

Pilot project on the promotion of self-care systems in the European Union. Platform of Experts.

Final Report Contract No. Sanco/2013/D2/027-SI2.682650

2014-2017

European Union, 2017

Reuse authorised.

The reuse policy of European Commission documents is regulated by Decision 2011/833/EU (OJ L 330, 14.12.2011, p. 39).

For reproduction or use of the artistic material contained therein and identified as being the property of a third-party copyright holder, permission must be sought directly from the copyright holder.

The information and views set out in this report are those of the authors, the PiSCE Platform of Experts and do not necessarily reflect the official opinion of the Commission. The Commission does not guarantee the accuracy of the data included in this report. Neither the Commission nor any person acting on the Commission's behalf may be held responsible for the use which may be made of the information contained therein.

Table of contents

1.	EXECUTIVE SUMMARY	4
2.	SELF-CARE IN CURRENT EU-POLICY	6
3.	THE PISCE PROJECT	14

REPORTS

SECTION 1 – GUIDELINES FOR THE PROMOTION OF SELF-CARE	29
SECTION 2 - GUIDELINES FOR COMMUNICATION TOOLS	136
SECTION 3 - POLICY RECOMMENDATIONS	205

1. Executive Summary

The future of Health Care – Integration of Self-care and Patient Empowerment

Evolution is a fact of nature. And naturally, evolution of the health care systems in Europe should be seen as such – a constantly, evolving mechanism to help citizens lead good, long, and healthy lives that changes and adapts to new circumstances as the demographic and socio-economic parameters in Europe change also. For the Platform of Experts this recognition - and the recognition that self-care, selfmanagement, patient empowerment, and also the role of the health care systems are part of the same continuum and should provide good interaction at a multitude of levels – has been at the center of our work.

Having had to base our work on 5 preselected minor ailments has both focused our work, but also helped the Platform of Experts to recognize how widely applicable the advice and tools could be. Self-Care within these 5 minor ailment categories of course has some specific characteristics, but even more so, the characteristics of good self-care seem to be applicable to a wider range of ailments – suggesting and supporting the recommendations that a wider and stronger investment within the EU towards self-care would have very significant impact on the health and wellbeing of the citizens of EU.

Guidelines for promotion of Self-care

The work to produce the guidelines for promotion of self-care has led to an extensive and elaborate body of work that can help at macro-, meso- and micro-level.

We believe that the guidelines to be the most ambitious and detailed of their kind within these five minor ailments that the PiSCE project centered on. We believe that similar guidelines on other minor ailments would be far easier to produce from now on, building on the bedrock of the guidelines created here.

Guidelines for Communication Tools

During the project the Platform of Experts also recognized that good communication within health care is not only about the specific tools. It is about the underlying principles of involvement of and considerations about the needs of the target audiences – especially in terms of health literacy.

Creating the guidelines for communication tools, it has also become clear that while the health care system is quite used to evaluating medical procedures, structured evaluation of communication efforts are not equally prioritized, and this impairs the dissemination of good communication practices within health in Europe.

Policy Recommendations

After an extensive discussion about suggestions for policy recommendations the Platform of Experts has produced a targeted, central, and essential list of recommendations, that we believe (if implemented) would fundamentally modify the

attitude towards health in Europe, with a much higher engagement and empowerment of the citizen – allowing for not only better lives when experiencing minor ailments, but also creating a better basis for self-management when chronic conditions arise as well as having potential economic benefits.

Even more important, the work of the Platform of Experts – drawn from a very wide range of fields, competencies, and countries – was not done by voting, but by consensus. The policy recommendations are therefore not only ambitious but also widely supported through the communities represented.

The project process

The PiSCE project was originally expected to take 18 months. This is a very useful time frame to create the results needed, but sometimes the bonds and interactions between the participants can only evolve so far in such a relative short period of time.

While the fact that the PiSCE project was considerably delayed as the original Project Lead had to file for bankruptcy, which was quite unexpected, the positive effect has been a much strengthened interaction between the remaining partners as the overall time frame of PiSCE will now have been almost three years.

We are quite proud – aside from time to legally clarify assignment of a new Project Lead – that timeframes and deadlines of the project have otherwise not been delayed. In light of the ambition of the project to create a strong Platform of Experts to support the implementation of self-care in Europe for minor and self-limiting conditions, this has provided one of the best ways to achieve commitment and engagement.

The future of Self-care

The work and experiences of the PiSCE Platform of Experts have shown that there is a strong and ambitious support for improved self-care across all stakeholders. Though the idea to focus on self-care initially has been seen by some as a kind of implied criticism of a perceived flaw in the health care systems in Europe, we believe that it has been shown to be a quite natural direction to take. The changing socio-economic landscape of Europe combined with the fact that the populations are more engaged in their own health than ever before creates a good environment for evolution of the entire society towards a more diverse, yet personalized care – sometimes supported, other times not - that will allow for better health and wellbeing for the individual.

This also signals necessary change for the health care systems themselves – mostly by encouraging stronger listening skills, better cooperation within the systems, and by a direct and supportive interaction with citizens that is based not only on the ability to provide care, but in the ambition to be more caring.

2. Self-Care in current EU-policy

Most healthcare systems within the EU, are setting up policies to stimulate the support of self-care, self-management and patient empowerment, and are looking at how and where these services could and should be offered by health professionals. That is, to identifying ways in which the public could be encouraged to be proactive in taking care of themselves and their health and to use healthcare services more effectively.

Good practices, guidelines and concrete policy actions will help professionals managing these systems to take the next steps in the implementation. This will be subject of this project as well as to identify facilitating factors and barriers that influence the process of successfully implementing, embedding and sustaining self-care in the EU.

2.1. Definition of Self-Care and a rationale for enhancing it

2.1.1. What is self-care?

Self-care and patient empowerment are promising areas that can support patient centered care and the effective and cost-effective utilisation of healthcare systems and resources. Self-care enhances patients' ability to be proactive with the support of professionals. In European society, this is an important theme as the burden on healthcare systems is growing significantly. As an increasing number of people are living longer and at the same time are living with one or more long-term condition and/or with minor or self-limiting conditions (Joint Aging Report EC, 2012). At the same time, the healthcare workforce will shrink in most European countries by 10% as a result of demographic developments between 2007 and 2025. Moreover, health problems and disease leads to loss of participation and labour productivity.

This poses a challenge to the healthcare sector and an opportunity for business, especially now while governments seek to deliver healthcare during a global economic crisis and in times of austerity. It implies more use of innovative technology and a transition from strict professional care to new combinations with self-care and informal care. Despite the large number of initiatives that have been undertaken in the last decade, self-care programs are still not available for the majority of citizens and patients in Europe, while this is crucial to implement it on a large scale and build solutions for the shortage of healthcare professionals and increasing costs of health care.

Special attention is needed for people with low health literacy, who have a lack of capacities for meeting the complex demands related to health and disease in modern society. Limited health literacy in Europe is a significant problem. About 12% of the population have inadequate general health literacy, and more than one third (35%) problematic health literacy (HLS-EU consortium 2012). Health literacy is associated with health outcomes (Berkman 2011), health service use (Brach 2012) and quality of health systems as well as capacity building for professionals (Paasche-Orlow 2005).

For the purpose of this project self-care was defined in the Tender specifications as:

"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" (UK, Department of Health 2005)

Self-care, or related concepts such as self-management (mostly used in cases of chronic disease) and patient empowerment, is relevant for both citizens with increased risk for disease, with minor of self limiting diseases, as well as for people with (one or more) chronic diseases or disabilities.

We consider self-care and self-management as being elements within a continuum. For **patient empowerment** a definition was developed during the first European Conference on Patient Empowerment by the European Network on Patient Empowerment (ENOPE) under the auspices of the Danish Presidency of the European Union (EU) in 2012, that closely relates to the concept of self-care:

"a process to help people gain control, which includes people taking the initiative, solving problems, and making decisions, and can be applied to different settings in health and social care, and self management (Editorial Lancet 2012)."

In the concept of self-care and patient empowerment people are conceived as selfdetermining agents with (some) control over their own health and healthcare, rather than as passive recipients of healthcare (Aujoulat 2008; Funnel 2003).

2.1.2. A PiSCE definition

A significant part of the work on policy recommendations in this project focused on a realization that the used definition on self-care was very much related to the role self-care could have in relation to diseases or their treatment—that within minor ailments this didn't really fit with the way every day self-care was actually used or could be used; as a part of the everyday lives of the citizens who didn't necessarily have other health issues. The PiSCE Platform of Experts therefore worked towards defining self-care as:

"a learned tool enabling people to maintain health and to cope with illness and disability. Along with better health literacy it also supports optimal and timely use of available health services while avoiding a total dependency upon them for minor ailments"

2.1.3. Why enhance self-care?

Effective support of self-care is aimed at enabling people in their ability to live independently. Informing the public about health, health risks, disease management etc. and supporting new behaviour in carrying out self-care, is crucial. It is also necessary for health care professionals to support citizens and patients in their selfcare where new technologies, like internet platforms, mobile apps, and sensor devices, offer new opportunities. Moreover, the way service delivery is organised and financed is an important factor in stimulating self-care and patient empowerment of citizens and patients.

The above conclusions are underlined by a recent study on Consumer Perceptions of Self-care in Europe (The Epposi Barometer 2013). The study shows that approximately 90% of consumers form 10 European countries view self-care as a vital part of the management and prevention of both minor ailments and chronic conditions and diseases. Although consumers are motivated to practice self-care, and agree it is their responsibility, only 20% feel very confident in managing their own health, which stresses the importance of adequate support of self-care. Consumers indicate that healthcare professionals play a key role, especially where knowledge of self-care is low.

There is increasing evidence that self-care support leads to better quality of life, higher efficiency and lower costs, especially by tele-healthcare in patients at highest risks of serious outcomes (McLean, 2013; Helping People Help Themselves, 2011; Blanson Henkemans, 2010). Although on the short term extra support to citizens and patients might be necessary, there are also indications that proper support of self-care and self-management has a positive effect on economic parameters and productivity of the health care sector (Blanson Henkemans, 2010).

Few studies focus on people with low health literacy or multimorbidity, whereas it is estimated that about 8%, especially the elderly, has several chronic diseases at the same time (Hoeymans, 2008). Furthermore, much of the research focuses on interventions to support citizens and patients, whereas far less work has been done to improve health care professionals skills and attitudes to enable them to support patients in their efforts to self-care and self-manage. This project will have a more comprehensive approach, looking both at communication tools, guidelines and concrete policy actions.

2.2. EU policy in the area of self-care and OTC medication

The importance of informing and involving patients in the choices regarding their health and treatment has been repeatedly underlined by the EU.

The Council of the European Union pointed out on the Council Conclusions on Common Values and Principles in European Union Health Systems (2006/C 146/01) that "All EU health systems aim to be patient-centred. This means they aim to involve patients in their treatment, to be transparent with them, and to offer them choices where this is possible, e.g. a choice between different health care service providers. Each system aims to offer individuals information about their health status, and the right to be fully Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE)

informed about the treatment being offered to them, and to consent to such treatment."

A recent study has focused on the perspectives of patients and practitioners towards patient involvement. Both parties view that there are more benefits than risks, although there were geographical differences between European regions. A changing patient-doctor relationship, having choice, information and communication were seen as important elements of patient involvement (Eurobarometer 2012). People with chronic diseases were significantly more motivated and sufficiently knowledgeable to be involved in decision-making and self-management. Members of the present Consortium are currently involved in delivering Tender EAHC 2013/Health/04 which addresses the chronic care end of the spectrum, as it were, and looks at key issues such as transferability of good practice, which will have relevance for this tender also.

Self-care goes a step beyond informing and involving patients as it relates to actions people take to prevent and care for their health (problems) and maintaining health and well-being after illness. This could refer to gathering information and sharing decisions, but it also relates to carry out concrete actions, which normally would be carried out by health professionals. As stated in the former paragraph, there is growing recognition of the importance of stimulating self-care in order to improve the quality of life of patients and citizens and deliver benefits for the healthcare systems in terms of saving time and resource efficiency.

A special element of self-care is the use of (non-prescription) medication. The importance of self-medication in empowering patients has been already underlined by the European Authorities in 2002 and 2008 (EU 2002; EU 2008).

In a survey carried out by the Pharmaceutical Group of European Union (PGEU 2012) it is stressed that safety and efficacy of self-care with non-prescription medicines and medical devices is critical. Relevant regulatory authorities assume that each non-prescription medicine is safe for self-use when the labelled directions of every product are read by patients and followed. But research shows that patients do not always use non-prescription medicines in an appropriate way (Eickhoff 2012, Sinclair 2000). The survey concludes that in the support of the use of (non-prescriptive) medication the role of the pharmacist is important, but that a specific approach to non-prescription medicines within the pharmacy curriculum is unnecessary. A requirement is that training in effective communication and counselling remain to be an integral part of the pharmacy qualification and that continuing professional development includes communication and clinical skills in the self-care context.

A recent report of a working group with representatives from competent authorities, pharmaceutical companies, consumers and patients, and health professionals that was co chaired by the UK Medicines and Healthcare products Regulatory Agency (MHRA) and the European Commission, considered ways of good governance of non-prescription drugs (Report working group promoting good governance of non-prescription drugs in Europe 2013).

This is necessary as a wider range of treatments is made available for self-medication in some Member States and this will progress as the importance of self-care within healthcare systems has become recognised. They indicate five elements of a successful switch in making a drug non-prescription:

- Safety, ease of use and appropriate monitoring for switched products.
- A clear beneficial impact on public health.
- Responding to the needs/demands of citizens and health professionals, in particular, in terms of patient empowerment, timely access, access to improved treatments and improved quality of life.
- Fulfilling unmet needs and addressing conditions that would otherwise remain untreated.
- Embraced by health professionals.

The Working group also gives recommendations for the broader implementation of non-prescription drugs and stresses the importance of i.e. early involvement of stakeholders, collaboration and engagement in an EU network or Forum, training of health professionals and improving knowledge and skills of citizens and patients.

A thorough study and assessment of the existing self-care and self-medication policy at EU level is the subject of work package 3. This includes an assessment of the sociomedical environment of the patient/person (including patient empowerment, health literacy, gender aspects, socio-economic situation related to access to healthcare and health inequalities, disability and grounds of discrimination as specified in art. 19 TFEU (discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation).

A combined methodology were applied to guarantee a thorough analysis of policy and relevant activities in the EU, which will be carefully followed by our consortia in the actions proposed in the contract. This included EU projects which offered valuable information from different perspectives such as medication use, health literacy, economic analysis, patient safety, eHealth development or medical technologies that make patients capable to self-care.

Some other good examples are the EMPATHIE project on patient empowerment (led by FAD), EMPOWER (self-management for diabetes patients), EU-WISE (self-care for long term conditions), HLS-EU (on health literacy), the SENSORART medical technological project, the DUQUE project, etc.

Self-Care and antibiotic resistance

The value of effective antibiotics in our modern healthcare systems cannot be overstated – and the rise of antibiotic resistance are a threat and development which needs attention from all sides. Self-care also has a strong role to play – directly by both preventing common, communicable diseases the need and perceived need of antibiotics will be reduced. And indirectly be directing the health behaviour and health literacy of citizens towards targeted use of antibiotics when the need do arise. Selfcare thus becomes a strong pillar in the overall framework to tackle AMR as reduction of infections and reduction in subscriptions will be a cornerstone in battling this challenge.

References

Aujoulat I, Marcolongo R, Bonadiman L, Deccache A: Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control. Soc Sci Med 2008, 66:1228–39.

Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K: Low health literacy and health outcomes: an updated systematic review. Ann Intern Med 2011, 155:97–107.

Blanson Henkemans, O.A., Molema, J.J.W, Franck, E.J.H. en Otten, W. Zelfmanagement als arbeidsbesparende innovatie in de zorg, TNO-rapport I KvL/P&Z 2010.017. Juni 2010, TNO Kwaliteit van Leven.

Brach C, Dreyer BP, Schyve P, Hernandez LM, Baur C, Lemerise AJ,Parker RM: Attributes of a Health Literate Organization. Inst Med 2012. http://www.iom.edu/~/media/Files/Perspectives-Files/2012/Discussion-Papers/BPH_HLit_Attributes.pdf.

Editorial. Patient empowerment—who empowers whom? Lancet, 2012 May 5;379(9827):1677.

Eickhoff C, Hämmerlein A, Griese N, Schulz M. Nature and frequency of drug-related problems in self-medication (over-the-counter drugs) in daily community pharmacy practice in Germany. Pharmacoepidemiol Drug Saf. 2012 Mar;21(3):254-60. doi: 10.1002/pds.2241. Epub 2011 Sep 28.

EU, Commission Communication 'Safe, innovative and accessible medicines: A Renewed Vision for the Pharmaceutical Sector', 2008. http://eurlex.europa.eu/LexUriServ/-LexUriServ.do?uri=COM:2008:0666:FIN:en:PDF.

EU, European Commission High Level Group on innovation and provision of medicines in the European Union - Recommendations for action. 2002. http://ec.europa.eu/health-/ph_overview/Documents/key08_en.pdf.

Eurobarometer Qualitative study Patient involvement. Aggregate Report. 2012. NS Qual+, at the request of the European Commission, Directorate-General for health and Consumers.

Funnell MM, Anderson RM: Patient Empowerment: A Look Back, A Look Ahead. Diabetes Educ 2003, 29:454–64.

Helping people help themselves. A review of the evidence considering whether it is worthwhile to support self-management. Health Foundation. May 2011

HLS-EU consortium (2012): Comparitive report of health literacy in eight EU member states. The European health literacy survey HLS-EU. www.healthliteracy.eu.

Hoeymans N, Schellevis F, Wolters I. Hoeveel mensen hebben één of meer chronische ziekten? In: Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid. Bilthoven: RIVM, www.nationaalkompas.nl. 12 december 2008.

Joint Report prepared by the European Commission (DG ECFIN) and the Economic Policy Committee (AWG). 'The 2012 Ageing Report. Economic and budgetary projections for the 27 EU Member States (2010-2060)'.

McLean S, Sheikh A, Cresswell K, Nurmatov U, Mukherjee M, Hemmi A, Pagliari C. The impact of telehealthcare on quality and safety of care: a systematic overview. PLoS One. 2013;8(8):e71238.

Paasche-Orlow MK, Parker RM, Gazmararian JA, Nielsen-Bohlman LT, Rudd RR: The prevalence of limited health literacy. J Gen Intern Med 2005,20:175–184.

Parekh AK, Goodman RA, Gordon C, Koh HK (2011) Managing multiple chronic conditions: a strategic framework for improving health outcomes and quality of life. Public Health Reports, july-august 2011, volume 126, 460-71.

PGEU Survey on Pharmacy Education in Relation to Non-prescription medicines/Self-care. 2012. Ref: 12.10.10E 005.

Report of the working groupon promoting good governance of non-prescription drugs in Europe. June 2013

Sinclair HK., Bond CM., Hannaford PC. Over the counter ibuprofen: how and why is it used? Int J Pharm Pract 2000; 8:121-127.

The Epposi Barometer: Consumer Perceptions of Self-care in Europe. Quantitative Study 2013. Epposi.

3. The PiSCE Project

In 2014 the consortium behind PiSCE reunited centres of expertise in various fields and backgrounds relevant for self-care. Already, a solid series of stakeholders engaged within the field provided as part of the consortium a solid ground for the EU policy-making process on self-care.

With the addition of a number of selected experts, the group altogether became both representative and very synergic through its networks. Combined the experts cover areas such as health promotion, health literacy, health education, self-management, patient empowerment and quality of care – and other aspects of self-care.

This includes patient and consumer representatives (EPF and BEUC), professional representatives organizations (CPME, RCPsych, V&VN, PGEU and EFPC), experts in health education (TNO, GÖG) and health literacy and patient empowerment (Global Health Literacy Academy, ENOPE, Third-I, EMHF, EIWH), pharmaceutical representatives (AESGP), universities (FAD, Masaryk University, Chalmers University, Kosice University and CEREF), health insurances (AIM), policy making (EHFF and Qveritas) and expertise in the field of self-management and translation of knowledge (DCHE).

Members of the consortium are currently engaged in relevant international and national initiatives in Europe. They also have extensive experience in the development and evaluation of best practices, qualitative, quantitative methods and policy strategies.

From past to future

The base of the consortium was formed by the EMPATHIE consortium, that carried out the EAHC contract "Empowering patients in the management of chronic diseases" (EAHC 2013/Health/04). With this base, the PISCE consortium was enlarged with expertise from health promotion/education and health literacy in particular.

Originally, the Platform was created by the now closed Dutch organization CBO that as Project Lead had to leave the project in 2015. A period of restructuring of the Platform of Experts ensued, but luckily, in 2016, the PiSCE Platform of Experts were able to resume their work to finalize the remaining work within the project it self, but also the effort to promote self-care in Europe in general. From the Final Conference of PiSCE in 2017, the Platform of Expert have formed a strong bond that will do its best to help DG Sante, the Member States, and all stakeholders in the field in a active and dynamic effort to implement self-care in Europe.

Table 1 Participant organization name

Name of organization	Country	Type of participation
and expert	country	Type of participation
Danish Committee for Health Education (DCHE) Expert appointed; Director Charan Nelander	Denmark	Coordinator WP-leader
Avedis Donabedian Institute, Autonomous University of Barcelona, Fundacion Avedis Donabedian (FAD) Expert appointed; Director Dr. Rosa Suñol	Spain	WP-leader
Standing Committee of European Doctors (CPME) Expert appointed; President Dr. Jacques de Haller	Belgium	WP-leader
European Health Future Forum (EHFF) Expert appointed; Network Director Dr. David Somekh	United Kingdom	Participant org. Coordination
Third-I Expert appointed; Jacqueline Bowman-Busato	Belgium	Participant org.
Masaryk University (MU) Expert appointed; Dr. Ales Bourek	Czech Republic	Participant org.
Netherlands Organisation for Applied Scientific Research TNO (TNO) Expert appointed; Psychologist Wilma Otten	The Netherlands	Participant org.
European Patient's Forum (EPF) Expert appointed; Director of Policy, Kaisa Immonen	Belgium	Participant org.
TUKE Kosice University Expert appointed; Professor Kristina Zgodavova	Slovak Republic	Participant org.
Royal College of Psychiatrists (RCPsych) Expert appointed; Dr. Alan Quirk	United Kingdom	Participant org.
Barbara Kutryba Qveritas Doradztwo (Qveritas) Expert appointed; Barbare Kutryba	Poland	Participant org
Centro Ricerca e Formazione (CEREF) Expert appointed; Director Piera Poletti	Italy	Participant org
Chalmers University (CU) Expert appointed; Professor Bo Bergman	Sweden	Participant org
European Network On Patient Empowerment (ENOPE) Expert appointed; Dr. Jim Philips	United Kingdom	Participant org
Expert appointed: Kristine Sorensen, Global Health Literacy Academy	The Netherlands	Platform expert
Expert appointed: Jeroen Havers, Vilans	The Netherlands	Platform expert
Expert appointed: Gustavo Maranes, AESGP	Spain	Platform expert
Expert appointed: Cristina Cabrita, BEUC	Portugal	Platform expert
Expert appointed: Jamie Wilkinson, PGEU	The Netherlands	Platform expert
Expert appointed: Herwig Ostermann, GÖG	Austria	Platform expert
Expert appointed: Ian Banks, EMHF	Northern Ireland	Platform expert
Expert appointed: Maria Merce Rovira Regas, EIWH	Spain	Platform expert
Expert appointed: Rotar Pavlic Danica, EFPC	Slovenia	Platform expert

4. Original objectives of the PiSCE project

Stimulating self-care starts with the recognition that patients are gradually taking a new and more active role and that the current health system could not survive due to the resources it requires. For both reasons, changes in people's ability and skills to take care of their own health needs and to be better able to avoid ill health are a crucial development for EU health systems. The general objective for this project is as follows:

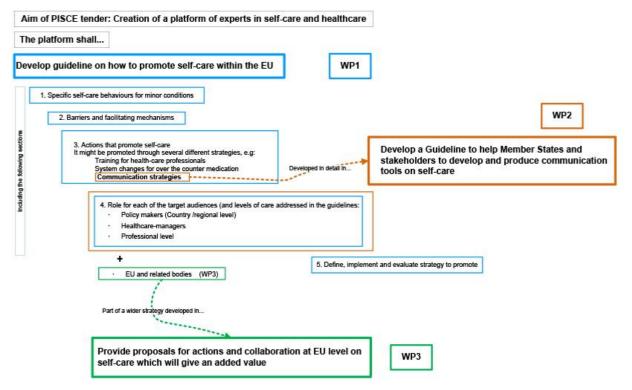
The creation of a platform of experts in self-care and healthcare to put in place a framework for action to enhance self-care at EU level and develop strategies to support the broader implementation of effective self-care.

In this project, an important step will be taken to enhance self-care at EU level and develop strategies to support the broader implementation of effective self-care. A platform of experts in self-care will be created that will develop:

- a guideline on how to promote self-care within the EU taking into account the outcome of the cost benefit analysis of self-care systems (EAHC/2013/Health/26) in the EU and the study of transferability of best practices.
- a guideline to help Member States and stakeholders to develop and produce communication tools on self-care. This guideline should amongst other things describe the information needed in a communication tool and the optimal way to present it to get a better understanding of the content by the patients.
- concrete proposals for policy actions and collaboration at EU level on self-care which will give an added value in supporting the broader implementation of effective self-care. In the process above mentioned cost/benefit analysis and the outcome of the call for tender in work plan 2013 of the Health Programme (2008-2013) "Empowering patients in the management of chronic diseases" (EAHC 2013/Health/04) will be taken into account.
- a closing/concluding conference will be organised on the discussions and outcome of the work of the platform. At first instance this project will focus on self-care in five self limiting and minor conditions, which will be defined at the beginning of this project as a result of the cost benefit analysis of self-care systems (EAHC/2013/Health/ 26). As the ambition stated in the Tender specification goes beyond these five selected conditions, the work carried out in this project will structurally pay attention to the generic aspects of self-care and self-management for other diseases for use in future developments. This would also influence the selection of experts for the platform and the participants at the closing conference.

4.1.Project development and process

The tender asked for the creation of a Platform of Experts to solve the three main objectives mentioned above. These three objectives were of course interlinked, as guidelines for promotion may point to policy, policies may point to communication – or vice versa. To resolve this potential overlapping, the project created this overview to ensure both a division and understanding between the different areas.



The development process in all three work packages has been very targeted and while it was initially expected that some matters would have to be either voted upon or perhaps be solved be dividing in a "majority and minority statement" solution, all three processes has been resolved by consensus – though naturally also by solid debate, argument, and search for common ground.

During the project, the original Project Lead, CBO of The Netherlands, had to file for bankruptcy and had to close. This meant a lengthy pause that has had a number of quite positive side effects. We would not recommend the experience for other projects, but will say that the resolve of the Platform of Experts has only been strengthened by the experience.

In the next sections the methodology and specific considerations behind the results and discussions in the individual work packages are explained.

5. WP1 – Guidelines for the promotion of self-care

Scope and objective

The WP was to describe best practices and recommend how to promote self-care actions in patients, family and the general public. The guidelines would be tailored to collect the most effective and efficient recommendations to facilitate the healthcare professionals, managers, non-governmental organisations and policy-makers role in promoting self-care practices.

The scope of the guidelines will be healthcare professionals (e.g. doctors, pharmacists, nurses) managers, non-governmental organisations and policy-makers across EU.

A wide geographical coverage would be ensured both through current evidence review and the participation of relevant experts. The suitability of the guideline to the specific groups of the target population will be achieved with the participation of relevant representatives of all groups (particularly patients) in the projects platform of experts and, therefore, in the consensus building process related to the WP.

Method and structure

The structure of the self-care guideline would include areas such as:

<u>Specific self-care behaviours:</u> taking into consideration all the different phases of the condition (such as symptom recognition, symptom evaluation, treatment decision, treatment implementation – as patient adherence to lifestyle recommendations, medication adherence, monitoring- and treatment evaluation).

<u>Self-care barriers for patients:</u> such as lack of information, poor quality/misleading information, poor health literacy, co-morbidity, age related issues, impaired cognition, impaired social and family relations, issues related to socioeconomic-status or minority group status, family beliefs and gender-related issues.

<u>Healthcare system barriers</u>: as low relevance of self-care promotion on healthcare education, healthcare professional culture (paternalistic approach), conflicting or incomplete information, healthcare organisational factors, lack of patient education and ease of access.

<u>Interventions that promote self-care in terms of</u>: skill development, behaviour change/lifestyle change, family and environment support, system of care and providing good quality information (taking into consideration the core quality principles for patient information on diseases and treatment options defined by the European Commission (1)).

<u>Effect of self-care on outcomes</u>: cost-effectiveness (drawing from the conclusion of EAHC/2013/Health/26), use of health services, quality of life, patient empowerment.

References

Core quality principles for patient information on diseases and treatment options [Internet]. Available from: http://ec.europa.eu/enterprise/sectors/healthcare/files/docs/itp_quality_en.pdf

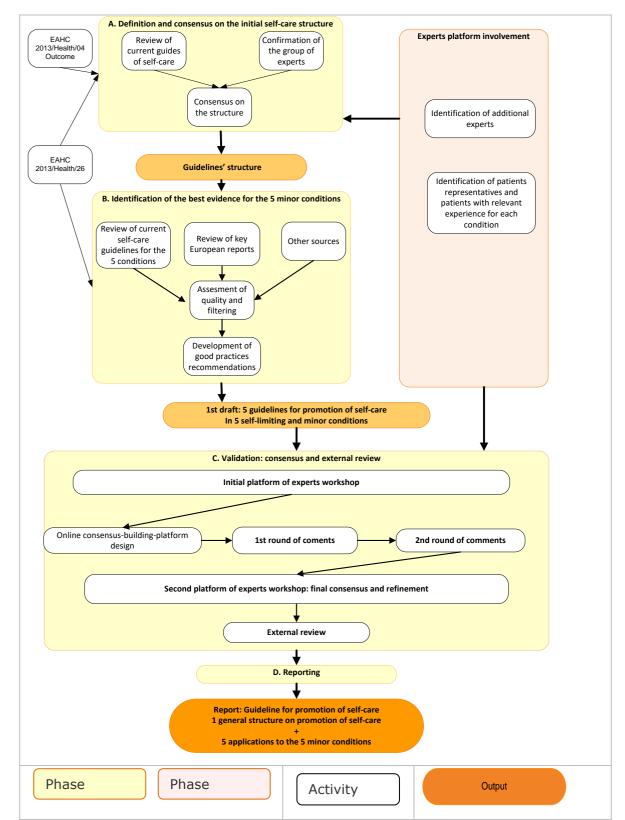


Figure 1 Work process diagram WP1

6. WP2 – Guidelines for Communication Tools

Scope and objective

The creation of guidelines for developing and producing appropriate and effective communication tools for the future self-care in the EU.

Methods and Structure

Though communication tools are essential to promote self-care, they need to be chosen in careful consideration of factors specific to different target groups, including the level(s) of health literacy, gender, socio-economic minority status, conditionsrelated specific needs, and age and how they can help alleviate inequalities in terms of health literacy and/or access to information for individual target groups whether they be identified as patients, persons or simply citizens.

Furthermore such tools are not only a means to disseminate specific information about self-care but are also necessary to promote self-care in general as a method, thus supporting the specific advice from WP1.

Therefore the guidelines for communication tools would not only be developed as a 'state of the art' collection of the tools themselves, but rather be built to support an on-going update. And thus allowing not only traditional media and communication technologies to be included but also new media and new ways to communicate - especially to people with low health literacy.

We furthermore believed the guidelines on communication tools for self-care should not only serve to promote self-care at the individual and national level, but also describe how the development process of communication tools could interact with its users (e.g. shared decision making, patient-professional communication), to allow a true co-ownership of the process and the communication about self-care to evolve.

References

In the course of development the platform of experts used several theories and models to decide the framework - among these the Persuasion-Communication Matrix of McGuire (1984, 1985, 2001) due to its general applicability, but also the even simpler AIDA-model.

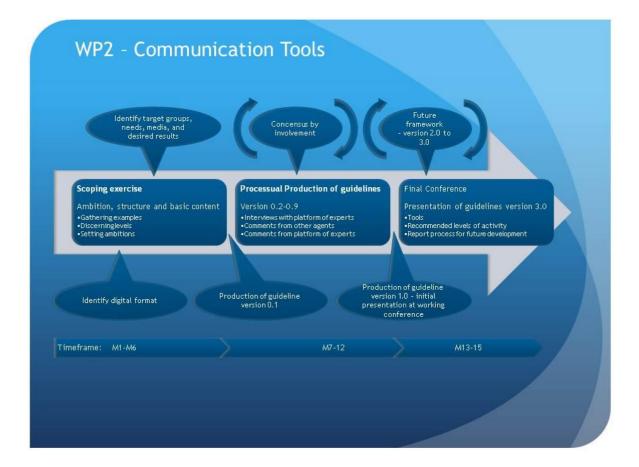
McGuire, W. J. (1984). Public communication as a strategy for inducing health-promoting behavioral change. Preventive Medicine, 13(3), 299–313.

McGuire, WJ (1985). Attitudes and attitude change. In G. Lindzay & E. Aronson (Eds.), Handbook of Social Psychology: Vol. II. Special fields and application (pp. 233-246). New York: Random House.

McGuire, W.J. Input and output variables currently promising for constructing persuasive communications. In: Rice, R.E. & Atkin, C.K. (Eds.), Public Communication Campaigns.Sage Publications, 2001.

Abraham and Michie (2008). A Taxonomy of Behavior Change Techniques Used in Interventions, Health Psychology, Vol. 27, No. 3, 379–387





7. WP3 – Policy recommendations

Scope and objective

The main objective of the work package was to propose concrete policy actions with added value at EU level regarding self-care. To do so involved taking into account synergies within existing EU policies in the remit of health as well as an inclusive consultative approach with relevant stakeholders and experts within the self-care platform of experts set up by the project. As a result, a set of recommendations to create a basis for a collaborative approach existing policies on self-care and selfmedication, proposing concrete synergies with added value at EU level. The feasibility of the proposed policy actions was achieved by involving project partners and external stakeholders (pharmacists, consumers, the self-medication industry) within the platform of experts a consensus building process.

Method and Structure

Based on an assessment of existing needs regarding self-care at EU level, regarding policies, the socio-medical environment around the patient needs (eg. patient empowerment, health literacy, the gender etc) and patient needs on self-care a list of objectives to enable better self-care would be created.

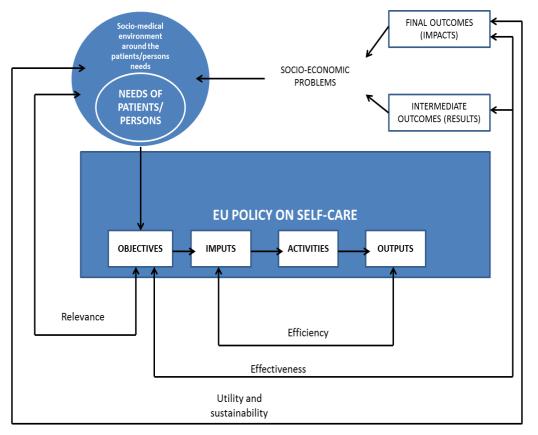


Figure 2: Adapted from: Pollitt, C., Bouckaert, G., 2004, Public management reform. A comparative analysis. The input/output model (pg 106)

References

Pollitt, C., Bouckaert, G., (2004) Public management reform. A comparative analysis. The input/output model (pg 106), Oxford University Press.

Pelikan, J., Röthlin, Ganahl, K. and contributing HLS EU consortium partners (2012) Comparative report on health literacy on 8 EU member states.

Beger, B., Immonen Kharalambous, K., Roedinger, A., Sørensen, K., (2013) Making health literacy a priority in EU Policy

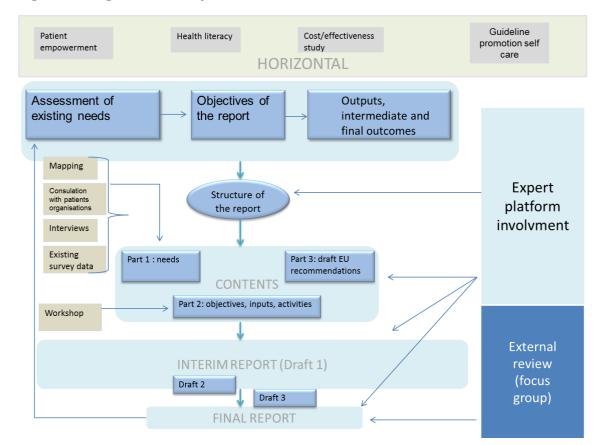


Figure 3: Diagram of work process WP2

8. Final Conference – Summary, Feedback, and Learning

Scope and objective

To prepare, coordinate and hold a concluding conference on the discussion and outcome of the work of the platform, in Brussels, Belgium.

The scope of the conference will be the conclusion of the project and the first step to further dissemination of the guidelines, policy recommendations and general/specific knowledge from the project to stimulate broad spread and implementation on a Europe wide level. The target group for this conference is the relevant stakeholders and representatives of Member States – covering at least 100 participants from these groups.

Method and Structure

The conference was created as a one day event to both serve as a dissemination of results, but also to gather feedback on the content and engagement among the participants to push self-care and collaboration on self-care further.

The participants were drafted from the following resources:

- The consortium members that have made the project application.
- The contractors that are carrying out contract EAHC/2013/Health/26.
- The additional experts joining the expert platform.
- Already existing networks of experts/stakeholders in the field of self-care (e.g.: IUHPE, EUROPREV, etc.).
- Suggestions for additional participants from DG SANCO.
- Interested parties that can motivate the added value of their participation in de the conference.

Programme for Final Conference

09:30 Welcome Moderator: Director Charan Nelander, DCHE

09:35 Key Notes

Self-Care – Implementing Sustainable Health In Europe Professor Ilona Kickbusch, Careum Self-Care – Challenges and Possibilities Dr. Bert Vrijhoef, Maastricht UMC Key Note Q&A

- 10.35 A healthier Europe perspectives and policies Director John Ryan, DG Sante
- 10:45 Break

Results of the PiSCE project

- 11:00 WP1 Guidelines for promotion of Self-Care Project Manager Marta Ballester, FAD - Fundación Avedis Donabedian
- 11:20 WP2 Guidelines for Communication Tools Project Lead Lars Münter, DCHE - The Danish Committee for Health Education
- 11:40 WP3 Policy recommendations Mr. Markus Kujawa, CPME - The Standing Committee of European Doctors
- 12:00 Lunch

Breakout Sessions

- 13:00 1. How to integrate Self-Care in practice?
 FAD & DCHE
 2. What are the barriers and opportunities for citizens to practice Self-Care?
 EPF with EMHF / EIWH / BEUC
 3. The impact of Self-Care on health and society: policy actions and collaboration?
 CPME & EHFF
- 14:30 Break
- 15:00 Experiences and ideas from the Breakout Sessions Facilitators reporting
- 15:30 Future of Self-Care in Europe Dr. David Somekh, EHFF
- 16:00 Reception

Presentations and other materials from the Final Conference can be found at www.selfcare.me, including a video presentation – highlighting key messages and experiences.

Learnings from the Final Conference

Overall the Final Conference showed a strong support towards self-care – especially in getting the issue and the self-care guidelines implemented across the Member States.



The presentation video at www.selfcare.me reflects this, but also very strongly underlines, that self-care is strongly linked to an overall sustainability of the European healthcare systems; an adaptation to changes in the overall society and culture which creates a natural evolution towards a more holistic health approach.

The presentations and the three breakout sessions also revolved strongly around the need for collaboration – across sectors, across disciplines, and across borders. The PiSCE Consortium has strongly resolved to make this happen – as a small start we ask interested experts and professionals to join the LinkedIn-group Self Care Initiative Europe, and by all means help us all towards better self-care by participating, sharing, and taking action.

Based on the breakout session 1 a workshop poster – or rather a learning tool – has also been developed that can supplement the guidelines found online or in this report. See www.selfcare.me for more.

This report has also been issued as an e-book to further enable sharing – this can also be found at www.selfcare.me.



9. Platform of Experts

Scope and objective

The objective of this work package was the creation of a platform of experts in selfcare and healthcare, composed of cross-functional stakeholders with expertise in this area.

The <u>expert platform</u> was to cover a minimum of 20 experts from cross- functional stakeholders (healthcare providers/professionals, patient groups, academics, industry, communication/health education) and other relevant stakeholders with experience in policymaking at both the National and EU-level. The selection, composition and establishment of the platform took place in consultation with DG Sanco.

Method and Structure

We composed the platform by drawing upon the following sources:

- The consortium members that have developed this project application.
- A representative from the contractors that are carrying out the work for objective 1 and 2, see EAHC contract N EAHC/2013/Health/26.
- An expert representing the European Consumers' Organisation (BEUC), the Pharmaceutical Group of the European Union (PGEU) and the Association of the European Self-Medication Industry (AESGP). Their expertise is missing in our proposal, but these organizations have promised to join the platform if our consortium is successful in applying for this tender.
- Suggestions for additional experts from DG Sanco / the Commission.
- Other experts that may be needed to complete the expert platform on basis of the criteria determined under step 1 and open applications.

With the names and people in place, our work focused on creating communication and interaction between the members to ensure to not only have a list of names, but a true collaborative unit of experts to discuss, agree, and promote self-care guidelines and policies – and be a basis for future self-care in Europe. This was done by a series of teleconferences, regular email contact, distribution of draft, co-creation of a joint website and three collective meetings.

Though we would not recommend it for future projects, the joint experience in the Platform of having to revive the project following the loss of CBO as the Project Lead has also given the Platform a unique interaction.

Future work of the Platform of Experts

Even more than expected this also led to a high level of interest and engagement in the following areas:

- Possible constructs for the structure of an effective platform on self-care and the need for seeking additional experts to strengthen the platform.
- Core values and pillars that underpin self-care approach that has been developed and laid down in the guidelines and conference.
- The layout of a strategic plan that builds on the work carried out in this project covering the period 2017-2019. Milestones and deliverables from this project can be used as the starting point for the strategy of the platform, taking into account the changing context for self-care in Europe in the next few years. Accordingly, the main objectives and activities of the platform can be described, followed by relevant strategy considerations that can be taken into account while achieving them.
- Means and support needed for facilitation of effective platform on self-care.

We believe that the creation of the Platform of Experts on self-care is a vital key to the success of promotion of self-care in Europe and a strong basis for a future discussion and vitality in the field.

We anticipate the continuation of the platform after the project has finished by developing different scenarios for how the network can operate effectively in supporting the broader implementation of effective self-care at the EU-level.

Section 1 – Guidelines for the promotion of Self-care

Content

SECTION 1 – GUIDELINES FOR THE PROMOTION OF SELF-CARE	29
HOW TO USE THIS GUIDELINE	31
GUIDELINE ON HOW TO PROMOTE SELF-CARE	
GUIDELINE ON HOW TO PROMOTE SELF-CARE: COLD	47
GUIDELINE ON HOW TO PROMOTE SELF-CARE: AHTLETE'S FOOT	
GUIDELINE ON HOW TO PROMOTE SELF-CARE: HEARTBURN (WITHOUT INDIGESTION)	
GUIDELINE ON HOW TO PROMOTE SELF-CARE: URINARY TRACT INFECTION (UTI)	103
GUIDELINE ON HOW TO PROMOTE SELF-CARE: COUGH	118
REFERENCES - ALL	133

SECTION 2 -	- GUIDELINES FOR COMMUNICATION TOOLS	136
SECTION 3	- POLICY RECOMMENDATIONS	205

About this guideline

Objectives

It has been agreed that the guideline should be focused on the following specific objectives:

Specific objectives for the guideline:

- To describe effective and efficient recommendations on how to promote self-care practices in minor conditions. Those will be addressed to the key stakeholders of the project: Policy-makers at national, regional and local level; Health-care managers; Health and social care professionals (and professional bodies); Industry, self-care medication and medical devices industry; Patients/consumer organizations and other NGOs; Educators & Workplace related stakeholders.
- To identify good practices and tools to illustrate how to promote self-care behaviours for minor conditions among patients/persons, families, informal caregivers and the general public.

How to use this guideline

This guideline aims to enable its target users to promote self-care in minor conditions; ultimately to enable the readers of this guideline to help people help themselves. The overall guiding principles of this guideline are to help the target users to promote safe self-care through evidence based recommendations.

The overall guiding principles of this guideline are to help the target users to promote safe self-care through evidence based recommendations.

To do so the guideline is structured in 5 steps as illustrated. Those 5 steps are the steps that a target user of this guideline should consider when designing an initiative to promote self-care in minor conditions.

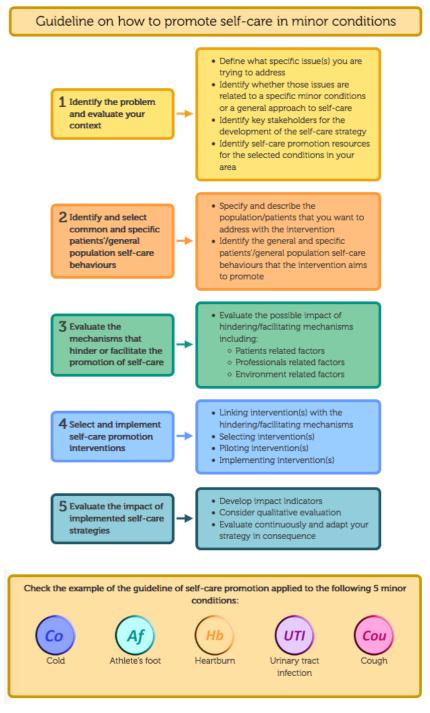
Each step might include remarks and tips for a specific group of target users. As a complement all the specific remarks and tips are collected on a final page dedicated for each specific target user group (represented with the coloured buttons on the right section of the diagram).

The step-by-step section of the guideline is complemented with a Catalogue of good practices and tools in the promotion of self-care in minor conditions.

Guideline on how to promote self-care

This guideline aims to help the promotion of self-care, through the stated specific objectives, for the following target users: Policy decision makers, Healthcare managers, Healthcare and social care professionals (and professional bodies), Patient organisations and other NGOs, Industry, over-the-counter medication pharma industry, Workplace related stakeholders and Educators.

