

## UNIVERSITATEA DE MEDICINĂ ȘI FARMACIE "CAROL DAVILA" din BUCUREȘTI



# UNIVERSITY OF MEDICINE AND PHARMACY "CAROL DAVILA" BUCUREȘTI DOCTORAL SCHOOL

DOMAIN: MEDICINE

### SYNTHESIS OF THE DOCTORAL THESIS

THE SOCIAL DIMENSION OF TYPE 2 DIABETES (T2D) IN MODERN ERA
STUDY CASE: A COMPARATIVE ANALYSIS OF 40 STATES CONSIDERING
THE IMPORTANCE AND VULNERABILITIES FACED BY THE NATIONAL
PLANS FOR COMBATING AND CONTROLLING T2D AND NATIONAL
REGISTERS FOR DIABETIC PATIENTS. A TOOLKIT FOR ELLABORATING
PUBLIC POLICIES DEVOTED TO DIABETES AS TOP PRIORITY FOR THE
AGENDA OF PUBLIC HEALTH IN ROMANIA

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3. 4. Results and discussions about global standards for public policies to combat and and
control diabetes41
3. 5. Partial conclusions43
CHAPTER 4. STUDY CASE. MODELS AND INSTRUMENTS FOR A NATIONAL PLAN FOR THE CONTROL AND PREVENTION OF DIABETES IN AGREEMENT WITH THE GOOD PRACTICES IN THIS DOMAIN AND THE NORMS OF
CREATING THE NATIONAL REGISTER OF PATIENTS45
4.1. Global stabdards for a puzzle for constituting public policies for the control and prevention of diabetes
4.2. Particular models for developing a national plan for diabetes and a national register for patients. Vulnerabilities and priorities
4.3. Legislative challenges in properly addressing diabetes as a social disease through the development of a national plan and patient registries84
4.4. Recommendations. A set of strategic measures for action and communication in order to develop public policies dedicated to combating and controlling diabetes in Romania
4.5. Partial conclusions92
CONCLUSIONS AND RECOMMENDATIONS94
REFERENCES96
INDEX101

## Table of contents

List of published works4
Abreviations5
Tables List6
Figures List6
INTRODUCTION7
THE GENERAL PART. THE STATE OF THE ART11
CHAPTER 1. DIABETES. PROPEDAEUTIC ASPECTS11
1.1. Nosology, taxonomy and economic-social impact of diabetes
1.2. Risk factors of type II diabetes and the relevance of social effects
1.3. Specific education of patients with type II diabetes
1.4. Components with social implications of clinical management in type II diabetes18
CHAPTER 2. DIABETES – FROM A SILENT GLOBAL PANDEMIC SOCIAL
DISEASE TO A NATIONAL CHRONIC DISEASE21
2.1. Models for defining diabetes as a social disease 1
2.2. Diabetes mellitus, social disease at global and national level31
2.3. Social effects of legislation and regulations regarding positive and negative discrimination
of diabetic patients34
2.4. Socio-economic factors relevant for changing the legislation regarding positive or negative
discrimination of diabetic patients37
PERSONAL CONTRIBUTIONS38
CHAPTER 3. ANALYSIS OF PUBLIC POLICIES REGARDING THE
FRAMEWORK OF DIABETES AS A SOCIAL DISEASE IN ROMANIA AND 40
OTHER COUNTRIES38
3. 1. Motivation of the research topic38
3. 2. Scope and objectives40
3. 3. Material and research methods

## MAIN ASPECTS OF THE DOCTORAL PROJECT

The main purpose of this thesis is to examine and define the social dimension of Type II Diabetes in the Modern Era. The research project has at its heart the attempt to compare and contrast the national approach of 40 states and Romania in what concerns the importance and the vulnerabilities of the national plans for combating and controlling Diabetes and the national registries for diabetic patients. Beyond an attentive look to these competitive instruments and policies for combating the widespread of diabetes, which progressively reached pandemic proportions, this doctoral research aims to develop a toolkit to elaborate public policies devoted to diabetes as top priority for the agenda of the public health in Romania.

