

## **Research Letter**

# **Testing outside of the National Bowel and Breast Cancer Screening Programs in Queensland, Australia.**

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### **Key words**

breast cancer; bowel cancer; screening; population screening programs; reporting

### **Abstract**

Bowel and breast cancer testing outside of the national programs is not routinely recorded in Australia limiting our ability to monitor and estimate true screening coverage. This study makes preliminary estimates of the proportion of eligible participants who test for bowel and breast cancer outside of national programs using a large convenience sample of 31,065 cancer risk calculator respondents. Logistic regression was applied to assess difference in cancer testing both within and outside respective programs between demographic groups. Almost one third (9456 respondents) were aged between 50 and 74 years and eligible to participate in the National Bowel Cancer Screening Program (NBCSP) with 8073 female respondents additionally qualifying for the national BreastScreen program. Out of 4166 respondents who reported not to participate in the NBCSP, over 2000 (48.4%) reported 'screening' outside the NBCSP. For breast cancer the rate of self-reported screening outside BreastScreen was even higher, with 2442 (73.8%) of 3308 respondents who did not participate in BreastScreen reporting undergoing testing elsewhere. Interestingly, outer regional or remote residence was associated with lower participation within the NBCSP (OR = 0.92;  $p = .05$ ) and higher testing outside of BreastScreen (OR = 1.21;  $p < .05$ ) screening programs. Findings provide preliminary support for the need to better understand the volume of cancer testing taking place outside the national programs and to address reporting gaps within the health system.

### **Introduction**

In Australia, free faecal occult blood tests (FIT) and mammography examinations are delivered through national population screening programs for bowel (NBCSP) and breast cancer (BreastScreen), however, only 41% and 55% of eligible people participate in these programs respectively (1,2). In the case of bowel cancer screening, it has been suggested that up to 30% of invitees who do not return their FIT kit may receive screening or surveillance testing outside of the program (3,4). Bowel cancer screening (via colonoscopy or FIT) and breast cancer screening (via mammogram and/or ultrasound) that occur outside of the national programs is not routinely recorded in Australia. This limits our ability to monitor and estimate true screening coverage, to measure progress towards population screening participation targets and to identify where recommended screening pathways are not being followed.

This study utilises a large convenience sample of 31,065 cancer risk calculator respondents to 1) make preliminary estimates of the proportion of respondents who self-report 'screening' for bowel and breast cancer outside of respective national and 2) describe the socio-demographic characteristics of this group. Findings will inform whether efforts are required to more formally record these data and/or to address public and healthcare provider adherence to recommended screening practices.

### **Methods**

The analysis utilised data collected through an online cancer risk calculator designed by Cancer Council Queensland (CCQ) to raise individuals' awareness of their modifiable cancer risk behaviour. The cancer risk calculator is an online tool available on the CCQ website and advertised to the Queensland community via a large, wide-spread social media campaign. It collects health behaviour data from users and gives them information on how much they are currently reducing their cancer risk based on their responses. The calculator included questions regarding whether individuals participated in national bowel and breast cancer screening programs or whether they screened outside of these programs (see Appendix for exact question wording). Although the word 'screening' was used in the question, the distinction between true asymptomatic screening and undergoing a test or procedure for surveillance or diagnostic purposes was not made, meaning responses likely refer to both. Hence, we refer more broadly to *testing* for cancer herein. Ethical approval for the use of this data was granted through a University Human Ethical Research Committee (ref. H20REA282)

Data were collected during August and September 2020. A total of 31,065 individuals completed the Cancer Risk Calculator in this time. The percentage of respondents who reported testing outside of each program were calculated and multivariate logistic regressions were conducted to test associations between age, gender (for bowel only), geographical remoteness and socio-economic status (SES) and testing outside each program. The socio-economic status was assessed on an area level using the Australian Bureau of Statistics' (ABS) Socio-Economic Indexes for Areas (SEIFA) tool (5) which ranks areas in Australia according to relative socio-economic advantage and disadvantage. Inner regional and outer regional/remote categories were compared with the major city category and polynomial and deviation contrasts (i.e., all levels compared to Quintile 1) were assessed for SES quintiles. Analyses included respondents who were eligible for the NBCSP, i.e. people aged between 50 and 74 years (n = 9456), most

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of whom were female (85.4%) and therefore also eligible for BreastScreen. The majority of respondents were Queensland residents (96.7%) and living in major cities (67.5%).

