

# Do They Realize They're Disclosing Their Health Status?

## Ethics of Social Media Recruitment for Cancer Research

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# The Problem: Meeting Recruitment Targets

- Only 55% of clinical trials in the UK reached their target sample size, and 45% required an extension of some kind<sup>1</sup>.

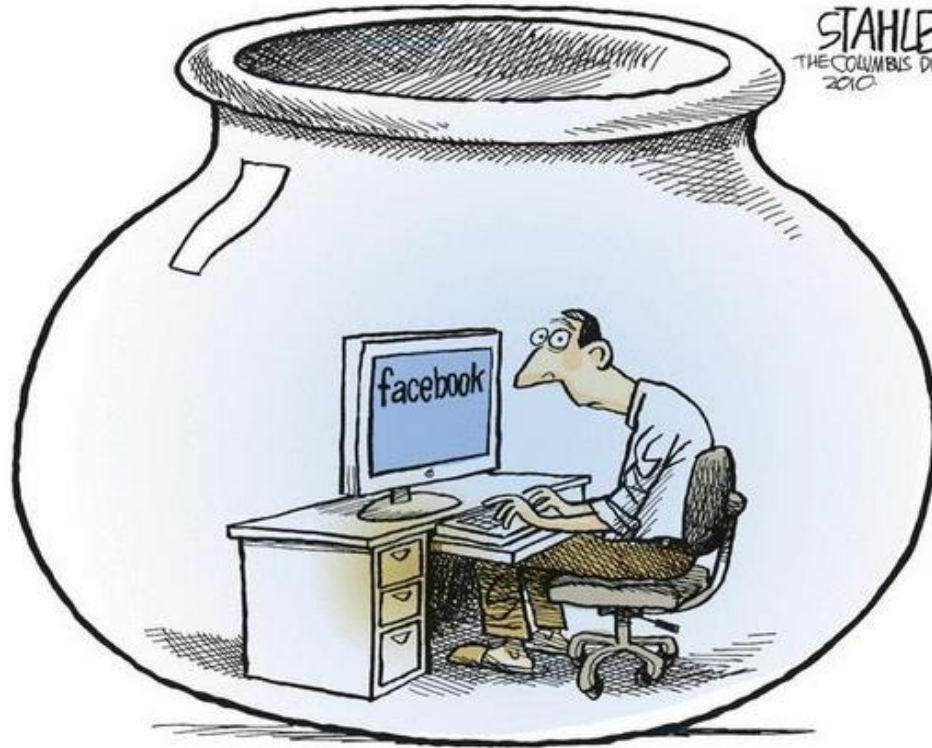


<sup>1</sup>Sully, Julious, Nicholl. A re-investigation of recruitment to randomized controlled trial multi-center trials: a review of trials funded by two UK funding agencies. BioMed Central 2013; 14:166.

# The Opportunity: Social Media Recruitment

- **REACH:** access to large populations and hard-to-reach groups, and the public can help spread the word (eg, 'liking')
- **FLEXIBLE:** recruitment notices can be turned on and off, and content can be changed in real-time
- **ECONOMICAL:** less time, effort to recruit large samples at reduced cost relative to traditional approaches<sup>2</sup>
  - Several studies report that large samples can be achieved through paid Facebook ads at relatively low costs<sup>2</sup>

