



2nd Annual Cardio-Oncology Workshop | December 1, 2017

**Session 6 From Big Data to Smart Data:
Identification of Cardiovascular Toxicities in Post Marketing**

Patient Generated Data | Sally Okun, VP Policy & Ethics | PatientsLikeMe



About PatientsLikeMe

Patient voice: a collaborative immuno-oncology project

- Ethnographic methodology
- Patient perspective on experiencing side effects
- Patient needs for identifying and managing side effects

Patient empowerment opportunities

About PatientsLikeMe



Engage

Patients in their care

- 600,000+ members
- 2700+ conditions
- Peer-to-peer network



Measure

Computable data that is medically relevant

- 40+ million data points
- 4+ million posts
- 15+ PROs
- Mapped to ICD-10, SNOMED, ICF, MedDRA, RxTerms



Research

& analyze findings to generate evidence

- 100+ publications, most peer-reviewed
- Research, bioinformatics, data scientists, clinicians
- Safety monitoring platform
- FDA Research Collaboration



Transform

Health & Healthcare

- Digital phenotyping
- Digital Life Alliance
- Empowering patients
- Advancing knowledge
- Improving treatments
- Improving care

Patient Generated Data

Patient-generated data are created, recorded, or gathered by or from patients (or family members or other caregivers) to help address a health concern. Examples include:

- health history
- treatment history
- PROs
- daily living functions
- symptoms
- lifestyle choices
- biometric data
- passive sensor data





Patient voice: a collaborative immuno-oncology project

Selected findings from NSCLC patient experience data

Methods: Ethnographic-style interviews of patients and caregivers

Interviews with patients and providers to gain a deep understanding of a patient community -- their experiences, goals, values, and needs

- Conversations, not surveys / questionnaires
 - Topics, not questions
 - Stories, not responses
 - Skills: Elicit a story, listen, follow, and know when and how to probe deeper
- Learn something unexpected
 - Surprises are good
 - Things we couldn't have imagined
 - Things that have a big impact
- Lots of unstructured data to analyze and report on
 - What does it mean?
 - How do we share it?



Patient perspective: side effects and immuno-oncology treatment

While providing more life and new hope for patients, challenges span the journey

Shared Side Effect Challenges

- **Follow up care/calls vary** by institution resources, model
- Doctors and patients are **co-learning about side effects**: what exactly to expect?
- Doctors focus on a severe AE checklist, mindful of SE escalation; **patients** care about different **SEs** that may go **unaddressed**
- **Delays in patient SE reporting**: lacking of clarity on how, when, fear of being taken off treatment

Patient-focused Opportunities

- **Identification**: what could be a side effect, how to manage through experience
- **Guidance**: when to call the care team (when will providers “care”; what could trigger discontinuation of treatment; what might be happening)

Personas vary: patients' lived experiences influence their needs

Support needs range from tactical to emotional

“Chuck”



- Waiting for a second scan
- Experiencing side effects
- Struggling with depression

What Chuck needs:

- Resources to know what's a side effect and what's not
- Encouragement to call his care team with concerns
- Information from other patients about what they've tried and what worked

“Kay”



- Responding well to I/O treatment
- Ready to move on with life
- Wishes she could be done

What Kay needs:

- Resources to help ameliorate even the minimal side effects she has
- Encouragement to share her story (help dealing with survivor's guilt?)

“Diane”



- Responding well to I/O treatment so far
- Powerful advocate for herself and for others

What Diane needs:

- Resources on side effects and side effect management
- Place to track her side effects and what she's done about them
- Opportunity to share and learn with others

A network diagram background consisting of a complex web of interconnected nodes and lines. The nodes are represented by small circles in various colors: grey, yellow, and black. The lines are thin and grey, creating a dense, interconnected structure that fills the upper right portion of the image. The overall aesthetic is clean and modern, suggesting a digital or data-driven environment.


Patient empowerment opportunities

Technology enabled side effect identification and reporting

Empower patients in early detection of potential toxicities

Combine high touch and high tech engagement in achieving best possible outcomes

- Provide patients practical information about signs and symptoms of cardiac related side effects – what to look for, what to call about
- Provide all patients receiving immuno-oncology therapy:
 - Tools for tracking day to day symptoms / functional status /
 - Access to 24/7 nurse call line
- Provide patients who have an identified cardiovascular risk:
 - Tools for tracking day to day symptoms / functional status
 - Access to 24/7 nurse call line
 - Digital sensor for pulse and BP
 - Smart scale
 - Urine test kits



“ To learn
listen well
to impressions voiced by
patients first ”

@SallyOkun