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Information Systems for Monitoring the Burden of Chronic Diseases in Public Reference Health Facilities in Central Africa

Frank Verbeke [a,b*], Théobald Hategekimana [d], Gustave Karara [a], Ousmane Ly [a,c], Marc Nimburanira [e], Charles Kayembe [f], Marc Nyssen [a,b]

[a] VUB: Department of biostatistics and medical informatics, Faculty of Medicine and Pharmacy, Vrije Universiteit Brussel, Brussels, Belgium
[b] REHCE: Regional e-Health Center of Excellence, Kigali Health Institute, Kigali, Rwanda
[c] ANTIM: Agence Nationale de Télésanté et d'Informatique Médicale du Mali
[d] CHUK: University Teaching Hospital of Kigali, Rwanda
[e] HMK: Military Hospital of Kamenge, Bujumbura, Burundi
[f] CUKIS: University Teaching Hospital of Kisangani, Democratic Republic of the Congo

Background and purpose: Chronic diseases are an increasingly important cause of death in sub-Saharan Africa. Diseases such as cancer, diabetes and arterial hypertension remained for years in the background, in the shadow of pandemics such as malaria, HIV / AIDS and tuberculosis. Chronic disease incidence in the Central African region however, is poorly documented. This study explores to what extent secondary use of clinical information stored in hospital information systems can help to provide evidence related to the burden of diabetes, cancer and hypertension in DR Congo, Rwanda and Burundi.
Methods: In the past 6 years, 4 reference hospitals of Kisangani, Bukavu, Kigali and Bujumbura implemented open source hospital information management tools integrating international classification systems such as ICD-10 and ICPC-2. Clinical and financial data from chronic disease treatments in the period 2006-2012 were merged into Diagnosis Related Groups (DRGs) for further analysis. Metrics related to case load, mortality load and financial burden have been calculated for diabetes, cancer and hypertension DRGs.
Results: 89,765 out-patient visits and 59,434 admissions have been analyzed in this study. The results show a worrying growth of the 3 chronic diseases in the region. Costs related to the studied diseases are expected to increase by 10% (diabetes) to 70% (cancer & hypertension) between 2011 and 2015 in the studied reference hospitals.
Conclusion: the study demonstrates that the problem of chronic diseases also grows rapidly in the Great Lakes region and therefore urgent steps must be taken, both by governments (Rwanda, DRC and Burundi), by the international donor community and by local hospital boards.

Keywords :Information systems, Diagnosis-Related Groups, Chronic Disease, Sub-Saharan Africa, Neoplasms, Hypertension, Diabetes

1 Introduction

Chronic conditions are estimated to cause more than 60% of all deaths worldwide. More than 80% of these deaths occur in the developing world [6]. The number of deaths from chronic diseases is higher in sub-Saharan Africa than in other regions of the world, yet far too little attention is paid to the problem [2]. To prevent future epidemics of diabetes, cardiovascular disease, stroke and cancer among Africans, policies and programs are needed for encouraging healthy lifestyles, adoption of policies aimed at

*Corresponding author: BISI, Department of Biostatistics and Medical Informatics, Faculty of Medicine and Pharmacy ,Vrije Universiteit Brussel,, Laarbeeklaan 103, B-1090 Jette (Belgium). Email: frank.verbeke@vub.ac.be, Tel: +32 475 621569
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controlling access to, and consumption of, food and drinks high in refined sugar and fat, and promotion of sports and exercise programs. The chronic disease problem is also expected to have serious implications on the African health workforce [5][8], which is already going through a serious crisis [7].

Because chronic conditions require ongoing management over a period of years or a lifetime, health systems must also plan for increasing burden and complexity of care. According to a World Bank report [8], within a few decades, chronic non-communicable diseases will dominate health care needs in most low- and middle-income countries as a result of the epidemiological transition and aging.

