

2<sup>nd</sup> 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



- 600,000+ members
- 2700+ conditions
- Peer-to-peer network
- 40+ million data points
- 4+ million posts
- 15+ PROs
- Mapped to ICD-10, SNOMED, ICF, MedDRA, RxTerms

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

- 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

patientslikeme

- 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

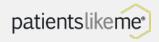


# Responding well to I/O treatment so far

 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



## Patient empowerment opportunities

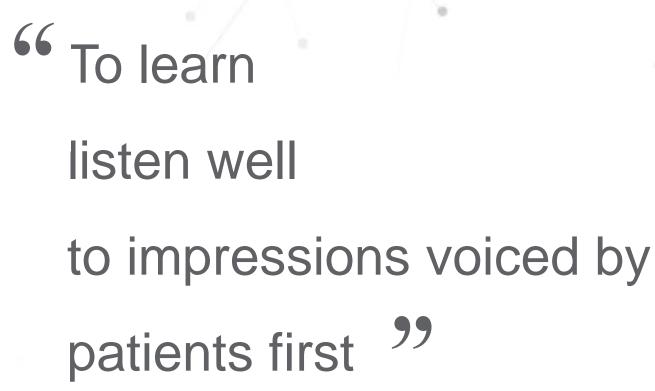
Technology enabled side effect identification and reporting

## 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





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