

# Global GS1 Healthcare Conference

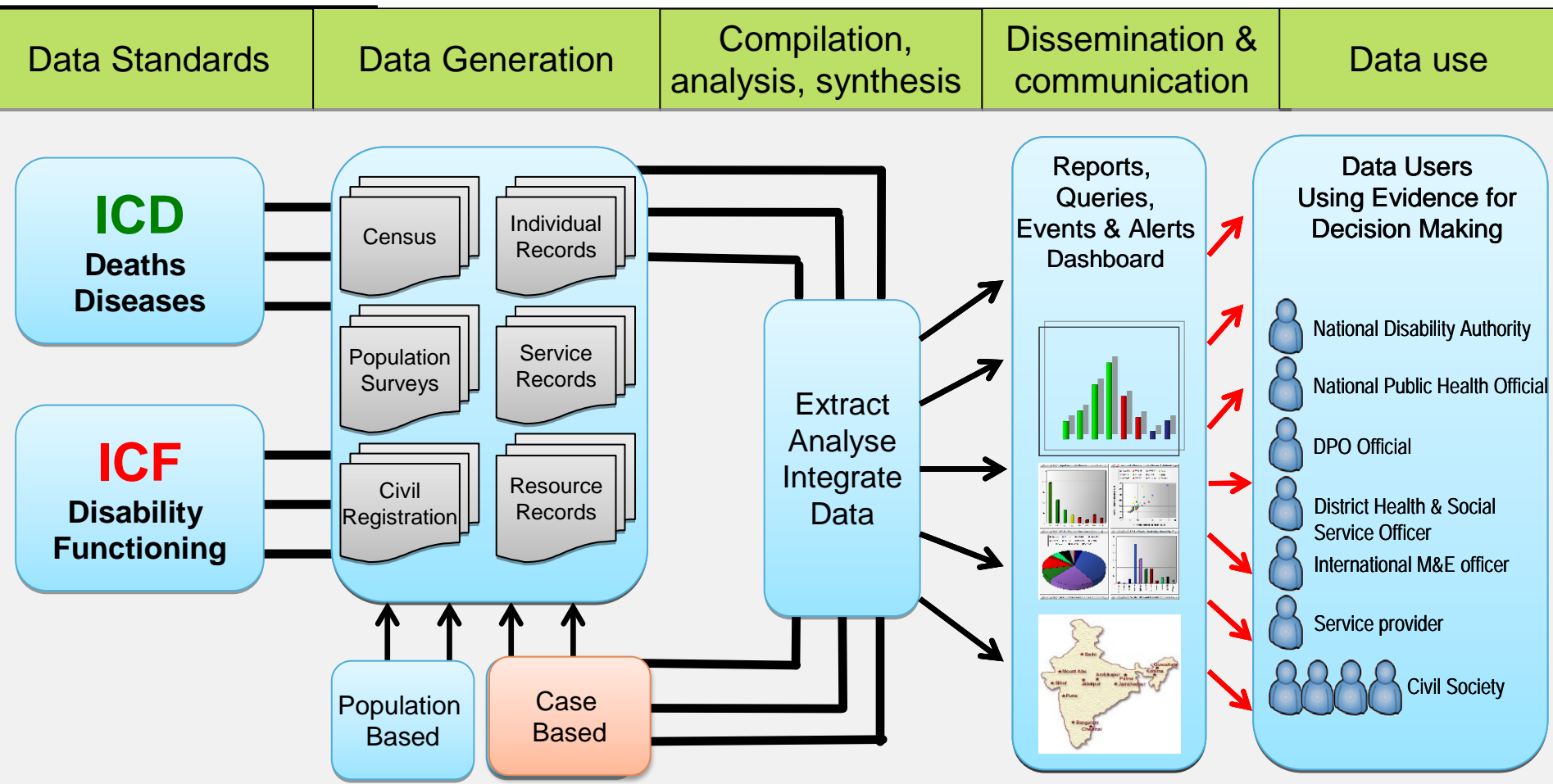
22-24 June 2010, Geneva Switzerland

## Building blocks of health information: Classifications, terminologies, standards

Bedirhan Ustün & Nenad Kostanjsek  
WHO Geneva

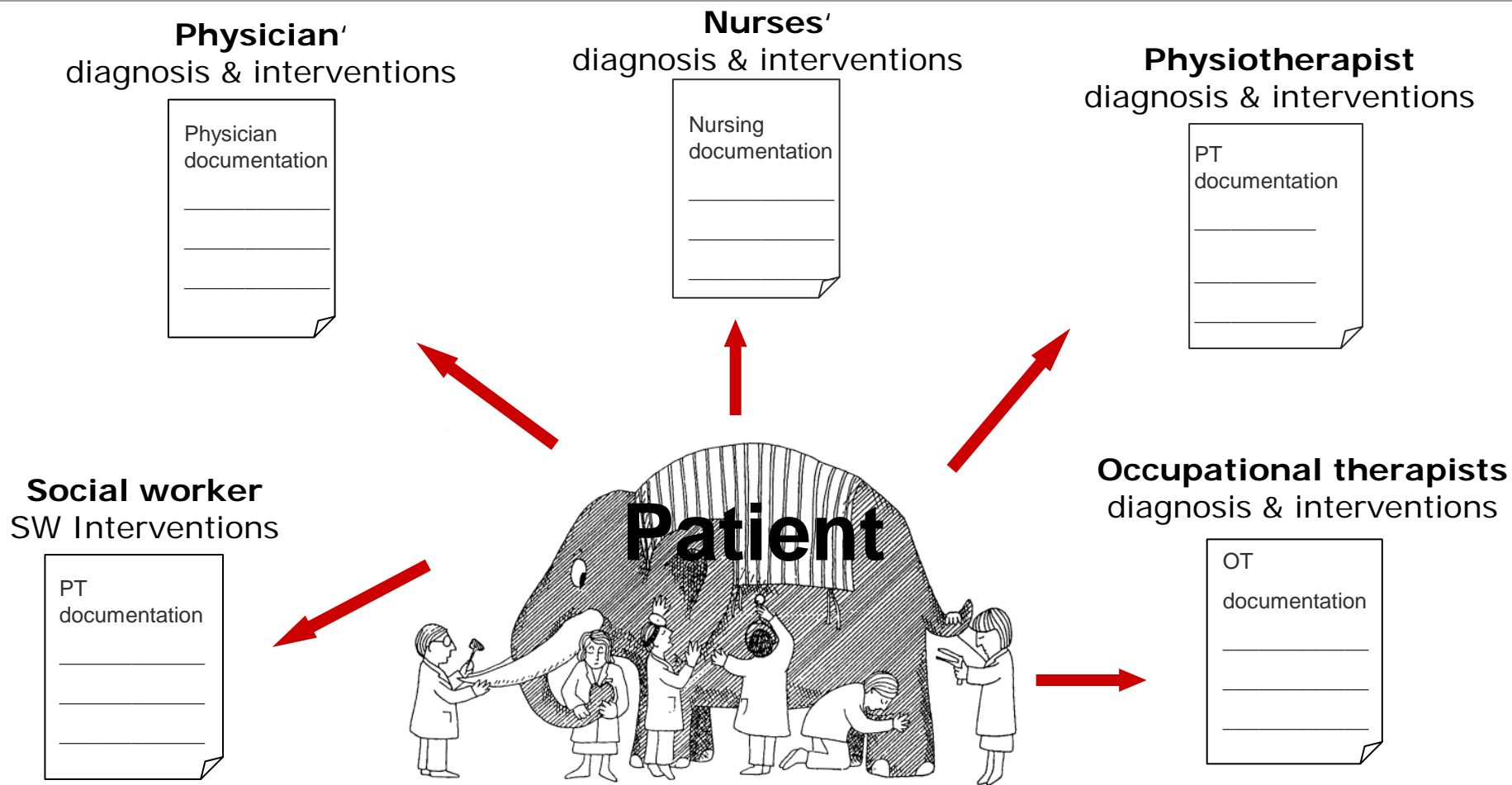


# WHO FIC = data standards for health information



Policies, Resources and Processes

# Information challenges in health care practice



Home	Public Health Mapping and GIS
About WHO	<a href="#">WHO &gt; Programmes and projects &gt; Public Health Mapping and GIS &gt; Tools</a>
Countries	<a href="#">B printable version</a>
Health topics	
Publications	The HealthMapper
Data and statistics	The HealthMapper is a surveillance and mapping



OpenMRS is a source, enterprise system framework constrained here welcome to code whether by im

ESRI GIS and Mapping

Home Products Services Industries

57 Better Decisions Through Modeling a Geographic Information System

66 67 68 69

GIS: Getting Started

Essential Information for

- Executives
- GIS Practitioners
- IT Professionals
- Developers
- New Users
- Educators
- Business
- Government

ESRI and GIS Technology Trends in GIS

Learn the Basics What is GIS?

User Community

Join the ESRI user community network of GIS colleagues and grow your expertise.

Get Connected

National Notifiable Disease Surveillance System

Data Systems

Public Health Surveillance

DevInfo

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DevInfo 5.0 Released

DevInfo 5.0, a powerful new version of DevInfo, has been released. This new version operates both as a desktop application and on the web. It delivers significant enhancements for easy access to information on human development. The system has been developed under UN partnership and is distributed royalty-free to all end users. Now national statistics offices, UN agencies, donors, NGOs and civil society can prepare reports ...more

DevInfo Adaptations

...more

- Web-enabled user interface
- Compliance with ISO metadata standards
- Enhanced map labeling with nudging

DevInfo and International Standards

The new version of DevInfo, version 5.0, includes significant advancements in handling metadata. It conforms to standardized information sharing models for metadata storage and dissemination. These metadata standards help achieve...more

DevInfo Showcased at the OECD World Forum in Istanbul

Organization for Economic Co-operation and Development (OECD) hosted the Second World

DevInfo Online

Download Epi Info 3.4.

