

JA-CHRODIS Work Package 7

Diabetes: a case study on strengthening health care for people with chronic diseases

Guide for National Diabetes Plans

Lessons learnt from National Diabetes Plans to support development and
implementation of national plans for chronic diseases



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Introduction

This document aims to inspire those readers, who see that the situation in healthcare could be improved and who are willing to take a part in the change, for example policy makers, healthcare institutions, patients and their associations, healthcare professionals and their associations. It could also be used for example as a background material for leading workshops at critical moments when strengthening of the implementation or the sustainability of existing plans is needed, or when new plans are under development and the major challenge is seen in how a written plan should result in actual implementation.

The document arises from the expertise of partners of work package of Joint Action CHRODIS that was focused on diabetes to serve as a model disease to study the concepts and approaches to strengthen health care for people with chronic diseases. Two workshops, one with partners of this work package and the other with representatives of Member States Ministries of Health, were also conducted in order to get different views, perspectives and inputs.

This Guide is a companion to other published results of our work package that should be also consulted and used. The “Policy Brief - National Diabetes Plans in Europe. What lessons are there for the prevention and control of chronic diseases in Europe?” (available at <http://emsa-europe.eu/ja-chrodis-policy-brief-on-national-diabetes-plans/>) identifies a range of factors that appear to facilitate the development, implementation, and sustainability of national diabetes plans, that served as a case to study this topic. “Recommendations to improve early detection, preventive interventions, and the quality of care for people with diabetes” (available at <http://www.chrodis.eu/outcomes-results/>) are among others defining the set of criteria, that should be taken in consideration when improving prevention and care of chronic diseases, such as design of the practice, promotion the empowerment of the target population, definition of an evaluation and monitoring plan, comprehensiveness of the practice, inclusion of education and training, ethical considerations, governance approach, interaction with regular and relevant systems, and sustainability and scalability. “SWOT analysis. Overview of national or sub national policies and programs on prevention and management of diabetes” (available at <http://www.chrodis.eu/our-work/07-type-2-diabetes/wp07-activities/overview/>) gives a qualitative overview of the current policies and programs on prevention and care of diabetes, including successful strategies, what makes a policy/program applicable, sustainable, and effective from a public health and from the stakeholders’ perspectives, what are the necessary preconditions for its implementation and what are the lessons learnt from the experience. It also provides a background perspective of the setting where good practices are developed.

Chapter one of this document addresses basic contents of any National Diabetes Plan, and should be complemented with the reading of Box 1 that contains the recommendation of the International Diabetes Federation. Chapter 2 and 3 discuss leadership through two complementary points of view: a top-down process, and a bottom-up movement. Chapter four addresses the basics for building the necessary links and coordination across organisation and institutional boundaries. Chapter five explores how the Plan organisational design and structure may support all three types of leadership that aim at implementation and sustainability of the Plan.



1. Topics and processes, that should be addressed in National Plans

Diabetes is here used only as a model disease to study the concepts and approaches to strengthen health care for people with chronic diseases. Topics can be easily generalised to other chronic diseases, or to a national plan that covers broader chronic disease framework. Please, consult also Box 1 on development, implementation and evaluation of the National plan.

A National Diabetes Plan (NDP) makes a clear case advocating for diabetes prevention and care.

The NDP addresses environmental interventions aimed at reducing and minimising risk factors for diabetes, including healthy urbanisation, healthy food, healthy business, healthy public policy, healthy schools at all educational levels, and cross-sectoral coordination. Since major risks are shared among most common chronic diseases, this focus may be covered in a national chronic disease prevention plan.

The NDP should involve a community awareness campaign.

The NDP includes approaches to identify high-risk individuals/groups and interventions aimed at reducing and minimising risk among these. There are strategies to identify high-risk individuals, to prevent/delay diabetes among high-risk individuals, to identify high-risk community groups, to prevent/delay diabetes in high-risk community groups, to identify high-risk individuals/groups at workplaces and to prevent/delay diabetes at workplaces.

The NDP has a strategy for early diagnosis of type 2 diabetes.

