

# Swiss Spinal Cord Injury Study (SwiSCI)

**“Research for and with  
people living with spinal cord injury  
in Switzerland”**



*Minisymposium SCIONN, 1 Oktober 2010*



# Overview

- 1. From disease to participation: A glance in history and the ICF: the SwiSCI framework.**
2. SwiSCI: an overview of the project
3. Outlook

# Trends over time in SCI clinical management and research

	1970	1980	2000
Dimension	Disease	Activity	Participation
Parameter for succes	No complications-healing	Basic ADL-mobility	Integration in community
Rehabilitation Interventions	No benefit	Structured program for all	Individual programs
Hypothesis	Destiny driven	High scores in activity leads to good participation	Participation needs individual goals

# Trends over time in SCI clinical management and research

	1970	1980	2000
Interventions	Palliative-conventional nursing care	Inpatient-ADL-Mobility	Inpatient-outpatient:home
Quality standards	No complications ( pressure sores, contractures)	Independent in ADL	Participation in the community
Measurements	Documentation in medical records	FIM, BI	QOL, IMPACT, social intergration,

# Emphasis of WHO on Functioning and Rehabilitation

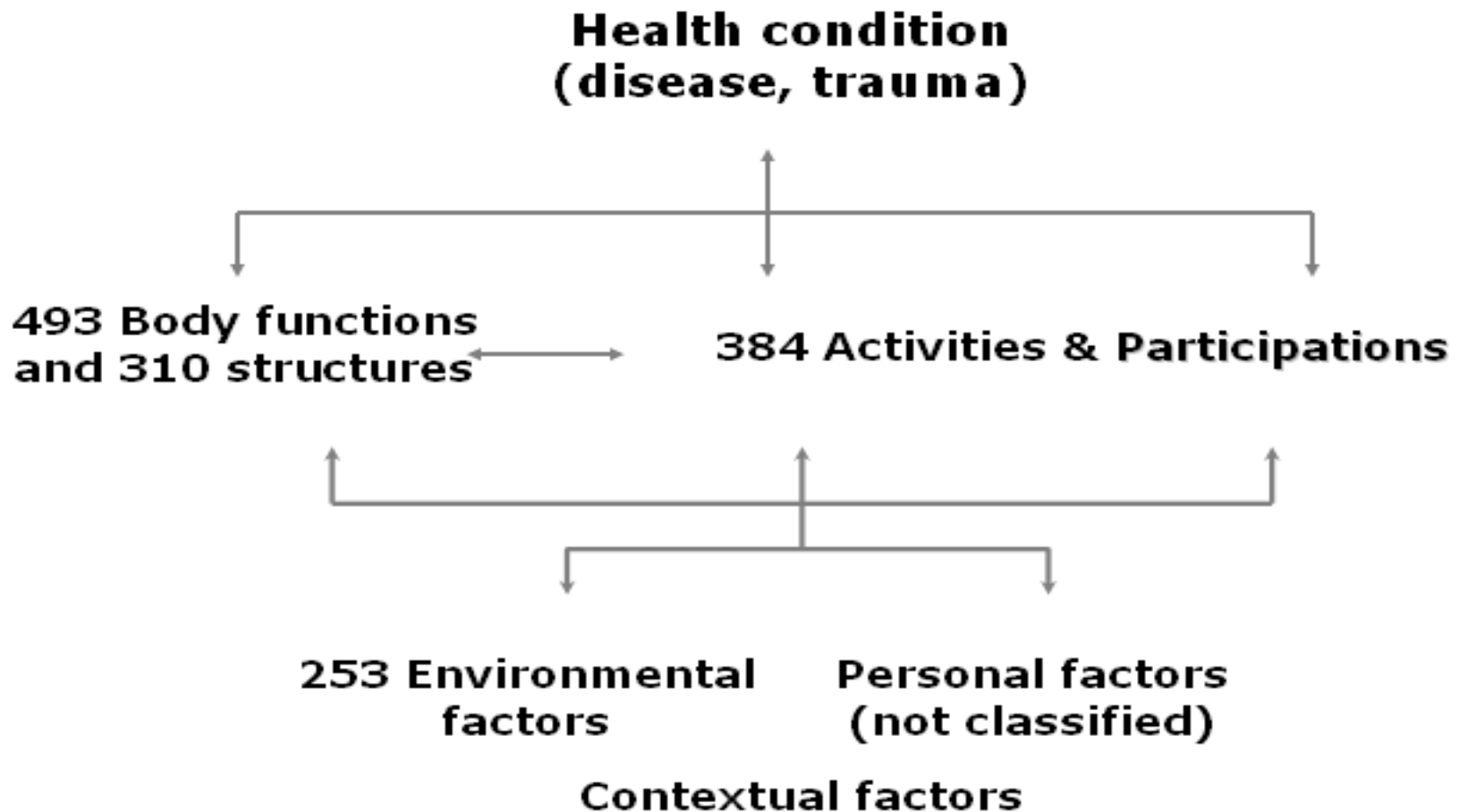
**Resolution by the  
World Health Assembly**