The guideline has been structured in 5 key steps. You can navigate through them using the interactive diagram, the menu on the right side of the webpage or by simply following the pages in sequential order.



Levels not specifically addressed in this guideline: EU and related bodies

This guideline is developed within the European context, taking into account European projects, reports and other evidence. However the goal of this guideline does NOT include the proposal of actions for the EU and related bodies. This level of intervention is specifically addressed in the policy recommendations of this project to ensure close coordination to ensure alignment.

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) - Section 1 - Guidelines for the Promotion of Self-Care

1. Identify the problem and evaluate your context

Describing the context in terms of the key issue that you want to address, the stakeholders that can be affected by the issue and the existing resources that exist/could be used to address the issue. This exercise would give a general idea of the starting point.

1 Identify the problem and evaluate your context

- Define what specific issue(s) you are trying to address
- Identify whether those issues are related to a specific minor conditions or a general approach to self-care
- Identify key stakeholders for the development of the self-care strategy
- Identify self-care promotion resources for the selected conditions in your area

1.1. Define what specific issue(s) you are trying to address

The first step when deciding to launch a self-care (or any other) initiative is to clarify **what is moving you** to launch this initiative. Specifically, to identify what are the drivers that are moving forward this need for change.

Some of the **key drivers** could be the following. These could be present or not depending on the healthcare system and process organisation:

Related with patients needs:

- Low awareness and/or knowledge of citizens on how to treat a minor condition.
- Patients with low literacy have difficulties to understand healthcare recommendations.
- Related to the strategic priorities in which you would like to act upon:
 - Promotion of patient empowerment.
 - Improvement of treatment and care appropriateness.
 - Alignment with other stakeholder strategies.
 - Improvement of patient experience.
- Linked to the current system of care for minor conditions (sustainability issues):
 - High numbers of potentially avoidable GP visits related to minor conditions (with the consequent time invested).
 - \circ $\;$ High numbers of ER visits for minor conditions.
 - Inadequate use/overuse of antibiotics.
 - High number of work leaves.
 - Clinical practice variation in the management of minor conditions.

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) - Section 1 - Guidelines for the Promotion of Self-Care

1.2. *Identify whether those issues are related to a specific minor conditions or a general approach to self-care*

Selecting the focus and broadness of your target can be key in determining if the selfcare promotion intervention. In some cases the strategy might be better of with targeting one or two conditions; for example, if you want to address the issue that 12% of the visits to the primary care services are due to colds or lower urinary tract infections, the strategy might be more successful by specifically targeting the self-care for those specific conditions. On the other hand if you want to target the inappropriate use of antibiotics, the strategy might need a general approach to prescription behaviours, not restricted to a singular minor condition.

1.3. Identify stakeholders and resources available for the self-care strategy

 Stakeholders involved for the self-care strategy: A key determinant of a successful intervention can be the inclusion of the relevant stakeholders. Anyone who wants to promote self-care should identify the stakeholders that are/could be involved and what is expected of each of them. Identifying those stakeholders at an early stage can facilitate a better coordination and a better use of all the available resources.

Stakeholders involvement could provide significant added value in multiple stages for the self-care promotion strategy, such as: identifying key drivers, identifying self-care behaviours, the selection and implementation of the self-care interventions, their evaluation and, specially, in the evaluation of mechanisms that might hinder or facilitate the promotion of self-care.

Stakeholders should be defined in each specific context. The following, but not limited to, key groups of stakeholders should be considered:

- Healthcare and social care professionals (and professional bodies)
- Educators
- Patient organizations and other NGOs
- Healthcare managers
- Policy decision makers
- Industry, self-care medication and medical devices industry
- Workplace related stakeholders

The following table exemplifies some of the different key stakeholders at local, regional and country level.

	Local level	Regional level	Country level
Healthcare and social care professionals (and professional bodies)	Primary health care professionals, Social services professionals	Scientific societies, Relevant regional professional bodies	National professional bodies, Scientific societies
Educators	Educators in local schools (educational institutions primary and secondary level)	Regional education authorities, Health education and promotion authorities, Professional bodies	National education authorities, Professional bodies
Patient organisations and other NGOs	Patient associations or local communities	Regional associations	National organisations, Umbrella organisations
Policy decision makers	Local authorities	Regional (or equivalent) government	Ministry, Government
Healthcare managers	CEO, Managers and directors of the primary care centres and hospitals	Regional/district Health authorities	National Health Authorities
Industry, self-care medication pharma industry	_	_	Pharmaceutical companies
Workplace related stakeholders	Local companies	Regional companies, Trade unions, Employer organisations	National companies, Trade unions, Employer organisations
Others (ex. patients or citizens at the individual level)	Patients or citizens	Patients or citizens	Patients or citizens

1.4. Identify the self-care support resources available in your context:

If you want to successfully promote self-care in your context, a key step can be to identify the existing resources. Some of the key resources that you might want to consider are:

Economic resources: for material to be developed, personnel required to implement self-care strategy,

Structural resources: which include some of the key resources for the implementation of self-care interventions such as network of community pharmacists, general access of the population to internet, etc.

Training: consider whether there are professionals trained to implement self-care interventions.

Technology: Existence of health web portals, health advice lines, etc. in your context (local, regional or national)

2. Identify and select common and specific patients'/general population self-care behaviours

Identify and select common and specific patients'/general population self-care behaviours that you want to promote (depending on the context problem you want to address)

2 Identify and select common and specific patients'/general population self-care behaviours

- Specify and describe the population/patients that you want to address with the intervention
- Identify the general and specific patients'/general population self-care behaviours that the intervention aims to promote

2.1. Specify and describe the patients/general population that you want to address with the self-care strategy

Depending on the results of the evaluation of the context and key issues and whether the strategy is general or specific to a minor condition, one should define the patients/general population that the interventions should be addressed to.

In doing so, consider:

- Characteristics of the general population
- People affected by the condition(s) the intervention is targeting
 - Demographic (including age and gender) and socio-economic characteristics
 - Possible co-morbidities
 - Health literacy, language, cultural traits

Depending on your target population a self-care strategy might face different <u>barriers</u>.

2.2. Identify the general and specific patients'/general population self-care behaviours that the intervention aims to promote

A key step if you want to establish a strategy to promote self-care is to determine the main self-care behaviours to promote. Establishing those behaviours will guide the development of the strategy and it will help identifying the mechanisms that can hinder or facilitate the promotion of self-care.

Depending on the results of the analysis of your context and issues that you want to address you can identify different behaviours to promote.

The following list presents the main types of self-care behaviour (see examples of the specific self-care behaviours in the examples of the guidelines for <u>cold</u>, <u>athlete's foot</u>, <u>heartburn</u>, <u>urinary tract infection</u> and <u>cough</u>):

- Preventing disease and leading a healthy life
- Awareness about self-limited conditions
- Recognizing symptoms
- Evaluating symptoms
- Selecting the appropriate healthcare provider and visiting them in a timely manner when needed
- Making a decision about the treatment (and turning to the relevant healthcare professional when needed)
- Implementing treatment (including adhering to medication)
- Monitoring
- Carrying out secondary prevention
- Evaluating treatment (and avoiding risks)
- Sustaining long-lasting self-care behaviours

3. Evaluate the mechanisms that might hinder or facilitate the promotion of self-care

Evaluate the mechanisms that might hinder or facilitate the promotion of self-care in your context (barriers and facilitators)

3 Evaluate the mechanisms that might hinder or facilitate the promotion of self-care

- Evaluate the possible impact of hindering/facilitating mechanisms including:
 - Patients related factors
 - Professionals related factors
 - Environment related factors

One of the most important steps in promoting self-care is the identification and analysis of the mechanisms that might hinder the promotion of self-care. Those can be present, hindering the implementation of the self-care strategy, but also as mechanisms facilitating implementation.

When designing a self-care strategy, one should identify and evaluate these mechanisms and adapt the implementation strategy accordingly. Often those mechanisms can inform the selection of the self-care intervention for your strategy. For example: if you are targeting a population with low health literacy the communication strategies should be designed based on easily understandable content.

To facilitate this step we propose a list of mechanisms that might affect the development of a self-care strategy. This list is not exhaustive but might be helpful to guide a systematic evaluation of hindering/facilitating mechanisms.

There are different types of techniques to identify these mechanisms that should be selected depending on the type of minor conditions, the objective of the strategy and the available resources (such as focus groups, interviews, etc.).

To see specific examples of hindering mechanisms, please see the guidelines for <u>cold</u>, <u>athlete's foot</u>, <u>heartburn</u>, <u>urinary tract infection</u> and <u>cough</u>.

List of key hindering/facilitating mechanisms **Patients**

- Knowledge
 - Low health literacy: low levels of health literacy can make it harder for patients/persons to engage in self-behaviours. It has been reported that *about* 12% of the European population have inadequate general health literacy, and more than one third (35%) has problematic health literacy.

Health literacy can be one of the key determinants to address as it has been proven to be associated with health outcomes, health service use and quality of health systems as well as capacity building for professionals.

- Poor information on condition (symptom recognition, possible treatment, usual evolution of symptoms...). The poor information can negatively affect self-care at any stage, for example: incorrect assessment of seriousness, delayed recognition of symptoms, biased expectations on the condition prognosis.
- Poor information on the treatment options. The poor information on treatment options could lead to unnecessary consultation with the GP, or applying incorrect treatments (for example non EB -evidence basedlay remedies).
- Poor information on navigation of the healthcare system. Poor information on the healthcare system can lead to unnecessary consultation with professionals.
- Skills
 - Lack of decision-making skills.
- Attitudes
 - People's tendency to delegate their health to professionals (low patient activation).
 - Health beliefs of a particular group/individual at family, level, community level and overall cultural level.
 - Lack of confidence on one's abilities to have an impact on one own health (low self-efficacy).
- Behaviours
 - Tendency to repeat behaviour. In most cases a consultation with a GP, even for self-limiting minor conditions leads to a prescription of treatment. This practice can affect potential changes towards self-care due to the tendency to repeat behaviours. For example, a study developed in the UK found that within the sample of people who had received a prescription from a general practitioner the last time they had a minor ailment, 62% visited a GP again when faced with a similar minor ailment. This tendency to repeat behaviour can also be presented as a facilitating mechanism, for example the same UK study reported that 84% of people that had past experience with self-care choose self-care for new episodes of minor ailment.
 - Patients/general population self-care health value, which might influence patients/general population self-care coping strategies. In long-term self-care strategies it has been recommended that attention is paid to the patient's self-care coping strategy, and that self-care protocols should be tailored to complement the different types of selfcare health values that patients might have.

- Co-morbidities: co-morbidities might make difficult self-care for minor conditions more complex and, crucially, can be a very relevant risk factor.
- Impaired cognition can complicate self-care in multiple aspects, including the access to relevant information.
- Demographic characteristics
 - o Age
 - Gender can have an impact on self-care in multiple aspects; particularly different conditions can have different effects on women and men. For example lower urinary tract infection is on the one hand much more common among women and on the other it can be much more risky for men.
- Socio-economic status (and or minority groups)
 - Financial resources: lack of financial resources can complicate self-care by hindering the access to self-care medication (or self-care devices), affecting the decision to take a sick-leave (maybe incurring on loss of (part of) the salary for some days), etc.
 - Social exclusion: people in situation of social exclusion can have a more difficult access to self-care resources such as information sources, advice from professionals, etc.

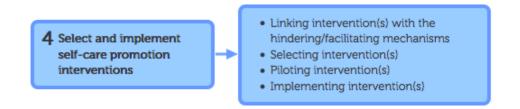
Professionals

- Behaviours
 - Prescription of antibiotics for self-limiting minor conditions. This behaviour might incentivise patients/general public to visit GPs whenever they have a minor condition.
- Knowledge
 - Professional education to promote patient self-care can be key for a successful intervention. A good education on promotion of self-care or lack thereof can be critical as a positive driver or as an important complication.
- Skills
 - Communication skills might not be a priority in the professional curricula.
- Attitudes
 - Healthcare professionals' attitudes: the attitudes of healthcare professionals towards the importance of the patients' self-care (including primary care, pharmacist, etc.) are a critical factor for the implementation of a self-care strategy. It can difficult the development of a self-care strategy greatly or it can facilitate it considerably depending if they have a negative or positive attitude towards it.

Environment

- Social factors
 - Social/cultural differences: might difficult understanding of self-care portals of information...
 - Low relevance of self-care promotion on health care education
- Organizational factors
 - Issuance of work leave (sick certificate): in many countries the work leave is covered by Social Security schemes/insurance schemes if this is linked to a medical certificate it directs people with a minor condition to directly consult with GPs, even for cases that could be self-treated (for example cold).
 - Access to resources: the variation in accessibility of key resources (for example web portals) to self-care can act as a barrier.
 On the other hand easy access can act as a facilitator. For example according to the survey of Chain of Trust Project, approximately 98% of EU citizens can reach their nearest community pharmacy within 30 minutes, while 58% of citizens indicate that their closest community pharmacy is within 5 minutes reach from their work or home. Take advantage of the community pharmacists could be a facilitator to promote the self-care in minor conditions.
- Economic factors
 - Financial incentives for professionals: a key issue might be the cases of linking a part of the GPs salary to the number of consults. This can act as a barrier for GPs to actively encourage self-care.
 - Financial incentives for patients in some systems to seek prescribed OTC: In many health systems prescribed medication is discounted, compared to OTC purchased directly at the pharmacy. This fact might affect the decision of citizens to attend primary care doctors instead of attempting self-care.

4. Select and implement self-care promotion intervention(s)



4.1. Linking intervention(s) with the hindering/facilitating mechanisms

Once the hindering or facilitating mechanisms have been identified a key next step can be to link interventions to those mechanisms.

4.2. Selecting intervention(s)

This section presents a general overview of possible interventions to promote selfcare. The degrees of complexity of those interventions are varied, however all are also susceptible to be combined to form an overarching strategy to promote self-care.

Using theories to facilitate the design process of the intervention could be useful at

this stage. 🖊

For this general presentation multiple interventions are presented and not all the readers of this guideline might be able to implement all of the interventions (for example, most healthcare professionals won't have capacity to decide over financing of the primary care system). It is recommendable to go through the general overview of self-care promotion interventions to have a broad idea on the issue.

- System-focused
 - Structural interventions
 - Staff-oriented interventions
- Financial interventions
 - Financial incentives to patients
 - Financial incentives to Primary Care Centers (or elimination of potential barriers such as payment by volume of visits)
- Patient-focused interventions
 - \circ Skill development
 - o Behaviour change
 - Family support
 - Information provision
- Professional-focused interventions
 - Educational interventions
 - Educational materials

- Large-scale educational meetings
- Small-scale educational meetings
- Outreach visits
- Use of opinion leaders
- $\circ \quad \text{Feedbacks and reminders}$
 - Feedback
 - Reminders
- Local consensus processes

4.3. Piloting intervention(s)

When preparing the implementation of a complex strategy it often useful to first pilot it. Depending on the position from where you are developing a self-care strategy (policy maker, professional, patient organization...) and the strategy you select the pilot will be significantly different. However piloting the strategy can be helpful to identify operational difficulties.

In piloting an intervention one should consider:

- Criteria for the selection of the sites for the pilot. Those could vary; usually the selection is based on sites that might be particularly willing to adopt new practices or on site where there issue at hand is most relevant.
- Criteria for a possible limitation of minor conditions. If the selected approach affects more than one specific minor condition one might want to consider limiting the pilot to just one condition.

4.4. Implementing intervention(s)

- Ensemble a working group representative of the stakeholders involved in the strategy.
- Design a strategy based on the different components (interventions). When preparing a strategy that combines multiple interventions, bear in mind that:
 - The combination of multiple interventions can be more effective than a single intervention, but even the combination of many different interventions does not guarantee effectiveness of the strategy.
 - The effectiveness of the combination will be determined by the effectiveness of the individual interventions and the interaction between them. This interaction can act as an enhancer of the individual interventions' effectiveness but also might reduce it.
 - \circ Considering the different phases of the process of change could facilitate the selection of intervention(s).

See further information on behaviour change theories below.

Phases on th	e process of behaviour change	
 Orient 0 0 	tation Promote the awareness of the strategy Stimulate interest and involvement	
• Insigh o	nt Stimulate the understanding of the changes required Facilitate insights on how the day to day of those involved might change	Communication Communication will play a key role
• Accep o	tance Promote the motivation for change and a positive attitude Stimulate the decision to change	throughout the process of implementation, and it should be adapted at each stage.
• Chang o	Promote and support the actual adoption of the required changes Confirm the benefits of the changes (see step 5: <i>Evaluate the impact of implemented self-care</i> <i>strategies</i>)	For more details see Guidelines for the development of communication tools
• Mainto	enance Integrate the new practices into the day to day routines Embed the new practices in the organisation(s)	

- Define the resources that will be needed to implement the strategy, based on the potential available resources identified in step 1: *Identify the problem and evaluate your context*. Pay special attention to the available budget and the effort and time required by those involved in relation to the expected effectiveness.
- Identify needs for the implementation. Those might include:
 - Professionals' training needs
 - Re-definition of professional roles
 - Development of new management tools (e.g: registration forms, medical history, new evaluation form for patients, etc.)
- Develop communication tools to accompany throughout the complete process of implementation
 - This element is thoroughly developed in the Guidelines for the development of communication tools
- Define the role of all the involved stakeholders
 - Flow diagrams might be useful to identify the role of each stakeholder in the overall process.

- Prepare a protocol or document that reflects the agreed upon flows.
- Develop and agree on an action plan
 - Any good action plan should at least answer the questions: When, where, how and by whom?
 - As a general guidance the action plan should consider the following 5 change elements, based on the behaviour change theories
- Try to gain the support of managers and other leaders in the main stakeholder groups (those leaders are not necessarily formal management positions).
- Communicate the strategy (for further details see the Guidelines for the development of communication tools)

5. Evaluate the impact of implemented self-care strategies



Evaluation activities are ideally integrated into the change process from the beginning.

Establish concrete goals against which to measure progress of the implementation. Goals should be ambitious but attainable and very concrete. For example: "Reducing the number of unnecessary GP consults for minor conditions" is not concrete enough, formulating it as "Reducing the number of unnecessary GP consults for minor conditions by 10% in a year" will help to evaluate the progress of the strategy.

5.1. Develop impact indicators

- Develop indicators for all levels of implementation:
 - Micro level: evaluate attitudes of professionals and patients, level of knowledge, use of information materials.
 - Meso level: evaluate the use of health services, the degree of implementation of the intervention(s)
 - Macro: evaluate costs, overall use of the developed self-care resources
- Consider the inclusion of indicators of structure, process and outcomes.

5.2. Consider qualitative evaluation (both by patients/general public and professionals)

• Qualitative techniques might be particularly useful to detect the acceptability of an intervention, identification of barriers and facilitators of the new intervention.

5.3. Evaluate continuously and adapt your strategy in consequence

Guideline on how to promote self-care: Cold

Guideline on how to promote self-care: Cold

Basic information about Cold

The common cold has been defined as an acute epidemic respiratory disease characterized by mild coryzal symptoms of rhinorrhea, nasal obstruction, and sneezing. The nasal discharge is usually copious and thin during the first 2 days of illness, and then it generally becomes more viscous and purulent. The disease is self-limited. Symptoms may persist from 2 days to more than 14 days; however, the cold may abort after only 1 day. Fever, cough, sore throat, or lacrimation may or may not be present[<u>1</u>].

Seasonal patterns of infection can be identified for some of the various types of viruses that are responsible for outbreaks of the common cold $[\underline{1}]$.

1. Identify the problem and evaluate your context

Describing the context in terms of the key issue that you want to address, the stakeholders that can be affected by the issue and the existing resources that exist/could be used to address the issue. This exercise would give a general idea of the starting point.

1 Identify the problem and evaluate your context

- Define what specific issue(s) you are trying to address
- Identify whether those issues are related to a specific minor conditions or a general approach to self-care
- Identify key stakeholders for the development of the self-care strategy
 Identify self-care promotion resources
- for the selected conditions in your area

1.1. Define what specific issue(s) you are trying to address

The first step when deciding to launch a self-care (or any other) initiative is to clarify **what is moving you** to launch this initiative. Specifically, to identify what are the drivers that are moving forward this need for change.

The key drivers depend on each specific context, however a review of the literature point towards some of most common drivers relating to common cold.

Some of the key drivers could be:

• The high incidence of cold among the population.

Common cold is in fact the most frequent acute illness across the industrialized world [(2)]. And the average incidence of the common cold is five to seven episodes per year in preschool children, and two to three per year by adulthood(3)]

• Impact on the life of those affected.

Although cold is a minor self-limiting condition it can have a relevant impact on the day to day life of those affected, even if for a short period of time, which includes work and school leaves. Annual absences from school and work in the United States due to colds caused 26 and 23 million lost days, respectively [(3)]. And in fact, colds account for 40 percent of all time lost from jobs among employed people [1].

Economic impact

A 2002 study in the US estimated the cost of colds in terms of productivity losses. The results found that each cold experienced by a working adult caused an average of 8.7 lost work hours (2.8 absenteeism hours; 5.9 hours of on-the-job loss), and 1.2 work hours were lost because of attending to children under the age of 13 who were suffering from colds. The authors concluded that

the economic cost of lost productivity due to the common cold approached \$25 billion, of which \$16.6 billion were attributed to on-the-job productivity loss, \$8 billion were due to absenteeism, and \$230 million were due to caregiver absenteeism [1].

Reduce unnecessary visits to GPs.

The high incidence of cold makes it one of the most numerous reasons for consultations to the GP. However for cases of common cold GPs can't provide a cure, but are limited to the ease of the symptoms through different medication and treatments that are also available without prescription. Differentiating between the uncomplicated cases of common cold (that can be self-treated) and the cases of more vulnerable population (children under 3, elderly people and/or people with comorbidities) and more complicated cases would help to ease the workload of GP's and emergency care services.

Pharmacists are healthcare professionals who have a detailed knowledge and understanding of medicines (including non-prescription medicines), responding to symptoms, treating minor ailments and providing advice on self-care. By making better use of other resources, such as for example consulting a pharmacist, we can further reduce the burden on GPs and emergency care services.

Reduce inappropriate use of antibiotics.

It is well known that antibiotics are used in circumstances where they are not necessary. One of the circumstances when antibiotic is unnecessarily used is to treat common cold. If fact the WHO referenced as part of the key recommendations to reduce the antibiotic resistance, avoiding the use of antibiotics to treat common cold [(4)].

Those drivers for change are just suggestions and need to be adapted to each context.

1.2. Identify whether those issues are related to a specific minor conditions or a general approach to self-care

Common cold is one of the most common minor conditions in terms of number of people affected. Therefore the key issues that drive the promotion of self-care are mostly common to other minor conditions. Particularly, reducing the inappropriate use of antibiotics is an issue that should be addressed across all the health system if a strategy should be effective.

Regarding the other highlighted issues (high incidence, severity of cases, unnecessary visits to the GP) those can also be shared with other minor conditions and the strategies used to tackle those issues can also encompass other minor conditions, albeit with specific elements that should be adapted to each specific condition.

1.3. *Identify stakeholders and resources available for the self-care strategy*

• **Stakeholders involved for the self-care strategy**: A key determinant of a successful intervention can be the inclusion of the relevant stakeholders. Anyone who wants to promote self-care should identify the stakeholders that are/could be involved and what is expected of each of them. Identifying those stakeholders at an early stage can facilitate a better coordination and a better *Pilot project on the promotion of self-care systems in the European Union.*

Platform of experts. (PiSCE) - Section 1 - Guidelines for the Promotion of Self-Care

use of all the available resources. Stakeholders should be defined in each specific context.

The following, but not limited to, key groups of stakeholders should be considered:

- Healthcare and social care professionals (and professional bodies)
- Educators
- Patient organisations and other NGOs
- Healthcare managers
- Policy decision makers
- Industry, self-care medication and medical devices industry
- Workplace related stakeholders

The table included in the general <u>guideline</u> exemplifies some of the different key stakeholders at local, regional and country level.

1.4. Identify the self-care support resources available in your context

If you want to successfully promote self-care in your context, a key step can be to identify the existing resources. Regarding the key issues that have been highlighted regarding cold the following resources could be particularly useful if available:

- Structural
 - Is there a plan to encourage the proper use of antibiotics in place?
 - Is there already good and systematic exchange of information between community pharmacies and primary care health canters and hospitals?
- Technology
 - Are health information portals already active in your context? Are they well known and used?

The following table illustrates a possible way to summarize the basic characteristics of an evaluation of the context for the self-care strategy. If possible, completing this review with all stakeholders might prove useful.

Note that depending on your position (policy decision maker; healthcare professional, member of patient organization...) you might have different possibilities and ability to involve other stakeholders.

1.1 Define issues		Key issues (suggestion of key issues that might impulse the need for promotion of self-care related to cold)			
		Reduce incidence	severity	unnecessary	Reduce inappropriate use of antibiotics
	General/specific issue				
1.2 Charact.	Level to address the issue (national/regional/local)				

	Healthcare and social care professionals (and professional bodies)	
	Educators	
	Patient/consumer organisations and other NGOs (
1.3.1 Identify key	Patient organisations and other NGOs	
stakehol	der Policy decision makers	
	Healthcare managers	
	Industry, self-care medication pharma industry	
	Workplace related stakeholders	
	Others	
	Economic resources	Budget allocated for material to be developed, personnel required to implement self-care strategy, etc.
1.3.2 Identify	System / structural resources	Potentially the key structural resources could be network of community pharmacists, general access of the population to internet, etc.
key resources	s Professionals training	Level of training of the different types of professionals that could be involved in the strategy (GPs, primary care nurses, pharmacists)
	Technology	Existence of health web portals, health advice lines, etc. in your context (could be from public institutions but also consider Patient Organizations web portals, etc.)

A strategy for the promotion of self-care should always include patients' perspectives. One of the best ways to include this perspective is to involve patient representative in the design of initiatives. However some initiatives are even more related to patients' perspective than other. In the key issues highlighted in this instance the inadequate use of antibiotics might be slightly less dependent on patients than the other issues.

() And should be considered when planning the strategy.

2. Identify and select common and specific patients'/general population self-care behaviours

Identify and select common and specific patients'/general population self-care behaviours that you want to promote (depending on the context problem you want to address)

2 Identify and select common and specific patients'/general population self-care behaviours

- Specify and describe the population/patients that you want to address with the intervention
- Identify the general and specific patients'/general population self-care behaviours that the intervention aims to promote

2.1. Specify and describe the patients/general population that you want to address with the self-care strategy

Once you have evaluated the context and key issues and reflected if the strategy you are defining is a general strategy for self-care or specific to common cold the next step should be to define if the strategy should be aimed to the general populations/patients or a specific group.

For the case of common cold there is probably no specific target population, as all the general population is affected by it. However there are some specific groups that should have special considerations, as they might be more vulnerable to complications or misdiagnosis:

- Children under 3
 - Children are particularly prone to get common cold. The average episodes in adulthood are 2 to 3, whereas in preschool children the average episodes are from 5 to 7 [3].
 Although children are prone to get several colds a year, cold are aren't usually serious. However any self-care strategy should take into consideration that children have a higher risk of developing complications such as ear infections and very occasionally other more serious problems such as pneumonia[5].
- Pregnant women or women that are breastfeeding
- Elderly people
- People with co-morbidities

2.2. Identify the general and specific patients'/general population self-care behaviours that the intervention aims to promote

A key step if you want to establish a strategy to promote self-care is to determine the self-care behaviours. Establishing those target behaviours will guide the development *Pilot project on the promotion of self-care systems in the European Union.*

Platform of experts. (PiSCE) - Section 1 - Guidelines for the Promotion of Self-Care

of the strategy and it will help identifying the mechanisms that can hinder or facilitate the promotion of self-care.

Depending on the results of the analysis of your context and issues that you want to address you can identify <u>different behaviours to promote</u>.

The following table presents considerations specific to cold for each of the main phases of self-care as well as some reflections regarding the patients/general population needs to achieve those goals.

All the behaviours included are considered relevant, however this classification might help to focus the self-care promotion strategy in a specific target.

The following table presents considerations specific to cold for each of the main phases of self-care as well as some reflections regarding the patients/general population needs to achieve those goals.

All the behaviours included are considered relevant, however this classification might help to focus the self-care promotion strategy in a specific target.

Main stages of the cycle of self-care	Main self-care behaviours to promote			
Prevention and healthy lifestyles	 Avoiding inhaling the air from another person sneezing or coughing, routinely washing hands and avoiding touching the mucous membranes (conjunctiva, nasal and oral mucosa). Sneezing and coughing into tissues as this will help to prevent the virus-containing droplets from nose and mouth entering the air where they can infect others; throwing away used tissues immediately and to wash hands. Cleaning surfaces regularly. Hand washing is an essential and highly effective way to prevent the spread of infection. Hands should be washed before preparing food and eating and after coughing, blowing the nose, or sneezing. While it is not always possible to limit contact with people who may be infected with a cold, touching the eyes, nose, or mouth after direct contact should be avoided when possible. In addition, tissues should be used to cover the mouth when sneezing or coughing. These used tissues should be disposed of promptly. There is no evidence that rinsing and gargling antiseptic solutions have shown any benefit. Controlled studies have a preventive effect on common colds. In the same way, Zinc tablets and Echinacea extracts have not shown better than placebo for the prevention of common colds. [5] [6] 			
Symptom recognition and evaluation	Identifying symptoms associated with cold:Sore throat			

- Nasal congestion
- Fever

A 2015 US study found that people that had experienced cold reported that colds typically started with sore/scratchy throat (39.2%), nasal congestion (9.8%), and runny nose (9.3%) and lasted 3–7 days. Cough, the most common cold symptom (73.1%), had a delayed onset (typically 1–5 days after cold onset) and a long duration (>6 days in 35.2%). Nasal congestion and cough were the most bothersome symptoms. [7]

- Being aware about the length of the cold symptoms:
- Cold caused by rhinovirus can last up to two weeks.
- - throat, cough, nasal congestion, sneezing, rhinorrhea, headache, fever). Combining treatment with rest, adequate fluid intake, eating healthily, including plenty of fresh fruit and vegetables and maybe steam inhalation. Avoiding antibiotics unless they are prescribed. Taking a timely decision to treat: many people with cold wait until symptoms are 'bad enough' (42.6%) or multiple

Using treatment directed to the relief of the symptoms (sore

Treatment decisionmaking

Self-monitoring &

early detection of complications

symptoms are present (20.2%) before using non prescription medications. [7]

As the treatment of cold is directed towards symptom relief, the adherence to such treatments might not be as problematic as with Treatment adherence other conditions, the most salient issue might be following treatment directions such as schedules, accompanying intake with food, etc.

> Consulting a healthcare professionals if symptoms and signs such as the following are detected:

Adults

- Increased respiratory rate when the person is at rest and open nasal airflow.
 - Persistent fever after two/three attempts to bring it down or high fever (39°C or 102.2°F).
 - Recently developed petechia (pinpoint red spots).
 - History of febrile seizure. .
 - Symptoms persist for more than three weeks.

Children

- A baby aged less than three months develops a fever higher than 38°C.
- Cold symptoms last for more than 10 days. Particularly if the child is coughing up green, yellow or brown sputum or has a fever – this could be a sign of a bacterial infection that needs treatment with antibiotics.
- Child is finding it difficult to breathe.
- Child complains of pain in the nasal passages after two to four days of home treatment.
- Baby or child has, or seems to have, severe earache (babies with earache often rub their ears and seem irritable).
- Child complains of throat pain for longer than three or four days, or their throat pain seems unusually severe.
- Child develops other symptoms such as pain or swelling in the face or in the chest, a headache or a very bad sore throat.
- Child seems to be getting worse rather than better.
- A rash appears and it does not blanche when pressure applied (i.e. rash does not disappear when a glass tumbler is rolled over the skin).

Co-morbidities:

Might require a closer follow-up by healthcare professionals.



Symptom Evaluation

Although a significant number of people self-care at home there are also numerous visits to primary health-care professionals regarding infections of the upper respiratory tract. Therefore healthcare professionals have a key role in the promotion of self-care. There is a key roles of healthcare professionals regarding treatment evaluation: to distinguish between cold and bacterial infections, allergies and epidemic diseases such as the flu.



Treatment decision-making

Although a significant number of people self-care at home there are also numerous visits to primary health-care professionals regarding infections of the upper respiratory tract. Therefore healthcare professionals have a key role in the promotion of self-care. There is a key roles of healthcare professionals regarding treatment decision-making: avoiding the prescription of antibiotic if it is not strictly necessary

3. Evaluate the mechanisms that might hinder or facilitate the promotion of self-care

Evaluate the mechanisms that might hinder or facilitate the promotion of self-care in your context (barriers and facilitators)

3 Evaluate the mechanisms that might hinder or facilitate the promotion of self-care

- Evaluate the possible impact of hindering/facilitating mechanisms including:
 - Patients related factors
 - Professionals related factors
 - Environment related factors

One of the most important steps in promoting self-care is the identification and analysis of the mechanisms that might hinder the promotion of self-care. Those can be present, hindering the implementation of the self-care strategy, but also as mechanisms facilitating implementation.

When designing a self-care strategy, one should identify and evaluate these mechanisms. To facilitate this step we propose a list of mechanisms that might affect the development of a self-care strategy. This list is not exhaustive but might be helpful to guide a systematic evaluation of hindering/facilitating mechanisms.

Note: When developing this step in a specific context, it could be very useful to involve all those stakeholders that have been identified to include their multiple perspectives, which can increase the chances of detecting the most relevant hindering/facilitating mechanisms and, ultimately, improve the chances of success of the promotion of selfcare guideline.

Patients	
Knowledge	 Low health literacy: low levels of health literacy can make it harder for patients/persons to engage in self-behaviours (for more general information see the general guide). Particularly relevant to self-care of common cold it should be noted that low health literacy can be particularly problematic with overthe-counter medications. A 2010 US study found that caregivers treating infants with over the counter medications had problems following the indications, even when those parents had a mean education level of 12.5 years[7]. More specifically the authors found that when examining the front of the product label, 86% of the time caregivers thought the products were appropriate for use in children <2 years of age. More than 50% of the time, parents stated they would give these over-the-counter products to a 13-month-old child with cold symptoms. Common factors that influenced parental decisions included label saying

"infant," graphics (eg, infants, teddy bears, droppers), and dosing directions.

Even further the study found that caregivers were influenced by the dosing directions only 47% of the time[<u>7</u>].

In addition, caregivers with lower numeracy skills were more likely to provide inappropriate reasons for giving an over-the-counter medication [7].

 Poor information on condition (symptom recognition, possible treatment, usual evolution of symptoms...). Can negatively affect self-care at any stage, particularly for the prevention stage. Regarding cold the recognition of symptoms and the information about the normal evolution of the condition can be two areas the hinder the reduction of unnecessary visits to GPs and the inappropriate us of antibiotics.

More specifically, a 2015 US study found that misperceptions regarding etiology and treatment of the common cold were prevalent. And pointed out that the main limitation is potential recall bias, since people with cold had to recall cough/cold episodes over the prior year to decide their self-care treatment [<u>6</u>].

• Poor information on the treatment options. This could lead to unnecessary consultation with the GP, or applying ineffective treatments (for example not-proven lay remedies) or unnecessary antibiotics.

A 2015 systematic review found a general lack of knowledge about antibiotics. More specifically the systematic review found that 53.9% of people did not know that antibiotics are not useful against viruses. In addition 26.9% of the people did not know that misuse of antibiotics can lead to antibiotic resistance. Finally, 47.1% of the people declared that they stop taking antibiotics when they start feeling better [<u>8</u>]

- Poor information on navigation of the healthcare system. Poor information on the healthcare system can lead to unnecessary consultation with professionals, as patients/general population might not be aware of other possible consultations with professionals that might be available (community pharmacists, health-information phone-lines, etc.).
- Lack of decision-making skills can be a hindering mechanisms for the reduction of unnecessary visits to the GP and crucial, the reduction of inappropriate use of antibiotics.
- Application of preventive measures. Reducing the contagion of cold could be one of the key benefits of the promotion of self-care. The poor skills of prevention can be one of the key hindering mechanisms particularly for the reduction of incidence.
- Attitudes and beliefs
 Beliefs about cold
 A 2000 US study [9] found that of the adults seeking care for a child or themselves:

 44% believed viruses alone cause the common cold; an

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) - Section 1 - Guidelines for the Promotion of Self-Care

Skills

additional 42% believed both viruses and bacteria play a role.

- Most thought rest (97%) and nonprescription medications (63%) were helpful for colds, which was consistent with published reports.
- Contrary to medical reports, however, most felt vitamin C (67%) and the inhalation of steam (70%) reduced cold symptoms, and 44% believed antibiotics help colds (c2=19.57; P=.0002).
- \circ $\;$ But 85% believed colds could resolve on their own.

Believes about the effectiveness of antibiotics

A 2000 US study on the characteristics of adults and caregivers of children with cold who want antibiotics found that those who ask for antibiotic are more likely to believe that antibiotics helps with cold symptoms, despite the abundant evidence. Similarly adults who want antibiotics were more likely to believe that they had previously recovered faster with antibiotic therapy and to be confident that they knew how to treat cold. In addition they were less likely to believe that too many people take antibiotics for cold [(9)][(10)].

• Health related quality of life

Health status

Demographic

characteristics

The authors of a 2015 study in Japan found association between Health related quality of life and self-care. They found that people who engage in self-care when treating the common cold had significantly higher levels of Health related quality of life than among individuals who preferred to attend a health clinic. It should be noted that the authors couldn't discern whether selfcare behaviour affects quality of life, or whether quality of life affects self-care behaviour. Even with this limitation the results of the study highlight the importance of the relationship between quality of life and self-care behavior. [12]

- Co-morbidities: co-morbidities might inhibit self-care for minor conditions and, crucially, can be a very relevant risk factor. Comorbidities are key factor to drive people to consult with their GP. In these cases consultation shouldn't be discouraged. However efficient systems of consultation (telephone, webcam) can be explored.
- Impaired cognition can complicate self-care in multiple aspects, including the access to relevant information.
- Age: regarding cold the effect of age is most clear on children under 3 or elderly people who might be more vulnerable to complications such as ear infections or pneumonia among others. Although more serious complications such as pneumonia are relatively rare, the risk of those specific age groups should be considered and can hinder the promotion of self-care.

It has to be considered that self-care should only be promoted if the expected benefits no not imply serious risk (or if it outbalances minor risks).

• Gender can have an impact on self-care in multiple aspects;

	particularly different conditions can have different effects on women and men. However it is not clear that it has a relevant impact regarding cold for those specific issues.
Socio-economic status (and or minority groups)	 Financial resources: lack of financial resources can complicate self-care by hindering the access to self-care medication (or self-care devices), affecting the decision to take a sick-leave (maybe incurring on loss of (part of) the salary for some days), etc. The pricing systems and prescription discounts in many countries across Europe might deter patients/general population from directly consulting the community pharmacist and purchasing over-the-counter symptomatic treatments and might even incentivise using antibiotics in the most problematic cases. Social exclusion: people in situation of social exclusion can have a more difficult access to self-care resources such as information sources, advice from professionals, etc.
Professionals	
Behaviours	• Prescription of antibiotics for self-limiting minor conditions. This behaviour might incentivise patients/general public to visit GPs whenever they have a minor condition. The prescription of antibiotics can reinforce a patient to repeat the consultation with the GP in future episodes of common cold.
Knowledge	 Professional education to promote patient self-care can be key for a successful intervention. A good education on promotion of self-care or lack thereof can be critical as a positive driver or as an important complication.
Skills	 Communication skills might not be a priority in the professional curricula. The lack or low confidence on the communications skills such it might inhibit the promotion of self-care treatment options regarding cold.
Attitudes	 Healthcare professionals' attitudes: the attitudes of healthcare professionals (including primary care, pharmacist, etc) are critical factors for the implementation of a self-care strategy. It can difficult the development of a self-care strategy greatly or it can facilitate it considerably depending if they have a negative or positive attitude towards it.
Environment	
Social factors	 Social/cultural differences: might difficult understanding of self-care portals of information Low relevance of self-care promotion on health care education
Organizational factors	 Issuance of work leave (sick certificate): in many countries the work leave is covered by Social Security schemes/insurance schemes if this is linked to a medical certificate it directs people with a minor

condition to directly consult with GPs, even for cases that could be self-treated (for example cold).

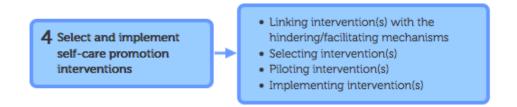
- Access to resources: the variation in accessibility of key resources (for example web portals) to self-care can act as a barrier.
- Financial incentives for professionals: a key issue might be the cases of linking a part of the GPs salary to the number of consults. This can act as a barrier for GPs to actively encourage self-care.
- Financial incentives for patients in some systems to seek prescribed self-care medication: In many health systems prescribed medication is discounted, compared to self-care medication purchased directly at the pharmacy. This fact might affect the decision of citizens to attend primary care doctors instead of attempting self-care.

As the review of potentially hindering or facilitating mechanisms reflect, there are **three potentially key areas of hindering or facilitating mechanisms to consider:**

Economic factors

- Patient/general population knowledge and skills as key mechanisms for all the target issues
- Organizational and economic factors to tackle a possible reduction of unnecessary visits to GPs and the reduction of inappropriate use of antibiotics (which also highly depends of professionals' clinical practice).
- **Specific population groups** (age and co-morbidities) that should be acknowledged when promoting self-care in cold.

4. Select and implement self-care promotion intervention(s)



4.1. Linking intervention(s) with the hindering/facilitating mechanisms

Once the hindering or facilitating mechanisms have been identified a key next step can be to link interventions to those mechanisms.

There are numerous interventions that could potentially contribute to the promotion of self-care in cold for the selected target issues (reduce incidence; reduce severity of cases; reduce unnecessary visits to GPs and reduce inappropriate use of antibiotics).

The table presented in point 4.2 highlights types of interventions that could target those issues addressing the detected hindering or facilitating mechanisms, with special attention **three key areas of hindering or facilitating mechanisms highlighted before:** the patients'/general population knowledge and skills, organizational factors and the specific most vulnerable groups in the general population.

4.2. Selecting intervention (s)

As it was highlighted in the subjective evaluation of mechanisms there are three key areas of mechanisms to consider:

- Patients and general population knowledge and skills, which might help to address all four issues.
- Organizational factors, which might be particularly useful to address the unnecessary visits to GPs and the inappropriate use of antibiotics (for both cases professionals clinical practice should be also considered).
- Specific vulnerable groups that should have some special considerations.

The following tables illustrate types of self-care promotion interventions that could address those mechanisms with the final goal of improving the key issues highlighted.

Suggested interventions by key issues

	Roduco	Reduce severity of cases	unnecessary	Reduce inappropiate use of antibiotics
Key characteristics of the issue				

General/specific issue

Level to address the issue

(national/regional/local)

Key focus that the self-care promotion strategy requires or should include

System-focused

- Structural interventions
- Staff-oriented interventions
- Financial interventions
- Financial incentives to patients
- Financial incentives to Primary

Patient-focused interventions

- Skill development
- Behaviour change
- Family support
- Information provision

Professional-focused interventions

- Educational interventions
- Educational materials
- Large-scale educational
- Small-scale educational
- Outreach visits
- Use of opinion leaders
- Feedbacks and reminders
- Feedback
- Reminders
- Local consensus processes

From this analysis the following type of interventions could be recommended: It is important to bear in mind that most interventions are multifaceted so include more than one area, however to facilitate the analytical line the interventions have been divided in **information strategies** and **organizational strategies**.

Information strategies:

• Information, with a special focus on symptom recognition and evaluation.

One of the identified potentially hindering mechanisms was the lack of knowledge regarding what to expect when someone has common cold, to be aware of treatment options and recommendations for symptom relieve. Information strategies can have some beneficial results to tackle this issue. Some examples of those initiatives are:

Examples of similar practices in:

- UK: NHS Choices Common cold [(12)]
- France: Améli.Santé Rhume [(13)]
- Netherlands: Zelfzorg.nl [(14)]
- Sweden: 1177 Vårdguiden Förkylning [(15)]
- **Know who to turn to:** as one of the hindering mechanisms identified is the poor knowledge of navigation health systems, it might be of interest to review information strategies specifically addressed to cover this issue, that usually also entail evaluation of symptoms and treatment decision making.

This style of information campaign has been applied in multiple primary care trusts across the UK. For some examples see:

• NHS Scotland: Know who to turn to [(16)]

With a combination of those two complementary information strategies would help to address two of them most relevant aspects: symptom recognition and information on navigation of health system.

Note: An information campaign should be tailored to the needs of its target population, so depending on the ethnic composition of the implementing context, the material of the interventions might have to be translated to multiple languages and be adapted to some cultural traits (see <u>implementing intervention sub-section</u>)

Note: One important consideration would be the different mechanisms to be used for such information campaigns, to that regard see **<u>Communication tools.</u>**

• Mass media campaigns

Public campaigns have been widely used for topics related to common cold. The authors of a review of public campaigns focused on improving the use of antibiotics in outpatients between 1990 and 2007 [(17)] found that although there is still missing evidence to prove a cause-effect relation, the available data suggests that public campaigns had a positive effect on the use of antibiotics. Particularly multifaceted campaigns repeated over several years had the greatest effect.

Example (UK experience)

In this retrospective study, there was incomplete reporting of adjuvant interventions undertaken by the PCOs intervention and comparison areas, so isolating the intervention, and attributing cause and effect is difficult. In this pragmatic evaluation the campaign was found to significantly reduce the volume of antibacterial drugs during the winter months of the intervention years. There were 21.7 fewer items prescribed per 1000 population (P < 0.0005), for the intervention populations over these winter months, equivalent to a 5.8% absolute reduction in prescribing. [18]

Example (New Zealand experience)

A study (19)] in New Zealand compared public views and use of antibiotics for the common cold before and after an education campaign. The authors found no change between 1998 and 2003 in public awareness that antibiotics are not helpful in treating viral infections (38%). However they did find a significant reduction in those attending doctor for the common cold (24% to 15%) and a reduction in of antibiotic prescriptions in favour of delayed prescriptions for those consulting with a GP.

