

Regional non-profit organisation (NPO) "Diabetic care"

Burgas, Bulgaria

Verena Struckmann, Francesco Barbabella, Antoniya Dimova, Ewout van Ginneken

Currently, an estimated 50 million people in the European Union live with multiple chronic diseases (multimorbidity) and this number is expected to further increase in the near future. As multimorbidity deeply impacts on people's quality of life -physically, but also mentally and socially-, there is a growing demand for multidisciplinary care that is tailored to the specific health and social needs of these people. Integrated care programmes have the potential to adequately respond to the comprehensive needs of people with multimorbidity by taking a holistic approach while making efficient use of resources. Such programmes are characterized by providing patient centred, proactive and coordinated multidisciplinary care, using new technologies to support patients' self-management and improve collaboration between caregivers.

In order to inform policymakers, managers and professionals working in health and social care as well as patients' and informal carers' representatives throughout Europe about promising initiatives providing integrated care for people with multimorbidity, a series of case reports describing these initiatives was written as part of the ICARE4EU project (see Colophon). This case report describes an innovative approach to providing integrated care for people with multimorbidity in Bulgaria.



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Summary of the 'Diabetic care' NPO The Bulgarian 'Diabetic care' NPO, founded in 1994 is situated in Burgas. It provides a comprehensive regional care programme primarily focussing on the problems of people with diabetes and their co-morbidities. The programme started in 1993 and is primarily targeted at patients with diabetes and their family members, but also at the entire population of Burgas, regardless of age and insurance status. The NPO provides comprehensive care for approximately 1,600 (mainly diabetic) patients per year. The NPO has around 380 members and everybody works on voluntary basis, without any financial remuneration. The guiding aim of the NPO is to provide access to care for patients with diabetes and other accompanying chronic diseases, irrespective of their level of frailty, age or insurance status. The programme addresses prevention, self-management, cooperation and gate keeping issues. The financing of the NPO's daily work is based on donations, member's contribution fees and a small annual contribution by the local government.

• The programme is continuously extending its scope and network. The approach is already transferred to other regions close to Burgas, with which active collaborations have been established.

1. Care for people with multimorbidity in Bulgaria

In 2014, 15.1% of the Bulgarian population (7.28 million in 2013) were aged 65 years and older, and 4.4% were 80 years and older (1). Of the population aged 16 to 64 years, an estimated 10.8% had at least one (self-reported) long-standing illness or health problem in 2013 (2). Of the population aged 65 and older 2.469 people per 100.000 are killed by cerebrovascular and ischemic heart diseases and 28% reported to have a bad or very bad self-perceived health status (3, 4).

Moreover, recent changes in life style, influenced by social and economic changes occurring after the post-communist era, have led to increasing numbers of patients with multiple chronic diseases in Bulgaria. These patients require care that is better coordinated across different providers and sectors. Health care reforms in Bulgaria have only recently started to address this challenge. A national program aiming to prevent chronic non-communicable diseases by reducing premature mortality, morbidity and the consequences for health of several chronic diseases has been implemented in 2014 (5). Besides, the Ministry of Health introduced awareness campaigns and prevention activities aiming at the most common chronic diseases. Hitherto there are no policies specifically addressing multimorbidity. The overall system for managing chronic conditions and multimorbidity in Bulgaria is fragmented since different healthcare providers work independently from each other and do not have common responsibilities in managing care.

2. Introduction to the NPO 'Diabetic care'

Founders

The local NPO ('Diabetes has no limits') was initiated in 1993 for public and social purposes, by a team consisting of a nurse, a cardiologist, a general practitioner (GP), an ophthalmologist and four persons suffering from diabetes. After having jointly initiated the NPO, they started educating people with diabetes from a clinical point of view. In 2001 the name was changed into 'Diabetic Care' and the range of services provided gradually extended. Their working model is already implemented in an adapted form in another region close to Burgas.

Aim

The overall aim of the programme is to improve the quality of life of people with diabetes, to increase their self-management capacities and to support their integration into society in the long term. Moreover, the NPO aims to empower patients, to protect patient's rights by means of assistance, education, information and counselling. The NPO acts as a 'hub' of care management and mediator between different professionals, institutions and across sectors. Access to their services is free of charge for all patients, irrespective of their insurance or socio-economic status.

