REVISTA DE ENFERMAGEM REFERÊNCIA

homepage: https://rr.esenfc.pt/rr/ ISSNe: 2182.2883



RESEARCH ARTICLE (ORIGINAL) 👌

Citizen Science for Health in the Co-Creation of Evidence Summaries for Citizens

A ciência cidadá na saúde para coconstrução de sumários de evidência para o cidadão

La Ciencia Ciudadana en la Salud para la Coconstrucción de Resúmenes de Evidencia para los Ciudadanos

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Recebido: 03.09.24 Aceite: 11.02.25



Abstract Background: Citizen science (CS) and health literacy (HL) promote citizen involvement in scientific research and access to health information. CS enables citizen involvement in co-creating knowledge, while HL enhances citizens' ability to make informed decisions.

Objective: To systematize older citizen involvement in the co-creation of evidence summaries for citizens (ESC), creating a replicable process and making health information more accessible.

Methodology: Methodological, qualitative study based on the assumptions of Polit and Beck and conducted with older people residing in the community. The data were analyzed according to Bardin's content analysis methodology.

Results: The participants were actively involved. They reflected on each step and contributed to enhancing the understanding of the information. This collaborative process results in a guide for ESC co-creation and co-validation.

Conclusion: The methodology proved effective in involving citizens in the ESC co-creation, promoting health literacy and increasing the social relevance of scientific research. The guide can be replicated and used by other professionals and researchers.

Keywords: citizen science; health literacy; citizen participation in science and technology; evidence-based practice; qualitative research

Resumo

Enquadramento: A Ciência Cidadã (CC) e a Literacia em Saúde (LS) promovem o envolvimento dos cidadãos na investigação científica e no acesso a informações de saúde. A CC permite aos cidadãos a cocriação de conhecimento, e a LS melhora a capacidade de tomar decisões informadas.

Objetivo: Sistematizar o envolvimento do cidadão idoso no processo de coconstrução de Sumários de Evidência para o Cidadão (SEC), criando um processo replicável e tornando as informações de saúde mais acessíveis.

Metodologia: Estudo metodológico, qualitativo, fundamentado nos pressupostos de Polit e Beck. Realizado com idosos na comunidade, os dados foram analisados segundo Análise de Conteúdo de Bardin.

Resultados: Os participantes estiveram ativamente envolvidos. Refletiram sobre cada etapa e contribuíram para favorecer a compreensão das informações. Deste processo colaborativo resultou um Guião de cocriação e covalidação do SEC.

Conclusão: A metodologia utilizada mostrou-se eficaz para envolver os cidadãos na cocriação de SECs, promovendo a LS e a relevância social da investigação científica. O guião co construído poderá ser replicado e utilizado por outros profissionais e investigadores.

Palavras-chave: ciência do cidadão; literacia em saúde; participação cidadã em ciência e tecnologia; prática baseada em evidências, investigação qualitativa

Resumen

Marco contextual: La Ciencia Ciudadana (CC) y la Alfabetización en la Salud (LS) promueven la participación de los ciudadanos en la investigación científica y el acceso a la información sanitaria. La CC permite a los ciudadanos cocrear conocimiento y la LS mejora la capacidad de tomar decisiones fundamentadas.

Objetivo: Sistematizar la participación de las personas mayores en el proceso de coconstrucción de los Resúmenes de Evidencia para los Ciudadanos (REC), creando un proceso reproducible y haciendo más accesible la información sanitaria.

Metodología: Estudio metodológico cualitativo basado en los supuestos de Polit y Beck. Realizado con personas mayores de la comunidad, los datos se analizaron según el Análisis de Contenido de Bardin.

Resultados: Los participantes se implicaron activamente. Reflexionaron sobre cada etapa y contribuyeron a favorecer la comprensión de la información. Este proceso de colaboración dio lugar a una guía de cocreación y covalidación del SEC. **Conclusión:** La metodología empleada demostró su eficacia a la hora de implicar a los ciudadanos en

Conclusión: La metodología empleada demostró su eficacia a la hora de implicar a los ciudadanos en la cocreación de los SEC, promoviendo la LS y la relevancia social de la investigación científica. La guía cocreada podría ser reproducida y utilizada por otros profesionales e investigadores.

