that the ICT vendor had advised the best method to determine which results were for primary screens was to use open/closed cases and pathway status. It was said that there had been over 11,000 closed cases in the Register with a pathway status that suggested they should not be closed (i.e. not 3-year recall, 5-year recall, withdrawn, unenrolled). The review panel was later informed that many of the 11,000 closed cases with a pathway status that should have an open case had been corrected by a combination of changing requirements, fixing defects and remediation. The number of ongoing closed cases was not specified but it was noted that the RCT was monitoring this issue as most of these cases were a result of manual adjustments.

Colposcopy referral follow up tasks

The clinical guidelines specify recommend referral for urgent colposcopy review:

- "Where participants have a test result of HPV detected Other with a cytology result suspicious of or definite for invasive cancer, they should be referred to a colposcopist for urgent evaluation within two weeks"
- "Participants with HPV detected 16 or 18 and a cytology result of ASC-H/HSIL, or any glandular abnormality (except atypical endometrial cells) should be referred for colposcopic assessment at the earliest opportunity and seen within 20 working days of the receipt of the referral."
- Participants with HPV 16 or 18 detected and low grade or negative cytology, "should be referred for colposcopic assessment and seen within 30 working days."
- "Where an HPV detected (16 or 18) result is from a swab-collected sample, referral to colposcopy will follow for all participants. Participants will be referred directly to colposcopy where a cytology sample will be taken during the colposcopic examination. Participants over 30, never screened or more than two years overdue for screening, should be seen within 20 working days".

The Register is intended to update the corresponding 'next expected event[42]' date based on the result reported. The review panel was told that, for urgent referrals, the Register set a due date of five working days with an overdue task created five working days after expected date has passed. For all other referrals a due date was set at 10 working days with an overdue task created 10 working days after the expected date has passed.

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[41] As described in the Clinical Practice Guidelines for Cervical Screening in Aotearoa New Zealand v1.1 June 2023

[42] This date is the 'Next Event Due Date' in the Register.

Once the date of the colposcopy clinic appointment has passed, if the Register is not notified that a visit or discharge has occurred, a follow-up task will be created. Regional Coordinators are expected to action these tasks by following up with the screen takers and/or colposcopy clinics, as required.

Register quality check

A 'register quality check' process was developed, to identify participants who had 'fallen' through the Register's safety net (both manual and automated) due to incorrect or missing data, code, and/or process in the Register. Scenarios with the potential for clinical harm were defined by the NCSP's clinical team and a series of queries to identify these cases of concern were developed.

The highest priority scenarios involved participants with, "High suspicion of cancer, but did not have a colposcopy referral accepted message within 12 working days" or "HPV 16/18 and high-grade cytology but did not have a colposcopy referral accepted message within 32 working days[43]".

The review panel viewed documentation on unraised tasks identified through one of these quality check processes. For these scenarios, the Register quality check identified where tasks hadn't been created as expected. This found (based on data from 12 July 2024 – see figure 13 in appendix 4):

- Eight instances where a referral had been made but the timeframe for the clinic appointment had passed, and no follow up task had been created.
- 65 instances where no referral had been made, the requesting facility was not a colposcopy clinic, and no manual or clinical follow-up Register tasks had been created.

11 other scenarios were also outlined including:

- Six different scenarios with persistent positive HPV other without high grade
- HPV other in any immune compromised individuals
- Failed test of cure
- Two repeated unsatisfactory cytology tests
- Three repeated invalid HPV
- HPV other over two years

The review panel was told that the NCSP uses these Register Quality Check scenarios to create Register tasks for the RCT to work through and resolve by calling screen takers, nurses, etc. It was noted that it takes time to successfully make all the calls and that sometimes the RCT must wait weeks for a response.

It was commented, however, that the Register Quality Check only looked at whether a task has been raised due to a missing or unaccepted referral. Where a referral has been made and accepted, the Register Quality Check process did not also check for whether a visit was arranged and held and so did not provide a complete safety net. It was commented that current checks did not, for example, provide visibility of whether tasks sent to Regional Coordinators had been completed before being closed. It was noted that while monitoring should pick up quality issues, this would be after the fact rather than in real time. A new 'pathway safety net' project was proposed to improve Register safety nets.

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[43] The review panel noted that these timeframes appear to be different to those outlined in the clinical guidelines. The reason why this was the case was not described.

Follow-up task outstanding 'incident'

On 17 September 2024, there was a request from the Auckland Regional Coordination Team for a bespoke report to identify participants with high grade cytology or HPV 16/18 results that needed to be followed up for colposcopy referral or visit that hadn't occurred after the specified period. The request was made as the view of overdue next expected events in the Register did not allow for the prioritisation of the highest risk tasks (e.g. individuals with HPV 16/18 or high-grade cytology). This task prioritisation visibility was on the list of planned register remediations.

The bespoke report provided included tasks for the Te Toka Tumai Auckland, Counties Manukau, and Waitematā districts and identified a significant number of tasks that exceeded the expected timeframes for management. It was then identified that the Auckland Regional Coordination Team had only been monitoring the Te Toka Tumai Auckland tasks list, as they were unaware of the other two lists. This finding triggered an incident response process, and an incident was opened and named the "Regional Coordinator Incident."

The initial report and subsequent investigation highlighted that, as of 23 September, there were 1,437 overdue follow-up tasks nationally, of which 395 were in the Auckland region. Tasks included in the scope of this reporting related to participants deemed to require expedited review, due to referral to colposcopy for suspicion of cancer, HPV 16/18 detected, and/or high-grade cytology.

As of 13 December 2024:

- 1,130 follow-up tasks had been completed
- 307 tasks were still in progress, of which:
    - 52 tasks were for colposcopy referral acceptance overdue – urgent follow up required to confirm if sample taker yet to send referral, clinic is yet to accept referral, or clinic has accepted but has yet to send acceptance to Register.
    - 255 tasks were for under specialist care, colposcopy visit overdue - urgent follow up required to confirm if participant is yet to attend a visit / be discharged by the clinic or a visit/discharge has occurred, but clinic has yet to send confirmation to Register

See figure 14 in appendix four for more details of these tasks.

Follow up task enhancements

A series of Register enhancements were developed and implemented on 26 November 2024 to help with the resolution of follow up tasks, including:

- Adding identifiers to tasks to specify if a colposcopy referral or colposcopy visit is overdue.
- Automatic closure of a task if the required clinical event is subsequently received (previously this had to be done manually)
- Preventing creation of duplicate tasks for the same issue
- Where the next expected event is a colposcopy referral or visit, automatically raising an overdue task if a correction to a test result or clinical event means the date of the next expected event has already passed.

At the time of the review, additional 'enhancements' were being tested, including:

- setting the priority of colposcopy referral tasks,
- changing the timing of when tasks are created, and

- changes to the rules/timing for setting the value of the expected date for a colposcopy referral.

These were subsequently reported to have been implemented.

Discharge to referrer messages

A discharge to referrer message is sent by a colposcopy clinic to the Register when:

- the participant has completed their colposcopy care, or
- the colposcopy appointment is not attended, and the clinic is discharging them back to the screen taker.

The discharge to referrer message usually contains both the follow-up test type and the follow-up timeframe. There are several scenarios in which the Register creates a task because of the discharge to referrer message (detailed is provided in appendix seven):

- Follow-up timeframe mismatch
- Follow-up test type not populated
- Discharge review if the follow-up test type is 'No Further Screening Required'
- Discharge without visit

Prior to go-live, there were discharge messages that did not have some data fields populated (e.g. follow-up test type). This was because, at the time, those fields were not part of the data specification. Post go-live, Solutions Plus[44] introduced a fix allowing clinics to select the correct follow-up type, which set the correct pathway. However, if clinics do not update correctly those pre-go-live discharge messages that are sent to the register will still have these fields missing.

Numbers of discharge to referrer messages as of 31 January 2025

As of 31 January 2025, 10,257 colposcopy tasks had been created of which all but 91 were discharge message tasks (see figure 15 in appendix four for complete figures). Of these:

- 6,726 had been completed
- 380 were in progress
- 3,151 had not been started

Of those tasks that had not yet been completed:

- 1,759 were clinical events with effective date **before** 1 July 2023
- 1,772 were clinical events with effective date **after** 1 July 2023

Clinical guidance is outstanding for the backlog of tasks where colposcopy messages have an effective date before 1 July 2023. The NCSP has noted that, with further guidance, it may be possible to bulk close some of these tasks.

Active follow up is said to be occurring for those tasks related to clinical events with an effective date after 1 July 2023.

A further review of colposcopy referrals is also underway. Part of this will include reviewing what the Register needs to capture for scenarios where a participant has: refused a colposcopy referral; does not attend their appointments; or cannot be contacted, and

[44] Solutions Plus is a software company in Auckland that provides Gynaecology Plus.

whether onwards referral to Support to Screening services is appropriate, and what the participant's screening tracking should be updated to for the various scenarios.

During interviews, the review panel heard that the RCT runs monthly reports to look for incorrect discharges. It was commented that sometimes participants are accepted by the Register but the pathway they are put on, e.g., five-year screening, is not correct. It was stated that colposcopy pathways are determined by the colposcopist and although the Register does some basic validation of the discharge message, to ensure it fits within standard parameters, in general it accepted what the colposcopist has noted in the discharge message.

Interviewee comments on discharge to referrer messages

For the RCT, the highest risk group was said to be the participants who are discharged without having been seen in a colposcopy clinic. For this group, it was said that the Register blanks their next expected event and pathway status. The Register calculates if a task is overdue based on the next expected event, which it was said makes this a risky situation. It was further noted that a blank pathway status would mean the screen taker may be unsure what next steps were required.

The review panel was informed that the RCT runs a report to look for 'discharge without visit' tasks that is checked twice a week. It was said there can be 50-100 of these tasks each week. If another clinical event or result has since come through, then the pathway is updated accordingly, this was said to be very few of the tasks. If not, which is most of the tasks, the task is assigned to the Regional Team to learn why the patient did not attend colposcopy. Once discovered, the task should be sent through to the RCT Clinical Leads to review the screening history and update the pathway.

It was noted that, at present, the time taken between the task being assigned to the Regional Team and it then being passed to the RCT Clinical Leads can vary. The average was reported to be 89 days, but it can be up to 262 days (five people). As of 24 January, there were 336 people with blank pathways. The time being taken to resolve these tasks was said to be of concern.

The RCT was also said to check for discharge messages that don't look correct, such as those discharged to five-year recall when they need a test of cure. It was noted that there was a risk that the participant won't be recalled by the Register for years but that there was no specific mechanism to pick up this type of error. It was commented that this sort of issue needs monitoring but also education for the colposcopy clinics, like the lab training funded by the NCSP.

It was commented there has been a lack of input from colposcopy clinics about what could have been improved from the old register, including discharge to referrer messages. Previously, the clinics would call or fax referrers to tell them when a patient had elected to be seen privately. It was commented that, had there been more consultation, the clinics would have advised designing the Register to provide enough information about the discharge, e.g. no visit because patient has gone private, moved overseas, etc. This was described as a missed opportunity, particularly given the reason for discharge is a mandatory field in Gynaecology Plus, so the information exists but it just not passed on to the Register. As the Register is not providing this information, clinics spend a lot of time going through spreadsheets to fix information that is not correct.

From a primary care perspective, it was noted that a discharge letter should be sent by the colposcopy clinic but until this was received the screen taker may not be aware if the individual is going to be seen. It was noted that it needed someone that the participant

knows and trusts to have a conversation about why they didn't go to their colposcopy clinic appointment, but that those conversations probably were not happening.

Discharge to referrer enhancements

There is a planned Register enhancement, to make the follow-up test type mandatory. This would, however, result in a message that the clinics would need to manage and resolve. There would be no visibility in the Register of this message, and there is concern that these messages would be missed by the clinics and the participant would be in a position where neither the clinic nor the Register is managing their screening.

Another planned register change would add discharge reason information to the discharge to referrer message. This will provide more context as to why a participant has been discharged and should enable the RCT to update the participant's records in the Register more quickly without needing to contact the colposcopy clinic or search in hospital records for clarification. It has been noted that, "This also requires a change to the HL7 spec and a change to GynaePlus".

Findings

- In the old cervical screening programme, individuals were invited through primary care, which limited the programme's reach but there was clear clinical responsibility for following-up participants who tested positive. The previous register was stated to provide a 'back-up' clinical safety net to primary care. The switch to an opt-out approach to screening that seeks to invite more participants not enrolled in primary care should expand the programme's reach, but there is greater risk of a lack of timely follow-up for unenrolled participants. In the context of the new programme, the Register's intended functionality to identify where follow-up has not occurred and initiate action to address this by creating tasks, is a critical safety process. This is particularly significant given that colposcopy waiting times currently far exceed recommended timeframes, due to high demand and low capacity.
- The Register's clinical follow up tasks create a lot of work to chase up overdue referrals, visits, etc. These tasks are an important safety measure, but this has been affected by their design and usability. The tasks have improved since go-live through better labelling, allowing for easier prioritisation.
- Some tasks may be redundant as they are based on out-of-date information, due to issues with the Register rejecting messages from older versions of Gynaecology Plus. Solving this issue, by upgrading to the latest version of Gynaecology Plus, may help to remove redundant tasks and so reduce the workload of those following up tasks, allowing them to focus on more urgent tasks.
- The panel did not see a breakdown of outstanding tasks, including those awaiting colposcopy, by participant demographics including ethnicity and other priority population groups for screening. If this analysis is not being undertaken, the NCSP is not able to understand who is most affected by outstanding tasks.
- One of the categories of tasks that the review panel identified as being of concern was for participants discharged without a colposcopy visit. This is a high-risk scenario and so was identified as requiring urgent attention in the February 2025 memo to the NPHS, which stated,

  "The review panel is concerned about the level of risk associated with individuals who are discharged without a visit. As of 31 January 2025, there were 226 of these tasks in progress and 431 that had not been started.

Tasks are created for all messages of this type, including for patients who have not been able to be contacted, have declined to be seen, or have chosen to be seen in private practice. Resolving these tasks is made more difficult by the fact that the reason for no visit is not visible to those following them up, making it difficult to prioritise. Delays in resolving these tasks carry clinical risk as the individual has been referred to colposcopy but not seen. While awaiting review, participants' tracking is not automatically updated and must be manually updated to recommence screening."

- The memo stated the review panel was particularly concerned about the time being taken to complete these reviews, due to the limited capacity of the individuals undertaking them, and the impact of delays on individuals at higher risk due to their clinical history. The review panel recommended the NPHS, "Increase staffing resources allocated to individual case reviews, to expedite their resolution."
- The memo to the NPHS also highlighted that:

  "During interviews, the review panel heard that there may still be gaps and overlaps in pathway safety nets and so there was a need to carry out work to check if failsafe reporting was adequate. It was reported that a pathway safety status workstream is soon to be commenced by the NCSP's clinical, quality, and programme teams and aims to fulfil this requirement.

  The review panel considers that this work is essential and should be prioritised to ensure that cervical screening participants are safe while remaining Register issues are resolved. It advises that this workstream should be prioritised and supplemented with additional resources to ensure it can be completed as quickly as possible."

- The review panel did not see documentation that explained what specific issues had caused participants, identified by the 'Register quality check' scenarios, to have 'fallen' through the Register's safety nets, both manual and automated.
- The Register's ability to initiate action and coordinate between services to progress participants through the screening pathway, from detection of an HPV positive result is not working as envisaged by the draft Te Tiriti o Waitangi and equity strategy. This includes the lack of Support to Screening Service tasks and the associated capacity issues with these services not in place in some areas. This is problematic given the success of the programme in decreasing rates of cervical cancer depends on successful follow up of abnormal results with LBC/cytology and/or colposcopy.
- The review panel did not see evidence of any other clinical quality or safety issues that are not currently known to the NCSP. It remains possible, however, that there could be undetected issues caused by technical deficiencies due to the lack of key controls such as robust failsafe reporting. It is therefore possible that the processes developed through the 'pathway safety net' project may detect more issues.

See recommendations 2, 6, 10, 11, 13, 14, 15, 19, 23, 35-37, and 41, which address these issues.

4.6 Data field configuration and completion

The review panel heard that the process for migrating data from the previous register had been good, with the ICT vendor said to have run a "tight ship". It was, however, reported that the quality of the data in the old register wasn't as good as was previously thought, with lots of NHI mismatches. It was said that this generated a lot of work and that overall, what was required for the data migration could have been quantified better.

