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PRO-STEP project
Promoting Self-management for chronic diseases in Europe

Pilot Project on the Promotion of Self-Care in Chronic
Diseases in the European Union

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Executive Summary

1.1 Why is self-management relevant now?

The population of the whole European Union is ageing. Today, two thirds of the European population over 65 live with chronic conditions and the figures are estimated to grow. The cost of chronic diseases in the EU is estimated at EUR 115 billon or 0.8% of GDP annually.[1] Health systems thus face a financial sustainability challenge. One area that can support the effective and cost-effective use of healthcare services and resources, and thus support the long-term sustainability of the healthcare systems, is the promotion of self-management, self-care and patient empowerment.

Against this background, self-management of chronic conditions is increasingly seen as a tool that may help struggling healthcare systems reduce costs. However, large-scale evidence is still missing on how self-management of chronic conditions can be beneficial to patients as well as to the whole society, including from a system and financial point of view.

Self-care was defined in the tender specification as follows:

> Self-care is "what individuals, families and communities do with the intention to promote, maintain, or restore health and to cope with illness and disability with or without the support of health professionals such as pharmacists, doctors, dentists and nurses. It includes but is not limited to self-prevention, self-diagnosis, self-medication and self-management of illness and disability."[2]

Given the focus of the present study on chronic diseases, the consortium developed the following working definition of self-management:

> Self-management of long-term diseases refers to the tasks a person can perform to minimise the impact of that illness on his/her health status by him/herself, or with the support of a healthcare provider. In practice, the self-management of a long-term condition requires that a person has the skills to self-monitor the symptoms and clinical markers of those conditions, to understand the associated implications, and to adjust medication, treatment or behaviour accordingly.

1.2 The goal of the PRO-STEP project

This project, financed by the European Commission, looked at self-management practices in chronic conditions and attempted to assess practices that promote self-management both in terms of the impact on improved health status and quality of life,

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[1] http://www.oecd.org/newsroom/europe-paying-a-heavy-price-for-chronic-diseases-finds-new-oecd-ec-report.htm

[2] See Annex Deliverable (D4)

as well as in terms of cost-effectiveness. This was to be done by conducting a study (consisting on a literature review and cost-benefit analysis) to identify the added value of self-care in six major disease-areas. In addition, the project arose from an overall policy objective of developing a framework for action to enhance self-management at EU level and to develop strategies to support the broader implementation of effective self-care policy and practices, parts of which were already addressed by the previous PiSCE study of self-care in minor and self-limiting conditions. This was carried out by setting up a Platform of Experts in self-care in the field of chronic diseases to explore and propose possible methods of promotion of selfcare for chronic diseases.

1.3 What evidence is there in published literature?

The project conducted a literature analysis of published systematic reviews and a cost-effectiveness assessment. Whilst there is substantial evidence on effectiveness, there are limitations to the conclusions that can be drawn, based on lack of data on cost-effectiveness (see D2 for further details on methodology), the most evidence was found in the following seven conditions that self-management interventions may be effective as well as cost-effective:

- Diabetes
- Obesity
- Asthma
- COPD
- Ischaemic heart disease
- Heart failure
- Hypertension

Self-management interventions were overall *cost-increasing* for the healthcare budget, but the increase in costs was associated with *increases in health* to such an extent that self-management can, in many instances, be cost-effective. In some cases, savings could be generated outside of the healthcare budget, for example through productivity gains. This is an area that needs to be further explored as the data is scarce and studies to date have not attended to adopt a societal perspective when assessing cost-effectiveness.

1.4 The PRO-STEP Platform of Experts

The Platform of Experts in self-management, set up within the PRO-STEP project, notwithstanding the caveat in the original tender specification that it would not necessarily be continued after the conclusion of the project, could contribute to implementation of the roadmap. The Platform offered a unique combination of expertise related to self-management, patient empowerment, health literacy, integrated care, health technologies, as well as expertise on EU and national health policy, and the selected chronic conditions.

The work of the Platform focused on the seven priority conditions selected by WP4 based on the findings of WP2 and WP3, listed above. With their input, the PRO-STEP project tackled the tasks of WP5 and WP6, including reflections on innovative practices, development of four scenarios for potential implementation of self-management, and developed the recommendations for policymakers as well as communication tools.

1.5 PRO-STEP recommendations for effective self-care policy

PRO-STEP does not focus recommendations on any single stakeholder group as the central vision emerging from this study emphasises that *promoting and realising effective self-care, including self-management, in the European Union is a matter for all stakeholders.* A strategic approach should be adopted at European level, supporting change at national and regional/local levels.

Recommendations

1. ***The European Commission should develop a mission and vision for self-care, including self-management of chronic diseases, which includes guiding principles,*** in order to effectively support policy and practice in Member States.
2. ***A strategic approach at policy level should encompass at least the following areas:***
    - *Health literacy*, including monitoring (e.g. via regular Eurobarometer surveys and by including health literacy measures in routine European health system statistics);
    - *Knowledge and skills* of all relevant healthcare professional groups that play a role in supporting self-care. At EU level, a "core" set of competencies could be developed, focused on self-care support and patient-centred skills on the lines of the key recommendations of EMPATHiE;
    - Promoting changes in *societal attitudes* related to the perceived benefits of self-care;
    - Strengthening relevant systems, structures and organisations, ensuring adequate resourcing of support for self-management.
3. ***The following key barriers should be addressed as part of any self-care strategy:***
    - Lack of or low health literacy, communication with hard-to-reach groups including people in a position of vulnerability (economic, social or cultural)
    - Health inequalities;
    - Navigability of the health (and social) care system;
    - Professionals' knowledge, attitudes and skills;

- Lack of integration and co-ordination in healthcare, including teamwork and communication.

If certain diseases are selected as priorities for policy and practice, it should be noted that the barriers may be quite different from one disease to another.

4. ***Cost-effectiveness of self-management needs to be assessed in a societal perspective.***
    - Self-management interventions that are identified as effective in studies should also be tested for cost-effectiveness;
    - Future studies should adopt a societal perspective in the analysis of self-management in order to gauge costs and benefits in wider society.
5. ***Health literacy should be adopted as a policy priority***
    - Stronger synergies and collaboration are needed between national ministries responsible for health and those responsible for education.
6. ***Communication should be seen as a key investment***
    - As effective communication is at the heart of self-care initiatives, policymakers should invest in it and ensure that communication efforts are evaluated, published and shared;
    - Policymakers and other stakeholders should make use of and further publicise the PRO-STEP communication tools and guidance; the PRO-STEP Portal should be hosted on an EU platform to ensure it remains accessible.
7. ***Innovation should be encouraged and supported***
    - Policies should allow room for innovative measures – carefully evaluated – as well as best practice approaches in order to foster take-up of self-care and self-management.
8. ***The potential role of digital technology in supporting self-care should be explored***
    - To reap the benefits of technology whilst avoiding a risk of fragmentation in policy and practice, an integrated approach is required.
    - Better synergies between current EU- and nationally-led initiatives in digital health should be ensured.
9. ***Further research should be supported to fill in gaps and further strengthen the evidence-base***
    - The lack of evidence regarding cost-effectiveness of self-management interventions in chronic conditions should be addressed by a study/-ies funded under European research instruments, such as the future research programme (FP9);

    - Patient involvement should be built into studies to ensure that their outputs are useful and relevant to patient needs;
    - To gauge the true cost-benefit / cost-effectiveness of self-management interventions, appropriate methodologies are needed to calculate financial impacts of interventions beyond the healthcare budget, such as in employment and social welfare.

Other important issues to consider

Finally, it is important to recognise that there are even more and wider implications for self-care which are yet to be fully explored and which were out of scope of the present project, including:

- Inclusion of health literacy and self-care as topics in the *education* system;
- Developing better understanding of self-care and self-management needs and possibilities in *mental health*;
- Exploring targeted prevention of treatment-requiring ailments in order to contribute to rational use of *antibiotics* and help combat resistance;
- In *digitisation*, further exploration of new and emerging techniques and tools to enable new pathways of communication and support, and their implications for patients.

1.6 The future of self-management

Vision on self-care in Europe: In the European Union, all people who need it will have the knowledge, motivation and competencies to implement self-care to maintain and improve health and quality of life in the context of chronic disease with the support of the community and health system.

Mission on self-care in Europe: To ensure that individuals, families and communities are capable of self-care: to promote, maintain, or restore health and cope with illness and disability with or without the support of health professionals such as pharmacists, doctors, dentists and nurses. It includes but is not limited to self-prevention, self-diagnosis, self-medication and self-management of illness and disability.

Guiding principles for self-care policies in Europe

- Human-centred
- Evidence-based
- Affordable
- Feasible
- Culturally sensitive
- Promoting health literacy

Guidelines for policy-makers on how to promote self-care: Generally, innovations and best practice approaches should include policy strategies, availability of self-care approaches, education, implementation and evaluation. Policies are only one of several complex domains related to the self-care continuum. Notably, policies should include:

- Recruitment of community members to use self-management
- Aiming to make communities more compassionate places to live
- Supporting people
- Inclusiveness
- Enabling sufficient community participation
- Sharing experiences
- Disseminating information
- Networking
- Fostering dialogue between people and stakeholders
- Integrated at all levels of care
- Focused on the quality of life

Essential for self-care and self-management policy design
✓ Ensure sustainability & continuity of funding
✓ Respect professional boundaries; anticipate potential conflicts
✓ Identify champions
✓ Ensure sustainability & continuity of support, esp. professional
✓ Ensure patient-centeredness
✓ Ensure use of effective technologies

2. The PRO-STEP Project

The PRO-STEP project, *Promoting self-management for chronic diseases in Europe*, arises from the need to investigate whether and how self-management of chronic conditions can be beneficial to patients, as well as to the whole society, from a system and financial point of view.

2.1 In a nutshell

The rationale behind the PRO-STEP project

The whole European region is more and more affected by a growing ageing population, with figures that provide a worrying picture: two thirds of the population over 65 live with chronic conditions. The incidence of chronic conditions is estimated to grow as the number of people in the EU over 65 is expected to increase to 152.6 million by 2060 (compared to 87.5 million in 2010)[3].

As health systems struggle with the growing burden on them, they face a financial sustainability challenge. One area that can support the effective and cost-effective use of healthcare services and resources, and thus support the long-term sustainability of the healthcare systems, is the promotion of self-management, self-care and patient empowerment.

In this light, the European Parliament acknowledged the urgent need for a study that would identify good/effective practices in the field of self-management of chronic conditions and assess the cost-effectiveness of self-management.

The project's objectives

The project has integrated as its own general objective, that of the objective stated in the European Commission Decision C (2013)4940 on a pilot project "Promotion of self-care systems in the EU": "to put into place a framework for action to enhance self-care at EU level and develop strategies to support the broader implementation of effective self-care."

In addition, specific objectives have been defined before implementation of the study. They include the identification of good practices, development of guidelines and tools for promotion of self-care, and concrete policy actions, which will help professionals and policymakers take the next steps in implementation.

In line with the tender requests, the study looked at the identification of good practices against defined criteria, definition of added value, identification of key

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[3] Population ageing in Europe: Facts, implications and policies, 2014, p.18
https://ec.europa.eu/research/social-sciences/pdf/policy_reviews/kina26426enc.pdf

elements to allow the scaling-up or transferability of good practices, either from one country to another or from one disease to another. To do so the study built on existing outputs developed by other EU-funded initiatives, such as the European Innovation Partnership on Active and Healthy Ageing (EIP-AHA) and the Joint Action CHRODIS.

