

Summary of results

Questionnaire 'Views on communicating early clinical cancer studies'

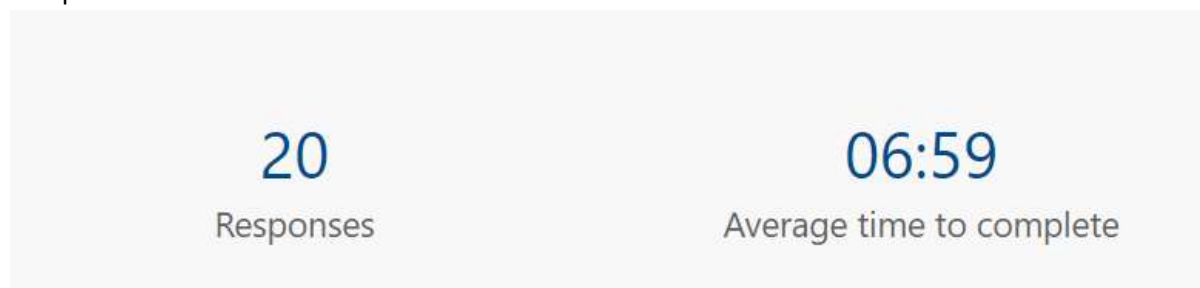
29 July 2022

1. About the questionnaire

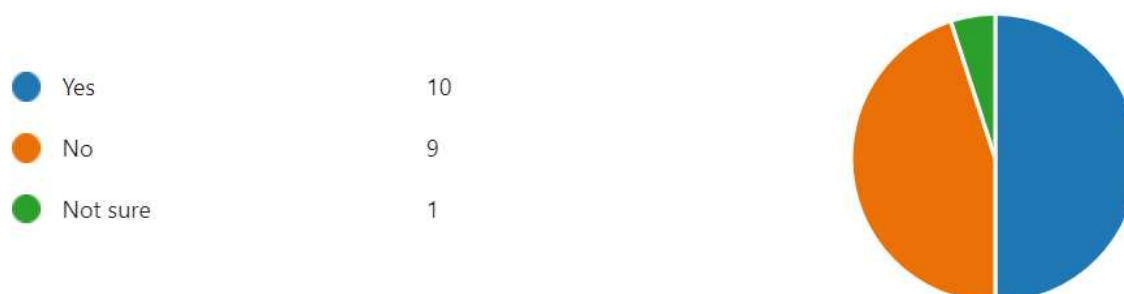
- **Aim:** Measure the impact of the documentary 'War in the Blood' (<https://www.bbc.co.uk/programmes/m0006nzt>) to gain insights about documentaries and other ways to communicate early clinical studies
- **Design:** Members of the Patient and Public Research Panel at Blood and Transplant Research Unit in Stem Cells and Immunotherapies and the Patient and Public Involvement Lead developed the questionnaire (see Appendix I) and used MS Office forms to collect replies
- **Duration of collecting replies:** The questionnaire was open for replies for 36 days from 21 June – 26 July 2022
- **Channels of publication:** It was published via emails to networks from Patient and Public Research Panel members and Patient and Public Involvement Lead, via social media from @BTRUinStemCells to relevant patient contacts and charities. Cancer Research UK included it on their opportunities' website and in the CRUK newsletter to patient and public member in July 2022. Antony Nolan was approached to promote it through their patient and family forum and University College London Hospitals Macmillan Cancer Centre to display posters (see Appendix 2) in patient waiting areas.

2. Summary of results

The questionnaire received 20 responses and took an average time of 6 minutes and 59 seconds to complete.



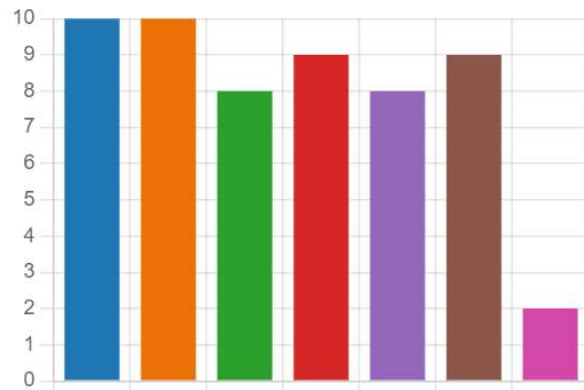
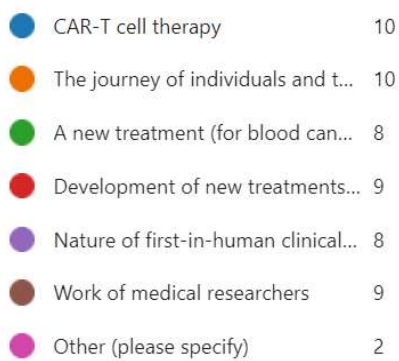
Half of respondents, 10 out of 20, recalled watching the BBC Two 'War in the Blood' documentary.



