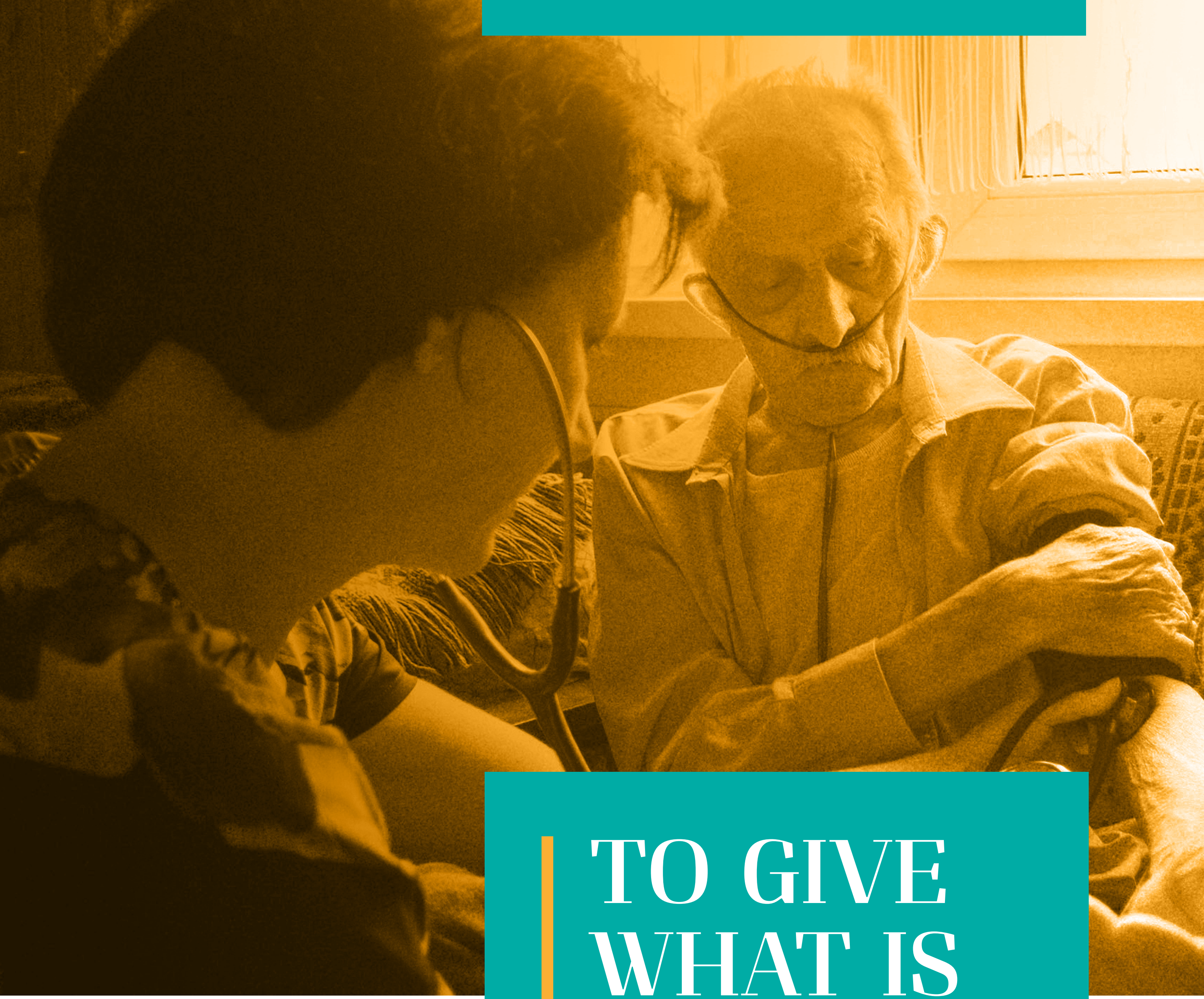

TO GIVE WHAT IS REALLY NEEDED

Description of the innovation and work plan

Proposal VP/2019/003/0068

"Dać to, czego naprawdę potrzeba" - "To give what is really needed"
An innovative model of professional home care for dependent, terminally ill
and chronically ill people and support for their carers in rural areas.