Project consortium

The study was carried out under the leadership and coordination of the European Patients' Forum (EPF - based in Brussels, Belgium) by a multidisciplinary consortium of four partners established in different countries:

- European Health Futures Forum (EHFF - Isle of Wight, United Kingdom);
- Fundacion Avedis Donabedian – Avedis Donabedian Research Institute (FAD-Barcelona, Spain);
- Danish Committee for Health Education (DCHE – Copenhagen, Denmark);
- Institute for Medical Technology Assessment, Erasmus University (iMTA, Rotterdam, The Netherlands).

Where EPF brought the patient perspective into the consortium, other partners contributed expertise in health education (DCHE), research and implementation (FAD) and health policy (EHFF).

The multistakeholder perspective was ensured also by the Panel of Experts (see Annex II) in self-care in the field of chronic conditions, which was composed of consumer representatives, healthcare professionals, disease-specific physicians, experts in the field of health literacy, etc.

The process

Building on expertise and outcomes emerged from previous and ongoing policy work and initiatives such as EMPATHiE (study on patient empowerment) and PiSCE (study on self-care in minor or self-limiting conditions)[4] the study was carried out in four distinct phases:

1. The Analytical Phase consisted mainly of desk work, including an extensive literature review and cost-benefit analysis. Six broad chronic disease-areas were defined in the tender specification; these were taken as a starting point to examine the scientific evidence for the added value of self-management in chronic conditions, by looking at prevention, monitoring and management practices.

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[4] For more information on PiSCE please see www.selfcare.nu

The literature review conducted by FAD included the identification of diseases where self-care is more effective. A taxonomy of existing good practices was produced and finally, in line with the priorities of the EIP-AHA, having identified best practices, identifying their scalability.

In parallel, a separate team of health economists led by iMTA worked to provide a cost-benefit analysis for the same conditions, looking at both a patient and a health system perspective. They considered not only the monetary costs related to self-care but also non-financial (societal) costs and benefits. The combined results of the two work streams formed the basis for starting the second phase.

2. The Building Phase consisted in selecting specific diseases out of the six disease groups of conditions that had been investigated during the Analytical Phase. The selection took into account took into account the evidence on the effectiveness of self-management interventions for disease prevention, monitoring and management, and their added value in terms of cost-benefit.

During this phase, the already-mentioned Panel of Experts – a cross-functional expert stakeholder platform – was set up. It was comprised of 20 recognised experts in chronic diseases, healthcare and self-care, with a balanced geographic representation to ensure the Panel would bring in experiences and knowledge from all over Europe.

This second phase was also aimed at conceiving and producing a comprehensive work plan for the Panel to carry out during the following phase.

3. The Developing and Innovative Phase represents the core set of activities of the whole project. In this phase, the Panel of Experts was asked to implement their tasks according to the workplan and by focusing on the selected diseases. The Panel of Experts developed the following outputs:

- Identified barriers that may hinder the development of self-care;
- Developed guidelines for national and local policy makers on how to promote self-care;
- Proposed scenarios for EU collaboration;
- Proposed innovative approaches for the development of self-care;
- Proposed and designed communication tools for patients/consumers to improve prevention and disease management.

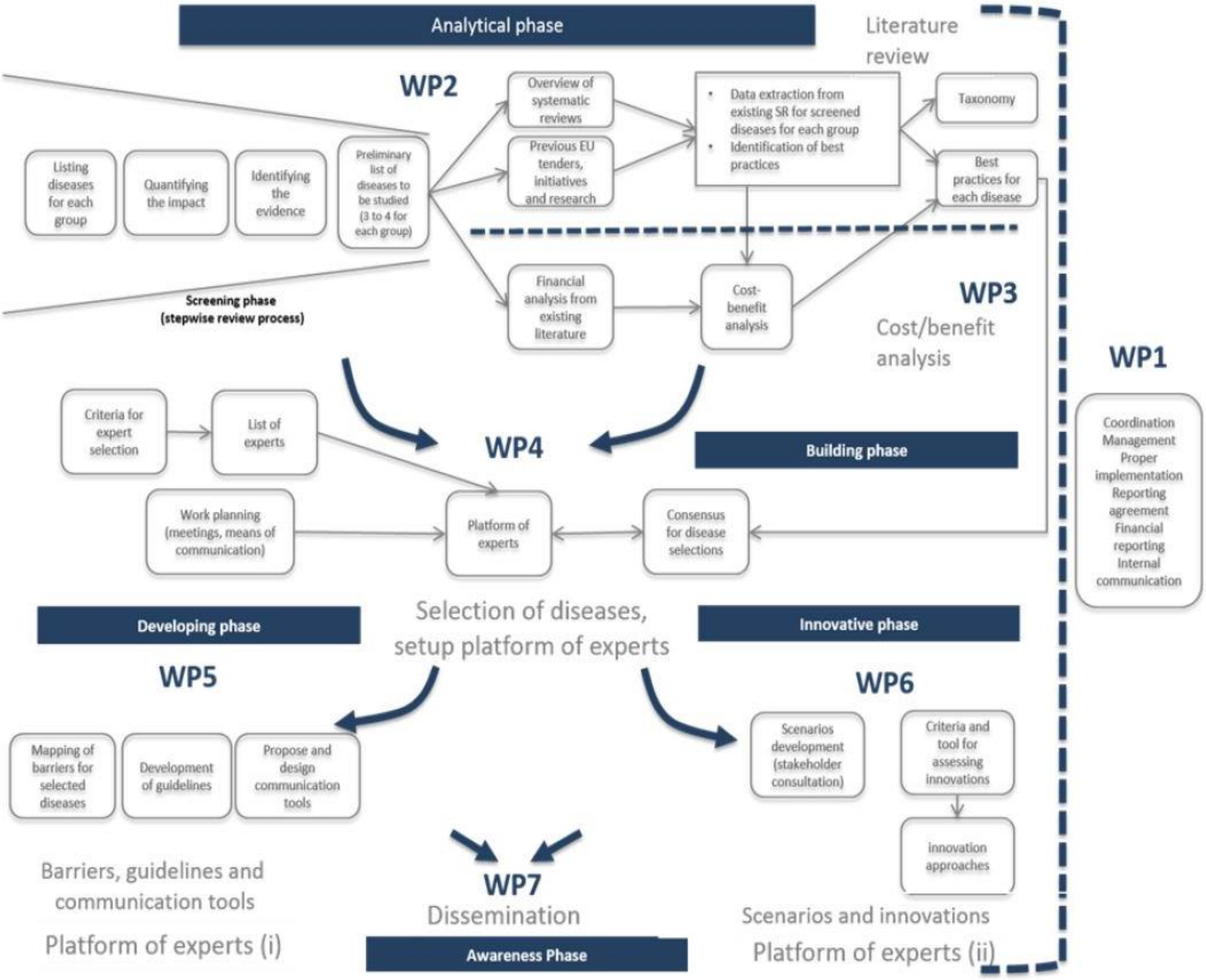
The work was led by DCHE and EHFF, where the former focused on the development of guidelines and communication tools as well the identification of barriers, while EHFF exploited their expertise in health policy at EU level to deal with the scenarios and innovative approaches to be proposed.

4. The Awareness Phase relates to dissemination of results arising from the study. The dissemination tasks were led by EPF, with its established expertise in reaching health experts, policy and decision-makers as well as the wider public. In order to ensure maximum outreach across EU countries and stakeholder groups, EPF worked on the one hand on regular dissemination of PRO-STEP key milestones, and on the other hand developed communication tools, such as a “PRO-STEP factsheet” and a video, summarising the key results.

A closing conference was organised to share and validate PRO-STEP results with a multistakeholder, multinational audience of almost 100 participants.

Elements of the dissemination/awareness phase are also expected to continue after the end of the project, to ensure maximum understanding by decision-makers and in order to set up policies and enable uptake of PRO-STEP recommendations at national/regional levels.

Fig. 2.1 Overview of the project structure



2.2 Structure

The project structure aimed to maximise the synergies between the work of the different partners; it was structured in seven work packages, representing four broadly defined phases:

WP1 Coordination and Project Management (EPF)	**1. Analytical phase:** WP2 Literature review (FAD) WP3 Cost-benefit analysis (iMTA)
	2. Building phase: WP4 Selection of diseases, and setting up the Platform of Experts and its work plan (EHFF)
	3. Development and Innovative phase: WP5 Guidelines on policymakers, mapping of barriers, communication tools to promote self-care (DCHE) WP6 Innovative practices and scenarios for EU collaboration (EHFF)
	4. Dissemination phase: WP7 Dissemination strategy and closing conference (EPF)

3. WP descriptions and outcomes

The following descriptive section comprises the project's work packages, their rationales, methodologies and main outcomes. It should be noted that the analysis conducted in WP2 and WP3 was done partly in parallel, and the subsequent selection of diseases (WP4) was the outcome of the combined results of both WPs. Furthermore, WP5 and WP6 were conducted largely in parallel work streams, both involving the Panel of Experts.

3.1 WP2 – Literature review

WP2 consisted of three phases:

- Scoping of chronic disease-areas in order to identify a "shortlist" of priority diseases,
- Overview of self-care practices for the selected diseases and input for the final selection of seven diseases for focusing of further work,
- Analysis of most effective self-care practices for the selected seven diseases.

Scoping

The scoping was carried out for the **six pre-defined chronic disease-areas defined in the tender specification**: chronic metabolic diseases, chronic gastro-intestinal diseases, chronic dermatological diseases, chronic respiratory diseases, chronic cardiovascular diseases and chronic circulatory diseases.

A step-wise approach was used to identify specific chronic diseases that would be potentially more relevant to be analysed in the in-depth literature review based on: frequency of the disease/condition; disease burden; available evidence; and modifiable behaviours in term of self-care.

The resulting list of pre-selected diseases and information was circulated for a consultation process with experts and the selection of a shortlist of **18 diseases** was approved by the PRO-STEP consortium in order to continue with the systematic review and cost-effectiveness analysis.

Overview

The overview of Systematic Reviews (SRs) was carried out to contribute to the selection of seven diseases to be included in the following phase involving the platform of experts. More specifically, the overview provided information in terms of the strength of evidence of self-management effectiveness, potential to be implemented in wider scales, consideration on contextual factors that can affect the applicability and the experience of implementation in Europe, specified as follows:

Criterion	Process of information
Availability of evidence	Number of SR identified for the specific disease.
Effectiveness	Percentage of positive outcomes over the total of outcomes reported for that disease in all intervention types.
Quality of the evidence	Percentage of positive outcomes based on a high-quality analysis over the total of positive outcomes.
Scalability	Percentage and ratio of "high scalable" intervention types over total of intervention types analysed for the specific disease.
Applicability	Percentage and ratio of "high applicable" intervention types over total of intervention types analysed for the specific disease, based on a qualitative review of the reported barriers and facilitators.
Existence of European initiatives	59 European initiatives were identified. To be considered, those initiatives had to have an element of self-management and had to be EU-funded projects or good practices as identified by the PASQ and CHRODIS Joint Actions. Most of the initiatives identified had a broad focus on chronic conditions. The numbers included in parenthesis represent initiatives that specifically addressed the disease. The score is based on those specific initiatives.
More details can be found in Appendixes of D1.	

The search yielded **257 systematic reviews that were analysed following these criteria**, as presented in the summary table (table 1, see next page).

The above-mentioned criteria were collected for all diseases as illustrated in the summary table below.

