MULTI-REGIONAL CLINICAL TRIALS
THE MRCT CENTER OF BRIGHAM AND WOMEN'S HOSPITAL and HARVARD

Representation in Research
LGBTQIA+

Tool 7: Exit Survey Inclusive of the LGBTQIA+ Participant Perspective

Introduction

It is important for participants in clinical research activities to give feedback about their experience. This feedback helps research teams and organizations better understand the participants' experiences of the research activity and learn how they can improve efforts to empower research participants and the participants' supporting families, friends, and communities. One way to gather feedback is through a survey, which may be given to participants periodically (e.g., once a month), and/or at the end of research activities (e.g., as an exit survey).[1,2] Other ways may include interviews, focus groups, or patient portals where participants can leave comments. In this tool, we aim to show examples of the topics that participants[a] may be asked about in a survey or interview or, if not asked, that the participant may wish to share with the research team in a patient portal, email, or other format.

Please note that the "Exit Survey Inclusive of the LGBTQIA+ Participant Perspective" is one tool in the LGBTQIA+ Inclusion by Design in Clinical Research Toolkit, and the third of three tools in the section of the Toolkit directed *more toward participants*. These participant-facing tools span the participant journey in clinical research, and we list all three below so you can see the other tools available for you on each phase in this journey:

- Site Feasibility Decision Tree from the LGBTQIA+ Participant Perspective. (For the recruitment phase of the trial- awareness of the trial, accessing a trial site).
- Participant Questionnaire from the LGBTQIA+ Participant Perspective. (For the participation phase of the trial- screening, informed consent, study visits).
- **Exit Survey Inclusive of the LGBTQIA+ Participant Perspective.** (For the end-of-trial phase: last visits, data analysis and return of results, potential follow-up and post-trial access to the study product).

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[a] This tool can also be used by sites and sponsors to evaluate participant experiences in clinical research activities inclusive of the perspectives of LGBTQIA+ people and other minority groups.

This tool is structured in two parts: 1) Research Experience and 2) Background questions. It includes questions for everyone and adds questions (in red font) that may be important for LGBTQIA+ people and other underrepresented populations. Please note that these questions are only suggestions, not a set list of what "must" be asked. We welcome you to select those questions most relevant for your situation and adapt/edit as you see fit.

Instructions:[b]

For the following questions, answer to the best of your ability. Please note that you may skip any question, and for any reason (e.g., you don't know how to answer the question, the question is not relevant to your experience with the research activity, or you are uncomfortable answering the question). This survey is anonymous; in other words, we will not be able to identify you or know who you are (and, therefore, cannot get back to you or answer questions). If, however, you were part of a small group for the research activity and you answered all the background questions in Part 2, the researchers may know who you are (e.g., there was only one gay male age 65+). You can opt out of any of the background questions that you are not comfortable with. Thank you for taking the time to complete this survey, the results of which will be used to improve the research activity experience for future participants.

If you have any additional questions about the survey, please contact:

Name, Title: ___________________________
Email: ________________________________
Phone: ________________________________

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[b] Please note that these are the typical instructions that research team will give with a survey. We provide them here for reference for participants, so they can know generally what they will encounter. Through these example instructions participants can also know that if certain pieces in these example instructions (e.g., questions are optional; contact information for the research team) are not provided to them, they can ask that such options and information be provided. These instructions are NOT for participants to fill out this example survey right now.

Exit Survey (Part 1)

Clinical Research Activity Experience Questions

1. The information given to me before I joined the clinical research activity was everything that I needed to know (e.g., purpose of the trial, visits, privacy, costs).
☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

2. I always had someone I could speak to about the research activity:
☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

3. Communication materials were respectful:
☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

4. Staff members were respectful:
☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

5. Staff members communicated with me (e.g., in-person, by phone, in text or other messages) in a sufficiently private way:
☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

6. I felt staff members could relate to me and understand where I was coming from:
☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

7. I felt comfortable discussing my sexual orientation and gender identity:
☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

8. I felt comfortable discussing other parts of my identity and my personal history:
☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

9. I felt comfortable discussing any questions or concerns that I had:
☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

10. Overall, I am satisfied with the answers I received to my questions or concerns during the clinical research activity:

☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

11. I felt that the personal questions I was asked about were asked for a good reason:

☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

12. I felt that I was safe participating in this clinical research activity:

☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

13. I felt that my personal data was kept safe during this clinical research activity:

☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

14. The way in which trial data was collected was acceptable to me (e.g., in person, online questionnaire, diary, wearable sensors):

☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

15. I feel that the clinical research activity will have a positive impact on my community:

☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

16. I would recommend participating in this type of research activity to my friends:

☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

17. I would recommend participating in a research activity at this site to my friends:

☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

18. I would recommend participating in a research activity with this research team to my friends:

☐ Strongly agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly disagree

19. Additional comments:

Exit Survey (Part 2)

Background Questions

20. Your role during the clinical research activity (check all that apply)

- ☐ Participant in clinical research
- ☐ Caregiver or other support person accompanying a participant in clinical research
- ☐ Part of IRB review committee
- ☐ Advisory group for clinical trial planning, recruitment, conduct, or results reporting
- ☐ Research advocate from the community (e.g., cultural ambassador, liaison, or other form of navigator between research organizations and communities)
- ☐ Other ______________________________

21. Demographic information[c]

a. What is your age?

☐ 0-17 ☐ 18-24 ☐ 25-34 ☐ 35-44 ☐ 45-64 ☐ 65-84 ☐ 85+

b. How would you describe your race?[3, d] (check all that apply)

☐ American Indian or Alaska Native ☐ Asian ☐ Black or African American
☐ Hispanic or Latino ☐ Middle Eastern or North African
☐ Native Hawaiian or Pacific Islander ☐ White

c. What is your sex, as listed on your birth certificate?

☐ Female ☐ Male ☐ I don't know

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[c] The terminology in questions 21-23 (i.e., demographics, communication preferences), and the response choices for those questions, are drawn from US-based sources. If using Tool 7 outside of the US, we recommend adapting it to align with the local terminology and recommended response options (e.g. for race, disability).

[d] Please note that US government documents listed as weblinks in this tool may not be available. Please see the end of this tool for replicated examples of SOGI questions and response options.

d. How would you, at this time, describe your gender identity (or how you see yourself)?[e]

☐ Female/Woman ☐ Male/Man ☐ Trans Feminine/Woman
☐ Trans Masculine/Man ☐ Nonbinary ☐ Two-Spirit
☐ I use another term ______________________________

e. Were you born with sex characteristics (e.g., chromosomes, hormones, genitalia, reproductive organs) that are different from what doctors say is most common for females or males?

☐ Yes ☐ No ☐ I don't know

f. Which best represents how you think of your sexual orientation? (check all that apply)[4, 5, 6, 7, 8, f]

☐ *Gay or lesbian* ☐ *Straight (not gay or lesbian)* ☐ *Bisexual* ☐ *Two-Spirit*
☐ *Queer* ☐ *Pansexual* ☐ *Asexual* ☐ *Aromantic*
☐ *I don't know* ☐ *I use another term* ___________________________

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[e] We recognize that sex and gender are not the same and that "[cisgender or transgender] woman and man" may be recommended to use as response options for gender. However, SOGI data collection experts have conveyed that survey administrators and survey respondents less familiar with queer health have found the use different response choices for sex and gender confusing. In aiming this survey example for a general audience, we have chosen an approach to attach "female and male" here to "woman and man."

[f] Questions and response choices listed in 21c-f are based upon review of multiple sources, and discussion with the working groups convened by the MRCT Center (inclusive of international perspectives). Please note: 1. These questions and response choices have been updated from version 1.0 of this toolkit, 2. In an effort to align with evolving US government guidance for federally funded studies, we have developed alternate questions and response choices to c-f, for possible use in such studies or in similar contexts (*see next page), 3. In the US, it has been recommended to add the response option for "Two-Spirit" if the option for American Indian or Alaskan Native is included in race question response options; In Canada, "Two Spirit" is more commonly included as a response option (for both sex and gender), 4. You/your organization/advisory groups may choose to use different questions and response options depending upon your situation, local context, audience, and whether the person giving the survey is familiar with queer healthcare, 5. Including questions and (non-mandatory) response options that enable participants to see that they are recognized and represented is important, and 6. The quest for "perfect" questions and response options shouldn't hold up inclusion of good ones.

(*Alternative c-f questions/response choices are listed below as options for **discussion** with your team, **if/where necessary**. Please note that these alternate questions/response choices are not based on documented best practice).

