

# DETERMINANTS OF DEVELOPING A PILOT OF COORDINATED CARE MODEL FOR PATIENTS WITH MULTIPLE SCLEROSIS IN POLAND

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**A** – study design, **B** – data collection, **C** – statistical analysis, **D** – interpretation of data, **E** – manuscript preparation, **F** – literature review, **G** – sourcing of funding

## ABSTRACT

**Background:** Multiple sclerosis is a chronic and highly debilitating disease with very high economic and social consequences. Designing changes to improve the functioning of the healthcare model primarily requires learning about the needs of beneficiaries.

**Aim of the study:** The purpose of our study is the results' description and summary of conclusions of the research conducted in the past years. These results are currently being used for the construction of a coordinated care model for MS patients.

**Material and methods:** One questionnaire survey addressed to MS patients, carried out between 01.12.2013 and 01.02.2014 and the second one addressed to Polish and European medical professionals, carried out between 01.09.2016 and 04.10.2016 performed in 51 European centers and 2 branches of the Turkish Association of patients with MS.

**Results:** In the first survey 84.4% patients declared that during the illness they received mental support mostly from their family: 48.5% received it from physicians; 42.1% from a nurse. 64.8% of the respondents declared that they received no support from social organizations and 77.6% received no support from religious organizations. According to the results of the survey for healthcare professionals in Poland and Europe, in 54.9% of the European institutions and in 22.4% of the Polish institutions, dedicated IT systems are used for processing MS patients' data. Among institutions using IT, 52.9% of the European and 10.1% of the Polish ones keep the patient's entire documentation, as well as a patient satisfaction survey, in an IT system.

**Conclusions:** Based on our studies described above, the patients' needs, resources and capabilities seem to indicate that the scale of system inefficiencies is such that remodeling care for this well-defined group of patients is justified and feasible.

**KEYWORDS:** multiple sclerosis, coordination, patient satisfaction

## BACKGROUND

In December of 2017, the possibility to implement pilot programs was introduced to the legislation on healthcare services financed by public funds

[1]. This change allowed the development of pilot programs directed at groups of patients whose disease requires the use of non-standard healthcare services.

A pilot test of an integrated care model for patients with multiple sclerosis (MS) is being prepared. MS is a chronic and highly debilitating disease with very high economic and social impact [2–6]. Some patients with the highest degree of impairment rate the state of their health as worse than death [7]. Kurtzke scale - Expanded Disability Status Scale (EDSS) - is used to quantify the clinical state of patients with MS. The scale ranges from 0 to 10 in a half-integer spectrum, where 0 stands for the normal neurological state of a patient, 9.5 - a patient who is completely dependent, bedridden, incapable of successfully communicating or eating on their own, and 10 - death. Using this scale makes possible the standardization of the stratification of the MS patients' population.

Treatments decelerating the impairment may have also a positive influence on the patients' quality of life. Introduction of so called "drug programs" in the previous decade has given Polish MS patients the possibility of being treated with advanced medicinal products, significantly slowing down the progression of the disease. Unfortunately, the results of analyses of these programs' still do not allow for a unanimous judgment of their effectiveness and costs incurred for reaching specific goals or patients' wellbeing.

#### AIM OF THE STUDY

The purpose of our study is the results' description and summary of conclusions of the research conducted in the past years. It is currently being used for the construction of a coordinated care model for MS patients in order to increase certainty that the programs being implemented adequately accommodate the needs of people suffering from this disease.

#### MATERIAL AND METHODS

Designing changes in the healthcare model to improve its functioning requires the learning of its beneficiaries' needs. In the past, this striving to learn the needs of, as well as opinions about the system of care for patients suffering from MS, became the foundation for conducting survey studies by the Urszula Jaworska Foundation (the representative of the patients) in tandem with the National Health Fund (the public payer). One was a patient satisfaction survey (the year 2013/2014, the respondents were patients suffering from MS) and the other was focused on a comparison of care standards in Polish and select European institutions treating patients with MS (2016, the respondents were the medical professionals working there) [8–10].

Both the above-mentioned survey studies, the first of which was directed at MS patients and the other at Polish and European medical professionals employed in institutions treating patients with MS, were conducted based on surveys designed by experts. The surveys were prepared according to the Delphi method, gathering and processing research questions formulated during

expert group meetings, which then repeatedly underwent moderated discussion ending with the consensus of the gathered members. Most of the questions in the survey are of a closed-ended structure, which facilitates the comparability of the answers.

