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ESTABLISHING A DIABETES REGISTRY TO IMPROVE QUALITY OF CARE FOR TYPE 1 DIABETICS IN RWANDA

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Executive summary

Background: Rwanda is establishing a National Diabetes Registry with a type 1 pediatric subcomponent to improve data for surveillance and quality of care. The registry will be created by the linkage of two routinely collected data sources at the health care facility level. We describe the process and basic core data of the established this diabetes registry in Rwanda.

Methods: The Quasi-experimental cohort study included 31 district hospitals in which the electronic medical records (EMR) module was created to include: patient demographics, patients' unique ID number, clinical characteristics, risk factors, treatment, and lab results, and patient movement between facilities to and out of the clinic. Health care providers received a training on the use of electronic medical records followed by data entry of all type 1 diabetic patients (<26 years of age) who were on follow up since followed from January 2011 to June 2019.

Results: A total of 470 type 1 diabetes cases (<26 years) from 31 district hospitals were identified and enrolled in the registry. The Majority of registered type 1 patients were are female 57%.The largest proportion, 38.7% of type 1 patients are in socioeconomic class two (middle income), with 35.9% in class three (high income) and 25.2% in Class one (low income). Type 1 diabetes among children and young adults is predominant in Age group 16-25 years (86.6%), and the majority were also diagnosed between 16-25 years of age (62.7%). There has been an increase of new cases over time in which 11 new cases were recorded in 2011 and 67 cases in year 2018. A Steady increase of cumulative cases was recorded between 2011 to and 2019 from 40 cases to 387 cases respectively; More than two thirds, 77% (95%CI: 71.8-81.7), had HBA1C above 7%.

Conclusion: The use of a diabetes registry is a crucial step towards distributing epidemiological data on type 1 diabetes. The registry has enabled the identification of a group with high prevalence in order to help develop strategies to reduce costs of care and help with the development of early detection and care programs for type 1 diabetes.

Introduction

Background

The prevalence of type 1 diabetes is growing globally and is a major health concern worldwide; While there are excellent data concerning improved knowledge, epidemiology and management of this condition in the developed worlds, this is not the case in developing countries where the burden of the disease is still huge.(1). The access to quality care is often limited in these areas, preventing patients from achieving the level of glycemic control necessary for the prevention/delay of complications (2).

With more than half of the countries in Africa lacking high quality data sources, data to estimate the numbers of children and adolescents with type 1 diabetes remains very scarce(3). A recent study conducted in seven districts of Rwanda showed the prevalence for known type 1 diabetes for ages <26 is 16.4 per 100,000 with a mean incidence of 2.7 per 100,000 between 2007-2011(4).

The use of a diabetes registry has been recommended as an approach to improve quality of care among patients by reducing errors, improving record keeping and strengthening targeted care thereby facilitating the management of complex clinical information(5).

Establishing population-based diabetes registries is a considerable step toward collecting, analyzing, and distributing data on diabetes incidence, prevalence and complications. The registry also enables the identification of at-risk groups to guide in developing strategies to reduce the cost of disease, which will help with the development of healthcare regulations, and evaluation of prevention and control programs.(6). However, WHO reports that less than half of countries (44%) have a diabetes registry globally. Among these countries, only 14% have a population-based type registry, whereas 19% reported a hospital-based registry. In the region of sub-Saharan Africa, only 1 out of every 3 countries has a diabetes registry(7)

In the process of improving data for surveillance and quality of care, Rwanda has established a National Diabetes Registry with a type 1 pediatric subcomponent that will be created by the linkage of two routinely collected data sources at the health care facility level. The Rwanda diabetes registry will enable us to ascertain the current model of care through the collection of data for demographics, clinical information, duration of disease since diagnosis, treatment modalities, various risk factors, complications, follow up and mortality reported among diabetes patients.

A health facility based electronic registry has also been proven to provide medical teams with demographic, clinical, investigational, and management information to improve care. It can also function as a surveillance-monitoring tool for clinical and epidemiology practitioners by providing key performance indicators related to diabetes(8)

This study sought to establish a diabetes registry among pediatric and adolescents type 1 diabetes patients followed in 31 Non Communicable Diseases clinics in Rwanda.

Objective

The main objective of this project is to establish a registry of type 1 diabetes to improve Diabetes treatment outcome among pediatric and young adults patients in Rwanda.

Specific Objectives

- Describe the process of establishing type 1 diabetes registry to date.
- Describe basic core data set for all district hospitals.

Methods

Study design

This is a descriptive cross sectional study design with Quasi-experimental component that was conducted in 31 districts. We enrolled all children and young adults with type 1 diabetes who consulted for follow up since 2011.

Setting and capacity building

The Rwanda Ministry of Health developed a EMR software module that was installed in health facilities that possess the appropriate computers and servers. There were 31 out of a total of 43 district hospitals countrywide that were able to install the new EMR in their computers.

As part of this project, we conducted a one day training on the process of data entry in the capital city, Kigali, that involved nurses in charge of each NCDs clinics from the 31 district hospitals. The training was followed by two days onsite mentorship at each facility to ensure data quality.

Table: List of health care providers in charge of diabetes registry in health facilities

| | Hospital | Names |
|----|------------|-------------------------|
| 1 | Butaro | Uwineza mediatrice |
| 2 | Byumba | Uwambajimana Vestine |
| 3 | Gahini | Irakiza Bernard |
| 4 | Gisenyi | Niyonzima Prosper |
| 5 | Kabaya | Mukandori Yvette |
| 6 | Kabgayi | Ndayisaba Jean |
| 7 | Kaduha | Mbanzimana Moise |
| 8 | Kibagabaga | Murekatete Nadine |
| 9 | Kibogora | Nyiransabimana Julienne |
| 10 | Kinihira | Manzi Rehema |
| 11 | Kirehe | Gahamanyu Cyprien |

| | | |
|----|---------------|------------------------|
| 12 | Kirinda | Samvura Jean Bosco |
| 13 | Kiziguro | Nyiransengimana Rachel |
| 14 | Masaka | Nirere Rachel |
| 15 | Mibilizi | Kanamugire Alphonse |
| 16 | Mugonero | Barutwanayo Innocent |
| 17 | Muhima | Mukamuhire Bora |
| 18 | Muhororo | Mugenzi Fabien |
| 19 | Munini | Mujejimana felix |
| 20 | Murunda | Uwingeneye Louise |
| 21 | Nemba | Mugemanyi Faustin |
| 22 | Ngarama | Mbandikure Claude |
| 23 | Nyagatare | Uwiragiye Monique |
| 24 | Nyanza | Semahoro Jackson |
| 25 | Remera Rukoma | Uwingabiye Fracoise |
| 26 | Ruhango | Umwali Evangeline |
| 27 | Ruhengeri | Uwimana Margarithé |
| 28 | Ruli | Hamenyiyaremye Alexis |
| 29 | Rutongo | Ndanguye Espoir |
| 30 | Rwinkwavu | Mutabazi Francis |
| 31 | Shyira | Mahoro Jean Pierre |

Data collection and entry into the registry

Data entry into the registry was conducted in 31 districts during this phase. Data collection was conducted between February 2019 to June 2019.