Table 1. Summary table of self management added value by diseases

	Availability of evidence (n SR)	**Effectiveness** (% of positive outcomes over all reported)	**Quality of the evidence** (% of positve outcome from high quality source over total positive outcomes reported)	**Evidence on costs (Health care perspective)**	**Evidence on cost-effectiveness (Value added*)**	**Scalability score** (% of intervention types with high scalability)	**Applicability score** (% of intervention types with high applicability)	**Existence of European initatives** (n specifically addressed)
Chronic metabolic diseases								
Diabetes (insulin dependent and non-insulin dependent (I and II))	116	52.80%	54.90%	Cost increasing (23/31)	Yes (10/16)	36% (9/25)	52% (12/23)	High (6)
Obesity	44	49.40%	56.00%	Cost increasing (17/19)	Yes (9/14)	16.7% (3/18)	27.8% (5/18)	Low (1)
Dyslipidaemia, Lipid disorder	0	NDA	NDA	NDA	NDA	NDA	NDA	NDA
Chronic gastro-intestinal diseases								
Malignant neoplasm colon/rectum	4	56.07%	63%	Cost saving (1/1)	NDA	0% (0/4)	0% (0/3)	NDA
Liver disease (hepatic steatosis, Hepatitis (viral/infectious), Cirrhosis)	1	0.00%	NDA	Cost saving (1/1)	Yes (1/1)	0%(0/1)	0%(0/1)	NDA
Duodenal ulcer and Peptic ulcer other	0	NDA	NDA	NDA	NDA	NDA	NDA	NDA
Chronic dermatologic diseases								
Malignant neoplasm of skin	2	100%	50%	Cost saving (3/4)	Yes (1/1)	0% (0/2)	NDA	NDA
Dermatitis/atopic	4	30.00%	66.67%	Cost saving (2/3)	NDA	0% (0/4)	0% (0/2)	NDA
Psoriasis	1	100%	0%	Cost saving (2/3)	Yes (1/1)	0%(0/1)	NDA	NDA
Chronic respiratory diseases								
Chronic Obstructive Pulmonary Diseases	22	49.08%	42.00%	Cost increasing (11/17)	Yes (6/9)	0% (0/9)	0% (0/5)	Medium (4)
Asthma	23	47.50%	61.40%	Cost increasing (12/20)	Yes (8/9)	14% (2/14)	0% (0/10)	Medium (3)
Sleep Apnoea Syndrome (Obstructive sleep apnoea	1	33.33%	0.00%	Inconclusive (4/4)	Yes (3/3)	0% (0/1)	NDA	NDA
Chronic cardiovascular diseases								
Ischaemic heart disease (with and without angina and including Acute myocardial infarction)	12	49.94%	47.73%	Cost increasing (13/17)	Yes (8/9)	20% (1/5)	75% (3/4)	Low (2*)
Heart failure	21	39.09%	56.77%	Cost increasing (13/21)	Yes (7/10)	10% (1/10)	66.67% (4/6)	High (6)
Arrhythmias / Atrial fibrillation/flutter Paroxysmal tachycardia /	2	50.00%	75.00%	Cost saving (1/1)	Yes (1/1)	0% (0/3)	0% (0/3)	Low (2*)
Chronic circulatory diseases								
Cerebrovascular disease / Stroke /cerebrovascular accident	19	25.47%	41.21%	Inconclusive (4/4)	Yes (2/3)	0% (0/9)	40% (2/5)	NDA
Hypertension	19	47.99%	61.51%	Cost increasing (12/14)	Yes (3/3)	20% (2/10)	33.33% (2/6)	Low (1)
Chronic Venous Insufficiency and Varicose veins	1	16.67%	100.00%	NDA	NDA	0%(0/1)	0%(0/1)	NDA

It should be borne in mind that the analysis of cost and cost-effectiveness was carried out by WP3, further detailed in the next section. In addition, please consider that the cost and cost-effectiveness results are based on individual studies, and therefore the link between this data and the data on availability of evidence, effectiveness, scalability and applicability, which were all based on SR's, should be interpreted with caution.

Most effective self-care practices

This project developed a summary score of the impact of self-management in terms of improving clinical, patient-reported and other relevant outcomes. This summary score helped in the selection of the six diseases for which there is more evidence of effective self-management interventions and a general idea of effective interventions.

However, if one seeks to go further in depth to select the most effective interventions for a patient living with a specific disease, it is important to highlight that different interventions have been associated with very different results, depending on the specific outcome(s) analysed.

This means that even within the group of interventions generally regarded as "effective" based on our data, different interventions will have positive effects on different outcomes.

It is also important to stress that not all studies analyse the same outcomes, therefore it is not possible to compare all interventions on their effectiveness in relation to a specific outcome analysed.

Taking this into consideration, WP2 identified the best practices for each disease by developing a summary for each disease, classifying the outcomes by the strength of the evidence of their effectiveness in improving each outcome type, as follows.

Classification	Meaning
Positive (+++)	Outcome measures with positive results, between 50% and 100% of them from high-quality SR.
Positive (++)	Outcome measures with positive results, between 0% and 50% of them from high-quality SR or combination of outcome measures with positive results, between 50% and 100% of them from high-quality SR and some inconclusive measures.
Positive (+)	Combination of outcome measures with positive results, between 0% and 50% of them from high-quality SR and some inconclusive measures.
Non-conclusive	Inconclusive results.

As this illustrates, we set a very high threshold to consider outcomes as very positive (+++) or positive (++). Therefore, the reader should be confident that where we concluded that an intervention type has a positive effect for an outcome, this conclusion is based on high-quality evidence.

The following tables present the interventions with very positive and positive results for each disease for the outcomes reported. **These interventions, organised following the taxonomy developed in WP2, would therefore constitute the best self-management practices for each of the analysed diseases**.

The full taxonomy and the practices that did not find such positive results (positive (+) or non-conclusive) are identified in Deliverable 1 (D1) of this project.

Asthma

Asthma – Best practices		
Interventions	Positive (+++)	Positive (++)
Patient education to young population	Other clinical outcomes	Quality of Life (QoL)
Patient education to young minority groups and/or young disadvantaged population	Knowledge Self-management / self-care behaviours	Exacerbation
Self-management interventions (broad focus)	Healthcare use measures (hospitalisations)	Asthma symptom Adherence to medication Healthcare use measures (emergency)
Self-management interventions focused on minority groups and/or disadvantaged people	Knowledge Self-management / self-care behaviours Healthcare use measures (emergency)	Healthcare use measures (hospitalisations)
Self-management interventions delivered by peers and focused on young populations	Knowledge /QoL	Self-efficacy
Self-management interventions including self-monitoring		Adherence to medication
Self-management interventions including self-monitoring in young populations		Adherence to medication Adherence to self-monitoring Cost related measures (productivity losses) Healthcare use measures
Self-management interventions including telemonitoring to young minority groups and/or young disadvantaged population		Adherence to medication
Self-management focused on lifestyle change behaviours	Exacerbation	Asthma symptom Anxiety and/or depression QoL
Shared-decision making		Self-efficacy Self-management / self-care behaviours

Organisational Changes	Severity Adherence to medication	Self-management / self-care behaviours Lung function (FEV1, FVC) QoL

Chronic Obstructive Pulmonary Diseases (COPD)

COPD – Best practices		
Interventions	Positive (+++)	Positive (++)
Patient education (broad focus)	QoL Healthcare use measures (emergency)	Adherence to medication Knowledge
Self-management interventions (broad focus)	Body weight (BMI, body weight, waist circumference...) COPD Symptoms Lung function (FEV1, FVC) Fatigue Physical activity Psychological outcomes (emotion)	Dyspnoea Knowledge Adherence to medication Exercise capacity Muscle strength Diet related measures Self-efficacy
Self-management interventions focused on minority groups and/or disadvantaged people		Smoking cessation
Self-management interventions including self-monitoring	Healthcare use measures (hospitalisations)	
Self-management interventions including telemonitoring	Exacerbation Other clinical outcomes Cost-effectiveness related measures Healthcare use measures (emergency) Healthcare use measures (hospitalisations)	Adherence to medication QoL
Shared-decision making	Exacerbation	

Organisational Changes	Exercise capacity Fatigue Psychological outcomes (emotion) Self-efficacy	Adherence to self-monitoring QoL Dyspnoea Physical activity Healthcare use measures (hospitalisations)

Diabetes

Diabetes – Best practices		
Interventions	Positive (+++)	Positive (++)
Patient education (broad focus)	Adverse events BP (DS, D, S) Fasting blood glucose Lipids (Cholesterol, triglycerides) QoL	Other clinical outcomes Process measures (care) Adherence to medication Psychological outcomes (non-specific) Self-efficacy Body weight (BMI, body weight, waist circumference...) HbA1c
Patient education focused on minority groups and disadvantaged people	Knowledge Self-efficacy	Clinical outcomes (non-specific) Diabetes knowledge Self-management / self-care behaviours HbA1c Lipids (Cholesterol, triglycerides)
Patient education using Health Information Technologies		Healthcare use measures Self-efficacy Self-management / self-care behaviours Physical activity Diabetes knowledge
Patient education to young population using Health Information Technologies		HbA1c Hyperglycaemia and /or Hypoglycaemia Knowledge Patient satisfaction Self-efficacy

Diabetes – Best practices		
Interventions	Positive (+++)	Positive (++)
Patient education provided by nurses	HbA1c	Lipids (Cholesterol, triglycerides) BP (DS, D, S)
Self-management interventions (broad focus)	Body weight (BMI, body weight, waist circumference...) Other clinical outcomes Patient satisfaction Well-being (health status)	Co-morbidity measures (cardiovascular) Diabetes Incidence Attitudes (diabetes, control, tools, complications) Diabetes knowledge Family involvement measures Perceived support (social, family) Self-efficacy BP (DS, D, S) HbA1c Mortality Lipids (Cholesterol, triglycerides)
Self-management interventions focused on minority groups and/or disadvantaged people		Patient satisfaction Self-management / self-care behaviours QoL
Self-management interventions to young population		Other clinical outcomes Diabetes knowledge Psychological outcomes (non-specific) QoL
Self-management interventions provided in groups	HbA1c Other clinical outcomes Diabetes knowledge Patient satisfaction Self-efficacy Self-management / self-care behaviours	Diabetes complications (neuropathy, nephropathy, retinopathy) Body weight (BMI, body weight, waist circumference...) Fasting blood glucose QoL

Diabetes – Best practices		
Interventions	Positive (+++)	Positive (++)
Self-management interventions using Health Information Technologies	Adverse events Process measures (care) Adherence Patient satisfaction	Co-morbiditiy measures (cardiovascular) Diabetes complications (neuropathy, nephropathy, retinopathy) Communication/interaction with providers Patient activation Process measures (access to info, usability acceptability) Self-efficacy Well-being (health status) Lipids (Cholesterol, triglycerides) BP (DS, D, S) Clinical outcomes (non-specific) Diet related measures
Self-management interventions using Health Information Technologies and focused on young populations		Attitudes (diabetes, control, tools, complications) Received support (social, family) Self-efficacy QoL
Self-management interventions delivered by nurses		HbA1c
Self-management interventions delivered by peers	Glycaemic control	Hyperglycaemia and /or Hypoglycaemia Communication/interaction with providers Glucose self-monitoring Other patient reported measures Received support (social, family)
Self-management interventions delivered by peers and focused on young populations	Hyperglycaemia and /or Hypoglycaemia	

Diabetes – Best practices		
Interventions	Positive (+++)	Positive (++)
Self-management interventions including self-monitoring	Diabetes complications (neuropathy, nephropathy, retinopathy) Attitudes (diabetes, control, tools, complications) Self-efficacy	HbA1c Hyperglycaemia and /or Hypoglycaemia Adherence to medication
Self-management interventions including telemonitoring		Fasting blood glucose Lipids (Cholesterol, triglycerides) Attitudes (diabetes, control, tools, complications) Communication/interaction with providers Received support (social, family) Psychological outcomes (depression) Self-efficacy Self-management / self-care behaviours Cost related measures HbA1c QoL Hyperglycaemia and /or Hypoglycaemia
Self-management interventions including telemonitoring in young populations		Cost related measures HbA1c
Self-management focused in lifestyle change behaviours	Diet related measures	Other clinical outcomes Physical activity Self-efficacy Smoking cessation Body weight (BMI, body weight, waist circumference...) Diabetes Incidence HbA1c

