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Clinical Research Needs a Moonshot

What Patients can teach us about Innovation

Alicia C. Staley
Chief Patient Officer

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My Cancer by the Numbers

3 cancer diagnoses (Hodgkin's and BC)

35 years of total survivorship

19 years old at first diagnosis

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Hodgkin's Overview

6 months until definitive diagnosis

1 bone marrow biopsy

1 chunk of left hip removed

15 weeks of radiation

33 radiation tattoos

2 major surgeries to prep before chemo

3 weeks longest hospital stay

1 ELF experience on the pediatric floor

8 cycles of ABVD chemotherapy

6 additional weeks of radiation

3.5 years for treatment journey

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Breast Cancer Overview

2 different breast cancer diagnoses

3 major surgeries

3.5 years for treatment journey

Additional Information

12 surgeries in total

5 organs removed

5 major medical imaging types

4 clinical trial opportunities

3 clinical trial opportunities declined

1 med device trial participation

1 functioning lung

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I'm quitting.

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I'm not stopping.

Why do you care about the Patient Experience?

My Patient 'Experience'

1,000+ pages of medical records, records from 1990-93 were not retained

300+ hours in travel time for Hodgkin's treatment

16 different patient portals at **4** different medical centers with different record retention policies

3 portal instances are now archived, not searchable, and currently not accessible or offline – this is my current fight with my healthcare team

Did not participate in **3** clinical trials due to lack of information and understanding of trial

No support group that covered my scenarios - created my own **#BCSM (40,000+)**

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What is a Moonshot?

"A **moonshot** is an ambitious, exploratory, and ground-breaking project aimed at achieving a significant, seemingly impossible goal. The term is inspired by **NASA's Apollo 11 mission** in 1969, which successfully landed humans on the moon—a goal that many considered unachievable at the time." - NASA Website

A moonshot is a **bold, innovative endeavor** aimed at solving **seemingly impossible challenges** with **transformative potential.** It embodies the spirit of pushing boundaries, embracing risk, and making a profound impact on the world.

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This is my moonshot. This is your moonshot.

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Leveraging the Patient Perspective to Enhance Clinical Data Management

- **I**dentify Pain Points in Data Collection from the Patient Perspective

- Enhance Data Accuracy Through Contextual Feedback

- Prioritize Patient-Centric Endpoints and Metrics

- Reduce Dropout Rates Through Improved Usability

- Build Trust and Compliance Through Transparency

By integrating the patient perspective, clinical data managers can **streamline data collection processes, improve data quality, and ensure that trials focus on outcomes that matter to patients**.

This not only **enhances compliance and retention** but also positions clinical trials to deliver **best-in-class, patient-centric solutions**.

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Building a Collaborative Framework to Patient Needs Through Data Management

- Recognize the Need for a new model Collaboration, Position Data Management to lead this new thinking

- Prioritize Patient Needs Through Data-Driven Insights

- Build Trust Through Transparency and Shared Governance

- Create Continuous Improvement Cycles Based on Patient Feedback

A true collaborative framework that addresses key patient needs requires **seamless data sharing, real-time feedback mechanisms, and transparent governance**. **Clinical Data Managers play a crucial role** by:

- **Standardizing data collection and interoperability**

- **Using predictive analytics to personalize trial experiences**

By embedding patient perspectives directly into data management processes, CDMs can help create a **best-in-class collaborative framework** that delivers not only **better data** but also a **better trial experience** for patients.

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The Future of Data Management as an Innovation Hub for Patient-Centricity

- Redefining Data Management as a Strategic Innovation

- Leveraging AI and Advanced Analytics for Patient-Centric Insights

- Creating Interoperable, Real-Time Data Ecosystems

- Data Management as the Guardian of Ethical and Transparent Data Practices

- From Reactive to Proactive Data Management: Continuous Improvement Loops

The future of data management lies in its ability to serve as an **innovation hub that drives patient-centricity** by:

By embracing these shifts, data management can evolve into a **strategic function that not only ensures data quality but also transforms how clinical trials are designed, executed, and experienced by patients.**

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Shift from Supporter to Innovator

- Transform data management from a support **function** to a **strategic innovation function** that drives patient-centricity

- Use **patient advisory boards and real-time surveys** to identify pain points in data collection, such as **c**omplex ePROs and lengthy consent forms

- Implement **AI-driven analytics** to predict **dropout risks** and identify data quality issues proactively

Patient-centric Data Management

- Bringing patient voices to the forefront of data management transforms trials from rigid processes to dynamic, responsive systems—proving that the future of clinical research is truly patient-centric

- Patient-centricity is the catalyst for innovation in data management—when we design protocols around patient needs, we unlock cleaner data, higher retention, and more meaningful trial outcomes.

- Innovation in data management starts with listening to patients. Real-time analytics and adaptive protocols can turn patient feedback into powerful insights that reshape clinical trials.

- Patient-centric data management means more than clean data—it's about capturing the full patient story through real-time feedback, adaptive protocols, and seamless data integration.

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The best data creates the best patient experiences.