All medical records of type 1 diabetes patients who were on follow up as since of January 2011 were collected and entered in a designed electronic medical record that would enable to provide a data set of all patients. Data sources include laboratory, hospitalizations, wards and outpatient clinics. Generated data sets are available and can be accessible at the server of each hospital.

Variables

The following variables were collected from registers and medical charts and entered into the registry:

1. socio demographic characteristics and clinical information from January 2011 to June 2019.

- Age
- Sex
- Family care giver
- Residence (Province, district, sector)
- Social social-economic class (ubudehe:1,2,3,4..)
- Date of diagnosis
- Hospitalization
- Signs on diagnosis
- Family History of diabetes
- Cormobidity
- Side effects
- Lost to follow up(dates)

2. Mortality from January 2011 to June 2019.

- Date of death
- Certified cause of death
- Previous blood sugar results
- Previous medication
- Previous HBA1C results
- Creatinine level
- Foot exam result

3. Glycemia control and retention to care among type 1 diabetes patients twelve months before January 2019 and twelve months after the January 2019 establishment and implementation of the Diabetes Registry.

- HBA1c results (Twelve months before and twelve months after January2019)
- Compliance with appointments (Twelve months before and twelve months after January2019)

- Adherence to medication(Twelve months before and twelve months after January 2019)
4. Compliance to with the management guideline by nurses for Insulin adjustment, foot exam, screening for kidney diseases and eye exam.
- Insulin adjustment (twelve months before and twelve months after January 2019)
 - Foot exam (twelve months before and twelve months after January 2019)
 - Screening for kidney diseases (twelve months before and twelve months after January 2019)
 - Screening for eye disease: Fundoscopy (twelve months before and twelve months after January 2019)

Participants and inclusion criteria

All children and young adults with type 1 that were followed as of 2011 up to 2019 within 31 district hospitals: Butaro, Byumba, Gahini, Gisenyi, Kabaya, Kabgayi, Kaduha, Kibagabaga, Kibogora, Kinihira, Kirinda, Kiziguro, Kaduha, Kirehe, Masaka, Mugonero, Muhima, Muhororo, Munini, Murunda, Mibilizi, Nemba, Ngarama, Nyagatare, Nyanza, Remera Rukoma, Ruhango, Ruhengeri, Ruli, Rwinkwavu, Shyira that also have the Diabetes EMR module included in the computer were included in the registry.

Type 1 diabetes was defined as all patients on insulin and whose diagnosis was made at age below 30 years.

Results

From the total number of 652 type 1 diabetic patients in the registry within 31 district hospitals, total of 182 were above the age of 25 and were not included in the analysis. A Total of 470 diabetics were eligible and included in the registry.

