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International Conference on Deep Brain Stimulation

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The practice of Deep Brain Stimulation –

An international survey on clinical and ethical issues

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Background:

Deep brain stimulation (DBS) has become a standard therapy for some movement disorders and is investigated for various other neurological and psychiatric disorders.

To obtain an overview of the global practice of DBS, two surveys among DBS experts and centers were performed that addressed clinical and ethical issues.

Methods:

We investigated the field of DBS along two dimensions:

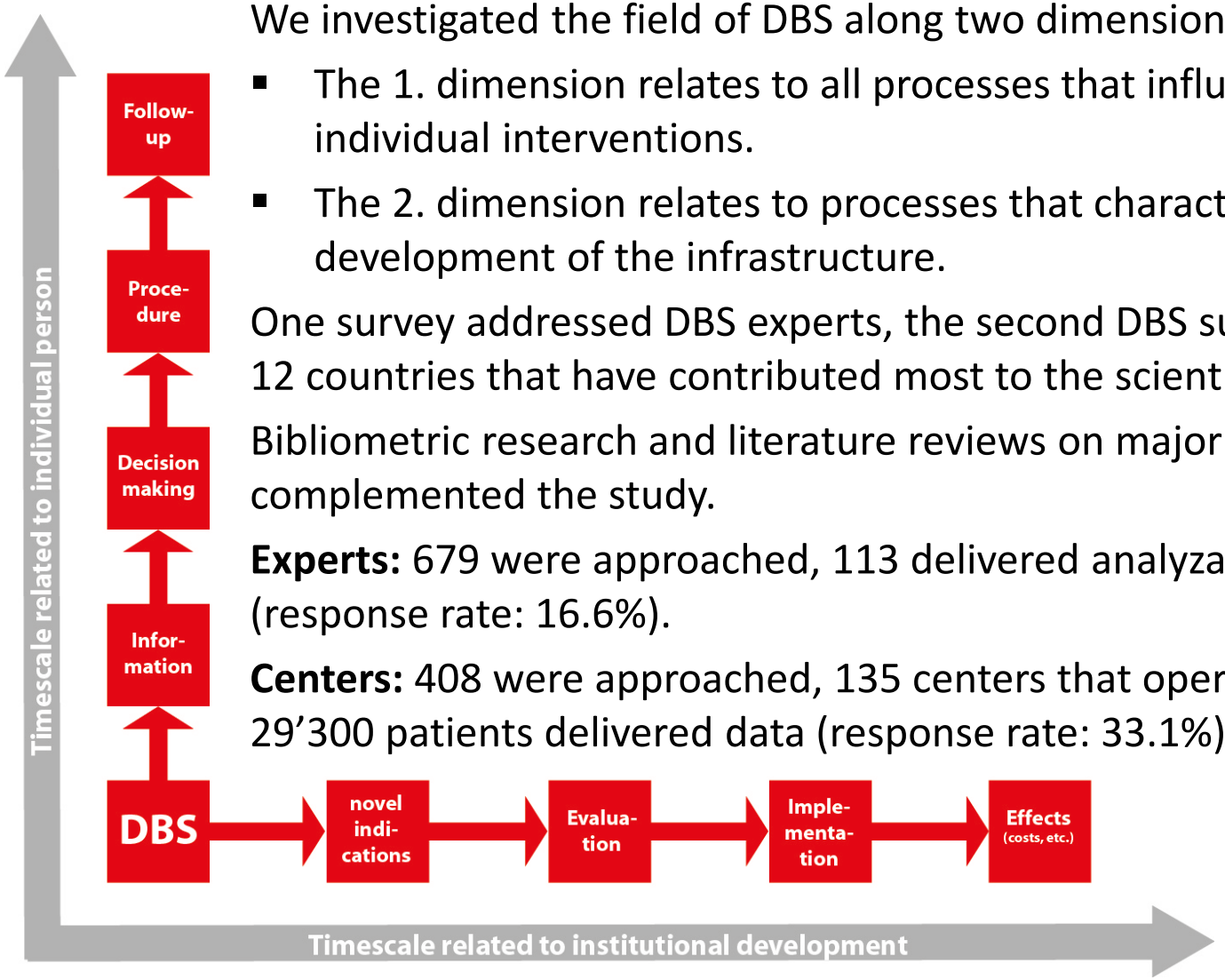
- The 1. dimension relates to all processes that influence the individual interventions.
- The 2. dimension relates to processes that characterize the development of the infrastructure.

One survey addressed DBS experts, the second DBS surgery sites in the 12 countries that have contributed most to the scientific DBS literature.

Bibliometric research and literature reviews on major DBS indications complemented the study.

Experts: 679 were approached, 113 delivered analyzable answers (response rate: 16.6%).

Centers: 408 were approached, 135 centers that operated more than 29’300 patients delivered data (response rate: 33.1%).



Results: Patient Dimension

- The neurologists (in private practice) is the decisive “entry point” for patients both with respect to referral and as information source for the patient.
- The frequency of patient fears and expert assessment of risk probability differ. Surgical complications are mentioned often by patients, although their incidence is small; technical problems and personality changes are less often mentioned, although they are more frequent.
- The experts estimate the frequency of apathy, depression and language problems as adverse events of STN-DBS significantly lower than described in the literature.
- 26.5% of the experts believed that “personality changes” may occur in more than 5% of the cases.
- 38.0% of the experts believed that “satisfaction gaps” occur in more than 10% of the cases.

Results: Institution Dimension

- 60.0% of DBS sites operated 20 or less patients per year (20 is minimum quantity for DBS training centers).
- Future DBS indications: Depression is the indication which is most frequently planned to be offered by the centers within the next 5 years (40.0%). 17.0% of the centers plan to implement DBS for Alzheimer's disease, although the experts consider the success probability to be low.
- More than one third of the centers involve only the core team (neurology and neurosurgery) and maximal one additional discipline in routine DBS interventions.
- More than half of the DBS papers that include funding sources mentioned private funding, i.e. companies or private foundations.
- There are considerable differences among countries with respect to supply density; this may affect the future growth of DBS. USA, Switzerland, Sweden and Germany have the highest supply density.

Conclusion

- The survey has identified potential shortcomings with regard to patient information about risks and side effects, surgery follow-up ("satisfaction gaps"), and the possibly premature application of DBS for new and less promising indications.
- The data furthermore indicate possible learning effects (reducing the number of adverse events) and potential habituation effects with respect to the numbers of disciplines involved. This may have both positive and negative consequences (better cost-effectivity, suboptimal patient care).
- More research is required for understanding the capacity of the DBS infrastructure in various countries in order to deal with the future patient load given a likely increase in DBS indications.

We suggest to focus DBS research also on psycho-social and health service research issues in order to ensure the ethical future of deep brain stimulation.