Diving through swirls: Experiences with establishing electronic data systems for maternal and child health in Sub-Saharan Africa

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What I am presenting

- 2 projects
- Some issues
- Some swirls

The ONGEZA Project

https://alert.ki.se/
Experiences from ONGEZA – Pilot project in 1 district in Southern Tanzania using “Smart Paper technology” SPT
ONGEZA: What are our findings?

- Well-appreciated
- Improves accountability
- No additional time burden

- BUT: the Pilot Project could not show good data quality

You know, with SPT you just tick. There is no need to write much. You can spend time with your client while ticking the form (FGD3post-intervention)
A perinatal e-registry implemented in 16 hospitals in 4 countries

Mother-held ANC card

Labour ward documentation

Postnatal ward documentation

Data clerk or health provider compiles and enters into a tablet-based application
4 countries PLUS GDPR
- 6 ethics application, 4 x yearly renewal

- EC demands data management according to GDPR
  ⬤ data ownership (safety)
  ⬤ data use
Perinatal mortality across countries

Benin (ratio 1.6)

Malawi (ratio 2.0)

Tanzania (ratio 3.1)

Uganda (2.5)
Problems with data.

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. tab q45status7 outcome, m

45. Status of baby 1 at day of discharge or referral or day 7

<table>
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<tr>
<th>outcome</th>
<th>maz still</th>
<th>fresh sti</th>
<th>1dayNN</th>
<th>alive at</th>
<th>.</th>
<th>Total</th>
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<tbody>
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<td>1. Alive</td>
<td>2</td>
<td>3</td>
<td>31</td>
<td>16,305</td>
<td>1</td>
<td>16,342</td>
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<td>2. Alive and referred</td>
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<td>1</td>
<td>0</td>
<td>36</td>
<td>0</td>
<td>37</td>
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<tr>
<td>3. Died within 24 h</td>
<td>169</td>
<td>273</td>
<td>74</td>
<td>48</td>
<td>2</td>
<td>566</td>
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<td>4. Died after 24 h</td>
<td>10</td>
<td>3</td>
<td>9</td>
<td>36</td>
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<td>58</td>
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<td>5. Unknown</td>
<td>101</td>
<td>68</td>
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<td>367</td>
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What does it take

The basis
- Partners
- Research team
- Stakeholder management
- Agreements

The innovation
- The right innovation at the right place and the right time

The implementation
- Skills/competences & attitude of primary users
- Data literacy
- Funding to work with barriers
The system incorporates various core functionalities/modules to serve the purpose:-

- Electronic Medical Record (EMR),
- Laboratory Information System
- Tracking and Inventory of Medical Supplies
- Billing and Revenue Collection
- Practitioner Performance Tracking
- Reporting (MTUHA Forms)
The swirls

• Stakeholder management – Northern Research institutions are detached from policy discussions
• Legal issues / GDPR vs decolonialization
• Data ownership & protectionism vs fruitful use of data
• Clinical training / carefulness in documentation → Pragmatism vs high quality
• Capacity to analyse / data use vs budget and capacity within teams