**2001 International  
Classification of Functioning,  
Disability and Health (ICF)**

**2005 Resolution focussing on  
disability**

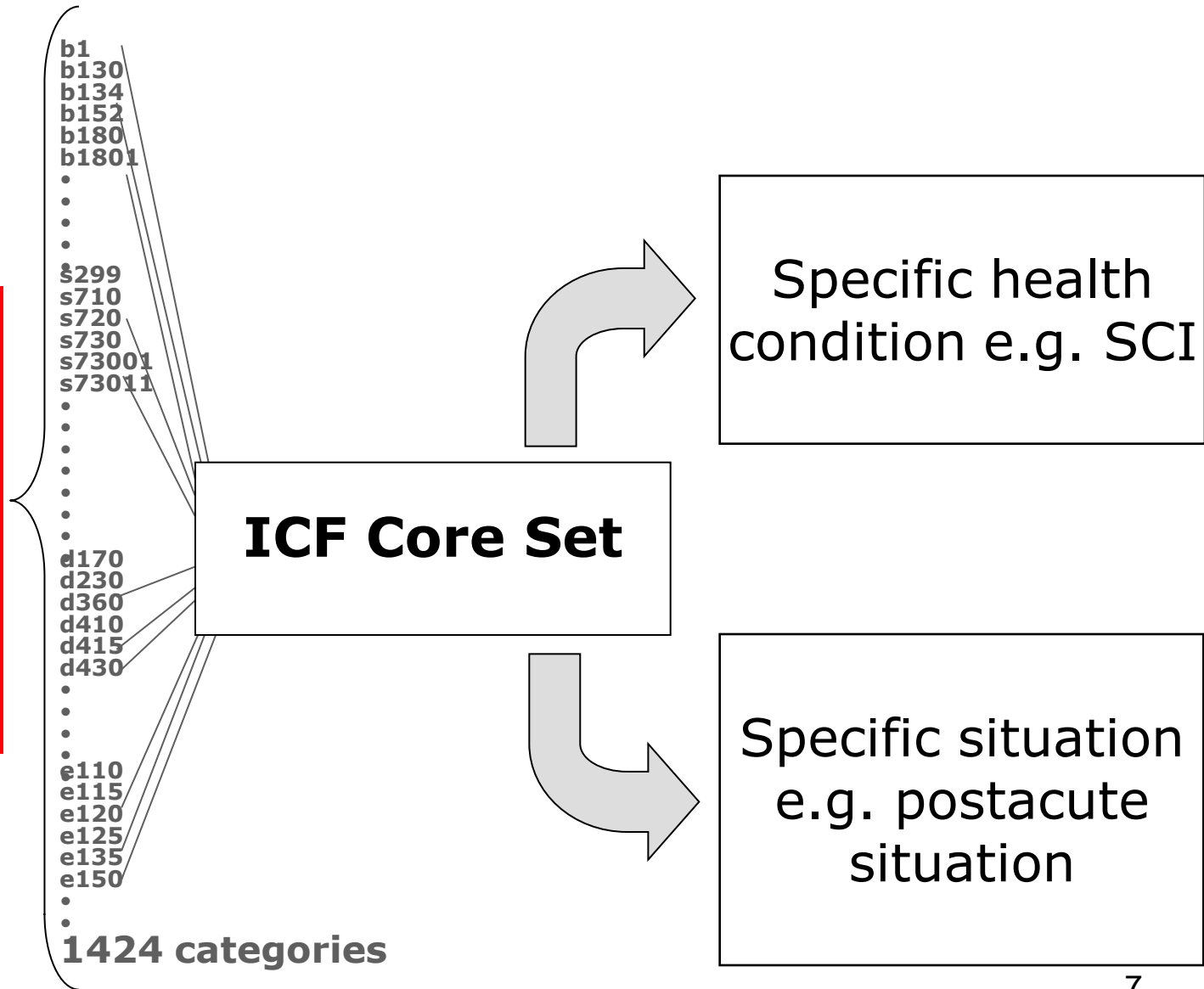


# ICF Framework of functioning and disability





# ICF Core Sets



# Relevant ICF Core Sets

## **Brief ICF Core Sets for SCI (25 and 33 -> in total 38 ICF categories)**

List of ICF categories that serves as the **minimal standard for reporting the functioning of persons with SCI** along the continuum of care (ranging from the acute hospital to rehabilitation facilities and community) and across sectors (health, education, labour and social affairs)

Ensure specific communication within and across services and comparability and interpretability of data of similar cases and populations

## **Generic ICF Core Set**

*Minimum standard for clinical encounters, service stays and studies*

Ensure general communication within and across services and comparability and interpretability of data across all cases and populations





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Swiss  
Paraplegic  
Research

# Swiss Paraplegic Research (SPF)



*Swiss Paraplegic Research (SPF)  
Nottwil, Switzerland*

# Swiss Paraplegic Research (SPF)

- 1. Mission:** Optimal functioning and social integration, health and quality of life for people with spinal cord injury
- 2. Research:** focused on functioning and disability in clinical and community setting
- 3. National & international network:**