Diabetes – Best practices		
Interventions	Positive (+++)	Positive (++)
Self-management focused in lifestyle change behaviours using Health Information Technologies		Body weight (BMI, body weight, waist circumference...) Clinical outcomes (non-specific) HbA1c Physical activity QoL
Self-management focused in lifestyle change behaviours to young populations	HbA1c	
Shared-decision making	Knowledge Self-efficacy Self-management / self-care behaviours	HbA1c
Organisational Changes		Fasting blood glucose Adherence to medication Healthcare use measures (hospitalisations) Diabetes complications (neuropathy, nephropathy, retinopathy) Lipids (Cholesterol, triglycerides)

Heart Failure

Heart Failure – Best practices		
Interventions	Positive (+++)	Positive (++)
Self-management interventions (broad focus)	Knowledge	Adherence to treatment Healthcare use measures (emergency) Adherence to medication
Self-management interventions using Health Information Technologies		Self-management / self-care behaviours Healthcare use measures (HF related hospitalisation) Mortality
Self-management interventions including telemonitoring	Mortality	Dyspnoea Edema Adherence to medication Adherence to self-monitoring Diet (fluid, alcohol and salt restriction) Knowledge Physical activity Psychological outcomes (stress or distress) Self-efficacy QoL
Self-management focused in lifestyle change behaviours	Exercise capacity QoL Healthcare use measures (HF related hospitalisation)	Self-efficacy Cost-effectiveness related measures Healthcare use measures (hospitalisations)
Self-management to carers	Carer knowledge and/or competence	
Organisational Changes		Patient satisfaction Cost related measures

Hypertension

Hypertension – Best practices		
Interventions	Positive (+++)	Positive (++)
Patient education (broad focus)	Blood pressure control	Healthcare use measures (hospitalisations) Healthcare use measures (planned contacts)
Self-management interventions (broad focus)	Blood pressure control Diastolic blood pressure Systolic blood pressure	BP (DS, D, S) Adherence to medication Psychological outcomes (anxiety, stress and fatigue)
Self-management interventions using Health Information Technologies	Systolic blood pressure	Patient activation Patient satisfaction Psychological outcomes (anxiety, stress and fatigue) Self-management / self-care behaviours
Self-management interventions delivered by nurses		Blood pressure control
Self-management interventions including self-monitoring	Adherence to medication Attitudes to device	Systolic blood pressure Cardiovascular status Diastolic blood pressure
Self-management focused in lifestyle change behaviours	Body weight (BMI, body weight, waist circumference...)	
Organisational Changes	Blood pressure control	

Ischaemic heart disease

Ischaemic heart disease – Best practices		
Interventions	Positive (+++)	Positive (++)
Patient education (broad focus)		Diet related measures Knowledge Patient satisfaction Physical activity Smoking cessation QoL
Self-management interventions (broad focus)	Adherence to medication Physical activity Physical limitation	QoL Cost related measures Healthcare use measures (hospitalisations) Angina (frequency and/or stability) Psychological measures (anxiety and/or depression)
Self-management focused in lifestyle change behaviours	Body weight (BMI, body weight, waist circumference...) Smoking cessation	
Organisational Changes		QoL Healthcare use measures (emergency) Healthcare use measures (length of hospitalisation) Lipids (Cholesterol, triglycerides) Mortality Coronary events

Obesity

Obesity – Best practices		
Interventions	Positive (+++)	Positive (++)
Carer education		DRM (caloric intake, sugary drinks)
Self-management interventions (broad focus)		DRM (healthy food) Physical activity Self-efficacy Body weight (BMI, body weight, waist circumference...)
Self-management interventions using Health Information Technologies		Body weight (BMI, body weight, waist circumference...)
Self-management interventions including telemonitoring		Adherence to programme
Self-management focused in lifestyle change behaviours		Physical activity Body weight (BMI, body weight, waist circumference...) Birth weight
Self-management focused in lifestyle change behaviours using Health Information Technologies		Process measures (acceptability)
Self-management focused in lifestyle change behaviours to young populations	BP (DS, D, S) Other clinical outcomes	Body weight (BMI, body weight, waist circumference...) Lipids (Cholesterol, triglycerides)
Self-management focused in lifestyle change behaviours delivered by nurses		Other clinical outcomes DRM (caloric intake, sugary drinks) DRM (healthy food) Physical activity
School based self-management interventions		Body weight (BMI, body weight, waist circumference...)
Self-management to carers		Diet related measures

3.2 WP3 – Cost-benefit analysis

The objective of work package 3 was to select conditions in which self-management can bring the most ‘value added’ in terms of a favourable cost-to-benefit ratio. To do so, published evidence about the costs and benefits of self-care interventions was collected.

Methodology

The methodology involved a systematic literature review of cost-effectiveness analyses in chronic conditions, a weighing of the ‘level of evidence’, and integration of the two to identify the probability that self-management interventions are adding value by bringing health at acceptable costs to more patients.

Perspectives

The analysis focused on a healthcare perspective, a societal perspective and a patient perspective. A *healthcare perspective* only includes costs and benefits that fall within the healthcare system. On the cost side, this means that only direct medical costs (i.e. costs attributable to the condition) are included. On the effect side, this means that only effects in patients are included. The *societal perspective* has a broader scope and incorporates a wider range of costs and effects. On the cost side, the societal perspective also includes costs to the patient and family, such as travel time and time spent on informal caregiving. Also, costs in other sectors than the healthcare sector are included, such as productivity costs. The *patient perspective* can be distilled by isolating the patient-specific costs that are included in the societal perspective. All costs were converted to 2014 euros average value.

Generic and comparable outcomes

The systematic literature review only included cost-benefit analyses which express benefit in terms of additional length and quality of life for a patient (commonly referred to as the quality-adjusted life year, or QALY). The purpose of this strict inclusion criterion is twofold. First, interventions should ultimately improve the length and quality of life of patients and hence this is a relevant outcome parameter for effectiveness. Second, the QALY is a measure that can be compared across diseases when assessing cost-to-benefit ratios, ensuring comparability of the assessment of the ‘value added’ criterion.

Assessment of cost-to benefit ratio

Included studies reported incremental cost-effectiveness ratios (ICERs). An ICER is simply a rewritten form of a cost-benefit analysis. For example, in very general terms, a self-management intervention is beneficial to society if its incremental benefit outweighs its incremental costs, as described in equation 1:

$$\Delta B - \Delta C > 0 \qquad 1)$$

where B is benefit and C is costs. In healthcare, benefit is preferably not described in monetary terms but in terms of quality and length of life. This requires that the benefit term B needs to be replaced with the quality-adjusted life year and the societal value of a quality-adjusted life year, resulting in the equation below:

$$v \cdot \Delta Q - \Delta C > 0 \qquad 2)$$

where v represents the monetary value of a QALY and Q represents quality-adjusted life years. Rewriting the equation to isolate the value of v results in the equation below:

$$v > \frac{\Delta C}{\Delta Q} \qquad 3)$$

The formula above gives us the definition: an intervention is beneficial to society when the value v of the amount of health gained outweighs the incremental costs c. In this study, we used common values of v between €20.000 and €50.000, which reflect societal willingness to pay for health gains. If interventions are less cost-effective than the values for v presented above, it means that spending resources on self-management has opportunity costs to either displace other care within the healthcare system, or other social services outside the healthcare system. In other words: if societies wish to spend resources on self-management, cost-effectiveness analysis can help identify if the same resources would have generated more health elsewhere in the system.

If the uncertainty analysis of the cost-effectiveness studies identified that there was 75% probability that the intervention meets the cost-effectiveness threshold, it was classified as 'high' or 'medium' when the probability of being cost-effective was between 50% and 75%, or 'low' when the probability was <50%.

Strength of evidence

The identified studies were ranked in terms of strength of evidence. Evidence was considered high when there were at least 6 individual studies, medium when there were 3 to 5 studies, and low when there were less than 3 studies.

Ranking of value added

Interventions were classified as being ‘value added’ when both the strength of evidence and the cost-effectiveness analyses were classified as at least ‘medium’. The ranking of ‘value added’ was expressed as the proportion of studies that identified at least ‘medium’ effect on cost-effectiveness out of the total number of studies for that condition. For example, when out of 10 cost-effectiveness studies, only two studies identified a probability of being cost-effective of at least 50%, the value added of the intervention is 2/10= 20%.

Results

Overall, there is limited evidence regarding cost-effectiveness of self-management in chronic conditions. More cost-effectiveness research has to be conducted to state with more certainty if effective interventions also add value from a societal and healthcare perspective. Given the limited evidence, the results reported here should be interpreted with caution.

The top 7 conditions in which self-management was ‘value added’ (a higher percentage indicates better added value) were: diabetes (61%), obesity (59%), asthma (67%), COPD (57%), ischaemic heart disease (73%), heart failure (45%), and hypertension (44%). All the self-management interventions in the conditions described above were both *health and cost-increasing* from a healthcare perspective. Self-management in ischaemic heart disease, asthma and obesity have the potential to be *cost-saving* from a societal perspective, but this finding should be interpreted with caution due to limited evidence and is likely only realised in specific subpopulations.

The most scalable interventions identified in the analysis were self-management supported by health information technologies, and school-based self-management programs. Face-to-face interventions had a higher value added than ICT (Information and communication technology) -only based interventions, suggesting that a combination of the two yields the most value for money.

Detailed analysis, including a focus on the particularities of interventions, can be found in the appendix for WP3 (Deliverable D2).

Conclusion

Generally, interventions were considered cost-increasing for the healthcare budget, but the increase in costs is associated with increases in health to such an extent that self-management can, in many instances, be cost-effective. In some cases, it could generate savings outside of the healthcare budget, for example through productivity gains, but up until now this societal perspective on costs and benefits of self-management outside the healthcare sector has received too little attention.

Self-management interventions in diabetes, obesity, asthma, COPD, ischaemic heart disease and hypertension increase both health and costs from a healthcare perspective, and have a positive assessment of being ‘value added’ technologies. Following from the analysis, it seems that self-management brings most value in ischaemic heart disease. Saving costs from a societal or healthcare perspective probably requires targeting specific high-risk, high-cost groups rather than large heterogeneous patient populations.

3.3 WP4 Creation of the Platform of Experts

Task 1. Rationale for the selection of diseases for further study

Introduction

WP4 consisted of three components related to the setting-up of the Platform of Experts. The first one was **the selection of six or more specific diseases which show added value in terms of the effectiveness and cost-benefit of the self-management interventions tested scientifically** (to quote the wording of the Inception Report). These would then be used as the basis for the work of the platform. The rationale for the selection is described in this section.

We started with the results of WP2 (*Literature review*), which includes the section on scoping and overview of the literature on effectiveness of several types of outcomes and WP3 (*Cost-benefit analysis*), which provides data associated with direct (clinical) and indirect (social) costs, presented together in the **Interim Report Deliverable 1**.

Challenging the provisional conclusions led to an intensive discussion of the most relevant variables to use from the mass of data that had been accrued, in order to make a rational final selection of diseases. WP2 would subsequently undertake further work on the good practices, to feed into the Platform’s work. Out of these discussions some minor modification of the criteria from Deliverable 1 was agreed. Part of this process was the recognition that disaggregating the data from WP2 and WP3 helped to clarify certain issues and this allowed a final selection which is the output of this Deliverable.