Web Install (more info)

Download Setup.exe

Installation instructions

g the world against AIDS

enlish | français | español | русский | Language disclaimer

ORS PARTNERSHIPS KNOWLEDGE CENTRE

Search

on System

to a need for an information system to assist that a system was needed to facilitate overall at country level. In response to these needs, of projects, routine monitoring at subnational and of data exchange.

2007, 23 countries had adopted it for monitoring of a national monitoring infrastructure.

Download Epi Info 3.4.

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Installation instructions

FIRSTGOV

CDC

This

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To date, our clients have included NGOs, governmental organizations, academic institutions, businesses, and passionate individuals. To learn more about our international and research projects, visit our [projects section](#).

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RTM 0.3

# Health information challenges

- **DATA SOURCES:** Increasingly complex and multiple sources
  - Heterogeneous: *Variations in conceptual frameworks*
  - Incomplete: *not the whole population is covered*
  - Non-comparable: *no mechanism to assure that entities/properties are comparable*
- **DATA PROCESSING:** Aggregation
  - Which public health indicators? *Relevant concepts are not agreed upon*
  - How do you combine data? *Different sources of data & logic not fully specified - transparent*
  - Mechanisms not automated: *Meta data and other relevant structured formalism are not fully specified*
  - input – output specifications: *Norms and standards are not fully identified*
- **QUALITY:** Reliability and Quality Assurance
  - Possible error sources
  - Coverage & completeness
  - Possible duplication and delay
  - Audit trails
- **PARTICIPATION:** involvement and empowerment of citizens
  - Privacy Protection
  - Prevention of misuse



# Health Information Systems

## Requirements for Digitalization

- **Common *terminology* → *ontology***
  - Universal descriptions for
    - genes, molecules, cells, diagnostic methods, signs, symptoms, interventions and other entities.
- **Common *structure***
  - Information models
    - Disease, disability, risk factors, interventions
- **Common *reporting methods***
  - casemix groupings
  - resource groupings
  - outcome measurement systems.



# Constraints in the real world

- Human variability
  - People can't always interoperate
    - Machines will never interoperate better than the people that use them
- Too many requirements ... so priorities unclear
  - Intimately intertwined with EHRs, Public health, Decision support, Clinical care...
- Poor match of problem space & solution space
  - Poor definition of purpose
    - "What's it for?"
- 20 years of intensive work in IT has not yet provided a solution
- Temptation to do more than is possible



