The German Institute of Medical Documentation and Information

and its contributions to the

WHO Family of International Classifications Network

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Within the scope of
Federal Ministry of Health

Topics of the presentation

- The German Institute of Medical Documentation and Information (DIMDI)
- Medical Vocabularies at DIMDI
- DIMDI as Collaborating Center within the WHO Family of International Classifications (WHO-FIC) Network

The DIMDI

- Director Dr. Dietrich Kaiser
- Institute within the scope of the German Federal Ministry of Health (BMG).
- Founded in 1969
- Approximately 150 employees in the three different departments and subsidiary units

➢ Main task is to provide information in all fields of life sciences to the interested public

The DIMDI

- 1969 Start with literature research and first medical databases
- 1975 Online research in MEDLINE via DIMDINET
- 1983 First drug information system
- 1992 New task Medical classifications
  - 1993 Publication of ICD-10 in German language
  - 1994 Publication of OPS (German procedure classification)
  - 2003 Publication of ICD-O-3 in German language
  - 2006 Publication of ICD-F in German language
- 1994 New task medical devices information system
- 2000 New task Health Technology Assessment (HTA)
- …

The DIMDI

- Department: Medical Information
  - Medical Vocabularies
  - Interdisciplinary Tasks for Medical Information
  - Information Systems for Drugs and Medical Devices
  - Information System Health Care Data (Data Transparency)
- Department: IT Technology
  - Applications and Databases
  - Software Development
  - IT Operations and Services
- Department: Administration
  - Organisation, Financing and Human Resources

The DIMDI

Subdivision Medical Vocabularies

- Head Dr Stefanie Weber
- 15 persons including 9 physicians with additional expertise in medical information management in the health care sector
- Publication of official German versions of classifications in health care
- National and international cooperation and projects
  - WHO Collaborating Center within the WHO Family of International Classifications (WHO-FIC) Network
  - The Iris Institute
  - EU projects on rare diseases
  - EU projects on standardization and telemedicine (i.e. epSOS)

Medical Vocabularies at DIMDI

- **ICD-10 WHO** German Edition (Mortality)
- **ICD-10 GM** German Modification (Morbidity)
  - Including **Alpha-ID**
- ICD-O-3 (Oncology)
- **OPS** German Procedure Classification (Morbidity)
- **ICF** International Classification of Functioning, Disability and Health (Rehabilitation)

- Universal Medical Device Nomenclature System (UMDNS)
- Anatomical-Therapeutic-Chemical Classification System (ATC)
- German translation of Medical Subject Headings (MeSH)
- German contributions to Unified Medical Language System (UMLS)

Medical Vocabularies at DIMDI

ICD-10

- Since 1998 use of the ICD-10-WHO edition in German language for coding death certificates
  - Translation into German by DIMDI, supported by the German medical scientific societies (particularly Chapter 5 Mental and behavioral diseases)
- Basis of diagnoses related mortality data and statistics in Germany inline with Volume 2 of ICD-10-WHO
- Reporting of mortality data to the WHO following World Health Assembly resolution of 22 May 1967
- Updating ICD-10 follows official recommendations of WHO
  - Publication of cumulated updates (minor and major updates) as ICD-10-WHO in German includes all three Volumes “every” three years
  - ICD-10 2019 will be the last official WHO version to be published due to upcoming ICD-11
- Implementation into Iris, an automatic system for coding multiple causes of death and the selection of the underlying cause of death

Medical Vocabularies at DIMDI

ICD-10

- In 2000 so-called SGB V version mandatory for coding diagnoses in both in- and outpatient care (Morbidity)
  - Modified German version based on the international WHO edition
  - Reduction of codes and entries, e.g. diseases that were meant to be rare in Europe (A20.2 Pneumonic plague) or were not needed according to the social security code or data protection act (e.g. Chapter 20, Chapter 21)
- Since 2003 introduction of the DRG system in Germany for reimbursement of patient care in hospitals
  - Use of specific codes of the ICD-10 Australian Modification to prepare for the introduction of the DRG system in 2001
- Since 2004 publication of an annual ICD-10 German Modification (GM)

