ICPM 2018 (International Conference in Pharmaceutical Medicine)

Workshop 4

Patient-centered medicines development (Roundtable)*

Written by Ingrid Klingmann [1)]

Chaired by Ingrid Klingmann [1)], Yoshihisa Yamano [2)]

Panellists: Satoshi Miki [3)]
Kay Warner [4)]
Taruho Kuroda [5)]
Greg Koski [6)]
Yuriko Oda [7)]
Kyoko Imamura [8)]

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7) Patient Association for Distal Myopathy (PADM), Japan
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In her introduction Ingrid Klingmann presented the recent development in Europe from focussing on patients' needs in medicines R&D ("patient-centricity") to "patient engagement" where well-educated patients participate in all steps of R&D from identification of most suitable molecules to clinical trial designs, study conditions, to lay summaries of study results in collaboration with pharmaceutical companies, academia, competent authorities, ethics committees and Health Technology Assessment (HTA) organisations. Although there are broadly recognised benefits of engaging patients into these processes there are many hurdles to overcome before this concept will be systematically implemented. Lack of knowledge about the medicines development science and methodology on the patients' side and lack of infrastructure to integrate patients into these processes on the side of industry, academia and authorities are the major hurdles to broad acceptance and practical implementation. Ongoing initiatives to increase patients' knowledge (e.g., EUPATI), to develop the governance infrastructure for collaboration with patients (e.g. PARADIGM, PFMD) and guid-

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ance initiatives were explained.

Yoshihisa Yamano presented the current situation of patient-centred medicines development in Japan. In comparison to Europe and USA the patient-physician relationship is based on trust of the patient in the authority and competence of the physician. Patient engagement concepts are in their infancy. They would have to be promoted and funded by the government. Currently there are not many reports on such collaboration available.

In the subsequent Panel Discussion the participants, starting with Yuriko Oda from PADM, presented their type of involvement in patient engagement from their organisation's and personal point of view. Oda reported how hard it was for her to become a driving force for the generation of a broadly respected patient organisation that made its voice heard. The industry representatives Kay Warner, Satoshi Miki and Taruho Kuroda stressed the global concepts of their companies but explained the regional differences in their execution and the role patient engagement functions /departments are playing in their companies. Greg Koski from ACRES, a global not-for-profit organisation driving professionalism in clinical trial sites, explained the relevance of patient engagement in clinical trial practicalities.

There was agreement amongst the panellists that many hurdles still need to be overcome in all regions of the world, internally in their organisation to get more systematic approaches implemented but also in the public environment to achieve broader acceptance of the concept and commitment from all stakeholders. Fundamental prerequisite in all regions is the education of patients in the R&D science and methodology to achieve better appreciation of their advice by the scientific and clinical experts in industry, academia and competent authorities. Kyoko Imamura pointed out the important role the University of Tokyo might play in this process.

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