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# Community perspectives on the return of research results and ownership of data and specimens for brain tumor genomic research

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ABSTRACT

This study explores community perspectives on operationalizing ethical values in genomic research involving individuals with low grade glioma (LGG) brain tumors – a condition in which genomic characterization is central to diagnosis, prognosis, and treatment. We conducted qualitative directed content analysis of data generated in the course of 11 facilitated engagement discussions conducted via a research advisory council and established brain tumor communities on social media with LGG genomic research community members—including patients, care partners, clinicians, and researchers. This analysis of data from LGG community engagement examines how operationalizing ethical values of autonomy, privacy, ownership, and relevance may guide participant recruitment, communication, and return of results LGG genomic studies. Engagement participants expressed strong support for receiving both individual and aggregate research results, viewing this as a matter of reciprocity and recognition for contributions to research. While engagement participants valued transparency and control over their data and specimens, many held misconceptions about research processes, including the clinical applicability of research findings and the logistics of specimen use. These findings highlight a gap between potential research participant expectations and current LGG genomic research practices, underscoring the need for clear communication and ethically-grounded participant engagement strategies. This analysis informed LGG genomic research participant recruitment and communication practices, including priorities for returning research results and clarifying data and specimen ownership in LGG genomic research.

## 1. Introduction

Trust is one of the most important factors in an individual's decision to participate in research – especially for research involving donation of biospecimens and in communities underrepresented in research (Napoles et al., 2017; Petersen, 2005; Hawkins & O'Doherty, 2010; Lee

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et al., 2019; Scammell, 2019; Majchrowska et al., 2022). Trust in research is based in part on a participant's perception of how well researchers uphold ethical values, such as perceived support for autonomy, privacy, ownership, and relevance (Rothstein, 2015; Gray & Thorpe, 2015; Kuchinke et al., 2016). In the context of genomic research, community engagement aids in addressing potential ethical concerns in the planning, conduct, and dissemination of the research (Watson et al., 2022). The purpose of this paper is to describe community perspectives (e.g., patients, advocates, clinicians, researchers) on how researchers may demonstrate adherence to these ethical values in the context of genomic research in a community for which tumor genomic characterization is central to diagnosis, prognosis, and treatment decision making: low grade glioma (LGG) brain tumors. We engaged LGG community members in understanding how research ethics principles may be best operationalized in recruitment and communication with potential LGG research participants.

Community engagement is a well-established approach to enhancing trust and representative participation in research (Cohn et al., 2015; Nunn et al., 2019). Engagement refers to meaningful involvement and partnership with representatives of communities potentially impacted by the research. Partnering with communities in research is a best practice, especially in populations in which socio-historical, cultural, and geopolitical factors have led to harm and diminished trust in the scientific enterprise (Lemke et al., 2022). Ideally, decisions about research priorities, study design, recruitment, ownership, analysis and interpretation of data, and reporting results are made in collaboration with communities (Lemke et al., 2022). Strategies that mitigate potential group and individual harms, reduce structural barriers to participation, address bias and discrimination, enhance trust, and cultivate benefits of research are thoughtfully considered in advance. Community engagement in research is first and foremost designed to build reciprocal relationships and enhance capacity for research (Sheridan et al., 2017). That is, community engagement activities – which often involve facilitated group discussions – can appear similar to research data collection techniques such as focus groups. However, the purpose is different in that engagement is not designed to answer generalizable research questions – which is, conversely, a purpose of qualitative research (Kwan et al., 2018). Yet use of qualitative methods to analyze qualitative data resulting from community engagement activities allows for systematic synthesis of community perspectives on the prioritization, conduct, and dissemination of research – an approach with established precedent in brain cancer (Cutshall et al., 2020; Salmi et al., 2020). This paper reports on a qualitative analysis of data collected in the course of community engagement in LGG genomic research.

Community engagement is a foundational feature of the National Cancer Institute's Cancer Moonshot Initiative's Participant Engagement and Cancer Genome Sequencing (PE-CGS) Network (Rebbeck et al., 2022; Schuster et al., 2023). One of five research centers funded as part of the PE-CGS Network, the OPtimIzing engageMent in Discovery of Molecular Evolution of Low Grade Glioma (OPTIMUM) project includes a partnership between the International Low Grade Glioma Registry and a research advisory council (RAC) comprised of representatives from the LGG community. Members of the RAC serve as subject matter experts (SME) and have lived experience with LGG. The LGG Registry conducts research on social, environmental, and genetic factors associated with low grade gliomas (LGGs), a class of rare malignant brain tumors with poor long-term prognosis that predominantly affect younger adults. Gliomas are primarily classified and graded according to their molecular profiles, notably based on the presence of certain genetic mutations (Louis et al., 2021). For instance, astrocytomas are gliomas characterized by *IDH* mutations while oligodendrogliomas are gliomas characterized by isocitrate dehydrogenase (*IDH*) mutations (*IDH1* and *IDH2* mutations) and 1p/19q codeletion; those with IDH mutant gliomas tend to have longer prognoses than those with *IDH* wildtype gliomas (glioblastomas) (Lerner et al., 2024). Precision medicine based on glioma genomics – such as new *IDH* inhibitor treatments for *IDH* mutant gliomas - highlight the importance of continued genomic research for improving poor long-term outcomes in LGG. The OPTIMUM study seeks to answer cancer genomic research questions about the extent to which LGG brain tumors change at the molecular level upon recurrence. Promoting participation in LGG genomic research is critical to continued advancements in this field.

OPTIMUM does this work in partnership with the LGG community, which includes patients, care partners, researchers, genomic experts, advocacy organization representatives, and clinicians. An important consideration for OPTIMUM was to collaborate with the LGG patient and care partner community in optimizing the ethical conduct of LGG genomic research to promote trust and participation in the LGG Registry. An initial objective was to conduct a quasi-experimental study of three LGG community engagement methods (parallel facilitated discussions with a research advisory council and two established LGG communities on popular social media platforms) comparing engagement participant characteristics, experiences, and recommendations for Registry recruitment and conduct across methods. A full description of this comparative engagement method study has been published elsewhere (DeCamp et al., 2025).