Since 2006, a series of hospital information management system (HIMS) implementation projects have been conducted in some 25 public and private hospitals in Rwanda, Burundi and the Democratic Republic of the Congo. Using open source HIMS software called OpenClinic [9], many of these health facilities have started systematic ICD-10, ICPC-2 and DSM-4 based coding of out-patient encounters and in-patient admissions, which was integrated in routine data registration procedures [10]. Based on international classifications, the University Teaching Hospital of Kigali developed in 2009 KPGS [11], a set of Diagnosis Related Group codes (DRGs) adapted to the sub-Saharan health care setting, enabling more efficient evaluation of clinical activities. In the light of what has been explained earlier, routinely registered KPGS-based out- and in-patient diagnoses have been collected from 4 different third line reference hospitals in Rwanda, Burundi and the Democratic Republic of the Congo for studying the regional evolution of incidence and financial burden of a number of chronic non-communicable diseases, more specifically cancer, diabetes and hypertension.

Study concept. This is a comparative retrospective study in which disease related information is studied including case load, mortality load, cost of provided health services and diagnostic coding using ICD-10, ICPC-2 and KPGS classifications.

2 Materials and methods

In 2006, the University Teaching Hospital of Kigali started systematic coding of all its discharge diagnoses using international ICD-10 and ICPC-2 classifications. This was done through the use of 3BT [13], a middleware clinical thesaurus which simultaneously linked a large set of keywords via clinical concepts to ICD-10 and ICPC-2 classification codes. This approach enabled the hospital to produce systematic clinical coding, which was performed by paramedical staff after a short training program [12]. In 2007, with the support of the Belgian Technical Cooperation (BTC), 3BT was also integrated in the hospital's new HIMS and diagnostic coding was extended to out-patient visits.

In 2010, two other reference hospitals in the same region (Eastern DRC) also implemented the same HIMS: implementations were provided to the University Teaching Hospital of Kisangani and the Provincial Reference Hospital of Bukavu through the EU funded eb@le-santé project.

Finally, the Military Hospital of Kamenge, situated in Bujumbura, Burundi, joined the group in 2011. This military health facility is open to the general public and also fulfils the role of a national reference hospital.

Diagnostic and financial data from the 4 hospital HIMS databases were merged, providing DRGs and financial transaction information on 84,713 in-patient admissions (period covered: January 2006 – August 2012) and 485,367 out-patient visits (period covered: August 2008 – August 2012). Diabetes was identified in the KPGS classification by DRG 04B, hypertension by DRG 09C and malignancy has been defined as the grouping of 3 complementary DRGs:

02A	MALIGNANT NEOPLASMS, STATED OR PRESUMED TO BE PRIMARY, OF SPECIFIED SITES, EXCEPT OF LYMPHOID, HAEMATOPOIETIC AND RELATED TISSUE
02B	MALIGNANT NEOPLASMS OF ILL-DEFINED, SECONDARY AND UNSPECIFIED SITES + MALIGNANT NEOPLASMS OF INDEPENDENT (PRIMARY) MULTIPLE SITES
02C	MALIGNANT NEOPLASMS, STATED OR PRESUMED TO BE PRIMARY, OF LYMPHOID, HAEMATOPOIETIC AND RELATED TISSUE

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For each of the chronic disease groups (cancer, diabetes and arterial hypertension), we have then calculated the following metrics (separately for in- and out-patients):

- **Absolute monthly DRG case load (AMCL)**: the number of encounters associated to a specific DRG
- **Relative monthly DRG case load (RMCL)**: the percentage of the total monthly hospital's case load associated to the DRG
- **Absolute monthly DRG mortality load (AMML)**: the number of deaths associated to a specific DRG
- **Relative monthly DRG related hospital mortality load (RMML)**: the percentage of the total monthly hospital's mortality load that was associated to the DRG
- **Relative monthly DRG specific mortality load (SMML)**: the percentage of DRG related admissions for which the patient died

3 Results

After performing necessary data quality and completeness verifications on the available dataset, 89,765 out-patient visits and 59,434 admissions remained available for our analysis, meaning that 80% of the outpatient encounters and 30% of hospital admissions were discarded, mainly because DRG codes were missing. Manual à-posteriori DRG coding on a random subset of 1.314 outpatient encounters and 432 hospital admissions from the discarded data showed no significant differences in chronic disease DRG distribution.

