Conference report:

PatientPartner final workshop: "Patients partnering in clinical trials"

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The following organisations are partners in the RESPECT project:
University of Gothenburg, Göteborg Pediatric Growth Research Center (Sweden)
University Hospital of Hamburg-Eppendorf, Department of Medical Psychology (Germany)
European Patients Forum, Brussels (Belgium)
University Children's Hospital Ljubljana and the Foundation of Child Neurology (Slovenia)
Good Clinical Practice Alliance Europe, Brussels (Belgium)
Azienda Ospedaliera di Padova (Italy)
Consorzio Valutazione Biologiche e Farmacologiche, Pavia (Italy)

Background

The FP7-funded project PatientPartner (www.patientpartner-europe.eu) aims to promote the role of patient organisations in the clinical trials context, based on the belief that involving patient organisations as equal partners at all stages of clinical trials contributes to research that is better adjusted to the real needs of patients. The study has examined the role that patient organisations play and are willing to play in clinical trials and seeks to stimulate dialogue between the stakeholders in clinical research.

The project has encountered a great number of examples of good practice in which representatives from patient organisations have contributed to the course of clinical research, e.g. by reviewing the protocol for a clinical trial. Patient representatives bring their own expertise to the table – the knowledge they acquire by being a patient, carer or patient advocate on a day-to-day basis. By sharing this patient perspective with stakeholders in clinical research, they can help form the development, conduct and implementation of clinical research, resulting in treatments that will be more representative of patients' real needs.

The previously held Regional European workshops were summarised as follows:

- Patient organisations wanted to be involved in all stages of the clinical trial development process to ensure the patient perspective was incorporated into the resulting trials. Important roles were seen for patient organisations in providing their members with information on where to find and how to take part in clinical trials, as well as having a say in the agenda-setting and ethical review of clinical trials.

- For academia and the pharmaceutical industry, patient organisations were found to have an important role in making protocols more patient-oriented and patient information and informed consent documents more understandable. Furthermore these two stakeholder groups foresaw a role for patient organisations in facilitating patient recruitment as well as raising awareness on the availability and opportunity to take part in clinical trials in Europe.

- On the topic of the need for knowledge, all represented stakeholders agreed that for patient organisations to fulfil their “new” role as a partner in clinical trials a certain level of training on the clinical trials development process needed to be provided.

- Finally the conjoined stakeholders identified that patient organisations, academia and pharmaceutical industry struggle in the identification of the “right” partner to work with on a certain clinical trial as well as lack the knowledge of each other’s competencies and drivers to do so.

The workshop

The final workshop focused on how to make the partnership between patient organisations and other stakeholders in clinical trial development work in practice. Breakout sessions covered:

- the “ethical principles” that are needed for patient organisations and the other stakeholders to work together in an ethical manner;

- how to “build the bridge” to partnership: looking at the practical issues in working together in clinical trial development. For example, by providing training for patient organisations on clinical research methodology, to help them be actively involved in clinical research in a meaningful way and thus help set the agenda for clinical research.
- how to “build the PatientPartner Networking and Communication platform” in order to fulfil the need for a matchmaking structure that was identified in the three regional workshops.

There was also an ongoing poster exhibition with a poster session showcasing examples of the active involvement of patient organisations in clinical trials. I presented a poster on the findings and recommendations of the RESPECT project.

Patient organisations attending the conference ranged from one caregiver running the whole association from home to major organisation with professional management. It was very interesting to see that a few patient organisations found support from retired managers of industrial companies which were not connected to the field of health and research and are now able to improve communication, administration and marketing.

The different patient organisations had different attitudes towards the pharmaceutical industry in general. According to this underlying general mistrust regarding the goals of pharmaceutical industry, they sometimes have great concerns about recommending their members to participate in a clinical trial. My impression was that the more professionally a patient organisation is administered, the more open-minded they are if asked about participation in medical research.