The survey for the first study (directed at patients) consisted of 45 questions which were divided into three topic blocks:

1. Metrics (the general section) - information characterizing the surveyed respondents (7 questions);
2. The disease - the treatment method and costs incurred by the patient (17 questions)
3. Quality of life - questions relating to changes in way of life before and after being diagnosed with multiple sclerosis, relating to private life and profession (21 questions).

This study was conducted in the period from 01.12.2013 to 01.02.2014 among 1000 patients suffering from MS. Two research methods were utilized [11].

1. Paper and Pen Personal Interview (PAPI) - conducting an interview using the paper version of the questionnaire; The survey was conducted in ten healthcare institutions in which those suffering from MS are treated, in: Gdansk, Grudziadz, Cracow, Lodz, Pila, Poznan, Rzeszow, Warsaw, Wroclaw and Zabrze (240 interviews).
2. Computer-Assisted Web Interview (CAWI) - online research using a website survey which was filled out by the respondents themselves on a computer (760 respondents). The people filling out the questionnaire in this way were verified (people who wanted to fill out the questionnaire had to send in an email, briefly introduce themselves and prove they have MS - only then did they receive a link to the online survey; the link to the survey was not directly shared on social media) to minimize the risk of the survey being filled out by people other than patients suffering from multiple sclerosis.

In the second study, the part directed at Polish medical professionals was done from 14.06.2016 to 04.08.2016 (52 days), whereas the portion directed at European medical professionals - in the period from 01.09.2016 to 01.10.2016 (34 days). 228 institutions participated in the Polish portion of the study and 51 in the European portion (49 clinical institutions treating MS and 2 departments of "The Multiple Sclerosis Society of Turkey"). These institutions were based in 19 countries: Belgium (15), Ireland (7), the Czech Republic (4), England (3), Norway 3), Germany (3), Turkey (2), Spain (2), Slovenia (2), Switzerland (1), Slovakia (1), Scotland (1), Portugal (1), The Netherlands (1), Lithuania (1), Iceland (1), Hungary (1), Finland (1), Bulgaria (1).

The survey for the second study consisted of 22 questions and spaces for additional remarks, where the first 5 questions identified the facility, and the following - the physician and the individual number of their contract with the public payer. The remaining questions

pertained to the organization of care and treatment for people with MS in the facility, access to specialists from different areas of medicine and to the IT tools used.

In the English language version sent out to the institutions in Europe, the beginning of the survey was modified by adding the name of the country and the facility's and physician's identifiers were left out.

Most of the questions contained in the survey had a closed-ended character, but for part of them, more than one answer could be given (especially those related to patient access to specialists and the tools assisting in treatment).

The method of gathering data relied on the active link to the online surveys (CAWI) that had been shared with respondents. In Poland, the studies were carried out in two ways:

1. The recruitment of medical personnel by the Urszula Jaworska Foundation was carried out by actively seeking out contacts to all neurological institutions in Poland, sending links and a request to fill out the survey by a medical representative in direct contact with patients with multiple sclerosis.
2. The recruitment of respondents from the administrative side was executed by the National Health Fund (NFZ) by sending out an active link to the survey study to the administrative personnel of the institutions tasked with treating neurological patients. Aside from hospitals, these were: neurological clinics, primary healthcare centers, and individual medical practices.

Furthermore, the model designed required epidemiological data pertaining to MS and the costs related to the treatment of this disease [12]. The lack of a Poland-wide register of those suffering from MS necessitates the use of reported data [13–15] by medical organizations realizing patient intervention for the public payer (the National Health Fund - the NFZ). Analyses of these data make it possible to connect the direct costs from the public payer's perspective with the therapy of specific patients, recognized in the payer's database according to the ICD-10 code G35, and the anonymization of their PESEL (a unique patient identification number in PL) numbers for analytical purposes [12]. The number of patients with MS in Poland (identified according to the ICD-10 code G35) shows large stability with low (+1.3%) growth dynamic yet with high (+14%) growth dynamic of direct costs [12].

## RESULTS

1000 patients with MS filled out questionnaires in research conducted in the years 2013/2014, of which 240 interviews were done (24%) according to the PAPI method and 760 interviews (76%) were done by the CAWI method.

