



Poster № 130

Theme 06, Game Changers in Global Society

Title: Availability of medical care and medicine support for patients with rare diseases across the RF territory over the period of 2013 through 2015

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Objectives: demonstrate the development level of medical service and medicine support for rare patients in the Russian Federation, basic approaches to solving vital tasks and further problem development trends

Methods: structured request of information, quantitative and qualitative examination

Evaluation: there are three groups of rare diseases distinguished in Russia which first of all differ in government guarantees in regard to patients.

The EAEU Institute* analyzed the availability of medical care and medicine support for patients with rare diseases across the RF territory over the period of 2013 through 2015 and has obtained:

- Clinicostatistical information (number of patients grouped according to diseases, disease prevalence, disability and mortality rates, ratio of adult patients to children)
- socioeconomic information (level of targeted therapy provision to patients with rare diseases, funding sources and amounts)
- information on the problem of regulation of medical care for rare patients.

Results:

Two levels of managing problems - various degree of 'maturity' of the system

- federal level - the 7 High-Cost Diseases Program has been in effect since 2008: uniform procurement, the list of drugs corresponds to the list of diseases, reallocation of drugs among RF regions is planned for 2016, etc.
- regional level - the List-24 program has been in effect since 2012: a registry of patients with rare (orphan) diseases is developed (as of March 2016 it covered over 14,000 citizens in 85 RF regions), no uniform regulatory instruments in RF regions, no possibility for negotiating prices with manufacturers, the issues of diagnostics, routing, dynamic observation of patients are under formation yet.
- Diseases not included in the List-24 are subject to another regulatory systems, etc.

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