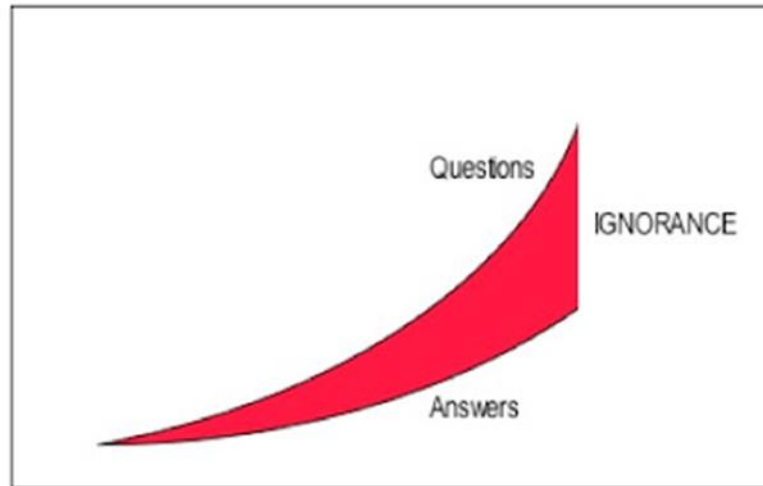


How to partner with decision-makers?

MOHA / Hungary /Borbála CSEH

1. Not „How” but the contact itself



Organizations for patients are able to form opinions – decisions are made by the Ministry. They are not co-partners of any decision-process, they meet the consequences of the legislative regulations.

2. The aspects of decision.makers

- The two main regulators are:
- - authority – decision is to be made by legislative political authorities including the entire process. Others are outsiders, opinions will be answered as any other inquiries used to be reacted according to the Ministry's PR policy.
- - finance - austerity measures on the first line. „generic medicine“, „rationality in starting an expensive cure“, „ask for an appointment and wait“ etc... mean really the dead-end in the case of cancer.

The patient is a disturbing object



Communication channels are marshy – the entire institutional system of medical service is getting incoherent



Patient is not a partner

- As Authority is not accountable by unauthorised institutions and as it never faces directly to the patient, decisions do not build a coherent medical service system but serve momentous interests. Feed-backs about the disfunctions are not awaited at all.
- There is a so called „National Patients’ Forum” – the example of hypocritical attitude. It is founded by the government, applies and pays a few name-and-powerless admins, there are some meetings for the publicity about the „challenging perspectives”.
- Patient organisations are NGO’s, working mainly in the form of foundation. Their financial base can come from the personal-income-tax : 1% can be offered for general public utilisation and foundations, caritative formations can advertise public for gaining supporters. Hunting for money is even more successful, if it is based on offensive campaigns such as dramatic photos of sick children, crying mothers, shocking music on TV. It is worth to invest in the advertisement as it brings a good benefit. Investing in the real work with patients is less profitable. The „gray zone” is wide: money-makers can find their play-ground. NGO-s are not welcome at all, as they mean critics for the authority. That’s why financial control is not more than checking stamps on papers instead of checking the real job.

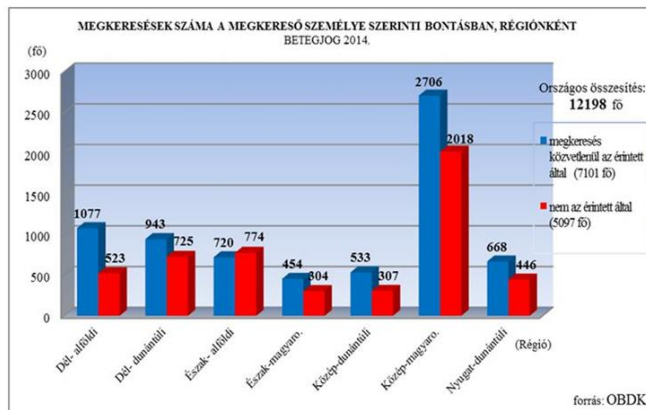
Press under pressure

- Free press is not accepted by the authority – social media and net is the best for finding information. Articles on cancer can be read mainly in women weeklies, heroic and sad stories without real information. Patients can hardly ever get a good use of the international websites and fora as the majority do not speak any foreign languages. MOHA works a lot to interpret reliable information for patients.

Knock on the door

- The Patients' Right Representative is paid by the state, belong to a governmental organization and its education is jura. Patients can discuss with governmental officials on legislative base – they can have legal transactions.
- There is a piece of paper hanging on a door somewhere in the hospital, official hours: every 2-nd week 1 hour. The room is totally unfriendly, I am urged as there are others outside. My problem is formed to a legal form - the upper authority will punish someone later, or not...
- Typical problems are elementary : poor cleanliness, bad food, no medicine...
- What makes patients' right is not a common sense.

... we have a problem...



- blue: the patient turned to the Patients' Right Representative
- red: not the patient itself
- high column: the capital and mid-Hungary
- other column: other parts of Hungary
- 2014- 12.198 person had a talk to the Representative.
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