In the questionnaire directed to the patients, 694 (69.4%) of respondents were women and 304 (30.4%) were men (0.2% declined to answer the question on

gender). Respondents were in the age of 16-71 years. The largest group of patients was in the age range of 31-40 years (354 respondents, 35.4%). The highest percentile had received higher education (538, 53.8%). 310 (31%) of respondents' place of residence were cities with over 500,000 inhabitants. For over half (634 - 63.4%) the family's total household income was less than PLN 4,000, of which 121 (12.1%) households had an income lower than PLN 1,500. The monthly household income for 169 (16.9%) of those surveyed equaled from PLN 4,001 to PLN 6,000. Merely 89 (8.9%) of the respondents had a household income grossing PLN 6,000, and for 19 respondents (1.9%) - it equaled more than PLN 10,000. 95 (9.5%) respondents didn't disclose the amount of their monthly household income.

Most patients (700 - 70%) had been diagnosed with MS between the years 2005 and 2014. 588 (58.8%) of them didn't receive any social care benefits related to their disease, 294 (29.4%) received a pension, 195 (19.5%) an attendance allowance, and 16 (1.6%) a sickness allowance. Medical counsel was mostly given by neurologists (972 - 97.2% - usually a physician providing drug therapy) as well as physiotherapists - 282 - 28.2%; psychiatrists - 116 - 11.6%; psychotherapists - 73 - 7.3%; the remaining specialists accounted for 10.4%. On Fig. 1 the source of mental support for patients during their disease has been presented.

Most of the respondents (in total, 844 - 84.4% of the responses was "yes" or "predominantly yes") declared that they had received mental support from their family, 485 (48.5%) from physicians, and 421 (42.1%) from nurses. More than half (648 - 64.8% of the responses were "no" and "predominantly no") declared a lack of support received from social organisations or 776 (77.6%) from religious organisations. 12.3% of respondents (n=123) covered the costs of adapting their living space with personal funds, and most of the time the cost amounted from PLN 5,000 to 15,000 (31% of answers). The disease and the applied therapy had a significant influence on the personal lives of the respondents. One of the most impactful decisions was about having offspring (the medications used in treatment create limitations in this area). 283 (28.3%) patients resigned from having offspring, 405 (40.5%) didn't resign, and 300 (30%) hadn't thought about this. Women made the decision to resign from having offspring more frequently. When asked a question on the need to use the help of others in normal life situations, 63% of the surveyed answered that due to MS, they were dependent on others, in 86 (8.6%) they were constantly dependent, 164 (16.4%) - often, and 380 (38%) - sporadically or only in specific situations have to enlist the help of others. Depression accompanied 587 (58.7%) of the patients.

Despite the inconveniences related to the disease, 712 (71.2%) of patients continued their professional activities. (Fig. 2)

The second survey, conducted in 2016, was directed to medical professionals employed in institutions (228

