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Should women aged 70–74 be invited to participate in screening mammography? A report on two Australian community juries

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ABSTRACT

Objective To elicit informed views from Australian women aged 70–74 regarding the acceptability of ceasing to invite women their age to participate in government-funded mammography screening (BreastScreen).

Design Two community juries held in 2017.

Setting Greater Sydney, a metropolis of 4.5 million people in New South Wales, Australia.

Participants 34 women aged 70–74 with no personal history of breast cancer, recruited by random digit dialling and previously randomly recruited list-based samples.

Main outcomes and measures Jury verdict and rationale in response to structured questions. We transcribed audio-recorded jury proceedings and identified central reasons for the jury’s decision.

Results The women’s average age was 71.5 years. Participants were of diverse sociocultural backgrounds, with the sample designed to include women of lower levels of educational attainment. Both juries concluded by majority verdict (16–2 and 10–6) that BreastScreen should continue to send invitations and promote screening to their age group. Reasons given for the majority position include: (1) sending the invitations shows that society still cares about older women, empowers them to access preventive health services and recognises increasing and varied life expectancy; (2) screening provides women with information that enables choice and (3) if experts cannot agree, the conservative approach is to maintain the status quo until the evidence is clear. Reasons for the minority position were the potential for harms through overdiagnosis and misallocation of scarce health resources.

Conclusions Preventive programmes such as mammography screening are likely to have significant symbolic value once they are socially embedded. Arguments for programme de-implementation emphasising declining benefit because of limited life expectancy and the risks of overdiagnosis seem unlikely to resonate with healthy older women. In situations where there is no consensus among experts on the value of established screening programmes, people may strongly prefer receiving information about their health and having the opportunity make their own choices.

INTRODUCTION

The appropriate age at which to cease mammography screening remains contested.1,2 Screening older women for breast cancer is intuitively attractive as the incidence of this condition increases with age. But detecting a breast cancer early is not always beneficial. Cancers detected in older women are more likely to be slow growing,3 and breast cancer mortality as a proportion of all-cause mortality decreases with age.4 At the same time, the impacts and side effects of breast cancer treatments for older women are often exacerbated by concurrent disease burdens.5 Although breast screening may be beneficial for women aged 70 years and older who expect to live at least another 10 years, this must be weighed against the risk

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Strengths and limitations of this study

► Community juries are a deliberative method that involves a process of iterative two-way exchange of information between members of the public and experts. By providing extensive information from a range of experts, and ensuring conditions for reasonable and extended debate, community juries elicit more considered judgements than other social research methods such as surveys or focus groups.

► Women aged 70–74 were asked to deliberate on a well-defined question: whether they should be invited to participate in mammography screening.

► Consensus was encouraged but not required; the reasons jurors gave for their decision, and dissenting views and minority positions were also recorded.

► The sample size was small, but this is an unavoidable characteristic of community jury methods and is necessary for high-quality deliberation.

► Results were clear and sustained across two juries, therefore, it seems likely the findings are replicable in women this age who have participated in screening for several decades.
of harm due to false positives, overdiagnosis and the side effects of treatment in cases of breast cancer that were never going to cause clinical harm. The scientific data relevant to mammography screening for women aged 70–74 is mixed and limited, and experts are divided as to the balance of benefit and harm of continuing to screen older age groups. The Australian breast cancer screening programme (BreastScreen Australia) offers free biennial screening to women over age 40. Since 1991, women aged 50–69 years have been specifically targeted via individual letters of invitation. Until 2013, women older than 69 were able to access free screening services if they chose, but they did not receive biennial invitations and mammography screening was not actively promoted to them. In July 2013, BreastScreen Australia extended the target age group for breast screening by mammography from 50–69 years to 50–74 years. Supporting promotion and marketing campaigns were implemented to encourage women to participate. Participation by women aged over 70 in breast cancer screening has increased from just over 220 000 per annum to almost 270 000 as a consequence of these changes. There have been significant tensions in Australia over extending the target age for the BreastScreen programme, which have not been resolved by evidence of benefit and harm. It is often proposed that the solution is to give women the opportunity to make an informed choice about whether to undergo breast screening, supported by balanced, objective information, but the complexity and relative paucity of evidence on the effect of screening on this older age group makes this task difficult.

