

DEVELOPING A DATA PROTECTION FRAMEWORK

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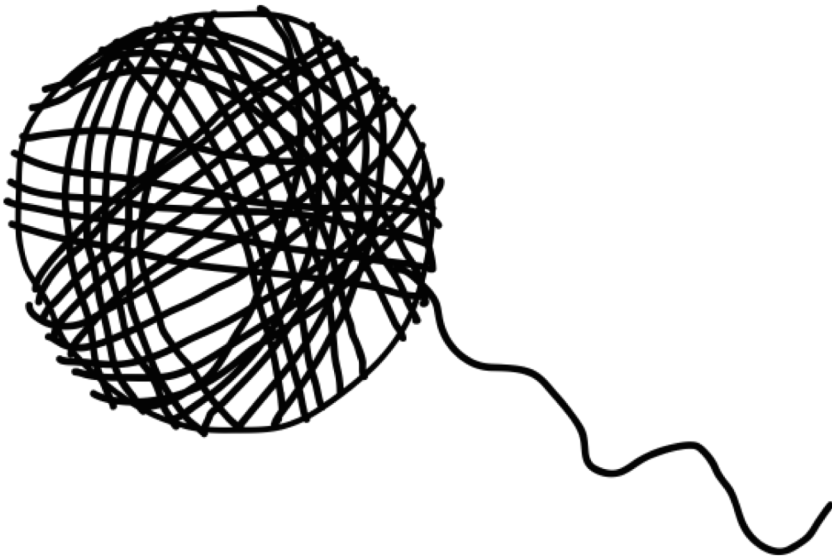
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The data revolution is here. Are we data ready?



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What is Data Literacy?

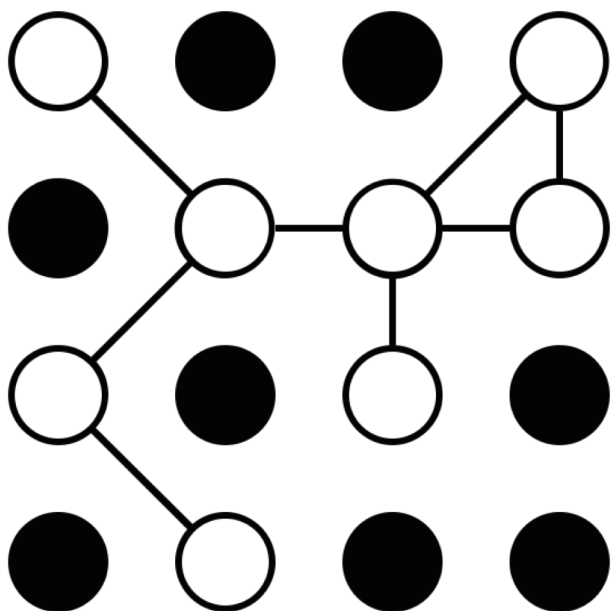


*“Data Literacy includes the skills, knowledge, attitudes, and social structures required for different populations to use data.”**

*Source: School of Data



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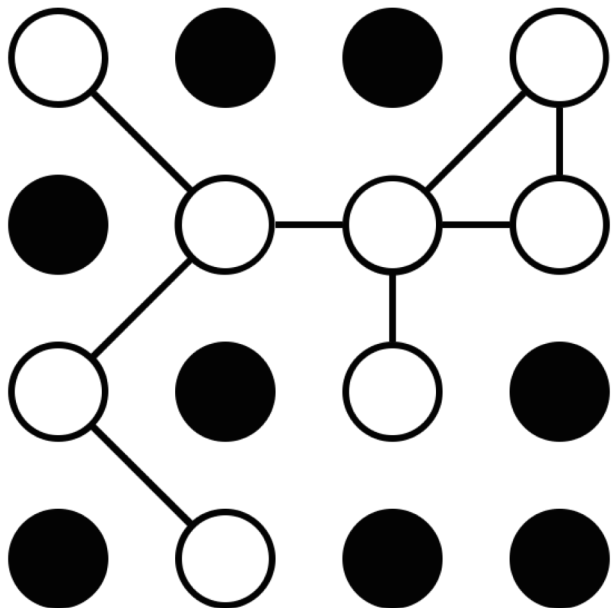
Responsible Data is:

The duty to ensure people's rights to consent, privacy, security and ownership around the information processes of collection, analysis, storage, presentation and reuse of data, while respecting the values of transparency and openness.

