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Improving cancer data availability within routine reporting systems in a low-income setting; The Case of Mbarara Regional Referral Hospital, Uganda

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Background and purpose: Worldwide, an estimated 19.3 million new cancer cases and almost 10.0 million cancer deaths occurred in 2020. In the same year, 801,392 new cancer cases and 520,158 cancer deaths occurred in sub-Saharan Africa where cancer survival is even disproportionately lower. In Uganda, there is limited knowledge about the usability levels of national electronic reporting systems with patient-level cancer data. Such data guide operational planning, track progress and performance over time, evaluate and understand cancer risk factors, study phenomena, explore relationships, test hypotheses, or draw meaningful conclusions. This study intended to fix the knowledge gap on the usability level of a routine electronic reporting system using standard tools.
Objective: To determine the usability of the developed reporting system at a cancer unit in a low-resource setting.
Methods: This observational study used a design science approach, configuring the Maintenance application and Tracker domains in DHIS2 version 2.40.3. Sixteen users participated in the study. The usability of the built cancer registry was determined using the system usability scale (SUS).
Results: 16 out of 21 staff achieved a mean SUS score of 72.34 (SD 11.23), a 76.19% response rate. Most respondents were male (12 out of 16, 75%) and had a mean age of 30.81 (SD 7.4).
Conclusions: A web-based DHIS2 instance improved access to comprehensive cancer data, demonstrating high usability. This system needs to be scaled to the remaining 15 regional hospitals, utilize prospective data in future studies, and conduct pre-training to enhance user engagement.

Keywords: Cancer, system usability scale (SUS), retrospective studies, Internet, prospective studies, electronic reporting systems.

1 Introduction

Cancer – a disease characterized by uncontrolled division of cells in a body part – is an increasing public health burden [1], [2], [3]. Worldwide, an estimated 19.3 million new cancer cases and almost 10.0 million cancer deaths occurred in 2020 [4], [5]. In that year, lung cancer was the leading cause of death before the age of 70 years in 112 of 185 countries while female breast cancer was the most commonly diagnosed cancer among new cases in a further 23 countries [4]. In that year alone, 801,392 new cancer cases and 520,158 cancer deaths were estimated to have occurred in sub-Saharan Africa [4]. Worryingly, cancer survival was disproportionately lower in sub-Saharan Africa than in the rest of the world regions [6]. In Uganda, cervical cancer was the leading cause of high cancer rates per year among women at 47.5 per 100,000 in 2020, likely due to the high prevalence of human papillomavirus, low screening rates mostly in urban areas, changes in population dynamics, lifestyles, etc [7], [8]. This is far from the 2030 global targets of reducing mortality from non-communicable diseases by a third and reduction of illnesses and death from hazardous chemicals and pollution [9]. However, cancer is neither a reportable nor notifiable disease in Uganda despite a rising burden [7], [10].

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In an ideal scenario, patient-level data should be integrated into a routine reporting system [11], [12], [13]. The data generated guide operational planning, track progress and performance over time, and strengthen accountability for better results [14], [15]. Such data are also used to evaluate and understand cancer risk factors, study phenomena, explore relationships, test hypotheses, and draw meaningful conclusions [16]. However, in Uganda, there is limited knowledge about the usability levels of the nationally approved electronic reporting system for comprehensive cancer data [17], [18]. In this study, usability is defined as how usable DHIS2 (District Health Information Software version 2) software is towards the intended purpose of making cancer data available in a routine reporting system [19], [20], [21]. Whereas there is no electronic system (DHIS2) at the Mbarara Regional Referral (RRH) System for reporting cancer, only 4% of the data is available nationally in aggregate form within the running DHIS2 platform, covering merely eight cancer types out of the over 200 types that exist globally [22], [23]. Consequently, it is challenging to determine patient care indicators for cancer at various levels of the healthcare system, assess potential risk factors, and formulate national cancer policies [8]. This study used software very similar to the nationally approved DHIS2 software, facilitating feasible integration and sharing of the cancer data [24], [25].

