WP 4 PLATFORM FOR KNOWLEDGE EXCHANGE

Task 1: selecting JA-CHRODIS criteria to assess good practice in interventions related to chronic conditions

INTERIM REPORT 3: Delphi Panel in the area of patient’s empowerment interventions with chronic conditions.
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Ms. Ana Toledo-Chavarri, Ms. Lilisbeth Perestelo-Pérez participated in the development of the Delphi questionnaire for the online consultation process.

Ms. Valentina Strammiello contributed to the recruitment of the expert’s panel for the Delphi process.

The experts’ panel in the Delphi on patient’s empowerment interventions with chronic conditions were:

Mr. Diederick Aarendonk, Ms. Judy Ammerlaan, Ms. Francesca Avolio, Ms. Marta Ballester Ms. Jo Bibby, Mr. Mathieu Boudes, Ms. Angela Coulter, Ms. Sandra Eismann, Mr Ove Gaardboe, Mr Frank Goodwin, Mr. Gōran Henriks, Ms Kaisa Immonen-Charalambous, Ms Mateja Krzan, Mr Joan Carles March, Mr Andrew McCulloch, Mr Don Redding, Mr. Kawaldip Sehmi, Ms. Kristine Sorensen, Mr. Peep Stalmeier, Ms Jurate Svarcaite, Mr Cristian Traicu, Ms Lynne Van Poelgeest and Matthijs Zwier.

Intended use of this publication

The content of this publication is the result of a consensus process among experts from a variety of domains and profiles. The criteria and indicators agreed under this consensus process are meant to be used as a whole, not being recommended the selection of a subset of criteria and categories for a purpose different to which they were agreed for (ie. assessment of practices involving chronic patients under a peer review process). Be aware that other uses may compromise the reliability of the instrument and are out of the scope of the CHRODIS project.
Introduction

The Joint action on Chronic Disease and Addressing Healthy Ageing across the life cycle (JA-Chrodis) is a collaboration across the EU that brings together over 60 associated and collaborating partners from national and regional departments of health and research institutions, and other stakeholders from 26 Member States during a three-year initiative (2014-2016). This project is led by the Spanish Ministry of Health, Social Services and Equity with the Health Institute Carlos III, and in the coordination of JA-CHRODIS collaborates the European Innovation Partnership on Active and Healthy Aging (EIP AHA) alongside other stakeholders and European initiatives.

Its aim is to promote and facilitate a process of exchange and transfer of good practices between European countries and regions, addressing chronic conditions, with a specific focus on health promotion and primary prevention of chronic conditions, organizations dealing with multimorbid patients, patient’s empowerment and diabetes.

Also, JA-CHRODIS is developing a ‘Platform for Knowledge Exchange’ (PKE), where decision-makers, caregivers, patients, and researchers across the EU can find and share the best knowledge and practice on chronic diseases. The platform includes a criteria agreed by experts across the EU and an online tool to allow users to evaluate practices, interventions and policies using assessment criteria established by JA-CHRODIS.

The CHRODIS Delphi consultation gathered an expert panel to decide on the suitability and priority of a series of criteria to assess whether an intervention -policy, strategy, programme/service, as well as processes and practices- can be regarded as ‘good practice’ in the field of patient’s empowerment interventions with chronic conditions.
Methodology

A RAND modified Delphi method was used to decide on the suitability and priority of a series of criteria to assess whether an intervention can be regarded as ‘good practice’ focused on patient’s empowerment interventions with chronic conditions.

This Delphi method has combined the use of questionnaires to elicit responses in a systematic manner over two online rounds consultation using a web-based questionnaire followed by a final face to face structured meeting process to gather information from the experts. In both online rounds, experts were also invited to add any criterion or driver they thought relevant and missing. The number of participants was restricted to a maximum of 30 and a minimum of 15, allowing for eventual drop offs.

The first web-based questionnaire use for the Delphi process included the criteria identified through a search and appraisal of primary and secondary documents from different sources. It also included conceptual models, assessment tools, frameworks and procedures identified at national and international level for the evaluation of good practice related to chronic conditions, in particular -but not exclusively- those focused on patient’s empowerment interventions in the area of chronic conditions. In addition, a reverse search was undertaken based on the identified and reviewed sources.

The complete list of sources consulted and retained to elaborate the criteria is displayed in annex 1. In annex 2 is also included the summary of the evidence compiled. The search to determine the criteria were guided by the model depicted below, with a view to cover all those aspects of evaluation.
Online Round 1 (R1)

The online questionnaire included all items in the exhaustive list extracted from the review. The questionnaire was organized into 14 thematic drivers including a total of 56 items clustered.

Experts were asked to judge how relevant each item was in assessing organizational interventions focused on dealing with chronic patients with multiple conditions using a scale of 1 (not relevant at all) to 9 (highly relevant). In this round they were able to suggest additional criteria. The scale was divided into 3 brackets for this analysis: scores 1-3 were interpreted as ‘irrelevant criterion’, 4-6 ‘not clearly relevant’ and 7-9 ‘relevant criterion’ (fig 1).

In order to establish the degree of agreement, the median and the distribution of votes for each score was examined. When the median and the votes fitted within the same bracket, it was concluded that there was an agreement among the experts about that particular item. Only those items for which agreement converged around ‘relevant’ were kept for priority setting in the following round; agreements on irrelevance or not clearly relevant led to dropping the item. Those items that did not reach any agreement were kept for reassessment in the second round (fig 2).

