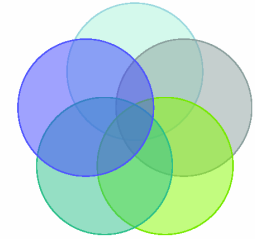


EHMA 2004, 25 June 2004, Potsdam



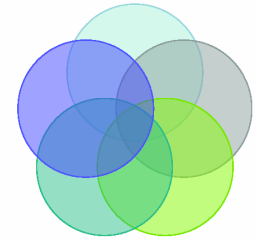
# **Analysing patient civil society using the CIVICUS Civil Society Index**

**Annette Riesberg\*,  
Wörz M, Mühr C, Reiß S, Busse R\***

Dept. Health Care Management,  
Technische Universität Berlin

\*and European Observatory  
on Health Systems and Policies

# Background



- Patient groups have become important actors in health care and much is talked about them
- but little is known about patient organisations, self-help organisations, disabled groups, consumers' organisations
  - in society as well as within the arena of patient organisations
  - Duplication of efforts
  - Impression of intransparency
  - dialogue and cooperation in patient CSI limited
  - Little dialogue with broader civil society

**CIVIL SOCIETY IS „THE AREA**

**between**

## **Definitions I**

**- family,**

**- government,**

**- and market,**

**where people voluntarily**

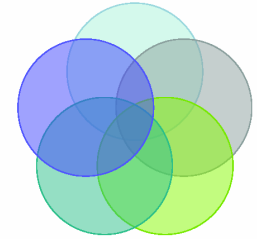
**associate to advance common**

**interests.“**

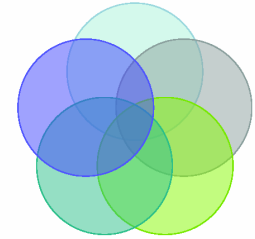
**Synonyms:**

**non-governmental sector, third**

**sector**



# Definitions II



## **Heterogeneity of (patient) civil society**

Public interest NGOs (PINGOs)

Quasi public NGOs (QUANGOs)

Business initiated NGOs (BINGOs),

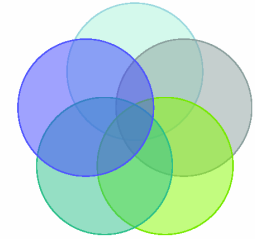
My own NGOs (MONGOs)

▶ Scope of this study limited to:

- self-help organisations, disabled groups, consumers' organisations
- as health care users or for health care users

▶ **Patient interest NGOs (PATINGOs)**

# Targets



...To generate knowledge and write an outline report about the German patient civil society as a basis for further dialogue at national and international level.

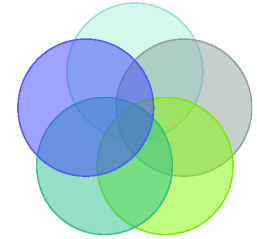
... To apply and test the usefulness of analytical tools for civil society in studying the subsector of patient civil society.

## **Methods and materials:**

Secondary analysis

- of scientific literature, legal documents,
- websites and other information of PATINGOS
- data and information from public bodies

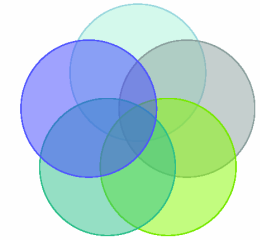
# Analytical framework: CIVICUS Civil Society