3.1 Cancer

A total of 1,193 out-patient visits representing 1.3% of the out-patient case load in the study period and 2,489 admissions representing 4,19% of the total in-patient case load have been collected. Out-patient cancer related AMCL significantly increased from 6 cases/month in 2008 to 29 cases/month in 2012 (linear regression: R=0,50, p-value of F-Test=0.0003) while in-patient AMCL grew from 9 to 42 monthly cases between 2006 and 2012 (R=0,75, p-value of F-Test <0.0001) as shown on the following charts:

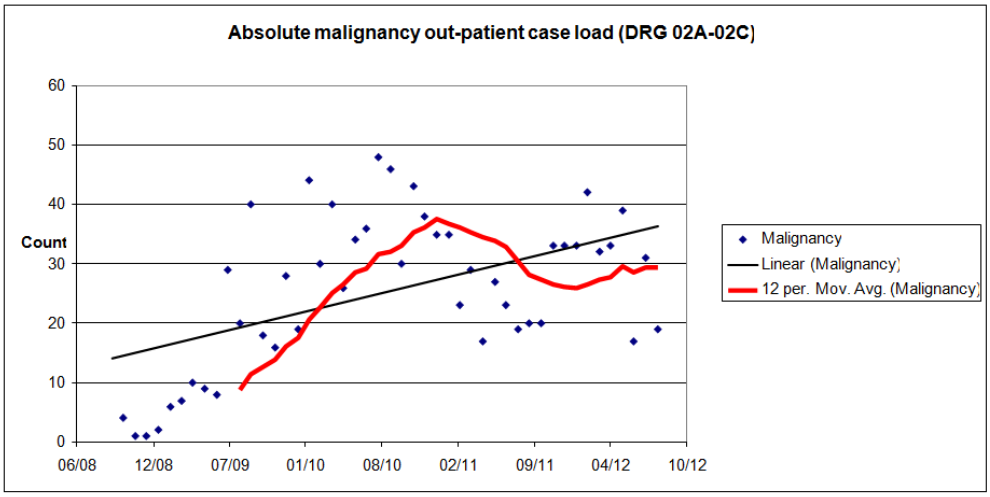

Fig. 1. Rise in malignancy related out-patient case load between 2008 and 2012

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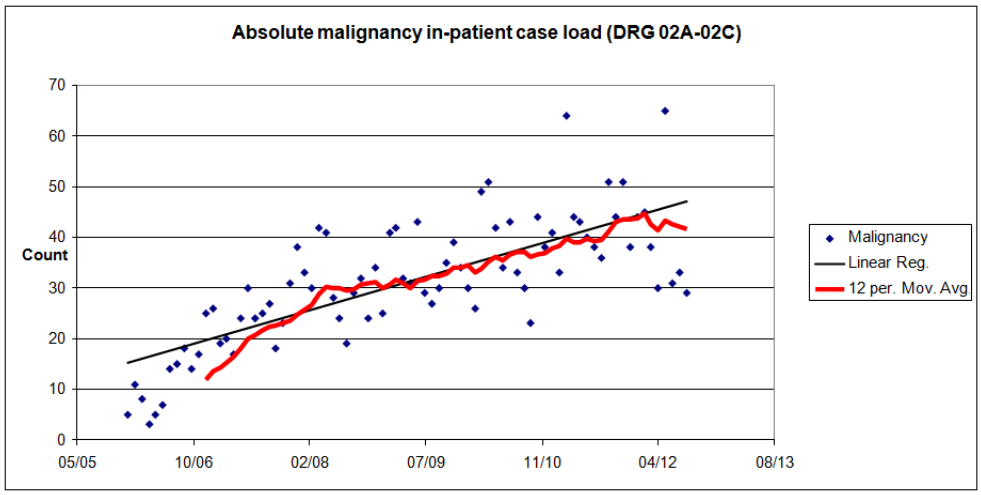

Fig. 2. Rise in malignancy related in-patient case load between 2006 and 2012

Relative in-patient mortality (RMML) due to cancer also more than doubled in the same period from 4.9% to 10.1% (R=0,41, p-value of F-test=0.0002).