# WHO classification development in the 20<sup>th</sup> Century

## Construction of ICD-10 & ICF:

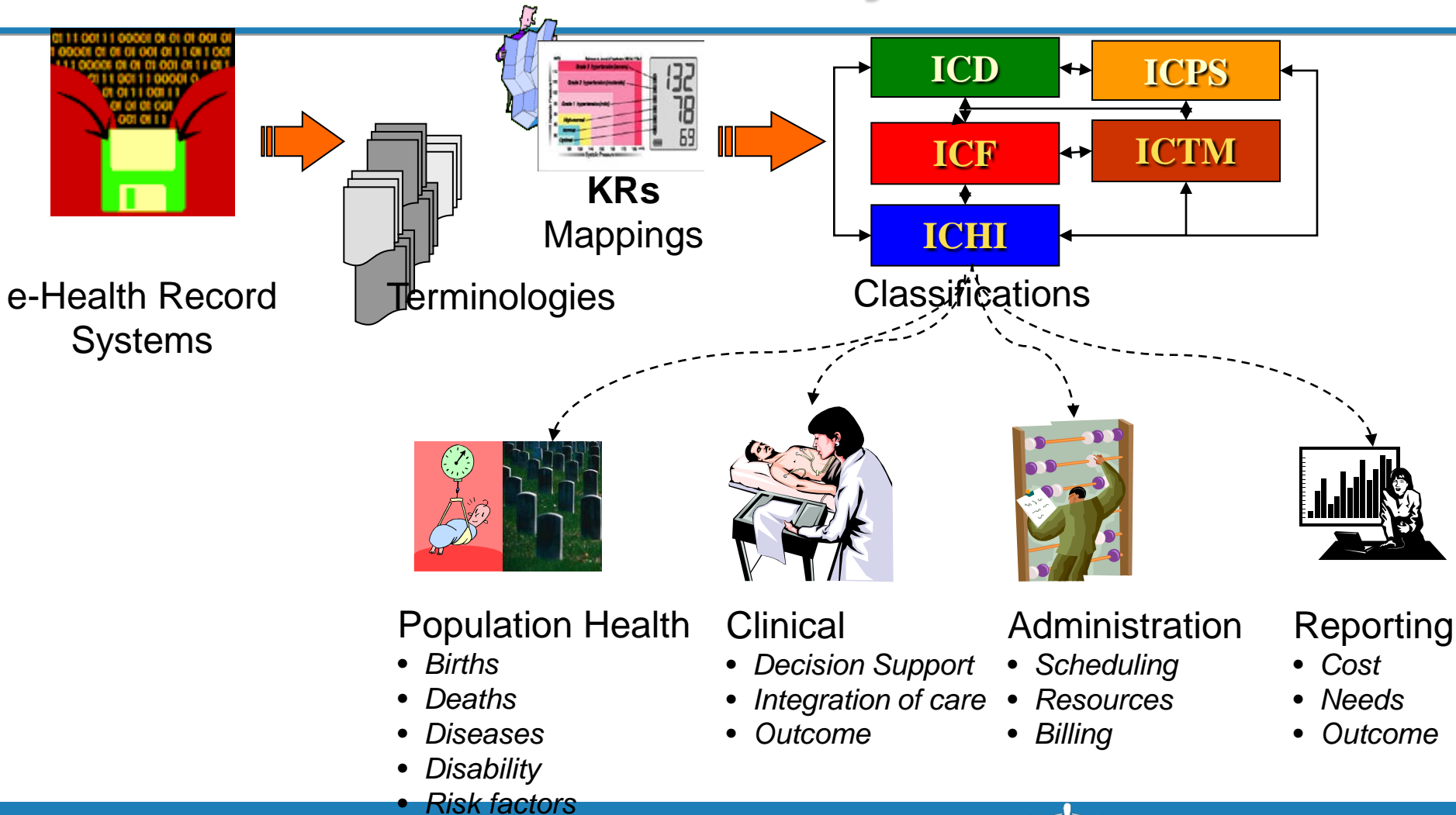


- ICD: 8 Annual **Revision Conferences** (1982 - 89)  
ICF: 7 int. & 38 nat. **Revision Conferences** (1994 - 2001)
- **ICD: 17 – 58 Countries** participated
  - 1- 5 **person** delegations
  - mainly **Health Statisticians**
- **ICF: 61 Countries** participated
  - 1- 5 **person** delegations
  - Multi-disciplinary
- **Manual** curation
  - List exchange
  - Index was done later
- "Decibel" ? Method of discussion
- ICF: Concept driven
- Output: **Paper** Copy
- Work in **English** only
- ICD: **Limited testing** in the field  
ICF: drafts **translated** into / **tested** in **27 languages**
- post-coordinated development of linkages to related classification, terminologies and assessment instruments





# Placing WHO Classifications in HIS & IT of the 21<sup>st</sup> Century



# The desiderata for a WHO FIC in 21st Century

- Evolve a **multi-purpose** and **coherent** classification which is
  - **consistent** yet **adaptable** and **interoperable** across
    - different uses (public health, service management, research)
    - the spectrum of health care (Primary, Secondary, Tertiary)
    - in developing and developed countries
  - compatible with other **WHO classifications**
- Serve as an **international** and **multilingual** reference standard for scientific **comparability** and **communication** purposes
- Ensure that ICPS will function in an **electronic health records** environment.
  - **Link WHO FIC logically** to underpinning **terminologies** and **ontologies** (e.g. SNOMED, GO, ...)
  - WHO FIC categories “**defined**” by “**logical operational rules**” on their associations and details



# WHO FIC deliverables

1. **Print versions** "fit for purpose" in multiple languages
2. **Web Portal** that allows to
  - **access and browse** the classification with definitions, descriptive characteristics and semantic linkages with other WHO FIC classification and related terminologies
  - **maintain and update** classification using a Collaborative Authoring Tool with established workflows
3. **formalized language**: Logical and machine readable knowledge representation of WHO classification entities (concepts with attributes) and their relationships



# Key workstreams & elements for developing WHO FIC

- Use cases
- Content model (parameter & value set)
- Population & peer review of content model
- Web based collaborative authoring tool (iCAT)
- Ontology development



# Use Cases

- Who are the **users**: ( Actors, settings, instances...)
- How do they **currently use classifications?**
  - Inputs
  - Process
  - Outputs
- What can be done to **improve the use?**
- Identify **requirements** for WHO FIC

# What is a Content Model (CM)?

- Captures the **key parameters** for the definition of an classification entity
  - *What is a concept – **entity** in a classification?*
  - *How do you define it: basic **attributes**?*
  - *What different **values** it can take?*
- in a **standard & systematic** way