# The Ethical Challenge



# Online Behavioral Advertising

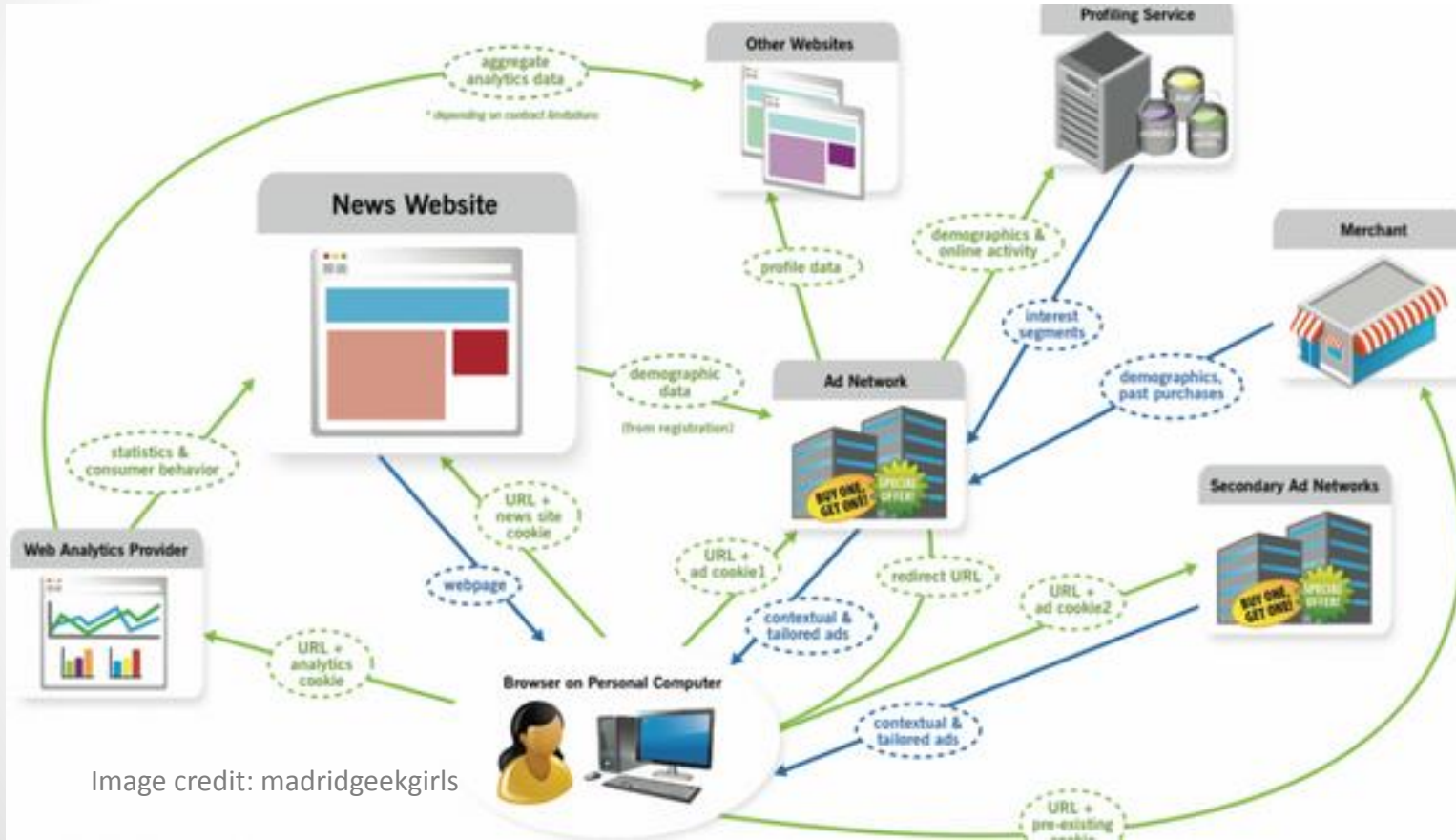



Image credit: madridgeekgirls

# Case Study

How could technology help enhance cancer survivors' dietary self-management behaviours?

