

# Diabetes Registry

## Rationale

- Diabetes is a growing burden for the individuals and for the society worldwide
- Diabetes has a relevant effect on Quality of life of the affected individuals, on the social structure and on the economies
- Need for action has been formally and strongly recommended by the major international institutions: WHO and UN, plus a number of regional and national institutions: GCC, EU, etc.
- The recommended action is to be focused on prevention of the disease by multifactorial intervention and on prevention of its complications through early diagnosis and delivery of effective and comprehensive diabetes care.
- The need to monitor the evolution of the disease in its various dimensions and to monitor the quality of care has been identified as the prerequisite for efficient planning and implementation of efficacious preventative programmes of diabetes and its complication.
- Appropriate instruments to fulfil the recommendations for intervention on diabetes are to be made available
- The diabetes registry is to be considered the backbone and the necessary platform for any action to be undertaken

# Diabetes Registry Targets (1)

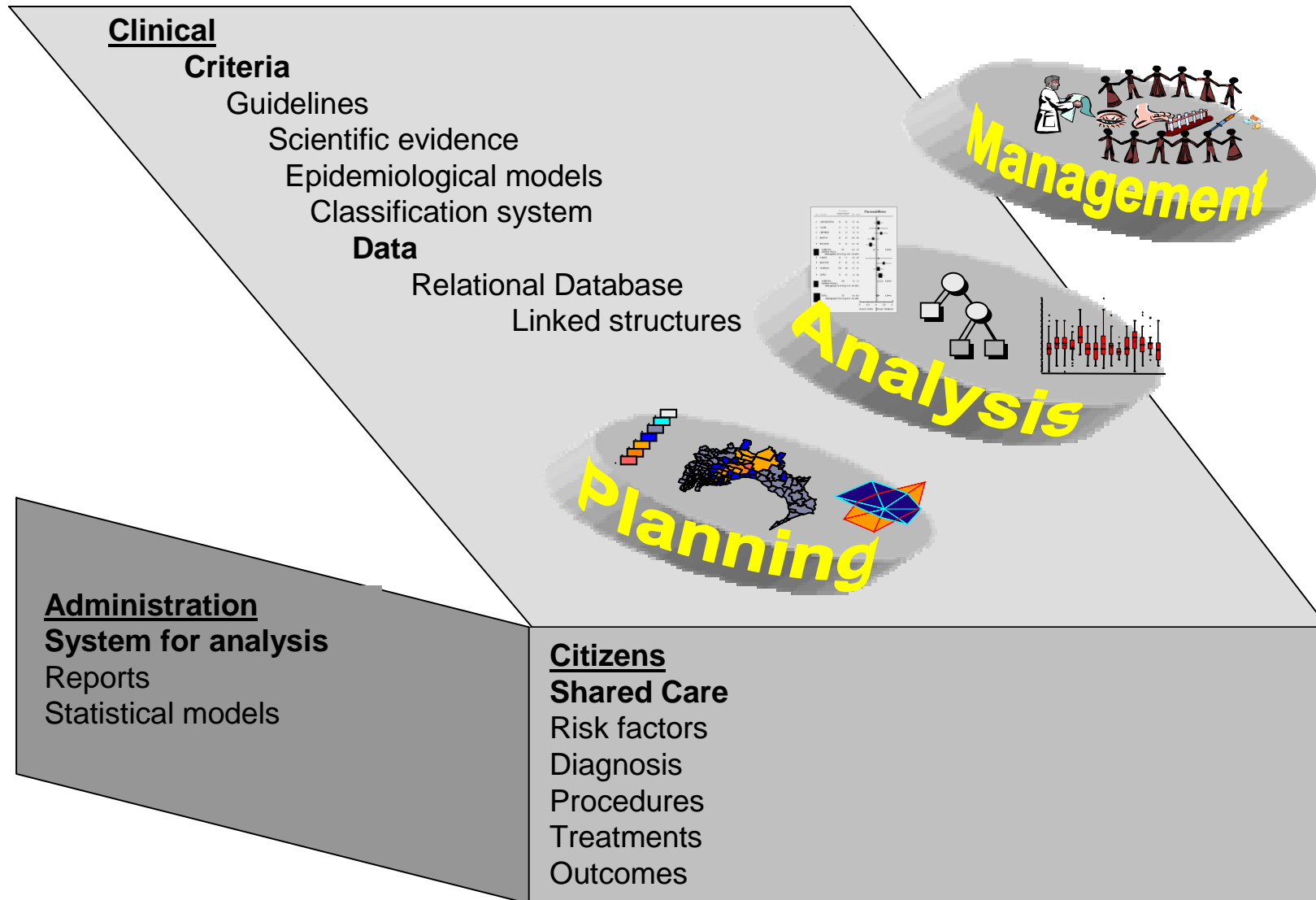
- to provide robust and timely information on Epidemiology of diabetes and its complications;
- to monitor the evolution of the disease and its complications in relation to time, interventions, conditions and changes of the environment;
- to evaluate the quality of care delivered to people with diabetes;
- to estimate the cost of the disease;
- to estimate the cost-effectiveness of the interventions
- to provide a solid platform for diabetes shared care
- to provide an essential tool for diabetes research