Methodology used for the disease selection

After Deliverable 1 was sent to the Commission, the data obtained from the results of the analysis of WP2 and WP3, was jointly assessed by the consortium via different prioritisation exercises. Each of the partners was consulted about these exercises, asking them to add other criteria and to review the results obtained from the first proposal of disease selection. After a rich technical discussion, an agreement was reached that we should consider as the most important variables the **amount of evidence, effectiveness,** and **cost-effectiveness.**

This decision was supported by several considerations. In health economics terms, these are different classes of data, both of which contribute to the health system. Effectiveness is measurable as contextual evidence, at a micro or meso level, whereas efficiency, usually measured at a macro level, relates to costs and benefits (but includes effectiveness). For a more detailed discussion, see the helpful section on health economics by Werner Brouwer of Erasmus University in the EXPH opinion on the future of quality and safety from August 2014.[5]

This consideration legitimises the interpretation of the contract specification contained in the bid (see p.43 of the Technical Annex), namely:" this information ('scientific evidence on added value') will be combined with results from WP3 ('added value in terms of cost-benefit') – see WP3 – in order to facilitate the process of selecting the six conditions."

Based on the findings of WP2 and WP3, the top 6 diseases with most evident CE (cost-effectiveness) results were ischaemic heart disease, asthma, diabetes, obesity, COPD and heart failure. The amount of evidence was larger for diabetes compared to ischaemic heart disease, but the probability of CE was higher in the latter (see Annex 4: Overview evidence on cost and cost-effectiveness). Therefore, the results were more in favour of ischaemic heart disease. Hypertension was debated for inclusion, since the adjusted added value of hypertension was almost equal to heart failure. However, the CE evidence for hypertension of an insufficient number of individual studies. On the other hand, allowing the inclusion of hypertension on the basis of the number of individual studies related to cost and adjusted added value in relation to cost-effectiveness, produced the same list of conditions as had been arrived at, using the outcome effectiveness measures above. Hypertension was thus included in the list.

Acknowledging an inevitable element of arbitrariness in fixing cut-off points, but essentially determined by the availability of evidence, we thus arrived at seven diseases which the Consortium as a whole agreed should be tendered to the Commission for their views as to their suitability for further work by the Platform of Experts, when it is set up. These are: **ischaemic heart disease** and **heart failure**

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[5] https://ec.europa.eu/health/expert_panel/sites/expertpanel/files/006_safety_quality_of_care_en.pdf

(cardiovascular diseases), **obesity** and **diabetes** (metabolic diseases), **COPD** and **asthma** (respiratory diseases) and **hypertension** (circulatory diseases).[6]

We failed to find any disease within the other two categories – dermatological diseases or gastrointestinal diseases – where there was sufficient data of sufficient quality to allow inclusion in the selection. We would have liked to have included either psoriasis or eczema (atopic dermatitis) as prevalent conditions where there are some well-established self-management practices. In terms of burden of disease, colo-rectal cancer was highlighted over the relatively common chronic gastrointestinal conditions, but given the definition of chronic disease described at the beginning of Deliverable 1, it only just squeezes into the category and the data was found to be too limited. There are obvious implications for future research from the – not unexpected – gaps in evidence that we have highlighted.

Task 2. Platform of Experts

Methodology for selection of self-management experts

Essential to this project is that it puts in place a framework for action that is directed at supporting the broader implementation of effective self-management in chronic conditions at the EU level. The creation of a high-quality Platform of Experts on self-management is the key to the success of this project, as the experts were a main source of knowledge in delivering the various tasks outlined in WP5 and WP6. In order to create such a high-quality Platform of Experts, several steps needed to be undertaken.

Defining the expertise needed

We were required to determine what self-management means and which related concepts are relevant for the implementation of effective self-management at EU level. On the basis of previous work and internal consultation we arrived at the following definition:

"A central element of patient empowerment is related to the actions that patients take in their day-to-day life, that is, in *self-management*. For the purposes of the PROSTEP project, self-management is considered as the naturalistic decision-making process

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[6] Regarding the evidence on cost the table in Annex 5 shows whether the self-care interventions under consideration are cost-increasing, cost-saving or inconclusive (with same amount of evidence for increased or saved cost) from a healthcare perspective. The ratio presents the number of studies with the reported outcome compared to the total amount of individual studies. In most diseases, the healthcare cost increased due to the self-care intervention. There are some diseases that showed cost savings as a result of the self-care intervention; however, the amount of evidence was too limited to justify attempting to interrogate this issue further.

that individuals use in the choice of behaviours that maintain physiological stability (symptom(s) monitoring and treatment adherence) and the response to symptoms when they occur in the context of their own health status. *The term, self-management of long-term conditions, refers to the tasks a person can perform to minimise the impact of that illness on his/her health status by him/herself, or with the support of a healthcare provider. In practice, the self-management of a long-term condition requires that a person has the skills to self-monitor the symptoms and clinical markers of those conditions, to understand the associated implications, and to adjust medication, treatment or behaviour accordingly."*

Defining the backgrounds and context of the expertise needed

The selection of people for the expert platform took into account the principle of cross-functional stakeholders (healthcare providers/professionals from both secondary and primary care), patient groups, academics, industry, communication/health education, carers and payers) from a balanced geographical background, who also have experience 'on the ground' rather than solely representing a stakeholder group at the policy level. The diversity in demonstrated expertise and geographical and stakeholder backgrounds assured that a network has been created that will be able to influence policy-making at national level in the different European regions as well as at EU level. Given the scope of the project covering six disease-areas, crucial to the initiation of the selection of experts was the decision by DG SANTE regarding the proposed areas of study submitted at the end of M6/7 as the first part of WP4 (Interim deliverable 2). Having had agreement for the seven areas of specific interest agreed, we could then identify appropriate high-calibre experts.

Defining the type of personal competences of the expertise needed

For self-management to be successful, actions are needed at several levels. Facilitating and hindering factors play a role on both the micro-level as well as the meso and macro-level, within (regions of) EU-countries, as well as in the European Union as a whole. Equally, attention needs to be paid to the types of activities developed within the domains and concepts that underpin self-care, such as self-management, patient empowerment, health literacy[7] and self-medication, and these domains and concepts reflect what we required from our experts. In addition to this, the experts are participating in their individual capacity, also represented through their organisational affiliations key actors that are essential to the implementation and deployment of self-management strategies: patient representatives, carers, primary

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[7] "The personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health." (WHO, 2015)

care physicians, pharmacists, nurses, communication specialists, academics, et cetera. In addition, approximately one in four of the experts were themselves living with chronic conditions and thus brought direct experience of self-management into their work.

Inviting potential experts for the platform

Following the above logic and in line with Technical Specification, a set of balanced criteria was agreed to assess whether potential experts are to be considered a high-quality expert for the purposes of this project. The experts thus identified were invited to apply for candidate status on the platform, by sending in their CV, a summary of achievements and an explanation on the added value they would bring to the platform, and a motivational letter. Experts drawn from the steering group were included based on the original tender submission). For further details, see the Appendices to deliverable D.2.

Specific competencies underpinning the choice of potential experts.

The following five main areas of competencies were defined for the selection of experts:

1. Expertise related to the domains and sub-domains underpinning self-care (self-management, patient empowerment but also health literacy, integrated care, health technologies and self-medication);
2. Expertise related to specific types of activities at EU, national, regional levels;
3. Expertise coming from the fact that experts are individuals with affiliations that represent central actors needed for EU, national, regional, local levels on self-care: primary care physicians, pharmacists, nurses, patients, academia, communication specialists, carers, et cetera;
4. On the ground/'hands-on' expertise in self-care that experts have built up through working in or with hospitals, primary care, municipalities or at the regional level;
5. Expertise on the specific disease areas related to both the original specification in the Call and the evidence based recommendations (i.e. extracted from WP2 and WP3) offered in WP4 part 1: ischaemic heart disease, heart failure, obesity, diabetes, COPD, asthma and hypertension.

As a result of this exercise the final Platform, which was approved by the Commission, amounted to 24 professionals, of which five were members of the steering group, and spread over the five geographic areas of the European Union representing 12 key stakeholder categories. For details, please see Appendices.

3.4 WP5 and WP6

Introduction

This section summarises the work carried out by the Platform of Experts, divided into *core groups,* each of which was allocated one of the five tasks specified in the Contract. There is then a short overview and commentary. The structure of the core groups related directly to the five objectives of WP5 and WP6:

- Policies;
- Barriers;
- Communication Tools;
- Scenarios;
- Innovation.

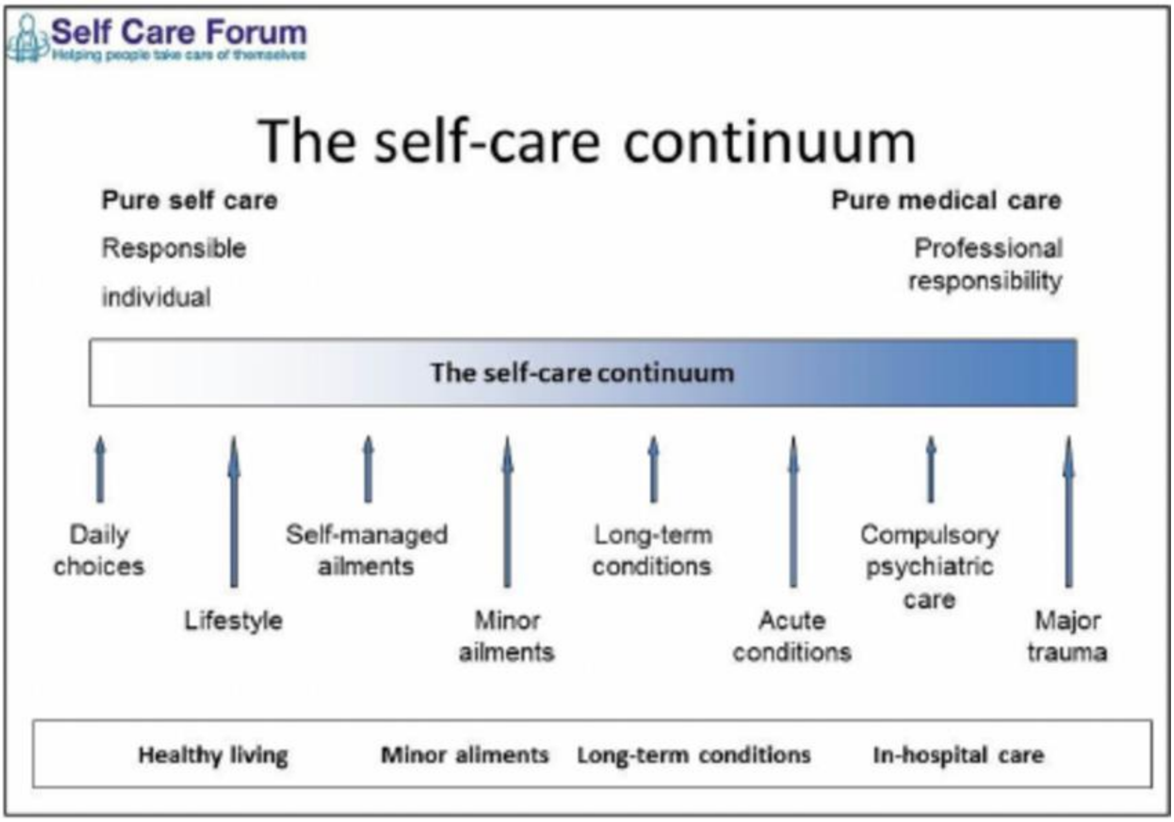
The key elements of the findings and suggestions from each of these five groups follow, each with a direct reference to the wording of the original tender specification.

3.4.1. Policies

The task of this core group was to **develop guidelines for national and local policy makers on how to promote self-care including self-management** (the latter being the focus of this tender).

For the future, we recommend that the European Commission consider developing a mission and a vision for self-care, which include guiding principles. The mission, vision and guiding principles can support decision-makers in Member States to develop national self-care policies, guidelines and action plans that are culturally appropriate, feasible and affordable. A proposal for consideration is provided as part of this report.