Palabras clave: ciencia ciudadana; alfabetización en la salud; participación ciudadana en ciencia y tecnología; práctica basada en la evidencia, investigación cualitativa

How to cite this article: Silva, S. M., Santana, E. S., Bernardo, J. V., Silva, A. C., Lopes, C., Almeida, C. V., & Apóstolo, J. L. (2025). Citizen science for health in the co-creation of evidence summaries for citizens. *Revista de Enfermagem Referência*, 6(4), e e36966. https://doi.org/10.12707/RVI24.96.36966





Introduction

Citizen science (CS) and health literacy (HL) are two concepts that have been highlighted in the literature in recent decades. CS refers to the active and conscious participation of citizens in the research process through their active involvement, contributing to research and knowledge construction for science and society (Vohland et al., 2021). This conscious process involves the integration of scientific concepts, which promotes citizens' scientific literacy (SL). HL, in turn, is the ability to access, understand, and use health information to make informed decisions and improve their health and well-being (Almeida, 2023). Therefore, the promotion of HL is an increasingly emerging need and consists of a two-pronged approach: first, making health information available in accessible and understandable formats; second, promoting citizens' education to obtain and critically evaluate health information from reliable sources. However, a significant proportion of the population does not have the necessary skills to understand and correctly apply the available scientific information, which can limit their autonomy and affect their access to quality health care (Arriaga et al., 2022; Gupta et al., 2020). In addition, there is still a lack of CC projects that promote the active and conscious participation of citizens in research as a way to foster their SL and effectively empower them to access and understand health information (Wood et al., 2023). The potential benefits of CC approaches to health promotion have been identified as including increased capacity to seek reliable information, integration of community perspectives on problems and solutions, increased public awareness of this need, and increased citizen acceptance of actions to promote health and well-being (Rowbotham et al., 2023). The intersection of CC and LS has been identified as a promising strategy for promoting health and well-being by stimulating citizens' deliberate participation in the scientific process and informed decision-making on health issues. Examples of approaches that strengthen HL and the democratization of scientific knowledge include the co-construction of information materials, the involvement of citizens in workshops and meetings, and the production of evidence summaries in accessible and simple language.

Consequently, the objective of this study is to systematize older citizen involvement in the process of co-creating lay evidence summaries, with the aim of facilitating their replication whenever researchers and/or authors intend to share their results with citizens, thereby enhancing the accessibility of health information.

Background

The relationship between CC and HL

CC employs a variety of approaches to citizen involvement, which can be classified as consultation, collaboration, and co-production. In these models, citizens, while members of the research team, can function as consultants, collaborators, or responsible for controlling, directing, and managing research at the same level as the researchers (Hickey et al., 2018). Regardless of the level of approach, it is essential to prioritize engagement with citizens in the field of SL, ensuring the provision of knowledge regarding scientific terminology to facilitate comprehension of the underlying research process. The Portuguese Society of Health Literacy (SPLS; Almeida, 2023) conceptualizes HL as the capacity to influence and support diverse stakeholders (individuals, organizations, communities, health professionals, media, policymakers) throughout their lives, enhancing their abilities to access, comprehend, and utilize health resources. Evidence suggests that a higher level of HL is associated with greater health care, better health promotion, and greater disease prevention, thus favoring more informed and conscious decisions by citizens (Almeida, 2023; Gupta et al., 2020). We start from the idea that involving citizens in the creation of information materials to make them simpler and more accessible through lay language represents a consultation approach to CC. On the other hand, strategies such as co-authoring content and selecting citizen representatives to share their experiences in workshops and meetings exemplify co-production and collaboration approaches (Santana et al., 2023).

The basic information used to make these materials must be scientific and valid. One example is Evidence Summaries. These are short summaries that combine international evidence on healthcare interventions based on literature (Apóstolo, 2017) and are designed for health professionals. They act as a summarized and solid basis for working with citizens to make an appropriate summary for their peers. In this case, it is a Lay Evidence Summary or Evidence Summary for Citizens (ESC).

