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Screening for colorectal cancer in remote, rural and metropolitan South Australia: analysis of the National Bowel Cancer Screening Program data

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Context and background

The early detection of colorectal cancer (CRC) is a major clinical and public health concern. CRC is now the second most commonly diagnosed cancer in Australia and has the second highest cancer mortality rate.¹ Around 1 in 19 men and 1 in 28 Australian women will develop the disease before 75 years of age.¹ In 2005 there were 4165 deaths from CRC in Australia, accounting for almost 11% of all cancer deaths.¹ Cancer mortality rates vary according to the remoteness of a person's place of residence.² The average annual death rate for CRC during 1998–2001 in Australia was highest in inner and outer regional areas (13.4% and 13.3%), followed by major cities (12.8%), remote areas (12.4%) and very remote areas (7.7%).² Survival is inversely related to the degree of cancer progression, and up to 90% of all deaths from CRC may be preventable with early detection.³

A number of randomised controlled trials have demonstrated the effectiveness of CRC screening for reducing its incidence and mortality. However, these benefits have been limited by a number of factors including the accuracy of screening technology,⁷ the willingness of eligible populations to participate,⁸ access to CRC screening^{4,5} and primary healthcare practitioners,⁹ geographical location,¹⁰ Indigenous status, and a range of social, demographic and economic factors.^{14,15}

The Australian CRC population-based screening program, the National Bowel Cancer Screening Program (NBCSP), was implemented in South Australia (SA) in January 2007. The NBCSP aims to facilitate Australia-wide access to CRC screening services. Phase one of the program (August 2006 – June 2008) offered free screening by faecal occult blood test (FOBT) to people recorded on the Medicare and Department of Veterans Affairs registers who turned 55 or 65 years of age between 1 May 2006 and 30 June 2008 (the NBCSP Register). The FOBT screening kits were also offered to people who had been invited to screen in the 2003 NBCSP and who were aged between 55 and 74 years on 1 January 2003. Eligible participants were sent invitation packages by Medicare that included an immunological FOBT kit, and were requested to mail their FOBT sample to a central pathology service for analysis. Participants who returned a positive result were advised by mail to visit a general practitioner (GP) to arrange further examination.

However, provision of the NBCSP to all population subgroups does not result in equity in screening uptake. In SA disparities exist in bowel cancer screening participation. People of male gender, in lower age groups, of lower socioeconomic status, from culturally and linguistically diverse (CALD) groups, and Indigenous people have lower rates of participation. This result is consistent with the national statistics on NBCSP participation rates.

Aim of study

This study aimed to explore the association between screening participation and different sociodemographic indicators in SA. This was part of a broader study that included a qualitative exploration of the barriers to and facilitators of NBCSP participation among selected ethnic groups, Indigenous Australians and people who speak English at home. This paper also draws on these qualitative findings in discussing the uptake of screening in rural, remote and metropolitan areas of SA.

Study design and methodology

The project was conducted over three stages, employing a mixed methodology approach including a literature review and quantitative and qualitative methods.

In stage 1, de-identified data for the South Australian population invited to participate in phase one of the NBCSP (between January 2007 and July 2008) were provided by Medicare Australia. The dataset included

the age, sex and postcode of those people sent the FOBT (i.e. invitees—the denominator in participation rates) and the age, sex, postcode, Indigenous status and language spoken at home of those who completed the FOBT (i.e. participants—the numerator in participation rates). Ethics committee approval was granted by the Departmental Ethics Committee of the Commonwealth Department for Health and Ageing and by the Social and Behavioural Research Ethics Committee of Flinders University.

The postcode variable was converted into two new separate variables for use in the analysis. First, each postcode was coded according to the Index of Relative Social Disadvantage (IRSD),¹⁶ a composite measure based on selected Census variables such as income, educational attainment and employment status. The IRSD scores for each postcode were then grouped into quintiles for analysis, where the highest quintile comprised the 20% of postcodes with the highest IRSD scores (the most advantaged areas). Second, each postcode was converted into a measure of 'remoteness' using the Accessibility/Remoteness Index of Australia (ARIA).¹⁷ This is an index of the accessibility of postcodes to service centers or, conversely, of remoteness of postcodes. The ARIA has both a 5-point and a 3-point scale. We chose to use the 3-point scale, which includes the categories of metropolitan, rural and remote areas.