## Diabetes Registry Targets (2)

The gathered information are to be made available, as appropriate and with the due restrictions, in suitable format to be used by:

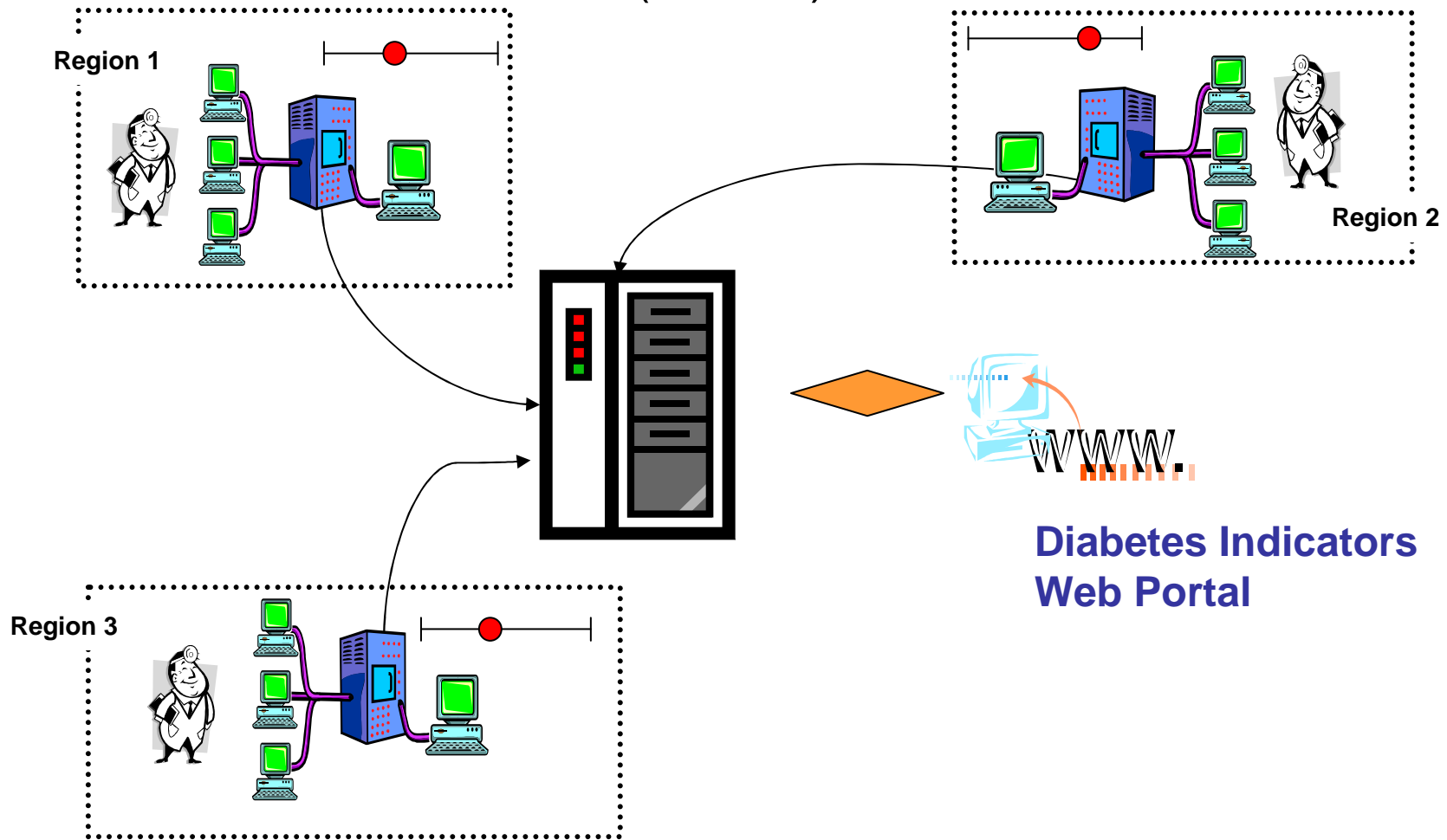
- National policy makers;
- Health care policy makers;
- Health care administrators;
- Health care deliverers;
- diabetes research institutions
- people affected by diabetes;
- the public domain.