[c (alternate version) What is your sex, as listed on your birth certificate?
☐ *Female* ☐ *Male*

[d (alternate version) Do you, at this time, describe yourself in a way that varies from the sex listed on your birth certificate?]
Open response: ______________________________

[e (alternate version) Were you born with sex characteristics (e.g., chromosomes, hormones, genitalia, reproductive organs) that are different from what doctors say is most common for females or males?]
☐ Yes ☐ No ☐ I don't know

[f (alternate version) How do you describe yourself in terms of romantic partner/s?][g]
Open response: ______________________________

g.	Do you consider yourself to be a person with a disability?	☐ Yes	☐ No
i.	Are you deaf, or do you have serious difficulty hearing?	☐ Yes	☐ No
ii.	Are you blind, or do you have serious difficulty seeing, even when wearing glasses?	☐ Yes	☐ No
iii.	Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?	☐ Yes	☐ No
iv.	Do you have serious difficulty walking or climbing stairs?	☐ Yes	☐ No
v.	Do you have difficulty dressing or bathing?	☐ Yes	☐ No

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[g] Romantic attraction is just one part of sexual orientation. To find out more, see: https://transstudent.org/gender; https://lgbtq.unc.edu/resources/asexuality-attraction-and-romantic-orientation/

vi. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone like visiting a doctor's office or shopping? ☐ Yes ☐ No

22. How did you find out about the opportunity to participant in this research activity? (check all that apply)

- ☐ Health care provider e.g., doctor, nurse, therapist, social worker)
- ☐ Friend/ [chosen] family
- ☐ Patient portal/app
- ☐ Email
- ☐ Mail
- ☐ Text
- ☐ Phone call
- ☐ Religious community
- ☐ Other community group or community activity (e.g., health fair, walk-a-thon, LGBTQ festival, parade, drag show, bear week, queer wine weekend, etc.)
- ☐ Facebook, Twitter, Instagram, YouTube, or LinkedIn
- ☐ Other social media (e.g., Tumblr, Grindr, Spaces, etc.)
- ☐ Online community (e.g., gaming)

23. During this research activity, how did you prefer to communication with the research activity team? (check all that apply)

- ☐ In person with the research team
- ☐ Patient portal/app
- ☐ Email
- ☐ Mail
- ☐ Text
- ☐ Phone call
- ☐ Facebook, Twitter, Instagram, YouTube, or LinkedIn
- ☐ Online community (e.g., gaming)
- ☐ Other: ______________________

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Please say why you liked these communication modalities.

Also, please say if there were any communication modalities you disliked, and why.

Finally, please add any other information here that you would like to share. This could include information that is important to you but was not listed in the questions (or options for answers) above.

Tool 7 Appendix: Key Resources and Recommendations for SOGI Data Collection

Key Resources[h]

The National Academies of Sciences Engineering and Medicines (NASEM): Measuring Sex, Gender Identity, and Sexual Orientation (2022)[81]

Released in 2022 at the request of the National Institutes of Health, the NASEM report examines the measurement of sex, gender identity, and sexual orientation, offering recommendations for specific measures to be used in surveys, research, administrative, and clinical health settings. It underscores the importance of distinguishing between sex and gender identity to improve construct validity (e.g., the construct/definition for "sex" represents biological sex) and recommends specific questions to assess sexual orientation, sex assigned at birth, and gender identity, including recognition of transgender and intersex experiences. The report advocates for the routine collection of gender data while cautioning against conflating gender with biological sex, emphasizing the need for precise terminology and clear measurement constructs to enhance data reliability.

Maintaining data privacy is a key concern in the NASEM report. In clinical settings, where these data play a critical role in patient care, ensuring privacy and appropriate use is essential. While the Health Insurance Portability and Accountability Act (HIPAA) provides safeguards by imposing penalties for unauthorized disclosure, legal protections alone cannot prevent mistreatment and other harms. To address this, the report highlights the need for clear organizational policies and workflows that address how such data are collected, accessed, and used. Establishing these safeguards not only helps protect participant privacy but also fosters trust in the healthcare system, ensuring that data collection efforts support equitable and inclusive care without contributing to potential harm or discrimination.

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[h] This appendix summarizes key resources that, with the exception of the [non-governmental, non-profit] Clinical Data Interchange Standards Consortium (CDISC) electronic case report form (eCRF) data standards, were produced by US government agencies and have been since removed from federal websites. While still public, the CDISC SOGI questions and response options are included here with those from now unavailable NASEM and the White House so that toolkit users can see the breadth of potential SOGI data fields.

Secretary's Advisory Committee on Human Research Protections (SACHRP) Recommendations for the Ethical Review and Inclusion of LGBTQI+ Participants in Human Subjects Research (2024)[18]

The SACHRP document was released in June 2024 and provides investigators, sponsors, IRBs/HRPPs, and research recommendations on ethical and regulatory considerations for LGBTQI+ research, including adults and minors. It emphasizes the need for inclusive research practices by addressing recruitment methods, data collection, and privacy protections while ensuring fairness in access and identifying risks specific to LGBTQI+ subgroups. Key recommendations include engaging LGBTQI+ individuals and communities in research design, developing separate research streams for different identities, and considering intersecting factors such as race, age, and disability. The document stresses the importance of legal and ethical compliance, cultural competency training, and the use of protective measures like anonymization and de-identification.

