## Towards patient-centered infertility health care: Case study Slovak Republic



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#### **Executive summary**

Research about patient centered infertility care (PCC infertility) has aimed to promote patient centeredness as one of the domains of a high quality health care and to encourage similar surveys in Slovakia.

We considered various theoretical and empirical subject matters that were related to PCC, in general, and PCC infertility, in particular. We dedicated special attention to patients' experience feedback about infertility health care in Slovakia. It helped us to provide evidence based recommendations tailored for providers and policy makers in order to improve quality towards more PCC.

Despite the fact that universal theoretical definition of PCC does not exist, in every day practice, PCC concept is usually mixed with "patient friendly" and "patient satisfaction" which are similar but conceptually different. However, patient is understood as the main driver of health care whereas patient experience feedback is seen as the key element of the PCC concept.

Health care providers, usually, have a blurry picture of what is the PCC itself, and what its implantations in practice mean. Benefits of PCC (such as health status outcomes, cost-effectiveness, increased safety, etc.) are followed by implementation's challenges and influenced by various factors on all levels - from individual to organizational and global. There is a tendency to link the quality of services with provider's payment (as effectiveness and safety are not enough itself). Patient-centeredness measured by patient's experience about health care service becomes a key quality indicator to measure the outcome.

Infertility care itself is specific in comparison with standard health care due to the fact that infertility care includes two persons (or even more) and at least one person as expected outcome of infertility treatment process. With higher number of people involved in the treatment, the number of needs and expectations raises as well. PCC emphasizes the quality of care perceived through patient's perspective; however, usually PCC is a neglected quality measure. PCC gives a chance to hospital management to become aware of hospital performance and a possibility for quality improvement of infertility care towards more PCC in the future.

Based on theoretical findings, we examined patient centeredness in infertility hospitals in Slovakia, within PaCe 2014 project, by asking patients about their experience with infertility care and we compared our results with the results from the Netherlands.

Data were collected trough standardized patient centered infertility questionnaire (PCQ) developed by Radboud University (the Netherlands), specially translated and adapted for Slovak context. Questionnaire covers eight domains (46 indicators): 1) Accessibility, 2) Information and explanation, 3) Staff's communication skills, 4) Patient involvement, 5) Respect of patient's values, 6) Continuity and transition, 7) Staff's competence and 8) Care organization.

Four out of eight Slovak fertility hospitals from different regions approved their participation in the project and data collection and they are: *Gyn-Fiv* (Bratislava), *Sanatorium Helios* (Martin), *Gyncare* (Košice) and *Sanatória pre liečbu neplodnosti SPLN* (Košice). Within 9 weeks (January 20– March 24, 2014) we collected 190 questionnaires in total, from the patients who underwent medically assisted reproduction treatment (ART) within previous 12 months or recently started their treatment.

The majority of the respondents belonged to the group of "higher or University" level of education with 52.10%, followed by 42.10% the "secondary or intermediate" group. Almost 2/3 of the participants (64.70%) were treated with *in vitro* fertilization (IVF) or intracytoplasmic sperm injection (ICSI) method and intrauterine insemination (IUI) (19.50%) while over 3/4 or 75.80% were women who were not pregnant.

Our results based on domains in score range from 0-3, show that patients highly ranked *Accessibility* (2.73), *Care organization* (2.72) and *Staff's competence* (2.68) domains. That means that patients did not have any problems to access the health care team in the hospitals (phone, email), did not need a lot

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of time to start or to finish their treatment and the staff appeared as highly competent to patients during treatment period. On another hand, *Staff's communication skills* (2.36) together with patients' experience on providing *Information and explanations* concerning the treatment (2.44), *Respect for patient values and needs* (2.42) and *Continuity and transition during patients' treatment* (2.51) present weak points of PCC in Slovakia. This means that patients experienced lack of information providing and explanations about investigations, treatment's expectations, comprehensiveness of the information and interest in patients' situation and emotions. However, in comparison with the Netherlands, Slovak results are higher in all domains except in *Staff's communications skills* domain.

In our Indicators' based comparative analysis, we gave an overview of the highest and the lowest scored indicators in Slovakia and a comparison with the results from the Netherlands.

The question concerning doctors competences has the highest indicator score in the whole research, therefore, patients see doctor as highly competent person who shares the decision making process with them. This result is even more interesting if we have in mind that 3/4 of questioned women were not pregnant and that status did not negatively affect their experience about physicians' competences. In Slovak infertility hospitals, patients did not need to wait for more than 3 weeks to make an appointment; the staff was never working disorderly and has never given some piece information that might be contradictory (and consequently confusing for the patients). Hospital staff was really ready to speak about errors or incidence when they happened. In all this six indicators, Slovakia got higher scores than the Netherlands but we need to keep in mind that Netherlands' score on these questions is high as well.

The lowest indicator score in the whole research got the question concerning patient's impression that stuff was speaking "about them" rather then to speak "to them" as well as question regarding providing information about how to get social worker' or psychologist' support. This means that Slovak patients

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almost never got the information about this type of support which may be attributed to the Slovak culture context (often expressed as "I don't need that kind of support"). It is interesting that these two questions are among five lower scored indicators as well in the Netherlands but their results are higher than in Slovakia.

Slovak patients experienced that lack of information concerning possible side-effects of prescribed medications; physicians lacked empathy for patient's emotions and current situation and two out of three patients did not have staff member assigned to contact in urgent question. These three indicators show better results in Netherlands than in Slovakia and they give us a good example of possibility to improve.

The two indicators in this lowest scored group got higher scores in Slovakia than in Netherlands. Having a staff member assigned to every patient, is not a very often case in Slovakia. Three out of four patients said that they did not have assigned contact person for night or weekend urgency. Slovak patients experienced waiting between 15-30 minutes for the examination.

We utilized these results to formulate evidence based recommendations for health care providers and policy makers.

Recommendations for hospital quality improvement towards more patientcenteredness, apart of using the PCQ-Infertility on regular basis as selfassessment tools are concerning:

- improvement of providing information and explanation about possible side-effects of prescribed medication and comprehensiveness of investigation's and treatment's information;
- improve care giver's clearness about expectations from the fertility care service;
- 3) raise physician empathy for patients' emotions and current situation;
- assigned staff member to contact at any time for questions or problems.

Recommendations addressed to policy makers are concerning:

- the promotion of PCC as public value and as an initiative for reimbursement and benchmarking;
- ensuring that PCC is happening in reality (PCC as an incentive for system reward and benchmarking);
- establishing the National assisted reproduction treatment register with obligatory providers' reporting.

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#### Notes

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## List of Acronyms and Abbreviations

AR	Assisted reproduction
ART	Assisted reproduction treatment
HIPAA	Health insurance portability and accountability
ΙΑΡΟ	International Alliance of Patients' Organizations
IOM	Institute of Medicine
ISCI	Intracytoplasmic sperm injection
IUI	Intrauterine insemination
IVF	In vitro fertilization
OOP	Out of pocket
P4P	Pay for performance
PCC	Patient-centered care
QoL	Quality of life
WHO	World Health Organization

# I Patient-centered care- a dimension of high quality health care

More than two decades, patient-centered care (PCC) is in the focus of (1) health care services' providers, (2) decision and policy makers on macro, mezzo and micro level, as well as (3) patients and (4) scientific community.

When we speak about the concept of patient-centered care we are actually speaking about one of the dimensions of broader concept named as high quality health care.

PCC concept became internationally recognized in 2001 when Institute of Medicine (IOM) from US published the book "Crossing the Quality Chasm: A New Health System for the 21st Century". According to IOM, patient-centered care is defined in its own right, as one of six bricks in constructing the high-quality health care. Apart of being PCC, health care has to be safe, effective, timely, efficient and equitable.

Everyday experience and multidisciplinary researches show that these six high-quality care concepts are highly interconnected (achievements in each of these concepts influence the outcomes of others).

## 1. Concepts of patient-centered health care

Many of the same core concepts are encompassed in numerous of proposed definitions of patient-centered health care. Overview of the evidence shows that a globally accepted definition is still lacking. In the following lines, we are going to overlook how World Health Organization (WHO), Institute of Medicine (IOM), International Alliance of Patients' Organizations (IAPO) and Picker Institute are defining this concept.

SWHO advocates for a "responsive" healthcare system that meets people's expectations<sup>1</sup> and for involving patients and carers as partners in initiatives to improve the safety and quality of care. <sup>2</sup> Consequently, responsiveness is seen as a crucial part of PCC. Responsiveness describes how a healthcare system meets people's expectations regarding 1) respect for people and their wishes, 2) communication between health workers and patients, and 3) waiting times.<sup>3</sup>

✓ Institute of Medicine (IOM) defined PCC as care which is "respectful of and responsive to individual patient's 1) preferences, 2) needs, and 3) values and ensures that patient values guide all clinical decisions".<sup>4</sup> According to IOM, patient is source of control in PCC and has the role in each level: from individual (experience) to clinical, than organizational and environmental level. Common role for all of these levels is that patient has to support and encourage the participation of patients and families.

