Session 1: Existing Registries and Population Monitoring

Follow-up of the Atomic Bombing Survivors

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15 minutes
Outline

- Long-term follow-up requires cooperation
- Good design and a specific research focus help keep research on track
- Must engage the study participants
Follow-Up Begins

- Study is 'beyond the scope...' of military affairs
- Long-range study of the medical and biological effects...
- President Truman approves funding in November 1946
- Continuous operation since 1946
Hereditary Effects

- Prior to the atomic bombings, plant and animal experiments had shown that ionizing radiation could cause mutations that were passed to progeny.
- Hereditary effects after radiation exposure among humans was unknown—and was a major concern.
- Therefore, one of the Atomic Bomb Casualty Commission’s (ABCC) first major studies was to investigate genetic effects among the children of the survivors.
Recruitment for Hereditary Effects Study

Pregnant women requests food rations at city office

Pregnant Woman

Mid-Wife

ABCC

- Parental Exposure
- Reproductive History
- Due date, Address, etc.

- Birth Date, Sex
- Birth Weight, etc.
- Current Address

ABCC

Home Doctor Visit

- Health Status
- Malformations
- Etc.
Nurse, doctor and driver preparing for a home visit

Part of ABCC’s fleet of jeeps
Home Visit
More than 90% of all pregnancies within Hiroshima and Nagasaki were documented between 1948-1953 (N=76,000)

- Importantly, exposure categories were ascertained prior to observing the outcome
- Large range (and all combinations) of parental exposures
- Consistent coding of diagnoses by trained personnel
1950 Japanese National Census

- In the wake of WWII and the destruction of much of Japan’s infrastructure, the best tabulating equipment in the country was at the ABCC in Hiroshima.
- The Japanese government asked ABCC to tabulate the 1950 National Census.
- In a *quid pro quo* arrangement, ABCC asked that the Census include a specialized question: Were you in Hiroshima or Nagasaki at the time of the bombing?
284,000 persons indicated they had been in either city at the time of the bombing
  – 197,000 were still residents of either city
  – 99.1% were interviewed (or a proxy) for location at the time of the bombing

“Master” list of resident survivors

Ishida et al., ABCC TR 04-59, 1959
“The uncertain years...”

- The needed work at ABCC was epidemiological in nature, yet many of the studies were opportunistic and conducted by medical scientists from the perspective of medicine and pathology [Jablon S. *RERF Newsletter*. 1988;14:36-37]
  - No consistency in research
  - Difficulties in recruiting US scientists
  - 1947-1957, 6 different directors / slipping morale
- Korean war (fiscal constraints)
Missteps and Loss of Trust

- As US occupation draws to a close, survivors find their voice
- Complaints that ABCC draws blood but does not provide treatment
  - Resentment builds as survivors feel like “guinea pigs”
- ABCC viewed with suspicion, “closed and secretive”
- Uncomfortable truths
  - Photos of children for studying growth patterns
  - No feedback of results to survivors
Unified Study Program (1958)

- Fixed populations
  - Life-span Study (based on 1950 Census + interviews re: location at the time of the bombing)
  - F1 Mortality Study
  - In Utero Study
- Linkage with Japanese *koseki* (mortality)
- Adult Health Study
  - Morbidity surveillance on fixed subset of LSS
- Postmortem program
- Local cancer registries initiated by ABCC in Hiroshima and Nagasaki (2nd and 3rd cancer registries in all of Japan)
ABCC ➔ RERF (1975)

Hiroshima

Nagasaki
Results Used Around the World...

United Nations Scientific Committee on the Effects of Atomic Radiation (UNSCEAR)

International Commission on Radiological Protection (ICRP)

Japan, U.S., etc.

IAEA, WHO, etc.

RERF
Risk Estimates

US National Academies of Science (NAS)

National Council on Radiation Protection and Measurements (NCRP)
Lessons Learned (and still learning...)
Required: Good Design + Long-Term Follow-up

- Sound & innovative epidemiological design
  - Census, rations, fixed cohorts, prospective follow-up
- Long-term funding commitments from the USA and Japan + surveillance linkage
- Massive efforts to document exposure status of each survivor (exposure before outcome)
- Unfortunately, you can’t see the future...
  - No effort to document PTSD or any other psychosocial issues (a major point of emphasis in current research)
Listen / Explain

• Through stakeholder work groups, we have recently heard complaints:
  – “Why am I being asked to donate blood samples?”
  – “What is the purpose of the research?”
  – “How are my data being used?”
  – “The Informed Consent is too technical”
    • What does this mean?
    • Didn’t I already sign something like this?
    • What has changed?
Foster Relationship with Participants

- Transparent intentions with active feedback
  - Survivors are elderly—website is a poor medium
  - We use post cards and newsletters (but content must be more specific)
- Be clear with scope
  - We perform health examinations but not full cancer screening
  - A survivor was recently diagnosed with a cancer and was bitter that we hadn’t detected it during her examination
- Reinforce the importance of the research to keep participants interested and engaged
“Scientists here [at RERF] say that humanity owes a debt of gratitude because you all are willing to be a part of these tests.”

–Seth Doane (CBS News)

“It’s strange to say it’s an ‘honor’ but if our data is of use, I’m gratified.”

–Takashi Yamada
(A-bomb Survivor and RERF Health Study Participant)

CBS Evening News. August 9, 2015
Summary

• With participants, must:
  – Listen and provide feedback
  – Be transparent with purpose and intentions
  – Be clear with scope—avoid disappointments

• Good design and a specific research focus help keep research on track
  – Can’t go back...

• Long-term follow-up requires cooperation
  – Research Organization
  – Government/funding agency