Communications plan: Issue relating to address updates in bowel screening register

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Issue:

A review of Bowel Screening Pilot (the Pilot) records during the transition to the National Bowel Screening Programme has found that a number of people eligible to participate in bowel screening were not sent screening invitations.

This was due to a technical issue related to the updating of addresses in the Bowel Screening Pilot register. This issue has been corrected for the National Bowel Screening Programme. An external review (root cause analysis) is underway to determine how and why this problem happened.

The National Screening Unit (NSU) has a policy of open communication when errors occur. This strategy outlines a plan for informing affected individuals about this issue and telling them what action has, and is, being taken.

Background:

A review of the Pilot records has found that some people who were eligible to participate in bowel screening were not sent their screening invitations when their addresses were updated in the bowel screening register. For a small number, this may have resulted in their bowel cancer diagnosis being delayed.

The Ministry of Health regards this incident as serious. Steps have and are being taken to:

- contact affected individuals and their families
- improve processes to prevent it happening again
- find out how and why this happened via an external review (root cause analysis)

In 2011, the Bowel Screening Pilot was launched in the Waitemata DHB area, offering screening to eligible people aged 50 to 74 years. This is an invitation-based programme. Anyone not wanting to take part is required to notify the programme of their decision to opt out, either through notification from their GP or by contacting the programme themselves.

Due to a technical issue related to the updating of addresses in the Pilot register (which is the subject of an external review) some people, who could not initially be contacted because of outdated addresses, were not sent new invitations when their addresses were updated.

Updated address details are now known for approximately 2,500 people. Those who are still within the eligible age range, and who live in a DHB area which offers bowel screening (Waitemata, Hutt Valley or Wairarapa) will be sent new bowel screening invitations.

Significantly, three people in this group have been identified as having been diagnosed with bowel cancer during the time between their address information being updated and it being identified that they had not been sent a new screening invitation. One of these three people has died.

It is not possible to say whether the outcomes for these three people would have been different, had they received their invitation to take part in bowel screening. This is because of a number of factors. These include:

- not everyone sent a screening invitation takes part. About half of those who are invited go on to do the test.
- the screening test detects blood in the bowel motion, and some cancers do not bleed all of the time. This means that cancer can sometimes be missed.
- not everyone who receives a positive test result chooses to progress to further investigation (usually colonoscopy).

Despite this, the Ministry acknowledges that these people weren't offered the opportunity to have their cancer detected at an earlier stage, and for that it is sincerely sorry.



Actions:

Immediate action was taken when this issue involving the Pilot register was identified. It has been corrected, and does not affect the National Bowel Screening Programme register.

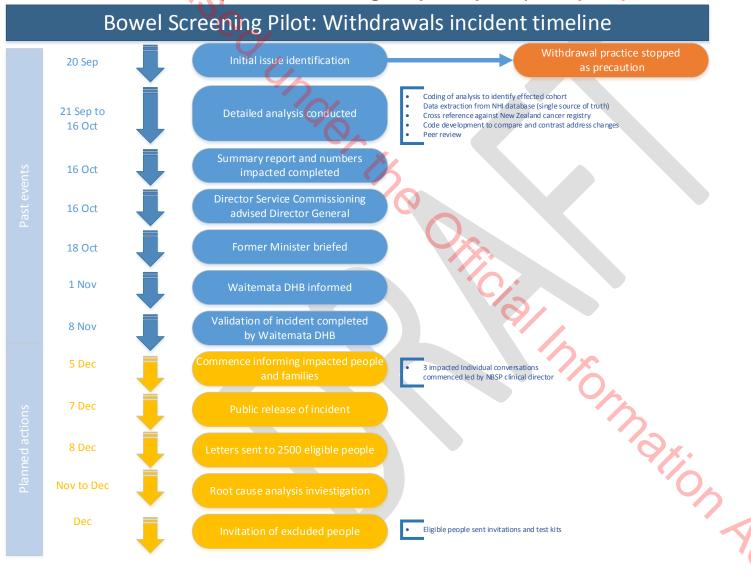
An external review (root cause analysis) is underway to determine how and why this problem happened.

Jane O'Hallahan or Susan Parry will contact the GPs of the three people directly affected, to explain what has happened and inform them of the Ministry's intention to contact those affected or their families by phone, in person is preferred, and then by email or mail.

Letters will be sent to the approximately 2,500 people, to acknowledge the delay in them receiving their screening invitation and let them know they will be invited within the next few weeks.

Key messages and a holding statement have been developed for reactive use. No proactive communication, beyond the contact with the three individuals directly affected and those who are being sent new invitations, is planned.

Timeline of events (withdrawal of eligible participants)* not yet updated to reflect no public release



Risks and mitigation

Risk	Mitigation
Someone who believes their bowel cancer would have been detected if they'd had the chance to participate in bowel screening will go to the media	 Ensure care of those directly affected is comprehensive and that the Ministry is doing all it can to address any harms Alert those affected to likely media interest and possible consequences of engaging Have a media release/holding statement drafted and ready to go
Public confidence in the NBSP will suffer	 Demonstrate actions to address harms and ensure system errors have been fixed
Participation rates for the NBSP will reduce	Emphasise that action has been taken, including the commissioning of an external review which is underway. Repeat key messages about bowel cancer rates and importance of screening, as adjunct in all communications related to these issues.

