

A novel framework for the routine production of EU indicators: the BIRO system

F. Carinci [1], V. Baglioni [2], C.T. Di Iorio [1], L. Rossi [1], J. Azzopardi [3], P. Beck [4], S. Cunningham [5], S. Skeie [6], G. Olympios [7], S. Pruna [8], M. Massi Benedetti [2]

Serectrix snc (Pescara, Italy) [1], University of Perugia (Italy) [2], University of Malta (G'Mangia, Malta) [3], Joanneum Research (Graz, Austria) [4], University of Dundee (Scotland) [5], NOKLUS (Bergen, Norway) [6], Ministry of Health (Nicosia, Cyprus) [7], Paulescu Institute, Telemedica Consulting (Bucharest, Romania) [8]

Research Problem

Despite of an overwhelming amount of individual data recorded on a routine basis, health information across Europe is still fragmented, underutilized and insufficiently summarized for the needs of policy makers. The EU Programme of Community Action in the Field of Public Health included actions to produce comparable information on health and health-related behaviour of the population, diseases and health systems. Sustainable systems to produce structural, process and outcomes indicators on a continuous basis are increasingly required for high priority areas.

Theory and Research Methods

The BIRO project ("Best Information through Regional Outcomes") supported by DG-SANCO (2005-2009) developed a new method to realize a transnational information system linking heterogeneous diabetes registers (Figure 1). A general approach allows turning heterogeneity into comparable information (Figure 2). In the BIRO System (Figure 3), client software incorporates routines mapping local definitions to EU standards, transforming data into a common format, to run statistical procedures that deliver fully standardized "local" reports of quality and outcomes indicators. Aggregate data resulting from the calculation of on-site indicators ("statistical objects") are transmitted towards a central repository, which maintains and runs server software to produce an overall European "global" report on a dedicated web portal (Figure 4). Multivariate logistic regression allows producing risk adjusted indicators in the BIRO fashion, using the AHRQ methodology on top of finely tuned aggregated data.

