Workshop 5: Increased safety of diagnostics and treatment - checklists and other tools

Patient Safety — Involvement of Patients in Regulation and Governance in Germany

Cordula Mühr, MD MPH
Patient Representative in the Federal Joint Committee (G-BA), Germany

2nd Global Ministerial Summit on Patient Safety
Bonn 2017
Levels of patient involvement in Germany

**Makro:** Law making

Topic-specific patients` organisations are invited to give formal comment on drafts concerning healthcare and patient safety.

**Meso:**
Federal Joint Committee (G-BA):
mandatory guidelines concerning e.g. patient safety and quality

**Highly important (for patient safety) in Germany:**
Patients organisations are entitled to make proposals, to be present at debates and decisions, but may not vote.
Health insurances, physicians and hospital associations are entitled to vote.

**Mikro:**
Hospital, clinic, physician:
mostly depending upon individual decision e.g. patients advocates in hospitals

Methods and importance of patients involvement in micro management vary greatly.

As most issues concerning patient safety are decided at the Federal Joint Committee - as a „minor law-giver“ in terms of translating law into compulsory implementation - patient involvement at this point is most important. We will look into it in more detail further on.
Division between sectors (hospital/physician), competition and cost restraints intensify the problems deriving from the difference between cost-minimal production and longterm social optimum. External control and enforcement of patient safety and quality issues are necessary.
Decision making on patient safety in G-BA: **general view**

**Statutory health insurance:**
- minimising costs
- maximising scope for competitive behavior
- moderate interest in quality

**Care givers associations:**
- maximising income for members
- minimising „bureaucracy“ and cost-effective regulation
- low interest in quality and transparency

**Patients’ organisations & representatives**

As patient representatives have no votes, low and moderate interests in patient safety, quality and transparency dominate decision making in Federal Joint Committee. Nevertheless patient organisations continually put forward initiatives to improve patient safety as will be shown by some examples further on.
Decision making on patient safety in G-BA: Example complaint management

- **2003**: local patients' organisations in the city of Hamburg put across the self-commitment of all local hospitals to implement a patient orientated complaint management and to report on it annually („Hamburger Erklärung“ [www.hamburgerkrankenhauspiegel.de])

- **2012**: patients' organisations in G-BA proposed to establish a mandatory guideline for extern quality assurance of complaint-management, including patient experience, external benchmarking and public reporting on the way of dealing with complaints

- **2013**: according to the Act on Patients' Rights all hospitals are obligated to establish patient orientated complaint management

- **2015**: upgrading the first guideline for intern QM (2006) the G-BA enacted a cross-sectoral intern QM-guideline, for the first time containing tools like patient-/ staff-inquiry and complaint-management

There is lack of evidence for impact of intern QM-guidelines on patient safety. Evaluation of the cross-sectoral QM-guideline is still missing.
Decision making on patient safety in G-BA: Example hygiene

- **2009**: on proposal of the patients` organisations the G-BA commissioned the development of a quality assurance procedure regarding the prevention of nosokomial infections, notably bloodstream infections. De facto the content-related design of the order was so restricted, that only 0,5% of infections were expectable to be recorded.

- **2011**: The Law on the Prevention of Infection committet the G-BA to specify in his guidelines appropriate measures to improve hygiene quality and to report publicly on the results.

- **1.1.2017**: a cross-sectoral quality assurance procedure in order to prevent surgical wound infections was launched.

Although the role of understuffing in nosokomial infections is well known the determination of staff-requisition in G-BA guidelines is highly conflictive and from patients` standpoint still insufficient (unless e.g. nurse-to-patient-ratios are fixed)
Decision making on patient safety in G-BA: Example hospital discharge

Patient safety is especially compromised at transitions of care at the sectoral borders in Germany

- Since **2007** patients have a legal right on **cross-cutting healthcare management**
  
  (§ 11. 4 German Social Code, Book Five) The level of implementation is up to now unknown.

- **2013**: on proposal of the patients` organisations the G-BA commissioned the development of a quality assurance procedure regarding **hospital discharge**

- **2015**: the law for strengthening the medical care for statutorily insured patients (GKV-VSG) codified a **structured discharge management** as part of stationary medical services, including patients` entitlement to discharge interviews, medical discharge reports and medication plans (§ 39.1a German Social Code, Book Five)

---

Implementation and quality assurance of structured hospital discharge management is currently curbed by objection proceedings of the hospitals` organisation, fearing the need of extra staff and time resources that had to be provided.
The program urges patients to:

- **Speak up if you have questions or concerns.**
- **Pay attention to the care you get.**
- **Educate yourself about your illness.**
- **Ask a trusted family member or friend to be your advocate (advisor or supporter).**
- **Know what medicines you take and why you take them.**
- **Use a health care organization that has been carefully checked out.**
- **Participate in all decisions about your treatment.**

Patients ` organisations in G-BA continually put forward initiatives to provide the conditions for patients to **SPEAK UP**, e.g. by promoting patient surveys as data sources for QS and by reinforcing patients information and shared decision making as important indicators for quality and patient safety.
Levels of public trust in healthcare systems in many countries are already low (OECD 2017)

The public expressed a particular faith in patients' organisations, as well as corporatist actors and independent experts.

How big should be the influence of the following institutions and organisations on Health Policy?

How Do Voters Want to Be Treated?
Health Care Policymaking in the Eyes of the Public

Representative survey 2012 in Germany, (N 1772, statutorily and privately insured individuals aged 18-79)
Patient involvement can be an essential tool in order to achieve, ensure and maintain patient safety.

Patient involvement is all the more important if health-care-systems underly intensified competition conditions.

In strategic terms involvement of patients and patients’ organisations should be implemented in all system-and organisational levels.

In terms of public policy expanded and serious involvement of patients and their organisations in regulation and governance can help regaining public trust in healthcare systems.

Conclusions
Thank you for your attention!