One issue with data migration that was raised was that some participants couldn't easily be mapped across and so the wrong pathway status was purposefully selected, to match them to a pathway with the correct timeframe. It was described that this had led to screen takers calling to ask why the individual had the wrong pathway status recorded. This was 'remedied' by blanking this information in the Register while retaining them in the same pathway.

With the go-live date unable to be delayed further, some data migration had to be deferred beyond go-live. Data remediation began following launch, and it was commented during interviews that it was prioritised based on need as well as feasibility of carrying out in bulk. Interviewees commented data remediation had made significant progress since launch but acknowledged that there was still work to be done and that data remediation issues still affect the functionality of the Register.

Outstanding data migration reviews

At go-live, there were several categories of individuals for whom data migration could not be completed, requiring remediation or review. A number of these issues have since been addressed (see appendix eight), but there are still three main categories where work is ongoing (see figure 16 in appendix 4 for a table of figures).

Cancer

This relates to participants identified as currently or previously having cervical and/or vaginal cancer. As of 31 January 2025, there were 869 cancer cases awaiting review by the NCSP clinical team, down from a figure of 3,353 in January 2024. Resolving these cases was said to currently involve accessing the NZ Cancer Registry reports although it was noted the NCSP was exploring access to Clinical Portals to allow for the results to be looked up directly. It was also noted that, to check the accuracy of the coding to stop this situation arising in the future, the screening laboratories would need to send the full text histories to the Register.

On the new clinical pathway participants recovered from cancer could return to routine screening. The NCSP rated this as being of 'medium' clinical risk and it is noted that risk exists mainly in cases of superficially invasive cancers, where Test of Cure and continued screening is recommended. If not correctly categorised, these individuals may be incorrectly unenrolled when they should in fact be screened.

During the interviews it was commented that, from a laboratory perspective, there had been no clear guidance on what to do in case of individuals with a history of cancer until about eight or ten months after launch. It was said that, for these individuals, the laboratories had been asked to go back and change recommendations retrospectively. This was said to have not been possible for some, as their laboratory information systems would not allow for a code that did not exist at that time to be entered retrospectively.

HPV research studies

This relates to participants flagged as being in at least one HPV study and requiring review to ensure their clinical pathway information is correct. These participants require review to be integrated into the cervical screening programme.

As of 31 January 2025, there were 1,066 such cases awaiting review by the NCSP clinical team, down from a figure of 7,722 in January 2024.

The NCSP rated this as being of 'low' clinical risk. It noted that there are participants from two remaining studies where their pathway status and next expected event need to be

updated. Until this is done, notifications and tracking are switched off but the most urgent next steps (e.g. referral to colposcopy) should have been actioned by the research team.

Hysterectomy

Participants who have undergone a total hysterectomy need to have their case reviewed to assess if a further HPV test is required before they stop screening. As a placeholder, this group was migrated to a temporary pathway status of three year or five-year recall while review takes place, with notifications and tracking switched off.

As of 31 January 2025, there were 1,600 such cases awaiting review by the NCSP clinical team. This number was down from a figure of 2,721 in January 2024. It was noted that a manual review is required of each case, and there is no opportunity for bulk remediation

The NCSP rated this as being of 'low' clinical risk, noting that the clinical risk is a delay in the final HPV test. During interviews, it was noted there were still issues with the quality of information recorded about hysterectomies despite work carried out to improve it.

Screening for immune compromised participants

The clinical practice guidelines (34), published in June 2023, describe the approach to be taken for immune compromised participants, including three-yearly repeat screening where HPV is not detected, rather than a five-year interval.

During interviews, it was commented that definitions of immunosuppression were 'woolly' at go-live and as a result a lot of people were flagged by screen takers when they shouldn't have been. It was commented that sample takers are understandably cautious, and that educational material has been sent to the primary care sector to improve understanding of definitions. It was noted that laboratories double-check the available clinical information to ensure the correct recommendation is made and that this issue has improved over time.

Findings

- Data migration was not completed prior to go-live. Several cohorts of participants with a more complex history migrated from the old register were not able to be automatically integrated into the screening pathways and needed review. While a lot of progress has been made on these reviews, there are still some that have yet to be resolved.
- The review panel highlighted the need to urgently address these outstanding reviews in its February 2025 memo to the NPHS. It was highlighted that these unresolved cases are clinically risky, and that resolution should be expedited through increasing capacity.
- Given that it was known prior to go-live that manual review of participants on more complex pathways was needed, extra resources should have been brought in, to review these cases before or shortly after the launch of the Register.
- Resolution of these outstanding data migration cases is also important due to the potential for there to be an interaction with other issues. For example, if data remediation is required to ensure the Register holds up to date information about cancer history, this could cause a lab recommendation mismatch.
- Regarding the data remediation for participants in HPV research studies, the review panel understands that positive results are being considered when reviewing these cases and determining participant pathway. The test results, however, are not being recorded and displayed in the Register and negative results are not considered in

mapping participant pathways. These participants with negative results from tests that had not been validated at the time would therefore be re-screened. The review panel was concerned that these individuals are subject to the risks associated with over screening and their confidence in the study they have participated in and the NCSP may be undermined.

- There may be an issue of understanding amongst screen takers around definitions of 'immunosuppressed', which is leading to over-identification of participants. This is problematic as it has the potential to contribute to laboratory recommendation mismatches. Clarity and communication of definitions and education of screen takers, including in primary care, are likely to be needed to address this.

See recommendations 28, 35, and 41, which address these issues.

4.7 End-user accessibility

Different groups of users access Register information in different ways. The Register Central Team and Regional Coordinators have direct access to the Register. Laboratories, Support to Screening services, and colposcopy clinics do not have direct access to the Register but instead are able to access screening information through Whaihua[45].

Laboratories

The review panel was told that the day-to-day laboratory user experience of Whaihua was an improvement on the old register in terms of the speed of loading results. It was commented, however, that the design of information flows could have been better. It was said that there had been an expectation from some users that they would be told what the Register considered to be the correct recommendation, with the option to override in exceptional circumstances. It was said that there is very little choice of what the correct recommendation is and therefore lab staff had, "a job of finding the right recommendation and it's pass/fail". It was also commented that the logic could have been built with a statement of why there is a mismatch. Or better, still the feedback about a mismatch could be in real time.

Managing mismatch tasks has become a burden for the laboratories, particularly because it is not always clear why a task has been created and what is needed. It was estimated that, in the old register, a laboratory may have someone spending two to three hours a week on tasks, but that it now takes up 15 to 16 hours a week.

It was also commented that the laboratories sometimes found participants with an incorrect pathway status, and that this was time consuming to raise and remedy. The Review panel heard this included higher risk situations including laboratories noticing people who were meant to be on annual screening recall whose pathway status said five-year recall.

Regarding why mismatches were occurring, it was commented that it has taken time for laboratory staff to understand the clinical pathways in the new programme. It was also said that laboratory systems did not always hold a complete clinical history, such as if a biopsy had been performed. The review panel also heard that at times, Whaihua lacked information such as hysterectomy details, and therefore the lab was acting on more complete information to make the correct recommendation, but a mismatch task was raised

[45] Whaihua is a digital interface, launched in December 2023, that allows health providers to view information held in Health New Zealand registers.

erroneously. That was said to be a source of lots of tasks early on, with delays in getting information into the Register.

It was said that there have been a lot of older recommendations that needed correction and that it took a long time for the RCT to get them to the labs. There have been examples of amendments to recommendations after up to 12 months. It was said this could be embarrassing for the laboratory and that there have been calls from clinicians asking why the change has occurred and why so late after the test result. Over time, this has improved, and it was said that mismatches were now mostly being fixed within a week of occurring.

Colposcopy clinics

The review panel heard colposcopy clinics had experienced difficulties in getting access to Whaihua for clinicians, so screening histories could be viewed. There was said to be a lot of barriers and in particular excessive training requirements, including clinicians being asked to do privacy training courses before being granted access, despite already having done a similar course. There were said to be examples of specialist gynaecologists being asked to do online HPV training.

It was noted clinics had seen a trend of laboratories making incorrect recommendations for referral to colposcopy clinic due to not having access to complete clinical information, which would inform them a referral should not be made. It was said that where this occurred, and the sample taker then made a referral to colposcopy as recommended by the laboratory, the clinic would then need to spend time working out why the recommendation had been made. More time was then needed to inform sample takers of correct clinical guidelines, i.e., that colposcopy referral wasn't necessary.

Due to the way that the Register implemented the clinical guidelines, it was said there was no flexibility of interpretation, allowing for the use of clinical judgment where there was a sound clinical rationale. An example given was of colposcopy clinics wanting to take the opportunity to screen someone opportunistically, such as a family member accompanying their whānau attending a colposcopy clinic appointment. The concern raised was that a screen outside of the prescribed interval may not been interpreted by the Register as fulfilling re-screening requirements and so a further invitation for screening could occur.

Another issue raised was the workload from messages from Gynaecology Plus being rejected. For example, it was said that, if a full stop was not put at the end of the episode, it would not be accepted. This issue was said to have created a lot of work for clinics as these rejected messages must be corrected and resubmitted, e.g. by adding full stops.

Overall, it was said the workload of administrative issues had increased significantly. The review panel heard of monthly issue lists being sent to clinics, with 60-160 issues each month, along with additional weekly lists with 10-30 more items. These lists included missing clinical information, follow-up mismatches and other issues to be resolved. Clinics were said to have had to move resources around to create enough capacity to manage these error reports. The clinics were said to be expected to send a response to monthly task lists within two weeks, which was described as challenging given the workload.

Register Central Team

The RCT works to ensure information in the Register is correct. It works with laboratories to resolve recommendation mismatch tasks, with colposcopy clinics to ensure results are complete and correct and enters information from manual colposcopy forms. The RCT also

withdraws participants and responds to requests for screening histories from providers who do not have access, such as primary care providers for whom direct access to screening histories is still being developed.

It was said the move to a population-based register created new issues, including engaging with people who do not need to be contacted, such as people who have moved overseas, and that this was a ‘time drain’.

It was noted that there had initially been large numbers of laboratory recommendation mismatches but that numbers had reduced as the laboratories have become more familiar with the new guidelines. The review panel heard that now, more of the RCT’s work was with the colposcopy clinics, chasing up visit information and referrals. This was said to be time consuming and that responses sometimes took several months.

The complexity of the HPV screening programme was said to have brought a high level of complexity to the work of the RCT. It was said that its team was having to make borderline clinical decisions when reviewing tasks, which required working closely with the NCSP clinical team. It was noted that the RCT needed more nursing resources, particularly in the context of an experienced member of the team leaving soon.

It was said that there were limitations to what the RCT could do to make changes, given the complexity of the tools the Register was built with, and that lots of issues had to be handed on to the ICT vendor to resolve.

Regional Coordinators

Regional Coordinators teams are located across the country, divided into 13 teams. They are a key part of the Register’s manual safety net, following up screening programme participants living in the region each team serves.

They receive Register tasks to follow up on participants with abnormal screening results who have not progressed to the next stage of the screening pathway as expected, based on the data the Register holds for the individual. This includes following up:

- sample takers to make a referral for colposcopy,
- colposcopy clinics to ensure colposcopy appointments are booked and visit details recorded,
- individuals who have missed their colposcopy appointment, including sourcing participant contact details and referring participants to Support to Screening Services, where required.

They are also a local point of contact for screening providers in their region. The Register Central Team and Regional Coordinators communicate closely together, for example, The Register Central Team refers on follow up tasks identified from their operational reporting for Regional Coordinators to follow up.

It was said there is a lot more work for Regional Coordinators now, compared to the previous programme, with many Register tasks being generated, but that Regional Coordinator resources had not increased and that this led to delays. It was commented that, by the time the Regional Coordinators get round to addressing a task, the overdue event may have taken place, making the task redundant. These redundant tasks were said to take away from other, more urgent tasks.

The review panel heard that the connection between the Register and Gynaecology Plus had created issues (see the section 4.3). It was also noted that chasing some private clinics (those who do not use Gynaecology Plus) to complete paper-based colposcopy forms, which need to be filled at each colposcopy visit, was another source of work, as it had been prior to the introduction of the Register.

Previously, some Regional Coordinators were said to have had access to Gynaecology Plus and so could lighten the load of colposcopy clinics in resolving some tasks. Now, these tasks were being referred on to the RCT, and the process was described as very time consuming. It was stated that this change had been made to meet privacy requirements.

Regional Coordinators were said to have observed colposcopy nurse administrative burden had impacted their workflow. It was said nurses can't always upload the information to the Register in a timely fashion, such as a colposcopy appointment having taken place. New Regional Coordinator follow-up tasks are created when the Register believes a colposcopy clinic appointment is overdue and so delays in recording these creates more work for the Regional Coordinators. This issue was stated to be getting worse rather than better.

Regional Coordinators cannot record in the Register when a participant is referred to Support to Screening Services nor send information via the Register to these Services. One region was said to receive electronic referrals from GPs but then had to use manual spreadsheets to work with the Support to Screening Services. This situation is likely exacerbating colposcopy waiting times.

Support to Screening services

Support to Screening services are local teams of clinical and non-clinical staff, who follow up people who face barriers to getting a screening test. At times they are asked to assist people who have been screened whose test shows they need further assessment or treatment[46]. They receive referrals from health professionals, e.g., from General Practices.

Those eligible for Support to Screening are individuals:

- aged 30-69 who have not had a screen in the last five years,
- aged 30-69 who have never had a cervical screen (unscreened)
- who identify as Māori or Pacific.

Staff from some Support to Screening services make visits in the community and home visits to provide screening tests and follow up while others are based in a clinic. The teams are spread across many parts of the country and serve people who live in their local regions. The review panel heard that some regions lacked Support to Screening services and that there was a lack of available funding to address this. The review panel saw NCSP documentation dated August 2024 (35) that stated there were no Support to Screening services in the following Districts: Taranaki, Whanganui, Nelson Marlborough, and Te Tai o Poutini West Coast. The Support to Screening services that are in place were described as having short-term contracts with a lack of certainty about renewals.

Support to Screening services do not have direct access to the Register but instead are able to access screening information through Whaihua. This was said to contrast with the previous programme, in which they had direct access to the old register. It was also said to have been difficult for some Support to Screening service staff to get access to Whaihua and

[46] Screening Support Services also support people to access the breast screening programme.

that this had at times taken months, whereas in the old programme Support to Screening service managers had administrator rights to set up new Register users.

Interviewees commented that their access to information through Whaihua was limited, and less than the level of information that was accessible to them in the old register. Information missing was said to include the details of the screen taker and screening location (e.g. a screening event day or primary care) as well as some clinical information such as if the patient had had a hysterectomy.

It was noted this lack of additional clinical details could cause issues. For example, it was commented that a Support to Screening service might call someone who appeared overdue for HPV screening, to then be informed by the participant they had had a total hysterectomy. It was said this could be an unnecessary and distressing conversation for the participant.

It was noted that Support to Screening service staff had 'read-only access' to information, through Whaihua, and that they could not edit information. The review panel was told that it was not yet possible for Whaihua to give 'write access' so that information could be edited and that these changes would be sent back to the Register, but that this was a 'desired future state'.

Another key piece of Register functionality for Support to Screening services was said to be the ability to receive referrals electronically. This functionality was said to have been anticipated but not yet delivered with no indication of when or if it would be. Instead, there is a continued reliance on 'manual' referrals of lists of unscreened patients by GPs and PHOs. These do not therefore include referrals of patients not enrolled in primary care, which was described as worrying. Several interviewees commented that individuals not enrolled in primary care who were unscreened or under-screened were the people that Support to Screening services were hoping to reach and that they wanted access to this data so they could try to reach these people and support them into screening.

Priority ethnicity (Māori and Pacific) participants may be referred to a colposcopy clinic by a Support to Screening service. Similarly, a participant who misses a colposcopy clinic appointment may be referred by the clinic to Support to Screening services, where these are available. It was noted that there can easily be breakdown in communication, and lack of shared visibility of a participant's status in the screening pathway was said to be an issue. One example given was when a Support to Screening service refers to colposcopy, no response is received confirming the referral is accepted.

Findings

- End users described their experience, reflecting that the number of, and processes for managing Register tasks is laborious and time consuming, which leads to delays to these tasks being resolved. This can lead to more urgent tasks not being acted on urgently enough, which is a safety risk. Changes to historic recommendations may also undermine confidence in the programme of clinicians and participants.
- The large number of Register tasks also create inefficiencies as older tasks may no longer be relevant by the time they can be addressed, leading to wasted effort. A process to find and automatically close these would help to reduce the workload of those managing tasks and allow them to focus on unresolved tasks.
- Systematic solutions, such as improving laboratory system integration with the Register and ensuring all hospitals are provided with the latest version of Gynaecology Plus, that prevent the need for tasks to be raised, would provide the most benefit to all Register users.