The relative in-patient malignancy case load (RMCL) increased from 1.5% in 2006 to 5.5% in 2012, showing that in-patient neoplasm treatment had gained a lot of attention in the group of 4 central African reference hospitals. However, the opposite was true for out-patient visits: relative case load dropped from 4.0% to 1.1% between 2008 and 2012, showing that despite the growing number of cancer-related consultations taking place, a number of other diseases had generated an even more important increase in out-patient activity. In this case, this was due to the opening of a new gynaecology-obstetrics (GO) department at the University Teaching Hospital of Kigali in 2008, causing an important relative case load drop for non-GO DRGs in the first year, after which out-patient non-GO AMCL values stabilized.

After splitting up cancer DRGs into subtypes based on underlying ICD-10 codes, we obtained a cancer subtype distribution pattern that was somehow different from averages that had been reported for Africa by the World Bank in 2006 [16]. The relative importance of stomach-, oesophagus-, prostate- and cervix cancer showed to be lower in our study whilst non-Hodgkin lymphoma and the group other cancers had higher incidences.

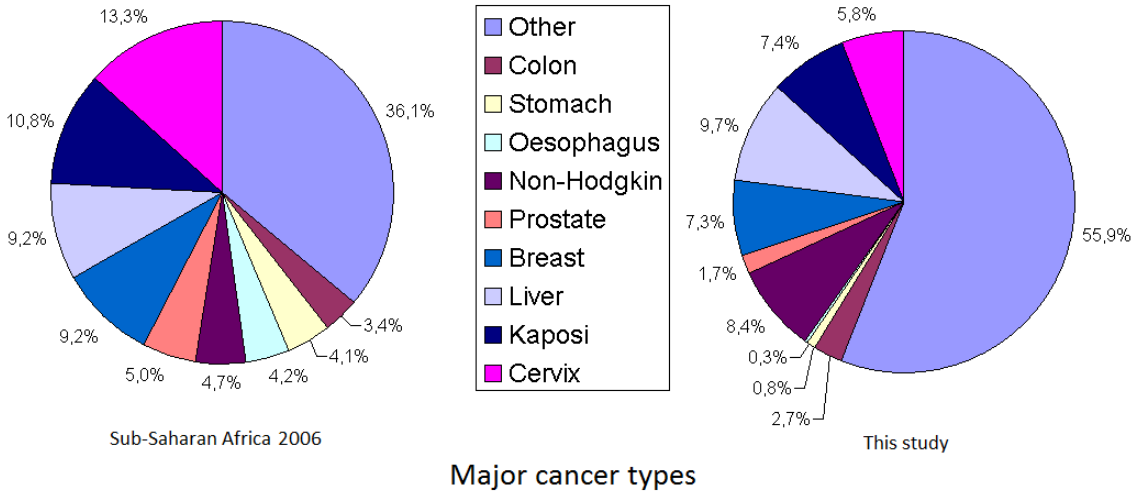

Fig. 3. Differences between African average and study distribution in cancer subtypes

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3.2 Diabetes

After the publication of a number of papers on the worrying growing burden of diabetes in sub-Saharan Africa [2][14][15], also emphasizing the high rate of undiagnosed diabetes in most countries of the continent, different diabetes awareness campaigns have been set up in our study region. Obviously, these campaigns had a clear and measurable effect on the numbers of diabetes related out-patient visits, which suddenly grew from 4 to almost 120 a month (n=3,288). Yet, this effect only lasted for some 18 months, after which diabetes out-patient incidence levels dropped again to a much lower level of about 62 consultations a month, which however still constituted an important rise compared to 2008.

