BRIDGEHEALTH
BRidging Information and Data Generation
for Evidence-based Health Policy and Research

EUBIROD
NETWORK

Population-based Disease Registries

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UNIVERSITY OF SURREY 4TH BEST UNIVERSITY IN THE UK GUARDIAN LEAGUE TABLE 2016   Athena SWAN Bronze Award

Patient registry
PARENT Joint Action Guidelines (1)

„... an organized system that collects, analyses, and disseminates the data and information on a group of people defined by a particular disease, condition, exposure, or health-related service, and that serves a predetermined scientific, clinical or/and public health (policy) purposes"

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Types of Patient Registries
PARENT Joint Action Guidelines (2)

http://patientregistries.eu/documents/10184/14613/Methodological+guidelines+and+recommendations+for+effici
ent+and+rational+governance+of+patient+registries/5bf3ea46-26ca-4d91-b459-47dce18a8846

Category	Diseases and conditions	Products	Services, events
Object type	chronic, acute communicable, rare diseases, disabilities, cause of death	medicines, devices, equipment	diagnostic, curative, preventive, discharges, births, abortions
Purposes / objectives (primary and secondary)	disease surveillance, control, natural course of disease	post-market surveillance	intervention evaluation, quality of care
	health outcomes (objective, patient reported)		
	effectiveness (clinical, comparative, financial)		
	safety and harm (HTA, vigilance)		
	intervention (planning, guidelines, reminders)		
Coverage (geographical and organizational)	health care unit (GP, hospital)		
	local (counties, districts, insurers, professional associations, NGOs)		
	national (MS, non-MS)		
	international (regional, EU, European region, global)		
Population definition	population (geographically based)[3]		
	population based (exposition dependent)[4]		
Observation unit	patient (user, client, insured party)		
	person with a characteristic of observation	person related device, equipment item	person related event (birth, death,

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Disease registry
PARENT Joint Action Guidelines (3)

„Disease or condition registries are defined by patients having the same diagnosis, such as cystic fibrosis or heart failure, or the same group of conditions such as disability. As an example of an EU project/initiative concerning improving disease registries in terms of defining purposes, legal context, semantic and technical aspects, EUBIROD is mentioned here....Overall, EUBIROD can serve as a good example and model to be re-used for other chronic diseases as well".

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Population registry
PARENT Joint Action Guidelines (4)

„… is a registry that intends to cover all residents in a given geographic area within a given time period. The coverage of the specific registry may, however, be incomplete, but it is nevertheless a population registry if the aim is to include all the individuals in the target population. A population is defined by geographical boundaries, but usually only residents (or citizens)within a given time period are included in the definition.“