Spis treści

1. Introduction,

where we describe **in what socio-economic reality** the idea of the innovation was born.

In Poland, almost 40% of its citizens live in rural areas, which constitute over 93% of the country's territory. Despite statistics showing that there is an increase of 500,000 people in rural areas every ten years, we are witnessing aging and depopulation of rural areas. As the research of the European Fund for the Development of Polish Villages shows, the availability of medical services in the villages is 2-2.5 times worse than in the cities. Poverty also affects the inhabitants of rural areas more strongly. The report of the Supreme Audit Office (NIK) shows the inefficiency of social care provided to the elderly in the place of residence[1]. The old, incurably ill and chronically ill, dying, living in rural areas, full-fledged citizens of Poland and the EU, are people who, for obvious reasons, cannot fight for their rights. Even more vulnerable are people in rural areas with a low or very low level of socio-economic development, in poor, sparsely populated areas, far from larger centers. After eight years of operation, we have experienced that the system offering specialized hospice and long-term care is inefficient in rural areas. It is difficult to talk about "comprehensive and holistic care" as defined by hospice care, [2] when such important aspects as "alleviating mental, spiritual and social suffering" are not sufficiently guaranteed in the framework of public health service.

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[1] "Nursing services provided to the elderly in the place of residence. Information on audit results", NIK, identification number, 31/2018/P/17/043/KPS

[2] The concepts of hospice, palliative or palliative-hospice care are defined differently in different EU countries. When we write about hospice care, we understand it in its original, broad sense - caring for incurably, chronically ill, dying, dependent people - who require professional support. The closer to the end of life, the more emphasis is placed on improving its quality, even at the cost of resignation from procedures that are burdensome in this period of life and are burdened with the risk of complications.

We are asked for help and support for dependent persons not only by family doctors, but also by communal social welfare centers, the State Fund for the Rehabilitation of the Disabled (PFRON), parish priests and village leaders from nearby villages who know their needs well. Sometimes they are neighbors who are concerned about the health of the neighbor behind the fence. Good cooperation with all of them (with really small human resources in our sparsely populated areas) is one of the most important keys to success. Our other experience is the awareness that, being a unit operating in a remote province, we are too weak a voice to influence the change of regulations. That is why we decided to try to change the reality closest to us in a partnership with an institution influencing the shaping of social policy (ROPS). We decided to implement and test in our organization an innovation that could propose a new model of care for chronically ill and terminally ill people, effectively operating in rural areas.

By joining the innovation, we are the voice of about 50% of the inhabitants of our region and almost 40% (39.8%) of the population of Poland[3]. In the near future, the problems of the elderly, chronically ill, will strongly affect other EU countries, where rural areas cover approx. 77% of the country's area and are inhabited by half the population of the European Union (2013). For every society, the old, sick, suffering and dying man/woman has been a challenge. The measure of civilization progress is not only the development of technology, but the way society faces this exact challenge and how it treats its weakest citizens.

2. Chapter one

here we describe **why** it was us who, disagreeing with the current state of affairs, decided to take up the challenge and test the innovation.

The project leader, the Prophet Elijah Hospice, has been operating for the eighth year in the rural areas of eastern Podlaskie. As a non-governmental organization, we are constantly improving and changing, trying to best respond to the needs of those who we support. We operate in areas with a low and very low level of socio-economic development[4], depopulating and aging areas. The recipients of our activities are people from several groups - the chronically ill, terminally ill, dependent people, their guardians, but also recipients of our educational activities. So far, we have looked after over 1,000 people - terminally ill and dependent in their homes, their carers and family members. In the case of institutions like ours, operating in rural areas, far from large urban centers, especially those run in large areas with insufficient medical and transport infrastructure, the decision not to admit a patient who needs home hospice care, but does not meet formal criteria, is particularly dramatic, as it means condemning the patient to suffering - often alone - at home, for a lack of a real alternative. Less than half of our patients meet the criteria for being covered by state-reimbursed hospice care. For the rest, we try to “tailor-made” the aid, which unfortunately is not refunded from public funds. By conducting educational classes and proprietary workshops "Dying is a human thing", we reached several hundred students of medicine and nursing. We were invited as experts to give speeches to the Senate of the Republic of Poland (The situation of rural women) and the Supreme Audit Office (NIK) in Warsaw in 2018, as well as to the Polish Ombudsman (RPO) in 2019. We conduct meetings for volunteers, children and young people, as well as lectures for senior clubs and students of the Universities of the Third Age and informal groups - at parishes and village community centers. We have been running it continuously since the foundation of our Foundation, constantly expanding the group of recipients (e.g. mentally disabled people, prisoners, people in mourning).

