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Introducing Record Linkage

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In collaboration with the TAZAMA Project, NIMR Mwanza

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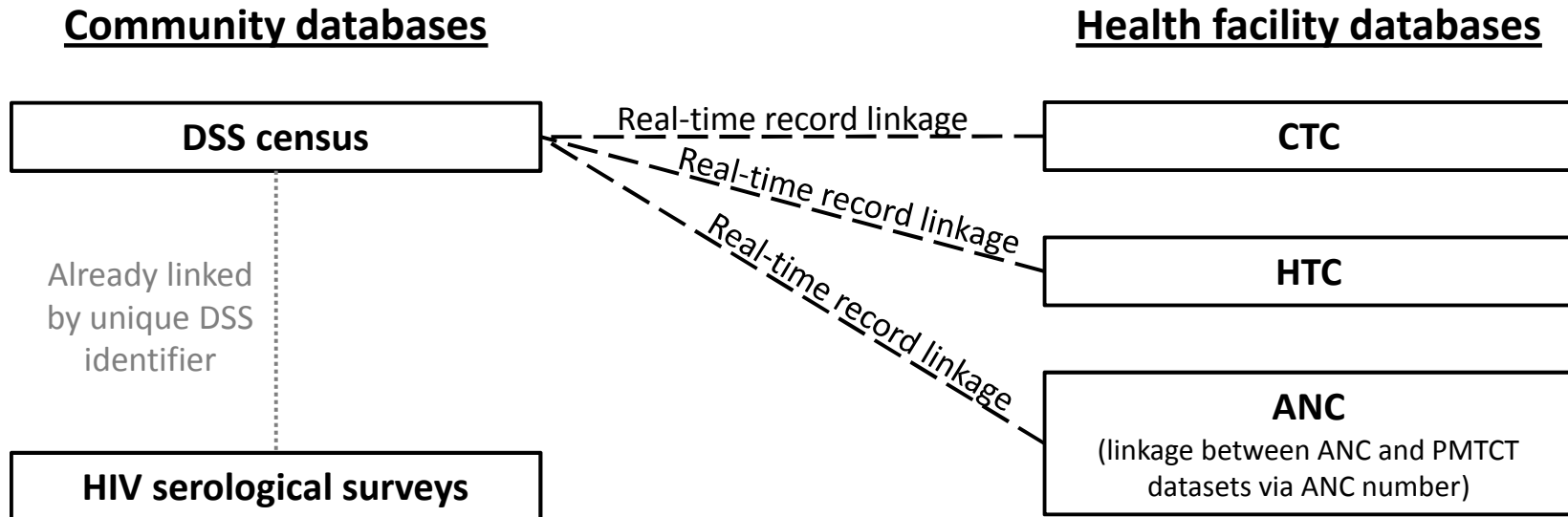
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Summary

- What is record linkage?
- Why is record linkage important?
- How does record linkage work?
- Results from pilot
- Challenges
- Future visions

What is record linkage?

- Matches (or “links”) an individual’s records between 2 or more existing databases
- In Kisesa, we want to link a patient’s health facility records to their community records