The objectives designed for this doctoral project concern:

- (1) Understanding the nosology, taxonomy and impact of diabetes by considering genetic and non-genetic factors, in order to establish their relevancy on the social effects involved by T2D.
- (2) Framing the diabetes as a social disease by recourse to medical analysis and ethical models of justifying the social implications of diabetes, in order to encompass the large spectre of the evolution of such disease from a silent global pandemic to a national chronic affection.
- (3) Elaborating a study-case on 40 states that deal with limits and vulnerabilities of national legislation in combating and controlling diabetes, closely mirrored by the structure and morphology of National Plans and National Registers of Diabetic Patients.

The first part of the doctoral thesis tackles the current state of the art.

Chapter I, inspired by the need to analyse propaedeutic aspects, explains the main reasons for which the current research has been narrowed exclusively to Type 2 Diabetes, and highlights the risk factors associated with such disease that impose a particular health management. As diabetes requires expensive medication and associated medical services for connected cardiovascular, renal or dyslipidaemic affections, the profile of such disease reveals that at least from a social standpoint, it represents a chronical affection widespread for particular vulnerable groups, with professions that challenge individuals by stress and sedentarism, favouring the rise of diabetes. Unhealthy life habits, such as smoking, consuming

alcohol, or predispositions to depression and anxiety complicate the management of diabetes, that require four canonical steps: therapy, education, monitoring and evaluation. A particular dimension of this chapter has been consecrated to the specific education of T2D patients, reflecting on interactive methods of explaining how to administrate treatment based on insulin, how to overcome emotional and psychological barriers, how to improve the quality of life and how to manage the risks of insulin therapy. The last part of this chapter is devoted to the social implications of clinical management applied to T2D, reflecting on indicators belonging to the structural domain, the clinical and biological domain, and their related social impacts.

Chapter II provides a wider analysis on the double character of diabetes, that of a silent social pandemic and that of a chronic national affection. In what concerns the management of T2D, physical, intellectual, emotional and social aspects have been largely treated along the second chapter of the doctoral thesis, closely referring to the impact of socio-demographic factors on the rise and spread of diabetes, and to the role of personality traits, relationship between patients and doctors and capacities of cooperation that significantly contribute to the control of diabetes. The most challenging part of this chapter is represented by the explanation of the so-called Leventhal model, a dynamic and complex pattern that represents the manner in which subjects tend to pursue factors of aversion against their health throughout local symptoms and proper medical monitoring and consequently develop cognitive and emotional representations. In short, the Leventhal structure consists in external stimulus of diagnosing T2D - meaning evaluating symptoms and applying medication; cognitive representations meaning identifying chronic affections, identifying causes of different diseases, identifying the debut of the sickness and its consequences, and applying treatment; emotional representations - reduced to understanding and accepting the dependency on treatment, representing the public mentality on the causes and consequences of such disease and its associated social behaviours, accepting risk factors and their social impact, evaluating psychological effects produced by insulin therapy and monitoring a potential depression caused by the methods of applying the treatment. The Leventhal model also includes strategies for approaching medication, implementing diet, correlating diet and physical activity and maintaining results of pharmaceutical control. Criticizing the Leventhal model led me to the following conclusions. First, the genetical factor is the most current and invoked cause of such disease. Secondly, a stressful lifestyle mainly causes depression, anxiety and other psychological problems that contribute to the rise of T2D. Thirdly, it is crucial the manner in which patients learn to become self-responsible dealing with diabetes. Fourthly, prohibition is