Stage 2 of the study employed a qualitative method to explore barriers to, enablers of and cultural appropriateness of bowel cancer screening in SA. In-depth interviews were conducted with three population subgroups. Group 1 included South Australians from three ethnic groups: Greek, Vietnamese and Iranian. Criteria for selection of ethnic groups were based on population size in SA, average population age, average length of stay in Australia, resources available to ensure study feasibility, and whether the community had already been studied on this question. The second group included Anglo-Australian residents who were native English speakers. Based on our postcode mapping in stage 1, we selected locations with the highest and lowest rates of participation and advertised in local papers in selected areas to recruit study participants. Group 3 included Indigenous Australians living in SA. Participants were selected from males and females aged between 50 and 75 years.

Data analysis

Statistical data were analysed using the Statistical Package for the Social Sciences version 15.0. In total there were 92279 invitees during phase one of the NBCSP (January 2007 to July 2008 in SA), including the 17497 who had been involved in the pilot phases of the NBCSP. The pilot invitees were removed from the data analysis because their prior exposure to CRC screening may have had a confounding effect on NBCSP participation. Therefore, our final dataset for analysis included 74782 South Australians who had been invited to undertake CRC screening for the first time by the NBCSP. It was not possible to ascertain if these people had previously been offered, or participated in, CRC screening.

Mapping and analysis of the NBCSP data was performed by placing Australian Bureau of Statistics (ABS) Census of Population and Housing data and NBCSP data for Adelaide into a geographic information system (GIS) using ESRI ArcGIS software, MapInfo, Microsoft Access and Microsoft Excel. Data was aggregated to postcode and participation was then mapped according to overall participation rates, sex and age. Postcodes with less than 20 participants (9 in the Adelaide Metropolitan area and 48 in rural and remote SA) were considered to have insufficient data for mapping.

Bivariate analysis using chi-square (χ^2) tests was undertaken to analyse the associations between participation in the NBCSP and sociodemographic variables (age, sex, Indigenous status, language spoken at home, IRSD and ARIA). All variables associated with NBCSP participation rate at the $p < 0.25$ level¹⁸ at a univariate level were then entered as independent variables into a logistic regression analysis (block-enter method), with participation rate in the NBCSP as the dependent variable. The final multiple regression model was checked for collinearity and included only those variables that were statistically significant and added to the fit of the model.

Qualitative data were analysed in the following manner. Following transcription and checking for accuracy, interview data were loaded into the qualitative software package NVivo 8. A coding structure that combined inductive and deductive elements was developed by Sara Javanparast (co-author) in collaboration with the other research team members. The coding structure emphasised the following key concepts

from the research questions—perceptions about disease prevention, perceptions about cancer and cancer prevention, knowledge and experience about bowel cancer, participation in bowel cancer screening, barriers and enablers for screening test uptake, cultural issues and recommendations. In addition to these deductively derived codes, the team also generated codes inductively to capture unexpected concepts in participants' accounts. This combined coding structure was used to code all of the data, and the same structure was applied across all study groups to enable comparisons between groups.

Results

Stage I: Epidemiological analysis of the NBCSP in South Australia

Based on the findings of stage I, 46.9% of invitees of the SA NBCSP agreed to participate in the program by completing and returning their FOBT and participant details form. Our findings revealed that rates of participation varied according to place of residence, gender, age, socioeconomic status, ethnicity and Indigenous status. Table 1 profiles the South Australian NBCSP participants within these categories.

Figure 1 shows the overall participation rates in rural and remote SA for phase^a one of the NBCSP, plotted for each postcode region.

Postcode

In the Adelaide Metropolitan region there were generally higher participation rates in the south and east, and lower participation rates in the centre, west and outer north. Geographical variation in participation rates was also revealed in rural and remote SA, with higher participation in the south-east. The highest participation rate in rural SA was 70%, compared with 79% in the metropolitan area (Figures 1). However, in the north, east and west of regional SA, there were large areas excluded from analysis because of insufficient invitees per postcode.