### Results

Almost one third (9456 respondents; 8073 female) were aged between 50 and 74 years and eligible to participate in the NBCSP and/or the national BreastScreen program. Of these, 5281 respondents (55.9% of eligible) participated in the NBCSP and 4760 (59.0% of eligible) participated in BreastScreen. Almost half ( $n = 2019$ ; 48.4%) of respondents who did not participate in the NBCSP and three quarters ( $n = 2442$ ; 73.8%) of those who did not participate in BreastScreen reported testing outside of the programs. This suggests that a large proportion of people undergoing testing for bowel or breast cancer, do this outside of the national screening programs. In our test population, the reported testing rate outside the national screening programs was as high as 21.4% for bowel cancer and 30.0% for breast cancer. It has to be taken into account that these high respondent-reported numbers are likely to reflect surveillance testing of individuals with (perceived or actual) higher cancer risk as well as true screening activity outside of the national program, since the risk calculator tool's questions did not distinguish between these.

Older age (OR 1.29 for BreastScreen, OR 1.66 for NBCSP;  $p < .001$ ) and higher socioeconomic status (OR 1.21 for BreastScreen and OR 1.17 for NBCSP;  $p < .05$ ) predicted participation in the national screening programs. Compared to people living in major cities, living in outer regional or remote areas was associated with lower participation within the NBCSP (OR = 0.92;  $p = .05$ ) and higher testing outside of BreastScreen (OR = 1.21;  $p < .05$ ). People 65-74 years old who did not participate in the NBCSP were more likely than younger people to report testing for bowel cancer outside of the program (OR 1.60;  $p < .001$ ).

### **Discussion**

This study shows that a large proportion of people who completed an online Cancer Risk Calculator reported testing for bowel and breast cancer outside of the respective free national cancer screening programs. This is in stark contrast to the current national data in Australia showing the percentage of invitees who deferred, opted out or skipped a screening round is reported as only 5.6% of the eligible population (2). This indicates that there may be an as yet un-accounted for proportion of the population that does complete testing outside the national programs but is not recorded as 'deferred, opted out or skipped' within the national programs.

Results from this sample suggest that national program participation records alone may not accurately estimate cancer screening coverage particularly in older age groups and outer regional and remote areas. However, to generalise this finding to the wider-population, replication in a more representative, gender-balanced sample is needed as it is likely that those motivated to complete the calculator generally had higher levels of motivation around cancer prevention. To better understand screening behaviours outside of the program, more detailed information should also be collected on the reasons for screening outside of organised programs to distinguish between screening for diagnostic and surveillance purposes. In addition, data should be collected on which alternative screening methods are accessed. These alternative screening methods should then be assessed, as public health messaging may be required to ensure that people who do screen outside of national programs are doing so using safe, appropriate and evidence-based alternatives.

Despite the sampling limitations, these findings provide preliminary support for the need to better understand the volume of cancer screening and surveillance testing taking place outside the national programs and to address reporting gaps within the health system. In Australia, data on screening invitations, participation and pathology are held by various public

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and private providers and not easily linked, making it difficult to capture true screening coverage in the same way that it might be captured in international settings with universally public health care. For example, although clinicians are expected to report all colonoscopies to the National Cancer Screening Register, reporting remains inconsistent (6), and currently there is no mechanism for providers of private breast screening services in Australia to share data with the national registry meaning private mammography rates along with the use of other screening procedures such as ultrasound remain unknown.

In the absence of a single-payer health care system, like those established in the UK and many European nations, Australia must rely on a co-ordinated approach to reporting from private and public vendors. Establishing mandatory reporting or alternate means of data supply such as data linkage networks for colonoscopy and FIT results, and all forms of breast cancer surveillance and diagnostic procedures would substantially increase our ability to capture the true level of screening coverage in the Australian population. Development of a system that utilises patient records and clinical management software to record and provide patients' screening histories to a national register may be one way to approach this issue.