Clinics & Programs    Classes & Events    Connect with ELLICSR

ELLICSR Kitchen    WE-Can




with Spiced Yogurt    Spring Pea Split Pea Soup    Shamrock Blueberry Matcha Cake

## ELLICSR Kitchen

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### In Today's Class - Nutrition Month: Small Changes for Big Results




**Christy Brissette**  
Registered Dietitian  
@80stwenyrule

**Jeremy Capone**  
Wellness Chef  
@JeremyCapone

**ELLICSR KITCHEN**

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**Recipe of the week**



**Stir Fried Rice Rolls with**

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Feb 11, 2016  
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By Kolly-Anne Kerrigan

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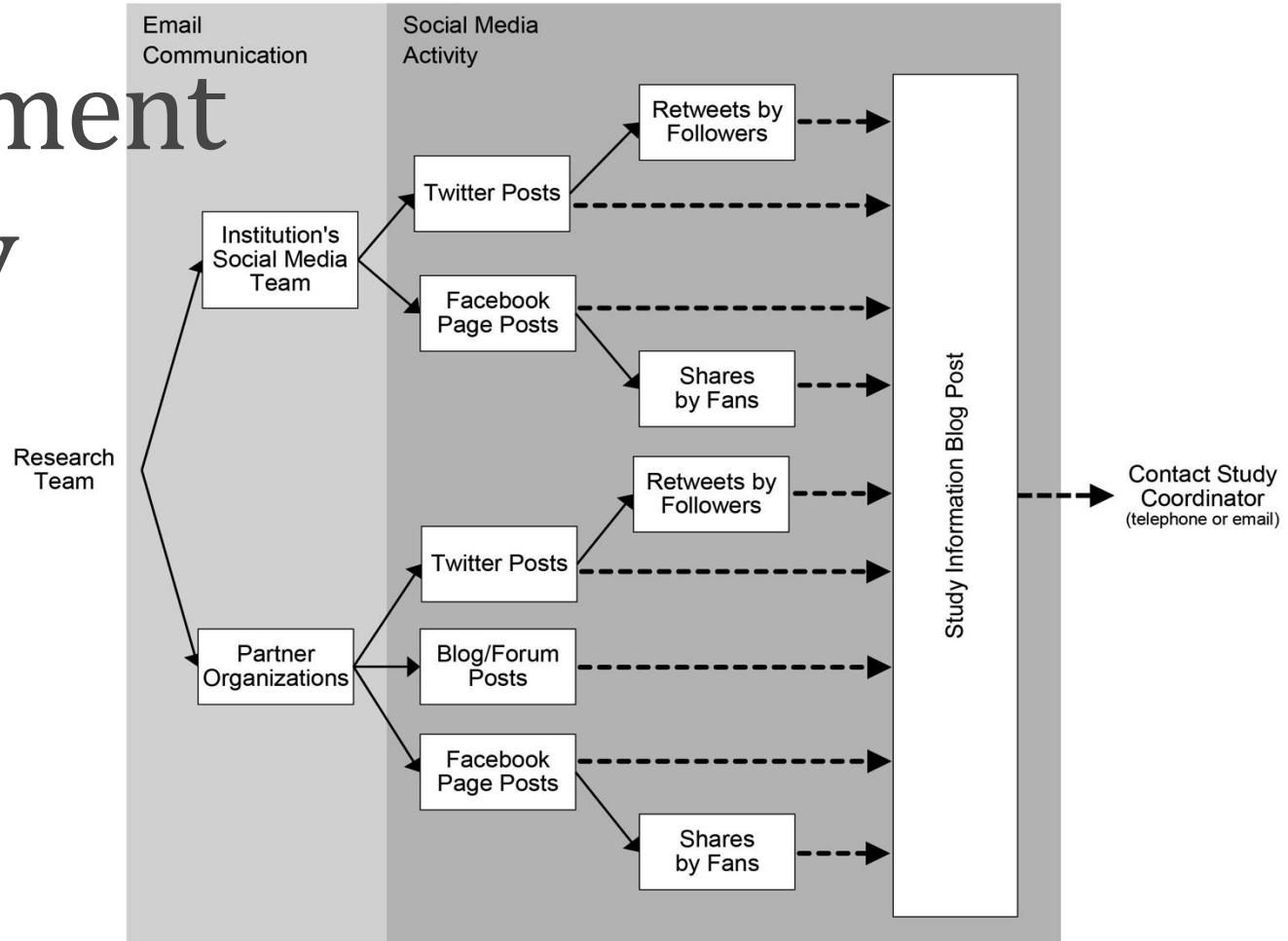
# Study Rationale