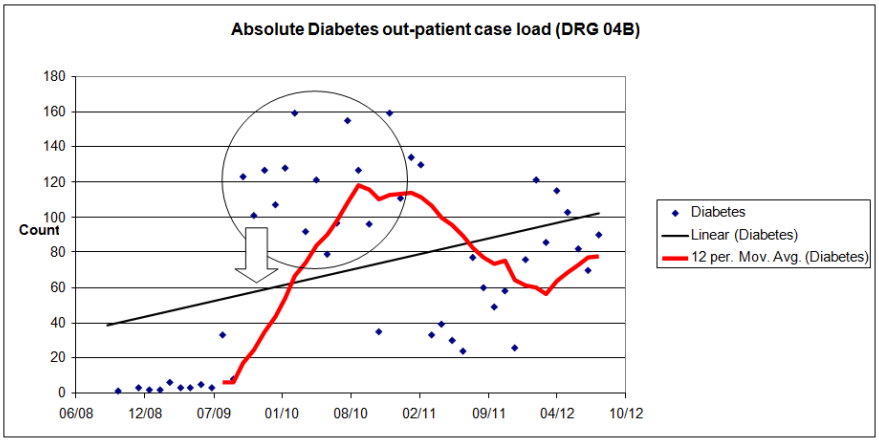

Fig. 4. rise in diabetes related out-patient case load between 2006 and 2012. The white arrow indicates start of diabetes awareness campaigns

Interesting enough, similar effects could not be demonstrated on the in-patients sample, although a significant growth from 6 to 15 diabetes related admissions a month has been seen between 2006 and 2012 (n=885). Relative diabetes related in-patient mortality (RMML) at the same time increased from 0.9% to 2.4%.

Diabetes AMCL results showed a remarkable seasonal variation, with lowest incidences seen in June and the highest between October and March. Seasonal diabetes incidence variations had already been described for other sub-Saharan countries [1][16], but no data could be found in literature for the Great Lakes region where our study sites are situated. Results from our research seem to rather well match the ones obtained by McLarty [1] from a study in Tanzania. Vitamin D (diabetes type 1) and seasonal fluctuations of virus infections (diabetes type 1 & 2) have been forwarded by some authors as possible pathways for explaining this phenomenon.

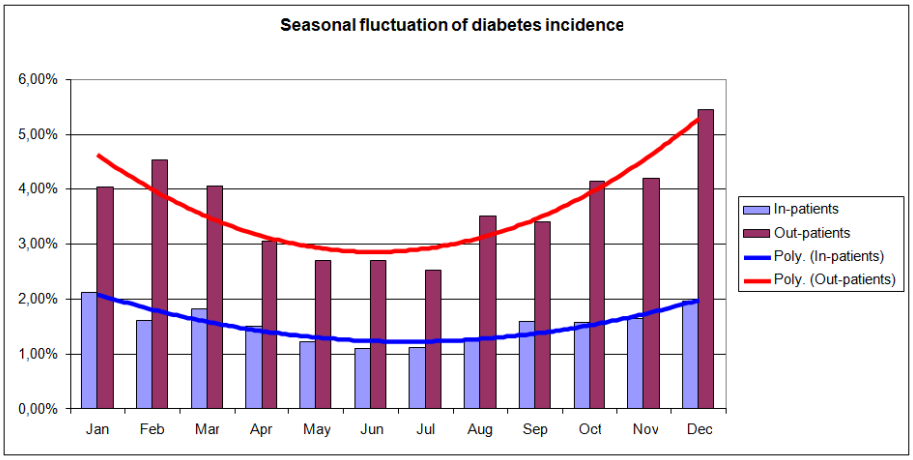

Fig. 5. Seasonal fluctuation of diabetes incidence (Polynomial regression)

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3.3 Arterial hypertension

In the 4 years period between August 2008 and August 2012, out-patient case load for arterial hypertension showed an evolution which more or less followed the pattern seen in diabetes: awareness campaigns had of course also identified many hypertensive patients amongst diabetics. After an initial steep increase during 18 months, hypertension incidence levels also dropped to a lower level, still showing a significant increase from 3 to 53 cases a month. No significant difference was found between incidence data from hypertensive diabetes patients and hypertensive patients without diabetes.