This paper reports on the findings of a subsequent in-depth qualitative analysis focused on LGG community perspectives on how the Registry may best operationalize select research ethics concepts in LGG genomic research. Discussions focused on building trust in LGG genomic research, in which discussion prompts were framed according to four priority ethics values identified as especially relevant to genomic research, informed by our team's experience with bioethics and research in biobanking: autonomy, relevance, privacy, and ownership of data and specimens. These results were used to inform strategies for communication about data and specimen ownership and return of individual and aggregate research results to LGG Registry research participants.

## 2. Methods

### 2.1. Setting and design

This analysis was conducted using data generated from community engagement activities performed in partnership with the LGG Registry in 2022 (DeCamp et al., 2025). OPTIMUM's Engagement Optimization Unit aimed to identify effective and feasible strategies for engaging people with LGG and others (e.g., care partners) in the planning, conduct, and dissemination of LGG genomic research. This in-depth analysis focused on a subset of data from engagement activities coded as aligned with the four ethical values represented in the Registry's conceptual model for promoting broad, representative participation in LGG genomic research (Fig. 1). Data resulted from facilitated discussions with 1) a research advisory council (RAC) consisting of 25 patient, care partner, researcher, clinician, and regulatory representative members, 2) the “open to the public” #btsm (brain tumor social media) community on Twitter (now X), and 3) Oligodendroglioma/Low Grade Glioma Warriors, a private LGG-focused Facebook group with several thousand members. Engagement activities included facilitated discussions about trust in LGG genomic research recruitment, data sharing, and return of results. Each group participated in a series of facilitated discussions over several months, 11 total, including: four RAC meetings, four “tweet chats” (scheduled group discussions on Twitter organized by the #btsm community), and three Facebook discussion posts, with discussion prompts used with each group reflecting the conceptual model depicted below (See Supplemental File 1 for all discussion prompts; discussion topics were the same in each group, with tailoring to the language and format appropriate for the platform). Impromptu probing and clarifications were used as needed by the facilitators of each engagement to ensure mutual understanding among participants.

All RAC meetings occurred over Zoom video conference and lasted approximately 1 h. On Facebook, the research team posted a series of four posts, one per day, over the course of a week on the Warriors page.

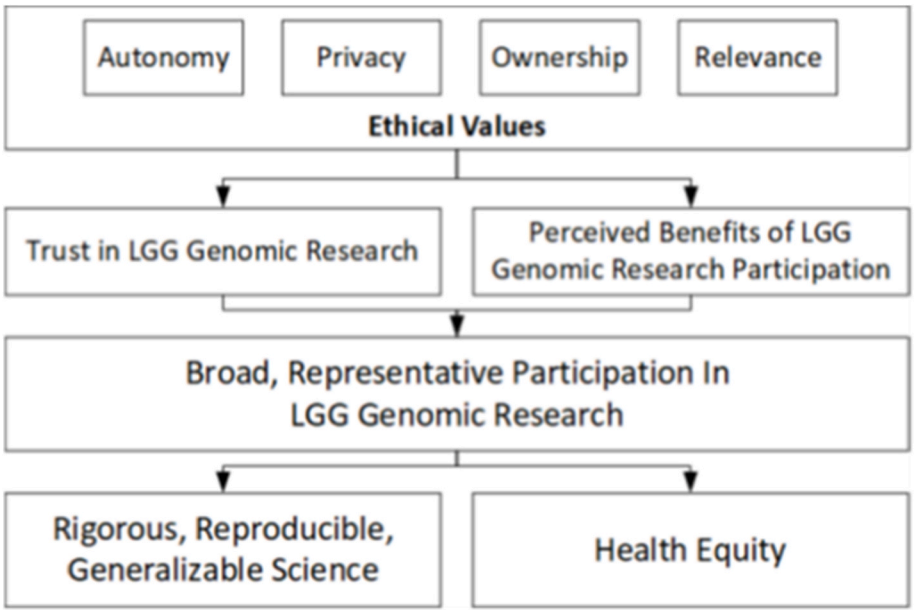


**Fig. 1.** Conceptual Model for Promoting Broad, Representative Participation in LGG Genomic Research
Image Description: A graphic depicting a model in which adhering to established ethical values (Autonomy, Privacy, Ownership, Relevance) promotes trust and perceived benefit of LGG genomic research among potential genomic research participants, promoting broad and representative participation in LGG genomic research, which enhances rigorous science and health equity.

Group members reacted asynchronously, typically in the 24-48 h after the post was made but there was no official cutoff for responses; transcripts were generated using Symplur ® several months later. Each "live" Tweet chat lasted 60 min in length and was hosted by an established brain tumor community that has regularly held monthly tweet chats since May 2013 through the volunteer-run account @BTSMchat (Wikipedia, 2026). Tweet chat data included tweets that were posted using the #BTSM hashtag and which tagged the @BTSMchat account during the chat and 12 h after each chat. We conducted a qualitative directed content analysis (Hsieh & Shannon, 2005) of transcripts generated from RAC meeting audio recordings and discussion data gathered from the social media platforms. Transcripts were stored in ATLAS. ti data management software. This manuscript was written following the Consolidated Criteria for Reporting Qualitative Studies (COREQ) standards (Tong et al., 2007). This study was approved by the Colorado Multiple Institutional Review Board (protocol #20-1001).

### 2.2. Conceptual model

Fig. 1 outlines the conceptual model that guided this work, which depicts how upholding ethical values of autonomy, privacy, ownership, and relevance may enhance trust and the perceived benefits of LGG genomic research. Upholding these values in the conduct of research is expected to lead to broad and representative participation in LGG genomic research. The selected ethical values were included in the conceptual model based on our team's prior experience and existing literature on ethical considerations in genomic research and biobanking. With respect to genomic research and biobanking, autonomy values relate to informed consent and opt-in/opt-out processes, preferences for return of individual research results and incidental findings, and the withdrawal of consent (Brothers et al., 2011; Forsberg et al., 2009/12; Hug et al., 2012/12; Schrö et al., 2011; Simon et al., 2011; Steinsbekk et al., 2013/9; Parent, 2012; Ursin et al., 2009). Privacy considerations relate to de-identification and re-identification processes (Bialobrzeski et al., 2011/11; McGeveran et al., 2012), permission to contact (LeBlanc et al., 2013/6), fear of health coverage repercussions in the event of discovering a pre-existing condition, and data access policies (Capps, 2012/11; Goddard et al., 2009/6). Ownership values relate to access to and ability to share health information (Ursin, 2008) and biospecimens. Relevance values reflect interest in knowing what one's genes reveal and perceived moral imperatives to contribute to scientific evidence (Steinsbekk et al., 2013). For instance, it is well established that many people deem it important to receive personally-relevant clinically actionable results (Middleton et al., 2016).