For the highlighted most vulnerable groups

• Children under 3 – partnership with nurseries to educate both educators and parents in the recognition of symptoms.

Organizational strategies:

• **Delayed prescriptions:** in some cases the prescription is for self-care for a given period of time. If in this period of time the symptoms do not improve significantly the patient can get the prescribed antibiotic without returning to the GP consultation (important: the antibiotic is only available after a given number of days from the prescription and not before).

This strategy can help reduce the use of antibiotics as in many cases the symptoms will subside after some days of proper self-care.

In addition the prescription of self-care encourages a conversation about the importance and effectiveness of self-care in minor conditions.

 Minor ailments schemes, partnerships between GPs and community pharmacists

These types of program are based on directing people with minor ailments to the community pharmacist as the first health professional (instead of consulting to the GP as the first access point). Minor ailments schemes are a national health program in Scotland, Northern Ireland, Wales and some primary care trusts in England.

This approach has been adapted with some different characteristics however, most programs include two key aspects:

 Including the treatments that the pharmacist might suggest in the prescription system, so if someone is eligible to free prescriptions or a discount when they consult with their GP they will also have those free or discounted prescriptions if they consult with the community pharmacist.

This eliminates one of the barriers that might inhibit people from consulting with pharmacists: the payment barrier.

 $_{\odot}~$ Establishing a fast-track for GP consultation if the pharmacist decides to refer to GPs.

A European study [20] found that Minor Ailments Schemes have shown the potential to substitute for other health service and to reduce GP consultations for minor ailments (in Scotland, where the scheme has been in place since 2006). The same study analysed the cost/benefit of the Minor Ailments Schemes, factoring the time dedicated to consult the pharmacists vs. the GP among other variables. They found that patients exempt of prescription charges benefit from about 8£ by consulting with a pharmacists instead of a GP (compared to a benefit of 5.73£ if there is no minor ailment scheme).

To see estimated results of the cost/benefit analysis for GPs, pharmacists and overall health system, see: A cost/benefit analysis of self-care systems in the European Union (link to study).

For some specific examples see:

Greater Manchester Minor Ailments Scheme – Pharmacy First [(21)]

NHS Scotland – NHS minor ailment services [(22)]

Remember that before implementing a piloting of the interventions is recommended. For tips regarding Implementation of interventions see the section in the <u>general</u> <u>guideline</u>

5. Evaluate the impact of implemented self-care strategies



Evaluation activities are ideally integrated into the change process from the beginning.

Establish concrete goals against which to measure progress of the implementation. Goals should be ambitious but attainable and very concrete. For example: "Reducing the number of unnecessary GP consults for minor conditions" is not concrete enough, formulating it as "Reducing the number of unnecessary GP consults for minor conditions by 10% in a year" will help to evaluate the progress of the strategy.

5.1. Develop impact indicators

- Develop indicators for all levels of implementation:
 - Micro level: evaluate attitudes of professionals and patients, level of knowledge, use of information materials.
 - Meso level: evaluate the use of health services, the degree of implementation of the intervention(s)
 - Macro: evaluate costs, overall use of the developed self-care resources
- Consider the inclusion of indicators of structure, process and outcomes.

5.2. Consider qualitative evaluation (both by patients/general public and professionals)

• Qualitative techniques might be particularly useful to detect the acceptability of an intervention, identification of barriers and facilitators of the new intervention.

5.3. Evaluate continuously and adapt your strategy in consequence

Bibliography

1. Kirkpatrick GL. The common cold. Prim Care [Internet]. 1996;23(4):657–75. Available from: http://www.ncbi.nlm.nih.gov/pubmed/8890137

2. Bramley TJ, Lerner D, Sames M. Productivity losses related to the common cold. J Occup Environ Med [Internet]. 2002 Sep [cited 2015 Sep 10];44(9):822–9. Available from: http://www.ncbi.nlm.nih.gov/pubmed/12227674

3. Sexton D, McClain M. The common cold in adults: Diagnosis and clinical features. UpToDate [Internet]. 2014; Available from: http://www.uptodate.com/contents/the-commoncold-in-adults-diagnosis-and-clinical-features

4. World Health Organisation. WHO - How to reduce the spread of antibiotic resistance [Internet]. 2011. Available from: http://www.euro.who.int/en/health-topics/disease-prevention/antimicrobial-resistance/news/news/2012/11/antibiotic-resistance-a-growing-threat/how-to-reduce-the-spread-of-antibiotic-resistance

5. NHS Choices. Common cold - Children [Internet]. 2015. Available from: http://www.nhs.uk/Conditions/Cold-common/Pages/Commoncoldinchildren.aspx

6. Blaiss MS, Dicpinigaitis P V, Eccles R, Wingertzahn MA. Consumer attitudes on cough and cold: US (ACHOO) survey results. Curr Med Res Opin [Internet]. 2015 Aug [cited 2015 Sep 10];31(8):1527–38. Available from: http://www.ncbi.nlm.nih.gov/pubmed/25535904

7. Lokker N, Sanders L, Perrin E, Kumar D, Finkle J, Franco B, et al. Parental Misinterpretations of Over-the-Counter Pediatric Cough and Cold Medication Labels. Pediatrics. 2009;123(6):1464–71.

8. Gualano MR, Gili R, Scaioli G, Bert F, Siliquini R. General population's knowledge and attitudes about antibiotics: a systematic review and meta-analysis. Pharmacoepidemiol Drug Saf [Internet]. 2015 Jan 24 [cited 2015 Sep 10];24(1):2–10. Available from: http://www.ncbi.nlm.nih.gov/pubmed/25251203

9. Braun BL, Fowles JB. Characteristics and experiences of parents and adults who want antibiotics for cold symptoms. Arch Fam Med [Internet]. 2000 Jul [cited 2015 Sep 10];9(7):589–95. Available from: http://www.ncbi.nlm.nih.gov/pubmed/10910304

10. European Commision, Directorate-General for Health and Food Safety. Special Eurobarometer 445 - Antimicrobial Resistance (Report) [Internet]. 2016. Available from: http://ec.europa.eu/dgs/health_food-safety/amr/docs/eb445_amr_generalreport_en.pdf

11. Shaku F, Tsutsumi M, Miyazawa A, Takagi H, Maeno T. Self-care behavior when suffering from the common cold and health-related quality of life in individuals attending an annual checkup in Japan: a cross-sectional study. BMC Fam Pract [Internet]. 2015 Jan [cited 2015 Sep 10];16(1):91. Available from: http://www.biomedcentral.com/1471-2296/16/91

12. NHS. NHS Choices - Common cold [Internet]. 2015. Available from: http://www.nhs.uk/conditions/cold-common/pages/introduction.aspx

13. Ameli-sante. Ameli-Sante - Rhume [Internet]. 2015. Available from: http://www.ameli-sante.fr/rhinopharyngite-de-lenfant/definition-symptomes-evolution.html

14. Zelfzorg. Zelfzorg - Verkoudheid [Internet]. Available from: http://zelfzorg.nl/verkoudheid

15. 1177 Vardguiden. 1177 Vårdguiden - Förkylning [Internet]. 2016. Available from: http://www.1177.se/Fakta-och-rad/Sjukdomar/Forkylning/

16. Know who to turn to [Internet]. NHS Scotland. Available from: http://www.knowwhototurnto.org/

17. Huttner B, Goossens H, Verheij T, Harbarth S. Characteristics and outcomes of public campaigns aimed at improving the use of antibiotics in outpatients in high-income countries.

Lancet Infect Dis [Internet]. 2010;10(1):17–31. Available from: http://dx.doi.org/10.1016/S1473-3099(09)70305-6

18. Lambert MF, Masters G a., Brent SL. Can mass media campaigns change antimicrobial prescribing? A regional evaluation study. J Antimicrob Chemother. 2007;59(3):537–43.

19. Curry M, Sung L, Arroll B, Goodyear-Smith F, Kerse N NP. Public views and use of antibiotics for the common cold before and after an education campaign in New Zealand. - PubMed - NCBI. N Z Med [Internet]. [cited 2015 Sep 10]; Available from: http://www.ncbi.nlm.nih.gov/pubmed/?term=Public+views+and+use+of+antibiotics+for+the+c ommon+cold+before+and+after+an+education+campaign+in+New+Zealand

20. Ostermann H, Renner A-T, Bobek J, Schneider P, Vogler S. A cost / benefit analysis of self- care systems in the European Union. 2015.

21. Greater Manchester Minor Ailments Scheme – Pharmacy First [Internet]. Community Pharmacy Greater Manchester. 2016. Available from: http://psnc.org.uk/community-pharmacy-greater-manchester/services/greater-manchester-minor-ailments-scheme-pharmacy-first/

22. NHS Scotland. The new NHS minor ailment service at your community pharmacy. Scottish Consum Counc [Internet]. Available from: http://www.psd.scot.nhs.uk/docs/minor_ailment.pdf

Guideline on how to promote self-care: Ahtlete's foot

Guideline on how to promote self-care: Athlete's foot

Basic information about Athlete's foot

Athlete's foot is a common fungal infection of the foot.

An itchy red rash develops in the spaces between your toes. The affected skin may also be scaly, flaky and dry.

The medical name for athlete's foot is tinea pedis [1].

Tinea pedis, tinea foot or athlete's foot are all terms used for fungal infection caused by dermatophyte fungi.

Tinea pedis is a dermatophyte infection of the soles of the feet and the interdigital spaces (isolated involvement of the back of the foot is considered ringworm of the body -Tinea Corporis). Athlete's foot is a term that covers all those infections that affect the foot when it becomes macerated and suffers occlusion (that usually happened to athletes who had hypersweating and used breathable footwear while exercising).

1. Identify the problem and evaluate your context

Describing the context in terms of the key issue that you want to address, the stakeholders that can be affected by the issue and the existing resources that exist/could be used to address the issue. This exercise would give a general idea of the starting point.

1 Identify the problem and evaluate your context

- Define what specific issue(s) you are trying to address
- Identify whether those issues are related to a specific minor conditions or a general approach to self-care
- Identify key stakeholders for the development of the self-care strategy
 Identify self-care promotion resources
- for the selected conditions in your area

1.1. Define what specific issue(s) you are trying to address

The first step when deciding to launch a self-care (or any other) initiative is to clarify **what is moving you** to launch this initiative. Specifically, to identify what are the drivers that are moving forward this need for change.

The key drivers depend on each specific context, however a review of the literature point towards some of most common drivers relating to athlete's foot.

Some of the key drivers could be:

• Reduce the incidence among the general population

Tinea pedis are common worldwide and their incidence continues to increase, being one of top 10 dermatosis types in Dermatology practices. The vast majority of population in developed countries has had or will have an episode of tinea pedis, often subclinical infection. Nearly 15% of population suffers from fungal foot (tinea pedis or athlete's foot). Although tinea pedis may occur as several forms, toes web (interdigital) and plants, heels and sides of foot (plantar or moccasin distribution) are the most common. Once infection has been contracted it can spread to other places such as fingernails, which can be a source of reinfection.

This infection spread worldwide but mostly in urban environments. It predominantly affects young adult males who wear occlusive footwear, although it can be seen in both sexes and at any age. It is more common during spring and summer months. The principal causative agent is Trichophyton rubrum, which tends to be chronic and often subclinical infection. (2)

• Increase the adherence to treatment

In general, compliance among patients suffering from dermatomycosis, especially in the feet and nails, is very low and unsatisfactory. Patients do not carry out properly the treatment; they reduce number of daily doses to apply of antifungal ointment and also drop out of treatment prematurely.

Many topical antifungal medications do not help to easy comply the treatment. Ointment should be applied regularly throughout the day, and for long periods of time, even after the symptoms of fungal infection have disappeared.

The fact that some patients do not consider important fungal infection of the foot due to ignorance of its possible complications also contributes to this situation.

This is worrying not only by increasing recurrences involved, but also the risk of creating strains resistant to various antifungal.

It is therefore essential to ensure patient compliance through a proper healthcare professional-patient communication and the use of antifungal medication that minimize this risk, either because they require less daily applications but also a shorter duration of treatment.

• Reduce unnecessary visits to GPs.

The high incidence of athlete's foot makes it one of the most numerous reasons for consultations to the GP. In general terms a study for the UK found that 39% of GP time is spent dealing with patients suffering from self-treatable minor ailments. (3).

Most cases of athlete's foot are mild and can be treated with an antifungal medication. In most cases in a first visit the GP will prescribe an antifungal medication [(1)].

If someone affected with athlete's foot waits to go to the GP after selftreating with antifungal medication for the recommended period (if symptoms do not start getting better within the 7-10 days), it could reduce the number of visits to GPs and the visit in itself would be more significant. At that point proper diagnosis might need tests administered by healthcare professionals.

• Reduce inadequate use of antibiotics.

It is well known that antibiotics are used in circumstances where they are not necessary. One of the circumstances when antibiotic is unnecessarily used is to treat athlete's foot, antibiotic should be only used with professional prescription in specific circumstances (for example if there is a bacterial superinfection, oral or topical antibiotics should be added to the treatment).

Those drivers for change are just suggestions and need to be adapted to each context. It could be that when planning a self-care in your context you find that you want to tackle the low adherence to treatment and the inadequate use of antibiotics, but in

your context the number of visits to the GP is not an issue, or is not an issue that you can tackle at this point in time.

1.2. Identify whether those issues are related to a specific minor conditions or a general approach to self-care

Athlete's foot is a very common minor condition in terms of number of people affected. Therefore the key issues that drive the promotion of self-care are mostly common to other minor conditions. Particularly, reducing the inadequate use of antibiotics is an issue that should be addressed across all the health system if a strategy should be effective.

Regarding the other highlighted issues (high incidence, low adherence to treatment, unnecessary visits to the GP) those can also be shared with other minor conditions and the strategies used to tackle those issues can also encompass other minor conditions, albeit with specific elements that should be adapted to each specific condition.

Although there is no data comparing by minor conditions it might be that treatment adherence is particularly low in the case of athlete's foot. Probably this can be related to the long periods of treatment and a relatively low perception of risk of complications.

1.3. Identify stakeholders and resources available for the self-care strategy

Stakeholders involved for the self-care strategy: A key determinant of a successful intervention can be the inclusion of the relevant stakeholders.
 Anyone who wants to promote self-care should identify the stakeholders that are/could be involved and what is expected of each of them. Identifying those stakeholders at an early stage can facilitate a better coordination and a better use of all the available resources. Stakeholders should be defined in each specific context.

The following, but not limited to, key groups of stakeholders should be considered:

- Healthcare and social care professionals (and professional bodies)
- o Educators
- Patient organizations and other NGOs
- Healthcare managers
- Policy decision makers
- Industry, self-care medication and medical devices industry
- Workplace related stakeholders

The table included in the general <u>guideline</u> exemplifies some of the different key stakeholders at local, regional and country level.

1.4. Identify the self-care support resources available in your context

If you want to successfully promote self-care in your context, a key step can be to identify the existing resources.

Regarding the key issues that have been highlighted regarding athlete's foot the following resources could be particularly useful if available:

- Structural
 - Is there a plan to encourage the proper use of antibiotics in place?
 - Is there already good and systematic exchange of information between community pharmacies and primary care health centers and hospitals?
- Technology
 - Are health information portals already active in your context? Are they well known and used?

The following table illustrates a possible way to summarize the basic characteristics of an evaluation of the context for the self-care strategy. If possible, completing this review with all stakeholders might prove useful.

Note that depending on your position (policy decision maker; healthcare professional, member of patient organization...) you might have different possibilities and ability to involve other stakeholders.

		Key issues (suggestion of key issues that might impulse the need for promotion of self-care related to athlete's foot)			
1.1 Define issues		Reduce the incidence among general population	Increase adherence to treatment	Reduce use of antibiotics	Reduce number of unnecessary visits to the GP
1.2	General/specific issue				
Characteristics	Level to address the issue (national/regional/local)				
	Economic resources				
1.3 Identify key resources	System/structural resources				
0	Professionals training				
	Technology				

🤨 And should be considered when planning the strategy

2. Identify and select common and specific patients'/general population self-care behaviours

Identify and select common and specific patients'/general population self-care behaviours that you want to promote (depending on the context problem you want to address)

2 Identify and select common and specific patients'/general population self-care behaviours

- Specify and describe the population/patients that you want to address with the intervention
- Identify the general and specific patients'/general population self-care behaviours that the intervention aims to promote

2.1. Specify and describe the patients/general population that you want to address with the self-care strategy

Depending on the results of the evaluation of the context and key issues and whether the strategy is general or specific to a minor condition, one should define the patients/general population that the interventions should be addressed to. In doing so, consider:

- Characteristics of the general population
 - People affected by the condition(s) the intervention is targeting
 - Demographic (including age and gender) and socio-economic characteristics
 - Possible co-morbidities

• Health literacy, language, cultural traits

For the case of common athlete's foot all the general population is affected by it, however it is common among teenagers and young adults that use occlusive footwear so, some of the strategies might have to be adapted to this specific target group.

However there are some specific groups that should have special considerations:

- Children, pregnant women and elderly people for which some of the antifungal treatments might not be adequate
- People with co-morbidities, particularly for diabetes, for which athlete's foot might more easily develop complications

2.2. Identify the general and specific patients'/general population self-care behaviours that the intervention aims to promote

A key step if you want to establish a strategy to promote self-care is to determine the ideal self-care behaviours. Establishing those ideal behaviours will guide the

development of the strategy and it will help identifying the mechanisms that can hinder or facilitate the promotion of self-care.

Depending on the results of the analysis of your context and issues that you want to address you can identify <u>different behaviours to promote</u>.

The following table presents considerations specific to athlete's foot for each of the main phases of self-care as well as some reflections regarding the patients/general population needs to achieve those goals.

Main stages of the of self-care	Main self-care behaviours to promote	
Prevention and he lifestyles	 Performing proper hygiene of the feet and keeping them dry interdigitally. Washing the feet with soap and water and wiping up the area completely and carefully. Trying to do this at least twice a day. Using natural fabrics in stockings and socks (yarn, cotton, etc.). Wearing appropriate footwear. Wearing shoes that are airy and preferably made of a natural material like leather. It helps to alternate shoes each day, so they can dry completely. Avoiding shoes with plastic coating. Not using other people's shoes or socks. Socks should be changed as often as possible to keep feet dry; this should be done at least once a day. Using slippers when changing or showering in public places and avoiding using other people's towels. It should also be noted that there are some individual/genetic factors that favour it include suffering from peripheral vascular disease, diabetes mellitus or immunologic disease. 	
Symptom recognit evaluation	 Identifying symptoms associated with athlete's foot: appearance of intensely itchy Sometimes painful, Red blisters between the toes or on the soles of the feet Sometimes, it will simply look like dry, flaky skin on the feet Patients could be encouraged to check visual materials such as online pictures to aid them in the recognition of signs. 	
Treatment decisio making	Using appropriate over-the-counter antifungal products.	

All the behaviours included are considered relevant, however this classification might help to focus the self-care promotion strategy in a specific target.

Pilot project on the promotion of self-care systems in the European Union.

Platform of experts. (PiSCE) - Section 1 - Guidelines for the Promotion of Self-Care

Treatment adherence	 Being aware of the importance of completing the treatment fully. For example: Over-the-counter antifungal creams or powders should be applied 1 to 2 weeks after the infection is cured not to risk infection reappearance. Implementing the treatment following the directions of the product.
Self-monitoring & early detection of complications	 Athlete's foot is a minor and self-limiting condition, however it can present some risks depending on the evolution and the characteristics and/or situation of the person affected. If athlete's foot does not improve in 2 to 4 weeks and reappears frequently, medical attention should be sought. Antibiotics could be needed to treat secondary bacterial infections. Emergency visit in case foot is swollen and feel warm to the touch, especially if there are red lines, as these are symptoms of a possible bacterial infection. Other symptoms may be the presence of pus, secretion and fever. Medical visit is always advisable if the patient is suffering from diabetes, peripheral vascular disease or has impaired immune system. Recommendations to help prevent the spread of athlete's foot are equivalent to those that should be taken in prevention of athlete's foot.

3. Evaluate the mechanisms that might hinder or facilitate the promotion of self-care

Evaluate the mechanisms that might hinder or facilitate the promotion of self-care in your context (barriers and facilitators)

3 Evaluate the mechanisms that might hinder or facilitate the promotion of self-care

- Evaluate the possible impact of hindering/facilitating mechanisms including:
 - Patients related factors
 - Professionals related factors
 - Environment related factors

One of the most important steps in promoting self-care is the identification and analysis of the mechanisms that might hinder the promotion of self-care. Those can be present, hindering the implementation of the self-care strategy, but also as mechanisms facilitating implementation.

When designing a self-care strategy, one should identify and evaluate these mechanisms. To facilitate this step we propose a list of mechanisms that might affect the development of a self-care strategy. This list is not exhaustive but might be helpful to guide a systematic evaluation of hindering/facilitating mechanisms.

Note: When developing this step in a specific context, it could be very useful to involve all the relevant detected stakeholders to include their multiple perspectives, which can increase the chances of detecting the most relevant hindering/facilitating mechanisms and, ultimately, improve the chances of success of the promotion of self-care guideline.

Patients	
Knowledge	 Low health literacy: low levels of health literacy can make it harder for citizens to engage in self-care behaviours. It has been reported that about 12% of the European population have inadequate general health literacy, and more than one third (35%) has problematic health literacy [(4)]. Health literacy can be one of the key determinants to address as it has been proven to be associated with health outcomes, health service use and quality of health systems as well as capacity building for professionals. Health literacy affects any strategy promoting self-care for any condition, including common athlete's foot, and it can be one of the most relevant hindering mechanisms. Poor information on prevention of athletes' foot or condition (symptom recognition, possible treatment, usual evolution of symptoms).The poor information can negatively affect self-care at any stage, for example: incorrect assessment of severity, delayed

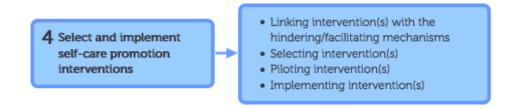
	 recognition of symptoms, biased expectations on the condition prognosis. Poor information on the treatment options. The poor information on treatment options could lead to unnecessary consultation with the GP, or applying ineffective treatments Particularly for athlete's foot, patients should be more aware of the importance of completing the foot treatment and the associated self-care measures (dry the area well, etc.)
Skills	 Lack of decision-making skills. The lack of decision making skills can be a hindering mechanism for the reduction of unnecessary visits to the GP Application of preventive measures. Reducing the contagion of athlete's foot could be one of the benefits of the promotion of self-care. The poor skills of prevention can be one of the key hindering mechanisms particularly for the reduction of incidence.
Attitudes	 Health beliefs of a particular group/individual at family, level, community level and overall cultural level. Lack of commitment to completing the treatment.
Health status	 Co-morbidities: co-morbidities might difficult self-care for minor conditions and, crucially, can be a very relevant risk factor. For athlete's foot special caution should be paid for patients with diabetic foot (and patients with other types of neuropathies). Impaired cognition can complicate self-care in multiple aspects, including the access to relevant information.
Demographic characteristics	 Age: it seems that the group that tends to be more affected by athlete's foot are teenagers and young adults. Gender can have an impact on self-care in multiple aspects; particularly different conditions can have different effects on women and men. However it is not clear that it has a relevant impact regarding athlete's foot for those specific issues.
Socio-economic status (and or minority groups)	 Financial resources: lack of financial resources can complicate self-care by hindering the access to self-care medication (or self-care devices). The pricing systems and prescription discounts in many countries across Europe might deter patients/general population from directly consulting the community pharmacist and purchasing over-the-counter symptomatic treatments and might even incentivise using antibiotics in the most problematic cases. Social exclusion: people in situation of social exclusion can have a more difficult access to self-care resources such as information sources, advice from professionals, etc.
Professionals	

Knowledge	 Professional education to promote patient self-care can be key for a successful intervention. A good education on promotion of self-care or lack thereof can be critical as a positive driver or as an important complication.
Skills	 Communication skills might not be a priority in the professional curricula. The lack or low confidence on the communications skills such it might difficult the promotion of self-care treatment options regarding athlete's foot.
Attitudes	• The attitudes of healthcare professionals (including primary care, pharmacist, etc) is a critical factor for the implementation of a self-care strategy. It can difficult the development of a self-care strategy greatly or it can facilitate it considerably depending if they have a negative or positive attitude towards it.
Environment	
Social factors	 Social/cultural differences: might difficult understanding of self-care portals of information Low relevance of self-care promotion on health care education
Economic factors	 Financial incentives for professionals: a key issue might be the cases of linking a part of the GPs salary to the number of consults. This can act as a barrier for GPs to actively encourage self-care. Financial incentives for patients in some systems to seek prescribed self-care medication: In many health systems prescribed medication is discounted, compared to self-care medication purchased directly at the pharmacy. This fact might affect the decision of citizens to attend primary care doctors instead of attempting self-care.

As the review of potentially hindering or facilitating mechanisms reflect, there are three potentially key areas of hindering or facilitating mechanisms to consider:

- Patient/general population knowledge and skills as key mechanisms for all the target issues
- Professional behaviour, knowledge and skills can be key in the reduction of incidence, increase of adherence to treatment and reduced use of unnecessary antibiotics.
- **Specific population groups** (young adults, co-morbidities) that should be acknowledged when promoting self-care in Athlete's foot.
- •

4. Select and implement self-care promotion intervention(s)



4.1. Linking intervention(s) with the hindering/facilitating mechanisms

Once the hindering or facilitating mechanisms have been identified a key next step can be to link interventions to those mechanisms.

There are numerous interventions that could potentially contribute to the promotion of self-care in athlete's foot for the selected target issues (reduce incidence; reduce severity of cases; reduce unnecessary visits to GPs and reduce inadequate use of antibiotics).

The table presented in point 4.2 highlights types of interventions that could target those issues addressing the detected hindering or facilitating mechanisms, with special attention **three key areas of hindering or facilitating mechanisms highlighted before:** the patients'/general population knowledge and skills, organizational factors and the specific most vulnerable groups in the general population.

4.2. Selecting intervention (s)

As it was highlighted in the subjective evaluation of mechanisms there are three key areas of mechanisms to consider:

- Patient/general population knowledge and skills as key mechanisms for all the target issues
- Professional behaviour, knowledge and skills can be key in the reduction of incidence, increase of adherence to treatment and reduced use of unnecessary antibiotics.
- **Specific population groups** (young adults, co-morbidities) that should be acknowledged when promoting self-care in Athlete's foot.

The following tables illustrate types of self-care promotion interventions that could address those mechanisms with the final goal of improving the key issues highlighted.

Suggested interventions by key issues

	Reduce incidence	severity	Reduce unnecessary	Reduce inadequate use of antibiotics
Key characteristics of the issue				

General/specific issue

Level to address the issue

(national/regional/local)

Key focus that the self-care promotion strategy requires or should include

System-focused

- Structural interventions
- Staff-oriented interventions
- Financial interventions
- Financial incentives to patients
- Financial incentives to Primary Care

Patient-focused interventions

- Skill development
- Behaviour change
- Family support
- Information provision

Professional-focused interventions

- Educational interventions
- Educational materials
- Large-scale educational meetings
- Small-scale educational meetings
- Outreach visits
- Use of opinion leaders
- Feedbacks and reminders
- Feedback
- Reminders
- Local consensus processes

It is important to bear in mind that most interventions are multifaceted so include more than one area, however to facilitate the analytical line the interventions have been divided in **information strategies** and **organizational strategies**.

Information strategies:

• Information, with a special focus on symptom recognition and evaluation.

One of the identified potentially hindering mechanisms was the lack of knowledge regarding what to expect when someone athlete's foot to be aware of treatment options and recommendations for symptom relieve. Information strategies can have some beneficial results to tackle this issue. Some examples of those initiatives are:

Examples of similar practices in:

- UK: NHS Choices Athlete's foot [(5)]
- France: Améli.Santé
 Pied d'athlète [(6)]
- Netherlands: Zelfzorg.nl Voetschimmel [(7)]
- Sweden: 1177 Fotsvamp [(8)]
- **Know who to turn to:** as one of the hindering mechanisms identified is the poor knowledge of navigation health systems, it might be of interest to review information strategies specifically addressed to cover this issue, that usually also entail evaluation of symptoms and treatment decision making.

This style of information campaign has been applied in multiple primary care trusts across the UK. For some examples see:

- NHS Scotland: Know who to turn to [(9)]
- NHS Grampian: Know who to turn to [(10)].

Both cases exemplify a combination of those two complementary information strategies would help to address two of them most relevant aspects: symptom recognition and information on navigation of health system.

Note: An information campaign should be tailored to the needs of its target population, so depending on the ethnic composition of the implementing context, the material of the interventions might have to be translated to multiple languages and be adapted to some cultural traits (see implementing intervention sub-section)

Note: One important consideration would be the different mechanisms to be used for such information campaigns, to that regard see **Communication Tools.**

For the highlighted most vulnerable groups

 Children under 3 – partnership with nurseries to educate both educators and parents in the recognition of symptoms.

Organizational strategies:

• **Delayed prescriptions:** in some cases the prescription is for self-care for a given period of time. If in this period of time the symptoms do not improve significantly the patient can get the prescribed antibiotic without returning to

the GP consultation (important: the antibiotic is only available after a given number of days from the prescription and not before).

This strategy can help reduce the use of antibiotics as in many cases the symptoms will subside after some days of proper self-care.

In addition the prescription of self-care encourages a conversation about the importance and effectiveness of self-care in minor conditions.

 Minor ailments schemes, partnerships between GPs and community pharmacists

These types of program are based on directing people with minor ailments to the community pharmacist as the first health professional (instead of directly consulting to the GP). This approach has been tested and adapted in the UK in several NHS areas, with some different characteristics. However, most programs included two key aspects:

- Including the treatments that the pharmacist might suggest in the prescription system for (people marinating the free-of-charge or discounts)
- Establishing a fast-track for GP consultation if the pharmacist decides to refer.

Those schemes have reported promising results.

For some examples see:

- Greater Manchester Minor Ailments Scheme Pharmacy First [(11)]
- NHS Scotland NHS minor ailment services [(12)]

Remember that before implementing a piloting of the interventions is recommended. For tips regarding Implementation of interventions see the section in the general guideline.

5. Evaluate the impact of implemented self-care strategies



Evaluation activities are ideally integrated into the change process from the beginning.

Establish concrete goals against which to measure progress of the implementation. Goals should be ambitious but attainable and very concrete. For example: "Reducing the number of unnecessary GP consults for minor conditions" is not concrete enough, formulating it as "Reducing the number of unnecessary GP consults for minor conditions by 10% in a year" will help to evaluate the progress of the strategy.

5.1. Develop impact indicators

- Develop indicators for all levels of implementation:
 - Micro level: evaluate attitudes of professionals and patients, level of knowledge, use of information materials.
 - Meso level: evaluate the use of health services, the degree of implementation of the intervention(s)
 - Macro: evaluate costs, overall use of the developed self-care resources
- Consider the inclusion of indicators of structure, process and outcomes.

5.2. Consider qualitative evaluation (both by patients/general public and professionals)

 Qualitative techniques might be particularly useful to detect the acceptability of an intervention, identification of barriers and facilitators of the new intervention.

5.3. Evaluate continuously and adapt your strategy in consequence

Delayed prescriptions:

- Rate of use by GPs over the total number on consultations related to minor conditions.
- Evaluate how many patients finally use the medication prescription

Bibliography

1. NHS Choices. Athlete's foot - Treatment [Internet]. 2014. Available from: http://www.nhs.uk/Conditions/Athletes-foot/Pages/Treatment.aspx

 Ameen M. Epidemiology of superficial fungal infections. Clin Dermatol. 2010;(28):197– 201.

3. Working in Partnership Programme, Proprietary Association of Great Britain. Evaluation of the "Joining Up Self-Care" Project - Report to the Working in Partnership Programme. 2006;(October).

4. Heijmans M, Uiters E, Rose T, Hofstede J, Devillé W, van der Heide I, et al. Study on sound evidence for a better understanding of health literacy in the European Union. 2015.

5. NHS. NHS Choices - Common cold [Internet]. 2015. Available from: http://www.nhs.uk/conditions/cold-common/pages/introduction.aspx

6. Mycose cutanée : symptômes - ameli-santé [Internet]. [cited 2016 Dec 20]. Available from: http://www.ameli-sante.fr/mycose-cutanee/symptomes-mycose-cutanee.html

7. Zelfzorg. Zelfzorg - Voetschimmel [Internet]. Available from: http://zelfzorg.nl/voetschimmel

8. 1177 Vårdguiden. 1177 Vårdguiden - Fotsvamp [Internet]. 2014. Available from: http://www.1177.se/Fakta-och-rad/Sjukdomar/Fotsvamp/

9. Know who to turn to [Internet]. NHS Scotland. Available from: http://www.knowwhototurnto.org/

10. NHS Grampian. Know who to turn to [Internet]. Available from: http://www.know-whoto-turn-to.com/11. Greater Manchester Minor Ailments Scheme – Pharmacy First [Internet]. Community Pharmacy Greater Manchester. 2016. Available from: http://psnc.org.uk/community-pharmacy-greater-manchester/services/greater-manchesterminor-ailments-scheme-pharmacy-first/

12. NHS Scotland. The new NHS minor ailment sevice at your community pharmacy [Internet]. Available from: http://www.psd.scot.nhs.uk/docs/minor_ailment.pdf

Guideline on how to promote self-care: Heartburn (without indigestion)

Guideline on how to promote self-care: Heartburn (without indigestion)

Basic information about Heartburn

The heartburn is described as a burning sensation, burning or fire or retroesternal (pit of the stomach) which can be up to the throat and moderate intensity. Sometimes accompanied by spontaneous return of reflux or gastric juice into the mouth irritate the mucosa in its passage through the oesophagus.

This is a symptom that accompanies various digestive diseases either as the only manifestation or part of a larger picture. It is the common symptom of gastroesophageal reflux disease (GERD) defined by at least weekly heartburn and/or acid regurgitation.

A systematic literature review of the Cost/benefit analysis of self-care systems in the European Union $[\underline{1}]$ found good evidence for the effectiveness of some treatments of heartburn, which can be used for self-care.

Evidence found mostly referred to products, which can be usually purchased over the counter and have little side-effects such as proton-pump inhibitor (PPI) and H2-receptor antagonists.

However, future evaluations on self-care for heartburn should pay more attention to clearly distinguish between heartburn, gastroesophageal symptoms and Gastro-Esophageal Reflux Disease.

1. Identify the problem and evaluate your context

Describing the context in terms of the key issue that you want to address, the stakeholders that can be affected by the issue and the existing resources that exist/could be used to address the issue. This exercise would give a general idea of the starting point.

1 Identify the problem and evaluate your context

- Define what specific issue(s) you are trying to address
- Identify whether those issues are related to a specific minor conditions or a general approach to self-care
- Identify key stakeholders for the development of the self-care strategy
 Identify self-care promotion resources
- for the selected conditions in your area

1.1. Define what specific issue(s) you are trying to address

The first step when deciding to launch a self-care (or any other) initiative is to clarify **what is moving you** to launch this initiative. Specifically, to identify what are the drivers that are moving forward this need for change.

The key drivers depend on each specific context, however a review of the literature point towards some of most common drivers relating to Heartburn (without indigestion).

Some of the key drivers could be:

The high prevalence of heartburn (without indigestion)

This is a very common gastrointestinal symptom. It is estimated that 40% of adults experience heartburn at least once a month, and half of those affected, once a week, although it is difficult to know exactly true prevalence of heartburn in general population, as not all individuals who has it requested medical attention. [2].

An approximate prevalence of 10-20% has been identified for GERD (defined by at least weekly heartburn and/or acid regurgitation), in the Western world [3].

There are no significant differences in prevalence of heartburn by sex, although clinical studies agree that males experienced it most intensely. It is not a symptom that is often occurred in childhood, although it can occur in young people. Disproportionately it affects people over 55 years.

The incidence of heartburn in the population is generally very high, observing even with an increase in recent decades. In Western countries it affects daily 3-10% of the population or in other words approximately 1 out of 10 adults at least once a week. Prevalence increases also with age. [4]

Impact on the life of those affected

Study Psychological Well Being Index shows 73% of patients report symptoms interfere quite in their daily activity and 4.8% only occasionally. Psychological stress and psychiatric disorders (anxiety, depression, chronic stress, ...) have been associated with symptoms of GERD (Gastroesophageal Reflux Disease) and functional dyspepsia.

- Reduce self-medication (inappropriate use of antacids)
 The heartburn is one of the most common complaints in GP representing
 around 8.2% of the population examined. However, only 50 % of patients go to
 see a doctor when this symptom occurs. As this is not associated with any
 particular disease, usually they do not go to see a doctor and inappropriate
 self-medication with antacids could be observed.
- Reduce the completion of initial diagnostic from initial symptoms (reducing severity or early diagnosis)
 Elderly patients, institutionalized or with social integration problems have more difficulty or trivialization of identifying initial symptoms and diagnosis before first symptoms (dysphasia, odynophagia, HDA, recent clinic onset in patients older than 45 years, significant weight loss, etc.).

1.2. Identify whether those issues are related to a specific minor conditions or a general approach to self-care

Heartburn (without indigestion) is one of the usual minor conditions in terms of number of people affected. The key issues that drive the promotion of self-care are mostly common to other minor conditions.

Regarding the other highlighted issues (high incidence, severity of cases, selfmedication..) those can also be shared with other minor conditions and the strategies used to tackle those issues can also encompass other minor conditions, albeit with specific elements that should be adapted to each specific condition.

1.3. Identify stakeholders and resources available for the self-care strategy

Stakeholders involved for the self-care strategy: A key determinant of a successful intervention can be the inclusion of the relevant stakeholders.
Anyone who wants to promote self-care should identify the stakeholders that are/could be involved and what is expected of each of them. Identifying those stakeholders at an early stage can facilitate a better coordination and a better use of all the available resources. Stakeholders should be defined in each specific context.

The following, but not limited to, key groups of stakeholders should be considered:

- Healthcare and social care professionals (and professional bodies)
- \circ $\;$ Industry, self-care medication and medical devices industry
- Pharmaceutics
- Patient organisations and other NGOs
- Healthcare managers
- Policy decision makers

• Workplace related stakeholders

The table included in the general <u>guideline</u> exemplifies some of the different key stakeholders at local, regional and country level.

1.4. Identify the self-care support resources available in your context

If you want to successfully promote self-care in your context, a key step can be to identify the existing resources. Regarding the key issues that have been highlighted regarding Heartburn (without indigestion) the following resources could be particularly useful if available:

- Structural
 - Is there a plan to encourage the proper use of antacids?
 - Is there already good and systematic exchange of information between community pharmacies and primary care healthcentres and hospitals?
- Technology
 - Are health information portals already active in your context? Are they well known and used?

The following table illustrates a possible way to summarize the basic characteristics of an evaluation of the context for the self-care strategy. If possible, completing this review with all stakeholders might prove useful.

Note that depending on your position (policy decision maker; healthcare professional, member of patient organisation...) you might have different possibilities and ability to involve other stakeholders.

1.1 Define		Key issues Suggestion of key issues that might impulse the need for promotion of self-care related to Heartburn (without indigestion)			
issues		Reduce incidenc e	Reduce severity of cases	Increase timely visits to GPs	Reduce inadequate use of antiacid
	General/specific issue				
1.2 Charact.	Level to address the issue (national/regional/local)				
	Economic resources				
1.3 Identify key resources	System/structural resources				
0	Professionals training				
	Technology				

🔨 And should be considered when planning the strategy

2. Identify and select common and specific patients'/general population self-care behaviours

Identify and select common and specific patients'/general population self-care behaviours that you want to promote (depending on the context problem you want to address)

2 Identify and select common and specific patients'/general population self-care behaviours

- Specify and describe the population/patients that you want to address with the intervention
- Identify the general and specific patients'/general population self-care behaviours that the intervention aims to promote

2.1. Specify and describe the patients/general population that you want to address with the self-care strategy

Depending on the results of the evaluation of the context and key issues and whether the strategy is general or specific to a minor condition, one should define the patients/general population that the interventions should be addressed to. For the case of common Heartburn (without indigestion) there is no specific target population, as all the general population is affected by it.

However there are some specific groups that should have special considerations as they might be more vulnerable to complications or misdiagnosis:

Elderly

From age 65, the prevalence rises to 20%, as it is closely linked to age and progressive deterioration that affects the body, specifically the digestive system.

Almost one out of two senior patients who visit the physician for any reason is diagnosed with an acid peptic disease. Often severity of symptoms does not correspond to severity of lesions detected. In fact, less than 30 % of elderly refers their characteristic symptoms, as they seem to perceive a lesser extent of oesophageal pain than young people do. It is an under diagnosed disease among this population.

Pregnant

Studies suggest that more than 50 % of pregnant women may have symptoms of heartburn during pregnancy, reaching 80% in the third quarter. Most women's symptoms of heartburn solve after delivery. It is directly related to gestational age, number of previous pregnancies and with a history of gastroesophageal reflux and an inverse correlation with the age of the mother.

2.2. Identify the general and specific patients'/general population self-care behaviours that the strategy aims to promote

A key step if you want to establish a strategy to promote self-care is to determine the ideal self-care behaviours that should be promoted. Establishing those ideal behaviours will guide the development of the strategy and it will help identifying the mechanisms that can hinder or facilitate the promotion of self-care.

Depending on the results of the analysis of your context and issues that you want to address you can identify <u>different behaviours to promote</u>.

The following table presents considerations specific to Heartburn (without indigestion) for each of the main phases of self-care as well as some reflections regarding the patients/general population needs to achieve those goals.

Main stages of the cycle of self-care	Main self-care behaviours to promote	
Prevention and healthy lifestyles	 Managing stress or anxiety including: Mild exercise, such as walking or cycling Listening to music Massage Relaxation techniques Following lifestyle and dietary hygiene measures including: Eating healthily Losing weight if they are overweight Not smoking Avoiding known causes that may be associated with symptoms, including smoking, alcohol, coffee, chocolate, fatty foods and being overweight Other factors that might help, such as raising the head of the bed and having a main meal at least 3 hours before going to bed. 	
Symptom recognition & evaluation	 Identifying usual or associated symptoms for early treatment: Common: burning sensation in stomach and acid regurgitation. Associated: belching, nausea, hipersalivation, hiccups. 	
Treatment decision- making	 Adults who present to their community pharmacist may be able to alleviate and manage their symptoms by making changes to their lifestyle and using over- the-counter (usually antacid or an alginate) 	

All the behaviours included are considered relevant, however this classification might help to focus the self-care promotion strategy in a specific target.

	 Deciding to visit to the GP when: There are symptoms several times a week. Over-the-counter medications aren't helping. The symptoms are severe. Difficulty swallowing. There are possible signs of a more serious problem, such as persistent vomiting, vomiting blood or unexplained weight loss.
Treatment adherence	 Following treatment from physician, that may vary according to intensity and frequency of discomfort symptoms. Monitoring symptoms after treatment discontinuation in acute cases. Avoiding inadequate and permanent use of antacids without prescription or medical follow-up.
Self-monitoring & early detection of complications	Unwanted side effects are very rare on both antacids and proton-pump inhibitor (PPI). Maintaining healthy lifestyle in order to reduce the occurrence of episodes of heartburn (see <u>Prevention and</u> <u>healthy lifestyles</u>). Heartburn is not a dangerous condition; however, according to aetiology, age of the patient or presence of co-morbidity may lead to complications where early detection will be important. Visiting GPs it is recommended should be advised if symptoms have persisted for several weeks, get worse over time, do not improve with medication or alarming symptoms. Symptoms that act as alarm indicators on heartburn such as: Disphagia Odynophagia Upper gastrointestinal bleeding Recent clinic onset in patients older than 45 years Significant weight loss Pregnant women.

3. Evaluate the mechanisms that might hinder or facilitate the promotion of self-care

Evaluate the mechanisms that might hinder or facilitate the promotion of self-care in your context (barriers and facilitators)

3 Evaluate the mechanisms that might hinder or facilitate the promotion of self-care

- Evaluate the possible impact of hindering/facilitating mechanisms including:
 - Patients related factors
 - Professionals related factors
 - Environment related factors

One of the most important steps in promoting self-care is the identification and analysis of the mechanisms that might hinder the promotion of self-care. Those can be present, hindering the implementation of the self-care strategy, but also as mechanisms facilitating implementation.

When designing a self-care strategy one, should identify and evaluate these mechanisms. To facilitate this step we propose a list of mechanisms that might affect the development of a self-care strategy. This list is not exhaustive but might be helpful to guide a systematic evaluation of hindering/facilitating mechanisms.

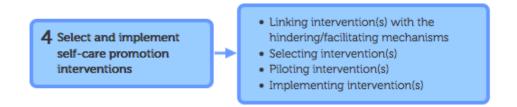
Note: When developing this step in a specific context, it could be very useful to involve all those stakeholders that have been identified to include their multiple perspectives, which can increase the chances of detecting the most relevant hindering/facilitating mechanisms and, ultimately, improve the chances of success of the promotion of selfcare guideline.

Patients	
Knowledge	 Low health literacy: low levels of health literacy can make it harder for patients/persons to engage in self-behaviours. It has been reported that about 12% of the European population have inappropriate general health literacy, and more than one third (35%) has problematic health literacy. Health literacy can be one of the key determinants to address as it has been proven to be associated with health outcomes, health service use and quality of health systems as well as capacity building for professionals. Health literacy affects any strategy promoting self-care for any condition, including heartburn (without indigestion), and it can be one of the most relevant hindering mechanisms. Poor information on the treatment options. Poor information on treatment options could lead to delay the visit to the GP.