Vision on self-care in Europe: In the European Union, all people who need it will have the knowledge, motivation and competencies to implement self-care in their daily lives and to use self-management to maintain and improve health and quality of life in the context of chronic disease, with the support of the community and health system.



Mission on self-care in Europe: To ensure that individuals, families and communities are capable of self-care; that is, to promote, maintain, or restore health and to cope with illness and disability with or without the support of health professionals such as e.g. pharmacists, doctors, dentists and nurses and others. It includes but is not limited to self-prevention, self-diagnosis, self-medication and self-management of illness and disability.

Guiding principles for self-care policies in Europe

To develop these future self-care policies, the expert group discussed and agreed on six key principles:

- Human-centred
- Evidence-based
- Affordable
- Feasible
- Culturally sensitive

- Promoting health literacy

Guidelines for policy-makers on how to promote self-care

From these principles, the experts analysed existing policies and decided on essential structures for these policies. Generally, innovations and best practice approaches should include: policy strategies, availability of self-care approaches, education, implementation and evaluation. Policy is only one of several complex domains related to the self-care continuum.

Notably, modern policies should have these steps:

- Recruitment of community members to use self-management
- Aim to make communities more compassionate places to live
- Support people
- Inclusiveness
- Enable sufficient community participation
- Share experiences
- Disseminate information
- Network
- Fosterdialogue between people and stakeholders
- Integrate at all levels of care
- Focuss on the quality of life
-

The PRO-STEP roadmap for self-care policy development

Using the established principles and the structured approach, the experts developed a roadmap for future policies.

This roadmap builds on

1. research evidence regarding the benefits of self-care and self-management, policy examples from Europe and North-America;
2. in-depth case studies to explore the dynamics around policy implementation;
3. lessons learned from previous EU projects and other workgroups within the PRO-STEP project.

All of these aspects are important for any policy development, but the following proposals (below) are of particular importance when designing self-care and self-management policies:

Essential for self-care and self-management policy design
✓ Ensure sustainability & continuity of funding
✓ Respect professional boundaries; anticipate potential conflicts
✓ Identify champions
✓ Ensure sustainability & continuity of support, esp. professional
✓ Ensure patient-centredness
✓ Ensure use of effective technologies

3.4.2 Barriers that need to be addressed at policy level

The experts were asked to **identify any barriers that may hinder the development of self-care**. Having made an extensive study of barriers, both generic and per disease, described in the body of the report, an extensive survey among the experts was conducted. If the experts would have to choose which barriers to address as a priority they would pick: (lack of) integrated care (13%), (lack of) professional knowledge and skills (33%), values and beliefs of patients (13%) and health literacy (40%).

(*For clarification: from the survey data, looking at the most frequent responses from all participants, these four factors are present in the proportions indicated by the percentages.*)

A strategic approach at policy-making level is needed to support self-management and should focus on three major areas:

- Supporting health literacy, defined as "the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health." (WHO, 2015);
- Providing relevant information, supporting knowledge and developing skills of healthcare professionals to be able to support patients in building up motivation and self-confidence, and support changes in societal beliefs (including those of healthcare managers) related to the perceived benefits of self-management;
- Strengthening systems, healthcare organisations and ensuring adequate resourcing to be able to support self-management.

Multifocal strategies and interventions are needed at EU, national and regional levels, that should address cultural, as well as system/organisational changes and changes at individual as well as at a societal level. Knowledge from the medical field should be broadened via knowledge, approaches and expertise from the social sciences, such as sociology, anthropology, philosophy, psychology and others. If certain diseases are selected as the focus of interventions, it is worth noting that specific barriers may feature to a different degree in the different diseases.

Action plans may in the short term address the barriers that have high impact and seem to be the ‘most easy to tackle’ barriers, that are related to strengthening health literacy with respect to how to navigate in the system, supporting patients' self-efficacy, developing the knowledge and skills of healthcare professionals and increasing the effectiveness of communication among team members.

In the intermediate term, changes in system/organisation and resourcing have to be planned. In the long term, changes in culture (i.e. the beliefs and expectations related to health and healthcare, availability of support from family/friends, and personal difficulties with lifestyle changes, and personal values, attitudes and beliefs) will have greater importance.

3.4.3 Communication Tools

(‘Propose and design communication tools aimed at patient/consumers to improve prevention and disease management’)

The Platform of Experts has proposed and designed communication tools to improve prevention and disease management – including self-prevention, self-diagnosis, self-medication and self-management of illness and disability.

Some areas already have many proven communication tools, while other areas might lack good working tools. This proposal task includes **identifying and involving local target groups in the development process, implementing the communication tools, exploring the fundamental requirements for effectiveness, and possibilities for local adaptation to specific needs.** The Platform of Experts also offers suggestions on how to measure and evaluate results for both dissemination and benchmarking purposes.

Structure of the Communication Tools Report

1. Checklist for better communication tools, including advice about identifying and involving local target groups.
2. Results of the survey looking at specific and a general expert group using communication about self-care.
3. Three specific design guides for three communication tools needed for knowledge sharing and issues management
    a. A website repository and advice platform – PRO-STEP Portal
    b. A cartoon-style video promoting self-management, called PRO-STEP Portrait.

    c. A series of publications in a pdf format for easy sharing and download called PRO-STEP Pages

4. A guide to implement the PRO-STEP Portal, Portrait, and Pages in Europe.

3.4.4 Scenarios

(‘Propose scenarios for EU collaboration’)

Methodology used by the group

There is no single preferred methodology for scenario development, or indeed a single type of preferred scenario. Scenarios are not predictions [1]. The PRO-STEP Platform of Experts took as its cornerstone, the previous work done within the EMPATHIE project on patient empowerment in chronic disease (EAHC/2013/Health/04), which developed four potential scenarios for EU collaboration between stakeholders on patient empowerment. However, it should be noted that the EMPATHiE project benefited from a far longer timeframe and resources, with an entire work package dedicated to scenario development, and thus allowed for the implementation of a full stakeholder consultation process. Such an extensive process was beyond the scope of PRO STEP. Therefore, the resources available determined the approach adopted. Methodologically, it fits best within the characteristics of pre-policy decision support (van Notten, 2006). The approach is explicitly *normative* – the goal of promoting self-management is acknowledged as a desirable end – and the scenarios aim to identify *driving forces, opportunities and dangers for policy development* – in our case focusing on identifying the key stakeholder groups whose support and engagement is needed to ensure effective future policy, as well as other societal factors that need to be considered. The approach of the group adopted was *intuitive* – that is, depending on qualitative knowledge and insight – and *participatory* – that is, with ideas generated by the participants and explored during PRO-STEP workshops. This was the most logical way of benefiting from the expertise of the Platform of Experts, selected by the Commission, for their experience and insight. Qualitative inputs are typically used in analysing complex situations characterised by high levels of uncertainty, when relevant information is scarce.

The group felt that the work in EMPATHIE was useful as a precedent: those scenarios were purposely framed as explorations of different aspects of patient empowerment and their implications for stakeholder engagement, rather than alternative futures, as this was deemed more relevant for policy. We approach the scenario not as a story [2] but as a framework exploring benefits, disadvantages, risks and success factors, as this is deemed more relevant for informing future policy. Thus, the present group decided to adopt the EMPATHIE scenario framework with minor modifications to suit the needs of the tender.

The adopted framework consisted of the following elements:

- Vision and objective;
- Rationale;
- Method(s) of implementation, including stakeholders, target groups, evaluation;
- Opportunities/benefits for different stakeholders;
- Challenges/risks for different stakeholders;
- Key considerations for success;
- EU and/or Member State competencies, EU policy relevance;
- Costs and cost-effectiveness;
- Proposed milestones for short/medium/long term, where feasible.

The group chose to present two horizontal (i.e. not disease-specific) and two vertical (disease-specific) scenarios in order to to illustrate barriers and opportunities in realising self-management. The drafting of each scenario was led by one member of the group, with discussions within the group to develop it further. Four scenarios are contained in the report: one exploring the possibility of developing a self-management "core" model; disease-specific scenarios on obesity and COPD; and a horizontal scenario exploring the possibility to promote informal care. We note that none of the scenarios should be considered fully complete or definitive in and of itself due to the inherent lack of information available to the group.

3.4.5 Innovation ('Propose innovative approaches for the development of self-care')

A review of literature was undertaken in order to get more insight into the concept of innovation in health. Using material from this review, a working definition of healthcare innovation for use in the PRO-STEP project was produced, along with a review of the available taxonomies of innovation.

The next task was to develop a classification tool. In order to test its utility, 32 examples of systematic reviews of the effectiveness of self-management interventions were extracted from the results of WP2.

It was concluded that the most rational approach was to examine case examples from the viewpoint of: a) originality or ‘newness’, b) effectiveness and c) degree of diffusion or implementation.

Having found many examples of incremental innovation but little that went beyond that, the same approach was applied to a set of 50 EU projects also collected for the WP2 review. As only six specifically dealt with self-care in chronic diseases and of these, only one seemed to meet the criterion of being more than incremental innovation, we asked members of the PRO-STEP Expert Platform to offer what they observed as examples of innovation within their specialist fields. Of these examples, a few were analysed in more detail.

It was concluded that the attempt to define objective measures of innovativeness was not practical, but a descriptive classification helped to clarify thinking about the potential value of an intervention. We proposed the idea of an ‘innovation lens’ or way of looking at innovation(s) which brings together the issues that arose from attempting to identify novel approaches to the development of self-management of chronic diseases.

Examples of these are: that there is a substantial amount of incremental innovation, which from another perspective would be called quality improvement. On the other hand, the process of ‘emergent’ innovation becoming transformational is inevitably lengthy and unpredictable. Self-management in chronic diseases, with or without new technologies is itself a case in point of emergent innovation. Human factors are a major influence on the adoption of new methods whether at the level of the individual patient (behaviour change and health literacy issues) or at the organisational level (readiness for change). Co-production, here defined as professionals and service users working meaningfully together to create new products or services that genuinely reflect user-identified needs and are experienced as 'user-friendly'', whether in early technical product design or in process re-design, is a crucial component in bringing about effective change and it also helps ensure that innovation meets patient/citizen needs and can improve quality of life, especially relevant for those living with and managing chronic diseases.

3.4.6 Final commentary and reflections

Work in progress

The five areas that WP5 and WP6 encompassed each had a dedicated team of experts looking into the challenges, potentials, structuring, and summarising of these objectives – always also looking to consistency with the findings of WP2 & 3 and the earlier work done in other EU-projects, especially in EMPATHiE and PiSCE, but certainly also in the JA CHRODIS, which some of us took part in and Action group B3 of EIP-AHA (integrated care), again, which several of us are currently still involved with.

Those of us that participated in managing all three of the projects recognise the origin of the funding and the interest that prompted this call for a pilot project in this field. That vision is identified in the wording of *C (2013) 4940 final,* the financing decision by the Commission in October 2013 to fund four pilot projects, one of which was 'to put in place a framework for action to enhance self-care at EU level and develop strategies to support the broader implementation of effective self-care.'

"These objectives shall be achieved by:
1) An independent cost/benefit analysis of self-care oriented health systems in the European Union and the current frameworks in place to enhance self-care oriented heath care systems and patients' empowerment.
2) The creation of a platform of experts in self-care and healthcare gathering cross-functional stakeholders such as policy makers, patients' groups and healthcare insurers and consumers. In the process of analysing further action to take at EU level, the platform shall build on the outcomes from the above-mentioned cost/benefit analysis and take account of the call for tender in work plan 2013 to the Health Programme (2008-2013) "Empowering patients in the management of chronic diseases"
Activities foreseen will, among others, be publication of a guideline on how to promote self-care and patient empowerment and preparation of different communication tools on prevention and disease management."