Routine continuous care of diabetes (Type 2, Type 1 and gestational diabetes) is addressed in the NDP, including dietary modification, physical activity, complication screening at diagnosis, medications and medical devices, regular clinical management of multifactorial treatment (glycaemia, blood pressure, blood lipids) and for the early detection of diabetes complications, setting and disseminating standards of care, health care services, appropriately staffed and equipped, monitoring the processes and outcomes of care and self-care education. Adequate diabetes care during acute episodes and in in-patient facilities needs to be assured.

The NDP should address early detection and timely comprehensive care of the chronic complications of diabetes, in particular cardiovascular disease, eye damage, kidney damage, neuropathy (including lower limb amputation).

The NDP considers the role of patients, their carers and families and through education, ensures that they become empowered to care for their own health and wellbeing.

The NDP addresses the possible mental health burden of diabetes and ensures access to psychological and other therapies if needed.

The NDP aims to assure equality of access to routine care and education with particular emphasis on essential medicines and medical devices, and to diabetes research.

The NDP includes/supports the development and use of guidelines for diabetes care and prevention including: prevention at whole population level, prevention for children and adolescents, prevention before and during pregnancy, high-risk individuals/groups at whole population, high-risk individuals/groups for children and adolescents, high-risk pregnant women, type 1 for children and adolescents, type 2 for children and adolescents, gestational diabetes, type 1 for adults, type 2 for adults.

The NDP addresses the needs and perspectives of vulnerable population, such as ethnic minorities and those from a lower economic and social status. It also addresses gender issues.

Issues related to training and developing diabetes healthcare professionals and services are addressed in the NDP, including education on how to work in multidisciplinary teams and outside of traditional profession-specific silos.

The NDP includes strategies for meaningful diabetes-related data collection, sharing and use.

The NDP seeks linkages with other chronic disease plans, for overlaps, complementarity, human resource sharing and mutual outcomes.

Box 1: Development, implementation and evaluation of the National Plan

Development and endorsement of national plan

- Developed through extensive consultations with all relevant stakeholders – multi-sectoral planning, having carefully considered the situation analysis of the burden and health system capacity to respond, now and in the future
- Identifying who will carry out the above process, under whose authority?
- High level (political) commitment/endorsement (for the duration of plan – withstanding political changes)

Financial resources

- Allocated budget (ear-marked), ideally from multiple sources to reduce risk of shortfall
- Expenditure framework (for the duration of the plan)
- If not fully financed – plan for attracting funding, either as borrowing or other – in line with current economic conditions as well as growth of disease burden

Have priorities for spending if budget shortfall

- Procurement (medicines, medical devices, equipment, etc.) covered, including projections until the end of the plan, possibly beyond

Implementation and management

- Communication strategy to publicize the plan - to the public, political leaders, public health experts, etc.
- Lead agency, authority, organisation identified to oversee all aspects of plan implementation
- All implementing partners understand their role and responsibilities, in line with overall plan objectives and desired outcomes
- Ensuring adequate human resources for implementation – making available where required

Monitoring and Evaluation

- Indicators and targets set against goals and objectives
- Data collection takes place to serve purpose of evaluation as well as national data repository (if applicable)
- Regular reviews, periodical assessments to maintain track or to adjust services/intervention/resources towards aspects requiring further support
- Process of monitoring and evaluation woven into national plan
- Responsibilities assigned – independent evaluation
- Structured evaluation: process – outcome - impact

Link to other chronic disease plans

- Explored and identified possibilities to combine prevention measures, human resources, facilities, implementing actors
- Share financial resources and infrastructure, not compromising objectives and goals for any disease-specific approach