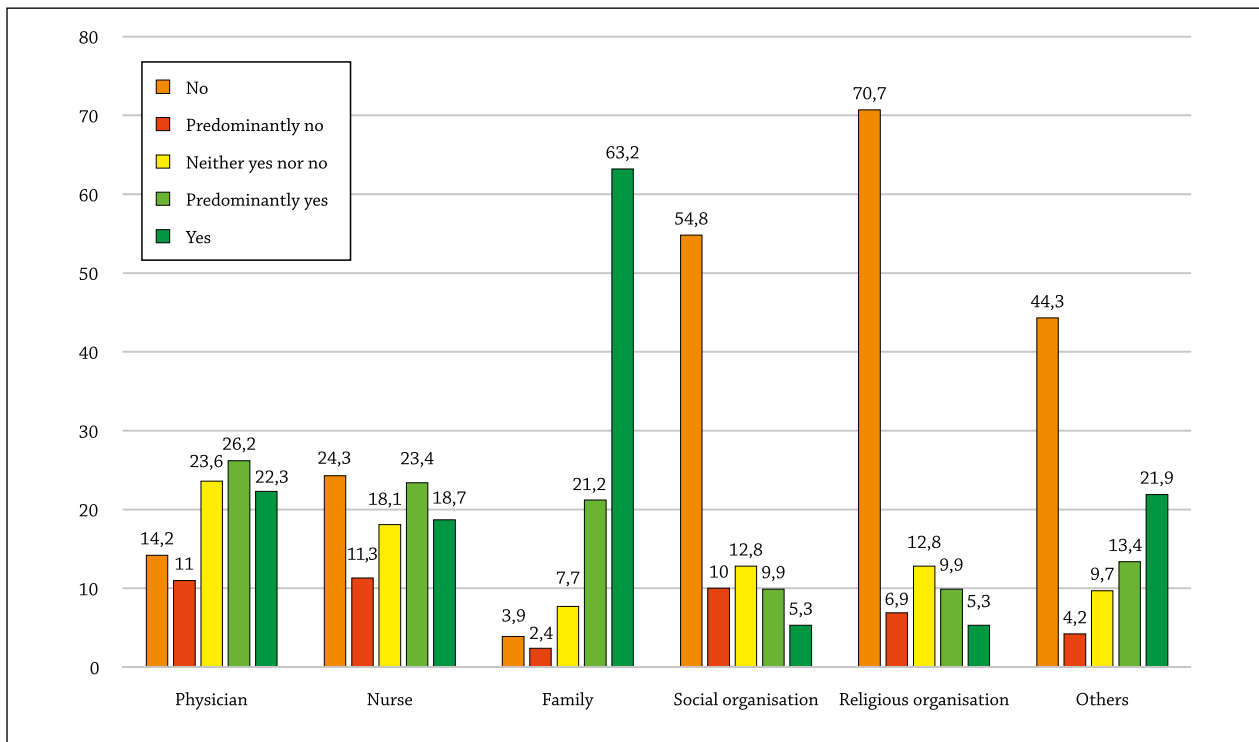


Figure 1. The assessment of mental support received based on the responses of the surveyed

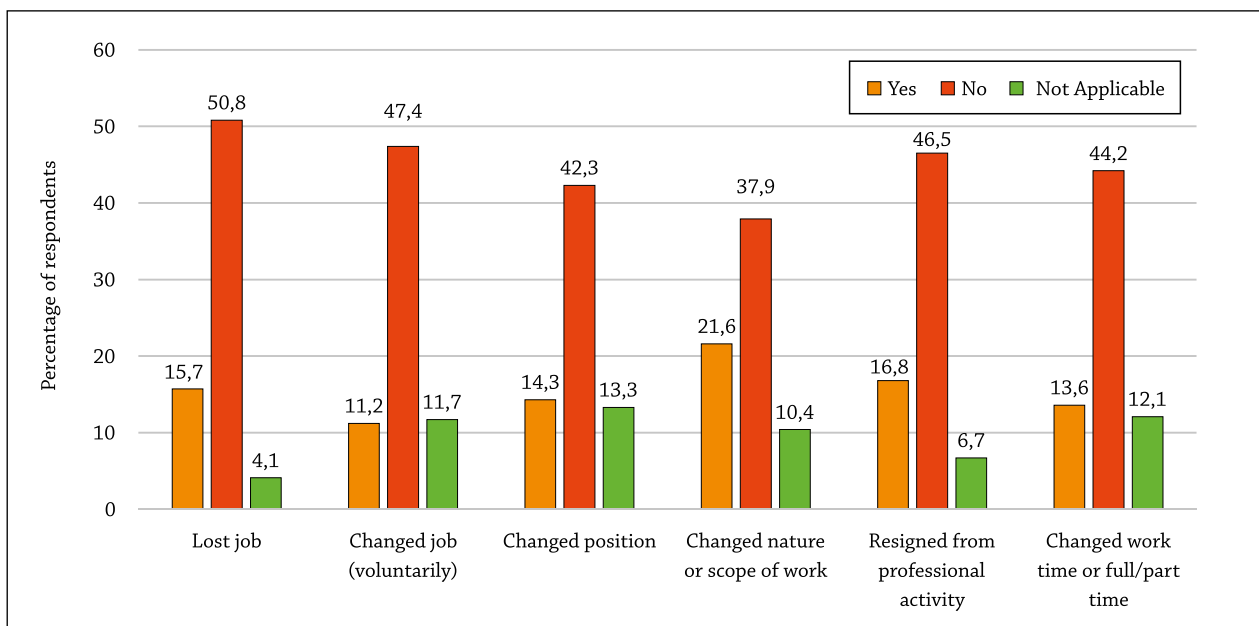


Figure 2. Professional activity status of the respondents

in Poland and 51 in the rest of Europe) treating patients with MS.