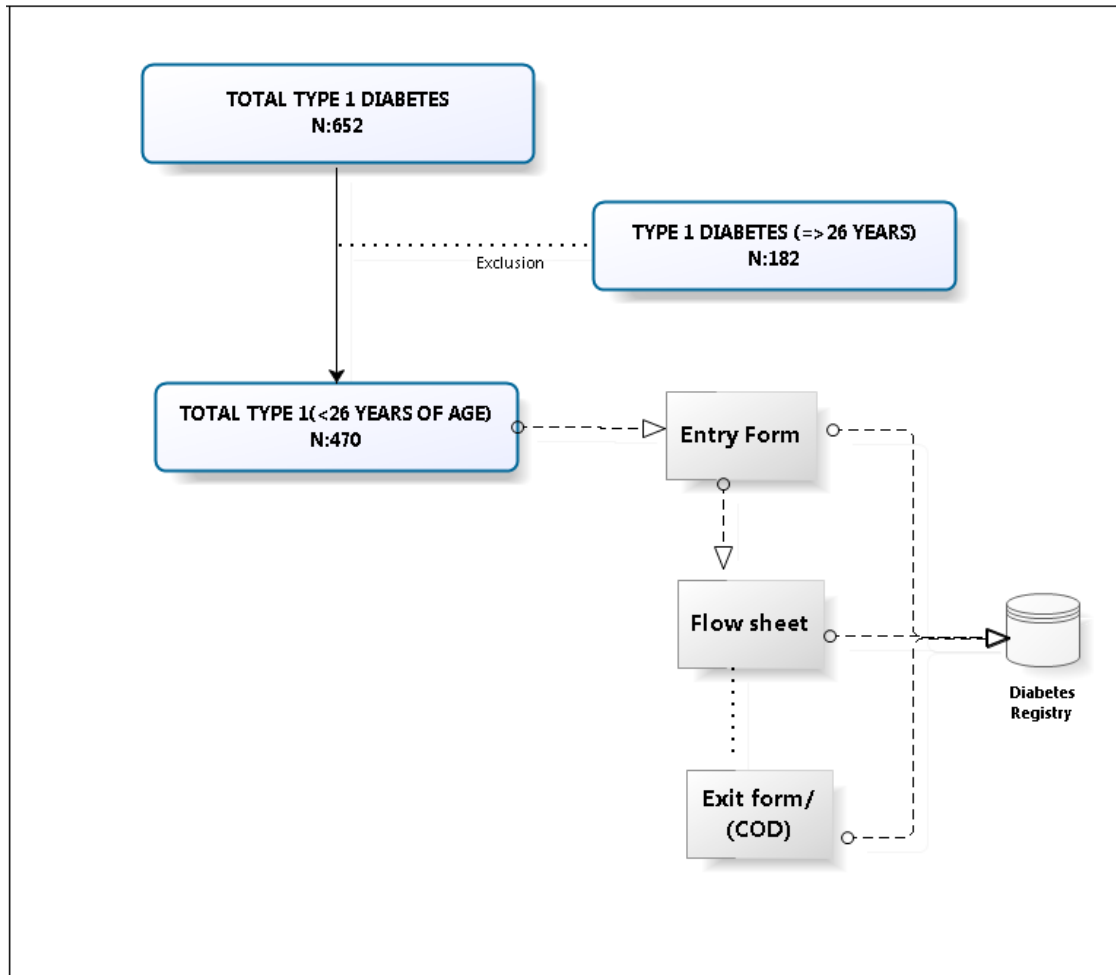
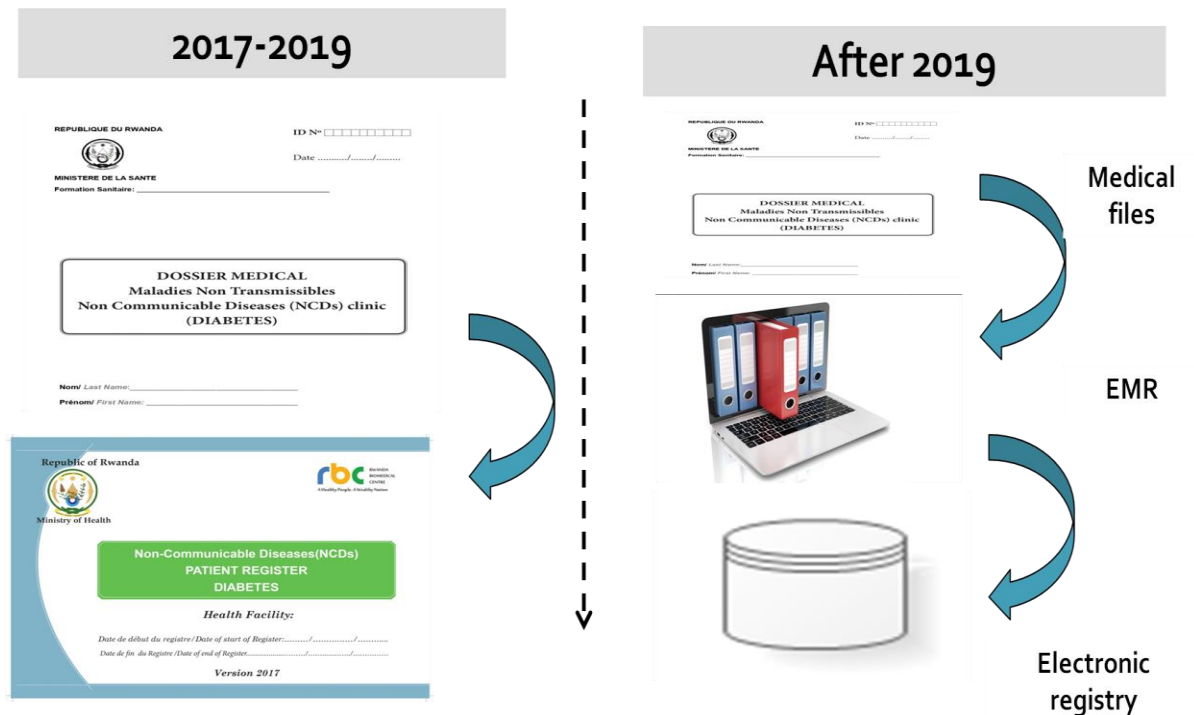


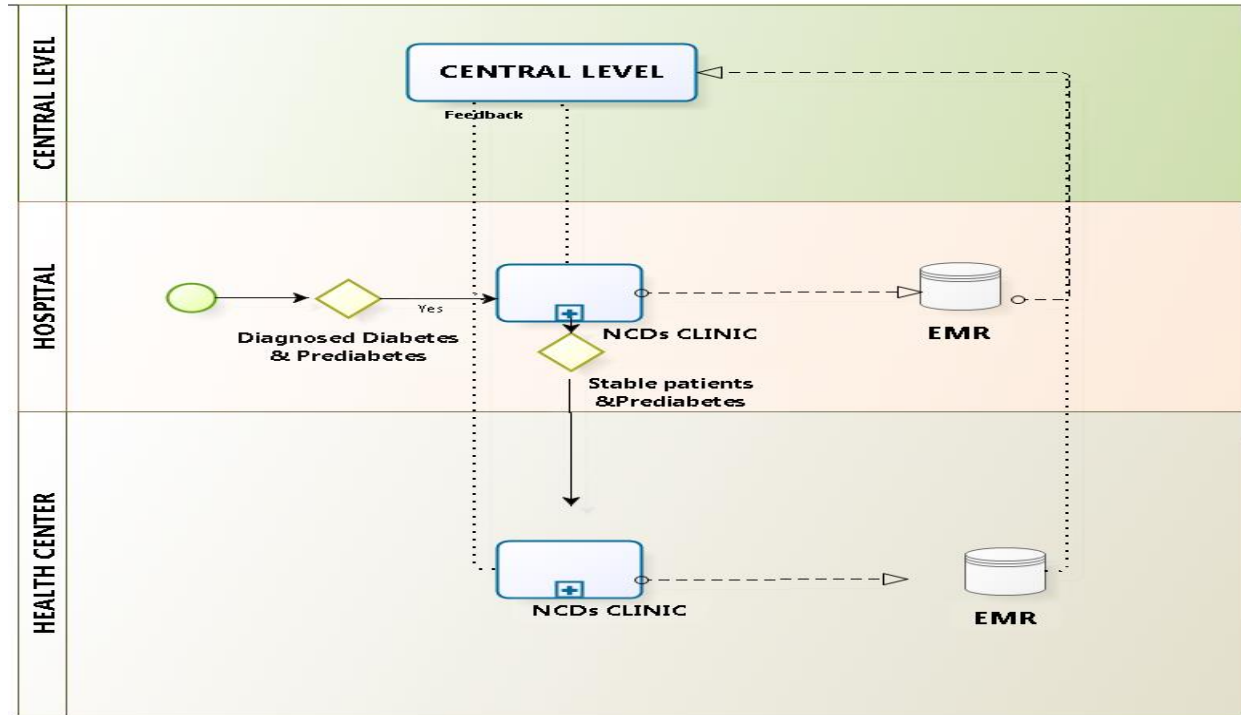
Figure 1: Type 1 diabetes patient exclusion flow for analysis

Model and process of establishing diabetes registry in Rwanda

The process of establishing diabetes registry for type 1 diabetes pediatric and young adults involved capturing retrospective patient information on follow up as of January 2011 from medical records to Electronic medical records. The shift also involves phasing out of paper based health facility registry that was established between June 2017 to Feb 2019.



