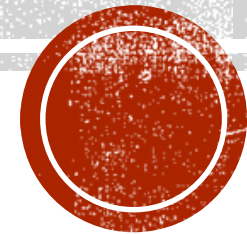




# PILOTING FEMALE GENITAL MUTILATION SURVEILLANCE IN SUDAN: ACHIEVEMENTS AND LESSONS

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# **SURVEILLANCE DEFINITION (WHO)**

**The continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice, which can:**

- **serve as an early warning system for impending public health emergencies;**
- **document the impact of an intervention, or track progress towards specified goals;**  
**and**
- **monitor and clarify the epidemiology of health problems,**
- **inform priority setting and public health policy and strategies.**



# BACKGROUND

- Health sector action plans include activities for FGM prevention and care
- FGM data is not routinely collected within the health sector information systems
- Population-based studies are only source of data on FGM, but they are too costly and not regular enough to inform monitoring or to measure programmatic impact



# FGM SURVEILLANCE MODELS IN THE HEALTH SECTOR

- **Mainly from high income countries with low FGM prevalence**
  - *Notification system that requires clinicians to identify, manage and notify cases among girls 16 years old and younger (UK)*
  - *UK Obstetric Surveillance System (UKOSS) estimates the prevalence of Type 3 FGM*
  - *Australian Pediatric surveillance used by pediatricians to measure FGM prevalence among children*
- **Few models for countries with high FGM prevalence**





# SUDAN'S FGM PROFILE (1)



- ~ 87% of females (15-49 years) mostly WHO type III (77%)
- Prevalence varies between generations<sup>1</sup>
  - 66.3% [0-14 years]
  - 88.3% [30-34 years]
  - 91.8% [45-49 years]
- Increasing trend in FGM medicalization (55 - 76%)

<sup>1</sup>2014 Sudan Multiple Indicator Cluster Survey



# DEVELOPMENTAL PHASES OF FGM SURVEILLANCE IN SUDAN (1)

SINCE 2015 – TO DATE

- Consultative meetings held within MOH<sup>1</sup> and FGM Surveillance Committee<sup>2</sup> to discuss
  - Purpose (Why)
  - Type of indicator and frequency (What)
  - Health service outlet type and coverage (Where)
  - Data collectors and data users (Who)
  - Data source, data entry platform collection frequency, data flow and analysis (How)

<sup>1</sup> Federal health Information and Statistics directorate, Federal Maternal and Child Health Directorate, National Reproductive Program, Federal, Khartoum Health Promotion Directorate, Khartoum Child Protection Unit

<sup>2</sup> National Child Health Program, School Health Program, Ministry of Education



Why	What	Where	Who	How
Planning, Implementation and evaluation	FGM prevalence	Outpatients	Data collectors: - Health Care Provider - Researcher - Other	Source – Client (self- report) , guardian reporting, or HCP (genital examination)
Notification	Typology prevalence	Inpatients		Routine, periodic data collection or research
	Re-infibulation prevalence	All levels versus selected levels		
	De-infibulation prevalence	Utilization rates	Data Users: - Health Care Provider	Integrated or vertical
	FGM practitioners	Specialized Gynecologic, pediatric clinics, school health program	- Programme planners - Policy makers	All sites versus sentinel sites
	QoL of FGM survivor			Paper based versus electronic
	FGM Attitudinal shifts			HMIS data and Intersectoral data flow
	Reason why FGM performed			Centralized or decentralized analysis
	Prevention and care			



# FGM SURVEILLANCE IN ANC PILOT PHASE (1)

- 10 ANC sites in two states
  - Khartoum state 6 [3 hospitals and 3 health centers]
  - Gedaref state 4 [2 hospitals and 2 health centers]
- Criteria for selection
  - Willing to participate
  - Busy ANC



# FGM SURVEILLANCE IN ANC PILOT PHASE (2)

- Data collection over 3 weeks (N=2,000)
  - 76.3% have FGM (median/mean age 30 years)
  - 55.4% reported health personnel performed first cut (54.2% by midwives) mostly at age 6-10 years (47.7%)
  - 5.5% underwent de-infibulation mainly for health complications (75.9%) e.g. tightness
  - 35.2% reported re-infibulation, increasing trend observed with age, performed mainly by midwives (95.5%) however missing data was 68.5%



# EVALUATION (1)

- Data Quality
  - 10% transcription errors
  - Missing data – 2-3%
    - high missing data: person who perform re-infibulation (69%), age undergone FGM (25%), person conducted FGM (25%)
- Data collectors profile
  - Statisticians – 40%, Counselors – 20%, Nurse – 15%, Doctors – 1%, Others 20%



# EVALUATION (2)

- 22% of data collectors reported facing any challenge (missing data 45.6%)
  - No privacy for sensitive questions (93%)
  - Unclarity of questions (2%)
  - Women refused to respond (3%)
  - Time limitation (2%)



# IN THE PIPELINE

- FGM Surveillance in School Health Program in four states (Northern Kordufan, Gezira, Khartoum and Gedaref)
- Selection criteria for pilot
  - States with active school health program
  - Schools in densely populated localities
  - Willingness to participate
- Expected when school year resumes in mid-August
- Expected sample 2,500



# LESSONS LEARNT SO FAR (1)

- **Design Phase**
  - Country context determine the model design
  - Select few clear and relevant indicators
  - Integrate within existent information system flow structure
  - Championing and advocacy essential because of other competing health issues
  - Commitment and buy in of relevant stakeholders key for ownership and implementation
  - Easier to work with one sector than with two



# LESSONS LEARNT SO FAR (2)

- **Pilot phase**

- Buy in and commitment of sites essential
- Close supervision and monitoring during implementation (data quality control)
- Specific questions on FGM prevalence and practitioners to ANC women poor response and not useful
- Iterative process to problem solve and improve performance



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