# What is a CM Parameter ?

- A group name for **Common Characteristics** / Attributes
- Which describes a **particular component or perspective**
  - kind, scope, size, location, origin, ...
- Useful to understand the entity mentally and define it in an **unambiguous** way
- Refer to the entities in a **systematic** way
  - Allow **sorting** into classes, **grouping**, indexing, searching...
  - Useful to teach computers (*also humans !!*)



# Example Parameters

- Symptoms and Manifestations
  - signs, symptoms and findings
- Etiology
  - underlying explanatory mechanism(s)
- Course and Outcome
  - distinct pattern of development over time





# What is a Value Set?

- This **list of possible terms** or options within each parameter
  - Every word, phrase, or statement that can be used by a computer and a human to describe a diagnostic entity or intervention



# Example Value Sets – Body Systems

- Cardiovascular System
- Digestive System
- Endocrine System
- Integumentary System
- Musculoskeletal System
- Neurological System
- Reproductive System
- Respiratory System
- Urinary System



# Why do we need a Content Model?

- To organize knowledge in a consistent, structured way
- To facilitate efficient and productive drafting
- To prepare for computerized terminologies and ontologies
  - Electronic Health Records
- To ensure the most useful document for end-users



# ICD 11 is no longer just lists...it is based on a content model

A000	Cholera due to <i>Vibrio cholerae</i> 01, biovar cholerae
A001	Cholera due to <i>Vibrio cholerae</i> 01, biovar eltor
A009	Cholera, unspecified
A0100	Typhoid fever, unspecified
A0101	Typhoid meningitis
A0102	Typhoid fever with heart involvement
A0103	Typhoid pneumonia
A0104	Typhoid arthritis
A0105	Typhoid osteomyelitis
A0109	Typhoid fever with other complications
A011	Paratyphoid fever A
A012	Paratyphoid fever B
A013	Paratyphoid fever C
A014	Paratyphoid fever, unspecified
A020	<i>Salmonella</i> enteritis
A021	<i>Salmonella</i> sepsis
A0220	Localized salmonella infection, unspecified
A0221	<i>Salmonella</i> meningitis
A0222	<i>Salmonella</i> pneumonia
A0223	<i>Salmonella</i> arthritis
A0224	<i>Salmonella</i> osteomyelitis
A0225	<i>Salmonella</i> pyelonephritis
A0229	<i>Salmonella</i> with other localized infection
A028	Other specified salmonella infections
A029	<i>Salmonella</i> infection, unspecified
A030	Shigellosis due to <i>Shigella dysenteriae</i>
A031	Shigellosis due to <i>Shigella flexneri</i>
A032	Shigellosis due to <i>Shigella boydii</i>
A033	Shigellosis due to <i>Shigella sonnei</i>
A038	Other shigellosis
A039	Shigellosis, unspecified
A040	Enteropathogenic <i>Escherichia coli</i> infection
A041	Enterotoxigenic <i>Escherichia coli</i> infection

Details for I21 'Acute myocardial infarction'

Clinical Description | Diagnostic Criteria | Causal Mechanism and Risk Factors

**Body System:**

label	Ontology			
Circulatory System		X		

+ Add new value

**Body Part:**

label	Term ID	Link			
Myocardium structure (body structure)	74281007		X		
Entire heart	<a href="http://ihtsdo.owl/snomedct">http://ihtsdo.owl/snomedct</a>		X		