The health facility diabetes registry includes information such as patient demographics, patients' unique ID, clinical characteristics, risk factors, treatment, lab results and retention to care. The Diabetes registry was created by deterministic linkage of 2 routinely collected data sources (i.e., database)



The EMR based registry has the potential to advance quality of health care by providing timely access to patients' health information records, tracking patients over time to ensure that they receive guideline-recommended care and offering decision-support mechanisms to reduce medical errors.

The Individual Medical care follow up in EMR is done by recording patient's name, Identification number, address at the village level, contact details, date of birth in an initial diabetes visit form called "donnee de base". Detailed diabetes history includes date of diagnosis, and associated diseases. Social history, including smoking, education level, marital and socio-economic status, is also recorded.

Kirehelab test IMB Primary Care Registration ID: **42407P9Y-6**

4 yrs (~ 26-Jul-2015) Health Center: **Kirehe Hospital**

BMI: ? (Weight: , Height:) CD4: | Regimen:

Last encounter: **ASTHMA VISIT @ Kabarondo Health Center, 26-Aug-2019**


-

Enter Form

| Name | Version | Encounter Type |
|--|---------|----------------|
| NCD DIABETES FLOW SHEET | 1.0 | DIABETES VISIT |
| NCD Diabetes: Diagnosis and Problems | 0.1 | DIABETES VISIT |
| NCD Diabetes: Enrollment form | 1.0 | DIABETES VISIT |
| NCD Diabetes: Insulin List | 0.1 | DIABETES VISIT |
| NCD Diabetes: Medication List | 0.1 | DIABETES VISIT |
| NCD Diabetes: MedicationExam | 0.1 | DIABETES VISIT |
| NCD Diabetes: Other Investigations | 0.1 | DIABETES VISIT |
| NCD Diabetes: rendez-vous | 0.1 | DIABETES VISIT |

Search: Include Retired

At each consecutive visit, a diabetes form called “Fiche de Suivi de Diabetes” is filled out with clinical values such as height and weight (EMR generates BMI) in the patient record. Other recorded values during visits are blood pressure (every visit), fasting blood sugar, random blood sugar(every visit), and glycated hemoglobin (every quarter) . Laboratory measurements are also entered with urinalyses for protein. Additional information on insulin and oral agents is also recorded, as well as chronic complications and foot exam. EMR also provides a system of clinical reporting for patient follow up.

| | | | | | | | | | | | | |
|---|----------------------------|--|----------------------|-------------------------------|--|--------------------------------------|----------------------|----------------------|----------------------------------|--|--|--------------------------------------|
|  REPUBLIC OF RWANDA MINISTRY OF HEALTH | | RENDEZ-VOUS / CLINIC VISITS IMB ID: [42407P9Y-6] Nom / Last name: test Prénom/ First name: Kirehelab | | | | | | | | | | |
| Clinique / Clinic: <input type="text" value="Choose a Location..."/> | | Date: <input type="text"/> (dd/mm/yyyy) Provider: <input type="text" value="Choose a Provider"/> | | | | | | | | | | |
| RENDEZ-VOUS / CLINIC VISITS | | | | | | | | | | | | |
| Poids/ Weight | Taille/ Height | T.A/BP | Pouls/ Pulse | Protein urie | Glycemie | HbA1c | Na (SERUM SODIUM) | K (SERUM POTASSIUM) | Créatinine and clearance | Compliance/ Adherence | Pieds/ Feet | RDV |
| <input type="text"/> | <input type="text"/> cm | <input type="text"/> mmHg | <input type="text"/> | <input type="text"/> mg/dl | <input type="text"/> mg/dl ○ F ○ R | <input type="text"/> % | <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="radio"/> oui/yes <input type="radio"/> non/no | Sensation: D/R: <input type="text"/> /6 D/L: <input type="text"/> /6 Plaies/sores <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="text"/> (dd/mm/yyyy) |
| Episodes d'hypoglycémie(Meme aujourd'hui/ History of Hypoglycemic episodes including today: <input type="checkbox"/> oui/yes <input type="checkbox"/> non/no Quand?/When?: <input type="checkbox"/> le matin/morning <input type="checkbox"/> l'après midi/Afternoon <input type="checkbox"/> le soir /evening A manqué de nourriture?/Lacked of food? <input type="checkbox"/> oui/yes <input type="checkbox"/> non/no | | | | | | | | | | | | |
| Note: Lab. tests according to protocol Glycemie: F=Fasting/ A jeune R=random/ Aleatoire | | Section pour Commentaires/Comment Section <input type="text"/> | | | | | | | | | | |
| Pain evaluation | | | Physical | | | Psychological (if applicable) | | | Spiritual (if applicable) | | | |
| Score(0-10) | | | <input type="text"/> | | | ○YES ○NO | | | ○YES ○NO | | | |
| Comments <input type="text"/> | | | | | | | | | | | | |

There are system-generated reports such as a consultation sheet and a Late Visit report which contain patients identifiers, their latest visit dates, key results and Diabetes medications, as well as alerts reminding clinicians to take action. The system also generates aggregate reports of key indicators related to volume and characteristics of diabetes patients, treatment, ongoing care, and outcomes.

