

HOW ARE PATIENTS NAVIGATING THE COLLECTION OF DATA?

The View of the Pulse Inframe Patient Advisory Board



WHO IS PULSE INFOFRAME?

Pulse Inframe is a real-world evidence generation health informatics company with a technology platform designed to ingest, curate and analyze data to help research in rare diseases, cancer and chronic conditions. Pulse Inframe partners with patient advocates, researchers and sponsors to build these registries that support natural history studies and a variety of other observational and regulatory-grade studies that can accelerate drug development and improve quality of life.

In our quest to ensure that we represent the patient voice throughout our product, we recently formed the Pulse Inframe Patient Advisory Board (PAB). Launched in October 2022, this collaborative group consists of patients and patient organization leaders from diverse conditions and a wide range of professional and geographic backgrounds, representing both rare and chronic diseases. We held our first quarterly PAB meeting in October 2022 via Zoom.

Our PAB members will participate for a minimum of one-year to provide guidance and better insights into a “patient first” strategy, through the evidence generation trajectory.





Mark Dant

Dr. Stacey Feuer

Laurence Woollard

Director of On The Pulse Consultancy.
Rare disease advocate and speaker.

We focused our discussion in two distinct areas:

1 Understanding the burden and perceived importance of data collection from the patient and patient organization perspective.

2 Understanding the value of professional meetings and conferences from the patient perspective.

There is widespread survey fatigue because so many companies are asking patients the same questions. Patients spend a lot of time sharing data and then have no idea what happens to the data:

"We get nothing back—it's like yelling into a void and having no idea what happens after that."

It would help engagement to see how the data are being used through dashboards and posters. We also need a feedback loop that continuously updates patients on how their data are being used.



What are the unmet needs in your patient community?

The PAB provided us with several important points and questions to consider, when considering how best to think about “unmet” need and how we get an accurate representation of this, given the following:

- **Are we only asking the most motivated and active patients to share their data?**

What about patients who are not engaged with a patient organization?
What about patients who are not technologically savvy?

- **How do we make sure we’re collecting data from smaller patient groups?** How do we reach patients globally?

- **Some patients only get their information from their healthcare provider.** How do we ensure healthcare providers are educated about the opportunities for data collection?
- **Chronic disengagement**, including the sharing of data, is especially problematic with minority communities.
- **The same patients repeatedly show up for meetings and talk to each other** the other 90% are not heard from. How can advocacy groups reach out to everybody, not just the same people over and over again?

What are the challenges your community faces to participate in a registry?

- **Motivating patients to continue entering data after the first big launch is important.** You cannot just launch a registry, you need to build capacity and continue to build the community.
- **Registries are for the patient** — sometimes that gets lost in all the detail that are asked..
- **The challenge is not in setting up the registry**, it’s populating the data. This is especially true with small patient groups.

- A lot of companies are saying, “we are the ones to help you create a registry,” but patient groups struggle to decide which one to choose. They are bombarded by companies making them a lot of promises.
- Capacity building is an area where patient groups need coaching. Ensuring they have a good understanding of data collection processes and can sustain a registry after the launch is critical for success.
- There is a big disconnect between scientists and clinical trial organizers in understanding the need for a registry. For example, the debate that self-reported data are not “good data.”



Where do you go for guidance on data?

- Word of mouth
- Trusted colleagues



UNDERSTANDING WHERE PATIENT COMMUNITIES GET THEIR INFORMATION IS VITAL.

We asked the PAB to share their sources of information

Which meetings are important for your patient community to attend and learn about data/registry opportunities?

- Mass Bio, and other state biotech conferences
- Some patients just talk directly with their doctors



SUMMARY & KEY TAKEAWAYS

Holding the first Pulse Inframe PAB meeting gave us unique insights to the success and challenges faced by advocacy groups in considering a patient registry and the ensuing data collection.

The themes highlighted illustrate that there is still a lot of work to be done to educate patient communities on the power that high quality data can have in developing treatments.

A clear issue facing many is that there are lots of companies who are offering data collection services that can help patient groups manage their data requirements, but they don't all live up to what they are promising. The PAB noted that many patient advocacy groups are confused about how to make an informed decision when it comes to selecting a registry platform. They struggle to understand the differences between the platforms on the market and are unclear about what key functionality they need to consider. They actively seek guidance from their support networks, but this is an area which many feel needs to be improved.

Patients and advocacy groups were noted to rely on certain conferences and word of mouth to make their decisions on data. There is a need to educate and articulate the differences between various technologies on the market and to clearly articulate what defines platforms on the market so that they can find a solution that best suits their needs. Some patient groups need a full-service platform while others need a simple contact database. However, it was noted that the ability to grow with their data platform is vital, so that they don't have to keep investing in new technology when they outgrow what they initially need. This is something we have addressed with intent in the development of the Pulse Inframe platform.

PATIENT & ADVOCACY GROUP UNMET NEEDS

Patient Engagement	<input type="checkbox"/>
Continuous Feedback Loop	<input type="checkbox"/>
Eliminate Survey Fatigue	<input type="checkbox"/>
Funding	<input type="checkbox"/>
Understand Different Data Capturing Platforms	<input type="checkbox"/>
Help Growing their Registry	<input type="checkbox"/>
Capacity Building for Smaller Groups	<input type="checkbox"/>
Better Racial and Ethnic Diversity	<input type="checkbox"/>
See Where Their Data Goes	<input type="checkbox"/>
Education on Purpose of Registries	<input type="checkbox"/>
Ability to Share Registry Insights with their Healthcare Professional	<input type="checkbox"/>



The PAB also highlighted that patient groups need help with capacity building, especially the smaller groups, to ensure they cannot only create a registry, but continue to contribute data after the initial launch. One of the main areas that advocacy needs support for is ensuring that their patient community continues to contribute post-registry launch. As an industry, we need to do more work on this. The board concluded that there needs to be a focus not only on educating the patient or parent/carer on using a registry, but also the advocacy groups themselves. This will help them target more diverse communities, which will give a better representation of patients.



The PAB stated that there is a no feedback loop: Patients feel like they enter their data and get nothing back. Whether we are researchers or pharma or biotech, collectively we as an industry, we need to provide feedback on a regular basis. In addition, patients and patient groups are overwhelmed with requests for data collection, and they are suffering from collective survey fatigue.

Conclusion

Having the opportunity to work with a PAB truly helped us better understand some of the real challenges and concerns that patients face, when it comes to data needs and technology. We would like to thank our PAB members, Jean Campbell, Dr. Stacey Feuer, Mark Dant and Laurence Woollard for the opportunity to spend time with them, during this inaugural meeting. Their experience, dedication and passion to help patients was palpable. Their insights will continue to drive forward the work we are doing at Pulse Inframe with the benefit of their lens. Translating this knowledge to others is something we believe in and hope that this whitepaper, at the very least creates the forum for discussion and debate.

