Health Information Systems for HIV in very poor Countries

Experience of french NGO Solthis

Grégoire Lurton

Solthis

March 2012
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   Who we are
   What we do
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Created in 2003 in Hôpital Pitié Salpêtrière by Pr Christine Katlama, Pr Brigitte Autran, Pr Patrice Debré & Pr Gilles Brucker.

- 5 missions in Africa + Headquarter in Paris.
- 94 employees (37 technical staff, 57 support staff).
- Budget 2011 - 3 450 000€ from Bettencourt Schueller Foundation (80%), GFATM, Mairie de Paris.
Health System Strengthening for HIV

Five main axis of intervention

1. Political coordinating bodies
2. Medical Workforce
3. Health Information System
4. Pharmaceutical System
5. Laboratories
Three means of action

1. Capacity Strengthening
2. Operationnal Research
3. Advocacy
Capacity Strengthening

Normative Level
Organisational Level
Individual Level
Overview

Current Programs
Partial Programs
Previous Programs
Overview
Overview

Human Development Index

HIV Prevalence (%)

Mali
Guinée
Sierra Leone
Niger
Overview

[Graph showing the relationship between Health Expense per capita ($) and HIV Prevalence (%).]

- Guinée
- Mali
- Niger
- Sierra Leone

Health Expense, per capita ($) vs. HIV Prevalence (%)

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Niger - some actions

- Training of almost all teams involved in ART care or PMTCT
- Support for Grant Request to Global Fund
- Direct support of PSM at national level
- Development of a Nationwide Database
- Technical support for Viral Load access in the Regions
- Research on HIV among malnourished children
Mali - some actions

- Decentralization of HIV Care in Ségou and Mopti Regions
- GF financed Technical Support for PSM strengthening
- Support for implementation of computerized data system in Ségou and Mopti
- Participation in installation of DNA sequencer in Bamako
- Operationnal research on Loss to Follow-up
Guinea - some actions

- Development of TB/HIV coinfection care
- Deconcentration of care in Conakry
- Revision of Monitoring and Evaluation Framework and Tools
- Installation of VL machine in Conakry
- Support for quantifications of HIV drugs needs
- Research Project on the care of neurological infections
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4 The way forward - some ideas
Abou Zahr et al. (2007) From Data to policy: good practices and cautionary tales
Building Blocks of HIS Strengthening

Data Collection \rightarrow Information Definition \rightarrow Data Analysis \rightarrow Datawarehouse and diffusion
<table>
<thead>
<tr>
<th>Strength</th>
<th>Weakness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper based system</td>
<td>Computer based system</td>
</tr>
<tr>
<td>Applicable everywhere</td>
<td>Need for infrastructure</td>
</tr>
<tr>
<td>Robust System</td>
<td>Need for Human Resource</td>
</tr>
<tr>
<td></td>
<td>Fragile System</td>
</tr>
<tr>
<td>Data collection and analysis at base level</td>
<td></td>
</tr>
<tr>
<td>Workload</td>
<td></td>
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<td></td>
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</tbody>
</table>
Acute vs Chronic Disease Data

Acute type Data

Fixed data quantity
Constant data workload

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HIS for HIV
Acute vs Chronic Disease Data

Acute type Data

- Fixed data quantity
- Constant data workload

Chronic type Data

- Variable data quantity
- Growing data workload

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Different domains

- Adult Care
- PMTCT
- Pediatric Care
- Laboratory
- Pharmacy
So... what we are aiming at

- Chronic data collection systems
- No work overload at Facility level
- Fit for different data needs
- Unified immatriculation systems
Sommaire

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HIV facilities
HIV facilities

Hôpital National de Niamey
MVS
CTA
HNL
CHA
CHRP
Aim of a computerized Datasystem

- Data Collection
- Information Definition
- Data Analysis
- Datawarehouse and diffusion
Data Entry System

