



Survey fraud is increasingly threatening the credibility and integrity of market research. This white paper examines the scope and impact of fraudulent data and outlines a prevention-first approach to protecting sample quality. Drawing on Rare Patient Voice's proven verification practices, it offers practical recommendations to help research organizations strengthen trust and safeguard insights.

## **FRAUD ON THE FRONT LINES**

**A Rare Patient Voice White Paper**

## EXECUTIVE SUMMARY

Fraud in survey research has become a critical challenge facing the market research industry in recent years. According to Kantar, approximately 38% of survey data must be discarded due to quality issues and fraud—a staggering statistic that threatens the validity of research findings and wastes significant resources.

This white paper examines the fraud challenge through the lens of Rare Patient Voice (RPV), a specialized research panel company that has developed effective strategies to combat fraudulent survey responses. Founded in 2013, RPV has built a community of nearly 200,000 patients and family caregivers across more than 1,500 diseases, operating in nine countries.

Through careful attention to patient sourcing, verification processes, and quality control measures, RPV has successfully maintained panel and data integrity. This paper distills the key lessons learned and provides actionable recommendations for seeking to protect studies from fraud.

## THE SCOPE OF THE FRAUD PROBLEM

### UNDERSTANDING THE CHALLENGE

Survey fraud has evolved from an occasional nuisance into a systematic threat to research quality. Fraudulent respondents have become increasingly sophisticated, using advanced techniques to bypass screening questions and quality checks. The motivations are simple: financial incentives for completing surveys have attracted organized fraud operations that can significantly compromise data integrity.

The 38% data discard rate reported by Kantar represents not just wasted survey responses, but also:

- Increased project costs due to oversampling requirements
- Extended fielding periods and delayed insights
- Potential contamination of final datasets if fraud goes undetected
- Erosion of client trust in research findings

### REAL-WORLD IMPACT: THE MULTIPLE SCLEROSIS CASE

One particularly striking example highlighted in RPV's experience involved a survey targeting multiple sclerosis (MS) patients. A client team had completed a multiple sclerosis study (with another vendor, not RPV) with patients, and afterward their client had come back to them – the data didn't make sense. They were not real MS patients, they were fraudulent. Fortunately, it was discovered before the results were acted upon, and a new study was fielded with authentic MS patients.

When fraudulent responses contaminate such studies, the consequences extend beyond data quality metrics. Invalid data can lead to:

- Misguided treatment development priorities
- Inaccurate understanding of patient needs and experiences
- Wasted resources pursuing insights based on false information
- Delayed access to beneficial treatments for real patients

## THE TRUE COST OF SURVEY FRAUD

While the 38% data discard rate provides a quantifiable metric, the full impact of survey fraud extends far beyond this statistic to include:

### DIRECT FINANCIAL COSTS

- **Wasted incentive payments** to fraudulent respondents
- **Additional costs** to replace discarded responses
- **Extended fielding time** and associated project management costs
- **Data cleaning and quality control** labor

### OPPORTUNITY COSTS

- **Delayed insights** pushing back critical business decisions
- **Research resources** diverted from productive work to fraud management
- **Reduced research capacity** due to budget consumed by fraud

### STRATEGIC AND REPUTATIONAL RISKS

- **Compromised decision-making** based on contaminated data
- **Loss of confidence** in research findings among stakeholders
- **Damaged reputation** if fraudulent data leads to public errors
- **Industry credibility erosion** as fraud undermines trust in market research

### HUMAN IMPACT

Perhaps most significantly, in healthcare and patient research:

- **Misallocated resources** for treatment development based on false patient needs
- **Delayed patient access** to beneficial treatments due to research setbacks
- **Inaccurate understanding** of patient experiences and needs
- **Squandered opportunity** to genuinely improve patient lives

## THE RARE PATIENT VOICE APPROACH TO FRAUD PREVENTION

RPV operates on a fundamental principle: **start with clean sample rather than trying to clean dirty sample**. This represents a strategic choice between two approaches:

Traditional Approach: Clean Dirty Sample	RPV Approach: Start with Clean Sample
Open recruitment with minimal barriers to entry	Verified recruitment through trusted sources
Heavy reliance on post-collection data cleaning	Prevention-focused with upfront verification
High volume, high waste rate (up to 38%)	Targeted recruitment, minimal waste
Respondents select themselves into studies	Researchers select qualified respondents
Anonymous or pseudo-verified participants	Real, verifiable real people

## KNOW YOUR SOURCE: THE FOUNDATION OF QUALITY

The single most important question in preventing survey fraud is: **What is the source of your respondents?** Rather than relying on anonymous online panels where respondents self-select into studies, RPV has built its community through verified, traceable sources:

### IN-PERSON RECRUITMENT

RPV maintains a presence at patient conferences, meetings, and advocacy events, recruiting participants face-to-face. This approach offers several anti-fraud advantages:

- Direct verification of participant identity and condition
- Establishment of personal relationships with participants
- Natural filtering—fraudsters don't attend disease-specific patient conferences

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## PATIENT ADVOCACY PARTNERSHIPS

RPV has established a referral program with patient advocacy organizations, support groups, foundations, and individuals. These partners serve as trusted intermediaries who:

- Pre-verify members' conditions through their existing relationships
- Maintain ongoing communication with their communities
- Provide an additional layer of accountability
- Help educate participants about legitimate research opportunities

## 5 KEY FRAUD PREVENTION STRATEGIES

### 1. HUMAN VERIFICATION: PHONE VERIFICATION AND HUMAN CONNECTION

Direct phone contact with participants serves multiple purposes:

- **Identity Verification:** Confirming the participant is a real person with genuine experiences
- **Knowledge Assessment:** Validating that participants have authentic knowledge about their condition or profession
- **Relationship Building:** Establishing trust and ongoing communication channels
- **Fraud Deterrence:** Creating accountability—fraudsters avoid situations requiring personal interaction

This approach recognizes a fundamental truth: **real people talk to other real people**. The willingness to engage in conversation, answer follow-up questions, and maintain ongoing communication naturally filters out most fraudulent attempts.

### 2. PHYSICAL ADDRESS VERIFICATION THROUGH PAYMENT CONTROLS

RPV requires initial payments to be sent to physical addresses rather than relying solely on electronic payment methods. While this may seem old-fashioned, it provides several anti-fraud benefits:

- **Verification of Physical Presence:** Confirms participants exist at a real, verifiable location
- **Fraud Economics:** Makes large-scale fraud operations less economical and more complex
- **Paper Trail:** Creates documentation useful for verification and audit purposes
- **Fraud Pattern Detection:** Multiple payments to the same address raise red flags

While electronic payments offer convenience, they also enable automated fraud at scale. Mail adds friction that disproportionately affects fraudulent operations while having minimal impact on legitimate participants.

### 3. RECONTACT AND LONGITUDINAL RELATIONSHIPS

Fraud thrives in one-time, anonymous survey environments. RPV's model is built on ongoing relationships. The ability to maintain ongoing relationships with panel members provides:

- **Consistency Verification:** Responses can be compared across multiple studies for consistency
- **Follow-up Validation:** Suspicious responses can be investigated through follow-up contact
- **Quality Improvement:** Feedback can be provided to improve participant understanding
- **Accountability:** Knowledge that recontact is possible deters fraudulent behavior

The ability to recontact participants shifts incentives from short-term gain to long-term credibility.

### 4. QUALITATIVE RESEARCH AS A BUILT-IN FRAUD DEFENSE

RPV notes that qualitative research methodologies are inherently less vulnerable to fraud. Video interviews, focus groups, and phone discussions require:

- **Real-time verbal communication** and spontaneous responses
- **Visual verification** (in video sessions) of participant authenticity
- **Demonstration of genuine knowledge** through detailed discussions
- **Ability for moderators to probe and validate responses** in real-time

While quantitative surveys will always be necessary for certain research objectives, incorporating qualitative elements can significantly improve data quality.