+ Find term  
+ Add term

**Signs and Symptoms:**

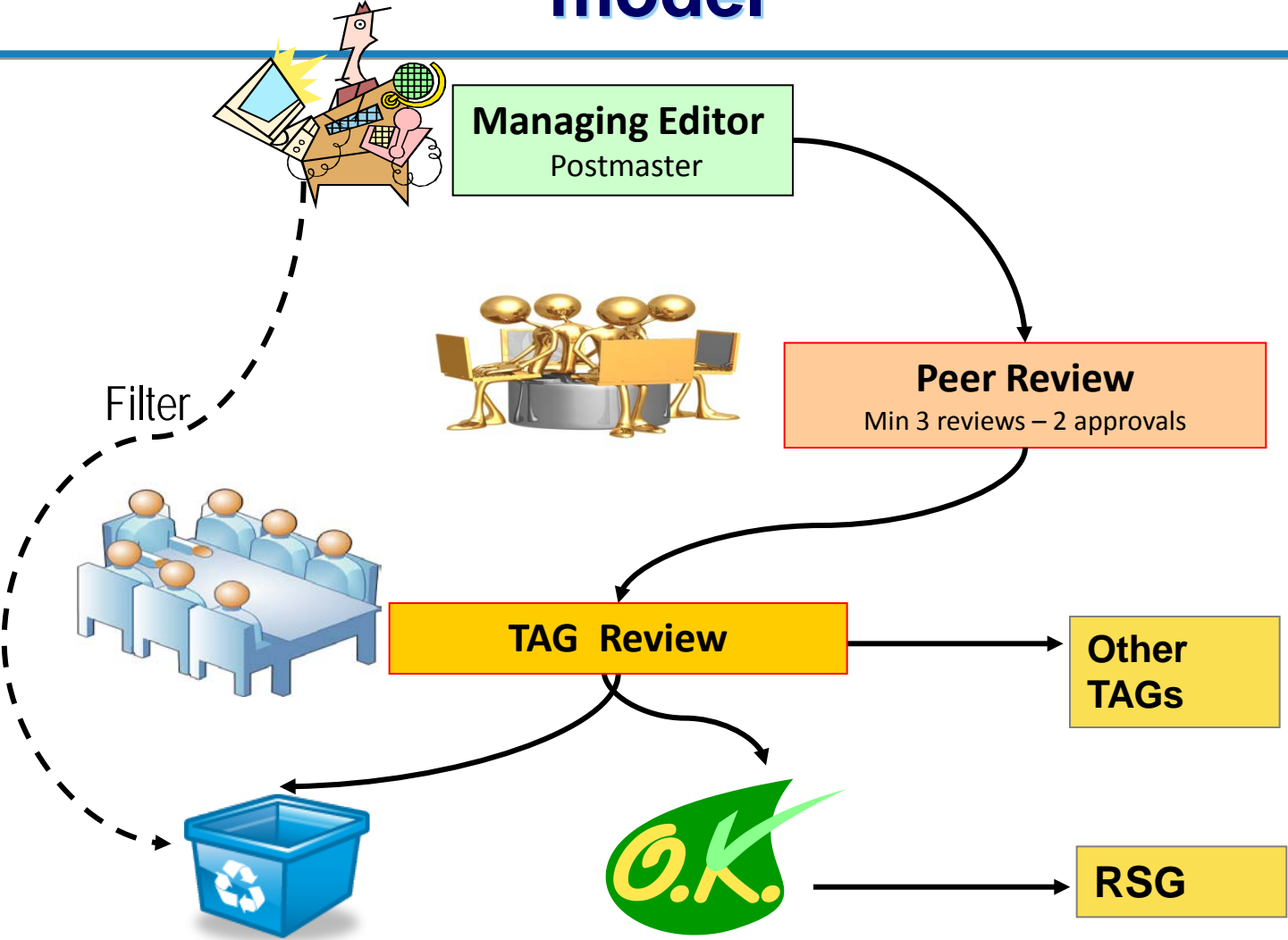
label	Term ID	Link			
Chest pain	139228007		X		
Shortness of breath	267036007		X		

+ Find term  
+ Add term

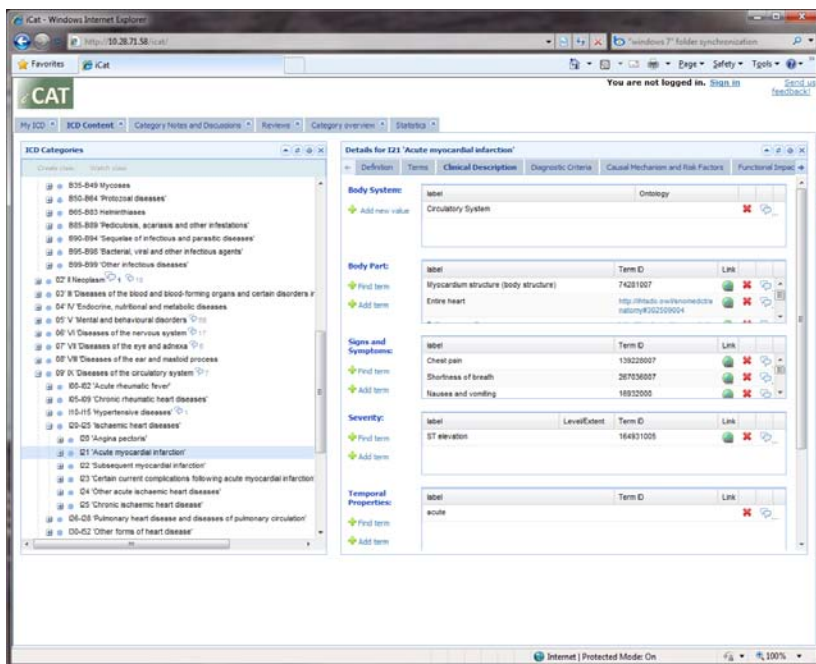




# Populating and reviewing the content model



# Web based collaborative authoring tool (iCAT)



- **display & browse** taxonomy with its content model rubrics
- allow user to **comment** on the content
- allow users **editing** the content and facilitate the use of value sets derived from other classifications and terminologies
- allow user **restructuring** the classification
- Incorporates **multiple level of user access**
- supports **multilingual** representation
- **ontology** tooling interface with description logic technology

