Citizen Empowerment: Opportunities and threats for Health Management

- Implementing reforms: the new interface
- between patient organisations
- and established actors
- in decision-making bodies
- of German social health insurance

Cordula Mühr, Riesberg A, Wörz M, Busse R
Dept. of Health Care Management, Technische Universität Berlin, Germany
Participation of Patients Organisations in German Social Health Insurance System

- Overview:
  - Background
  - Implemented reforms
  - Demands and concerns
  - Legitimization criterias and access
  - Approved organisations
  - Dimensions and areas of participation
  - First experiences
  - Summary and future tasks
Political Background

- **Demands of patients organisations**

- **WHO**: “The citizen’s voice and choice should make as significant a contribution to shaping health care services as the decisions taken at other levels of economic, managerial and professional decision-making” (Ljubljana Charta /1996)

- **EU**: “…ensure that citizen’s participation should apply to all aspects of health care systems, at national, regional and local levels and should be observed by all health care system operators, including professionals, insurers and the authorities” (EU-Council / 2000)

- **German Health Experts** (e.g. SVR 2003/ Badura /Hart) require implementation of citizen- and patient-partizipation, especially in presence of allocation and lack of ressources
Until 2003:
- Core decision-making body in German social health insurance: joint-committee (BA)
- Sector-specific sub-committees decide on benefits, quality, access and reimbursement
- Self-administration of sickness-funds and physicians, dentists and hospital associations
- Lack of citizen- and patients participation

Law of Health Modernization 2004:
- Fusion into one Common Federal Committee (GemBA)
- Access of patients representatives
- Patients commissioner on federal level
Demands and concerns

- **Legitimacy**: Representativeness and financial independency

- **Competency**: lack of expert-knowledge and public accountability

- **Efficiency**: delay and complication of decision building
Approval and legitimization-criterias

- Ministerial regulation in December 2003:
  - proved independency by disclosing financial incomes
  - work for patient or self-help purposes on a federal level
  - work at least since 2000
  - work on a not-for profit-base
  - work according to internal democratic rules
  - corresponding membership
  - sufficient capacities and previous activities
Accredited organisations

1. German Council of Disabled Persons (DBR):
   Umbrella organisation of 44 different suborganizations, concerning on different groups of diseases, chronically sick and/or disabled persons

2. German Federation of Self-Help-Groups (DAG-SH):
   Umbrella organisation dealing with coordination, promotion, support and advice of self-help-groups

3. Federal Federation of Patient Centres and Initiatives (BAGB):
   Umbrella organisation of 12 centres dealing with information and counseling of patients in questions of health and patients rights

4. Federal Association of Consumer Centres (VZBV):
   Umbrella organisation dealing with consumer advocacy and advice
Dimensions and areas of participation

- **Board of GemBA:**
  - 9 jointly consented representatives of patients organisations, opposed by each 9 delegates of established actors (sickness funds and physicians), headed by a neutral president

- 65 representatives in 13 sub-commissions of GemBA

- Entitlement with consultative and propositional function, but no power of decision

- Confidentiality
First experiences

- Conclusions on controversial issues have been drawn (e.g. co-payment exemption rules, otc-list, payment of transport-costs, rules on physiotherapy and other cure-disciplines)
- Patients issues and arguments has been listened to and taken into account
- Progress in transparency could be achieved
- Patients organisations complaints refer to lack of personal, organisational, financial and time ressources
- They firstly agree with having only limited consulting rights, avoiding to be a fig-leaf for unpopular decisions
Summary and future tasks

- If supported by political intention, constructive working relationships can be established within a short time.
- Still lack of information about structures of decision-bodys and new tasks of patients organisations.
- Necessity of systematic support on infrastructure and expertise for patients organizations (including financial compensation).
- Decision rights should be striven for.
- Role of patients in „Institute of Quality and Economic Efficiency“...
Procedures according to § 139 b

Ministry of Health

Order

Recommendation

Financial commitment

Refusal

Order

Institute of Quality and Economic Efficiency

Orders

Results

Experts

Request for order

Joint Committee

Patient Organisations
Association of Health Insurances
Associations of Hospitals
Association of Physicians
Federal Patient Commissioner

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Thank you for your attention