Key messages

- The Ministry apologises to those who were eligible for bowel screening but, due to a technical issue, were not sent invitations to take part.
- The Ministry accepts this may have caused harm to some individuals and their families, and takes this matter very seriously.
- As soon as the issue was discovered, immediate measures were taken to identify individuals who may have been affected.
- The Ministry is in the process of contacting affected people and/or their families.
- Those whose address details have been updated and who are still eligible for screening will be sent a letter advising that they will be sent a new invitation and text kit within the next few months.
- An external review is underway.
- The Ministry of Health encourages New Zealanders to take part in the free bowel screening programme when they're invited. Bowel cancer, when detected in its early stages, can often be successfully treated.

Draft media release/holding statement

Review of bowel screening invitation processes

The Ministry of Health has improved its processes to ensure that people eligible for free bowel screening are invited to take part.

This follows the discovery that around 2500 people who were eligible to take part in the Bowel Screening Pilot did not receive their invitation. This was due to a technical error related to the updating of address details in the screening register.

The Clinical Director of the Ministry of Health's National Screening Unit, Dr Jane O'Hallahan says, of the 2500 people affected, the Ministry has identified three people who have developed bowel cancer; including one who has died.

Dr O'Hallahan says, "It is impossible to say whether the outcomes for those three people would have been different if they had been given the opportunity to participate in bowel screening; but they didn't get that chance and for that we are very sorry.

"We are in the process of contacting that small group of people. We will be explaining what happened, offering an apology and doing all we can to support them."

Dr O'Hallahan says the issue was discovered in September when data from the Bowel Screening Pilot was being reviewed as part of the transition to the National Bowel Screening Programme.

"It relates to the updating of address details in the bowel screening programme register. Procedures have been changed and an external review is underway to try to determine exactly how and why this happened, with findings expected to be released by March 2018.

"The National Screening Unit takes full responsibility for this issue, and for ensuring it is appropriately investigated. We want to emphasise the crucial role that the Bowel Screening Pilot has played in learning about how best to provide a safe and effective bowel screening programme throughout the country," Dr O'Hallahan says.

Those whose updated address details are now known, and who are still within the screening age-range and living in a DHB area where bowel screening is available, will be sent a new invitation and screening test within the next few months.

We encourage anyone who has any questions or concerns to contact the National Bowel Screening Programme information line on 0800 924 432, or email info@bowelscreening.health.nz.



Background (for inclusion with media release):

- The Bowel Screening Pilot has invited 185,000 people for screening since it started in 2011. A recent review has shown that approximately 2,500 people who should have received a screening invitation did not.
- Three of these people have been identified as having been diagnosed with bowel cancer; one of whom has died.
- In order to protect the privacy of this small number of individuals, the Ministry will not be releasing any details which could lead to them being identified.

Bowel screening:

- Hutt Valley and Wairarapa District Health Boards (DHBs) became the first DHBs to join the National Screening Programme, in July 2017. All other DHBs will follow in stages.
- This is an invitation-based screening programme. To be invited people must be aged 60 to 74 years, and eligible for publicly funded health care.
- The Bowel Screening Pilot ends in December 2017. Waitemata DHB, which has managed the Pilot, will become part of the National Bowel Screening Programme in January 2018. As of 31 March 2017, a total of 375 people who returned a positive bowel screening test as part of the Bowel Screening Pilot had gone on to be diagnosed with bowel cancer.
- Homecare Medical has been awarded the contract to manage the bowel screening National Coordination Centre. Coordination centre services
 have now transitioned from Waitemata DHB to Homecare Medical. This contract was announced in August, before the issue relating to address
 updates was identified.

Bowel cancer:

- New Zealand has one of the highest bowel cancer rates in the world.
- Bowel cancer is the second highest cause of cancer death in New Zealand.
- Each year, more than 3000 people are diagnosed with bowel cancer and more than 1200 die from the disease.

- Bowel screening every two years can save lives by helping find bowel cancer at an early stage, when it can often be successfully treated. There may be no warning signs that you have bowel cancer.
- Bowel cancer is more common as you get older, particularly from the age of 60.
- It's important to note that:
 - the screening test detects blood in your bowel motion, and some cancers do not bleed all of the time. This means that cancer can sometimes be missed.
 - bowel cancer may start to develop between screening tests.

This is why regular screening is important.

• If you notice any possible symptoms of bowel cancer, such as blood in your bowel motions or a change in your normal bowel habit that continues for several weeks, it is important that you talk to your doctor.

Draft Letter to eligible participants

Dear

Our records show that we sent you an invitation to take part in the free bowel screening programme, but you did not receive it due to a change of address.

Although your address has now been updated in our system, a technical issue has caused a delay in us sending you a new invitation. We apologise for this delay. This problem has been corrected.

We will send you a free bowel screening test kit within the next few weeks. We recommend you do the test, as screening can help detect bowel cancer at an early stage when it can often be successfully treated.

Bowel screening is for people who don't have any symptoms of bowel cancer. It's important that you talk to your doctor if you notice any possible symptoms of bowel cancer. These could include blood in your bowel motions (poo), or a change in your bowel habit that lasts for several weeks.

If you have any questions you can call the bowel screening information line on 0800 924 432 for free, or email info@bowelscreening.health.nz. Information on bowel screening is also available at www.bowelscreening.health.govt.nz and in the All About Bowel Screening booklet that came with this letter.

Yours sincerely

Dr Susan Parry

Clinical Director (Gastroenterologist) National Bowel Screening Programme