Medical Vocabularies at DIMDI

ICD-10 Alpha-ID

In 2005 publication of the first so-called Alpha-ID version of ICD-10-GM

- Introduction of a unique identifier to all alphabetical terms
- Possibility to code specific medical terms or “sloppy terms” in use
- Identification of specific medical entities that are hidden behind an ICD-10 class with less specificity (typically “.8” codes)
- Particularly useful for identifying rare diseases that typically do not have a separate code in ICD-10

Q82.8 Sonstige näher bezeichnete angeborene Fehlbildungen der Haut

Abnorme Handfurchen
Cutis laxa (hyperelastica)
Dyskeratosis follicularis vegetans [Darier]
Familiärer benigner chronischer Pemphigus [Gougerot-Hailey-Hailey-Syndrom]
Hautleistenanomalien
Hereditäre Palmoplantarkeratose
Zusätzliche Hautanhängsel

Exkl.: Ehlers-Danlos-Syndrom (Q79.6)

Akanthose L83
– benigne Q82.8
– erworben L83
– kongenital Q82.8
– seborrhoisch L82
– Zunge K14.3

Cutis
– hyperelastica Q82.8
– – erworben L57.4
– laxa
– – congenita [Cutis laxa (hereditaria)] Q82.8
– – hyperelastica Q82.8
– – senilis L57.4
– marmorata R23.8
– – teleangiectatica congenita [CMTC] Q27.8
– osteosis L94.2
– rhomboidalis nuchae L57.2
– vagantium R85.1
– verticis gyrata Q82.8
– – erworben L91.8

Alpha-ID	ICD-10-GM	Term
I32234	Q82.8	Angiomatosis
I109391	Q82.8	Anhidrosis hypotrichotica
I82910	Q82.8	Bloom-Machacek-Torre-Syndrome
I82912	Q82.8	Brauer-Syndrome
I82911	Q82.8	Brugsch-Syndrome
I81729	Q82.8	Christ-Siemens-Touraine-Syndrome
I82913	Q82.8	Clouston-Syndrome
I68454	Q82.8	Cutis hyperelastica
I30858	Q82.8	Cutis laxa congenita
I87509	Q82.8	Cutis laxa hyperelastica
I69040	Q82.8	Cutis verticis gyrata
I11497	Q82.8	Darier-I-Syndrome
I17209	Q82.8	Dermatochalasis