Those 10 respondents who watched the documentary, they gained the following insights from watching it:

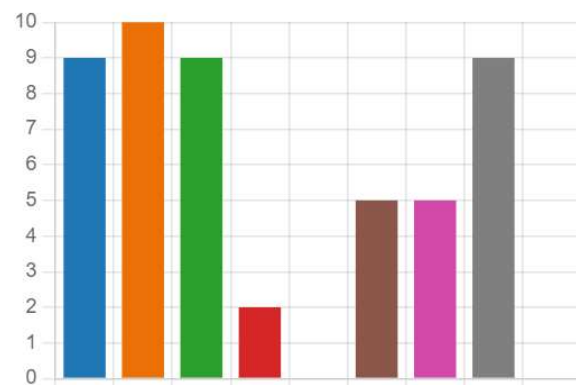
- All 10 gained insights on CAR-T therapy and the journey of patients and their families taking part in clinical studies

- 9 of 10 gained insights on the development of new treatment/research and the work of medical researchers
- 8 of 10 gained insights on the nature of first-in-human clinical studies and a new treatment for (blood) cancer
- Other insights from 2 respondents gained were:
 - How much courage it takes on all sides to develop new treatments
 - Amazement of the courage of patients, the families and researchers



In reply to the question 'How do you feel about the outcomes for the two patients followed in the documentary?',

- 10 out of 10 respondents who watched the documentary felt the greatest respect for patients and their families taking part in early clinical studies
- 9 out of 10 respondents felt grateful for the courage of patients and families taking part in studies to help develop new treatments for others, and sad to see that the treatment did not work for all patients
- 5 out of 10 respondents felt the need for more information on first-in-human/early clinical studies, and feeling more inclined to take part in (early) clinical studies
- 2 out of 10 thought that the outcomes for patients in the documentary could put patients off considering CAR-T therapy as a form of treatment
- None of the respondents stated that watching the documentary 'War in the Blood' made them less inclined to consider taking part in (early) clinical studies



All, 10 of 10 respondents who watched the documentary replies that the BBC Two ‘War in the Blood’ documentary help you to better understand CAR-T therapy. 9 of 10 said they felt that the documentary helped them to better understand clinical studies, 1 of 10 was not sure.

4 respondents who watched the documentary took part in a clinical study. 6 of 10 who did watch and 2 of 10 who do not recall watching the documentary did not take part in a clinical study. We did not collect replies from 8 of 10 respondents who did not watch the documentary on the following questions because of a glitch in the questionnaire.

Clinical trials were described as studies in people to evaluate a medical, surgical, or behavioural intervention. It is the main way to find out if a new treatment, like a new drug, diet or medical device, is safe and effective in people.

● Yes	4
● No	8
● Not sure	0
● Prefer not to say	0

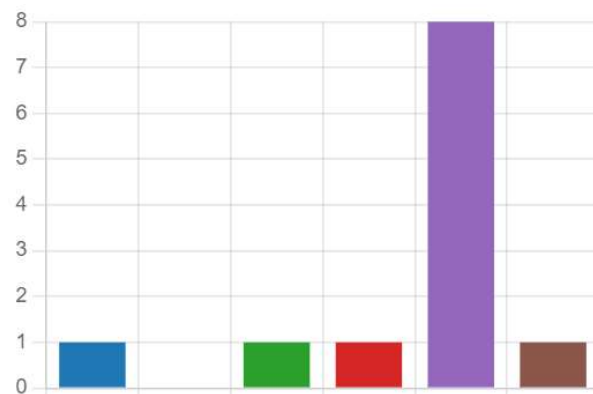


Out of 10 respondents who watched the documentary

- 1 respondent received CAR-T therapy themselves
- 1 respondent knew someone who had received CAT-T therapy
- 1 respondent had a recipient of CAR-T therapy in their patient network
- 7 did not know anyone who received CAT-T therapy or weren't aware of it

2 out of 2 recorded respondents not seeing the documentary, did not know anyone who received CAR-T therapy.