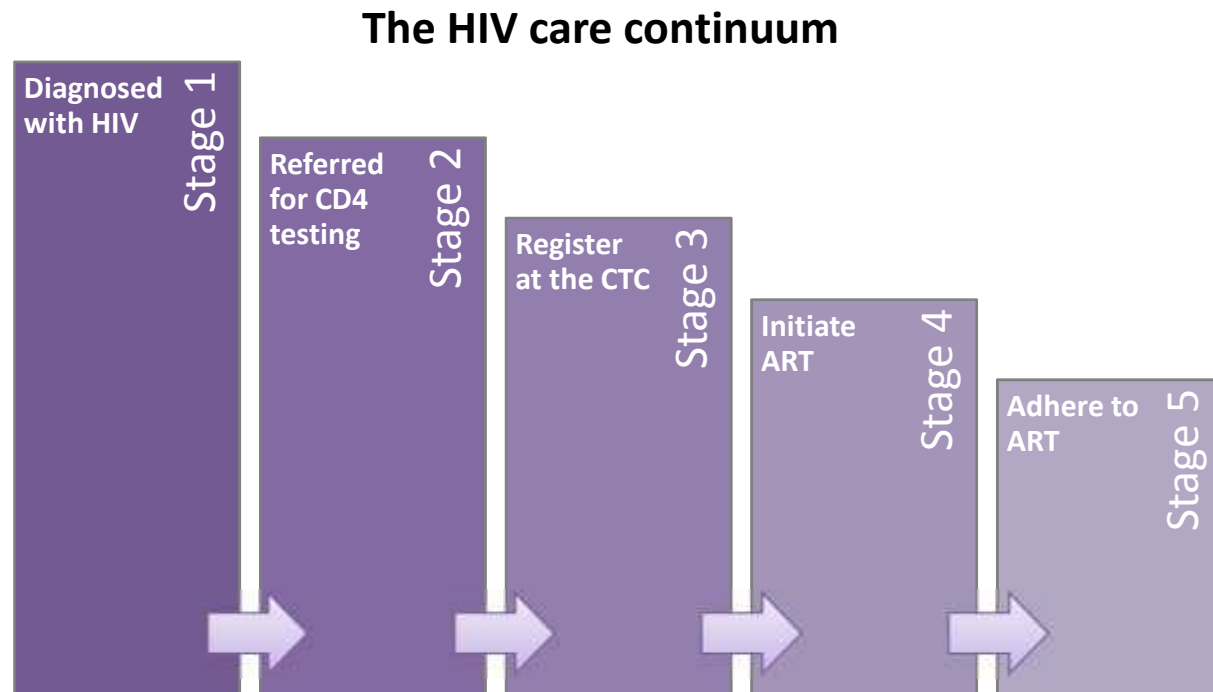
Notes: DSS = Demographic Surveillance System; CTC = HIV care and treatment centre; HTC = HIV testing and counselling; ANC = antenatal clinic; PMTCT = prevention of mother-to-child transmission

Why is record linkage important?

- Access to HIV services has risen over the years, but still remains low (~55% ever tested; 30% ART coverage)
- Currently, we can only research those who access the services, like testing and treatment
- With linked records, we can now know about those who do and do not access HIV services
- Knowing which individuals do not access health services will help us to find out why they do not attend and allow us to better design local health systems and simple interventions to improve HIV service access

Why is record linkage important?

- With linked records, we can also examine how well HIV-infected individuals navigate the HIV care continuum
 - We can detect differences in the duration of time in between each stage and how this differs by location of HIV diagnosis



How does record linkage work?

1. NEW PATIENT (only with patient; not treatment supporter):
Introduce self and project, input personal identifiers into DSS search facility, and verify if correct person found.
 - a. If found, ask patient if s/he consents to linking her/his health records to her/his census records.
 - i. If yes, perform informed written consent, collect clinic identifiers, and assign match to DSS with date of visit. Give individual a study information sheet and thank them for their time.
 - ii. If no, give individual a study information sheet and thank them for their time.
 - b. If not found, store personal identifiers, search criteria, and notes detailing the likely reasons why not found (i.e., just moved to Kisesa, etc). Additionally, if the individual declares to be a resident of the DSS coverage area, ask patient if s/he consents to linking her/his health records to her/his census records.
 - i. If yes, perform informed written consent, collect clinic identifiers, and assign match to DSS with date of visit. Give individual a study information sheet and thank them for their time.
 - ii. If no, give individual a study information sheet and thank them for their time.

How does record linkage work?

2. RETURN PATIENT (either patient or treatment supporter):
Introduce self and project. Ask attendee if s/he has already participated. If yes, enter the individual's clinic identifier (personal identifiers will automatically be populated in the software)
 - a. If previously consented to link records, store new visit date
 - b. If previously did not consent to link records, ask again
 - a. If yes, perform informed written consent and assign match to DSS with date of visit.
 - b. If no, thank them for their time.

