

**Report of the
1st International Conference on Patient education in MS
and RIMS “SIG Patient education” meeting
from 22.-23.01.2010 in Hamburg:**

The meeting was opened by **T. Henze** (Executive Board, RIMS), **R. Martin** (Director INIMS, Hamburg - Germany) and **M. Härter** (Director Med. Psychol., Hamburg - Germany).

A. Steckelberg (Unit of Health Science and Education, University of Hamburg - Germany) started the meeting with a review about criteria for evidence-based patient information which can be found in patient information despite a proliferation of information tools for patients. Examples were given on misleading information obtained from reporting relative instead of absolute risk reduction. Despite now existing criteria, “evidence-based” is often used just as a label. A generally accepted implementation concept has not been developed yet, although it might be appreciated by health management institutions.

W. Gaissmaier (Max Planck Institute for Human Development, Berlin - Germany) started with the overall fear and bad reputation about statistics while on the other hand emphasizing that management of uncertainty as a major issue. Often information has moralizing or marketing goals rather than informing purposes. A study on how alemtuzumab treatment results were reported on major newspapers shows that especially anonymous articles rarely reported harms associated with treatment. He asked, what causes more distress: illusions (and fears about uncertainty) or realistic knowledge about risks? There are however examples (e. g. in health insurances, airplane-security) of realistic risk assessment being very effective.

R. Crockett (Health Psychology, King’s College, London - UK) focussed on how to measure and judge on health choices. She defined informed choice as being characterized by the following: 1. Relevant knowledge; 2. A choice that is consistent with the decision makers’ values and that is 3. “behaviourally implemented”. The theory of planned behaviour was cited as a conceptual framework for this approach. Interestingly, in the area of screening information being critically about the usefulness of tests often lead to even more uptake of screening. It might be that extensive information makes the possibility of getting ill more real thus leading to more screenings. Furthermore, persons with affected relatives might tend to screen despite critical information. More personalized information might help to give correct and valuable material to individuals at the same time preventing cognitive burden.

C. Goss (Dep. of Psychiatry, Verona - Italy) reported on how to measure and judge on health choices focussing on the paradigm of shared decision making. She studied patient involvement in psychiatrists’ and GPs’ encounters using the OPTION scale. She found that about 20% of patients did not want to take part in decision making, although they wanted to be fully informed. Psychiatrists showed more involvement abilities than GPs, although the quality was overall modest. Presence of emotional distress, openly questioning GPs and patients expressing more cues, opinions and questions were factors associated with greater involvement. It was also discussed that involvement in decisions should congruent with patient preference.

V. Matthews (MS Trust, UK) reported on the governance concept of the MS trust and the developmental stages of patient information. She stressed the key role of community nurses in information provision. High quality materials should be produced tailored to and with direct participation of patients. A lots of different tools, some paper based, some electronically are regarded relevant. A continuous check of usability, request and updating is necessary.

P. Flachenecker (Quellenhof, Bad Wildbad, Germany) reported on an education concept focussing on coping strategies implemented in a German rehab centre for early MS patients. He presented data showing that physicians took less than 15 minutes when disclosing an MS

diagnosis or when discussing treatments. The education program showed lasting effects on psychological and quality of life outcomes.

A. van Nunen reported on educational concepts in the National MS Centre Melsbroek (Belgium). Four major information tools have been developed: the MS-School, an energy management program, an early guidance program and an information carousel / MS-academy. She stressed the attitude to give the right amount of information at the right time for a given patients as well as the helpfulness of groups. Limiting the potential stress triggered by information is a major issue.

J. Kasper (UKE, Hamburg - Germany) claimed that there is no need for one universal theoretical framework for educative interventions. Any framework might be usable, provided it is able to measure the investigated parameters. He stressed that it is not the underlying theory per se that makes research of good quality, but a well-defined hypothesis and a detailed research plan to test such hypothesis.

S. Köpke (Unit of Health Science and Education, University of Hamburg - Germany) explained the difficulties of designing and evaluating complex interventions e.g. choosing an adequate control intervention is not easy and conceptually blinding of patients is often impossible. Referring to the CONSORT-statement for complex interventions he stressed that detailed strategies to achieve standardizations of functions and processes are required. This approach allows the intervention to be tailored to local conditions. Possible outcomes are discussed as patients' knowledge, patients' experience, use of health services, effects on health behaviour and health status. Finally, an overview about past and current RCTs of the Hamburg group is given. He concluded that more studies with rigorous designs are needed and that outcome measures need urgently to be further developed.

A. Solari (Istituto Besta, Milano - Italy) lined out the concept of complex interventions, of which decision aids and patient education interventions are part. Along with RCTs, which remain the gold standard to assess the efficacy of interventions (including complex interventions), qualitative research should be planned together with RCTs. RCTs and qualitative results provide different (and complementary) information. It is also essential that qualitative studies are planned, conducted and reported according to high standards.

Six short presentations followed, on patient education modules in different setting.

M.Bochnig (Stifung Lebensnerv, Hannover - Germany) focussed on an empowerment training approach based on the Salutogenesis concept. He claimed that education is a too paternalistic term. **S. Köpke** reported on the EBSIMS training program on relapse management in MS. In this RCT the intervention not only was effective in terms of improved patient relapse management, but there was a reduced relapse rate in patients assigned to the education program. **U. Lang** (Neuropoint Academy, Ulm -Germany) reported on the extensive "Neuropoint" program attached to his practice, which is highly appreciated by diverse neurological patient groups and has changed the interaction pattern between patients and physicians. **B. Seestaedt** (DMSG, Hannover - Germany) presented the new e-learning module "e-train" of the self-help organisation addressing different complexity levels. **J. Drulovic** (Neurology Clinic, University of Belgrade - Serbia) reported on educational programs at the MS Unit. **G. Pearce** (Sydney - Australia) focussed on informing sessions for newly-diagnosed MS patients. **K.Voigt** (Dep. Neurology, Rostock - Germany) presented an RCT on a psychoeducative training in MS.

The conference closed with a joint discussion on implementation of education into routine care. The following points were made

- To better implement an educational program, evidence is needed: evaluation of patient education programs is highly important!
- Rehab centres are relevant sites to assess and put into practice information and educational interventions. This should be enhanced through dedicated governmental

funding for patient education. An example for a realised implementation is the EBSIMS relapse management program, which has involved several German rehab centres.

- Information is extremely important for early-diagnosed patients: it is desirable that every person with newly-diagnosed MS or clinically isolated syndrome should be offered to take part in an education program.
- Different settings for the implementation of information and educational interventions are possible: i.e. pubs, town halls aiming to stay away from medical settings which might enhance patients' participation.
- Information should be personalized as much as possible on one hand and be given to a wide public as well.
- Information should reach people in their daily lives.
- Doctors and nurses need training as well: they have to be trained to use information materials and decision aids, and to improved communication.