

S.T.o.Re Project Turkey Meeting S.T.o.Re Projesi Türkiye Toplantısı

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In recent decades, both the specialization of the instruments of medicine, as conventionally understood, and the bureaucratization of the health care system, have focused on diseases rather than on people, radicalizing Evidence Based Medicine (EBM), understood as the conscientious, explicit, and judicious use of current best scientific evidence in making decisions related to patients care. Narrative Based Medicine (NBM) wants to act as a complementary approach to EBM (the gold standard for clinical practice over the last few decades), paying attention to stories of illness as a way to understand people and place them correctly in their specific context, focusing on the needs, but also on new strategies of intervention.

The aim of this project is to offer physicians a respectable intellectual framework – no longer rooted in this old-fashioned mind/body dualism – to work with, together with the instruments to implement it in everyday practice. The framework is NBM and the instruments are integrated medical records.

Ultimately, the Project purpose is that of enriching both the physician's work by drawing their attention to the variety of cultures and beliefs with which they come into contact with, and patient's experience of the health care system, particularly in the matter of chronic conditions, especially rare diseases. Indeed, an important outcome of this Project will be the exchange of new ideas and approaches from different cultural perspectives, the transfer of new methodologies and the development of training guidelines that can be implemented, in the initial phase, by all partners involved and subsequently to more European countries.

On 28 October 2013, all partners (14 people) have arrived at Izmir airport and have been safely transferred to the hotel by Turkish Project staff. All the attending Project team have been taken from the hotel and

transferred to the Kick-off Meeting place – Izmir Katip Celebi University in Cigli/Izmir.



Prof. Dr. Mehmet Ali Malas (Dean, Izmir Katip Celebi University (IKCU)) welcomed the international participants at the main building of the IKCU, where they received a detailed description of the Project for the realization of the University campus. The meeting started with a brief table presentation of the people attending the meeting. After, all the Partners representatives presented their respective organizations using the template provided by the coordinator during the preparation phase for the 'Komunikujeme'. These presentations will be uploaded on 'Teambox' (the Electronic Communication Systems adopted by the partnership) and will be made available on the Project web site when it will be ready. During the coffee break, the participants had the chance to look at the printed version of three versions of the project logo proposed by the Greek Partner. Just after the break, the logos have been voted and the first version won with almost the totality of the preferences.

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The second part of the first meeting day has been dedicated to the presentation of the Project objectives, activities and products, as well as the general rules for reporting and financial administration. The Project manager, Ms. Amalia Egle Gentile from Italian National Centre for Rare Diseases, Italian National Institute of Health, Rome (P1), presented a general overview of the Project with key data and main responsibilities of the partner organizations.



Important issues have been discussed and agreed with in the partnership.

- a) When sending formal communications about the project, all partners will use the full name of the project “Story Telling on Record” and the Project number.
- b) The final meeting in Italy will be combined with the organization of the Festival and International Conference on Narrative Medicine and Rare Diseases by (P1), in June 2015.
- c) The preparation and updating of the electronic photo gallery will be managed by AUSL2 Umbria (P2) which is already in charge of the web site design and maintenance.
- d) Being the lead partner of Dissemination, KOMUNIKUJEME (P5) will take care of the preparation of guidelines for booklets elaboration.
- e) The Greek Dementia Association (P6) proposed itself for being the responsible partner for the preparation of guidelines for focus groups and interviews.

Ms. Gentile, together with Mr. Altheo Valentini, presented the workflow for the implementation of project. Phases, roles and timing have been shared with the partners. Here, the difference between scientific and progress reports have been introduced, and times have been agreed both for setting up working deadlines and for the organization of the next meetings.

At the end of the day there was a social program. First, with all partners there has been a sight seeing around the Izmir Bay and after we went to Kemeraltı, a historical market (bazaar) district of Izmir, Turkey. And after that at dinner there had been a delicious meal with Turkish Kebab and meals at a very famous restaurant.

On 29 October 2013, the second day of the meeting, in order to set the basis for the future implantation of the Project activities. The first task was to identify a common and shared definition of narrative medicine or narrative based medicine (NBM), the key topic of the STORE project. During the preparation phase of the KOM, partners were asked to send their own definition of NBM. These definition were collected and discussed at a very interestin groundtable, where all the partners, on the basis of their respective expertise and experience on the field. The partnership agreed on the following definition of NBM as: ‘A complementary approach to classic medicine. Treating by the narrative competencies is conducted through the doctor’s and patient’s understanding of the origin of the illness following the background of the problems, the reason of the illness and the whole body approach.’ The roundtable, then, continued with a constructive debate on the definition of Integrated Medical Records (IMRs), where various operational and problematic aspects have been highlighted; time and economic constraints, methodological aspects, format and extend.



Finally, the partnership agreed on the fact that the thread to connect the different phases of the research will be to identify the best simplification method for the collection and maintenance of the patient’s stories, taking advantage of already existing classification measures, operation tools and online databases, but focusing on a more complex solution that can ensure the transnational and interdisciplinary sustainability of Project products,

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with a view of a further exploitation in future experimentations.

At a very basic level, the final result will be a change on the minds of the doctors and the hospital operators thanks to operative implementation of specific training guidelines. It has been clarified that the Publication Policy applies only to the publication of sensitive and/or scientific information on the Project and that any communication has to be previously done to the Project coordinator if related to the promotion and/or dissemination of the project objectives and activities.

The partners also agreed the date for the organization of the second meeting in Athens/Greece, 10-11March 2014. After the meeting ends, all partners have taken a family photo and Turkish staff have given a surprise to all attendees with traditional gifts unique to Turkey.

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