S International Alliance of Patients' Organizations (IAPO) in Declaration on Patient centered healthcare define patient-centered healthcare as healthcare system which is "designed and delivered to address the healthcare needs and preferences of patients so that healthcare is appropriate and cost-effective".<sup>5</sup> In Declaration is stated that patient-centered healthcare leads to improve 1) health outcomes, 2) quality of life and 3) optimal value for healthcare investment by promoting greater patient responsibility and optimal usage. According to IAPO healthcare must be based on following five principles if we want to achieve patient-centered healthcare:

<sup>&</sup>lt;sup>1</sup> World Health Organization (2000). The World Health Report; Health Systems: Improving Performance. Geneva: WHO, 1-215

<sup>&</sup>lt;sup>2</sup> World Health Organization (2010). Patients for Patient Safety.

Retrieved from: <u>www.who.int/patientsafety/patients\_for\_patient/statement/en/index.html</u>, Accessed 18 May, 2014,

<sup>&</sup>lt;sup>3</sup> World Health Organization (2000). The World Health Report; Health Systems: Improving Performance. Geneva:, 1-215

 <sup>&</sup>lt;sup>4</sup> Institute of Medicine. (2001). Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press.
<sup>5</sup> Declaration on Patient-Centered Healthcare (2006). International Alliance of Patients'

<sup>&</sup>lt;sup>5</sup> Declaration on Patient-Centered Healthcare (2006). International Alliance of Patients' Organization.

- 1) *Respect* Patients' unique needs, preferences and values, as well as their autonomy and independence should be respect.
- 2) *Choice and empowerment* Patients have a right and responsibility to participate, to make informed healthcare choices.
- Patient involvement in health policy To share the responsibility of healthcare policy-making.
- Access and support Patients must have access to safe, quality and appropriate services, treatments, preventive care and health promotion activities, regardless of their condition or socio-economic status.
- 5) *Information* Accurate, relevant and comprehensive information is essential to make informed decisions about healthcare treatment and living with their condition.

Solution Picker Institute<sup>6</sup> is pioneer in producing scientifically valid surveys on nationwide level and databanks on patient-centered care.<sup>7</sup> The aim of such an approach is to educate hospital staff on improving service from patients' perspective. According to Picker Institute, simple patient satisfaction questionnaires do not produce useful results; therefore, research should focus more on patients' reports on what happened to them rather than to rate how satisfied they were with service and providers.

Eight domains of patient-centered care are used for measuring patient experience with health care<sup>8</sup>. According to them, PCC includes:

- 1) Respect for patients' values, preferences and expressed needs
- 2) Coordination and integration of care
- 3) Information, communication and education

<sup>&</sup>lt;sup>6</sup> The Picker Institute was established in 1994 in US, with the goal to foster a broader understanding of the practical and theoretical implications of patient-centered care by focusing on the concerns of patients and other healthcare consumers.

<sup>&</sup>lt;sup>7</sup> Picker Institute surveys are used by regulators in the US, UK, Canada and Australia to measure patient-centered care.

<sup>&</sup>lt;sup>8</sup> Find out more about the Picker Institute's eight dimensions of PCC on their website: http://pickerinstitute.org.

- 4) Physical comfort
- 5) Emotional support and alleviation of fear and anxiety
- 6) Involvement of family and friends
- 7) Continuity and transition
- 8) Access to care

Even if is difficult to find one definition what PCC is, we can agree that there are some common, overlapping issues in all four concepts that we exposed above.

We can conclude that patient within PCC concept is seen as the main driver of health care. Patient is empowered to be involved (together with his/her family and friends) in health policy partnership with the health care providers on all levels, building qualitative personal, professional, and organizational relationships. On another hand, providers have to be respectful of and responsive to individual patient values, need, preferences, and expectations, providing physical comfort and equal access to health care, fostering information and communication together with emotional support. In the same time, care organization has to accomplish patients' continuity and transition during the treatment and coordination of care.

## 2. Some associated terms and concepts

Exploring the concept of patient-centered health care, we have found wide range of terms which is used to describe PCC. Terms are conceptually similar and that similarity laying down in putting the patient, family, health care givers and consumer in the center of individual and broader aspects of the health care.

*"Patient satisfaction"* and *"patient-friendly health care"* are the most associated with PCC and very often used as synonyms in every day practice.

#### **Patient satisfaction**

Patient satisfaction with health care service is increasingly recognized as quality of care asset. Patient satisfaction has been variously defined as "an individual's positive evaluations of distinct dimensions of health care" <sup>9</sup> and as "an evaluation by the patient of a received service where the evaluation contains both cognitive and emotional reactions".<sup>10</sup> For some patients, satisfaction can mean a minimum of acceptable health service while for other it can be maximum (perfection) with the service. Therefore, we need to be careful speaking about patient satisfaction bearing on mind that this concept excludes equity and safety as very important elements of high quality of care.

#### Patient friendly health care

Concept of patient friendly care, especially in infertile health care, usually refers to medical evaluation and degree of treatment. Concept represents a mix of four criteria: cost-effectiveness, equity of access, minimal risk for mother and child and minimal burden for patients.<sup>11</sup> "Patient - friendly IVF must be associated with

<sup>&</sup>lt;sup>9</sup> Linder-Pelz S. (1982). Toward a theory of patient satisfaction. Soc Sci Med, 16, 577-782.

<sup>&</sup>lt;sup>10</sup> Fitzpatrick R. (1997). The assessment of patient satisfaction. In Jenkinson C. Assessment and evaluation of health and medical care. Buckingham: Open University press, 85-101.

<sup>&</sup>lt;sup>11</sup> Pennings G. and Ombelet W. (2007). Coming soon to your clinic: patient-friendly ART. Hum Reprod. 22(8), 2075-9

a healthy newborn achieved in a safe, cost-effective, and timely manner."<sup>12</sup> Nevertheless, we also need be aware using these terms because patient friendly has false attractiveness, it is too positive to present assisted reproductive treatment (ART) as ART itself is not friendly.<sup>13</sup>

These two concepts shouldn't be mixed but consider their redefinition and reconceptualization improved with the patient-centeredness as dimension of high quality care.

## 3. Myths about patient-centered health care

As we saw from the theory, patient centered health care is complex concept existing of many dimensions. Such a situation might confuse health care providers and tempted them to have blurry picture what is PCC and some predjustices about PCC implementation in practice.

According to Frampton at all.<sup>14</sup>, we are going to present overview of some recognized myths in the practice. However, providers (health care managers and medical workers) might consider that:

- Providing patient-centered care is too costly.
- Patient-centered care is "nice," but it's not important.
- Providing patient-centered care is the job of nurses.
- To provide patient-centered care, we will have to increase staffing ratios.
- Patient-centered care can only be truly effective in a small, independent hospital.
- We may think patient-centered care is an effective model for care delivery, but there is no evidence to prove it.
- Many patient-centered practices compromise infection control efforts, and therefore, cannot be implemented

<sup>&</sup>lt;sup>12</sup> Flisser, E, Scott, R.T Jr. and Copperman, A.B., (2007). Patient-friendly IVF: how should it be defined?. Fertil Steril. 88(3), 547-9.

<sup>&</sup>lt;sup>13</sup> van Empel, I.W., Nelen, WL, Hermens, R.P., Kremer, J.A. (2008). Coming soon to your clinic: high-quality ART, Hum Reprod. 23(6), 1242-5.

<sup>&</sup>lt;sup>14</sup> Frampton, S. et al.(2008). Patient-centered care improvement guide, Planetree, Inc. and Picker Institute, US

- The first step to becoming a patient-centered hospital is renovation or construction.
- Patient-centered care is the "magic bullet"- i've been looking for improve patient satisfaction, improve employee morale, enhance revenue streams, etc.
- We can't implement a shared medical record policy. That would be a violation of health insurance portability and accountability (HIPAA)
- We have already received a number of quality awards, so we must be patient-centered.
- We're already doing (*some specific model*), so we can't take on PCC
- Our patients aren't complaining, so we must be meeting all their needs
- Being patient-centered is too time-consuming. Staff is stretched thin as it is.

These myths seem universal and common, no matter on socio-economical context of any national or organizational culture. They might be hurdles in process of understanding the core values of PCC. As soon as providers overcome them, they will have greater chance to deal with implementation of PCC in practice.

