



The Need to Standardize the Reanalysis of Genomic Sequencing Results: Findings from Interviews with Underserved Families in Genomic Research

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Abstract The reanalysis of genomic sequencing results has the potential to provide results that are of considerable medical and personal importance to recipients. Employing interviews with forty-seven predominantly medically underserved families and ethnographic observations we argue that there is pressing need to standardize the approach taken to reanalysis. Our findings highlight that study participants were unclear as to the likelihood of reanalysis happening, the process of initiating reanalysis, and whether they would receive revised results. Their reflections mirror the lack a specific focus upon reanalysis within consent and results sessions as observed in clinical settings. Mechanisms need to be put into place that standardize the approach to reanalysis in research and in clinical contexts. This would enable clinicians and genetic counsellors to communicate clearly with research participants with respect to potential for reanalysis of results and the process of reanalysis. We argue that that the role of reanalysis is too important to be referred to in an ad-hoc manner.

Furthermore, the ad-hoc nature of the current process may increase health inequities given the likelihood that only those families who have the means to press for reanalysis are likely to receive it.

Keywords Genomic sequencing · Reanalysis of genomic results · Interviews · Health inequalities

Introduction

The reanalysis of genomic sequencing results—the reinterpretation of existing results in the light of new genomic information—has the potential to produce classificatory revisions that have significant clinical and non-clinical implications. We argue in the following paper that given the importance of reanalysis to patients and/or research participants and their families, the absence of defined pathways to initiate and communicate reanalysis of results is highly problematic.

In its updated guidelines on reanalysis the American College of Medical Genetics and Genomics (ACMG) writes that “variant classification remains a dynamic process, and previously classified variants will frequently benefit from periodic reevaluation” (Deignan et al. 2019, 1267). It should be noted that the ACMG guidelines are most specifically addressed to the clinical context. In turn, the American Society of Human Genetics (ASHG), referring predominantly to clinical research, writes “currently,

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research-related recontact typically happens on an ad hoc basis, which can lead to inequitable information provision and outcomes. Guidance is needed on how recontact should be operationalized in both clinical and research settings” (2019, 579). While figures differ considerably according to context (indication for testing/symptoms tested for), study criteria (inclusion and exclusion criteria), and the genomic sequencing technology employed (such as exome sequencing vs genome sequencing), data suggests that reanalysis can considerably increase diagnostic yield (Al-Murshedi, et al. 2019; Al-Nabhani, et al. 2018; Aronson, et al. 2012; Baker, et al. 2019; Eldomery, et al. 2017; Ewans, et al. 2018; Frey, et al. 2015; Liu, et al. 2019; Lu, et al. 2020; Nambot, et al. 2018; Wenger, et al. 2017; Wright, et al. 2018).

A number of recent studies have been undertaken exploring the ethical and logistical issues concerned with reanalysis and contact with patients and/or research enrolees in respect to re-analysed results (Applebaum, et al. 2020; Bombard, et al. 2019; Carrier, et al. 2017; Carrier, et al. 2019; Carrier, et al. 2016; Chisolm, et al. 2018; Dheensa, et al. 2017; El Mecky, et al. 2019; Knoppers, et al. 2019; Otten, et al. 2015; Ploem, et al. 2018; Pyeritz 2011; Stevens, et al. 2017). These have highlighted both the need for reanalysis in order to provide the most up-to-date diagnostic analysis and, conversely, the absence of standard practices in respect of the current reanalysis process. Based upon the likely benefits of reanalysis for diagnostic accuracy it has been argued that the reanalysis of results should be made routine, but there remains little guidance as to how this should be achieved in practice (Wright et al. 2018; Applebaum, et al. 2020; Bombard and Mighton 2019; Giesbertz, et al. 2019).

We present here qualitative findings and discussion of how reanalysis is currently being presented to parents enrolled in the UCSF Prenatal and Pediatric Genomic Sequencing (P3EGS) Study which provides paediatric and prenatal genomic sequencing free of charge to study enrolees. Potential study participants were first referred to the study because their child or fetus had an undiagnosed deleterious condition that was suspected to be genetic in origin. In the study, reanalysis included both variant-level re-evaluation defined by the ACMG (Deignan, et al. 2019) as “the interrogation and potential reclassification of previously reported variants” (1268) and case-level reanalysis, as defined by

the ACMG “the review of all variants in an exome or genome, both reported and unreported” (1268).

