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## What can We Learn From High-Performing Screening Programs to Increase Bowel Cancer Screening Participation in Australia?

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# What can We Learn From High-Performing Screening Programs to Increase Bowel Cancer Screening Participation in Australia?

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## Abstract

**Background:** Colorectal cancer (CRC) is the second most diagnosed cancer in men and women and second most common cause of cancer death in Australia; Australia's CRC incidence and mortality are among the world's highest. The Australian National Bowel Cancer Screening Program began in 2006; however, only 33% of those approached for the first time by the Program between 2018 and 2019 returned the kit. Of the 5.7 million kits sent during this period, only 44% were returned. Our aim was to identify practices and features of national bowel cancer screening programs in countries with similar programs but higher screening participation, to identify potential interventions for optimising Australian CRC screening participation.

**Methods:** We searched published and grey literature for CRC screening programs reporting at least 50% screening participation using postal invitation and free return of iFOBT home kits. Interviews were conducted with cancer registry staff and academic researchers, focused on participant and practitioner engagement in screening.

**Results:** National programs in Netherlands, Scotland, Denmark, and Finland reported over 50% screening participation rates for all invitation rounds. Shared characteristics include small populations within small geographic areas relative to Australia; relatively high literacy; a one-sample iFOBT kit; national registration systems for population cancer screening research; and screening program research including randomised trials of program features.

**Conclusions:** Apart from the one-sample kit, we identified no single solution to persistent Australian low uptake of screening. Research including randomised trials within the program promises to increase participation.

**Impact:** This screening program comparison suggests that within-program intervention trials will lead to increased Australian screening participation.

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## Keywords

screening, colorectal cancer, epidemiology, health care, population

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## Introduction

In 2021, there were 15,541 Australians diagnosed with colorectal cancer (CRC), and 5296 deaths from the disease.<sup>1</sup> It is the second and third most diagnosed cancer for women and men respectively and second only to lung cancer for mortality. The age-standardised rate of 33.1 per 100 000 population is among other high incidence countries (2020 estimates, see Table 1).<sup>2</sup> Early detection via screening with a faecal occult blood test or FOBT has been shown by randomised controlled trials in other countries to reduce CRC-related mortality.<sup>3</sup> Based on this evidence, as well as successful feasibility trials, the National Bowel Cancer Screening Program (NBCSP) was funded and officially launched in 2006 across Australia. As a phased roll-out, immunochemical faecal occult blood test (iFOBT) screening was offered to an increasing number of age groups each year, and by 2019 biennial screening was offered to all Australians aged 50-74.<sup>4</sup> In line with similar national bowel cancer screening programs, the Australian Screening Program sends a pre-invitation letter followed by the screening pack containing instructions, information, the kit to sample two separate bowel motions and a toilet liner, a return-paid envelope, and a single written reminder if the kit is not returned within 6 weeks.

Despite the proven benefits and ease of screening (the screening test kit is free, safe and samples for testing are collected in the home), participation in the Australian program has been low. Of all those approached for the first time by the Program between 2018 and 2019, only 33% returned the kit.<sup>(1)</sup> Of all 5.7 million kits sent in the same period (including Australians sent their first or subsequent kit), only 44% were returned.<sup>1</sup>

This under-participation in the NBCSP has important health implications and impact on the health budget. Modelling has determined that with a 40% participation in the screening program, approximately 70,000 colorectal cancer deaths would be prevented over 40 years; if participation could be increased to 60%, the number of prevented deaths would increase to 90,000.<sup>5</sup> Cost-effectiveness analyses have demonstrated that a 20% increase in screening participation would yield 37,300 fewer colorectal cancer diagnoses and 24,800 fewer deaths over 25 years, and would result in AUD \$400 million savings to the health budget.<sup>6</sup>

We suspect that overall increases in screening participation are feasible given participation rates are 10-20% higher in European national bowel cancer screening programs that employ similar postal test kit programs to the Australian program, albeit with single-sample tests.<sup>7</sup> The Australian

program has not yet tested invitation or test kit modifications via randomised trials to address low participation.