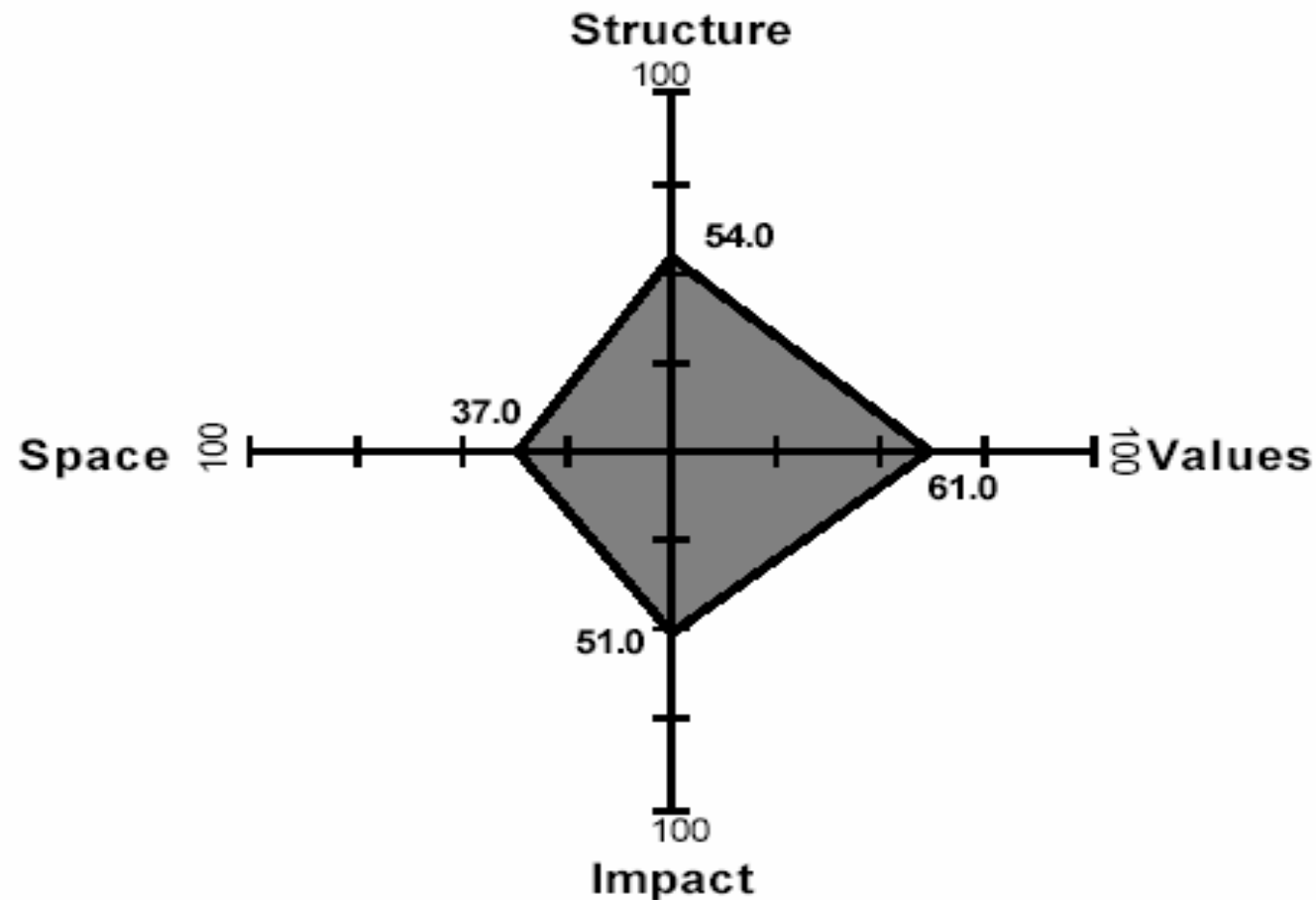
## Index

- International comparative and participatory approach to increase knowledge about civil society and improve the social impact of civil society,
- currently performed in 70 countries
- coordinated by CIVICUS Alliance for Citizen Participation, Johannesburg (600 member organisations in 110 countries)
- German partner: MAECENATA Institute, Berlin

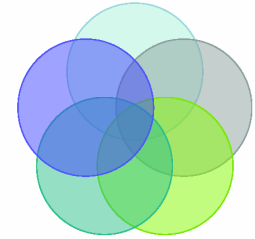
# The CIVICUS Civil Society „Diamond“



The Civil Society Status Diamond for Romania:



# Subdimensions and selected indicators of „Structure“ (I)

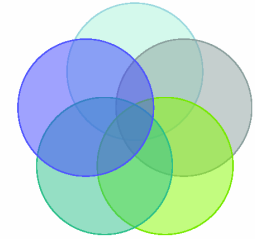


## **1) Breadth of engagement**

- 34% voluntary engagement (survey 99)
- 1-4% health related self help (Borgetto 02)
- 6-9% among chronically ill (Borgetto 02)
- 70 000-100 000 self help groups
- about 40-60 000 in health
- of these only 300 are active at federal level
- 250-300 self-help contact and support centers



