

# Constructing Consent:

ethical challenges to information  
innovation in humanitarianism



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# Argument

- ① The information systems and affordances produced by ICTs necessitate a conception of direct responsibility for using or collecting information
- ② The idea of “Consent” is a primary challenge
- ③ Relevant standards are improving, but still far from operational, and don’t account for the contextual pressures and trade-offs of humanitarian action
- ④ We need piloting, documentation and a “user-centric” approach to bridge the gap between standards and praxis



I  DATA

# Risks

(as articulated by Humanitarianism in the Networked Age)

## Accuracy and Utility

The increased complexity of data and data streams make data increasingly difficult to manage, and increases the risk of compound errors.

## Bias

“Systemic bias often arises as the result of a deliberate agenda”

“Participation bias [reflects] underlying differences in access...”

## Power

ICTs tend to replicate, and may even magnify existing power relationships.

## Information Overload

“...people expect their communications to generate action...”

# Responsible Data Risks

- ① Schrödinger effects
- ② Exacerbation of power imbalance
- ③ Enabling negative actions





## Timeline Photos

[Back to Album](#) - [REDACTED] - [REDACTED]

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[REDACTED]  
ALL orphaned children and minors (below 18) in the devastated areas ay kukuhanin na ng Amerika. All of them will be brought to the USA where they can begin their new lives.

Album: [Timeline Photos](#)

Shared with:  Public

[Open Photo Viewer](#)



# Conceptualizing Direct Responsibility

## Types of Risk

- ⊙ Collection effects
- ⊙ Policy effects
- ⊙ Misuse
- ⊙ Data ripples

## Potential Damage

- ⊙ to individuals
- ⊙ to communities or groups
- ⊙ to projects / credibility
- ⊙ to efficiency

# A Focus on Data

## Why Data?

- ⊙ Proxy for ICTs?
- ⊙ Highlights the importance of existing information ecologies and power relationships

## Modes of Data Collection

- ⊙ Direct communication with individuals
- ⊙ Scraping and Mining activities
- ⊙ Unilateral communications
- ⊙ Active collection/ generation without direct contact

# Direct Effects and Responsible Data

- ① In situations where ICTs facilitate the accessibility or utility of data for humanitarian programming or interventions
  - a) (building on established ethical standards
  - b) and because the scope & immediacy of ICTs present new relational paradigms and challenges):
- ② the ethical responsibilities owed to individuals or groups
- ③ when using data they provide, or in which they are reflected.

# Technology in Peacebuilding

(Laurruri & Kahl, 2013)

	Early Warning	Collaboration	Peaceful Attitudes	Policy Change
<b>Data Processing</b>	U-Shahid Voix des Kivus Uwiano peace platform	CRMA Iraq Monitor		Syria Tracker Satellite Sentinel
<b>Communications</b>	Georgia early warning	#18 days in Egypt	Peace Factory Shoot your identity Umuzi Photoclub PeaceTXT	I paid a bribe
<b>Gamification</b>		Country X	Sambaza peace game Slavery footprint Acts of kindness	
<b>Engagement</b>		Mahallae MasterPeace	Soliya HarrassMap	Turning Tables

# Issues for Direct Responsibility

- ⊙ Consent
- ⊙ Informational self-determination
- ⊙ Identity
- ⊙ Re-use

# Traditional Definition of Consent

## Application

- ⊙ “Research”
- ⊙ Human Subjects

## Components

- ⊙ Participants are presented with purpose, methods and possible outcomes (including risks or harms)
- ⊙ Provided “sufficient opportunity to consider them and enquire about any aspect of the research prior to granting consent”
- ⊙ Participate willingly

# Challenges: whose consent ?

## secondary subjects and 3<sup>rd</sup> parties

**Secondary subjects** exist when an investigator asks a primary subject, with whom the investigator is directly interacting, to provide information about other individuals.

“A **third party** is an individual (or organization or institution) who is not a researcher or a subject, but who is affected by the relationship between those persons” (Resnik, D. B. & Sharp, R. R. (2006, p. 2).