● Myself	1
● A close relative/friend	0
● Someone I know	1
● A contact in my patient network...	1
● No	8
● Other (specify)	1



Respondents rated their knowledge about clinical studies aiming to develop new or better treatments as follows:

- 8 as good
- 3 as fair
- 1 as little

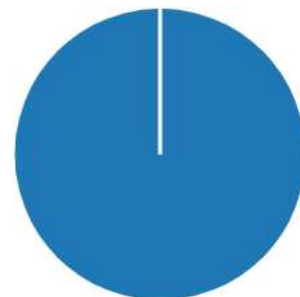
This includes 1 of the respondents not seeing the documentary rating their knowledge about clinical studies as good and 1 as little.

● Very little	0
● Little	1
● Fair	3
● Good	8
● Very good	0



All 12 respondents, 10 who watched the documentary and 2 who did not, thought that documentaries can help understanding about early clinical studies.

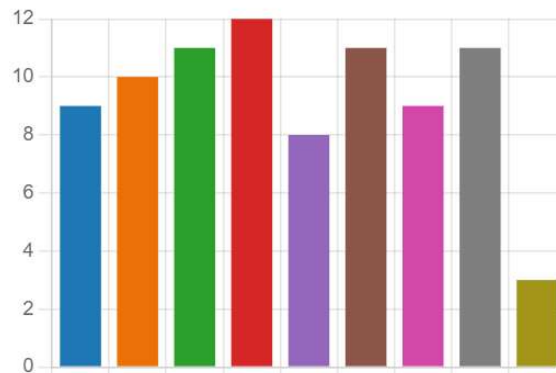
● Yes	12
● No	0
● Not sure	0



Respondents thought such trials should be reported to the public as follows:

- 12 of 12 respondents choose documentary
- 11 of 12 respondents choose TV, charity newsletter or website and patient network or support group
- 10 of 12 respondents choose radio
- 9 of 12 respondents choose hospital/medical team and newspaper
- 8 of 12 respondents choose social media
- Comments from 3 respondents included:
 - I think you should use as many methods as possible, but they need to be trustworthy & not liable to be misrepresented
 - Newsletter for hospitals listing all the trials/research underway on site, websites for the studies themselves, maybe a 'universal' site with more clinical trials/studies results, - basically as open and as wide as possible
 - You need to use all channels to target different demographics and different behavioural patterns
 - Interviews with people involved in it (patients, researchers and clinicians)

● Newspaper	9
● Radio	10
● TV	11
● Documentary	12
● Social media	8
● Charity newsletter or website	11
● Hospital/medical team	9
● Patient network or support group	11
● Other (please specify)	3



Other comments about communicating clinical studies from 6 respondents included:

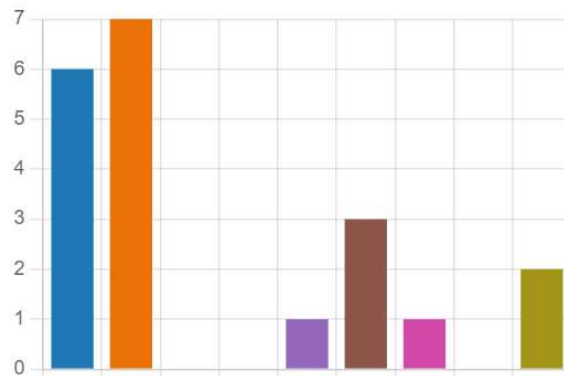
- *'A fascinating area to learn about'*
- *'I believe everyone should be able to access more information about clinical trials. It can be very confusing for people who do not have a scientific or healthcare background and this may put them off or prevent them from asking questions. I think barriers could be removed by normalising documentaries and telling patient stories'*
- *'Good easy to understand information should be shared but only for good peer reviewed/gold standard studies not spurious ones'*
- *'Definitely not via social media as it will end up being taken out of context and forwarded without the full facts and with incorrect information'*
- *'Any PR that can be utilised is beneficial to help spread the word. At a minimum it should be shared to relevant charities and patient groups for them to communicate to those with connections to the condition. I watch documentaries for cancer and research areas that I am interested in, but I would rather funding not be used for creating a documentary and go to further research instead.'*
- *'It's important that the widest possible audience is kept up-to date & informed about clinical studies, but generally people don't want to know until the topic affects them & then, sometimes, by that point it's too late. So the wider you can communicate & the more long-lasting you can make that information (so it's easy to find later) the better.'*