Patient File → Duplicate → Data Entry
How long does it take?
Data entry

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Niger
Useful for basic epidemiology

Distribution des CD4

Inclusion

Initiation
Useless for M& E
Next steps

1. Strengthen supervision
2. Backup with a paper system
Prévalence du VIH estimée

Guinée – EDS 2004
Information Definition

Data Collection → Data Analysis → Datawarehouse and diffusion
Redefinition of M&E Needs

Document de référence sur l'opérationnalisation du système de Suivi/Evaluation de la lutte contre le VIH en Guinée

Harmonisation des indicateurs et définition des outils

<table>
<thead>
<tr>
<th>PTME-05a</th>
<th>Nombre de femmes vues en consultation prénatale qui ont été conseillées et testées pour le VIH.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outil de base</td>
<td>Registres de CPN</td>
</tr>
<tr>
<td>Remontée</td>
<td>Rapports CPN</td>
</tr>
<tr>
<td>Fréquence</td>
<td>Trimestrielle</td>
</tr>
<tr>
<td>Responsable</td>
<td>PNPCSP</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PTME-05b</th>
<th>Pourcentage de femmes vues en consultation prénatale qui ont été conseillées et testées pour le VIH.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numérateur</td>
<td>Nombre de femmes vues en consultation prénatale qui ont été conseillées et testées pour le VIH.</td>
</tr>
<tr>
<td>Source</td>
<td>PTME-05a</td>
</tr>
<tr>
<td>Dénominateur</td>
<td>Nombre de femmes vues en consultation prénatale.</td>
</tr>
<tr>
<td>Source</td>
<td>PTME-04</td>
</tr>
<tr>
<td>Fréquence</td>
<td>Trimestrielle</td>
</tr>
<tr>
<td>Responsable</td>
<td>PNPCSP</td>
</tr>
</tbody>
</table>

L'indicateur PTME-05a est disponible à travers les registres de laboratoire des centres de consultation prénatale. Il est recommandé de veiller à ce que l'identification des femmes qui viennent pour une consultation prénatale soit effective dans ces centres.

Le dénominateur de l'indicateur PTME-05b est disponible au SNIS.

Le PNPCSP est responsable pour la mise à disposition de cet indicateur.
Data Collection → Information Definition → Data Analysis → Datawarehouse and diffusion
A new data collection system

- General Register
- Register 2011
- Pharma Register 2011
- Register 2012
- Pharma Register 2012
A new data collection system

- Patient file only used for patient monitoring
- Progressive computerization where possible
- Yearly reevaluation of actively followed patients
- Adult and pediatric in the same tools
- Easy to analyse
Modification of Tools and methods
Modification of Tools and methods
Implementation of new tools
Implementation of new tools
Results and next steps

- Revision of cohort estimations
- Revision of PMTCT and Labs registries
- Strengthening of HIS Management and Supervision
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4 The way forward - some ideas
Evaluation of Three Sampling Methods to Monitor Outcomes of Antiretroviral Treatment Programmes in Low- and Middle-Income Countries

Jean-Michel Tassio, I; Karen Malatsane, 2; Mar Pujolos-Rodriguez, 3; Elisabeth Poulet, 4; Diane Bentini, 5; Anthony Harris, 6; Mary Mehly, 7; Maria Schuster, 7; Yves Soupart, 7; Françoise Delbo 7 for the ART Line of IsDEA and MEF collaborations

Abstract

Background: Retention of patients on antiretroviral therapy (ART) over time is a key indicator of quality of care and an outcome indicator to monitor ART programs. Using existing databases (Isolated in low Income Countries and the International Database to Evaluate AIDS and Medicines Access Program) and testing three sampling approaches, we evaluated these sampling approaches to simplify the generation of outcome indicators.