- The process for granting colposcopy clinic Whaihua access is overly restrictive, delaying or preventing clinician access to screening histories.
- This decision for some user groups to have access to information through Whaihua, rather than the Register itself, has created problems for some users being able to access and edit information, such as participant's preferred contact details, as required to fulfil their roles effectively.
- The notification strategy states that reaching individuals not enrolled in primary care was a high priority and that Support to Screening services, and the associated Register referral tasks, would assist with this. The implementation of the Register, without the capability for electronic referrals to be made to Support to Screening, and with referral tasks disabled, means that Support to Screening services continue to rely on their old processes for identifying individuals to follow up. This largely involves working from PHO reports of individuals overdue for screening, and therefore those high priority unenrolled individuals continue to not be as well served by the new screening programme, Support to Screening, and the Register.
- Support to Screening services are not available in all districts and the continuity of the ongoing provision of existing services is unclear. This means that the Support to Screening service Register tasks system has not been able to be utilised as originally intended and so the new Register has not had the impact on improving equity that was envisaged.
- Laboratories should easily and quickly be able to notify the Register of a participant with a seemingly incorrect pathway status. This reporting should then feed into an event management process, with root cause analysis to determine why the pathway status is incorrect.

See recommendations 6, 7, 13, 20, 23, 25, 36, 39, and 41, which address these issues.

5. Monitoring and reporting

5.1 Operational reporting

Operational reporting, focused on the day-to-day activity of the Register, is done by the RCT. The NCSP Service Delivery Manager, Digital Services, and the ICT vendor also undertake Register operational reporting The review panel was told the launch reporting requirement was a like for like replacement of reporting available in the old register, including all high-risk test results in the last 30 days, adapted for the new HPV programme.

There were differing viewpoints on the Register's ability to provide relevant operational reporting. One stated view was that the new Register provides more flexibility for the Register Central Team to create any report they want. However, the review panel also heard there were limitations in how data could be linked within the Register, to be able to create meaningful operational reports. It was commented there had not been a good process for bringing together technical and operational perspectives to ensure the RCT got information in the format they needed.

The review panel was provided with a list of 'Monitoring and Actioning Reports' (36) run by the RCT. These reports were divided into three 'reporting type' categories; 'correspondence', 'full register monitoring', and 'H-code flows'.

The review panel heard from interviewees that, during implementation, decisions were made to not migrate every test result and clinical event from the old register into the new register directly. It was said that in practice this meant there was not a complete history in the Register for most participants with only the most recent screening episode visible and the accompanying prior recommendation. Therefore, a report run directly from the Register wouldn't include everything. It was also commented that this decision has not been well communicated. As a result, it was said the Register's reporting capability does not fully meet the RCT's requirements, even though it had been intended that all operational reports would be run from the Register.

Although not in the Register, the review panel was told that every test result from the previous register had been migrated to the screening history data warehouse. Some reports were being run for the RCT from the data warehouse to fully meet operational requirements. This reporting was said to include:

- All operational reports requiring information on unscreened and/or under-screened participants (see section 4.2).
- Fortnightly PHO cervical screening status report cannot be run from the Register, as it can't derive new variables or reformat such that the report layout is suitable, and it can't easily disseminate the reports to the different PHOs.
- Monthly 42-month lookback lab retrospective reviews report for high grade histology with non-correlating cytology for cytology labs. The Register can't produce this as most test results are only in the data warehouse.
- The screening intelligence team is also supporting data quality analysis work using the data warehouse. Where the register hasn't put participants onto the correct pathway, such as due to a lack of access to key clinical information, and no tasks have been raised, the RCT must investigate and then manually raise tasks. Analysis by the screening intelligence team is used to find these participants.

It was also noted that neither the Register nor the data warehouse can provide complete Support to Screening follow up lists. Reasons for this include the following:

- Information on which participants have been referred to Support to Screening is not held in Whaihua, the Register, or the data warehouse.
- It is not possible to use 'HPI ID' to identify if the requesting facility/health worker was a Support to Screening service as HPI IDs are used by facilities both when the test was done under Support to Screening and when it wasn't. Some requesting facility/health worker data is in the Register, but most is only in the data warehouse.

The review panel heard the NCSP clinical team does not see operational reporting and so did not have oversight of the number of notifications going out and if they were higher or lower than expected. It was noted numbers of notifications were monitored by the RCT but not measured against anything. Absolute numbers are reported rather than what proportion of notifications, of the numbers expected/modelled, have been sent.

5.2 Programme performance reporting

The review panel heard the data warehouse is the preferred source for programme performance reporting.

The review panel asked about the production of a publicly accessible cervical screening monitoring report. It was stated this was not yet available as quality indicators were still being built following consultation including with the Māori Monitoring and Equity Group. External peer review of the indicators being built was said to have been carried out by the Cancer Council of New South Wales.

A copy of a document titled 'Programme monitoring overview' (37) was shared with the review panel in January 2025. This included a list of 35 proposed indicators, of which 15 were said to be 'in place' or 'ongoing'. 12 others were labelled as being planned for 2025 while the other eight were described as requiring further consideration or discussion.

Regarding a formal programme performance monitoring report, it was stated the original plan had been for this to be produced by an external monitoring group but there had been delays to procuring these services and the first monitoring report would now be done internally. It was stated a first monitoring report was being targeted for the first half of 2025, including the indicators that had been built to date. In the meantime, the data from the built indicators was being presented at a monthly internal meeting.

The review panel was told the delay to produce a programme performance monitoring report was not due to the quality of data in the data warehouse, but rather a lack of resources. It was noted some resources were lost in 2024, and the future structure of the screening team within the Intelligence directorate was uncertain, including personnel key to the cervical screening indicators and quality report.

The review panel heard the Register did not identify explicitly whether HPV and LBC test results were for a primary screen or a follow up test (see section 4.5) It was said that this information is critical to understand to ensure appropriate use in reporting. This issue was said to have impacted on programme monitoring by leading to an overcount of primary screen volumes and the incorrect inclusion of some test results in other indicators, e.g., HPV primary screen results.

5.3 Quality monitoring

Labs

It was noted that there was a system in place for monitoring the quality of messaging from laboratory systems, but that an incident in October 2024 had raised the question of whether monitoring was sufficient. The incident involved one lab, for which there were missing histology results for the period 16 July to 27 October 2024 (and possibly missing messages dating back to launch). The lab advised it had not been monitoring messages that are not acknowledged by, and so not entered into, the Register. It had not therefore been resending histology test results and ensuring an acknowledgement was received.

It was found reporting was no longer being completed on data analysis that potentially would have alerted the NCSP to this issue sooner. A report for messages that were rejected and have been corrected and resent was developed. It was subsequently found a second lab had an expired certificate, impacting its results from 20 August 2024 onwards, and this was still ongoing.

Screen taker

The review panel was informed that reporting on screen takers is available on request from the RCT having been implemented at go live as it is a quality standard. It was noted, however, that the NCSP does not hold a complete list of all accredited screen-takers and so it was not possible to ensure reporting was comprehensive.

Colposcopist

The review panel heard colposcopy quality reporting at a clinic level was not yet possible. Clinical event messages are associated with a colposcopy clinic using the HPI facility ID. It was said some colposcopy clinics have not been using the same HPI facility ID consistently, so clinical events weren't associated correctly at the clinic level. Work was said to be underway to address this issue, beginning with the public colposcopy clinics.

In addition, the NCSP does not hold a definitive list of all colposcopy clinics (public and private) and their HPI Facility ID. It is not therefore possible to compare the list against the clinical event messages in the Register to determine which messages are coming from facility IDs not on that list. The RCT provided a list, which is the best available, but it is not confirmed as correct and many IDs for individual colposcopists at private clinics are known to be missing.

The review panel was informed that Gynaecology Plus was also capable of monitoring, auditing, and reporting. It was stated that, of all the colposcopy data entered by clinicians into Gynaecology Plus, currently only about 10% goes to the Register. The rest of the data is therefore available for reporting within Gynaecology Plus but not the Register. It was said most of the colposcopy standards[47] could be fully reported from within Gynaecology Plus.

It was said that Gynaecology Plus had previously been used to produce six-monthly audit reports, but this has since stopped, with funding said to be needed to continue this. As a

[47] See interim NCSP Policies and Standards Section 6: Providing a Colposcopy Service, Part A: Colposcopy Standards: https://www.tewhatuora.govt.nz/assets/Policies-and-Standards/two_4959_ncsp_pands_s6_colposcopyservice_interim_v1.0.pdf

result, the NCSP had lost visibility of volumes of referrals. Interviewees commented that the NCSP and Solutions Plus should work together to avoid duplication and ensure reporting efforts complemented each other.

Findings

- Details of operational reporting done by the RCT appeared to cover the kinds of scenarios where follow-up action by the RCT would be expected, albeit the review panel could not conduct a comprehensive assessment. Given, however, the Register does not have comprehensive screening history information, this reporting lacks the ability to determine which individuals have significant screening histories. This is concerning as it undermines the RCT's ability to identify individuals at higher risk due to their screening history, who are overdue for screening, referral, follow-up testing, etc.
- Additional operational reporting undertaken using the data warehouse, which has complete screening data, provides a backstop but this is not as efficient or flexible as it would be if able to be done within the Register.
- The review panel has not seen operational reporting of notification completion rates. If this reporting is not already in place, the review panel considers that it should be and that it should include assessing whether a disproportionate impact of unsent notifications falls on particularly cohorts of eligible individuals. It would draw attention to where there may be unresolved technical issues which can be analysed to find the underlying root cause(s).
- It appears information from operational reporting is not shared across the NCSP clinical team. While it may not be necessary for the whole clinical team to have access to individual operational reports, summary information would help inform decision making and ensure there is opportunity to identify issues with clinical significance as they arise.
- Some progress has been made in developing quality indicators, but these are not yet complete and as a result, no monitoring report has yet been produced. A partial, interim, and internally produced monitoring report is planned for 2025. In future, an externally produced monitoring report would provide a more robust, peer review of the programme, but there is still a lot more work to do reach the point where a comprehensive, independent monitoring report can be produced. Concerningly, screening intelligence resources have been lost, and it appears resourcing may yet decrease further.
- The review panel was not given confidence that quality reporting for laboratory messaging was effective, considering incidents detected in October 2024, which may have been ongoing since launch.
- Screen taker, and colposcopy clinic quality monitoring is also not yet in place, with a lack of comprehensive HPI information being a key limiting factor. This is another important piece of programme quality assurance that should be developed.

See recommendations 1, 12, 18, 29 and 30, which address these issues.

6. Adaptability to future requirements

6.1 Register adaptability

The review panel heard there was an agreed level of functionality planned to be introduced following launch and that further changes had continued ever since. It was said there had been nine major releases and eight ‘hot fixes’ since go-live, with ‘about 40’ tickets remaining in the back log.

A copy of a document titled ‘CSR Jira Backlog 07.03.25’ (38) was provided to the review panel. This contained ninety items, of which 39 had been given a priority of ‘low’ or ‘lowest’, 46 ‘medium’ and five ‘high’ or ‘highest’. 52 of the issues had a status of ‘backlog’, while the other 38 had a status of ‘open’, ‘in progress’, etc. Of the five issues with a priority of ‘high’ or ‘highest’ four were in the backlog and one was ‘in development’ which was, ‘Modify 'Overdue Next Expected Event' list views’, which was raised on 20 September 2024.

Interviewees had differing opinions about how ‘flexible’ the Register was to make changes. Some stated that they believed that the Register was inherently flexible. It was also suggested using Salesforce (the IT platform chosen to build the Register) meant it should have been possible to build a flexible register, but the approach used to build the rules for clinical pathways flexibility had been designed out.

It was stated changes could be made, but it would be difficult and therefore expensive. It was suggested it could sometimes be easier, or cheaper, to find solutions outside of the Register. It was said that there needed to be investment to finish the job of building the Register, but funding was uncertain amidst ongoing Health NZ restructuring, including in relation to the Digital Services team.

It was commented during interviews the NCSP would have benefited from a ‘solution architect’ (i.e., someone who designs and oversees the implementation of technical solutions to ensure they meet business needs) during development and implementation of the Register, and that this resource would be helpful now to develop requirements for future changes. It was also said the NCSP would benefit from having a fulltime Business Analyst to help communicate requirements to the Digital Services team and therefore to the IT vendor.

6.2 Clinical guideline changes

Interviewees commented about the need for the Register to adapt to future changes to clinical guidelines for HPV screening. The review panel was told the draft revised clinical guidelines had been sent out for consultation and would be submitted to the screening Clinical Oversight Group in early 2025.

It was commented that the proposed clinical guideline revisions would be very difficult to implement in the Register. It was estimated 75% of the coding of Register rules for the cervical screening clinical pathways would need to be rewritten to implement the proposed clinical guideline changes. It was estimated it may take 12 months to implement if there was no change to the developer resources available.

The review panel also heard it would be helpful to look ahead to what likely clinical guideline changes there would be in the next three to four years to inform planning.

6.3 Communication method changes

The review panel discussed with interviewees issues with participant postal address information quality (see section 4.1). It was initially planned that the Register would have the functionality to enable email and text message notifications to be sent. The notification strategy states, “The Register will enable communications to be sent via different channels including email/ SMS [text message]/ letter/ phone call.” The review panel learned this functionality was removed from the scope of the Register’s design at a relatively early stage (see section 3.4).

Interviewees commented there was now a need to adopt alternative communication methods. Their view was that using email would have better engagement and would enable tracking. It was also noted email would help with catch-up on the tens of thousands of outstanding notifications. The decision to adopt new communication methods was said to sit with the NCSP, and then Digital Services would be involved in making decisions about when changes would be made.

It was stated work was underway to enable notifications to be sent by email. A pilot email campaign had started, using the Consumer Population Identification and Registration Service. Emails were sent to a group of unscreened participants in February 2025, with their outcomes being tracked. As of mid-March, none of the recipients had been screened.

6.4 Change management

The review panel heard there had been a lot of requests for changes since the Register’s launch. It was commented there was a need to get out of the mindset of making changes as soon as they were requested and to think more carefully about prioritising change requests, the costs of making changes, and ensuring a change did not create new problems. It was explained an online change request form had been introduced, as part of a new change request process (see figure 17 in appendix four).

It was noted that, to ensure changes wouldn’t cause new problems, testing was required. To assist this, the review panel was told automated testing had recently been introduced, to test Register functionality not directly affected by a change, to check there were no new issues caused. It was commented, if a lot of change needed to be made, it may be necessary to increase the testing resources allocated to the NCSP.

The ICT vendor and Digital Services were reported to hold quarterly planning sessions to map out future releases in a ‘product road map’, delivered through monthly releases. Decision making around timing of releases was said to be driven by prioritisation set by the NCSP clinical team, but where a fix for a priority issue would take longer to develop, a lower priority fix may be introduced prior, if the development time was short.

The review panel was told information packs were sent to Register users, explaining upcoming changes and what the impact for the user would be. It was acknowledged this process was missing a feedback loop to make sure Register users had a voice in the change and ongoing register improvement process.

Findings

- The review panel acknowledged that there had been several changes to the Register made, since it launched in September 2023. Some of these changes were fixes for

logic problems while others were completing data remediation that was not complete in time for the Register's launch. This demonstrates the Register can be changed when requirements are identified, at least to some extent.

- The 'backlog' of issues seen by the review panel appeared to be combination of a list of upcoming development and a risks and issues register. Some items had been on the list for years, including some seemingly important issues, e.g. 'wrong date on an updated result'. It also wasn't clear which of the issues were being worked on currently and when they would be addressed through changes. There may be other 'roadmap' documentation, but if so, this was not seen by the review panel, and it was therefore concerned this information may not be well communicated to the NCSP.
- There did not appear to have been any progress made in delivering major improvements to planned functionality, such as flagging under-screened participants. This is despite this functionality being outlined as a high priority since early in the planning of the HPV Primary Screening Implementation Project. This suggests the Register's adaptability to some types of key required changes may be limited.
- The review panel cannot comment on whether the underlying Salesforce platform is inherently inflexible, or whether adaptability has been limited by the way in which the Register has been designed and built as testing by the panel was not able to be carried out.
- Substantial changes will need to be made to introduce the upcoming new clinical guidelines. It was stated this may take up to a year to complete. While it is acknowledged that changes must be delivered carefully, this suggested timeline is concerning given the direction that cervical screening is moving. While in the past, changes to clinical guidelines may have been substantial but infrequent, the sector is moving towards 'living guidelines', with much more frequent required changes anticipated and already underway internationally. The forthcoming changes will be a significant test of the Register's adaptability and therefore long-term viability.
- It is positive to hear there is a quarterly forum to plan changes over the medium-term. Although it was said that decision making was driven by prioritisation set by the NCSP clinical team, the review panel was concerned that decisions about if changes were feasible would be made without direct clinical input, potentially delaying important improvements.
- The review panel supports the suggestion there should also be a longer-term, multi-year, view of future changes including forward planning for future clinical guideline line changes.