Key features

The NPO is the only institution in Burgas offering affordable and easily accessible care for patients with diabetes, as well as possible co-morbidities and other chronic conditions. With their integrated care approach they enable comprehensive care across health service sectors and access to social services. All patients receive access to care and education opportunities, irrespective of (a) the severity of their chronic disease(s), (b) insurance and socio-economic status, (c) age and care needs.

Target group

The programme addresses patients with diabetes in the Burgas area, possibly suffering from additional chronic diseases (e.g. cardiovascular diseases, cancer, and depression). Patients with multimorbidity are increasingly visiting the NPO because other disease-related organisations in the area do not offer such comprehensive care. Generally, persons using the services provided by the NPO have a low social status, no insurance and a high morbidity rate. Every patient can opt for a free treatment at the NPO; they do not have to be permanent members. Most patients are treated over a longer time and are encouraged to be actively involved in their treatment processes, not only in terms of receiving care but also in terms of being volunteers helping others.

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Services provided

The NPO coordinates care for patients and supports access to appropriate specialised care by providing direct basic, primary care and help navigating across the different health care professionals for secondary care. Care services are provided both at the headquarters of the NPO in Burgas and at home (if the patient is not able to reach the facility). The rationale is that care becomes more efficient if unnecessary physician and nurse visits are avoided through directly accessible primary care provision and improved care coordination. All persons working for the NPO do so voluntarily and are chronically ill (diabetes) themselves. Although patients with multimorbidity are not the exclusive target group of the NPO, their numbers are increasing. Activities offered include:

Self-management

The NPO emphasises the self-management skills of their diabetes, cardiovascular or multimorbid patients. Volunteers train patients in improving their coping skills and the organisation of their daily life and include relatives in the care process. They are encouraged to take more responsibility in their health matters. Patients are provided with a 'patient passport', which includes all care received by NPO and other health facilities, and a 'care diary', a personal journal to be used at home for periodically monitoring vital signs (e.g., blood pressure).

Directly accessible primary care

The NPO acts *de facto* as a diabetes primary care centre offering basic assistance to patients in terms of measuring blood pressure and sugar level; wound care; rehabilitation and group exercises; as well as health promotion and prevention activity. The volunteers of the NPO are trained by physicians and nurses to provide basic care tasks to patients. Thanks to the involvement of volunteering GPs and nurses (from the hospital and retired nurses), home care can be provided as well if the patient is not able to visit NPO. All received care is recorded in the 'patient passport' which is a paper version of a clinical record.

Specialised care, cooperation and gate keeping

The NPO cooperates with the Cardio Centre Pontika private hospital (6) in Burgas in providing secondary care without charging fees to patients. A volunteer of the NPO arranges an appointment with the Cardiology unit. The examination includes a check of drug prescriptions with the aim to reduce or adapt the therapy, blood pressure measurement and an ECG. In many cases, volunteers of the NPO or a relative attend the consultation at the hospital in order to provide feedback to the patients or further explain the treatment plan. The NPO is cooperating also with other health related organisations (e.g., for people with cancer, physical disabilities,

deaf or blind people) thereby optimising care coordination. Depending on the severity of the disease and the needs of the patients, social care or emergency care are also arranged.

Awareness campaigns

In order to prevent the development of multiple chronic diseases already at a younger age, the NPO and the Cardio Centre Pontika offer a jointly developed information programme. Several times per year, they target their health promotion activities at students in primary and secondary schools. In particular, this health promotion activity is performed by the younger volunteers, since they are closer to the target audience. Adults, on the other hand, are targeted with regular education programmes in the community to enable informed and responsible choices about their personal health. Risk factors for chronic diseases are explained, their blood pressure and sugar is measured and they receive dietary advices.

3. Patient-centredness

Elements

The NPO realises a patient-centred approach by means of the following elements:

- involving patients in their treatment, treatment goals are explained and transparent, patients are fully informed about their disease(s) and the related treatment;
- Enhancing patient self-management and shared decision-making by volunteers who are chronically ill themselves;
- Offering different care options if possible;
- Involving patients and their relatives in the entire care process;
- Involving patients in the implementation and improvement of the programme (sharing experiences, receiving and giving support etc.);
- Designing patient motivation strategies, including social activities and community building.