Methods and Findings: We used individual patient data from 17 ART sites and included 2,301 ART naive adults (≥15 years) who initiated ART in 2006. For each site, we generated two outcome indicators at 12 months, retention on ART and cumulative mortality rates for follow-up periods of 6 and 12 months. We evaluated the feasibility of summarizing these indicators of outcome using three sampling approaches (random, systematic, and consecutive sampling). For each site and each outcome indicator, a sampling frame of 162 patients was generated, and the average results were compared with the unsampling results. The 162 sampling distribution was simulated to estimate the 95% confidence interval from the 162 patients. Overall, for both indicators (retention on ART and cumulative mortality), the results of the 162 sampled patients (81.9% of the unsampling patients) were similar to the results of the original 2,301 patients. For retention on ART, the unsampling results were 83.8% (95% CI 81.2–86.4) and the sampling results were 86.0% (95% CI 83.6–88.4). For cumulative mortality, the unsampling results were 1.7% (95% CI 0.5–3.9) and the sampling results were 2.0% (95% CI 0.5–3.9). The sampling generated similar results for the two indicators, and 50% of sites had 50% of the unsampling sites.

Conclusion: Our results suggest that random, systematic, or consecutive sampling methods are feasible for monitoring ART retention at national level. However, sampling may not produce precise estimates in some sites.

Introduction

In the end of 1990s, more than 3 million people were receiving antiretroviral therapy (ART) in low and middle-income countries, 1 out of 33 million people were infected with HIV [1]. This represents a 60% reduction in new cases and a 25% reduction in ART since 2003. Monitoring of ART programmes is critical for understanding why they are underperforming and improving the potential impact of treatment, at the population level, and for program managers to design and implement quality improvement of the health systems. As a result, reporting of ART indicators to assess national and global commitments to monitor quality of care whilst expanding access to ART and its growing use.

Many countries are still struggling to report national programme indicators. In 2009, 70% of 169 low and middle-income countries (57%) reported data on patient numbers on ART at 12 months and 30% (50%) at 18 months [2]. The outcome indicators of routine care outcomes are used to measure the effectiveness of ART programmes in reducing mortality and morbidity. Although, many challenges remain, including inadequate infrastructure, delays in treatment initiation, difficulty in generating high-quality information. Many ART programmes are relatively recent, and facing large and rapid increases in the number of patients starting therapy. They have
Improving data monitoring

- Provide tools to screen data from facilities
- Handle Overdispersion of indicators
Improving data monitoring

Papers

Bias in meta-analysis detected by a simple, graphical test
Matthias Egger, George Davey Smith, Martin Schneider, Christoph Minder

Abstract

Objective: Funnel plots (plots of effect estimates against sample size) may be useful to detect bias in meta-analyses that were later contradicted by large trials. We examined whether a simple test of asymmetry of funnel plots predicts disappearance of results when meta-analyses are compared to large trials, and we assessed the prevalence of bias in published meta-analyses.

Design: Medline search to identify pairs consisting of a meta-analysis and a single large trial (considered to reflect the true treatment effect) in the same field. The funnel plot was examined for asymmetry.

Main outcome measure: Degree of funnel plot asymmetry as measured by the intercept from regression of standard normal deviates on sample size.

Results: In the eight pairs of meta-analysis and large trial that were identified (five from cardiovascular medicine, one from diabetics medicine, and one from systemic lupus erythematosus), there were four concordant and four discordant pairs. In all cases, discordance was due to meta-analyses showing larger effects. Funnel plot asymmetry was present in three of four discordant pairs but in none of concordant pairs. In 14 (88%) journal meta-analyses and 13 (81%) Cochrane reviews, funnel plot asymmetry indicated that there was bias.

Conclusions: A simple analysis of funnel plots provides a useful test for the likely presence of bias in meta-analyses, but as the study to detect bias will be limited when meta-analyses are based on a limited number of small trials, the results from such analyses should be treated with considerable caution.