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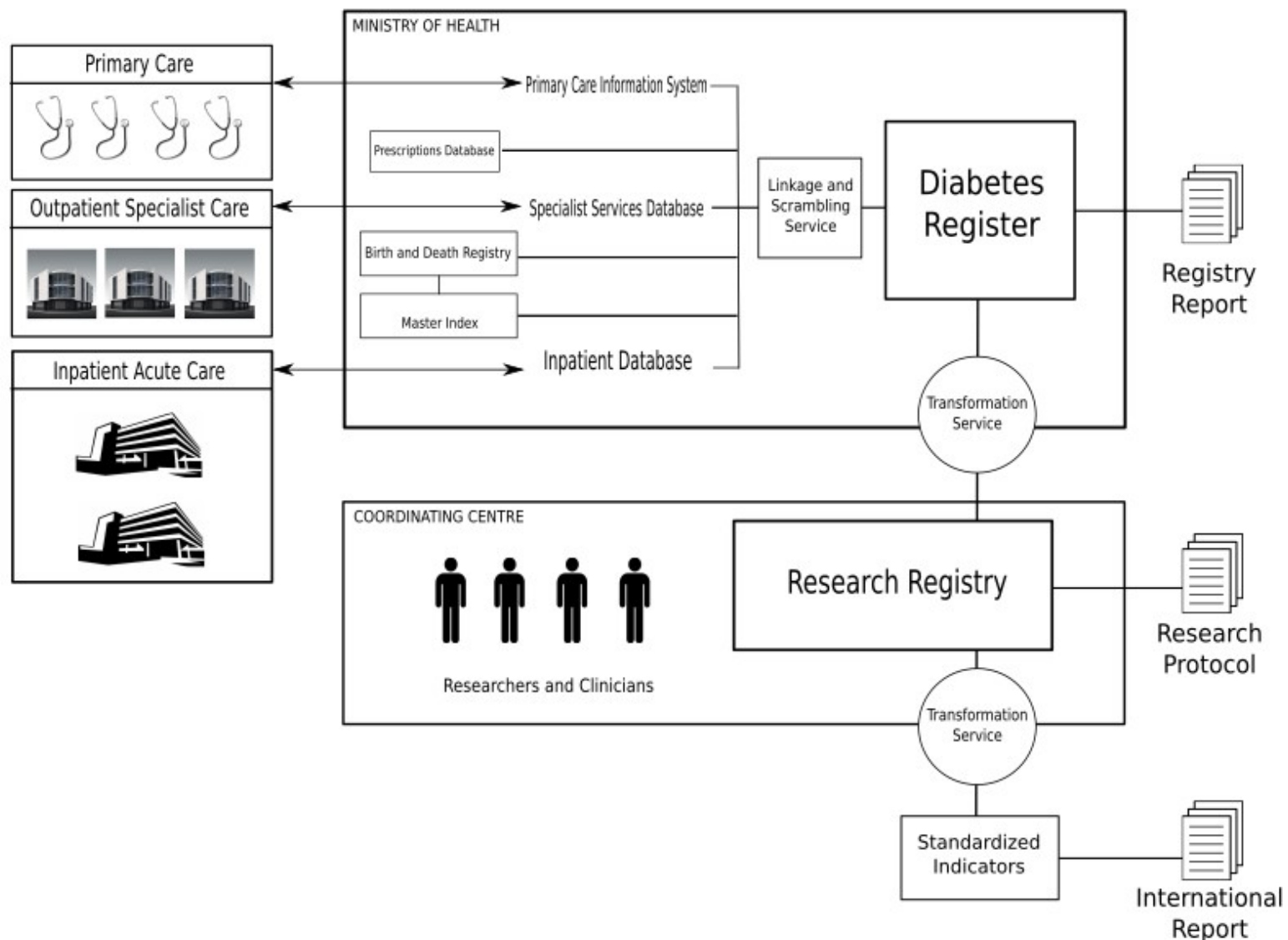SURREY

Population-based registries
PARENT Joint Action Guidelines (5)

„The term 'population-based registry" should be used when all persons with a given trait, exposure or event, are intended to be included in the registry. If the registry includes everyone in the population (even the oldest), it becomes a population registry. Intention rather than performance defines the terms. A population-based disease registry aims at including everyone with the disease in the population, be it self-reported, clinically diagnosed or detected at screening. Population and population-based registries may be further classified as of good or bad quality depending on coverage or other characteristics"

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Structure of an integrated diabetes register

Carinci F, Di Iorio CT, Massi Benedetti M, Standardized information exchange in diabetes: integrated registries for governance, research and clinical practice, in Bruttomesso D, Grassi G (eds), Technological Advancements in the Treatment of Type 1 Diabetes, Front Diabetes, Basel, Karger, vol 24, 1-14, 2014

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Why population-based disease registries?