  - Dept. of Health Sciences & Health Policy, University of Lucerne
  - World Health Organization: Development of ICF Core Sets in ICF Research Branch
  - Patient Association (ESCIF, Swiss)
  - Other research projects in SCI e.g the Dutch



# SCI in Switzerland

**Prevalence:** estimated 4000 persons with SCI in Switzerland

Estimate based on Swiss Paraplegic Association (SPV)

- organised in 27 local wheelchair clubs
- about 3000 members with SCI
- coverage of about 80% of SCI population (unique in European countries)

**Incidence:** about 200 to 400 new cases each year

Estimate based on yearly reports (2002) of 3 SCI centers (Nottwil, Balgrist, Basel) (Eberhard 2004)

& international data from similar settings



# Overall goals

SwiSCI will be a collaborative research project that aims to:

- develop a comprehensive and patient-oriented understanding of **functioning and disability** as well as **health maintenance** and **ageing** with SCI along the continuum of care and along the life span;
- provide reliable **epidemiological data** for traumatic & non-traumatic SCI in Switzerland;
- build a **research platform** for Nested Projects and Research Collaborations

# SwiSCI themes

- Participation
- Social integration / Labour market integration
- Complications & health behavior
- Ageing with SCI
- Disability policy e.g. fair opportunities
- Personal factors
- Service provision in clinical & community-based rehabilitation
- Benefit (& harm?) of new curative approaches