When considering potential reasons for non-participation (barriers), or identifying opportunities to increase screening (enablers), it is crucial to understand the process of the screening program including: the method of approach to the potential participant; the documentation provided with the home sampling test kit; the ease of home stool collection; and the method for returning the kit. It is also crucial to understand the public awareness, acceptance, and promotion of the screening programs, although these parameters are not part of this international comparison of screening programs.

Our aim was to identify practices and features of national bowel cancer screening programs in other countries with similar screening programs but with higher screening participation, to identify possible potential interventions for optimising Australian CRC screening at the individual level. We did not address population-wide interventions or targeted community-wide interventions to increase screening participation.

## Methods

National screening programs reporting at least 50% screening participation using a home iFOBT kit were identified from reviews and reports of international cancer screening comparisons in published and grey literature. We used the following search terms in Google and in PubMed to identify all national bowel cancer screening programs similar to the Australian program, i.e., a nationally-funded government program that mailed an iFOBT kit to the home of eligible citizens. The following search terms were used: "bowel cancer," "colorectal cancer," "colon cancer" AND "screening," "program," "national," "federal" AND "FOBT," "iFOBT," "FIT," "faecal occult blood test," "faecal immunochemical test," "fecal occult blood test," "fecal immunochemical test." All identified publications and websites were read to determine the programs similar in design to the Australian program. These were reviewed to determine the overall participation rate (proportion of kits sent that were returned). Screening program and cancer registry directors of these programs were contacted and invited with their staff to participate in interviews regarding protocols and participation.

The aim of the interviews with cancer registries and screening or research programs was to obtain a comprehensive understanding of screening processes and to examine the decisions taken to establish the pathway to testing and implementing interventions. Notes from interviews with

screening program and cancer registry experts were recorded (LF), then summarised and checked for thematic content (LF, MJ). At each screening program visit we asked:

- What is the standard pathway for recruiting, contacting, inviting and following up participants in these national screening programs?
- What factors that may influence participation have been studied?
- What health service and behavioural interventions were used to maintain and increase screening participation, particularly for those in the population at the lowest levels of participation?

For each site we sought information through searches for published cancer screening participation and published screening program trials for the following screening program features based on registry data, surveys, focus groups and/or clinical trials, including:

- The most recent participation rates (see [Table 1](#));
- Whether the kit invitations came from a trusted source;
- Screening invitation language, and instructions for use, storage and postal return of the kit;
- Form of the kit (one- or two-sample design);
- Primary care involvement in support of participation, including incentivisation and/or general practitioner information kit and training modules; and
- Trials of any interventions to increase participation of selected demographic groups.

### Human Research Ethics

This work was supported by the University of Melbourne, Melbourne School of Population and Global Health, Human Ethics Advisory Group. Project title: “Consultation to understand international differences in bowel cancer screening participation,” ID 2057312.1

### Results

Screening programs with features similar to the Australian National Bowel Cancer Screening Program (e.g., a postal invitation and free test kits for home sampling with free postal return) in the following countries were identified as having screening participation over 50%: the Netherlands, Denmark, and Scotland.<sup>7-11</sup> We also included the Finnish Colorectal Cancer Screening Program although the program ended in 2016, as this Program obtained a participation rate exceeding 50% using the guaiac FOBT; and national screening resumed in 2019 using the iFOBT. CRC as a ranked cause of cancer death in each country is discussed below. A summary of the key characteristics of these programs is given in [Table 1](#). Interviews with personnel at screening registries and research

centres informed the discussion of program features and further published trials, described below.

### Netherlands: Program Features and Participation Research

The **Dutch Bowel Cancer Screening Program** is a national screening program coordinated by the Centre for Population Screening of the National Institute for Public Health and the Environment (RIVM-CvB), supported by Erasmus University Medical Centre (Erasmus MC) for monitoring and evaluation, and Amsterdam UMC, University of Amsterdam for academic research. Colorectal cancer is the second most common cause of cancer deaths in this country (<https://www.cijfersoverkanker.nl/nkr/index>). After extensive piloting, the program began in 2014 with biennial iFOBT screening offered to 55-75-year-olds. It has centralised structured screening evaluation and monitoring oversight. The Program includes a biennial postal advanced notification and free postal kit return, a one-sample iFOBT, and a reminder letter for non-respondents. General practitioners do not have a direct role in the CRC screening program, rather they provide patient information when consulted. Research into screening participation has been embedded in the Dutch program from its start, including extensive pilot trials in the Dutch population. Cancer screening invitations are written to enhance informed decision-making about participation rather than increasing uptake.