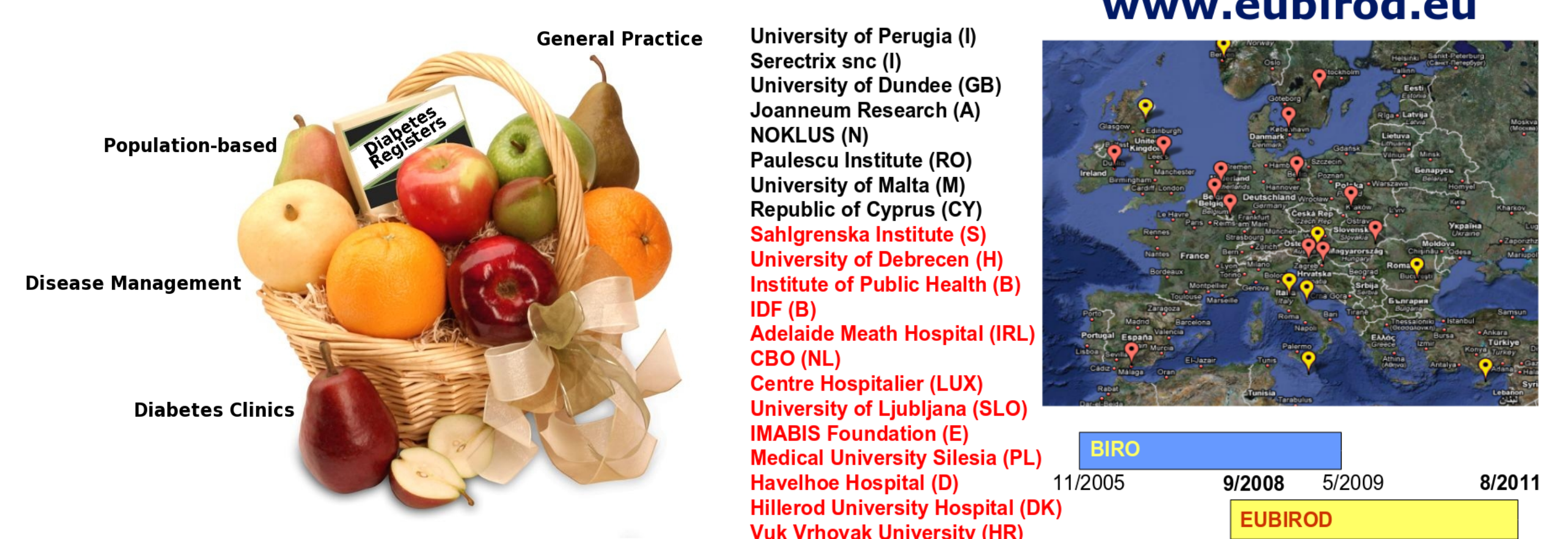


Figure 1. Heterogeneity of Diabetes Registers in the EUBIROD network

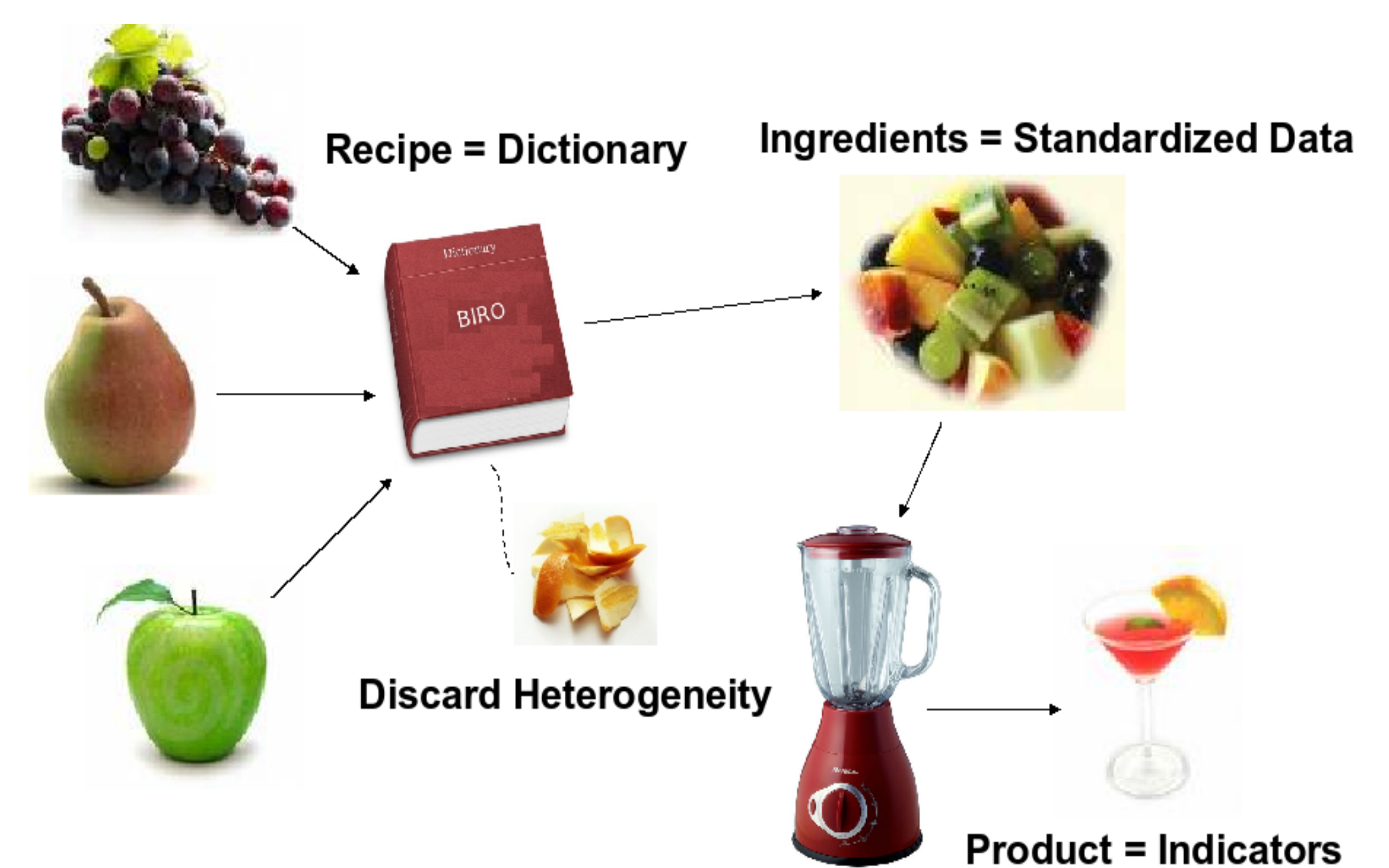


Figure 2. Turning apples and pears into Standardized Information

"Region": network of centres sharing a homogeneous set of organizational aspects, including the definition of individual data items and the way they measure/collect them.

"Statistical object": an element of a distributed information system that carries essential data in the form of embedded, partial aggregate components, required to compute a summary measure or relevant parameter for the whole population from multiple sites.

