When small signals make big impact

What can happen when patients gather online in large numbers?
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-deprived 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
I'm 64 and just diagnosed with micro papillary carcinoma of the bladder. I'm still at state T1.

No spreading was found in last week's CT or MRI but if it has spread, my time will be very limited.

There is a 94% chance that the micropapillary carcinoma has already metastacized ... Neither radiation nor chemotherapy is effective with what I have.

Bladder Prostate removal & Ileal conduit done. The very rare untreatable micropapillary carcinoma I "had" was removed successfully with no metastizing in lymph glands.

6 months after my big surgery to remove my bladder, prostate, and part of urethra tubes, now I have some mild pain on either side of my guy where blood used to fill the spaces.
57 years old; female; Moyock, NC; has pulmonary fibrosis

Shortness of breath; taking oxygen

Concerned about polymyositis

Loss of appetite; nausea; fatigue; taking Prilosec

Formerly took Esbriet; never took prednisone, NAC, Cytoxan, Imuran, Cellcept or Myfortic; currently taking Ofev.

Completed lung transplant at UVA

Caregiver to prostate cancer patient who is receiving radiation therapy

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
Autoimmune disease and improved cancer survival?

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

1,455 <redacted> responded to outreach, completed screener, 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
Thank you

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