Meanwhile, other electronic systems such as health management information systems (HMIS), CANREG, etc have supported patients in cancer treatment in some countries but not Uganda [20], [26], [27]. The barriers to the limited use of these systems in Uganda include lack of local ownership and accountability, lack of health worker competence in e-health, poor interlinkages among existing systems, reliance on donor funding which is volatile, lack of proper implementation frameworks, poor health worker attitudes, lack of intuitive user interfaces, etc [14]. This study's cancer registry system built aimed at improving patient-level cancer data available. It also solves the issue of interoperability with the existing national information system since both have DHIS2 as the core software. Therefore, it is easier to work across both systems seamlessly such as the exchange of data or reports from one system to the other. The system improves health worker competence through the use of open-source software with an intuitive user interface. Whereas the usability of a medical system or device is vital and mandatory [28], there is limited knowledge on the usability level of routine information systems with patient-level cancer data in a low-resource setting such as Uganda [11]. Multiple studies have focused on data quality within DHIS2 with few or no studies on the usability of that system in low-income settings [29], [30], [31], [32]. Even for the few implemented systems in low-income countries like Uganda, there are reports of usability challenges hence different usability is expected [19]. Therefore, this study determined the usability level of DHIS2 in a regional public health facility without an electronic information system.

2 Materials and methods

2.1 Study location:

This study was conducted in Uganda, a low-income, landlocked country in sub-Saharan Africa. It is located between 1° N and 4° N latitude, and 30° E and 35° E longitude, sharing borders with South Sudan, Kenya, Tanzania, Rwanda, and the Democratic Republic of Congo. As of July 2023, Uganda had 146 districts and 10 cities, with Kampala as the capital. The districts operate under a decentralized governance system across four regions: Northern, Eastern, Central, and Western, where Mbarara Regional Referral Hospital is situated [33].

2.2 Characteristics of Study Site:

Mbarara Regional Referral Hospital (RRH) was the study site because there was a functional cancer unit that lacked an open-source cancer electronic reporting system. The RRH is in Mbarara City, Ankole sub-region, and is located within the central business district of the city [34]. This is approximately 268 kilometres (167 mi), by road, southwest of Mulago National Referral Hospital, in Kampala, the capital city of Uganda. It is the referral hospital for that region serving but not limited to the districts of Bushenyi, Ibanda, Isingiro, Kiruhura, Mbarara, and Ntungamo. The hospital serves as the teaching hospital for Mbarara University of Science and Technology [35]. The implementation was carried out at the Uganda Cancer Institute (UCI) Mbarara unit located within the hospital. It is supervised by UCI

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Kampala and the Ministry of Health (MOH) [36]. It is divided into two sections: children (pediatric oncology) and adults (adult oncology).

2.3 Study design:

This was an observational study with a design science approach [37] carried out from 1st May – 31st July 2024. The setup of the cancer registry included downloading and installing open-source health information software (DHIS2 version 2.40.3) [38]. It was hosted virtually on the Google Cloud servers [39] despite the drawbacks of cloud storage [40] and was available at https://robertm.codezoneug.com/rob/

While using the Maintenance application and Tracker domain in the DHIS2 platform, design changes were made in the configuration layer to develop a data entry form similar to what has been used in most African cancer registries to capture cancer data [31], [41], [42], [43]. The cancer notification form [43] provided the use-case from which the tracked entity attributes (data elements or variables), option sets, and options were identified and associated with the program under design. The metadata setup of the DHIS2 instance was composed of the option sets, data elements, and data element groups, which were added to the created program. From this stage, a Tracker program entry form was created according to the format of the use-case. Meanwhile, a standard coding reference book for oncology (ICD-O-3) was selected and uploaded to provide the disease coding options for data elements morphology and primary site of tumor [44]. The use-case used in this study was adapted from the form being used at the Kampala cancer registry and it contains forty-six (46) variables [7], [43]. These variables were organized into five frames, which are patient, tumor, treatment, source of information, and follow-up. The patient frame or stage had 19 variables and these are ID number, given name, surname, date of birth, age, sex, usual residence address (with variables zone, village, parish, sub-county, county, and district), patient or next-of-kin telephone number, LC1 leader name/telephone number, religion, ethnic group, occupation, education, and marital status. The tumor frame or stage had seven (7) variables, which were date of incidence, basis of diagnosis, primary site of tumor, morphology, and stage. The treatment frame had four (4) variables that included surgery, radiotherapy, chemotherapy/hormone therapy, and others while the source of information stage had institution/ward, case number, laboratory, and lab number as variables. The fifth frame (follow-up) had nine (9) variables which included date of last contact, status at last contact, cause of death, form filled by, data entered by, date, and signature. To maintain consistency, options sets were allocated their respective variables and such variables included sex, the basis of diagnosis, treatment, status at last contact, and cause of death. Some of their options included 1 = male, 2 = female, 9 = not known, 0 = death certificate only, 1 = clinical only, etc. The enrolment date and cancer registry number preceded the frames on the final data collection form. The metadata was assigned respective sections on the data collection form after which they were registered into the program stages. Thereafter, the program was assigned to specific organization units, i.e. Uganda Cancer Unit (UCI) Centre Mbarara Regional Referral Hospital, UCI Kampala, and Mulago Specialized National Referral Hospital. Sharing settings were then applied to the users and user roles created previously. User access was limited through password controls to maintain confidentiality and privacy [45]. A pilot run of the instance was conducted at UCI Mulago.