While some of that vision has been realised by the activities required by the PiSCE and PRO-STEP tenders, it is evident that other aspects have not and this potential additional work will be addressed later.

Sustainable health
The vision and subsequent decision to strengthen the understanding and framework for self-management and self-care in Europe has allowed the involved stakeholders, in the PRO-STEP project specifically, but building on the work from the previous two projects (and allied work from undertaking such as the EIP-AHA and Chrodis JA) to gain and share insights and understanding of the intricacies of the healthcare systems and political frameworks across Europe which provide the context for the necessary change which will be needed in order to realise the vision.

Looking across the findings of PRO-STEP it is perhaps obvious and striking at the same time, that the need to enhance health literacy in Europe underlines most of the recommendations (and the fact that the same theme runs through the findings and recommendations of PiSCE and EMPATHiE is no coincidence). There is quite clearly a need for a holistic, strategic, and dedicated effort to bring a stronger understanding of health and prevention to the hearts and minds of Europe, as this will not only enhance health, but also improve quality of life. The aim is for Europeans to lead longer, healthier lives, but also to create a more sustainable lifestyle to the benefit of society, the economy and the environment alike. Shifting the balance from a preoccupation with ‘illness care’ to more investment and appreciation of the value of prevention of sickness and promotion of good health is one aspect. Equally, for healthcare systems themselves to remain sustainable in the light of the increasing burden of chronic disease management, it is logical that effective self-management is a potentially crucial factor.

More work ahead?

Whilst promoting health literacy creates a strong argument for further efforts and changes in the educational system, healthcare communication, development of healthcare communication tools and so forth, these essential activities seem to imply the need for more collaborative, co-ordinated policy action both at European and Member State levels, always with the involvement of key stakeholders particularly patients and healthcare professionals.

The benefits of patient empowerment still merit further exploration, as the indications from the three related projects suggest that organisational and sociological issues would also be central to address in addition to the political framework and support, or the communication possibilities. Although scenarios for EU collaboration on patient empowerment were an output of the EMPATHiE project, the guideline for promotion of patient empowerment mooted in the 2013 Commission Decision has not been requested nor created so far. It must be stressed that this goes beyond promoting self-management but includes promoting shared decision-making (for which published evidence is less well established than for self-management but steadily accumulating) as well as (yet again) education of both patients and health professionals to facilitate the implementation of this principle.

Although not featured in the original tender specification, following discussion during the kick-off of this project, it was agreed with the Commission (quoted in the PRO-STEP inception report) that ‘Technology, particularly eHealth and mHealth will be considered throughout the tender as relevant.’ In 2013, it could not have been foreseen how quickly technological development in these areas has progressed in the area of self-management. However, such developments also bring with them the challenges of integration, data quality, data security, and equal access to health together with considerations such as digital literacy, again, both of citizens/patients but also of healthcare professionals. Another major challenge is that of collaborating across traditional ‘silos’. This is what is being attempted both in the EIP-AHA with DG SANTE and DG CONNECT and also to some extent in relevant current projects of Horizon 2020, and the experience gained demonstrates how difficult cross-boundary work of this kind can potentially be. However, as already noted, this is an area where there is potential for step-change innovation.

As a final comment, the newly formed high-level Steering Group for Prevention and Promotion, is hoped to also positively influence this area of policy development.

3.5 WP7 Dissemination and Conference

EPF has been the leader of this WP, in cooperation with all partners of the Consortium to bring together a complete, coherent and balanced representation of the project results.

The overall aim of this work package was to make sure that the outcomes of the PRO-STEP project would reach not only the "usual suspects" (health system stakeholders – policy makers, healthcare professionals, patients), but also the wider population, such as the general audience and laymen. The second main objective of the WP was to organise and deliver a final closingconference of the project.

Under this work package four main tasks had to be delivered:

Task 1. Dissemination strategy development:

The development of the dissemination strategy has been done in close interaction with all other work packages and took into account the different tasks, the results achieved, and the challenges encountered by them. Based on this input, we have identified the goals for successful, optimal, targeted and resourceful dissemination. A stakeholder analysis, drawing on knowledge gained in the EMPATHiE project and the PiSCE tender, identified key target audiences at European, national and local levels. Key messages were identified for each target audience in close collaboration with the relevant WP and agreed by the project steering committee. All methods of project outcome dissemination have been agreed with the European Commission throughout the duration of the project.

Task 2. Proposed dissemination channels:

In this task, EPF has proposed key dissemination channels to ensure effective dissemination of the project outcomes. Twitter accounts of the Project Consortium have been used as a powerful tool to promote the project outcomes during the two-day Conference, taking into account the opinion of the European Commission. The monthly EPF newsletters have been promoting the pre-and post Final Conference outcomes. The EPF website has always been a powerful tool in promotion not only to the EPF's 74 European and national Member organisations, but to the general public as well.

Task 3. Closing (Final) project conference:

The Project Consortium, led by EPF, organised and delivered an intriguing Final Project Conference. Prior to the Conference, this work package had envisioned the following objectives:

- Conference facilitation;
- Production of a follow up report;
- Development of a thorough conference communication plan, including materials; and a social media plan;
- Creation of the Conference agenda, giving visibility/floor to the widest possible healthcare stakeholders viewpoints;
- Identify, invite and support speakers/panellists and/or moderators (see biographies in the Annex of D6).

Task 4. Production of dissemination tools:
To ensure dissemination to a wider public, an external video editor and graphic designer have been brought on board in order to develop two key promotional deliverables:

- a Fact Sheet to promote the Project's outcomes during the two-day Conference and after the Conference itself (see Annex D6);
- a promotional video to describe the whole project.

Final Conference

The main objectives of the PRO-STEP Final Conference were (a) to bring together relevant stakeholders to raise awareness of the PRO-STEP project, its outputs and results; (b) to explore specific issues, such as barriers, opportunities and needs of different stakeholders in different EU Member States, (c) to share effective self-management strategies and lastly (d) to collectively reflect on follow up actions needed to promote self-management in Europe.

Key Outcomes and Further Discussions

During the Conference, there were 10 individual presentations, representing the viewpoints of: a young patient with a chronic condition, academia and research centres, healthcare professionals from different disease areas, PRO-STEP project partners and various patient organisations and a patient innovation platform. Overall, topics discussed during the Conference can be summarised into the following categories: **cost-effectiveness and self-management**; **innovation and self-management**; policies needed, existing barriers and communication tools in self-management today; including **patients' experiences** in self-management. Furthermore, there were two intensive panel discussions: one was dedicated to cost-effectiveness during day 1 and the other aimed to present innovation in healthcare, putting self-management in the spotlight. EPF and the Project Consortium made sure that the speakers, presenters and panellists came from various backgrounds and represented as many healthcare stakeholders as possible, in order to achieve a higher number of opinions heard.

Key messages: As a starting point, although PRO-STEP is part of the EMPATHiE/PiSCE/PRO-STEP trilogy of projects, there was a clear differentiation between what self-care is and what self-management is; **Self-care** is related to *"the actions people take for themselves, their children and their families to prevent and care for minor ailments and long-term conditions and maintain health and well-being after an acute illness or discharge from hospital" (See D6)*, while **self-management** in long term conditions *involves the tasks a person can perform to minimise the impact of that illness on his/her health status by him/herself, or with the support of a healthcare provider* (See D6). And yet, for the purpose of the project, and especially during the Final Conference, in many occasions, both self-care and self-management concepts were used interchangeably. The audience received a strong message from a young patient representative, and later by other presenters and participants who all stated that **health literacy** (HL) (working project definition: *"The capacity to obtain, process and understand health information and to use it to make decisions about health and healthcare")* from early age is crucial when it comes to self-management of chronic conditions. Another very important point on HL was that it can be described as a two-way journey 'it is not only the people/patients that need to learn how to navigate the healthcare system, however the system needs to change and incorporate important issues such as multi-morbidity', which is a major challenge today. As a last point on health literacy, it was agreed that the lack of HL can lead to an even larger burden on the healthcare systems today, and furthermore, HL should play a central role and not only in the context of self-management of chronic conditions. The presentation on the Cost effectiveness of HL took place prior the cost effectiveness panel opening the scene for further discussions. This panel discussion was dedicated to **cost-effectiveness** and self-management. As a main argument, it can be highlighted that self-management interventions can be effective from healthcare system point of view and therefore are worth investing in. As a reality check, it was well-recognised that healthcare (and medicine in specific) is meant to be about health and better outcomes for patients and not economic rules, such as supply and demand. However, recognising the limits of financial resources is very important as well, thus there is a need to prove beyond doubt that it is worth spending money in the present day in order to harvest good results in the long term. Patients need to be empowered; their health literacy is of vital importance to the future of healthcare (systems).
During the second day of the conference, the main topic of the discussions was (patient) **innovation** in healthcare and respectively in self-management. One of the

biggest challenges for innovation progress in healthcare today is the fact that a major change needs at least three years to be achieved, however every two years governments change and/or adapt different parts/segments of their healthcare system, which leads to poor implementation results. At the same time, it is certain that technology will continue to drive the development of self-care/self-management as it has been the case for the last few decades and all stakeholders in the healthcare ecosystem should take this into account. At the same time, innovative solutions provided by patients for patients is a reality today. While realising the potential risks for patients’ health when it comes to solutions not always validated by the central governments, there are definitely great opportunities to be discovered and invested in for the future. Today, patients are innovating and taking initiatives into their own hands for better self-management outcomes.

Final Remarks: Both participants and presenters agreed that major improvements have been made to the present time in self-management, however there is a need for a constant improvement of the conditions and tools that patients have at their disposal in order to achieve better outcomes not only for the patient, but for the healthcare system as a whole. Self-management is about working together more effectively- patient(s), network and professionals. There is a gap between the people/patients and the policy that must be closed. A potential strategy could be to “keep” this gap as little as possible by trying to offer solutions which will have more successful outcomes e.g. through having been co-produced and this automatically will convince the policy makers to act accordingly.

Background Information: The Conference took place over two days and the structure was a mix of plenary and working group sessions to encourage high-quality, interactive collaboration that facilitated meaningful understanding of the topic, its relevance and applicability. The Conference was professionally moderated by an external facilitator. Following the Conference, an internal evaluation was conducted in accordance with key indicators linked to the objectives of the meeting. Overall, the two-day Conference, held on 23-24 October 2017, was very well attended by nearly 100 participants, representing *21 European countries*, fromnumerous stakeholder groups, and debates and discussions were fruitful, practical and full of innovative ideas on the improvement of self-management on the European continent. The participants represented a wide spectrum of stakeholders in the healthcare sector: a). patient representatives in the selected disease areas; b). healthcare professionals (doctors, nurses, pharmacists, health managers and others); c). payers, e.g. national health insurance organisations; d). EU Member States’ policy-makers at national /regional levels; and finally, e). industry and commercial actors, e.g. pharmaceutical, MedTech and ICT industry.

For a full profile/list of participants see AnnexD6

Dissemination tools:

1. Fact Sheet Development

The Project Consortium developed a comprehensive and coherent informational leaflet (A4 format, two-sided), focussing on the major project results deriving from the Interim Report D4 (see Annex D4). During the Final Conference, the leaflet was presented to the audience and waswell-received. The purpose of the leaflet was to promote the Project's findings in a concise and easy-to-read format not only to policy makers, HCPs and patient organisations, but to the general audience as well.

2. Promotional Video

The Rationale behind the development of the Promotional Video was to present a snapshot of the Project, shed some light on the main achievements of PRO-STEP and at the same time visualise the success of this tender project and be used as a dissemination tool for further promotion of the Project's results. Promotional video link: http://www.eu-patient.eu/whatwedo/Projects/prostep/

4. Conclusion

In this section, we present a number of key points and recommendations for further action in order to promote self-management of chronic diseases in Europe. We stress that no one single strategy will be effective, as this task will require changes at all levels: individual (patients, citizens, professionals), organisational (hospitals, primary/community care) and systems (governance, policy, financial management), as well as addressing cultural factors. Thus, multi-focal strategies and interventions are needed.