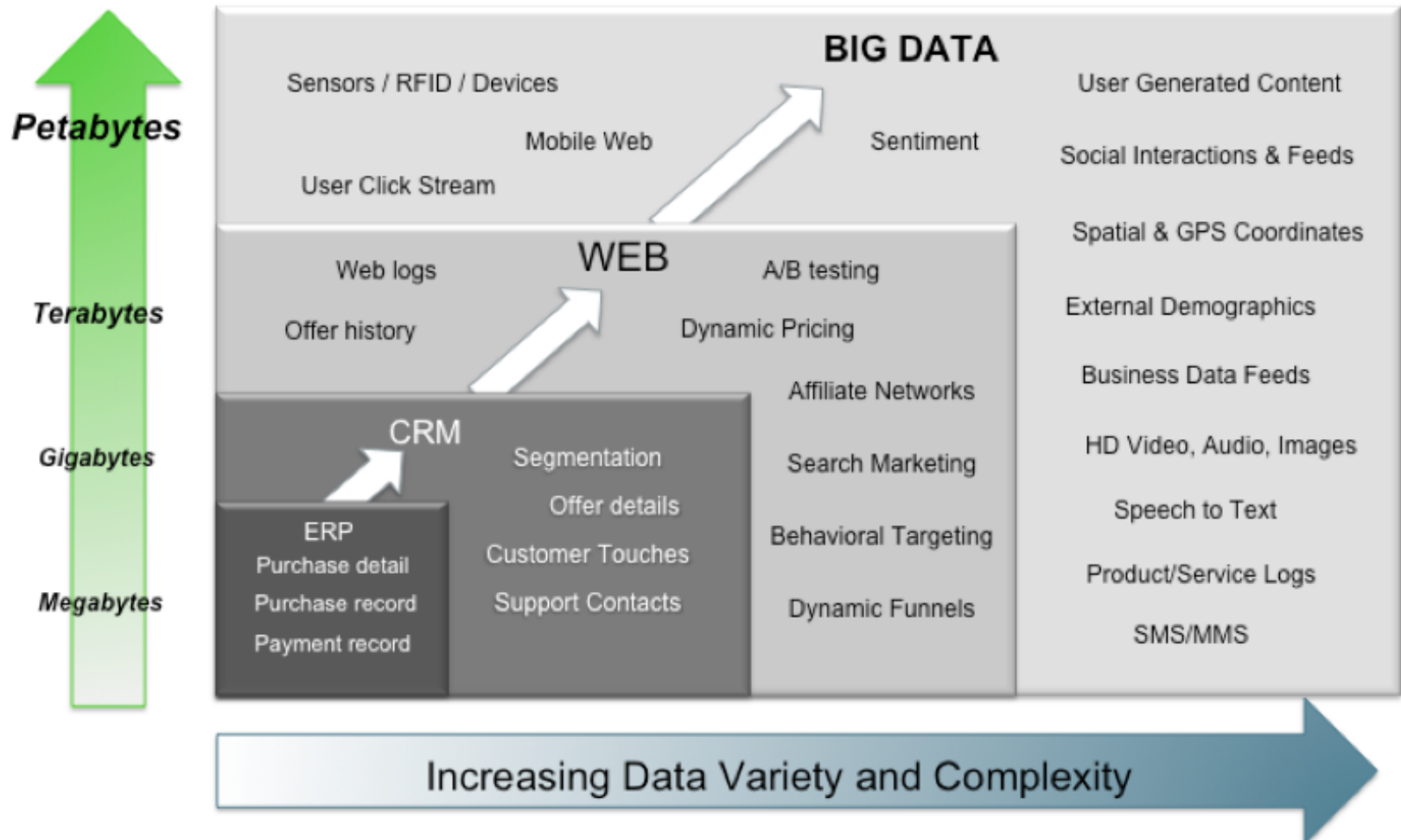
**Directly affected third parties:** “are identifiable individuals or organizations whose rights or welfare may be adversely affected by research procedures” (Resnik, D. B. & Sharp, R. R. (2006, p. 2).



# Challenges: how do you get it?

## big data scraping/mining

Big Data = Transactions + Interactions + Observations



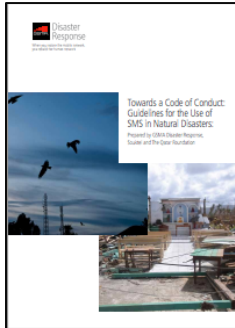
*Source: Contents of above graphic created in partnership with Teradata, Inc.*

# Challenges: how do they know?

modeling threats and anticipating harm

- ⊙ Changes in political context
  - ⊙ Limited information
- ⊙ Changes in data management

# Relevant Standards (1)



## GSMA's SMS Code of Conduct for Disaster Response

7

### PERSONAL IDENTIFYING INFORMATION

SHOULD NOT BE MADE PUBLIC UNLESS PRIOR **CONSENT** IS PROVIDED BY THOSE TEXTING INTO AN SMS INFORMATION SERVICE.