**NCD Program
Diabetes Quarterly Clinical Report**

Start Date: 01/Apr/2018
End Date: 30/Jun/2018
Location: Rwinkwavu Hospital

| Number | Indicator | Values |
|--|--|----------------------|
| A Volume & Characteristics of patients | | |
| A1 | Total # of patient visits to DM clinic in the last quarter | 289 |
| A2 | % of newly enrolled patients in the last quarter | 0.90% 111 |
| A3 | Total # of patients ever enrolled | 206 |
| A4 | Percentage of active patients | 94.07% 111 118 |
| A5 | Proportion of all active patients with age < 27 years | 14.41% 16 111 |
| A6 | Proportion of all active patients with age < 16 years | 1.80% 2 111 |
| A7 | Of all active patients, % male | 44.14% 49 111 |
| Total active patients disaggregated by BMI category | | |
| A8 | Underweight | 7.21% 8 111 |
| | Normal | 46.85% 52 111 |
| | Overweight | 25.23% 28 111 |
| | Obese | 9.01% 10 111 |
| A9 | Proportion of patients ever enrolled who are currently enrolled | 57.28% 118 206 |
| A10 | % of all patients who were seen in the last year who died in the reporting period | 0.00% 0 112 |
| A11 | % of patients who completed their program during the period who did not die and who were not lost to follow up | 0.00% 0 1 |

| Number | Indicator | Values |
|------------------------------------|--|---------------------|
| B Treatment , Ongoing care. | | |
| B1 | Of total active patients, % who had Urinary Albumin tested at least within 12 months of the end of the reporting period. | 43.24% 48 111 |
| B2 | Of total active patients, % who had Creatinine tested at least within 12 months of the reporting period | 77.46% 86 111 |
| B3 | Total active Diabetes patients who enrolled at least 3 months before the end of the reporting period, % of who had HbA1C documented in the Q | 70.27% 78 111 |
| B4 | % of active patients on oral therapy only | 36.04% 40 111 |
| C Outcomes | | |
| C1 | Of total DM active patients, % with a visit in last 12 months but no visit within last 6 months. | 4.50% 5 111 |
| C2 | Of all active patients with HbA1c tested in the last 6 months, % with last HbA1c <= 8.0% of all active for the Q, % hbA1C <= 8% | 63.92% 62 97 |
| C3 | of active patients and creatinine checked in past 12 months, % with Cr > 200 at last visit | 0.00% 0 86 |
| C4 | Of total DM active patients with blood pressure checked at last visit date, % with BP <= 130/80 mmHg | 36.04% 40 111 |
| C5 | Of patients currently enrolled, % Lost to follow up | 5.93% 7 118 |

Basic core data set for all district hospitals

Distribution of type 1 diabetes patients (<26 years) by Health facilities

Figure 1 shows distribution of registered type diabetes patients by health facilities; In total 470 type 1 diabetes cases (<26 years) were identified in 31 district hospital and patients entered in the Diabetes registry from Butaro(N=11), Byumba(N=21), Gahini(N=6), Gisenyi(N=21), Kabaya(N=8), Kabgayi(N=59), Kaduha(N=9), Kibagabaga(N=6), Kibogora(N=21), Kinihira(N=8), Kirinda(N=24), Kiziguro(N=26), Kaduha(N=1), Kirehe(N=14), Masaka(N=4), Mugonero(N=5), Muhima(N=6), Muhororo(N=25), Munini(N=27), Murunda(N=11), Mibilizi(N=5), Nemba(N=17), Ngarama(N=11), Nyagatare(N=9), Nyanza(N=21), Remera Rukoma(N=25), Ruhango(N=12), Ruhengeri(N=12), Ruli(N=4), Rwinkwavu(N=16), Shyira(N=9).

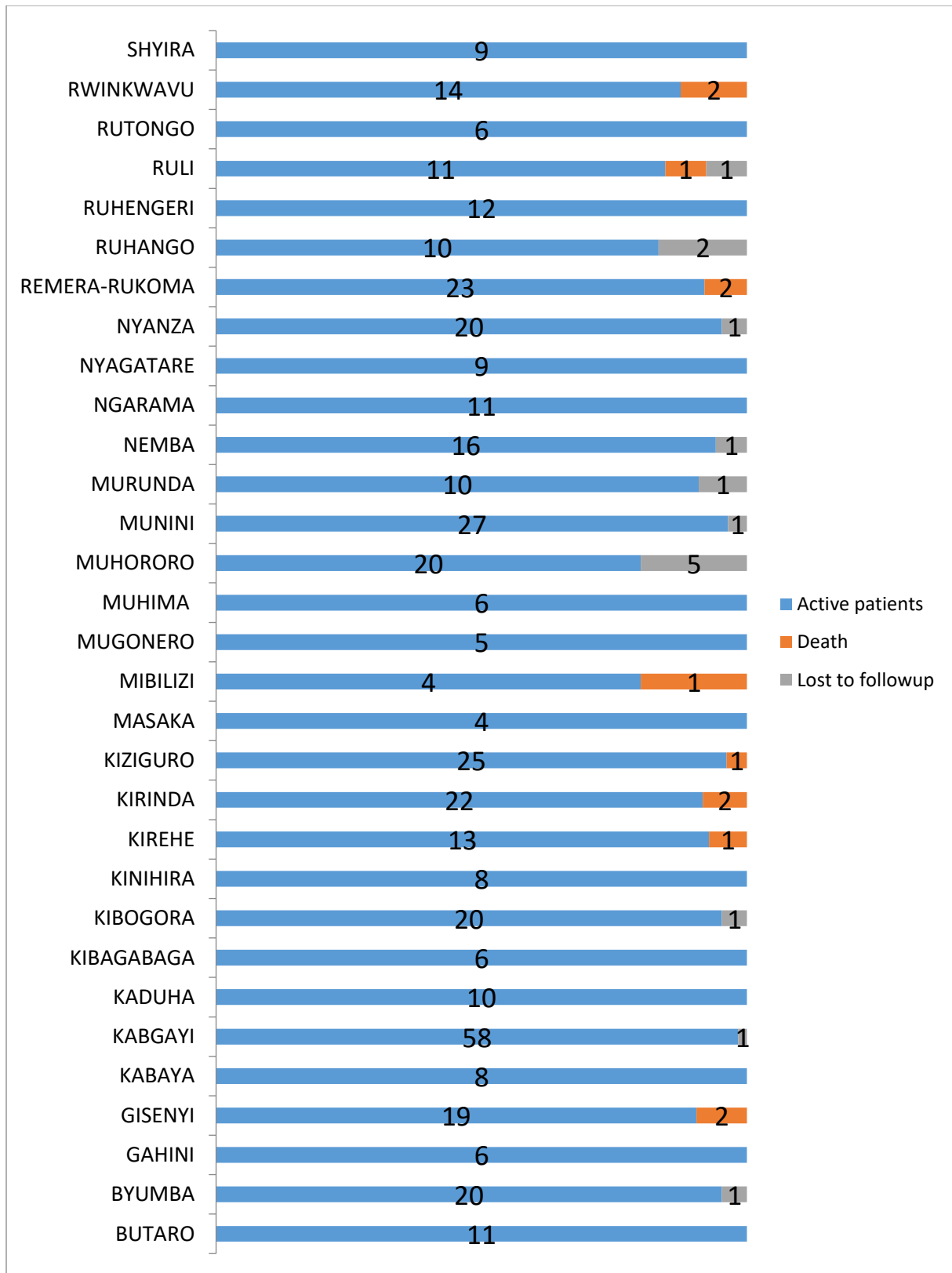


Figure 2. Distribution of type 1 diabetes patients (<26 years) by Health facilities as of June 2019

Distribution of type 1 diabetes patients (<26 years) by Sex

Figure 2. Shows distribution of type 1 diabetes patients(<26 years) by sex, Of the total registered type 1 patients 57%(272) were Female while male were 43%(198).