ARIA

Overall participation rates were similar in metropolitan and remote areas (45.6% and 46.0% respectively) and rates were slightly higher in rural areas (48.6%). The rural and remote SA participation rates were statistically significantly different ($p < 0.001$) by gender (46.7% for males and 53.3% for females), age (45.2% for 55 year olds and 52% for 65 year olds) and socioeconomic

status (43% in most deprived quintile through to 50% in most affluent quintile).

Table 1: Profile of South Australian NBCSP participants

Characteristics	Metropolitan		Rural/ remote		Total
	n	%	n	%	
Gender					
Male	12447	45.1	3223	46.7	15670
Female	15126	54.9	3684	53.3	18810
Age (years)					
55 to 58	25700	56.9	3705	53.6	29405
65 to 67	11869	43.1	3202	46.4	15071
Indigenous status					
Neither	26489	96.1	6612	95.7	33101
Aboriginal nor Torres Strait Islander	72	0.3	37	0.5	109
Indigenous (Aboriginal, Torres Strait Islander, South Sea)	1012	3.7	258	3.7	1270
Not stated					
Language at home					
English	24984	90.6	6751	97.7	31735
Other	2589	9.4	156	2.3	2745
SEIFA					
Lowest	3863	14.0	1245	18.3	5108
Low	4610	16.8	2417	35.5	7027
Middle	5493	20.0	2065	30.3	7558
High	5720	20.8	1036	15.2	6756
Highest	7831	28.5	52	0.8	7883

SEIFA: Socio-Economic Indexes for Areas

Age

Participation across SA was 42.8% for 55 year olds and 51.2% for 65 year olds. These figures demonstrate a statistically significant difference in participation rate on the basis of age ($p < 0.0001$).

^a Additional graphs representing rural and remote SA and metropolitan Adelaide phase one NBCSP participation rates by age, gender and postcode are available from Paul R Ward (paul.ward@flinders.edu.au).

Gender

The participation rate was higher for women (49.9%) than men (43.9%). In the Adelaide Metropolitan area there were generally higher participation rates in the south-east and lower rates in the centre, north and north-west. Similar patterns of gender disparity in screening participation were found in rural and remote areas, with significantly more postcodes recording high female participation rates of 60–100% compared with male rates.

IRSD / SEIFA

Participation rates varied significantly ($p < 0.001$) by IRSD quintiles and SEIFA classifications. There was a gradient in participation linking increasing affluence with increasing participation, although, after the middle quintile, participation rates began to plateau. The participation rate for the lowest IRSD quintiles was 40% compared with 48.1% for the highest quintile.

Language other than English

The dataset included details of the language spoken at home for the NBCSP participants (but not for invitees), which is particularly important for a postal screening program. Given the large number of languages spoken, we created a dichotomous variable for comparison purposes—spoke English only at home versus spoke a language other than English at home. Of the people who participated in the NBCSP, 8.0% (CI 95% 7.7–8.3%) reported speaking a language other than English at home, compared with 17.0% for the same age group in SA in the 2006 Census.¹⁹ As this proportion is not within the confidence interval of the sample, the proportion of NBCSP participants who spoke a language other than English at home was statistically significantly lower than we would have expected. This suggests an inequity on the basis of language spoken at home.

Indigenous status

Self-reported Aboriginal and Torres Strait Islander status was available only for participants who completed the FOBT, with the Indigenous status of invitees who failed to return their FOBT unknown. The total proportion of Indigenous participants was 0.24% (CI 95% 0.20–0.30%). Given that the reported proportion of Indigenous people of the same age group within SA in the 2006 Census was 0.54%,¹⁹ and that this proportion is not within the confidence interval of the sample, the

proportion of Indigenous people who participated in the NBCSP was statistically significantly lower than we would have expected. However, given that we do not have sufficient details about the Indigenous status of invitees, we cannot compute an overall participation rate.

Stage 2: Participant interviews

The second stage of the study explored participants' perceptions about cancer and cancer prevention programs (with a focus on bowel cancer), as well as barriers to and facilitators of bowel cancer screening uptake. In total we interviewed 114 people: 24 Iranian, 23 Greek, 24 Vietnamese, 27 Anglo-Australian and 16 Indigenous.