## 4. Benefits of patient-centered health care

Research studies about patient centered health care give us the clue that there are several outcomes (individual or multiple) which can be correlated with the PCC approach.

Most researchers who have studied patient-centeredness systematically have found that patient-centeredness does often have a positive relationship to classical health status outcomes.<sup>15</sup> A patient-centered focus can improve

<sup>&</sup>lt;sup>15</sup> Epstein, R.M. and Street, R.L., (2008). Patient-centered care for the 21st century: Physicians' roles, health systems and patients' preferences. American Board of Internal Medicine Foundation.

healthcare quality and outcomes by increasing safety, cost-effectiveness, and patient, family and staff satisfaction.<sup>16, 17</sup>

Effective physician-patient communication positively affects the patients' emotional health and leads to symptom resolution, functional and physiologic status and pain control. <sup>18</sup> PCC help patient to feeling respected, involved, and valuable and such a status can be great support to the patient to feel distress with illness or expected treatment.

Infertility health care is specific itself, as well as benefits which are depending on the nature of the care encompassed with universal benefits values. Researchers found that associations exist between the level of patient-centeredness, patients' quality of life (QoL) and their levels of anxiety and depression.<sup>19</sup> Having this on mind, we have a clue that paying attention to these variables and more tailored care could lead to improved patient-centeredness of care and further more to positive well-being and care experiences.<sup>20</sup> As providers and patients we should be aware that the effect of patient centered infertility care on health outcomes, however, most often will be indirect.

PCC is recognized as a predictor of a good patient experience. Improving patient experience is justified not just clinically (good health outcomes and safety issues) but also financially. On the organizational level, patient-centered care was associated with decreased utilization of health care services and lower total annual charges.<sup>21</sup> That is why PCC is important for health care providers and organizational performance improvement.

<sup>&</sup>lt;sup>16</sup> World Health Organization, (2007). People-Centred Health Care: A policy framework. Geneva: WHO.

<sup>&</sup>lt;sup>17</sup> Mead, N. and Bower, P. (2000). Patient-centeredness: a conceptual framework and review of the empirical literature. Soc Sci Med. 51, 1087- 110.

<sup>&</sup>lt;sup>18</sup> Stewart, M.A. (1995). Effective physician-patient communication and health outcomes: a review. CMAJ, 152(9), 1423-33.

 <sup>&</sup>lt;sup>19</sup> Aarts J.W. et al. (2012). How patient-centred care relates to patients' quality of life and distress: a study in 427 women experiencing infertility, Hum. Reprod., 27(2),p. 488-95
<sup>20</sup> Ibid.

<sup>&</sup>lt;sup>21</sup> Bertakis, K.D and Azari R. (2011). Patient-centered care is associated with decreased health care utilization. J Am Board Fam Med. 24(3), 229-39.

Health insurances have tendency of the linking quality of service with provider's payments. Patients' experience on health care is seen as a key quality indicator to measure outcome (usually, is expressed in the form of quality reporting). These reports are used as financial incentives and main drivers for creating the services toward patient-centered care. Such an experience is found in the UK and US who provide financial incentives to some healthcare providers for adopting improved quality practices, including clinical outcomes and some patient-centered care principles. This is the tendency that *"pay for performance"* (P4P) model, defined as *"financial incentives that reward providers for the achievement of a range of payer objectives, including delivery efficiencies, submission of data and measures to payer, and improved quality and patient safety"<sup>22</sup> start more often to include PCC as quality indicator.* 

## 5. Challenges for implementation patient-centered care

Implementation of patient centered care isn't always straightforward. Concept can be highly positioned on the political agenda, but we can't say that is implemented. It is necessary to ensure that PCC is happening in the reality, but with awareness that not all hospital worldwide provide PCC.

Patients' behavior is usually conditioned by their expectations whereas expectations are based on how things are, have to be and/or have been. As PCC itself is based on relationship between providers and patients, we can see that organizational culture as well as individual characteristics of hospitals stuff and patients are one of the main challenges for implementation. However, these factors exist in broader cultural social patterns and legal norms that are defining the nature of relationship, which should be taken into consideration.

<sup>&</sup>lt;sup>22</sup> Agency for Healthcare Research and Quality. Available at:

ttp://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/pay4per/index.html, Retrieved May 17, 2014.

Introducing innovative concepts are often big challenge for PCC implementation, but more than useful to improve dimension of PCC (accessibility, staff's communication etc.).

For the patients who obtained treatment in different European member states, upcoming challenge is reimbursement on European Union level while, in the same time, providers are facing challenge of benchmarking.

In summary, implementation is challenged on all levels- from individual to organizational and global ate influenced by various factors. Therefore, "efforts to promote patient-centered care should consider patient-centeredness of patients (and their families), clinicians, and health systems." <sup>23,24</sup>

## II Patient centered infertility health care

Infertility care is specific itself in comparison with standard health care as infertility care includes two persons (or more) with at least one person as expected outcome. Due to this fact, health care providers aren't just responsible for one but more persons who are involved in the treatment. With higher number of involved people raise the number of needs, values and expectations trough different phases of patient's journey which has to be met by providers.

Sometimes providers' and patients' preferences aren't overlapping. In infertility care in Europe patients and physicians ranked success rates as the most important attribute, but the patients valued patient-centered care more than physicians would recommend.<sup>25</sup>

In reproductive medicine, quality measures mainly concentrate on effectiveness (e.g. pregnancy rates) and safety (e.g. frequency of multiples),

<sup>&</sup>lt;sup>23</sup> Epstein, R.M. and Street R.L. Jr.. (2007). Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. Bethesda, MD: National Cancer Institute, NIH.

<sup>&</sup>lt;sup>24</sup> Epstein, R.M., Fiscella, K, Lesser, C.S., Stange, K.C. (2010). Why the nation needs a policy push on patient-centered health care. Health Aff (Millwood). 29(8), 1489-1495.

push on patient-centered health care. Health Aff (Millwood). 29(8), 1489-1495. <sup>25</sup> van Empel I.W.et al (2011). Physicians underestimate the importance of patient-centredness to patients: a discrete choice experiment in fertility care. Hum Reprod., 26, 584–593.

while patient-centredness is neglected.<sup>26</sup> Situation doesn't differ in China, as one example from other cultural context, where fertility care providers emphasize treatment effectiveness while infertile patients attached the greatest importance to physicians' attitudes.<sup>27</sup> Patient preference in Chine doesn't go in line with the fact that Chinese doctors' social status and reputations in the medical field are measured mainly by medical not by humanistic skills.<sup>28</sup>

Patients' needs and expectations in infertility care can be framed by looking at the 'patient journey' as summary of all the different points of the health care contact related to an individual patient. Needs and expectations might change in different stages of assisted reproduction treatment and depends on the type of the treatment (ovulation induction, IVF/ICSI, any type of donation etc). The 'patient journey' in infertility health care has many different stages and only narrow defined indicators for each of the stages of the patient journey can measure patient-centeredness and give us possibility to really understand patient experience.

Furthermore, patient characteristics 'type of treatment' and 'women's level of education' were found to be associated with the level of patient-centeredness in infertility heath care.<sup>29</sup> Thus, patients' experiences with fertility care are only slightly different between women and their partners<sup>30</sup> which health care providers in infertility hospital need to bear on mind when they provide service.

"Positive experiences regarding information received, respect from staff about values and preferences, continuity in treatment and competence of staff are directly associated with higher compliance intentions, while positive experiences regarding accessibility to and involvement in the treatment and

<sup>&</sup>lt;sup>26</sup> van Empel IWH, Nelen WLDM, Hermens RPMG, Kremer JAM. Coming soon to your clinic: high-quality ART. (2008). Hum Reprod, 23,1242–1245.

<sup>&</sup>lt;sup>27</sup> Cai, Q.F. at al. (2014). Fertility clinicians and infertile patients in China have different preferences in fertility care, Human Reproduction, 29(4), 712–719. <sup>28</sup> Yuan et al.,(2013). Young Chinese doctors and the pressure of publication. Lancet 2013;38:e4.

<sup>&</sup>lt;sup>29</sup> Van Empel I.W.H. et al. (2010a). Measuring patient-centredness, the neglected outcome in fertility care: a random multicentre validation study. Hum Reprod., 25, 2516-2526.

<sup>&</sup>lt;sup>30</sup> Huppelschoten A.G. et al. (2012). Do infertile women and their partners have equal experiences with fertility care? Fertil Steril, American Society for Reproductive Medicine.

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communication with staff are indirectly associated, via associations with less concerns about treatment".<sup>31</sup> Clinics should allow patients to establish stable relationships with a reference doctor who is competent and respectful of their interests and values and who provides them with the information they need.<sup>32</sup> Thus, they need to ensure that these professionals are easily accessible, have good communication skills, and involve patients in the treatment process and associated decision-making.<sup>33</sup> This is seen as the best way to promote treatment compliance.