**THE RAW CONTENT OF TEXT MESSAGES SHOULD REMAIN CONFIDENTIAL AND HOSTED ON A SECURE PLATFORM.**

### RETENTION OF PERSONAL DATA, PARTICULARLY MOBILE USERS' PHONE NUMBERS,

SHOULD BE LIMITED TO A SPECIFIC PERIOD OF TIME FOLLOWING THE DISASTER AND SHOULD NOT BE TRANSFERRED TO THIRD PARTIES WITHOUT PRIOR **CONSENT**. RECOGNITION OF PREVAILING PRIVACY LAWS IN SPECIFIC COUNTRIES IS IMPORTANT, AS ARE REGULATIONS THAT STIPULATE THAT MOBILE NETWORK OPERATORS PROTECT THEIR CUSTOMER DATA.



### ACHIEVING A MUTUALLY-UNDERSTOOD AGREEMENT

[BETWEEN USERS AND SERVICE PROVIDERS] WHERE IDENTIFYING INFORMATION IS SHARED SHOULD ALWAYS BE DONE IN A WAY WHICH PROTECTS THE INDIVIDUAL [SERVICE USER].

# Relevant Standards (2)



## 2010 HAP Standard in Accountability and Quality Management

<b>4.3</b> The organisation shall enable the people it aims to assist to provide feedback and influence or make decisions about the project in a way that is continuously adapted to the context and the intervention. As a minimum, informed consent shall be obtained for the action.	<table><tr><td data-bbox="994 695 1105 1001"><b>1</b></td><td data-bbox="1105 695 1833 1001">Observation, records, and interviews to confirm a process through which the organisation assesses the capacity to participate and decides what is appropriate</td></tr><tr><td data-bbox="994 1001 1105 1172"><b>2</b></td><td data-bbox="1105 1001 1833 1172">Records of informed consent and other participatory activities</td></tr><tr><td data-bbox="994 1172 1105 1286"><b>3</b></td><td data-bbox="1105 1172 1833 1286">Examples and records that input is affecting decisions</td></tr></table>	<b>1</b>	Observation, records, and interviews to confirm a process through which the organisation assesses the capacity to participate and decides what is appropriate	<b>2</b>	Records of informed consent and other participatory activities	<b>3</b>	Examples and records that input is affecting decisions
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<b>3</b>	Examples and records that input is affecting decisions						

## Relevant Standards (3)



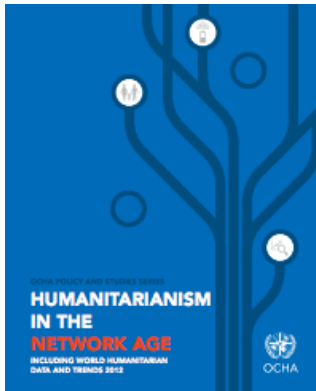
# Big Data, Communities and Ethical Resilience: A Framework for Action

At its core, an ethical framework for data aims to enhance agency: the ability for individuals and communities to be able to make decisions about how, where, why and for how long their data is used.

...

Informed consent goes beyond merely making people aware of the terms of service or that data is being gathered about them, **but a clear articulation of how data might be used, whether third parties will get access to that data, and how people can opt out or limit how much of their data is gathered.**

# Relevant Standards (4)



## ANNEX A

### Further operational recommendations

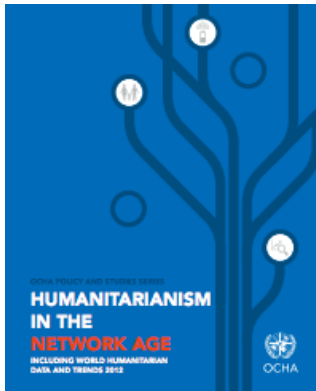
#### *4. Develop robust ethical guidelines around the use of information*

Specific operational recommendations:

##### Humanitarian organizations

- No later than 2014, develop “Do No Harm” standards for the ethical use of new forms of data, including protocols for protecting privacy and guaranteeing informants’ safety, and develop frameworks to hold practitioners responsible for adherence to ethical and technical standards. Ensure that these clearly address the separate issues of liability, privacy and security.
- Adopt information management principles as a source of guidance for adapting to the network age.
- Ensure that all projects include complaint and accountability mechanisms that can rapidly respond to issues of concern, abuse, exploitation, etc.