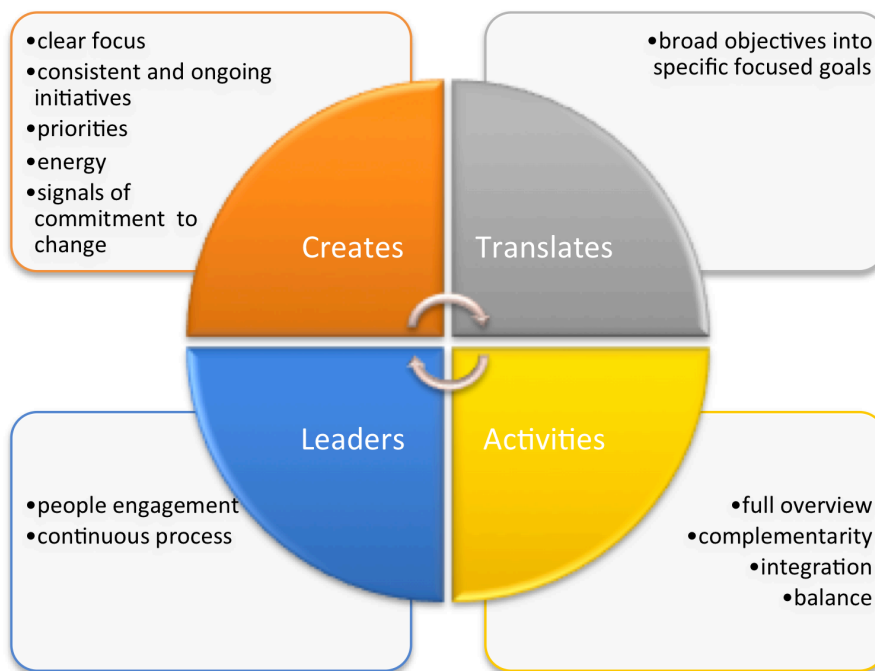
Source: International Diabetes Federation. A Guide to National Diabetes Programmes 2010. Available at <http://www.idf.org/publications/guide-national-diabetes-programmes>.

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2. Setting up the leadership: top-down leadership

Top-down leadership is needed. Successful leadership for change creates clear focus, and consistent, ongoing initiatives. Leadership clarifies priorities, creates energy and signals commitment to change. It translates the broad objectives into specific, focused goals. It has a full overview of the activities, assures their complementarity, integrates them and takes care of the balance. Leaders have the skills to define the goals in a way that engages people, and to do that continually.



As far as top-down leadership is concerned, whether the same person or persons (the scope of the Plan suggests perhaps the need for more than one) are sustained throughout the process, the Plan needs to proceed. A leader or leaders need allies on all levels, but owns the ability to engage and influence others to participate in the task.

Top down leadership is needed at a policy level but needs supplementing from the bottom up. Information should be continuously shared in both directions, top-down and bottom-up. 'How to do' is a job for front line teams – there needs to be understanding between the leader and those front line teams on a common set of goals.

There are three fundamental aspects of top-down leadership, vision, inclusiveness and specific skills. A leader or leaders 'walks the talk' as far as committed to the mission of diabetes prevention, having a vision of diabetes prevention for the whole country and being able to convey that vision to others in an understandable manner. As a role model, there will be a proven track record from before, an ability to inspire, a willingness to take risks, based on confidence in their abilities and total commitment to the task.

For inclusiveness; there is a need for understanding and synthesising the perspectives of those from different backgrounds, to allow more effective implementation. A wide range of partners supports this. Hence leadership should not shy away from inter-sectorial cooperation and effective engagement of all stakeholders would be a part of the implementation process, without preconditions.

For specific skills; while the leader or leaders need to know what's going on at all levels and to review activity, they shouldn't be dictatorial, but be seen as facilitating and available for problem solving. Good communication skills are essential, being supportive but also showing appreciation of achievements. Leadership needs to be delegated also at different levels to share responsibility in an appropriate manner. Other skills include coordinating the process while leaving an open flow of ideas, which might lead to modification of objectives, and ensuring implementation relevant to the individual contexts of the target groups.

How representatives of Ministries of Health see it:

"Change of structure in my organisation needed top-down leadership because other levels were not as convinced. Better communication of structure beforehand could have been needed."

"In order to engage people you have to be clear about the objectives you want to achieve. "

"National strategy on nutrition and physical activity. The strategy helped to make more activities of this area. "

"Umbrella is needed in order to supervise implementation. Feedback mechanisms for multisectorial communication are in place at that level. Case example: Prevention law, Germany 2015 - legal framework for bodies for governance."