The instance was installed on a computer in the data room at UCI Mbarara from where cancer records were entered and validated [46]. Since the paper records have very sensitive and personal information, the clinic management purposively selected and provided access to only those paper records of 104 cancer patients enrolled in FY 2023/2024. Data from these records was entered in the instance by the clinic staff. This sample size provided was within the range of 100 – 400 records as used in survey studies involving information studies [47]. A larger sample size like this one improves the credibility and validity of the findings unlike previous usability studies involving DHIS2 which had varying and less sample sizes [19], [48]. Analysis and visualization of entered data was conducted by the researcher concurrently with the clinic staff using the Data Visualizer app within DHIS2 and the dashboard. The data visualizer app was used to create, edit, manipulate, share, and/or download the entered comprehensive cancer data according to period and organization units [49]. Examples of data visualizations included line charts, pivot tables, column charts, bar charts, scatter diagrams, pie charts, etc. This demonstrated the practical usability of a system that met the key aspects of cancer care and data availability, including reviews and downloads of entered data at UCI Mbarara [41]. The author and each of the 16 staff rated and reviewed the 104 records of the new cancer cases in the system. A questionnaire was digitized using KoboCollect software and

administered to smartphones of 16 consenting users at the center to determine the system usability score (SUS) [50].

In this study, usability is defined as the extent to which the DHIS2 instance could be used by the clinic staff to attain the availability and accessibility of patient-level cancer data with effectiveness, efficiency, and satisfaction at UCI Mbarara [51]. The author used the system usability score (SUS) to measure the extent of the instance's usability since it has been used in previous usability studies within Uganda [19], [20], [21], [52]. The SUS is a simple and effective tool that measures the perceived usability of a system in real-time. It is a 5-point Likert questionnaire with 10 questions. Each question scores a maximum of 10 points when normalized by a factor of 2.5 [19]. The SUS total scores range from 0 to 100, they are not percentages nor percentiles, and high scores indicate better usability of a system. SUS scores above 80.3 are graded A and considered excellent while scores in the range 68 – 80.3 are good and graded B. SUS score 68 is considered okay and graded as a C, scores in the range 51 – 68 are poor while scores below 51 are worse and graded F. Software systems with scores below 68 are considered unusable [53]. The study aimed to have at least a mean SUS score ≥ 68 for an optimal system to be considered usable for a sample size of at least 15 participants [54]. Some of the other benefits of SUS include providing a quantitative measurement, enhancing user-centered evaluation, promoting consistency, offering speed and simplicity, ensuring user feedback, and aiding resource allocation [54].

The dataset obtained was downloaded as a CSV file from which the SUS was calculated using the formula stipulated by [54]. In it, SUS was calculated as stated; Y was 25 minus the sum of all points for even-numbered questions while X was the sum of all points for odd-numbered questions minus 5. The sums of all points for even-numbered questions and odd-numbered questions were calculated for each respondent and thereafter used to calculate Y and X. Therefore, SUS is the product of (X + Y) * 2.5 from which product the mean SUS, standard deviation, and 95% confidence interval are calculated from all the respondents [52].