Patient-centred care processes and patient empowerment

Volunteers working at the NPO are trained by physicians and nurses for half a year according to continuing education programmes provided by the World Health Organization (WHO) (7). They are trained in caring for patients with diabetes and other chronic problems (e.g. cardiovascular diseases), in supporting patient self-management and shared decision-making. When a patient visits the NPO for the first time, a comprehensive check-up follows from a trained volunteer.

If they are not able to care for the patient's needs, an appointment with a GP or a specialist is arranged. Based on the completion of a patient questionnaire regarding their general health situation, further treatment goals are set. Volunteers teach the patients and often also their relatives how to adapt their daily lives to their chronic disease(s). As the volunteers have a chronic disease themselves, they can not only provide patients with expert and practical knowledge but also relate better to them through their own daily experiences. Information provided is tailored to the patient's needs, in written or oral form, including booklets developed by the NPO, dietary self-control protocols, dietary information and information regarding further treatment options. Volunteers take pictures during the care process, to keep patients motivated and to enhance their compliance by visualising their care progress. The patients are empowered to take care for their own health and to pursue their prioritized, but realistic health goals.

Patient-centredness is also supported by frequent contacts between patients and volunteers, and the good availability of the latter compared to regular care, since patients can visit the NPO headquarters seven days per week, from 7 a.m. until midnight. Depending on the patient's needs, they visit the NPO up to three times per day. Their care process is continuously monitored, either at the NPO or during home visits. Home visits are conducted for all patients living in rural and remote areas who have no opportunity to drive to the NPO or whose health status does not allow travelling. If patients succeed to live longer than the national statistical average with their chronic disease they receive a certificate to motivate them to continue with this health life style etc.

Activities at the NPO

The care services offered at the NPO and the collaborating hospital have been continuously developed since the beginning of the programme in 1993 (Box 1.)

Box 1. Key activities of the NPO, 1993-2015

- Diabetes mellitus type II management
- Cancer management in collaboration with other NPO's
- Lifestyle intervention for patients with Diabetes and cardiovascular diseases
- Patients and family members education and consultations
- Mediation regarding social integration of patients
- Home and office based health services
- Diabetic foot management and care
- Active health promotion for patients and health education for students and the elderly
- Intervention by psychotherapists/psychiatrists in case of acute personal crisis
- Coronary heart disease management in collaboration with the Cardio Centre Pontika
- Regional and international conferences and networking
- High blood sugar screening programs
- Social enterprises "Diabetic foot" and "Diabetic care"

Volunteers and patients are actively involved in the development and assessment of the programme. Volunteers' experiences show that patients treated at the NPO had higher compliance and better health outcomes compared to patients treated in regular care. Due to the NPO's activities patients have been able to realise a healthier lifestyle and to manage and care for wounds adequately. Public prevention and education programmes about self-care and for instance treating a diabetic foot are absent in Bulgaria. The prevention of highly specialised and costly procedures such as amputations related to a diabetic foot is not part of any national strategy. The peer relationship between volunteers and patients seem to positively influence health outcomes. Moreover it produces a virtuous cycle of self-promotion of the NPO's work.

4. Integration, management, competencies

Partners and their role in the programme

The role of the volunteers participating in the daily work of the NPO can be best described as a mixture of social assistance, nursing, community health work and case management. 380 members of the NPO (including approximately 25 trained social assistants¹) and over 20 specialists, psychologists, nurses and other care providers in the community) participate in the NPO's activities to improve the quality of life of around 1,600 patients, to empower them and to educate them. Some of these members are volunteers and actively participate in the daily work of the NPO. All members are chronically ill, thus they make use of the services provided for them, too. Others, e.g. relatives of chronically ill, support the work in form of regular donations in kind and monetary donations.

In addition to usual health care providers also community groups, associations and self-help groups are involved, such as education centres, the so-called 'blue circle of hope' (see Box 2) and other disease-related NPOs (8).