Table 1 shows definitions of autonomy, privacy, ownership, and relevance used by the analysis team to inform coding of the data. We collaborated with LGG patient advocates (including #btsm and

**Table 1**
Definitions of ethical values applied in qualitative coding.

| Ethical Value | Conceptual Definition |
|---|---|
| Autonomy | Refers to self-determination, or a person being capable of deliberation about personal goals and of acting under the direction of such deliberation. To respect autonomy is to give weight to autonomous persons' considered opinions and choices while refraining from obstructing their actions unless they are clearly detrimental to others. To show lack of respect for an autonomous agent is to repudiate that person's considered judgments, to deny an individual the freedom to act on those considered judgments, or to withhold information necessary to make a considered judgment, when there are no compelling reasons to do so. |
| Privacy | A right against interference that includes control over who can access information about a person and what can be done with that information; privacy-based harms can arise at all stages of data collection, analysis, and dissemination; privacy refers to "appropriate" flows of information where appropriateness is defined by the context. It is important to note that privacy is not protected merely by telling people about privacy risks (i.e. privacy is distinct from autonomy). Privacy requires active steps to protect those risks. |
| Ownership | Ownership typically refers to a right to decide what happens to something (be it data, objects, land, etc.). This is true whether or not discussing private property or a commons. |
| Relevance | Refers to whether a piece of information is useful to a person for their decision-making. For example, in genomics, the concept of medical relevance has been used to refer to whether a primary or secondary genetic test result would be useful for a person to have in order to aid their health care decision-making. Importantly, relevance occurs at a collective level too, in whether a research project is "relevant" to a community's expressed needs and values. |

Facebook group leaders) to integrate these ethical values into discussion prompts for engagement activities in ways that would resonate with the patient, care partner, and clinician experience. The ethical values were central to discussion prompts in the first set of engagement discussions, and peripherally considered in subsequent engagement activities, with each group. For example, during the first engagement, autonomy was reflected in the prompt: *"What would you want to know BEFORE you decided to participate in research that studies low grade glioma genes?"* Privacy was reflected in the prompt: *"How comfortable are you with sharing information about your/your loved one's brain tumor genes for research?"* Ownership was reflected in the prompt: *"What would you expect researchers to tell you about what's happening with your data and tumor samples?"* Relevance was reflected in the prompt: *"How might research into brain tumor genes help you as a brain tumor patient?"* The data coded with ethics-associated codes used in this analysis included both data from the first engagement discussions with the RAC and both Facebook and Twitter groups, which were purposefully designed around these ethics concepts, as well as data from subsequent engagement discussions in which ethics concepts arose organically. For instance, Engagement #4 with each engagement group was focused on return of results – and ethics concepts of autonomy and relevance often arose organically in discussions around this topic.

### 2.3. Population

Participants in the facilitated discussions included those representing a range of perspectives including people living with LGG or other brain tumors, volunteer patient community leaders, regulatory experts, health care professionals, genetics and genomics experts, advocacy organization representatives, care partners, and researchers. There were 25 RAC members who participated in at least one RAC discussion, 197 people who participated in the #btsm tweet chats, and 133 people who engaged with the Facebook discussion posts. Note, the total number of unique individuals who participated across all discussions is not known, as some individuals engaged in more than one facilitated discussion, in more than one platform, and social media handles can be anonymous and differ across platforms. Demographics for the social media discussion participants are not known. RAC member demographics are shown in Table 2.

**Table 2**
LGG registry RAC member characteristics (self-reported).

| Community Member Role (n = 25) (not mutually exclusive) | N (%) |
|---|---|
| Person living with LGG | 19 (76%) |
| Patient community leader | 3 (12%) |
| Regulatory Expert | 2 (8%) |
| Health Care Provider for people with LGG | 1 (4%) |
| Genetics expert | 1 (4%) |
| Advocacy organization representative | 1 (4%) |
| Care Partner | 1 (4%) |
| **Gender (n = 25)** | |
| Woman | 13 (52%) |
| Man | 12 (48%) |
| **Age (n = 25)** | |
| 18-24 years old | 2 (8%) |
| 25-34 years old | 8 (32%) |
| 35-44 years old | 5 (20%) |
| 45-54 years old | 9 (36%) |
| 55-64 years old | 1 (4%) |
| **Highest level of education (n = 25)** | |
| Some college but no degree | 3 (12%) |
| High school graduate (high school diploma or equivalent including GED) | 1 (4%) |
| Associate degree in college (2-year) | 1 (4%) |
| Bachelor's degree in college (4-year) | 6 (24%) |
| Master's degree | 9 (36%) |
| Doctoral degree | 1 (4%) |
| Professional degree (JD, MD) | 4 (16%) |
| **Hispanic/Latino ethnicity (n = 25)** | |
| Yes | 4 (16%) |
| No | 21 (84%) |
| **Race (n = 25) (select all that apply)** | |
| White | 21 (84%) |
| Black or African American | 3 (12%) |
| Asian | 1 (4%) |
| Other | 1 (4%) - (Middle Eastern) |
| **LGG diagnosis (n = 25)** | |
| Astrocytoma | 8 (32%) |
| Oligodendroglioma | 8 (32%) |
| Other low grade glioma | 3 (12%) |
| No, I have not personally been diagnosed with a low grade glioma | 6 (24%) |
| **Insurance (n = 25)** | |
| Private insurance provided by my or a partner or parent's employer | 20 (80%) |
| Private insurance purchased on my own (e.g., through HealthCare.gov or a state insurance marketplace) | 2 (8%) |
| Other type of insurance | 3 (12%) - Private by Employer and Medicare |
| **Income (n = 25)** | |
| Less than $50,000 | 5 (20%) |
| $50,000 to $99,999 | 4 (16%) |
| $150,000 or more | 7 (28%) |
| I prefer not to say | 9 (36%) |

### 2.4. Analysis

This was a directed content analysis using coded data that reflected the ethical values depicted in the conceptual model. The experienced analytic team included a master's prepared qualitative methodologist (JGB), a master's prepared qualitative analyst (CR), and a bioethics expert who is also a board-certified pathologist (IP). Multiple rounds of analysis were conducted, building upon prior coding and analysis, to determine results (Crabtree & Miller, 2022).