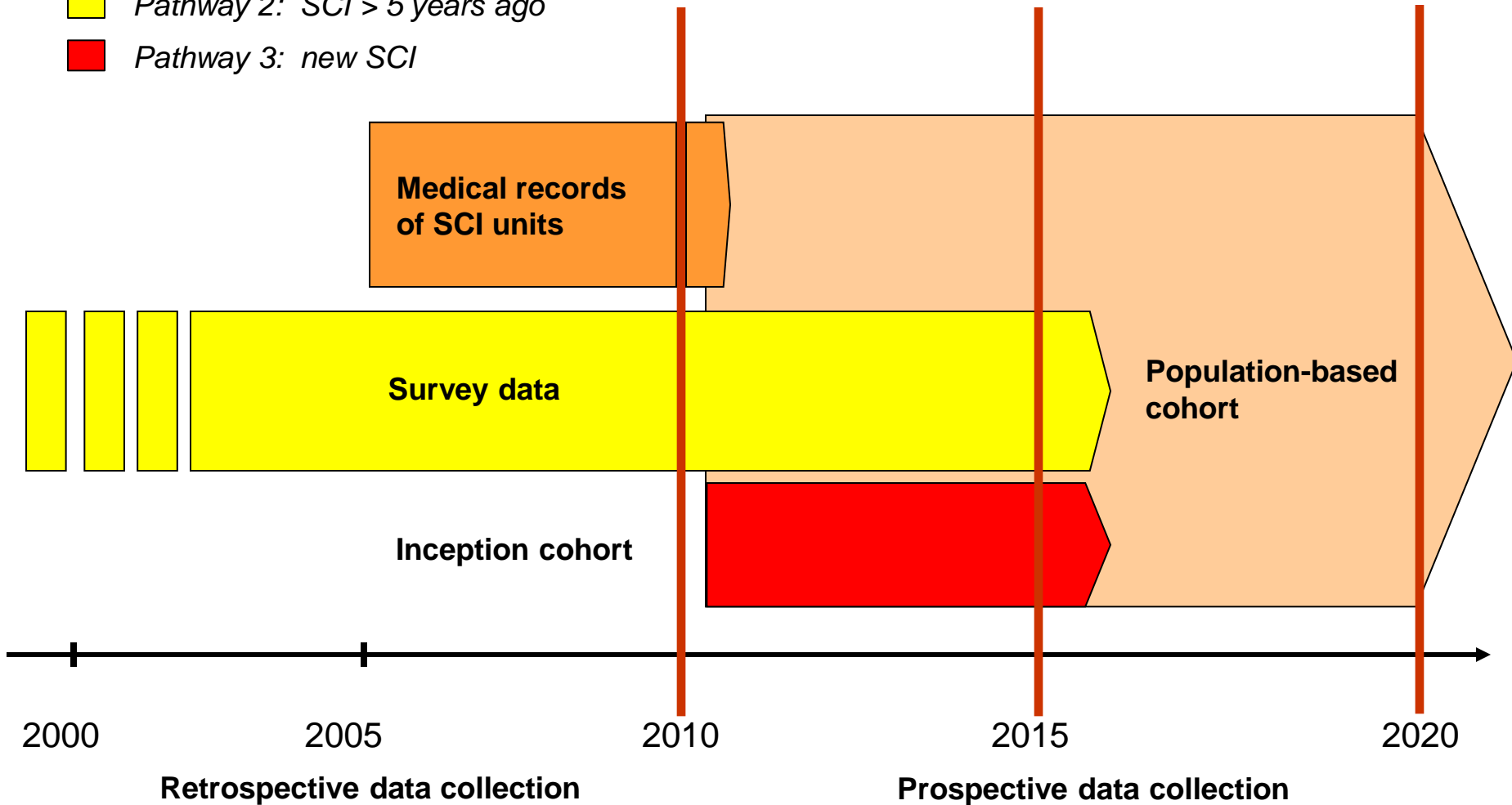
# Study population

- Diagnosis of acquired SCI
  - Traumatic or non-traumatic
  - All levels of injury (cervical, thoracic and sacral lesions incl. cauda equina syndrome)
  - All levels of sensory-motor impairment
  - Excluded: Spina bifida, MS, ALS
- All adults (16+ years, pediatric substudy may added later)
- Resident in Switzerland
- Informed consent for follow-up



# SwiSCI Pathways

- Pathway 1: SCI in last 5 years*
- Pathway 2: SCI > 5 years ago*
- Pathway 3: new SCI*





## Pathway 1: SCI in last 5 years

- Identification of participants with recent SCI (2005 – 2009) from medical records
- Limited retrospective data (age, sex, AIS score)
- Prospective follow-up with SwiSCI dataset
- Objective:
  - Rapid establishment of cohort (start 04.10.2010)
  - Control population before introduction of new health technologies (e.g. for SCI cure)
  - „Patient trajectories“ (e.g. using EMSCI data)<sub>18</sub>