We report on two community juries convened to consider dilemmas raised by inviting women aged 70–74 to participate in mammography screening. Our aim was to elicit the informed views of Australian women aged 70–74 as to the acceptability and perceived legitimacy of continuing to invite women in this age group to the Australian mammography screening programme. Community juries are an established, appropriate method to achieve this. Unlike surveys and focus groups, the process involves extensive provision of information, constructive, structured dialogue between public and experts, and adequate time for consideration. The method assumes that people can think rationally and change their views should the evidence warrant it. The process is like a legal proceeding, but the outputs are not legally binding: instead they provide evidence of public values and the likely acceptability and perceived legitimacy of different policy alternatives to assist policy-making.

We consulted with major stakeholders (consumer organisations, epidemiologists, women’s health physicians and the Cancer Council of Australia) to determine the most appropriate questions for the community juries to consider (figure 1). Because of continued uncertainty as to the balance of benefits and harms of breast cancer screening in older women, all stakeholders agreed that the key issue to consider was whether BreastScreen Australia should continue to invite women aged 70–74 to participate in its programme. Even though a further change in policy is not currently being considered, the results of this study could be used to inform discussion and provision of information about overdiagnosis and overtreatment of screen detected breast cancer in older women and to inform future research on health communication. Additionally, the results may assist in developing policy in other jurisdictions where changes in the target age group for breast cancer screening are being

**Figure 1** The charge/question for the jury.
considered, such as the UK. This work was supported by an award from the National Health and Medical Research Council of Australia (CRE 1104136). The funding organisation had no role in the design, conduct, analyses or reporting of this study.

METHODS
Design and study setting
A community jury (similar to the proprietary method citizens’ juries) is a group of citizens brought together to receive detailed evidence about and deliberate on a specific issue. Community juries have been used in Australia and elsewhere to consider issues surrounding cancer screening. Community juries are a deliberative method, with these general characteristics:
1. A group of citizens is convened for 1–3 days.
2. They are asked to consider a specific issue.
3. They hear evidence from (often opposed) experts, and ask questions of those experts.
4. They are given time for deliberation, and to come to a conclusion, which is documented.

There are two main approaches to community juries. In the first, participants work as a group to draft open sets of recommendations on an issue; in the second, jury members vote on options presented by researchers. We used a combined approach (figure 1). Both juries were held over 2 days in May 2017 at the University of Sydney.

Participants and recruitment
We contracted an independent professional research service to recruit two juries of women aged 70–74 living in Greater Sydney, Australia from randomly generated list-based samples and random digit dialling. We selected women based on their sociodemographic characteristics, as well as their eligibility and availability. Because women born in the late 1940s are likely to have had more limited educational opportunities than subsequent generations, and because many of them are long-term residents of recently gentrified suburbs, we chose to prioritise the stratification of participant education levels in our recruitment strategy. Potential participants with a personal history of breast cancer (themselves or close family member) were excluded through a screening interview, as were health professionals and those working in breast cancer advocacy. Thirty-four women were recruited (table 1). The juries were socially and culturally diverse, sampling was skewed towards higher levels of socioeconomic advantage and lower educational attainment than the average for the Australian population (table 1). All jurors received a modest honorarium in recognition of their participation and contribution to jury processes and outcomes.