Surveys and qualitative research were conducted to understand colorectal screening knowledge and attitudes. These included: discrete choice experiments for individual screening program features among screening-naïve and screening participants, showing that all features significantly influenced respondents’ preferences, especially type of bowel preparation, risk reduction of CRC-related death and length of screening interval<sup>12</sup>; questionnaires sent to participants to evaluate reasons for participation, showing the vast majority of participants decided to participate to learn more about their chances of developing cancer<sup>13</sup>; telephone surveys of non-participants to identify reasons for non-compliance, showing a low priority for screening in the majority of the reported reasons not to participate<sup>14</sup>; studies of the accessibility of the screening program among low health-literate screening invitees, based on analysis of the text and design of information materials that was then explored in interviews and an online survey<sup>15</sup>; qualitative studies of the health belief model among first-generation immigrants born in Turkey, Morocco and Surinam<sup>16</sup>; and focus group studies of health literacy and decision-making amongst people eligible for screening and health experts, identifying specific health literacy skills linked to decision-making stages for CRC screening, and differences in perceptions between screening invitees and experts, especially in perceived importance of CRC screening information for individual decision-making.<sup>17</sup>

**Table 1.** National Population-Based Colorectal Cancer Screening Programs With Free Postal Invitation and Return of Home Faecal Sample Test Kit (gFOBT/iFOBT), Australia Compared to High-Performing European Programs, 2017.

	Australia	Netherlands	Scotland	Denmark	Finland
Population in millions, 2017	25	17	5	6	5
Age-standardised rate of CRC per 100 000, 2020 <sup>1</sup>	33.1	41.0	34.1 [UK]	40.9	25.7
Program start	2006	2014	2000	2014	2004 [iFOBT 2019]
Percent uptake of combined screening rounds <sup>2</sup>	40.9 <sup>3</sup> iFOBT	73 <sup>4</sup> iFOBT	56.0 gFOBT <sup>5</sup> , 68.0 iFOBT <sup>6</sup>	63 <sup>7</sup> iFOBT	66.3 <sup>8</sup> gFOBT [79.3 iFOBT]
Index year for comparisons <sup>9</sup>	2015-16	2016	2015-17 gFOBT, 2017 iFOBT	2014-16	2014
Target age group for screening	50-74	55-74	50-74	50-74	60-69 [60-68 iFOBT]
Source of invitation and home sample test kits	Commonwealth of Australia (Medicare)	Regional health centres	NHS Scotland, Scottish Cancer Registry head	Regional screening units	National centre, via local municipal authority
Home sample test kit features	2 tube iFOBT for gains in sensitivity compared to 1 tube	1 tube	1 tube (2017)	1 tube	3 test cards gFOBT <sup>2004-16</sup> ; 1 tube (2019)
Research program and targeted interventions <sup>10</sup>	Indigenous Australians and Torres Strait Islanders	Low participation groups	Low participation groups	Low participation groups	

Trials were conducted on the effect of features of the screening program on increased participation. These included randomised trials demonstrating preference for iFOBT kits over the older technology guaiac faecal occult blood test (gFOBT) kits<sup>18</sup>; preference for ease of use in comparable iFOBT types<sup>19</sup>; addition of a reminder letter in the initial and subsequent rounds<sup>20</sup>; including an advanced notification letter in the screening pathway which increased participation<sup>21</sup>; and a faeces collection paper which did not increase participation.<sup>22</sup>

Monitoring of participation was conducted to identify any heterogeneity by ethnicity, with 25-50% lower participation for non-Dutch invitees compared to ethnic Dutch participants.<sup>23</sup> Modelling research was undertaken to gauge the impact of screening fatigue and decreased participation over time on the effectiveness of the program, after observing a second trial round drop in participation which was likely due to lower participation amongst previous screeners as well as first-time participants.<sup>24,25</sup>

### Scotland: Program Features and Participation Research

The NHS Scottish Colorectal Cancer Screening Program is located in Dundee, in association with the Colorectal Cancer Screening Research Unit, University of Dundee. Research support is located at the Centre for Research into Cancer Prevention and Screening, University of Dundee, the Institute

of Population Health Science, University of Edinburgh, and the Department of General Practice and Primary Care, Institute of Health and Wellbeing, University of Glasgow. Colorectal cancer is the second most common cause of cancer deaths in this country (<https://www.isdscotland.org/Health-Topics/Cancer/Publications/2018-10-30/visualisation.asp>).