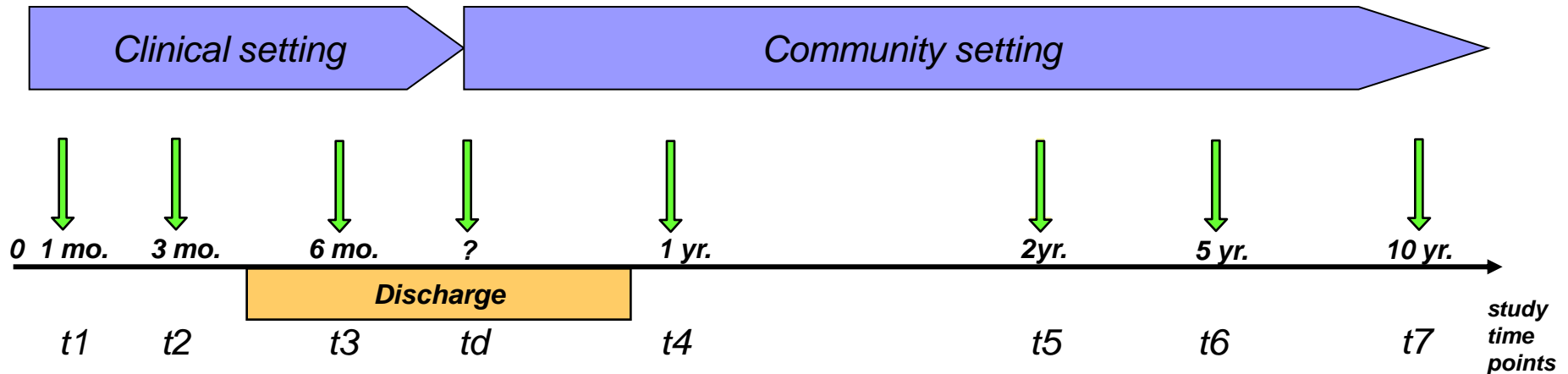
## Pathway 2

- Survey in SCI community every 5 years
- Currently measurements defined and development of new instruments.
- Collaboration with organisations: SPV, Parahelp, etc.
- Mailing of self-reported questionnaires
- Objective:
  - Description of current situation („snapshot“)
  - Epidemiological data for policy & planning
  - Identification of problems & „gaps“ to be addressed by SwiSCI in the future

## Pathway 3: new SCI

- Inception cohort: enrolment in 1st rehabilitation
- Collaboration with specialized SCI units
- Complete follow-up from time of injury
- Objectives:
  - Association between „early factors“ (incl. rehab care) and outcomes in later life with SCI (e.g. participation)
  - Clinically oriented „outcomes research“
  - Health services research