2.4 Ethical Considerations:

The study was approved by the Research and Ethics Committee of Makerere University School of Public Health (MakSPH-REC) under protocol number 347 on 27th March 2024 and even provided an introduction letter valid for one year. The letter delineated the study purpose and was thereafter presented to the Uganda Cancer Institute and Mbarara Hospital administration, which granted permission to conduct the study and access to the patient's records. Consent was provided by the clinic management to utilize some patient records for the study as per the current national data protection and privacy regulations [45]. Also, informed consent of patients was not sought much as the law covers for collection of de-identified and limited personal data for research purposes. However, informed verbal consent was sought from the study participants (staff at UCI Mbarara) before carrying out the study with nobody withdrawing at any stage thereafter.

3 Results

3.1 Characteristics of Study Participants and Site:

The study participants were staff at the UCI Mbarara in the pediatric and adult oncology units. Out of the total staff (21) available then and interacting with cancer data, 11 staff were nurses, and nine of them were in the pediatric section. All the 21 staff interact with cancer data daily, and these were purposively selected to participate in the study. The center is supported occasionally by postgraduate student doctors, nurses, and interns from Mbarara University who rotate in the unit. On average, the new cancer cases were 15-20 monthly among children and about 100 among adults. The cancer deaths were about 5 -7 deaths per month among children and about 25 – 30 deaths monthly among adults [55]. This unit had a paper-based record system, with records being kept in two secured data rooms. With consideration for confidentiality and privacy, the unit management purposively selected and granted access to 104 records of new cancer cases for entry and validation into the instance [47]. The inclusion criteria included records of new cancer cases registered for the period 1st April – 30th June 2023, active for the financial year (FY) 2023/24, included all age categories, and had been filled. The exclusion included records not entered, such as those declined

access, inactive, dead, lost-to-follow-up, incompletely filled, and files of other months that were in circulation during clinic visits of the patients at the time of research.

3.2 Performance of the developed DHIS2 instance:

The instance configured and labeled as Mbarara Cancer eRegistry produced data visualizations as dashboards consisting of several chart types such as pie charts, pivot tables, graphs, line lists, etc. Each chart could be modified using the internal Data Visualizer app. The built system or cancer registry showed an ability to enter and validate more cancer records, though the study was limited to just >100 but less than 400. This sample size was in line with the survey findings of sample sizes of studies conducted for information systems. The minimum threshold was 100 entries while the maximum threshold was not exceeding 400 entries to produce valid results [47]. However, some usability studies involving DHIS2 have used smaller and varying sample sizes [19], [48] unlike this study which had a larger sample size. This study entered 104 records of new cancer cases in the inclusion period. Data entered could be shared or extracted in three formats, either as Graphics (in the form of images as .png files and/or PDF format) as plain data sources (in the form of JSON, XML, Microsoft Excel, CSV), or as advanced (as data value sets, JRXML, raw data SQL) [31]. Since this was sensitive and personal information, data captured was secured at different levels using user names and passwords to control and secure access [45].

3.3 System Usability Score (SUS) of the developed instance:

Sixteen (16) out of 21 answered the SUS digital questionnaire and produced a 76.19% response rate. The majority of the respondents (75% i.e. 12 out of 16 respondents) were male, with a mean age of 30.81 and a standard deviation of 7.4 [56], [57]. Due to technological difficulties in answering a digitalized questionnaire, five staff declined to respond and these were not included in the analysis of the responses.

Following the formulae stipulated in section 2.3 above, the instance scored an average SUS of 72.34 which is higher than the target mean score of 68 for a system to be usable [28], [47], [54]. The standard deviation was 11.23, and the 95% confidence interval was 72.34 ± 5.51 (±7.61%) (Maple Tech 2024a). This means the developed instance had a moderate usability level above the target threshold. With an overlap between the confidence interval and mean score obtained, the results had no statistical significance.