Answers from 51 European and 228 Polish institutions were received. In European institutions, the surveyed noted that patients have access to a care coordinator in their site (lack of such a function in the Polish healthcare system). In the case of disease flare-up most patients in Poland are referred to hospitals, whereas in European institutions, an ambulatory setting is preferred (Fig. 3).

In most (28- 54.9%) of the European institutions, dedicated IT systems are used for processing MS patients' data. In Poland 177 (77.6%) institutions do

not employ IT systems to register patients with MS and process their data. Among institutions using IT, 27 (52.9%) European and 23 (10.1%) Polish ones keep the patient's entire documentation, as well as a patient satisfaction survey, in an IT system. The areas supported by systems have been described below (Fig. 4, Fig. 5).

Online registration is available more often in institutions in Poland (44 institutions – 19.3%) than it is in European ones (5 institutions – 9.8%); in contrast, online contact with medical professionals is much more available in European institutions (36 institutions – 70.6%) than in Polish ones (32 institutions – 14.0%).

The cooperation of social care and healthcare is poorly regulated in Poland compared to other European countries (Fig. 6).

Cooperation in the realm of patient care between the healthcare system and social care is meager and insufficient almost everywhere (Fig. 6). In the European systems, only 18 (35.3%) respondents indicated the existence of such a cooperation (in Poland 32 – 14.0%).

**DISCUSSION**

Compiled results obtained with the use of PAPI and CAWI have revealed a high percentage of answers indicating an inadequate securing of MS patients' needs. It is not at all comforting that both patients and medical professionals in other countries also indicate similar areas in need of improvement. The natural course of the disease leads to gradual and (at present) inevi-

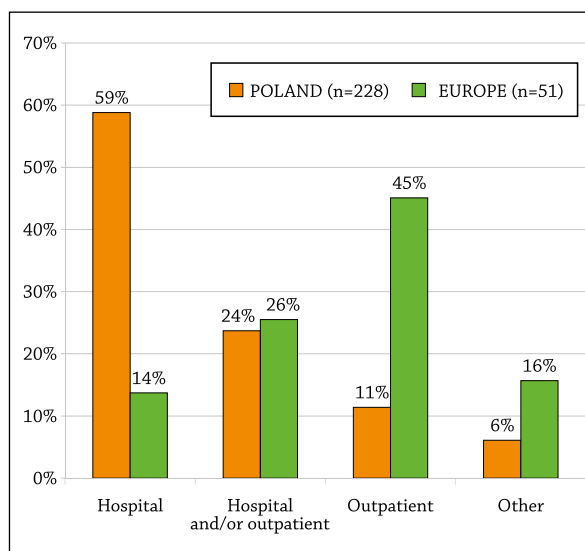


Figure 3. The area where an intervention is performed in case of disease flare-ups