The organizational process in fertility centre has important role in achieving patient-centeredness and should be considered in analysis. We should bear on mind the distribution and proportion of the professionals as they are providing the most of the information and instructions related to the treatment process

Thus, national regulatory frame is important for better understanding of working process. We can find countries where psychological counseling in relation to fertility treatment is not mandatory. For instance, in Denmark psychological counseling is not under obligation and less then 3% of the patients at public clinics are referred to psychological counseling or to non-professional support groups outside the clinics.<sup>34</sup> Such facts we need to take into account when we are assessing and benchmarking patient-centeredness.

Patient-centered infertility health care gives chance to the hospital management to look into the hospital performance as well as a great possibility to tailor improvement in the future. The measurement of patient experiences supposes to be an important component of health services' evaluation on hospital and national level, enhancing the effectiveness of benchmarking.

<sup>&</sup>lt;sup>31</sup> Pedro J., et al. (2013). Positive experiences of patient-centred care are associated with intentions to comply with fertility treatment: findings from the validation of the Portuguese version of the PCQ-Infertility tool. *Hum Reprod*. 28(9), 2462-72.

<sup>&</sup>lt;sup>32</sup> Ibid. <sup>33</sup> Ibid.

<sup>&</sup>lt;sup>34</sup> Schmidt L, et al. (2003). High ratings of satisfaction with fertility treatment are common: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme, Hum Reprod., 18(12), 2638-46.

#### Slavica Karajičić: Towards patient-centered infertility health care: Case study Slovak Republic

Patients are witnesses of differences in health-care organizations and performances among infertility hospitals. However, patients' perspectives on important infertility care aspects are suppose to be standard of high quality performance and care.

Fortunately, there is the tool that assesses patients' specific experiences rather than their global satisfaction with infertility health care. Group of researchers from the Radboud University in the Netherlands, based on eight Picker dimension, developed and validated patient-centeredness questionnaireinfertility (PCQ-infertility).

## 1. Case Study Slovakia

After examining legal, financial and health care policy on infertility health care in Slovakia<sup>35</sup>, we decided to focus our research on quality of health care and patient centered health care as one of its domains.

As our aims in PaCe 2014 research project, we defined following:

1) to examine in which extend patient-centered infertility health care is present in Slovakia and to compare with the results from the Netherlands.

2) to define certain set of recommendations for the hospitals treating infertility problems as well as for health policy and decision makers.

Based on the results, we aimed to point out positive patients' experience and whether providers have to intervene in some dimensions or issues in order to achieve better quality of service and consequently better patients' experience on their service.

Bearing in mind the lack of national strategies and initiatives promoting PCC in Slovakia, this research supports PCC (as a measurable and reportable component of health care quality) and definition of the national policy towards embedded patient's experiences.

#### 1.1. Market share

In Slovakia, assisted reproduction treatments are carried out in eight Slovak clinics which are having contract with three health insurance companies (Dôvera, Union and VšZP) to finance different ARTs.

Due to the fact that Slovakia doesn't have the National register which would collect the data about performed cycles, we mainly deal with the estimations.

<sup>&</sup>lt;sup>35</sup> Karajičić S., (2013) Policy on Assisted Reproduction in Slovakia, HPI, Bratislava

Collected data from hospitals and health insurance companies as well as estimations based on provided data, give us the clue that in year 2013 there were approximately 3166 IVF cycles.<sup>36</sup> This number includes: started IVF cycles without oocites retrieval, IVF cycles without embryo transfer and completely performed IVF cycles (embryo transfer included).

In Slovakia, the cost of infertility treatment (excluding medication and laboratory part for ICSI treatment) is covered by health insurance companies. Estimation says that in 2013 that three health insurance companies in Slovakia spent approximately 3, 4 million Euros for 3166 IVF.<sup>37</sup> There are no available data for the number of patients who pay their treatment out of pocket (OOP) and consequently no data on total Slovak OOP expenditure for ART. We have to bear on mind that patients in Slovakia might pay up to 2.200 euro in Slovak hospitals to obtain IVF/ICSI treatment (price of embryo transfer is included).

#### 1.2. Materials and methods

#### Setting and study design

This research is aimed to collect couples' experiences on patient centered infertility care in the hospitals performing ART in Slovak Republic.

The data were collected through standardized patient centered questionnaire (PCQ) infertility with permission of Radboud University from the Netherlands. They developed and validated this questionnaire as an instrument reliable to measure patient-centeredness.

For the purpose of PaCe 2014 project, we translated and adapted Slovak version of PCQ-Infertility, which assessed infertility PCC in Slovakia. Letters about project research, detailed methodology explanation and invitations for the cooperation has been sent via post and email to all eight hospitals performing ART in Slovakia. Four out of eight Slovak fertility hospitals from different regions approved their participation in the project and data collection (Picture 1):

 <sup>&</sup>lt;sup>36</sup> Trendy v asistovanej reprodukcii a zdravotná starostlivosť zameraná na pacienta, Press Conference, Health Policy Institute, Jun 12, 2014. Bratislava
<sup>37</sup> Ibid.

- Gyn-Fiv (Bratislava)
- Sanatorium Helios (Martin)
- Gyncare (Košice)
- Sanatória pre liečbu neplodnosti SPLN (Košice).

Picture 1: Geographical distribution of participating hospitals



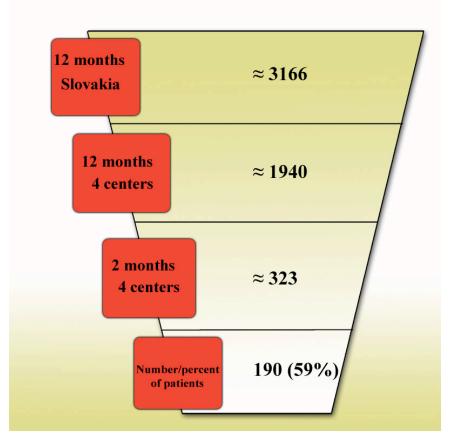
These four hospitals are private and covering different geographical regions (two large cities and the capital city), whereas two of them are having the highest number of cycles performed per year on the national level.<sup>38</sup>

<sup>&</sup>lt;sup>38</sup> Trendy v asistovanej reprodukcii a zdravotná starostlivosť zameraná na pacienta, Press Conference, Health Policy Institute, Jun 12, 2014. Bratislava

## Recruitment of patients and data collection

We collected 190 questionnaires in total in four participating hospitals. Data collection was conducted within 9 weeks (January 20 - March 24, 2014). According to the estimation that there are approximately 3166 ART per year in eight centers in Slovakia, we calculated that these 190 respondents represent 59% of total number of patients in four hospitals that could be possible to reach within given timeframe of two months.

Picture 2. Recruitment of patients in Slovak infertility hospitals based on estimation



Source: Author

Distribution of sampled patients per hospital is presented in Figure 1. The highest share in answered question had Gyn-Fiv (34.21%) and Gyncare (26.84%).

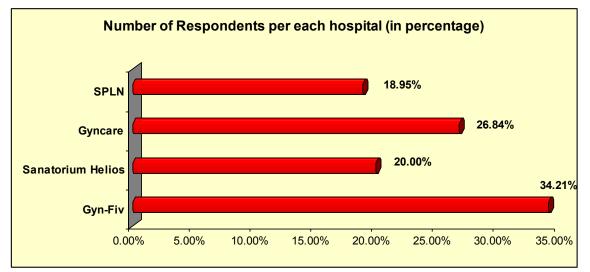


Figure 1: Number of Respondents per each hospital (in percentage) Source: Author

The questionnaires were shared among women (Slovak speaking infertile heterosexual couples) who underwent medically assisted reproduction (AR) in these hospitals within previous 12 months (April 2013 - March 2014) or recently started with the ART. Women who were eligible to participate were those who: (1) started or treated with ovulation induction, intrauterine insemination (IUI,) *in vitro* fertilization (IVF) and/or intracytoplasmic sperm injection (ICSI), (2) awaiting the outcome of the previous fertility treatment, and (3) had recently achieved pregnancy. There was suggestion to fulfill the questionnaire together with their partner.

Patients were informed that all replies will be treated as anonymous, confidential and only for the purpose of this research. In order to keep anonymity, we have provided envelopes with printed logos where women disposed their fulfilled questionnaires. The questionnaires were distributed by researcher or personnel of each hospital who were provided with the information and instructions relating to the research process.

#### Measurement instrument

As we mentioned above, in this research we used the PCQ-Infertility (46 items), a validated instrument measuring the level of patient-centredness in fertility care, to assess patients' experiences with care and discriminate between the patient-centredness of different fertility hospitals. The items (indicators) were grouped into the Picker Institute's eight domains of patient-centred care.<sup>39</sup> Domains and indicators' examples are shown in Table 2.