In Portugal, most people have enough health literacy (65.0%), but only a few have excellent levels (5.0%; Arriaga et al., 2022). The same study also showed that people who can *understand information* have better health literacy and identified older people as a risk group in this area. Demographic changes and the increasing global aging of the population mean that HL is critical to empowering older people to lead more active lives and better self-manage their chronic health conditions (Eronen et al., 2021). Research consistently shows the impact of HL on healthcare use and medication management (Schönfeld et al., 2021), reinforcing its promotion as an essential strategy for this population.

Older people have been involved as *citizen researchers* in studies on environmental change and local policy (King et al., 2020; Winter et al., 2016), healthy eating, and the promotion of active living (Winter et al., 2016). They also collaborated on data collection, discussion, coding, and data synthesis, demonstrating that they could learn to use technology and collaboratively analyze their own data (King et al., 2020). Even after the projects ended, they continued to use the skills they had learned (Winter et al., 2016).

Older adults are the primary audience for this research because of the urgency of their needs. We also highlight the important link between CC and HL in creating information that is appropriate for the audience. We did



not find any guides for the co-creation process in the studies we reviewed. This motivated us to create a guide for the co-creation process in this study.

Research question

How can the involvement of older citizens in co-creating ESC be systematized?

Methodology

This methodological study, as outlined by Polit and Beck (2011), aims to facilitate a nuanced and contextualized comprehension of the evolution and applicability of tools and methods, ensuring their efficacy and relevance within specific contexts. This study adhered to the model's development and validation phases.

A convenience sampling strategy was employed to select participants, comprising a group of four older individuals registered to a Community Care Unit (UCC) in central Portugal, devoid of cognitive impairment and with prior engagement in CC initiatives. The primary inclusion criterion was the availability of the participants, given the limited public awareness of this particular co-production approach, which influenced the selection of the target population. The initial invitation was extended by the nurse responsible for the UCC, who has previously facilitated community projects with these older adults. Data collection occurred during two meetings in November 2023 involving two Focus Groups (FG). Each FG session lasted 90 minutes and was audio-recorded with the participants' consent. The FGs served as a methodological instrument consistent with the qualitative nature of the study. Prior to conducting the FGs, a script was prepared for the facilitator, drawing upon the general guidelines previously defined by the researchers and informed by prior interactions with the group. This script was instrumental in systematizing the session's structure, including a dynamic introduction to the topic, which was designed to facilitate discussion and encourage the participation of the older adults. It also ensured the organization of the time dedicated to each phase, thereby ensuring a balanced duration for the session. Furthermore, it created a satisfying moment of conviviality for the participants at the end of the session. While this initial script proved useful for organizing the team of researchers, it remained open to alterations in the process. The FGs were facilitated by two female nurses and PhD researchers. One of the researchers was already familiar with the group and acted as the main facilitator, and the other researcher was in a supporting role in facilitating and collecting data. To this end, an orientation grid aligned with the initial script was used. In addition to the facilitators, there were other researchers who were in the research initiation pathway and still learning. These researchers provided logistical support, helping to distribute documents and organize the space. A graphic design professional participated in the sessions, collaborating with the researchers for the

visual co-creation. The first FG meeting comprised three stages. Firstly, objectives and expectations were defined, including an initial presentation of the team, a reminder of the activities of previous research projects in which they had been involved, a reflection on the importance of CC for the development of health information, and, finally, the validation of informed consent. Secondly, an example of an Evidence Summary for Laypeople was presented, and one of the participants read the document aloud, subsequently leading to a discussion centered on comprehending the textual information. The entire methodology of the process was defined and agreed upon by and in conjunction with the citizens. To assess the language and interpretation of the texts in the summaries, a Cloze test was administered, a method that involves omitting words in a text and prompting the reader to fill in the missing words so that the text remains coherent (Oliveira, 2009, as cited by Dias & Silveira, 2014). Thirdly, participants were tasked with co-creating a new Evidence Summary based on the previous summary, emphasizing the changes necessary to enhance both the textual and visual components. Participants examined the entire design, including colors, figures, typography, font size, and format of the summary.

At the second FG meeting, the two evidence summaries (original and co-created) were presented and issues such as improvements, impacts, and ways to systematize citizen participation in the co-creation of the ESC were discussed. The collected data were transcribed and analyzed according to the thematic content analysis proposed by Bardin (2022) by two researchers, both nurses with a PhD, experience in qualitative research, and no direct link to the participants. The data analysis was then validated by a third researcher, also a nurse with a PhD and experience in qualitative methodology. At the second FG meeting, the results of the ESC were returned to the citizens to allow for a confirmation process on their part. The use of independent data analysis minimized bias and ensured impartial analysis.