# Follow-up (pathway 3)



## *Data sources:*

*Medical record,  
Questionnaires,  
Clinical assessment*

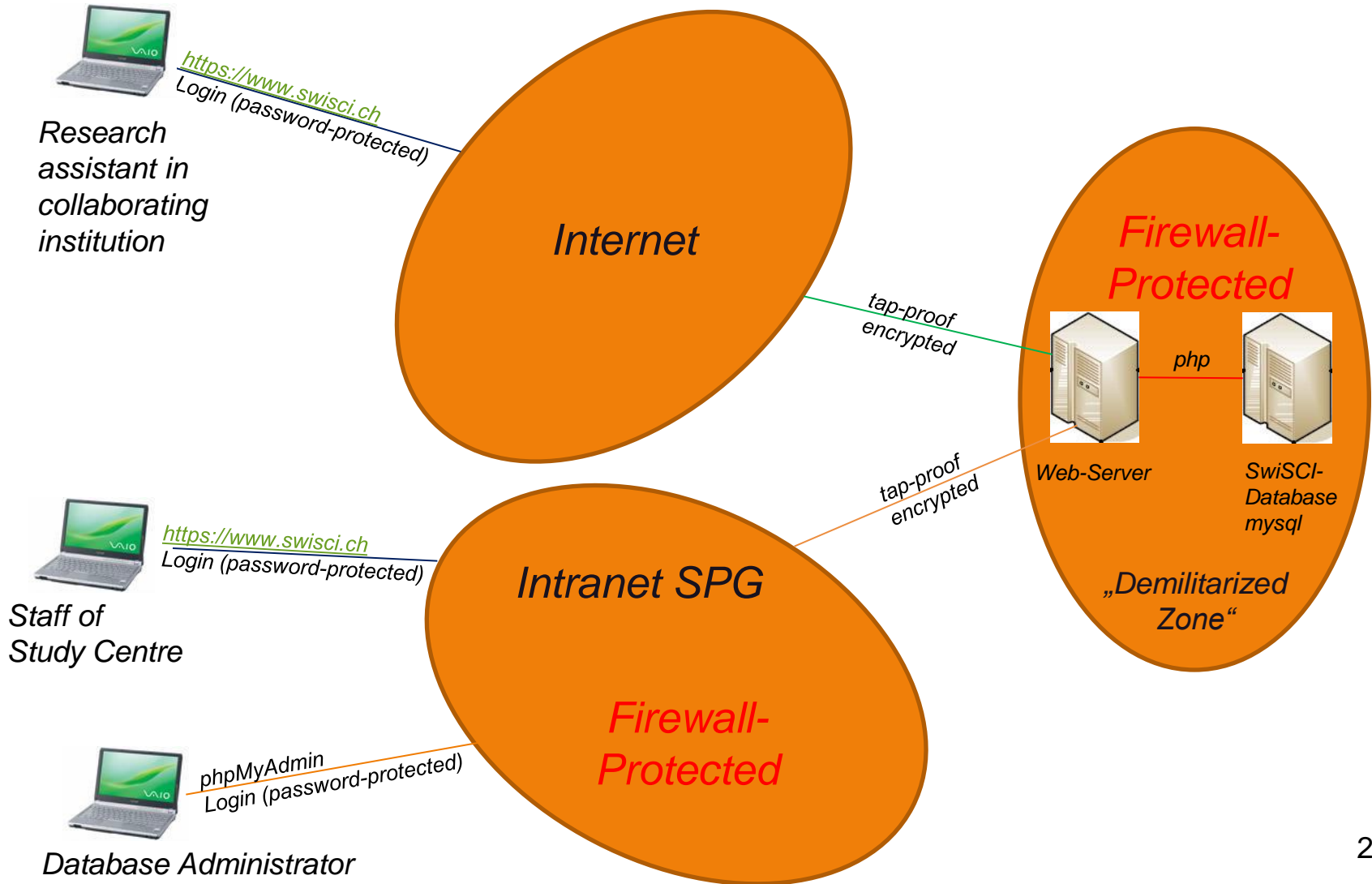
*Questionnaires,  
Annual follow-up in SCI unit,  
General practitioner*



# SwiSCI Dataset

- Data collection adapted to different pathways, e.g. self-reported questionnaires in survey (pathway 2)
- Variables will cover items
  - defined by ICF core set for SCI,
  - defined by generic ICF core set,
  - identified by focus groups and experts,
  - describe health state over time,
  - needed for additional objectives
- One central database maintained at SwiSCI study centre