Procedures
Each jury commenced with an orientation session introducing the questions and the process, where written consent was also obtained. Jury day 1 focused on interrogating the epidemiological evidence and understanding basic cancer biology and common clinical and practical issues (table 2). Testimony from four experts was prerecorded and shown to jurors as video presentations. Experts were selected on the basis of their institutional roles, experience and expertise, to provide balanced and factual information and the best case ‘for’ and ‘against’ continuing to invite women their age. The expert presentations covered: (1) the varied nature and incidence of breast cancer, and common clinical care pathways and treatment outcomes in Australia; (2) the concept of overdiagnosis and the difficulties of evaluating the value of mammography screening for individuals and populations and (3) opposing perspectives on the efficacy and potential impacts of including women their age in mammography screening programmes (table 2). Each presentation ran for approximately 20 min. Prerecording ensured the format of the evidence presented was standardised across juries. Each expert’s biosketch and the video presentations shown to the juries are available online.

After each expert’s video was screened, we opened a conference call between that expert and the jurors for questioning. Facilitated by a researcher, these question and answer sessions allowed jurors to clarify or challenge the arguments presented, ask further questions, and raise and discuss practical and clinical

Table 1 Characteristics of jury participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Jury 1 (n=18)</th>
<th>Jury 2 (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>70–74</td>
<td>70–74</td>
</tr>
<tr>
<td>Median</td>
<td>71.64</td>
<td>71.24</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>18</td>
<td>16</td>
</tr>
<tr>
<td>Highest educational attainment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Trade/diploma</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>University degree</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Cultural background/ethnicity*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australian/New Zealand</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Southern/Eastern European</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Southeast Asian</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Northeast Asian</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Southern/Central Asian</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Northwest European</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Socioeconomic status of suburb†</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Middle</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>High</td>
<td>13</td>
<td>12</td>
</tr>
</tbody>
</table>

*Based on Australian Standard Classification of Cultural and Ethnic Groups. †Based on Socioeconomic Index for Area.
issues that were important to them. Participants asked the experts their individual questions directly via telephone, following a brief preparatory discussion among the group. At the end of the interaction with each expert witness, jurors were asked whether they were satisfied or had further questions. Because new issues can emerge and gain importance to jurors during the course of a citizens’ jury, expert witnesses remained available via email to answer any further questions that arose during subsequent proceedings. Facilitation focused on promoting constructive dialogue and fair interaction among jurors.

For the first hour and a half of jury day 2, jurors reflected on, discussed and debated the evidence, aided by a researcher acting as facilitator. Juries then deliberated for an hour without researchers present to come to a majority verdict on the questions posed and a set of recommendations. The verdict, underpinning reasoning and dissenting views were recorded to the research team in a final facilitated feedback session.

Data collection and analysis
The unit of analysis in this study is the deliberative group (jury). All jury deliberations (facilitated and unfacilitated) and expert question and answer sessions were audio recorded and transcribed. Previous research indicates that Australian women are generally enthusiastic about screening but have minimal awareness about overdiagnosis.\(^{25, 26}\) In our previously reported trial of a decision aid about whether to continue or stop screening among women aged 70 years, 78% reported a positive intention to continue screening at baseline.\(^{27}\) To track changes in the positions held by individual jurors, participants completed an anonymous ballot at three time points during jury proceedings (after they had been presented all the evidence at the conclusion of day 1; after they had had time to consider this evidence overnight at the beginning of day 2 and after the deliberation and delivery of the verdict at the end of day 2). Jurors also completed an Exit Survey for the purposes of process evaluation at the very end of the final jury session. During the final session of each jury, the verdict and reasons were recorded by a researcher on a flipchart. Each point was reviewed by the jury to ensure accuracy. Jury transcripts were subsequently reviewed to further explore and clarify the key reasons why jurors supported or rejected the presented options. In what follows we have summarised jurors’ own descriptions of the rationale and reasoning that underpins their responses to the question asked of them. In analysis of all the data collected, the differences between lay perspectives and those held by epidemiologists came into sharp focus and showed the challenges of changing how screening services are targeted and organised, and of communicating about screening risks, including overdiagnosis. For reasons of space in this paper, we will report only on the jurors’ response to PART A (figure 1). The response of the jurors to PART B, and a more detailed analysis of the values and priorities revealed during their deliberations will be reported elsewhere.