Box 2. Blue circle of hope

The "Blue circle of hope", a partnership network, started in 2011. It was initiated by the Diabetic Care NPO and involves several other diabetic organizations from different countries. In the beginning their cooperation included 10 organisations from Bulgaria. Over time the number of partner organisations continuously grew and different countries joint, such as Serbia, Turkey, Russia, Ukraine and Italy. Each organisation signed an agreement for cooperation. Regular meetings are organised to share their daily experiences and scientific information about diabetes and treatment options. The NPO devotes much effort to the further development of the network and the idea is to extend the Blue circle of hope to a Balkan center of Diabetic care. The intention is to establish public funding for diabetic care across borders in order to support each other financially, but also to stimulate the development of additional projects, journals about Diabetes and scientific research.

¹ Social assistants provide home care to people with disabilities. They are trained to work with people with disabilities in a program approved by the Ministry of Labour and Social Policy. It is financed by the national program "Assistants to people with disabilities" (run by the Employment Agency of the Ministry of Labour and Social Policy). The program aims to assure work for unemployed people.

Since health promotion is a key instrument in preventing especially multiple chronic diseases and raising people's awareness, relevant activities and programmes are offered to schools, workplaces and unemployed people. Prevention activities offered at schools are performed by younger volunteers affected by a chronic disease in order to better reach the target group. The NPO is responsible for the coordination of all volunteers and other providers participating in the network. Participating volunteers play a key role in the patients' care process, as patients often prefer treatment provided by them, instead of physicians. They are responsible for an initial health assessment and care coordination, since patients most often first visit the NPO. In contrast to the usual situation in Bulgaria, an equal relationship, based on mutual respect and learning between the patient and the volunteer providing the care is an essential element of the NPO's work. Usually there is an increased trust among patients and the volunteers, compared to the patient-doctor relationship.

Home care is provided for patients living in rural areas and, if required, social assistance particularly with respect to daily activities is offered too. During in-patient care nurses from the hospital are involved, but the role of nurses in not only limited to this episode of care. Some of the volunteers working at the NPO are retired nurses and they also conduct home visits. Besides, two nurses working as volunteers are specialised in providing care for oncological diseases and for haemodialysis patients. They are involved in the care for patients in need for specialised nursing services.

Besides the activities made available directly at the NPO, the hospital and the remaining cooperating organisations in Burgas, the NPO is cooperating in a network of health care providers involved in the care for patients with diabetes. Four conferences are organised on annual basis to exchange information, experiences, methodology and latest scientific results regarding the prevention and cure of diabetes.

Coordination of care

Access to care for all patients, the promotion of collaboration and comprehensive care are major activities of the NPO. Much effort is devoted to the further development of coordination and cooperation among providers and facilities in a very fragmented health care system, particularly between the ambulatory and hospital sector.

The fragmentation of service delivery, a key concern in several European health care systems, is also impeding coordinated care provision in Bulgaria. Health service delivery by the NPO differs from usual care, as it facilitates the exchange of information between patients, volunteers GPs, medical specialists and the hospital. Paper records of care, examinations and results are kept by both the NPO (main registers of patients) and the single patient (through the 'patient passport' and the 'care journal'). In particular, the 'patient passport' includes information on diagnosis, therapy,

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hospitalisation, visits to NPO and specialists, medications, weight and other vital parameter records for continuous monitoring (see Fig. 1). These documents can be accessed by health professionals in hospitals or community centres, although not everybody in the health sector is in favour of this selfmanagement of clinical records. To improve the patient's motivation and to increase their compliance, chronically ill volunteers coordinate the care process and cooperate with the patient's relatives and other required health care professionals. Besides, the partnership with the Cardio Centre Pontika allows the programme to coordinate post-discharge care to reduce readmission rates. Vice versa, physicians either working in ambulatory care or in the hospital send patients with diabetes to the NPO (as its activities are well known in the area). Physicians from the Cardiology unit at the Cardio Centre Pontika and NPO volunteers perform free examinations for all patients and they also make home visits for those in remote areas.

