Sharing Expectations:

How Enrollees and Epidemiologists May View the Role of a Radiation Registry Differently

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Overview

- Potentially nonconforming ideas and perceptions about a radiation registry – epidemiologists and enrollees:
  - Registry ≠ Research
  - Health Effects ≠ Holistic Impacts
  - Alert ≠ Action
  - Cohort ≠ Community
  - One Voice ≠ Many Voices
- Recommendations for a radiation registry's planners and communicators

Registry versus Research

Tension/Uncertainty

Is the registry:

A public health good for affected communities and individuals?

– or –

An observational experiment by hardboiled public health researchers?

- Long-term monitoring as an act of “observation” may prompt:
  - Belief that generating bio-scientific knowledge is more important than protecting the public’s actual health
  - Images of “living lab” experimentation especially among groups who have experienced past betrayals
- Undermining faith in monitoring as a public good are long shadows of:
  - Tuskegee syphilis study
  - USG human radiation experiments during Cold War

Health Effects versus Holistic Impacts

Tension/Uncertainty

Is the registry focused:

Narrowly on the health effects of radiation on a “body”?

– or –

Broadly on the holistic impacts of major traumatic event(s) on a “person”?

- Harm of a nuclear/radiological incident exceeds biological effects of ionizing radiation…
- …e.g., relocation/displacement tears people from familiar places, predictable resources, psychosocial supports, and known care providers
- Fukushima evacuees experienced major stressors leading to deaths, mental health problems, and life-style-related illnesses
  - Relocation: up to 7 times for some
  - Sheltering in high radiation areas
  - Missing medical support for the fragile
  - Stigma

Alert versus Action

Tension/Uncertainty

Is the registry:

An information-generating system that sends out an alert about health effects?

– or –

A care-provisioning system where an alert translates into action upon health effects?

- “Health” – while a continuous experience for a person – is still managed by 2 unevenly coordinated sectors in the US.
- Enrollees may feel long term monitoring automatically confers unencumbered access to care.
- An optimal threat warning is accompanied by specific “next steps” guidance that helps foster a sense of self-efficacy.

Cohort versus Community

Tension/Uncertainty

Does the registry consist of:

An aggregate of individuals whose data underpin a sound longitudinal analysis?

– or –

A community of people who bear the common mark and experience of a mass tragedy?

- *Cohort* suggests the sharing of a variable (e.g., rad exposure) while *Community* involves common experience, identity, connection
- Survivors may eschew cohort membership: e.g., asymptomatic in Fukushima: psychological distress and stigma via thyroid screenings
- Enrollees may come together to grieve and make collective sense of the mass tragedy
- Expectation of compensation or other social recognition may accompany victimized status

One Voice versus Many Voices

Tension/Uncertainty

Who is registry’s leading voice in a social media environment:

Epidemiologists communicating their authoritative knowledge out to enrollees?

– or –

Enrollees sharing their experiential knowledge with each other and wider world?

- Social media is altering the dynamics between health experts and the patients and populations they serve
- Laypersons are more readily turning to one another to share and interpret health experiences
- Via social media, individuals can find practical information and a sense of community, but also encounter misinformation

Recommendations

- Accept that suspicion toward “research” is reasonable given historical misdeeds; engage local opinion leaders to gain more awareness and enlist communication allies (registry/research)
- Concede the gap in focus on ionizing radiation’s bodily effects vs. incident’s psychosocial consequences; create outlets where enrollees can relate their larger story and access resources – e.g., affinity groups, broader studies (health/holistic effects)
- Recognize distinction between “public health” and “medicine” as an arbitrary one for enrollees; develop a referral system and construct easy on-ramps to care (alert/action)

Recommendations, cont'd

- Honor the communit-y/-ies that can emerge as result of the shared experience of a radiological/nuclear event (cohort/community)
  - Do not impede enrollee interactions, as they fulfill psychosocial needs
  - Expect/enable memorialization: e.g., touch on anniversaries for enrollees
  - Respect people's decision to *opt out* of cohort identity and obligations
- Plan for social media's influence on how people locate, process, transmit, and act on "trusted" health information (one/many voices)
  - Anticipate multiple narratives to circulate about an event's long-term effects
  - Engage with enrollees in their virtual communities
  - Tap into social media exchanges to locate "signals" for long-term effects

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Thank you. Any questions?

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