They came from near and far
We welcomed all with open arms.
We had a purpose.

- **Roles**
  - Mark
  - Diana
  - The Host Team
  - The Participants

- **Goal**
  - Our goal is to advance self-reported, participatory surveillance for influenza and other diseases.

- **Objectives**
  - Explore opportunities to improve data collection and visualization platforms.
  - Explore how regional systems can operate as an integrated global resource.
  - Explore broader applications for pandemic threat detection beyond influenza.
We devised a plan to spend 48 hours together.
We elicited desired outcomes toward our 3 objectives.

- This project needs to be taken seriously.
- Surveillance standardization
- Discuss/Assess the right tools for the job
- Different groups can have their own systems: develop their own tools/reports.
- Have a good incentive model for PPL to participate in disease surveillance.
- What do we do with info collected by disease surveillance system? How do we use it?
- How to balance bet. certainty of results vs. early release timing of results? Balance between complicated reporting & simple, consistent reporting?

**Tools**

**Participants' Outcomes**

- Utility of tool for EID tracking
- How to incorporate CLOUD data w/going data?
- How to have surveillance in resource constrained settings?
- Interest in exploring beyond flu?
- What's working/not working? Social media: what are others doing?
- Mobile phones: specifically in remote areas around the world.
- What is the best system/platforms?
- How do you get people involved/informed?
- How do you get different communities to access the internet? System? Report to it? Share the info?

**Outreach + Recruitment**
- DATA Visualization → appealing for Public Use?
- Validation of Results + Integration w/Existing Tools
- DATA Analysis

**Analyze + Compare Data**

**Empowerment of People**
- Go Beyond self-reporting to self-reporting,
- From ID to Non-communicable;
- From developed world to developing world.

**Improve Participation + Keeping People engaged**
- Explore new ways to collect DATA.
- Link Academia + communities of Practice/surveillance.
We allowed for one hour of potential negative energy...
...no one ever said our mission would be easy.
We shared learnings, experiences, and perceptions about the utility of weekly self-reported surveillance for symptoms of the flu with developers of three systems:

Flu Near You in the U.S.
Flutrack in Australia
Influenzanet in Europe
**AUSTRALIA**

**FLUTRACKING**: Australia online Surveillance-like Illness.

- Can we do this every week on the internet?
  - 2012: 394 participants
  - 2013: 15,000 participants

**Recruitment of Participants**
- Flu Program
  - Script
  - Media Release
  - Emails
  - Promotions
  - We do Domain Analysis

- People sent out emails to friends to participate
  - May 1, 2012: Launch
  - 15,000 participants

**Challenges**
- Younger People w/ higher rates of ILI but lower rates of vaccination
- Does high socio-economic status of our participants threaten bias info?
- Is it FLU near you?
  - We don't do OFF-Season?

**PARTICIPATION**

**Weekly Survey**
- Fever?  
  - Yes  
  - No  
  - Don't know
- Cough?  
  - Yes  
  - No  
  - Don't know

**Hunters New England NSW \& Health**

**Burden of Illness**

**Diagnosis**
- Lab Tests

**Field Vaccine Efficacy**

**Some Insights**
- Recognised early that 2009 pandemic was mild in most
- Detect bias of the "health care system"
- Rapid changes in vaccine uptake detected
- Developed burden of disease pyramid
Influenzanet

- Participation
  - 2003 Netherlands
  - Belgium
  - The Great Influenza Survey
    - It was set up in a matter of weeks.
    - Single intake questionnaire:
      - Postal code
      - Age
      - Smoker
      - Vaccine
      - Allergy
    - Recruitment: Media
      - From west to east and from north to south (3 months)
    - How will we have the flu?
      - All European countries relying on system
  - Cough
  - Fever
  - Muscle Pain
  - Fatigue
    - Participate at least 3 times
    - Ignore symptoms participants already had on registration.
  - Contact patterns
    - Mobile apps
      - Facebook
      - Twitter
    - Subgroups
      - Age groups
      - Vaccination
      - Behavior
      - Socio-Economics
  - Disease Radar
    - Pneumonia survey in the Netherlands
    - Infectious disease(s) radar
    - Rats/animals
    - Children/Parents
    - Women: more flu symptoms
  - Behavior
  - GP systems
    - Not consistent between countries
    - How many people visit a doctor?

- Seasonal Flu
  - Young Children
  - Brothers/Sisters
  - Mother
  - Father
  - Should I go to work if I'm sick?
  - Public Transportation
  - Rainy Season
    - Data on tropical influenza remains scarce -- no data.
    - Do Earth's seasons create a belt? ??
    - "Highways" in a global circulation pattern may have been observed.

- Epiwork
  - Produces forecasts
    - All graphs collect real time info
    - Look at the graphs! Download the data!
From west to East and from South to North (3 months).

