ScienceDialogue – Dr. Katharina Zöller – Info@DialogZ.de – 0881/9245 1381

EU Project: Patient and Citizen Participation in Basic Research on Arthritis

Arthritis is a painful disease; more than half of the population will suffer from it at the age of 65 and older, prevalence in women is higher than in men. So far, treatment is mainly symptomatic and not curative. With this project, it can become possible in the future to cure affected joints after injecting layers of biomaterials, mesenchymal stem cells, vectors ("gene vehicles") and nanoparticles directly into the affected structures. These layers can enable joint regeneration.

Health Technology Assessment – the judgment of chances and risks of health technologies - is usually done by experts only and is mainly performed when a new application is at least in clinical studies or available on the market. With this project, we will integrate patients and lay people's view into early research and pre-product development. Through so-called patient panels and citizen panels we will involve affected and interested people to discuss chances, risks and ethical as well as social aspects of the research at eye level with the researchers in the consortium and other stakeholders. The involved scientists can therefore include future patients and interested citizen's views into their research, implementation and communication strategy; the patients and citizens can take advantage of being part of the development of new curative measures.

To overcome the classical one-way communication with scientists in the role of experts providing information and citizens in the role of lay people receiving information, we will engage in a two-way dialogue at eye level between scientists and patients/citizens. In so-called patient and citizen panels participants are in a first step introduced to the field of innovative research on arthritis, for example through expert presentations during the panels and a hearing with experts selected by the citizens in the citizen panel.

With the support of independent neutral facilitators, the participants in a second step negotiate about the benefits, risks and ethical/social aspects in the field. As a result, the patients and citizens "assess" the work of the scientists and the whole subject from their special point of view with relevance to societal sights and values and outline recommendations for the scientific world and other societal sectors such as politics and industry. In this dialogue, both "parties" (scientists and patients/citizens) learn from each other. In addition, politics, administrative and industrial bodies will benefit of the participants assessments as their judgments and associations point out the level of acceptability for decisionmakers. Key fields of interest in this project are the use of stem cells, the practice of gene therapy and nanomedicine.

The following people are members of the dialogue team:

- Dr. Katharina Zöller, dialogue-workpackage leader and co-facilitator (www.DialogZ.de)
- Maren Schüpphaus, facilitator (www.dialogimpulse.de)
- Sven Siebert, project manager (www.konzept-gruen.de)
- Beatrice Lugger, scientific journalist (responsible for info brochure for the panels)

Duration of the project: September 2010 – August 2012
Patient Panel: May 2011
Citizen Panel: September/October 2011
Panels in Ireland/Switzerland: first half 2012