The program began in 2007 with biennial gFOBT offered to those aged 50-74, and was fully rolled-out by 2009. Screening participation research has been part of the program from its start; transition to biennial iFOBT began in 2017.<sup>26</sup>

Surveys showed that participation from the start was lower in men, in people living with socio-economic deprivation and in younger end of the age spectrum, indicating a need for targeted interventions.<sup>27</sup> Analysis of prevalence and incidence screening also revealed that repeated invitation resulted in an overall increase in the number of people who eventually participated, supporting efforts to repeat invitations to those who initially declined screening.<sup>28</sup> The impact of primary care on screening participation is unclear; however, there is evidence from a feasibility study that a brief intervention consisting of a conversation and provision of written information during a routine consultation can result in a modest increase in participation.<sup>29</sup> A feasibility study of men attending for primary care abdominal aortic aneurysm screening who had not accepted their last bowel screening invitation were asked to consider a further bowel screening test. Those that agreed received a home sample test kit from the program, resulting in a 50% participation of bowel screening in those who had not engaged with the previous offer.<sup>30</sup>



Trials in the program included a pre-notification letter sent 14 days in advance of and separate to the formal invitation to participate and postal delivery of the home sample screening test kit<sup>31</sup> that increased screening participation by 5% for both men and women, across the deprivation gradient and in all age groups. As a result, pre-notification was introduced into the screening algorithm for national roll-out after 2011. Psychological interventions to increase participation included a three-arm randomised study in which all invitees to the gFOBT screening programme were sent either the normal invitation (control), a health locus of control questionnaire, or a health locus of control questionnaire containing additional questions to provoke anticipated regret. Screening participation was not affected by the health locus of control questionnaire alone; however, there was a 4.8% increase in participation in people with a weaker intention to screen after exposure to anticipated regret, suggesting that anticipated regret might be an effective strategy for previous non-responders.<sup>32</sup>

Monitoring of participation rates before and after the transition from gFOBT to the iFOBT began in 2017 showed that the iFOBT was associated with increased participation across Scotland.<sup>33</sup> Multivariate analyses showed that the iFOBT was associated with increased participation in men, in deprived groups and in the younger age ranges.<sup>34</sup> The reasons for this difference may be due to several factors including the iFOBT having a more hygienic collection device, the need for only one sample, and possibly the perception that the process is more technologically advanced or perceived to be more “scientific” than the card-based gFOBT system.

### **Denmark: Program Features and Participation Research**

The Danish Bowel Cancer Screening Program offers biennial iFOBT to residents aged 50-74 years. The Program is based on national screening guidelines issued by the Danish Health Authority and administered in each of the five Danish regions. The administration of the Bowel Cancer Screening Program of the Central Denmark Region covering 22% of the Danish population is located in the Department of Public Health Programmes at Randers Regional Hospital with Breast and Cervical Cancer Screening Programs, supported by a designated academic cancer screening research unit affiliated with Aarhus University. CRC is the third most common cause of cancer deaths in Denmark.<sup>35</sup> The Danish Health Authority launched the bowel cancer screening programme in 2010, with implementation of a 4-year prevalence round in 2014.<sup>36,37</sup> Ongoing qualitative and quantitative research programs are tracking participation in the screening program.

A qualitative study with a subsequent implementation study of a web-based decision aid to support those with lower educational attainment in making informed screening decisions has resulted in higher screening participation amongst

the study sample which has led to plans to employ the decision aid more broadly.<sup>38,39</sup> Tailored efforts to increase participation based on knowledge and perceptions of cancer screening among ethnic minority women are underway, based on results of individual and group interviews that stressed face-to-face screening instructions in participants’ language.<sup>40,41</sup> A randomised trial of invitation letters to increase participation was launched in 2019 as part of the Program’s quality assurance protocol. (Larsen 2019, personal communication).