	 Poor information on navigation of the healthcare system. Poor information on the healthcare system can lead to underuse consultation with professionals, as patients/general population might not be aware of other possible consultations with professionals that might be available, such as pharmacist.
Skills	 Lack of decision-making skills can be a hindering mechanism to consider not necessary a visit to the GP and establish a drug treatment and appropriate dose, avoiding misuse of antacids. Application of preventive measures. Following general recommendations on healthy lifestyle general and specifically aimed at preventing heartburn. The poor skills of prevention can be one of the key hindering mechanisms particularly for the reduction of incidence.
Attitudes and beliefs	• Contrary to popular culture milk is not indicated for heartburn. A glass of milk can relieve heartburn, although only temporarily because its content in calcium, protein and fat in particular stimulate stomach to produce more acid.
Health status	 The objectives of this study were to assess health state utilities in patients with gastroesophageal reflux disease with heartburn and to analyze if severity and annual frequency of heartburn can predict utilities. A total of 1011 patients in Germany and Sweden participated in telephone interviews, where utilities were assessed using the rating scale (RS), EQ-5D, time trade-off (TTO) and standard gamble (SG) instruments. The average RS, EQ-5D, TTO, and SG utilities were 0.69, 0.70, 0.88, and 0.89, respectively. Linear regression analyses showed that the EQ-5D and RS utilities were negatively and significantly related to the severity and frequency of heartburn. The EQ-5D and RS results indicate that patients with heartburn assign their health states substantial disutility and that it is feasible to estimate regression equations to predict utilities from heartburn-specific variables. In the TTO and SG analyses, the impact of heartburn was in the expected direction but smaller and in general not significant. However inadequate and prolonged use of antacids, can cause serious digestive problems and even gastritis.
Demographic characteristics	 Age: Extreme ages (infants and elderly) are more vulnerable to the presence of pictures of dysphasia due to immaturity in infants and changes in esophageal motility in the elderly, who also refer attenuated symptoms and not for the importance of the lesion, thus favouring the occurrence of unexpected complications. In these cases it is useful for primary care and routine visits of patients over 60 years, a special interest or a proactive approach to periodically review the onset of symptoms that on normal circumstances would not be cause for consultation. Gender: Literature describes a certain predominance in men but

evidence is not conclusive. Pregnant women: It is part of the usual cohort of symptoms • accompany-ing pregnancy but is a self-limiting symptom in a vast majority of women. Socio-economic Economic: payment for visit to GP can prevent some people to status (and or attend even when thy needed. It does not probably affect countries minority groups) where access to healthcare is universal (e.g. Spain). **Professionals** Lack of communication skills to devote to education in healthy lifestyles. Lack of communication skills and time to educate patients on: • Help patients identify triggers of heartburn and/or GERD presented, so this will help you and give adequate advice to minimize them. Skills • Explain them content of treatment and chance of taking alternative treatment or intermittent on-demand. • Explain them why only treatment with antacids is not sufficient and why self-medication with substances such as bicarbonate of soda is not advised. Report them that obesity, smoking and certain medications 0 can worsen symptoms. **Environment** • Availability (or not) of educational information to disseminate healthy lifestyle or adequate treatment or linguistic educational level Organizational to population. factors High average of visits to physician does not allow spending time explaining self-care. Countries where access to healthcare is not universal or there is Economic factors copayment for prescriptions.

4. Select and implement self-care promotion intervention(s)



4.1. Linking intervention(s) with the hindering/facilitating mechanisms

Once the hindering or facilitating mechanisms have been identified a key next step can be to link interventions to those mechanisms.

There are numerous interventions that could potentially contribute to the promotion of self-care in Heartburn (without indigestion) for the selected target issues (reduce incidence; reduce severity of cases; reduce unnecessary visits to GPs).

The table presented in point 4.2 highlights types of interventions that could target those issues addressing the detected hindering or facilitating mechanisms, with special attention **three key areas of hindering or facilitating mechanisms highlighted before**: the patients'/general population knowledge and skills, organizational factors and the specific most vulnerable groups in the general population.

4.2. Selecting intervention(s)

The following tables illustrate types of self-care promotion interventions that could address those mechanisms with the final goal of improving the key issues highlighted.

Suggested interventions by key issues					
	Reduce incidence		Reduce unnecessary visits to GPs		
Key characteristics of the issue					
General/specific issue					
Level to address the issue (national/regional/local)					
Key focus that the self-care promotion strategy requires or should include					
System-focused					
Structural interventions					

• Staff-oriented interventions

- Financial interventions
- Financial incentives to patients
- Financial incentives to Primary Care

Patient-focused interventions

- Skill development
- Behaviour change
- Family support
- Information provision

Professional-focused interventions

- Educational interventions
- Educational materials
- Large-scale educational meetings
- Small-scale educational meetings
- Outreach visits
- Use of opinion leaders
- Feedbacks and reminders
- Feedback
- Reminders
- Local consensus processes

From this analysis the following type of interventions could be recommended: It is important to bear in mind that most interventions are multifaceted so include

more than one area, however to facilitate the analytical line the interventions have been divided in **information strategies** and **organizational strategies**.

Information strategies:

Information, with a special focus on symptom recognition and evaluation.

One of the identified potentially hindering mechanisms was the lack of knowledge regarding what to expect when someone has common Heartburn (without indigestion), to be aware of treatment options and recommendations for symptom relieve. Information strategies can have some beneficial results to tackle this issue. Some examples of those initiatives are:

Examples of similar practices in:

- UK: NHS Choices Gastroesophageal reflux diseases [5] (
- **Know who to turn to:** as one of the hindering mechanisms identified is the poor knowledge of navigation health systems, it might be of interest to review information strategies specifically addressed to cover this issue, that usually also entail evaluation of symptoms and treatment decision making.

This style of information campaign has been applied in multiple primary care trusts across the UK. For some examples see:

• **NHS Scotland:** Know who to turn to [6]

With a combination of those two complementary information strategies would help to address two of them most relevant aspects: symptom recognition and information on navigation of health system.

Note: An information campaign should be tailored to the needs of its target population, so depending on the ethnic composition of the implementing context, the material of the interventions might have to be translated to multiple languages and be adapted to some cultural traits (see implementing intervention sub-section)

Note: One important consideration would be the different mechanisms to be used for such information campaigns, to that regard see **Communication Tools.**

For the highlighted most vulnerable groups

Organizational strategies:

- Targeting population
 - Active information or distribution of written information to target patients in primary care centres, hospitals, etc. to help them recognize situations where they should visit their GPs.
 - Active distribution of information or documentation illustrated with tips to follow for a healthy life (quality of life and reduce amount of severe cases).
 - \circ $% \left(Active distribution of information or documentation for the correct use of antacids. \right)$
 - Training and information by paediatricians and nurses to parents of children under 2 years old.
- Targeting professionals
 - Receive general training in communication skills.
 - Receive specific training in patient education roles and methods of healthy lifestyle for population as well (including patients with symptoms of heartburn and GERD).
 - Be provided with elements of support to inform and educate (charts, internet, advertisement, screen on centres, etc.).
 - Have professional training specialists.
 - Information campaigns/broadcasting in social clubs for elderly people.
- Specific groups:pharmacists

- Agree on strategies to identify patients who self-medicate and refer them to doctor's GP.
- Alert patients who go to pharmacy and ask counter PPI or antacids with neither prescription nor pharmacist's advice.
- Targeting managers
 - Designing training and information programs through internet for patients who suspect presence of heartburn can make appointment and clear doubts and perhaps avoid unnecessary visits (consumption) and especially not to delay first consultations (late diagnosis or alarm symptoms).
 - Promote development of treatment protocols agreed from GPC of proven sources at local or regional level.
 - Coordination programs with pharmacies
 - \circ $\,$ Software to know consumption of antacids and adherence to treatment in chronic patients.
- Minor ailments schemes, partnerships between GPs and community pharmacists

These types of program are based on directing people with minor ailments to the community pharmacist as the first health professional (instead of directly consulting to the GP). This approach has been tested and adapted in the UK in several NHS areas, with some different characteristics. However, most programs included two key aspects:

- Including the treatments that the pharmacist might suggest in the prescription system for (people meriting the free-of-charge or discounts).
- Establishing a fast-track for GP consultation if the pharmacist decides to refer.

The piloting of those schemes has reported promising results.

For some examples see:

- Greater Manchester Minor Ailments Scheme Pharmacy First [7]
- NHS Scotland NHS minor ailment services [8]

Remember that before implementing a piloting of the interventions is recommended. For tips regarding Implementation of interventions see the section in the <u>general</u> <u>guideline</u>

 Help patient to detect which foods cause reflux more often and avoid consumption of these.

5. Evaluate the impact of implemented self-care strategies



Evaluation activities are ideally integrated into the change process from the beginning.

Establish concrete goals against which to measure progress of the implementation. Goals should be ambitious but attainable and very concrete. For example: "Reducing the number of unnecessary GP consults for minor conditions" is not concrete enough, formulating it as "Reducing the number of unnecessary GP consults for minor conditions by 10% in a year" will help to evaluate the progress of the strategy.

5.1. Develop impact indicators

- Develop indicators for all levels of implementation:
 - Micro level: evaluate attitudes of professionals and patients, level of knowledge, use of information materials.
 - 1. Number of performed training sessions for patients/year.
 - 2. Number of patients attending training sessions.
 - 3. Number of training sessions for professionals.
 - 4. Number of professionals who have attended and % of those who should attend.
 - Meso level: evaluate the use of health services, the degree of implementation of the intervention(s)
 - 1. Level of knowledge of information acquired by patients (survey).
 - 2. Skill acquired by professionals in communication (specific question in survey patient).
 - $_{\odot}$ $\,$ Macro: evaluate costs, overall use of the developed self-care resources $\,$
 - 1. Number of website visits of education program.
 - 2. Consumption of over-the-counter antacids (Pharmacy).
 - 3. Referred patients from Pharmacy
- Consider the inclusion of indicators of structure, process and outcomes.

5.2. Consider qualitative evaluation (both by patients/general public and professionals)

• Qualitative techniques might be particularly useful to detect the acceptability of an intervention, identification of barriers and facilitators of the new intervention.

- 1. Conducting one focus group with elderly people attending sessions in nursing homes.
- 2. Some interview with professionals who are in direct contact with elderly people in nursing homes (not managers).

5.3. Evaluate continuously and adapt your strategy in consequence

Annually assess results of indicators and of qualitative evaluation, pull out less productive strategies and especially those which provide a lower cost/benefit ratio.

References

1. Ostermann H, Renner A-T, Bobek J, Schneider P, Vogler S. A cost / benefit analysis of self- care systems in the European Union. 2015.

2. Liker H, Hungin P, Wiklund I. Managing gastroesophageal reflux disease in primary care: the patient perspective. J Am Board Fam Pract. 2005;18(5):393–400.

3. El-Serag HB, Sweet S, Winchester CC, Dent J. Update on the epidemiology of gastrooesophageal reflux disease: a systematic review. Gut [Internet]. 2014;63(6):871–80. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4046948/

4. El-Serag HB. Time trends of gastroesophageal reflux disease: a systematic review. Clin Gastroenterol Hepatol [Internet]. 2007;5(1):17–26. Available from: http://www.ncbi.nlm.nih.gov/pubmed/17142109

5. Heartburn and gastro-oesophageal reflux disease (GORD) [Internet]. NHS Choices. 2016. Available from: http://www.nhs.uk/conditions/Gastroesophageal-reflux-disease/Pages/Introduction.aspx

6. Know who to turn to [Internet]. NHS Scotland. Available from: http://www.knowwhototurnto.org/

7. Greater Manchester Minor Ailments Scheme – Pharmacy First [Internet]. Community Pharmacy Greater Manchester. 2016. Available from: http://psnc.org.uk/community-pharmacygreater-manchester/services/greater-manchester-minor-ailments-scheme-pharmacy-first/

8. NHS Scotland. The new NHS minor ailment sevice at your community pharmacy [Internet]. Available from: http://www.psd.scot.nhs.uk/docs/minor_ailment.pdf

Guideline on how to promote self-care: Urinary Tract Infection (UTI)

Guideline on how to promote self-care: Urinary Tract Infection (UTI)

Basic information about Urinary Tract Infection

Urinary tract infection **(UTI)** is an infection that affects the lower part of the urinary system, basically urethra and bladder, causing urethritis as well as cystitis, prostatitis and orquiepidedimitis symptoms.

The most common UTI affect the bladder, known as cystitis which often entails the so-called micturition syndrome consisting of pain or burning sensation during urination, a persistent urge to urinate, and with more frequent than usual. In most there are bacteria in the urine (bacteriuria), the most common of which is: E. coli. [1]

This guide addresses a UTI presentation as "uncomplicated UTI".

1. Identify the problem and evaluate your context

Describing the context in terms of the key issue that you want to address, the stakeholders that can be affected by the issue and the existing resources that exist/could be used to address the issue. This exercise would give a general idea of the starting point.

1 Identify the problem and evaluate your context

- Define what specific issue(s) you are trying to address
- Identify whether those issues are related to a specific minor conditions or a general approach to self-care
- Identify key stakeholders for the development of the self-care strategy
 Identify self-care promotion resources
- for the selected conditions in your area

1.1. Define what specific issue(s) you are trying to address

The first step when deciding to launch a self-care (or any other) initiative is to clarify **what is moving you** to launch this initiative. Specifically, to identify what are the drivers that are moving forward this need for change.

The key drivers depend on each specific context, however a review of the literature point towards some of most common drivers relating to Urinary tract infection.

Some of the key drivers could be:

 The incidence of Urinary tract infection (UTI) among the population. Urinary tract infection (UTI) is a common ailment, particularly among young women. It is estimated that around 10–20% of women will experience a symptomatic UTI at some time [2]. Men have a lower incidence (estimated 3-10% men aged 50 or older) [3].

Its incidence rises with age for both sexes. It is estimated that 10% of men and 20% of women over 65 years of age have asymptomatic bacteriuria $[\underline{2}]$.

- Since the appearance of UTI can be reduced with appropriate hygiene practices and healthy lifestyle behaviours incidence of UTI can be a strong driver for selfcare promotion.
 - Recurrence rate of UTI.
 UTI is prone to recurrence, it is estimated that more than 20% of no pregnant women with UTI will experience a recurrence. Among these, 80% are due to reinfection (new infection) and 20% to relapse in 6 months [4].
 Reduce severity.
 Untreated UTI can cause complications and/or lengthen the cure.
 Improve adherence to treatment.

Those drivers for change are just suggestions and need to be adapted to each context.

1.2. Identify whether those issues are related to a specific minor conditions or a general approach to self-care

The strategies to address the drivers of a self-care promotion strategy for UTI are quite specific to this condition.

Regarding its incidence, the particularities of each condition require a specific approach. In the case of UTI it is also estimated that the high recurrence rate, potential severity of the infection are topics that will need to be addressed from a specific strategy.

The improvement of adherence to treatment is a driver that can be shared with other minor conditions (See for example <u>Athlete's foot</u>) and thus could more easily be part of a general approach to self-care of minor conditions.

1.3. Identify stakeholders and resources available for the self-care strategy

• **Stakeholders involved for the self-care strategy**: A key determinant of a successful intervention can be the inclusion of the relevant stakeholders. Anyone who wants to promote self-care should identify the stakeholders that are/could be involved and what is expected of each of them. Identifying those stakeholders at an early stage can facilitate a better coordination and a better use of all the available resources. Stakeholders should be defined in each specific context.

The following, but not limited to, key groups of stakeholders should be considered:

- Healthcare and social care professionals (and professional bodies)
- Patient organizations and other NGOs
- Healthcare managers
- Policy decision makers
- Workplace related stakeholders

The table included in the general <u>guideline</u> exemplifies some of the different key stakeholders at local, regional and country level.

1.4. Identify the self-care support resources available in your context

If you want to successfully promote self-care in your context, a key step can be to identify the existing resources.

Regarding the key issues that have been highlighted regarding Urinary tract infection the following resources could be particularly useful if available:

Economic resources

Budget allocated for material to be developed, personnel required to implement self-care strategy, etc.

Structural

Use in the health system of antibiotic treatments in single-dose administration. General access of the population to internet (to access web portals or similar services), etc.

Professional training

Training in specific skills, particularly communication skills of professionals that could be involved in the strategy (GPs, primary care nurses, pharmacists, professionals staffing phone and online consultations...).

If the professionals don't have the training in the specific skills needed for your self-care promoting strategy consider whether training could be developed and included in continuous professional development schemes or similar schemes.

Technology

Existence of health web portals, health advice lines, etc. in your context (could be from public institutions but also consider Patient Organizations web portals, etc.).

Consider also: Are there any tools/information to help promote patterns and healthy lifestyles (health education)? Are they well-known and used? Are these websites multi-lingual and take into consideration most frequent languages in the communities that you want to address?

The following table illustrates a possible way to summarize the basic characteristics of an evaluation of the context for the self-care strategy. If possible, completing this review with all stakeholders might prove useful. Note that depending on your position (policy decision maker; healthcare professional, member of patient organization...) you might have different possibilities and ability to involve other stakeholders.

1.1 Define issues		Key issues Suggestion of key issues that might impulse the need for promotion of self-care related to Urinary tract infection			
		Reduce incidence	Reducing recurrence rate	Reduce severity	Improve adherence to treatment
	General/specific issue				
1.2 Charact.	Level to address the issue (national/regional/local)				
1.3 Identify key resources	Healthcare and social care professionals (and professional bodies)				
	Patient organisations and other NGOs				
	Healthcare managers				
	Policy decision makers				
	Workplace related stakeholders				

	Economic resources	Budget allocated for material to be developed, personnel required to implement self-care strategy, etc.
	System/structural resources	Use in the health system of antibiotic treatments in single-dose administration. General access of the population to internet (to access web portals or similar services), etc.
Profe	Professionals training	Training in specific skills, particularly communication skills of professionals that could be involved in the strategy (GPs, primary care nurses, pharmacists, professionals staffing phone and online consultations).
	Technology	Existence of health web portals, health advice lines, etc. in your context (could be from public institutions but also consider Patient Organisations web portals, etc.).

And should be considered when planning the strategy.

2. Identify and select common and specific patients'/general population self-care behaviours

Identify and select common and specific patients'/general population self-care behaviours that you want to promote (depending on the context problem you want to address)

2 Identify and select common and specific patients'/general population self-care behaviours

- Specify and describe the population/patients that you want to address with the intervention
- Identify the general and specific patients'/general population self-care behaviours that the intervention aims to promote

2.1. Specify and describe the patients/general population that you want to address with the self-care strategy

Depending on the results of the evaluation of the context and key issues and whether the strategy is general or specific to a minor condition, one should define the patients/general population that the interventions should be addressed to.

For the case of common urinary tract infection there are some specific groups that should have special considerations, as they might be more vulnerable to complications or misdiagnosis:

Pregnant

The prevalence of asymptomatic bacteriuria in pregnant women is 2-7% (presence of bacteria in the urine, but without symptoms). In the absence of antibiotic treatment, one third of pregnant women with asymptomatic bacteriuria develop pyelonephritis. The eradication of bacteriuria lowers this risk as well as the risk of premature birth and low weight newborn.

Elderly

The incidence of UTI and asymptomatic bacteriuria increases with age. It is considered that asymptomatic bacteriuria is very common in the elderly, especially if they are institutionalized.

Children

It is usually caused by urinary tract malformations.

Young woman with recurrent urinary tract infection

Recurrent UTI is considered when there are at least three episodes in the last year or two in the last 6 months. More than 20% of nonpregnant women with urinary tract infection will experience a recurrence. The causes of these recurrences are usually associated with a biological predisposition and are favoured by sex-related situations and spermicides. It is also a common problem in postmenopausal women.

Men

This is much less common in men and occurs in later decades of life. However most infections in adult men are complicated and related to abnormalities of the urinary tract, although some can occur spontaneously in otherwise healthy young men [2].

2.2. Identify the general and specific patients'/general population self-care behaviours that the strategy aims to promote

A key step if you want to establish a strategy to promote self-care is to determine the ideal self-care behaviours that should be promoted. Establishing those ideal behaviours will guide the development of the strategy and it will help identifying the mechanisms that can hinder or facilitate the promotion of self-care.

Depending on the results of the analysis of your context and issues that you want to address you can identify <u>different behaviours to promote</u>.

The following table presents considerations specific to urinary tract infection for each of the main phases of self-care as well as some reflections regarding the patients/general population needs to achieve those goals.

Ма	in stages of the cycle of self-care	Main self-care behaviours to promote	
	evention and healthy estyles	 Following lifestyle and hygiene measures including: Ensuring appropriate intake of water. Appropriate hygiene measures. Appropriate clothing Appropriate liquid consumption 	
_	mptom recognition d evaluation	• Common: Urinary frequency, dysuria and urinary urgency.	
	eatment decision- king	 urgency. Early antibiotic treatment by doctor's prescription. For many patients, access to care can be difficult. Some studies have shown that some women who self-diagnose a UTI may be treated safely with telephone management. Women who have had acute uncomplicated cystitis previously are usually accurate in determining when they are having another episode. [5] In a RCT it was concluded that the short-term outcomes of managing suspected UTIs by telephone were comparable with those managed by usual office care. * The self-care behaviours presented in this table are focused 	
Pilot proje		on non-recurrent UTI. Recurrent UTI (3 UTI in the last year or two in the last 6 months) requires a different approach and treatment. In those cases consider if appropriate self-start -care systems in the European Union.	

All the behaviours included are considered relevant; however this classification might help to focus the self-care.

Platform of experts. (PiSCE) - Section 1 - Guidelines for the Promotion of Self-Care

antibiotic therapy as an additional option for women with the ability to recognize UTI symptomatically and start antibiotics. Patients could be given prescriptions for a 3-day treatment dose of antibiotics. It is not necessary to culture the urine after UTI self-diagnosis since there is a 86% to 92% concordance between self-diagnosis and urine culture in an appropriately selected patient population. Patients are advised to contact a health care provider if symptoms do not resolve within 48 hours for treatment based on culture and sensitivity. [7] [8]

Treatment adherence

Self-monitoring and

early detection of

complications

- Completing antibiotic treatment, even if symptoms subside.
- Prophylactic measures against recurrent uncomplicated UTI:
 - Hygiene measures
 - Antibiotic prophylaxis (considering: continuous antibiotic prophylaxis, self-start antibiotic). [9]
 - Postmenopausal women consider vaginal estrogen creams or rings. [7]
- Consulting a healthcare professional if:
 - Symptoms persist after 24 hours of starting antibiotic treatment.
 - When it is accompanied by persistent fever and is suspected pyelonephritis. [7] [10]

3. Evaluate the mechanisms that might hinder or facilitate the promotion of self-care

Evaluate the mechanisms that might hinder or facilitate the promotion of self-care in your context (barriers and facilitators)

3 Evaluate the mechanisms that might hinder or facilitate the promotion of self-care

- Evaluate the possible impact of hindering/facilitating mechanisms including:
 - Patients related factors
 - Professionals related factors
 - Environment related factors

One of the most important steps in promoting self-care is the identification and analysis of the mechanisms that might hinder the promotion of self-care. Those can be present, hindering the implementation of the self-care strategy, but also as mechanisms facilitating implementation.

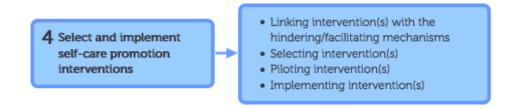
When designing a self-care strategy, one should identify and evaluate these mechanisms. To facilitate this step we propose a list of mechanisms that might affect the development of a self-care strategy. This list is not exhaustive but might be helpful to guide a systematic evaluation of hindering/facilitating mechanisms.

Note: When developing this step in a specific context, it could be very useful to involve all those stakeholders that have been identified to include their multiple perspectives, which can increase the chances of detecting the most relevant hindering/facilitating mechanisms and, ultimately, improve the chances of success of the promotion of selfcare guideline.

Patients					
Knowledge	 Low health literacy: low levels of health literacy can make it harder for patients/persons to engage in self-behaviours. It has been reported that about 12% of the European population have inappropriate general health literacy, and more than one third (35%) has problematic health literacy. Health literacy can be one of the key determinants to address as it has been proven to be associated with health outcomes, health service use and quality of health systems as well as capacity building for professionals. The poor information can negatively affect self-care at any stage, for example: incorrect assessment of seriousness, delayed recognition of symptoms, biased expectations on the condition prognosis. 				
Skills	 Application of preventive measures. Following the recommendations on general healthy life styles and specifically aimed at preventing UTI. Poor skills of prevention can be one of the key hindering 				

	mechanisms particularly for the reduction of incidence.
Attitudes	• Often not enough importance is given to the influence of certain hygiene practices.
Health status	Presence of pregnancy and urinary tract malformations.Diabetes.
Demographic characteristics	• Young and non-pregnant women are the population group with the highest incidence of UTI.
Socio-economic status (and or minority groups)	Institutionalization especially for women.
Professionals	
Behaviours	Lack of planning for managing patient education.
Knowledge	
Skills	• Lack of communication skills and education on healthy lifestyles.
Attitudes	
Environment	
Organizational factors	 Availability (or not) of educational materials to disseminate healthy lifestyle, adequate treatment or linguistic educational level of the population. High number of patients in consultations does not allow to spend time explaining the self-care. Lack of planning, space and/or means for patient education.
Economic factors	• Countries where access to healthcare is not universal or there is no copayment for prescriptions.

4. Select and implement self-care promotion intervention(s)



4.1. Linking intervention(s) with the hindering/facilitating mechanisms

Once the hindering or facilitating mechanisms have been identified a key next step can be to link interventions to those mechanisms.

There are numerous interventions that could potentially contribute to the promotion of self-care in urinary tract infection for the selected target issues (reduce incidence; reduce severity of cases; increase the adherence and reduce inappropriate use of antibiotics in asymptomatic bacteriuria).

The table presented in point 4.2 highlights types of interventions that could target those issues addressing the detected hindering or facilitating mechanisms, with special attention **three key areas of hindering or facilitating mechanisms highlighted before**: the patients'/general population knowledge and skills, organizational factors and the specific most vulnerable groups in the general population.

4.2. Selecting intervention(s)

As it was highlighted in the evaluation of mechanisms there are key areas to consider. The following tables illustrate types of self-care promotion interventions that could address those mechanisms with the final goal of improving the key drivers for selfcare promotion in ITU.

Suggested interventions by key issues				
	Reduce	recurrence	Reduce severity	Improve adherence to treatment
Key characteristics of the issue				
General/specific issue				
Level to address the issue (national/regional/local)				
Key focus that the self-care promotion strategy requires or should include				

System-focused

- Structural interventions
- Staff-oriented interventions
- Financial interventions
- Financial incentives to patients
- Financial incentives to Primary Care

Patient-focused interventions

- Skill development
- Behaviour change
- Family support
- Information provision

Professional-focused interventions

- Educational interventions
- Educational materials
- Large-scale educational meetings
- Small-scale educational meetings
- Outreach visits
- Use of opinion leaders
- Feedbacks and reminders
- Feedback
- Reminders
- Local consensus processes

From this analysis the following type of interventions could be recommended:

It is important to bear in mind that most interventions are multifaceted so include more than one area, however to facilitate the analytical line the interventions have been divided in **information strategies** and **organizational strategies**.

<u>Information strategies</u>: Information, with a special focus on symptom recognition and evaluation.

One of the identified potentially hindering mechanisms related to urinary tract infection was the lack of knowledge regarding the prevention behaviours and techniques.

Information strategies can have some beneficial results to tackle this issue. Some examples of those initiatives are:

Examples of similar practices in:

• UK: NHS Choices – Urinary tract infection [10]

- France: Améli.Santé Infection urinaire [11]
- Netherlands: Zelfzorg.nl [12]
- Sweden: 1177 Vårdguiden Urinvägsinfektion [13]

In those cases the challenge would be how to reach the susceptible population (particularly young women) prior to experiencing a UTI. For more tips on how to communicate check the Communication Guideline - information based strategies should also pay special attention to health literacy checklist there.

Note: An information campaign should be tailored to the needs of the population, so depending on the ethnic composition of the implementing context, the material of the interventions might have to be translated to multiple languages and be adapted to some cultural traits (see <u>implementing intervention sub-section</u>).

Given the high recurrence rate of UTI, there are also opportunities for communication directly between GPs and patients in the occurrence of an episode of UTI. Focusing on prevention strategies in this moment can be particularly effective due to the sensibilisation of patients at that moment.

Consider active distribution of information or documentation illustrated with tips to follow to prevent future UTIs, mainly lifestyle and hygiene habits (for more information see <u>table on self-care behaviours to promote</u>).

In order to promote this communication at consultation level two essential strategies should be included: training for professionals on communication skills (if needed) and providing support elements to professionals to inform and educate patients (graphics, internet, ads, screens in consultations, etc.).

Organizational strategies:

One of the identified organization strategies to promote self-care for ITU is the selfdiagnosis for telephone management.

Some studies have shown that some women who self-diagnose a UTI may be treated safely with telephone management. Women who have had acute uncomplicated cystitis previously are usually accurate in determining when they are having another episode. [5]

Remember that before implementing a piloting of the interventions is recommended. For tips regarding Implementation of interventions see the section in the <u>general</u> <u>guideline</u>.

5. Evaluate the impact of implemented self-care strategies



Evaluation activities are ideally integrated into the change process from the beginning.

Establish concrete goals against which to measure progress of the implementation. Goals should be ambitious but attainable and very concrete. For example: "Reducing the number of unnecessary GP consults for minor conditions" is not concrete enough, formulating it as "Reducing the number of unnecessary GP consults for minor conditions by 10% in a year" will help to evaluate the progress of the strategy.

5.1. Develop impact indicators

- Develop indicators for all levels of implementation:
 - Micro level: evaluate attitudes of professionals and patients, level of knowledge, use of information materials.
 - Number of performed training sessions for patients/year.
 - Number of patients attending training sessions.
 - Number of training sessions for professionals.
 - Number of professionals who have attended and % of those who should attend.
 - Incidence rate of ITU
 - Incidence of recurrent rate of ITU
 - Meso level: evaluate the use of health services, the degree of implementation of the intervention(s)
 - Level of knowledge of acquired information by patients (survey).
 - Acquired skills by professionals in communication (specific question in survey patient).
 - Incidence rate of ITU
 - Incidence of recurrent rate of ITU
 - Macro: evaluate costs, overall use of the developed self-care resources
 - Number of website visits of education program.
- Consider the inclusion of indicators of structure, process and outcomes.

5.2. Consider qualitative evaluation (both by patients/general public and professionals)

• Qualitative techniques might be particularly useful to detect the acceptability of an intervention, identification of barriers and facilitators of the new intervention

for example, interviews with GP that have been educated in communication skills to determine the applicability of the acquired knowledge.

5.3. Evaluate continuously and adapt your strategy in consequence

Annually assessing results of the indicators and qualitative evaluation, and redesign or abandon unproductive strategies, especially those providing a lower cost/benefit ratio.

References

1. Badalato G, Kaufmann M. ADULT UTI [Internet]. American Urological Association. 2016. Available from: https://www.auanet.org/education/adult-uti.cfm

2. National Institute for Health and Care Excellence (NICE). Urinary tract infections in adults [Internet]. 2015. Available from: https://www.nice.org.uk/guidance/qs90

3. National Institute for Health and Care Excellence N. Lower urinary tract symptoms in men. 2010.

4. Al-Badr A, Al-Shaikh G. Recurrent urinary tract infections management in women: A review [Internet]. Sultan Qaboos University Medical Journal. 2013. p. 359–67. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3749018/

5. Colgan, R., & Williams M. Diagnosis and Treatment of Acute Uncomplicated Cystitis. Am Fam Physician [Internet]. 2011;84(7):771–6. Available from: http://www.aafp.org/afp

6. Barry HC, Hickner J, Ebell MH, Ettenhofer T. A randomized controlled trial of telephone management of suspected urinary tract infections in women. J Fam Pr [Internet]. 2001;50(7):589–94. Available from:

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=11485707

7. Dason S, Dason JT, Kapoor A. Guidelines for the diagnosis and management of recurrent urinary tract infection in women. Can Urol Assoc J [Internet]. 2011;5(5):316–22. Available from:

http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3202002&tool=pmcentrez&renderty pe=abstract

8. Arnold JJ, Hehn LE, Klein DA. Common questions about recurrent urinary tract infections in women. Am Fam Physician. 2016;93(7):560–9.

9. Dason S, Dason JT, Kapoor A. Guidelines for the diagnosis and management of recurrent urinary tract infection in women. Can Urol Assoc J [Internet]. 2011;5(5):316–22. Available from:

http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3202002&tool=pmcentrez&renderty pe=abstract

10. Urinary tract infections in adults [Internet]. NHS Choices. 2016. Available from: http://www.nhs.uk/conditions/Urinary-tract-infection-adults/Pages/Introduction.aspx

11. Ameli-sante. Ameli-sante – Infection urinaire [Internet]. 2014. Available from: http://www.ameli-sante.fr/cystite-aigue/definition-symptomes-causes.html?xtmc=infection urinaire&xtcr=6

12. Neprofarm. zelfzorg.nl [Internet]. 2016. Available from: http://zelfzorg.nl/

13. 1177 Vårdguiden. 1177 Vårdguiden – Urinvägsinfektion [Internet]. 2016. file://localhost/Available from/ http/::www.1177.se:Fakta-och-rad:Sjukdomar:Urinvagsinfektion:

Guideline on how to promote self-care: Cough

Guideline on how to promote self-care: Cough

Basic information about Cough

A cough is a reflex mechanism to clear the airways of mucus and irritants such as dust or smoke.

In the absence of significant co-morbidity, an acute cough is normally benign and self-limiting. This document refers to cough only as minor self-limited condition, and not as a symptom associated with chronic diseases (COPD, asthma, etc.), in which cough usual is part of a medical condition. Acute cough is most commonly caused by a viral upper respiratory tract infection (URTI) due to a cold.

Most coughs clear up within three weeks and don't require any treatment. Also children usually do not need to go see their GP, even if the child has a mild cough for a week or two. In both cases for more persistent coughs, patients should be advised to visit their GP so they can investigate the cause [1].

1. Identify the problem and evaluate your context

Describing the context in terms of the key issue that you want to address, the stakeholders that can be affected by the issue and the existing resources that exist/could be used to address the issue. This exercise would give a general idea of the starting point.

1 Identify the problem and evaluate your context

- Define what specific issue(s) you are trying to address
- Identify whether those issues are related to a specific minor conditions or a general approach to self-care
- Identify key stakeholders for the development of the self-care strategy
 Identify self-care promotion resources
- for the selected conditions in your area

1.1. Define what specific issue(s) you are trying to address

The first step when deciding to launch a self-care (or any other) initiative is to clarify **what is moving you** to launch this initiative. Specifically, to identify what are the drivers that are moving forward this need for change.

The key drivers depend on each specific context, however a review of the literature point towards some of most common drivers relating to cough.

Some of the **key drivers** to start a promotion strategy to improve self-care behaviours for cough could be:

 The high incidence of cough and its impact among the population: Most adults experience episodes of coughing between two and five times a year, and about one in five people suffers from coughs during winter months.
 [2]. Furthermore, although cough is almost always harmless and usually starts to improve within three weeks, it can be distressing (both for patients and others living or working with them) and a nuisance because it often lasts for several weeks affecting quality of life. [2]

Reducing costs associated to cough:
 Due to its high frequency cough can drive high costs. For example it is estimated that the cost of acute cough to the UK economy is at least £979 million. This comprises £875 million to loss of productivity and £104 million cost to the healthcare system and the purchase of non-prescription medicines. Regarding the costs related to healthcare system it is relevant to highlight the volume of cough-related visits to GP. For example in the UK over half the population consult their doctor each year for a minor symptom, and acute respiratory symptoms (eg, cough, sore throat) are the most common cause of consultation. [3]

Reducing unnecessary use of medication:

There is little evidence that over-the-counter medicines that claim to suppress patient's cough or stop bringing up phlegm are more effective than simple home remedies [1]. The expense on those medicines is one of the cost categories associated to cough.

 Reducing improper use of antibiotics in cough: Antibiotics do not work against viral infections, which cause most acute coughs. Promotion campaigns could be triggered because an inadequate or overuse of antibiotics associated to cough is being observed. [2]

1.2. Identify whether these issues are related to a specific minor conditions or a general approach to self-care

Common cough is one of the most common minor conditions in terms of number of people affected and can often be closely linked to cold. Therefore, the key issues that drive the promotion of self-care are mostly common to other minor conditions and cold, more specifically.

Particularly, reducing inappropriate use of antibiotics for cough caused by viral infections and self-medication with drugs for which there is not enough evidence on effectiveness is an issue that should be addressed across all the health system if a strategy should be effective.

Regarding the other highlighted issues (high incidence, quality of life ...) these can also be shared with other minor conditions and the strategies used to tackle these issues can encompass other minor conditions as well, although specific elements should be adapted to each specific condition.

1.3. *Identify stakeholders and resources available for the self-care strategy*

Stakeholders involved for the self-care strategy: A key determinant of a successful intervention can be the inclusion of the relevant stakeholders.
 Anyone who wants to promote self-care should identify the stakeholders that are/could be involved and what is expected of each of them. Identifying those stakeholders at an early stage can facilitate a better coordination and a better use of all the available resources. Stakeholders should be defined in each specific context.

The following, but not limited to, key groups of stakeholders should be considered:

- Healthcare professionals, basically GPs (and professional bodies)
- \circ Industry, self-care medication and medical devices industry
- Pharmacist
- o Mass media
- Healthcare managers
- Policy decision makers
- Workplace related stakeholders

The table included in the general <u>guideline</u> shows some of the different key stakeholders at local, regional and country level.

1.4. Identify the self-care support resources available in your context

If you want to successfully promote self-care in your context, to identify existing resources is a key step.

Regarding the key issues that have been highlighted about cough, the following resources could be particularly useful when available:

Economic resources

Budget allocated for material to be developed, personnel required to implement self-care strategy, etc.

Structural

Existence of network of community pharmacists. General access of the population to internet (to access web portals or similar services), etc.

Professional training

Training in specific skills, particularly communication skills of professionals that could be involved in the strategy (GPs, primary care nurses, pharmacists, professionals staffing phone and online consultations...).

If the professionals don't have the training in the specific skills needed for your self-care promoting strategy consider whether training could be developed and included in continuous professional development schemes or similar schemes.

Technology

Existence of health web portals, health advice lines, etc. in your context (could be from public institutions but also consider Patient Organizations web portals, etc.).

Consider also:

Are there any tools/information to help promote patterns and healthy lifestyles (health education)? Are they well-known and used? Are these websites multi-lingual and take into consideration most frequent languages in the communities that you want to address?

The following table illustrates a possible way to summarize the basic characteristics of an evaluation of the context for the self-care strategy. If possible, completing this review with all stakeholders might prove useful.

Note that depending on your position (policy decision maker; healthcare professional, member of patient organization...) you might have different possibilities and ability to involve other stakeholders.

1.1. Define issues		Key issues (suggestion of key issues that might impulse the need for promotion of self-care related to cough)		
		Incidence and impact	Associate costs	Improper use of antibiotics
1.2.	General/specific issue			
Charact.	Level to address the issue			
	Healthcare professionals, basically GPs (and professional			
1.3.1. Identify	Industry, self-care medication and medical devices industry			
key	Pharmacist			
stakeholde	Mass media			
	Healthcare managers			
	Policy decision makers			
	Workplace related stakeholders			
	Economic resources	Budget allocated for material to be developed, personnel required to implement self-care strategy, etc.		
1.3.2. Identify	System / structural resources	Existence of network of community pharmacists. General access of the population to internet (to access web portals or similar services), etc. "Delayed prescription" systems.		
key resources (j)	Professionals training	Training in specific s skills of professional strategy (GPs, prima professionals staffin	ls that could be ary care nurses,	involved in the
	Technology		Ild be from publ	alth advice lines, etc. ic institutions but also portals, etc.)

And should be considered when planning the strategy.

2. Identify and select common and specific patients'/general population self-care behaviours

Identify and select common and specific patients'/general population self-care behaviours that you want to promote (depending on the context problem you want to address)

2 Identify and select common and specific patients'/general population self-care behaviours

- Specify and describe the population/patients that you want to address with the intervention
- Identify the general and specific patients'/general population self-care behaviours that the intervention aims to promote

2.1. Specify and describe the patients/general population that you want to address with the self-care strategy

Depending on the results of the evaluation of context and key issues and whether strategy is general or specific to a minor condition, one should define target patients/general population to whom interventions should be addressed to. Regarding cough, probably there is no specific target population as all general population is affected by it.

However there are some specific groups that should have special attention, as they might be more vulnerable to complications or misdiagnosis:

- Smokers
- People affected by seasonal allergies
- Children younger than 3 months
- Patient with chronic diseases (respiratory and cardiologic diseases)

2.2. Identify the general and specific patients'/general population self-care behaviours that the intervention aims to promote

A key step if you want to establish a strategy to promote self-care is to determine the self-care behaviours that should be promoted or those that should be discontinued or avoided. Promoting these behaviours will guide the development of the strategy and it will help identifying the mechanisms that can hinder or facilitate the promotion of self-care.

Depending on the results of analysis of context and issues that you want to address, you can identify <u>different behaviours to promote</u>.

The following table shows specific self-care behaviours that should be promoted (or avoided) for each one of the main phases of self-care, as well as some reflections regarding patients'/general population needs to achieve these goals.

All the behaviours included are considered relevant, however this classification might help to focus the self-care promotion strategy on a specific target.

Main stages of the cycle of self-care	Main self-care behaviours to promote	
Prevention and health lifestyles	 Quitting smoking: Smoking is one of most common and frequently reported underlying causes of chronic cough. Quitting smoking – or at least smoking less does not only improves patients' cough, but also benefits patients' in other health issues. Preventing cold (see Promotion of <u>self-care for cold guideline</u>). 	
Treatment decision- making	 Avoiding unnecessary antibiotics. Considering whether treatment is necessary, for mild, short-term coughs. Treating the underlying cause (if appropriate). If an infant younger than 3 months old has cough, consulting the paediatrician or GP. 	
Treatment adherence	As the treatment of cough is directed towards symptom relief, the adherence to such treatments might not be as problematic as for other conditions.	
	Monitoring and consulting a GP if the following symptoms or signs appear:	
Self-monitoring & early detection of complications	 Coughing up blood. Coughing for more than three to four weeks. Chest or shoulder pain. Breathlessness. Weight loss: losing weight for no apparent reason over a period of six weeks or more. Voice changes: becoming hoarse for longer than three weeks, and hoarseness persists after cough has settled. New lumps or swellings: new swellings anywhere in the neck. [1] 	

3. Evaluate the mechanisms that might hinder or facilitate the promotion of self-care

Evaluate the mechanisms that might hinder or facilitate the promotion of self-care in your context (barriers and facilitators)

3 Evaluate the mechanisms that might hinder or facilitate the promotion of self-care Evaluate the possible impact of hindering/facilitating mechanisms including:

- · Patients related factors
- Professionals related factors
- Environment related factors

One of the most important steps in promoting self-care is the identification and analysis of the mechanisms that might hinder the promotion of self-care. Those can be present, hindering the implementation of the self-care strategy, but also as mechanisms facilitating implementation.

When designing a self-care strategy, one should identify and evaluate these mechanisms. To facilitate this step we propose a list of mechanisms that might affect the development of a self-care strategy. This list is not exhaustive but might be helpful to guide a systematic evaluation of hindering/facilitating mechanisms.

Note: When developing this step in a specific context, it could be very useful to involve all these stakeholders that have been identified to include their multiple perspectives, which can increase the chances of detecting the most relevant hindering/facilitating mechanisms and, ultimately, improve the chances of success of the promotion of selfcare guideline.

Patients	
Knowledge	 Low health literacy: The poor information can negatively affect self-care at any stage. Low levels of health literacy can make it harder for patients/persons to engage in self-care behaviours. It has been reported that about 12% of the European population have inappropriate general health literacy, and more than one third (35%) has problematic health literacy. Health literacy can be one of the key determinants to address as it has been proven to be associated with health outcomes, health service use and quality of health systems as well as capacity building for professionals. Poor information on condition: Cough is a symptom of other conditions, not a condition in itself, as such it might be difficult to identify relevant information for lay persons.

People with acute cough, not related to chronic conditions, often do not have reliable information that cough is a self-limited process. This might incentives unnecessary self-medication.

- Lack of decision-making skills can be a hindering mechanism for the reduction of unnecessary visits to the GP and crucially for the reduction of inappropriate use of antibiotics.
- Application of preventive measures. Reducing the contagion of underlying causes of cough (such as cold) could be one of the key benefits of the promotion of self-care. The poor skills of prevention can be one of the key hindering mechanisms particularly for the reduction of incidence.
- Some population groups believe that the best treatment in the presence of cough is taking antibiotics. In most cases of acute cough, antibiotics are unnecessary [4] because its most frequent cause are viral infection. The use of antibiotics without medical prescription involves health risks and could contribute to the promotion of resistant bacteria.
- Patients with respiratory or cardiac comorbidity can lead to confuse self-limited and acute cough with secondary cough to chronic process.
 - Financial resources: lack of financial resources can complicate selfcare by hindering the access to self-care medication (or self-care devices), affecting the decision to take a sick-leave (maybe incurring on loss of (part of) the salary for some days), etc.
 The pricing systems and prescription discounts in many countries across Europe might deter patients/general population from directly consulting the community pharmacist.
 - Social exclusion: people in situation of social exclusion can have a more difficult access to self-care resources such as information sources, advice from professionals, etc.

Professionals

Behaviours

Knowledge

Socio-economic

minority groups)

status (and or

Skills

Attitudes and

Health status

beliefs

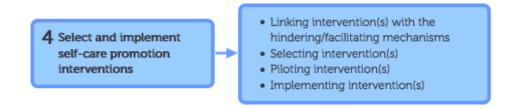
•	Unnecessary prescriptions of antibiotics for self-limiting minor
	conditions. This behaviour might incentives patients/general public
	to visit GPs whenever they have a minor condition. The prescription
	of antibiotics can reinforce a patient to repeat the consultation with
	the GP in future episodes of common cold.

- Professional education to promote patient self-care can be key for a successful intervention. A good education on promotion of self-care or lack thereof can be critical as a positive driver or as an important complication.
- SkillsCommunication skills might not be a priority in the professional
curricula. The lack or low confidence on the communications skills
such it might inhibit the promotion of self-care treatment optionsPilot project on the promotion of self-care systems in the European Union.