The first step of the analysis involved applying a codebook representing the ethical values of autonomy (Beauchamp & Childress, 2019), privacy (Solove, 2008), ownership (Nielsen & Nicol, 2024) and relevance (Burke et al., 2014) as defined by the ethics experts (IP, MD) with reference to the existing literature. The analytic team began by coding with the accepted definitions of these four ethical values. Following the coding of the data by ethical value, the coders conducted rounds of review of a code query for each value to inductively derive the application, conceptualization, and resonance of the ethical value across the dataset. This immersed the coders in each ethical value in the dataset and enhanced understanding to develop subcodes for each parent ethical value code, which provided more specificity to the coding. The final codebook totaled 68 codes: 4 main codes representing the ethical values, 2-4 subcodes to capture subtleties in each of the ethical constructs, and 18 additional inductively-derived codes.

Analysis continued with rounds of reviews of parent and subcode code queries within and across ethical values and engagement groups, memoing by the coding team, and debriefing with the broader research team about emerging understandings of findings. Modification of some subcodes occurred following team debriefings, and coding was revised and applied to previously coded transcripts to reflect these changes. Throughout the rounds of analysis, the analytic team clarified potential findings and checked biases during the debrief sessions with the broader study team (Olmos-Vega et al., 2023/03). Analysis completed and results were determined once it was agreed the research team had reached detailed understanding of the variation of views on the four ethical values within and across the engagement groups (Creswell & Poth, 2016). To strengthen trustworthiness of results, the team followed established standards for qualitative analysis by employing triangulation (multiple sources of data), confirmability (results shaped by participants and not researcher bias), and dependability (thick descriptions and multiple supportive quotes from each group). (Guba & Lincoln, 1989; Morse, 2015).

## 3. Results

### 3.1. Community perspectives on support for ethical values in LGG genomic research

Supporting **autonomy.** Discussion participants expressed strong support for the right of research participants to receive results from genomic research studies to which they contributed personal data. This included belief that research participants are entitled to receive both individual and overall research results, if requested – even if the clinical implications were not yet well understood. Discussion participants indicated that prospective research participants should receive this information in return or exchange for donating their clinical information and tumor specimens. One RAC research representative noted, "the vast majority of participants … do want that [research results] information … [to] just have as much as they can rather than not have it at all." (RAC Engagement 4) A RAC patient representative emphasized, "the person who did provide the sample is interested in better understanding, from whatever perspective they choose, how they have contributed to making low grade gliomas more treatable." (Patient, RAC Engagement 1) A patient advocate noted, "I would want updates on what is being studied and what is being learned, how it is being used. I am a huge research proponent but not if the patients and their care partners get kept in the dark since the research wouldn't happen without their participation." (Tweet Chat 1).

Recognizing the value of research participants' autonomy regarding whether and how they receive research results, discussion participants stated research results should be returned for the purposes of both current and future personal medical care or decision making, just in case there are potentially relevant scientific advances. For example, in one exchange with the discussion facilitator who asked, "What do you expect to be informed of during the process of your data being involved in the research study?" a discussion participant responded:

> "I would want to know, what did they find out specifically about my genomic markers and that sort of stuff. As seen on the—on my sample. Also, as I'm going through the research, what treatments have they found that would be beneficial based off [my information]? I want to know that information for the future if I'm agreeing to provide my medical history and all that sort of stuff … because maybe my oncologist don't [won't] know about it." (RAC Engagement 1)

However, discussion participants acknowledged potential limitations in understanding information contained in genetic/genomic test results returned from research and indicated that having an expert explain or interpret the results was also important. For instance, when asked *when* they would like to receive individualized research results, one RAC patient representative responded, "every time a conclusion is reached, or the results of a test are obtained. It would be interesting to see what those results are, what the conclusions are, and with, I would say, of course, a bit of a lesson associated with it, since I am not educated in—I don't have a medical degree." (RAC Engagement 1).

**Respecting privacy.** Findings related to the ethical value of *privacy* emerged in discussions oriented towards identifiability in research, information that should be kept private, legislation and protections for patient privacy, and concerns about data being sold or others profiting from accessing participants' confidential information. Regarding identifiability, participants reported being mostly comfortable sharing their health information and specimens for research, even if it was identifiable. For example: "I am comfortable sharing whatever information researchers think will be helpful. I've tried to be pretty open about my low grade tumor diagnosis, so I personally wouldn't be bothered if I was identifiable." (Patient, Facebook Engagement 1) There were a few caveats. Participants expressed concern about identifiable information being shared with insurance companies or impacting their employment in any way:

> I think when it comes to genomic research, many people are afraid of what's gonna be found out about my genome, and how can it be used against me. There [are] specific laws that we help enforce, that make sure—the information that's given to your insurance companies, for instance, and when individuals apply for a job, that they don't have access to that data, or we mitigate what kind of access they have. Not unlike the HIV scenario that you [another participant] mentioned, genomic research, in my mind, carries the same kind of risks of bias that we're very sensitive to. (Regulatory representative, RAC Engagement 1)

Though many communicated that they wouldn't mind if information about their brain tumors were shared, others expressed that dissemination of their genomic information could be cause for bias (i.e., from employers or health insurance companies). Often, participants rationalized their comfort with sharing their information for research by commenting that the benefits of helping people and advancing research outweigh the risks of identifiability:

> I don't care at all. They can have access to every facet of my tumor's genetics, my lifestyle, family history, location I grew up. I am more than willing to give up any and all privacy if it helps researchers find a cure for future generations. (Patient, Facebook Engagement 1)

In fact, some participants reported preferring to be identifiable, as a way for researchers to trace their results back to them and communicate information about the results, potentially in recognition for their contributions to research.

Participants wanted to decide which information is kept private and which is shared with researchers and third-party data collection companies. For example, participants expected information like therapy notes, behavioral oncology notes, sexual health information, and personal information (e.g., address, social security numbers, tax identification numbers) would be kept private:

> There can be really sensitive information in clinical visit notes sometimes about addiction or children or abusive partners. There are all kinds of things that may or may not be relevant to the research that are super personal, that might show up in the clinic visit notes that are a part of the medical record that patients would be very protective of and not want to share it if it wasn't absolutely necessary. (Patient, RAC Engagement 3).