Monitoring program quality via the national database measures participation rate, number of positive tests, adherence to colonoscopy and results of colonoscopies amongst other key performance indicators, with overall high program quality.<sup>42,43</sup> Participation rate at the end of the prevalence round was 61% with a positivity rate of 6.9% and adherence to colonoscopy of 90%. Participation rates were lower for men, ethnic minorities, people living alone, for those living on social welfare, and those with lower income.<sup>44</sup>

### **Finland: Program Features and Participation Research**

The Finnish Colorectal Cancer Screening Program database is located at the Finnish Cancer Registry, Cancer Society of Finland, Helsinki. The Cancer Society of Pirkanmaa, Tampere, was responsible for running the program in 2004-2016. An iFOBT-based pilot was launched in 2019 and has been ongoing since with one central laboratory, Fimlab Laboratoriot Oy Ltd, responsible for invitations and analysing the tests. CRC is the fourth most common cause of cancer deaths in women and third in men in Finland, but it is second in cancer incidence in both genders (<https://cancerregistry.fi/statistics/cancer-statistics/>). The former national program was designed as a randomised health services study and was based on mail delivery and return of the test-kits with a reminder letter approximately 8 weeks later if the test was not returned; test positives were referred for colonoscopy in the regional health care system. Local municipalities provide primary care including national screening programs and their implementation; however, the colorectal cancer screening program was organised on a voluntary basis in 2004-2016.<sup>45</sup> Initial monitoring of the randomised program roll-out and ongoing program evaluation has supported robust screening participation through the shift from gFOBT to iFOBT.

The gFOBT with three test cards per screening was used in this randomised health services study, achieving over 60% participation. By 2012, the program had expanded to include 43% of the target population aged 60-69 years. After evaluating preliminary results on mortality with a median follow-up of 4.3 years there was overall benefit for screening in those invited vs those not invited.<sup>46</sup> Due to these results, new individuals were not randomised into screened or control groups after 2014 and the program was discontinued after completion of follow-up in 2016.

Participation and other performance parameters comparable with other European screening trials and the increased

sensitivity of immunochemical tests led to resumption of CRC screening with an iFOBT-based test in 2019, coordinated centrally as a national pilot program.<sup>47</sup> This program targets people aged 60–68 years, and includes information on CRC screening, the test kit and instructions for the single sample, a return letter, and a questionnaire concerning e.g., family history and symptoms of CRC. Two reminders are sent to the non-participants at four and eight weeks. The overall participation rate at the initial round in 2019 was 79%, and the participation rate of women (83%) was higher than that of men (75%). By the reminder round, participation had increased by 25% in both sexes.<sup>47</sup> The pilot program will run through 2021, then colorectal cancer screening will be implemented nationally from 2022 with a target age group of 56–74 years eventually after a 10-year gradual expansion period. Screening legislation was updated in August 2021 to cover colorectal cancer screening from January 2022.

## Discussion

These high-participation screening programs in Scotland, the Netherlands, Denmark, and Finland vary slightly by the age range in the populations they are attempting to screen, and in minor features in the home sample test kit design and messaging. However, all programs including the Australian National Bowel Cancer Screening Program are functioning within a similar screening pathway and delivery system, across a similar population distribution, and approximately similar socio-economic gradient. What these programs do have in common are various roles for primary care in providing screening information and support, whether through individual general practitioners or through regional primary care centres; and the existence of incorporated research projects to understand characteristics of non-participants and low participation groups. Overall, there are as yet untested characteristics that may contribute to high participation in these four programs such as national registration systems for population cancer screening research. There may be additional features of messaging that stem from national differences in trust in government institutions that deliver services, or national differences in adult literacy that impact the success of health messaging, but these have not been formally tested.