4.1 Key message: a strategic approach is needed at European level

There is a need for a holistic, strategic, and dedicated effort to shift focus onto health promotion and disease prevention, in order to enhance people's health, but also improve quality of life. Supporting patients' capacity to effectively self-manage chronic diseases is entirely consistent with this aim. The need to enhance health literacy is at the heart of promoting self-management, consistent with and reinforcing the findings of the previous related projects, PiSCE and EMPATHiE. Knowledge from the medical field is important but needs to be broadened via knowledge from the social sciences, such as sociology, anthropology, and others. A strategic approach should be adopted at European level, supporting change at national and regional/local levels.

4.2 Recommendations for policymakers and other stakeholders

We have opted not to target specific recommendations for different stakeholder groups, as we felt that may place undue responsibility on one single stakeholder group whilst undermining the fundamental message that *promoting and realising effective self-care, including self-management, in the European Union is a matter for all stakeholders acting in concert*. Health professional skills and competencies, for example, are not only a matter for the professions but also for national governments and regulators, the European Union (through its workforce policy), and of course for patient organisations in order to ensure that skills and competencies are focused on the needs of patients.

A European vision and mission for self-care

The European Commission should develop a *mission and vision* for self-care, including self-management of chronic diseases, which includes *guiding principles*. These are in our view necessary to effectively support policy and practice in Member States to develop self-care policies, guidelines and action plans at national, regional and/or local levels that are culturally appropriate, feasible and affordable to implement. It is also necessary to adopt a consistent approach in view of the persistent *health inequalities* across but also within EU Member States, which form an important barrier to making self-management a reality for all regardless of socio-economic status or cultural background. Investment possibilities through the EU Structural Funds could be explored.

As part of the above, Guidelines for the promotion of patient empowerment (as called for in the 2013 Commission Decision) should be developed at European level, in collaboration with patient organisations; they should address the three aspects of empowerment identified by the EMPATHIE study – self-management, health literacy and shared decision-making.

Key elements of a strategic self-care policy

A strategic approach at policy level should encompass at least the following areas:

- A strategy and action plan for increasing *health literacy*, including monitoring (e.g. via regular Eurobarometer surveys and by including health literacy measures in routine European health system statistics);
- Ensuring adequate *knowledge and skills* of all relevant healthcare professional groups that play a role in supporting self-care – at European level there is potential scope for developing a "core curriculum" or core set of competencies for professionals' training focused on self-care and self-management support as well as patient-centred skills on the lines of the key recommendations of EMPATHiE;
- Promoting changes in *societal attitudes*, including those of healthcare managers and professionals, related to the perceived benefits of self-care;
- Strengthening relevant systems, structures and organisations, ensuring adequate resourcing of support for self-management.

The following *key barriers* should be addressed as part of any self-care strategy:

- Lack of or low health literacy, communication with hard-to-reach groups including people in a position of vulnerability (economic, social or cultural);
- Health inequalities;
- Navigability of the health (and social) care system;
- Professionals' knowledge, attitudes and skills;
- Lack of integration and co-ordination in healthcare, including teamwork and communication.

If certain diseases are selected as priorities for policy and practice, it should be noted that the barriers may be quite different from one disease to another.

Cost-effectiveness of self-management needs to be assessed in a societal perspective

Self-management interventions can be cost-effective, but not necessarily so. Therefore, self-management interventions that are identified as effective in studies *should also be tested for cost-effectiveness*, in order to avoid spending resources on self-management that would generate more health elsewhere in the healthcare system.

Cost-effectiveness analyses of self-management interventions have paid too little attention to costs and benefits in wider society, i.e. outside the healthcare system, such as productivity losses, costs to patients and families, informal caregiver burden, and costs in life years gained. Future studies should *adopt a societal perspective* in the analysis of self-management.

In view of the limited published evidence, however, no straightforward conclusions can be drawn about cost-effectiveness and caution should be exercised before interpreting lack of evidence as lack of (cost-)effectiveness.

Health literacy is of critical importance

Better integration of education for professionals and for the public – in other words, the need for higher health literacy levels in society – is a key conclusion in the work on barriers. This would call for stronger interaction between the ministries responsible for health and those responsible for education in Member States.

Communication should be seen as a key investment

Resources spent on communication are often used or seen as add-on, even though this is often the core tool of self-care initiatives. Policymakers should invest appropriately in professional communication expertise and ensure that communication efforts are carefully evaluated and subsequently published, as they could be shared across Member States as a resource to improve communication in self-care and public health generally.

Policymakers and other stakeholders should make use of and further disseminate/publicise the PRO-STEP communication tools and guidance. The PRO-STEP website repository and advice platform (PRO-STEP Portal) should be eventually hosted on an EU platform to ensure it remains accessible also in future.

Innovation should be encouraged and supported

Policies should allow room for innovative measures – carefully evaluated – as well as best practice approaches; there is still much to learn in how to support and nurture self-care and self-management.

An important caveat should be borne in mind when it comes to the evidence-base for innovative practices. Policymakers often wish to implement innovative practices that are proven effective– which is something of a contradiction in terms. Innovation often starts from “bottom up” and is often specific to a context, such as a community or organisation; a truly innovative practice will by definition not necessarily have a solid evidence base behind it. In order to thrive, such innovation does need the right kind of support from the “top down”, e.g., through relevant policy and appropriate resourcing.

The potential role of digital technology in supporting self-care should be explored

While digital health is widely recognised as a potentially extremely fruitful field for development, and indeed there is already some impact in specific chronic conditions such as diabetes and some respiratory conditions, there is a risk of fragmentation of policy and practice – and as a consequence, less effectiveness and efficiency – unless great care is taken to ensure an integrated approach. Greater synergy is required between the numerous current initiatives, including the Digital Health Society launched during the 2017 Estonian Presidency of the EU, the output of the European Institute of Technology (AIT) on health, the recently launched Chrodis Plus Joint Action, and the work of DG Connect on the Digital Single Market – this being far from a complete list.

Further research should be supported to fill in gaps and further strengthen the evidence-base

The lack of evidence regarding cost-effectiveness of self-management interventions in chronic conditions should be addressed by a study/-ies funded under the European research instruments, such as the future research programme (FP9). Specific calls should be co-developed with patient organisations, and an appropriately resourced role for patient representatives should be built into the design of the studies, to ensure that their outputs are useful and relevant to patient needs.

To gauge the true cost-benefit / cost-effectiveness of self-management interventions, appropriate methodologies are needed to calculate financial impacts of interventions beyond the healthcare budget, such as in employment and social welfare.

5. Next Steps

> *The Road goes ever on and on*
> *Down from the door where it began.*
> *Now far ahead the Road has gone,*
> *And I must follow, if I can,*
> *Pursuing it with eager feet,*
> *Until it joins some larger way*
> *Where many paths and errands meet.*
> *And whither then? I cannot say.*
> (JRR Tolkien, "The Fellowship of the Ring")

Aside from the important findings and recommendations about self-care and self-management arising from the PRO-STEP project, as well as collectively from the three projects EMPATHiE, PiSCE, and PRO-STEP complemented by the case findings of the CHRODIS Joint Action, these projects have also led to a much stronger linkage between European project partners and stakeholders active within the self-care continuum.

The consortium partners, their networks, the conference participants, the communication recipients, and the wider arena of stakeholders within this area of healthcare – from analysis and research to clinicians and practicioners, all the way to strategists and futurists – our increased dialogue has led to many new connections and a recognition of the need, challenges, and potential for change.

Therefore, this section lays out our proposals for future steps to continue this dialogue and collaboration locally, nationally, and internationally.

Initiatives

A widening network of experts and organisations have formed the Self Care Initiative Europe – or SCiE. The SCiE is meant to support a continued mapping of a European network of self-care experts, projects, cases and organisations, to provide a forum for political and strategic dialogue about self-care at a European level, and a continued and hopefully expanding effort to ensure citizen engagement in self-care.

Engagement campaigns already exist at a national level in the UK, Denmark and Sweden, and to lesser degree also in the Netherlands and Austria. Towards 2018 and beyond the hope is to build an expanding Self Care Week Europe that can provide awareness, political impetus, practical and communication guidance towards better use and understanding of self-care across EU Member States – in People's daily lives and in healthcare strategies.

Meetings

At a political level, the consortium partners in PRO-STEP will join forces in engaging Members of the European Parliament (MEPs) in 2018 for a collective discussion about self-care and self-management as an effective strategy in chronic conditions as well as minor ailments. A first step will be a meeting held in the first half of the year in Brussels for MEPs across the Member States and across the political spectrum and policy areas (including health, education, labour, internal market, housing, and environment) as the area has multi-faceted implications for society.

For organisations and decision-makers, the SCiE is arranging a summit conference in Copenhagen on 11-12 April 2018 entitled "Future Healthcare AD2030", which aims to gather a significant part of the wider stakeholders in the area for discussions about future strategy, investment, incentives, engagement, and links to sustainability goals and efforts.

Networks

In addition, the many strong partners that have been part of these projects will continue to carry forward the recommendations and ideas generated in their individual activities and their European and international collaborations. For the European Patients' Forum, this will entail presentations and discussions at meetings involving their membership, with stakeholders and policymakers, and at conferences, as well as integrating the findings into EPF's future policy and advocacy work; for the European Health Futures Forum this will entail strategy workshops for members and partners; and for the Danish Committee for Health Education this will entail including this topic in the large Danish Folkemødet-event.

Projects

The consortium partners will carry on working on better self-care and self-management in other project structures. Already, a number of partners are involved in the Horizon 2020 "Compar-EU" project, led by FAD and IMTA which will gather more knowledge about the assessment of self-management interventions.

Similarly, EPF, EHFF, DCHE, and the NIJZ are involved in the CHRODIS PLUS Joint Action to further explore and use the findings of EMPATHiE, PiSCE, and PRO-STEP in this strategic, Member State-driven project.

Discussion

Finally, it is important to recognise that there are even more and wider implications for self-care, including self-management, that we have yet to fully explore and touch upon and which were out of scope of the present project. Four of these are education, mental health, antibiotic resistance, and digitisation.

- In ***education***, the inclusion of health literacy (as both a goal and a strategy) and of self-care and self-management as topics, is a very long-term strategy but one that is vital for the future health of Europe. This will require a widened dialogue including the educational system and actors to ensure that these "health" issues are not seen as an extra requirement, but integral elements of a wider societal transformation.
- In ***mental health***, our understanding of self-care and self-management will need new paradigms, as we move outside of the area of somatic diseases. Recognising the close inter-linkages between physical and mental health as well as the specificities of mental health conditions, clearly there are many more possibilities for across the continuum of health promotion, prevention, self-management, and self-care, but these do need additional focus and interest.
- In ***antibiotic resistance***, there are a number of good initiatives already underway. However, many of these – whether national, European, or global – are looking mostly at research and regulation, whereas targeted prevention of treatment-requiring ailments is not fully explored. Especially the area of prevention of urinary tract infections (UTIs) is showing very positive signs, but this needs further implementation and wider use.
- In ***digitisation***, there is an abundance of new techniques and tools emerging to enable new pathways of communication and support. These should be explored and mapped better in the coming years, but also scrutinised in terms of their implications such as data security and other implications for users.

Future of self-care and self-management

We are all deeply committed to our work to better implement, understand and support self-care and self-management – and as mentioned above, will continue to drive this work and the self-care agenda onwards. Exactly where this road will lead us is of course yet unknown, but we are convinced it will help create more sustainable and people-centred European health systems.