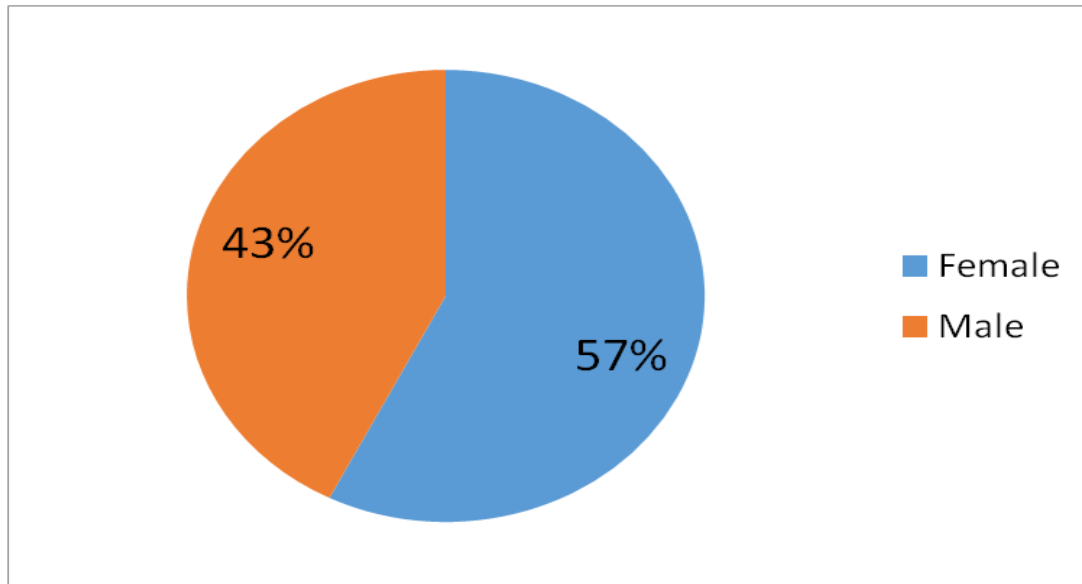


Figure 3. Distribution of type 1 diabetes by sex

Distribution of type 1 diabetes patients (<26 years) by Age category

Figure 3. Shows distribution of type 1 diabetes patients (<26 years) by age category. Among the total registered type 1 patients, Age group 16-25 were predominant at 86.6%(407); Age category between 6 and 15 years was at 12.5%(59) while the age category between birth and 5 years was at 0.8%(4).

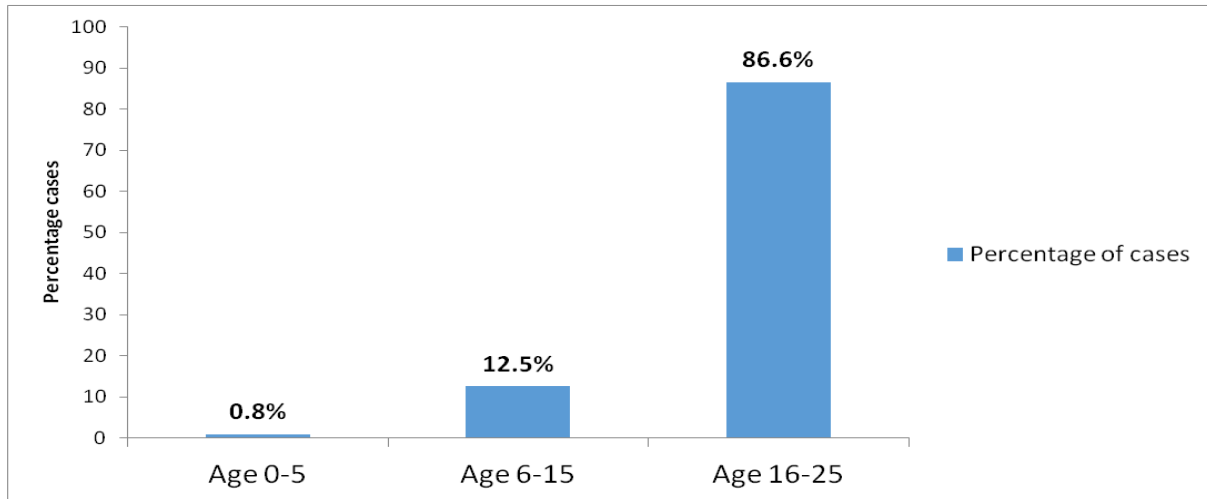


Figure 4. Distribution type 1 patients by age category as of June 2019

Distribution of type 1 diabetes patients (<26 years) by Age at diagnosis

Figure 4. Shows distribution of type 1 diabetes patients (<26 years) by age of diagnosis. Among the total registered type 1 patients, the largest proportion of type 1 patients were diagnosed at the age between 16-25 with 62.7%(255), those diagnosed between age category 6-15 were at 32.2%(131) and patients diagnosed between 0-5 were 5.2%(21).