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[3] Source: GUS, Rural areas in Poland in 2016.

[4] The report "Monitoring of rural development. Stage I", 2014, EFRWP, IRWIR PAN.
from: https: //bs.net.pl/aktualnosci-zrzeszen/monitoring-rozwoju-obszarow-wiejskich

In practice, this means many hours of observation, meetings and talks about the needs, difficulties and challenges faced by chronically ill and terminally ill people and their relatives. We have more and more experience and we recognize and are able to better identify the needs and concerns of our beneficiaries. Being close, we have learned to look at them from the perspective of the sick and their relatives living in the countryside of our country.

What motivations, what mechanism underlies our willingness to engage in the innovation? From its beginnings, the hospice movement is a grassroots initiative, resulting from the deep need of people who are sensitive, indifferent to human poverty, sensitive to misfortune, weakness and loneliness of their neighbor(s). Even when it was taken into an institutional framework, its aim was never merely to implement norms, procedures or to strictly adhere to rules. It was created and led by charismatic people who deeply felt the meaning of their actions, who could draw others with them, infect them with their commitment and devotion to the sick and suffering. These people responded to the real needs of their wards and were not afraid to propose changes, or, as we would call them today, "innovations" – from deacons and pious widows of the first centuries of Christianity, from Basil the Great, who built the first hospitals for the dying, to Dame Cicelly Saunders or Hanna Chrzanowska. The latter (a lady from a good home, a professor's daughter), in the times of deep communism, had the courage, with her feet firmly on the ground, to nurture and care for the dying in their homes and to create the foundations of modern community nursing. She was also not afraid to talk about the spiritual needs of the dying[5]. Similarly, seeing the possibilities of solutions and ways of helping our proteges more effectively, we practice them and want to share our proven solutions with others.

The care for the incurably ill, for the dying, is changing, evolving and has to constantly grow up and adapt to the new, ever-changing reality. We see this and feel responsible for the chronically ill and terminally ill entrusted to us. We change for the better (and we want to do it better and more effectively) their difficult reality by offering a comprehensive, professional help to the sick and those who look after them in their homes.

3. Chapter two,

in which we explain **how** it will be done (work plan).

Within 36 months, we will prepare (months 1-4) and then implement (months 5-34) activities related to innovation's testing (see - Application form). The leader, with the support of the Regional Center for Social Policy (ROPS), will define and create a network of local resources of health institutions and social assistance and other institutions invited to act within the network. As beneficiaries of the project, we accepted people who did not meet the requirements for hospice care financed from public funds (NFZ), but being seriously, terminally ill, with disabilities and with various degrees of dependence - they required such care and support at home. Due to ineffective other methods of support in rural areas, without our commitment they would not have received the help adequate to their needs. The creation of a "new", extended hospice team is another task. Based on the existing home hospice team, probably working mainly in cities, but inefficient in rural areas - we will expand the team with new professionals - carers, dietitians and provide them with support (as well as other network members) by recruiting the Dependent Care Coordinator (KOOZ). We will prepare the scope of KOOZ's responsibilities in advance in cooperation with partners, as well as the whole recruitment process for this position.

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[5] Florkowska M.: The joy of giving. Hanna Chrzanowska in memories, letters and anecdotes. St. Stanislaw Publishing, Krakow, 2017.

Part of the task is a scientific research to monitor the effect of the innovation implemented for 2.5 years. Currently, we only draw conclusions about improving the quality of life and quality of dying from conversations with beneficiaries - the sick and their relatives. The research is needed to reliably test the improvement of these aspects of functioning. It will be constructed and conducted by specialists from the Institute of Rural and Agricultural Development, Polish Academy of Sciences (IRWIR PAN). The control group will be selected at the study preparation stage. The research and the course of innovation will be substantively supported by the Regional Center for Social Policy (ROPS). Experts will organize networking meetings and trainings, as well as meetings where social policy makers will be presented with the conclusions of the innovation. The project partners will also meet several times to jointly evaluate the course of innovation's testing and learn about the results of the innovation research.