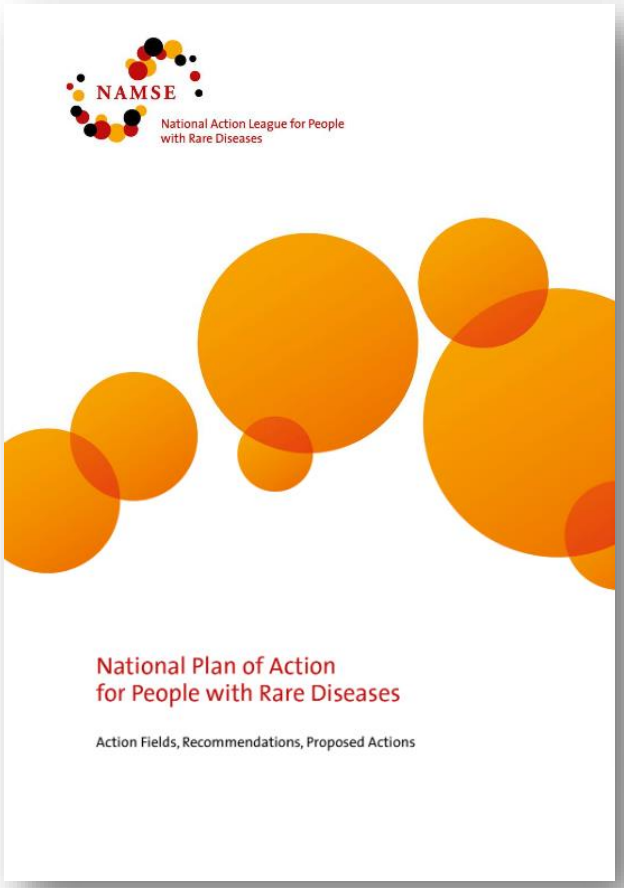
Medical Vocabularies at DIMDI

ICD-10 Alpha-ID

Several national and international project on the European level and Orphanet

- National Plan of Action for People with Rare Diseases
- Joint Action on Rare Diseases of EU
- Alignment with Orphanet database for rare diseases

National Plan of Action for People with Rare Diseases



Proposed action 19:

A uniform coding scheme for all patients with rare diseases employing the Orpha diagnostic coding system in conjunction with ICD-10 GM and in anticipation of the publication of ICD-11.

Implementation: short-term
Responsible bodies: Orphanet Germany, German Institute of Medical Documentation and Information (DIMDI, part of the German Federal Ministry of Health)

Until the ICD 11 becomes available, however, NAMSE recommends developing resource low solutions. A project should investigate the possibility of automatically linking or coupling the alpha ID of the ICD 10 to the Orpha code number provided by Orphanet. The goal would be to have a clear and uniform codification of the rare diseases available at the Centers for Rare Diseases to be used in research and care activities. In this sense it might also be possible that software algorithms be implemented as part of existing medical practice software in order to point toward rare diseases in the light of certain symptom constellations. NAMSE suggests testing which of the existing software packages would be suitable and how the software manufacturers could integrate rare diseases into their software.

Medical Vocabularies at DIMDI

OPS the German Procedure Classification

- Based on ICPM of WHO from 1978
- In use in Germany since 1995
- Annual revision process with many proposals from users and stakeholders in the health care sector
- Mainly driven by the German DRG and reimbursement system
- Number of codes raises from some 23 K in 2004 to some 30 K in 2017

Medical Vocabularies at DIMDI

OPS

Six chapters covering

- Diagnostic interventions
- Medical imaging
- Surgical procedures and other interventions
- Specific high priced drugs
- Non-operative interventions and so called “complex codes” for specific settings
- Nursing procedures and psychiatric treatment