Platform of experts. (PiSCE) - Section 1 - Guidelines for the Promotion of Self-Care

	regarding cough prevention and control measures.
Attitudes	 The attitudes of healthcare professionals (including primary care, pharmacist, etc) are a critical factor for the implementation of a self- care strategy. They need to be aware about the importance of educating patients and carers about how to prevent and reduce the impact of cough.
Environment	
Social factors	 Social/cultural differences: might difficult understanding of self-care portals of information Low relevance of self-care promotion on health care education.
Organizational factors	 Issuance of work leave (sick certificate): in many countries the work leave is covered by Social Security schemes/insurance schemes if this is linked to a medical certificate it directs people with a minor condition to directly consult with GPs, even for cases that could be self-treated (for example cold). Access to resources: the variation in accessibility of key resources (for example web portals) to self-care can act as a barrier.
Economic factors	 Financial incentives for professionals: a key issue might be the cases of linking a part of the GPs salary to the number of consults. This can act as a barrier for GPs to actively encourage self-care. Financial incentives for patients in some systems to seek prescribed self-care medication: In many health systems prescribed medication is discounted, compared to self-care medication purchased directly at the pharmacy. This fact might affect the decision of citizens to attend primary care doctors instead of attempting self-care.

4. Select and implement self-care promotion intervention(s)



4.1. Linking intervention(s) with the hindering/facilitating mechanisms

Once the hindering or facilitating mechanisms have been identified, linking interventions to theses mechanism is a key step.

There are numerous interventions that could potentially contribute to the promotion of self-care in cough for selected target issues (reduce incidence; reduce unnecessary visits to GPs, reduce inappropriate use of antibiotics).

The table showed in point 4.2 highlights types of interventions that could target these issues addressing the detected hindering or facilitating mechanisms, with special attention to **three key areas of hindering or facilitating mechanisms highlighted before:** the patients'/general population knowledge and skills, organizational factors and specific most vulnerable groups in the general population.

4.2. Selecting intervention (s)

The following tables illustrate types of self-care promotion interventions that could address these mechanisms with the final goal of improving the key issues highlighted.

Suggested interventions by key issues				
	and	Associated costs		Unnecessary use of medication
Key characteristics of the issue				
General/specific issue				
Level to address the issue (national/regional/local)				
Key focus that the self-care promotion strategy requires or should include				
System-focused				
Structural interventions				
Staff-oriented interventions				

• Financial interventions

- Financial incentives to patients
- Financial incentives to Primary Care

Patient-focused interventions

- Skill development
- Behaviour change
- Family support
- Information provision

Professional-focused interventions

- Educational interventions
- Educational materials
- Large-scale educational meetings
- Small-scale educational meetings
- Outreach visits
- Use of opinion leaders
- Feedbacks and reminders
- Feedback
- Reminders
- Local consensus processes

The following type of interventions could be recommended from this analysis: It is important to bear in mind that most interventions are multifaceted, so include more than one area; however, to facilitate the analytical line the interventions have been divided in **information strategies** and **organizational strategies**.

Information strategies:

Information, with a special focus on symptom recognition and evaluation.

One of the identified potentially hindering mechanisms was the lack of knowledge regarding what to expect when someone has cough, to be aware of treatment options and recommendations for symptom relieve. Information strategies can have some beneficial results to tackle this issue.

Know who to turn to:

A combination of these two complementary information strategies would help to address two of the most relevant aspects: symptom recognition and information on how to navigate the healthcare system.

Self-medication

Often, the first professional to where patients go is the pharmacist. In these

cases the implication of this professional is critical because they are the first point of contact from a healthcare professional.

- **Improper use of antibiotics** Involvement of pharmacists to educate patients about the use of antibiotics.
- **Dispensing prescription-only antibiotics** This is a widely extended measure in European countries and a very effective strategy to reduce Antibiotic Self-medication.
- Mass media information campaigns
 Generating awareness about how to self-care, how to mitigate the effect of the cough in the quality of life (relieving the symptoms) and how to reduce the contagious for viral infections (mainly during winter seasons).

Reduction of GP appointments Phone consultation to reduce GP workload Easy access to easy self-care

programs (from mobile phone or other media) recommended by phone consultant/carrier, although this might leave some groups out, such as elderly and non-income population.

Habits and behaviours for a healthy lifestyle
 Messages to the public.
 Sessions on healthy lifestyle offered and conducted in health centres.

Organizational strategies:

Mass media information campaigns on acute cough as a self-limited process.

Graphic information (posters, brochures, etc.) displayed on main locations and points of contact, especially in pharmacies and care centres.

5. Evaluate the impact of implemented self-care strategies



Evaluation activities are ideally integrated into the change process from the beginning.

Establish concrete goals against which progress of the implementation can be measured. Goals should be ambitious but attainable and very concrete. For instance: "Reducing number of unnecessary GP appointments for minor conditions" is not tangible enough, however drawn up as "Reducing number of unnecessary GP appointments for minor conditions by 10% in a year" will help evaluate progress of the strategy.

5.1. Develop impact indicators

- Develop indicators for all levels of implementation:
 - Micro level: evaluate attitudes of professionals and patients, level of knowledge, use of information materials, use of healthcare resources and prescription.
 - Use of antibiotics
 - Level of bacterial resistant
 - Number of visits to the GP
 - Meso level: evaluate the use of health services, degree of implementation of the intervention(s). Based on the examples of good practices some could be:
 - Number of pharmacists involved in an alliance with GP
 - Training sessions or educational activities on healthy lifestyles
 - Number of schools participating in educational prevention strategies
 - Macro: evaluate costs, overall use of the developed self-care resources
 - Number of centres with call centre/hotline
 - Number of calls to call centre/hotline regarding a minor condition
 - Number of consultations to the "online physician"
 - Reduction of GP consultations regarding acute cough in the first three weeks since the appearance of the symptom
- Consider including indicators of structure, process and outcomes.
 In the examples provided the existence of centres with call centres is a structure indicator, the number of calls to the centre is a process outcome and

the reduction of GP consultations regarding acute cough in the first three weeks since the appearance of the symptom would be an outcome process.

5.2. Consider qualitative evaluation (both by patients/general public and professionals)

• Qualitative techniques might be particularly useful to detect the acceptability of an intervention, identification of barriers and facilitators of new intervention.

5.3. Evaluate continuously and adapt your strategy in consequence

Bibliography

1. Cough [Internet]. NHS Choices. 2015. Available from: http://www.nhs.uk/conditions/Cough/Pages/Introduction.aspx

2. Craig R. Pringle, BSc P. Cough in Adults. Merck Man Prof Version [Internet]. 2014;7(7):1–9. Available from: http://www.selfcareforum.org/wp-content/uploads/2013/04/7-Cough.pdf

3. Morice a H, McGarvey L, Pavord I. Recommendations for the management of cough in adults. Thorax. 2006;61 Suppl 1:i1–24. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2080754/

4. National Institute for Health and Care Excellence (NICE). Respiratory tract infections (self-limiting): prescribing antibiotics [Internet]. 2008. Available from: https://www.nice.org.uk/guidance/CG69

References - all

Cold

- Bramley TJ, Lerner D, Sames M. Productivity losses related to the common cold. J Occup Environ Med [Internet]. 2002 Sep [cited 2015 Sep 10];44(9):822–9. Available from: <u>http://www.ncbi.nlm.nih.gov/pubmed/12227674</u>
- World Health Organisation. WHO How to reduce the spread of antibiotic resistance [Internet]. 2011. Available from: <u>http://www.euro.who.int/en/health-topics/diseaseprevention/antimicrobial-resistance/news/news/2012/11/antibiotic-resistance-agrowing-threat/how-to-reduce-the-spread-of-antibiotic-resistance
 </u>
- 3. Sexton D, McClain M. The common cold in adults: Diagnosis and clinical features. UpToDate [Internet]. 2014; Available from: <u>http://www.uptodate.com/contents/the-common-cold-in-adults-diagnosis-and-clinical-features</u>
- NHS Choices. Common cold Children [Internet]. 2015. Available from: <u>http://www.nhs.uk/Conditions/Cold-common/Pages/Commoncoldinchildren.aspx</u>
- Hemilä H, Chalker E. Vitamin C for preventing and treating the common cold. Cochrane database Syst Rev [Internet]. 2013 Jan [cited 2015 Aug 29];1:CD000980. Available from: <u>http://www.ncbi.nlm.nih.gov/pubmed/23440782</u>
- Karsch-Völk M, Barrett B, Kiefer D, Bauer R, Ardjomand-Woelkart K, Linde K. Echinacea for preventing and treating the common cold. Cochrane database Syst Rev [Internet]. 2014 Jan [cited 2015 Sep 7];2:CD000530. Available from: <u>http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=4068831&tool=pmcentrez&r endertype=abstract</u>
- Blaiss MS, Dicpinigaitis P V, Eccles R, Wingertzahn MA. Consumer attitudes on cough and cold: US (ACHOO) survey results. Curr Med Res Opin [Internet]. 2015 Aug [cited 2015 Sep 10];31(8):1527–38. Available from: <u>http://www.ncbi.nlm.nih.gov/pubmed/25535904</u>
- Heikkinen T, Järvinen A. The common cold. Lancet [Internet]. 2003 Jan 4 [cited 2015 May 24];361(9351):51–9. Available from: <u>http://www.ncbi.nlm.nih.gov/pubmed/12517470</u>
- Lokker N, Sanders L, Perrin EM, Kumar D, Finkle J, Franco V, et al. Parental misinterpretations of over-the-counter pediatric cough and cold medication labels. Pediatrics [Internet]. NIH Public Access; 2009 Jun 1 [cited 2015 Sep 10];123(6):1464– 71. Available from:

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2911576/?report=abstract

- Gualano MR, Gili R, Scaioli G, Bert F, Siliquini R. General population's knowledge and attitudes about antibiotics: a systematic review and meta-analysis. Pharmacoepidemiol Drug Saf [Internet]. 2015 Jan 24 [cited 2015 Sep 10];24(1):2–10. Available from: <u>http://www.ncbi.nlm.nih.gov/pubmed/25251203</u>
- Braun BL, Fowles JB. Characteristics and experiences of parents and adults who want antibiotics for cold symptoms. Arch Fam Med [Internet]. 2000 Jul [cited 2015 Sep 10];9(7):589–95. Available from: <u>http://www.ncbi.nlm.nih.gov/pubmed/10910304</u>
- Shaku F, Tsutsumi M, Miyazawa A, Takagi H, Maeno T. Self-care behavior when suffering from the common cold and health-related quality of life in individuals attending an annual checkup in Japan: a cross-sectional study. BMC Fam Pract [Internet]. BMC Family Practice; 2015 Jan [cited 2015 Sep 10];16(1):91. Available from: <u>http://www.biomedcentral.com/1471-2296/16/91</u>

- Huttner B, Goossens H, Verheij T, Harbarth S. Characteristics and outcomes of public campaigns aimed at improving the use of antibiotics in outpatients in high-income countries. Lancet Infect Dis [Internet]. Elsevier Ltd; 2010;10(1):17–31. Available from: <u>http://dx.doi.org/10.1016/S1473-3099(09)70305-6</u>
- 14. Lambert MF, Masters G a., Brent SL. Can mass media campaigns change antimicrobial prescribing? A regional evaluation study. J Antimicrob Chemother. 2007;59(3):537–43.
- 15. Curry M, Sung L, Arroll B, Goodyear-Smith F, Kerse N NP. Public views and use of antibiotics for the common cold before and after an education campaign in New Zealand. – PubMed – NCBI. N Z Med [Internet]. [cited 2015 Sep 10]; Available from: <u>http://www.ncbi.nlm.nih.gov/pubmed/?term=Public+views+and+use+of+antibiotics+fo</u> <u>r+the+common+cold+before+and+after+an+ education+campaign+in+New+Zealand</u>
- 16. Schneider P. A cost / benefit analysis of self- care systems in the European Union.

Heartburn (without indigestion)

- El-Serag HB. Time trends of gastroesophageal reflux disease: a systematic review. Clin Gastroenterol Hepatol [Internet]. 2007;5(1):17–26. Available from: http://www.ncbi.nlm.nih.gov/pubmed/17142109
- Vigneri S, Termini R, Leandro G, Badalamenti S, Pantalena M, Savarino V, et al. A comparison of five maintenance therapies for reflux esophagitis. N Engl J Med. 1995;333(17):1106–10.
- 3. Alexander GC, Mohajir N, Meltzer DO. Consumers' perceptions about risk of and access to nonprescription medications. J Am Pharm Assoc (2003). 2015;45:363–70.
- Rockafellow S, Berardi RR. Self-Treatment Tips for Heartburn [Internet]. Pharmacy Times. 2009. Available from: <u>http://www.pharmacytimes.com/publications/issue/2009/2009-05/counselingheartburn-</u>0509
- 5. Wertheimer AI, Serradell J. A discussion paper on self-care and its implications for pharmacists. Pharmacy World and Science. 2008. p. 309–15.
- Kartman B, Gatz G, Johannesson M. Health State Utilities in Gastroesophageal Reflux Disease Patients with Heartburn: A Study in Germany and Sweden. Med Decis Mak [Internet]. 2004 Feb 1 [cited 2016 Nov 14];24(1):40–52. Available from: http://mdm.sagepub.com/cgi/doi/10.1177/027298X03261563
- Heartburn and gastro-oesophageal reflux disease (GORD) [Internet]. NHS Choices. 2016. Available from: <u>http://www.nhs.uk/conditions/Gastroesophageal-reflux-disease/Pages/Introduction.aspx</u>
- 8. Know who to turn to [Internet]. NHS Scotland. Available from: http://www.knowwhototurnto.org/
- 9. Know who to turn to Pharmacies [Internet]. NHS Scotland. Available from: http://www.knowwhototurnto.org/Pharmacies.aspx
- Greater Manchester Minor Ailments Scheme Pharmacy First [Internet]. Community Pharmacy Greater Manchester. 2016. Available from: <u>http://psnc.org.uk/community-pharmacy-greater-manchester/services/greater-manchester-minor-ailments-scheme-pharmacy-first/</u>
- NHS Scotland. The new NHS minor ailment service at your community pharmacy. Scottish Consum Counc [Internet]. Available from: <u>http://www.psd.scot.nhs.uk/docs/minor_ailment.pdf</u>
- 12. Ostermann H, Renner A-T, Bobek J, Schneider P, Vogler S. A cost / benefit analysis of self- care systems in the European Union. 2015.

Urinary Tract Infection (UTI)

- 1. Badalato G, Kaufmann M. ADULT UTI [Internet]. American Urological Association. 2016. Available from: <u>https://www.auanet.org/education/adult-uti.cfm</u>
- 2. National Institute for Health and Care Excellence (NICE). Urinary tract infections in adults [Internet]. 2015. Available from: <u>https://www.nice.org.uk/guidance/qs90</u>
- 3. National Institute for Health and Care Excellence N. Lower urinary tract symptoms in men. 2010.
- Al-Badr A, Al-Shaikh G. Recurrent urinary tract infections management in women: A review [Internet]. Sultan Qaboos University Medical Journal. 2013. p. 359–67. Available from: <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3749018/</u>
- Colgan, R., & Williams M. Diagnosis and Treatment of Acute Uncomplicated Cystitis. Am Fam Physician [Internet]. 2011;84(7):771–6. Available from: <u>http://www.aafp.org/afp</u>
- Barry HC, Hickner J, Ebell MH, Ettenhofer T. A randomized controlled trial of telephone management of suspected urinary tract infections in women. J Fam Pr [Internet]. 2001;50(7):589–94. Available from: <u>http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citatione&list_uids=11485707</u>
- Dason S, Dason JT, Kapoor A. Guidelines for the diagnosis and management of recurrent urinary tract infection in women. Can Urol Assoc J [Internet]. 2011;5(5):316– 22. Available from: <u>http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3202002&tool=pmcentrez&r</u> endertype=abstract
- 8. Arnold JJ, Hehn LE, Klein DA. Common questions about recurrent urinary tract infections in women. Am Fam Physician. 2016;93(7):560–9.
- 9. Urinary tract infections in adults [Internet]. NHS Choices. 2016. Available from: http://www.nhs.uk/conditions/Urinary-tract-infection-adults/Pages/Introduction.aspx
- 10. Securité sociale MA. ameli-sante.fr [Internet]. Available from: <u>http://www.ameli-sante.fr/</u>
- 11. Neprofarm. zelfzorg.nl [Internet]. 2016. Available from: <u>http://zelfzorg.nl/</u>
- 12. Vårdguiden O 1177. 1177.se [Internet]. 2015. Available from: <u>http://www.1177.se/</u>

Cough

- Cough [Internet]. NHS Choices. 2015. Available from: <u>http://www.nhs.uk/conditions/Cough/Pages/Introduction.aspx</u>
- Craig R. Pringle, BSc P. Cough in Adults. Merck Man Prof Version [Internet]. 2014;7(7):1–9. Available from: <u>http://www.selfcareforum.org/wp-content/uploads/2013/04/7-Cough.pdf</u>
- Morice a H, McGarvey L, Pavord I. Recommendations for the management of cough in adults. Thorax. 2006;61 Suppl 1:i1–24. Available from: <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2080754/</u>
- National Institute for Health and Care Excellence (NICE). Respiratory tract infections (self-limiting): prescribing antibiotics [Internet]. 2008. Available from: <u>https://www.nice.org.uk/guidance/CG69</u>

Section 2 - Guidelines for Communication Tools

Content

SECTION 2 - GUIDELINES FOR COMMUNICATION TOOLS	
GUIDELINE CONTENT	138
Preparing Communication	139
COMMUNICATION SITUATIONS	143
COMMUNICATION GOALS	148
Advanced Introduction to Behaviour Change	151
COMMUNICATION PLANNING AND DEVELOPMENT	153
COMMUNICATION FOR FIVE MINOR CONDITIONS	155
COMBINING COMMUNICATION TOOLS – EXAMPLES	159
STEP BY STEP CHECK LIST	162
Evaluating Communication	164
COMMUNICATION INDICATORS	169
COMMUNICATION AND ACTIVATE SELF CARE	172
Leaflets	173
Websites	174
Events	176
Campaigns	179
Apps	182
Multi-level Initiatives	184
HEALTH LITERACY IN COMMUNICATION	188
HEALTH LITERACY CHECK LIST	192
CATALOGUE OF TOOLS & CASES	194
CASES FROM EUROPE	200
SECTION 1 – GUIDELINES FOR THE PROMOTION OF SELF-CARE	29

Selfcare.nu and Selfcare.me

The Guidelines for Communication Tools have been created by WP2 in a webformat at www.selfcare.nu and will later be added to www.selfcare.me also - the following shows the content of these guidelines, but naturally not with the all the same functionalities as the webpage in terms of intertextual links, highlights etc.

The overall idea is to provide users with information and advice on how to Prepare and Develop Communication Tools, to Produce and Use Communication Tools, and to Optimize and Evaluate the efforts.

Considerations	Activities and Initiatives – How to			
Prepare, Plan, and Evaluate	Produce a Leaflet			
Using these guidelines Above, we suggest you always prepare, plan, and evaluate	Create a Website			
communication. Right, we suggest communication activities to help you – from basic at	Put on an Event			
the top to advanced at the bottom. Below, we suggest you always consider health literacy and use cases	Build a Campaign			
as inspiration.	Build an App			
Health Literacy and Inspiration	Take a Multi-level Initiative			

Communication Guideline

Share your experience and good practices!

We would like to add to our list of good practices about self-care communication tools, so do please write to us with information about your own - about the target group, the situation, and (as much as possible) the impact it had, as well as attaching or providing a link to your tool.

Contact kfs@sundkom.dk.

Guideline Content

To enable users within a wide range of communication experience and a somewhat differing experience within self-care also (and perhaps within only one of the minor conditions) the Guidelines on Communication Tools contains the following (as can be seen on the previous page)

- a section about preparing, planning, and evaluation of communication either as individual tools or efforts, or by using multiple tools in combination – and on evaluation of it all
- a section containing advice about the creation, development, and use of different communication tools and activities
- a section about health literacy, considerations, and inspiration by cases

In this document this content is thus shown as

- Preparing Communication
 - Communication Situations
 - Communication Goals
 - Advanced Introduction to Behaviour Change
- Communication Planning and Development
 - Self Care Communication
 - Combining Tools
 - Step by Step Check List
- Evaluating Communication
 - Communication Indicators
- Communication Activities
 - Leaflets
 - Websites
 - Events
 - Campaigns
 - o Apps
 - Multi-level Initiatives
- Health Literacy in Communication
 - Health Literacy Check List
- Catalogue of Tools & Cases
 - New Cases form Europe

Preparing Communication

Preparation and Analysis before Communicating

Good planning and execution can help you achieve your communication objectives. If you are new to communication this section will help you towards securing a proper basis for choosing the right communication tool(s), using the appropriate content and language, and finding viable evaluation methods for your communication. You can use this in relation to a specific health condition or in communicating about self-care in general.

This section has a series of questions for you to consider, especially about your

- Intention
- Audience
- Situation
- Budget
- Evaluation
- Strategy

Below you will also find a simple Health Literacy check list.

Note: These are quite basic considerations for some – if you feel confident as to your goal and intention, we recommend our 6-step check list – <u>click here</u>. So before commencing your communication development and efforts have you considered;

Intention and Message What do you hope to achieve with your communication – have you considered a specific goal? And what area would you like to focus on, why, and for whom?In other words what would you like your communication to achieve (Attention, Interest, Desire, Action?) – or perhaps something even more specific? If you're in doubt read more here.

More information about self care <u>This guide</u> can help you if you need to narrow down your objectives as to self care – which area and groups you would like to adress. Your audience at a national/general level – possibilities of cooperation

To improve your scope and communication environment as consider and research the possibilities for communicative and collaborative partners. This means considering collaborations with such different organizations and parties as

- patient groups
- consumer associations
- associations for elderly citizens
- retailers
- unions / trade unions
- other government agencies (perhaps environmental or educational)
- ngos
- social workers
- other citizen groups

For more information about stakeholders This guide can help you if you would like to know more about the challenges of different self care audiences.

Your audience at a specific/group level

Know your target group – who, how many, where are they – and are you communicating directly to them or through (other) professionals?

Consider using focus groups, analysis of the level of health literacy, statistical data on age, gender, occupation etc. <u>This guide</u> can also help you to analyze your specific potential for persuasion in the Persuasion-Action Matrix – and how to take this into account when planning your communication.

How should/would <u>health literacy</u> in the target groups affect language, tools, and situation?

Considering the communication situation – how, when, and where would you like to communicate – and what does this mean in terms of choice of tools?

Are there e.g. sufficient time or setting to read/listen/learn in the situation?

More about Communication Situations? This guide can help you analyze a specific communication situation.

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) - Section 2 - Guidelines for Communication Tools

Audience and target groups

Situation and timing

Consider your budget – how can you do enough – and how can you do more for the same amount?

Different kind of campaigns should be considered if need be; If there isn't time/ressources to build a website could a leaflet do the job? How does new material interact with existing material "in the market" – and can they supplement each other?

Different media (e.g. a book) have different potentials for interaction with your target group(s) – and likewise your choice of channels;

- Hospitals
- Institutions
- GPs
- Homes
- Pharmacies
- Retailers
- Schools
- Day care
- Digital/Social Media

 you can also consider joining forces with some of the <u>different</u> stakeholders within self care to achieve more.

Note: Channels are not necessarily the same as media and vice versa; Through schools one could both consider printing books, leaflets, courses, websites, etc. – the channel can used with many different media. And some media might be used in quite different channels.

More information on tools? <u>Read more about individual tools here</u> – or look at cases in our catalogue of European cases here.

Measuring your success is vital for you to document your progress and merit – ensuring further work to ensure self care.So consider different methods of measuring effect – and if your communication tools can/should be used without measuring effect – why?Considering your evaluation methods also ties into your work

Evaluation and effect

Channels, media

and budget

<u>Read here</u> for more information about evaluation of communication and defining success criteria.

towards defining different levels of success. So what are these?

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) - Section 2 - Guidelines for Communication Tools

More about Evaluation?

There are many different ways to establish a strategy for your communication – but some key elements are;

Basics

Intent, Plan, Interaction with other media/campaigns, Variation

Results

Desired Outcomes – in Behavior, Activation of target groups, Number of articles etc.

Possibilities for cooperation Network

Budget Partners

Take time to ponder each of the above points and pay special attention to the need to plan and maintain variation – communication is never a quick fix, but creates results through care and consideration where you build trust and nurse good examples and ideas into your network and target groups – doing it right will get you early adopters, islands of success and eventually, perhaps, widespread change.

The last remark should remind you that will probably never be alone in communicating with and affecting your target audiences – therefore patience and perseverance should also be on your list of virtues in developing and producing communication.

See either our <u>catalogue on European self care communication cases</u> or our <u>two scenarios on Combined Communication</u> to learn more about ideas for practical use of communication.

Health Literacy Check List

And once you have come this far, please use the check list below to ensure that the basic steps have produced a result that might cause action.

Five basic Health Literacy questions

- 1. Can the target group easily access or obtain the information?
- 2. Can the target group understand the information?
- 3. Can the target group judge if this is relevant to them?
- 4. Does the information enable the target group to make a decision and apply the information?
- 5. Can the target group with this information evaluate if the decision taken resulted in achieving the desired outcome?

Were any of the answers above a No?

If so, then either you should consider repeating the step 1-6 above or read more about <u>working with</u> <u>Health Literacy here</u>. Without clearing the Health Literacy Check List you risk either missing your target group entirely or not achieving the success criteria that you have set.

Perhaps your present work can/could be used at a later stage in your communication – or by partnering with other stakeholders?

Communication strategy

Communication Situations

Build your Communication with respect to relation and situation

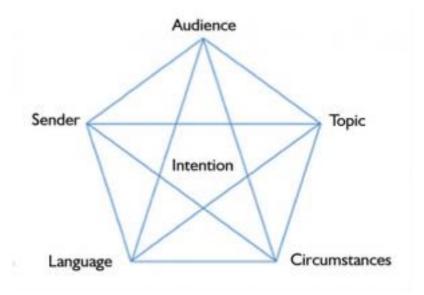
Any communication effort should be considered, analysed and planned. Not necessarily in lengthy reports, but at least by contemplating the factors that surround your specific situation, intent and target group. There are many ways to ensure such proper preparation but many experienced communicators go through steps like these to increase the chance of good results.

- 1 The Communication Pentagram
- 2 <u>The Communication Situation</u>

1. The Communication Pentagram

When engaging in communication you are faced with a range of choices and considerations. Communicating effectively is rarely easy and straightforward, but you can increase your chances of success by considering how to deal with the interaction between the different points of the communication pentagram.

The pentagram is not merely a graphic way of showing you the Sender, Audience, Topic, Circumstances, and Language in regards to a specific Intention – the pentagram also signifies, that the individual elements are related and co-dependent, so change in any dimension should cause you to consider how this effects all the other elements.



Sender	 The sender – you or your organization – are an entity. This entity perhaps has a high level of trustworthiness, but some users and target groups might be sceptic in regards to your role as sender. So consider how you as a sender influence the other points of the pentagram; Are the Audience used to your communication? Are they used to a certain language from you? Is this a Topic that the Audience expects you to communicate about? Considering your strong and weak points as to the other parts of the pentagram will increase the chances of you finding the right Language to fit the Topic as to this Audience in this Circumstance. If you have a strong relation with your Audience you will perhaps need to use less to establish your credibility – if not, perhaps you will need to tell a bit more about who you are and why your message is relevant to them.
Audience	 What is your Audience? What are their challenges and interest – and can you use them to good effect? Are they interested in this Topic? If not – what does that might motivate them towards this? Do they have other priorities? Could these match your message? Are they health literate (think also about Language)? (see below) Are there better/right Circumstances for you to communicate with them? Could you change to do this? Do they have a stronger relation with another Sender? Can you perhaps cooperate? Look here for more information about specific stakeholders within self care.

 What is the appropriate Language as to the Topic and these Circumstances? Would the intended Audience (or others) take offense as to certain types of Language being used? Would the Audience appreciate or feel distanced if you used advanced terminology as to the symptoms or measures? How should/could Language be adapted as to the health literacy, age, gender, or perhaps culture of the Audience? The capacity and openness of the Audience to appreciate and consider your message is critical for the Intention to actually work. See more about health literacy here.
 Are the Circumstances fitting for effective communication or a considered communication tool/media? Would the Audience have time to read a poster/leaflet/sign? Would they be distraught by other activities or worries? Trying to either find the best set of Circumstances to attempt communication or to at least find the right tool/media and Language to fit the best case scenario of Circumstances is one of the best ways to avoid wasting time and efforts towards communicating in impossible Circumstances – see below as to more about <u>The Communication Situation</u>.
 Is this a Topic that the Audience is familiar with? Would the Audience need further explanation? Is this a Topic that they have experienced communication about in these Circumstances before (and how)? What kind of Language would usually be associated with this Topic? And is this a Topic that would normally be associated with you as a Sender – and if not, then who would be? Considering all aspects of the Topic – including also any previous attempts of communication as to the Topic – will help the present development of good communication. Research as to previous communication on the Topic and the results of these

Intention

What are you aiming to achieve? Better Awareness in the Audience? Introduction of new ways to communicate as to this Topic? 10% increase in the use of X?

Being specific and aware about the Intention of your communication is key to combine the considerations of alle of the points of the pentagram in a good manner.

Prepare your communication

Especially if you're new to communication a good exercise might be to write two or three observations as to each or these points to help you develop your communication and communication tools in the right direction and achieving the Intention. Even for trained communicators good preparation and careful considerations of these points makes for better results in the end.

2. The communication situation

Of course you can never fully control all factors in a communication or a specific situation. Indeed there will be many times where control is very limited and the best you can do is just to try to interact with your Audience in a productive manner.

Nevertheless the circumstances of a specific communication situation are very much worth considering.

- Would this specific situation be one to one or one to many or indeed a situation with communication from competing sources?
- How would any communication tool match the context, the surrounding circumstances (competing communication efforts, political or personal circumstances, time to read/absorb etc)?
- What are the language constraints, and similar challenges to enhance the chances of achieving the intended understanding and indeed effect in the audience?

As mentioned you would rarely find yourself in a situation where you could control the communication situation. But by analysing the possible, the likely and the probable elements of each communication situation involves looking at the different set of people, place, message, communication tool, time and surrounding activities that plays a role in the transfer of information, experiences or tries to create persuasion or action through communicative interaction.

Some of these can be called unique (where only a certain, specific tool and approach will work can do the job – and then wouldn't work towards other) – some situations are more generic, especially if the Audience are positive and attentive to

your message to begin with.

All should be considered with care as the different choices and interactions play a crucial part in the chances for a good outcome of the communication efforts.

What should I consider?

So looking at the different possibilities for communicating with the target audience one should try to imagine the actual situation.

- What is the likely state of mind of the target group?
- If communication is in written form will they have time to read? For how long? Perhaps a poster is all they have time for?
- Will this be able to contain enough information? Are there then other choices of time and place with a better allowance with respect?

E.g. handing out information about self-care at restaurants might give the audience enough time – but since they are more likely to be thinking about their guests/food this might not be very effective. Producing communication tools to be used at the pharmacy might in contrast give a better mind-set for the audience – but are you then preaching for the choir? Look also at <u>the Persuasion-Action Matrix</u> to consider this.

At this stage in your planning you might also want to consider how well you've adapted your communication to the level of <u>health literacy</u> in your audience.

Indeed there will quite often be conflicting issues. Perfect communication situations simply do not exist in abundance – and so you shouldn't be discouraged by these challenges, but rather try to adapt.

Communication Goals

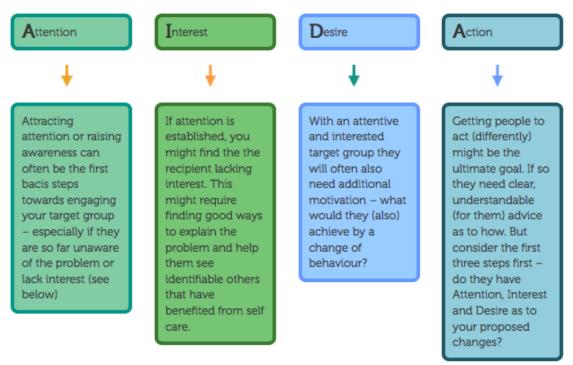
Consider your Intent and potential for Outcome

- 1 Communication Intention AIDA
- 2 Communication Outcomes The Persuasion-Action Matrix

1. Intention – AIDA

The acronym AIDA is a handy tool to remember that communication should always consider how it corresponds with the Audience and the specific Intention of an end result. In this context it can also help you narrow down your specific goal for your communication

The AIDA tool has four steps:



2. The Persuasion-Action Matrix

When choosing a communication tool you should of course also consider the desired outcome – the Intention – both for the benefit of your audience and your own efforts. But be aware also (as mentioned above) that sometimes your Intention might not be possible.

If you are trying to produce a specific action (self-care, reading information on a website or even the signing up for a newsletter) then for your Audience to actually act upon your communication, it is essential that they not only understand and agree with your message, but also that they are indeed able to act.

To exemplify, look at the below table, and imagine that you sent out a letter urging the receiver to adopt a new healthy habit, that will also be more expensive for them. Willingness in this sense basically means that the target group posses the adequate set of values to want to adopt the habit. Ability here means having the financial capacity, but could refer to other basic conditions – social, demographic, geographic or other.

	Unwilling to act	Willing to act
Unable to act	<i>Unwilling and unable</i> Negative response and no action.	<i>Willing but unable</i> Good possibilities of an attentive, positive response, but no change.
Able to act	<i>Able but unwilling</i> Negative response and no action.	Willing and able Good chances of affecting change.

The Persuasion-Action Matrix

• Unwilling and Unable

This group is farthest from change. If you decide to target such a group your efforts should not be directed towards producing action, but towards either Attention or Interest (to increase willingness) or possibly towards information on low level involvement (to point towards future ability).

- Able but Unwilling Communication efforts directly towards action would fail. Instead this group might though be future users if efforts are made towards pointing to common basic values, examples of other users that they can identify with or other ways to increase willingness.
- Willing but Unable Communication efforts aimed directly towards action would fail. You would need to show cheaper ways to get started, examples of local partnerships to support initial "investments" or similar ways to show alternative ways to achieve the desired
- Willing and Able Communication efforts can be performed with good chances of achieving

actual change. Good use of adequate communication tools will have a more than fair chance of producing intended actions

Measuring effect

Successful communication efforts cannot always be measured in increased compliance. Depending on your Intention and the potential Outcome some indirect ways to measure effect might be worth considering – positive changes in responses compared to results from earlier focus group feedback.

If digital, number of views, or number of ordered flyers. Increase in Twitter, Facebook or LinkedIn activity?

Effects can/should be measured in many other ways than simply compliance – or "try outs". Even with a willing and able target group competing communication or "offers" might be about.

Communication efforts/tools should be chosen to match the actual potential of the individual target group – not just by the desired end result; If the tool does not work with the audience, the error is not in the audience.

More about Evaluation?

<u>Read more about evaluation</u> methods and considerations.

A more advanced model?

In this basic AIDA-model the philosophy is that you need first to create attention or raise awareness to be able to produce any effect. If an attentive environment exists you can try to raise interest, then desire and ultimately action.

In reality producing change through communication is quite a bit more complex than this. Therefore a more advanced model such as Schwarzer / McGuires might lead you to a more specific understanding of the situation at hand – <u>click here to read more</u>.

The advanced model is also a good way of remembering that your goal should always be chosen with care, depending on your possibilities and target audience.

But for introductory planning of your communication efforts at least consider these different levels of end results and the ramifications this has for your measure of effect and evaluation methods.

Advanced Introduction to Behaviour Change

A short introduction to more advanced communication theories on behavioural change and health actions

Health Action Process Approach (HAPA)

The health action process approach (HAPA) is a psychological theory of health behaviour change. It has been developed by Ralf Schwarzer, Professor of Psychology at the Free University of Berlin, Germany. It is an open framework of various motivational and volitional constructs that are assumed to explain and predict individual changes in health behaviours such as quitting smoking or drinking, and improving physical activity levels, dental hygiene, seat belt use, breast selfexamination, or dietary behaviours.

HAPA suggests that the adoption, initiation, and maintenance of health behaviours should be conceived of as a structured process including a motivation phase and a volition phase. The former describes the intention formation while the latter refers to planning, and action (initiative, maintenance, recovery). The model emphasizes the particular role of perceived self-efficacy at different stages of health behaviour change.



The health action process approach (HAPA), developed by Ralf Schwarzer, Professor of Psychology e

In the more simple AIDA-model for persuasion-communication mentioned in our Basic Introduction only four goals and outcomes of communication were possible. In reality there are off course quite a few more nuances and a deeper understanding of these different outcomes may sometimes hold the key to developing good, targeted communication tools that address the specific issues that a selected target audience may have.

A more advanced model of a Persuasion-Communication Matrix is that of McGuire (1984, 1985, 2001) that has a bigger and more in-depth model for inputs and outputs applied to persuasion communication.

The inputs are the different aspects of the persuasion-communication attempt:

- 1. message source (e.g., credibility, attraction, trustworthiness of the sender)
- 2. message design (e.g. content, the type, strength, repetition of the argument)
- 3. delivery channel (e.g. type of media, way the message is "broadcast")
- 4. receiver (e.g., attitude, beliefs, prior knowledge etc. of the person receiving the message). For instance health literacy is one of the aspects of Receivers.
- 5. context (e.g. environmental factors, noise, clutter etc. influencing the message)

The outputs are 12 steps that an individual passes through in the persuasioncommunication process:

- 1. Exposure to the message (Exposure)
- 2. Attention to the message (Attention)
- 3. Interest in or personal relevance of the message (Interest/Liking)
- 4. Understanding of the message (Comprehension)
- 5. Personalizing the behaviour to fit one's life (Acquisition)
- 6. Accepting the change (Agreeing)
- 7. Remembering the message and continuing to agree with it (Memorising)
- 8. Being able to think of it (Retrieving)
- 9. Making decisions based on bringing the message to mind (Deciding)
- 10. Behaving as decided (Acting)
- 11. Receiving positive reinforcement for behaviour (Reinforcement)
- 12. Accepting the behaviour into one's life (Consolidation)

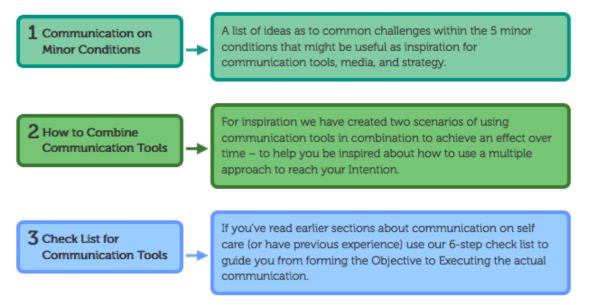
There is some discussion about the linearity of the steps and the cognitive/rational/conscious nature of the steps. However, these steps once again show that there are different outputs of a communication, varying from awareness, knowledge, attitude change, decisions to behavioural change – they are therefore suited for a diverse array of target audiences, cultural settings, and medical conditions and behaviours.

Communication Planning and Development

Three ways to guide you towards communication about minor conditions and ailments

Here are three approaches to help you produce and develop good communication tools on self-care as to the 5 selected minor conditions; Athlete's foot, Cold, Cough, Heartburn (without indigestion), and Lower urinary tract infection.

These guides are meant for those with short or intermediate experience in communication development and production. However if the concepts and advice presented here makes little sense, we recommend you read more in the earlier section on <u>communication basics</u> – if they make too much sense and are too basic, see the sections on <u>health literacy</u>, <u>evaluation</u> or <u>communication cases</u> for your next step instead.



Background for the guides

The Platform of Experts on Self-care was formed to strengthen the efforts towards increasing appropriate use of self-care for minor health conditions in the EU. The Platform of Experts was asked to focus attention on the five minor conditions mentioned above.

Transferability

Much of the information and advice contained in these guidelines is however easily transferable to other minor health conditions, including mental health conditions.

The five chosen minor conditions will be very familiar to many citizens, but they are not always treated or responded to in the best way – people often ignore symptoms (allowing them to progress), use treatments that do not work, or over-treat, for example by using antibiotics to treat a simple cough or by repeated visits to the GP instead of proper self-care.

This section therefore offers advice on communication tools and strategies that might be used to work towards increasing self-care for these five minor conditions in the target groups in which they often occur.

Communication for five minor conditions

Advice on communication about the five minor conditions

- 1. Athlete's foot
- 2. <u>Cold</u>
- 3. <u>Cough</u>
- 4. <u>Heartburn (without indigestion)</u>
- 5. Lower urinary tract infection

This section is about Communication

How to actually perform care is very important and should of course be at the center of all your communication. In this section, however, we focus on some of the communicative potentials and challenges of the 5 minor conditions – read more about the actual acts of self-care <u>here</u>.

1 Athlete's Foot

Primary causes

Athlete's foot is a common fungal infection of the foot. An itchy red rash develops in the spaces between the toes. The affected skin may also be scaly, flaky and dry.

Reflection

As the best way to prevent Athlete's foot is to practice good foot hygiene, the focus in prevention should be to promote good basic hygiene and care. Repeated treatments (e.g. by antifungal creams) are not recommended, but information and knowledge dissemination about good care practices can help people to alleviate symptoms.

Suggested tools, media, or target groups

As it important to keep your feet clean and dry in preventing and caring for Athlete's foot, using targeted communication tools to inform shoe stores and sporting goods retailers on how to inform customers about wearing good socks with natural fibers and regularly changing them might be considered.

Communication tools might include posters and leaflets. These could be distributed through shoe stores, so that citizens are informed in a situation (buying shoes) where they may be more receptive than usual to messages about proper foot care.

Sports facilities, changing rooms and showers are other potential venues, because again they are situations where users are more acutely aware of their health and possible foot-related ailments.

2 Cold

Primary causes

Colds are usually caused by a mild viral infection of the upper respiratory tract which primarily affects the nose. Symptoms include coughing, sore throat, runny nose, sneezing and fever, and usually resolve in seven to ten days, with some symptoms lasting up to three weeks. Well over 200 virus strains are implicated in the cause of the common cold; the rhinoviruses are the most common. The immunity status after specific viral infection, for example rhinoviruses, does not protect the individual against other viral respiratory infections and another cold.

Reflection

A common cold should not be cause for alarm, however inconvenient it may be. So far there is no clear evidence for medication or herbal remedies shortening the duration of the disease. Good self-care involves proper hydration and having plenty of rest – possibly the use of painkillers to alleviate symptoms – but not antibiotics! There are very good and effective ways of preventing the infection, the foremost being hand washing.

Suggested tools, media, or target groups

Good hand hygiene practices – both at the right times and in the right way – can hinder most cases of cold from occurring in the home. Adults practicing this – and especially showing and teaching children in the home – is a good prevention method.

In some countries national campaigns, involving instruction events in schools, day care centers, work places, hospitals etc., have been quite popular. Stickers on bathroom mirrors – especially in combination with signs, instructions and other information – have proven effective in some target groups.

3 Cough

Primary causes

A simple cough may be the cause of quite banal irritation of the throat (from exposure to dust, smoke, or even by straining the vocal cords) or the precursor to more serious illness.

Reflection

Good self-care would entail a consideration as to severity and time span of the cough. As most cases are quite banal, one should consider whether the cough is severe (either associated with pain or even the taste or specks of blood) or extended (continuing for more a few days).

Suggested tools, media, or target groups

Relevant places for communication would be where citizens buy cough relief products or at GP surgeries. This might be best achieved by putting up small signs and placing concise handout leaflets next to relevant products in retail outlets, or in the GP's waiting room.

Information about quitting smoking might also be a way to inform about good selfcare on cough (beside other health benefits).

4 Heartburn (without indigestion)

Primary causes

Heartburn is usually associated with regurgitation of gastric acid (gastric reflux), which is the major symptom of gastroesophageal reflux disease (GERD). It may also be a symptom of ischemic heart disease, though this is true for only 0.6% of those experiencing heartburn.

Reflection

Immediate help should be sought if one experiences severe chest pain or pressure, especially when combined with other signs and symptoms such as pain in the arm or jaw or difficulty breathing. Chest pain may be a symptom of a heart attack. So, people should contact their GP if symptoms are persistent or happen often. Occasional heartburn is not a matter for concern and treatment of its symptoms will lead to better well-being.

Focus of information could be to enable citizens to both better distinguish between serious and benign cases of heartburn, and making common self-care practices better known.

Suggested tools, media, or target groups

As diet is a contributing factor in some cases, retailers might be used to inform their customers about dietary considerations for heartburn. It would probably be harder to get restaurants involved, but national TV/media could have a role in promoting "heartburn-friendly" diets. Information about quitting smoking might also be a way to inform about good self-care on heartburn (beside other health benefits).

5 Lower urinary tract infection

Primary causes

A urinary tract infection (UTI) is also known as acute cystitis or bladder infection. In uncomplicated cases, UTIs are easily treated with a short course of antibiotics, although resistance to many of the antibiotics used to treat this condition is increasing. In complicated cases, a longer course or intravenous antibiotics may be needed, and if symptoms have not improved in two or three days, further diagnostic testing is needed.

However, good prevention (drinking proper amounts of water, wiping with care front to back and avoiding the use of strong hygienical products in the genital area) would be much better than any treatment.

In women, UTIs are the most common form of bacterial infection with one in ten infected yearly. In those who have bacteria or white blood cells in their urine but have no symptoms, antibiotics are generally not needed, although pregnant woman are an exception to this recommendation.

Reflection

Personal hygiene is essential in preventing UTI frequency for the average citizen. The use of urinary catheters for other conditions poses a challenge; they should be used as little and for as short of time as possible to prevent infections.

Suggested tools, media, or target groups

Most cases of UTI affect women so to some extent a prudent way of communicating about better self-care would be to use either media (by use of PR) or associations with a high proportion of woman (perhaps by use of printed material or joint ventures as to courses and training on women's health).

Men should not be disregarded as a target group, especially as many men who are at risk of UTIs are unaware of this. Targeted information towards male dominated trades or associations might be considered, e.g. by use of printed material or information/training events on health.

Combining Communication Tools – examples

Inspiration by example

Using any one communication tool in a strategic and well planned manner can create a desired change or effect in your target audience. However, using a combination of tools often should be considered also as any single tool might not produce the desired result by itself. In this section we describe how individual tools might work together in two different scenarios and at various stages of the communication process, also corresponding to the continuously evolving relation with the target audience.

Why use multiple tools?