The analysis allowed interpreting and structuring the participants' contributions to the co-creation of the guide, following four phases described by Bardin (2022). In the *pre-analysis* phase, general perceptions of citizen participation were identified. In the *exploration* phase, the data were coded into recording units related to the dynamics and needs identified, which were then grouped into specific themes. In the *categorization* phase, the themes were consolidated into two main axes, with sub-themes detailing the stages of the process. Finally, the *inference* phase made it possible to interpret the results in light of the study's objective, systematizing the steps and providing clear guidelines for the sessions and the aspects to be worked on. This process ensured alignment with the needs of the participants and the methodological guidelines. This study was approved by the Ethics Committee of the Health Sciences Research Unit: Nursing, Coimbra (Opinion No. P967_09_2023). All participants provided signed informed consent. The study adhered to the tenets of the Declaration of Helsinki, and confidentiality and anonymity were maintained throughout the study.



This article follows the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.

Results

Four older adults participated in the study, three women (R, 76 years old; Ma, 72 years old; and J, 69 years old) retired from sewing, and one man (A, 72 years old) retired from construction. The results are presented according to the moments of the process, known as *co-creation* and *co-validation*.

Co-creation

During the presentation to define objectives and expectations, the group was clearly motivated to join the co-creation process and comfortable with being asked to participate in solving a problem with which they were intimately familiar. They then accepted the distribution of a simple text of an ESC on cancer created by a team of researchers. They decided to read the summary together, and everyone agreed. The group recognized difficulties with the use of acronyms and font size:

"I'll start, I need some clarification here. In this country, at the moment, they only use abbreviations, and what if I don't know what the abbreviation stands for?" (A). "And because I read very little, I have little information. And not only do I have little information, I can't express my opinion because I only read the big letters in the newspaper, I ignore the small ones. (R)

In addition, they quickly recognized the WHO abbreviation that was much talked about "during the pandemic". They then discussed the advantage of providing information in audio format, arguing that this format reduces the effort of reading and allows them to access the information while doing other household chores. Participants pointed out that the repetition of short, concise information seems to facilitate comprehension and assimilation. They also emphasized the importance of using concise sentences with essential information to warn about changes in behavior: "These warnings here are a sign that if you have a problem like this, it has to be like: 'I read this somewhere and I think I have to . . . "". (R) This reflection shows how much they value clear and direct communication between the symptom they identify and the behavior to be recognized in the ESC.

The content analysis using the cloze test revealed some difficulty in finding different vocabulary. Although the difficulty identified was not initially expressed verbally, there was discomfort in admitting that some words were too complex to understand. A concrete example was the word *vilão*, meaning "villain" or "villager," which the participants considered inappropriate because they felt it did not fit the message being conveyed, which in a quick reading, as well as being confused with the word *filão*, meaning "mineral vein", took away the meaning of the sentence. After finally exploring the issue, the participants said that, to make the process easier, they could identify the unknown/difficult terms themselves and the team could also provide word options for substitution beforehand:

If you presented the options, it would be easier and it wouldn't take so much thought But the thing is, it forces you to look at the words carefully, and this thing with *filão/vilão* is an example of that, because I know, man, and it's not used properly here, so after reading it a second time, you come to the conclusion that it is . . . Of course, when we look at the words here, there are some that we think are more difficult, more difficult to interpret, because there can be two interpretations. (A)

On the other hand, participants recognized that presenting word suggestions could condition their choices, which led them to leave both options open to the group: presenting the researchers' word suggestions as well as introducing new words to substitute: "Do you think this, that or the other is better? And if you push me a bit, maybe I'll go for a food I don't really like." (A)

They then moved on to evaluating the graphic design and visual elements. Initial ideas about possible images to compose the document revealed a preference for the possibility of improving comprehension and conveying a positive visual message: "Suddenly, I thought of a doll, a cancer, that moves until it disappears and the person loses it completely . . . And improve the person's appearance until they are healthy." (A)

Comments on the graphics revealed the influence that the use of certain colors and images has on the message to be conveyed. Participants considered it important to be careful when choosing colors associated with more cheerful feelings (bright pink, turquoise blue, striped green, white, toasted yellow) and to limit the use of sad colors (black, dark blue, purple) associated with a worse state of illness. There was no consensus on the use of red, so we suggest not using this color. They also suggested that pictures should be congruent with the text information, but not too many, and be images of real people rather than figurative or stylized, "Otherwise we'll think we're watching cartoons" (Ma), and not overcrowded to avoid confusion, "Yes, the page must not be full of images" (A), demonstrating the importance of empty spaces for understanding information.