In general, the majority of our participants were preventive oriented and used the maxim 'prevention is better than cure'. A wide range of actions were reported by study participants as measures to promote health and prevent disease, including healthy eating, physical activity, regular medical check-ups, mental health and stress management, avoiding smoking and alcohol consumption, and building social capital through community group involvement and as serving community members. A number of themes were identified, the most common being a double identity of cancer, a lack of awareness about bowel cancer and screening, and facilitators of and barriers to screening uptake.

Double identity of cancer

The concepts of cancer and cancer prevention were discussed during interviews. Our study showed that cancer has a double identity within population groups. At one end of the spectrum cancer is perceived as a dreaded, feared and horrible disease. However, at the other end it is seen as a treatable disease like other chronic diseases. These two framing identities, although completely contradictory, exist side by side in the community. Importantly, the Anglo-Australian group were more likely to emphasise the second framing, while the other groups identified the first framing, seeing cancer as an incurable disease leading to death.

Lack of awareness

With respect to bowel cancer, our study revealed a lack of awareness about the disease and its screening tests among all members of study groups. A large number of the participants did not have any information about

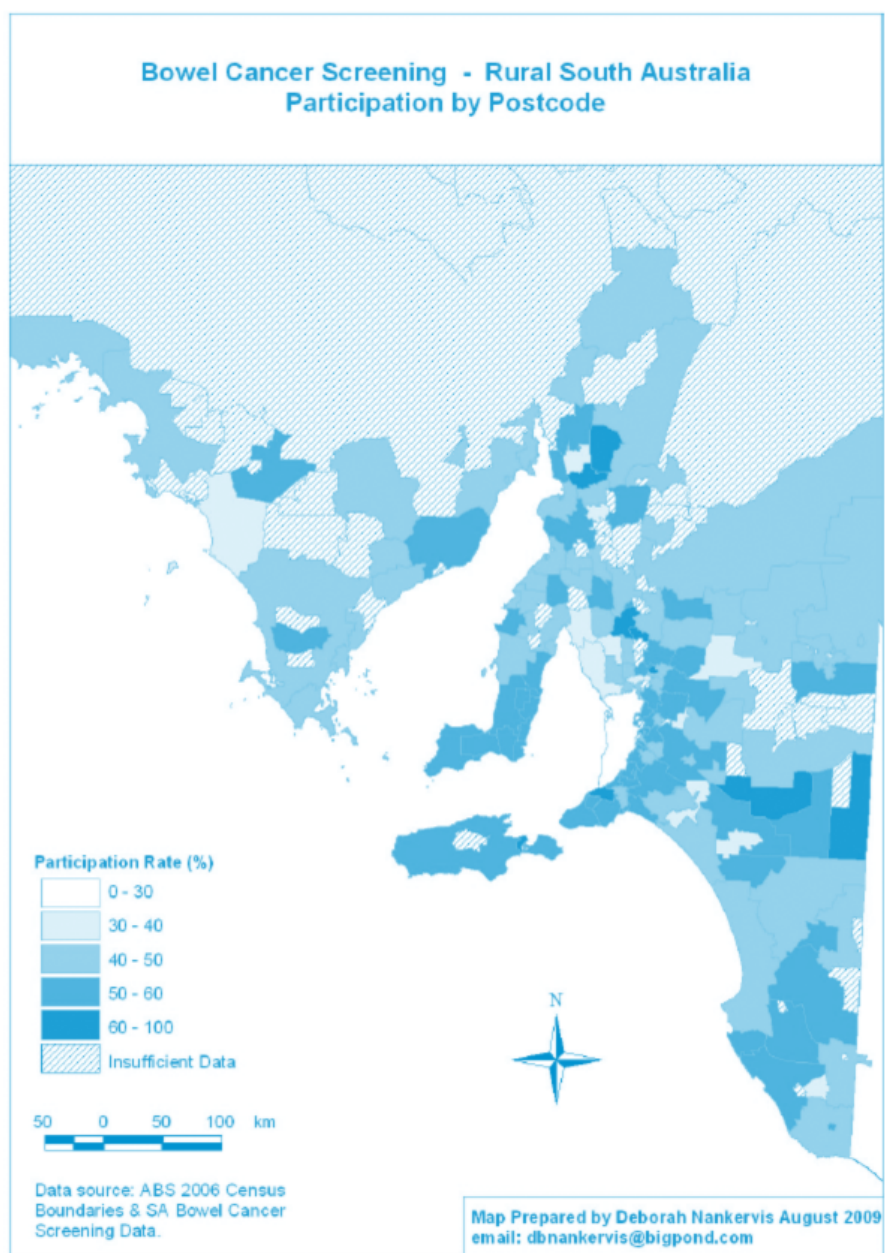


Figure 1: NBCSP participation rates in rural and remote South Australia by postcode