Table 2 Expert testimony provided to the community juries

<table>
<thead>
<tr>
<th>Expertise</th>
<th>Expert area</th>
<th>Data provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 Clinical epidemiology and family medicine (general practice)</td>
<td>Screening evaluation, clinical guidelines and overdiagnosis.</td>
<td>(1) Review of the benefits and harms of population screening (and how the balance between them changes with age). (2) The nature of overdiagnosis, overtreatment and their relationship to population screening programmes. (3) The importance and limitations of evidence in making decisions about screening.</td>
</tr>
<tr>
<td>3 Cancer control and cancer service management</td>
<td>Healthcare administration, cancer primary prevention and palliative care.</td>
<td>(1) Their expert opinion as to likely impacts and implications of ceasing to invite women aged 70–74 to participate in mammography screening. (2) The most compelling and important reasons for continuing to invite women aged 70–74 to participate in screening mammography.</td>
</tr>
<tr>
<td>4 Medical epidemiology, clinical trial design, execution and analysis</td>
<td>Women’s health epidemiology.</td>
<td>(1) Their expert opinion as to likely impacts and implications of continuing to invite women aged 70–74 to participate in mammography screening. (2) The most compelling and important reasons for ceasing to invite women aged 70–74 to participate in screening mammography.</td>
</tr>
</tbody>
</table>
Research question development was informed by our previous work with Australian women exploring their attitudes to screening and understanding of the concept of overdiagnosis.\textsuperscript{25–27} Patients or members of the public were not involved in study design or recruitment. Study results will be disseminated to participating member of the public through providing them with a one-page summary and copies of published reports.

**RESULTS**

Both juries reported a majority verdict that BreastScreen Australia should continue to invite women 70–74 to participate in the government-funded breast screening programme and promote participation to this age group. Table 3 shows that this position was more strongly held by jury 1 than Jury 2. Even though the overall balance of votes remained fairly stable during the course of both juries, analysis of the three time point ballots indicates that several participants changed their positions during jury proceedings (three in jury 1 and five in jury 2). Although some individuals changed their position, the overall majority position of the groups did not change. This is because individuals shifted in both directions—towards and away from supporting screening (table 3). The results of the Exit Surveys support our impression that all of the jurors were confident in their interactions with each other and the experts. Transcripts of questions and discussions during proceedings indicate that over the course of the jury proceedings the vast majority of the jurors comprehended concepts being discussed and that all of them understood the trade-offs implicit in the question we were asking them to address during their deliberations. While we avoided formally ‘testing’ participants so as not to intimidate them, the Exit Surveys for both juries show that all participants believed that the process was fair and that they had sufficient understanding of the evidence presented to discuss the issues important to them and come to a final decision. Table 4 illustrates the range of ways in which jurors justified their positions. The key reasons jurors gave for their decision are as follows:

**Reasons to continue inviting**

**Being invited to be screened has symbolic importance**

Many jurors said that extending the invitation to participate in screening to older women showed that society still cared about them. The invitations demonstrated ongoing investment in maintaining the health of older women. This relied on arguments that breast cancer remained relevant in this group (older women could still get a fatal breast cancer), arguments about life expectancy and arguments about the function of an invitation.

Health professionals cautious about screening in this age group argue that these women’s life expectancy is too short for them to benefit from screening. Women who said screening was symbolically important rejected the life expectancy argument, for two reasons: (1) average life expectancy was increasing; (2) some women lived much longer than average. Using average life expectancy to limit resources for early breast cancer detection was therefore seen as unfairly discriminatory. As a participant in jury 1 noted:

“Today a 70-year-old still has a lot to contribute to a society and needs opportunity to live a full and healthy life as any other citizen.”

In the ‘symbolic importance’ view, invitations had a certain function: they signified a respect/recognition that older women mattered, ensuring that women who wanted to continue to participate in screening knew they were still eligible. The invitation allowed women to decide for themselves if they still wanted information about their breast cancer status, and receive reassurance that they remained cancer free.