4 Discussion

A web-based DHIS2 version 2.40.3 was configured and customized to a patient-level cancer instance. It was able to capture and validate cancer records. The instance produced a mean system usability score (SUS) of 72.34 at a 76.19% response rate and various visualizations. The standard deviation was 11.23 and a 95% confidence interval of 72.34 ± 5.51 (±7.61%). The instance performed beyond expectations as evidenced by the high usability score obtained for that new system, as compared to a minimum expected target of 68 for a usable system.

These results are consistent with similar research carried out in Iran by Jamshidi et al. in the year 2022 and a 2021 Guinea study by Eggers et al [46], [58]. In both situations, DHIS2 instances were developed and utilized successfully for bone cancer and Ebola surveillance respectively. In a multi-country study published in 2022 by Kinkade et al, DHIS2 was extended and strengthened for successful surveillance of COVID-19 in Uganda, Sri Lanka, and Sierra Leone [59]. As stated by WHO, visualization dashboards supported with easier access to COVID-19 vaccination data [60], thus they were utilized to improve data accessibility and availability, to make timely decisions, and to inform public health policy. This shows that DHIS2 is user-friendly, highly intuitive, attractive, and acceptable as an open-source health information system in a low-income setting. It performed better than similar software such as CANREG in terms of data visualization, analysis, data security, etc [61], [62], [63], [64]. In a few cases, though, there has been low usability of DHIS2, poor performance, and no improvement in health information systems among health workers, for example among nurses in emergency hospitals in Iran [65].

This study is the first of its kind to provide findings on usability scores of open-source health information systems in cancer care in Uganda [19], [20], [21], [52]. Though many studies have been done on DHIS2, most of them have concentrated on the evaluation of data quality in low-income countries [30], [31], [32].

Few or no studies have been conducted on the usability of DHIS2 within a similar context, unlike this study [48], [66], [67], [68], [69]. Secondly, the mean SUS score of the cancer instance obtained in this study competes favorably with some long-established software applications. For example, in a 2022 study, the mean SUS score of Microsoft Word was 74.7 at a 95% confidence interval [70]. This further strengthens the applicability and acceptance of DHIS2 in global healthcare. Thirdly, the use of a built DHIS2 cancer registry in this study provided a software system similar to the nationally approved routine reporting system in Uganda [71], [72]. This cancer registry relates to the national system by both being built from DHIS2 open-source software, thus they share similar core properties and source codes. This would also improve the inter-linkage and interoperability among both systems according to the interoperability prerequisites [73], thus enabling easier reporting, assessment of cancer indicators, and improvement of cancer data available in a routine reporting system. The problem of silos among software developers would also be reduced [74], [75].

A detailed analysis of the SUS results showed general agreement (mean obtained 4) in questions 1, 3, 5, 7, and 9. These correspond to the system's frequency of use, ease of use, system functions well integrated into context, ease of learning, and confidence in system use. There was a neutral response (mean obtained 3) to questions 4 and 10, which cover technical support and learning of new things. If addressed in future research, these areas can also lead to higher usability obtained with the cancer system [29]. However, questions 2, 6, and 8 received a mean of 2. These indicated disagreement with the unnecessary complexity of the system, inconsistency, and cumbersomeness of the system. This further indicates the persistent challenges encountered in digitalizing some areas in the health sector [58], [76]

Despite these strengths of the study, there were key limitations to the study. Firstly, data in our study was based on programmatic information retrospectively abstracted from a portion of records for new cancer patients of FY 2023/24 provided by the hospital management. This led to selection bias and some misclassification of some cancer types or potential risk factors. This offered an opportunity for more research on instances with prospective cancer records. Secondly, the web server costs for hosting the instance were unsustainable since this study had no external funding. This was overcome by setting up idle modes of the instance when not in active use, hence reducing the costs of full-time access to the instance even when not in active use.

The study faced the challenge of limited user engagement in responding to the study questionnaires. One of the reasons cited included the heavy workloads faced by the staff at the cancer, affecting the responses to the questionnaires. The other reason was the limited technological competencies to answer digital questionnaires,, it led to a suboptimal response rate. This underscores the urgent need to conduct pre-training of software or system users before deployment in future studies.