(Responsible Data Forum, working definition, September 2014)



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On Data Protection:

Protecting the Personal Data of individuals is an integral part of protecting their life, integrity, and dignity. This is why Personal Data protection is of fundamental importance for Humanitarian Organisations.

(Brussels Privacy Hub/ICRC Handbook on Data Protection, ICRC, forthcoming 2017)



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Data Management in Outbreaks

Ebola case Study



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DATA PLAYBOOK: SLIDEDeck 10



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EVD Response

The Ebola Virus Disease (EVD) outbreak in West Africa continues almost one year after it was officially declared on March 21, 2014. The International Federation of the Red Cross and Red Crescent Societies (IFRC) and the affected National Societies in Guinea, Sierra Leone and Liberia have been actively engaged since March in key components of the response, including **case management, contact tracing, psychosocial support, social mobilisation, and safe and dignified burials**, with over **6,000** volunteers mobilised on the ground at the height of the epidemic. All of these activities are significantly contributing to ending the epidemic, but the Red Cross work in safe and dignified burials is at a scale never seen before

EVD Pillars of Response



Why is so much Data sharing needed in epidemics?



Data collected by NS SDB teams

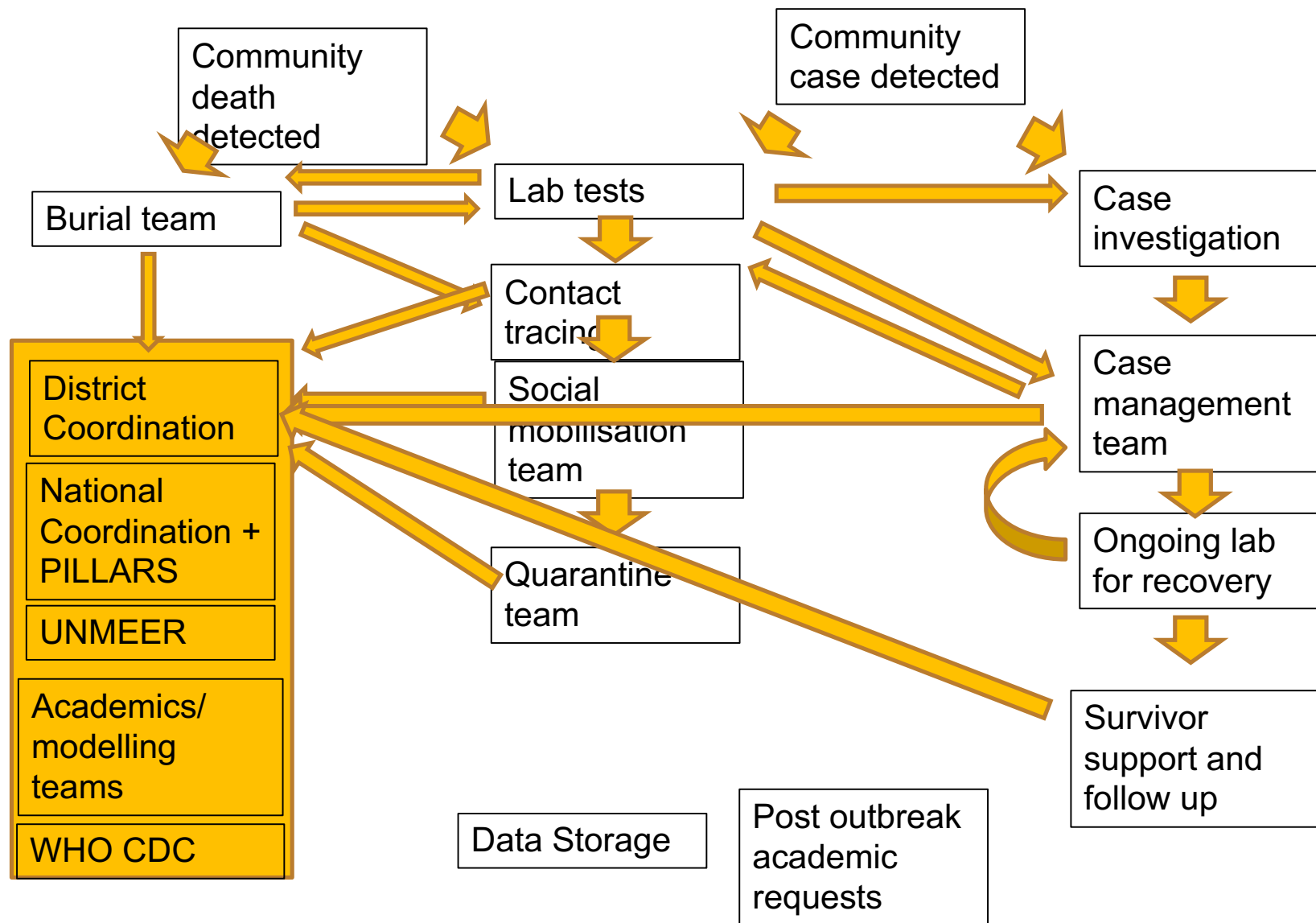
Information collected

- Individual burials
- Demographic data
- GPS location
- Contact details for next of Kin
- Risk exposure - had the body been moved before the team arrived
- Basic information on history of illness and risk exposure of deceased

For bodies without identification a photograph and GPS was captured assist with identification at a later time.

Operational Indicators

- Time from alert received to collection
- Number of teams and composition
- Amount of personnel protective equipment used every day
- If religious leader attended burial ceremony
- Security incidents/ community resistance





Key Questions Exercise