Domain	Number of items	Indicator
1. Accessibility	2	Accessibility of the team for questions (by email or phone )
2. Information	11	Sounds instruction on how to inject hormones
3. Communication	7	Specialist shows interest in the patients as person
4. Patient involvement	3	Honesty and clarity on what to expect of the fertility services
5. Respect of patient's values	7	Physician had empathy with your emotions and actual situation
6. Continuity and transition	7	One caregiver as central point for problems or questions
7. Competence	6	Staff used difficult words without explaining them
8. Care organization	3	Waiting time between first visit and receiving treatment plan

#### Table 2: Eight PCC domains and indicators' examples

Adapted from: van Empel et al, 2010 and IAPO, 2012.

The questionnaire was translated in Slovak language and adapted to medical context and IVF service in Slovak Republic. Higher level of patient-centredness is presented with the higher scores (range 0–3) on the total PCQ scale or one of eight subscales (domains).

<sup>&</sup>lt;sup>39</sup> See more about Picker Institute in Section 1 of this publication.

## **1.3. Research Results**

#### **1.3.1.** Distribution of respondents according to the level of education

The majority of the respondents belong to the "higher or University" educational level group with 52.11% followed by the "secondary or intermediate" (42.10%) level of education (Figure 2).

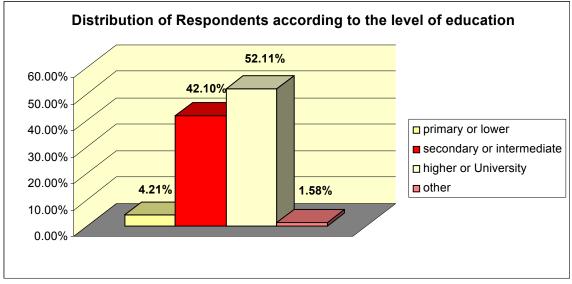


Figure 2: Distribution of Respondents according to the level of education *Source: Author* 

#### 1.3.2. Distribution according to treatments

This research included patients that underwent or are undergoing different AR treatment in last 12 months in given hospital. Our data from the research shows that almost 2/3 of the participants (64.74%) were patients who were treated with IVF/ICSI method. The number of those patients who underwent intrauterine insemination (IUI) (19.47%) and those who had experience with ovulation induction (OI) treatment (10%) are significant, as well (Figure 3).

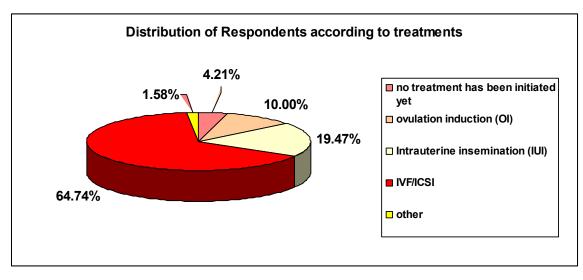


Figure 3: Distribution of Respondents according to the treatment *Source: Author* 

## 1.3.3. Distribution according to pregnancy

The distribution of respondents according to pregnancy status is imbalanced. Our results show that 3/4 or 75.79% patients answered negatively on the question regarding pregnancy status in the moment of filling the questionnaire, while only 24.21% answered positively on the same question (Figure 4).

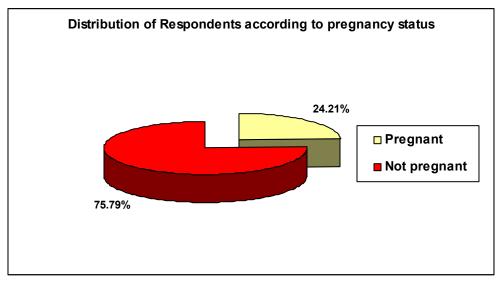


Figure 4: Distribution of Respondents according to pregnancy status *Source: Author* 

#### 1.3.4. Results according to the domains

Mean scores differ among eight domains and all of them are having values which are over the average of 1.5 (score range 0-3) (Figure 5). In overall assessment, mean scores range from minimal 2.36 for *Staff's communication skills* to maximum 2.73 for *Accessibility* domain followed very closely with *Care organization* (2.72).

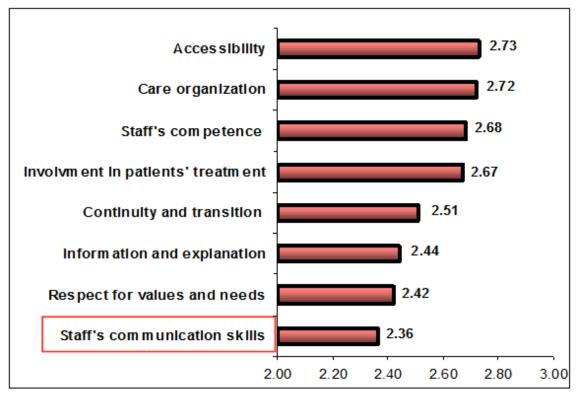


Figure 5: Slovak results based on PCC domains *Source: Author* 

This results show that most of the patients, based on their experiences, did not have problems either 1) to access to their treating team in examined hospitals (2.73) nor 2) to finish or to start next treatment in short time within care organization (2.72). *Staff competence* appeared to the patient to have high level of quality since that patient assessed this dimension with high mean score (2.68) together with experience on *Involvement in their treatment* (2.67).

Staff's communication skills (2.36) together with patients' experience on providing Information and explanations concerning the treatment (2.44), Respect

*for patient values and needs* (2.42) and Continuity and transition during patients' treatment (2.51) appeared to be less strong points of PCC in Slovakia.

Nevertheless, we found that overall patients' satisfaction with total fertility care in these hospitals is very high.

In the following pages, we will present our findings separately for each of eight domains of PCC.

#### I) Accessibility

This domain gives us the answer on patients' experience with the attainableness of their treating team by phone.

Results from our research show highest mean score in this domain (2.73) for the question how was difficult for the patient to contact staff when they had any question. This high score shows that patients (no matter on their level of education, treatment or pregnancy status) didn't have problem to contact staff.

The lowest score in Accessibility domain has question related to the patients' ability to speak to someone immediately when they called hospital (2.65) and it was happening from "usually" to "always".

#### II) Information and explanation

Providing patient with comprehensive, written information about his/her treatment procedure as well as possible side effects of the treatments and drugs, are seen to be standard procedure in infertility health care worldwide.

Mean scores of the questions within this domain are higher than domain's average (2.44), except the mean score in Question 11 (0.84) which is related to the staff's information about how to get support from a social worker or a psychologist (Table 3). In the same time, mean score of this question is the second lowest in the whole research. Although, we have collected few patients' answers who admitted they didn't need support from psychologist or social worker, indeed.

Item	PCQ-infertility item description	Mean score (SD) range (0-3)
Inform	ation and explanation	<b>2.44</b> (1.08%)
Q3	Did you receive contact numbers for urgent questions or problems at nights or weekends? Was the information about the investigations you	2.26
Q5	would undergo comprehensive?	2.58
Q6	Were different treatment options discussed with you? Were you informed of any possible side-effects of	2.76
Q9	the medication prescribed to you? Did the staff inform you how to get support from a	2.28
Q11	social worker or a psychologist? Did you miss any instructions from a nurse?	0.84
Q12	If so, when?	2.72

Table 3: Information and explanation domain - the key results

Results show that information and explanation dimension is dependent on treatment level and gravidity status. The lowest mean score for this dimension is found in the cases of women who didn't start the treatment (1.97) and women who underwent IUI (2.29). However, non pregnant women experienced more lack of information and explanation during their treatment process (2.39) in comparison to the pregnant (2.57).

Differences are not found in correlation between information and explanation domain and level of education. This result gives us the clue to say that medical workers are providing equal information and explanation among all patients.

The highest scores are noticeable in Q6 (2.76), Q10 (2.74) and Q12 (2.72). It means that different treatment options were discussed with the patients. For the patients the instructions how to inject hormones were comprehensive and instructions from a nurse were not missing. Those who answered that they missed some instructions said that is happened after they got the treatment plan, or when they started with the new medicament in the treatment.

One of the lowest scores within this domain is for Q3 (2.26) and Q9 (2.28), which means that 75,2% (n=143) patients didn't have contact number for urgent questions or problems at night or during weekends as well as they haven't been

informed of any possible side effect of prescribed medication. On this questions not pregnant had less positive experience which can be partly explained by psychological reasons. It is interesting that the patients from higher educated group (2.13) had more negative experience than those with primary (2.71) or secondary (2.29) level of education.