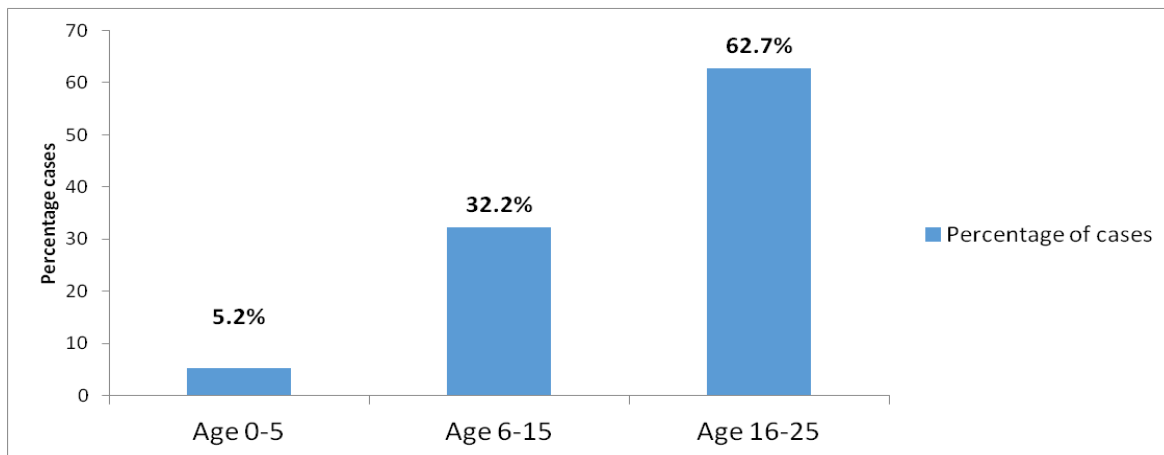


Figure 5 Distribution of type 1 patients age at diagnosis by June 2019

Distribution of type 1 diabetes patients (<26 years) by socioeconomic class

Figure 5. Shows distribution of type 1 diabetes patients (<26 years) by social economic class with class 1 as a group of people who are in families that earn less and class 3 are the group of people with higher income. Most of type 1 patients are in social economic class two 38.7%(164) with a slight difference to class three 35.9% (152) and class one 25.2% (107).

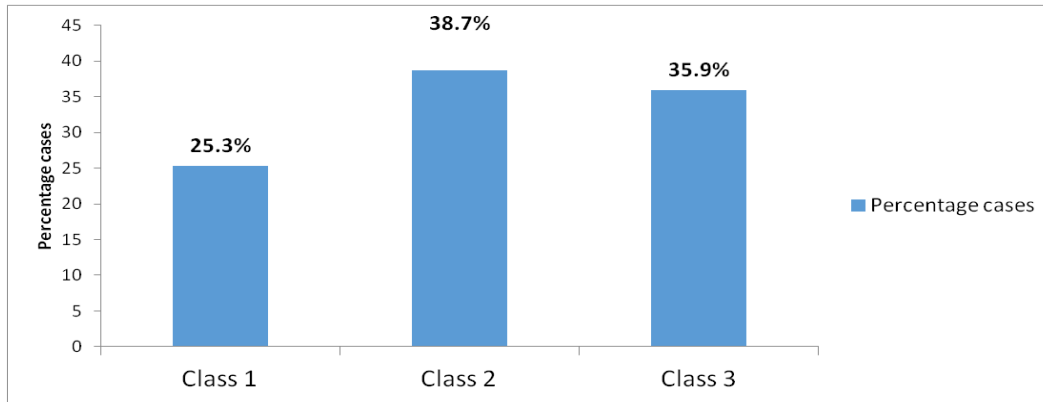


Figure 6. Distribution of type 1 patients by social economic class

Trend of new and cumulative cases of type 1 diabetes between 2011-2019.

Figure 6 shows the trend of type 1 diabetes, new and cumulative cases. There has been an increase of new cases over time in which 11 new cases were recorded in 2011 and 67 cases in year 2018. A Steady increase of cumulative cases was recorded between 2011 to and 2019 from 40 cases to 387 cases respectively.

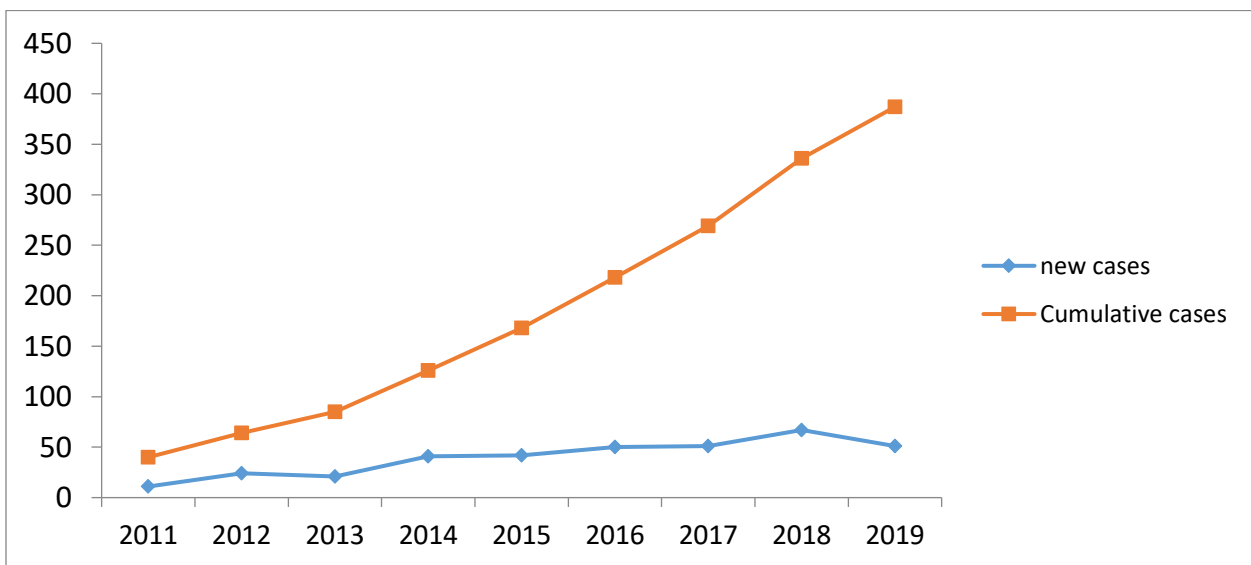


Figure 7. Trend of type 1 diabetes (<26) new and cumulative incidence 2011-2019

Distribution of last HBA1c among type 1 diabetics

Figure 7. Shows distribution of last glyceimic control as evidenced by HBA1c among type 1 diabetes patients (<26 years).

More than two thirds 77% (95%CI: 71.8-81.7) had HB1AC>7% and the mean A1C was 9.4 (95% CI:9.1-9.7).