"Data Standards": Common Dataset, Activity Table, Population Tables, Source Profile

"Indicators": Demographic (N=2), Clinical (N=18), Health System (N=21), Population (N=3), Standardized / Risk Adjusted: Epidemiology (N=2), Process (N=16), Intermediate Outcomes (N=7), Terminal Outcomes (N=3)

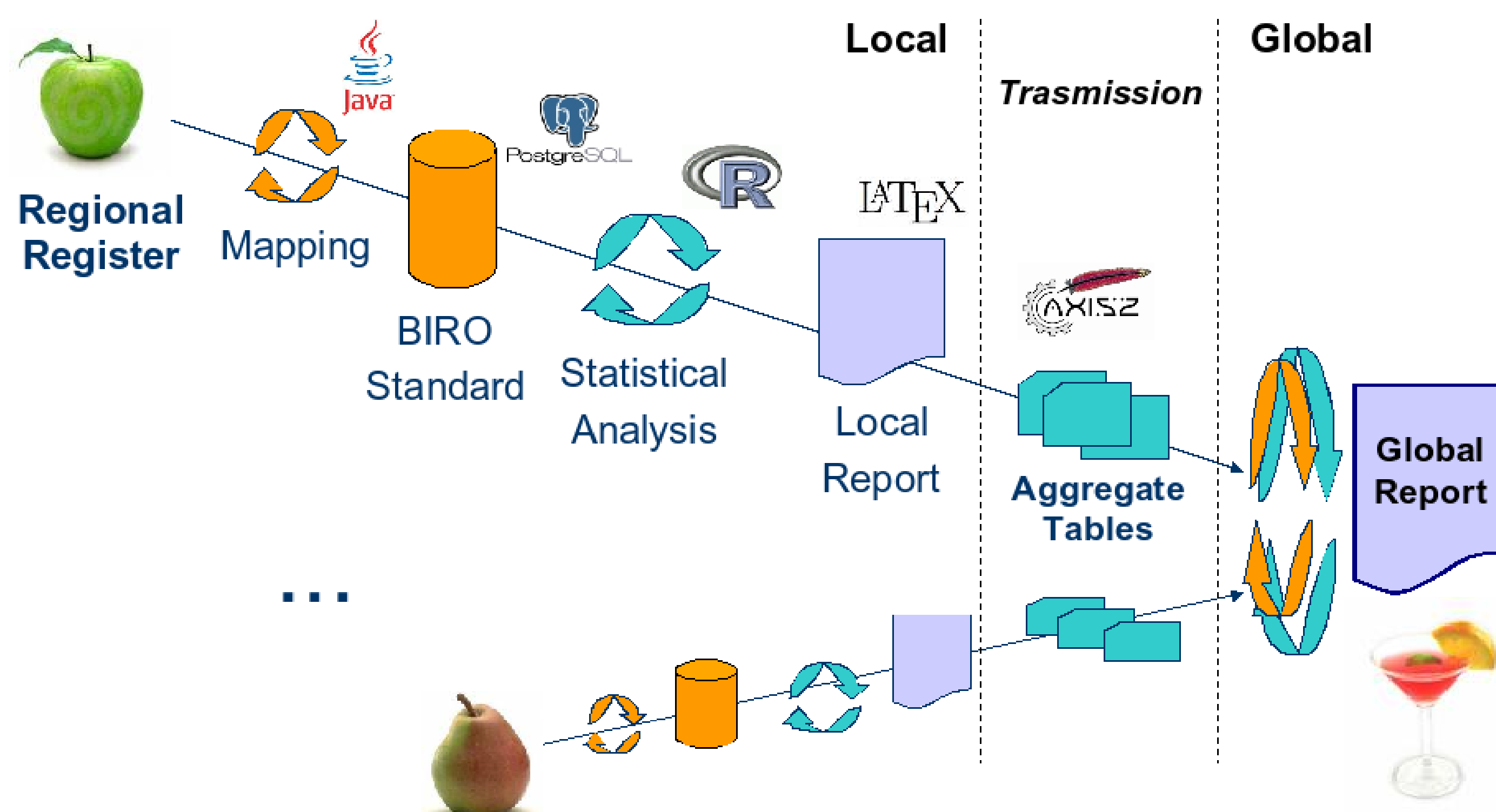


Figure 3. Design of the BIRO System

Main findings

The system has been fully implemented, is stable and shows high levels of performance. The architecture has been designed and validated against principles of the **EU Data Protection Directive** through a formal procedure of **privacy impact assessment** [1]. The uptake is facilitated by a model that is completely based on open source, using Java, PostgreSQL, R, Latex, and various other tools, allowing to embed epidemiological reasoning into a specialized package that runs on Windows/Linux. The application of our standards has been particularly effective in Cyprus: in only three years, the Government created a first diabetes clinic in Larnaca and started a local BIRO registry that now includes over 1,000 patients, announcing the launch of a national network of diabetes clinics. The BIRO