Despite these limitations, this study provides important evidence supporting the use of routine reporting systems to enhance the availability of patient-level cancer data in low-income settings. Future research should focus on exploring the use of prospective data to validate these findings further and the online sustainability of such systems amid funding considerations. Additionally, similar implementations in different settings could provide a broader understanding of the system's effectiveness and adaptability.

In conclusion, a web-based DHIS2 instance made cancer data easily available despite an unsustainable online presence. The usable instance led to increased access to cancer information as per the 2030 targets of the Sustainable Development Goals and consequently improved quality measurements and patient safety [9], [77]. The programmatic implication for UCI Mbarara is to seek international support and/or development assistance for infrastructure through enhanced financial, technological, and technical support to African countries. As for UCI Kampala and MOH, there is a need to scale the instance to the remaining 15 regional hospitals out of 17 [36]. To improve the usability of DHIS2 further at UCI Mbarara, the following are recommended: (1) Conducting system training regularly (2) Motivating system users with incentives (3) Upgrading existing infrastructure to be compatible with DHIS2 (4) Regularly upgrading system modules (5) Providing appropriate user access rights and access levels to UCI Mbarara staff and (6) Providing adequate ICT support and assistance to UCI Mbarara [19]. The author also recommends the following to the Research agencies: (1) Use of prospective programmatic data in future studies (2) Conduct system pre-training to improve user engagement (3) Utilize open-source systems to achieve universal health coverage through increased access to cancer information and quality healthcare [9], [78].

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Statement on conflicts of interest

There was no conflict of interest by the authors.

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Appendices

Appendix 1: System Usability Questionnaire

IMPROVING CANCER DATA USABILITY WITHIN ROUTINE REPORTING SYSTEMS IN A LOW-INCOME SETTING; A CASE OF MBARARA REGIONAL REFERRAL HOSPITAL, UGANDA.

The below is a standard tool modified for measuring the usability of an electronic application or system. Please select the answer (using **X** or ✓) that best describes how you feel after using the cancer instance today.

Table 3: System usability scale

SYSTEM USABILITY SCALE	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I think I would like to use this instance frequently.					
2. I found the instance unnecessarily complex.					
3. I thought the instance was easy to use.					
4. I think that I would need the support of a technical person to be able to use this system.					
5. I found the various functions in this instance were well integrated.					
6. I thought there was too much inconsistency in this instance.					
7. I would imagine that most people would learn to use this instance very quickly.					
8. I found the instance very cumbersome to use.					
9. I felt very confident using the instance.					
10. I needed to learn a lot of things before I could get going with this instance.					

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Appendix 2: Dashboards for the instance (Cancer eRegistry Mbarara)