Introduction

Systematic review of the bias available evidence regarding the harms and risks of essential interventions can inform decision making in clinical practice and public health. Such reviews are inherently possible (based on meta-analysis) as a “statistical analysis which combines or integrates the results of several independent clinical trials considered by the analyst to be homologous.” However, the findings of some meta-analyses have been contradicted by large randomized controlled trials. Such discrepancies may be due to publication bias, which is the tendency to publish only those trials showing positive results. In this article, we present a method to detect publication bias in meta-analyses.

Methods

Measures of funnel plot asymmetry

We used a linear regression approach to measure funnel plot asymmetry on the natural logarithm scale of the odds ratio. This corresponds to a regression analysis of Gart’s random-effect model, although in the present context the regression is not assumed to run through the origin. The standard normal deviate (SND) defined as the odds ratio divided by its standard error, is regressed against the estimates, which are the same as the estimates but standardized to 1. This regression equation SND = a + b*estimates. As previously stated, large sample size, small trials will be more likely to show large trials with the same estimates, but because the
Improving data monitoring

Papers

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Abstract
Objective: Funnel plots (plots of effect estimates against sample size) may be used to detect bias in meta-analyses that are later condensed to large trials. We examined whether a simple test of asymmetry which checks presence of excess of studies when meta-analyses are compared to large trials, and which assesses the presence of bias in published meta-analyses.

Design: A search in PubMed identifies pairs consisting of a meta-analysis and a single large trial (concordance of results was assumed if there were in the same direction and the meta-analytic estimate was within 80% of the true estimate of a funnel plot from 57 meta-analyses identified from a hand search of four leading general medical journals; 1995 through 1996). The funnel plot is based on the fact that estimates in the underlying treatment effect will increase as the sample size of component studies increases. Results: Studies from small studies will appear further on the left plot than that on the right, which is often used to assess the possible excess of small trials. In the absence of all the cross study of funnel plot asymmetry the funnel will resemble a symmetrical inverted symmetrical funnel. Overall, there is bias in funnel plots as often observed on asymmetrical.

The value of the funnel plot has not been systematically examined, and symmetry (or asymmetry) has generally been defined informally, through visual inspection. Importantly, funnel plots have been interpreted differently by different observers. We measured funnel plot asymmetry using a new metric for each study, which we called funnel plot asymmetry, and that of possible bias, among meta-analyses that use funnel plot asymmetry in a Cochrane review, funnel plot asymmetry was indicated that there is bias in the funnel plot asymmetry.

Methods: A simple analysis of funnel plots provides a useful test for the likely presence of bias in meta-analyses, but as the validity of the funnel plot will be ruled limited when meta-analyses are based on a limited number of small trials for results such analyses should be treated with considerable caution.

Introduction
Systematic review of the base available evidence regarding the bias in the evaluation of number of local reviewers can inform decisions making in clinical practice and public health. Such reviews are inherently possi-
ble, based on meta-message and meta-data. It is a systematic analysis which suggests that the results of several independent clinical trials are considered by the analysis to be "consistent." However, the findings of some meta-

analyses have been contradicted by large randomized controlled trials. Such discrepancies have brought discredit on a technique that has been contro-

versial since the outset. The presentation of misleading meta-analyses is not escaping considering the existence of publication bias and the many other issues that may be introduced to the process of meta-analysis, especially in meta-

analytic reporting, and combining studies.

Funnel plots, plots of the trials' effect estimates against sample size, may be useful to assess the validity of meta-analyses. The funnel plot is based on the fact that estimates in the underlying treatment effect will increase as the sample size of component studies increases. Results: Studies from small studies will appear further on the left plot than that on the right, which is often used to assess the possible excess of small trials. In the absence of all the cross study of funnel plot asymmetry the funnel will resemble a symmetrical inverted symmetrical funnel. Overall, there is bias in funnel plots as often observed on asymmetrical.