# An Ontology for WHO FIC

- **ENTITIES:**

- categorization of information
  - using a standardized set of concepts
  - with agreed definitions
  - Uniquely identified terms
- based on explicit **attributes/values**

- **RELATIONS:**

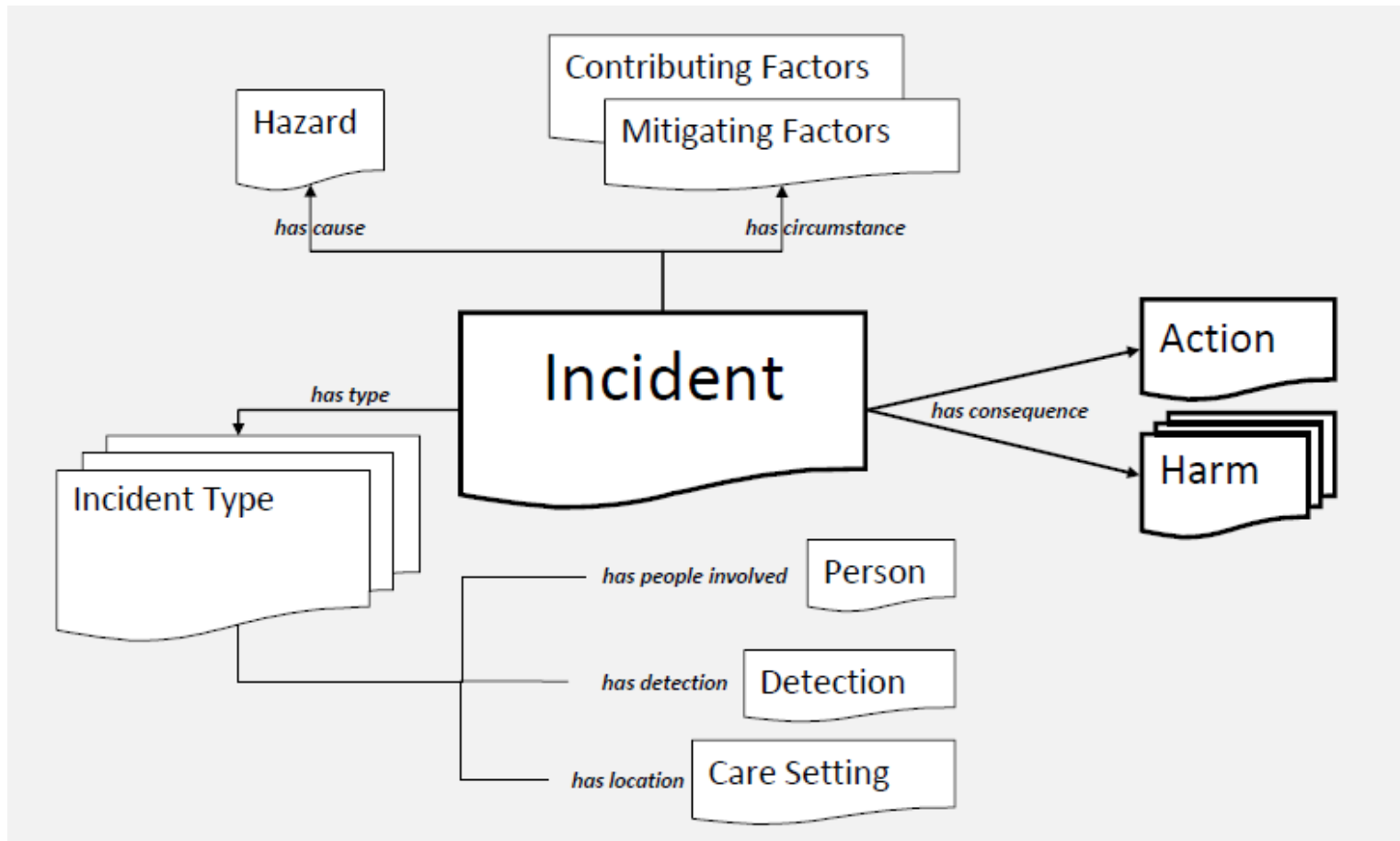
- **relationships** between the key concepts





# ICPS Incident Concept

as proposed in ICPS categorial model



# What difference ontologies can make?

## Coding cycling accident in ICD-10



- V12.24 Pedal cyclist injured in collision with two- or three-wheeled motor vehicle, unspecified pedal cyclist, non-traffic accident, while resting, sleeping, eating or engaging in other vital activities

# The history of cycling codes

- 1972 ICD-9 (E826): 8 codes
- READ-2 (T30..): 81 codes
- READ-3: 87: 82 codes
- 1999 ICD-10: 587 codes