Respondents reported the following connections to cancer:

- 7 of 20 respondents identified as cancer patients
- 6 respondents as blood cancer patients
- 3 respondents as family members of a close relatives with cancer
- 1 respondent as family members of a close relatives with blood cancer

- 2 respondents report another connection to cancer:
 - Ductal Carcinoma In Situ (DCIS) with radiotherapy
 - Works with blood cancer patients

● Blood cancer patient	6
● Cancer patient	7
● Carer of a blood cancer patient	0
● Carer of a cancer patient	0
● Family member of close relative ...	1
● Family member of close relative ...	3
● Member of the public intereste...	1
● No direct connection	0
● Other (please specify in questio...	2

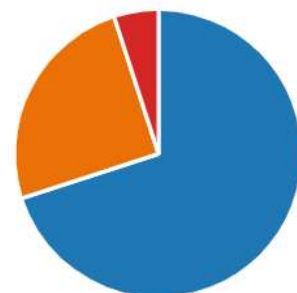


Respondents came from the following age groups:

Age range	Number of respondents
Under 18	0
18-29	2
30-39	3
40-49	2
50-59	1
60-69	8
70-79	3
Over 80	0
Prefer not to say	1

14 of 20 respondents were female (including transgender woman) 5 were male (including transgender men), 1 preferred other.

● Female (including transgender ...	14
● Male (including transgender men)	5
● Prefer not to say	0
● Other (please specify)	1



The ethnic background of respondents was:

- 12 of 20 respondents reported an English/Welsh/Scottish/Northern Irish/British background
- 6 of 20 a white background
- 2 of 20 reported another ethnic background

Other comments included:

- *'Please keep communication research to patients and the public'*
- *'I have very rare vaginal cancer and whilst it's not a blood cancer etc there's very little data and research into my type of cancer'*
- *'Restricting reporting of clinical study results to recognised academic/clinical/medical journals is not enough. Study information outcomes & results should be widely & openly available for everyone to access the information & benefit from the knowledge.'*

In addition to the following comments on the questionnaire 'I object to the category including trans women they are not women' and 'some odd questions?'

Many thanks to all respondents for taking the time to complete this questionnaire, and to members of the Patient and Public Research Panel at the BTRU in Stem Cells and Immunotherapies at UCL for shaping it.

Appendix I - Questionnaire design

Give us your views on communicating early clinical cancer studies

We would like to learn about your views using documentaries, such as the BBC Two documentary 'War in the Blood', to communicate insights about early clinical studies and hear from you which other ways can be best used to share information about early CAR-T therapy and other clinical cancer studies.

Thank you for considering to complete this questionnaire, it will only take a few minutes.

About 'War in the Blood', a BBC Two documentary:

'War in the Blood' is a BBC Two documentary that follows two patients and their families taking part in first-in-human CAR-T cell therapy studies for blood cancers. Thanks to them and others who took part in clinical studies, CAR-T therapy is now available as NHS treatments for two types of blood cancer. CAR-T therapy treatments have made tremendous progress since the documentary was filmed, being better fine-tuned and in development for other forms of cancer.

When filming for the BBC Two 'War in the Blood' documentary started, the outcomes of both patients taking part in CAR-T therapy studies were unknown. Patients and their families in the documentary agreed to share their journey for others to learn about CAR-T therapy and the important contribution of taking part in early studies.

It is through health care research that we develop new and better treatments. Without the vital part of people taking part in clinical studies this would not be possible. However, the real benefits for people taking part in early clinical studies of a potential new treatment are unknown at this stage.

What is CAR-T therapy?

Chimeric Antigen Receptor (CAR) T cell therapy uses T cells (a form of white blood cells in the immune system) that have been re-engineered in a laboratory to produce an artificial T cell receptor to find and destroy cancer cells.