- Cancer and its treatment is associated with numerous side effects that affect nutritional status<sup>3</sup>
  - Decreased appetite
  - Mouth sores
  - Difficulty chewing swallowing
  - Bowel changes
- Healthy dietary behaviour can help to:
  - Maintain healthy weight
  - Prevent muscle loss
  - Prevent/manage nutrition related side effects<sup>3</sup>
- Lack of nutritional knowledge and culinary skills reduces the likelihood of practicing dietary self-management behaviours<sup>4</sup>

<sup>3</sup>American Cancer Society. Nutrition and Physical Activity Guidelines for Cancer Survivors. CA for Clinicians 2012; 62:275

<sup>4</sup>Garcia et al. Evaluation of a cooking skills programme in parents of young children Public Health Nutrition, 2013; 17: 1013-21.

# Recruitment Strategy



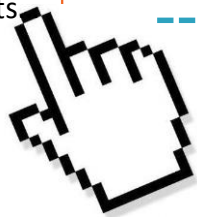


# REB Concerns

1. How will you inform users about the potential for privacy breaches and their implications?
1. How will you protect users from privacy breaches or inadvertently sharing potentially identifying information about themselves?



Recruiting cancer patients



Oh, you have cancer. Then we'll send you cancer related ads.

## News Release

### Google ads sparked by web surfing on health sites violate privacy rights, investigation finds

**Ottawa, January 15, 2014** — Google's online advertising service used sensitive information about individuals' online activities to target them with health-related advertisements, contrary to Canadian privacy law, an investigation has found.

In response to the investigation by the Office of the Privacy Commissioner of Canada, Google has agreed to take steps aimed at stopping the privacy-intrusive ads.

"We are pleased Google is acting to address this problem. Most Canadians consider health information to be extremely sensitive. It is inappropriate for this type of information to be used in online behavioural advertising," says Interim Privacy Commissioner Chantal Bernier.