The task will result in recommendations (months 35-36) on how to care for chronically ill and terminally ill people in their homes, presented to decision-makers at regional (meetings organized by ROPS) and national level. They will include assumptions about the necessary system reforms, the construction of long-term care and care for terminally ill people, dependents and their carers - in their homes, in the countryside.

The task will be carried out, documented and disseminated in such a way as to provide models and tools for future planning and monitoring of long-term care policy, as well as support for carers of the dependent, terminally ill and chronically ill people in their homes.

The project administration will be carried out by Specialists from the NGO's Support Center (OWOP) - they will fulfill the reporting obligations and do the accounting of the project. Guiding these tasks through this unit will enable innovators and researchers to focus on the task at hand, leaving this part of the project work to an experienced partner.

A detailed action plan is available in the Application form, however the schedule plan has been prepared by numbered months, the total number of which will be 36. The specific day dates have been adjusted to the plan due to the design of the application form (date selection cells from the calendar) and they are set indicatively.

4. Chapter three.

Here we tell you what **goals** we want to achieve.

Our proposed method of caring for terminally ill, dependent and dying people in rural areas will significantly improve the availability, quality of care and the quality of life of chronically ill and terminally ill people and their caregivers, as well as the quality of life at its end and the quality of dying[6] in the countryside. We also want to create jobs that bring tangible benefits to our proteges, and give our team members joy, satisfaction and a sense of meaning in their work.
The goals are described in detail in the Application form, below are a number of goals (some of them are "soft" goals) that we expect to achieve by implementing goal No. (1):

(1.) testing and careful development of proposals for an innovative approach to the provision of long-term care for the elderly and dependent, chronically ill and terminally ill, in rural areas,
(2.) improving the availability of specialist help from a team of professionals operating on the network for chronically ill and terminally ill people, dependent and dying people and their caregivers in rural areas (free aid for beneficiaries),

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[6] The terms Quality of Life (QoL), Quality of Dying and Death (QoDD) have been known in medicine since the 1960s and 1970s.

(3.) improving the quality of life and quality of dying of these people,

(4.) providing respite support for home caregivers, often also elderly and sick people.

(5.) Constant evaluation and improvement of the quality of the services we provide, remembering that the caregiver at home of the sick person is also our beneficiary and also requires support.

(6.) Caring for the employee. Creation of jobs, building a team that brings satisfaction to people employed and involved in helping terminally ill people - the possibility of professional development, broadening and deepening the competences, as well as fair remuneration for the work performed. These are the factors that act against burnout, which they are particularly exposed to in this type of work. This innovation would not be successful without the active participation and involvement of the network members and people from informal groups. It will be an important issue to use local employee resources.

(7.) By acting locally, we want to have a global impact. This slogan is known from our previous initiatives, but here it seems particularly appropriate. We want to share the experience of this innovation. We talk about it in the media, on our website and in social media, as well as during scientific conferences and meetings to which we are invited or which we organize ourselves.

(8.) Creating a model that is sustainable, effective, replicable, and networking (scarce in rural areas) the resources that help at multiple levels - from neighborhood help and informal groups to public sector organizations and NGOs.

(9.) Lowering the costs of running day care and preventing additional costs resulting from the neglect or ineffective home care of the beneficiaries.

(10.) The use of a tested innovation, supported by reliable research of the project partners (IRWIR PAN, ROPS) to shape long-term care policy, care for the chronically ill and terminally ill, in the region, country, and Europe.

(11.) Creating an innovation that can be multiplied and successfully used in other parts of rural areas of Poland and Europe.

5. Chapter four.

Here we share our hopes regarding **benefits** from the innovation and mention our **fears** about it.

