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

- Predisaster
  - Threat
  - Warning

- Heroic
  - Impact
  - Inventory

- Honeymoon (Community Cohesion)

- Disillusionment

- Reconstruction
  - A New Beginning
  - Coming to Terms
  - Working Through Grief
  - Trigger Events and Anniversary Reactions

---1 TO 3 DAYS---  Time  ------------  1 TO 3 YEARS-------------

Slide by Robert Ursano
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
“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