# Database & Network



# *Nested Projects & Research Collaborations*

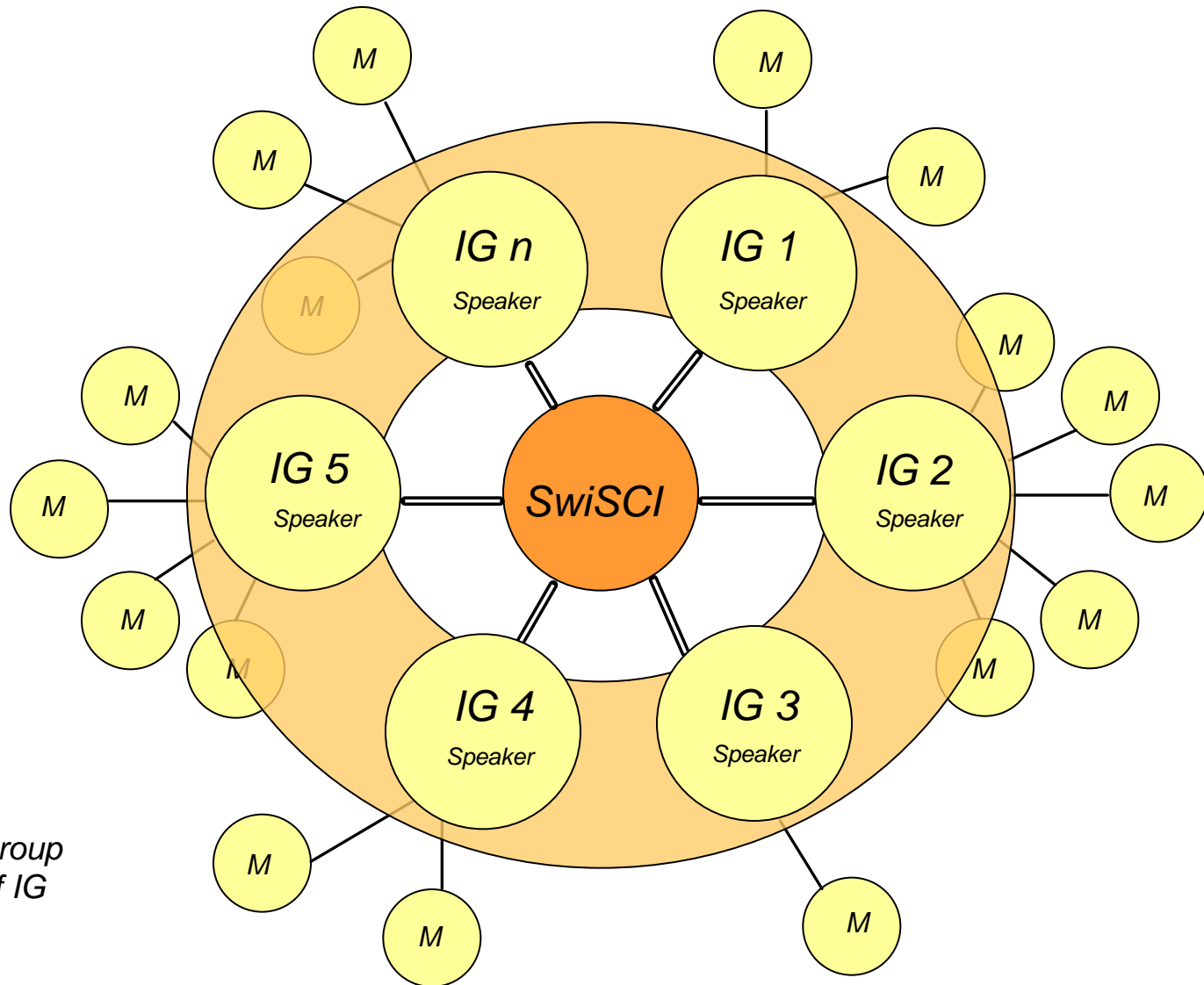
- SwiSCI will be a research platform
- Main study will not cover all aspects in all participants
- „Nested Projects“ to cover specific research questions in more detail; calls for research
- Independent funding of competitive research
- Identification & planning in „Interest Groups“ (IGs)







# Interest groups



*IG = Interest Group*  
*M = Member of IG*



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# SwiSCI outlook

- Visible high-quality research at the crossroads of biomedicine and social sciences
- Attracting competitive funding
  - nationally: SNSF, SWTR (Art. 16), private funds
  - internationally: 7th European Framework
- Research that matters to people with SCI (i.e. asks the right questions)
- Research that helps people with SCI (i.e. getting research into practice)



# Merci Vöelmalls an Die Holländer:

- **Luc, Sonja en Marcel:** voor hun ondersteuning, input, kritiek vanaf het begin.
- **Govert en Henk:** voor hun zit in de WBR.
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- en iedereen die ook een Dank-je-wel verdient maar ik vergeten ben.

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