### 5. ALTERNATIVE VALIDATION METHODS

RPV suggests exploring additional verification approaches that obtain the patient's in order to then obtain their electronic medical records, which confirm their exact diagnosis. While these systems require careful attention to privacy and consent, they offer:

- **Objective verification** of medical conditions and treatment history
- **Reduced burden on participants** to document their conditions
- **Additional data points** for research enrichment
- **Strong fraud deterrent** due to the verification requirement

## DUE DILIGENCE: IMPORTANT QUESTIONS TO ASK YOUR RESPONDENT PROVIDER

RPV emphasizes the importance of thorough vetting of research and respondent providers. Just as *"you wouldn't hire a job candidate without any vetting,"* you should seek to understand your provider's quality controls. Here are the critical questions to ask:

### RECRUITMENT PROCESSES

- **Where do you source your respondents?** Can you provide specific recruitment channels and methods?
- **What percentage of your panel was recruited through verified channels** (in-person events, professional organizations, advocacy groups) versus open online recruitment?
- **Can you trace the origin of each respondent** in a study back to a verified source?
- **Do you use sub-suppliers or aggregators?** If so, what verification do you perform on their sample quality?

### VERIFICATION STEPS

- **What steps do you take to verify that respondents are real people** with genuine qualifications?
- **Do you conduct phone verification or in-person validation?** For what percentage of your panel?
- **Can respondents be recontacted** for follow-up verification or additional research?
- **What documentation or proof** do you require from panel members (e.g., medical records with consent, confirmation of diagnosis)?

### FRAUD PREVENTION STRATEGY

- **Do you prevent fraud from entering your panel,** or do you primarily attempt to clean it out afterwards?
- **What is your data discard rate** due to quality and fraud issues? (Compare to the 38% industry benchmark.)
- **What specific fraud detection methods** do you employ during data collection?
- **How do you handle suspected fraud?** What is your process for investigation and removal?

### TRANSPARENCY AND ACCOUNTABILITY

- **Will you provide detailed sourcing information** for respondents in my study?
- **Can you share case studies or examples** of how you've identified and addressed fraud in past projects?
- **What guarantees or recourse** do you provide if fraud is discovered after data collection?
- **Are you willing to provide references** from other clients regarding quality?

## RECOMMENDATIONS FOR RESEARCH ORGANIZATIONS

### FOR RESEARCH BUYERS AND END CLIENTS

- **Make sample quality a primary consideration in vendor selection**, not a secondary factor behind price and speed.
- **Require detailed recruitment sourcing information** as part of research proposals and reporting.
- **Ask the tough questions** outlined in this whitepaper before committing to a sample provider.
- **Budget appropriately for quality sample**. Cheap sample often means fraudulent or low-quality data.
- **Consider incorporating qualitative elements** into research designs to add verification checkpoints.

### FOR PANEL PROVIDERS

- **Invest in verified recruitment channels** rather than relying on open online enrollment.
- **Implement prevention-first strategies** rather than detection-and-cleaning approaches.
- **Build partnerships with trusted intermediary organizations** in the communities you serve.
- **Maintain recontact ability for all panel members** through verified contact information.
- **Be transparent about sourcing and verification methods**. Make this information readily available to clients.
- **Measure and report data discard rates** as a key quality metric.

### FOR RESEARCH AGENCIES AND CONSULTANCIES

- **Develop and maintain vetted networks of quality recruitment companies**. Don't default to the cheapest or fastest option.
- **Educate clients about the true cost of fraud** and the value of quality sample.
- **Recommend research designs** that incorporate fraud-resistant methodologies.
- **Build fraud prevention checkpoints** into standard research processes.
- **Hold sample providers accountable** through contracts that include quality guarantees and recourse for fraud.