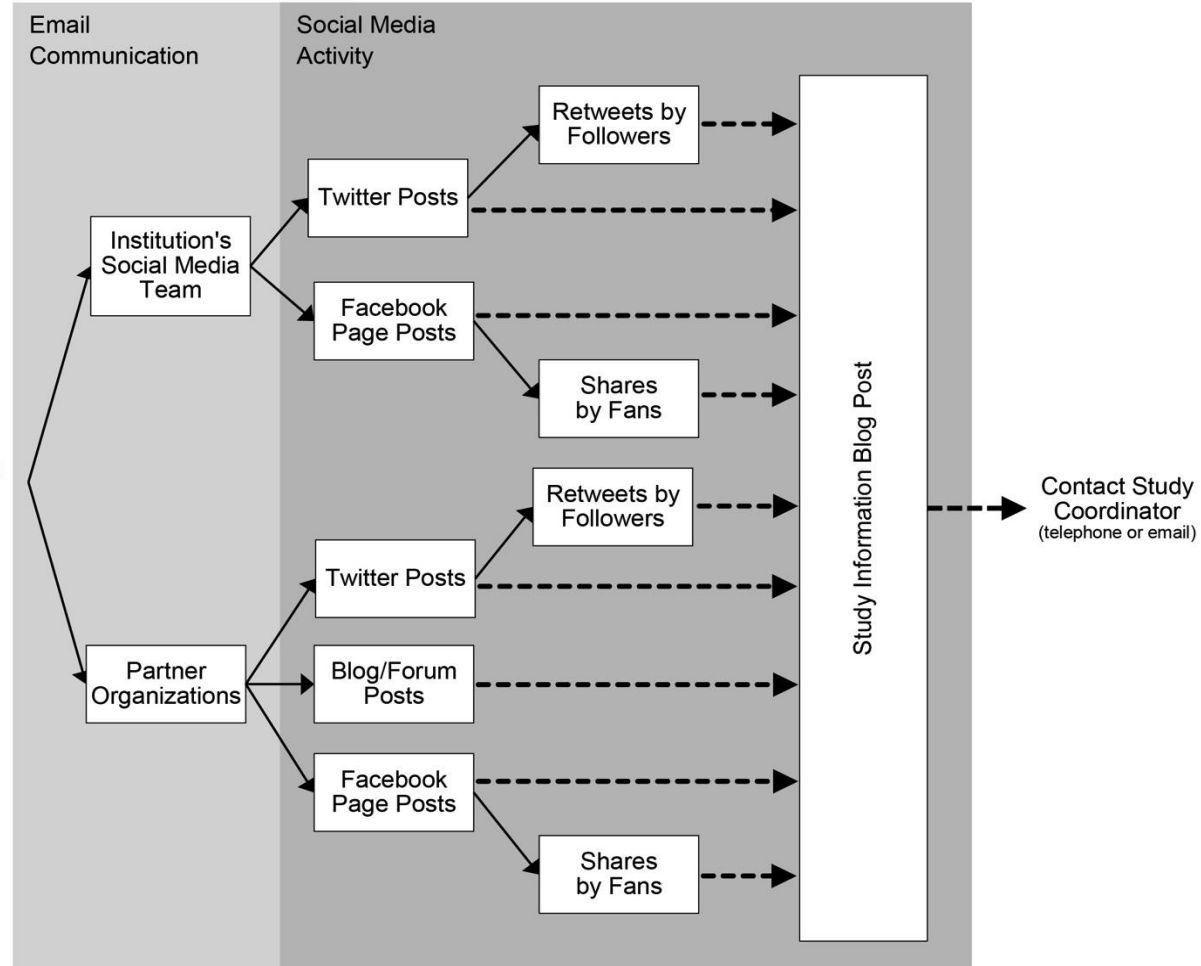
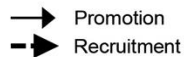
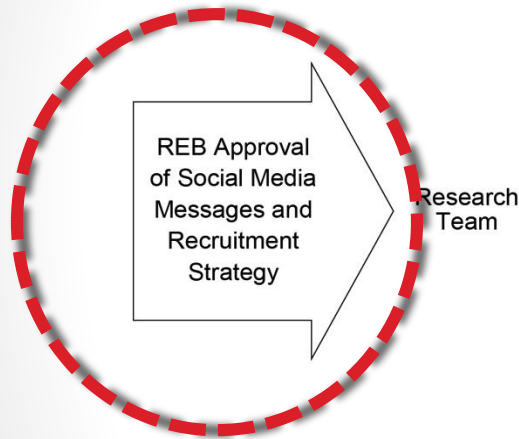
# Privacy Enhancing Strategies

1. Disclaimers
2. Click-bait



Image credit: europarl.europa.eu

# REB approval of all posts



# Disclaimers



EMAIL: Please note that the security of email is not guaranteed. Messages may be forged, forwarded, kept indefinitely by others using the Internet. Do not use email to discuss information you think is sensitive.



FACEBOOK: Please note that the privacy and confidentiality of content (text or pictures) shared on social media platforms is not guaranteed. Content may be forged, forwarded, kept indefinitely or seen by others using the Internet whether you share publicly to everyone or privately to specific people.



TWITTER: The security of social media is not guaranteed. Contact us about the study. Don't post info if concerned about privacy.