"Active" Patients (Centre)

OUTCOMES

People with DISEASE

Catchment Area

Total Population (Region)

DATA

INDICATORS

Numerator

Denominator
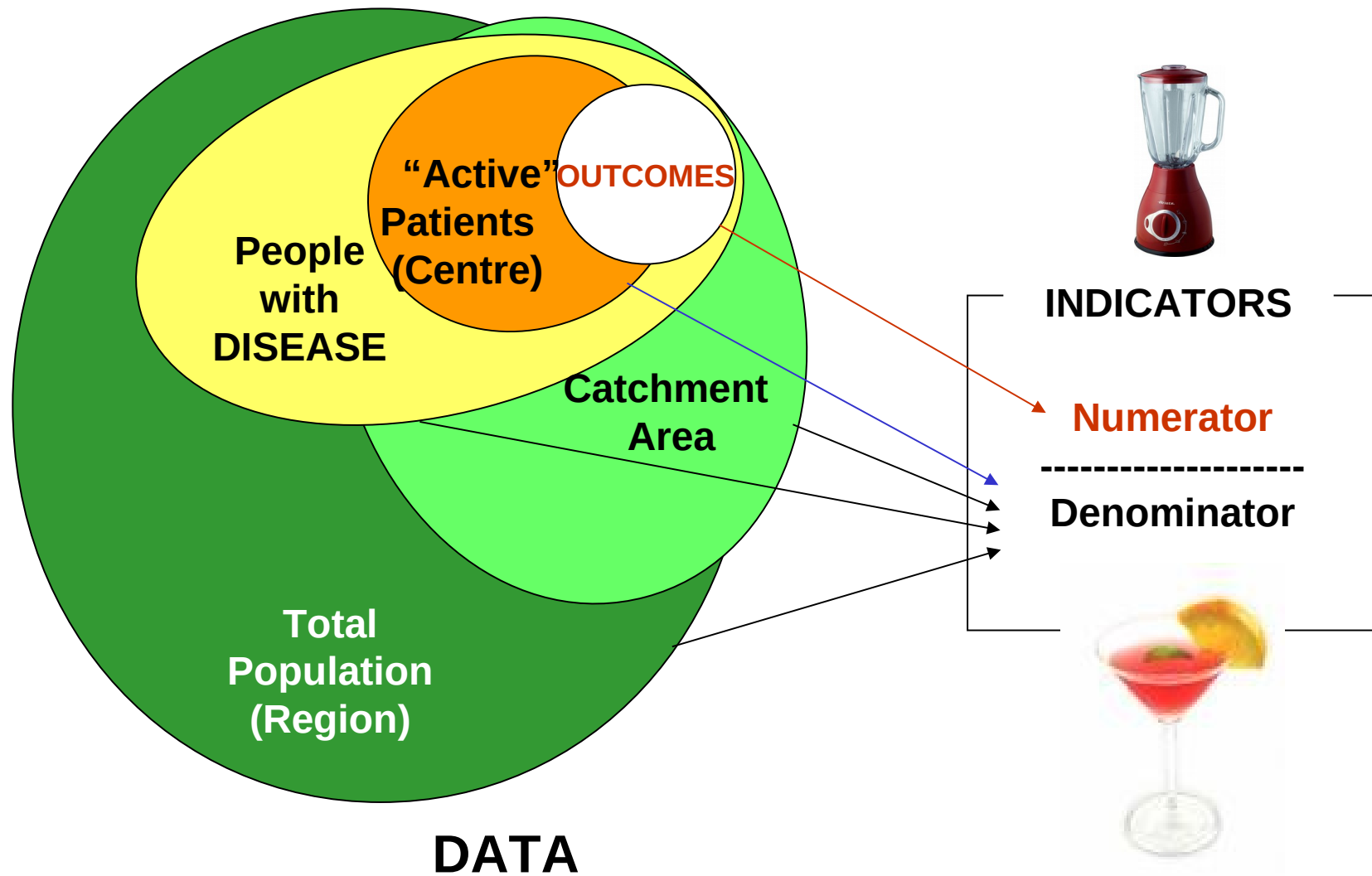
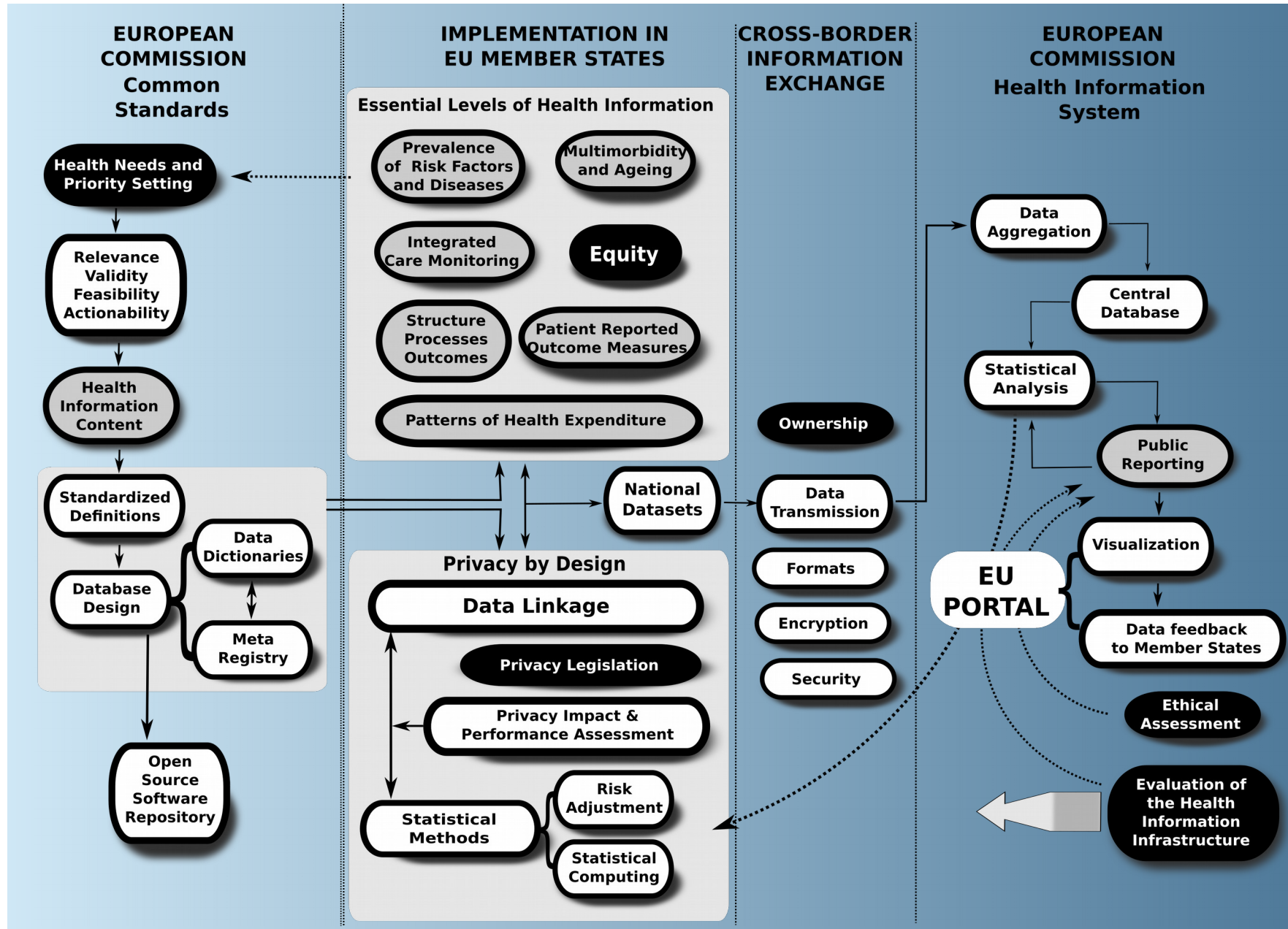# Essential levels of health information in Europe