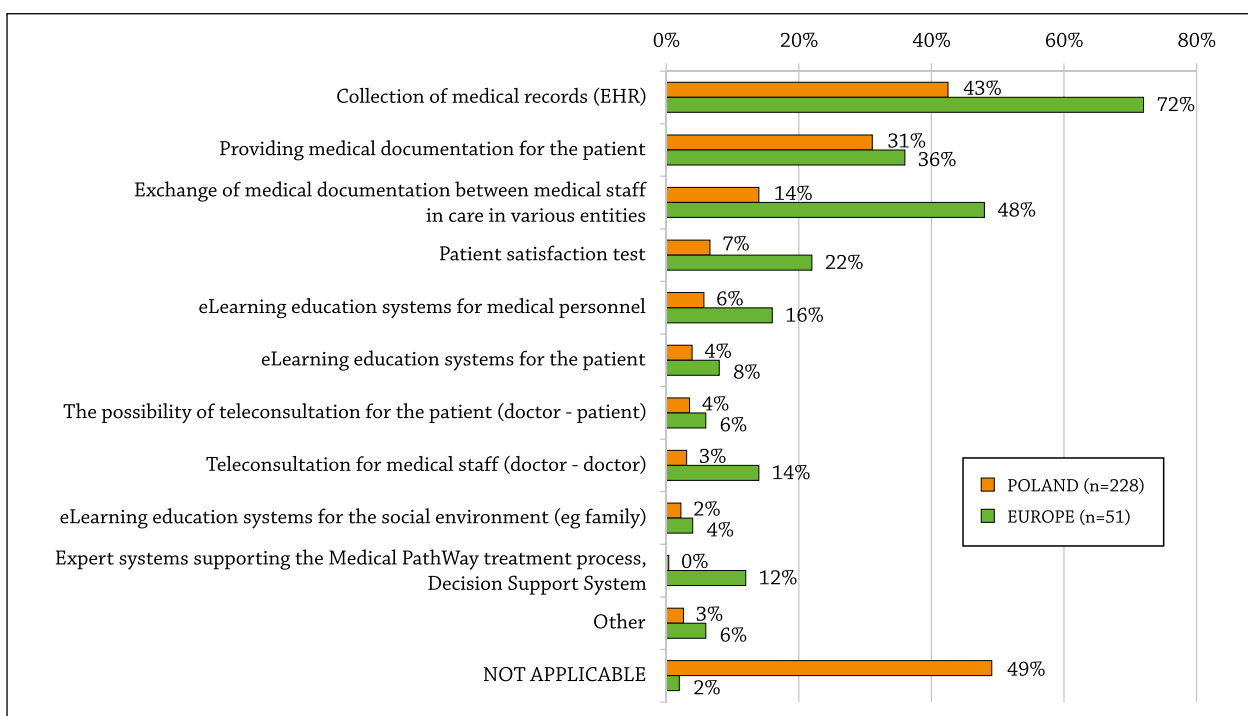


Figure 4. IT support for areas of care for a patient with SM in Poland and in Europe

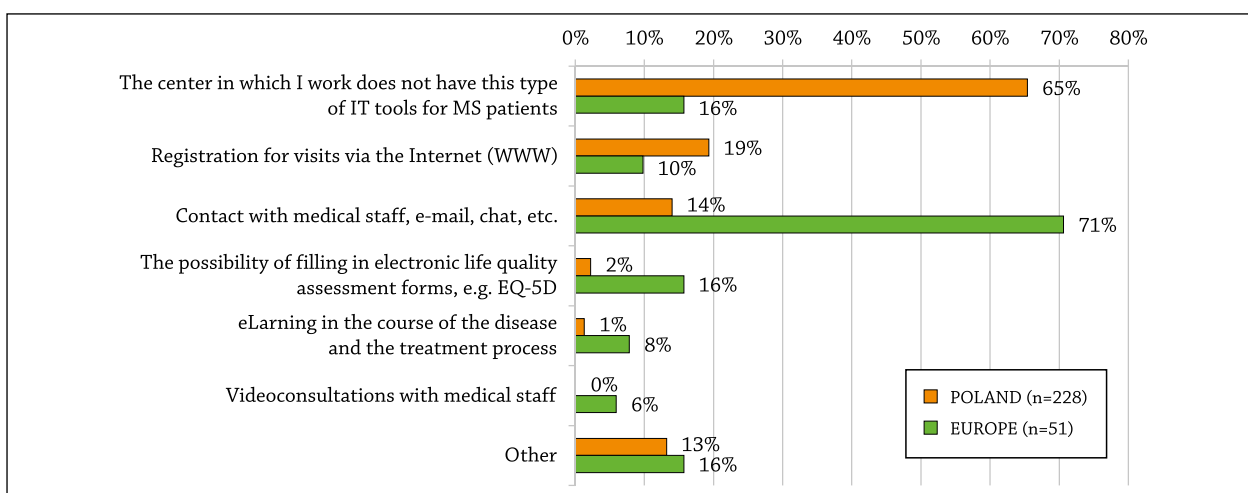


Figure 5. IT tools supporting patients in Polish and European institutions



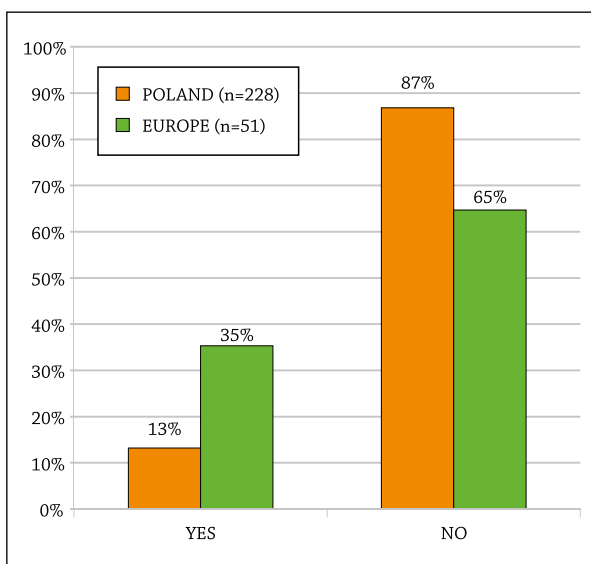


Figure 6. Exchanging information about a patient with SM between healthcare and social care

table impairment, especially in the physical sphere. It starts from mild prodromal symptoms and usually ends – regardless of the treatment used – with severe disability, when palliative care is the only therapeutic option.