# Design for Multilevel outputs

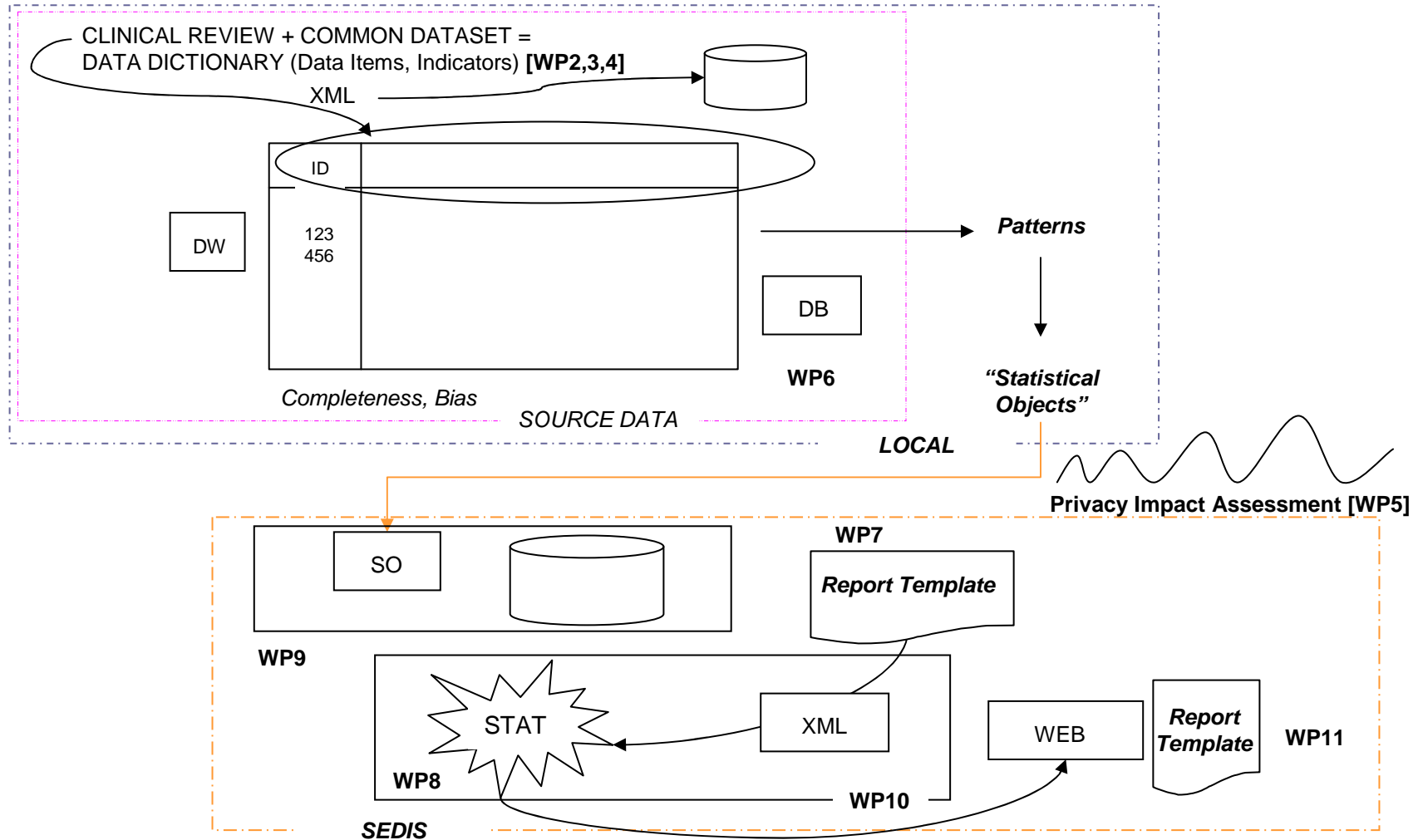


# Design (2) – Information Exchange

## Shared Evidence-Based Diabetes Information System (SEDIS)



# Design (4) - BIRO Technology



# Diabetes Registry Strategy (1)

- The Registry for diabetes is owned by the Ministry of Health
- The Dasman Centre for Research and Treatment of Diabetes (DCRTD) has been given the responsibility by, and will act under the umbrella of, the MoH to secure the development, implementation and maintenance of the Registry according to advanced specific methodologies.
- The Registry for diabetes is a flexible instrument which need to evolve with the evolution of needs, knowledge, technologies and according to the available resources (economical, cultural, structural).
- The original design of the registry need to satisfy such concept which will allow to produce information of progressively increasing complexity as a function of its evolution.
- The evolution of the registry need to guarantee the coherence of the information throughout the time

## Diabetes Registry Strategy (2)

- In any part of the world the design and the evolution of the registry are heavily influenced by the local prevailing culture and processes for the delivery of diabetes care which need to be taken into consideration, but need to be made compatible with an advanced diabetes registry.
- It is to be accepted and taken into consideration that factors outside the Health Care System might interfere with the evolution of the diabetes registry (i.e. the overall communication infrastructures, etc)
- It is consolidated experience that unrecognised and unexpected barriers can jeopardize the success of the diabetes registry.
- A detailed preliminary and careful system analysis is to be carried out in order to prevent such risk.



## Diabetes Registry Strategy (3)

- The planning and the implementation of the registry is a powerful instrument for standardizing the quality of diabetes care in the involved environment.
- The diabetes registry can be successful only if all the relevant stakeholders are involved in its planning and in its realization according to their institutional roles.
- In consideration that the diabetes registry is an ongoing indefinite term activity, formal procedures need to be adopted to prevent any negative influence by the more or less frequent natural turnover of the different stakeholders (Politicians, administrators, professionals)

