

Security classification: In-Confidence

Quill record number:
File number: AD62-14-2018
Action required by: 6 April 2018

Memorandum: Bowel Screening Pilot invitation issues

To: Hon Dr David Clark, Minister of Health

Purpose

This memo provides information on two new issues that have been identified in relation to the identification and invitation of eligible people within the Bowel Screening Pilot.

Background

1. In November 2017 you were informed of an incident that had occurred in the Waitemata DHB Pilot (the Pilot) where eligible people were incorrectly excluded from participating in bowel screening and as a result three people could have been harmed as their diagnosis may have been delayed.
2. On 31 January 2018 your office was informed that a new issue had been identified in the pilot that may have resulted in people not receiving invitations following an address update as an address override code had been applied to their record. This may result in participants having their diagnosis of bowel cancer delayed.
3. On 12 February 2018 you announced an independent review assurance review of the National Bowel Screening Programme. This review has commenced and is being led by Professor Gregor Coster.
4. On 4 April 2018 the Ministry informed your office that two new invitation issues have been identified that has resulted in eligible people not receiving an invitation for screening.
5. The Bowel Screening Pilot was transferred to the National Screening Unit in late 2016 and since that time there has been ongoing audit and review of the Pilot systems and processes as part of the preparation for the introduction of the National Bowel Screening Programme in July 2017.
6. The National Coordination Centre received two phone calls in late February 2018 following the publicity of the earlier incidents from two members of the public who had not received an invitation for screening during the Pilot. The details of these people were passed onto the NSU for further investigation. In addition in late March 2018 Waitemata DHB informed the NSU that they had been made aware of a person who also indicated they had not been invited.
7. Following detailed review of the records of these three people and the systems and processes used in the Pilot the NSU has identified two further issues related to invitation processes in the Pilot.

Issue 1: "do not load list"

8. The original Bowel Screening Pilot (BSP) Register (the Register) was created in 2011 and included the 50-74 age cohort in the Waitemata DHB area. It was created using an extract from the National Health Identifier (NHI) that enabled the identification of the eligible cohort for the Pilot in the Waitemata DHB area.

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9. This extract was about one third larger than the census based population estimates and it was agreed at that time that the extract included a large proportion of records of people who were not accessing health care (i.e. had moved out of the region, or were foreign visitors).
10. A process was undertaken using a tool called "Health Tracker" that identified people who had not had contact with the health system for at least 2 years or more (the exact time period is unclear at this point). This created a list of people labelled the "do not load list". Anyone on the "do not load list" was automatically removed when records were loaded against the Register. It appears during the Pilot this list was not regularly checked to identify people who may have become eligible.
11. With the extension of the Pilot in 2015 to six years, a refresh of the Register was undertaken by using the NHI database. This refresh process allowed for ongoing identification of people newly eligible for the programme (i.e. turning 50 years of age or had moved into the Waitemata DHB area). It appears that these people were inadvertently added to the "do not load list" rather than invited.
12. The "do not load list" contains the records of 87,749 people. Detailed analysis shows that the vast majority of the people on the list have not had contact with the health care system for a long period of time and should not be invited.

Impact of the do not load list

13. The "do not load list" includes the records of 87,749 people of these¹:
 - a. 9,540 people from this list should have been invited for screening.
 - b. 31 people (of the 9,540) have a diagnosis of bowel cancer on the New Zealand Cancer Registry.

Actions:

14. The use of the "do not load list" was stopped on 4 April 2018 when this issue was confirmed.
15. Waitemata DHB was informed on 4 April 2018.
16. A communication plan, inclusive of invitation and timelines is being progressed in conjunction with Waitemata DHB and the National Coordination Centre for the invitation of the 9,540 people eligible for screening. This will be provided to your office early next week. It is necessary to carefully plan the invitation of this cohort of people to ensure sufficient colonoscopy capacity is available at Waitemata DHB to support a temporary increase in volumes.
17. A change is required to the information system to enable the invitation of people for the full Pilot age range (50-74). The Pilot identified that the age range for the National Bowel Screening Programme to 60-74.
18. Analysis is being undertaken to identify the timeline and pathway of the people who have had diagnosis of cancer on the NZ Cancer Registry.
19. Following the analysis the NSU will follow the same protocol as for the previous issue which includes:
 - a. Commissioning a clinical review of those participant's records with a diagnosis of bowel cancer to ascertain whether or not the delay in invitation due to the address override issue has had an adverse impact on their outcome and may have caused harm.
 - b. Undertaking a process of open communication, through their General Practitioner with participants who may have been harmed by not receiving an invitation during the Pilot.
20. Continuous monitoring of results for the people invited for screening and support as required.
21. Eligible people on the "do not load list" who ring up the Coordination Centre can be added manually to the Register.

¹ Note that the numbers of people affected may vary over time as the data is pulled from a live system.

Issue 2: Simple NHI

22. This issue relates to a data script (called “the simple NHI data load”) developed for the Pilot in 2015. This script is a set of codes that is used to build the population register for the Pilot. It identifies the eligible people and checks this against a number of other health care systems (e.g. PHO register) to find newly eligible people who have had contact with the health care system in the previous three years. This data set is provided by the Ministry's Data Warehouse team to the NSU on a weekly basis and is loaded to the Register and new people are then invited to the programme.
23. The NSU has identified the records of people with multiple NHIs were not appropriately updated. This means that a small cohort of eligible people may not have received an invitation for screening.

Impact of the “Simple NHI issue”

24. It is estimated that approximately 200-300 people may be affected by this issue, however further work is required to determine exact numbers and explore whether any people within this group have a diagnosis of bowel cancer on the New Zealand Cancer Register.

Action to date

25. The data script has been amended to appropriately identify and update people with multiple NHIs.
26. Invitation of these people has automatically started now the script has been amended.
27. Waitemata DHB was informed on 4 April 2018.
28. Further data analysis is being undertaken to determine whether any of these people have a diagnosis of bowel cancer on the NZ Cancer Registry and the same protocol will be followed for any people with a bowel cancer diagnosis as for the “do not load list”.

Additional assurance work being undertaken

29. Since the identification of the first issue in November 2017 the NSU has continued to correct anomalies and put systems and processes in place that will provide assurance around the invitation process, this includes:
 - a. A senior analyst continuously reviews all data anomalies across the screening pathway for all participants.
 - b. A tool to measure invitation cohorts for each DHB against census data to identify significant differences between these two parameters.
 - c. An NSU Public Health Medicine Specialist is embedded within the National Coordination Centre to be the first port of call to discuss and resolve any issues that may arise in relation to invitation, recall and pathway.

Risks

30. There is an ongoing risk that further issues may be identified in the pilot system. The NSU is mitigating this risk by applying analytical processes and tools to monitor invitation processes and participant pathways. These tools are continuously being updated and improved to provide assurance in relation to processes used during the pilot.
31. The Terms of Reference of the independent assurance review includes an in-depth review of the BSP and associated operational processes to provide advice and assurance on its functionality to support the NBSP in the initial roll out phases (DHB 1-8) and as the programme continues to be rolled out.

END.