**Screening is different from treatment**

As indicated above, most participants held that receiving more knowledge about their health was beneficial, and saw screening simply as a source of such knowledge, enabling choice. It was good for a woman to know if she had breast cancer, even if the potential consequences were extremely uncertain. The jury process was crafted to ensure jurors understood the extent and significance of this uncertainty. Nonetheless, many jurors insisted that the problem was not the information from screening, but the side effects of treatment that followed for a breast cancer that would not have caused harm. Speaking on behalf of the majority position, a juror from jury 2 said:

“…over-diagnosis, it’s the wrong expression. It skews the research in the wrong direction… collecting knowledge is not harmful, it’s what you do with it that can cause harm.”

JURORS acknowledged that the potential for screening to cause unnecessary harms was a highly significant issue, but were unconvinced this should restrict opportunities for individuals to receive information...
and make choices. Instead, medical professionals should improve the guidance they provided to women diagnosed through screening, and should tailor a woman’s treatment, if any, according to their preferences, profile of comorbidities and specific circumstances.
There is too much uncertainty to arrive at a definitive answer

Finally, participants in both juries found arriving at a decision difficult because of the types and levels of uncertainty surrounding the evidence. Key concerns for jurors included:

► That there was no guarantee that an apparently indolent cancer would not become life threatening at a later stage.
► That the cut-off ages for screening target groups are based on out-of-date demographic data that do not reflect recent shifts towards longer life expectancy.
► That environments are increasingly carcinogenic and therefore we cannot know what the future risk is for people living now.
► That once defunded, it would be difficult to reinstate the programme as the money would be allocated elsewhere.

For these reasons, jurors argued that decision-makers should be cautious about limiting opportunities for early detection. This was because they ascribed a broader set of benefits to screening invitations and participation than those commonly recognised by epidemiologists. Invitations to women in this age group, they argued, should cease only when the evidence of an adverse balance of harms to benefits is solid and not contested by experts.

Reasons to stop inviting

Iatrogenic harms

The key reason given for the minority position was the potential for unnecessary iatrogenic harms and in particular the risk of overtreatment. Participants who took this position in both juries gave great significance to evidence that pre-existing conditions such as heart disease and preclinical cognitive disorders (which may be unknown to the individual affected) can interact with and compound the harms of standard breast cancer treatments.

The shock of cancer heterogeneity

Almost all of the jurors were surprised to learn that not all breast cancers inevitably cause morbidity and mortality if left untreated. This is consistent with previous studies of public awareness around cancer overdiagnosis. For jurors who voted against continuing to invite women, the possibility that many cancers picked up by screening were harmless undermined the value of early detection, especially as modern treatments mean that those with more advanced disease are now able to be treated more effectively.

Opportunity costs

Some women, thus, argued that money spent on offering organised screening to women aged 70–74 would be better spent on breast cancer research. These women also tended to endorse the proposal put forward by expert 4 that clinical examination was a more trustworthy means of detection in older women.

DISCUSSION

After 2 days of information and deliberation, the majority of both juries voted to continue to send invitations and promote participation in mammography screening to women aged 70–74. Neither jury was unanimous in their vote, consistent with previous studies indicating that women’s responses to information about the relationship between mammography screening and overdiagnosis are diverse. Participants’ responses reflected a central conceptual problem in reasoning about screening. Both the mortality benefit and the harm of overdiagnosis and overtreatment—at least in breast cancer—can only be seen at the level of populations, so there is always uncertainty as to which individuals benefit from participation and which are harmed. Nevertheless, the majority of participants in both juries maintained that an opportunity to detect a potentially fatal breast cancer early was highly important. In their deliberations, several jurors argued that even imperfect information could assist women to make their own choices. Notably, however, during the reporting of the verdicts jurors also sought to emphasise that their support for this position was amenable to change. Many jurors who voted to continue to invite women now said if the current UK age extension trial found definitive evidence of significant harms from screening participation they might alter their position.