# Relevant Standards (4)

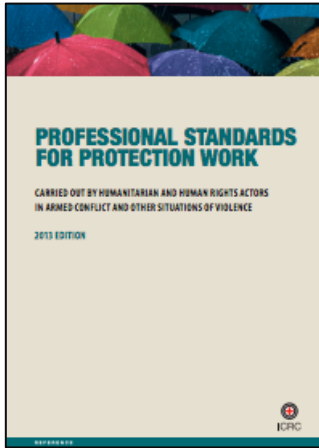


## Humanitarianism in the Networked Age (2012)

Concern over the protection of information and data is not a sufficient reason to avoid using new communications technologies in emergencies, but it must be taken into account. To adapt to increased ethical risks, humanitarian responders and partners need explicit guidelines and codes of conduct for managing new data sources. (pg 46)



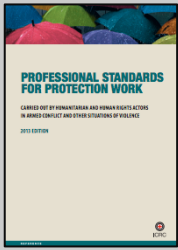
# Relevant Standards (5)



ICRC Professional Standards for Protection Work (2013) **By far the most detailed, operational and authoritative standard.**

## **Chapter 6: Managing Sensitive Protection information (Standards and guidelines 36-50)**

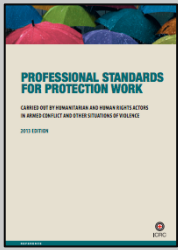
- ⦿ Only capable org's should collect sensitive info (37)
- ⦿ Burden of assessing risk lies w/actors seeking info, building platforms (39, 40, 46)
- ⦿ Info security safeguards must be in place ex-ante (45)
- ⦿ Inf. consent for sharing prsnl info from interviews (47), dealing with the crowd (48)
- ⦿ Inform communities of how information is used (49-G)
- ⦿ Establishing info management and security procedures (53-G)



# Relevant Standards (5)

**40. Protection actors setting up systematic information collection through the Internet or other media must analyse the different potential risks linked to the collection, sharing or public display of the information and adapt the way they collect, manage and publicly release the information accordingly.**

- ⊙ 5 checklist questions for evaluating risks associated with digitally collected and managed information
- ⊙ 5 questions to guide the publication of information that will help individuals evaluate the risks of providing information
- ⊙ References the importance of including contextual knowledge in planning and implementation
- ⊙ Acknowledges that full information security is an illusion

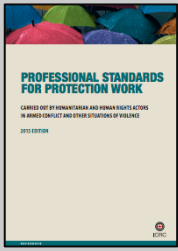


# Relevant Standards (5)



**48. Protection actors must integrate the notion of informed consent when calling upon the general public, or members of a community, to spontaneously send them information through SMS, an open Internet platform, or any other means of communication, or when using information already available on the Internet.**

- ⊙ Acknowledges that once information is released publicly, there is no longer any control
- ⊙ Assigns responsibility to the data collecting party in the event of data sharing and coordination



# Relevant Standards (5)

## Overarching Questions re the IRCRC standards

- ① Allocating responsibility
- ② Time pressure and competing norms of protection and due diligence
- ③ Capacities and resources along the data pipeline

# Challenges

- ① Whose consent?
- ① How do you get it?
- ① Anticipating risks?

# “Implied Consent”

Reaching out to @FrontlineSMS users in #Haiti with hopes of establishing local SMS gateway for <http://haiti.ushahidi.com>

1:38 PM Jan 13<sup>th</sup> via web

Reply Retweet



joshnesbit  
Josh Nesbit

Robert Munro  
Mission 4636

“Thanks Patrick!  
That’s reassuring!  
I can go with whatever  
was decided [...]”

— Jan 19, 3.14pm EDT



<http://4636.Ushahidi.com>



THE FLETCHER SCHOOL  
OF LAW AND DIPLOMACY  
TUFTS UNIVERSITY

“[...] It seems quite clear to me that if you are able to obtain their numbers and they are sending you this information, consent is implied.” — Jan 18, 4.45pm EDT

“If people are texting you, with the intent of getting aid or reaching out to someone, then consent would be implied.” — Jan 18, 5.47pm EDT

“I, for one, never again want to spend 24+ precious hours debating whether or not urgent life-and-death text messages can or cannot be mapped because of uncertainties over data privacy and protection.”

# Regarding Haiti 4636

- ⊙ Who was it shared with?
  - ⊙ How was it shared?
- ⊙ What kind of information was included?
- ⊙ What control mechanisms were in place to monitor these factors?



# Moving Forward

- ① Clear and universal delineation of responsibilities
- ② Operational tools for specific types of data management processes
  - a) Developed in collaboration with actual users
  - b) Piloted and validated with affected/reflected individuals and communities

thanks

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