Figure 1.Continuous control circle



Jointly developed care pathways, agreed between hospitals and the NPO, are other facilitators of better coordinated follow-up care. Establishing links between participating providers and health care facilities is a priority for the NPO, thus their network has been continuously enlarged. The NPO aims to facilitate and foster interdisciplinary networking by exchanging information between the volunteers, the hospital and the remaining participating care providers. Within their network meetings with the health care providers involved in the care for patients with diabetes potential improvement of the programme are discussed.

Figure 2. The network of providers



5. Financing of the NPO

Sources of funding

The financing of the NPO's daily work and the payment of their volunteers is rather unique. On a yearly basis the NPO receives funding from the local government (municipality of Burgas). However, this budget is not secure, since the NPO has to apply for it on a yearly basis and the overall sum can vary (latest funds were around 2,000 Euros). The amount they receive is independent of their activities, the overall health benefit of the population or achieved savings. Half of this budget is invested in the rent of the building, actually owned by the municipality itself, and the other is spent on blood sugar tests, which are quite expensive. Moreover, the 380 members of the NPO pay an annual contribution of 5 Euro per person, constituting indeed their only fixed income. Other funding sources include private donations. These have however decreased during the last years, mostly due to the effects of the economic crisis and changes in the legislation. The latter makes donations less attractive, as a tax deduction for donated money has been abolished. Some of the NPO. Overall, the budget is insufficient for carrying out all activities needed by members and patients accessing the NPO services.

The NPO does not earn any surplus or bonus and providers do not receive any reimbursement or additional payment for their work. Their additional time spent with the patients of the NPO and their participation in further activities offered is not refunded. For the patients treated at the NPO or from participating providers, all interventions and activities are available free of charge.

Realised savings and sustainability

The overall aim of the NPO is to improve the lives of people with multiple chronic diseases in their community; they do not pursue any economic interests. Although direct cost savings were not the aim of the project, indirect cost savings were expected due to the development of a more efficient care delivery process. One of the interesting outcomes in this respect, according to internal evaluations, was a reduction in hospital admissions and amputations due to the holistic and proactive approach applied by the NPO. Internal evaluations state that NPO activities since 2010 helped to prevent over 400 amputations in most complicated diabetes cases. The cost savings for local care providers amounted to about 1,2 million BGN (more than 600 000 Euros). Savings are calculated using the price paid to hospitals by the National Insurance Fund per amputation, per price of device (e.g. wheelchair) and per payment for a social assistant. Data regarding the prevention of amputation is based on the patient records. Moreover, inefficiencies of the fragmented health care system are reduced, primarily due to the coordinating activities of the NPO. This means the NPO's work has the potential to reduce overall costs for the health care system in a medium- and long-term. Although the project was not externally evaluated, the members of the NPO do not doubt that their programme is saving costs.

6. Conclusions and observations

6.1 Innovative aspects

Paradigm shift

The care offered by the NPO is a positive and particular exception among other programmes in Bulgaria due to its freely accessible care, its holistic approach and its orientation on the improvement of the quality of life of their patients. Instead of charging fees for their services, the NPO focuses on empowering their patients and producing better health outcomes. Care is offered free-of-charge and targets the most vulnerable population groups, such as those facing social and economic deprivation. So far, internal evaluation has shown that the activities of the NPO and their cooperating institutions have resulted in better health outcomes compared to usual care. Patients are more satisfied with the care provided at the NPO than with usual formal care services, as with the latter there are problems with respect to coverage, intensity and quality. Particular for this success is their guiding principle: equality and empowerment. They have created new professional roles by training volunteers and a mutual learning approach. This has changed the relationship among patients and care providers resulting in higher trust, respect and improved patient satisfaction. Access barriers are also reduced, as every patient is treated equally and access to care is free of charge.

Network

It took years to establish a network that enables comprehensive and patient-centred care. As a result, the NPO coordinates its activities with those of other institutions in their network. They have constantly extended the scope of their health care interventions and always adapted to changes in their circumstances (e.g., changes in the level of funding).

As the NPO is often the first point of contact for patients in need for care, they act as gatekeepers for many. This means that unnecessary interventions are avoided and that patients benefit from improved care coordination. Moreover, the NPO has improved patient-centredness by supporting patients and their relatives, establishing effective collaborations, and securing the commitment of the volunteers and their closeness to the patients.