Possible limitations to this study include: (1) the small size of the groups and (2) the relatively high socioeconomic status of the residential areas from which participants came. With respect to group size, however, we note that this is an inevitable characteristic of jury research. Community juries are composed of small groups of ‘engaged citizens’. Community juries are designed to promote participant inclusivity and deliberative participation rather than achieve statistical representation. Juries are typically composed of a manageable number of people (12–15) to ensure the quality of participation and deliberation: in larger groups it is difficult to ensure quality of process. The constitution of these juries was in fact a strength. While most of the participants lived in areas of relative socioeconomic advantage, the rapid gentrification of some areas of Sydney make this socio-demographic distinction difficult to interpret for older age groups. We paid close attention, through participant screening, to obtaining a socially and culturally diverse sample. Because two juries came to similar conclusions underpinned by similar reasoning, it seems likely our findings are replicable.

A possible limitation is the absence of expert testimony from patients with breast cancer or survivors. However, because all of the expert witnesses have previously occupied or continue to occupy relevant clinical roles, they were able to reflect and comment on the more personal aspects of breast cancer diagnosis and care in response to jurors’ questions and discussions. A strength of this study was the quality and reputation of the experts who gave testimony, and the process by which they moderated one
another’s presentations until all experts could accept that all views presented could be argued from the evidence.

Breast cancer is an emotive subject with a high public profile and most people have direct experience of loved ones affected by the disease. Consistent with recent findings from the USA and UK, most jurors were and remained enthusiastic about screening and rejected the use of average life expectancy to decide screening programme exit points. They did not find statements about overdiagnosis to be persuasive or important to their decision-making about screening participation. For many jurors, being invited to participate in screening programmes validated their continued worth to society; they deserved the same opportunities to maintain their health as younger people. To remove services on the basis of projected life expectancy was seen as being fundamentally ageist and entirely unjust.

Importantly, the reasons given by jurors diverged from those often debated in the epidemiological and clinical literature on the pros and cons of breast cancer screening. Jurors were less concerned with consequences, and utilitarian calculations of the balance between benefits and harms, or estimates of net benefit. They focused more on other attributes of moral good, such as the protection of an individual’s right to choose and recognition of the value of individual lives. Moreover, the results of our research stand in contrast to a citizens’ jury held in New Zealand composed of women who had yet to commence screening, after the cut-off for programme entry was lowered to 45 years. The jury of women aged 40–49 was asked: Should the New Zealand government offer free screening mammography to all women aged 40–49 years? Participants were unanimously in favour before the jury, but voted 10–1 against after. The balance of harms and benefits is different between women 40–49 and 70–74. However, we speculate that the difference in outcome between the two studies may arise in part from strong personal investment in the value of breast screening because of past participation.

Our study has significant implications for those advocating for extending or de-implementing screening services to older target groups. The balance of benefits and harms from screening is often finely balanced, when viewed from the perspective of guidelines committees (or individuals) adopting an evidence-based approach to utility assessment. As our results show, once a screening programme becomes socially and culturally embedded it may develop significant symbolic value. Epidemiologically evidenced, population-based information about potential benefits and harms of participation does not appear to resonate sufficiently with many women so as to lead them to reassess the symbolic and personal values and meanings they ascribe to screening. Consequently, any changes in the organisation of mammography screening need to be strongly founded in evidence, but are also likely to require greater-than-usual transparency and engagement with other relevant community values.

**CONCLUSION**

In the face of expert disagreement, members of the public may have a strong preference to continue to receive interventions that give them information about their health (however uncertain). Older women, even those who have been informed in detail of the potential benefits and harms of screening participation, may highly value early detection programmes, seeing the invitation to screening as an opportunity for choice and a demonstration that society continues to recognise and invest in them. Current arguments for withdrawal of breast screening because of harms associated with overdiagnosis in people with reduced life expectancy seem unlikely to resonate with older women. This study suggests that broader cultural values will need to be addressed if cancer screening is to be de-intensified or de-implemented because of epidemiological evidence of harm.

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9 Open access

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