The document also emphasizes the importance of collecting and analyzing sexual orientation and gender identity data using inclusive and culturally appropriate terminology. Where possible, researchers should allocate resources for the collection and subgroup analysis of this data, ensuring appropriate methodology, privacy protections, and transparent reporting. Special considerations for minors include avoiding public postings and exploring online recruitment through platforms commonly used by LGBTQI+ youth, provided these platforms offer adequate privacy protections. Establishing youth advisory boards that include LGBTQI+ minors can also help ensure that research is responsive to their needs.

Finally, the document highlights the importance of implementing stringent data protection measures, such as using research IDs instead of recording names in consents or databases, working in safe spaces, and providing detailed and clear training to data collectors (i.e., data controllers and data processors) on confidentiality, anonymity, and data protection. Additional safeguards include technical protections against hacking of data storage spaces, conducting a risk assessment on data storage mechanisms, and testing whether data protection procedures can be breached.

White House recommendations on the best practices for the collection of sexual orientation and gender identity data on federal statistical surveys[83]

Following the June 2022 Executive Order 14075 on Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals, the Office of the Chief Statistician of the United States put together this report to offer recommendations for federal agencies on the best ways to collect self-reported sexual orientation and gender identity (SOGI) data in federal statistical surveys. The report highlights the importance of continual learning, offering considerations for including SOGI items on surveys, providing example approaches for collecting and reporting this information, and guidance on safeguarding SOGI data. It also discusses the challenges that require further research.

Key considerations include starting with the planned uses of the data, strategies to ensure sufficient sample sizes, addressing sensitivity and burden for all respondents, using tested terminology and translations, utilizing design elements that improve data quality—such as allowing respondents to select multiple response options—and confirming gender minority status. Privacy considerations are also central, requiring an evaluation of the risks associated with collecting, maintaining, and using SOGI data throughout its life cycle, particularly when intermediaries such as state, local, tribal, and territorial governments, schools, grantees, and contractors are involved. Agencies must balance the need for new information against potential privacy risks, develop a data governance plan that includes the disposition of data, assess statutory authority to protect confidentiality, and ensure respondents receive the strongest available protections. Additionally, agencies should carefully control access to microdata (e.g., educational status of women aged 18-24 in a specific zip code vs. metadata like average education status of adults in that zip code), particularly if it is linked or linkable to a specific individual and prepare strategies to handle requests (e.g., in the US, through the Freedom on Information ACT [FOIA]) that could disclose sensitive data.

Regarding sample size considerations, the report acknowledges that there is no single best practice for the minimum sample size needed to collect SOGI data. Agencies may find it useful to leverage current estimates of sexual and gender minority population prevalences to conduct power analyses for key survey outcomes and to compare estimated cell sizes against agency standards for publication.

Recommended Questions/Response Choices

CDISC[85]	NASEM[81]	White House[83]
Order of Questions		
What sex were you assigned at birth on your original birth certificate? (check one): ☐ Female ☐ Male ☐ Intersex ☐ Not Reported Were you born with a variation in your physical sex characteristics? (this is sometimes called being intersex or having a difference in sex development)? ☐ Yes ☐ No ☐ Unknown ☐ Not Reported	Use a stand-alone measure that asks respondents to report their intersex status. Do not add intersex as a third response category to a binary measure of sex. Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a difference of sex development (DSD) or were you born with (or developed naturally in puberty) genitals, reproductive organs, or chromosomal patterns that do not fit standard definitions of male or female? ☐ Yes ☐ No ☐ (Don't know) ☐ (Prefer not to answer)	Whenever an individual's responses to the two-step gender identity items classify the respondent as a gender minority a confirmation questions can be used to verify. For example, a respondent who indicates their sex at birth was "Female" and selects "Male" as their current identity would be asked to confirm these responses. SOGI questions are typically placed at the end of demographic questions, with the gender identity series (as shown in the Example SOGI Module below) appearing together (i.e., not split up) for appropriate context. Because sex assigned at birth does not define gender, respondents should not be asked to provide their sex assigned at birth unless they are also given the

	Use the following pair of questions for assessing sex assigned at birth and gender identity: Q1: What sex were you assigned at birth, on your original birth certificate? ☐ Female ☐ Male ☐ (Don't know) ☐ (Prefer not to answer) Q2: What is your current gender? [Mark only one] ☐ Female ☐ Male ☐ Transgender ☐ [If respondent is AIAN:] Two-Spirit ☐ I use a different term: [free text] ☐ (Don't know) ☐ (Prefer not to answer)	opportunity to provide their current gender identity.