There are few differences in specific features of the Australian screening program compared with the European programs apart from the two-sample iFOBT test kit. The Australian program uses a sampling kit and pathway similar to these European programs including instructional text and graphics and a paper liner for the toilet bowl. It has been observed that despite the very great geographic distribution of the Australian population across the continent, it is the variation in behavioural and lifestyle factors that are associated with differences in screening participation rather than geographic differences per se that are associated with higher cancer incidence and mortality in regional and remote areas compared to urban areas.<sup>48</sup>

The major difference between the Australian and European programs is that the European programs conduct research on program performance and participation, embedded within the respective national screening programs, whereas the Australian program does not. Although studies of advanced notification to increase screening participation have been used in the design of Dutch and Scottish programs, and are being trialled in the Danish program, and the Australian program does include advanced notification, these and other factors to improve participation have not yet been trialled within the Australian program. For example, Australian evidence for the impact of an advanced notification letter included randomised trials based on small samples of participants recruited outside the Program across a limited geographic area; thus the effect of the intervention across the national program invitees cannot be gauged.<sup>49</sup> Information material provided with the kit has been redesigned with input of health communication expertise,<sup>50</sup> but it is not yet possible to determine the effectiveness on increasing participation because the kit design was not randomised within the trial. Ongoing pilot research of an alternative pathway to the national program for indigenous Australians is embedded within the National Indigenous Bowel Screening Program (<https://www.indigenusbowelsscreen.com.au/>), rather than the national program. Thus, positioning a research program within the Australian screening program and/or facilitating external research on screening program invitees is an underutilised avenue to increase screening participation.

Possible explanations for the low Australian screening participation that we could not directly address by studying these successful European programs include international differences in the impact of trust in the government institutions promoting public health measures including screening; international differences in adult literacy rates which impact health literacy; and opportunistic screening participation occurring outside the national screening program. Further, screening participation research stems from international consensus that structural barriers such as diverse attitudes and primary care providers' knowledge do affect screening participation, as well as the diverse knowledge and belief barriers within the target populations.<sup>51</sup> These factors may well mediate the observed association of socioeconomic factors with screening participation.<sup>52</sup> For example, we note that ambivalence about CRC screening participation has been observed in some but not all Australian focus groups,<sup>53</sup> suggesting that there are complex drivers behind the low participation of Australian screening.

## Conclusion

Apart from the Australian reliance on a two-sample test compared to the wide-spread use of single sample test, our comparison does not reveal any specific interventions not used in Australia, that are used to ensure high screening participation amongst these European programs. However, we did note a common research and policy approach in these

programs that Australia should adopt—that of incorporating ongoing research trials within the screening program. Most promising are randomised trials in the screening program of measures to increase participation, which the Dutch Bowel Cancer Screening program, Scottish Colorectal Cancer Screening Program and the Danish Bowel Cancer Screening Program have initiated focussing on their screening invitees. We suggest that randomised trials of proven and novel interventions within the Australian National Bowel Cancer Screening Program may yield comparable robust findings to lift Australian screening participation to the standards of international high performance in colorectal cancer screening.

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### Data Availability

Data generated in this study are available upon request from the corresponding author.

### Ethical Approval

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### Notes

1. IARC 2020, Cancer Today GLOBOCAN, <https://gco.iarc.fr/today/home>
2. Percent participation overall for returned kits/invited participants, all screening rounds combined.
3. NBCSP Monitoring Report 2018 <https://protect-au.mimecast.com/s/FXWMCXLKNwFW0MzrhVmWEz?domain=aihw.gov.au>
4. RIVM 2018, personal communication (S Zelle), RIVM, National Monitoring of the Colorectal Cancer Screening Programme, 2016.
5. FOBT NHS Scotland, <https://protect-au.mimecast.com/s/KSbmCJypvAf7NoM5SVJIKn?domain=isdscotland.org>
6. FIT participation, 2018, personal communication (R Steele)
7. Danish Quality Report on Colorectal cancer screening 2014-16

8. <http://stats.cancerregistry.fi/joukkustilastot/suolisto.html>. Finnish gFOBT screening ended in 2016; FIT screening will begin roll-out in 2019.
9. This is the year used in the EU Cancer Screening Report to compare key performance indicators.<sup>7</sup>
10. These include research on potential interventions in screening program messaging to target under-represented groups, eg, Australian Aborigines (<https://www.indigenoussbowelscreen.com.au/community/>)

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