the most common factor of turning the patient's condition to different vulnerabilities. In this sense, family, as a social nucleus, reflecting values and life habitus, is empowered to contribute to the control of diabetes, by avoiding conflicts of investment into bio products, adopting eco trends for alimentation, producing solidarity between the diets of different family members to avoid carbo products or excluding sweets from regular shopping. Along the second chapter of the doctoral thesis, I have closely criticized the return of different scholars to an alternative paradigm to the Leventhal model, which is the Giddens paradigm. Recent ethnographic studies of controlling T2D reflect that social architecture, reducible to norms, moral codes, institutions and social, cultural or economic systems influence and constrain the values and behaviours of individuals, who compulsively tend to reproduce social structures. As any society is transgressed by cultural contradictions, there are gaps between the popular knowledge that individuals have on a certain disease and the level of knowledge that a patient should have. Therefore, the Giddens model needs an urgent upgrade to have the capacity to accurately reflect the dynamics of individual and social agencies in the management of the disease. The third model that ends this series of competitive paradigms explaining the rise and control of T2D is advanced by Stones and surprises simultaneously atomized and collective factors of impact for diabetes, as follows. First, external structures are considered the core of the disease: the social ecosystems, the material conditions of life etc. Secondly, the internal structures appear to be reduced to past and particular experiences of individuals in what concerns world attitudes, senses and decisions. Thirdly, actions, reflected in particular actions and fourthly, results, with intended or unintended impact, close the series of components of such model. Unlike Giddens' model, which is quite sociologically tailored, the model advanced by Stones is more sympathetic with ethical implications of patients' behaviours and tends to conceive broadly hermeneutical the level of knowledge of individuals on such disease before and after becoming patients. The last part of this chapter briefly undertakes two psychological theories relevant to test the social support of individuals in controlling T2D, by overlooking their principles, values, emotions and behaviours. On the one hand, there is the theory of Kiesler, mainly interpersonal, stating that the social interaction of individuals is either marked by affiliation-hostility attitudes, or by domination-subjection reports. On the other hand, we deal with the theory of self-determination, stating that and individual behaviour fulfils three psychological and fundamental human needs: social connexion (that strengths love, affection and care), competence (increasing self-esteem, efficiency and autoevaluation) and autonomy (that enhances the liberty of decisions and actions). Both theories conclude that accepting T2D without undermining the autonomy of the patient and his/hers capacity of self-management

might be a better way of confronting such disease and monitoring it. The model largely accepted for the control of T2D is the so-called Hill model, that briefly considers diabetes provoked by the consecution of the following factors: social conditions of life, poverty, material scarcity of core-resources for a qualitative life, chronical stress, bio- and psychological implications. Implicitly, the management of T2D should be adapted to this large spectre of factors. The most important assumption of the Hill's model is that T2D is a disease with a cyclical morphology, meaning that it emerges from and contributes to adverse effects. As an example, poverty involves bad diet, and overcoming such context means stress that in its turn contributes to the acceleration of T2D. Finally, chapter II draws some conclusions on the pandemic aspect of diabetes. As T2D is fourth times more spread than cancer diabetes turns from a chronic to an epidemic profile. 18 million individuals die annually due to cardiovascular complications in which diabetes and hypertension play major roles. However, in the latest years, prediabetes has recently been addressed as an overdiagnosis: more than 50% of those identified as prediabetic do not have pathogenic conditions necessary for the development of diabetes.

Thus, on a social and economic level alike, it is found that overdiagnosis against the background of assuming the epidemic character of diabetes is generated by professional organizations and pharmaceutical companies that stimulate public awareness and the risks of the condition through the financial considerations of expanding the service market they offer. Diabetes becomes economically instrumentalized - hence the global, epidemic character of this condition, specific to modern society. The figures that determine the frequency of the disease worldwide strongly support the combined industrial and economic interests behind them. 425 million people with diabetes in 2017 is the figure provided by IDF Diabetes: according to INSP, for 2045 the number is expected to increase to 629 million patients, while European statistics announce 66 million people suffering from diabetes and an increase, up to 81 million by 2045. In what concerns the situation of Romania, in 2017, in an adult population of 14,382,000, there were 1,785,300 cases of diabetes in adults aged between 20 and 79, with a prevalence of 12.4%; the number will decrease to 1,246,000 in the year 2045." The concrete question that emerges from these quantifications is how can we decrease the prevalence of diabetes nationally from 1785300 cases to 1246000?