Quantitative performance indicators are increasingly being used to monitor providers of health care, particularly in choosing such "institutions"—which may be a health authority, hospital, or even an individual surgeon—against a "standard" or "target," which may be essentially imposed or simply an average true. A common technique for making such comparisons is to produce a confidence interval for the observed (possibly adjusted) performance in each institution and to compare it with the "standard" or "target." Such comparisons of performance are commonly undertaken in health care; those of others may be under the comparison among hospitals or between a hospital and a benchmark. This is a natural task for a nurse or "anesthesiologist" plot study in which the results are the most commonly used in meta-analysis. Figure 1 shows 95% confidence intervals for the 36-month period to 26 hospitals conducting bypass grafts in England in 2002-2003, in which the standard is the national average (the second of all analyses; this paper is downloaded from Commission for Health Improvement (CHI) which contains full details of the construction of the funnel plot and the names of all institutions). An alternative way of presenting such data as a "funnel" plot, which has been recommended as a means of avoiding the random scatter evident in scatter plots and is used as an increasing number of tools. It also avoids any difficulties assigning 95% intervals for low counts. This plot the observed bias against the mean of the study (with the sample size), expresses the target as a horizontal line, and indicates the level of the observed and the comparison, which may be significantly different across the three groups. The use of limits to 95% confidence intervals (CI) and 2 standard deviations (SD) is illustrated in Figure 2. The limits of limits might be taken as indicating a "warning" and "alert" limits. A funnel plot of the fishbone data on coronary artery bypass grafts in Figure 1B, showing the funnel in the "normal" area and one "alert." It needs to be strongly emphasized that these indicators take no formal account of the multiple comparisons implicit in the funnel plot and that crossing a threshold does not indicate high or low quality, but it may be useful to investigate means for the apparent dissatisfaction.

OVER-DISPERSION
Figure 2 shows the distribution among the 30 successive discharges from hospital in England. The present is clearly different from that of Fig 1 in that the majority of hospitals now lie outside the 99% threshold indicating "in control" institutions; the number lying in each of the five bands formed by the four central limits is shown in row 2 of table.
Provide new tools for data analysis

Correcting Mortality for Loss to Follow-Up: A Nomogram Applied to Antiretroviral Treatment Programmes in Sub-Saharan Africa

Matthias Egger 1, 2, Ben G. Spyker 1, John Sible 1, Ralf Weigel 1, Elvin H. Gna 3, Matthew P. Fox 3, Patrick MacPhail 4, Gilles van Cutsem 1, Eugène Messoou 2, Robin Wood 5, Denis N‘Dri 6, Margaret Panda 7, Diana Dickson 8, Jean-François Blard 9, James A. McIntyre 10, Martin W. G. Brinkhof 11, for iCHAPA East Africa, West Africa and Southern Africa

Background: The World Health Organization estimates that in sub-Saharan Africa about 4 million HIV-infected patients had started antiretroviral therapy (ART) by the end of 2005. Loss of patients to follow-up and care is an important problem for treatment programmes in this region. As mortality is high in these patients compared to patients remaining in care, ART programmes with high rates of loss to follow-up may substantially underestimate mortality of all patients starting ART.

Methods and findings: We developed a nomogram to correct mortality estimates for loss to follow-up based on the fact that the mortality of all patients starting ART in a treatment programme is a weighted average of mortality among patients lost to follow-up and patients remaining in care. The nomogram gave a correction factor based on the percentage of patients lost to follow-up at a given point in time, and the estimated rate of mortality between patient loss and not lost to follow-up. The corrected mortality among patients lost to follow-up in a treatment programme can be computed as a geometric mean of the mortality among patients lost to follow-up and patients remaining in care. The correction factor can be used to calculate the corrected mortality among patients lost to follow-up in a treatment programme, using information on the percent of patients lost to follow-up, the number of patients lost to follow-up, and the estimated rate of mortality between patient loss and not lost to follow-up.