Participants also reported concern about their submitted health information and data from research being sold or others profiting from accessing their information: "is this data for sale and if so to whom and where do profits from my data go?" (Patient, Tweet Chat 1). Some participants noted they would want assurances that their data were not going to be sold for financial gain. Relatedly, participants highlighted that their comfort with sharing information for research and privacy concerns relied heavily on the legislation, policies, procedures, and governing bodies in place to protect patient data, including Institutional Review Boards, hospital policies, and legislation like the 21st Century Cures Act and GINA (Genetic Information Nondiscrimination Act):

> I feel very comfortable with it [sharing information for research] because I know that if it's gotten to that stage, it's gone through IRB approval, and I know there are safeguards in place to keep things private … just knowing that there is a level of accountability that just because I shared this information, there are things in place to make sure it's not just gonna be used, however. There are rules and procedures, and that gives me confidence. (Patient, RAC Engagement 1)

**Clarifying ownership.** Discussion participants expressed they lacked clarity about who would own a patient's tumor specimens from surgical resections or blood or saliva samples—and subsequent information about those samples—if submitted to a hypothetical research study. Many participants spoke in possessive language when discussing both submitted samples and information, and data resulting from

research based on someone's submitted materials. For instance, participants used phrases such as "my health information should be my property" (Patient, Tweet Chat 3). Participants also discussed concerns around when ownership is transferred, such as data from a submitted sample, or the sample itself, becoming property of a research institution. A participant highlights this lack of clarity over ownership of patients' medical samples or information, and insists on their right to results and the remaining specimen:

> If I was going to give my information, I would expect to get some kind of feedback and say not just, "Here's my tissue, do whatever you want with it. Please give me feedback. It's mine. I want to know. Even if it's bad news, tell me something." This would be something that I would like to have an exchange [a give and take]. I wouldn't mind giving it, do whatever you have to, but, if you find something, give it back to me … It's my tissue. You're studying it, but it's mine. (Patient/Researcher, RAC Engagement 1)

Several participants alluded to ownership considerations when discussing situations in which others access information about patients or their family members, even if individuals did not elect to share it (e.g., when a family member submits a sample for genetic analysis to a commercial company). Participants also discussed desiring recognition for donating data and samples to research, such as wanting to know if one's genomic information eventually contributes to a major scientific breakthrough.

Participants discussed an expectation to know the intended use of their tumor samples and data as a condition of contributing to research. In addition to wanting assurances that participant information/data were being used for their intended purposes (e.g., to advance science regarding treatments), participants wanted fears addressed that information/data were not being used for inappropriate purposes (e.g., sold for marketing). This transparency of intended use affected willingness to consider participation in research, including LGG research. In response to the prompt, "What would you want to know before feeling comfortable sharing information for research?" one patient responded, Just, I guess, what their intentions are to do with my information like you said like, "We're not gonna know who you are, but this is how we're going to use it." Just knowing those things up front. (Patient, RAC Engagement 1).

Participants also expressed ownership in the sense of their submitted tumor samples being a limited resource, that could potentially "run out." In this regard, participants communicated a willingness to share their tumor sample if it did not impact their ability to use the sample or have remaining sample left for clinical purposes.

**Ensuring research relevance.** Discussion participants viewed research as relevant when an individual's results could potentially inform personal medical decision making. This potential relevance was principally attributed to uncertainties with LGG (e.g., treatment, recurrence, and impact on quality of life). Because of these unknowns, participants believed that research results, while considered "preliminary" in nature, could offer some guidance to them and their health care team in making future treatment decisions. For instance, one patient representative considered implications of results in the instance they need to choose between treatment options:

> Well, how do I know which is the best one [treatment option] for me? … If there was something out there [from research] that said, "Hey, this is maybe a good idea for you. If it [the brain tumor] comes back, then we would try this," then you'd have a little bit more comfort in making your decision. (RAC Engagement 1)

These participants expressed comfort with some uncertainties related to research results being unconfirmed, for what they saw as a larger benefit gained from knowledge to inform their medical decision making.

Other participants shared their experiences with receiving genomic testing on their tumor for clinical purposes too late to inform treatment. A patient argued that it was medically relevant for them to know their genomic results prior to agreeing to a particular course of treatment. Without that information, they made what they considered to be a wrong medical decision:

> I had extensive genomic testing done AFTER I went through my initial chemo and radiation. The testing revealed that I wouldn't respond well to that- which I didn't. My tumor grew then. Would've been nice to have that info earlier. (Tweet Chat 1)

Hearing people with LGG express interest in receiving research results to inform their medical decision-making prompted caution from a neuro-oncology researcher participant. The researcher elaborated:

> I'd be worried sometimes about overpromising because the likelihood of a result from a particular patient being valuable to them … is, in my experience, at least in neuro-oncology, it's relatively low … for most patients, there's nothing gonna be actionable about it … there won't be many interventions that they can pursue, based on that information. (researcher, RAC Engagement 2)

Another participant who is both a clinician and regulatory representative noted:

> The rules get a little more subjective with regard to the returning of individual [genetic] reports [created as part of a research study]. I think what we've seen recently is some research that … will yield genetic reports, but we don't know what to make of them. In other words, we don't know what they mean.…We decide we won't return them, either for a scientific integrity purpose, or that we have no idea what to tell people about these results. (clinician, RAC Engagement 3)

These two quotes by participants who work in research or as clinicians illustrate the uncertainty regarding research results' medical relevance for patients.

Additional aspects of medical relevance discussed by participants with LGG or their care partners included remaining aware of their tumor sample's physical location. Discussion participants wanted to know where their tumor sample (submitted for research) was located in the event they needed it for future testing and medical decision making. One patient/researcher participant elaborated on this point, explaining why they would want the opportunity to use their tissue sample for medical decision making:

> What if you get a recurrence and the pathologist … says, "Hey, I need to see the previous tumor," and you say, "Oh, it's in some place in research." "Where?" "Well, I don't know. Let's call the Registry." Now the Registry has to find it. They [sent] it to [research institution A], but [research institution A] sent it to [research institution B], and now we don't know where it is … I think that's something that should be important [for the patient] to know. (RAC Engagement 1)

Finally, although discussion participants recognized the choice of receiving results without clear meaning as a critical aspect of support for autonomy, the information is relevant to medical decision making only if the patient understands what can be reasonably done with the information. During these discussions among participants about the relevance of research results, they also highlighted challenges with understanding their genomic results and needing professional assistance in deciphering them were in concert with the autonomy discussions described above.