See recommendations 5 and 8, which address these issues.

7. Other issues arising

7.1 Governance

Governance roles and responsibilities

Interviewees discussed the 'siloing' of the teams involved overseeing the Register, describing that clinical, technical, and operational teams were not well integrated. It was said that the different teams looked at the Register from different perspectives, including variously as a technical or clinical solution and this contributed to different ways of looking at problem-solving. It was suggested that a translational role between the clinical, technical, and operational teams was needed, but was currently lacking.

It was noted in interviews that the NCSP clinical team is separate from the NCSP operations team. It was stated there was a 'partner approach', between the NCSP Programme Manager on the 'operations side' and the Clinical Director Screening on the 'clinical side'. With regards to the Register, it was said that Operations were responsible for the Register's performance while Clinical provides subject matter expertise, such as in to planning future improvements (see section 6.4).

The review panel heard that it has been unclear who holds the governance responsibility for the Register and this needs to be explicitly defined. Interviewees expressed the opinion that governance of the NCSP should be led by the 'NCSP Programme Manager' position but that this role had turned over several times in the last year. A new NCSP Programme Manager was permanently appointed during this review. It was commented during interviews there were now 'the right people in the right roles', and things were working much better than before.

The review panel also heard the NCSP previously had support from the NSU Quality Manager, but the role was disestablished in a previous organisational restructure. In 2024, a Principal Advisor Quality was engaged by the NCSP on a short-term contract to develop the NCSP Quality Framework and manage the NCSP Incident, Complaint and Risk Management register and processes. It was commented the NCSP needed a Quality Manager and that with the right structure in place, concerns could better be managed when they arose. It was noted there had been someone working on updating the interim NCSP policies and standards issued in 2023, but their role was also disestablished. The review panel was told that the NCSP was currently being supported by the Prevention Quality Team.

The review panel heard from some interviewees that the Register Product Owner, a role in Digital Services, was a key role in decision making. It was stated that the expectations of this role had not been well defined, and interviewees expressed differing views about the best approach. Some noted that this role did not need to be part of the NCSP team itself but should be well connected to it. Some suggested the role should be far more involved and integrated with the business of the NCSP to truly understand what is required of the Register and therefore in a position to communicate requirements to technical teams. It was suggested that the 'Data Warehouse Product Owner' role was a good model for how things could and should work.

It was said that some clinical team members had had to develop technical skills, beyond the scope of their roles, to try to bridge the gap between the clinical and technical teams. It was

suggested a clear understanding of roles and responsibilities was required and particularly important due to the complexity of the programme and the rate of staff turnover.

It was commented to the review panel that, with the current level of staff resources, the NCSP was in a vulnerable position and that it may be necessary to pause trying new things for the rest of 2025, to get back on track. The review panel noted that a new Quality and Safety manger had been recently appointed at the NPHS Prevention level and that part of their remit included leading a 'pathway safety net' project.

Clinical governance

The review panel heard there was not a good collective understanding of clinical safety risks and issues and that differing views of risks, between teams, may come from working in silos. It was said that processes for freely raising risks were not well developed, with no clear escalation pathways, and that when someone raised an issue or risk it was likely to be assigned to them to find a solution.

It was commented clinical risk management may be improving with the development of a 'quality forum'. The review panel heard there had been difficulty defining clinical risk and clinical harm, but there now was a definition of high clinical risk. This was said to have been developed over the last six months and was now used to take a methodical approach to problem solving. This definition was not shared with the review panel.

The review panel heard that there was not a deep understanding of clinical risk amongst senior decision makers. It was commented this may be because of a lack of detailed information on Register risks and issues that is visible to senior governance decision makers. It was commented, therefore, that though many people knew about some aspect of the Register, few had the whole picture. It was commented that trying to understand the Register was "a full-time job", and programme capacity was lacking for individuals to be able do this.

Governance meetings

The review panel heard that NCSP Leadership Team meetings were held regularly and included Programme, Quality, Clinical, Digital, and Project leads. It was also reported that weekly meetings on notifications were led by the NCSP Programme manager, through which decisions on notifications are made.

The review panel was told that it was not always clear which was the correct decision-making forum to escalate issues to, which it was said had previously been affected by managerial changes.

The review panel also heard that risks and issues related to the Register had been presented to Health NZ's Clinical Quality and Safety Committee, which meets monthly. Information is also provided to the Technology Portfolio Board, which was said to keep track of significant technology investment like the Register.

Documentation of risks and issues

Weekly remediation updates

The review panel was told that much of the focus of the NCSP over the last year had been remediation of Register defects and data quality issues. This involved lots of separate Jira

'tickets' which had been raised. It was said there was a sense of there being a level of clinical risk but no clear 'problem statement'.

An exercise was undertaken by the NCSP project team, in January 2024, to review the various outstanding tickets, and with input from the NCSP clinical team assess and prioritise them. An overview of the outstanding remediation issues was updated weekly [48]and circulated by email to relevant staff. This has continued and been iterated on ever since. It was commented during interviews that senior management felt this had brought clarity to the previously ill-defined problems. These weekly remediation updates do not include information on progress in actioning recommendations in the notification review. The review panel was told that notifications were discussed at a separate weekly meeting led by The NCSP Programme Manager.

The content and format of the weekly remediation update changed during this review. For example, at one-point weekly remediation updates included slides on the register 'quality check', these were removed to form part of the pathway status safety work.

Risks and issues registers

The review panel was provided with recent risk and issue registers for September 2024 (39) (40) , February 2025 (41) and March 2025 (42). These used an NPHS Prevention[49] directorate level risk and issue register template. Each issued had a named 'delegated manager' assigned and each risk had a named 'Owner', mostly this was the NCSP Programme Manager. Each risk had causes and potential consequence described and had been given a consequence rating of minor, moderate, major or severe, and a likelihood rating of unlikely, possible, likely, or immediate. Issues had 'current controls' described, while all risks had 'Mitigations/Action Plan Initiatives' detailed.

The March 2025 risk register included 14 issues, of which six related to the Register including 'ineffective safety nets', data remediation, large volumes of tasks and three related to implementing the notification strategy. It also included 15 risks, of which six were rated as 'high priority', which included three related to the Register (see figure 19 in appendix four for a summary of these three risks and their mitigations).

As noted in section 6.1, the review panel also saw a separate list of issues in the document, 'CSR Jira Backlog 07.03.25' (38), some of which were labelled as 'risks' or 'issues'. Other tickets were labelled as bugs, defects, tasks, themes, data remediation, enhancements, etc. Some of these were from as early as 2022 but were still classed as "open" while other tickets were as recent as March 2025.

Adverse events recording

A 'Prevention Adverse Event Register' (32) was also provided, which several recent Register-related events, including:

- NCSP Register - regional services tasks (see section 4.5)
- NCSP Missing Histology (see section 5.3)
- NCSP Overdue participants in pathway, described as, "Number of participants overdue in the pathway prior to go-live in the new register. Number of outstanding tasks." (see section 4.5 'Register quality check)

[48] NCSP Register Remediation and Remaining Scope for MVP and improvements weekly updates 23 August 2024 – 16 May 2025

[49] Prevention Directorate in the NPHS includes Immunisation and other screening programmes.

- NCSP Reminder Letters Not Sending (see section 4.2)

For each event, an event type was given and for those four events listed above this was 'process error' for the 'NCSP Register - regional services tasks' and 'Register error' for the other three. Most events had a Severity Assessment Code rating, although 'NCSP Missing Histology' was given a n/a rating and a rating had not yet been assigned to 'NCSP Reminder Letters Not Sending'. Each event had Contributing factors (as reported by provider) and 'Healing, learning and improving outcomes' described.

Incident management

It was noted by interviewees that Incident Management processes for the Register needed to be improved. Appropriate response to incidents was noted to be very important and that this needed a quality systems approach with adequate resourcing, rather than just being one person's role. There was some acknowledgement that some incident management processes had improved, but that processes needed to be formalised in writing.

It was said there was a lack of integration between technical and clinical teams, and this could lead to a lack of understanding of where specialist clinical input was required for 'technical' issues. An example was given of an earlier 'letter not sending' incident. It was said this was initially seen solely as a technical issue, initially there was no clinical input to the incident management. There was no visibility of subsequent documentation of the incident for the clinical team as this was kept on a system the clinical team did not have access to.

It was said it was unclear to the NCSP clinical team if there was adequate monitoring in place to confirm that events were a one-off or if they were ongoing. There was concern the clinical team could not investigate and 'look across' events. It was reported that sometimes events were escalated to people with the wrong expertise and/or with the wrong level of urgency.

Who holds the role of incident manager was said to be unclear with individuals at times assuming this role due to lack of clarity. It was said to have been difficult at times to differentiate between business-as-usual Register issues and adverse events. It was also said the framework for defining 'harm' had been hard to define. The long time taken to close a recent event was also noted.

Lack of escalation processes for adverse events was referenced in a piece of work undertaken to compare the notification strategy to the Register's current notification functionality. This concluded the application of cohorting to the recall of individuals to screening after an LBC test result didn't arrive within three months posed a high risk (see section 4.2). A draft memo with recommendations to address risk was prepared, but no route to escalate these issues was identified.

Findings

- Governance of the Register is in effect shared between the NCSP, including both clinical and operational teams, and Digital Services. There appears to be a lack of clarity around some roles and responsibilities, including escalation pathways and decision making. Many of the governance and project management issues identified in the rapid independent review (20) in the lead-up to go-live have remained challenges in the post launch period.
- A lot of responsibility for governance sits with the role of the NCSP Programme Manager, who was the named owner of most of the risks and issues in the Prevention

risks and issues register. Given, however, that the clinical responsibility sits with the Clinical Director, Screening and the nominated Register Product Owner is in Digital Services, there is no single point of responsibility or authority.

- There is, therefore, a need for effective communication and team working between these three functions (clinical, technical, and operational) and a shared understanding of objective, priorities, and risks. It does not appear that any of the three functions currently feels that this is in place.
- High rates of staff turnover and multiple wider organisational changes may have contributed to the fragmented governance, including confusion and gaps in roles and responsibilities.
- Disconnection of teams means there is a risk that issues will be misunderstood by one or more functions, that responsibility for decision making may be assumed to rest with one team rather than another, and that working in isolation could lead to duplication of efforts or working at cross purposes or towards different priorities.
- In particular, the review panel was concerned that clinical risk may not always be fully understood by the Digital team and as a result also by the ICT vendor. The panel observed gaps in:
    - translating clinical requirements into business rules,
    - risk/issue visibility and escalation,
    - incident management processes,
    - responsibility for decision making when risks, issues and incidents have arisen.
- The NCSP has appropriate processes in place to document risks and issues, assess and score risks, and to document proposed mitigation measures. These risks and issues are documented in a standardised template and are understood to be aggregated to a Prevention-wide level allowing for oversight.
- The review panel was, however, aware of another processes for documenting risks and issues used by Digital Services, facilitated by the Jira system. It wasn't clear if these risks were also fed into the Prevention level documentation to ensure there was a single source of truth covering all risks and issues.
- While risks and issues are documented, what was less clear was whether this then led into action which effectively and significantly remediated risks and issues. Many of the register risks and issues identified through the review process have been known to the NCSP for some time, with evidence of some of these being recorded in risk and issue registers dating back to July 2024. This includes critical safety issues of failures in the register's clinical safety net for participants with high-risk test results, individual case review workload to put participants on the correct pathway, and challenges with volumes of regional Coordinator and RCT tasks. The review panel concluded therefore that there was limited capacity to undertake the substantial pieces of work required to address these issues.
- There has been similar long-standing awareness of multiple issues in delaying implementing the notification strategy which are described as delaying in inviting people to screening, delaying receiving the right follow up advice and lack of referrals from the register to Support to Screening. For various reasons they have only partly been able to be acted on or not acted on to resolve at all. Funding and human resource constraints appear to be implicated for some issues.
- The review panel acknowledged that there has been such a significant number of Register issues since launch, that understanding, documenting, and effectively communicating them is both difficult and time consuming. Significant progress in drawing attention to issues of significant risk was made by bring many of them together into weekly remediation updates. This appears to have improved visibility of these issues,

including for senior management, and may have helped to facilitate progress in addressing some of these issues. As noted above, however, capacity constraints mean that there is still substantial work required particularly regarding individual case remediation and pathway status safety work as was identified in the review panel February memo to the NPHS.

- Another issue identified by the review panel was that these weekly remediation updates did not address the outstanding issues with notifications, identified by the notification review. It appears these issues were seen as being separate and it appeared that as a result, they have not had the same level of visibility. It also appeared that a lack of visibility may have meant that addressing these issues was de-prioritised, given a lack of capacity to address all issues at once.
- Incident management processes are in place and the review panel has seen evidence of adverse events being documented, risk rated and investigated. The review panel felt, however, that incident management processes could be better supported with dedicated resource to investigate issues rather than this falling on the NCSP operational team. It was noted that investigations are time consuming and could derail business as usually work if additional support was not available. There is also a role for deeper learning from incidents, by further exploring root causes, to determine if there remain undetected systematic deficiencies in the Register. Given that several new incidents came to light during this review, many of which dated back to the launch of the Register, it is likely that further problems do exist and are yet to have been identified.
- It was not clear to the panel that the governance envisioned in the draft Te Tiriti o Waitangi and equity strategy, described as, “a co-governance partnership with a group made up of tangata whenua partners who can oversee and steer all NSU programmes” is in place yet.

See recommendations 15-17, 19, and 37, which address these issues.

7.2 Relationship with the National Kaitiaki Group

The NKG was established in 1995 by the Minister of Health under the Health (Cervical Screening (Kaitiaki) Regulations 1995[50]. The NKG is appointed by, and accountable to, the Minister of Health. The NKG considers applications for approval to disclose, use, or publish ‘protected information’ from the Register and that identifies the individual to whom the information relates as being Māori. The NKG protects Māori cervical screening data by ensuring that this data is not used or published inappropriately or in a way that reflects negatively on Māori and instead is used to benefit Māori.

The review panel was provided with dates of and NPHS attendees to recent meetings with the NKG. These meetings took place on 19 February, 18 March, 15 April, 20 May, 16 September, 21 October, and 18 November 2024 and 17 February, 17 March, 28 April, 19 May, and 16 June 2025.

The review panel heard there had been many applications in the last few years, but this has declined and that there had not been any applications to the NKG over the past six months or so. It was suggested this may be because of the recent changes to the Health System.

It was commented the interaction between the NKG and the NCSP had become ‘fractured’. Concern was expressed there may be a lack of knowledge about the NKG and the regulations governing its role, or that it was seen as an inconvenience and therefore

[50] https://www.legislation.govt.nz/regulation/public/1995/0029/4.0/DLM2195902.html

avoided. The NKG was said to have voiced these concerns constantly over the past several years. The review panel was told the NKG reviewed quarterly reports, but no reports had been received for review in recent months. It was noted, even if reports were not being produced, this should be communicated to the NKG to ensure it was kept well informed.

The review panel heard about a July 2024 issue reported to the NKG, when 461 letters were reported to have been sent to the wrong addresses, including 62 Māori individuals. It was explained the NKG was not alerted to the data breach until two weeks after the incident at which point it was asked for recommendations because some of those affected were Māori. It was noted that, if a family member or anyone known to the affected individuals opened that letter, and an assumption was made about a link to sexual activity, there could be a significant implication for the individual. It was said that it was often overlooked that Māori data, as a Taonga, is precious and therefore to be cared for as such.

It was commented this breach raised the issue of why personal details, including an NHI number and date of birth, were included in letters, and whether they could be removed to minimise the impact of data breaches such as this. This data breach also raised concerns about how issues were communicated to the NKG. The NKG was told there had been several technical issues involved and reassured it would not happen again, but it did not receive a report on the root cause.