Carinci F. Health Policy. 2015 Apr;119(4):530-8.

- Recently, the European Commission coordinated a discussion between MS and Expert Networks on how (and whether) to realize the system.

- The idea of „essential levels of health information" originated from this experience

- The conceptual framework proposed in this presentation is an extract from this paper

Essential levels of health information in Europe: An action plan for a coherent and sustainable infrastructure

Fabrizio Carinci [a,b,*]

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A B S T R A C T

The European Union needs a common health information infrastructure to support policy and governance on a routine basis. A stream of initiatives conducted in Europe during the last decade resulted into several success stories, but did not specify a unified framework that could be broadly implemented on a continental level.

The recent debate raised a potential controversy on the different roles and responsibilities of policy makers vs the public health community in the construction of such a pan-European health information system.

While institutional bodies shall clarify the statutory conditions under which such an endeavour is to be carried out, researchers should define a common framework for optimal cross-border information exchange.

This paper conceptualizes a general solution emerging from past experiences, introducing a governance structure and overarching framework that can be realized through four main action lines, underpinned by the key principle of "Essential Levels of Health Information" for Europe.

The proposed information model is amenable to be applied in a consistent manner at both national and EU level. If realized, the four action lines outlined here will allow developing a EU health information infrastructure that would effectively integrate best practices emerging from EU public health initiatives, including projects and joint actions carried out during the last ten years.

The proposed approach adds new content to the ongoing debate on the future activity of the European Commission in the area of health information.

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Essential levels of health information in Europe

Carinci F. Health Policy. 2015 Apr;119(4):530-8.

Bridge Health

Reply to call:

action "2.1.3.3. Towards a sustainable health monitoring and reporting system" of the priority area 2.1.3. Actions under thematic priority 3 –

Contributing to innovative, efficient and sustainable health systems in the Work Programme 2014 of the Public Health Programme of Community action in the field of health (2014-2020).

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Aims

Using the comprehensive experience and assuring a knowledge transfer from past health and research frameworks:

- to work towards an European health information (EU-HI) and data generation networks covering major EU health policy areas:

- comprehensive, integrated and sustainable

- supporting evidence-based health policy and research for the EU and Member States

- providing blueprints and/or concepts of building blocks for a future EU-HI research infrastructure consortium (ERIC-HI)

- to bridge key EU projects in *domains of population and health system monitoring and indicator development, health examination surveys, environment and health, population injury and disease registries, clinical and administrative health data collection systems and methods of health system monitoring and evaluation.*

Generic objectives (1)

- ensure sustainability of key health information activities that have been run under the past EU-health and research framework programmes and enhance synergy among these activities;

- enhance the transferability of health information and data for policy and improve the utility and use of data and indicators for stakeholders in policy making, public health surveillance and health care

- reduce health information inequality within the EU and within MSs

- enhance information on regional variations of indicators, on inequalities and on specific population groups such as children and the elderly

Generic objectives (2)

- develop a blueprint for a sustainable and integrated EU Health information system by developing common methods:

- standardizing the collection and exchange of health information (including meta-data, role of different data sources) within and between domains, between MSs

- ensuring data quality, including procedures for internal and external validation of health indicators

- undertaking priority setting exercises for health information

- addressing ethical and legal issues associated with the collection and use of health data within MSs and the EU.