# Blog Disclaimer

## Want to help us?

We are looking for people touched by cancer – that includes people who have or had cancer, family members, friends, and caregivers, – to participate in a 90 minute focus group or a one-on-one interview. Focus groups will be held at ELLICSR followed by a Live Kitchen Demonstration and meal samples. To take part you should be:

- over the age of 18;
- comfortable using the Internet; and
- able to read and speak English.

## Interested in lending a hand?

Contact Nour Alkazaz to find out more about this research study.

Phone: 416-581-7524

Email: [Nour.Alkazaz@rmp.uhn.on.ca](mailto:Nour.Alkazaz@rmp.uhn.on.ca)



24 Aug 2015 - [Chemo Questions & Concerns](#)

[See calendar >](#)

DONATE TODAY



VOLUNTEER NOW



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Please also note that the privacy and confidentiality of content (text or pictures) shared on social media platforms is not guaranteed. Content may be forged, forwarded, kept indefinitely, or seen by others using the Internet whether you share publicly to everyone or privately to specific people. Do not use social media to discuss information you think is sensitive. While you may share this information with a select group of people, someone in your networks may share it more widely without your consent.

# Facebook Disclaimer



ELLICSR  
waiting together

**Ellicsr: Health, Wellness & Cancer  
Survivorship Centre**

Page Liked · February 3, 2014 · 🌐

Have you ever googled "nutrition and cancer"? We did, and came up with millions of hits! It's confusing, isn't it? How do you like to find information online about nutrition, cooking, and healthy meals? Consider participating in a focus group. It will be held at ELLICSR followed by a Live Kitchen Demonstration and meal samples. Visit our blog for more information about the study: <http://ow.ly/teBVg>

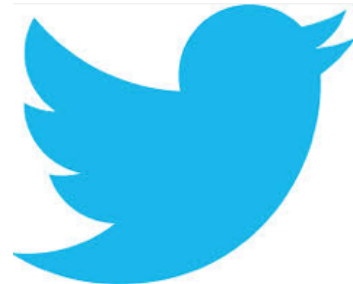
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Like · Comment · Share



# Click-bait

- Original Tweet: “Seeking **cancer patients** for a study of nutrition and cooking. Join a focus group @ELLICSRKitchen to share your thoughts and experiences owl.y URL”
- Revised Tweet: “Does #nutrition matter to you? Tell us what you think about **#cooking** and **#cancer** @ELLICSRKitchen owl.y URL”