# Diabetes Registry Strategy (4)

- The collection of data needs to be based on routine clinical practice and to be done automatically without interfering with the usual routine activity nor producing any adjunctive work load to the clinical settings.
- The collection of data need to be based on Information Technology and electronic medical records. Manual input of the data has proven to be the main reason for failure of diabetes registries.
- The production of data in standard electronic format is to be adopted for securing effective interfacing of the different electronic medical records with the registry data base
- The evolution of the registry and the completeness of the data are directly dependent by the capacity of the diabetes care network to produce information.
- A strong policy for the adoption of electronic medical records in routine clinical practice in the diabetes care settings is to be heavily promoted and supported.

## Diabetes Registry Strategy (5)

- The diabetes registry need to be able to accept data produced by the different electronic medical records adopted in the various public and private clinical settings
- Provided that the adoption of identical medical electronic records in the different settings is a non viable option, standardization of the communication procedures is a must.
- Relevant data resident in administrative data bases are to be considered for transfer and inclusion in the diabetes registry.

## Diabetes Registry Strategy (6)

- A comprehensive and specific system for the analysis of the information is to be tailored to fulfil the targets of the registry.
- A precise model for making the information available to the interested constituencies, as appropriate, is to be defined and implemented taking advantage of advanced communication technologies.
- An explicit policy for data protection is to be adopted and implemented

# OPPORTUNITIES FOR A SUCCESSFUL DEVELOPMENT OF DIABETES REGISTRY IN KUWAIT

- Already existing network for Diabetes Care in the country
- Already routinely used Electronic Medical Records in Diabetes Primary Care settings of MoH
- IT diffusely available in Secondary and Tertiary care settings
- Vast administrative data bases possibly available
- B.I.R.O. Technology fully available for data aggregation and processing

The formal process for developing a Diabetes Registry in Kuwait according to the mentioned strategy has already been initiated