

Doing Data Right from a Scientific and Human Perspective

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OBJECTIVES

Patient advisory boards have been highlighted as being key in the development of any product for any disease. They add value not only through lived experience, but truly understanding what the patient needs are. Patient Advisory Boards (PABs) provide the perfect opportunity to gain rich insights and the valuable feedback can be used to inform a variety of topics, including protocol designs and patient engagement strategies which ultimately improving the overall experiences of trial participants¹. The benefits can then be passed directly to patients, and when they are given the opportunity to have easy access to their own health data and the power to research, they can make informed decisions about their own treatment options².

METHODS

In September 2022 Pulse Inframe launched a Patient Advisory Board (PAB) to support the development of our industry leading real-world data (RWD) platform to ensure it meets the needs of all the respective stakeholders: patients; clinicians; researchers; industry; and regulators.

Name	Track Record
Mark Dant	-Volunteer Executive Director of the Ryan Foundation -Former Chair of the board of the EveryLife Foundation for Rare Diseases.
Laurence Woollard	-Director of On The Pulse Consultancy. -Rare disease advocate and speaker.
Dr. Stacey Feuer	-Director of the Health Psychology Department at Duly Health Care. -Rare disease advocate and speaker.
Jean Campbell	-Co-founder and board member of Professional Patient Advocates in Life Sciences and founder of JF Campbell Consultants. -Former vice president of Membership Development at NORD.

Four well respected leaders from the rare disease community joined the Pulse PAB program and as part of this have been providing insights that collectively have the potential to make real change in the collection of RWD from various patient communities. The insights from the PAB were gained through focus groups with its members, where various themes were discussed and reviewed through qualitative analysis. These themes included:

Figure 1. Patient Advisory Board Meeting Main Themes

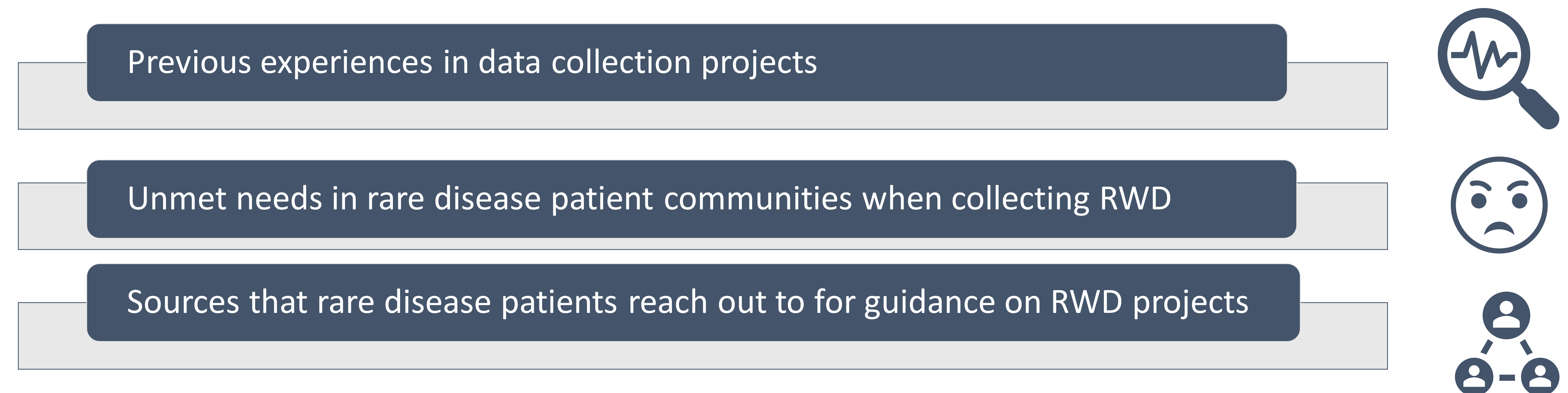


Figure 2. Unmet Data Collection Needs in Rare Disease Communities

Patient Engagement	Funding	Capacity building for smaller groups	Education on purpose of registries
Continuous feedback loop	Help growing registry	Better racial and ethnic diversity	Ability to share registry insights with their healthcare professional (HCP)
Eliminate survey fatigue	Understanding different data capturing platforms	See where their data goes	

CONCLUSION

As part of this project, it is vital that the opinions and experiences of patients and advocates are at the forefront of any technology development. It is widely accepted that it is evident that the role of technology in healthcare is bound to grow exponentially in the time to come². Due to this, Pulse has been proactive at implementing adaptations to its platform as recommended by the PAB so that is accessible to multiple rare disease patient communities. You learn more about our patient advisory board and their thoughts on data collection for patient advocacy groups by reading our latest white paper via the QR code.



PAB White Paper

1. <https://www.cisr.org/the-value-of-patient-advisory-boards-in-understanding-receptiveness-to-new-technologies-in-healthcare-and-clinical-research/>
2. <https://www.pluginandplaytechcenter.com/resources/rise-technology-patient-centric-care/>