# Defusing the exploding bicycle: 500 codes in pieces

- 10 things to hit...
  - Pedestrian / cycle / motorbike / car / HGV / train / unpowered vehicle / a tree / other
- 5 roles for the injured...
  - Driving / passenger / cyclist / getting in / other
- 5 activities when injured...
  - resting / at work / sporting / at leisure / other
- 2 contexts...
  - In traffic / not in traffic

V12.24 Pedal cyclist injured in collision with two- or three-wheeled motor vehicle, unspecified pedal cyclist, nontraffic accident, while resting, sleeping, eating or engaging in other vital activities



# Conceptual Lego... it could be...

## Goodbye to picking lists...

Structured Data Entry

File Edit Help


### Cycling Accident

What you hit

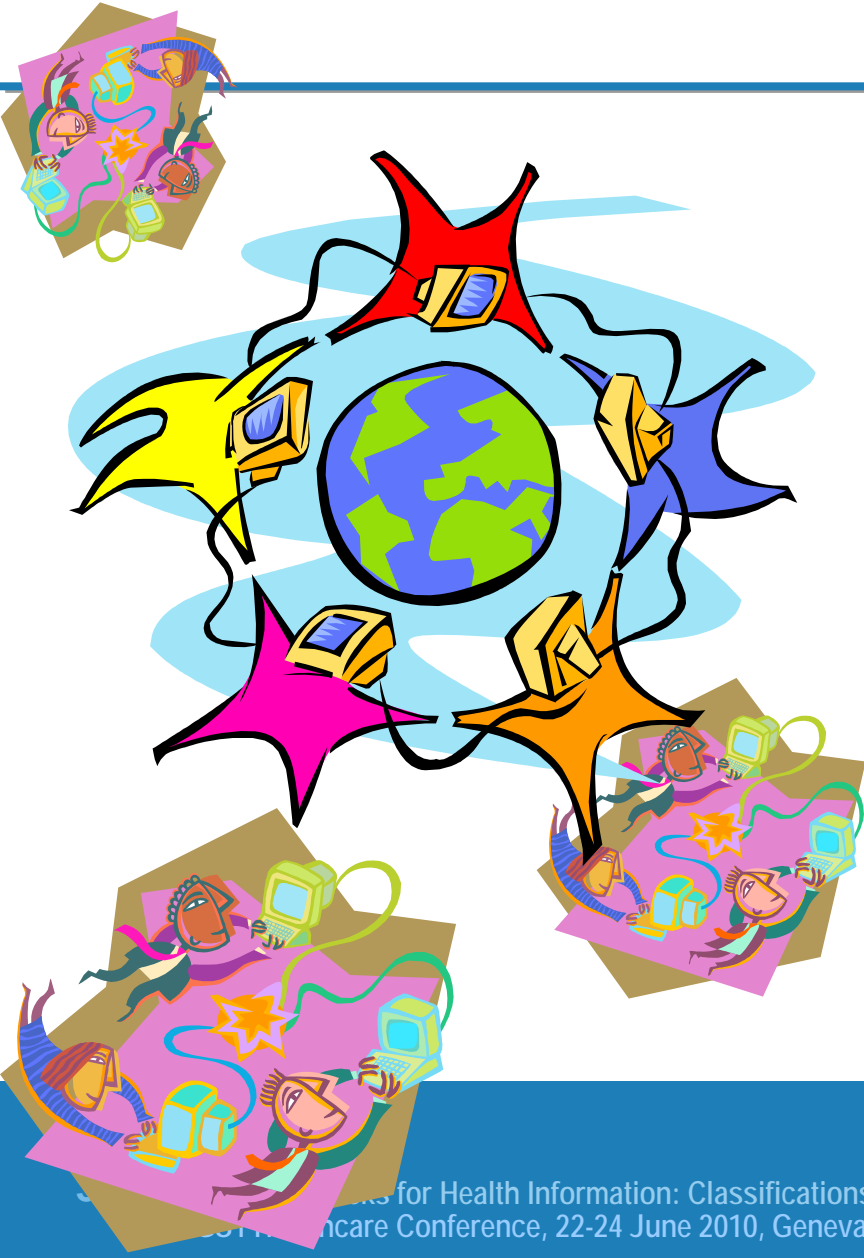
Your Role

Activity

Location



# WHO classification development in the 21<sup>th</sup> Century



- **Internet-based permanent platform**
  - All year round
  - Open to all people in a structured way
  - Content experts & users are empowered
- **Digital curation**
  - Wiki enabled collaboration
  - Ontology based
- **Enhanced discussion & peer review**
- **Electronic copy** → print version
- **Work in multiple languages**
- **field tests**
  - Based on Use Cases

# What is the answer? ... what is the question?



Computers are useless. They can only give you answers.

Pablo Picasso (1881-1973)