The annual national revision process

ICD-10-GM and OPS

Medical Societies
Users in hospitals
“Self-governing Body”
and Others

Proposals

DIMDI

Preparation of Proposals

WG ICD + WG OPS of KKG

DIMDI

Decision + Realisation

New Version ICD-10 OPS

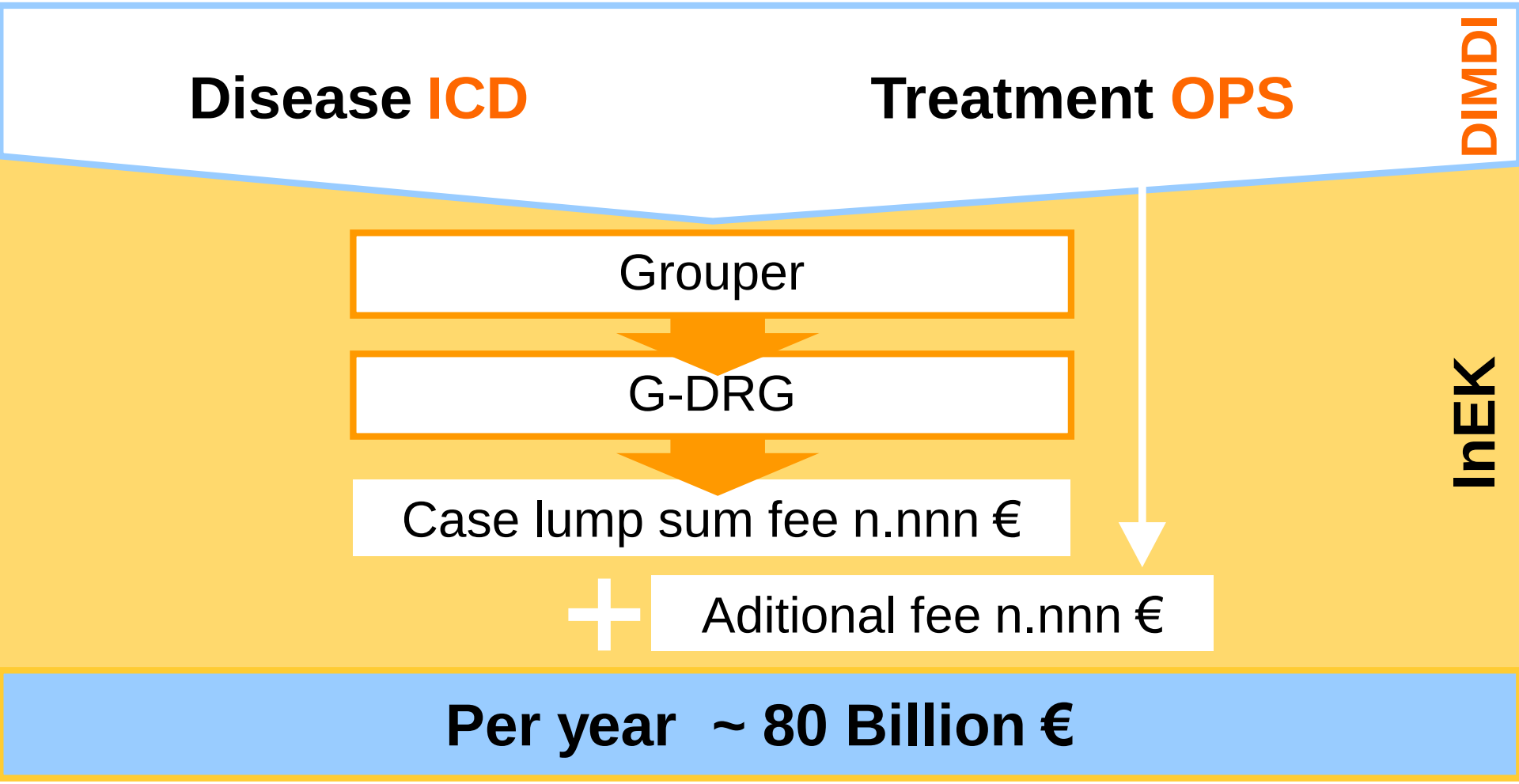
Tabular List
Alphabetical Index
Update List
Crosswalks
Metadata

The DRG System in Germany

- Organisations of the so-called “self-governing body” in Germany are responsible for the system of Diagnosis Related Groups (DRG)
- The system is based on the medical classifications published by DIMDI (ICD-10-GM and OPS)
- National Coding Standards (DKR) for the use of ICD-10-GM and OPS in hospitals are published by the InEK Institute and may overrule Volume 2 guidelines of the international WHO version
- Thus DIMDI acts as an advisor to these bodies for all problems related to the classifications that come up during the development and maintenance of the DRG system

The DRG system in Germany

ICD-10-GM and OPS inside



Medical Vocabularies at DIMDI
ICF

- In 2005 publication of the ICF in German
- Mainly used in rehabilitation medicine for which it has a legal basis
- A number of scientific studies are evaluating ICF for use in hospitals and in particular in post-procedural care
  - Due to its complexity as a multi-dimensional tool, several ICF core sets have been developed
- Currently, there is no general use of the ICF in Germany