Patient registration/follow-up visits

Kisesa DSS-Clinic Record Linker

Health Facility Name: KISESA Health Facility Department:

Patient registry Linkage with DSS Progress Report

Registration date: YY-MM-DD 04/Dec/2014 05/Dec/2014 Consent status: CONSENTED

Clinic Identifiers
File Ref: 2219 Unique CTC ID Number: Tazama Green Referral Form Number:

Personal Identifiers
First name: Middle name: Last name: NYENYEKA
Sex: MALE Date of birth: 1968 01 01 Telephone:

Place of residence details
Village: KISESA Sub village: NG'WAHALANGA Date started living at current residence: 1994 MM DD
Ten Cell Leader First Name: Ten Cell Leader Middle Name: JUMANNE Ten Cell Leader Last Name:
HH Member First Name: HH Member Middle Name: HH Member Last Name: DEOGRAIUS

Match Status
Status: DSS ID: Last search date: Last search for match notes:

Save Edit Clear

Visit Information
Visit Date: Visit By: Save Visit Date

Visit Date	Visit By
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Data Source: WINDOWS\WORKHORS\SQLXPRESS Database: KisesaDSSClinicLinkSystem User: Admin

Search and linkage with DSS

Kisesa DSS-Clinic Record Linker

Health Facility Name: **KISESA** Health Facility Department:

Patient registry | **Linkage with DSS** | Progress Report

Search DSS Assign match Save search for match notes Matched DSSID: **40113018021**

First Name: **[REDACTED]** ☒ use Middle Name: **[REDACTED]** ☒ use Last Name: **NYENYEKA** ☒ use Sex: **M** ☒ use DOB: Year **1968** ☒ use Month **01** ☒ use Day **01** ☒ use

Village: **KISESA** ☒ use Sub Village: **NG'WAMALANG** ☒ use TCL First Name: **[REDACTED]** ☒ use TCL Middle Name: **JUMANNE** ☒ use TCL Last Name: ☒ use

Household Member: First Name: **[REDACTED]** Middle Name: **[REDACTED]** Last Name: **DEOGRATIUS**

Search for match notes

	First Name	Last Name	Sex	DoB	Ten C Leader First Name	Ten C Leader Last Name	Village	Sub Village	StartDate
▶	ZAB	GUKE	M	1968-06-15	DO	NKILIGI	KISESA	KISESA KATI	2003-03-10
	ZAB	GUKE	M	1968-06-15	AL	AMANI	KISESA	KISESA KATI	2003-11-10
	ZAB	GUKE	M	1974-09-15	DA	MABEYO	KISESA	NG'WANG'HALAN...	2008-10-31
	MAN	ZABRON	M	1967-01-15	DA	MACHIRYA	ISANGILO	NG'WABONGOSO	2004-06-01
	CHA	NGUDE	M	1968-07-01	MA	KAYEGO	KISESA	KISESA KATI	2001-04-20
	DEL	NYESE	M	1968-07-01	MO	ABDALLA	KISESA	KISESA KATI	2001-04-03
	DEL	NYESE	M	1968-07-01	MO	ABDALLA	KISESA	KISESA KATI	2012-08-29
	PHA	NYESE	M	1968-07-01	DA	MABEYO	KISESA	NG'WANG'HALAN...	1997-09-02
	PHA	NYESE	M	1968-07-01	DA	MABEYO	KISESA	NG'WANG'HALAN...	2010-11-23
	ROF	ZABRON	M	1967-07-01	SA	MAGFI F.IA	KITUMBA	KIGILINGUMI II	1995-12-17