Sexual Orientation		
Was SOGI (Sexual Orientation and Gender Identity) data collected? ☐ Yes ☐ No What sex were you assigned at birth on your original birth certificate? (check one): ☐ Female ☐ Male ☐ Intersex ☐ Not Reported Were you born with a variation in your physical sex characteristics? (this is sometimes called being intersex or having a difference in sex development)? ☐ Yes ☐ No ☐ Unknown ☐ Not Reported	Which of the following best represents how you think of yourself? [Select ONE]: ☐ Lesbian or gay ☐ Straight, that is, not gay or lesbian ☐ Bisexual ☐ [If respondent is AIAN:] Two-Spirit ☐ I use a different term [free text] ☐ (Don't know) ☐ (Prefer not to answer)	Which of the following best represents how you think of yourself? ☐ Gay or lesbian ☐ Straight (not gay or lesbian) ☐ Bisexual ☐ I use a different term [free text] ☐ I don’t know

Which of the following represents how you think of your sexual orientation at this time? (Check all that apply) ☐ Lesbian ☐ Gay ☐ Straight or Heterosexual ☐ Bisexual ☐ Queer ☐ Pansexual ☐ Asexual ☐ Aromantic ☐ Unknown ☐ Not Reported		

Gender Identity		
Was SOGI (Sexual Orientation and Gender Identity) data collected? ☐ Yes ☐ No What is your gender identity at this time? (Check all that apply): ☐ Cisgender Woman/Girl ☐ Cisgender Man/Boy ☐ Transgender Woman/Girl ☐ Transgender Man/Boy ☐ Gender Queer ☐ Gender Fluid ☐ Non-Binary ☐ Unknown ☐ Not Reported	Q1: What sex were you assigned at birth, on your original birth certificate? ☐ Female ☐ Male (Don't know) (Prefer not to answer) Q2: What is your current gender? [Mark only one] ☐ Female ☐ Male ☐ Transgender ☐ [If respondent is AIAN:] Two-Spirit ☐ I use a different term: ☐ [free text] ☐ (Don't know) ☐ (Prefer not to answer)	Q1. What sex were you assigned at birth, on your original birth certificate? ☐Female ☐Male Q2. How do you currently describe yourself (mark all that apply)? ☐ Female ☐ Male ☐ Transgender ☐ I use a different term [free text] Q3: Just to confirm, you were assigned {FILL} at birth and now you describe yourself as {FILL}. Is that Correct? ☐ Yes ☐ No <skip back to Q1 and/or Q2 to correct> Example gender question: Are you: Mark all that apply ☐ Female ☐ Male ☐ Transgender, non-binary, or another gender

LGBTQ Status		
Which of the following represents how you think of your sexual orientation at this time? (Check all that apply) ☐ Lesbian ☐ Gay ☐ Straight or Heterosexual ☐ Bisexual ☐ Queer ☐ Pansexual ☐ Asexual ☐ Aromantic ☐ Unknown ☐ Not Reported		Q1. Which of the following do you consider yourself to be? You can select as many as apply. ☐ Straight or heterosexual ☐ Gay ☐ Lesbian ☐ Bisexual ☐ Transgender

Gender Reporting		
	Q1: What sex were you assigned at birth, on your original birth certificate? ☐ Female ☐ Male ☐ (Don't know) ☐ (Prefer not to answer) Q2: What is your current gender? [Mark only one] ☐ Female ☐ Male ☐Transgender ☐ [If respondent is AIAN:] Two-Spirit ☐ I use a different term: [free text] (Don't know) ☐ (Prefer not to answer)	Cisgender Male – would be determined by Q1 "male" AND Q2 "male" OR "I use another term", accompanied by a write-in response that codes as male. 2. Cisgender Female – would be determined by Q1 "female" AND Q2 "female" OR "I use another term", accompanied by a write-in response that codes as female. 3. Gender minority - would be any of these combinations: - Q1 female and Q2 male - Q1 male and Q2 female - Q2 transgender - Q2 "I use another term", accompanied by a write-in response that codes the response as gender minority 4. Another gender identity – would be determined by Q2 "I use another term", unless accompanied by a write-in response that codes the response into a different category.

References

Tool 7: Exit Survey Inclusive of the LGBTQIA+ Participant Perspective

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