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**Table 1.** Socio-demographic sample characteristics of respondents aged between 50 and 74 years (n = 9456)

	<b>n (%)</b>
<b>Age</b>	
Under 65 years	7382 (78.1%)
65 years and older	2074 (21.9%)
<b>Gender</b>	
male	1377 (14.6%)
female	8073 (85.4%)
<b>Geographic remoteness</b>	
Major city	6385 (67.9%)
Inner regional	1820 (19.4%)
Outer regional and remote	1200 (12.8%)
<b>Socio-economic status (quintile)</b>	
1 (lowest)	1049 (11.2%)
2	1281 (13.7%)
3	1739 (18.5%)
4	3245 (34.5%)
5 (highest)	2080 (22.1%)

Valid percentages reported here.

**Table 2.** Socio-demographic predictors of program participation and screening outside the program.

Indicator	Bowel			Breast			Bowel			Breast		
	<i>Participated in program</i>						<i>Screened outside of program</i>					
	n (%) <sup>†</sup>	OR	CI	n (%) <sup>†</sup>	OR	CI	n (%) <sup>^</sup>	OR	CI	n (%) <sup>^</sup>	OR	CI
<b>Age</b>												
50 – 64 years	3932 (53.3%)	1.00	-	3649 (57.8%)	-	-	1599 (46.4%)	1.00	-	1954 (73.3%)	1.00	-
65 – 74 years	1349 (65.2%)	1.66**	1.50 – 1.84	1111 (63.4%)	1.29**	1.15 – 1.44	420 (58.3%)	1.60**	1.36 – 1.88	488 (76.1%)	1.18	0.96 – 1.44
<b>Gender</b>												
male	763 (55.5%)	1.00	-	-	-	-	299 (48.9%)	1.00	-	-	-	-
female	4516 (56.0%)	1.03	0.91 – 1.15	-	-	-	1718 (48.4%)	0.97	0.81 – 1.15	-	-	-
<b>Geographic remoteness</b>												
Major city	3588 (56.3%)	1.00	-	3223 (59.3%)	1.00	-	1346 (48.3%)	1.00	-	1626 (73.4%)	1.00	-
Inner regional	1031 (56.6%)	1.07	0.99 – 1.16	942 (60.3%)	1.10*	1.01 – 1.20	371 (47.0%)	0.91	0.80 – 1.03	447 (72.0%)	0.87	0.75 – 1.02
Outer regional and remote	641 (53.4%)	0.92*	0.84 – 1.00	582 (56.8%)	0.93	0.85 – 1.02	287 (51.3%)	1.10	0.97 – 1.25	344 (77.8%)	1.21*	1.02 – 1.43
<b>Socio-economic status<sup>#</sup></b>												
		1.17**	1.04 – 1.32		1.21**	1.06 – 1.38		0.98 <sup>#</sup>	0.82 – 1.17		1.01 <sup>#</sup>	0.80 – 1.27
1 (lowest)	559 (53.3%)	Ref. <sup>†</sup>	-	515 (57.0%)	Ref. <sup>†</sup>	-	238 (48.6%)	Ref. <sup>†</sup>	-	284 (73.0%)	Ref. <sup>†</sup>	-
2	698 (54.5%)	.96	.87 – 1.06	640 (57.9%)	.96	.86 -1.07	275 (47.2%)	.94	.81 – 1.08	346 (74.2%)	.99	.82 – 1.19
3	1008 (58%)	1.11*	1.01 – 1.21	896 (60.0%)	1.04	.95 -1.15	369 (50.5%)	1.09	.95 – 1.24	449 (75.1%)	1.06	.89 – 1.25
4	1825 (56.2%)	1.04	.97 – 1.2	1616 (58.5%)	1.00	.93 -1.09	693 (48.8%)	1.01	.91 – 1.13	838 (73.0%)	.96	.83 – 1.10

5 (highest)	1165 (56.1%)	1.05	.96 – 1.15	1077 (61.4%)	1.15*	1.04 -1.27	428 (47.0%)	.95	.83 – 1.09	499 (73.8%)	1.02	.85 – 1.21
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n (%)<sup>y</sup> = number and valid percent of people participating in program from total sample, n (%)<sup>^</sup> = and number and valid percent of people screening outside of program from people who did not participate in program; OR: Odds Ratio, CI: 95% Confidence Interval; # linear effect via polynomial contrast testing; †OR derived from deviation contrast testing;

\*\*p<.001, \*p <.05