Regarding copyright, participants did not initially consider including their names, but after reflecting on the purpose and principles of CC, they all agreed on the importance of recognition in this process.

Throughout the process, researchers were keen to introduce concepts that promote CC, such as sampling and quantitative/qualitative research, asking citizens to explain what they understood by these concepts and analyzing examples that could enlighten them. There was a palpable curiosity to learn the language of science and to apply it to the research they were participating in.

Co-validation

During the co-validation session, the new evidence summary, co-created and revised by the designer based on the participants' feedback, was presented. The participants seemed satisfied with the changes and confirmed them. At this stage, the participants suggested minor changes to the font size and images: "The information is



the same, but it's clearer . . ." (M); "The other thing had smaller symbols" (J). "The colors are brighter, the others were more muted" (R); "There's more joy, I don't know how to put it . . ." (M).

The research team included the names of the participants in the copyright, identifying them as Citizen Researchers, as suggested by the participants themselves. This recognition has led to satisfaction among the participants. They chose to use only their first names because they felt this preserved their individuality while allowing for peer recognition. They also highlighted the complexity of the process of developing health information for society and the importance of involving citizens to increase the social impact of the results:

It's a lot of work and I didn't know how much work these things are and I didn't . . . I didn't think it was important, just the picture or what it means or what it refers to, but I didn't know it was so much work, I had no idea, did I? I would overlook it actually . . . (R); "But we don't really know, but we really don't know how much work this is..." (J)

Together with the citizens, we analyzed how this process could be designed and extrapolated to other groups of citizens and topics. Regarding the number of sessions, two sessions of about 60 to 90 minutes are sufficient for the co-creation and co-validation of ESCs. The importance of organizing the materials in advance proved to be a crucial element, and it should also be noted that this process needs to be adapted to the age group and limitations of the citizens. To improve compliance with this co-creation process, participants stressed the importance of raising awareness and inviting professionals and/or structures in the community with whom they already have a relationship of trust.

Participants valued the process and identified the mutual benefits for their HL and for understanding participation from the perspective of altruism and support/outreach to society.

The information about the process was synthesized in the guide (Figure 1).



Figure 1

Guide for the co-creation and co-validation of the Summary of Evidence for Citizens by citizen researchers

Recommendations and preparation:

- Prepare age-appropriate materials, considering the possible preference for using printed and individual materials to facilitate group reading.
- When writing the text, pay attention to clarity, preferably using language appropriate for elementary education, and avoid the use of abbreviations.
- Adapt the format of the ESC to the age group: It was suggested to extrapolate the formats, such as the use of podcasts, audio programs, and short videos, among other possibilities that facilitate the retention of information in everyday life and adapted to the age group.
- Apply internationally consolidated guidelines for the development of health information to support the process of prior production of scientific information.
- Organize the co-construction process at different times to encourage understanding, discussion, and construction tion of the process.

Session 1 - Language and Text Interpretation

1- A volunteer reads the text;

2 - Discuss the content and understand it, pointing out difficulties;

3 -Each citizen underlines the words they find difficult to understand or which could be changed to make them easier to understand;

- 4 Collect the individual documents and combine the words that have been identified into a single document;
- 5 Do the cloze test in a large group using the underlined words and any others you deem appropriate (interactive cloze and post-oral reading cloze);

6 - Gather and agree on proposed text changes;

Graphic Design and Visual Elements (if applicable)

1 – Ask them to indicate what they imagine the content should look like: description of images, colors, content, distribution of content (take notes).

2 – Considerar the indications:

To convey positivity: white, bright pink, turquoise blue, striped green

To convey negativity: black, dark blue, purple

3 – Ask for examples, a detailed description of the images. Consider movement, presence of animals and/or people, stylized or not.