Genomic research was also seen as reflecting relevance values when it improved the science of cancer etiology, diagnosis, and/or treatment. Clinician researchers and participants with LGG also noted the relevance of LGG research to advance an overall understanding of LGG. As one researcher described:

> One of the benefits of accruing a large group of individuals who have a low-grade glioma and whose treatment information is also known

[is] so we can begin to connect those dots of what is it that is present with the initial tumor that may clue us into whether a patient responds to this therapy positively or potentially negatively. (RAC Engagement 4).

As discussed above in the privacy results section, people with LGG and their care partners expressed strong support for research participation, recognizing it as a path towards advancing knowledge in LGG. As a care partner emphasized during a RAC meeting:

When I look at my wife [who has brain cancer] … how can she help others? Is there something unique to her genetics or her tumor DNA? It's not necessarily around how can this program help us, it's, "how can we give back to others in the brain cancer community?" (RAC Engagement 1).

Care partners were mindful of the relevance that participating in LGG research can have on the community of people with LGG.

### 3.2. *Synthesis across ethical values: the reciprocity principle for LGG genomic research*

Considering results across these four ethical values indicates a belief in a principle of reciprocity between researchers and participants in the conduct of genomic research (see Fig. 2). Specifically, when these results are taken together, they suggest an expectation among genomic research participants that they will receive research and individual-level findings in exchange for contributing specimens and health information to a research study – reflecting the ethical values that underpin trust in research. This expectation represents both a desire for research participants to maintain some *autonomy* in research endeavors and for researchers to recognize continued *ownership* by participants with LGG over their health information and specimens. They described trusting researchers to protect their *privacy* as part of their research participation. Further, discussion participants reported research participants should receive individual research results because they saw the results as *relevant* to their lives, supporting their autonomy by informing their personal medical decision-making.

## 4. Discussion

In this study, we applied a bioethics lens to qualitative analysis of data generated from brain tumor community engagement discussions about trust and participation in LGG genomic research. Grounded in the ethical values of autonomy, relevance, privacy, and ownership, we identified community perspectives on the return of both individual and overall research results as well as ownership of data and specimens contributed to LGG genomic research studies. An overarching theme of reciprocity suggested that there is an expectation of receiving both recognition for contribution to scientific advances and potentially actionable information in return for sharing one's personal health data and limited tumor specimen resources for LGG genomic research. People were willing to risk the loss of privacy and the loss of opportunity to use tumor specimens for their own future clinical care given the importance of research in this rare disease. However, the lack of evidence for significant psychological harm and the clear benefits to some research participants suggest that researchers should return actionable individual research results to participants.

Our results are generally consistent with established literature on these topics (Vears et al., 2021). For instance, it has been noted that people with LGG may expect that contribution of biospecimens for research may yield actionable changes to their care (Darrigues et al., 2021), aligned with several studies documenting that patients often expect genomic research participation to directly inform clinical

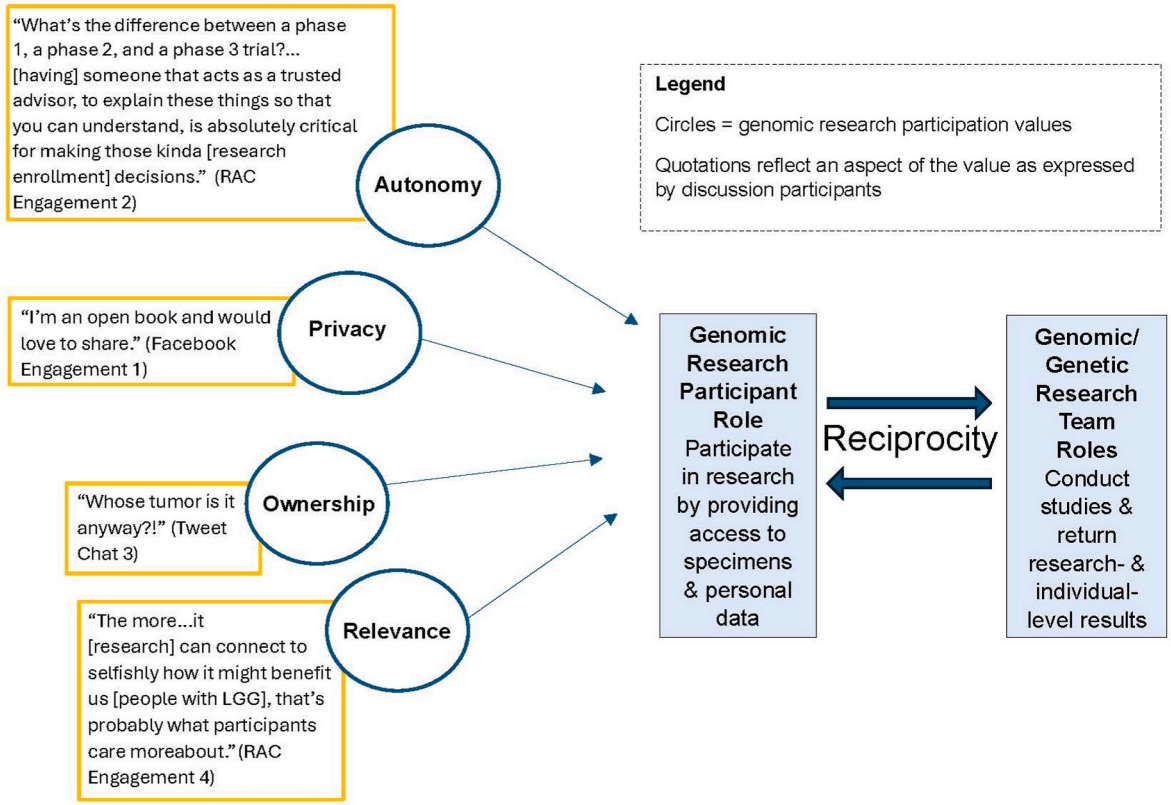


**Fig. 2.** Ethical Values-Informed Expectation for Reciprocity Between LGG Genomic Research Participants and Researchers
Image Description: A text-based figure in which key ethical values (Autonomy, Privacy, Ownership, Relevance) are illustrated with quotes from engaged genomic research participants, and connect to a concept of Reciprocity between LGG genomic research participants and genomics research teams.

decision-making (Roth et al., 2021; Spector-Bagdady et al., 2022). The overarching theme of expectations of reciprocity is consistent with insights from community engagement in other research contexts and populations (Lewis et al., 2021; Ralefala et al., 2020). However, our discussions revealed multiple instances of misalignment between potential LGG research participant expectations and current research practice and policy, as well as a misunderstanding of the process of research. These gaps in shared understanding and expectations between researchers and potential LGG research participants may well present an opportunity for enhanced communication strategies and processes for patients and providers as they consider research opportunities.