Findings

- The review panel was concerned that the decrease in applications for data to the NKG, could be due to systemic barriers leading to data needs being underserved. It notes that this warrants investigation.

See recommendation 34, which addresses this issue.

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Appendix 1: Terms of Reference

Purpose of the review

The purpose of this review is to assess the clinical safety and quality of the National Cervical Screening Programme (NCSP) population-based register ("the Register"). This includes reviewing the following aspects of the Register:

- whether implementation meets the intended design and what can be learned from the implementation process
- current functionality including ensuring participants receive notifications and managing screen detected abnormalities
- monitoring, audit, and reporting capabilities
- ability to adapt to future requirements.

The clinical safety and quality of the Register across each of these aspects directly contributes to the ability of the NCSP to deliver an equitable screening programme and meet its Te Tiriti o Waitangi responsibilities.

Background

The Register went live on 12 September 2023. The switch from liquid cytology-based screening to human papillomavirus (HPV) Primary Screening occurred on the same date. This joint implementation was planned, with the Register a means to support the updated HPV screening programme and associated updated clinical pathways.

In addition to the change in the primary screening test and more complex clinical pathways, there were other significant changes between the previous cervical screening programme and the renewed one. These changes included shifting to a population-based register for the first time, which had planned proactive communication and safety nets for different population groups, building in checks for lab recommendations in the register, among others.

A population-based register is a key requirement of successful population-based screening programmes. The Register uses National Health Index (NHI) / National Enrolment Service (NES) information to identify eligible participants. It is designed to have the capacity to contact all eligible people for screening to send screening invitations, reminders and recalls ("Notifications"). The Register is also the basis for tracking, monitoring, auditing, and quality assurance. The Register was planned to be "a single source of truth for screening records and individual schedules."

The development of a "Notification Strategy" provided strategic guidance and policy on the uptake and follow up of screening. It specified how notifications should be tailored based on clinical history and demographic characteristics, and primary care enrolment status. The Notification Strategy was designed to be equity focused, phasing in groups to start receiving notifications for HPV primary screening, aiming to prioritise the highest need groups to receive screening invitations first.

Issues with register notifications were identified by The National Public Health Service (NPHS) Prevention Directorate's operational and clinical teams. This led to a "Notifications Review", with a report published in April 2024. The Register issues identified in the

"Notifications Review" included clinical, equity, programme, and technology issues, including:

- Some notification types not being sent and/or incomplete sending of notifications
- Previous participants being sent new enrolment notifications
- Referrals to screening support services not aligned with strategic direction provided by the notification strategy
- Lack of business processes to support referrals to screening support services
- Some cohorts of participants not yet live for eligibility and recall letters where intended
- Issues with incompleteness of key data, including correspondence address, Circle of Care (primary health organisation (PHO) enrolment) information, and NHI active field blank.
- No confirmed business process to follow up on notifications unable to be sent.

Remedial work to address the issues identified in the "Notifications Review" is underway.

Additional issues beyond the scope of the "Notifications" function of the Register (and therefore beyond the scope of the "Notifications Review"), were identified by or reported to operational and clinical teams. Examples of these issues include:

- the accuracy of screening histories (e.g. out-of-sequence results, health facility not displaying)
- Incomplete information for PHO enrolment and not systematically updated
- No derived field for previous screening status (i.e. flagging if someone was previously unscreened or under-screened), relevant to notifications and other areas.
- Tasks arising from 'H flows[51]' not yet as automated as originally intended, resulting in high volume of tasks having to be handled manually by Register Central Team, with significant backlog in managing these by Register Central Team and laboratories.

Scope

The review's scope will be to assess if the identified clinical safety and quality risks and issues are being managed and rectified adequately and to identify and rapidly address any other potential safety and quality issues. This includes reviewing:

- Eligible population identification[52] and implementation, including responsiveness to the highest need populations.
- Notification strategy design and the Register's ability to implement it. This will take account of progress made on addressing the recommendations of the "Notifications Review"
- Flow of information from and to other systems that communicate with the Register (e.g., lab systems, Gynae Plus, etc.)
- Automation of lab recommendation validation and resolution ('H flows' process)

[51] 'H flows' check the lab recommendation issued after each result and update a participant's next steps.
[52] Including identifying and reaching wāhine Māori/whānau with a cervix, Pacific Peoples and non-binary/transgender people with a cervix.

- Register pathways for abnormal result and high-risk event management[53]
- What impact the identified clinical safety and quality risks have on the goals of the introduction of HPV Primary Screening and the Register Implementation's, i.e., to reduce, and eliminate inequities, in cervical cancer incidence and mortality.
- If the Register is end-user friendly, including whether its functionality is sufficiently flexible and if the terminology used is intuitive for users (e.g., those in primary and community care and screening support services).
- Data field configuration and completion[54]
- Operational reporting capability[55]
- Programme performance reporting capability[56]
- Task prioritisation tools including those used for quantifying the clinical risk for and prioritising tasks identified by the Register that need remediation,
- If the Register is flexible enough to allow timely adaptation to changes, such as updated clinical guidelines.
- Whether the Register is future proofed to allow for new communication methods (e.g., emails, texts, etc.) to be used.

These issues will be reported on to the extent required as indicated by the findings of the review. In addition to the specific matters set out under the purpose and scope of this review, the reviewers may report findings and provide recommendations on any other important matters arising during the review such as how Māori Data Sovereignty principles are applied.

The review will address the current state, identify any gaps, and make prioritised recommendations, including any risk mitigation/remediation required. The review panel may also provide recommendations on any other significant matters arising during the review. These recommendations will be presented separately to those addressing the scope of the Terms of Reference of this review.

The review panel will urgently notify the NPHS' Prevention Directorate of any immediate and significant clinical risks identified during the review to ensure these can be acted upon.

Exclusions

The review will not:

1. re-visit implementation issues not related to the safety and quality of The Register

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[53] Including whether the Register accurately identifies individuals who have not progressed to the next step of the screening pathway and generates the intended actions (notifications, referrals, and tasks/reports) and whether these Register actions are supported by appropriate business processes. This will be to determine if there is an appropriate 'clinical safety net' that aligns with the current clinical guidelines and notification strategy, to ensure screening participant safety.
[54] Whether the Register has all required data fields, whether the information for each of those fields is accurate or accurately imported, and whether the Register can 'look back' beyond current status as needed. Whether the information in the Register (accuracy of data fields, configuration and naming of fields, time stamps, appropriate opening/closing of screening episodes, flags where cases are under review, etc.) is robust enough for the data warehouse to generate accurate programme monitoring to ensure data quality checks can be performed
[55] Including reporting for data validation, task resolution, reports for individuals that Regional Coordinators need to follow up on, technical fail safes etc.
[56] Including reporting on equity goals, such as increasing screening coverage to those populations with historically reduced access to the programme and reducing Cervical Cancer incidence and mortality in the most affected populations.

2. consider the implementation and functionality of other population-based registers that the NPHS' Prevention Directorate is responsible for, except where it may be relevant to the functionality of the NCSP register
3. include consideration of practitioner quality monitoring that is done using other IT systems
4. have access to identifiable personal information.

Process

The review panel will review relevant documentation identified by the Planning, Funding, and Outcomes (PFO) team within Health New Zealand. This will include documentation relating to the commissioning, design, and implementation of The Register, including the Notification Strategy.

The NPHS' Prevention directorate's "Notification Review" remedial work and work to identify instances of potential and actual harm will also inform the review.

The review panel may also review audits of cohorts of participants (using non-identifiable data, complying with data privacy requirements) to understand the adequacy of The Register's pathways and associated actions.

It will also request and then review any additional documentation relevant to the review.

The review panel will interview current and/or former staff involved in the development, deployment, and programme management of The Register. It will also interview Register end-users, members of the NCSP Partnership, Action and Equity Rōpū, and others as required, such as participant/consumer representatives and representative(s) of the National Kaitiaki Group.

Review panel

The review will be conducted by an appropriately qualified review panel, independent of the NPHS' Prevention Directorate. The review panel will be accountable to the Health NZ Executive Leadership Team (ELT).

Review panel members will bring the following expertise:

- clinical expertise in cervical cancer and screening,
- clinical expertise in obstetrics and gynaecology,
- Hauora Māori, including screening for Wāhine Māori,
- information technology and clinical informatics,
- quality monitoring/audit and/or quality review.

The review panel will also seek the input of cervical screening participant representatives, as it deems appropriate.

Additional reviewers with other areas of expertise may be appointed to support the panel, as required.

Secretariat support

The PFO team will provide secretariat support to the review team to ensure timely delivery of the findings. This will include:

- sourcing background materials and documents
- providing agendas and supporting materials for the review panel's meetings
- support with analysis, including data analysis, and drafting the review panel's report and recommendations.

Deliverables

The review panel will report to Health NZ's ELT. The panel will produce a report that will address scope described in these terms of reference and make recommendations as appropriate.

The reviewers will also provide interim updates on progress to Health NZ's ELT as required.

The NPHS' Prevention Directorate will consider the findings and recommendations of the review and based on these, develop an action plan for implementation.

Timeframes

The review panel will report to Health NZ's ELT with a draft report by the end of 2024 if possible or in early 2025 with a final report provided thereafter.

Issues, conflicts, and risk resolution

Issues, potential conflicts, and/or risks will be identified and documented by review panel members and escalated within Health NZ as identified.

Appendix 2: List of documents reviewed

- Address Management Playback Pack – Cervical – December 2023
- Aligning notification review findings to cohorts in notification strategy – 9 August 2024
- Answers provided to questions raised - 9 October, 22 October, 5 November, 19 November, 3 December, 16 December 2024
- Appendix A: National Screening Solution Functional Requirements
- Appendix B: National Screening Solution Non-Functional Requirements
- Appendix C: National Screening Solution Business Scenarios
- Business Case - Sustainability of the National Cervical Screening Programme – v.3.2b – May 2022
- Cervical High-Level Functional Capability Blueprint – 25 March 20234
- Cervical screening - Your test your-choice v17067503202 31 January 2024
- Cervical Screening Register - Batch & Scheduled Jobs – 6 March 2025
- Cervical Screening Register Privacy Impact Assessment – 1 September 2023
- Cervical Screening Review Architecture Overview Slides
- Change Authorisation Agreement – CR001 relating to Statement of Work for Professional Services No. 28 (Cervical Blueprint) – 12 May 2022
- Change Request Process
- Clinical Practice Guidelines for Cervical Screening in Aotearoa New Zealand v1.1 June 2023
- Clinical risk narrative to accompany the NCSP Register Remediation slide pack – 1 October 2024
- Clinical team outstanding tasks and reports 3 Dec 2024
- Correspondence - Unable to send – 7 March 2025
- CSR Jira Backlog – 7 March 2025
- Deloitte - signed CSR01 - Sprint 1 and 2 – 13 July 2022
- Deloitte Register workstream weekly reports from April-June 2023
- Draft Memo - Current state of eligibility and recall letters, and approach to cohorting going forward 25 Oct 2024 v0.1
- Draft user profiles for Whakarongorau Aotearoa review - 10 September 2024
- HPV Implementation Business Case – 1 April 2023
- HPV Primary Screening Induction Pack
- HPV Primary Screening Performance Assessment v.1.1
- HPV Primary Screening Performance Assessment v.1.2
- HPV Primary Screening Performance Assessment v.1.3
- HPV Primary Screening Road to Rollout
- HPV Primary Screening Road to Rollout one pager
- HPV Programme – Go-Live Readiness, Assurance & Launch – September 2023
- HPV Release 1.1 Change Impact Assessment – September 2023
- HPV Simple NHI Active Spec v1.0 – 11 October 2023
- HPV Technical Delivery Plan - Moving items to release 1.1
- Implementation Business Case - Sustainability of the National Cervical Screening Programme – v.3.1 – 22 March 2023
- Indicator Template – Up to Date Coverage – 30 June 2023
- Induction content - NCSP and NCSP-R - 8 August 2024

- Letter confirming approach to data integration of participants' results in NCSP register – 27 August 2024
- List of Validated Work tasks
- Memo - Approach to recording cervical screening qualification and HPV training at practitioner level – 20 July 2023
- Memo - Regional Coordinator Tasks Adverse Event – 19 December 2024
- Memo - Reporting cytology taken at gynaecology clinics where the result is AG2 or AC2 - 4 December 2024
- Monitoring and Actioning Reports RCT – 7 March 2025
- NCSP coverage data from 2024 Health New Zealand annual report
- NCSP HPV Primary Screening Notification Strategy (MVP version, with Phase 2 requirements)
- NCSP HPV Primary Screening Notification Strategy v2.0 2 April 2024
- NCSP HPV screening equity strategy_P5_V2 - September 2023
- NCSP Policies and Standards - Cervical Screening Service v1.2 November 2023
- NCSP Register - Cervical Register Review Panel Introductory Presentation
- NCSP Register Remediation and Remaining Scope for MVP and improvements weekly updates 23 August 2024 – 16 May 2025
- NCSP Register Safety Framework
- NCSP reports for HPV Primary Screening-140125-204048
- NCSP Sector Updates March, May, November 2024
- NCSP Status Report – 16 December 2022
- NCSP-R Competency Framework - October 2024
- NCSP-Register Review - current status of unsent notifications - 22 June 2025
- NCSP-Register User Guide Gone No Address (GNA) v1.0
- Notes from AAG meeting – Walkthrough of readiness – 27 July 2023
- Notification Matrix
- Notification Review v1.1 23 April 2024
- Notification Strategy Review v.1.0 – 5 April 2024
- Notifications Review - Action Tracker - 2 Oct 2024
- Notifications Review - Action Updated 25 November 2024
- NSSH-HPV Test Summary and Exit Report Release 1.0 – 12 September 2023
- NSSH-System Architecture and Technology Blueprint (CSR)-070325-005549
- NSSH-System Architecture and Technology Blueprint (CSR)-091224-005857
- Overview of Register Checks Validations diagram from 24 January 2023 Clinical Workstream meeting
- Part 1: Request for Proposals National Screening Solution
- Phase 1 Risk Register - HPV PS
- Prevention Adverse Event Register - NCSP
- Prevention Risk Register - NCSP Issues – September 2024
- Prevention Risk Register - NCSP Risk and Issues – March 2025
- Prevention Risk Register - NCSP Risks – September 2024
- Prevention Risk Workbook - February 2025
- Programme monitoring overview
- Regional Coordinator Process for No More Correspondence
- Register Quality Check 13 September 2024
- Report on User Acceptance Testing for Central Register Team – 4 September 2023
- Requirements Specification - NCSP Register Letters – Changes 1 October 2024 v.7

- Risk Register - Phase 2 - 2024
- Risk update 12th July
- Risks for participants in the HPV Cervical Screening Programme – 4 April 2025
- SOP Transgender Participants V1 12 April 2024
- SOP Updating Sex on a Person Profile V1 12 April 2024
- Statement of Work for Professional Services Cervical Screening CSR04 – 17 February 2023
- Statement of Work for Professional Services CSR No. 10 – 22 April 2023
- Whaihua release summary pack – 29 August 2023

Appendix 3: Summary of interviews held

Interviews with 43 staff/stakeholders were conducted by the review panel on 16, 17, and 30 January. These included representation of the following groups:

Health New Zealand

- NCSP Clinical team (current and former members)
- NCSP Operational team
- HPV Implementation Project team
- National Public Health Service
- Prevention Quality team
- Regional Coordination Centres
- Digital Services
- NCSP Partnership, Action and Equity Rōpū
- Planning, Funding, and Outcomes Health Equity

External

- Screening laboratories
- Deloitte
- Whakarongorau Aotearoa
- National Kaitiaki Group
- Support to Screening Service providers
- Colposcopy clinic staff
- Primary care staff
- Solutions Plus Ltd

