The “Patient” Perspective

Real-World Evidence on Medical Product Development

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PXE international

Genetic Alliance

What is this perspective then?

“I don’t want to be here.
I did not choose to be here.
I would like to leave here.”

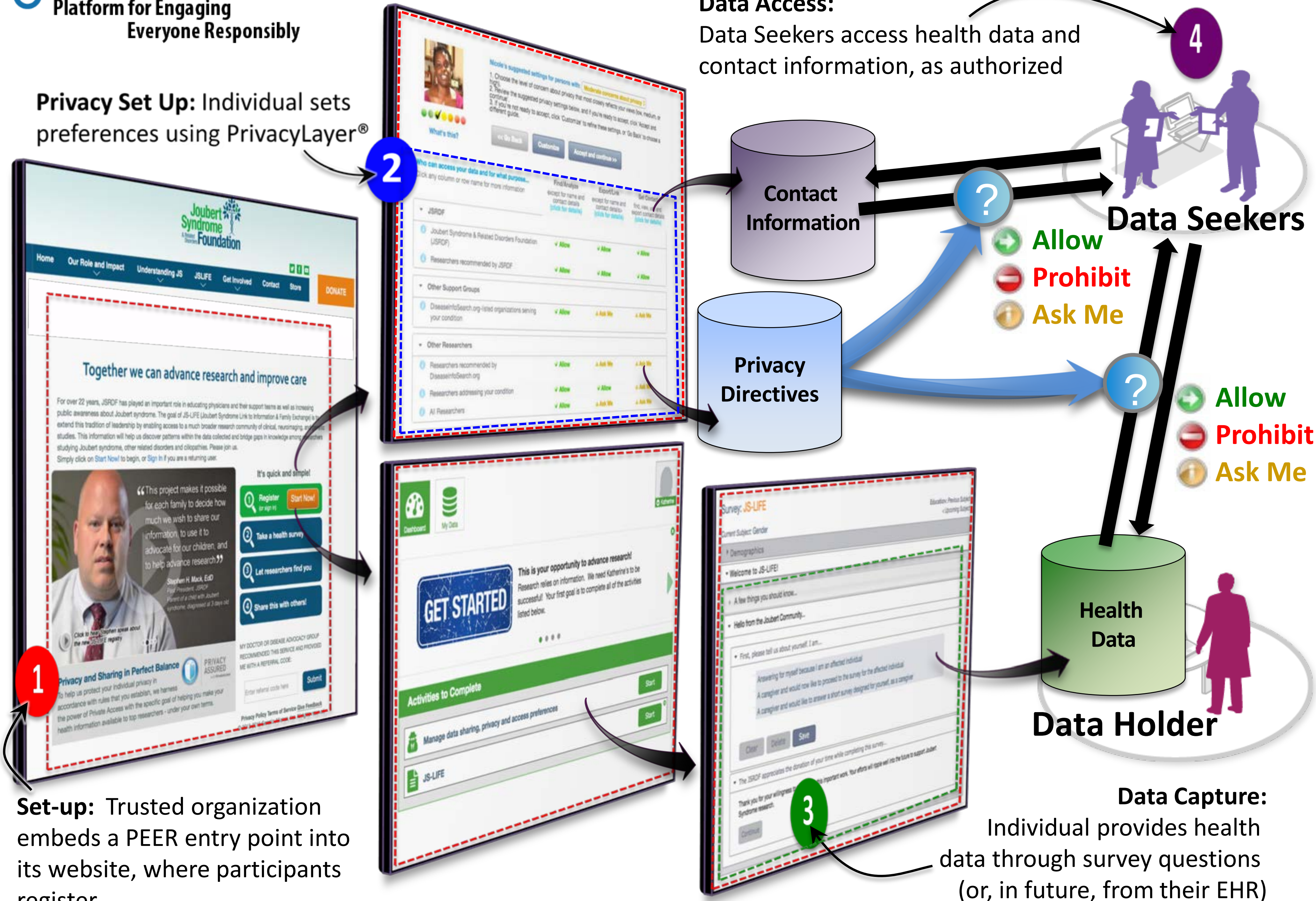
Communities have gathered evidence for years.

Abundant evidence exists for disease advocacy (patient) organizations, community-based participatory research, activist-led, and citizen science contributions to biomedical, outcomes, and health research.

Registries as portals into RWE

- Community/affinity (including device)/advocacy based
- Run by those with lived experience of the condition and device
- Understand opportunities and risks and can decide for their community
- Need rigorous AND accessible methods for validation
- Integrate education in the registry experience

PEER
Platform for Engaging Everyone Responsibly



Privacy Set Up: Individual sets preferences using PrivacyLayer®

Data Access: Data Seekers access health data and contact information, as authorized

Set-up: Trusted organization embeds a PEER entry point into its website, where participants register

Data Capture: Individual provides health data through survey questions (or, in future, from their EHR)

Nothing about us without us

- Unleash the power of communities
- Build on successes
- Keep people in the center
- Do not lose sight of what matters