We found that the choice to receive individual results about genomic characteristics of one's tumor (separate from germline testing) is desired, even if the implications of the results are not yet known. Allowing participants the choice reflects respect for autonomy. Historically, policy guidance stated that disclosure of results should occur only when findings are scientifically valid and confirmed, have significant implications for the subject's health concerns, and a course of action is clear (National Bioethics Advisory Commission). This guidance stemmed in part from concern of harm in sharing individual results of research analyses when the meaning was not known. The cost of preparing such findings and presenting the results along with the opportunity for clinical counseling remain practical considerations. Particular concerns relate to the filtering, interpretation, and reporting of genomic variants by a research team, which may not follow the standards used in clinical laboratories and which may require additional clinical evaluation or confirmation (Wolf & Green, 2023). In a qualitative study involving semi-structured interviews with 21 genetic and non-genetic clinicians concerning experience with returning genomic sequencing results, findings suggested that returning genomic results was complicated by the complexity and potential uncertainty of the results; managing patient expectations remains an ongoing challenge (Wynn et al., 2018). Furthermore, some populations who have inadequate access to healthcare may worry about their ability to adequately follow up on concerning findings (Wolf & Green, 2023). Yet overall, the policy guidance and culture appear to be shifting – and the LGG community perspectives identified in this analysis suggest LGG genomic research should prioritize transparency and reciprocity in order to promote trust and broad research participation.

In 2018, the National Academies of Sciences, Engineering, and Medicine (NASEM) reviewed the science and offered guidance on returning individual research results to participants in biobanks (a type of biorepository related to but distinct from the Registry) (National Academies of Sciences, Engineering, and Medicine, Health and Medicine Division, Board on Health Sciences Policy, Committee on the Return of Individual-Specific Research Results Generated in Research Laboratories, 2018, p. 370). As revealed in our work, researchers must often weigh competing interests: "privacy and consent against ease of research and outputs; and individual control over biobanks against benefits and risks to communities and nonconsenting individuals." (MacLean & Burgess, 2010) A 2022 NASEM workshop on research involving biospecimens emphasized balance between the desirable goal of returning individuals' results and an expected onerous and costly process within the context of limited research resources (National Academies of Sciences, Engineering, and Medicine; Division of Behavioral and Social Sciences and Education; Committee on National Statistics). The stated desire for individual results must also be informed by the objective of research, which is to discover new knowledge that benefits society as a whole, rather than to deliver individual medical information (National Academies of Sciences, Engineering, and Medicine; Division of Behavioral and Social Sciences and Education; Committee on National Statistics).

This issue informed decisions about what results to share with participants in LGG Registry research in which genomic analysis identifies changes in molecular characteristics of tumor specimens from initial surgical resections and recurrent tumors. Even with guidance from NASEM and other entities, how best to operationalize return of results in genomic research is still under discussion (Wolf & Green, 2023). The National Cancer Institute's Participant Engagement and Cancer Genome Sequencing (PE-CGS) Network, which funds the LGG Registry's research on molecular characterization of recurrent low grade gliomas, has a policy of return of individual results to participants. The PE-CGS Program engaged 150 clinicians, scientists, genetic counselors, and representatives of potential study participants and their communities to set research priorities for patient engagement, one of which was personalizing the return of genomics findings to participants (Schuster et al., 2023). The LGG Registry's consent allows participants to indicate interest in receiving individual results (and who should receive them, including one's doctor). In collaboration with the LGG Registry's RAC, we co-designed a return of results report that includes some results with as-yet unclear implications for clinical management (e.g., changes in tumor mutational burden), as well as results that are generally available in standard-of-care tumor molecular testing. Given recent rapid advances in molecular testing for brain tumors – with possible implications for diagnosis, treatment, and prognosis – the decisional balance favored returning results of unknown significance. The LGG Registry's report includes caveats stating that these results should not be used to guide clinical decision making without confirmation and consultation with a clinician. While participants in our engagement discussions wanted the results in case of personal relevance, the inclusion of such caveats about the importance of clinical confirmation is a recommended practice and may be required by IRBs. Given changes in the culture and practice of immediate and open access to individual laboratory testing results in clinical contexts, research participants may increasingly expect similar rapid access to individual research results – thus requiring clear communication about the timeframe for conducting research analyses. Research analyses can take months if not years, compared to hours or days for clinical lab testing. In some instances, medical institutions may not release specimens in a timely fashion despite written consent from a participant and sufficient remaining tissue.

In addition to receiving individual genomic testing results, there was interest in receiving aggregate research results – that is, lay summaries of research results across all participants. The return of aggregate results to participants is widely recognized as an aspirational goal for all types of research – including genomic research (Morain et al., 2025). In our analysis, the return of results was seen as an important way researchers can recognize efforts shown by patients for the betterment of the brain cancer community: contributing to scientific advancement and being acknowledged for that contribution. Specifically, people want to be *recognized* for being part of advancing science and helping others facing this disease. This implies that what participants value is not simply knowing the results of the research but also knowing that one's data and samples were used to generate those findings.

A third key finding concerned community perspectives about access to and ownership of clinical data and specimens – presenting opportunities for clarification with research participants as well as policy advocacy. There was an admitted lack of knowledge about how much control patients have regarding how their clinical data and tumor specimens are used for research. According to the Health Insurance Portability and Accessibility Act (HIPAA), patient consent – i.e., HIPAA authorization – is required unless data shared with researchers have been de-identified; patients have the right to request their data be shared with designees, including researchers (McGraw et al., 2009). Legally, in the U.S., patients do not have ownership of anything removed from their bodies (Hakimian & Korn, 2004). One implication of this is that medical institutions may prevent a participant's inclusion in a research process by virtue of refusal of specimen release. Thus, while discussion participants spoke in terms of having a sense of *ownership* over their data and specimens, the current reality is nuanced. Our recommendation is that researchers clearly explain to participants what will happen with their data and specimens (including both storage location, access rules, and timeframe for the research), how much will be used for research

purposes (e.g., the specific data elements and volume of specimens), and how much will be preserved for clinical purposes. Laws and policies may need to be updated to reflect the changing landscape of current views of ownership to specimens and data from patients (National Academies of Sciences, Engineering, and Medicine; Division of Behavioral and Social Sciences and Education; Committee on National Statistics).