Conclusion: This nomogram for correcting mortality among patients lost to follow-up is an important tool for evaluating the impact of mortality among patients lost to follow-up on the overall mortality among patients starting ART. The nomogram can be used to estimate mortality among all patients who started ART, for a range of plausible mortality rates among patients lost to follow-up.


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*E-mail: m.egger@unige.ch
Provide new tools for data analysis

Correcting Mortality for Loss to Follow-Up: A Nomogram Applied to Antiretroviral Treatment Programmes in Sub-Saharan Africa

Matthias Egger*1,2, Ben D. Spycher3, John Sibley3, Ralf Weigel3, Elin M. Gene3, Matthew P. Fox4, Patrick MacPhail5, Gilles van Cutsem6, Eugène Messo6, Robin Wood6, Denis Nash6, Margaret Piazza6, Dana Diclinos7, Jean-François Etard3, James A. McDowell8, Mario W. D. Brinkhof3, for MASA East Africa, West Africa and Southern Africa

*Institute of Hygiene and Preventive Medicine (IHP), University of Bern, Switzerland, 1Sha Tin and South East KwaZulu-Natal Research Facility, Durban, South Africa, 2School of Public Health, University of Hong Kong, Hong Kong, 3School of Public Health, Columbia University, New York, New York, United States of America, 4MRC Biostatistics Unit, Cambridge, CB2 2SR, UK, 5Faculty of Medicine, University of Alberta, Edmonton, Alberta, Canada, 6Centre for International Health, University of KwaZulu-Natal, Durban, South Africa, 7Academic Department of Medicine, Imperial College London, London, UK

Abstract

Background: The World Health Organization estimates that in sub-Saharan Africa about 4 million HIV-infected patients had started antiretroviral therapy (ART) by the end of 2009. Loss of patients to follow-up and care is an important problem for treatment programmes in this region. As mortality in these patients compares to patients remaining in care, ART programmes with high rates of loss to follow-up may substantially underestimate mortality of all patients starting ART.

Methods and Findings: We developed a nomogram to correct mortality estimates for loss to follow-up based on the fact that mortality of all patients starting ART in a treatment programme is over-estimated by about 5% due to lower mortality of patients lost to follow-up and patients remaining in care. The nomogram gives a correction factor based on the percentage of patients lost to follow-up at a given point in time, and the estimated ratio of mortality between patients lost to follow-up and not lost to follow-up. The correction factor can be derived from a calibration tool to obtain an estimate of the true mortality of patients lost to follow-up and patients remaining in care. The nomogram can be used to compare mortality between different ART programmes or over time within a single programme.

Conclusions: The nomogram can be used to correct mortality estimates for loss to follow-up. The correction factor can be used to compare mortality across programmes or over time. The nomogram can be used to compare mortality between different ART programmes or over time within a single programme. The correction factor can be derived from a calibration tool to obtain an estimate of the true mortality of patients lost to follow-up and patients remaining in care. The nomogram can be used to compare mortality between different ART programmes or over time within a single programme.

1. INTRODUCTION

Demand for increased accountability of public services has led to increased attention to institutional comparisons on the basis of quantitative outcome measures, whether school examination results, surgical mortality rates, or research output from universities. Here, ‘institutions’ refers to any unit of analysis, which in the health context could be a health authority, hospital, surgical team or even an individual named surgeon. Such comparisons commonly lead to the production of ‘league tables’, in which institutions are ranked according to a performance indicator and, possibly with the aid of confidence intervals, ‘outlying’ institutions identified. For example, Figure 1 shows a league table of hospitals based on mortality following a fractured hip—this display is similar to that of the original publication [3]. Such presentations have been criticized as leading to a spurious focus on rank ordering, when it is known that the rank of an institution is one of the most difficult quantities to estimate [2, 3]. Mohamed et al. [4] argued strongly that a more appropriate presentation would be based on Showhart’s control charts [5], in which ‘in-control’ institutions are assumed to be subject to ‘common-cause’ variability, whereas those that are ‘out-of-control’ will exhibit...