When small signals make big impact

What can happen when patients gather online in large numbers?

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Web of Health
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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

Inspire

Types of member data

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

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

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

38,819,682 search queries

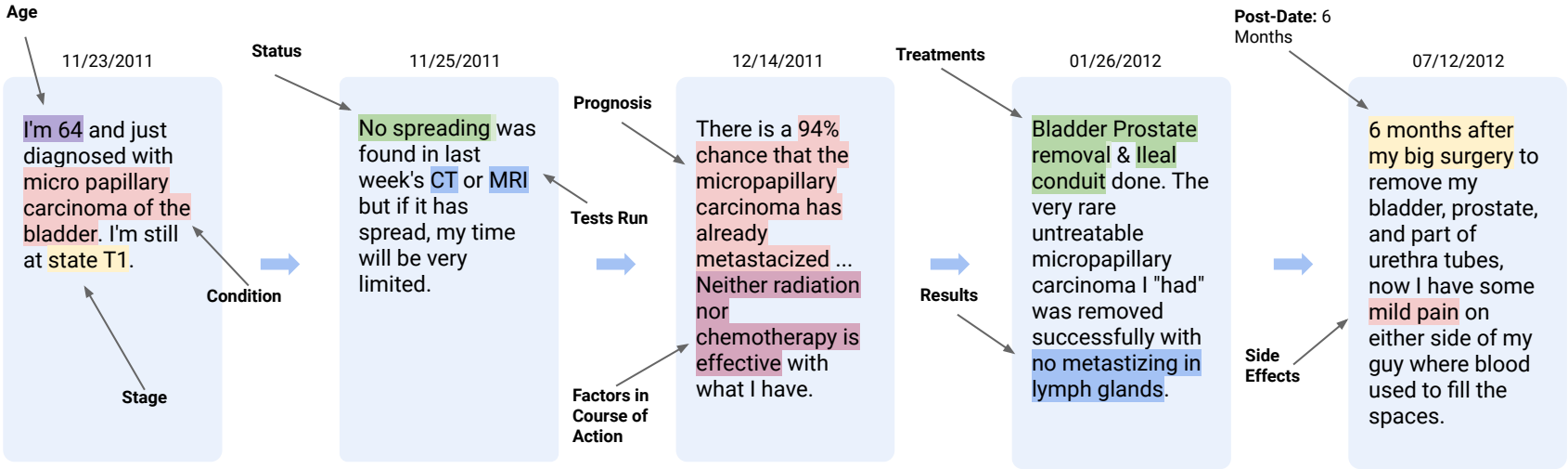
5,574,168 survey answers

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

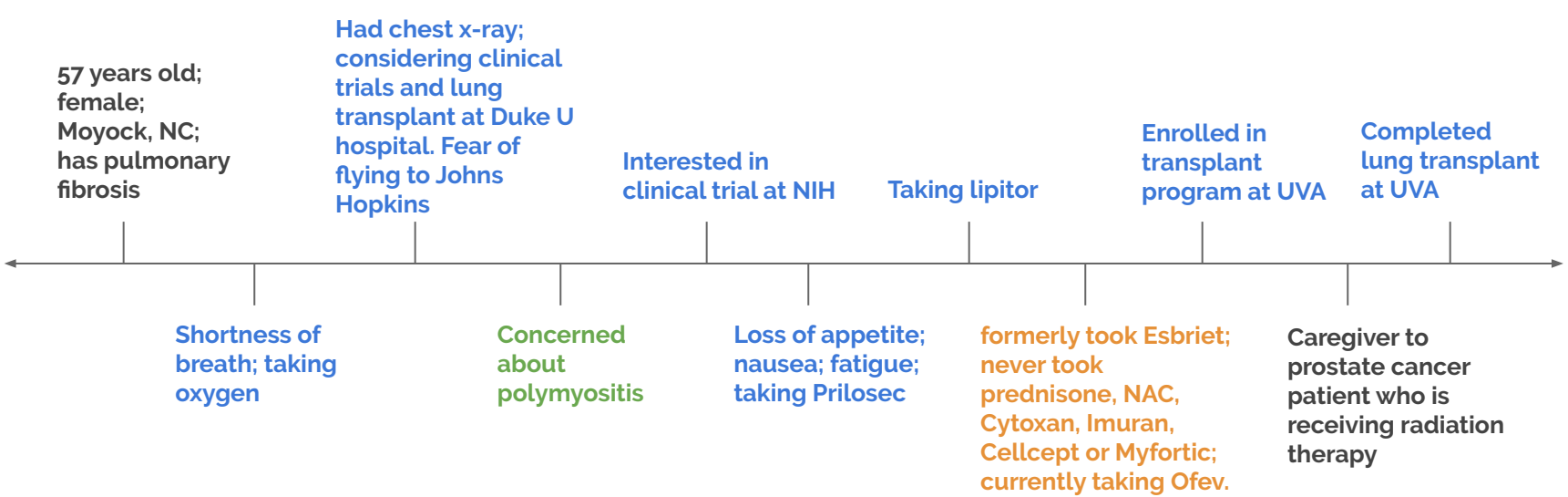
Ethical principles

- 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



Novel Adverse drug Reactions

8 million posts (patient-authored text)

