CONDUCTING ETHICAL RESEARCH DURING DISASTERS

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INTRODUCTION

- Disaster is an incident or a series of incidents which threaten and disturb the life of society so that cause human victims.
- Indonesia is a country lay in the “Ring Of Fire “, and between the intersection of “three tectonic plate” of three continents which really vulnerable against disaster.
- To maximize respons and treatment to disaster victims, studies which involve human subject are needed.
Research involving human subject can affect Human Rights, so data collecting should be done ethically.

Although research involving disaster victims in Indonesia is still rare, this is a challenge to be done in the future.

Research can also support government’s step through BNPB/NDMB (National Disaster Management Berau) in providing and managing data to overcome disasters and have optimal impact to the disaster victims.
DISASTER IN INDONESIA

- Earthquake & Tsunami
- Bomb Explosion
- Technology Failure
- Heavy Floods
- Conflict
- Earthquake
- Volcanoes Eruptions
- Mud Floods
- Land Slide
### Many Disasters in Indonesia

<table>
<thead>
<tr>
<th>No.</th>
<th>Event</th>
<th>Victim</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>EARTHQUAKE AND TSUNAMI</td>
<td>DIED : 120.000</td>
<td>ACEH  2004 NORTH SUMATRA</td>
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<tr>
<td></td>
<td></td>
<td>MISSING : 93.088</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>INJURED : 4.632</td>
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<tr>
<td>2.</td>
<td>EARTHQUAKE</td>
<td>DIED : 5778</td>
<td>JOGJA &amp; CENTRAL JAVA, 2006</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HOSPITALIZED : 26.013</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>OUT PATIENTS : 125.195</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>BOMB EXPLOSION</td>
<td></td>
<td>BALI, 2002</td>
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<tr>
<td>4.</td>
<td>VOLCANOES ERUPTION</td>
<td>DIED : 347</td>
<td>MERAPI MONTAIN JOGJA &amp; CENTRAL JAVA 2010</td>
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<tr>
<td></td>
<td></td>
<td>HOSPITALIZED : 258</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>OUT PATIENTED : 52.272</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>EVACUATED : 61.154</td>
<td></td>
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<td>5.</td>
<td>EARTHQUAKE</td>
<td></td>
<td>Sumatera Barat</td>
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</table>
The General Policies

1. Victims get health service as soon as possible maximally and humanly
2. Emergency medical overcome toward injured victims, and death victims identification
3. Routine health services have to be done optimally
4. Implementation of health crisis overcome cannot be done gradually
5. Health assistance from inside or outside country must follow legal regulations
6. Periodic monitoring and evaluation of health crisis have to be done by all related stakeholders
Research To Disaster Victims

Disaster research, especially the impact to the victims, provide many information which can give correction and improvement to prevention, mitigation, and recovery action if the disaster occur again in the future.
Well designed research plan, knowing and understanding disaster research ethics, include:

- Research funding
- Asking research approval to the related institution as soon as possible, including local research ethics commission
- Schedule and protocol of the research,
- Tools and materials which will be used
- Rescue access to the disaster victims and their families
- Control the sampling bias
- Maintain and keep the condition of the subject who are very **vulnerable** which definitely disturb their social and psychological condition.
- Prepare the appropriate inducement and provide help for subjects.
Arrange Guideline of Research Ethics in Disasters

The Principles

- Need special protection for Vulnerable Persons (people who relatively or totally are unable to protect their interests themselves)

- Understanding local culture and wisdom

- Need fast and simple process for research approval from the authority institution.
General Principles of Research Ethics

According to International Guideline of CIOMS, Epidemiologic Research (1991) as well as Human Individual Research (2002), it’s universally agreed that all health research involving human as subject must be based on basic ethical principles, such as respect for persons, beneficence, and justice.
Informed Consent

Informed Consent is the main problem in a research involving human subject in disaster condition.

The prominent aspects in an informed consent is “information, comprehension, and voluntariness”.

An informed consent must have an explanation the research which will be done.

Statement made in informed consent must be clear, easy to understand, so subjects knowing clearly the procedure of the research, and subject must give their consent voluntarily.
The Benefit Aspects of Informed Consent

1. Respect for the subject
2. Protection to the subject
3. Protection to The Investigator
4. Secrecy of The Information
WAIVER OF INFORMED CONSENT

An exceptional research without an informed consent for an emergency research because it inefficient if fulfill some criteria as follow:

1. A research with minimum risk only;
2. Dispossession of approval/informed consent won’t give negative impact to the rights and prosperity of subject;
3. Unpractical and having problem if research done after the informed consent;
4. Give information verbally to subject about everything related to the research.
A research in disasters without informed consent must get *ethical approval* from local Health Research Ethics Commission, called as “*emergency research permission*”. 
THE REQUIREMENTS FOR EMERGENCY PERMISSION

- Subject is only a population who can participate

- Informed consent is unpractical (for example, subject is in unconscious or in life threaten condition)

- Risk-benefit appraisal which give advantages to the disaster victims

- The candidate research participant have been informed the research purpose and procedures of the research.
Subject identity is kept confidentially and assure the continuity of the research

Get verbal approval from subject or anyone who represent them.

Subject who want to drop out their participation during the research must be respected.

Investigator have met local Health Research Ethics Commission to discuss whether the research can be performed without written informed consent.
CONCLUSION

- Indonesia is a country which get a nickname “Disaster Supermarket”.
- Health research involving human subject must be based on ethical principle include respect for person, beneficence, nonmaleficence, and justice.
- Researcher must have prepare a good protocol with well arranged research method
- Researcher should refrain from a research for profit, drug toxicity and also risky experimental research
- Investigators are knowing and understanding research ethic to disaster victims, and preparing the research funding.
CONCLUSION

- The local Research Ethical Commission must give *ethical approval* as soon as possible.
- Researchers have to prepare the materials and tools which will be used in the research.
- Preparing medical care for the victims and their family.
- Maintain and keep that the victims not become have psychological stress.
- Researcher should provide inducement to the subjects, such as fund, medicine, food & drink, medical aid, clothes, evacuation place, etc.
Thank You