Privacy, Security and Confidentiality of Data Sharing and Storage:

Domain Specific Examples

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Médecins Sans Frontières
Cybersecurity in health care.
Perakslis ED.

A cybersecurity primer for translational research.
Perakslis ED¹, Stanley M².
tranSMART: An Open Source Knowledge Management and High Content Data Analytics Platform

Elisabeth Scheufele, MD, MS,¹,² Dina Aronzon, MS,¹ Robert Coopersmith, Ph.D,¹ Michael T. McDuffie, MS,¹ Manish Kapoor, MS,¹ Christopher A. Uhrich,¹ Jean E. Avitabile,¹ Jinlei Liu, MS,¹ Dan Housman,¹ and Matvey B. Palchuk, MD, MS¹,²

http://transmartfoundation.org/bibliography/

2017: 18 papers
2016: 18 papers
2015: 27 papers
<table>
<thead>
<tr>
<th>Date of Report</th>
<th>Feb 01, 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>Shortly after birth, the patient was noticed to have decreased tone and difficulty breathing. She struggled to drink from a bottle and would breathe liquids into her airway (aspirate). At 6 months, a G tube was placed. Currently she struggles with chewing and swallowing and is unable to drink out of a cup or straw. The patient said her first words at 13 months and began walking at 22 months. She gets tired easily (easy fatigability) and makes rhythmic and repetitive movements with her upper and lower limbs (stereotypic movements).</td>
</tr>
</tbody>
</table>
Human Data (Deep Phenotyping and Molecular Profiling) Strategy

- Gaming Neuro. Evaluation
- Wearable Technologies
- Sequencing or Microarray
- Gut Microbiome
- Wearable Technologies
- Somatic Mutation Analysis (NGS)
- Cognition & Psycho Social
- Vital Signs Monitoring
- Germline Genetics
- Gastrointestinal Flora
- Activity and Movement Disorders
- Tumor Profiling


Clinical Data Management

- **Adult Survivors:**
  - Issa Kamara: 45M
  - Mabinty Bangura: 38F
  - Fatmata Bangura: 30F
  - Ya Alimamy Kanu

- **Positive Cases:**

- **Children Survivors:**

- **Negative D/C:**

- **Total Survivors:** 132

- **Lab Issues:**

- **Total 13/Jan:**

- **Gov’t Transfers:**

- **Deaths:**

- **Notes:**
  - Hassan Dumbuya: Obstetrics 12O
  - Rama 2: Obstetrics 328
  - Baroka: Obstetrics
Have you had contact with an Ebola case, alive or dead?

- Y: Admit and perform full EVD triage:
  - Fever?
  - Feeling weak?
  - Diarrhea?
  - Joint/muscle pain?
  - Headache?
  - Sore throat?
  - Hiccups?
  - Nausea?
  - Red eyes?
  - Abdominal pain?
  - Vomiting?
  - Difficulty breathing?
- N: Perform Cholera Triage:
  - Watery Diarrhea?
  - Many stools?
  - Vomiting?
  - Extreme thirst?
  - Feeling restless
  - Or irritable?
  - Muscle cramps?

Have you had unexplained bleeding

- Y: Perform general exam?
  - Complete TB Triage & Perform sputum AFB and chest X-ray
- N: Have you had fever?
  - Y: Have you had cough?
    - Y: Cough for more than 2 weeks or Cough up blood?
      - Y: Have you had rash?
        - Y: Assess for Measles
      - N: Perform general exam?
    - N: Have you had cough?
      - Y: Complete TB Triage & Perform sputum AFB and chest X-ray
We learned how fast technologies could be learned, absorbed, mastered and put to use.
We learned that people of all ages will try new things and fight for themselves.
You can make a difference.

Jun 7

Hi Dr. Eric

Hi Vamba, Great to hear from you. I hope all is well.

7:13 AM

Jun 8

Everything is well. We have expanded our mobile data collection project and now we have about 110 CHWs and they are all going to start using CommCare by next week. We are always and will continue to be grateful for the support you gave us during the EVD.

5:58 AM

Thanks Vamba. Working with you was a great pleasure. I am so glad to hear of the growth and success and would love to know more. Is the