



INAME Supports SMA Research With 89% Verified Surveys

 **Industry:**
Nonprofit

 **Customer Since:**
2024

 **Products:**
Experience Studio

 **Features:**
Surveys, Automation

COMPANY BACKGROUND

[INAME](#) is a nonprofit organization supporting people with SMA across Brazil. Working with patients, the industry, and government agencies, INAME helps expand and regulate access to treatment for people with SMA. To support families directly, INAME lends equipment like respirators, shares information with diagnosed patients, and provides guidance through support groups.

INAME'S CHALLENGE

INAME's patient registry survey was difficult to complete. That challenge was important because most participants rely on mobile devices. INAME's surveys also lacked save-and-resume functionality, among other issues. Participants who left before finishing had to restart it. For surveys completed on mobile, participants may lose progress, abandon the survey, or struggle to complete the registry.

The survey supports SMA research, so INAME needed a secure way to manage patient data, consent, and ethics requirements in Salesforce.

TITAN'S SOLUTION

INAME implemented Titan Experience Studio, creating advanced patient registry surveys connected to Salesforce.

Save-and-resume functionality was introduced, allowing participants to complete questionnaires without losing progress. The surveys were also optimized for mobile compatibility and include optional file uploads for genetic test verification.

Consent and ethics requirements are built into the survey flow, so participants review information and approve participation before continuing.

Every response connects to Salesforce, helping INAME securely manage patient registry data.



KEY RESULTS

- ✓ **89% of Long Patient Registry Surveys Verified:** Around 887 of INAME's 994 completed surveys include an attached and verified genetic test, giving the organization stronger data for SMA research in Brazil.
- ✓ **Save-and-Return for Long Surveys:** Participants can save progress and return later, making long patient registry surveys more practical to complete on mobile devices.
- ✓ **Support for Privacy and Ethics Requirements:** Consent steps, privacy information, and Salesforce-connected data capture help INAME manage sensitive research data in line with approval requirements and data privacy laws.
- ✓ **Complex Survey Logic:** Titan supports the advanced branching and conditional logic INAME needed for large-scale patient registry surveys.
- ✓ **SMA Research Supported in Brazil:** The patient registry surveys help support scientific research into the natural history of SMA and its development among Brazilians.
- ✓ **SMA Advocacy Supported in Brazil:** The patient registry surveys help create real-world evidence about SMA to support advocacy for treatment access in Brazil.

"We feel safe with Titan because it's connected to Salesforce. We also have a really strong relationship with the Titan team, which matters a lot for us as a nonprofit since we have very specific survey requirements." – Isabella Araujo, Executive Director at INAME.