system is currently rolled out to partners from 20 EU countries in the framework of its sequel (also funded by DG-SANCO): EUBIROD. The project will consider the subtle implications of fragmented/selected population data implied by the flexible definition of region (required to accept diverse registers), to further refine the statistical engine (Figure 5). Dissemination will be enhanced through a specific activity (the BIRO Academy). Install/usage of the software will be further facilitated through a stand-alone multi platform distribution: "BIROX". Publication of the first EUBIROD Diabetes Report is scheduled for late 2010.

Conclusion

The BIRO system is ideal to connect institutions that have full access to linked databases. It can distribute the workload of statistical analysis and share the results obtained without any information loss or threat to individual privacy. Its general approach can be further applied to other areas, allowing a rapid implementation of European systems of quality indicators in a framework aimed at strengthening population-based analysis.

REFERENCES

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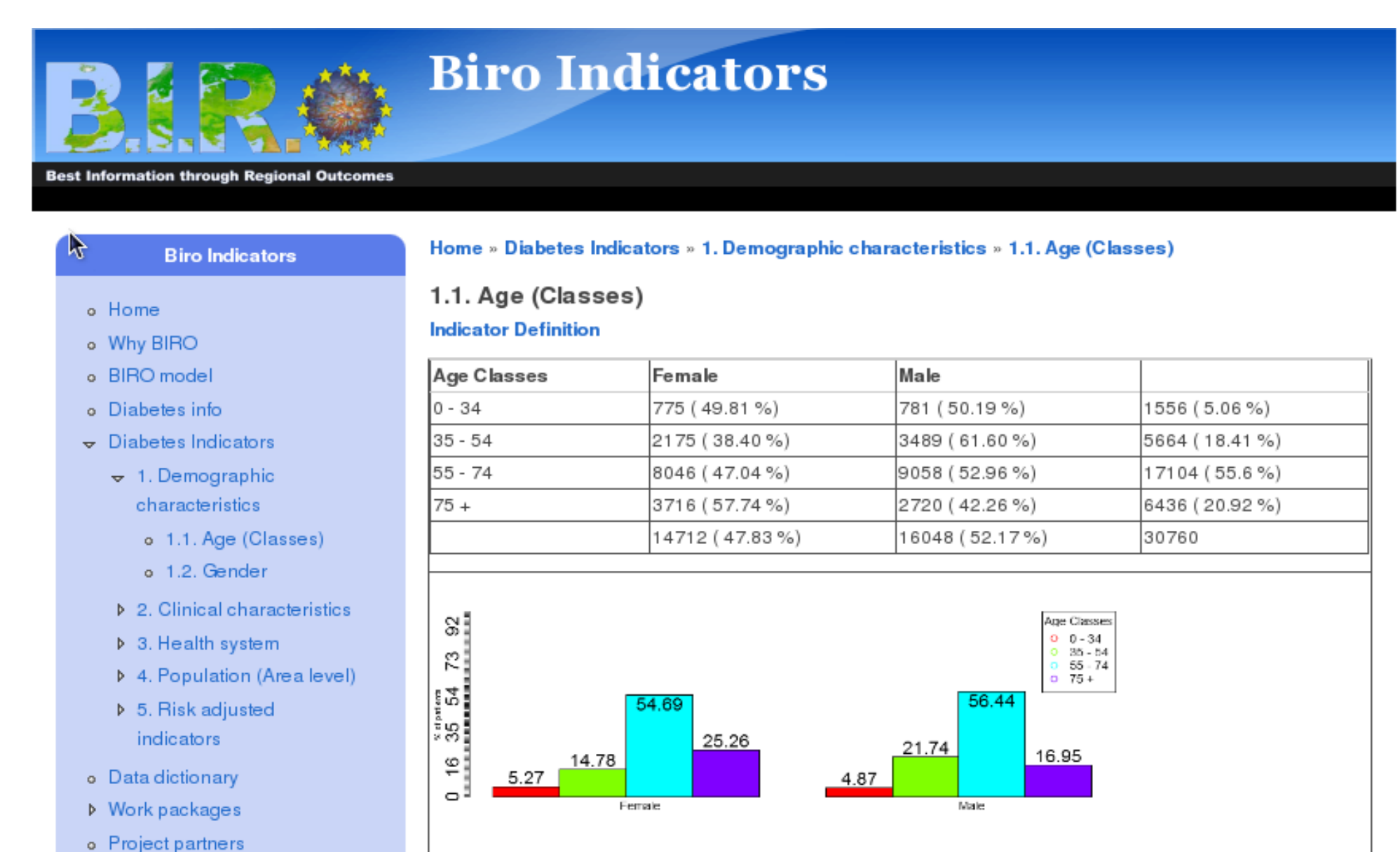