We must remember that the previously mentioned figures cannot be isolated from a reality essential to the management of this disease in Romania: we are the first country in Europe to declare the essential character of diabetes as a social disease, since 1941 when the

first Diabetes Registry in Bucharest was created still functional today and unmatched in Europe. Moreover, Dimitrie Gusti's sociological contributions become guidelines for legitimizing diabetes as a social disease: 6 nurses trained by him were employed in the Antidiabetic Center by Prof. Ion Pavel, the one who declared diabetes as a social disease. And yet, the evolution of diabetes in Romania reveals that we still fail to accommodate patients with T2D as a social distinct class, with particular needs and rights. The final part of this chapter evaluates forms of positive and negative discrimination of patients diagnosed with T2D. The forms of positive and negative discrimination vary depending on the social context in which they are addressed: on the one hand, when employed, diabetic patients frequently encounter negative discrimination practices depending on the way in which the evolution of the disease can affect the professional activity (in terms of efficiency, yield, etc.); on the other hand, identifying solutions to compensate for the additional needs that diabetes imposes by following an appropriate diet, a work schedule with breaks to allow glycemic monitoring or treatment administration, excluding shift activities and actions that may interfere with treatment entitles us to diversify the interpretations of diabetes as a social disease and from the perspective of the effects, not only of the causes of this disease. Consequently, I have briefly criticized the socioeconomic factors relevant to modify legislation in order to avoid positive or negative discrimination of patients diagnosed with T2D.

The second part of the thesis (the rest of the chapters) concerns the personal contributions to the current state of the art. It is mainly concentrated on a study-case devoted to the evaluation of 40 states that took different attitudes and responsibilities in developing the National Plan for Diabetes. This idea was inspired by the need to adequate the framework prescribed by JA-CHRODIS on designing and implementing national plans for diabetes as strategic projects based on public policies, activism and actions. But, in the same time, at a closer and more attentive look, we will see that national plans are far from reflecting a unitary formal project in Europe. As Norway prefers to maintain a larger framework for combating diabetes as any other chronical disease, some European states created a real difference by including their national plan within the programs of combating diabetes as particular chronical disease. Here, the most important distinction, usually underestimated, is that between plan and program, meaning, between large strategies of combating and preventing diabetes and specific programs dedicated to the management of such disease. In my research, I have also found that some countries hardly prefer to address children or teenagers as particular target groups for their national plans, although they are the most exposed and vulnerable. Nordic states are, counterintuitively, more

vulnerable from this standpoint. Nonetheless, national plans differ from one state to another through standards of early diagnosing, routine and care of the diabetic patient, capacity of offering medication or access to medical services. National plans are still underestimated as useful tools to allocate resources for services of prevention and monitoring, or consolidating medical assistance and training new medical staff for taking care of diabetic patients.

In chapters III and IV, I found that NPDs (National Plans for Diabetes) involves a puzzle made up of pillars common to European states, such as:

- a) Early detection of the disease: NPD involves early detection and the analysis of correlated risk factors in only one third of the European states. The Nordic countries insist on establishing a risk profile of the diabetic patient, trying to avoid overdiagnosis or pathologizing according to vulnerable social categories. Thus, the NPD assumes yet another challenge from the perspective of capacitating employers from both the public and private environments, to contribute to the involvement of medical services for early detection and monitoring of employees.
- b) Diabetic patient care routine: patient education for monitoring and self-care must be completed through national campaigns and support services at the level of medical units, given that the medical staff is not always sufficient or fully qualified to advise patients and train necessary care skills. Patient care is a complex, broad spectrum of measures that include diet, physical activity, periodic clinical monitoring, and assessment of complications. Therefore, NPD must insist on the development of qualified medical workforce for the allocation of monitoring services and education of diabetic patients for the management of the disease.
- c) Skilled human resources involved: PND should support training and qualification courses for secondary clinical staff for the education and counselling of diabetic patients, through regulated and nationally recognized certificates.
- d) Monitoring and evaluation of diabetic patients through correlated IT systems: the collection of diabetic patients' data is necessary but not sufficient; these data require processing of an interdisciplinary nature and can represent a valuable resource for medical studies. Nordic states insist on prevention, central and southern European states insist on surveillance and monitoring. In both situations, however, the IT system must contain and organize the information, in different databases, which require complete updating. In addition, the digitization of patient information can contribute to a better allocation of resources, a better

territorial representation of diabetic patients and a better understanding of the effects of standardized and customized treatment regimens.

- e) Involvement of stakeholders: the development of NPD is not exclusively a state project. National associations for the light and prevention of diabetes, patient organizations and non-governmental structures can suggest better and more critical visions for the implementation of the NPD, respectively for the allocation of the necessary resources in monitoring and evaluation.
- f) Good practices to stimulate local and regional innovation in NPD adoption and dissemination: Spain, for example, has developed a register of good practices to collect suggestions and information on access to health care resources and services, printing annually, with the support of the ministry Health, a guide to best practices in different medical sectors. The practices are selected according to their efficiency, transferability, level of innovation, sustainability, compliance with the principle of equality in access to medical services, the gender share of patients and the social risk group, respectively the ethical implications of public systems and policies of health.

Along my research I have reached ten partial conclusions:

- 1. Although the legislative texts respect the EU provisions, as well as the pillars of the public policies proposed by JA.-CHRODIS Joint Action on Chronic Diseases and Promoting Healthy Aging across the Life Cycle, the national plans contain material errors.
- 2. Many of the NPDs have difficulties in expressing the urgent nature of the need for coordinated public actions to prevent the spread of diabetes, given that 8.5% of the adult population of Europe (56 million) suffer from DM.
- 3. Although national registries have a morphology capable of collecting, recording, monitoring and managing epidemiological information, however, national registries are not fully functional, operable, nor do they assume a complete character. In approx. 12 of the analyzed states have no information collected on gestational diabetes, and less than half of the analyzed states have not integrated the collected information into national registries.
- 4. There is no qualified staff to process and update the national registers in time, which would simplify both the activity of specialized medical units and the clinical studies of researchers or the access data needed for the statistics operated by representatives of the pharma industry.

- 5. Although progress has been made in the development of national registers for a decade, they are not a priority and their digitization process is slow.
- 6. 30 states are currently implementing NPDs, and another 10 believe that while diabetes used to be part of broader national chronic disease programs, they are now able to operate a NPD to implement in the short term.
- 7. Monitoring and evaluation of diabetic patients is dominant, prevention campaigns are still supported by third parties (representatives of civil society, NGOs, etc.)
- 8. Services for eye or kidney care are not sufficiently correlated with T2D assessments and this element remains a factor in accelerating inequalities in access to health services.
- 9. All the analyzed states feel an acute need for specialized personnel in the care of diabetic patients, secondary medical personnel receiving specialized training in parallel with the care of diabetic patients, not beforehand.
- 10. The pressure on the medical system is high in the absence of auxiliary staff specialized in the care of diabetic patients, which makes the control flow for monitoring and evaluation not regular.