In presenting these findings we seek to examine the subject of reanalysis *as part of the overall participant experience* of being enrolled in the study and receiving study results. Through interviews and ethnographic observation we explore participants’ recollections of what they were told about the reanalysis process and what we observed about these discussions. In our analysis, we review these findings in respect to calls for the reanalysis of genomic sequencing results to become standard practice. We argue that reanalysis is essential for the provision of the most up-to-date accurate assessment of clinically relevant genomic results and that a thorough review of current practices is needed to address client (patients and study participants) needs in both research and clinical contexts. Finally, we explore whether current practices are meeting the overarching objective of maximizing the benefit of sequencing to all populations and thus reducing health inequalities.

Methods

Setting

The data presented in this paper were collected through interview and observational analysis conducted as part of the UCSF P3EGS project. This study was approved by the IRB of UCSF. The study provides clinical sequencing to families as part of research wherein families are being asked to complete follow-up surveys and/or interviews. The P3EGS study is part of a large NIH-funded multi-disciplinary, multi-site research study, the Clinical Sequencing Evidence-Generating Research (CSER) project.

Recruitment of at least 60 per cent of participants from medically underserved populations was determined by the original funding call provided by the U.S. National Institutes of Health (NIH). Within the P3EGS demographic information was collected by genetic counsellors and/or clinical research coordinators at enrolment, including health insurance status, household income, highest level of education, and the self-reported race and ethnicity of the proband’s parent(s). Parental address was also provided. While multiple different demographic variables were employed in subsequent analyses from the broader

study, the overall category of “underserved” was determined as follows: i/ insured through Med-Cal or uninsured (not being privately or employee-insured) ii/ living within an officially defined Health Professional Shortage Area [HPSA] (ascertained through the parents’ address) iii/ being self-identified as a member of a racial/ethnic population that has been historically underrepresented in biomedical research (not self-identifying as White). If parents met two or more of these three measures, they were considered to be members of a medically underserved population. A total of 841 families were enrolled in the P3EGS study. Of these 78 per cent were classified as medically underserved and/or under-represented minorities.

Ethnography and Interviews

The team observed sixty-four enrolment/consent sessions and eighty-five return of results sessions (from which the interviewed families were selected). Ethnographic observations of clinical encounters were arranged in conjunction with the clinical team at UCSF and were in accordance with the permission of families and IRB protocols. Ethnography—specifically the observation of study enrolment and returning of results to enrolled participants—was employed both as a vehicle for understanding parent–clinician interactions and to provide context for interviews. Ethnographic fieldnotes indicated certain issues that could be explored in interviews, such as interactions that resulted in parental confusion or uncertainty or topics that were of particular interest during enrolment or returning of results (including the subject of reanalysis). Through ethnographic observation and interviews we were able to examine the relative importance or lack of importance placed upon reanalysis in clinical encounters and probe further in interviews as and when appropriate.

A semi-structured interview guide was developed by multiple members of the ethnographic team including two of the papers authors (SO and SA). The interview guide covered a wide range of questions concerned with families’ social environment, interactions with the medical profession prior to study enrolment, expectations for genomic sequencing, understanding of results (interview guide provided as an online supplementary file).

All families who entered the study were eligible to participate within the interview study. Families did not have any relationship to the ethnographic study team prior to entering the study. Upon enrolment in the study, study participants were informed in writing and verbally about the ethnographic and interview study and asked for verbal consent to be observed by a member of the ethnographic team prior to enrolment and/or return of results session. In addition, at the time of enrolment and/or return of results sessions participants were asked by genetic counsellors and/or members of the ethnographic team if they would be willing to receive a phone call with an invitation to participate in an interview. Ethnographic observations and interviews respectively were ended when no further information was being provided through their continuance (Hennink, et al. 2017; Saunders, et al., 2018). Rather than relying on a specific pre-determined target number, this sampling decision was made through discussion within the ethnographic research team and in accordance with the broader P3EGS research leadership.

A total of forty-seven interviews were conducted between two and four weeks after results sessions and thirty-seven follow-up interviews were conducted six months after results sessions (ten families declined to participate in the second interview). They include in-person, videoconferencing, and phone interviews. Interviews lasted from thirty-five to sixty minutes with an average of approximately forty-five minutes. Interview notes were taken directly after interviews and these professionally transcribed and were checked for quality and anonymity by the UCSF P3EGS ethnographic study team.