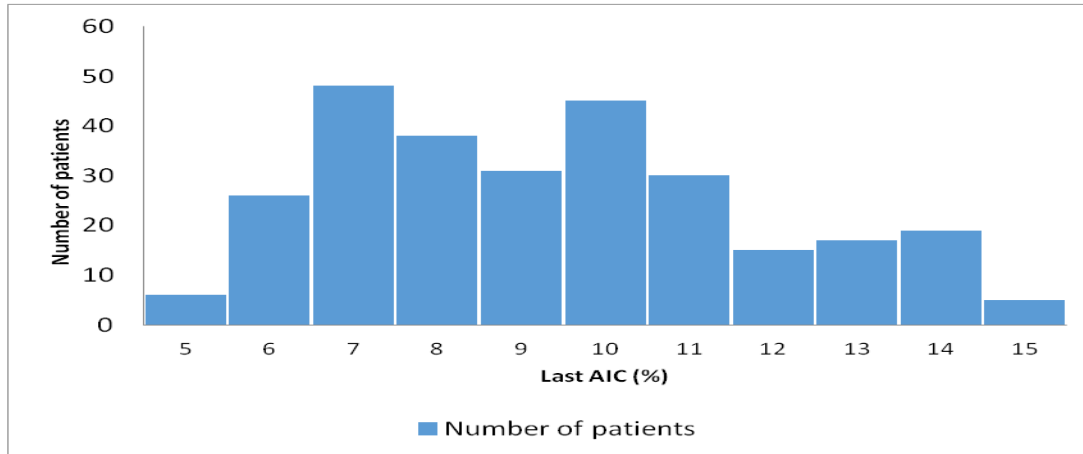


Figure 8 Distribution of last A1C among type 1(<26 years of age)

Discussion and conclusion

The established registry has the ability to improve quality of health care by providing timely access to patients' health information records, tracking type 1 diabetes patients and providing alerts to remind health care workers to provide guideline-recommended care and offering decision-support mechanisms to reduce medical errors. The established registry can capture patient demographic, patients' unique ID, clinical characteristics, risk factors, treatment, and lab results and patient movement between health facilities. Components of this registry are comparable to features for successful implementation of diabetes registry by Gabbay et al that described similar clinical features as the established registry(9).

The established diabetes registry for type 1 paves the way to address the gaps in identifying diabetes patients, demographic characteristics, at risk group and geographic dispersion(6). The use of a diabetes registry is a crucial step towards distributing epidemiological data of type1 diabetes in Rwanda.

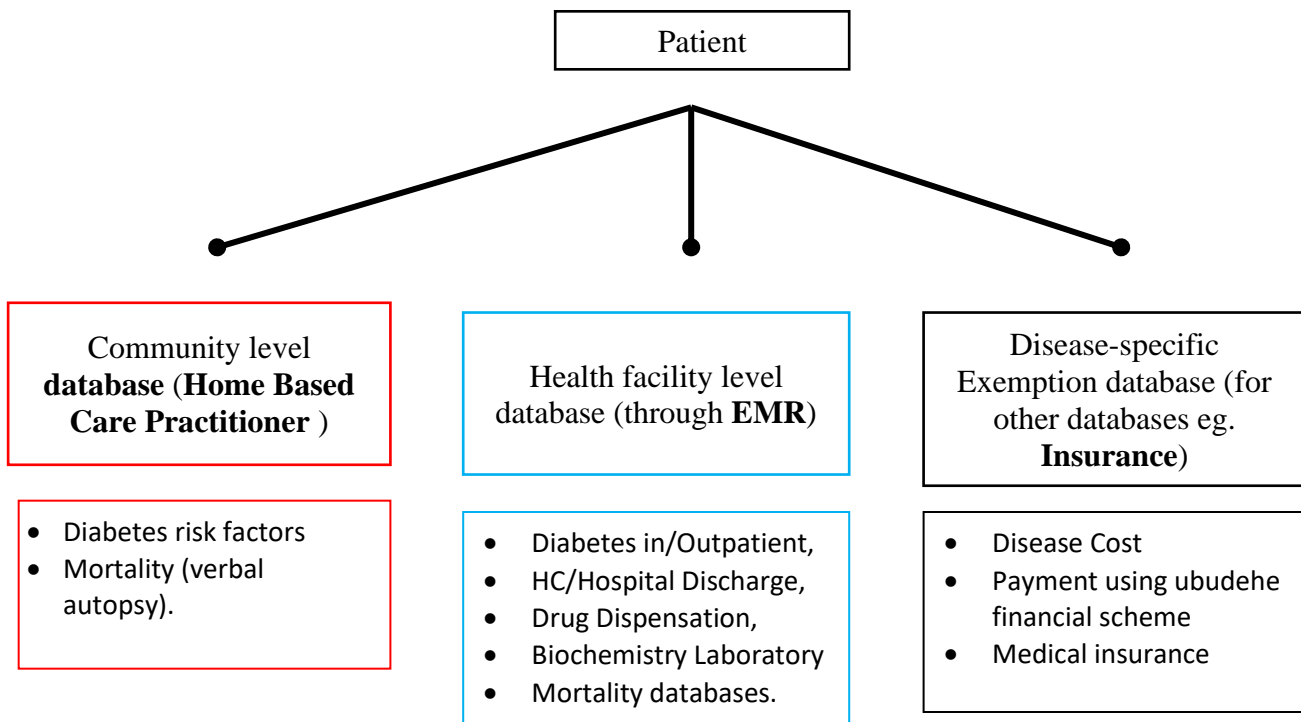
Limitations

During the establishment of diabetes registry and data entry, Following few challenges were encountered.

- There is not one unique ID for each patient to enable tracking that individual from one health facility to another.
- There is Paucity of data available before 2019 when EMR came in general use
- There are many important missing information in medical files with only 64%(n:177) patients with records of previous HBAIC, 86.6%(n:407) records of age of diagnosis and cause of death that need to be entered in the registry.

Way Forward

- I. Following the establishment of the diabetes registry, we will
 - Assess the epidemiology and short term mortality of children and young adults with type 1 diabetes.
 - Assess the effect of electronic diabetes registry in improving quality of care of children and young adults with type 1 diabetes.
- II. The linkage of the community based database through home based care program, health facility data will be a crucial step to ensure all data is well captured including death occurring at community level. With the existing Home based care practitioners platform, the Community based database monitors information related to diabetes risk factors and cause of death (Diabetes) using verbal autopsy.



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