The background features a network of overlapping circles in various shades of blue. Some circles are solid, while others are dashed. Inside several of the solid circles is a white icon of a person with arms raised, representing a patient or user. The overall theme is digital connectivity and healthcare.

When small signals make big impact

*What can happen when patients gather
online in large numbers?*



Brian Loew

Web of Health
May 15, 2019

Inspire overview

- 1.7 million patients & caregivers
- 10 million annual visitors
- 35% cancer and 25% rare disease
- 3,300 diseases represented
- 1.5 billion words written



Types of member data

Email address, zip code, age,
gender for 1,500,000 members

2,750,000 structured medical
conditions for 990,000
members and 250,000
NLP-derived medical
conditions for 190,000 free-text
answers by 106,000 members

1.52 billion words in 1.13 million
posts written by 440,000 members,
and 56,938,132 NLP-derived tags



9,464,702 tags from user
searches and free text
interests

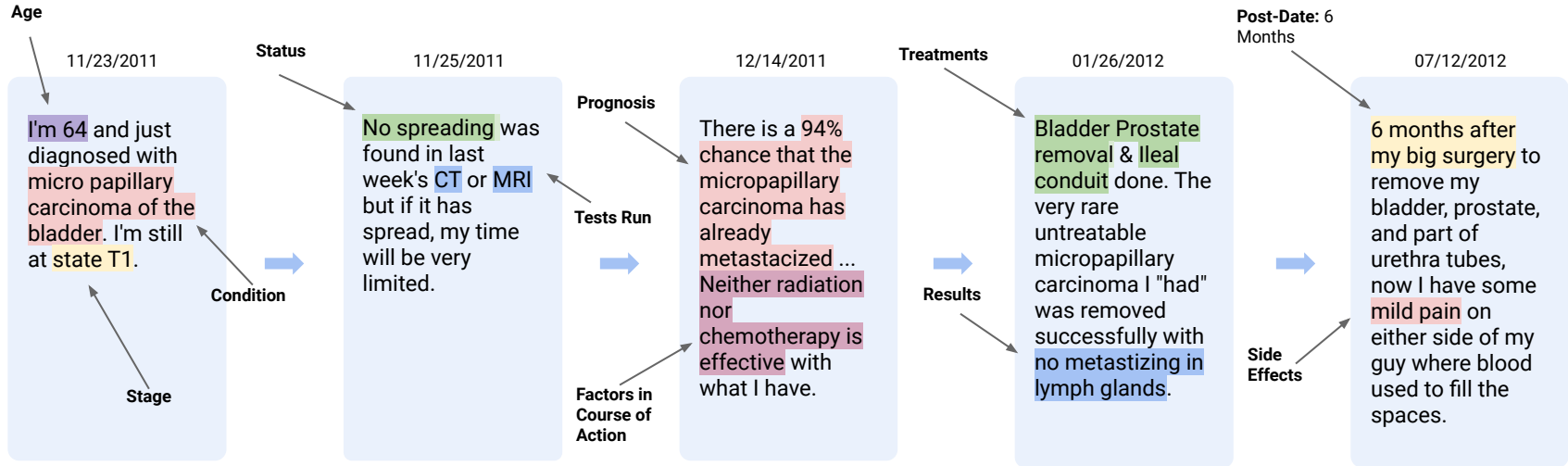
38,819,682 search queries

5,574,168 survey answers

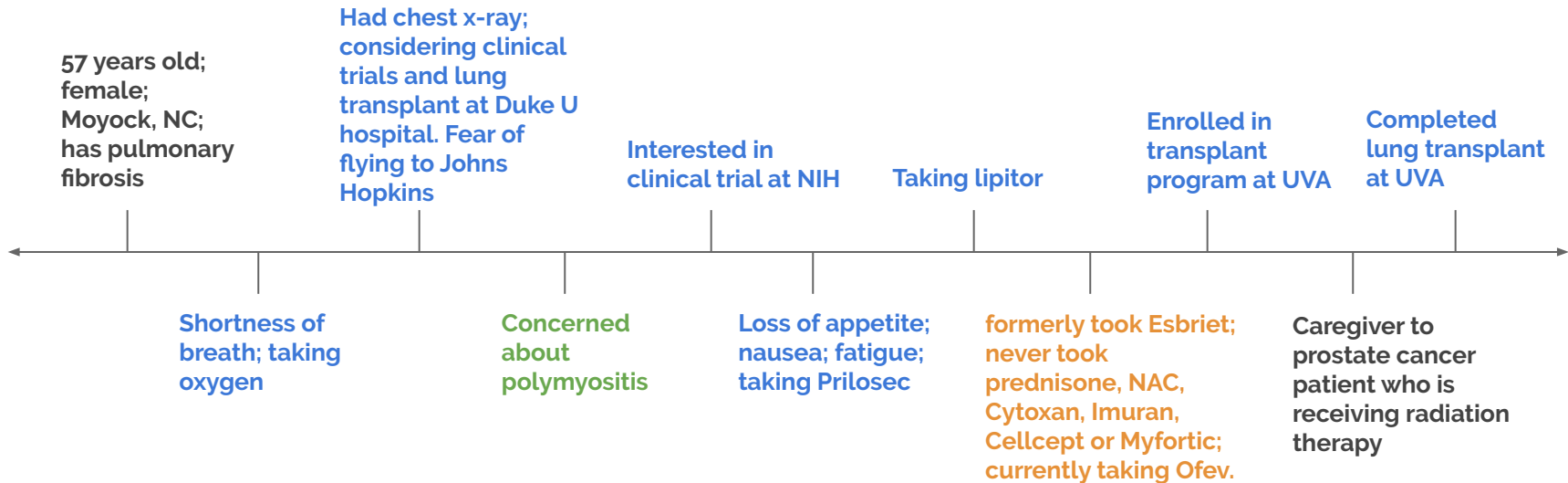
Ethical principles

- Health is special
- The law alone does not protect patients sufficiently
- Members must be in control; permission is explicitly granted
- We communicate clearly with our members
- We treat our members as we would our own family

Patient journey (bladder cancer) with NLP



Patient journey (pulmonary fibrosis) with NLP, Health Profiles, surveys, and search



Legend:

● Health profile ● Survey ● Search ● NLP

Novel Adverse drug Reactions

8 million posts (patient-authored text)

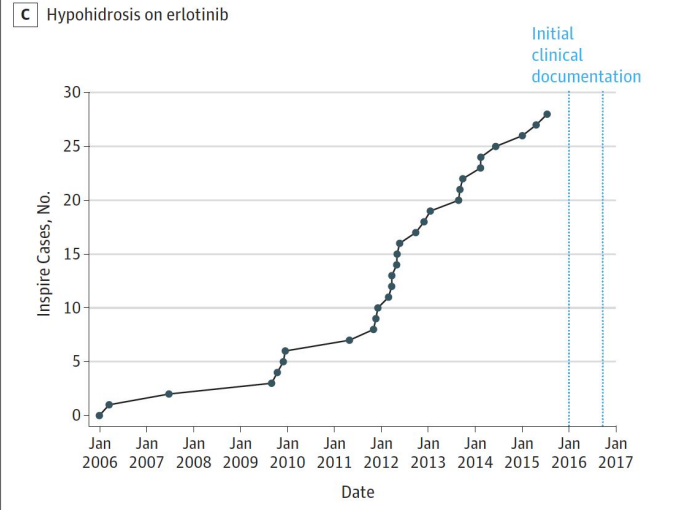