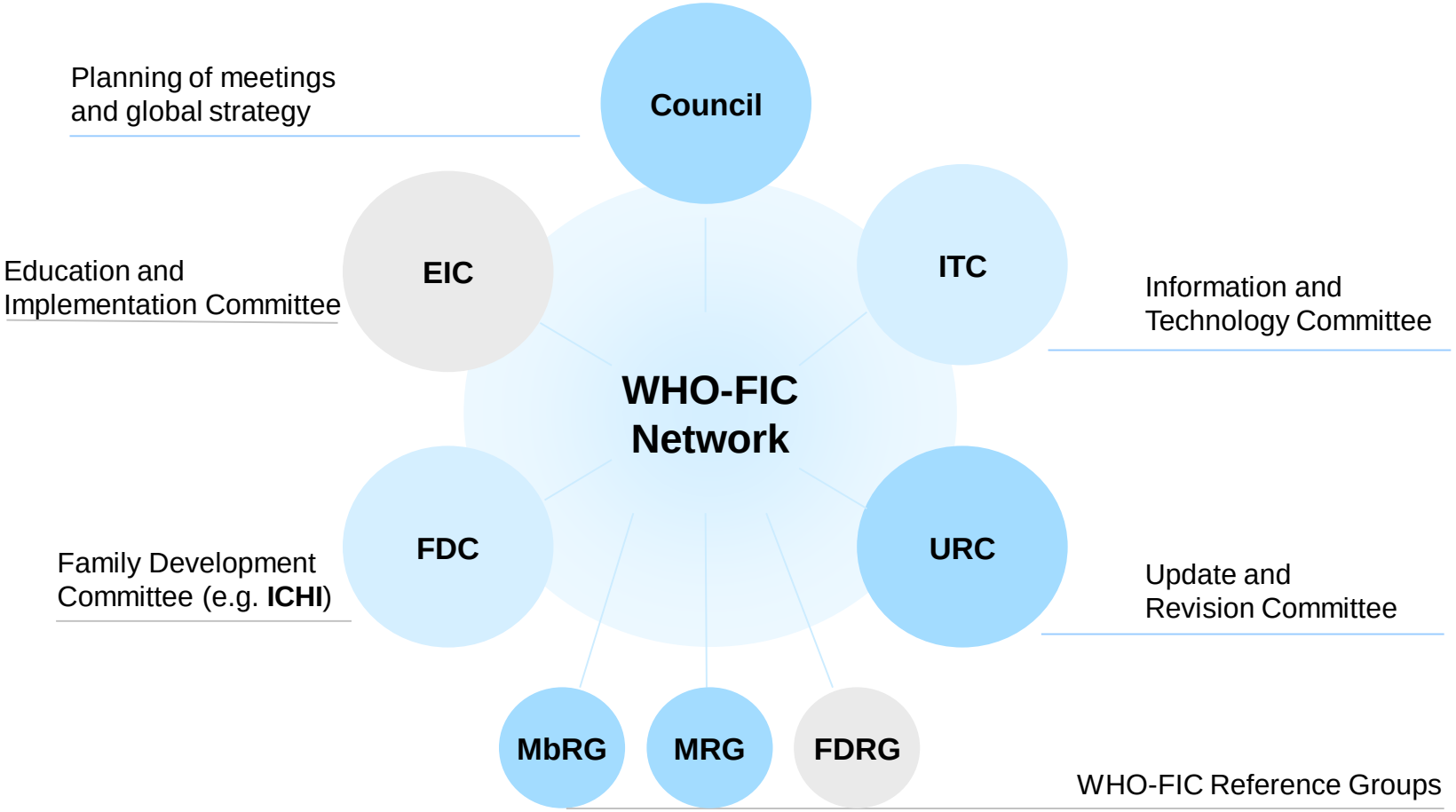
DIMDI as Collaborating Center within the WHO-FIC Network

- Designation as WHO Collaboration Center within the WHO Family of International Classification Network in 2003
- Three members of staff including head (Dr Stefanie Weber, Dr Ulrike Trinks und Ulrich Vogel)
- Holding several co-chairs of committees and working groups as well as of WHO-FIC Council over the many years
- Since 2015 co-chair and member of the Joint Task Force of WHO for the ICD-11 revision process