Interesting findings along my study case, worthy to be mentioned in a brief synthesis concern state attitude in front of national plans and national registers. It is remarkable that 30 states reported a platform similar to the national diabetes register, managed by public health authorities – this being the trend at European level – with exceptions such as Luxembourg, which prefers the management of the register by medical units, i.e. by hospitals, in real time. At the world level, only Israel and Sweden have these complete registers, but at the European level, 85% of the registers are incomplete, only two states, the Netherlands and Cyprus, explaining that the policies or legal frameworks on the protection of personal data prevent the creation or expansion of such national registers. In particular, Finland and Switzerland – paradigmatic states for development and health infrastructure – stated that current legislation prohibits the creation of particular disease registries.

We find that for the monitoring, control and prevention of the disease, it is not the clinical considerations that stand in the way of the development of related public policies, but the legal ones, accompanied by an appropriate financial framework. However, national plans cannot be properly developed in the absence of knowledge of the particular situation, in terms of the number of patients, treatments, control and prevention, at the local, community and regional

level. The first observation is that the impossibility of developing, updating and operating data from national registries of patients diagnosed with diabetes delays any European aggregate plan for the prevention and control of the disease. States such as Albania, Germany, Luxembourg, UK are among those that do not have a plan at all or do not yet have a definitive plan, but have joined global or European initiatives for the prevention, control and treatment of diabetes; on the other hand, Estonia, Iceland and Latvia do not have tools to implement policies for the prevention and control of diabetes, at the level of public health and care strategies.

From here, we conclude on the second crucial observation of the present analysis: the fight against diabetes is compromised or delayed by what we might call "a national political will" to restructure legislative frameworks. Although at the level of national plans, prevention remains the main topic, in 35 states, followed by patient care, in 34 states, self-care support, in 33 states, screening and diagnosis in 28 states, however, the lack of responsiveness and analysis of reactions to current public policies do not represent criteria of interest for the analysis of the efficiency of national plans.

This is how I reached the third core-observation of my study: NPDs are a puzzle of public health policy focused on three questions: *Who pays?*; *Who cares?*, respectively *Who educates?* Only 19 states recognize diabetes care as worthy of licensed medical personnel specializing in this area, and only 5 states consider trained nursing personnel to require continuing education, typically as a career opportunity for nurses. Unfortunately, in more than 29 states, medical staff specialize in this direction after being recruited into a specialty department, not before, which means that education overlaps with the process of interacting with patients.

However, what no state is able to vehemently enforce is the awareness of the need to define workable diabetes registries as a source for the development of additional benefits for patients: doctors can develop better standards of care and track changes in the behavior and condition of patients, self-control of the disease can be better optimized according to the related information and the results obtained. In addition, such a registry can be a valuable impetus for research: it can represent a starting point for clinical trials and accelerate interdisciplinary cooperation between clinical and medical entities. For example, in Italy, the registry for patients with T1D resulted from the 1996 cooperation between the Italian Society for Diabetes and the Italian Pediatric Society for Endocrinology and Diabetes.

At the end of this analysis concentrated on 40 states, including Romania, dealing with T2D, my interest is on the political responsibility and challenges that different agencies should take in combating diabetes. In my opinion, there are seven major priorities and challenges that might tackle the role of this political framework, as it follows:

- a) Politically supported campaigns, as well as the political will to change the legislative framework for carrying out the campaigns, respectively the national register of patients, must focus mainly on prevention and on impregnating the mentality of a healthy lifestyle. Therefore, the focus must be on goals that express the quality of life in the long term, not medium and short.
- b) Screening and early diagnosis should be encouraged through an appropriate legal framework. It is found that the campaigns to combat the causal factors (alcohol or tobacco consumption) were successful, but that the implementation of campaigns focused on diabetes as a social disease is almost non-existent.
- c) Social inequalities are still not treated as the main cause of unequal access to information and medical services.
- d) The most effective form of prevention is applied to young people: the promotion of physical activity, especially in schools, eliminating the old mentality that physical activity is incompatible with academic excellence is a priority for the public agenda of relevant ministries.
- e) Especially after the pandemic, access to medical services mediated by digital tools has become a favorable emergency solution for doctor-patient interaction. To overcome barriers related to either convenience or risk minimization, one solution to increasing awareness of prediabetic monitoring may be 'telediagnosis' (Timpel et al 2019, 1849). Such a measure involves the allocation of budgets for certifications and the payment of digital services for prevention, which can be left in the responsibility of public institutions and insurance companies.
- f) Assuming diabetes as zero priority on the public health agenda can impact research costs, allocating larger budgets for medical research in the field, even stimulating interdisciplinary cooperations such as those located on the border between medicine and sociology.
- g) After decades of reform, especially in the countries that belong to the former Soviet bloc, therefore with imperfect but perfectable democracies, a long-term vision can make a