#### III) Staff's communication skills

The way how medical team communicates with patients is based on individual communication skills of medical stuff.

Results in this domain didn't show differences among different educational level of patient. Overall results show a slight difference among patients who are not pregnant (2.34) where answers might be influenced by their emotional status rather than objective experience. Among treatment groups, patients who are undergoing ovarian stimulation give slightly higher mean score (2.42). This is one of the phases when patient actively interact with the medical staff.

ltem	PCQ-infertility item description	Mean score (SD) range (0-3)
Staff's	communication skills	<b>2.36</b> (1.05)
Q14	Were caregivers honest and clear about what to expect from the fertility care service?	2.50
Q19	How often did you have the impression that staff was talking "about" you instead of talking to you	0.39
Q20	Was staff willing to talk to you about errors or incidents?	2.86

Table 4: Staff's communication skills domain- the key results

Mean scores from almost all questions from this domain are high (Table 4). For example, mean score for Q20 is 2.86 out of maximum 3, which give us the clue that staff was willing to speak about errors and incidents when they happened. There are few questions within this domain which patients assessed as good. Patients had very positive experience with the physicians who had very often time for them, listened to them very carefully, together discussed results of the investigations and their infertility problem was taken by the physician seriously.

Although, patients expressed that they almost never had impression that staff was talking "about" them instead of talking to them (0.39). Mean score for this question is the lowest in this domain as well as in whole research.

Answering on question whether caregivers were honest and clear about what patient to expect from the fertility care service, patient with secondary education expressed their more positive experience (2.56) comparing with primary (2.25) or higher (2.45) level of education.

#### IV) Involvement in patients' treatment

This domain's aim is to measure patient experience about extend of their involvement in treatment.

High score results in this domain give us the clue that Slovak patients are involved in their treatment especially pregnant women (2.77).

The physicians gave patients the opportunity to ask questions very often, were opened to hear patients' opinion and ideas about the treatment and shared decision-making with the patients in all treatment stages equally.

ltem	PCQ-infertility item description	Mean score (SD) range (0-3)
Involve	ement in treatment	<b>2.67</b> (0.61)
Q21	How often was your physician open to your opinion and ideas about treatment?	2.54
Q23	Was decision-making shared with you, if you preferred?	2.73

Table 5: Involvement in patients' treatment domain- the key results

In question concerning physician's openness to patient's opinion and ideas about treatment, we found that those with high school education had better experience (2.67) in comparison to the patients with elementary (2.25) or University degree

(2.45). Nevertheless, results on opportunity to ask physician questions do not differ among patients with different level of education (Table 5).

However, difference exists in the question about shared decision-making (Q23). Patients with lower level of education had lower score (2.63) in comparison to the secondary (2.73) and higher (2.73) educational level.

#### V) Respect for patients' values and needs

Each patient has own values and needs on which she/he bases own expectations. Patients expect from hospital's stuff to get personal attention and support, understanding for their emotional status, empathy and interest in their personal situation and problem.

Answers' mean scores within this domain range from 2.32 to 2.55. It gives us conclusion that patients had positive experience regarding partner's involvement in treatment (2.55). Thus, patients experienced that nurses usually gave attention and supported them during their treatment period (2.40) and usually showed understanding for their personal situation (2.49).

According to the results, patients experienced that physicians showed more interest in patients' personal situation (2.42) but less empathy for patient's emotions and their current situation (2.32) (Table 6).

ltem	PCQ-infertility item description	Mean score (SD) range (0-3)
Respec	ct for your values and needs	<b>2.42</b> (0.81)
Q24	Did you have access to your own medical record during the treatment period?	2.36
Q26	How often did your physician have empathy for your emotions and your current situation?	2.32
Q27	Did nurses show understanding for your situation?	2.49
Q28	Did staff also involve your partner?	2.55
Q29	How often did you receive any personal attention and support from nurses during your treatment?	2.40

Table 6: Respect for patients' values and needs domain- the key results

Trend of decreasing scores of this domain is related to level of education and pregnant status. Patients with primary education (2.53) and those who are pregnant (2.56) have positive experience about respect to their values and needs in comparison to the patients with University degree (2.40) and not pregnant women (2.38). Women who did not succeed in pregnancy after the assisted reproduction treatment reported the lack of information, explanation and respect for their values and needs during the treatment. In half of the questions within this domain results the scores were lover in not pregnant women group.

Our results show that patients from different treatment groups have similar experience on respect to their values and needs. Such results tell us that medical workers in examined hospitals are acting respectfully from the beginning until the end of the treatment process.

Less than average domain's mean score is achieved for patient's access to own medical record during the treatment period (2.36). In other words, patients had access to their medical record during their treatment period between "insufficient" and "absolutely".

### VI) Continuity and transition during treatment

The elements of this domain are the uniformity within patient care is present and cooperation of the care givers. Sometimes health care provision in hospitals can be subjects of fragmentation and insufficient coherence which apparently lead to the limitation of patient's health outcomes and treatment efficiency.

Our research in this domain shows that Slovak patients have experienced uniformity within their care and cooperation between caregivers with the mean score range from 1.96 to 2.86 (Table 7).

Item	PCQ-infertility item description	Mean score (SD) range (0-3)			
Contin	Continuity and transition during treatment <b>2.51</b> (0.93)				
Q31	Was one staff member assigned to you to contact any time you had any questions or problems (e.g. a nurse)?	1.96			
Q33	Did you have one lead physician (a physician for moments of evaluation and decision-making)?	2.52			
Q36	How often did you get contradictory information or advice?	2.65			
Q37	Did caregivers contradict each other in policy (one says one thing, the other says something else)?	2.86			

Table 7: Continuity and transition during treatment domain- the key results

On this domain's level, the difference is found among treatment groups. Patients who did not start (2.66) or those who underwent IUI (2.55) had higher scores than patients who experienced OI (2.49) or IVF/ISCI (2.49).

Pregnant women had more positive experience on continuity and transition during the treatment (2.59) and those with primary education (2.57). Particularly speaking, patients with primary level of education had less positive experience about repeating the same story to different physicians and they did it from "usually" to "sometimes".

Having contact hospital's staff that patients could contact anytime (in case of any questions or problem) is recognized as important issue by patients, however, had lower score in this domain (1.96). Results on this question gives us the lowest score in this domain where around 2/3 of interrogated patients (n=124) gave negative answer. Nevertheless, patients were almost univocal in their experience on non contradiction in policy among care givers.

### VII) Staff's competence

This domain shows patients' experience of skills and competences of hospital's staff during the treatment.

Overall score in this domain shows high results and patients' positive experience with the staff's competences.

Table 8: Staff's	competence	domain- 1	the key results	

Item	PCQ-infertility item description	Mean score (SD) range (0-3)
Staff's competence		<b>2.68</b> (0.59)
Q38	How often did caregivers use difficult words without explaining them to you?	2.64
Q40	Did the physician(s) seem competent to you?	2.90
Q41	How often did staff work disorderly?	2.66
Q43	How long did you usually have to wait in the waiting room?	2.19

Question related to the physicians' competences reached the highest score (2.90) which, in the same time, is the highest mean score of all questions in this research (Table 8). In the eyes of the patients, staffs appear to work harmonically (2.88).

According to the results, higher number of patients usually experienced the waiting time in waiting room from "15 minutes to half an hour", no matter on treatment but with the difference between pregnant (2.39) and not pregnant women (2.19). This question has the lowest mean core of this domain (2.19) and in the same time it doesn't affect not pregnant patients' perception of overall staff competence (2.68).

Patients expressed their positive experience with the good preparations of the physician for their appointments (2.82) and almost always smooth staff's logistic in the hospital.

It is interesting to remark that not pregnant women accessed slightly higher physicians' competence (2.91) than pregnant women (2.87).

All educational level groups concerned physicians as high competent professionals. Nevertheless, primary educated patients answered that caregivers usually used difficult words without explanation (2.38) comparing to secondary (2.58) or University (2.71) education level group.

#### VIII) Care organization

As time is going, woman's reproductive time is decreasing. Therefore, waiting time is usually seen as an obstacle. This domain is about the time it takes woman to finish ART or to start with another treatment.

Mean score of this domain (2.72) is the highest among others, which means that patients have positive experience regarding care organization and waiting time (Table 9).

In general, less positive experience on care organization had patients from the group of patients with the secondary level of education (2.69).

Table 9: Care organization domain – the key results
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Item	PCQ-infertility item description	Mean score (SD) range (0-3)
Care o	rganization	<b>2.72</b> (0.61)
Q44	How often did you have to wait more than 3 weeks if you wanted to make an appointment with the physician?	2.85
Q45	How much time passed between your first hospital visit and the moment you received your treatment plan?	2.61

Patient never needed to wait more than 3 weeks to make an appointment with the physician (2.85) and less than two months passed usually between first hospital visit and moment when they received treatment plan (2.61).