Proactive Pharmacovigilance:
An Inspire-Stanford Collaboration

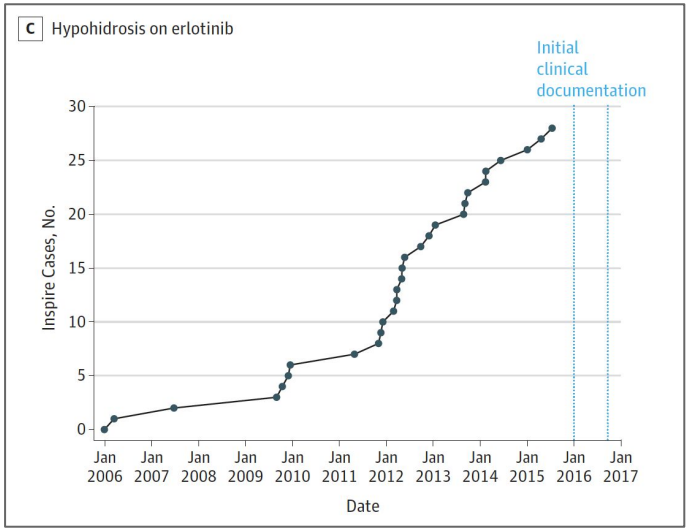
- Research published in JAMA Oncology showed Inspire's dataset captured known and novel ADRs before traditional mechanisms

- Demonstration of the capacity of deep machine learning capability to detect ADRs in online content

JAMA Oncology

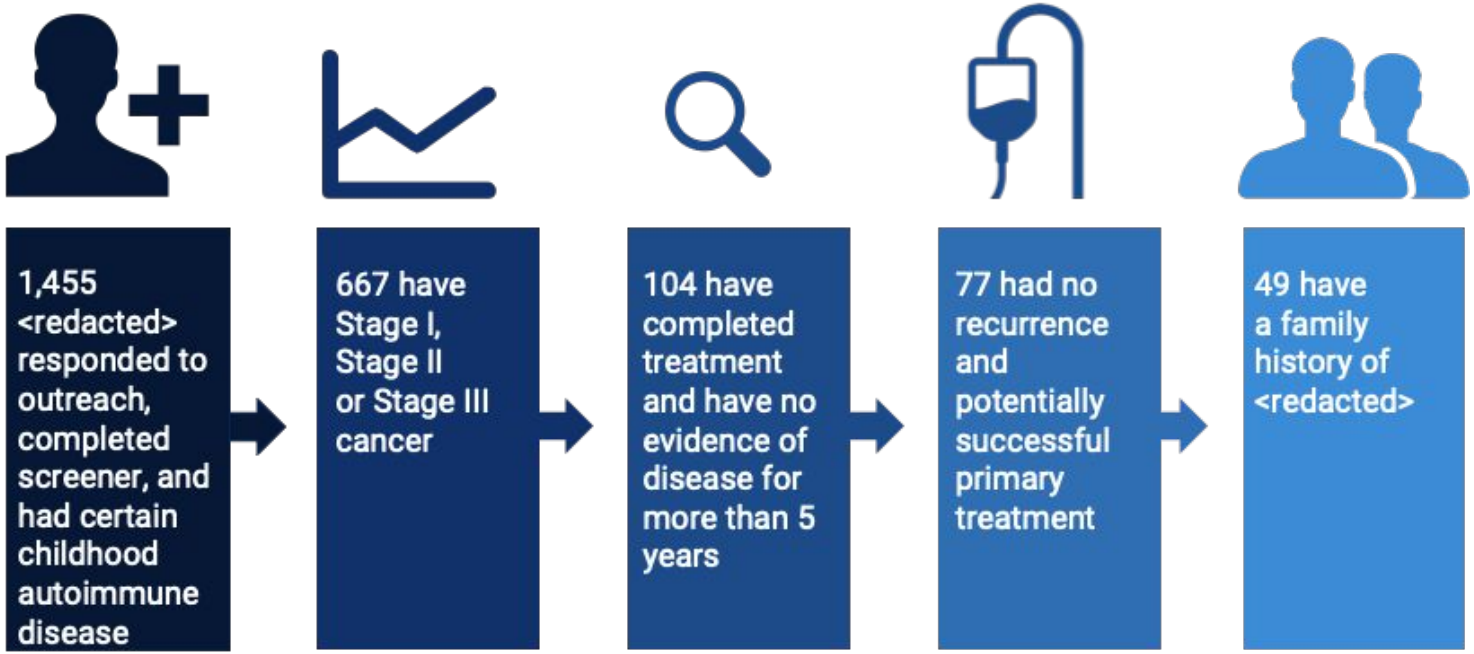
RESEARCH LETTER

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



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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

Inspire

Thank you

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