As a result of the U.S. 21st Century Cures Act (Office UGP and USFaD), which went into effect in 2021, health care recipients in the U. S. have become accustomed to the immediate availability of health information shared through online portals (Salmi et al., 2021; Steitz et al., 2023). The intent of the Cures Act was to advance science by removing complicated processes faced by patients when requesting copies of medical records to seek second opinions or participate in research (Venkataraman et al., 2024). Patient access to nearly everything in their medical records is now typical. While not all people choose to review the information in their medical records, the use of online patient portals is rising as a direct result of the COVID-19 pandemic and the implementation of the Cures Act (Salmi et al., 2024; Turer et al., 2021). As demonstrated in these results, research participants are expecting similar accessibility to research results as they enjoy for their medical information more broadly.

## 5. Conclusions

LGG genomic research participant preference for receiving both individual and overall research results aligns with a broader shift toward information transparency and patient engagement in health care overall, though challenges remain in ensuring that results are accurate and meaningful. The increasing use of online patient portals, driven by the COVID-19 pandemic and legislation such as the 21st Century Cures Act, has also influenced participants' expectations for timely access to both their health information and research findings.

Furthermore, participants' nuanced views on data and specimen ownership suggest the need for improved education and potential policy updates to reflect these evolving perspectives and promote more equitable partnerships. Working closely with LGG community members and within frameworks such as the International Low Grade Glioma Registry and the NCI's PE-CGS, we can develop tailored approaches to returning genomic results and clarifying ownership that support ethical, participant-centered genomic research. Ultimately, these findings help advance practices that balance scientific progress with respect for individual rights and values in rare disease research. Doing so may foster greater trust in genomic research by people impacted by cancer thereby improving the diversity of participants' information included in treatment- and etiology-focused studies.

## 6. Limitations

This study has several limitations. The qualitative analysis approach and focus on a specific brain tumor community afforded depth of understanding of nuanced perspectives among a diverse group of LGG patients, care partners, clinicians, and researchers; yet, it may not represent perspectives among other cancer communities, who may have other perspectives impacting trust in research. Also, these results may be influenced by selection bias since individuals supportive of research endeavors generally may have been more likely to participate in the community engagement activities. Importantly, although these engagement discussions included people with both more longitudinal relationships with research team members and thus perhaps higher baseline levels of trust (such as our RAC members) as well as people with less community-engaged research experience (such as social media engagement discussion participants), we did not compare or analyze the differences between those with more vs less experience with community-engaged research in the analysis reported in this paper. Future research may benefit from exploring how prior experience with community engaged research influences perspectives on how to build trust or how to operationalize ethics values in genomic research – which may be especially relevant to factors related to privacy.

The complexity of genomic research and evolving policies as well as knowledge of the different processes of clinical testing and delivery of results to patients versus research processes and testing with study participants may have challenged participants' comprehension, impacting the depth of responses. Further, these findings are limited by the community engagement study design which does not include probing of participants as frequently or in as much depth of detail as would occur in a qualitative research study. Power dynamics between researchers and participants could also have influenced openness. Finally, rapid advances in genomics and shifting ethical norms necessitate ongoing reassessment. Despite these limitations, the study provides valuable insights to inform more transparent communication and ethical practices in LGG genomic research.

## 7. Future directions

These findings suggest several avenues for future research. Future research into community engagement may explore differences in perspectives between highly engaged LGG community members, such as the RAC participants, and those engaged through social media platforms to better understand how different levels of involvement shape expectations and concerns in genomic research. There are also opportunities for research on how return of both individual and aggregate genomic research results influences trust and broad, representative participation in research. For instance, there may be value in developing and testing standardized, community-informed frameworks for clear communication about data and specimen ownership, return of results, and privacy protections. Studies exploring the feasibility and impact of returning LGG genomic results of uncertain significance on psychological well-being and healthcare decision-making are needed to guide ethical policies in the conduct of LGG genomic research. As digital health tools and patient portals evolve, investigating how these platforms can facilitate timely, understandable return of research findings will be valuable. IRBs should consider adapting informed consent processes to accommodate participants who seek a deeper understanding and greater engagement with their own research data. Policy analyses and advocacy should address gaps between legal frameworks and patient expectations regarding ownership and control of clinical data and biospecimens. Expanding community-engaged approaches in LGG genomic research will foster trust, respect, and equitable partnerships, enhancing both scientific progress and participant benefit.

## CRediT authorship contribution statement

**Bethany M. Kwan:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Conceptualization. **Juliana G. Barnard:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Conceptualization. **Carly Ritger:** Writing – review & editing, Formal analysis, Data curation. **Elizabeth W. Staton:** Writing – review & editing, Writing – original draft. **Ifeoma Perkins:** Writing – review & editing. **Ricardo Gonzalez-Fisher:** Writing – review & editing, Formal analysis. **Lindsay A. Lennox:** Writing – review & editing, Project administration, Data curation. **Nestelynn Gay:** Writing – review & editing, Conceptualization. **Kevin C. Johnson:** Writing – review & editing. **Roel G.W. Verhaak:** Writing – review & editing. **Elizabeth B. Claus:** Writing – review & editing. **Matthew DeCamp:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Conceptualization. **Liz Salmi:** Writing – review & editing, Writing – original draft, Formal analysis, Data curation.

## Consent to publish

Permission was requested and granted for publishing direct quotes

reported in this paper from identifiable individuals.

## Declaration of competing interest

R.G.W.V. is a co-founder and has equity interest in Boundless Bio. LS reports speaking honoraria from Medscape Oncology. No other authors report a conflict of interest.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ssmqr.2026.100741.

## Data availability

The datasets generated during and/or analyzed during the current study are not publicly available, but are available from the corresponding author on reasonable request.

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