For questions, please contact:

Linda von Neree, Patient and Public Involvement and Engagement Lead, NIHR Blood and Transplant Research Unit for Stem Cells and Immunotherapies (UCL BTRU)

Email: l.vonneree@ucl.ac.uk

The Patient and Public Research Panel at the UCL BTRU co-developed this questionnaire.

NIHR Blood and Transplant Research Unit for Stem Cells and Immunotherapies Co-Directors: Dr Claire Roddie and Professor Karl Peggs

1. Did you recall watching the BBC Two 'War in the Blood' documentary?
(please select one)

- Yes
- No
- Not sure

2. What did you take away from watching the 'War in the Blood' BBC Two documentary?

I gained insights on

- CAR-T cell therapy
- The journey of individuals and their families taking part in clinical studies
- A new treatment (for blood cancer)
- Development of new treatments/research
- Nature of first-in-human clinical studies
- Work of medical researchers
- Other (please specify)

3. If you chose 'Other' in the question above, please specify.

Enter your answer

4. How do you feel about the outcomes for the two patients followed in the documentary?

I feel... (Please select all that apply)

- Sad to see that the treatment did not work for all patients
- The greatest respect for patients and their families taking part in early clinical studies
- Grateful for the courage of patients and families taking part in studies to help develop new treatments for others
- That it could put patients off considering CAR-T therapy as a form of treatment
- Less inclined to consider taking part in (early) clinical studies
- More inclined to consider taking part in (early) clinical studies as it may help me and others
- The need for more information on first-in-human/early clinical studies
- That I gained a better understanding of CAR-T therapy and the efforts it takes to develop new and better future treatments
- Other (please specify)

5. If you chose 'Other' in the question above, please specify.

Enter your answer

6. Did the BBC Two 'War in the Blood' documentary help you to better understand what CAR-T therapy is?

- Yes
- No
- Not sure

7. Do you feel that the BBC Two 'War in the Blood' documentary helped you to better understand clinical studies?

Yes

No

Not sure

8. Did you take part in any clinical study?

Clinical trials are studies in people to evaluate a medical, surgical, or behavioural intervention. It is the main way to find out if a new treatment, like a new drug, diet or medical device, is safe and effective in people.

Yes

No

Not sure

Prefer not to say

9. Have you or anyone close to you received CAR-T therapy?

Myself

A close relative/friend

Someone I know

A contact in my patient network or support group

No

Other (specify)

10. If you chose 'Other' in the question above, please specify.

Enter your answer

11. How do you rate your knowledge about clinical studies aiming to develop new or better treatments?

Very little

Little

Fair

Good

Very good

12. Do you think documentaries can help understanding about early clinical studies?

Yes

No

Not sure

13. How do you think such trials should be reported to the public? (Select all that apply)

Newspaper

Radio

TV

Documentary

Social media

Charity newsletter or website

Hospital/medical team

Patient network or support group

Other (please specify)

14. If you chose 'Other' in the question above, please specify.

Enter your answer

15. Please use this space for any other comment or thoughts you have about communicating clinical studies.

Enter your answer

16. What is your connection to cancer? (Please select the most relevant answer)

Blood cancer patient

Cancer patient

Carer of a blood cancer patient

Carer of a cancer patient

Family member of close relative with blood cancer

Family member of close relative with cancer

Member of the public interested in cancer research

No direct connection

Other (please specify in question below)

17. If you chose 'Other' in the question above, please specify.

Enter your answer

18. What is your age group?

Under 18

18-29

30-39

40-49

50-59

60-69

70-79

Over 80

Prefer not to say

19. What is your gender?

Female (including transgender women)

Male (including transgender men)

Prefer not to say

Other (please specify)

20. If you chose 'Other' in the question above, please specify.

Enter your answer

21. What is your ethnic background?

Asian/Asian British

Indian

Pakistani

Bangladeshi

Chinese

Any other Asian background

Black/African/Caribbean/Black British

African

Caribbean

Any other Black/African/Caribbean background

Mixed/Multiple ethnic groups

Asian and Black African/Caribbean

Asian and White

Black African/Caribbean and White

Any other Mixed/Multiple ethnic background, please describe

White

English/Welsh/Scottish/Northern Irish/British

Irish

Gypsy or Irish Traveller

Any other White background

Other ethnic group

Arab

Any other ethnic group, please describe

Prefer not to say

22. Please describe your ethnic background, if other than the above.

Enter your answer

23. Please add any other comments or questions.

Enter your answer

Thank you, we greatly appreciate your time to complete this questionnaire!