"Top-down leadership can only be successful, if it manages to bring across the message about why things are important to happen. A second criterion for success is the flexibility to change plans even in a top-down approach in order to get people on board and improve the original plan."

"I agree with these sentences. The absence of a clear and strong guide most probably leads to worst outcomes. The real success is reached when the leader is able to reach the final objective taking into account questions and suggestions of his/her team."

"Firstly a common goal needs to be set in place. In defining the common goal all members need to feel it as "their project". Top-down only works when you make the project "their project" and act as that was their plan initially."

“Experience of national plan for nutrition & physical activity and health started from a committed team with a lot of expertise - it went through years of different government cabinets and build an enduring and clear vision helping stakeholders understand the stakes and goals. “

“Law on Tobacco consumption in closed places in Spain is a good example.”

“Top down leadership: 1) political agreement on the vision, where to go, towards our future health care system, "towards integrated care". 2) inspiring, motivational speaker with a clear vision, who is aware of the change process and its barriers and can manage those uncertainties.”

“Be sure that you have evidence, researches, statistics to create a sense of urgency. Minister should present this data in public (not in the first place in parliament but at the opening of hospital etc.). Message of minister should be clear and short and repeated in several occasions. Involve experts, be sure of their commitment. It helps if they meet with Minister.”

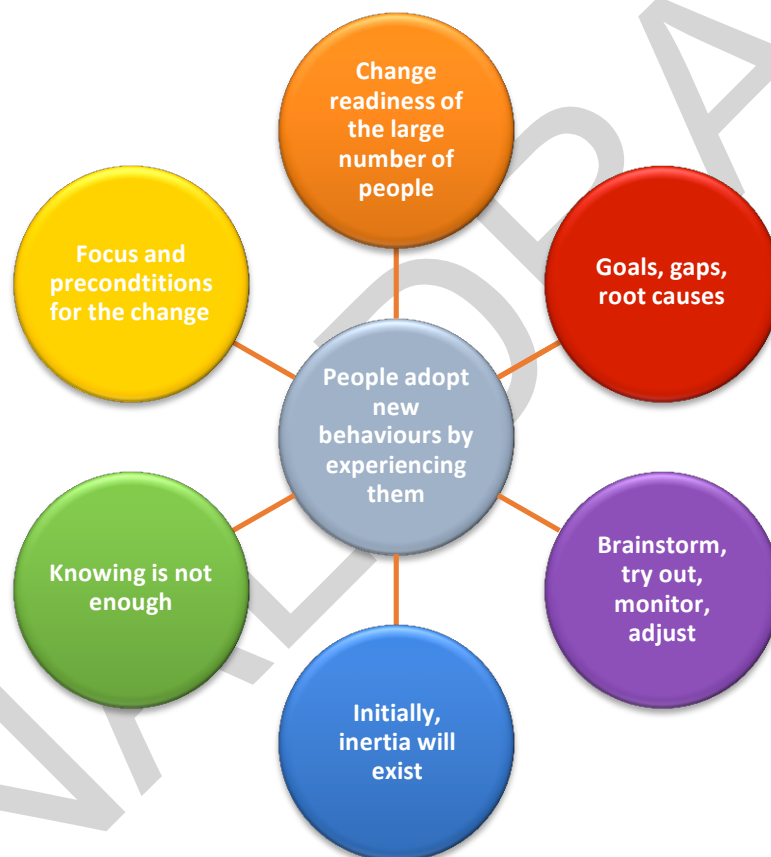
“From my experience maybe the best experience (most successful) was implementation of quality management in organization when leader of project successfully implemented it although at the beginning of the process the resistance to the changes was really big.”

“Strategies - collaboration - participation. Governance of strategies on health as a collaborative and participative way of defining strategic lines, goals and recommendations. It is an inclusive model to include all stakeholders.”

“Making a law for Antimicrobial Resistance Control and Health Care Associated Infections. We implement the law and a regulation on own Health Care Units.”