Uniqueness

The work of the NPO is unique and innovative, as they are the only institution in the Bulgarian health care system providing comprehensive diabetic care and care for people with multimorbidity at such levels of intensity, coordination and community building.

6.2 Challenges

E-Health

A challenge for future implementation of the programme is the inclusion of electronic systems in the care process, for instance as supporting tools for storing patient records and enabling communication within the NPO. So far, patient records are paper-based and the exchange of information between volunteers, physicians, specialists, hospitals and other participating providers is conducted via the telephone, written documents or face to face conversations. The NPO does not have a website yet: the NPO promotes itself through periodical appearances in local TV and radio shows, as well as articles published in newspapers. The communication between the doctor practices and patients rely heavily on the telephone. E-health tools are not used since the implementation of such an infrastructure is not affordable. Moreover, the acceptance of e-health differs between the type of volunteers working at the NPO, especially depending on their age group.

The NPO could benefit much more from low-cost e-health applications such as mobile technology. Major obstacles in this respect are the relatively poor internet infrastructure in the remote areas of Burgas and the lack of money to invest in this respect.

Financial system

Funding is an issue and the NPO has difficulties to do any medium or long-term financial planning. Funds from the local government vary year by year but could perhaps be optimised through a system

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that combines a guaranteed fixed sum per year with incentives to reward those organisations producing real health cost savings. These have to be recognised by policy makers and awarded accordingly. More financial stability should be assured so that e.g. NPO's are not depending only on contributions by volunteers and donations. In that sense, if the cost-saving potential could also be proven through external evaluations, the Bulgarian health system could consider funding such initiatives as part of the formal care system.

Transferability

Another issue is the programmes transferability to other regions in Bulgaria and to what extent it could serve as a good practice for other countries. The engagement of the head of the NPO and its members is unique and serves as a strong basis. However, the possibility of replicating an experience highly depends on the motivation, devotion and persistence that members have. This arguably relies more on individual attitude and personal factors. A national rollout of the NPO's approach might be easier if external conditions are favourable. Examples include strong leadership, secure and stable funding sources, a supportive policy context, awareness of policy makers and a positive attitude among local care providers. That said, the fact that the NPO's approach is already applied in 12 municipalities in the Burgas region and also throughout Bulgaria (the 'blue circle of hope') already provides real evidence of the feasibility of transferring this model – at least in Bulgaria.

Attitude

The NPO is supported in all their activities by various health professionals (specialists, GPs, nurses) who dedicate part of their time in volunteering for the organisation's purposes. However, they only constitute a small proportion of care providers in the local area. The majority of health care professionals are still reluctant to collaborate with the NPO because they have a more traditional view on the patient-physician relationship. The concepts of self-care, peer support and health promotion are not at the core of their daily practice and thinking. A cultural change has to develop over time on a national level that is supportive for initiatives such as the 'Diabetes care' NPO if these programs are to be scaled up on a national level.

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Colophon The ICARE4EU project and the selection of 'high potential' programmes

The ICARE4EU project aims to identify, describe, and analyse innovative integrated care practices for people with multimorbidity in European countries, and to disseminate knowledge and experiences from these practices to all European countries in order to support further implementation of effective and sustainable care approaches for European citizens with multimorbidity (www.icare4eu.org).

Multimorbidity is defined in this project as the presence of two or more medically (somatic or psychiatric) diagnosed chronic (not fully curable) or long lasting (at least six months) diseases, of which at least one is of a primarily somatic nature.

In 2014, country experts in 31 European countries identified programmes at a national, regional or local level that focus(ed) on providing care for adult (or older) people with multimorbidity, or contain(ed) specific elements for this target group. Programmes had to comprise a formalized cooperation between two or more services, of which at least one medical service; and they had to be evaluated - or had an evaluation planned - in some way. Detailed information about these programmes was collected via a survey to be completed by the programme coordinator. In this way, country experts identified 178 programmes, of which 101 (from 24 countries) were considered eligible for analysis by the project team.