When will we have the FLU?

In 6 weeks!

All European countries using ONE system collect real-time info.

Detail from Influenzamet
a special visitor...
WELCOME!
DAY 2
July 26, 2012.

REFLECTIONS of Day 1...

- I want to REPORT from where I was!!
- Where did you get sick?
- EMPLOYMENT... What kind of health care do you do?
- Background Survey
- Weekly Survey
- Contacts Survey
- Conferences
- One-to-one contact
- Who did you speak with?
- Relevance of the System
- How do people report when they TRAVEL
- FLU related to Birds/Swine.

- Participants reporting on their own animals.
- Early Signals:
  - Choice: to unsubscribe.

- Who participates?
  - Diff levels of education.
- Create a "Manual" Best Practices.
- Newsletters, to people who respond to the survey.
- More Representation
- Share Best Practices!

- Education
  - Publish the data!
- Reaching people who don’t have access.
  - Reporting through the community.

- Technical barriers.
- I have no access to the Internet.
- Do you have contact w/children, sick patients??

- We need to make children aware of this... "Mad cow" = angry words!
We split into three groups to see if each could come up with the ‘perfect’ system...
**TITLE: REAL-HEALTH**

**CUSTOMIZABLE + STANDARDS**

*An ECO SYSTEM of Interacting Tools*

- **INPUT**
- **STORAGE**
- **ANALYSIS**
- **OUTPUTS**

*The Interoperable system between Human Health and Animal Health*

**ETHICS/PRIVACY/SHARING**

- Different Reporting Apps
- Federated, de-centralized DBs
- Viz & Analysis Apps

**RISK COMMUNICATION**

- Mobile
- Web
- Phone, Social

skollglobal threatsfund
U-NAME IT!

CUSTOMIZABLE • OPEN SOURCE • MODULAR

Syndromes
Collection Methods
User Feedback

Questions

Flu
Whooping Cough
Dengue

Self-report
Group report
Event reporting
Input

Health Report
Points/rewards
Self-care tips based on symptoms
(Not diagnoses)

Prevention
* Anonymity
* Periodically, weekly?
* Is it a tool for authorities to use for action??

Demographics
- Basic
- Optional
- Travel
- Occupation
- Exposures
- Child sex

Get OFFICIAL Messages Out

Where does it hurt?

* Quick & easy

N total

Health

Title
TITLE: GLOBAL HEALTH SURVEILLANCE
FOR the People, By the People!

130 countries Participating!
WHO endorsed.

Centralized Agreements on the translation of the questions.
Validation of the system.

WHAT Actions will be taken when you have the information?

2014 TIME

Monitoring Global Burden of Disease and Health Seeking behavior.
Weekly! Quick! Under a minute! Real-time Surveillance

Interoperability
Personalizable and fun

Flexible Modules + Standardized Outputs.

Integration of Core Questions

Customized to geographic context

Epidemiology

Individual/families Level Systems

Algorithms

EDUCATION
The Perfect System

Nobody suggested this should only be about FLU...

Nobody owns the data.

Value in data.

*Is it self sustainable?

*Who’s responsible for the aggregated data?

One Health & Event Reporting.

Communication

*Governance + Distributorship

Distributed + Customizable

Standards

Open Source

Real-time

Multi Purpose

Clearly communicated to the user (the purpose of what it’s used for)

CUSTOMIZABLE

TRANSPARENCY with the end user.

Maintain TRUST

Connected to validation system ??

An official challenge for validation (customizable).

Open Architecture

Can we use your Userbase?

Question

Who are the customers of the system?

SHOULDN’T BE FOR COMMERCIAL PURPOSE.

Can you use the data?

Ensuring one regulated body

Unified dissemination

Actively linked to health authorities.

(local, international, etc)

Health authorities may want to use the system to report back!
The ‘perfect’ system was tweaked by the participants.
Welcome Day 3

Collaborative Consumption

We need an active brand coming from a Resource Poor Setting

Governance Issue

We should start doing this in THAILAND

We need to talk to each other

3 systems coming together

This is the first meeting. It can be the beginning of a community

Who can act on any source of information

Animal data

Climate

People data

Geography

What would be the right structure to keep the conversation going to action?

It needs to be:

- Nimble
- Transparent
- Small

What's the best mechanism to work with a group of people?

Social Media

A source of information

Open Source

Customizable

Measuring illness

Show people in public health what the system can do

Partnerships

Relationships

Give advice on what kind of testing they should have.

Threat: We distribute the information too quickly before it gets integrated.

Health Care

Public Health
The Commitment Wall...

Our goal is to advance self-reported, participatory surveillance for influenza and other diseases.
...and so it begins.