3. Setting up the leadership: bottom-up leadership

Top-down leadership, if successful, creates focus and the necessary preconditions for the change, but alone cannot achieve it. To achieve successful implementation of initiatives that require fundamentally new ways of functioning, the approach has to include actions tailored to specific challenges, skills and change readiness of large numbers of people implementing the action at the front-line. The leadership for bottom-up initiatives is successful if it supports goal-setting, determination of the gaps, understanding the root causes, brainstorming and trying out solutions, monitoring the results and making adjustments. It has to acknowledge that initially, inertia will exist, that knowing is not enough, and that people adopt new behaviours by experiencing them.



Key functions that have been identified, in order to achieve the above are:

Good coordination among the partners involved in development, delivery and implementation, especially involving local leaders to empower them.

An adaptable framework to translate the vision and high-level plan for different local environments and circumstances, sensitive to the local cultures.

A participatory style that promotes bottom-up consensus-building and promotes mutual trust and also acknowledges that some changes need time, to help people adjust to new behaviours that may be required of them.

A recognition of training needs and the ability to meet them

A commitment to evaluating results as well as tracking the process of change

Effective, regular and structured communication through and across all levels

Sincere and meaningful attention to both gender issues and those of vulnerable groups rather than paying lip-service to political correctness

How representatives of Ministries of Health see it:

"People are experts of their own life; this is what has to be acknowledged also by healthcare system and local leader. Empowering patients, reviewing and evaluating local conditions and basing local strategies on this info is crucial. Local strategies need to be in local political agenda and linked to budgetary decisions & reporting of implementation of strategies. We have that since 2010."

"Agree with last part of last sentence ("and that people adopt new behaviours by experiencing it"). If you have a good product/concept/action, you need to convince people to experience it and let word of mouth. Also give the word to communities, let them say what they want/could focus on. For example - World Diabetes Day. International Diabetes Federation gave the message but diabetes communities would work on their own activities. "

"Germany being a federal state with many decision making levels needs top down and bottom up activities when implementing measures at the community level (Example INFORM – Germany's national initiative to promote healthy diets and physical activity).

"Clear definition of needs and existing gaps. Flexibility to incorporate other's needs. Flexibility to adapt several actions to change in the context factors & different outcomes of implementations. Overview is needed to not get lost in too many details."

"The key is finding the leaders in the system. Local incentives cannot be put down. Currently we have a great experience in one local community hospital, where manager is willing to take the lead in piloting a new integrated care model. This initiative has been welcome by the ministry and will also be separately financed by the ministry."

"I agree. In a community (+/- 200.000 inhabitants) a project leader in a hospital could motivate different partners to participate in brainstorm sessions and got the agreement of most of the partners to submit a proposal that affects the whole region (health care & social care). "

"Everyday work in my group rises up many ideas which I as a leader have to structure and prepare for action. "

“ If change is going to happen, you have to get all levels in the organisation with you. There are several ways of doing that - but some kind of involvement that ensures some kind of ownership is essential. Remember also that the patients are the strongest agents of change.”

“Preparation and implementation of first National Diabetes programme in Croatia was a good example of bottom up leadership when initiative rise from professional organizations and doctors from clinical practice.”

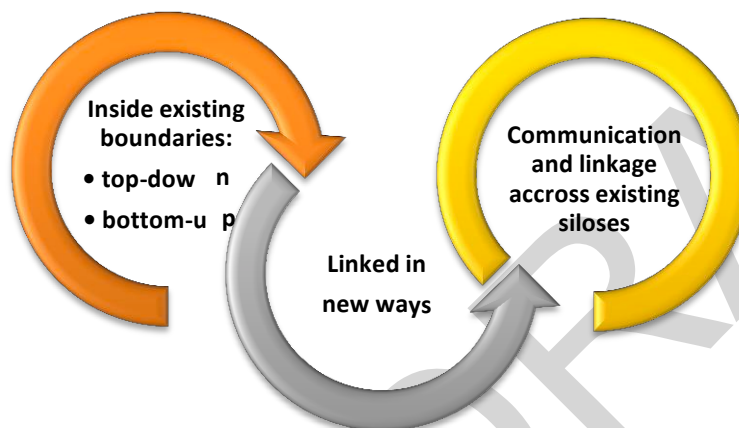
“Health screening at school is a good example in our country. A reform has started at schools by doctors and parents.”