Appendix 4: Supplementary charts and tables

Figure 1. Notification types

Key

Population Coverage

Clinical Safety

Compliance/ Administration

More info on categories in Foundational information

Notification Types

Notification Code	Notification Template Name	Text Variations	Description	Live Date
ELG0	Eligibility	-	Participant is due for first time screening (aged in or new NHI)	11/12/2023
ENRLD	Enrolment	CR1 – (>20 Years of Age)	Once the register has received a participant's first test result, this notification lets them know they have now been enrolled.	23/11/2023
		CR2 - (<20 Years of Age)		
REC0	Recall	CR1 – Recall (Routine Screening)	Recall time for subsequent screening episodes has been extended	3/11/2023
		CR2 – Recall (Repeat HPV/Annual)	Recall for LBC as next screening test; previous test result found HPV other and negative or low-grade cytology.	
REM0	Reminder	CR1 – Reminder (Routine Screening)	Participant is overdue for their regular screening test.	3/11/2023
		CR2 – Reminder (Repeat HPV)	Expected LBC not received; 3 months since 1 or 2 year surveillance screening recall	
		CR3 – Reminder (Cytology)	Participant just had an HPV Test with HPV other; follow up cytology result not received as expected after 3 months	
REM1	Reminder (Unsat./Invalid)	-	Reminder to return to do a repeat regular screening test, due to the first test being "Invalid" or "Unsatisfactory"	3/11/2023
REM2	Reminder (Post-colp/Annual)	-	3-month reminder, after colposcopy, for the follow-up co-test. No recall sent.	3/11/2023
WDL1	Withdrawn (Acknowledgement)	-	Participant has requested to withdraw from the NCSP	-
WDL2	Withdrawn (Receipt)	-	Participant's request to withdraw has been received	11/12/2023
WDL3	Withdrawn (Confirmation)	-	Participant has been withdrawn from the NCSP.	-
WDL5	Withdrawn (Cancellation)	-	Withdrawal cancelled; only applicable to participant's who are currently completing the withdrawal process.	11/12/2023
NMOR	No More Screening	-	Acknowledgement of participant's wish to have no more screening. Participant is under 70 years of age.	11/12/2023
OVE70	Over 70 Acknowledgement	-	Participant's last screening test result was normal and the participant is 70 years of age or over	11/12/2023

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Figure 2. Proportions of notifications sent/unsent

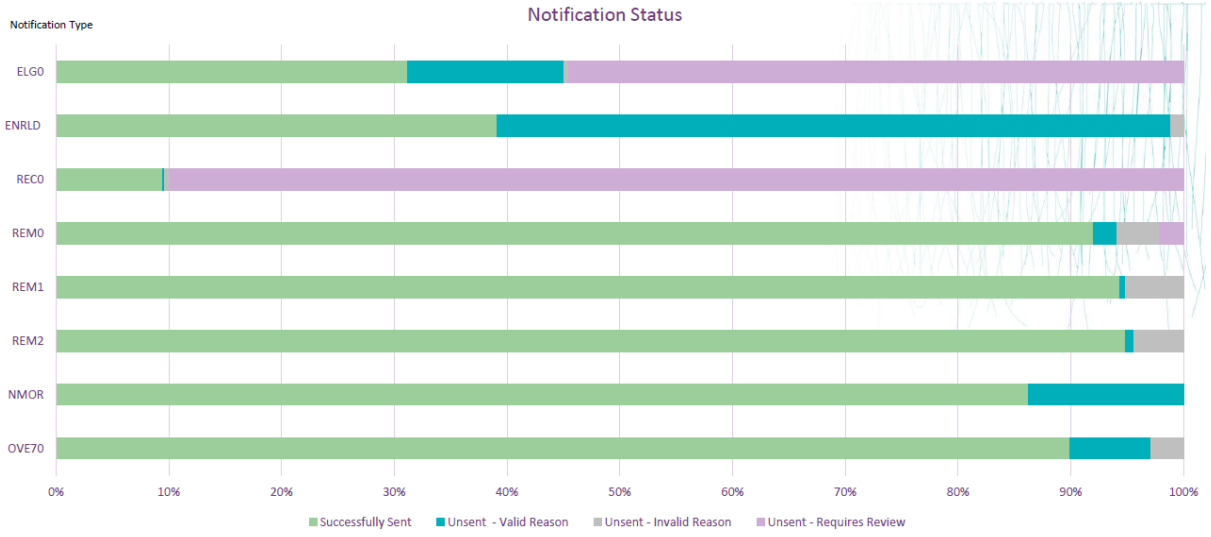

Figure 3. Notifications triggered/not triggered and sent/unsent

Group	Definition	Notification Type										
		ELG0	ENRLD	REC0	REM0	REM1	REM2	WDL1	WDL2	WDL3	WDL5	NMOR	OVE70
Successfully sent	Notification sent as per design	39,840	27,096	3,155	112,528	201	4,895	N/A	12	N/A	1	100	5,986
Unsent - Valid Reason	Notification not sent with pre-approved reason as per the design Includes Unable to send reasons of: • Do not send correspondence • Previously Scheduled • No correspondence address • Remediation • Previously eligible • Previously withdrawn	17,726	41,447	52	2,591	1	37	N/A	N/A	N/A	N/A	16	479
Unsent – Invalid Reason	Notification not sent with no business process for follow-up Includes Unable to send reasons of: • No Mailhouse Confirmation • Mailhouse Error 1.7	531	809	173	4,563	11	228	N/A	N/A	N/A	N/A	0	194
Unsent - Requires Review	As built flow meets the design - however the Programme needs to review the design Includes Unable to send reasons of: 3.1 • Inactive Cohort • NHI not active in last 6 years 1.6	69,583	0	29,985	2,630	0	0	N/A	N/A	N/A	N/A	0	0
Total Triggered	Total notifications that have been sent & unable to send	127,680	69,352	33,365	122,312	213	5,160	0	N/A	N/A	N/A	116	6,659
Not Triggered	Not triggered but meets the criteria for sending (transition scenarios etc.)	Upper limit – 740K 1.3	11K 2.2 3K 2.3		30K 1.1	<100 5.3	28k 6.2					2k 2.2 <300 11.1	11k 2.2

Figure 4. Workflow of reminder tasks

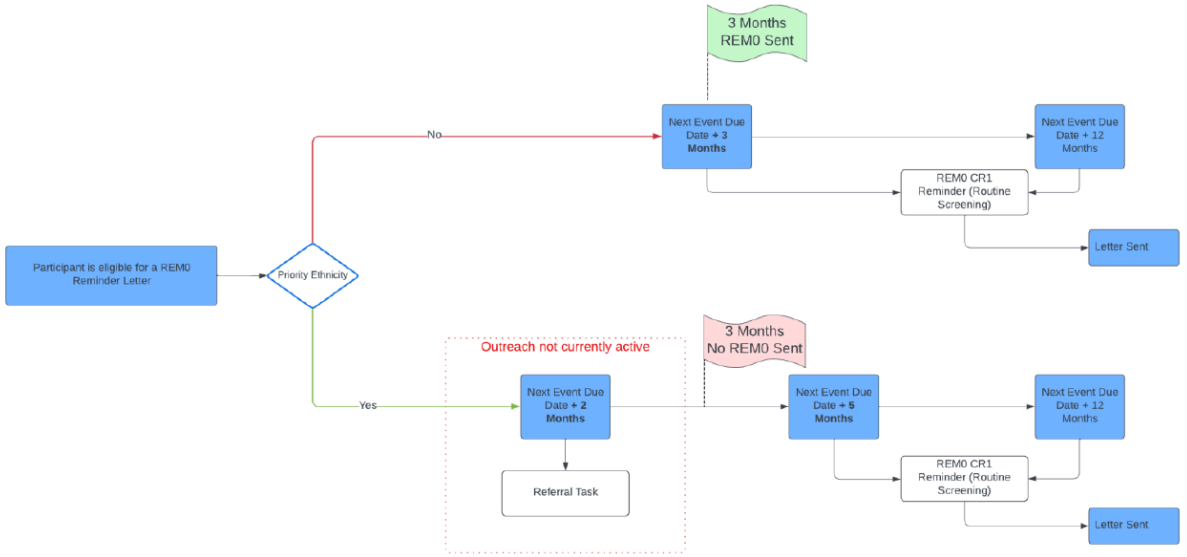

Figure 5. Notification Volumes at 22/6/25

	Group	Definition	Notification Type									
			ELG0	ENRLD	REC0	REM0	REM1	REM2	NMOR	OVE70	Total	Avg monthly change
Sent	**Successfully sent**	Notification sent as per design	**109,606**	102,165	**4,483**	735,095	1,986	28,982	**1,705**	**25,595**	**1,009,617**	
Triggered but not Sent	**Unsent - Valid Reason**	Notification not sent with pre-approved reason as per the design Includes Unable to send reasons of: • Do not send correspondence • Previously Scheduled • Previously eligible • Previously withdrawn	28,175	49,570	128	16,774	35	785	714	2,693	98,874	**2-3K↑**
	Unsent – Invalid Reason	Notification not sent with no business process for follow-up Includes Unable to send reasons of: • No Mailhouse Confirmation • Mailhouse Error (14) • No Correspondence address (9)	524	378	125	2,905	5	149	1	100	4,187	**8↑**
	Unsent - Requires Review	As built flow meets the design - however the Programme needs to review the design Includes Unable to send reasons of: • Inactive Cohort (REC0 & REM0) • NHI not active in last 6 years (ELG0)	107,632	-	48,536	2,629	-	-	-	-	158,797	**3-4K↑**
Not Triggered	**Notification review outstanding Gaps**	6.2, 3.1, 1.3, 2.2	655,595	11,000	-	-	-	6,591	-	11,000	684,186	Small ↓
	Incidents/ Technical change required	INC0335158, INC10002827	-	-	-	102,107	-	8,976	-	18,000	129,083	↑
	Manual sending of outstanding notification required	Consolidation of the above grey sections	**763,227**	**11,000**	**48,536**	**104,736**	**-**	**15,567**	**-**	**29,000**	**972,066**	

Figure 6. High-level Register architecture

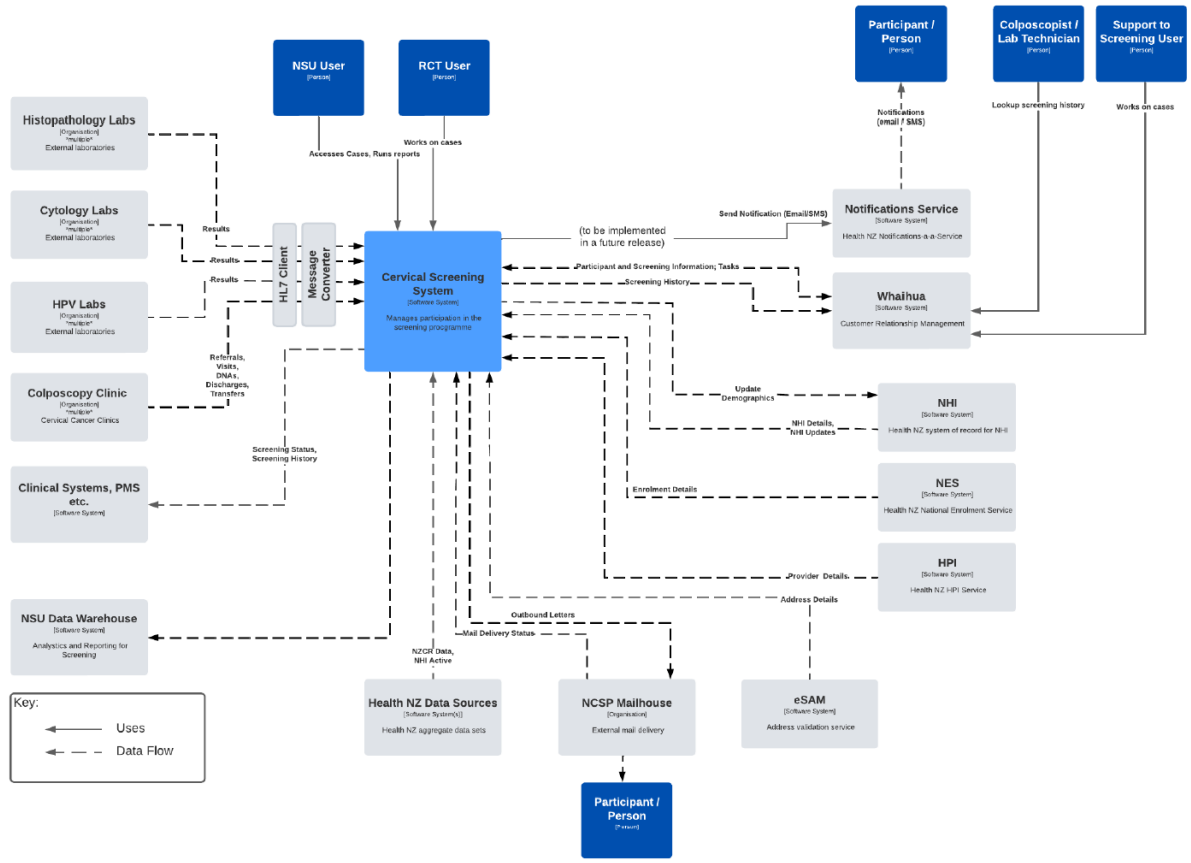

Figure 7. Overview of Register checks/validations

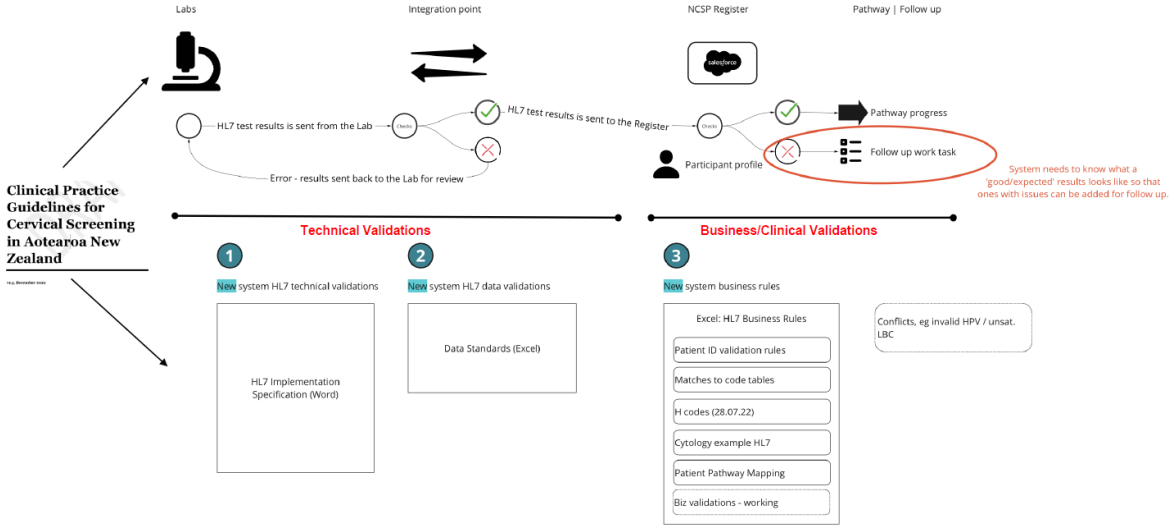

Figure 8. Outstanding RMMs as of 31/1/25

RMM code	Labs	NCSP clinical	RCT	RCT clinical	Total
H1	193	18	73		284
H2	93		3		96
H3	1	2			3
H4	3			1	4
H5	101	1	23		125
H6	3		1		4
H7	43	20	7	1	71
H8	59	2	8		69
H9	1			1	2
H10	10	11		1	22
H11	31	4	25	1	61
H12	1			1	2
H13	32	4	2728		2764
H14	10	11		1	22
H15	31	4	25	1	61
H16	6	2	14		22
H17	33	774	11	1	819
H18	36	14	220		270
H20	2			1	3
Histology		1		3	4
Total	689	868	3138	13	4708

