The "ideal" NCP from the patient's perspective

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European Patients' Forum Conference

2 July 2015, Brussels





Introduction



- Patients face "a labyrinth of confusing, sometimes insufficient and sometimes too detailed information"
- NCPs play a critical role in enabling meaningful decisions
- NCP should be a gateway rather than a gatekeeper in healthcare
- "working with the patient, for the patient."



Fundamental principles



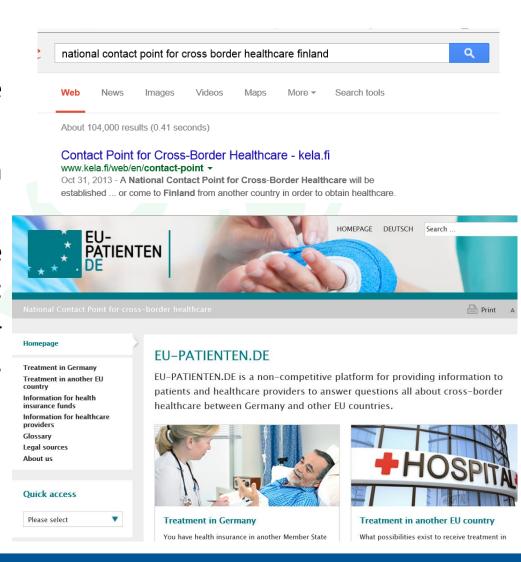
- Independence specific mandate and operational budget
- Protection of the patient's interests as a priority
- Culture of helping and providing solutions
- Human response, respect for dignity, nondiscriminatory
- Trained personnel
- Works with stakeholders to find solutions to ensure the principle of equity of access



Accessibility and visibility



- Highly visible, easy to find
- Communicates in simple language
- Provides information in other languages
- Accessible in real-life situations, not just online: email, free telephone, 24hour emergency hotline, physical premises
- Regional contact points



Operation



- Transparent procedures, clear timelines
- Case managers
- Can deal with advocates/legal representatives
- Facilitates translation of documents
- Mediates patient contacts, e.g. by liaising with other NCPs re access to specialist treatment
- Offers support and advice in case of complaints & problems
- Maintains a list of patient organisations
- "One-stop shop" as far as possible



Information



- Accurate, reliable, up-to-date, easily understandable
- "Designed for and by patients"
- Simple step-by-step guides on application processes
- FAQs online and in print
- Customised information packages
- Information on ongoing clinical trials
- Website is user-friendly, includes a feedback facility



Conclusion: continuous improvement



- Independent assessment of performance
- Some indicators could be:
 - Timeliness of answer (1-2 weeks, "fast-track" option)
 - Clear explanations of all decisions
 - Patient-friendliness
 - Continuous improvement system
 - Effective complaints and feedback process
 - Seeks feedback on its performance and acts on this feedback
- Engages with patient organisations for continuous improvement
- Collects data
- Highlight any gaps and dysfunction to national and European authorities



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