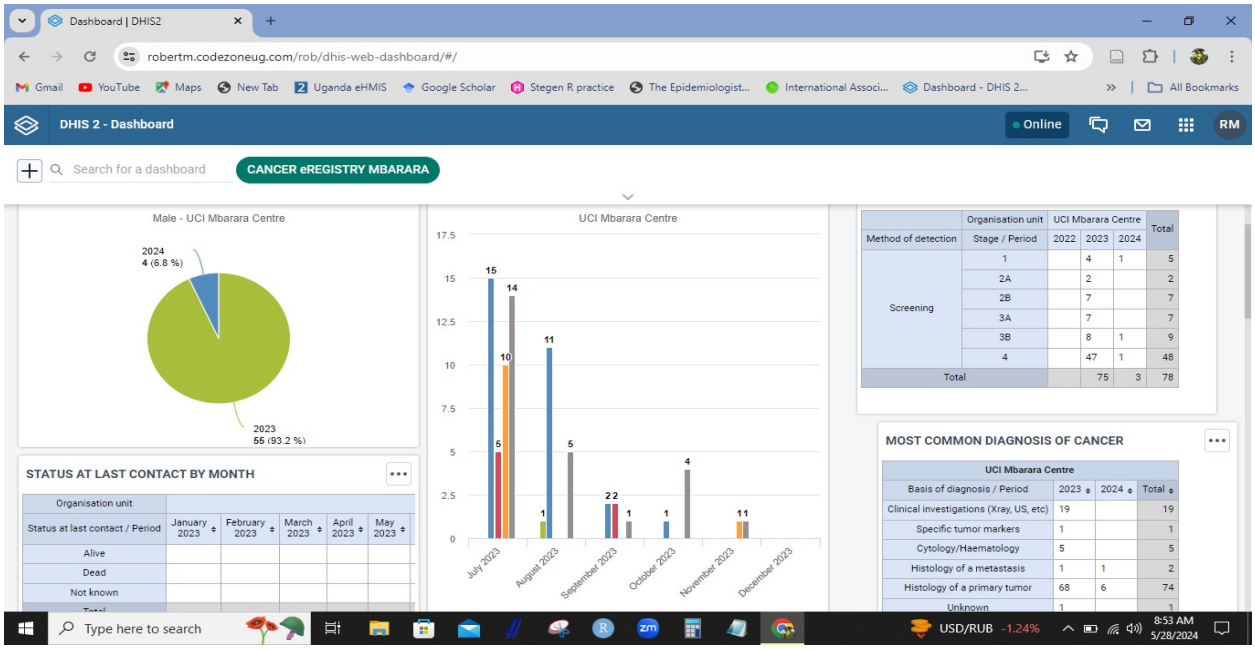

Figure 1: Screenshot 1 of the dashboard in the configured cancer instance

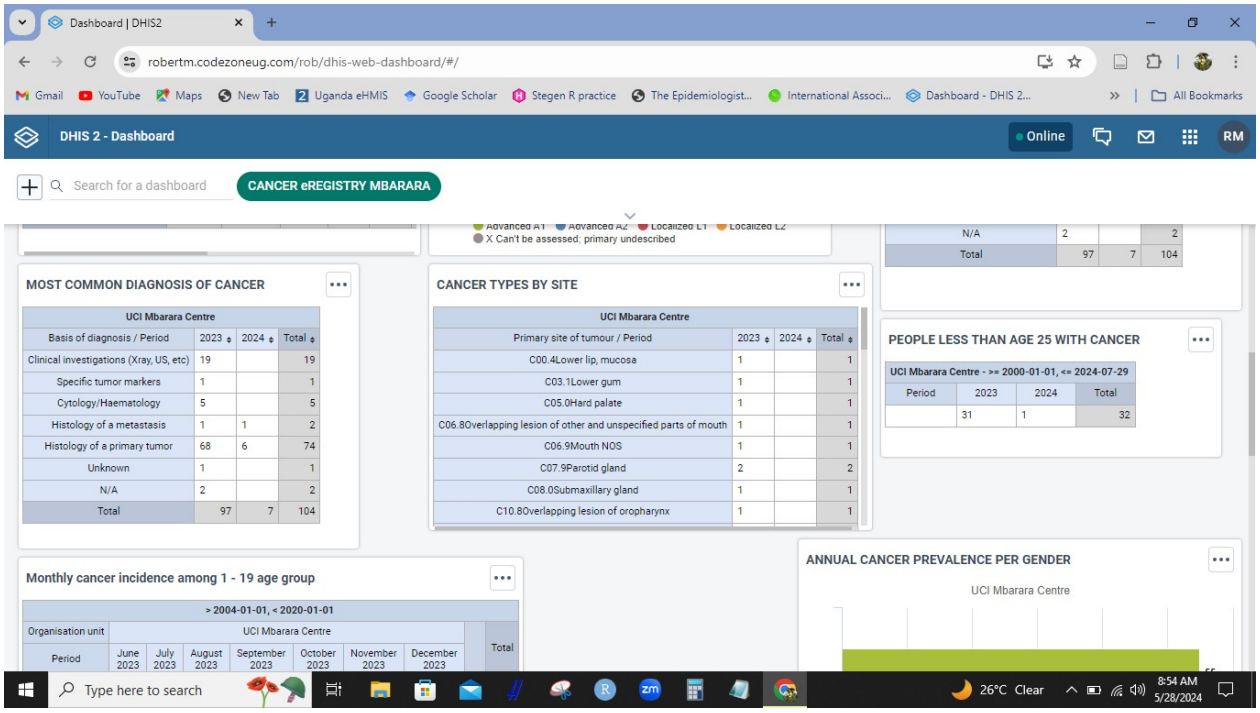

Figure 2: Screenshot 2 of the dashboard in the configured instance

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