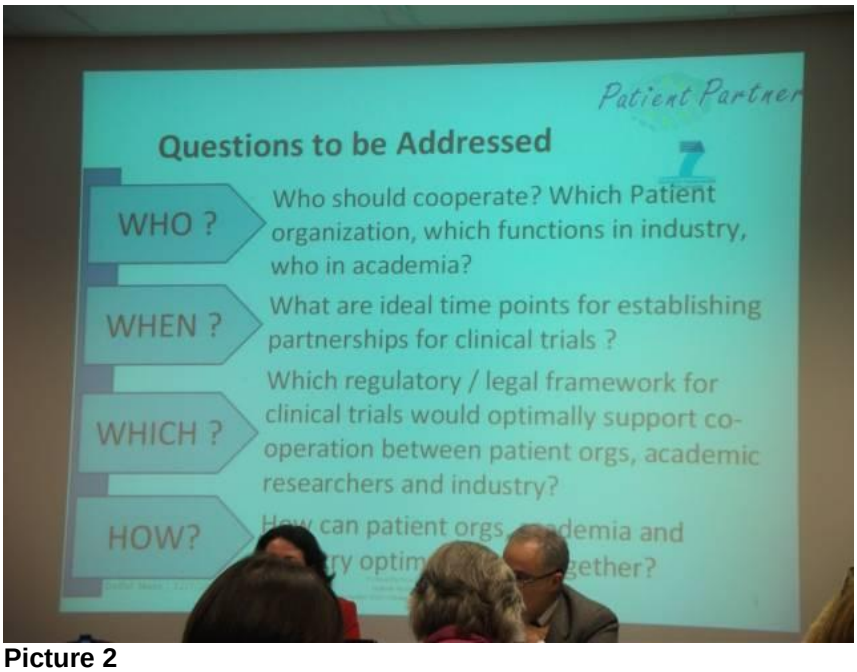
The representatives of the pharmaceutical industry I met were very positive about integrating patient organisations into the whole process of medical research. Patient organisations can contribute to the design of a study, help finding eligible participants, disseminate the outcomes (if disclosure is possible) and empower patients as a patient’s advocate. At the poster session, I had very interesting conversation with Ms Kay Warner from GlaxoSmithKline. She is very interested in the results of RESPECT, especially the generic decision aids which may help her to empower and educate potential participants before enrolling in a study.

I attended all breakout sessions in group 2:

Breakout session A2: we discussed the ethical principles in partnership, see picture 1

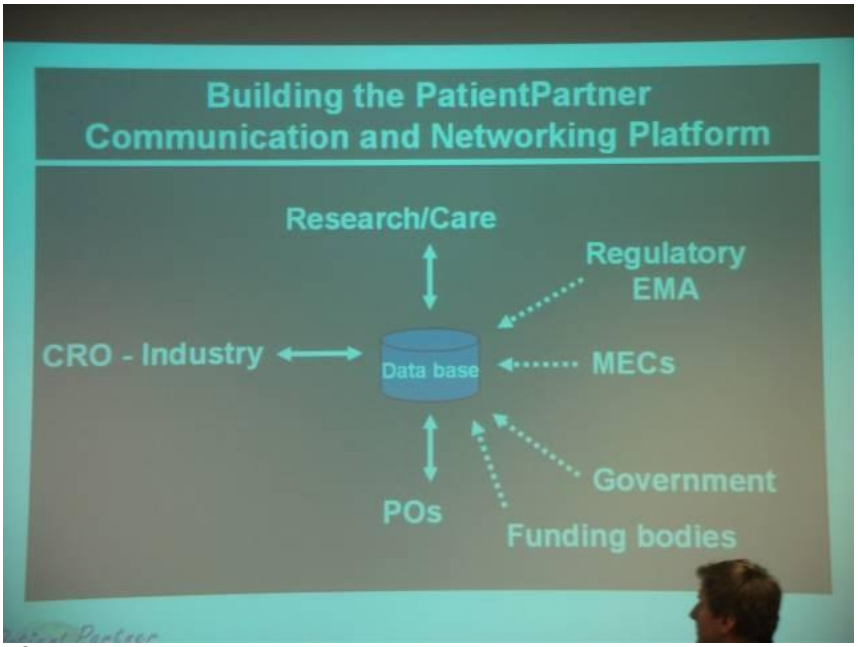
Picture 1

Breakout session B2: we discussed how to build bridges to partnerships, see picture 2