Analysis

The analytical process followed that of thematic analysis as developed by Boyatzis (1998) and Braun and Clarke (2006) and further detailed by Deterding and Waters (2021) in respect to the employment of qualitative software to analyse interviews. Fieldnotes and interview transcripts were uploaded to Dedoose qualitative software allowing for multiple persons within the analysis team to share data. All interviews (forty-seven initial interviews and thirty-seven follow-up interviews) and all field-note transcripts (sixty-four enrolment sessions and eighty-five return of results sessions) were coded

within Dedoose. In total we drew from twenty-three ethnographic fieldnotes and nineteen interviews to examine in-clinic experiences and family perspectives on reanalysis. A total of twenty-one families were included in the analysis.

In accordance with standard practice (Braun and Clarke 2006; Boyatzis 1998; Deterding and Waters 2021) our analysis involved initially reading and re-reading interview transcripts before developing inductive codes. At the initial stages of code development, team members reviewed and tested codes with the aim of ensuring clarity and consistency of use within each interview transcript. Codes were amended following their trial application within Dedoose. Upon finalization of the code list, qualitative coding was led by a core team of highly experienced qualitative researchers along with members of the project from genetic counselling. Each document (fieldnotes and interview transcripts) was reviewed by at least two members of the team for consistency in applying thematic codes. It is estimated that consistency between reviewers (overlapping coding using a blinded coding methods) was approximately 75 per cent to 85 per cent. Given the conceptual and methodological approach taken, a Kappa Coefficient for consistency was not deemed necessary. Coding overlap provides as an indication of how codes were consistently applied while a lack of overlap was not necessarily something to be rectified; instead, this was seen as an opportunity to widen the scope of interpretation of the code during the subsequent analysis and manuscript writing process. The coded data was discussed among the research team and in order develop the themes reported in this and other manuscripts.

The next step of our analytic process involved the identification of broad themes, such as patient understanding of results, physician explanations of uncertainty, and informed consent. We then honed these themes down to a particular subject of interest such as parental vs. physician understandings of causality, impact of results on family planning, or explanations and understanding of DNA/inheritance. Among the topics identified (there were many, given the size of our data set and goal of conducting multiple analyses), reanalysis emerged as one of importance in both observations and in a subset of interviews, as well as through review of the broad literature on clinical genomic sequencing practice and policy.

Results

Interviewee Characteristics

A total of eighty-five families were called to request an interview, and forty-seven agreed. Those who declined interviews were either passive decliners (no response to three requests by phone) or stated that they did not want to be interviewed. The predominant reason given for declining to be interviewed was lack of time to schedule an interview. Forty-seven Time 1 interviews were conducted and thirty-seven Time 2 interviews (ten families did not return requests for a second interview).

Of these forty-seven families, thirty-two (68 per cent) were classified as underserved by insurance status (governmental or uninsured status). Thirteen (28 per cent) were living in a medically underserved area/ member of a medically underserved population as defined by the Health Resources and Services Administration. Seven (15 per cent) or were living in a health professional shortage area, also defined through the HRSA (HRSA, 2023). Both categories were determined using the residential address of study participants. Seven (15 per cent) were living in a health professional shortage area as determined by residential address and thirty-seven (79 per cent) were from under-represented (non-European/White) populations.

The breakdown of interviewees is as follows: Time 1 Interviews: Mother only thirty-four (72 per cent), Father only three (8 per cent), Mother and Father both present ten (21 per cent); Time 2 Interviews: Mother only thirty (81 per cent), Father only four (11 per cent), Mother and Father both present three (8 per cent). The proband (son or daughter) was present at four T1 and four T2 interviews but interview questions were addressed to parents. Twelve (26 per cent) T1 interviews were conducted in Spanish and eleven (30 per cent) of T2 interviews were conducted in Spanish. The genomic sequencing results for families interviewed were as follows: positive result twenty-two (47 per cent), negative fourteen (30 per cent), inconclusive eleven (23 per cent). Interviewees respective GS results were positive (50 per cent), negative (28 per cent), inconclusive (22 per cent).

Key Themes

Based upon interviews and ethnographic observations we identified three themes: i/ general awareness of reanalysis as a possibility; ii/ timing of reanalysis; and, iii/ initiation for reanalysis. Each of these themes is exemplified through the interview quotes provided in Table 1(below) and discussed further in the sections below. In addition, observations of clinical encounters highlighted the significance of being part of research study in terms of resources; this is also discussed below.