difference in the sense of the transition from one mentality to another. Therefore, it would be effective to approach a Finnish paradigm, where health reforms are not the project of a government, do not carry a political imprint, but rather represent a country project.

The doctoral thesis ends with an innovative part of advancing a toolkit with ten pillars to design public policies to combat and control T2D. It aims to:

- a) Increase the emerging responsibility of academic and clinical medical staff
- b) Involve stakeholders and third-party agencies with medical responsibility and profile
- c) Develop the workforce of qualified medical personnel for care
- d) Recruit approved medical personnel for the care of diabetic patients
- e) Accelerate the need to impose a national plan and a correlated national register
- f) Combat positive or negative discrimination of patients in different risk groups
- g) Eliminate conflict factors between the private and public environment in the conduct adopted in the collection of data and their processing for medical purposes
- h) Increase the degree of trust of audiences from civil society and the public sphere in combating campaigns
  - i) Increase the literacy of risk groups in the sense of medical knowledge
- j) Eliminate unequal access to medical services or establishing a set of priorities between patients diagnosed with DZT1 and those diagnosed with DZT2.

The ten pillars of this original toolkit target: unitary legislation, voluntary character and attitudes, correlated free medical services, certifying the medical training of care of diabetic patients, distinct domains for unique registers, education related with constrains provided by social ecosystems, access to complementary medical services through NPDs, encouraging interdisciplinary medical research and budgetary transparency.

The doctoral thesis ends with nine major conclusions of this research project, that reflect the most important contribution of the last chapter.

1. Medical information is insufficiently processed, measured, evaluated, and that is precisely why the results in the perspective of preventing or combating diabetes are modest.

- 2. The digital environment develops increasingly interactive ecosystems that can fundamentally support diabetic patients both in the use of innovative technologies for consultations and in the application of innovative therapies.
  - 3. Medical systems have deficiencies in primary and integrated medical care.
- 4. In the absence of the recruitment of a new category of medical workforce, namely personnel specialized in the care of diabetic patients, the pressure on the medical systems will not be decongested and equitable access to monitoring, evaluation and therapies will be delayed.
- 5. Clinical and digital innovation is present at the level of medical research but absent from the perspective of digitization and operationalization of national registers.
- 6. There are clear, indisputable examples of good practice in outsourcing digitization and information processing services to diabetic patients. In Sweden, since 1996, the national register continues to be updated and developed including all associated pathologies of the patients, while in Denmark or Bulgaria specialized centers are emerging that process the information.
- 7. Research centers and associations for patients with diabetes (following the Belgian or Portuguese model) continue to be competitive and offer education and medical care to them, also undertaking training actions for qualified personnel. The model can, by extension, lead to better control of the spread and monitoring of DZT2.
- 8. The main problem remains late diagnosis, the lack of frequent companies to encourage medical control and the development of public policies that encourage top treatments or digital health.
- 9. In Romania, there is no unified toolkit for public policies to combat and prevent diabetes. The example presented at the end of the research can substitute a flexible working tool in order to develop such contents that correlate medical services and gratuities, certifications and medical specializations in care in the field, distinct fields for unique registers, educating communities according to the social ecosystem, regulation to complementary medical services through PND, encouraging the academic environment in interdisciplinary research and budget transparency.

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