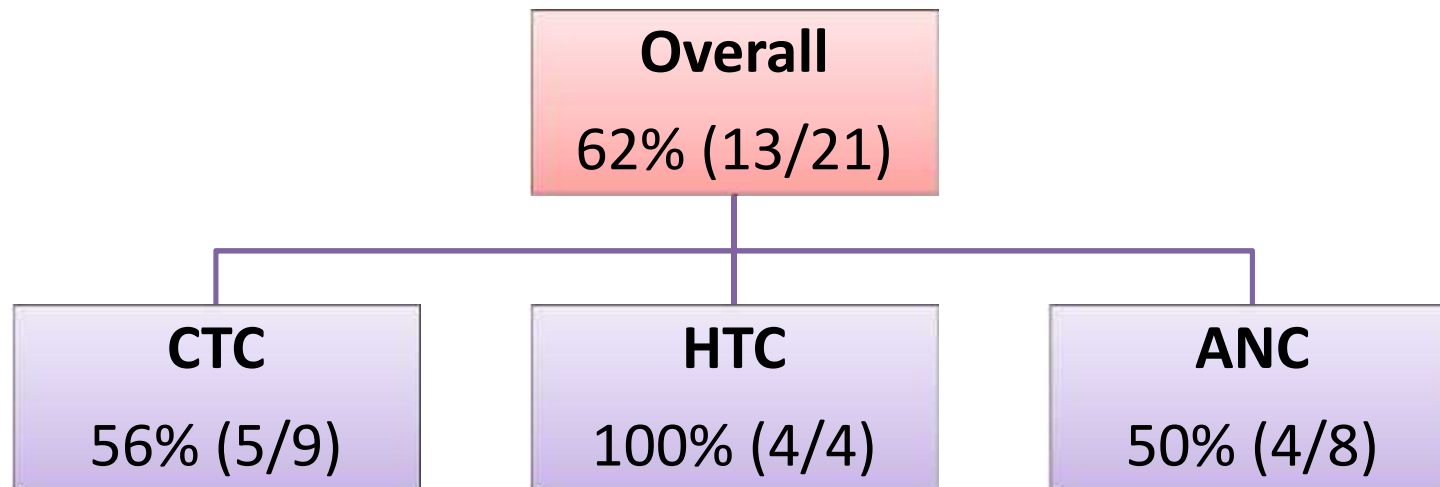
Name	Sum
MAR	MAYA
MIN	KASU
NCH	LIMBE
PEN	LIMBE
PEN	SHAB
RAH	ELISH
SAL	LIMBE
SHI	LIMBE
SIT	ZABR
STE	BERN

Data Source: WINDOWS\WORKHORSE\SQLXPRESS Database: KisesaDSSClinicLinkSystem User: Admin

Resulting database

RecordNo	HealthFacilityName	FileRef	UniqueCTCNumber	Id_Long
100002	KISESA	1404	19-02-01-0100-1164	20102053001
100003	KISESA		- - - -	20206006017
100006	KISESA		- - - -	20605012008
100012	KISESA		- - - -	40107042020
100019	KISESA		- - - -	40404012008
100020	KISESA		- - - -	40401014003
100022	KISESA		- - - -	60103104006
100023	KISESA	42685918	- - - -	50103004001
100024	KISESA	42685530	- - - -	10103029001
100025	KISESA		19-02-01-0100-1961	30101023006
100027	KISESA	2111	19-02-01-0100-1884	40302167002
100028	KISESA	1214	19-02-01-0100-0971	60108037002
100029	KISESA	1730	19-02-01-0100-4427	60201004002
100033	KISESA	2219	- - - -	40403106001

Results from pilot (% matched)



Reasons for no match found:

- Resides outside of Kisesa
- Multiple names
- Uses different name in village
- Only moved into Kisesa recently to be near family during pregnancy

Notes: CTC = HIV care and treatment centre; HTC = HIV testing and counselling; ANC = antenatal clinic

Challenges

- No centralized patient registration
 - Multiple record linkage points in one health centre
- Health facility identifiers sometimes assigned after record linkage
- Past and future mobility
 - Internal migration
 - External migration
- Paper-based medical records

Future visions

- Capacity development
 - Data manager
 - Continuation of studies in computer programming
 - Data clerks
 - Research ethics and patient interactions
- A centralized patient registration system
 - Unique patient IDs that travel with the patient between clinics in Kisesa...in Tanzania??
- A single electronic medical record system???



Questions or comments?

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