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DATA PLAYBOOK: SLIDEDECK 10

Consent

What are the attributes of legal consent for data collection process?



Data Collection and Minimization

- How do we define minimization and Personally Identifiable Information?
- What type of personal identification or authentication can be used? Consider that some Ministry of Healths require line reporting including names and other personal data.
- How can we obtain legal guidance for the data project managers (controllers)?

Data Sharing

- How can we share data within the Red Cross Red Crescent?
- What type of data can and cannot be transferred across borders? What type of data is stored on local server and what type of data can be stored abroad?
- How to Data Share with other Humanitarian actors? Researchers? governments?

Data Storage

- What are the legal jurisdictions for the data management - storage, use and sharing of the data?
- For the Digital Health Information system (DHIS), where will the primary and backup softwares be?
 - In Geneva offices? In the cloud?
 - If in the cloud, in which country/countries?

Data Backups

- If there are data backups, who is accountable to keep these up to date?
- And are the backups in the same or different legal jurisdiction?
- How many copies of the data will be kept and where? (cloud server? remote server? local server?)
- Number of years data can be stored and description of the procedure for data destruction

Potential issues for a Governance group work

- SOP for data management, data use (for decision making) and data sharing
- Guidelines on data sharing with researchers
- Governance structure for different authorisations: data sharing with different partners and different level of data to be shared (raw, anonymised, aggregated), also for creation of new users at different authorisation levels.
- Guidelines for identification or authentication of patients/beneficiaries in different contexts
- Confidentiality agreement that ERU personnel need to sign on use of data and data protection
- SOPs for data breaches
- SOPs for changes in data content and adding data collection fields or data collection forms.

THANK YOU

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