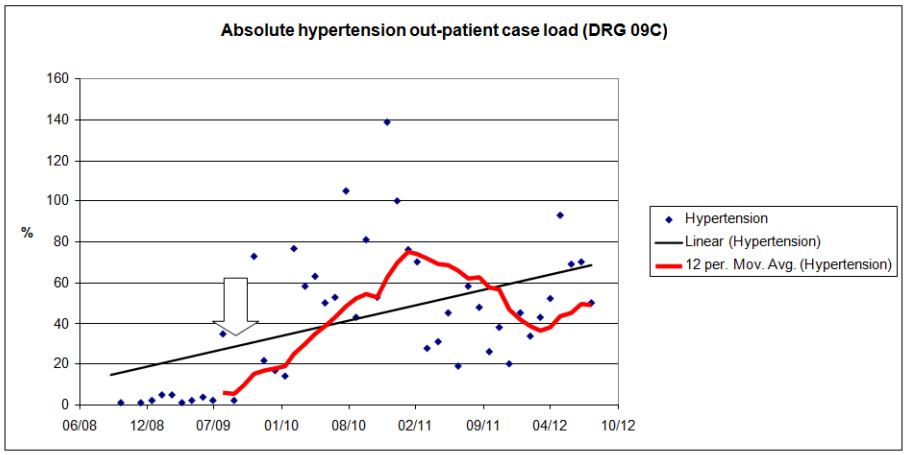

Fig. 6. Rise in hypertension related out-patient case load between 2008 and 2012

In-patient hypertension related case load analysis showed a more constant growth from a mere 3 cases a month in 2006 to 9 cases a month in 2012. The number of patients which were admitted for hypertension related problems and died from it (SMML), did not change significantly in this period and remained at a high level of 10,57%.

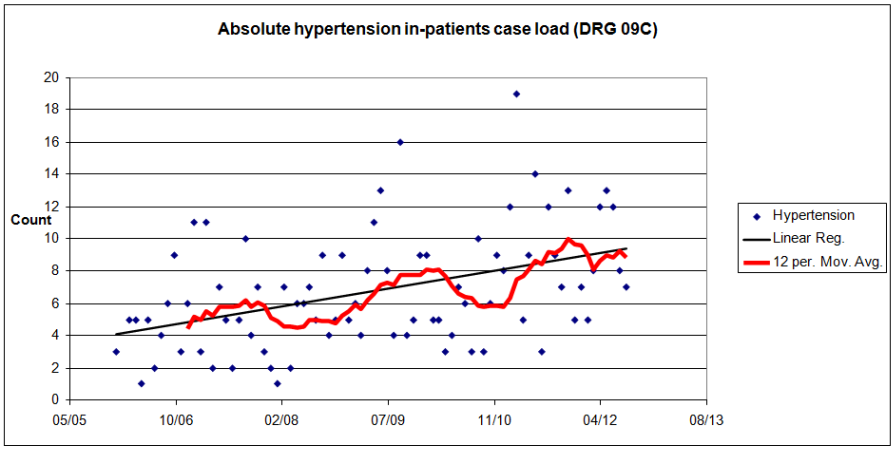

Fig. 7. Rise in hypertension related in-patient case load between 2008 and 2012

3.4 Cost of care

Calculating the exact costs associated to the treatment of the chronic diseases we studied, was not feasible in our research setting. Therefore, we have chosen to use an available proxy metric in the form of direct payments. Direct payment for medicines and health services at the time of need [18] is one of the most common forms of health sector payment in the world. In spite of the willingness of a number of African leaders to take strong action to remove financial barriers for vulnerable groups [19], direct payment