Furthermore, based on the results, patients needed to wait in average one month before being able to start the next treatment. Woman who were not pregnant had experienced longer waiting time before starting the next treatment, which can be rather explained with the medical reasons than some problem in care organization.

## 2. Comparison with the results from the Netherlands

In order to see the position of Slovakia in the European context, we are comparing the results from Slovakia and the Netherlands.<sup>40</sup>

Such a comparison is possible as in both researches was used PCQinfertility as tool to measure PCC. Having on mind that the results are based on different sample sizes (Slovakia n=190, the Netherlands n=888), we decided to make comparison on higher level of recommendations for quality improvement towards achieving greater PCC in Slovakia. In our comparison and analysis, we assume that differences in scores are the results of sample size; therefore, we sometimes stay on the point of the assumptions.

Results from our research show differences between Slovakia and the Netherlands in mean scores of eight PCC domains and domains' indicators.

### Domains' based comparison

In Figure 6, we can see the difference between Slovakia and the Netherlands based on the domains' results. Domains are listed based on the score gap (mean scores' difference for each of these domains between these countries). The highest score gap is evident in the domain of *Accessibility* while the lowest in the domain of *Information and explanations*.

<sup>&</sup>lt;sup>40</sup> The results from the Netherlands are presented in: van Empel IWH et all (2010a). Measuring patient-centredness, the neglected outcome in fertility care: a random multicentre validation study. Hum Reprod., 25, 2516-2526.

Domains	Slovakia	Netherlands
1. Accessibility	2.73	Ļ
8. Care Organization	2.72	
7. Staff 's competence	2.68	
5. Respect for your values and needs	2.42	
6. Continuity & transition during your treatment	2.51	
4. Involvement in your treatment	2.67	
3. Staff 's communication skills	2.36	Î
2. Information and explanation	2.44	

Figure 6: Domains' based comparison between Slovakia and Netherlands

We can see that Slovak results in comparison with the Netherlands are higher in all domains except in the domain of *Staff's communications skills*. This result is going in line with result of our research (see Figure 5) where this domain is the lowest scored in whole research and present a confirmation that is necessary to improve this infertility care domain in Slovakia.

Accessibility: Regarding accessibility domain, we noticed higher scores on questions in favor of Slovakia. Slovak patients were able to speak "usually" or "always" to someone in the hospital immediately when they called them and almost "didn't have problem" to contact staff by phone or email if they had question. Unlike this, patients from the Netherlands answered on these questions from "sometimes" to "usually" and from "a minor problem" to "no problem", respectively.

*Information and explanation:* Results from Slovakia and the Netherlands show that patients had very different experience on information and explanation

received during their treatment in the hospitals. Slovak patients' had more positive experience with providing information (e.g. written information has been provided apart of verbal information as well as the contact number for urgent questions). Patients from the Netherlands had positive experience with 1) explanation and comprehensiveness of investigation's and treatment's information and 2) explanation about any possible side-effects of prescribed medication. Based on low mean scores, we found out that staff in both countries does not or just insufficiently inform patients about how to get support from a social worker or a psychologist. Two-thirds of the participants had a negative experience with the information provision about how and where to get psychosocial support. <sup>41</sup> A possible explanation for these findings is that psychosocial care isn't an integral part of fertility care in these countries.

Staff's communication skills: Patients from both countries had positive experience with the physicians who had very often time for them, listened to them very carefully, and discussed the results of the investigations with the patients. Above all, patient's infertility problem was taken seriously by the physician. Caregiver's clearness about expectations from the fertility care services had higher score in the Netherlands.

*Involvement in patients' treatment:* Results from both countries give us the clue that patients are involved from "usually" to "always" in their treatment.

Respect for patients' values and needs: Access to their own medical record during the treatment period seems as one weak point of respect for patient's values and needs, based on patient's experience in both countries. Although, results on physician empathy are very similar with the regard that in the Netherlands, the results on this question presented the highest score on questions within this domain while in Slovakia the lowest.

Continuity and transition during patients' treatment: Patients from these countries experienced to have from "one or two" to "three or four" physicians

<sup>&</sup>lt;sup>41</sup> van Empel IWH et all (2010a). Measuring patient-centredness, the neglected outcome in fertility care: a random multicentre validation study. Hum Reprod., 25, 2516-2526.

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involved in their treatment. However, patients had one leading physician seeing him/her from "too little" to "always" who provided them contradictory information or advice from "sometimes" to "never".

*Staff's competence:* There is no doubt that staff, according to the patients, appeared competent and skilled in both countries, Slovakia and the Netherlands. Unlikely this, using difficult words without explaining them to the patients and usual waiting in the waiting room appeared as less positive experience in both countries.

*Care organization:* Unlikely to the Netherlands, we found that Slovak patients had more positive experience regarding waiting time to make an appointment with the physician and to get treatment plan.

These differences might be great indicators for Slovak health care centers and their medical staff to improve all indicators that appear as weak (had lower scores). Some of these results might be explained by the nature of the national health care system, different social context and personal expectations as wells as provider's organizational culture. Hospitals, their managers and all staff are leaders in health care improvement and innovations. Netherlands' experience is teaching us that it is possible to provide patients with better explanation relying on high communication skills of hospitals' staff.

#### Indicators' based comparison

In our comparative analysis based on the indicators we decided to give overview of the highest and the lowest scored indicators in Slovakia and compare with the results from the Netherlands.

Based on our analysis (see Section 1.3.4) we chose six indicators that have *the highest score* in our research and ranked them according to the score gap for each of these indicators.

Indicators	Slovakia (n=190)	Netherlands (n=888)
Q44. How often did you have to wait more than 3 weeks if you wanted to make an appointment with the physician?	2.85	Ļ
Q23. Was decision-making shared with you, if you preferred?	2.89	Ļ
Q20. Was staff willing to talk to you about errors or incidents?	2.86	Ļ
Q40. Did the physician(s) seem competent to you?	2.90	Ļ
Q37. Did caregivers contradict each other in policy (one says one thing, the other says something else)?	2.86	Ļ
Q41. How often did staff work disorderly?	2.88	Ļ

Figure 7. The highest ranked indicators in Slovakia in comparison with the Netherlands

The highest score gap we found in the question concerning waiting time to make an appointment with the physician, while the lowest is in question concerning how often staff worked disorderly.

In Slovak infertility hospitals, patients did not need to wait for more than 3 weeks to make an appointment which goes in the line with highly assessed *Care organization* domain.

Slovak patients see doctors as highly competent who shared decision making process with them. This indicator has the highest score in whole research. This result is even more interesting if we know that 3/4 of women were not pregnant and their status did not negatively affect their experience about physicians' competences.

Staffs in Slovak infertility hospitals never worked disorderly and never give some information that might be contradictory (consequently confusing for the patients). Even thought mistakes happened rarely, hospital's staff was really ready to speak about errors or incidence.

In all this six indicators, Slovakia got higher scores than the Netherlands but we need to keep in a mind that Netherlands' score on these questions are high as well.

In Figure 7, we present seven indicators which appeared to have *the lowest score* in our research. Indicators are listed according to the score gap for each indicator.

The lowest score got the question concerning patient's impression that stuff was speaking "about them" rather then to speak "to them". This is indicator of *Staff's communications skills* domain and apparently shows the hospitals' staffs in Slovakia were having lack of it.

How to get support from the social worker or psychologist is also asset very low. It means that Slovak patient almost never got the information about this type of support. With this question we need to be careful because this result may be attributed to the Slovak culture context (often expressed as "I don't need such a support"). However, infertility is very complex treatment with strong emotional impact and it is up to provider to find solution how to inform patient about this possibility (e.g. written form, leaflet in the waiting room, etc.)

According to the Netherlands' results, it is interesting to notice that these two questions are among five lower scored indicators as it is the case in Slovak research. However, score gaps and differences show us that Netherlands have better results than Slovakia and should be good example for further improvement.

Indicators	Slovakia (n=190)	Netherlands (n=888)
Q19. How often did you have the impression that staff was talking "about" you instead of talking to you?	0.39	1
Q11. Did the staff inform you how to get support from a social worker or a psychologist?	0.84	1
Q43. How long did you usually have to wait in the waiting room?	2.19	Ļ
Q3. Did you receive contact numbers for urgent questions or problems at nights or weekends?	2.26	Ļ
Q31. Was one staff member assigned to you to contact any time you had any questions or problems (e.g. a nurse)?	1.96	1
Q9. Were you informed of any possible side-effects of the medication prescribed to you?	2.23	1
Q26. How often did your physician have empathy for your emotions and your current situation?	2.32	1

Figure 8. The lowest ranked indicators in Slovakia in comparison with the Netherlands

There are three indicators more where the Netherlands shows better results in comparison to Slovakia. Slovak patients experienced that lack of information concerning possible side-effects of prescribed medications. Furthermore, we found that Slovak patients (at least two out of three patients) did not have staff member assigned to contact any time in case of urgent question and problems. As we presented above, physicians had high competences but patients experienced physicians' lack of empathy for their emotions and current situation. Experience from the Netherlands give us a good example how is possible to achieve better results in these indicators.