# Structure (II): other subdimensions and indicators



## 2) **Depth of engagement:**

**Amount of private resources: money, time**

**3) Diversity:** Member structure, regional distributions

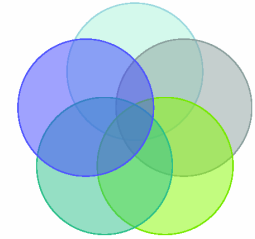
**4) Level of organisation, infrastructure**

**Umbrella organisations, self regulation,** capacity building in the arena: training, international networks

**5) Networks within the arena:** Communication, exchange of information, cooperation, joint purchasing, strategic

**6) Capacities/Resources:** Financial, personnel,

# Subdimensions of „environment“



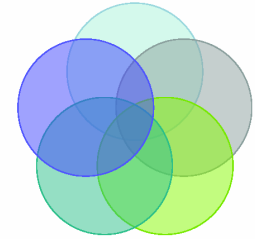
- 1) Political environment**
- 2) Legal environment (see presentation of C Mühr)**
- 3) Sociocultural environment**
- 4) Socioeconomic support**

Total financial resources for health related self help groups in 2001: 436 Mio. Euro

- private households and organisations: 416 Mio. Euro
- social health insurance: 20 Mio. Euro
- States and municipalities: not included in this source (ca. 10 Mio. Euro, decreasing in most states)

(Federal Statistical Office 2003, [www.gbe-bund.de](http://www.gbe-bund.de))

# Subdimensions of „Values“



## **1) Internal democratic order and rules**

- Membership representation, consultation, minority vote
- Activities to strengthen..

## **2) Transparency**

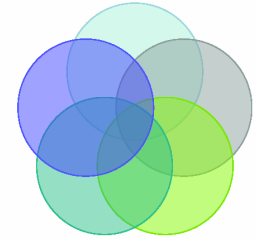
- Flow of information in the arena and within organisations
- Internal corruption
- Transparency of finances

## **3) Tolerance**

- Within the arena, within organisations
- Activity to strengthen tolerance in the arena, organisations, among political stakeholders and citizens

## **4) Non-violence, 5) gender democracy, 6) poverty reduction**

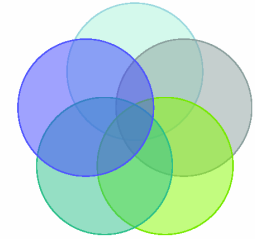
# Subdimensions of „Impact“



- 1) Impact on political decision-making
- 2) Holding government and business accountable
- 3) Responsiveness to societal interests
- 4) Supporting citizens
- 5) Responsiveness to social needs

.....

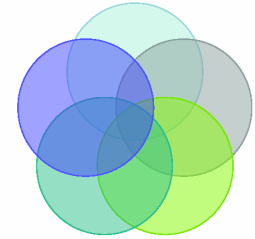
# Discussion and conclusions (I)



## The patient civil society in Germany:

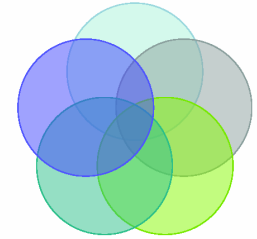
- Rich and heterogeneous arena
- With recent increase in organisational level
- With strong values of autonomy and self-help
- Recent increase of self-regulation and external regulation
- Recent enlargement of political and legal space
- Recent professionalisation (and funding) for public patient information services