The systems scaling and integrating the actions of various entities are gaining recognition to an ever-higher degree. Models of complex integrated care are meant to determine a rhythm of intervention of varying entities cooperating in the health domain toward the individual patient. The inadequacies and inconveniences, especially of communication and logistical nature, revealed in the survey, lead to the conclusion that it is necessary to remodel the organization of the healthcare and social services rendered in Poland to MS patients to gain greater effectiveness within the same catalog of interventions available. Considering a relative surplus of hospital services, yet concurrent deficits in other segments of this domain exist. The solution could be strengthening the link between health and social care, including increasing the number of “nursing” beds by replacing strictly “hospital” ones. This could significantly lower system costs, especially in departments treating elderly patients, whose hospital stay is a result of an inability to provide the minimum of care at home (single people, working families, etc.). On one hand, it is local infrastructure deficits that have an impact on the length of hospitalization, which is inadequate to state of health and severity of the disease or its stage. On the other hand, it’s the systemic limitation in the ability to execute certain procedures in non-hospital institutions or in the patients’ place of residence (e.g. dispensing medication by nurses, minor procedures etc.).

In 2014 the World Health Organization (WHO) issued a new definition of care focused on the patient, which has been recognized as the definition of integrated care: it is medical services administered and rendered to people in a manner ensuring the procurement of a health-promotion continuum, disease pre-

vention, diagnosis, treatment, disease management, rehabilitation and palliative medical services, on varying levels and in different areas of the healthcare system, suitably to needs, throughout the entire lives of and in the form of constant dialogue with patients. The Triple Aim rule, a basic rule of integrated care and one described by Guus Schrijvers in his book “Integrated Care - Better and Cheaper” [16], pertains to all sides participating in healthcare. Improving the population’s state of health, improving patient-care quality and reducing per capita healthcare costs, are three tasks that fall within the philosophy of the Triple Aim whose realization is advantageous for the patient. In integrated care, patients and healthcare employees become partners. The phrases: *according to need* and *in the form of continuous dialog with patients*, found in the WHO definition, define the change of patients into partners, consumers, active participants in the care process.

The starting point should be the analysis of the causes, not the consequences (i.e. observed ineffectiveness). A key element, crucial for effective conducting of the project, is the creation of an information system allowing the processing of the data necessary to analyze them, control the system and make decisions for all sides involved, including the National Health Fund and Ministry of Health. Such a system should integrate data from bases currently available for National Health Fund, medical and social care institutions on a central and local level. Simultaneously, performed also based on the data presented in this paper, analysis of patient needs in particular stages of the disease could make it possible to postulate rules of medical and socio-nursing services reference ability, then adequately adapt the rules of financing in terms of the mechanisms that reduce the overproduction of services and their improper reporting, but stimulate the maximization of pro-health- effects. Data analysis based on the postulated system should be automated and enable the identification of signals, i.e. specific deviations based on the analysis of large data sets (big data). The above-mentioned system could be the foundation for the electronic patient medical documentation (EDM) system. Obligatory registration of such data in the shared information system of the payer and service provider would enable easy generation of meeting the expected standards. This is essential, as currently the ability to conduct a quantitative (in a monetary dimension) analysis of system change impact is limited. We should also consider some limitation of actual systems, e.g. the denoting of flat-rate paid services as having no financial value. Hence, the possibility of combining seemingly excess data can be useful for the possibility of reaching the goal indicated above.

## CONCLUSIONS

Based on the above-described patients’ needs research, resources and abilities of the entities, it

appears that the scale of system ineffectiveness is large enough to justify implementation of the new model of care for this well-defined group of patients. Due to

the possibly far-reaching consequences of a complete change, a pilot program would be required for no more than 5-10% of patients and related stakeholders.

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