Even without considering the challenge of different levels of <u>health literacy</u> the basic concept of self-care might be thought of and perceived quite differently by the target audience. Therefore a strategic approach and combination of different communication tools might be worth considering to achieve the necessary trust by the target audience to also affect actual behaviour and then finally the intended result.

This is not necessarily the same as just using multiple media at the same time. This is rather a strategic approach to use various strengths of various media in supporting a growing culture of self-care. Getting people to start engaging in self-care should only be seen as a starting point for an ongoing effort – just as promotion of good traffic safety never really ends.

Two scenarios

As mentioned, this section describes two realistic combinations of communication tools. The idea is to visualize the qualities and potentials of combining individual communication tools and thus inspire you to consider using multiple ways of communicating to reach your objectives. The end goal will still be to achieve either the specific desired act of self-care – or help further the full transition of the non-self caring towards at least appreciation of self-care or indeed actual self caring.

In this section is therefore described scenarios of communication towards promoting self-care

1. A "post-hospitalization"-scenario; initially of course individual-focused, from the day the patient leaves the hospital to the adaption of self-care.

2. A "group of former patients"-scenario; a scenario that initially at least has to engage larger groups of citizens to create either attention, interest, desire and finally to adopt self-care.

We can also recommend you to look at our <u>catalogue of cases from across Europe</u> where a varied combination of communication tools and channels have been used to promote self-care.

1 "Post-hospitalization"-scenario

Discharged patients are often especially vulnerable to or worried about some of the five minor conditions considered in these guidelines. A range of communication tools can be used to promote good self-care in short and longer term.

- 1. Posters in waiting room areas at hospital
- 2. Postcare handouts/Leaflets
- 3. Invitation to webbased newsletters/webgroups
- 4. Follow-up newsletters
- 5. General, continuous information about self caring tips and practices in national, regional and local newspapers highlighting the individual minor conditions and the idea of self-care in general.
- Invitation by newsletters, posters and websites to engage in questionnaires, minor competitions, surveys etc. – both to gather knowledge and remind the former patient
- 7. Posters and leaflets in waiting rooms at the GP
- 8. Potential invitation (with opt-out) to focus groups to improve communication (strenghtening the individuals potential adherence to self declared values and beliefs) and later to communicate these results to improve communication to others users, and improve identification for new "former patients" to the concept of self-care.
- 9. Direct mail letters with information towards pharmacists to improve their awareness/knowledge about self-care to enable them to engage customers (former patient) about the benefits of self-care
- 10. Posters at pharmacies a low-level invitation to discuss self-care
- 11. PR-efforts to promote the benefits of self-care and the challenges to adopt new habits in public media (magazines/radio/tv)

2 "Group of former patients"-scenario

Former patients with the same diagnosis often share the same health issues and concerns. Therefore they tend to also be interested in information regarding their former diagnosis and information related to this – and they will often also have relatives with a positive attitude towards ensuring good self-care and thus supporting the communication effort.

- 1. Efforts to promote the benefits of self-care and the challenges to adopt new habit in public media (magazines/radio/tv)
- 2. General, continuous information about self caring tips and practices in national, regional and local newspapers highlighting the individual minor conditions and the idea of self-care in general.

- Public invitations (e.g. by newsletters, posters and websites) to engage in questionnaires, minor competitions, surveys etc. – both to gather knowledge and remind the former patient
- 4. Posters and leaflets in waiting rooms at the GP
- 5. Postcards with invitations to webbased newsletters/webgroups
- 6. Postcards with invitations to peer-to-peer driven support groups
- 7. Follow-up newsletters (with opt-out)
- 8. Mail invitations (with opt-out) to participate in surveys, competitions
- 9. Direct mail letters with information towards pharmacists to improve their awareness/knowledge about self-care to enable them to engage customers (former patients) about the benefits of self-care
- 10. Posters at pharmacies a low-level invitation to discuss self-care
- 11. PR-efforts to promote the benefits of self-care and the challenges to adopt new habits in public media (magazines/radio/tv)

As is quite obvious the two scenarios use some of the same tools to achieve some of the same effects. This is quite natural, as the end result (increase in self-care) and the target group (former patients) are similar.

Examples across Europe

In the <u>catalogue here</u> the guidelines mention specific communication tools and tools used in combination – building large, multi-tool/multic-channel communication are not necessary for communication to be successful, but are merely mentioned to inspire you to consider different options.

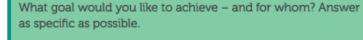
Step by Step Check List

To ensure all the previous planning steps have been used and considered, the guidelines contain a checklist - to ensure Objective, Audience, Budget, Selection of Tools, Testing are done before Execution and Evaluation.

Step by Step Check List

6 steps in Communication Planning and Development

This step-by-step list should help you towards execution, but first of all serve as a check list. If you are in doubt at any point, recheck earlier sections of the guidelines – if you're past the need for checking, look for more advice on health literacy, evaluation considerations, or visit the tool and case-catalogue for more information.



Remember: Establishing your desired objectives is vital for your work towards building successful communication tools and campaigns, and also vital to determine the realistic/satisfactory outcome of your efforts.

If you're in doubt, click for more information on choosing specific goals.

2 Know your audience and their situation!

1 Know your objective!

Do you know the characteristics of your audience? Remember considering factors as current habits, abilities, level of health literacy, demographics, and even geography. This will help you target your communication and message.

If you're in doubt click for help on analysing your target audience and your communication situation.

3 Know your budget and options!	 what resources you have available and how best to use them. Consider seeking extra resources and reaching out to partners in your country. <i>This could involve</i> Change champions Networks and partners Key opinion leaders If you need help, click to find more information about different stakeholders within self care and consider how this might be used to gather resources for joint benefit.
4 Know the appropriate communication tool(s)!	From steps 1-3 you should already know enough about your objective, your audience and your resources to be able to choose a communication tool – or perhaps a combination of tools. Remember also to consider your selected tools in relation to your channels of distribution – e.g. through GPs, pharmacies and other agencies? Have you engaged with any of these agencies to ensure this? (see step 3 above). FYI the guidelines also has a section with specific European cases for inspiration.
5 Test your tool(s)!	Remember to engage members of your target audience in your development – either by focus groups, advice from patient, consumer, or citizen organizations or by known key members. Getting early report on your deliberations will help overcome many challenges. You should especially remember to make sure that your communication (tools) matches the level of health literacy of your target group – if you're in doubt, click to read more on this.

Attempting to do a lot with too little resources is hard – very hard. To help you reach your goal, remember to think about

6 Remember to Execute AND Evaluate

Putting your plans into action is of course key. But remember to measure and evaluate your results – whether they are as expected, better, or worse your evaluation will be essential for you to improve and perhaps expand your next communication efforts.

Remember to consider the appropriate time of evaluating/measuring effect. Measuring outcomes or reactions too early will sometimes not give correct answers.

Any intervention – with or without involving communication tools – should last long enough to make changes. But there are cases in which the intervention was successful and also the tools, but the assessment of them were conducted too early to initially show this.

If you're not sure, click to learn more about communication evaluation and help you establish useful success criteria.

Evaluating Communication

Key elements in Communication Evaluation and Success Criteria

Setting up Success Criteria and subsequently evaluating your communication can help answer several questions:

- 1. Is the communication feasible and usable?
- 2. Is the communication process in itself successful, like the dissemination and population reached?
- 3. <u>Is the communication effective?</u>

Each question can be answered in various ways, but important is that expectations as to each question are addressed before the communication starts. For each question we describe key elements and provide examples.

1 Is the communication feasible and usable?

When developing a communication it is important to check with your target group if the communication is feasible and usable.

Involving the target group

Minimally this involves that your communication is piloted with some members of the target group.

Maximally, the communication may be developed iteratively in co-creation with the target group.

Irrespective whether the communication channel is digital, written, video, oral or personal it should be tested whether:

- it is understandable
- the intended message comes across
- it is liked
- people know what to do
- it is culturally sensitive (i.e., people are not insulted because of violating cultural norms), and more questions promoting the use of the communication.

It is important that the communication will indeed used by the target group. For instance, using "thinking aloud" procedures when navigating a website or reading a brochure. The instruction is to verbalize all your thoughts while using the communication.

Another method is to interview members individually or in a group (e.g., focus groups) regarding their experiences with using the communication. One could also use eye trackers to see which part of a screen or text people focus at, with a website use the log data to examine how people navigate, or use quantitative questionnaires to assess the opinion of the target group regarding the communication. Be aware to involve members of the target group that vary on important dimensions that may affect their usability judgments, like health literacy, digital experience, age, or culture.

Look at the communication environment

A good starting point for your evaluation and success criteria is to look at what information already exists and to see how other communicator do and use as goals in their communication evaluation. You can also look into published papers on communication efforts to get an idea about benchmarks and possible goals.

For example, if you are about to embark on a campaign to increase people's perceptions of the value for money (or value of efforts) of doing self-care activities, you could consider what other existing communication efforts in other areas are using as rating good value for money/efforts.

Online information about users and national information usage like offered from Google Insights is particularly useful source for understanding the prominence of certain news topics over time in your particular country or region.

2 Is the communication process successful?

A process evaluation usually focuses at two points: (a) the amount of the communication that goes to the intended target group and (b) if the communication is delivered as intended (fidelity). A process evaluation will tell you if your communication was successfully delivered. Next step is if your communication was effective (question 3). However, if a communication is not effective, it could be because it did not reach the intended target group. So if no one read your brochures on how to treat athlete's foot, then no effect is to be expected from your communication.

Some key process evaluation components are (Linnan & Steckler, 2002):

- Reach: the proportion of the intended target group to whom the program is actually delivered
- Dose delivered: the amounts of intended units of each communication component that is delivered
- Dose received: the extent to which the target group engage with the communication
- Fidelity: the extent to which the communication was delivered as intended

Some examples:

- Reach: counting the number of brochures distributed, counting the number of visits to a website, asking in a questionnaire if one received the communication
- Dose delivered: did the target group read the brochure and watched the video online that was promoted in the brochure
- Dose received: log data whether all pages of a website were visited, time spent, asking whether one read all parts of the brochure, how much one thought about the communication
- Fidelity: a pharmacist did not distribute the whole communication, but only the simplified leaflet and not also the extensive brochure

3 Is the communication effective?

Your communication is effective if you reached your goals in your target group with your communication. This implies that you should be able to assess change in your target group on instruments/indicators that measure your goals.

Change

One way to assess change is to have a pre-posttest design. This implies that you need to know how your target group scores on instruments/indicators before the communication started. You have to repeat this measurement at least once after a specified time slot with the same instruments/indicators. Arguments regarding the time slot are when you expect change in the instruments/indicators. For instance, changes in knowledge are usually quite fast, changes in behavior or health take more time.

Example: Online information about users and national information usage like offered from Google Insights is particularly useful source for understanding the prominence of certain news topics over time in your particular country or region. Another way to assess change is to use a control group that not receives the communication. The control group should be very comparable to the communication group, so that differences between the two groups can be attributed to the communication and not to other differences between the groups. The distribution of the target group to the control or communication group should ideally be random and blinded, but in practice that is often not feasible. Also, the combination of pre-post with an intervention-control design is most ideal, but most labor-intensive.

Usually you will not be able to collect data from all the persons in your target group. Therefore, you have to determine how you can approach a representative sample of your target group. The main point is to avoid selection bias. For instance, only inviting target group members that visited the website, while also non-visiting persons were exposed to the communication.

Instruments/indicators

Your instruments/indicators should measure your specific goals within your target group. Those goals could be determinants of behavior (e.g., awareness, comprehension, attitudes, self-efficacy, social norms), behavior itself (self-care or health care use) and the resulting health. It could also include measures at a more societal/political level like costs or savings.

Types of outcomes

Just as your communication should be targeted to specific goals within your target group, your evaluation outcomes should correspond with these to look at shifts in awareness, comprehension, attitudes, as well as behaviors.

If we can say that behavior would be more people using your online self-care guide, then discussions on social media might give you an idea about changes in attitudes, increase in time used reading / listening / viewing relevant information at your site might give you an idea about change in comprehension, and more users at the site in general might be a measurement of increased awareness.

But not all communication efforts can be measured online. Some might be measured by monitoring increase in calls to your self-care helpdesk, number of leaflets removed from stands, number of questions about specific topics at the GPs (so measure by asking at least some of these as well), others by the increase in requests / questions asked at local pharmacies or other health care professionals. Therefore a wider view as to effect and evaluation should be taken and would benefit you in your work to show the different outcomes of your efforts.

Instruments at individual level

When possible, in-depth qualitative or quantitative data for evaluation will also be very helpful. This includes observation sessions to see actual use of tools, to observe interaction and uptake, it could include interview sessions or focus groups also. In addition questionnaires to individual users, or by combining logging data (geographically – or if user data isn't sensitive in terms of patient information) with targeted forms on site.

Communication Indicators

Key elements in Communication Evaluation and Success Criteria

Indicators for better self-care and indicators for good communication are not the same. Of course your communication should help promote self-care, but this may be a very lengthy process – eg. changes in dental hygiene took a generation or so – and therefore measuring communication should look for other indicators to help ascertain whether you are successful in your endevaours.

- 1 Leading Indicators for Evaluation of Communication
- 2 Lagging Indicators for Evaluation of Communication

1 Leading Indicators

Leading indicators show initial effect(s), user behaviour in response to your communication – these are significant to show that/how the communications tools are performing. They are also indicators that lead to your actual goal.

So for the communication tools, significant areas where you should / could consider setting up key evaluation points and success criteria are eg. Media Coverage and User behavior.

Media Coverage

In large scale communication and campaigns measuring media coverage may be relevant to evaluate your communication. One consideration at this stage is setting up a system of not only counting in quantity, but also in terms of quality. This may require you to establish when a coverage is "positive", "useful" or perhaps "critical" or "negative".

And likewise also to try to prioritize the different media – are any more important to you (or your target group) than others? The answer to this question might also be useful for you in considering your current and future communication efforts.

User Behaviour

Of course you would like very much to see direct change in behaviour towards better self-care. However this may not always be possible in a short term – but there are other changes in user behaviour / attitudes that might help you measure an effect.

Website usage

Increase in number of users, change in user behaviour, ordering/use of specific items on your website can play a part in evaluating your communication. More specifically there is an entire field of web analytics, that can track specific user behaviour before, during, and after other communication efforts to measure changes.

This should often be used in combination with other data as this only tracks the users actions – not their perceptions, knowledge, or attitudes.

Newsletters

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) - Section 2 - Guidelines for Communication Tools If you use mail based newsletters towards larger groups of users tracking clickthroughs, opt-out (and opt-in) numbers, and potentially time on site after release of your newsletter might be a very direct way of measuring your communication. But also try to evaluate and track which parts of your newsletter the recipients responded to; The three-step guide, the article with the new pictures, or perhaps the video from an event? Knowing more about the type of content that appeals to your users can help to optimize your communication efforts.

Social Media

Measuring the activity on Social Media (via a specific hashtag or a specific page) can be worthwhile – or indeed be set up as a concrete way to enable you to measure the effect of other communication efforts. If you encourage your users to ask questions via eg. Facebook or Twitter – how many react? What do they ask about? In what tone?

Leading to change

Remember to set up indicators leading to change. Would you like to reduce infections? A leading indicator could/would be better use of preventive measures – use of hygiene, interest in hygiene courses, distribution of soap/hand disinfectants, interest in hygiene campaigns.

Would you like to reduce the unnecessary use of antibiotics to treat cough? Can you target and measure a number of GPs communicated to about this? A number of community HCP to address the issue in meetings?

2 Lagging Indicators

Lagging Indicators are closer to your end goal – the actual change in self-care.

Significant areas where you should / could consider setting up key evaluation points and success criteria:

- Use of specific advice
- Interest
- Observing/Monitoring

Use

Depending on your specific target audience and self-care initiative, you would have specific wishes for the behaviour of the users. What are these? Your lagging indicators should of course support your end goal, but should be set up to help you point your attention and efforts to the factors that might support steps towards this goal.

Interest

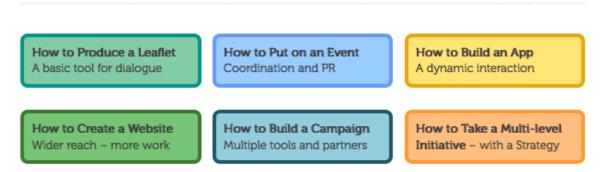
Improving interest and activity in selected groups are key to the chances of actually producing change. Where/how might you measure such extra interest? At GPs, pharmacies, self-care courses for citizens, increase in courses for day care centers or schools – or?

Social Media

As mentioned above, social media can be one way of measuring this. As a lagging indicator, this will of course require a more in-depth analysis of the type of conversation on social media. However user behaviour in as to search terms, types of questions raised in blogs, issued discussed (perhaps combined/compared to numbers discussing other, similar issues) are potential lagging indicators as well – or might give good insights on how/where to setup these indicators.

Communication and Activate Self Care

Communicate and Activate – Self Care



Share your experience and good practices!

We would like to add to our list of good practices about self-care communication tools, so do please write to us with information about your own – about the target group, the situation, and (as much as possible) the impact it had, as well as attaching or providing a link to your tool.

Contact kfs@sundkom.dk.

For each of these six types of communication activities the WP2 has created a short how to description to allow users to get inspiration at the level of experience that they are comfortable with and have the budget/opportunity/network to develop.

The first, Leaflets, is shown here in the same format as on the website.

Leaflets

Leaflets

This guide will advise to about central steps to enable you to create a useful leaflet about self-care. A leaflet itself is just a tool though – the effect depends on your effort to create new understanding and perhaps change.

1. Choice of topic/target

If possible in your budget, creating separate leaflets with targeted information and concrete advice are advised – if you create information with very general information is will often only be useful in a general sense. See list of guidelines on the five minor ailments to see more about self-care acts here – or see more information about establishing purpose and goals here.

2. Intent/Content

What would you like to achieve? How much would you like to say? Instead of writing an entire text to begin with, using bullets and quick notes can help you estimate how much to include in you leaflet and what to consider for another format or another time.

3. Illustrations

Using only text might be a poor choice even with a target audience with a joy for words – or good health literacy. For most audiences good readability also depends on the way text and illustrations combine modes of dissemmination. Read more about health literacy here.

4. Budget

Good communication tools are best created by good graphic designers. Alternatives can be generic templates at online services or even using templates in basic office software. Regardless of choice you should think about how many to produce and in which quality of paper/coating. Higher numbers is always cheaper pr. print – but prices vary considerably depending on these choices – and whether you choose a local print agency, online printing service or something else. Different layouts can also affect the price of production.

Remember to consider your needs in a short and long term view – e.g, can you store 2.000 leaflets? Can you use 500 copies before information needs updating?

5. Use/Distribution

A tool laying oon a shelf does little good. How can/will you ensure that your target audience gets to see your leaflet? Personal hand outs, distribution at public libraries, or perhaps sent by mail? Different ways of distribution have different costs and effect; a personal hand out also provide an opportunity for dialogue – but of course is more time consuming. Still – consider your options and advantages – perhaps you know partners/organisations to assist?

6. Effect/Evaluation

Was/Is your time and money well spent? Consider what would be goal – or at least your measure of success? Are there metrics to help you document these results? Evaluating your effort(s) and the results obtained should be as vital a point as all your other work – you will need this evaluation in your later work; "What we did had these effects". Read more about evaluation here.

Inspiration?

Would you like to read more about possible uses, other tools or combinations? See our catalogue of tools <u>here</u>.

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) - Section 2 - Guidelines for Communication Tools

Websites

This guide will advise to about central steps to enable you to create a website to allow you to inform a larger audience regionally, nationally, or internationally about self-care – in general or specific to e.g. an ailment or a narrow target audience.

A website is not a solution, but a tool – and a tool that will probably still need an active effort for people actually use it. A website can often require more continuous work than a folder – but in of course also instantly adaptable.

If you consider a longer term effort to promote self-care, creating a website should be considered a must to enable users to learn more and find contact information.

1. Content/Structure/Functionality

A website can essentially hold all the information you like. However less can often be more – or at least you should carefully consider the structure and navigation of your site. To begin with describing your information in bullets or by using post-it notes as way to visualize your information and ways to structure it could be a good idea, before writing or designing anything. Research also other, similar sites; How is the information presented? How much? Which functionalities do they offer? Which functionalities are absent? What would be a useful domain-name (is it available)?

Good research and preparation can help you clarify your path towards a useful website – but remember also to think hard about what it is you are hoping the site will help you do, for whom, to what extent.

Look at the guidelines on the five minor ailments to see more about self-care acts and consider how a website can support you to promote these here – and read more information about establishing purpose and goals here.

2. Usability

Regardless of your intended target audience you should consider both the relation between your site and their digital literacy – and the information you provide and their health literacy. Both relations should be optimized to increase the usability of the site for your users. Read more about health literacy here.

3. Design/Budget

How much can you spend on creating a website? Unless you are already an experienced webdesigner remember that this is also an art form; to create good sites. And these services/qualities aren't free. However if you do have a limited (or non-existent) budget, using some savvy to navigate existing, adaptable templates provided by a webhotel or other online service can help you create very useful websites. The budget for website design can vary extremely depending on your choices of functionalities and level of ambition – so despite the advice above, don't give up if any initial offers are more than you have – but be realistic and try to find the right solution for you.

At this point you should also consider design/budget in a longer term. How/When will you update your information? If the website are to contain "news" who will create these? Consider your future workflow to ensure your design works outside the short term.

4. Distribution/Presence

Once your site is online – ready for service, then what? How will you make sure anyone – in or outside your target audience – knows of its existence? Will you be handing out folders? Make sure there are links to your site from other relevant sites/communication tools? Inform key professionals via meetings/conferences or? The website can help you reach many, but make sure it is also known by many or it can turn out to be used by few. Therefore creating a website is often more an enabler for you to do more than an excuse for you to relax. But remember you can probably engage others in this work – ngo's, patient organizations, municipalities – these may be your target audience, but they could also be your partners in promoting your site.

In our catalogue of tools here you can find other self-care sites – perhaps the people behind some of these can share their experiences with you?

5. Effect/Evaluation

Based on your ambition(s) how might you measure the effectiveness of your website? Including how to improve even smaller issues and functionalities. Most webhotels offer statistics that will allow you to see numbers of users over time, to which pages, and where they found your site (e.g. by web search or other, known sites). This is one measure of success of course – to have many users. But are they using your information as you intended? What might they be looking for – and do you help them find this?

Number of users, newsletter sign-ups, number of appointments/forms filled out – all these can be measures in numbers and should provide you with multiple ways to assess and improve your site. Remember also to engage your users to learn how they experience your site – and thus how you can further help them self-care.

Learning more about your site's performance and usefulness can also help you better understand and improve self-care in other communication settings. Read more about evaluation here.

Inspiration

There are many websites on self-care to study – perhaps a rather confusing way to research would be to search self-care in any search engine, but it will give you an idea of the many possibilities.

If you are working at a national level the Swedish 1177 can be one example to study, as this combines online information in several languages, call service, etc.

Events

This guide will advise to about basic considerations in creating a larger event – eg. a conference or perhaps another type of physical meeting – to promote self-care locally or nationally.

Such an event can of course bring you closer to your target audience, but can often also be used to allow other media to help you tell the central messages that you would like to promote. An event requires planning – not years, but certainly often months, if it is to succeed. So patience and cooperation are to key words in creating events.

1. What and when?

Perhaps you've attended other events about self-care before. Did you like them? Were they useful to you or your target audience? Why/Why not? Considering useful formats and experiences can help you plan and execute your own. In our catalogue of tools here you can find examples of other self-care events.

You should answer (at least) the following;

- WHO Who would I like to address? And who would I like to come? Do they attend/follow similar? Which of these are popular – and do you know why?
- WHAT Your key messages? Your "gift" to the participants? Aside from "a cup of coffee" what will attending help them do/think? What is your – specific – idea of an activity or line of speakers? Do these require a longer planning period? Or have challenging calendar?
- WHEN Day time, afternoon, morning – local or central? What hours and geography might benefit the event?

Creating just a single page of notes AND a preliminary dummy of your programme/invitation can help you greatly in getting others to understand your intent and gather early support.

Look at the guidelines on the five minor ailments to see more about self-care acts and consider if you would like to promote self-care in general (in a political, practical, or perhaps philosophical way – or other). Or which ailment you would like to focus on.

Read more about the five minor ailments of the PiSCE-project here – and read more information about establishing purpose and goals here.

2. Budget/Partnerships

Getting people to attend is one thing – having a place for them to come is even more important. So consider your budget for people/activity, venue, communication tools, and perhaps catering – do you have any? Should/could you have the event be financed by participant fees? Or via partnerships/sponsors? Or look for support from foundations?

The two latter both require additional planning – the first can be a challenge depending on your target audience. But perhaps a partner organization has a venue you can use for free? Preferably with useful transportation options. Perhaps you can consider community centres, public libraries, or scientific institutions? These might be interested in collaboration about the programme and funding catering also?

A good budget gives you many more options to easily design your event – but if you look at your event as a jigsaw puzzle, perhaps quite different pieces can be put together to create a wonderful picture?

But to try to create an overview, think;

- How many am I hoping to get to attend? And where can they go? Be specific and try to research venues in different categories to support this.
- How long should/can it last and how are participants going to get there? Be realistic – travel times has to be added to the time of the event itself, so having people travel four hours for 30 minutes of event (and four hours back) might not be feasible.
- What does the event require in terms of catering, speaker fees, travel subsidies etc.? Spending money may be nice if you have them – but spending them wisely is important.

A preliminary budget will help you assess your options – and need for partnerships/funding. Don't be discouraged if the numbers don't add up – be creative and see how alternatives might reduce expenses or increase budget, – e.g. by spreading risk/burdens.

3. Talk to partners/networks

Are they planning similar – do their plans conflict with yours? Are there other big events that conflict with yours? Can their websites, newsletters, or social media might be used to promote your event? Would they perhaps like to be a part of your programme/attend? Would you like them to?

Even with the best of intentions and good planning, getting people to participate in your event will only happen if they know it exist! So establishing how to get the date and messages communicated to your network (the earlier the better) is vital for your success.

4. Should you adjust programme/date/timing?

Depending on your research in your network/potential partners you should consider how this might be used to optimize your programme/activity.

And certainly at this point (if not before) you should also consider how your information about the event corresponds with the health literacy of the intended participants. Read more about health literacy here.

5. Spread the word

Have you created a wonderful event? Good – now comes the hard part; getting people to attend. Your event is (however nice it may be) competing with other events, work, family, other interests, budget, stress, and a lot of other factors – if you've created a website remember to post it there.

How are people to sign up? By mail, website, phone call – make it easy on them and you to register participants if you are aiming for a conference or seminar. If you are creating a more public event, trying to ascertain either a large or small turnout is more than helpful for your communication and effect. But reminding people of the reminder to the good, relevant invitation sent well in advance is often necessary.

6. Execute – or not?

Be prepared to take hard decisions – respect your speakers and participants; if attendance is low you should act, possibly postpone. This need not mean you cannot try again – but perhaps you should reconsider partners/channels, or timing.

If all is well, good luck on a successful execution – remember to take pictures and save presentations (ask permission) for later distribution.

7. Then what? – Effect/Evaluation

Following your event, evaluation both the event itself and the effects it may have had should both be undertaken.

Hopefully this is not the last time you are to plan such an event – but what did you learn? Earlier planning, different partner, larger budget, fewer participants, longer/shorter programme – try to think each point through to increase your chances of continued success.

Read more about evaluation here.

Campaigns

This guide will advise to about how to try to put together a campaign on self-care; A communication activity involving multiple communication tools and channels in a strategic, planned manner. If you haven't tried this before we recommend you also look at the advice on creating an event, a website, and a folder to see examples of how individual tools might be created.

And we also recommend you look at our catalogue of tools here to find inspiration from other campaign in this area.

A good campaign requires good planning – and can take both days, months or years to execute, depending on your ambition.

1. Why, who and when?

Above all else establishing your purpose and goals in putting together the pieces of a communication campaign is a must. Each tools and element can help achieve different things that might not work if the right combination of other tools and elements are employed. So first of all, try do describe in one sentence, why you should create the campaign. And try, for your own sake, to be as specific as possible; "Because I want to change the world" may be a good motivation, but too overall. "Because I want to help my husband to change his socks more often" might be too narrow.

But nonetheless, articulate your purpose – discuss it in your network, perhaps. Who would then be the persons to communicate to? The better you can describe the target groups the better. Read more about target groups and adapting your communication here.

When would to like to execute this? Next week, next month, next year? All answers are correct, you might say – except perhaps if some specific deadline should be observed. Otherwise you can bear in mind that your audience knows very little about your intentions – if you choose to execute in two months rather than two days, they won't be offended. On the other hand, if you try to communicate ill prepared they might actually hold it against you and your message – so try to set a realistic time line.

Read more about the five minor ailments of the PiSCE-project here – and read more information about establishing purpose and goals here.

2. Assets – economical, political, human, or...

Naturally not much can happen without effort. But great communication campaign need not use large budgets. Of course a budget gives you more options and, if used correctly, a higher likelihood of success. But more than money the right idea and execution is what a creative campaign is about.

Look at our catalogue of cases from the EU here. These cases have very varied compositions and budgets – some have been extremely successful – some perhaps more modest. But consider your different assets before you try describe which tools to use, where and how.

Organizational assets might be a mailing list. Members in an organization. A strong partner with an annual, relevant conference. A government program to support causes like yours – assets might have many forms, but take some time to think about which channels and opportunities you might be able to use.

3. Talk to partners/networks

Are they planning similar – do their plans conflict with yours? Are there similar initiatives at a local and European level (if you didn't see is as an asset, why not – perhaps to narrow a scope)?Your idea about a campaign might fit well with other intentions and initiatives and could/should perhaps be coordinated to not overlap too much or risk create useless noise instead of understanding. Or your idea might not fit well – but then you would be better able to compensate accordingly if you still would like to go ahead.

4. Consider your message/messages

When using multiple tools and channels, choosing a single message or recognizable slogan becomes more important. Campaigns does not always use the same message or slogan, but more often than not try to use messages, word, or content of similar nature to also allow the target audience to also recognize the same message multiple times.

In the development of your campaign, the ability to state the message clearly will both help you decide types of tools, images, words etc. – and help your audience receive the message. The message would probably not be the same as the sentence you stated to begin with (see above) – but the intent and the message should of course be very strongly linked. Depending on your research in your network/potential partners you should consider how this might be used to optimize your programme/activity. And certainly at this point (if not before) you should also consider how your information about the event corresponds with the health literacy of the intended participants. Read more about health literacy here.

5. Choose your tools

Considering the previous points - how might the right tools help you?

You should both try to consider or even directly research, which communication tools your target audience is used to using, and what their ideas about your intent and message – try holding a focus group. Try looking for interest to hold a national event about your intent – are other organizations/experts potentially on board as partners and channels? And if you carry out such an event, who came? – Can they play a role in your campaign?

Read either here about choosing tools or here to see two examples of campaigns – but essentially there are many ways to combine communication tools, and you should

choose the types and number that your budget and organization can put to good use. This might be combing a folder, a website, and an event – it could be by using another combination of possibilities.

Of course you always need to consider your budget, but remember that money can be spent in many different ways – indeed even without funds at all, social media or self-sustaining events can still be used to good effect.

6. Effect/Evaluation

Speaking of effect; How will you measure it? Try to setup some key, measurable ways for you to measure the effect. You need this both to optimize your campaign as it happens, but also simultaneously, to document your progress for partners, potential funders, media, authorities etc. E.g. if you can document a significant rise in the number of X following your campaign, some will be more likely to work with you to promote Y.

An overall evaluation should not just look at the effects – but also the execution phase and perhaps side-effects. Perhaps you might find your campaign didn't change any numbers (sadly) but perhaps it meant you gained a new strategic partnership? Such a side-effect should be included in an evaluation – read more about evaluation here.

Inspiration

If you would like to study one such campaign, look at the Hygiene Week here, organized by the Danish Council for Better Hygiene – so far held since 2009, now covering both Denmark and Sweden.

Apps

This guide will advise to about central steps to enable you to build an app to allow smartphone or other personal device interaction with your audience.

An app can be rather passive or active, intrusive or indifferent as to user lifestyle, But special as it may potentially be a tool for your user/audience as much as for you – and have great potential for user interaction also. Apps can be expensive to create, hard to maintain, and the solution to all your answers at the same time.

1. Functionality vs. Content

If your are considering to build an app the first thing you should think about is functionality. What function(s) would you have the app provide for your users? And what kind of use would to hope for (see evaluation also)?

A calculator – advanced maybe? Shortcuts – introducing targeted information? Selfmonitoring – with or without dynamic feedback? In many ways you can create more or less any kind of functionality in a smartphone, tablet, or smartwatch-app – but you should think about the app as a tool you are building for the sake of your users rather than for your own (communicative?) purposes.

Because, essentially, if you are only interested in providing information (however well displayed) then perhaps building a website optimized for mobile devices would be easier and cheaper.

If you're not sure at this point we would recommend you wait till the idea and service you want to create become clearer – feel free to be inspired (within limits) by other apps. And of course look at the guidelines on the five minor ailments to consider how an app can support the specific acts of self-care acts you can read about here – or read more about preparing communication here.

2. Involving your users / Health Literacy

Apps potentially provide you with a direct and personal interface with your target audience. So even more, involving them in your process and regarding their health literacy should be very high on your list of considerations when creating – or updating – an app. Read more about health literacy here.

3. Design/Budget/Development

There are a lot of great tools that can help you create an app. So far however, most are still rather advanced – platform software and hardware are still evolving and giving both more options, but also questions for you to consider. What if you can measure heart rate – should you use this? What if you can transform the app to be used in automobiles – can/should you use this? What if 30% of your users have changed their device to a different platform – should you also?

A lot of these questions are of course for the future – you just have to try. And try

again. But you should of course consider whether your budget can carry not only the present situation but a lot of add-ons and tweaks and... An app can become obsolete just as quickly as a leaflet.

4. Distribution/Presence

The basic distribution channels of apps are rather obvious. But they are only a first step. Having your app ready and possible for download doesn't ensure users. So just as (indeed even more so) with a website, creation is only half the challenge – getting users to know and download your app (and use it) will require even more hard work.

Where can you get your app reviewed (magazines, other websites, app of the month). Who can be your partners or champions in your distribution? How can you interact with your users to get them to create a word of mouth? Any and all of these options should be used in some form – because just decorating the shop and opening the door is not enough to ensure your target audience will come running.

In networks for communication or health care professionals you might find seminars, workshops, or similar knowledge sharing communities – this might be an idea to expand your understanding of the possibilities. If you are a happy users of a similar app yourself, perhaps approach the developers of this app to learn more?

5. Effect/Evaluation

Well basically, someone has to want to use your app. And of course not only download it, but use its different functions. A high number of downloads might not be the only way to measure success – you can/should consider how else interaction with your app might measure into your evaluation – the results (in anonymous form) of the self monitoring feature, perhaps? Number or type of case stories provided by users? Some effects can be quantitative, other may be qualitative – both are important.

Even with a high number of happy users – are you really promoting self-care? Or are you, perhaps, just promoting a better conscience or actually taking way initiative ("Well I've downloaded this app – problem solved")? Engage with your users to learn more. Read more about evaluation here.

Inspiration?

Searching in app stores can give you many insights – both about how to promote your own app, and the difficulties users can have finding it. But with copying any specific app, we can recommend to try to look at similar self-care apps, such as these from the UK.

Multi-level Initiatives

This guide will advise to about how to try to put together a multilevel initiative – this is more advanced than "simply" a traditional communication campaign, as it integrates tools of public affairs, stakeholder engagement, grassroots inspiration and lobbyism.

To create or carry out a multilevel initiative you should keep in mind that change is never easy – and (lack of) communication not the only challenge. So any initiative of this sort could/should be considered in a long term perspective.

If you wish to create transformative changes then a simple communication tool or even a very creative campaign will probably not be enough – remember they are tools for you to build change – but then, as you surely know, great things can happen when good people decide to take decisive action.

1. Why, who and when?

As you may have read in the section about Campaigns here, a multilevel initiative should also start with a research and analysis phase to help you clarify why you want to use this approach, who you would like to engage, and what time frame you foresee.

Barriers

In a multi level initiative you would be using not only communication tools, but also work by other means to engage professionals, decision makers, or the public in your work. Your analysis should give you these answers; what are the prime barriers to self-care in your community/region/country – people, legislation, rules, lack of education, other? The answer will probably not point to any single one issue, but probably a multitude of reasons. And may also point to the fact, that there might be barriers not quite described yet. Nevertheless – we recommend looking at these barriers, and then ask the next hard question; how can I/we change these barriers?

For instance; How do I lobby politicians – and for what? How do I help create better dialogue between communities/municipalities and hospitals to improve preventive measures? How do I change curriculum for in natural science related educations like medicine, nursing, or perhaps biology? Or in educations for kindergarten or school teachers? Or how do I help create more community based courses on healthy living?

Your answers may end up to be different than these – but a clear picture of the barriers you see and a path to change them will help you define your initiatives.

Stakeholders

After an analysis of barriers you should also try to map the relevant stakeholders. Who they are, what their interest is, level of importance, what they are doing at present, how they normally interact with others, how they might help or oppose your initiative.

Be prepared to also show your stakeholder map to others – they might help you find your blind spot, or have a valuable key to one of your central stakeholders.

You might also peruse the different good advice on the five minor ailments of the PiSCE-project here so you can try to select specific advice or areas you would like to focus on. Read more information about establishing purpose and goals here.

2. What can you do?

Establish partnerships, create debate, engage media, bring new research to the table, help create patient to patient self-care courses, look for inspiration in other national og international initiatives for your own implementation – your choices are many.

What works best in your position is a decision you have to make yourself. But first of all we would recommend you try to create an overview of your existing assets (be they economical or intangible) – and especially try to create a strategy of how your intangible assets can support your intentions over time.

Waiting for a better, bigger budget is not the solution. If you would like change, initiative and action will always create better results than a reactive position.

Look at our catalogue of cases from the EU here – but this time not for what they've done, instead look harder at Who. Several or most of the cases are relatively small organizations with strictly limited resources. Yet they've managed to create communication tools and initiatives that can now inspire professionals in all the Member States – quite an achievement also.

3. Talk to stakeholders/partners/networks early on

With the intention and the idea of concrete initiatives at multiple levels you should sound of your ideas – this can give you valuable advice, start building your partnerships, and also give you a clearer idea of possible opposition to your initiative.

You should expect a certain level of opposition also. Perhaps a lack of interest in the media or among local authorities. There might be conflicting agendas or priorities in the field. Your map of barriers and stakeholders will help you foresee, but not necessarily avoid, challenges like these.

Opposition – sometimes quite strong – can certainly happen when you are working for change, regardless of the basic merit of self-care. A good advice is to try to establish personal dialogue and engage your key stakeholders as soon as possible – debating or arguing about key points via media or third party convinces very few and changes very little.

As mentioned above, a stakeholder analysis should be one of your first actions – at this point you should perhaps try to place them also in the persuasion-action matrix you see here – perhaps this will enable you to focus your efforts on key audiences and stakeholders to begin with.

4. Consider your message – and your vision

In a multi level initiative you certainly run the risk of stakeholders, outsiders – or even your insiders – losing track of your progress and direction. Part of this is a normal side effect of engaging multiple audiences in different ways over a longer period. But still, it is a thing to try to avoid.

So aside from having a clear message throughout, you should aim to describe your Why, your What and your With who from the points above in a short form. Perhaps as a mission statement, a joint declaration, a vision that you have people debate and vote for even.

To create debate and engagement are key to be able to unfold other activities in your initiative. Therefore we would recommend to include your partners and stakeholders in this process. And at this point (if not before) you should also consider how health literacy plays a role in your messages.

5. Choose your strategy and your tools

With a multi level initiative you have all the choices in the world of course. But your work so far should by now have helped you to more than one idea of how specific barriers are seen by specific stakeholders, and how initiatives and actions could change these factors.

Some might be issues that involves mostly communication tools, some mostly direct dialogue – all are useful. You might find it helpful to see your challenge as having to put together a three-dimensional puzzle. It requires looking at different pieces and seeing how they might fit. And once you find the right piece, you will often find that it unlocks new opportunities in different dimensions at the same time. You will probably also find that some parts of your puzzle progresses nicely, while other part seems stuck.

Your stakeholders and partners can be a valuable asset in trying to find the right strategy – as you will have to consider a strategy that correspond with your ressources, financial as well as strategic. If you so far feel you have neither, perhaps you should consider a less ambitious approach and see how you can change the basic interests in the field first.

6. Effect/Evaluation

The more activities and tools you use, the harder it might get to point to very specific acts of self-care and use these either as proof of success or measures of progress.

In a multi level initiative other a longer period of time there are a lot of other factors to consider that might work counterproductive to your own efforts. A good idea it therefore again to possibly involve your stakeholders and partners in co-defining various metrics on your path to better self-care.

You can read more about evaluation here, but in generally remember that sharing your ideas and results with others will not only potentially inspire others, but also enable them to support your work.

Inspiration

If you would like to study one such multi level initiative, look at the Self-care Week here organised by the Self-care Forum – so far held since 2011.

The Swedish webservice 1177, mentioned in the section about websites, can also be seen as a multi-level initiative, as it also incorporates other options, e.g. telenursing Swedish 1177.

Health Literacy in Communication

What is health literacy?

Health literacy is closely linked to literacy and entails the knowledge, motivation and competency to access, understand, appraise and apply information to form judgment and make decisions concerning healthcare, disease prevention and health promotion in everyday life to maintain and promote quality of life during the life course. Knowledge and skills related to self-care forms an integral part of health literacy.

Health literacy is dependent on individual and systemic factors:

- Communication skills of lay persons and professionals
- Lay and professional knowledge of health topics
- Culture
- Demands of the healthcare and public health systems
- Demands of the situation/context

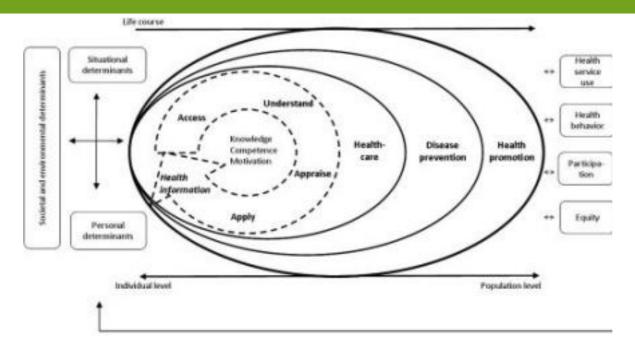
Health literacy affects people's ability to:

- Navigate the healthcare system, including filling out complex forms and locating providers and services
- Share personal information, such as health history, with providers
- Engage in self-care and chronic-disease management
- Understand mathematical concepts such as probability and risk

Health literacy includes numeracy skills. For example, calculating cholesterol and blood sugar levels, measuring medications, and understanding nutrition labels all require math skills. Choosing between health plans or comparing prescription drug coverage requires calculating premiums, copays, and deductibles.

In addition to basic literacy skills, health literacy requires knowledge of health topics. People with limited health literacy often lack knowledge or have misinformation about the body as well as the nature and causes of disease. Without this knowledge, they may not understand the relationship between lifestyle factors such as diet and exercise and various health outcomes.

Health information can overwhelm even persons with advanced literacy skills. Medical science progresses rapidly. What people may have learned about health or biology during their school years often becomes outdated or forgotten, or it is incomplete. Moreover, health information provided in a stressful or unfamiliar situation is unlikely to be retained.



Sørensen et al. Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health, 2012, 12:80.

Some basic tips

– to consider in trying to adapt your communication to the proper level of health literacy

- 1 Plain Language
- 2 Audio / Video
- 3 Personalized Communication
- 4 Cultural Sensitivity

1 Plain Language

Plain language is a strategy for making written and oral information easier to understand. It is one important tool for improving health literacy.

Plain language is communication that users can understand the first time they read or hear it. With reasonable time and effort, a plain language document is one in which people can find what they need, understand what they find, and act appropriately on that understanding.

Key elements of plain language include:

- Organizing information so that the most important points come first
- Breaking complex information into understandable chunks
- Using simple language and defining technical terms
- Using the active voice

Language that is plain to one set of readers may not be plain to others. It is critical to know your audience and have them test your materials before, during, and after they are developed.

Speaking plainly is just as important as writing plainly. Many plain language techniques apply to verbal messages, such as avoiding jargon and explaining technical or medical terms.

2 Audio / Video

Using digital media enables users to hear / see another person explain the medical relevant information to them. Advanced models of this can even be interactive so the users can dig deeper into simple, intuitive menus / questions that they would like more information about. This can both be used online (also for mobile devices), by using info-screens onsite, distributed by DVD, or in some cases also incorporated (e.g. for younger audiences) into simple books with built in automatic audio. Using af combination of text, audio, and video this can also be a part of the "after-discharge"-communication efforts that allows users to interact with relevant information and based their reported symptoms can get clear, relevant advice as to proper self-care.

3 Personalised Communication

Health literacy friendly communication highlights the need for personalized approaches that match the need of the people, clients and patients. It takes into account their health beliefs, their age and education, their knowledge and competencies to make health decisions and manage their own health. It uses appropriate ways of communicating with people without stigma. In prevention related to self-care and self-management one to one counselling at home with the help of trained health counsellors using personalized approaches and a focus on coping skills has been a fruitful communication strategy.

4 Cultural Sensitivity

Cultural sensitivity needs to be taken into account when designing health literacy friendly communication strategies. Cultural differences between patient and provider, if left unaddressed, have been shown to contribute to poor health outcomes through misunderstanding, value conflicts, and disparate concepts of health and illness. Training providers to attend to both issues can reduce medical errors, improve adherence, patient-provider-family communication, and outcomes of care at both individual and population levels. Translation barriers can be identified and cared for in terms of using professional translators or closely related adult family members and peers. Furthermore, cultural aspects may impact people's attitude, behavior and confidence with regards to their health, hence cultural awareness and sensitivity is needed to foster better communication.

Links to suggestions for further reading on Health Literacy

Health Literacy. The Solid Facts. European Office of the World Health Organisation

Building Health Literate Organizations. Health literacy guidebook. UnityPoint Health.