Data Source: Australian Bureau of Statistics 2006 Census Boundaries and SA Bowel screening data.
Map prepared by Deborah Nankervis, August 2009.

bowel cancer or the national screening program. Suggestions to overcome the lack of awareness about bowel cancer included public education using national and local media, culturally friendly sessions and national campaigns.

Facilitators to screening

Factors that were considered to be facilitators of screening uptake were peace of mind, the chance to detect cancer in the early stages, no cost for the test, having a personal history of cancer, being able to do the test privately, having done other screening tests,

doctors' recommendations, obligation and respect to what is offered for peoples' health, reminder letters and being encouraged by family and friends.

Barriers to screening

Based on the barriers identified by different groups of participants, a few remedial actions were recommended to improve the rate of participation in the NBCSP. Overcoming language barriers was commonly recommended by people with different ethnic backgrounds. The engagement of medical practitioners in the program was the most effective action suggested by many of the Anglo-Australian people. The most frequent barriers to bowel cancer screening cited by the study participants were embarrassment, doubt about test accuracy, difficulty in dealing with faeces and sending the sample via mail, lack of knowledge about the screening test, a fatalist view about cancer and unwillingness to know the result, fear of doing further invasive tests, inability to read English and following the instructions, and lack of a physician's recommendation.

Discussion and conclusion

In this study we examined the association between sociodemographic characteristics and screening participation among those aged 55 and 65 years in metropolitan Adelaide and rural and remote SA who had received a written invitation to participate through the NBCSP. In order to gain a deeper understanding of the barriers and facilitators of screening participation, we also conducted qualitative interviews with Indigenous people and other cultural groups who speak a language other than English at home (Greek, Vietnamese and Iranian people), as these are known to have lower participation rates. For comparative purposes Anglo-Australian people were also interviewed.

Overall, our analysis revealed lower NBCSP participation rates for men compared with women, for populations residing in areas of relative disadvantage, for 65 year olds compared with the 55 year old group, and for people from metropolitan and remote areas compared with those from rural areas. In addition, comparison with the most recent Census data indicated that South Australian participants in the NBCSP who reported speaking a language other than English at home, and those who reported an Indigenous background, were under-represented. These differences in screening

participation rates, while potentially explainable in part by other factors, highlight the high likelihood of inequity for CRC screening in SA. These findings are consistent with results from other cancer screening programs, which suggest that inequitable patterns of participation may arise from a variety of factors including those associated with gender,^{20,21} ethnicity,^{22,23} socioeconomic status^{24,25} and Indigenous status.^{26,27} The uptake of cancer screening is particularly poor for older rural and remote residents, men, Indigenous people, lower socioeconomic groups and those living in Far North SA.

Our findings are also consistent with the national data on CRC screening participation for metropolitan, rural and remote areas, with people of male gender, in the younger of the two age groups (i.e. aged 55 years at the time of screening), living in areas of relative disadvantage, who do not speak English at home, and Indigenous people having lower rates of participation. While there are common and group-specific barriers and enablers that prevent or facilitate screening uptake nationally, this study revealed that group-specific inequalities also exist within NBCSP participation in SA. While being preventive oriented, identifying cancer as a treatable disease was less evident among the ethnic groups and Indigenous people interviewed. A sense of dreading the disease combined with poor awareness of screening and language difficulties may also contribute to explaining inequities in screening uptake.

This study did not address the inequity in opportunity to participate for some population subgroups, for example people who do not appear on the NBCSP invitee Medicare register, prisoners, those without regular mail service or the homeless. The overall participation rates also obscure the differences in rates shown on various maps.

Variation between regions in the rates of CRC screening of different subpopulations is conveniently visualised in the participation maps subdivided by postcode. The utility of such maps is to assist in planning services and interventions aimed at maximising participation in FOBT-based CRC screening. The maps also serve as baseline data for visualising the effectiveness of future interventions aimed at increasing participation, particularly in subpopulations.

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