General Awareness of Reanalysis

Among interviewees discussing the potential for reanalysis, the level of awareness among participants of the specific details was relatively low,

MOTHER: I also got the impression, and I mean it may be mistaken, but I also got the impression that just in general as the genetic testing advanced, they might retest our samples basically just to see, okay, is there any ... Now we found a new way to diagnose this, that wasn't possible five years ago, so now we should test,

retest these samples for this. [ID235/Positive Result]

While details of the process may be lacking, for interviewees with negative results, knowing or expecting that reanalysis could happen was of considerable comfort. One interview reported being “at ease because they said they were going to continue with more studies in the future” [ID108/Negative Result] and another that “we’re happy to know that we could have more information just from having it [reanalysis] done” [ID7/Inconclusive Result]. For others, the emotional tone seems perhaps resigned simply to waiting,

I think they told me that everything was normal and that we would have to wait for a while, maybe six months or a year, to review the results again to see if something new came up. [ID108/Negative Result]

Interviewees recollections reflect what was observed through ethnographic fieldwork, wherein the subject of reanalysis was more frequently referred in the context of reporting negative or uncertain results but was still rarely the subject of in detail. Within the enrolment sessions observed it was not brought up as a subject of discussion. Even

Table 1 Participant understandings of reanalysis

Theme	Example Quotes from Interviews
General Awareness of Reanalysis	I think you guys said that they were going to be retested or looked at again and compared with the other results [ID89/Negative Result] I hope they can perform the studies again or try to review the tests they performed to see if they have found something new [ID108/Negative Result] ... they said is that they would keep all of our samples on hand and continue to test them. And they said that periodically as things advanced, other things might come up [ID235/Positive Result]
Timing of Reanalysis	They told me after the result, they told me that they were going to keep it for a year and then after a year, I don't know if it was going to be retested again [ID89/Negative Result] I don't know how many genetic codes they had tested to search part by part to find the result for her illness but they didn't find anything and they told us that in six months they will repeat it. And they said they would call us [ID93/Negative Result] I'm sure there'll be more information. And [the genetic counsellor] said this herself, that in a year, she may have even said in number of months. But I expect more like in one or two years you'll have a little more information [ID273/Inconclusive Result]
Initiation of Reanalysis	... they told us that in six months they will repeat it. And they said they would call us. [[ID93/Negative Result] I don't know if you guys have a tracking system to proactively reach out or if I should just plan to. I mean, I guess research will probably change, so who knows what's happening in a couple of years, but just make a mental note to myself, check in, or if you guys have a way [ID273/Inconclusive Result]

when referred to during results session, reanalysis was explained in relatively non-specific terms, for example,

GENETIC COUNSELOR: next time we see her [the daughter of the parents] we'll want to look to see, are there more children who've been reported in medical literature since now, who had differences in the same gene ... it might help us have more evidence if this is the answer, or maybe have different problems or no problems at all and then we would think it's less likely to be the answer. [ID70/Inconclusive Result]

Timing of Reanalysis

Interviewees had different recollections as to the timing of reanalysis. One interviewee referred to the clinician informing them that that they would be “testing the samples periodically as things progress to see if there were anything else” [ID235/Positive Result]. Their impression was that this would be “a long- term thing.” Others referred to a presumed six-month time period and held out some hope that reanalysis might produce a revised result. For example,

MOTHER: They gave me an appointment here in six months and the next one in a year. Let's hope that there's something new during that year.”

Adding “,

I have faith that something new might come up.” [ID70/Inconclusive Result]

To a certain extent participants' hopes for reanalysis within this time period were conflated with the structure of the research itself, within which part of the research protocol was to include a six-month follow up appointment. This six-month follow up may have implied to some patient-enrollees that there would be something new to say at this follow up appointment and that they should wait (possibly tied to reanalysis of the results).

Others took the position waiting for the research team to get back to them with more information, rather than necessarily expecting something after a certain period had elapsed.