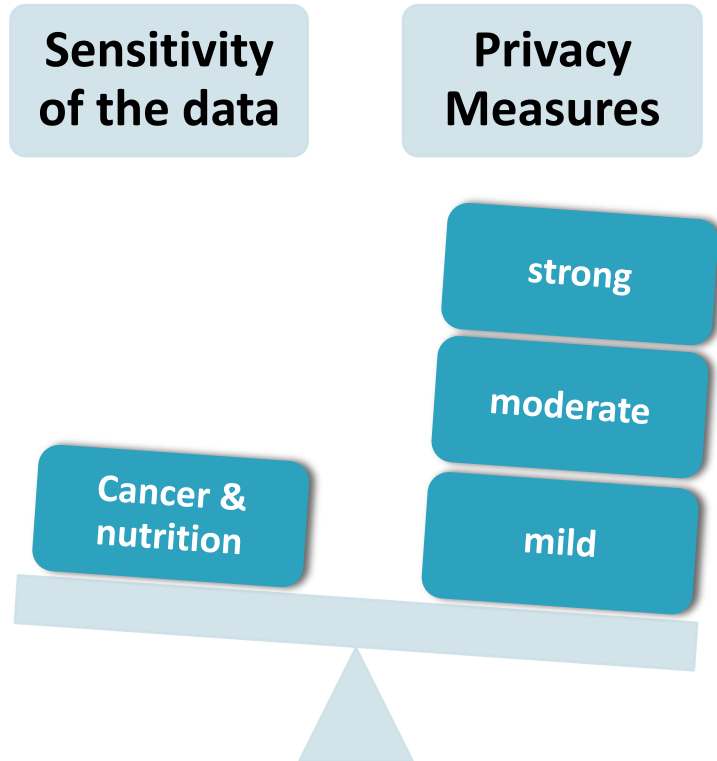


# Privacy by Design

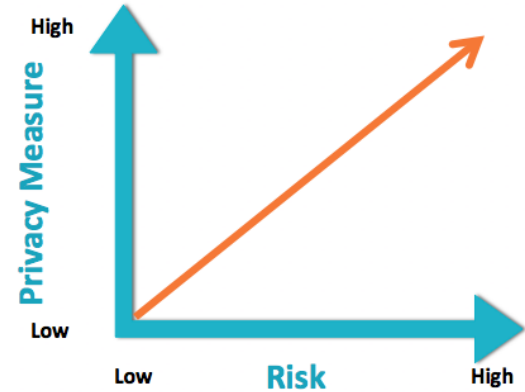
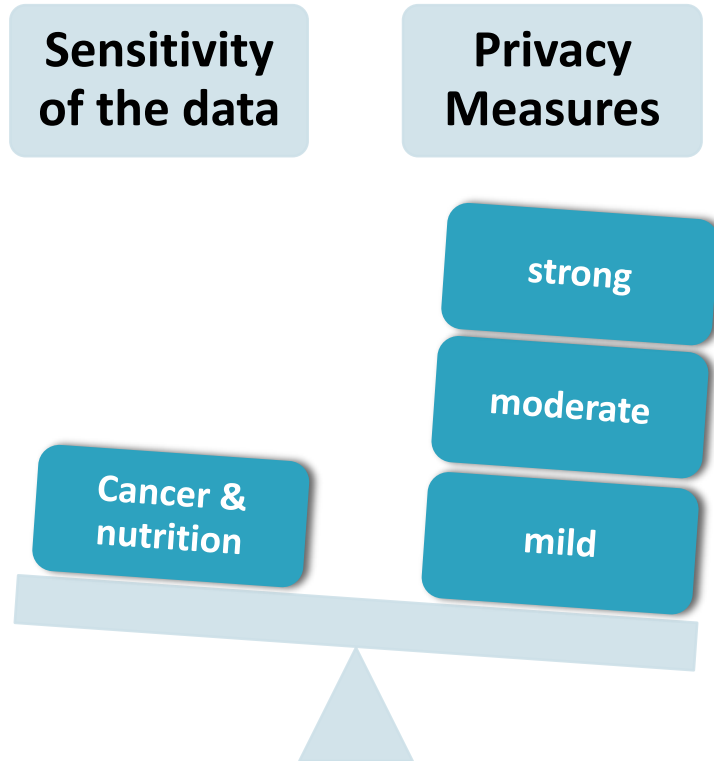
1. Proactive not Reactive; Preventative not Remedial
2. Privacy as the Default Setting
3. Privacy Embedded into Design
4. Full Functionality – Positive-Sum, not Zero Sum = win/win!
5. End-to-End Security – Full Lifecycle Protection
6. Visibility and Transparency – Keep it Open
7. Respect for User Privacy – Keep it User-Centric



# The balance



# The balance



# Considerations for social media recruitment

- Match the privacy measures to the sensitivity of the data
- Be proactive, not reactive (e.g. use strong privacy defaults)
- Give appropriate notice in user-centric ways
- Aim for win/win approaches; avoid unnecessary trade-offs
- Engage the REB in dialogue early and throughout the project

# Thank you!

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@benderjack

- Alaina Cyr - ELLICSR
- Colleen Young – Mayo Clinic
- Dr. Lorraine Ferris – VP Research Oversight University of Toronto
- Dr. Alan Barolet – Chair University Health Network REB
- Dr. Luk Arbuckle - University of Ottawa eHealth Information Privacy Lab