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4. Setting up the leadership: leadership for supporting linkage across existing boundaries

Top-down and bottom-up efforts are very important, but work within existing organizational boundaries. Some changes, however, can happen only when institutions, people, activities and information are linked in new ways. Leadership for these changes is successful if it supports communication and linkage among existing silos and care that is currently fragmented.



To achieve new kinds of linkages, the leader(s) need to be open to inter-sectorial thinking where people's issues are viewed within the broader perspective. Change is easier if it includes some change in organisational boundaries.

However, it is necessary to respect the natural tendency of partners to protect their area of influence and resources. The best solution for this potential barrier is increased communication.

Networking opportunities and incentives for networking need to be developed in order to facilitate the exchange of information and ideas, and the structures to support this. Leadership may need to establish completely new communication structures to create new links between partners.

Finally, the task of identifying and addressing barriers to change, especially of organisational boundaries, is something that can involve all partners working together.

How representatives of Ministries of Health see it:

“Create opportunities for face to face meetings within the same organisation to provide people with the possibility of directly link with each other. Facilitate exchange across hierarchies.”

“I think this type of changes needs a person or group in the organisation that is personally driven/involved in them. Personal enthusiasm helps to start changes and puts issues on the agenda. “

“You need to have structures to support linkages. We in Finland have the law that multisectoral committees (including NGO's) at municipality level have to be established. Committee for public health is established at national governmental level.”

“Communicate your approach clearly and gather experiences from people who are experiencing the changes and communicate also those experiences.”

“Organizing a Diabetes Forum has brought together ministry, patient organizations, doctors, universities, health care system...and this event had some very important conclusions.”

“Detailed exchange of problems, obstacles, encouraging results etc. is needed in order to enable members of project to have the others' perspective. It takes time to bridge the gap between different perspectives. “

“Clear communication from all levels needed. And openness to listen to the others.”

5. Topics, processes and leadership combined in the Plan organisational design and structure

The Plan organisational design and structure, as set up below, may support all three types of leadership that aim at implementation and sustainability of the Plan.

The Plan exists and is publicly available.

The Plan involves all core partners. Partners are involved in the development and implementation of the Plan.

National policy level commitment is in place.

Advocacy from patients' associations and scientific societies is in place.

The Plan involves partners from sectors outside healthcare.

The goals and objectives of the Plan are clearly documented.

In the Plan, the extent of the problem is described and there is analysis of what is happening now and what needs to happen in order to achieve the goals is performed.

There is a documented implementation/ action plan, tailored to the context of the State or Region.

The resources for its implementation are allocated.

An appropriately constituted steering committee or task group (i.e. involving partners like government authorities, patients' representatives, specialists and primary care healthcare professionals and other relevant national health organisations) prepares and oversees the implementation of the Plan. Voices of vulnerable groups are represented. The responsibilities of the partners are defined.

Leadership should combine a top-down approach that is focused, consistent and ongoing, and a bottom-up process that addresses the large number of people implementing the Plan, and supports communication and linkage across the (organisational) boundaries.

Leadership acknowledges that for successful implementation and sustainability, sometimes existing structures may need to be changed fundamentally. New organisational boundaries are identified and links established. Front-line individuals need to be involved.

The culture of change is created; the room for change is identified. Communication and cooperation are fundamental characteristics for this.

There is a communication strategy of the Plan, internal and external. Internal communication among the partners is continuous.

There is an evaluation strategy of the Plan, with processes for continuous improvement in place. Successes are defined and celebrated; failures are taken as signs to learn to find another way. Failures are not punished. If gaps are identified in the process, the plan is adapted accordingly.

The plan is flexible and can be easily adapted for local use within different contexts.

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