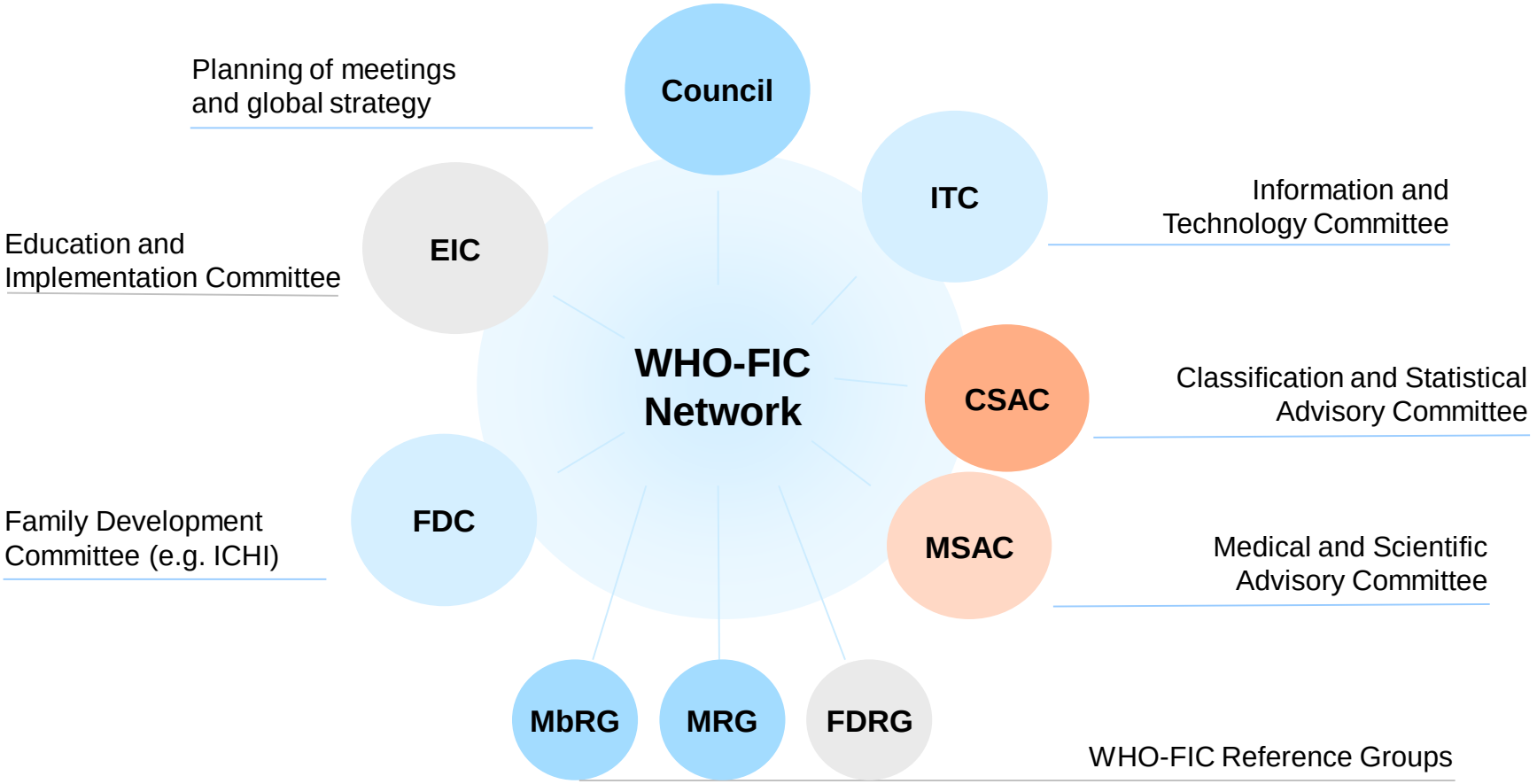
International cooperation

- Joint software development with WHO for the Classification Tool Kit (CTK)
- Joint software development with other countries (France, Sweden, Italy and Hungary) for the Iris application