AHRQ Health Literacy Universal Precautions Toolkit. Agency for Healthcare Research and Quality

Or try our <u>Health Literacy Check List (netxt page)</u>

Health Literacy Check List

Basic steps in Health Literacy – and how to improve them

The previous page covers the basic logic of health literacy – here are five check points for you to consider and possibly revise:

- Can the target group easily access or obtain the information? Can providers easily distribute the information to relevant target groups?
- Can the target group understand the information? Have providers made the information easily understandable?
- Can the target group judge if this is relevant to them? Have providers made different choices and scenarios available for people to choose from to ensure it fits their needs and fulfill informed consent if applicable?
- Can the target group easily make a decision and apply the information to treat a disease and promote their health? Have providers equipped people with enough information to ensure they can use the information made available for further action?

Access and obtaining information

When developing information on self-care it is important to ensure that it is easy accessible for people to find or get.

It can be digital information on the Internet. Websites with online information should be easy to track and easy to navigate. Essential health information can be combined with patient stories, illustrations, photos, videos and other means of communication to ensure that all people will benefit from the messaging. Appointments at health services can be made available through web-based self service or phone service with office hours.

It can be written information with leaflets on self-care at the general practitioner, the pharmacists and at other health professionals or at for example the library or in community centres.

It can be information using media and social media informing people and directing them towards sources of information with more in-depth details building knowledge and skills on self-care. When designing information that is easily accessible for people, it should be easy to find and to navigate.

Understanding information

Have you tried asking members of the target group to read/see and explain information provided by you? Consider asking a numbers of individuals to read, and possibly explain, the information you provide to a third party. Did the message get across?

To increase understanding you can work with the choice of words, length of sentences, and different choices of style. Plain language can be tested to enhance the understandability of the information. You can also choose to inform orally, by video, by webinars (streamed or recorded), by recording another members of the target group interviewing you, by pod cast, by segmenting further, or perhaps by looking to spouses or next of kin as an alternate target group.

Consider whether translations are necessary for people who are not fluent in the provided languages of the information.

Is the information design cultural sensitive? Is it appropriate for all people when taking into account gender, age, sexual preference, ethnicity and religion?

Appraising and judging information

When providing information on self-care it is important to make sure that the target group finds the information timely and relevant to be used by them. Personalized approaches with choices that match the needs of the target group can help enhance the impact of the information provided. Health literacy is content and context specific. Self-care may need to be framed differently depending who is the target group. For example self-care fore parents with children may need one type of communication, whereas elderly would need another type of communication. Self-care solutions need to be developed that can match the different needs.

Furthermore, information needs to be reliable for people to use for self-care. It can be evidence-based information and information from trustworthy sources and people should be able to judge how the information matters to them.

Application and usability of information

The communication strategy on self-care should ensure that the information provided is useful and meaningful for the target group. How do the people for whom it is intended receive it? How can people take action based on the information? How are the people supported in taking actions? Are there any follow up mechanisms?

A note to call a certain telephone number may not always be enough. Often people with limited health literacy face other challenges that complicate their lives and opportunities, which makes it difficult for them to follow up on information they are provided.

Interactive and personalized strategies can enhance the outcome of the communication on self-care. Engaged health professionals who understands how health literacy play a role for health outcomes can help target groups to move from self-care awareness to empowered people with skills and competency to manage their own health through self-care.

Catalogue of Tools & Cases

There are many possible communication tools to use to either raise Attention, increase Interest, create Desire towards change, and enable Action as to self-care. These are "only" tools to communicate the how, why, when of self-care.

If you are looking for specific care acts, look at the advice about self-care <u>here</u>.

If you have a specific condition, Intention and <u>communication situation</u> in mind, you can consider looking at the <u>Advanced Matrix section</u> to match individual communication tools with individual stages of self-care communication.

This catalogue of tools is probably not complete – and should perhaps be looked upon as a constant "work in progress" as new possibilities for communication tools are constantly appearing.

Some of these communication tools may not previously have been used in self-care promotion in your country or region – their addition to this list is both to signify the potential to look at new approaches and tools in the future and likewise to inform you about experiences with other tools, that you may want to disregard in your development process.

We've divided the catalogue of tools into four segments below:

- 1. Personal
- 2. PR and existing mass media
- 3. Digital/Multimedia
- 4. Printed

If you would like to be inspired by cases look at our section on cases from various countries and regions in the EU <u>here</u>.

1 Personal (events, conferences, courses etc.)

Using human resources and events are a great way of showing the value of selfcare and getting messages across. The challenge is both reaching people that are unaware of the challenge or unwilling to be interested – and also to create a long term effort that is not just preaching for the choir.

Personal (events, conferences, courses, etc.) – Indirect		
Туре	Good for	Consider
1:1 meetings	Engaging influencers/ stakeholders; building knowledge and trust; building or maintaining key relationships.	The messages you want to give in the meeting and how to follow up to ensure the relationship is maintained.

Group meetings, Listening; brainstorming; relationship Time and cost resource: do participants

workshops, conferences	building; building and sharing purpose; exchange of complex learning and information; building trust and loyalty; engaging early adopters.	have sufficient time/motivation to attend? Timing and location: make it easy/appealing to attend or piggy back on existing meetings.
Train the trainer-courses	Internal morale; stakeholder awareness; coordinated messages of high quality; relationship building	Time and cost resource: developing "textbook"-material takes huge effort. Consider using existing concepts (or adaptations) – getting people to use more than one day can be hard to achieve. Timing and location: With smaller groups you can repeat the same course many times – possibly also adapting to input from the attendees.
Launch events	Internal morale; stakeholder awareness; can provide a hook for media coverage.	Time and cost resource: do target audiences have sufficient interest/ motivation to attend? Timing and location: make it easy/appealing to attend. Media coverage: do you have something genuinely newsworthy?
National campaigns through self- care professionals	Internal morale; stakeholder awareness; can provide a hook for media coverage – and also to engage other decision makers.	Time and cost resource: requires engaged professionals and perhaps years of repetition to get citizens activated Timing and location: can be easily managed time wise, but hard to control in location/substance – low control over actual events. Media coverage: can you present the same message in new ways each time?
"The Experts Panel"	Stakeholder awareness; good for media coverage; very responsive/identifiable – and also to engage other decision makers.	Time and cost resource: requires a selection and managing of engaged professionals and needs a combination with PR efforts. Experts might participate for professional reasons but need administrative help to maintain structure.

TypeGood forConsiderThe Self- care SupportProvides hooks for Media Coverage; Puts a human face on complexRelatively time/resource consuming to build and maintain – number of people reached directly will be low compared to resources	Personal (events, conferences, courses, etc.) – Direct		
care Provides hooks for Media Coverage; and maintain – number of people reached	Туре	Good for	Consider
	care	5,	and maintain – number of people reached

Team"	issues; Raises Awareness	used – but has huge potential for concrete human dialogue to convince members of target groups
Handout tools	Interactive tools (calendars, calculators, digital devices) to help users not only perform self-care but interact with professionals/others as well	Development can be expensive – the more advanced the better for self-care, but worse in terms of budget. Consider using other platforms (apps, smartphone) for distribution – but traditional, physical elements still has use.
Citizen Groups	Relationship building; Direct interaction with target groups; Good way to gain feedback on other efforts	Long term strategy – such groups work best by repeated sessions over several years to gain trust and feedback on several issues.

2 PR and existing mass media

Using existing mass media and trade media to engage your target groups and professionals alike can be a good way to raise awareness, inform about new practices, events, ideas, and get various messages out. However your message is not the only one trying to use this approach so care and effort are key to success – and should be combined with other communication efforts as well as interaction with readers / listeners / viewers is limited.

s media	
Good for	Consider
Credibility (a third-party endorsement) and reputation; internal morale; improving awareness; influencing political/social debates and agendas.	Time and skills required; need to be able to respond to potential interest in very short timeframes; lack of ability to 'control' the message. Plan any media activity with the knowledge of senior sponsors and their communications leads.
Credibility (a third-party endorsement) and reputation; internal morale; improving awareness; influencing professional debates and agendas.	Time and skills required; better timeframes and more time to plan and go in-depth with topics – giving a somewhat better ability to 'control' the message. Fewer readers and perhaps more "already convinced" makes the potential for concrete change a bit different.
Make it easier for other media to use your messages by providing	Can be time-consuming to produce, and need to be updated frequently.
	Good for Credibility (a third-party endorsement) and reputation; internal morale; improving awareness; influencing political/social debates and agendas. Credibility (a third-party endorsement) and reputation; internal morale; improving awareness; influencing professional debates and agendas. Make it easier for other media to

	generic texts (possibly with proper blanks), digital infographics, statistical material (explained) and similar easy-to-use supplementary press material. Provides a knowledge-based base for correct information about your topic.	And though you need to ensure that sources are aware that such material exists you have little or no control over when, how, and where material will be used.
"Mr./Mrs. Expert	An identifiable and recognizable expert to champion your message – a good way for you to gain trust in other media and for target groups to remember the message	Requires a good communicator with the ability to explain complex issues easily and possibly in soundbites – thus willing to also be misquoted and criticized for the efforts.
	, Longevity; visual impact; thanking and recognizing supporters and celebrating success.	Budget: is the cost justified? How will it be perceived by others? Developing tools that combine your message with useful content for your audience in a format they will use.
Adverts	Communicating a strong, clear message; controlling how your message is received.	Can you measure its effectiveness and justify the costs involved? Can the channel owner demonstrate good return on investment and data on the readership that reflects your audience?
Strategy for presenting new knowledge, results of surveys etc.	Media work by calendars as well – by presenting good, relevant information, surveys, research results etc at relevant periods in a year (or study media planners guide to topics in the coming year / other relevant events)	Survey/Research require planning and resources – with little or no guarantee of impact as other news stories might steal the show at the last minute.

3 Digital/Multimedia

Digital channels gives you the opportunity to distribute at a very low cost – or in interactive ways that other media cannot provide.

Digital		
Туре	Good for	Consider
Social media	Finding or creating networks	Content: who will post and regularly update/

(eg Twitter, Facebook, LinkedIn)	with niche specialization or interests; building a profile; directing to other communications (website or blog); brief, real-time updates; maintaining relationships; exchange of information/ learning; place for like-minded to interact; reaching early adopters.	respond? Need to focus more time on reacting/ responding to others to build relationships. How can you use this to cross-promote other communications (eg blogs).
Webinars / Streaming video	Exchange of complex information or learning; maintaining relationships; project management among dispersed teams.	Scheduling: think of a time likely to be convenient to most participants. Promoting: make sure people know about it and remind them. Organizing: give it some leadership and structure. Ensure the content is engaging. Streaming video might help you distribute the content or feel of existing events to others.
Website (and/or intranet sites)	range of work: attracting now	Time and cost resource for initial and ongoing development; ability to keep up to date; analytics for evaluating use/ impact. Consider creating a web page hosted on the website of the sponsor organization/partners.
Film/animation	Creating an emotional connection with a cause; telling stories that can illustrate complex issues; longevity (can be used more than once).	Resource and budgets; how will you promote/ distribute/make it available to ensure return on investment? Length: online films should be as short as possible (1-3 minutes as a general rule). And remember to tag any video – without tags the video is un-searchable by others and the content therefore isolated.
Games		Resource and budgets; any game needs to be distributed, even through online-platforms. Depending on the type of game you will sometimes also need to reach a critical mass of players in order for the game to work.
Apps	Facilitating information exchange; building a community. Giving concrete advice by push services	Mobile phone apps (either as games, reminder- capable, information-content, a combination, or other setup) are a good way to give direct link and interaction with your target group. Building and updating apps can require a lot resources, however, and remember that you need other channels to support distribution.
Stories / Podcasts /	Voice media carries strong, compelling ways to deliver your message – either in the	Resource and budgets; Recording is the easy part – you have to have a website, a Facebook- page, blog, or similar for distribution. A strategy

Radio	form of stories, debates, FAQs, or any other kind. It often gives you more time to explain.	for how many, how often, types of topics would help you in your production and interaction with users/contributors. Depending on type you can use quite different lengths, but try not to overestimate the will to listen.
Blogs	Demonstrating expertise, learning and knowledge transfer; content for social media; can boost traffic to website; place for like- minded to interact.	Content: a subject your audience cares about; a central point, argument or call to action. Promoting the blog through social media channels. Blogging through existing sites with an established audience.
Email	Low cost, regular updates; driving traffic to website or blog.	Writing style and visuals: emails are easy to delete. Ensure that the content and look of yours is audience-focused and stands out from crowd.
Mobile technology/SMS	Flagging new content. Quick delivery of short, simple messages or tools.	Is the content valued and does it address a genuine need? Advanced system might solve this as users are only giving information/response based on their specific needs and answers – this requires careful thought to plan and data manage, but has a huge potential to target information only as needed.
Newsletters (e- news/hard copy)	Keeping a defined group of people up to date with your activities; keeping in touch.	Can you achieve more impact submitting content to existing newsletters run by others?
Online network	Facilitating information exchange; building a community.	Cloud-based technology make this possible and affordable. Easy to set up groups through social media, eg LinkedIn, but they need to be actively maintained.

4 Printed

With a lot of digital media some classical elements may seem outdated or more costly to produce and distribute. However the tangible qualities can make for more care in reading and understanding.

Printed		
Туре	Good for	Consider
Leaflet, brochure, flyer, quick reference cards	Longevity; visual impact; means of communicating quite detailed information; control of message/s.	Resource for production and effective distribution (too often they are produced

		distribution).
Letter	Now more unusual/ distinctive than email; easy to personalize if small print run.	Language, layout, audience focus – the usual principles for good communications apply.
Posters	High visual impact if placement is right. In many cases users have very little time to read / understand the messages, so in terms of dissemination the effect can be small.	Image, font, clarity, brevity – and some serious consideration as to expectations as to effect.
Books/Booklets	Good for strong readers – though more graphics may help younger audiences and weak readers there are limits to this as easy-to-read books carry certain negative connotations (for adults) that may discourage them from the message.	Can be fairly costly to produce – and print. But if produced in good quality to the right target group it may be a tool that is kept for many years.
Games/Competitions	Just as digital games the idea of gamification of self-care issues can be used to good effect – from simple role playing, advanced board games, use of game pieces to simplify the complex, or indirect competitions (small prizes or even social dimensions) can have strong motivation power.	Depending on the game idea this can by costly to develop and produce. Results may often be found in basic understanding of issues rather than clear change.

without sufficient thought/budget for

Cases from Europe

Communication Tools in action across Europe

To enhance sharing of experiences and ideas we have gathered a list of examples of tools produced to promote health through self-care. The list is not as such comprehensive so we would very much like to add further examples to the list. Please contact us if you know of good existing tools that should/could be added to the list.

- 1. United Kingdom
- 2. Scandinavia
- 3. <u>Netherlands</u>
- 4. Poland
- 5. <u>Spain</u>

Share your experience and cases!

On our list of cases about self-care communication tools we welcome yours as well. Please write us – attaching or linking to your tool and explain about the target group, the situation, and (as much as possible) the effects.

Write us at kfs@sundkom.dk.

1 UK

Examples from the United Kingdom

Treat Yourself Better A campaign site by the <u>www.treatyourselfbetter.co.uk</u>

Self-care Forum.org www.selfcareforum.org/fact-sheets

A report with an evaluation of the Working in Partnership Programme Self-care in Action Initiative

www.leedsbeckett.ac.uk/hss/docs/SCinA Final Report.pdf

Fishermen and Farmers

A project which specifically targeted men on general health/use of services but linked to one geographical area (Yorkshire, which is a county in England near Lancashire) and occupation (farming). There is also an example of male targeting in another predominately male occupation (fishermen) which recognised an increased need for better self-care as these men are obviously often away for prolonged periods of time from any services. Both used a 'car manual' format for delivery of information.

<u>Farmers-content</u> – <u>Farmers-cover</u> <u>Fishermen-content</u> – <u>Fishermen-cover</u>

Self-care for Life

A project to help communities form <u>Self-care Support Groups</u>

Cases by Format	Uses, benefits and considerations
Animation	 Can be creative with visual to convey complex ideas, especially when you're doing lots of referring to and interpreting of figures Expensive and resource-intensive to produce.
	Example 1: Global Wealth Inequality
	Example 2: NHS Minor Ailment Service
Audio clip	 Cheap to produce and quick to turnaround Shouldn't be too long (max five min) unless it's very
	engaging
	 You can create free audio clips using Audioboom app (on all platforms, <u>https://audioboom.com/</u>)
	Example: www.health.org.uk/multimedia/audio/mike-durkin-feb-2013

	Audio slideshow Prezi	 Quick-win content, especially if a presentation has already been prepared for offline use (eg at a conference) Cheap to produce and fairly quick to turn around Can help to explain and illustrate ideas at the same
		time (through voice and visual)
		Example: <u>www.health.org.uk/multimedia/slideshow/what-we-know-about-how-to-</u> <u>improve-quality-and- safety-in-hospitals</u>
		 Interactive presentations Good for presenting content that is detailed and joins up in various ways – plays in a linear way but you can explore however you like Can simply be a more engaging way to do a presentation compared to PowerPoint Can embed videos, links etc which you can't do in an audio slideshow
		Example: <u>www.kingsfund.org.uk/topics/telecare-and-telehealth/what-impact-does-</u> telehealth-have-long-term-conditions-management
	Infographic	 Visual way of communicating data rather than simple chart or written copy great for illustrating what data means, quickly Can be flat infographics (eg http://bit.ly/Vlk6pc which are available as sets to download and use) or interactive (e.g. http://bit.ly/TKg6r0) Good for sharing on social media, especially Facebook where image-led updates get highest levels of engagement Costs can be relatively low for non-interactive but increase significantly for interactive
		Example: <u>www.kingsfund.org.uk/time-to-think-differently/audio-video/improving-</u> health-nation-infographics
	Slide pack	 Quick-win content, especially if a presentation has already been prepared for offline use (eg at a conference) Cheap to produce and fairly quick to turn around Slideshows can also be uploaded to Slideshare (open source software) which increases visibility of content
		Example: <u>www.slideshare.net/fullscreen/thehealthfoundation/nhs-finances-the-</u> <u>challenge-all-policital-parties-need-to-face/1</u>
	Video	 Good for showing at meetings and events, and provides a legacy for the project Brings life to ideas and concepts and an engaging way of telling a story and sharing the perspective of staff/patients Combinations of film locations – as opposed to a 'talking head' – generally more engaging Increasingly produced by amateurs, but can be expensive if involving a film production company You can share very short (six seconds) video clips using Vine (a free app, https://vine.co/) – they have a 'homemade' feel to them (see http://bit.

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) - Section 2 - Guidelines for Communication Tools

ly/16IN2Sd) and provide a visual snapshot

• People are increasingly used to watching video online, especially with rise of mobile and tablet use. Uploading films to YouTube which increases visibility of content in Google searches

Example: <u>www.health.org.uk/multimedia/video/shared-decision-making</u>

2 Scandinavia

The Hygiene Week

An annual prevention week in Denmark and Sweden – targeting (hand) hygiene – engaging professionals in municipalities to interact with citizens, colleagues, decision makers, consumers, children, and elderly and encourage all to work towards better prevention of communicable diseases.

<u>www.hygiejneugen.dk</u> and <u>www.hygienveckan.se</u> (needs English introduction)

1177.se

The Swedish communication channel 1177.se is much more general than a tool for self-care of minor conditions but do include this. It is a home page giving easy to read descriptions of a huge number of symptoms and diagnosis and also answeres questions related to health and sickness . It has been developed based on a tele medicine service (call 1177) which still is active. The different sections have been devloped by healthcare providers and a careful review process has been made (the reviewer's name is displayed for each item).

Many Swedes do use this homepage as a first resource whenever they have any questions about their own health or the health of someone close to them as for example their child etc.

http://www.1177.se/Skane/Other-languages/Engelska/Barn/Barnsakerhet-0-3-man/

3 Netherlands

http://www.thuisarts.nl

A site made by GP's which gives practical advice about ailments and when to contact a GP.

http://www.zelfzorg.nl

A site made by Neprafarm (umbrella organization for self-care industry, member of AESGP) which self-care advice for consumers.

http://www.zelfzorgondersteund.nl

A site made by a cooperation of health care Insurance companies, patient organisations and health care professional umbrella organizations, which gives the primary care organisations to implement self-management (of chronic diseases).

4 Poland

http://www.korektorzdrowia.pl/en/

Advice for Patients

PATtube was created for patients and their loved ones. Users can find here information and advices which in a clear way explain the basic problems and health issues associated with both diseases that commonly occur as well as rare diseases. In PATtube you can find information about: symptoms, recognition, diagnostics, treatment possibilities, guidelines and standards of practice, rehabilitation, nursery care etc.

ALL OF THE MATERIALS ARE IN POLISH for the Polish patient community to be found using the link <u>http://www.korektorzdrowia.pl/dla-pacjenta/porady-dla-pacjentow/</u>

5 Spain

Patient Information Sheets

Information sheets to help patients to understand the nature, the symptoms, prevention tips and recommended treatment of some common health conditions and/or minor ailments.

Currently there exist 81 different sheets, but they are continuously updated and new issues added according to society needs, ie. Exercising for obese patients, one of the last items to be added. A very good language adaption tool exist also.

Section 3 - Policy Recommendations

Content	
SECTION 3 - POLICY RECOMMENDATIONS	205
PROPOSING POLICY ACTIONS ON SELF-CARE AT EU LEVEL	206
I. INTRODUCTION	206
I.1 OBJECTIVES AND THE SCOPE OF THE STUDY	207
I.2 STRUCTURE OF THE REPORT	208
1.3 Links with the guideline on promotion of self-care (WP1) and communication (WP2)	208
II. EXISTING SELF-CARE RELATED EU POLICIES	209
II.1 DEGREE OF CONNECTIVITY	209
II.2 PERCEPTION OF SELF-CARE	213
II.3 THE MANAGEMENT OF SELF-LIMITING AILMENTS	215
II.4 HEALTH LITERACY	215
II.5 PATIENT EMPOWERMENT	217
II.6 PATIENT SAFETY	220
II.7 Self-medication	221
II.8 BUDGET ALLOCATION	222
III. PERSONS'/PATIENTS' NEEDS IN/FOR SELF-CARE	223
III.1 SURVEY ON THE SELF-CARE NEEDS OF PEOPLE/PATIENTS	223
III.2 Socio-medical environment around persons'/patients' needs	229
III.2.1 Use of the internet for health care information	229
III.2.2 Policy mechanisms to improve patient involvement in their own care	231
IV. EU POLICY RECOMMENDATIONS ON SELF-CARE	235
IV.1 ESTABLISHING A FRAMEWORK THAT WILL ENCOURAGE THE EXCHANGE OF BEST PRACTICES ON SELF	-CARE 235
IV.2 SECURING AN ENGAGEMENT PLATFORM TO SUPPORT NATIONAL OR REGIONAL INITIATIVES ON SEL	F-CARE
	236
IV.3 INCLUSION OF SELF-CARE IN SCHOOL EDUCATION AND LIFELONG LEARNING	237
IV.4 INCLUSION OF SKILLS TO SUPPORT SELF-CARE AS PART OF CURRICULUM IN EDUCATION AND TRAINI	NG OF
HEALTH PROFESSIONALS	238
IV.5 INTEGRATION OF NEW TECHNOLOGIES TO SUPPORT PEOPLE'S SELF-CARE	238
IV.6 Embedding self-care in health literacy initiatives	239
BIBLIOGRAPHY	241

Pilot project on the promotion of self-care systems in the European Union.Platform of experts. (PiSCE)Section 3 - Policy Recommendations

Proposing policy actions on self-care at EU level

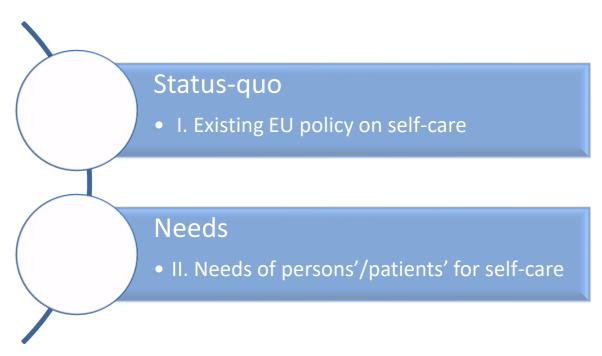
"Public health is affected by almost every policy in government, and almost every policy in government could potentially be seen as more or less successful public health policy."

(Greer 2013)

I. Introduction

The present interim report presents possible routes to policy actions on self-care at EU level as well as policy recommendations aiming to give an added value in supporting the broader implementation of effective self-care. These proposals, produced by the PiSCE platform, result from two main stages of analysis (Figure 1).

Figure 1. Main stages of analysis



Following these stages of analysis, each step converges towards a management model/cycle linking the main objective, to formulate policy recommendations on self-care with added-value at EU level with the necessary actions (Figure 2).

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) **Section 3 - Policy Recommendations**

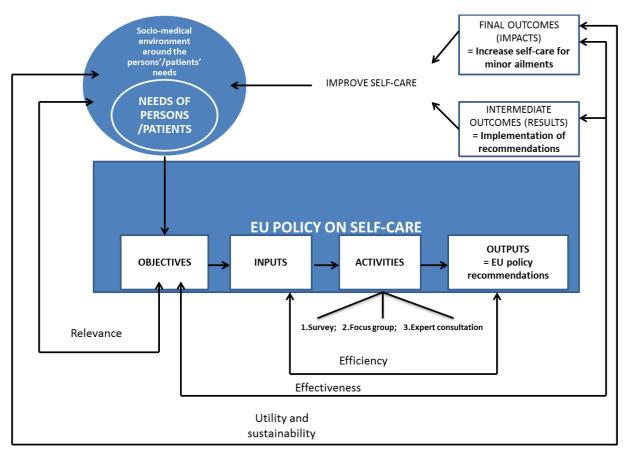


Figure 2. The input/output model for self-care

(Adapted from: Pollitt, C., Bouckaert, G., 2004. Public management reform. A comparative analysis. The input/output model (p. 106)

I.1 Objectives and the scope of the study

The main objective of Work Package 3 is to develop concrete proposals for policy actions and collaboration at EU level on self-care, giving an added value in supporting the broader implementation of effective self-care. Cost/benefit analysis studies and the outcome of the EMPATHIE (Empowering patients in the management of chronic diseases) project are taken into account in the process.

The present report proposes EU policy recommendations on self-care that are relevant for five self-limiting conditions: athlete's foot, cough, cold, lower urinary tract infection and heartburn. The selection of these conditions is taken from a longer list of minor ailments indicated by literature and practice. The PiSCE consortium was not involved in the study where the conditions were selected. These five conditions were discussed and validated with a primary care physician and public health experts participating in the EU tender on the Cost-benefit analysis of self-care systems in the European Union (EAHC contract N°EAHC/2013/Health/26). The selection was made by the European Commission as a part of the call for tender for the present study.

I.2 Structure of the report

The application of the public management model corresponds to the structure of the present report. Chapter II will map existing and related EU policies on self-care. They create a common ground of understanding the different speeds of development of related policies and possible links. Chapter III will present the needs of persons/patients regarding self-care and will outline the results of a survey carried out within patient and consumer representative organisations at EU level (EPF and BEUC respectively). This offers insights as to target groups, barriers to self-care, needs as well as necessary education interventions and the extent to which persons/patients would like to bear the costs of their own self-care. The final chapter, Chapter IV, offers final EU policy recommendations on self-care.

I.3 Links with the guideline on promotion of self-care (WP1) and communication (WP2)

Work Package 3 complements qualitative information collected from the survey on persons'/patients' needs with the analysis presented in the guideline to promote self-care at national level, that is, the output of WP1. This is presented in Chapter IV. Similarly, WP3 provides recommendations regarding communication on self-care at EU level, based, at least in part, on the outputs of WP2. This is also presented in Chapter IV.

II. Existing self-care related EU policies

The first step towards a well-connected and well-informed route of analysis leading to future recommendations and policy options is to map out existing policies, understand existing links and where they are situated in the policy cycle: agenda-setting, policy formulation, legitimation, implementation, evaluation, policy maintenance, succession or termination.

A list of related policy dimensions leads to a proper evaluation of trade-offs, and helps to explore unintended consequences, not only direct impacts. According to Canoy, Lerais and Schokkaert (2010) such mapping offers a frame of reference for organising the reflection on the policy proposal among the various organizations and social groups.

II.1 Degree of connectivity

Figure 3 maps existing self-care related EU policies. The mapping was constituted with input from the PiSCE Platform of Experts¹ trying to provide a complete picture of related policies. This platform was created with an aim to develop a guideline for promotion on self-care, a guide for the development and production of communication tools, and a policy brief proposing policy actions on self-care at the EU level.

The mapping shows how self-care is connected to policies related to health literacy, access to healthcare, patient safety, self-medication, long-term conditions and patient empowerment. An analysis of the evolution behind each of these policies can place them at a more advanced or less advanced stage within the policy cycle.

The policies were clustered based on their stage of development. The logic behind this process was to understand first the different possibilities to link future self-care recommendations with existing and related policies and second to understand what infrastructure exists behind these numerous policy initiatives (studies, EU projects, European Commission reports, communications). The stage of development is presented in Table 1.

¹ The PiSCE Expert Platform is composed of cross-functional stakeholders with expertise in self-care, including healthcare providers, patient groups, healthcare professionals, academics, communication experts and other relevant stakeholders with experience in policy making both at EU and national & regional levels (ground level expertise). The expert group has a balanced geographical coverage and consists of 25 experts.

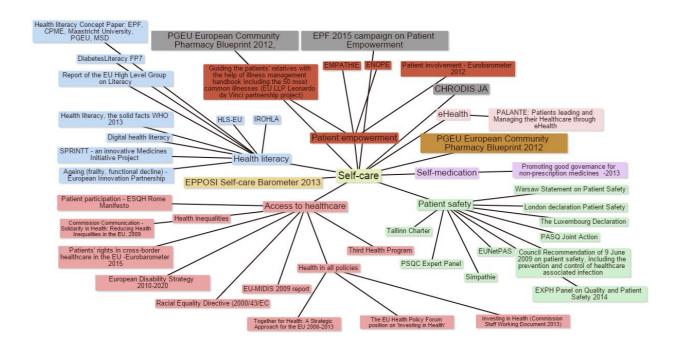


Figure 3. Existing EU Policies and respective actions on Self-Care

Figure 3 maps to a great extent the full range of initiatives under each policy related to self-care. Health literacy, long-term care and patient empowerment are at an incipient stage of the policy cycle where different projects identify problems and give an account of needs and ways forward towards policy formulation. Access to healthcare is part of a broader framework and it is a policy that has gained much attention at EU level but lacks concrete policy and implementation. Patient safety has been at a more advanced policy stage on the one hand due to existing legislation (soft law) and on the other due to the high interest received from Member States.

However, patient safety may no longer be considered a priority at EU level since e.g. the work of the EU Expert Group on Patient Safety and Quality of Care has been suspended for the time being. However, medication safety related issues are safely anchored in hard EU legislation. Finally, self-medication is the predecessor of self-care stripped out of activation and learning mechanisms of management and with a view of enforcing what delimits prescription and non-prescription medicines and their governance. It is situated at an advanced degree of development due to legislation and self-regulatory initiatives.

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) **Section 3 - Policy Recommendations**

Table 1. Existing policies: instruments, policy cycle, stage of development

Related policies	Main instruments	Policy cycle	Stage of development
Health literacy	EU projects (HLS-EU, IROHLA, EIPAHA)	Agenda-setting	Incipient
Self-care and long-term conditions	EU project	Agenda-setting	Incipient
Patient empowerment	EU tender, EU projects	Agenda-setting	Incipient
Access to healthcare	Legislative (Cross-Border Healthcare Directive, Racial Discrimination Directive)	Policy formulation	Medium
	EU platforms		
	The European Semester		
	The Health Systems Performance Assessment (HSPA) Framework		
Patient safety	Legislative	Implementation – Policy succession/mainte nance	Advanced
	Declarations (capacity and consensus building)		
	Joint Action, EU projects		
Self-medication	Legislative	Policy succession	Advanced
	Self-regulatory process (CSR)		

Table 1 identifies the main instruments driving policies forward to advance in their cycle but it does not take into account the interaction between these policies. To do so, it is necessary to see the policymaking system as a collection of numerous policy cycles and due to this predictability of outcomes decreases. It should also be remembered that sometimes EU level policy is driven by national priorities, or there are parallel policy cycles, sometimes aligned with what is happening at EU level and sometimes not.

Given the different stages of development, it is necessary to understand the degrees of connectivity/potential linkages between all the policy areas in order to amplify their role and potential in self-care. At what policy level is the fine grained distinction between self-care and self-management? How would patient empowerment and health literacy play a role to improve self-care rates in the EU and what added value does it have for EU level action? Last but not least, how can the patient safety and access to healthcare policy frameworks bring their contribution and what are the necessary facilitators?

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) **Section 3 - Policy Recommendations** Patient empowerment, self-management, health literacy, self-medication and access to healthcare all can have a direct contribution towards better self-care. Patient safety at EU policy level impinges indirectly on self-care through consensus between Member States and stakeholders, and self-care benefits directly from better access via tools which inform, enable and facilitate the patient in the healthcare pathway.

II.2 Perception of self-care

The PiSCE Platform of Experts defines self-care as "a learned tool enabling people to maintain health and to cope with illness and disability. Along with better health literacy it also supports optimal and timely use of available health services while avoiding a total dependency upon them for minor ailments".

Furthermore, UK Department of Health (2005) sees self-care as "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". A policy brief, *Where are the patients in decision-making about their own care?*, written for the WHO European Ministerial Conference on Health Systems (Coulter et al. 2008), states that it is vital to support these actions, as they already are a prevalent form of health care.

The Eurobarometer Qualitative Study on Patient Involvement (TNS Qual+ 2012) asked what do patients and healthcare professionals think about an active role of patients in their healthcare. The study concludes that patient involvement is sometimes interpreted as something practitioners do to patients rather than something patients do themselves. According to practitioners, it means informing patients and explaining diagnoses, conditions and treatment options, as well as educating patients about a healthy lifestyle. It was reported that patient involvement in healthcare had increased in many countries over the last ten years. Practitioners described patients playing a greater role in prevention, and searching for information about symptoms, conditions and treatments on the internet. (TNS Qual+ 2012.)

This study, which was conducted by in depth interviews in 15 Member States, indicates that being well-informed about health is linked to patients' greater involvement in health care. In all the 15 countries, practitioners and patients reported that patients are now better-informed due largely to the development of the internet which was accessible to all the patients interviewed. Almost all patients had used the internet to access healthcare information, and a few had found support in online patient forums. Patients rated their ability to be discerning and responsible about information found on the internet more highly than practitioners did. (TNS Qual+2012.)

Self-care was widely associated with "following doctors' orders", the issue of compliance which is seen throughout the results of this study. Some chronic patients reported more active self-care. Respondents were asked about the role of patients in self-care in either treatment or recuperation. There was near-unanimous agreement across all countries, amongst both practitioners and patients, that it is self-evident that persons/patients have a role in self-care. (TNS Qual+ 2012.)

Self-care was presented to respondents as follows: "You are given a role in self-care in the treatment or in the recuperation period (for example: doing exercises, taking medication)". Respondents usually described it in terms of medical compliance - patients were often described as being involved in self-care in terms of keeping healthcare appointments, taking medication or carrying out exercises prescribed by physiotherapists. In other countries, self-care was described in terms of following a healthy diet and lifestyle. (TNS Qual+ 2012.)

Practitioners and patients in eastern European countries were most likely to see the self-care role simply as one of living a healthier lifestyle, and complying with practitioners' instructions. In these countries, few mentioned the possibility of patients carrying out more active self-care and only under strict guidance. However, practitioners notably in eastern European countries wanted to see greater patient involvement in self-care which would improve the general state of health, aid recovery and improve treatment outcomes, particularly through patients improving their lifestyle. (TNS Qual+ 2012.)

Even if the cited survey provides some inputs on patients' views, more research is needed to better understand the phenomenon (considering the different patient characteristics and cultural country context), in order to develop effective self-care policies and strategies. Cultural differences within different European countries must be taken into account even when it comes to self-care. Some countries are further in the self-care development than others. Also the role of healthcare professionals differs. Therefore cultural differences will have an effect on the results in behaviour change.

The Epposi Barometer: Consumer Perceptions of Self-care in Europe, a 2013 survey carried out in 10 EU countries², asked respondents how they perceive the importance and benefits of self-care in managing and preventing their conditions and diseases, including minor ailments. It also asked whether respondents feel responsible for their own health and if they feel confident in doing so. The study sample consisted of 1901 respondents. The countries were chosen to achieve a geographical spread and to reflect differences in healthcare systems. The main findings of the study are that:

- 'Nine out of ten respondents see self-care as a vital part of the management and prevention of chronic conditions and diseases, including minor ailments
- Most respondents view improved health and quality of life, prevention and management of their conditions and diseases as the benefits of self-care, followed by greater independence, productivity and individual satisfaction
- Persons/Patients are willing to take care of their own health and the majority agree that it is their responsibility to do so. The highest score for this is in the Northern countries

² Denmark, Finland, France, Germany, Italy, Netherlands, Poland, Scotland, Slovakia and Spain

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) **Section 3 - Policy Recommendations**

- However, less than one in five respondents feel very confident to take care of their own health, ranging from 17% in the Northern countries to 11% in the Eastern countries
- Health literacy is pivotal. Better knowledge, skills and capacities for self-care are closely linked to confidence and willingness to undertake responsibility for their own health
- The findings confirm the diversity of available information sources for self-care but healthcare professionals still play a fundamental role. The lower the perceived knowledge, skills and capacities for self-care, the higher the dependence on healthcare professionals for information.'

II.3 The management of self-limiting ailments

While at first sight the difference between the two concepts of self-care and selfmanagement is not apparent, it is useful to propose that self-management refers to long term conditions whereas self-care is associated with the treatment of minor ailments. In this sense, it is still important to draw a parallel and see where transferability provides added value as models of self-management are more developed and ingrained in practice.

Written information on its own is rarely effective in changing people's behaviour or producing better health outcomes. Instead, active education and teaching practical skills are found to be productive. This kind of approach can be delivered via ICT; interactive applications have demonstrated the possibility of increasing patient knowledge, abilities and healthy behaviour, while patients also feel they need to receive satisfactory social support.

A study (Deakin et al. 2005) showcasing diabetes management highlights that efficient self-management education programs are the ones that are intensive and longest in duration, while they are also integrated into the health care system and reinforced by health care professionals. The study states that effort should be placed on providing opportunities for patients to develop practical skills and gain confidence in their abilities to manage their own health. In order to achieve this, participative learning styles should be preferred over traditional education methods.

These participative learning programs may be extended towards enhancing self-care skills for minor ailments. A recent report on *Informal and flexible approaches to self-management education for people with diabetes* (Wenzel 2016) concludes that the most effective diabetes education is flexible and is based on the needs of the people attending.

II.4 Health literacy

Further to the transferability of 'participative learning' and 'productive interaction' concepts from the area of self-management to that of self-care for minor ailments, EU

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) **Section 3 - Policy Recommendations** health literacy and patient empowerment initiatives play a significant role to the development of a future EU self-care policy for minor ailments.

Health literacy refers to the ability to access, evaluate, understand and use health information in order to make sound decisions about health and healthcare. It has been recently defined as "people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course."³ Low health literacy is associated with health inequalities; it tends to result in weaker health and poses a bigger risk for hospitalization.⁴ Although more research is needed on the costs of limited health literacy, these have been estimated to be 3-5% of total healthcare cost at system level.⁵

To make informed decisions about their health and treatment, it is vital that people can access all the relevant information they need in an easily understandable format. The health literate person is then able to process, appraise and apply the information to her or his own personal circumstances. This is usually defined as "functional" health literacy. More advanced levels of health literacy are "interactive" health literacy (the cognitive, literacy and social skills that enable active participation in healthcare) and "critical" health literacy – the ability to critically analyse and use information to participate in actions that overcome structural barriers to health.⁶

The European Health Literacy Survey (HLS-EU) shows that limited health literacy is a challenge in several countries in Europe. On average, 47% of the respondents across eight countries⁷ had limited health literacy. The levels differ considerably between the countries surveyed, but the research shows that health literacy is a problem not only for particular vulnerable groups, but also for the general population and society at large. (Pelikan et al. 2012.)

People with low health literacy skills can be targeted with special information and education campaigns. Three key objectives can be found in health literacy interventions: providing information and education, encouraging the use of health care

³ Sorensen K et al. (2012), Health literacy and public health: A systematic review and integration of definitions and models *BMC Public Health* 12:80 doi:10.1186/1471-2458-12-80.

⁴ *Health literacy. The solid facts.* Kickbusch, Pelikan, Apfel and Tsouros (eds.). WHO, 2013; "Making health literacy a priority in EU policy" multi-stakeholder consensus paper 2013. http://www.eu-patient.eu/globalassets/policy/healthliteracy/health-literacy-concept-paper_final.pdf ; "Health Literacy – part 2: evidence and case studies", World Health Communication Associates, 2010, pp. 20-22. Available online at http://www.whcaonline.org/uploads/publications/WHCAhealthLiteracy-28.3.2010.pdf

⁵ "The costs of limited health literacy: a systematic review", Eichler K, Wieser S, Bruegger U, *Int J Public Health*, 2009;54(5):313-24.

⁶ Nutbeam, D (2000) " Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century", *Health Promot. Int.* 15(3):259-267.

⁷ Austria, Bulgaria, Germany, Greece, Ireland, Netherlands, Poland and Spain.

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) **Section 3 - Policy Recommendations**

resources and tackling health inequalities. Health literacy is quintessential to patient empowerment and it has been proven to bring savings to health costs.

However, health literacy is not only a question of individual skills: it is a relational concept and a systems issue. Health literacy implies enhancing the interaction between people and their environments and addressing the power balance between service users and providers, or laypeople and specialists. Developing health literate settings – whether in healthcare or in education, employment or media – is vital (WHO 2013).

II.5 Patient empowerment

The EMPATHiE (Empowering patients in the management of chronic diseases) project, which was in the work plan 2013 of the Health Programme 2008-2013, helps to clarify the relationship between health literacy, self-care and self-management and patient empowerment. According to the 2014 EMPATHiE study, an empowered patient has control over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to achieve optimal well-being. Empowerment interventions aim to equip patients. The EMPATHiE study (2014) continues that empowerment interventions aim to equip patients (and their informal caregivers whenever appropriate) with the capacity to participate in decisions related to their condition to the extent that they wish to do so; to become "co-managers" of their condition in partnership with health professionals; and to develop self-confidence, self-esteem and coping skills to manage the physical, emotional and social impacts of illness in everyday life.

The EMPATHIE model has three complementary and sometimes overlapping components: education, self-management and shared decision making. An important point is that education includes both greater health literacy on the part of the patient with chronic illness but also ensures that healthcare professionals had the requisite skills to foster effective self-management and shared decision-making. On the principle that care is on a continuum from healthy lifestyles through minor conditions to chronic illness and in-hospital care, the same principles can copy across from selfmanagement of chronic conditions to self-care in minor conditions. There seems to be a very close relationship between the concept of self-management and self-care, especially in the field of chronic illness. In less severe or minor conditions, maintaining wellness/prevention seems more of an issue. What the EMPATHiE model helps clarify is the inter-relationship between health literacy, education of professionals and joint decision-making. As will be commented on later, for chronic care, the last mentioned process tends to be between medical professional and patient, for minor conditions it might be between patient and another professional such as a pharmacist. However, task shifting should only be promoted via consensus between all professions involved and not solely as a cost saving measure.

The EMPATHIE study had four phases: a literature search on best practices in patient empowerment, a multi-stakeholder survey across Member States on barriers and facilitators for empowerment, using both focus groups and an on-line survey, a study of transferability of good practices, and development of potential scenarios for future EU collaboration on the subject.

The majority of the high quality systematic reviews identified dealt with examples of good practice for patients with diabetes, chronic cardiovascular and chronic respiratory disease. Half of these related to self-management and the majority of the rest were to do with communication (education) and health literacy. Out of the study of barriers and facilitators, the top five issues identified were: that the professional has enough time for the patient; that the former has a holistic view of the patient, that health professionals work together and that healthcare provision is well coordinated. Finally, that the patient feels responsible for his/her health.

The study of transferability of good practices needs to be seen in the context of the subsequent study of transferability carried out as part of the cost-benefit analysis tender which was the predecessor of and complement to this present study. The former transferability Work Package looked in depth at context, content and process both at the initiating site and the place where the practice was to be transferred, to identify barriers to effective transfer.

Finally, and of direct relevance to Chapter IV of this report, following an extensive stakeholder consultation process, four scenarios were developed from the results, which included the key feasibility criteria (e.g. effort to start collaboration, perceived costs, EU added value and perceived risks). These four scenarios were rated to be capable of implementation at least partly and were seen as likely to be at least moderately effective in achieving patient empowerment. Moreover, all scenarios were rated as able to provide at least medium or high "EU added value".

The four scenarios are the following:

1. The informed patient

Ensuring that patients and citizens have easy access to information and health literacy covering all aspects of health, including prevention, treatment options, evidence-base for different treatments, and lifestyle advice (EMPATHiE 2014).

2. New professional skills, knowledge and attitudes

European collaboration focuses on ensuring that health professionals have the right skills, knowledge and attitudes to practice patient-centred healthcare, providing an enabling context for patient empowerment (EMPATHiE 2014) and advancing health literacy.

3. Self-management supported by technology

eHealth solutions, such as telemedicine, electronic health records and remote monitoring are mainstreamed into an integrated care approach. European collaboration focuses on developing and implementing ICT resources and tools for

patients and professionals to support patient empowerment through self-monitoring and self-management (Somekh 2014).

4. Transparent quality data for patient choice

European collaboration focuses on facilitating patient choice through making available transparent and comparable information on quality of care (EMPATHiE 2014).

However, the conclusion was that no scenario on its own would be sufficient to address all aspects of patient empowerment, and a future collaboration would need to combine elements from all or some of the four scenarios.

The report concludes that interventions targeted to patient empowerment tend to show positive results and that a stronger evaluative work at meso- and macro-level initiatives is desired.