4 - Consider presenting a sample document to find out their likes and dislikes.

Session 2 - Covalidation of the final document

Once the summary has been written according to the consensus of the group in the first session, the group should meet for a second session.

1- Validate the contents of Language and Text Interpretation and Graphic Design and Visual Elements, reaching a consensus with the citizens:

2 – Confirm image selection;

3 - Discuss graphic design and layout and organize information;

4 – Analyze colors, font, and white space (blank space);

5 - Identify visual elements that enhance clarity and accessibility.

Dissemination by other means: preparation of the evidence summary in digital format

Considering the suggestion of citizens to access the ESC in different formats (audio or video), we encourage and suggest that they consider the previous systematization when creating ESCs in audio and video formats.

Discussion

Citizen involvement in scientific activities is one of the principles of CC and a key resource for contributing to the relevance of scientific products and outcomes, fostering a culture of collaboration and dialogue (Vohland et al., 2021). This engagement not only gives access to information but also promotes the development of knowledge that enables people to make informed decisions about their health and well-being (Almeida, 2023).

The results of the study highlight the specific contributions of citizens in the co-creation and co-validation of ESCs, through a practical approach that made it possible to identify and implement improvements in language



and design, making the information more accessible to the target audience. The suggestions made by the participants to replace technical terms with more common expressions, reorganize the content to make it easier to understand, eliminate abbreviations, and use bright colors show that this collaborative work is in line with the main goal and purpose of science communication (Magalhães et al., 2022).

Previous studies, such as the European NEWSERA project (Magalhães et al., 2022), also highlight the importance of co-creation in fostering environments for reflection, dialogue, and mutual learning. This study reinforces this assumption by demonstrating that co-creation makes ESCs clearer and more accessible and increases citizens' ownership of the process. The use of the Cloze test proved to be an asset, as it allowed for the objective identification of gaps in understanding and the selection of simpler language. Citizens preferred to identify the words that caused them difficulty, using interactive cloze and postoral reading cloze (Oliveira, 2009, as cited by Dias & Silveira, 2014). In addition, the introduction of SL concepts allowed for the mobilization of knowledge for other contexts/investigations, broadening the understanding of science, research, and information in health.

It is also important to note that the premise of citizen participation advocated in this study contributes to the Open Science approach. The collaborative work and mutual learning offered by this process both raise awareness among researchers and empower citizens to be important communicators (Magalhães et al., 2022; Citarella et al., 2023). The activities carried out have shown that working on HL in this methodology is a strategy that provides added value for citizens, improving their HL in the area. The validation carried out by the citizens themselves during the sessions increased confidence in the results and promoted a process of collaborative and confirmatory analysis. This involvement not only helped to refine the ESCs, but also strengthened the HL of the participants, enabling them to understand and use the information more consciously and critically (Sørensen, 2022).

Despite the limitations identified, namely the small number of participants, the limited age range, and the need to validate the ESC guide with more heterogeneous groups, the results suggest that the approach used contributes significantly to improving HL. Involving citizens in this process promotes more effective interaction with health information and empowers citizens to actively engage in scientific dialogue and informed decision-making.

Conclusion

This study systematized the involvement of citizens in the process of co-creating information materials, namely ESCs, through a guide that emphasizes the adaptation of language, design, and content to the needs of the target audience. In addition to being an innovative, accessible, and easily replicable product, the guide represents a methodological advance in structuring the process of citizen participation in science communication. The results show that the principles of CC and HL contribute to bringing scientists and citizens closer together, thus promoting informed decision-making.

For scientific practice, this study could also contribute to the reflection of researchers and managers on the importance of actively involving citizens in their research projects and in the development of inclusive policies.

Author contributions

Conceptualization: Silva, S., Santana, E., Bernardo, J., Silva, A., Lopes, C., Almeida, C. V., Apóstolo, J.

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Investigation: Silva, S., Santana, E., Bernardo, J., Silva, A. Methodology: Silva, S., Santana, E., Bernardo, J., Silva, A., Lopes, C., Almeida, C. V., Apóstolo, J.

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Funding

Health Sciences Research Unit: Nursing, Nursing School of Coimbra, internally funded research.

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