## Discussion and conclusions (II)



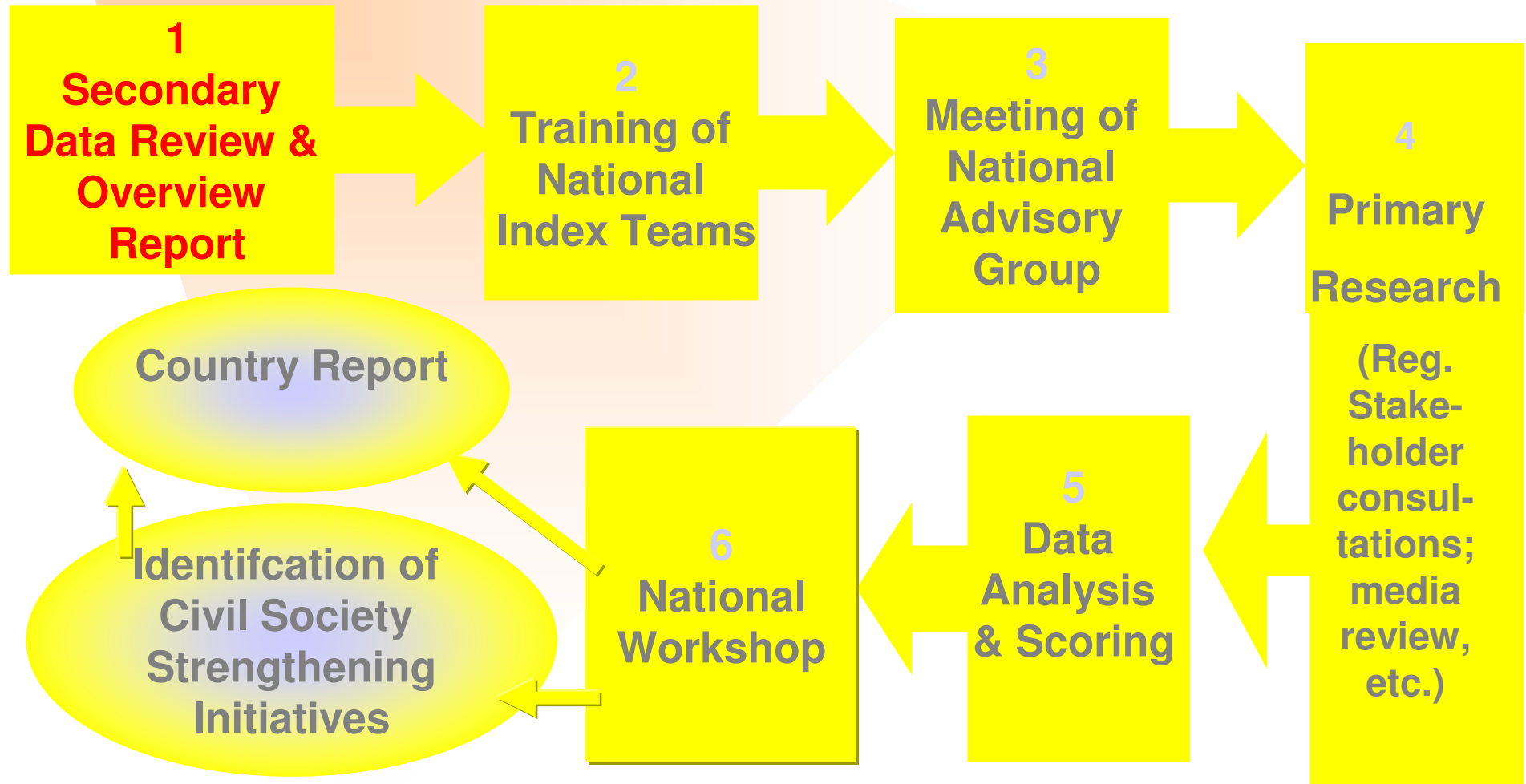
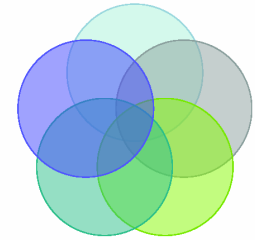
- Recent increase of political advocacy activities and political impact (see presentations of Muehr, Wörz and Isenberg)
- Increase of social health insurance funding but decrease of funding from federal states and municipalities
- Increase in responsibilities does not (yet) go along with more financial, personnel resources
- Increased requirement to cooperate in political advocacy while competing for economic resources

## Discussion and conclusions (III)



- The CIVICUS Civil Society Index is a useful analytical framework and tool to study the subsector of patient civil society at national level and international level
- adaption to national characteristics (federalism, social health insurance) is required
- Operationalisation for patient civil society is required
- For comparative purposes, a more patient specific template would be required
- Patchy written data + information ■■■

**... This overview report**  
**as a possible start of the full participatory**  
**CIVICUS Civil Society Index process?**





Download of this presentation:

<http://mig.tu-berlin.de>



Further information on the  
**CIVICUS Civil Society Index  
Project:**

[www.civicus.org](http://www.civicus.org)



Health care in transition profiles  
et al.

European **Observatory**



on Health Care Systems