Figure 9. Other RMMs outstanding as of 31/1/25

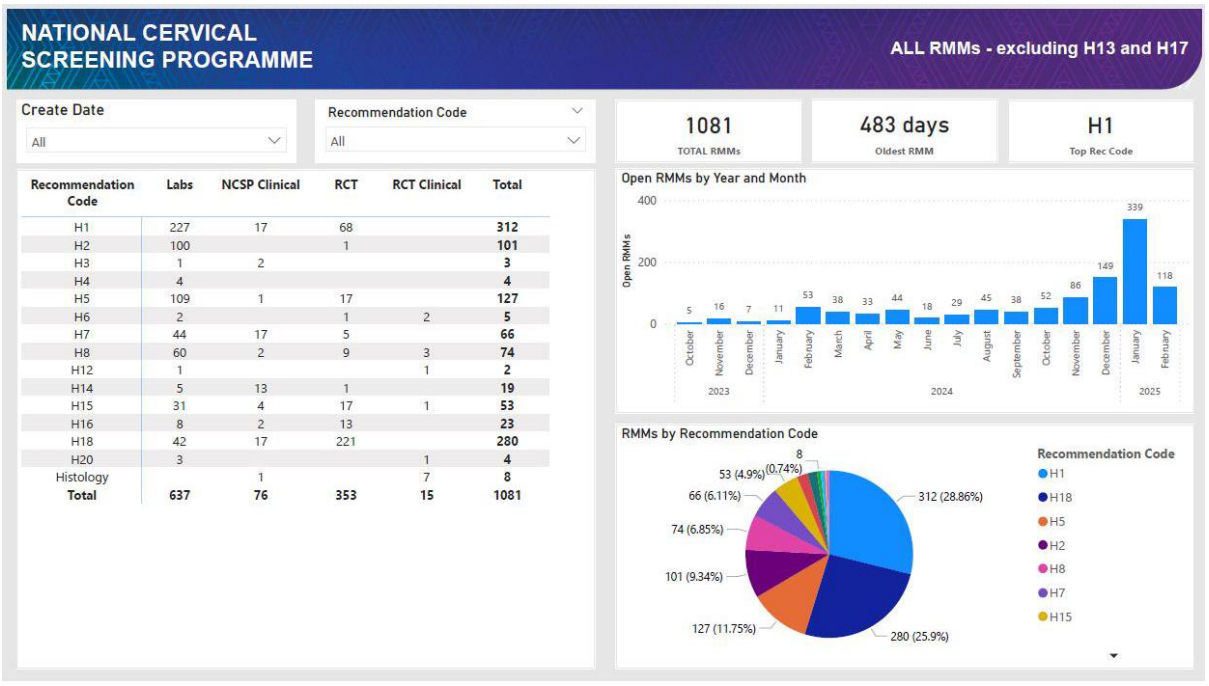

Figure 10. H13 RMMs outstanding as of 31/1/25

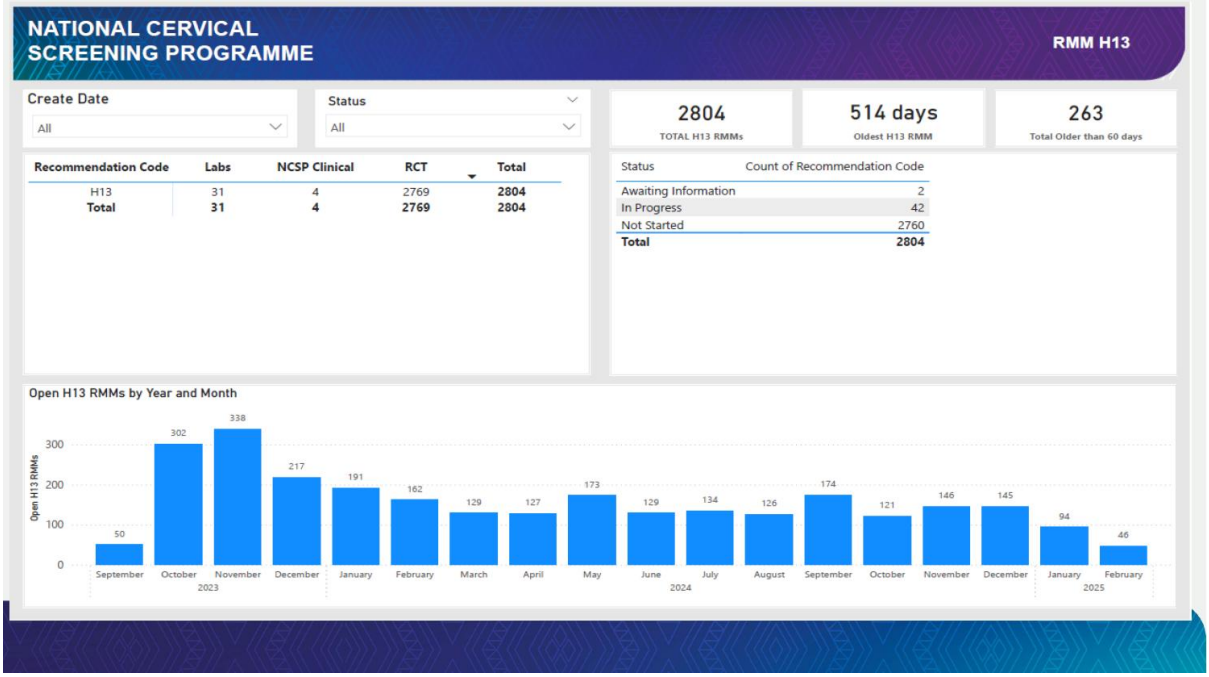

Figure 11. H17 RMMs outstanding as of 31/1/25

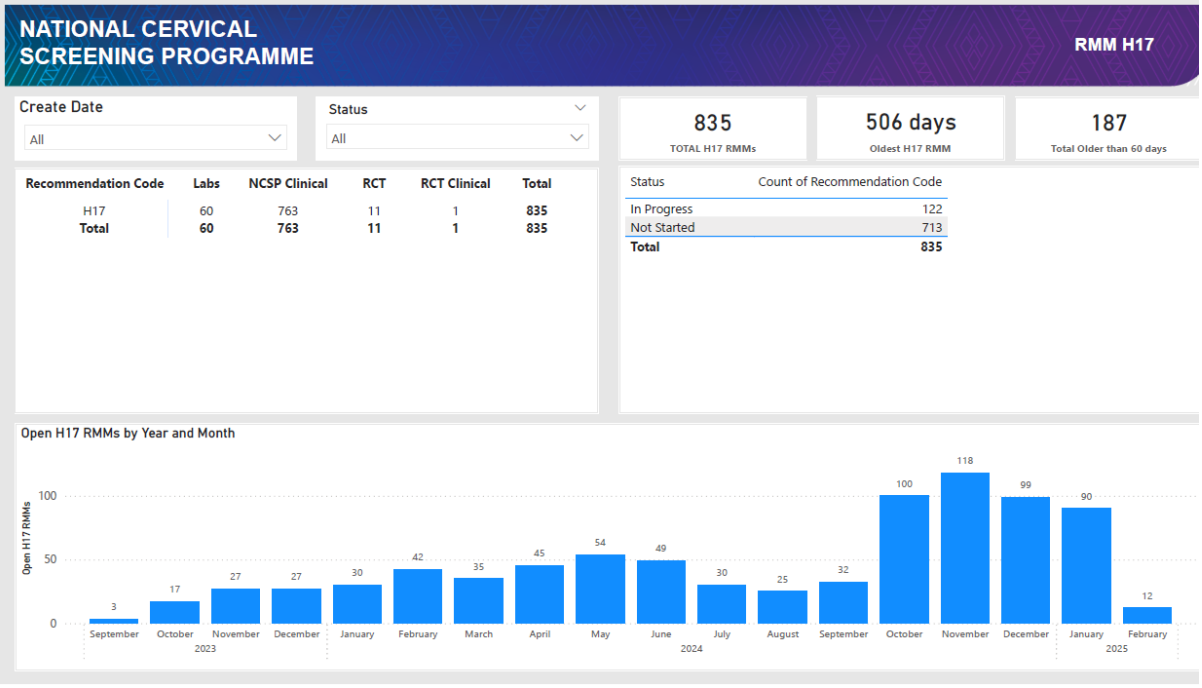

Figure 12. HPV screening pathway

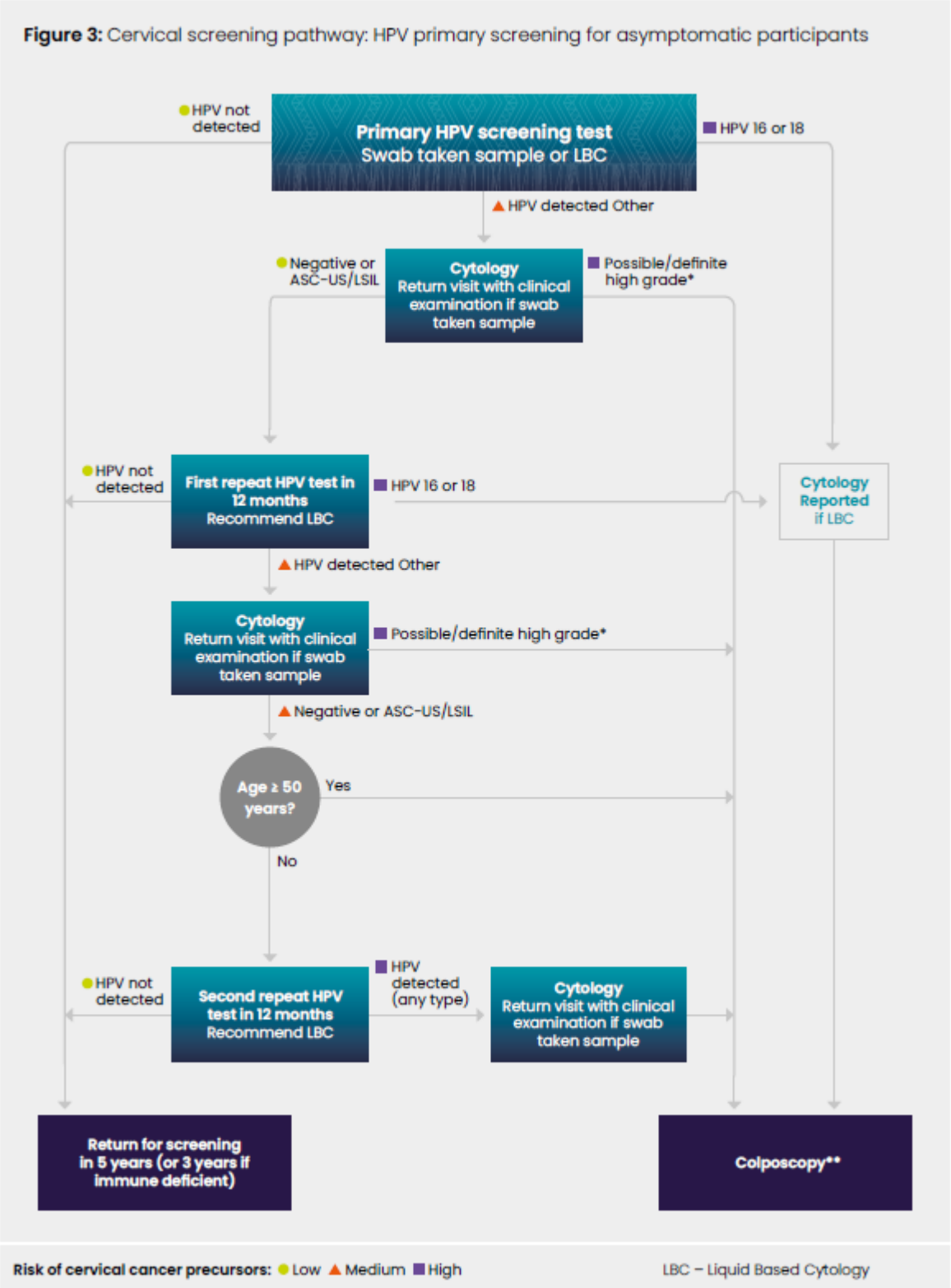

Figure 13. Register quality check

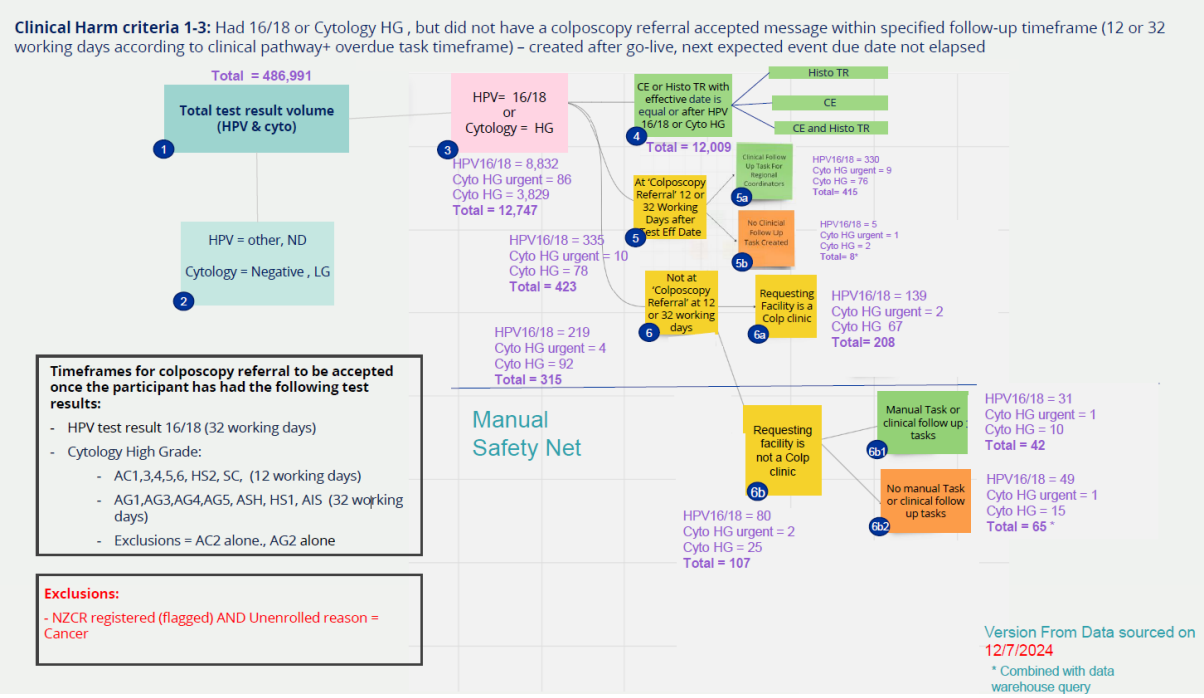

Figure 14. Overdue next expected event tasks

Incident - Next Expected Event Due Date is Overdue and follow-up (task) has not been completed			Total Tasks as at 23 Sept		Tasks in progress as at 13 Dec		Tasks Completed as at 13 Dec		Responsible for Review	Potential harm Under Review
			All Regions (excl. AKL)	Auckland	All Regions (excl. AKL)	Auckland	All Regions (excl. AKL)	Auckland		
Items for Review	Pathway Status Breakdown (in addition to base criteria)	Base Criteria for Participant Review: Participants requiring expedited review, due to being referred to colp for any of: - HPV of 16/18, - Cytology of HG (high grade), - Histology with grade - "C- cancer of the cervix", - Also Next Event Due Date (NEDD) is overdue	1,042	395	225	82	817	313		
1	Colposcopy Referral	Participants in this pathway are showing as overdue for having their referral accepted. Urgent follow-up with colp. clinics is needed for one of three reasons: 1) The clinic is yet to accept the referral, or 2) The clinic has accepted the referral, but hasn't yet sent this to the Register, or 3) The sample taker is yet to make the referral.	117	103	30	22	87	81	Danny Cooper	
2	Under Specialist Care	Participants in this pathway status are showing as overdue for their colp. visit. Urgent follow-up with colp. clinics is needed for one of two reasons: 1) The Participant is yet to attend a visit / be discharged by the clinic, or 2) A visit or discharge has occurred, but the clinic is yet to send this to the Register.	903	286	195	60	708	226	Regional Co-ordinators	
3	Any other pathway status	Participants that are no longer tracking under colp. pathway status' (i.e. colp referral or under specialist care) AND have a Next Event Due Date (NEDD) in the past. Urgent review is required to confirm whether the Participant is currently on the correct pathway status, or if they need to be reverted to a colp. pathway status.	22	6	0	0	22	6	Dr Alicia Blaikie	
		Totals	1437		307		1130			

Figure 15. Colp tasks including discharge messages

Colp Tasks Status Dec 2024

Internal – Not for Distribution

There are discharge messages prior to go-live that did not have certain data fields (e.g. follow-up test type) populated because at the time those fields were not part of the data specification. Post go-live, Solution Plus put a fix in place which clinics could select the correct follow up type which set the correct pathway. However if clinics do not update correctly (for example leave selection of LBC in place vs HPV +/- cyto) those pre go-live discharge messages that are sent to the register will still have these fields missing.