Proactive Pharmacovigilance: *An Inspire-Stanford Collaboration*

- Research published in JAMA Oncology showed Inspire's dataset captured known and novel ADRs before traditional mechanisms
- Demonstration of the capacity of deep machine learning capability to detect ADRs in online content

JAMA Oncology

RESEARCH LETTER

Detecting Chemotherapeutic Skin Adverse Reactions in Social Health Networks Using Deep Learning



Autoimmune disease and improved cancer survival?

Outreach to 75,846 patients and caregivers with a particular cancer



1,455
<redacted>
responded to
outreach,
completed
screeener, and
had certain
childhood
autoimmune
disease



667 have
Stage I,
Stage II
or Stage III
cancer



104 have
completed
treatment
and have no
evidence of
disease for
more than 5
years



77 had no
recurrence
and
potentially
successful
primary
treatment



49 have
a family
history of
<redacted>

What have we learned?

- 1) To make discoveries, we need all of the following:
 - Large sample and ability to characterize data ('digital phenotypes' including patient-authored text and user behavior in specific disease areas)
 - Continuous relationship with patients
 - Trust and willingness to share
- 2) A static data set is not enough; we need the ability to gather more data on demand and learn (with both supervised and unsupervised learning) from user data

The background features a network of overlapping circles in various shades of blue. Some circles are solid, while others are dashed. Several circles contain a white icon of a person with arms raised, symbolizing inspiration or achievement. The overall aesthetic is clean and modern.

Thank you

Brian Loew
brian@inspire.com