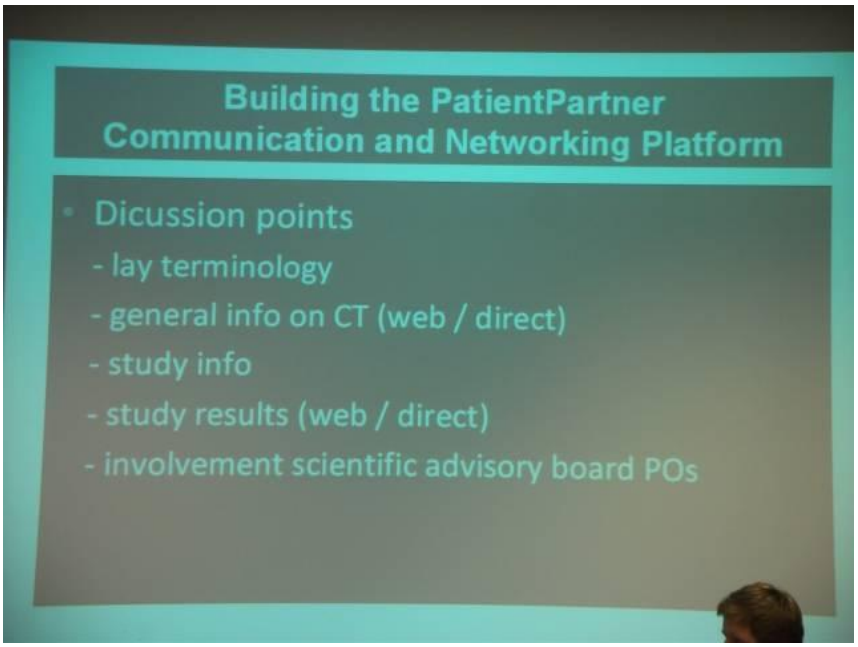


Picture 2

Breakout session C2: we discussed establishing the PatientPartner communication and networking platform, see picture 3-6

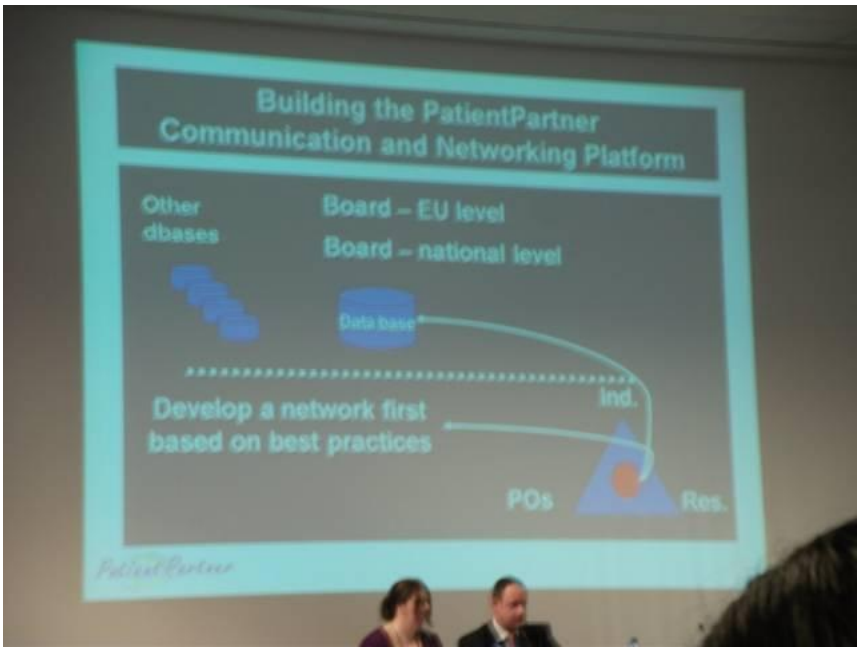


Picture 3



Picture 4

Picture 5



Picture 6

Final comments

It was very interesting to see this project with a similar aim to RESPECT setting the focus at a more macro level than our project. PatientPartner focuses on the stakeholders and the relations between big organisations as representatives of patients, regulatory bodies and pharmaceutical industry, whereas RESPECT examines the relations between the families, CT researchers and doctors. PatientPartner discussed many ethical issues whereas RESPECT concentrates on the psychological factors such as attitudes, fears, perception, understanding, decision-making and more.

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