Initiation of Reanalysis Process

Interviewees had different views on which party would initiate the process. For some interviewees, they felt they should wait, but without any certainty that this was the best approach,

MOTHER: I'm kind of more waiting for your team to let me know, once you have more information in terms of that specific mutation as more people get testing done. [ID273/Inconclusive Result]

Others seemed a little more certain that the research study team would initiate the process and call the family. For example,

MOTHER: I don't know how many genetic codes they had tested to search part by part to find the result for her illness but they didn't find anything and they told us that in six months they will repeat it. And they said they would call us.” [ID93/Negative Result]

Another interviewee suggested a more pro-active role for the patient-enrollee in the reanalysis process but also indicated that they were not sure what this role would be,

MOTHER: I don't know, there's some sort of like mechanism in place to have like structured follow-up. Maybe it's like, you get a flag like a year later, reminder to, I don't know. To see if they want any follow up or something like that. [ID273/Inconclusive Result]

Overall, it was evident interviewees were confused about when reanalysis might happen and their role in the process. For some, waiting for reanalysis to happen (or possibly happen) was satisfactory. For others there was a degree of frustration at not knowing what would happen and/or if they were required to be play an active role in initiating the process of reanalysis (or in actively pursuing feedback from any re-analysed results).

Research Structure and Resources

While by no means frequently observed, the question of resources came up in respect to reanalysis during several clinical observations. The following quote exemplifies the difficulties faced by clinicians

in explaining how reanalysis might or might not be available given limited research resources,

CLINICIAN: In a year we would look at the test results again. [Pause] Whether or not this study will be able to do this, we don't think we'll be able to do it as part of this study, but in a year it's possible UCSF might have the resources to look at it anyhow. We're not really sure yet. Can't promise. But our next step would be, because this test is being used in so many different families and for so many different children, that in a year we might know more information. So if we were to look at just the test results again, we might find something that we didn't notice this time. [ID89/Negative Result]

In another instance, the study participant asked if reanalysis would take place repeatedly and in response the clinician explained

We can ask if the study team has the resources, when we see you in six months we can see if they can look at the results again in case they do see something different or new. [ID93/Negative Result]

Finally, it is important to note that some interviewees saw themselves as part of an ongoing process wherein they are contributing to and potentially benefiting from advances in genomic science. This may have conditioned their expectation of reanalysis and increased their tolerance for uncertainty,

MOTHER: Hopefully over time more people will have gotten tested and somebody else will have had the variant and we will, you know, have more definitive understanding of it's pathogenic or not [ID273/Inconclusive Result]

By way of summary, we observed that clinicians may unintentionally gave study participants mixed messages: holding out the hope of reanalysis while also explaining lack of resources as reason it can't be done. This mixed message might well account for why some families were confused or frustrated while others re-shaped their understanding of resource restraints positively by emphasizing that their contribution to science might be useful in future.

Discussion

Summary of Interview and Ethnographic Observations

Interviewees were largely unclear as to the details of the reanalysis process in terms of what it would entail, when it might happen, and whether they need to be active in initiating the process. While some study participants were content to wait for the clinician to provide them with more information if or when it might emerge, others were frustrated that they didn't really know what would happen or whether they would receive any notification if reanalysis did happen. At least for some, their expectations of reanalysis were conditioned by the knowledge that they are contributing to an emergent science and will have to wait for definitive answers.

Key Findings and Recommendations

These findings highlight a mismatch between the importance of reanalysis for diagnostic sequencing and lack of detailed communication regarding the timing, initialization, and the resources needed and/or available to provide reanalysis (Carrier, et al. 2017; Carrier, et al. 2019; Carrier, et al. 2016; Taber, et al. 2018; Wong, et al. 2019). While to some extent our findings are specific to the parameters of the overarching study which is time and resource limited, we strongly suggest this lack of clarity regarding the potential for and process of reanalysis is not unique to the P3EGS project.

Clinicians find themselves in a difficult position, caught between study participants wanting to have hope that geneticists can provide answers in future and knowing that study constraints (time and funding) mean that they cannot provide assurance that reanalysis will be undertaken; even in cases which may well benefit from reanalysis there is no certainty that these will be initiated given funding constraints. As such, study participants' hopes for reanalysis need to be set against observations in the clinic wherein clinicians find it difficult to make promises. Given the lack of clarity as to how reanalysis might be undertaken post-research, we strongly suggest that, within the funding protocols of clinical genomic research such as the P3EGS, there should be a set of protocols regarding the provision of reanalysis within *and*

beyond the lifespan of research studies (Dheensa, et al. 2017; Fitzpatrick, et al. 1999).

