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 community(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
References


Thank you. Any questions?

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