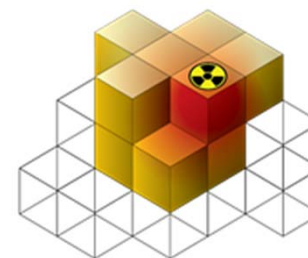




CHALLENGES IN INITIATING AND CONDUCTING LONG-TERM HEALTH MONITORING OF POPULATIONS FOLLOWING NUCLEAR AND RADIOLOGICAL EMERGENCIES IN THE UNITED STATES

A WORKSHOP

March 13, 2019



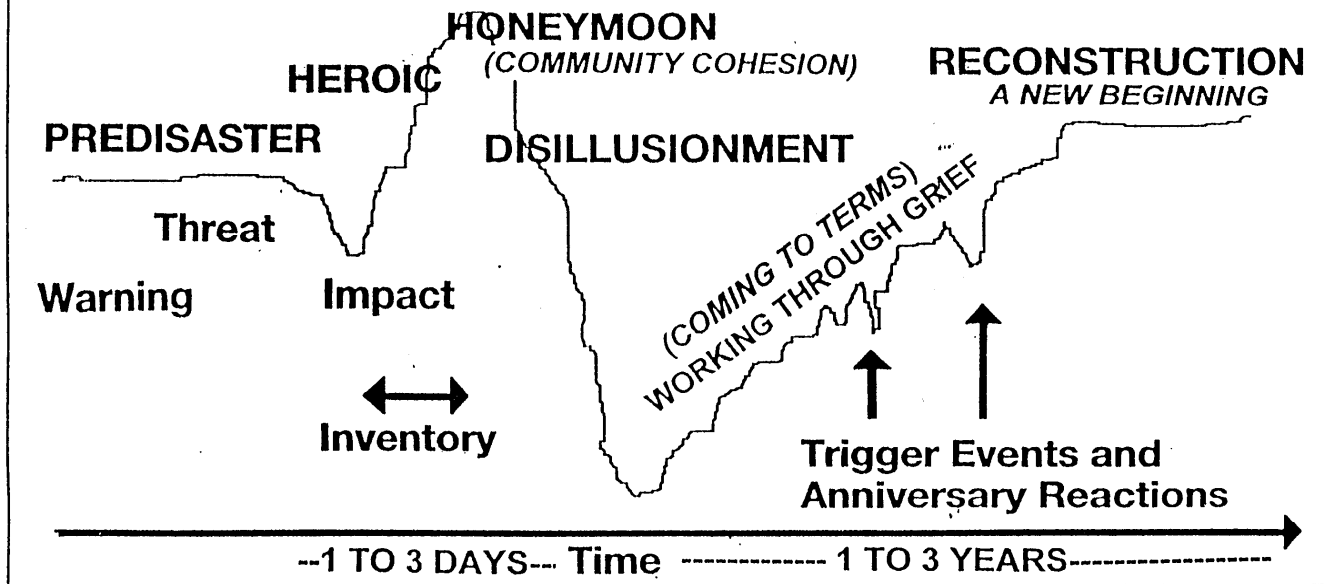
Key Points Summary
Jonathan Fielding, Committee Chair

Sponsor request (Armin Ansari)

- The purpose is to identify and discuss issues, challenges and considerations in establishing a registry, setting inclusion criteria, and providing the best care for affected people, taking into account implementation and practicality issues.
- Information and perspectives provided in this workshop will inform planning and preparedness activities for HHS/CDC and its public health partners.



Phases of Disaster



ZUNINMYERS

Operational Considerations

- ❑ Compartmentalization is the enemy
- ❑ Make key decisions collaboratively ahead of an incident
 - Federal
 - State
 - Local
 - The public
 - Contractors
- ❑ Define roles and responsibilities
 - Dosimetry
 - Screening
 - data collection and ownership
 - research priorities
 - communications with the public
- ❑ Training including exercises



Operational Considerations (cont.)

- Different levels of sophistication in data interpretation and use
- Be clear about scope of follow-up and timeline
- Different perspectives on role of registry that take time to resolve
- Plan for short- and long-term funding
- ? Dedicated registry strike team
- Hand-off of information from immediate health response to long-term follow-up
- Choice of survey methods and instruments



Operational Considerations (cont.)

- Pre-approved and/or expedited IRB approval
- HIPAA permitted uses and exemptions
- Types of outputs (e.g., dummy tables)
- Data ownership, use, confidentiality agreements
- Compatibility of different data systems
- Centralized data sources
- Collaborations throughout the registry operation
- Public engagement at all stages
- Support of local public health/environmental health departments



Screening

- Need clear rationale
- Balance of benefits and harms
- Cost versus potential benefit
- Evidence-based versus other considerations
- Throughput limitations
- Risk of overdiagnosis



Mental Health

- ❑ Common in all incidents
- ❑ Grossly underestimated
- ❑ Linked to risk perception
- ❑ Incorporate screening for mental health
 - PTSD
 - Depression
 - Increased drug, alcohol, and tobacco use
 - Family violence
 - Physical symptoms
 - Sleep problems
- ❑ Stigma associated with exposure/potential exposure
- ❑ Increased planning for response and recovery to
- ❑ Increase individual and community resilience



Slide by Jessica Wieder

*“A brilliant scientific
discourse is wasted if no one
listens or understands it.”*

-Journal of the American Medical Association



Communications

- Public attitudes and perceptions
- Engagement and transparency
- Pre-scripted messages
- Acknowledge audience needs
- Need for clear concise messaging; multiple languages
- Need for a single voice



Communications (cont.)

- Education of healthcare providers
- Treat enrollees as partners (not just research subjects)
- Communicate process (e.g., for setting safety standards, protective actions)
- Constructive use of social media



Life is like a bicycle
To keep your balance, you must keep moving

Albert Einstein