However, there are two indicators where Slovakia got higher scores than Netherlands. Even though Slovak patients did not need a lot of time to make an appointment in the hospital or to start with the new treatments, they experienced to wait between 15-30 minutes for the examination. In the case of the Netherlands, we see that score on this question is lower than in Slovakia and belongs to the group of five the lowest in Netherlands' research. *Care organization* domain is asset very high by Slovak patients; however this indicator should be improved.

Having staff member assigned to every patient, is not very often the case in Slovakia. Three out of four patients did not have assigned contact person for night or weekend urgency. This result is among the lowest in Slovakia but they are higher than in the Netherlands. This indicator is important because it helps to improve continuity and patient's transition during infertility care and prevent medical errors and mistakes that might appear.

# **Concluding remarks**

Project PaCe 2014 shows positive patients' experience with infertility care in Slovak infertility hospitals with high level of overall satisfaction. What kind of infertility care patients can expect to obtain in Slovak infertility hospitals?

Patients in Slovakia can expect to have good experience with accessibility care organization in hospitals. Our results show that most of the patients, usually, do not have difficulties either to access to their treating team using various communication channels (phone or email) nor to finish/ start the next treatment in short time. They almost never need to wait more than three weeks to make an appointment with the physician and usually, less than two months to receive the treatment plan. One month in average pass before patient starts with the next treatment. Patient in infertility Slovak hospital wait in waiting room usually from 15 minutes to half an hour, no matter on the treatment.

Patients' experience during the treatment shows that staff in Slovak infertility hospital, is highly skilled, competent, well prepared for appointments and usually involve patient in the treatment. Patient with lower education level face the problem usually to understand caregivers when they use difficult words without explanation. Patients can expect that hospitals' staff will not contradict in their policy, will provide written and comprehensive information about treatment and discuss about their treatment options. Staff's provision of information, explanation and discussion will be equally presented among all patients, no matter on patient's level of education. Patients can expect to have positive experience with the nurses in Slovak hospital regarding treatment instruction, very comprehensive instructions on how to inject hormones. Nurses very rare miss any instruction, show understanding for patient's situation and give attention and support during patient's treatment period, usually.

Based on Slovak results and comparison with the Netherlands experience, we underline those indicators which improvement will lead to more PCC infertility care in Slovakia. Results form the Netherland show it is possible to reach more positive patients' experience in the following domains and its indicators:

1) Information and explanation domain – Slovak patients have experience with insufficient provision of information and explanations concerning the treatment, possible side effects of the treatments and drugs as well as social worker/psychologist support.

2) *Staffs' communication skills* – Staffs' communication skills does not go in line infertility patients' expectations in Slovakia especially when they need from "usually" to "sometimes" to repeat the same story to different physicians. Patients expect from caregivers to be clear and comprehensive about expectations from the fertility care service, as well.

3) *Respect for patients' values and needs* - Physicians in Slovakia show more interest in patient personal situation then empathy for patient's emotions and current situation.

4) Continuity and transition during patients' treatment - Slovak infertility patients usually do not have contact number for urgent questions or problems at night or during weekends (two out of three patients do not have contact staff assigned to contact for the questions or problems any time and three out of four do not have assigned contact person during night and weekend problem that might appear).

Certain discrepancy between Slovak and the Netherland's infertility patients' experiences may be explained by two different healthcare systems, social characteristics, and patients' personal preferences and expectations based on previous experiences.

Nevertheless, PaCe 2014 results show high level of infertility care in Slovakia from PCC perspective. We need to underline that there is still place for improvement and tailoring services towards more patient's good experience and PCC.

# Recommendations

Our research shows important results and provides the information on which we can build our recommendation for different stakeholders who participate in building patient-centered infertility health care in Slovakia.

## **Recommendations for Providers**

Providers that took participation in this survey can use the data for driving their services and health care even more towards patient centeredness.

On the fist place, providers have to bare on mind, that each infertility patient is a unique person. We recommend to each management of infertility hospital in Slovakia to produce such action plans that recognize and respond flexibly to each patient, tailored to patient's values, needs and expectations. Hospitals need to create flexible organizational care system based on a patient-tailored approach.

Following our findings, we defined four groups of recommendations for hospital quality improvement towards more patient-centeredness.

- 1. As value of information and explanation plays a crucial role in PCC, we recommend hospital's staff to be more comprehensive when they provide investigations' and treatment's information. Furthermore, we strongly recommend them to provide sufficient information on possible side-effects of the prescribed medication and possible psychologist's and/or social worker's support. When they use vocabulary which is not comprehensive for the patients, we recommend taking additional time to explain those words that are understandable to them.
- Since that PCC itself has aim to build the trust between patients and providers, caregivers need to improve their clearness about expectations from the fertility care service. It is possible to achieve by improving staff's communication skills.

- 3. Empathy is the key element of communication competence. A person with high empathy skills has highly emphasized empathy in communication with other person. Empathy becomes a channel which helps to the physician to "open" the patient for communication and cooperation. That is why we recommend to the physician to be more empathic for patients' emotions and their current situation to be improved.
- 4. In order to improve patients' experience about uniformity of care in the hospitals, we recommend to providers to have assigned for each patient one staff member that can be contacted any time when patient has any questions or problem. Moreover, internal organization should be set in that way that the patients' waiting time in the waiting room is the shortest possible.

Whenever it is possible, we recommended improvement on providing information about psychologist's or social worker's support and patients' access to their own medical record.

We suggest to the providers to use PCQ-Infertility as self-assessment tools on regular basis (depending on size of the clinic) in order to be able to measure their quality improvement.

# **Recommendations for Policy makers**

Making patient centered infertility health care should not be addressed just to the health care providers. In general, PCC is joint journey of all stakeholders and has role to reconcile stakeholders' objectives and their activities with the higher-level objectives.

Based on theoretical and practical experience, we suggest four general recommendations for Slovak health policy makers with the special regard that infertility care is an integral part of health care.

1. From our perspective, focus on the experience of care and PCC should be recognized and defined as public value and understood as accountability mechanism. Open debate among all stakeholders on what PCC infertility care means for the health professionals and patients contribute to the cultural change. Cultural change itself gets formalized in clearly defined national strategies and a patients' chapter of rights and expectations. Such a process should be followed with permanent promotion of PCC and encouraging regulatory bodies, accreditation agencies, and professional associations to incorporate PCC into their core expectations and codes of ethics.

2. PCC appears to be a subject of policy decision agenda, but we have to ensure that it is really happening. In case of infertility health care, patients' experience and PCC as component of high quality care are having measurable and reportable characteristics. These characteristics should be used for two main discourses:

a) Once when the elements and indicators of PCC infertility are defined and adopted, we are able to have one dimension more towards measuring hospitals' performances. PCC is recognized as an incentive dimension which, in turn, should create possibilities for PCC rewarding incentive systems. We recommend creating policies which will foster awards for achievements in PCC based on empirical evidence. Reimbursement system of infertility care providers should be rewarded through PCC incentive as quality indicator, and motivate providers to produce high quality service on more efficient and patient's suitable way.

b) We recommend to policy makers to foster benchmarking which will motivate hospitals to produce better services. Benchmark reports have to be aimed to identify opportunities for optimization, thus to compare performance of infertility clinics and raise the quality of their services. Benchmarking can help to the patients to make informed-based decision on health care providers based on comparison.

3. Facing the lack of uniform collected data about assisted reproduction in Slovakia, we strongly recommend to establish assisted reproduction treatment

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register on the National level with the obligatory reporting, as priority. Data exists on providers' level and level of health insurance companies who pay providers. Policy makers should keep in mind that establishing the National register and obligatory reporting will facilitate, in general, data collection and information about ART concerning access, clinical outcomes and costs. Thus, register has to be in charge to establish patient-based database for ART services, develop linkages between ART and national perinatal databases (follow up after ART treatment) and, overall, will serve as an appropriate sources to the national ART statistic unit in Slovakia.

4. As standard of health services evaluation and permanent quality improvement, we recommend implementation of surveys on regular basis among infertility patients. Nationally and systematically collected experience feedback from patients and health care providers is implemented in the UK, US and some European countries (the Netherlands, Germany).

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