### FOR THE RESEARCH INDUSTRY

- **Establish industry standards** for sample sourcing and verification transparency.
- **Create certification programs** for sample providers that meet rigorous quality standards.
- **Share best practices and fraud patterns** through industry associations and forums.
- **Develop collaborative fraud databases** (respecting privacy laws) to identify repeat offenders.
- **Advocate for technology solutions** that make quality verification more accessible and affordable.

## CONCLUSION: FIGHTING FRAUD TOGETHER

Survey fraud represents one of the most significant current threats to the credibility and value of market research. With nearly 40% of survey data being discarded due to quality and fraud issues, the industry cannot afford complacency.

The experience of Rare Patient Voice demonstrates that fraud can be effectively prevented through:

- **Careful attention to respondent sourcing** from verified, legitimate channels
- **Prevention-first strategies** that stop fraud before it enters the system
- **Human connection and verification**, not just technological solutions
- **Recontactable, accountable respondents** rather than anonymous one-time participants
- **Shifting from respondent-selected to researcher-selected models** of participation

The key insight is deceptively simple: **know your source**. When you can trace every respondent back to a verified, legitimate recruitment channel—when you can pick up the phone and speak with them—when you know they're real people with authentic experiences—fraud becomes exponentially more difficult.

This is not just about protecting data quality metrics or avoiding wasted costs. In healthcare research in particular, fraud has real human consequences. The multiple sclerosis patient walking with assistance, the hemophilia nurses caring for their patients, the families navigating rare diseases—these are the voices that should be heard in research. When fraud drowns out authentic voices, everyone loses.

The battle against survey fraud is not one that any organization can win alone. It requires collective commitment from research buyers, sample providers, agencies, and industry organizations to:

- Prioritize quality over speed and cost
- Ask tough questions and demand transparency
- Invest in prevention rather than just detection
- Build relationships with respondents, not just collect responses
- Share knowledge and best practices across the industry

As Rare Patient Voice has demonstrated through over a decade of operation—during which they've awarded more than \$18 million since 2013 to legitimate participants across its community of 200,000+ verified individuals—high quality data is achievable. It requires deliberate effort, investment, and commitment, but the alternative—accepting fraud as an inevitable cost of doing business—is untenable.

The research industry stands at a crossroads. We can continue down the path of accepting 38% data loss as normal, or we can embrace the fight against fraud as a fundamental responsibility. The choice will determine not just the quality of our data, but the credibility and future of our entire profession.

Real people talk to other real people. Real people can be contacted again and again. Real people have authentic experiences worth capturing. By focusing on connecting with these real people through verified channels, the research industry can defeat fraud and reclaim the integrity that makes our work valuable.

**The fraud fighters are those on the frontlines who refuse to accept the status quo, who ask the difficult questions, and who invest in quality at every step. It's time for the entire research industry to join the battle.**

## ABOUT RARE PATIENT VOICE

Rare Patient Voice (RPV) was founded in 2013 with a mission to empower patients and family caregivers to share their voices through participation in research studies. What began as a focus on rare diseases has expanded to include both rare and non-rare conditions, building a community of over 200,000 participants across more than 1,500 diseases.

Operating across nine countries—the United States, Canada, United Kingdom, France, Germany, Italy, Spain, Australia, and New Zealand—RPV has established itself as a leader in patient research recruitment and engagement.

RPV has awarded patients and family caregivers over \$18 million for their contributions to research, demonstrating both the scale of their operations and their commitment to valuing participant time and expertise. The company's recruitment approach emphasizes in-person connections at patient events, partnerships with advocacy organizations, and verification of participant authenticity.

This whitepaper is based on a presentation delivered at ESOMAR, a global association for market research and data analytics professionals.

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## DISCLAIMER

*This white paper is based on a presentation delivered by Rare Patient Voice at a 2024 ESOMAR conference. The content reflects the experiences and perspectives of Rare Patient Voice and should not be construed as a comprehensive survey of all anti-fraud methodologies or as an endorsement of any particular approach over others. Organizations should evaluate fraud prevention strategies based on their specific research needs, populations, and operational constraints.*