



Shattering Rare Disease Registry Recruitment Targets with PIP-UK.

Real-world data from registries and other real-world evidence sources remain a fertile ground of opportunity for advocacy groups and biopharma companies to accelerate rare disease research and better characterize and manage these diseases, their progression and treatment.

Historically, the barriers to maximizing the value of registry data include:

- Lack of data security, quality, or trust
- Challenges with patient recruitment or engagement
- Narrow or incomplete data

Many patient registries are built for clinical use and do not provide patients with immediate access to aggregate, de-identified data that fosters a sense of community and increases engagement.

Pulse Infoframe's platform does, and as a result, PIP-UK was able to exceed their 12-month goal of enrolling 100 participants in just 2 weeks.

PIP-UK Overview

PIP-UK is an advocacy group based in England that focuses on promoting research into Poland Syndrome, a rare genetic condition. PIP-UK was founded in 2011 by Sam Fillingham after her son was diagnosed with Poland Syndrome. The organization set out with the mission of raising awareness for Poland Syndrome and pushing for earlier and consistent diagnosis and treatment paths for the community. Sam knew the first big step in making this vision a reality was to build a global Poland Syndrome register to better understand the condition and its progression for research.

Why PIP-UK Choose Pulse Infoframe

Since 2012, PIP-UK has worked with another group based in Italy who has had an established Poland Syndrome clinical register. By 2020, they were able to dedicate full time resources to PIP-UK. This is when they changed from a community group to a fully registered charity and put the plan for a global patient registry into motion. Sam was deeply immersed in the online Poland Syndrome patient community in the form of Facebook groups where patients come together to learn from and support one another. Since these groups were all run by patients, it served as a great tool to learn about what the community really wants and to engage with them well before the registry was established.

Sam extensively researched all the current registry providers. The registries she came across did not engage patients or capture their voices, quality of life and concerns the same way the Facebook groups do. Sam wanted the register to be patient-centric and deliver instant feedback to benefit the patient community on top of supporting research initiatives.

As Sam got closer to the patients, she realized that staying engaged and making them a part of shaping the registry was going to be crucial for its success. Poland Syndrome has an active patient community that wanted to see change and they were motivated to be part of the solution. Sam kept this at the front of her mind when she joined a webinar hosted by Pulse Infoframe founder Femida Gwadry-Sridhar. This webinar was centered around how Pulse Infoframe's platform provides end-to-end patient engagement in the form of having custom patient-centered visuals, embedded educational content, and having mobile access anywhere in the world. By the end of the meeting, Sam was sold and decided to move forward and use Pulse Infoframe to build the Poland Syndrome Community Register.



Recruiting Strategy

Build a List of Potential Participants

Once PIP-UK settled on Pulse Infoframe as the right partner for their registry, the recruiting efforts were kicked into high gear. PIP-UK had been collecting patient contact information via a Google form so when the register was up and running, they already had a database of participants to reach out to. Following the announcement of the partnership with Pulse Infoframe, the number of participants in the Google form increased from about 80 members to over 200. PIP-UK also leveraged Pulse Infoframe's FAQ library to address the usual questions and hesitations patients have regarding data sharing, privacy, and security. PIP-UK knew building a contact database was a good start, but to raise awareness and generate excitement, they needed the patient community to be a part of the effort.

Involve Patients in the Recruiting Process

Sam had spent years building relationships and discussing the global registry idea with several members of the Poland Syndrome community. Once the idea became closer to a reality, Sam wanted the patients to be involved in the awareness campaign as much as possible since the registry is primarily for their benefit. She reached out to a handful of the most engaged people online to become champions of the register and to record short interviews to encourage registry enrollment and educate other members of the online community. PIP-UK would then edit these interviews into shorter clips and share them through their own social media channels as well as the community Facebook groups, and the register's champions and ambassadors' personal profiles. This resulted in an organic and authentic campaign where the people who live with Poland Syndrome are the ones rallying the community. Sam credits these videos as being her biggest asset to spread awareness of the register.

On top of the videos she produced featured Rebecca Butcher, an ambassador and registry champion also produced several of her own videos and recruited another 6 community champions to further amplify the news of the registry and increase the reach of their promotional efforts. Rebecca leveraged news outlets to share her story and has been featured in numerous articles and YouTube videos that have gained over a million views



What's Next for PIP-UK?

As of August 2022, the Poland Syndrome community register has over 170 participants. On top of growing the presence of their global register, PIP-UK has worked with the patient community to identify what their next goals should be. These include developing surveys on surgical outcomes and how they impact Poland Syndrome patients, and another survey on aging with this condition to see how it impacts individuals later in life. Since the registry launch, PIP-UK has never had more conversations with clinicians and researchers. The registry gives them a database that opens the door for Poland Syndrome research.

Lessons to Learn

The work done by PIP-UK serves as a perfect guide to those who are looking to start a patient registry. While registries provide an immense amount of value for researchers, at the end of the day they are for the patient community. To facilitate successful recruiting for a new registry it is imperative to:

- Engage with the patient community well before beginning to build a register. Build a contact database to enable more effective outreach when the registry is live.
- Network with patients to determine what they want to get out of a registry and what research they would like to see.
- Involve patients in marketing and recruiting efforts. They are excited to see something being done and many would love to lend a hand. Their involvement increases the reach of your promotional materials.