Figure 4. The BIRO Web Portal

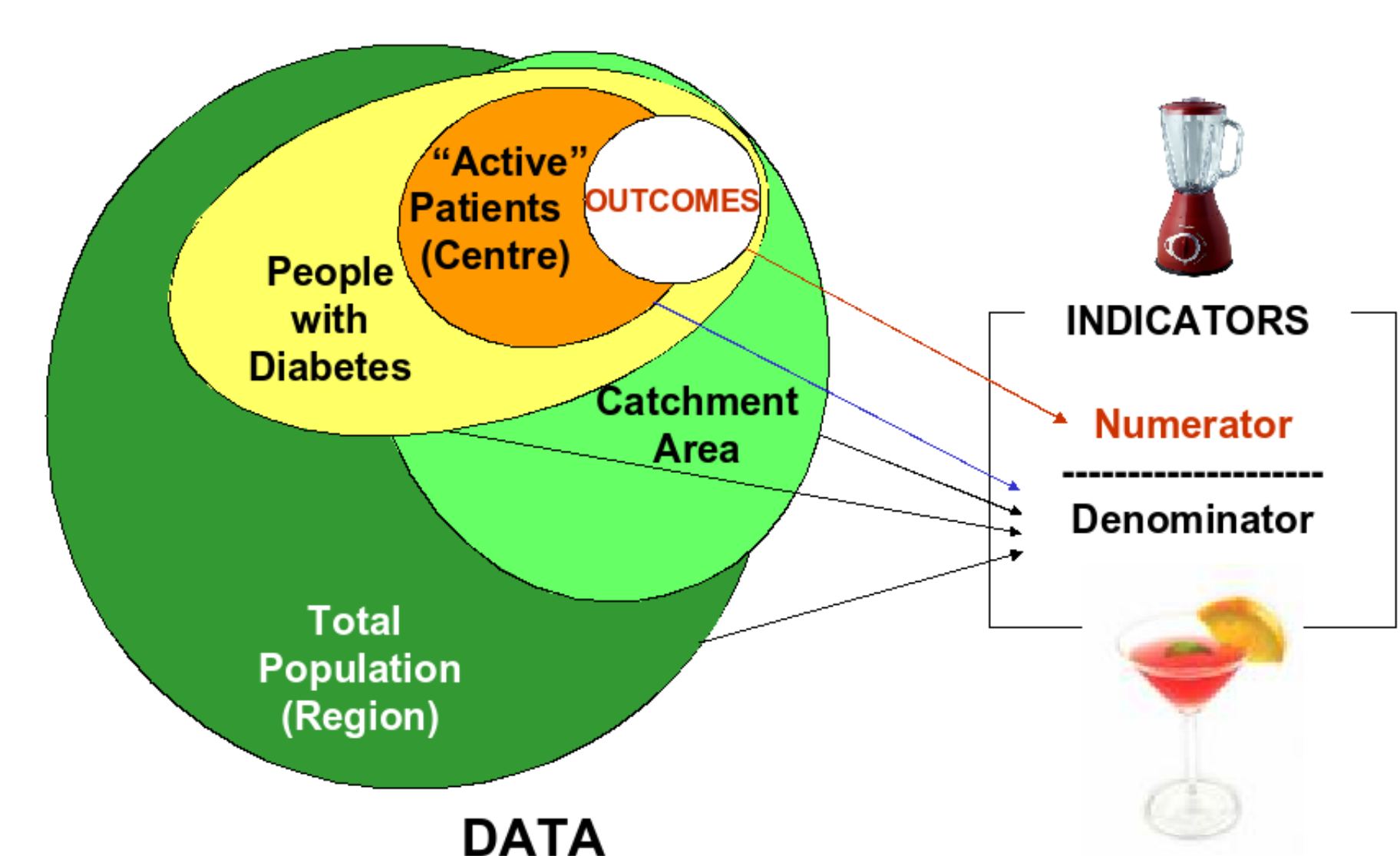


Figure 5. Selection Bias and Population-Based Indicators