The WHO-FIC Network until 2017



The WHO-FIC Network from 2018 on
Outlook



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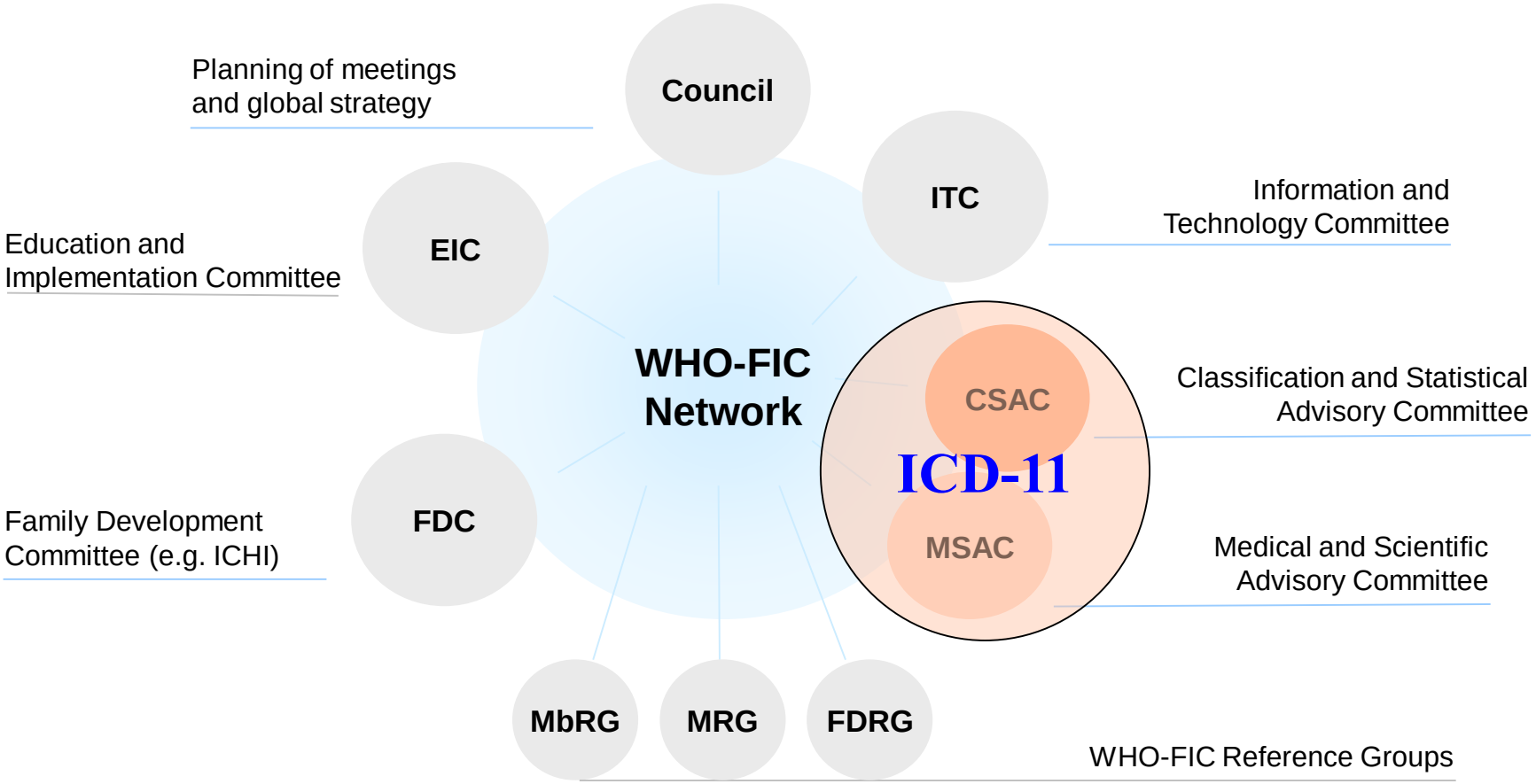

DIMDI as Collaborating Center within the WHO-FIC Network

Thank you very much for your attention.