As a next step in the project, these 101 programmes were evaluated by the project team based on quantitative and qualitative criteria. For each programme, five quantitative scores were computed, a general score (assessing general aspects such as its evaluation design, perceived sustainability and transferability) and four scores that provided an indication of its level of 1) patient-centredness, 2) integration of care, 3) use of eHealth technologies and 4) its innovativeness in financing integrated care services. Subsequently, members of the project team qualitatively assessed these four aspects again for a selection of programmes that had high quantitative scores. The qualitative evaluation was based on the available descriptive information gathered by the survey (e.g. description of the aims of the programme, the reported strengths and weaknesses) and already published evaluation reports. This resulted in a short list of so called 'high potential' programmes. To decide whether or not to select a programme of this list for further study, the project team checked with the country expert and/or verified information by contacting the programme coordinator. In this way, eight programmes were selected for a site visit; all programmes positively responded. The eight programmes that were visited were operational in Belgium, Bulgaria, Cyprus, Denmark, Germany, Finland, the Netherlands and Spain.

This case report is based on information about the 'Diabetic care NPO'. For this case report, the previously collected survey data were verified and enriched by data from internal (e.g., presentations) or external documents and qualitative interviews with the programme manager, a researcher, a social assistant, a cardiologist and a volunteer. The interviews were conducted by two members of the ICARE4EU project team, and were recorded. Interviewees received the draft text of the case report for validation, and approved the final report. All interviewees signed a written agreement to publish this case report.

Appendix 1 Some characteristics of the health care system in Bulgaria

Health care

In Bulgaria, public health services are provided by the state and organized and supervised by the Ministry of Health. Public Health activities and programmes are implemented by ministry's local branches, 28 Regional Health Inspections and by several national centres. The public health network also includes non-governmental (NGOs) and non-profit organizations (NPOs) such as associations of patients with chronic diseases (9).

The Bulgarian health insurance system is based on two pillars: social health insurance (SHI) and voluntary health insurance (VHI). The National Health Insurance Fund (NHIF), established in 1998, manages the SHI system, as a single payer. It guarantees a basic benefit package for the insured population. However, in 2011, 23% of the population was not covered by any insurance and in need of social assistance but not entitled to it. The NHIF yearly negotiates prices, services, rights and obligations with the professional associations of physicians and dentists, before signing the National Framework Contract (NFC). All private or public healthcare providers, meeting the NFC criteria and operating in a territory, sign individual contracts with a Regional Health Insurance Fund (RHIF) (9, 10). Primary health care is provided by GPs, who act as gatekeepers for specialized ambulatory and hospital care. The number of GPs has been steadily declining in the past years and their geographical distribution does not reflect the needs of the population. The state owns all university hospitals, specialised hospitals, psychiatric hospitals as well as 51% of the capital of the regional hospitals; the private sector only encompasses some of the hospitals. As the health care system is economically unstable, health care establishments suffer from underfunding, particularly hospitals (9). Bulgaria's public expenditure on health decreased to 57.8% in 2008, which is far below the average of EU-27 (76.6%), but comparable to the average of the CIS countries (58.8%). Private expenditures on health increased, since the introduction of the SHI system from 26.7% in 1995 to 42.6% in 2008. Private expenditure is a main source of revenue for the health care system and it is second highest in EU-27 after Cyprus (50.2%) (11).

Social care, long-term care and home care for the elderly

Long term-care is provided either in institutions (residential care) or communities (home care). Hospitals, medico-social care centres and residential homes provide residential long term and social care for chronically ill, physically or mentally disabled people. They are owned by the state, municipalities or private organisations. The quality of care varies and is highly dependent on ownership and financing type. Home care for elderly people is organized by the municipal social assistance services. Home care (including social, medico-social and medical services) is delivered by contractors or private providers and provided to people with physical disabilities. State funded services are financed by the Ministry of Health, Ministry of Labour and Social Policy, other services are reimbursed by the municipalities. In some cases, the services must be paid by the patient's family. The SHI does not cover long term nursing care and long-term care for elderly people (9) The provision of services for elderly people and people with physical and mental disabilities living at home is underdeveloped and the burden of care and costs remains largely on family members and relatives. The problem is however, that long-term and social care is insufficient in quantity and scope of service, ineffective in distribution and lacking real alternatives to residential care (9, 12).

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