Clinical Events Sub-Category	TOTAL				Clinical Events with Effective date < 1/7/2023				Clinical Events with Effective date => 1/7/2023			
					Waiting on clinical decision for any remediation support that can be provided				In hand with operational processes – active follow up occurring – Waiting for clinics to correct messages			
	Created	Not Started	In Progress	Complete	Created	Not Started	In Progress	Complete	Created	Not Started	In Progress	Complete
Person Not Active	91	4	1	86	37	0	0	37	54	4	1	49
Discharge Without Visit - Follow up Required	1709	431	226	1052	197	6	33	158	1512	425	193	894
Discharge to Referrer - Follow-up Test Not Populated	4277	1065	39	3173	1268	844	26	398	3009	221	13	2,775
Discharge to Referrer- Follow-up Tieframe Mismatch	3929	1543	84	2302	1075	790	46	239	2854	753	38	2,063
Discharge Review	251	108	30	113	17	11	3	3	234	97	27	110
TOTAL	**10257**	3151	380	**6726**	**2,594**	**1,651**	**108**	**835**	**7663**	**1500**	**272**	**5891**
% Complete				**66%**				**32%**				**77%**

Figure 16. Outstanding data migration from go-live

I007 – I010 Outstanding Data Migration

Internal – Not for Distribution

No	Description	To be remediated by	Volumes Jan	Apr	Aug	Dec	JAN	Status
1	Under Gynae-Oncology Review- Participants flagged as having or have ever had cervical and/or vaginal cancer. On the new clinical pathway participants recovered from cancer could return to routine screening	Clinical	3,353	3,004	1608	907	869	Under manual review. Data remediation is unlikely to be needed.
3	Pathway status under review – this includes participants flagged under data review for the following demographic reasons: - Pathway status under review (screening info blank on PHO report)	Clinical	2,091	1,866	204	0	0	REVIEW COMPLETED
2	HPV research study - Participants flagged as being in at least one of the following HPV studies: Swab HPV Study; Rangahau Hauora HPV Study; Te Ara Waiora HPV Study; Lets Test for HPV Study – and are requiring review to ensure their clinical pathway information is correct	Clinical	7,722	6,111	3446	1658	1066	Lets Test for HPV Study complete Rangahau Hauora HPV Study data received and completed. Te Ara Waiora Study – in progress
7	Participants with total hysterectomy migrated to 3-year or 5-year recall: screening info blank on PHO report)	Clinical	2,721	2,596	2,010	1700	1600	Manual review, no pattern suitable for bulk remediation.
	TOTALS		**15,887**	**13577**	**7,268**	**4,265**	**3765**	

Figure 17. NCSP Register change request process

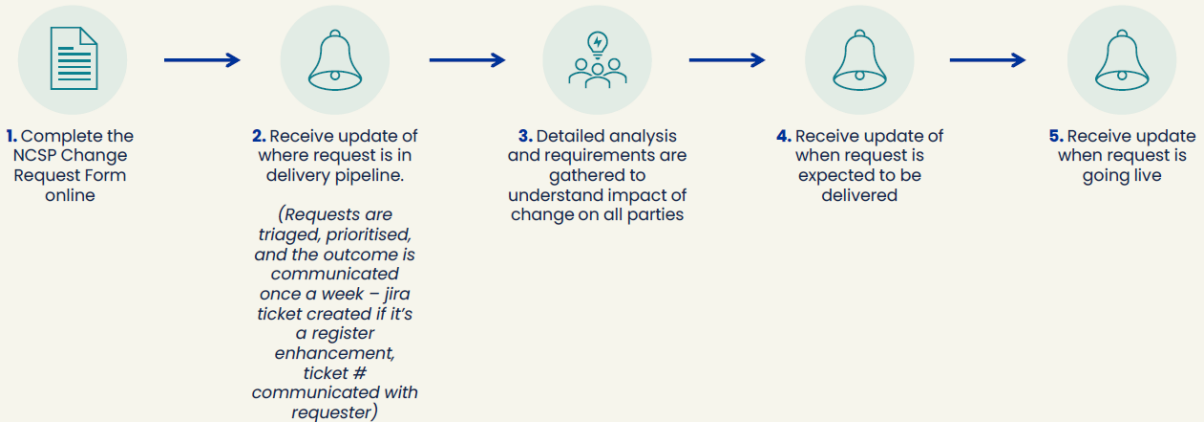

Figure 18. New governance structure from project reset

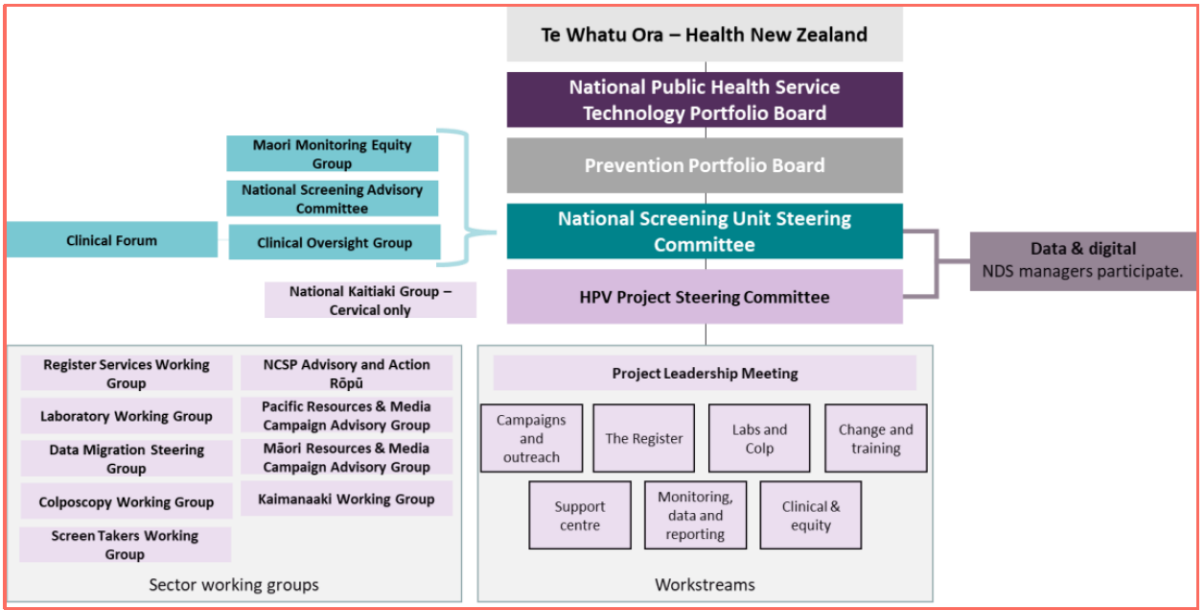

Figure 19. Summary of NCSP Register related risks rated 'High' – March 2025

High rated risk	Description	Mitigations planned
Register - Accuracy	If the data in the register is not accurate, then clinical pathways may not be followed, leading to adverse clinical outcome	NCSP team are working closely with central and regional register teams to support management of the new register. Regional Coordinator transitional support - SOPs have been developed to support management of the register. Monitoring reporting is under continuous improvement process with the SIA, D&D and clinical teams. Enhancement and remediation work for register functionality PMS integrations Updating Policies and Standards 07/2024 CQAC register review commissioned and in progress
Register - process automation	If pathway/process automation in the register is not correct, then clinical pathways may not be followed leading to adverse clinical outcomes	CSR development workstream Enhancement and remediation work for register functionality Remediation work: Migrated data Post go live issues Mismatched tasks Transition to BAU Notification strategy implementation 07/2024 CQAC review commissioned and in progress
Integration of IT systems and related services	If critical IT systems and related services are not integrated, then the effective running of the programme will be compromised, leading to an inability to respond to clinical and operational issues in a timely manner.	PMS integration workstream underway alongside Middleware and Deloitte. Clinical team work with Deloitte to correct errors in the register Remediation work with vendors (Gynae+, PMS, LIMS)

Appendix 5: National Simple NHI Data Extract Specification for the HPV Screening Programme' October 2023

It is specified that "contact" includes any of the following:

- Activity in the 'PRIMHD', the national mental health and addiction information collection
- Hospital discharge recorded in the 'National Minimum Dataset'
- Hospital emergency department or outpatient attendance recorded in the 'National Non-Admitted Patient Collection'
- Medication dispensed recorded in the 'PHARMS' pharmaceuticals database
- Visit date recorded in the 'LABS' community lab database
- Diagnosis in the Cancer database
- Service date recorded in the 'MAT' maternity collection database
- Visit recorded in in the Primary Health Organisation (PHO) data warehouse
- Visit recorded in the General Medical Services (GMS) database
- Rapid antigen test recorded
- COVID-19 Immunisation recorded.

Appendix 6: Summary of notifications review issues and fixes

Summary of issued identified by notification review

- '1.1' – Participants with a 'notified' pathway status[57] were not being sent reminder notifications as this pathway status was not included in the reminder logic. This had affected about 30,000 individuals.
- '1.3' – Participants who progressed to a 'registered' pathway status before notifications began being sent[58] were not being sent eligibility notifications. There were found to be 811,000 eligible participants with a 'registered' pathway status. Of these, 67% had an NHI profile activity field that was blank or more than three years inactive.
- '2.2' – This 'gap' affected three sub-groups of individuals who did not receive notifications during the 'transition period' of 12 September to 11 December 2023.
    - Enrolment – An enrolment letter should be sent after a participant's first test result is sent to the Register, but 11,000 participants had been moved to the 'Enrolled' pathway status before this notification was enabled and so their letters had not been sent.
    - No More Screening - 223 participants with a pathway status of 'Unenrolled' had not been sent a 'no more screening' letter. As such, they had not been informed of having been unenrolled from the programme and were therefore responsible for their own screening.
    - Over 70 Acknowledgement – About 11,000 participants were marked 'unenrolled', due to being over 70 years of age, during the transition period. Over 70 acknowledgement letters were not sent to these participants and so they were not notified that they had exited the screening programme and would no longer be invited to screen.
- '2.3' – Participants moving from a blank or 'Unregistered' programme status to 'Enrolled' were not captured by the enrolment notification logic. For example, where a test result was returned following early screening of a participant under 25 years old. About 3,000 individuals were said to have been affected. This was classified as a technical design 'gap', but no planned fix was mentioned in the notification review.
- '5.3' – Due to a data migration issue, about 100 participants requiring a repeat HPV or LBC test from the previous register were sent the wrong notification. They had received overdue reminder letters, intended to be sent when the initial recall screening test has not been completed, rather than a letter to remind them to do a repeat HPV or LBC test due an unsatisfactory result.
- '6.2' – Reminders for a follow-up co-test following colposcopy were only being triggered at a three-month interval and not also annually as per other reminder

[57] 'Notified' was a new pathway status introduced as part of the ELG0 flow. This new pathway status was not included any other notification flows as a valid pathway status. Therefore, no further notifications (like reminders) sent. Only if a participant receives a test result will they move into a different pathway status.

[58] 'Registered' was the pathway status of newly eligible participants during the transition period of 12 September to 11 December 2023 or to participants already eligible prior to the transition period who were unscreened but known in the population database.

notifications. Those who were already overdue by more than three months when the new Register was launched would therefore not receive any reminders. 28,000 participants were more than three months overdue at go-live and so affected by this issue. The notification review highlighted that these participants were, "…in a pathway status that are considered to be higher clinical risk".

- '11.1' – 'No More Screening' letters for participants who had opted out had been turned off since 2 February 2024, while an issue with Gynaecology Plus messages was resolved. 242 of these letters had not been sent as a result. It was noted that, "Messages were being received from clinics where the specialist had recommended 'none' as the follow up which was unenrolling a participant and sending a NMOR notification in inappropriate circumstances." 17 individuals had been inappropriately removed from screening. A Register fix was being developed to raise a task if a clinic selects 'none' as follow up so this can be manually reviewed before unenrolling a participant.

Summary of Register fixes introduced as of 25 November 2024, according to 'NCSP Notification Review Action Tracker on Key Findings'

- Reminder notification 'REM0' logic was amended to allow for these to be sent to participants in a 'Notified' pathway status. It was noted that there remains a large, fixed volume of approximately 30,000 priority ethnicity participants awaiting a 'catch-up' notification.
- A clinical decision was made to align the 'REM2' reminder frequency to 'REM0' and 'REM1' – i.e. at three and 12 months post next expected event date. Thereafter, fixes were introduced to address the issue of reminders not being generated at three months for participants on annual co-test pathway and to automatically trigger 'REM2' to be sent annually. A 'catch-up' batch of 460 reminder letters was sent to participants on an annual co-test pathway, with a next expected event date between November 2023 and 17 July 2024. It was noted that there remains a cohort of approximately, 18,200 individuals with an next expected event date prior to March 2022 for whom reminder notifications are outstanding.
- A fix was introduced to re-enable the sending of 'no more screening' notifications following completion of a change to Gynaecology Plus. A one-off 'catch-up' batch of these letters was sent to participants that have should have received them either during the transition period or while the notification was turned off.
- A bulk update of primary care enrolment data for approximately 1.1 million individuals was completed, increasing enrolment data in the Register to about 1.47 million as of September 2024. Integration of the Register with the National Event Management Service[59] (NEMS), to enable frequent automated updates to enrolment data, was deployed on 25 February 2025 accompanied by another manual bulk upload of enrolment records.
- Register fixes were implemented to stop the creation of Support to Screening services referral tasks for priority participants, to close open referral tasks, and to send reminder notifications at three months for all participants, including priority populations. A 'catch-up' batch of 308 'REM1', 'REM0 CR2', and 'REM0 CR3' reminder notifications were sent. It was noted that there remains a large, fixed

[59] NEMS is an event broker system enabling notification of data changes from one system to multiple other systems, such as a patient's change of address or their presentation to an emergency department.

volume of approximately 16,200 participants who we were awaiting a ‘catch-up’ ‘REM0 CR1’ notification.

- It was also described that work was underway to address issues of participants being sent enrolment notifications inappropriately, such as when they had already been screening in the previous programme. Work was being done with the NCSP clinical team to map requirements for “un-enrolment and re-enrolment scenarios before progressing with solution refinement and implementation”. Once requirements were complete, the fix was then to be prioritised, ‘early in 2025’. It was also recommended that the wording of the enrolment notification be changed to be more inclusive of re-enrolment scenarios, e.g. acknowledging the first test result in the new programme, rather than wording suggesting it was the first screening test done by the participant, for those who had taken part in the previous programme.

Appendix 7: Discharge to referrer messages

- Follow-up timeframe mismatch - if the follow-up is not within the expected timeframe for the associated follow-up test type, a task is created for RCT to check with the colposcopy clinic and ask them to resubmit the colposcopy message with a correction if this is found to be required. While the task is unresolved, the person's pathway status and next expected event date are likely to be incorrect. This means the Register either cannot track for the next event or is tracking for the wrong event.

  The NCSP has assessed the clinic risk associated with this as 'low'. This is because, 'this group has already been seen and treated in colposcopy', 'the screen-taker… may well have the correct follow-up, and if incorrect is likely to err on the side of overscreening', 'given follow-up testing is likely to be recommended for 6-12 months after the colposcopy visit, there is time to resolve these tasks'.

- Follow-up test type not populated - if the follow-up test has not been populated, a task is created for RCT to request the colposcopy clinic to resubmit the colposcopy message with the follow-up test type included. The participant's tracking is not automatically updated until a corrected message is received.

  The NCSP has assessed the clinic risk associated with this as 'low', for the same reasons as noted for follow-up timeframe mismatches above. It is also noted that, 'The monthly numbers for this are now low (<10 /month). This is due to the guidance/training to clinics to reinforce the importance of adding the Follow-up Test Type which had resulted in these reduced volumes of tasks being created.'

- Discharge review - if the follow-up test type is "No Further Screening Required", a task is created for RCT to review the participant's history to determine the appropriate update of their screening e.g. unenrolment.

- Discharge without visit – a message is sent by the colposcopy clinic when the participant is discharged from colposcopy without having had a visit. Participants in this scenario may have been discharged for a variety of reasons including if they declined the visit, elected to be seen by a private clinic, if the clinic visit was missed and no contact was able to be made, the individual has moved overseas. Tasks are created for all messages of this type. Regional Coordinators manage these tasks and follow-up with the participants where possible or refer them on to Support to Screening services. These discharge without visit scenarios have been noted to carry different levels of clinical risk. The participant's tracking is not automatically updated and must be manually updated as appropriate.

Appendix 8: Completed data remediation

Documentation provided to the review panel describes several data remediation issues which have been resolved since the Register's go-live date, including:

- Raising tasks for participants who have been unenrolled through Gynaecology Plus messaging discharging "None" follow up – remediation completed July 2024
- Screening History Data Store not updated with manually added test results/clinical events – remediation completed August 2024
- Removing pregnancy indicators for all participants on the register – remediation completed October 2024
- Removing booking priority from referral messages as they are displayed incorrectly based on code mapping which was agreed at go-live – remediation completed November 2024
- Clinical event tasks that were incorrectly closed on unrelated events, are reopened if necessary and are resolved and the participant is in the correct pathway – remediation completed November 2024