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remains a universal practice in sub-Saharan hospitals, even for government owned facilities. According to WHO, from a health care perspective, systems requiring direct payment at the time people need care, prevent millions from accessing services and result in impoverishment of millions more [18] and should as such definitely not be encouraged. Although direct payments are not restricted to low-income countries, their impact on the individual budget is a lot more important for poor than for rich people: even if the prevalence of direct payment procedures seems to be universal, they still account for a much higher percentage of total health expenditure in low-income countries. That being said, from an impact analysis perspective, the demonized but prevalent user fees constitute an interesting input measure for estimating the impact of chronic disease incidence change in our study.

In 2010, we developed at the CHUK a simple prototype method for calculating financial impact and comorbidity of clinical conditions treated in the sub-Saharan hospital context (CALCO method) [11]. An essential element of that study was to link a cost-related burden of disease index to each KPGS (DRG) code so that the KPGS instrument could later be used for cost and resource allocation purposes in health facilities. In contrast to original DRG logic however, the focus has not been on the development of a tool for reimbursement purposes, which would have assumed a high level of cost-related homogeneity of all diseases and clinical conditions mapping on a same grouping code (which obviously is not the case for KPGS). The goal of KPGS must rather be seen in the context of productivity analysis logic [20][21], where we wanted to deliver an instrument for making comparisons between groups of diseases in terms of resource consumption (called inputs).

Applying the CALCO method to our study sample, we were only able to calculate median direct payments allocated to malignancy, diabetes and hypertension related to in-patient admissions for the University Teaching Hospital of Kigali (too few financial data were available from the other hospitals). The results (expressed in US dollars) are shown in **Table 1** (amounts represent the median of total direct patient- and insurer payments made per admission):

Table 1. Median chronic disease related direct payments per admission between 2009 and 2011

	Malignancy	Diabetes	Hypertension
2009	$ 118	$ 179	$ 39
2010	$ 145	$ 181	$ 57
2011	$ 148	$ 175	$ 70

In-patient malignancy treatment became 30$ (25%) more expensive in 2 years' time while hypertension related costs increased by 31$ (79%). The cost of diabetes showed to remain somewhat stable, although from the start this was already at a level which is hardly accessible for a major portion of the population being served by the CHUK.

Combining direct payment data with case load information learns that the financial impact of the 3 studied chronic diseases can be expected to be very important in the next couple of years:

Table 2. expected growth of financial chronic disease costs between 2012 and 2015 at CHUK. Total growth = (1 + cost growth) x (1 + incidence growth) - 1

	Malignancy	Diabetes	Hypertension
Expected cost growth 2015	37,50%	-1,44%	39,50%
Expected incidence growth 2015	25%	11,73%	22,00%
Total growth	**71,88%**	**10,12%**	**70,19%**

By August 2015, cancer and hypertension related in-patient costs are expected to increase by more than 70% whereas the already expensive diabetes related admissions will become 10% more expensive. Monetary evolution and inflation of course have to be added to these estimates.

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4 Discussion

This study demonstrates the feasibility and usefulness of implementing ICT-based tools for international classifications based registration of diagnostic information, even in the sometimes technologically difficult settings of the reference hospitals of Kisangani, Bukavu, Kigali and Bujumbura. On all sites, structured diagnostic registration was part of routine data entry procedures and did not require any study-specific developments.

The results of this research clearly demonstrate the growing importance of chronic non-communicable diseases in the Great Lakes region. The global burden of chronic diseases can be expected to heavily weigh on available resources in third level health facilities in the next 5 to 10 years. Health care staff which have been adequately trained in chronic disease management are not available in sufficient numbers in the studied hospitals to cope with this problem.

Although communicable and non-chronic diseases still account for the bulk of hospital activity today, politicians, health administrations and health facility managers should prepare for the worrying progress of chronic health problems in the sub-Saharan region.

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