Structure
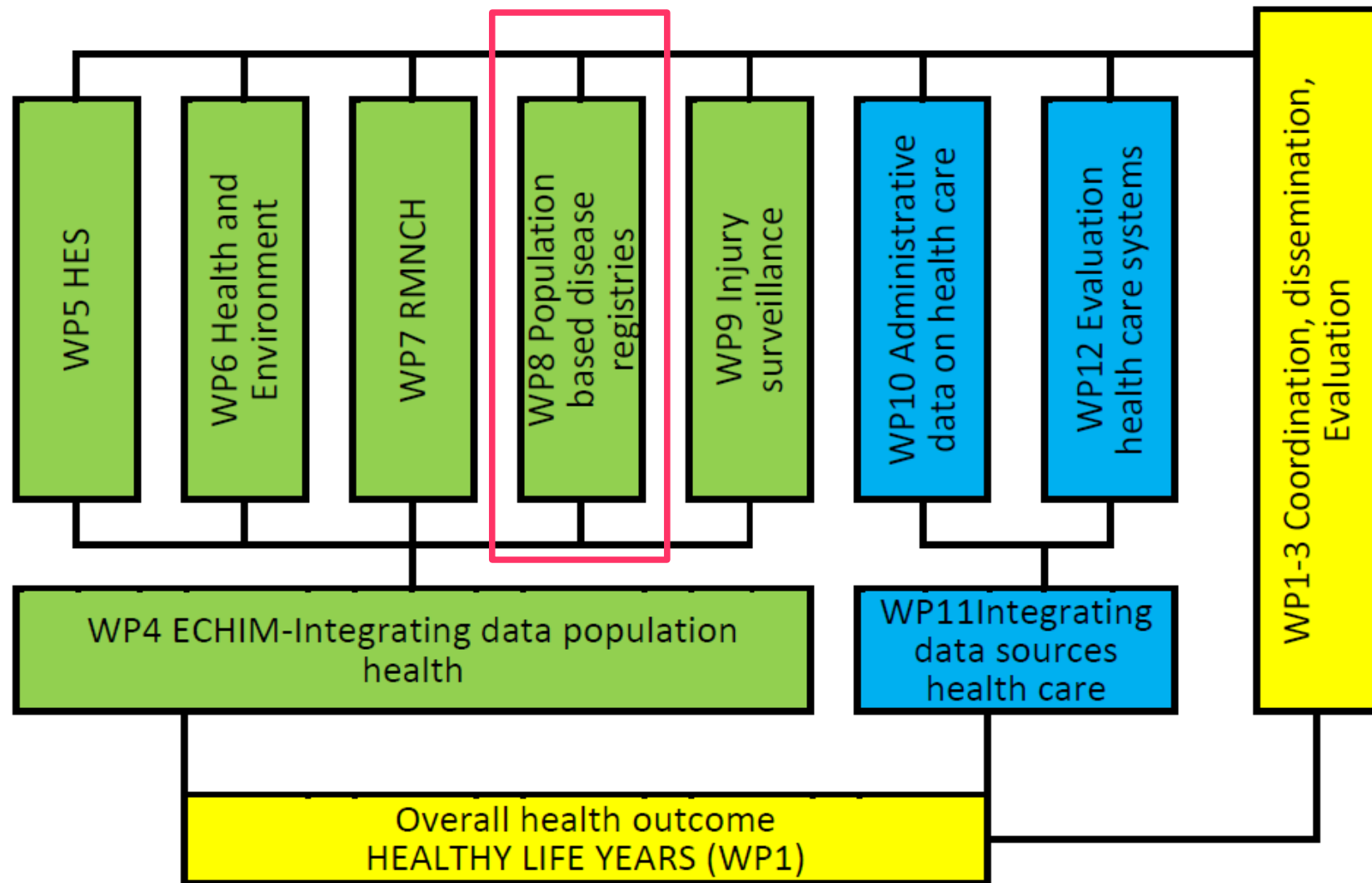
EUBIROD duties

WP8 (ISS)

M12, M24: 2 EUBIROD Network Meetings

M18 (Draft) - M30 (Final): Blueprint of open source software platform for population-based chronic diseases registries, based on the BIRO experience (UNITOV)

M18 (Draft) - M30 (Final): Manual of requirements and technical specifications for users and programmers (UNITOV)

WP10 (IACS)

M18: 1 Privacy Assessment Meeting

M24: Technical manual chapter on ethical and legal issues

WP11 (THL)

M30 Privacy impact assessment. Assessment of legal issues related to the approaches: contribution to the blueprint. **(THL)**

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Thanks for your attention

Questions..

Guildhall clock, Guildford, Surrey, UK

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