Analysing practical success and failure factors is crucial. It is also recommended that future work at European level could, for instance, focus on education of patients and the public and on an improved education of healthcare professionals. Furthermore, an EU level collaboration among vital stakeholders (health professionals, patients, consumers and healthcare industry) and a European network for facilitating patient empowerment could be beneficial in line with the network Health Literacy Europe.

The EMPATHIE study confirms that there is a strong interest among stakeholders to collaborate on patient empowerment at a European level. From the EU collaboration, stakeholders wish concrete actions, actions which preferably are linked to the existing initiatives. A European strategy and action plan on patient empowerment as a starting point is welcomed by the vast majority of stakeholders, as well as a common reciprocity of best practices and tools, development of common indicators and an improved evidence base concerning person empowerment. The current initiatives such as the European Innovation Partnership on Active and Healthy Ageing enable synergies and the contribution from the work that is already underway.

A base to build effective strategies for informing and empowering patients and involving them in their own health care is set, even though there are those who still question the financial benefit of such policies, despite the substantial body of work which confirms the improvement of health outcomes associated with patient empowerment.

An independent Expert Panel which advises the European Commission on matters related to effective ways of investing in health identifies in its opinion on *the Future EU Agenda on Quality of Health Care with a special emphasis on Patient Safety* (European Commission / EXPH 2014) five core aspects of health quality, of which one is person/patient-centredness. The opinion presents that 'patients, families and people should have a possibility to actively participate in the process of care and self-care, particularly for chronic conditions, health promotion, disease prevention, and patient safety activities. The patients (the persons, as we consider that a person can have health conditions that can be improved through their life) are, in this respect, active participants in the process. Therefore, the health services have not only to be

developed "for" individuals and populations, but also "with" and "through" individuals and populations. It is not only a question of "expectations", but also of empowering and increasing the capacity of individuals/patients to be able to care for themselves in partnership with professionals (e.g. in relation to diabetes, mental disorders, ageing with autonomy, etc.) and to achieve the "goals" in their lives that are relevant to them'.

Furthermore, the Expert Panel reminds that 'this new paradigm, derived from the best education of people, and the demographic and epidemiological transitions, must not be confounded with the inappropriate shifting of responsibility to patients, or with the reduction of public health resources in times of crisis. Nor is it that the patient has to assume the role of health professionals, or that computer programmes (apps) might replace health services of high quality. Better informed and empowered patients (user, person) will be able to maintain optimal well-being and will manage their health condition more effectively in the context of everyday life, with appropriate support of health professionals working in a well-funded and structured health care system. This could also imply the option to choose not to receive the treatment proposed. The empowered patient may choose not to participate (be involved) leaving decisions to the health professionals or, in other circumstances, the empowered patient may choose the 'no treatment' option (provided their conditions enable them to do so).' (European Commission / EXPH 2014.)

While empowerment is thus promoted it can be seen that health literacy, a key component, is fundamental. As Coulter et al. (2008) conclude, 'because health literacy is central to enhancing the involvement of patients in their care [including self-care], all strategies to strengthen patient engagement should aim to improve health literacy. If the problem of health literacy is not dealt with, inequalities could widen. Knowledge and understanding improve when health professionals engage patients actively in their care, leading to better outcomes.' As we shall see later, for self-care in minor conditions such professionals might not always be doctors or nurses.

II.6 Patient safety

Previous and existing actions at EU level in the fields of patient safety and quality and in access to healthcare offer a ready-made framework that connects with self-care in minor conditions. The EU Expert Group on Patient Safety and Quality of Care has been such an example as it has offered a communication forum for Member States discussing related areas such as patient empowerment. Self-care for minor ailments could be planned within this forum and with direct input from Member States and European stakeholders present. The Council conclusions of 1 December 2014 noted that patient empowerment and involvement are recognised as an essential part of good quality and safety of care and require an effort by Member States to exchange cross-country knowledge and effective tools (Council of the European Union 2014, p.3, par 22).

II.7 Self-medication

A report of the Working group on Promoting good governance for non-prescription drugs, within the Platform on access to medicines in Europe (European Commission 2013), describes in depth the role of competent authorities, pharmaceutical companies, consumers and patients, and health professionals in facilitating uptake and proper use of non-prescription medicines.

According to the report, self-medication is an important aspect of self-care in general and as such the matter is to have access to medicines and inform persons/patients when it is necessary to self-medicate. In terms of access to medicines, when Member States consider a switch from a prescription to a non-prescription medicine, the report recommends five main elements to take into account:

- 1. Safety, ease of use and possibility to monitor the switched products
- 2. Responding to the needs/demands of citizens and health professionals, in particular, in terms of patient empowerment, timely access, access to improved treatments and improved quality of life
- 3. Agreement of healthcare professionals
- 4. Clear beneficial impact on public health
- 5. Fulfilling unmet needs and addressing conditions that would otherwise remain untreated

The report also recommends further pharmacovigilance in case of switches, early collaboration with healthcare professionals, the need for safety evidence as well as knowledge and information of persons/patients concerning the correct use of the medicine. (European Commission 2013.)

II.8 Budget allocation

Horizon 2020

In the current financial programming for research, Horizon 2020 the allocated financing in the area of self-care is around 7% of the overall budget under health. This is divided as follows:

a) PHC 26 – 2014: Self-management of health and disease: citizen engagement and

mHealth

- b) PHC 27 2015: Self-management of health and disease and patient empowerment supported by ICT
- c) PHC 28 2015: Self-management of health and disease and decision support systems based on predictive computer modelling used by the patient him or herself (STARR project consortium 2016)

While results from these projects may not be available for some time, it is clear that such work potentially complements the policy directions sought here and also helps to bridge the gap between conventional health approaches and the drive to develop innovative use of eHealth tools to change the models of healthcare delivery for the better.

Third Health Programme

The Third Health Programme 2014-2020 allocates 449.4 million Euros towards four main objectives, out of which three are relevant for self-care (European Commission 2016):

- 1. Promote health, prevent diseases and foster supportive environments for healthy lifestyles taking into account the 'health in all policies' principle,
- 2. Contribute to innovative, efficient and sustainable health systems,
- 3. Facilitate access to better and safer healthcare for Union citizens.

For 2015, about 4.1 million Euros could also contribute to the promotion of self-care or intermediate goals:

- a) Prevention of frailty 3.5 million Euros (action with member states authorities)
- b) Economics of prevention grant to OECD 600.000 Euros
- c) Comparative assessment of the accessibility of healthcare services (Thematic priority 4.3. of Annex I to the Programme Regulation).

III. Persons'/patients' needs in/for self-care

In order to explore further persons'/patients' self-care needs, the PiSCE Platform of Experts carried out a small additional a survey. The Expert Platform was then consulted, to complement the data received. As mentioned earlier in the report, the Platform and the Focus Group consists of representatives of healthcare providers, patient groups, healthcare professionals, academics, communication experts and other relevant stakeholders with experience in policy making both at EU and national levels.

III.1 Survey on the self-care needs of people/patients

Patients' and consumers' representatives conducted a survey on the self-care needs of people/patients between March and June 2015. The aim of the survey was to provide information on the needs of people/patients on self-care, their understanding of self-care, main barriers and target groups to be prioritised when implementing self-care policies. The validity of the survey was provided by the type of respondents, representatives of patients and consumers targeted through their respective umbrella associations at European level, the European Patients' Forum (EPF) and the European Consumers' Association (BEUC).

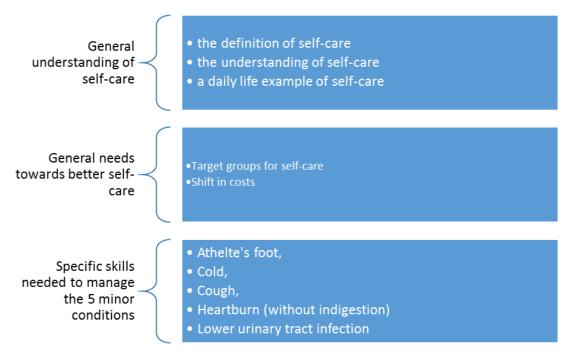


Figure 4. Main questionnaire blocs included in the questionnaire

As the present report aims to offer an understanding of necessary actions at EU level, the survey consultation with most representative organisations was deemed as an

appropriate measure to understand the main needs of people/patients on self-care. Selected organisations were the most relevant and representative to disseminate the survey. Overall, 29 responses were received, of which 14 were from consumer organizations and seven from patient organizations. In addition, eight responses were received from individuals.

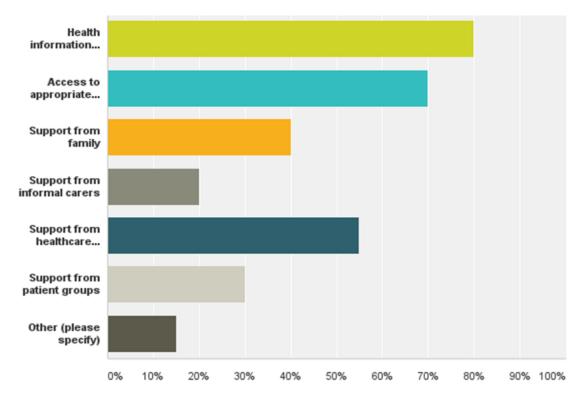
The design of the survey questions was determined through a previous qualitative consultation with EPF and BEUC, taking special care that questions were clear, understandable, reader-friendly and in direct connection with the aim pursued. The survey contained 26 questions centred around the understanding of self-care (including the definition of self-care and a daily life example where self-care was used), the needs for self-care (including which are main target groups and whether costs would be an issue) and specific skills needed to manage the five minor conditions: athlete's foot, cold, cough, heartburn and lower urinary tract infection. The survey was administered by an online platform.

The key outputs from the survey of patients and consumers relate to their agreement with the proposed definition and perception of the barriers to self-care (Q6/8 and Q12 in the survey, see appendix). We present below specific findings for the main areas of the survey.

1. Person needs

This section was designed to identify the key areas needed to cover in the selfmanagement guides for the five conditions. Survey respondents indicated that the top priority in terms of self-care needs refers to health information, including promotion of healthy lifestyles. This was a top priority of 16 out of 29 respondents. Second and third priorities were access to appropriate health services and support from healthcare professionals. The fourth suggestion was support from their own family. Please see figure 5



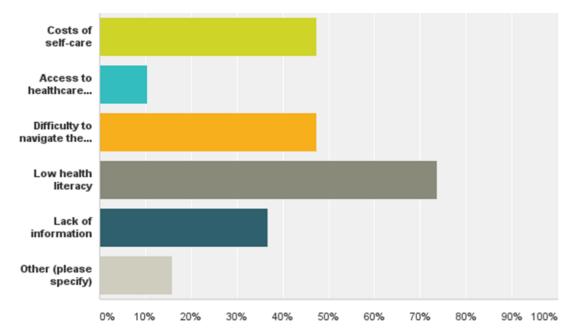


nswer Choices		Responses	
Health information (including promotion of healthy lifestyles)	80 %	16	
Access to appropriate health services	70 %	14	
Support from family	40 %	8	
Support from informal carers	20 %	4	
Support from healthcare professionals	55 %	11	
Support from patient groups	30 %	6	
Other (please specify)	15 %	3	
Fotal Respondents: 20			

 Barriers to be addressed to enhance and reinforce self-management Identified barriers were in accordance of persons needs reported in previous question. The main barrier was suggested to be low health literacy by 74% of respondents. This is in perfect agreement with the first need of persons/patients to receive health information (including promotion of healthy lifestyles). Other barriers identified were significantly lower in terms of

responses: 47% indicated that costs of self-care and difficulty to navigate the healthcare system as the main barriers.





Answer Choices	Responses	
Costs of self-care	47 %	9
Access to healthcare professionals/services	10.%	2
Difficulty to navigate the healthcare system	47.%	9
Low health literacy	73.%	14
Lack of information	36.%	7
Other (please specify)	15.%	3
Total Respondents: 19		

3. Target groups

Regarding target groups when formulating policy on self-care for minor conditions, respondents clearly identified vulnerable groups as the main target as well as children and young adults and the older population to be specially considered in the process of developing the guides.

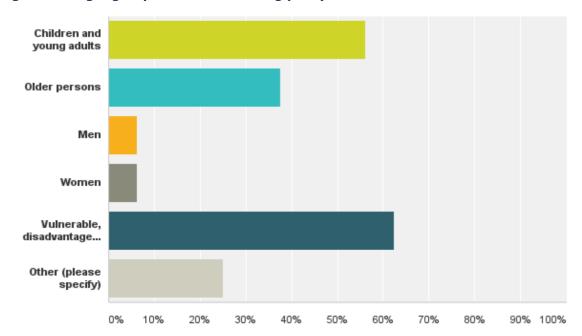
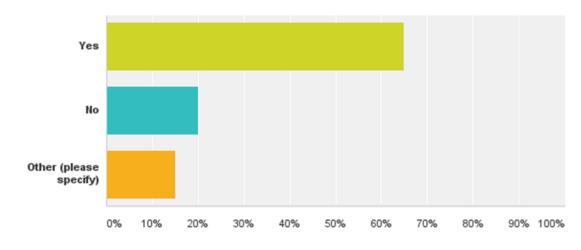


Figure 7. Target groups when formulating policy on self-care for minor conditions

Ans	swer Choices 👻	Respon	ises 📼
v	Children and young adults	56 %	9
Ŧ	Older persons	37.%	6
w.	Men	6.%	1
w.	Women	6%	1
Ŧ	Vulnerable, disadvantaged or hard-to-reach population groups (such as documented and undocumented migrants, minority groups, people living with disabilities)	62 %	10
w.	Other (please specify) Responses	25.%	4
Tot	al Respondents: 16		

4. Bearing the costs of self-care

Regarding the readiness to bear the costs of self-care, over 60% of respondents indicated their associates or themselves were ready to bear the costs of self-care. This would mean that necessary treatment for the minor conditions would not be expected to be reimbursed. Because this has been formulated as a general statement, this result will need further investigations in a more detailed questionnaire and also including qualitative techniques to be able to better understand more specific details about this matter.





Ans	swer Choices	*	Responses	
Ŧ	Yes		65 %	13
Ŧ	No		20 %	4
÷	Other (please specify)	Responses	15 %	3
Total				20

Other significant responses for the questionnaire include the perception of the role of education in furthering self-care and who or what might facilitate it (Q.18/9), the patients' expressed preference for tools to ensure health information that are based on evidence and key components of what is needed to promote an environment that encourages self-care (Q 23 and 24). All questionnaire details can be seen in this report Annex.

All data from the survey and the summary included in this report informed the project Work Packages developing the guides and strategies to implement self-management in minor conditions. Main findings of the survey can be summarised as follows:

- 1. The following needs were identified for persons who are exposed to selfmanagement interventions: health information, access, support from healthcare professionals, patient groups and families.
- Barriers to self-care include: 1.low health literacy (74%), 2. costs of self-care (47%), 3. difficulty to navigate the healthcare system (47%), 4. lack of information (37%).
- 3. According survey respondents, vulnerable group should be the main target group when developing and implementing self-care policies.

4. 65% of respondents indicated that they are ready and willing to bear necessary costs that would be shifted group should be the main target group when developing and implementing self-care policies.

III.2 Socio-medical environment around persons'/patients' needs

From the consultation that followed the survey, themes that arose were empowering patients by instilling confidence based on training which would include helping them be more 'internet-savvy' in terms of judging the quality of information, empowerment through knowing when to seek professional advice, good inter-professional cooperation and structural issues which can influence self-care such as perverse incentives related to employment contracts.

In regard to both promoting self-care and ensuring safety, it was felt that 'pull' rather than 'push' methods should be used. Again, the need to build in self-care actions that went beyond self-medication was emphasised as well as the need to educate doctors as much as patients to change their behaviours (e.g. good communication, not fostering dependency or disempowering patients). Finally, that safety had to be paid attention to, although inevitably, this creates a tension in terms of change and speed of change which inevitably carries risk.

More general points were: a greater proportion of healthcare budget allocated to education and prevention is recommended, health literacy used as the entry point to self-care, a concern from some quarters about risks associated with use of OTC medications, although it is accepted that during their approval process / switching process, safety must be demonstrated, and finally, a recognition of possible linkage points to other EU policies, such as links to EP Intergroups, cooperation with OECD and WHO, the Expert Group on Health Inequalities, the European Semester and work in access to healthcare and healthcare indicators.

III.2.1 Use of the internet for health care information

The *Eurobarometer Qualitative Study on Patient Involvement* shows how patients are using the internet to search for information on health care. According to this qualitative study which was carried out in 15 EU Member States⁸, practitioners tend to demonstrate negative attitudes towards patients' use of the internet and show concern towards the risk of misinformation. Furthermore, practitioners' worries are targeted towards the risk of hypochondria. The unregulated online information is a cause of concern as it may raise vexation and mistrust in the relationship between patients and

⁸ Austria, Belgium, Czech Republic, Finland, France, Germany, Greece, Hungary, Italy, Latvia, Poland,Romania, Spain, Slovakia and the United Kingdom

Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) **Section 3 - Policy Recommendations**

doctors. Yet, some doctors also see the internet as a useful tool, for instance, when providing community support for chronically ill patients, encouraging preventative behaviours and when used as a tool for post-diagnosis information search. (TNS Qual+2012.)

Consumers, on the other hand, seem to be almost uniformly positive towards the use of internet and see it as a useful and easy way to gather information. Patients also tend to feel they are able to use the internet responsibly and in constructive ways. A handful of patients also are aware that online information is not entirely reliable and some also acknowledge the risk of hypochondria. Yet, only few patients suggested that information found online might convince them not to see a doctor for their symptoms. (TNS Qual+ 2012.)

A survey on *European citizens' digital health literacy* finds that six out of ten respondents used the internet to search for health related information within a year. The main type of information searched for is general information, ways to improve health, and information on lifestyle choices such as nutrition, physical activity and smoking. Moreover, respondents had searched information on a specific injury, disease, illness or condition their symptoms. The majority found the information satisfying but also in this survey roughly half of the people found it not reliable enough, too commercially oriented, or not detailed enough. (TNS Political & Social 2014.)

Recent initiatives have focused on computer-based information and the development of websites, health portals and virtual support groups. Online health information has become a popular source for health information, but these sources also have limitations when it comes to equal access as well as quality and reliability of the information. While information in other electronic formats has had mixed results with improving knowledge, they can be effective tools when it comes to improving patients confidence and abilities to be involved in the decision-making process. Using electronic information tools to complement health education in clinical setting can improve clinical outcomes and, in the end, also have an effect on health behaviour. Furthermore, electronic tools can be helpful with reaching hard-to-access groups.

The policy brief (Coulter et al. 2008) written for the WHO European Ministerial Conference on Health System states that appropriate, relevant and reliable health information, which is available at specific milestones, should be provided for patients. Online information does not automatically fulfil these criteria, and tools for assessing quality information are useful. According to the policy brief, it seems that instead of mainstream medical information, patients are interested in aspects such as treatment options, their probability of success and how to best manage their condition.

As a caveat, this policy brief was written almost at the same time that the iPhone was launched as a product. The last seven years has seen an extraordinary growth in the world-wide ownership of mobile technology, which raises questions as to the authors' concerns about equality of access to information (although literacy issues remain). Secondly, the growth of social media, such as Twitter, has effects which we are only starting to understand. To give two examples, while peer-to-peer support remains an Pilot project on the promotion of self-care systems in the European Union. Platform of experts. (PiSCE) **Section 3 - Policy Recommendations**

important aspect of patient empowerment, traditionally this was via face-to-face meetings or internet fora. For a significant number of diabetics, Facebook and Twitter have become a resource for peer support since social media may make it easier to connect with people who have a similar condition and similar experiences (Cooper A. & Kar P. 2014). Similarly, in terms of reporting of adverse effects of common medications, pharmaceutical companies are starting to scan Twitter as a source of peer to peer reporting of unwanted side-effects, to support its product development.

Besides different social media channels, more traditional websites have also been proven to be successful self-care tools. In Sweden, the 1177 Vårdguiden website was developed next to the telenursing service to serve as a national hub and an online health care guide providing advice, information, inspiration and e-services. This platform is free from commercial interests and is owned by all county councils and regions. Nowadays it has around 7 million visitors per month (1177 Vårdguiden 2015).

Online self-care is a very rapidly developing area. As it was stated in the European Medicines Agency's recent workshop report (EMA 2016), much research in the fields of data-mining and health computing is currently ongoing, and analysis of social media data in healthcare is a reality

III.2.2 Policy mechanisms to improve patient involvement in their own care

As Coulter et al. (2008) comment, governments, health authorities or payers looking to educate, inform and empower patients need to agree on clear goals and a coherent strategy, with actions targeted at national, regional and organisational levels. The goal is cultural change, and a whole-system approach is therefore needed to strengthen interventions in various settings.

They continue that 'initiatives at different levels of the system should be mutually reinforcing and well-coordinated. The range and balance of initiatives should be culturally relevant and locally determined, and the vision and strategy must be clearly articulated so that everyone knows what is expected of them. It is not possible to develop a universal policy that works in every setting but the following initiatives are worth of consideration:'

- Actions at macro-level (national, federal, state government)
 - E.g. legislation concerning protection and promotion of patients' interests; requiring clinicians to ensure the maximum possible level of patient engagement in their own treatment and ensuring that people are kept informed of their rights and responsibilities. Explicit standards or targets can require care providers to demonstrate their competence in patient education and to provide evidence of patient involvement in decision-making (Coulter et al. 2008). Coordinated patient survey programmes have been shown to be a useful way of monitoring performance across the system.

- Actions at meso-level (regional health authorities, professional organisations)
 - Professional regulation can play a key role. Good practice standards developed by professional bodies can require clinicians to: involve patients in treatment and management decisions; provide them with education and support for self-management; and adopt strategies guided by evidence, to build health literacy.
 - Standards could also require clinicians to help patients navigate the system and to guide them to appropriate sources of health information and decision aids.
 - Once again, patient feedback obtained by means of standardized questionnaires can be used to monitor the performance of clinicians, reward good practice, and actively encourage such practices, improvements and innovations. National bodies responsible for professional education, including the development of educational methods, curricula and assessment, should ensure that care providers comply with patient-centred standards (Coulter et al. 2008).
- Actions at micro-level (clinical teams, group practices, local communities)
 - Fostering a culture of partnership between health professionals and 0 patients requires professionals to develop a specific set of skills and attributes (see Coulter et al. 2008 for an extensive list). Patient education needs to become an integral part of professional-patient interactions. This will require effective professional leadership and the development, implementation and evaluation of effective education programmes. Person/patient confidence and competence in selfmanagement can also be enhanced by providing appropriately targeted telephone and e-mail advice, telephone coaching and counselling, text messaging with prompts and reminders, so-called virtual support (such as interactive web sites and virtual networks), and assistive technologies and self-monitoring equipment. Encouraging patients to play an active role in decisions about their care can be an effective way of ensuring that treatment and disease management are appropriately tailored to the individual.

The European Observatory on Health Systems and Policies report, What do we know about the strengths and weaknesses of different policy mechanisms to influence health behaviour in the population? (McDaid, Oliver & Merkur 2014), aims to map what is known of the policy mechanisms that can be used to promote health. For now, taxation and legislation, health education campaigns and mass media campaigns have been popularly used methods. Combinations of several of these methods could also be effective, yet, individuals tend to be resistant towards changing their habits; some have difficulties with appreciating the risk, while for others social and environmental factors affect their abilities to adapt new behavioural models. The evidence base on what works to influence behaviour, and in what context, is still in development, with many unanswered questions on how best to design new innovative interventions that

can complement, and in some instances augment, these well-established mechanisms (McDaid, Oliver & Merkur 2014).

Despite there being plenty of policy ideas informed by behavioural economics, more ideas are needed in a health context and far more evidence is required on their likely effectiveness and cost effectiveness. Nevertheless, the application of 'behavioural economics' to public health is currently a popular idea, e.g. Applying behavioural insights to health, a 2010 discussion paper by the UK Cabinet Office, which suggests nine different pilot projects on themes ranging from smoking, teenage pregnancies, diet and weight to diabetes management in children, organ donation and social care.

The following key messages of the European Observatory on Health Systems and Policies report (McDaid, Oliver & Merkur 2014) are also relevant when thinking about policy mechanisms to improve patient involvement in their own care.

- Traditionally, public health policy has relied on a combination of tools, most frequently health-education and -information campaigns, taxation policies to influence decisions related to health behaviour, and legislation to prohibit unhealthy activities.
- While these approaches are effective and have led to many public health improvements, they are blunt instruments; individuals do not always respond to these tools and may even be resistant to changing their behaviours in the face of significant financial benefits. Rational persuasion can have relatively little impact on entrenched habits, particularly if they involve strong peer pressures or even addiction.
- In some cases, expansion in the use of strict approaches that limit choice, such as new legislation, can be unpopular with a public that may see some actions as an unnecessary encroachment into matters of personal choice.
- A better understanding of factors that influence behaviour change may help in designing public health strategies that reach segments of the population that have been impervious to existing public health strategies.
- There is a growing body of knowledge on mechanisms that directly seek to influence health behaviours, recognising that individual choice and decisionmaking is influenced by many different factors. Many of these approaches have evolved out of research focused on behavioural economics and psychology.
- However, while a lot is known about long-standing public health actions, such as the role of taxation, legislation and health-information campaigns, the evidence base on what works to influence behaviour, and in what context, is still in development; there are many unanswered questions on how best to design new innovative interventions that can complement, and in some instances augment, well-established mechanisms. These mechanisms can also have both positive and negative unintended consequences.
- There is little evidence that behaviour-change interventions, for instance those using standard financial incentives for change, or those that use techniques such as commitment contracts, with or without financial incentives, have a long-term impact on objectives such as weight loss. Changes to the environment, to make healthy lifestyle choices more convenient, may have

more long-term success, but again there is little long-term evidence available. The shorter the timeframe for impact to be achieved, the greater the chance of behaviour change – for example, the benefits of smoking cessation during pregnancy. Other behavioural interventions, for instance changing default decisions, such as having to opt out of organ donation, or reframing information with visual and other cues to address issues of cognitive bias, can also play a role, but information on their effectiveness is limited.

- Adopting a more positive approach to health-promotion messages, emphasizing the immediate enjoyment of a healthy lifestyle, is helpful.
- Examples of positive public-private-sector partnerships can be identified, especially where a business case for healthy living can be identified.
- Given the lack of robust evidence on mechanisms to influence change in health behaviour, it is important that, in planning implementation, an assessment of needs is undertaken and that planners are as specific as possible about the content, target group and provision of theories justifying the action.
- While some low-cost actions can be highlighted, it should be stressed that there is little robust information on the effectiveness, let alone the cost effectiveness, of innovative approaches to behaviour change. Therefore, careful evaluation, including analysis of costs, should be embedded into pilot phases of evaluation before scaling up interventions.

The European Observatory report (McDaid, Oliver & Merkur 2014) concludes that in some ways the implementation of public health policy has followed extremely conservative and traditional lines. Whether the effect of financial pressures or the increased use of the internet and mHealth tools will force a shift in delivery in the same way that it is postulated may happen with healthcare delivery in Europe remains a question which only time will answer.

What policy recommendations can do, as well as taking into account the best information available, is to look for clues from ongoing parallel activity as to emerging innovation, to actively support these into wider uptake and use to ensure continuous development and improvement in the area.

Definite suggestions should be based on identified deficiencies in areas such as improving patient education, considering patients as a part of the health care team in professional education, and taking advantage of health care industry innovations in the area of "fool-proof" tools for monitoring and improving self-care. Public health policy should actively support these areas in order not to stay extremely conservative and in traditional lines.

IV. EU policy recommendations on self-care

Within Work Package 3, the PiSCE platform has developed concrete proposals for policy actions and collaboration at EU level on self-care. These six recommendations, divided in three categories, will give an added value in supporting the broader implementation of effective self-care. After a careful review of existing EU policy related to self-care, a survey conducted on persons'/patients' needs on self-care, and discussion within the Platform of Experts, the PiSCE Platform encourages all stakeholders involved at EU level to support initiatives on self-care, in particular with regards to

- Implementation
- 1. Establishing a framework that will encourage the exchange of best practices on self-care
- 2. Securing an Engagement Platform to support national or regional initiatives on self-care
- \rm Education
- 3. Inclusion of self-care in school education and lifelong learning
- 4. Inclusion of skills to support self-care as part of curriculum in education and training of health professionals
- Public Health
- 5. Integration of new technologies to support people's self-care
- 6. Embedding self-care in health literacy initiatives

IV.1 Establishing a framework that will encourage the exchange of best practices on self-care

The PiSCE Platform recommends the EU to establish a framework that will encourage the exchange of best practices on self-care.

A targeted effort should be used to analyze the existing self-care knowledge, sharing best practices (e.g. Sweden, Finland, the UK, and the Netherlands), and establish how they can be transferred to other Member States lacking such self-care tools.

With the existing framework in terms of organization, technological platforms, and experience in dissemination the existing practices could/should be molded into language adaptable activities that Member States can choose to integrate - with EU or a designated partner/organization as the mediator in such knowledge and experience transfer. Ideally, with the help of the EU, Member States would be able to easily choose between at least two such practices and essentially each State then subsequently only bear the cost of specific language adaption and the actual implementation of the service.

To show the viability and usefulness the EU could support costs of such direct implementation 75% for the first Member State that chooses to do so, 50% for the second, and 25% for the third Member State to do so - all to show the usefulness of such tools, and the actual adaptiveness of the tools/practices.

The recommendation calls of course for an initial rating and taxonomy of these practices and of the technological, economical, and practical requirements for such a transfer and implementation. This initially will then form the basis of the implementation decisions at a Member States or perhaps partners/authorities at a regional level - in many ways just as the existing e-bug.eu framework does within the transfer of the platform of tools to promote knowledge within microbiology and communicable diseases.

IV.2 Securing an Engagement Platform to support national or regional initiatives on self-care

The PiSCE Platform recommends the EU to support the formation of an Engagement Platform that will serve as an umbrella for a series of national, regional or local initiatives on self-care.

Within other health issues, the possibility to have a common denominator (as 'Think Pink' for breast cancer or 'Movember' for men's health) to reference locally, has shown to be a huge advantage when planning and creating specific initiatives, events, or other activities.

The creation and support to create a joint framework and continuous gathering of national, regional, or local initiatives into a common initiative is therefore recommended. Specifically such an initiative would enable:

- 1. Engagement of a wider range of stakeholders to work on the topic together from a policy and implementation perspective at national and health regional level.
- 2. Better awareness for self-care through events and direct engagement with different stakeholders nationally, regionally and locally
- 3. Long-term communication to and education of all target audiences by providing information and coaching communicators

Such an Engagement Platform should have an ability to form core communication criteria and materials for joint initiatives, but also to gather the EU stakeholders themselves in a joint network to share and strengthen their commitment in promoting self-care. The PiSCE platform recommends the EU to support such an initiative initially, but envisage the actual work to be handled by an appropriate European partner, NGO, society, or similar that would create long-term viability.

IV.3 Inclusion of self-care in school education and lifelong learning

Investment in self-care as integral part of health literacy in the education system will be important in the future. Health literacy as a public health goal is a challenge for contemporary health education and communication strategies for the 21st century. The EU is encouraged to fund research and projects that will advance health literacy of children and adolescents in the school setting and in communities to enhance their self-care abilities. Research projects and best practice exchange are important mechanisms to support the development of health literacy at local level.

Building the foundations for self-care and health literacy in early child development is critical. The opportunities that toddlers have to learn are important for the years ahead. These include interacting with parents and other family members, early childhood educational programmes, play, child-to-child programmes and learning opportunities in child care settings. Applying participatory education principles appears to help parents in accessing, understanding and using health information to benefit their own health and that of their child (WHO 2013).

Health promoting schools aims to combine changing individual behaviour with changing organisations and policy. Introducing self-care as part of curriculum to develop health literacy will enhance the role on the promotion of health in everyday life. A policy glossary, *Learning for Well-being: A Policy Priority for Children and Youth in Europe* (Kickbusch 2012), underlines for example the uniqueness and diversity of all children and the need to develop systems that matches their needs; considers children as competent partners, nurturing personal responsibility more than compliance; and moves from standardised education to child-centered education.

Lifelong learning and practising strongly predicts health literacy. Participation in lifelong learning, both formal and informal, is one of the strongest predictors of health literacy among elderly. Interventions encouraging people to be lifelong learners (either participating in structured learning or through daily activities such as daily reading or learning computer skills) are therefore considered to be likely to facilitate the development and maintenance of health literacy skills. Therefore, barriers need to be tackled to enable people to take part in lifelong learning. The barriers can for example include lack of motivation related to the idea that the learning is not relevant for them; lack of interest or self-confidence; costs; lack of time; and poor awareness of options and lack of information. Learning programmes for adults with limited skills can also positively influence their children's learning (WHO 2013).

School teachers and adult learning instructors need to be equipped with the necessary skills and competences to facilitate the integration of self-care into their curriculum where appropriate. Investment in education and qualifications are keys to successful implementation of self-care abilities into school education and lifelong learning strategies. Moreover, it should be guaranteed that both sexes have an equal access to education on self-care.

IV.4 Inclusion of skills to support self-care as part of curriculum in education and training of health professionals

Increasingly, there is a demand for health systems to be safe, effective, patientcentred, timely, efficient, and equitable in order to become robust and functional (Institute of Medicine 2001). The challenge ahead is to educate future health professionals to be able to provide proactive, predictive, prospective, preventive, participative and personalised health services and processes. A patient-centered approach in supporting patients' self-care requires patient empowerment through for example shared decision-making and elicitation of the patient's values and preferences. This requires certain skills, knowledge and attitudes from health professionals - recognising the patient as an individual/personality; listening actively; communicating and exploring options; setting goals together; and supportiveness. The availability of accurate, relevant, up-to-date and easily understandable information is also necessary.

Self-care has progressively gained widespread support from healthcare professionals and from key organisations in primary care (www.selfcareforum.org 2016). In the United Kingdom more than nine out of ten General Practitioners now believe that selfcare by patients has an important role to play in general practice (Self-care Forum 2016). Focus on self-care will specifically be of interest for general practitioners, nurses, pharmacists, and physiotherapists who are often the contact points when people seek help for minor conditions. However, core competencies on self-care should form part of all health care professional training (Better Conversation; Health Coaching).

IV.5 Integration of new technologies to support people's self-care

There is a shift going on from paternalistic, curative medicine reflecting the industrial era to share care services resulting from the collaborative efforts of stakeholders acting in the information age. Electronic (digital based, for the sake of accuracy) healthcare platforms and use of digital health care data is one of the drivers leading to this paradigm change. However, when used, these electronic tools must guarantee privacy for users.

New technologies can enable patients to easily get information, which was traditionally held by professionals, to support self-care. Yet, professionals need also to develop the knowledge, skills and attitudes to master the new technological opportunities themselves to support patients who use technology. In this respect, issues of consent and privacy need to be carefully considered. Also areas where use of information that cannot be handled in the digital environment (e.g. emotional information), must be identified and handled appropriately.

eHealth solutions, such as telemedicine, electronic health records and remote monitoring should be mainstreamed into an integrated care approach. European collaboration should focus on developing and implementing ICT resources and tools for patients and professionals to support patient empowerment through self-monitoring and self-management (EMPATHiE 2014).

IV.6 Embedding self-care in health literacy initiatives

Health literacy refers to the ability to access, evaluate, understand and use health information in order to make sound decisions about health and healthcare. It has been defined as "people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course" (Sorensen et al. 2012). Low health literacy is associated with health inequalities; it tends to result in weaker health and poses a bigger risk for hospitalization. Although more research is needed on the costs of limited health literacy, these have been estimated to be 3-5% of total healthcare cost at system level (WHO 2013).

To make informed decisions about their health and treatment, it is vital that people can access all the relevant information they need in an easily understandable format. The health literate person is then able to process, appraise and apply the information to her or his own personal circumstances. This is usually defined as "functional" health literacy. More advanced levels of health literacy are "interactive" health literacy (the cognitive, literacy and social skills that enable active participation in healthcare) and "critical" health literacy – the ability to critically analyse and use information to participate in actions that overcome structural barriers to health (EPF 2015).

However, health literacy is not only a question of individual skills: it is a relational concept and a systems issue. Health literacy implies enhancing the interaction between people and their environments and addressing the power balance between service users and providers, or laypeople and specialists. Developing health literate settings – whether in healthcare or in education, employment or media – is vital (WHO 2013).

The EU is encouraged to support Member States in monitoring health literacy through surveys over a longer period of time and to assess impact of interventions to allow for comparability, and to inform future policy and practice (WHO 2013). Promoting investment in self-care as part of health literacy interventions could be possible through the mechanism of the EU Structural Funds. Only people with a demonstrated level of acquired health literacy should be encouraged to pursue the self-care process.

Involvement of EU stakeholders at all levels

The European Commission and its agencies and partners can help driving the needed change from hospital-centred to community-centred health care as its pathways adapt from the industrial society into the information society. The emerging European Reference Networks can play an active part in the process.

It is recommended to help setting up, declaring and providing support for an EU platform for healthcare educators and subsequent work on the transformation of

health care education for future needs, in line with organisations representing European healthcare professionals and educators, academics and learned societies.

Both patient safety and policies regarding universal access to health at EU level offer an existing infrastructure to link self-care for minor ailments. EU Health Policy Platform is such an example as it offers a forum of communication with member states and it already discusses related areas such as patient empowerment. Self-care for minor ailments could be planned within this forum and with direct input from member states and European stakeholders present.

BIBLIOGRAPHY

- 1. 1177 Vårdguiden (2015). *Healthcare Guide 1177*. Retrieved from: http://www.1177.se/Om-1177/1177--Health-care-advice-online-and-on-the-phone1/
- 2. Byrne, David (2004). Enabling Good Health For All: A reflection process for a new EU health strategy. European Commission.
- 3. Canoy, M., Lerais F. & Schokkaert E. (2010). *Applying the capability approach to policymaking: The impact assessment of the EU-proposal on organ donation*. The Journal of Socio-Economics, Volume 39, Issue 3, June 2010, Pages 391-399. Retrieved from: http://dx.doi.org/10.1016/j.socec.2009.11.002.
- COI for the Department of Health (UK) (2009). Tackling Health Inequalities: 10 Years
 On A review of developments in tackling health inequalities in England over the last 10 years. London: DH Publications Orderline.
- Cooper, Anne & Kar, Partha (2014). A new dawn: The role of social media in diabetes education. Journal of Diabetes Nursing 18: 68–71. Retrieved from: http://www.thejournalofdiabetesnursing.co.uk/media/content/_master/3630/files/pdf/jd n18-2-68-71.pdf
- 6. Coulter, A., Parsons, S., & Askham, J. (2008). *Where are the patients in decision-making about their own care?* Copenhagen: WHO Regional Office for Europe.
- Council of the European Union (2006). Council Conclusions on Common values and principles in European Union Health Systems. Official Journal of the European Union.
- 8. Council of the European Union (2007). Press Release 2837th Council meeting Employment, Social Policy, Health and Consumer Affairs. Council of the European Union.
- 9. Council of the European Union (2008). Council Conclusions on the Implementation of the EU Health Strategy Outcome of proceedings. General Secretariat, Council of the European Union.
- 10. Council of the European Union (2014). Council conclusions on innovation for the benefit of patients Employment, Social policy, Health and Consumer affairs. Council meeting Brussels, 1 December 2014. Council of the European Union.
- 11. Council of the European Union (2014). Council conclusions on patient safety and quality of care, including the prevention and control of healthcare associated infections and antimicrobial resistance Employment, Social policy, Health and Consumer affairs. Council meeting Brussels, 1 December 2014. Council of the European Union.
- 12. Council of the European Union (2014). *Outcome of the Council Meeting Employment, Social policy, Health and Consumer affairs*. Council meeting, Brussels, 1 December 2014. Council of the European Union.
- 13. Deakin, T., McShane C., Cade J. & Williams R. (2005). Group based training for selfmanagement strategies in people with type 2 diabetes mellitus. Cochrane Database.
- 14. EMA European Medicines Agency (2016). Sharing health information in the digital age: potential and challenges of social media. Report from a workshop on the impact of social media on patients, healthcare professionals and regulators. Retrieved from: http://www.ema.europa.eu/docs/en_GB/document_library/Report/2016/11/WC5002164 41.pdf
- 15. EMPATHiE (2014). Empowering patients in the management of chronic diseases. Final summary report. Retrieved from: http://ec.europa.eu/health/patient_safety/docs/empathie_frep_en.pdf.

- 16. EPF (2015). *EPF Background Brief: Patient*. Retrieved from: http://www.eupatient.eu/globalassets/campaign-patient-empowerment/briefing_paperpatientempowerment_final_external.pdf
- 17. EPPOSI (2013). *The Epposi Barometer: Consumer Perceptions of Self-care in Europe*. Retrieved from: http://epposi.org/wp-content/uploads/2015/07/EPPOSI-Self-Care-Barometer-Report-2013-EN.pdf.
- 18. EU Fundamental Rights Agency (2011). Presentation: *FRA's work on Roma health* at DG Sanco Experts' meeting on Health Inequalities. EU Fundamental Rights Agency.
- 19. European Commission (2013). Report of the Working group on Promoting good governance for non-prescription drugs. Platform on access to medicines in Europe.
- 20. European Commission (2014). *Background note Health in Europe Making it fairer* 18 March 2014, Brussels. European Commission.
- 21. European Commission (2014). Communication from the Commission on effective, accessible and resilient health systems. European Commission.
- 22. European Commission (2014). *Conference report Health in Europe Making it fairer* 18 March 2014, Brussels. European Commission.
- 23. European Commission / EXPH (2014). Expert panel on effective ways of investing in health (EXPH). *Future EU Agenda on quality of health care with a special emphasis on patient safety*. Retrieved from: http://docplayer.net/13384965-Exph-future-eu-agenda-on-quality-of-health-care-with-a-special-emphasis-on-patient-safety.html
- 24. European Commission (2014). Roma Health Report Health status of the Roma population Data collection in the Member States of the European Union. European Union.
- 25. European Commission (2014). The Commission's Second Report to the Council on the implementation of Council Recommendation 2009/C 151/01 on patient safety, including the prevention and control of healthcare associated infections. European Commission.
- 26. European Commission (2016). The 3rd EU Health Programme. Retrieved from Research & Innovation, Calls for Proposals: https://ec.europa.eu/research/participants/portal4/desktop/en/opportunities/3hp/index. html#c,calls=hasForthcomingTopics/t/true/1/1/0/defaultgroup&hasOpenTopics/t/true/1/1/0/default-group&allClosedTopics/t/true/0/1/0/defaultgroup&+PublicationDateLong/asc.
- 27. European Commission Directorate-General for Communication (DG COMM) (2013). *The EU explained: Public health*. Luxembourg: Publications Office of the European Union.
- 28. European Commission Directorate-General for Economic and Financial Affairs (DG ECFIN) (2010). *Joint Report on Health Systems* prepared by the European Commission and the Economic Policy Committee (AWG). European Commission.
- 29. European Commission Directorate-General for Health and Food Safety (DG SANTE) (2015). *Healthy diets pilot project for pregnant and lactating women, Literature review and best practices*. European Commission.
- 30. Greer, Scott L. (2013). European Union Public Health Policy: Regional and Global Trends. Routledge.
- 31. Institute of Medicine (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Retrieved from: https://www.ncbi.nlm.nih.gov/books/NBK222274/
- 32. Kickbusch, Ilona (2012). Learning for Well-being: A Policy Priority for Children and Youth in Europe. A process for change. Retrieved from: http://www.eiesp.org/hosting/a/admin/files/L4WB%20A%20Policy%20Priority%20for% 20Children%20%26%20Youth%20in%20Europe.pdf
- 33. McDaid, D., Oliver, A. & Merkur, S. (2014). What do we know about the strengths and weakness of different policy mechanisms to influence health behaviour in the

population? Retrieved from WHO European Observatory on Health Systems and Policies: http://www.euro.who.int/__data/assets/pdf_file/0003/270138/PS15-web.pdf?ua=1

- 34. Ostermann, H., Renner, A., Bobek, J., Schneider, P. & Vogler, S. (2014). *A cost/benefit analysis of selfcare systems in the European Union Final report*. Gesundheit Österreich Forschungs- und Planungs GmbH / European Commission.
- 35. Pelikan, J.M., Röthlin, F. & Ganahl, K. (2012). Comparative Report on Health Literacy in Eight EU Member States (The European Health Literacy Survey HLS-EU). The European Health Literacy Europe.
- 36. selfcareforum.org (2016). *Self-care: The story so far...* Retrieved from: http://www.selfcareforum.org/wp-content/uploads/2012/08/aboutselfcare.pdf
- 37. Somekh, David (2014). *The EMPATHiE tender: Empowering patients in the management of chronic diseases*. Retrieved from:
 - http://ec.europa.eu/health/patient_safety/docs/ev_20141218_co07_en.pdf
- Sørensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z. & Brand, H. (2012). *Health literacy and public health: A systematic review and integration* of definitions and models. BioMed Central Ltd.
- 39. STARR project consortium (2016). *Decision Support and Self-Management System for Stroke Survivors*. Retrieved from: http://www.starrproject.org/
- 40. TNS Political & Social at the request of the European Commission, Directorate-General Communication Networks, Content and Technology (DG CONNECT) (2014). *Flash Eurobarometer 404. European citizens' digital health literacy*. Retrieved from: http://ec.europa.eu/public_opinion/flash/fl_404_en.pdf
- 41. TNS Qual+ at the request of the European Commission, Directorate-General for health and Consumers (2012). Eurobarometer Qualitative Study. Patient Involvement. Aggregate Report. Retrieved from: http://ec.europa.eu/health//sites/health/files/systems_performance_assessment/docs/e urobaro_patient_involvement_2012_en.pdf
- 42. Wenzel, Lillie 2016. Informal and flexible approaches to self-management education for people with diabetes. Report commissioned by Diabetes UK. Retrieved from: https://www.diabetes.org.uk/Upload/Get%20involved/campaigning/Taking%20Control/I nformal%20and%20flexible%20approaches%20to%20diabetes%20education_Kings%2 0Fund%20report%20(web).pdf
- 43. WHO World Health Organization (1998). *Health Promotion Glossary*. Retrieved from: http://www.who.int/healthpromotion/about/HPR%20Glossary%201998.pdf