Study participants are also in a difficult position, caught between wanting definitive answers but at the same time being cautioned that this is research rather than clinical practice. There was an awareness among some research participants of being part of a broader research process for which they were contributing genetic data, clinical information, and demographic information for the purposes of advancing genomic science. This may provide a context wherein there is a greater degree of tolerance for continued uncertainty than in a purely clinical context (especially given that research participants are made aware by clinicians and counselors that research is ongoing). However, if research participants' respective contributions to science are not reciprocated through the provision of reanalysis (as and when this might be appropriate) participants may become disenchanted at the lack of action.

Given that the mechanisms of reanalysis—including costs, financing, processes, and personnel requirements (Bombard and Mighton 2019)—are yet to be fully evaluated it seems likely that communication on the subject of reanalysis with research participants and/or patients will remain ad-hoc and problematic for a considerable period of time. In respect to the research versus clinical context, each research project will necessarily be distinct in terms of what can be offered to study participants. In the clinical context (which is less directly impacted by time constraints), it may be possible to standardize an approach more easily in terms of whether reanalysis is appropriate, when it should be conducted, and how to recontact the patient and/or caregivers. However, a great deal remains to be worked out regarding costs, insurance coverage, and mechanisms for recontact even in the clinical context.

Outside of the research context (wherein initial and reanalysis might be provided free of cost) the cost of reanalysis—including staffing and/or sequencing—could lead to persons with private insurance being more likely to have reanalysis undertaken. Further research is needed in respect to this potentiality, given that private and public health insurance systems differ widely in respect to coverage for genetic sequencing. Furthermore, if reanalysis relies on patient advocacy, this will necessarily favour those with greatest resources

and against those with least resources (Sirchi, et al. 2018; Vears, et al. 2018). Those who are less well-resourced and less conditioned to self-advocacy are less likely to push for reanalysis and are thus less likely to see its benefits.

Limitations

Only a minority of those persons interviewed commented upon the prospect of reanalysis; this reflects the absence of any conversation about reanalysis in most of the clinical encounters observed. We only asked interviewees about reanalysis if/when this issue had been observed during enrolment and/or informed consent. Given that a minority of families who participated in interviews (twenty-one total) were informed about this subject in clinical encounters and/or discussed reanalysis during interviews, the range of views we were able to present is limited. As such, it was not possible to subdivide analysis by result and/or demographic indicators. While the researcher team was aware of the importance of this subject, we did not ask participants hypothetical questions about reanalysis. Our experience of asking hypothetical questions early on in the study—such as those pertaining to health insurance and life insurance issues—highlighted that such questions often caused confusion and concern about why an issue had not been discussed with the clinical team. Future qualitative and mixed-methods studies, in which a larger number of participants who are either offered reanalysis or receive reanalysis, would greatly benefit our understanding of this issue, and help to match patients'/parents' experience with the development of policy and practice. Furthermore, our findings pertain to a research context and therefore more data is needed to explore the relationship between the findings in this study and experiences in a clinical context (as is the focus of the ACMG guidelines referred to above). For the present, even this limited number of responses provides some important indicators of parental understandings of reanalysis, at least within the context of clinical genomic research. Moreover, to the best of our knowledge this is the first qualitative research report focused on reanalysis within the context of the provision of genomic sequencing services to families.

Conclusion

It is concerning that reanalysis seems to be only a minor part of the clinical encounters observed. Moreover, the lack of clarity about when and by whom reanalysis should be initiated, alongside uncertainty about the resources required to reanalyse findings and report back findings, is ultimately failing research participants. A systematic approach is needed to communicating with patients about the potential for reanalysis, both within and outside of research. Most concretely, the potential for reanalysis needs to become an integral part of informed consent and results return procedures. We recommend a widescale review of the logistics and cost of reanalysis. Such a review should be undertaken by clinical teams, laboratory personnel, academic and non-academic research boards, along with health insurance companies and state insurance systems. Without a review and revision of current practices, many patients and research participants will remain uncertain about the purpose and process of reanalysis, while the benefits will likely fall to those persons who push their providers hardest.

Declaration of Competing Interests The authors declare no conflict of interest.

Data Availability Statement The datasets from which excerpts are presented in this article are not readily available as a condition of the study is that raw data will not be shared outside of the research team. Upon request, sections of the data may be provided for specific research requests after the permissions of participants are requested and received.

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