We will publish a summary of findings from this questionnaire on our website at <https://www.ucl.ac.uk/cancer/research/centres-and-networks/blood-and-transplant-research-unit/news-and-events> and on twitter @BTRUinStemCells in summer 2022.

If you would like to find out more about CAR-T treatment, please visit:

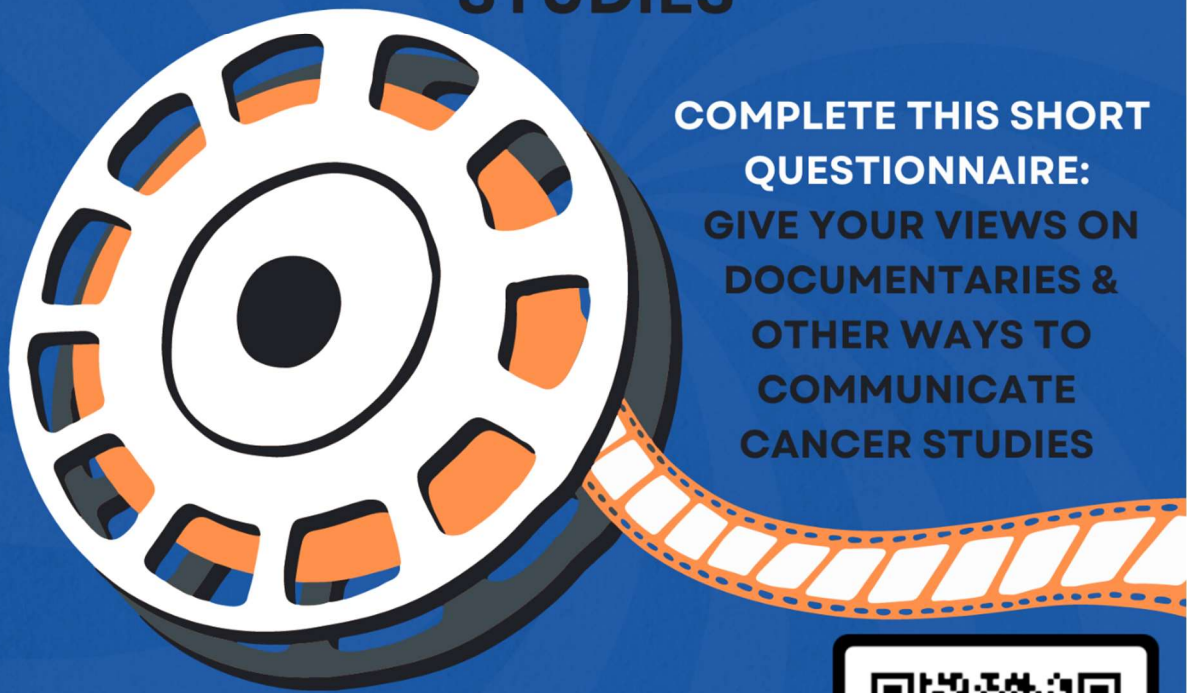
- The University College London CAR T programme, <https://www.ucl.ac.uk/cancer/research/ucl-car-t-programme>

- Animated film explaining CAR T-cell therapy, <https://www.ucl.ac.uk/cancer/news/2019/apr/animated-film-car-t-cell-therapy-launched-gcse-students>
- NHS CAR-T Therapy, <https://www.england.nhs.uk/cancer/cdf/car-t-therapy/>
- Written piece about CAR-T therapy on BBC News Health from 7 January 2022, <https://www.bbc.co.uk/news/health-59771464>
- Find out more about clinical studies/trials, <https://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/what-clinical-trials-are>

NIHR | Blood and Transplant Research Unit
in Stem Cells and Immunotherapies
at University College London

YOUR VIEWS

ON COMMUNICATING EARLY CLINICAL CANCER STUDIES



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DOCUMENTARIES &
OTHER WAYS TO
COMMUNICATE
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