The largest group of our potential beneficiaries are patients with worsening disability (e.g. in the course of dementia, after stroke, patients with completed cancer treatment or patients who, due to their poor health condition, were not diagnosed or treated and eventually sent home). The old, lying person, without a proper care and rehabilitation, quite soon develops bedsores, and the immobilized person dies of pneumonia or generalized infection originating in poorly supplied or untreated bedsores. **Benefits** from the innovation we implement will be felt by:

- chronically ill and terminally ill people who will be able to stay in their homes for the rest of their lives,
- their home carers, often old and sick themselves,
- network employees - professionals with a sense of the meaning of their work, developing professionally, caring for their own development and protected against professional burnout,
- other people and institutions who, having familiarized themselves with the proposed model of care, would wish
- to implement it in a place where they work for the benefit of the chronically ill and terminally ill people who stay in their homes,
- the state budget, which will save funds spent on unnecessary hospitalizations and escalation of unnecessary treatment activities that can be prevented.

Of course, we have **concerns** about implementing the innovation. We ask:

- How will the cooperation with the community providing medical care and social support in the region develop? What will their fears be about the new services offered to them? Will they be willing to enter into the innovation and go beyond the well-known and proven comfort zone in which they have been safely staying so far?
- How will the team relationships be going? Will people used to working in highly hierarchical healthcare structures be able to join a team of people with diverse, complementary and equally important competences from the point of view of the patient's well-being?
- How will the recruitment process and the search for a person with the expectable education, competences and professional experience (KOOZ, dietitian, carer etc.) look like in the areas inhabited mainly by seniors-farmers? Their children, if educated, look for a job in big cities and decide to move out and live there.
- Will we not meet with resistance from the potential beneficiaries? The mentality of the people in rural areas, where we test the innovation, is very concerned with the opinion "what will the neighbors say that I cannot cope on my own"? - the trust we have gained over the years allows us to hope that we have already mastered this challenge - the group of people who think like that will be smaller and smaller.
- How will we obtain funds for further financing of this type of care after the end of testing the innovation? The National Health Fund (NFZ) does not finance some diseases, including those which, according to the staff of the rural hospice, qualify the patient for home hospice care. As a result, an institution like ours, which wants to admit all the patients it can help and plans to introduce a flexible model of care, faces a serious challenge of finding additional financial resources, which may be quite difficult, especially in the case of a rural hospice, run in sparsely populated and poor areas.

6. Chapter five - the last one,

i.e. a few words at the end

A provision of the long-term, palliative and hospice care has overlapped, changed and adapted to the times and needs of those times. Hence we, as the successors of this tradition, have the courage to state that even today the methods of the institutional support for the chronically ill and terminally ill are not a reality that has been shaped definitively and forever. They can and should change and really respond to the needs of terminally ill, dependent and dying people.

In addition to consenting to the existence of institutions and public units, in which the possibilities of an action are regulated and in some way limited by rigid regulations, it is also necessary to allow those hospices that still cultivate the tradition of helping the elderly, dependent, regardless of whether the code of the disease qualifies them for the care financed from public funds. Institutions operating where these people will not receive other help - due to the ineffective system, the fragility of specialist staff, long distances or the poverty of people who need help. Having pre-tested our innovation, we want to share its effect, like a prescription, with others. Maybe this is not the only way, not the only remedy for the problems of people in the group we care for. We know that our method will not work when used alone, taken out of the social context, without the involvement of institutions and local communities. Together with a group of Innovation Partners, we will provide the necessary research to make them willing to engage in these activities with full conviction.

There are several arguments for the implementation of testing such a model of rural hospice functioning. We strongly believe that:

1. It will satisfy the real health needs of this group of rural residents.
2. It will enable flexible response to the needs of the beneficiaries.

3. It will offer a professional "service" of high quality, tailored to the needs of the beneficiaries.
4. We are convinced that it rationalizes (reduces) the costs of care.
5. It shows the real effectiveness of provided care.
6. It will allow to avoid artificial contracts, satisfying only institutions and officials, and operating only "on paper".
7. It will be able to be multiplied, duplicated and in the future it can serve other units/organizations operating in rural areas with similar health needs.

This model is an implementation of an approach that should underpin the philosophy of joint action of social support and health care. It combines these two areas, enabling a holistic approach to the patients. At the same time, it implements the principle of supporting dependent people in their local community and avoiding placing them in social welfare homes or in stationary hospices as long as possible.

Together with other partners, we are ready to devote our time and energy, our knowledge and experience to participating in the project to which we apply. We can see that these actions are purposeful, make sense and may result in the creation of beneficial solutions for an increasing group of citizens - seniors and the elderly living in rural areas of Poland and Europe.

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