Figure 1: answers range and possibilities of agreement

Figure 2: answers rate that did not reach agreement
Online Round 2 (R2)

The items on which experts had agreed as being relevant (7-9 score) in the first round were presented for rating on a priority scale from 1=lowest priority to 9= highest priority. The higher the value the participant chose, the more priority was attaching to the item to assess patient’s empowerment interventions with chronic conditions.

Likewise the first round, the median as well as the distribution of votes per score, were examined to determine whether experts agreed on the level of priority (1-3 low priority; 4-6 moderate priority; 7-9 high priority).

For the remaining items, which the experts had not reached agreement in the first round, were presented again this time, alongside with the median and range of variation of experts’ marks in the previous round. In light of this information, panellists were asked to rate again each item according to the proposed relevance scale (from 1=not relevant at all to 9=highly relevant).

To give a sense of the relative priority assigned to each item, the individual values of expert’s marks were summed up to build an item score. Drivers were also ranked according to the average score across the items they gathered.

Face to face

For the face to face meeting, a trained facilitator conducted the discussions following a structured consensus methodology. Two rapporteurs provided support in recording voting processes and modifications in phrasing and allocation accorded by experts’ consensus. In addition, sessions were tape-recorded (with experts’ consent) to enable an accurate account for discussions.

Each retained driver and the items clustered under it were presented following the order in the questionnaire. Reacting to a proposal by the CHRODIS Delphi Team, experts agreed to consider each driver as a criterion for intervention assessment, which was further specified into categories (the items composing each driver).

Priority-setting and weighting criteria took place in two stages: In the first step criteria and categories were presented one at a time and at this stage, merging, rephrasing and reallocating of categories across criteria were allowed.

Once consensus on the formulation of categories and criterion reached, experts proceeded to weight categories on a scale of 100. Whenever group discussions did not yield
consensus about weights distribution among categories, experts individual voting was called to allocate the 100 points using ballots. The final weight for each category was calculated averaging total points by the number of voters (dividing total points by number of experts and multiplying by 100, so the sum of categories’ weight within a criterion was always 100).

In the second stage panellists’ discussions were steered to obtain relative weights for the criteria consolidated in the previous stage. The weight given to a particular criterion was built on the concept of how the criterion was defined throughout its categories, and irrespectively of the number of categories (i.e., more categories did not mean more importance but a more nuanced definition of this criterion).

The group discussion about the relative importance of the criteria was followed by experts’ individual rating using ballots. The criteria relative weight was also rated in a 100 points scale. To determine the relative weight finally allocated to each criterion, experts’ votes were processed to obtain the average score per criterion (total sum of points divided by the number of voters and multiply by 100).

**Results**

- **Online Round 1 (R1)**

Round 1 was launched in October 19th 2015 and closed on November 16th 2015. The initial number of European experts invited to join the panel was 26. **Twenty one** of them actually completed the questionnaire in the first round: men=11 (52,4%) and women=10 (47,7%), the age-range included 19,05% within 25-34 years old, 14,3 % ages 35-44, 23,9% ages 45-54, 33,4% ages 55-65 and 9,6% >65 years old.

They came from different countries in Europe (Belgium, Denmark, Finland, France, Ireland, Italy, Lithuania, Netherlands, Slovenia, Spain, Sweden and United Kingdom); covering a variety of health system models as well as diverse individual expertise (academic, clinician, policy, advocate,). Their common feature was holding knowledge and experience in the field of patient’s empowerment interventions with chronic conditions.

In this first round, all items have passed to this 2nd round. Agreement was reached about **thirty eight** items as relevant (7-9 score) for assessing practices and, thus, they passed onto the second round for priority assessment (table 1); As for the remaining **eighteen** questions, there was no consensus among the experts, with opinions evenly split between the “not clearly relevant” and “relevant” brackets of the scale (figure 2). Those questions passed onto the second round for reassessment by the experts, this time in light of the median and range of the valuations assigned by their colleagues in the first round (table 2).
### Table 1. Relevant drivers and items for interventions’ assessment obtained from online round 1

<table>
<thead>
<tr>
<th>Driver-ID</th>
<th>Driver</th>
<th>Item-ID</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Defined intended effect</td>
<td>1</td>
<td>Key elements of the intervention embraced patient-centred care seeking self-management improvement as stated effect.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2</td>
<td>Key elements of the intervention embraced patient-centred care seeking shared decision making as stated effect.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4</td>
<td>The objectives showed alignment with patient preferences and values.</td>
</tr>
<tr>
<td>2</td>
<td>Theory grounds of intervention</td>
<td>6</td>
<td>The intervention was aligned with a comprehensive approach to patient’s empowerment.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8</td>
<td>The intervention was based on the patient’s and/or carer’s specific values, preferences, beliefs, needs, capacities, circumstances and wishes.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11</td>
<td>The intervention considered health professionals’ needs in terms of enhancing/acquiring the right skills, knowledge and attitudes to foster patient empowerment (i.e. Self-management, shared decision making, education-knowledge and value concordance).</td>
</tr>
<tr>
<td>4</td>
<td>Target group / population addressed</td>
<td>15</td>
<td>All actors intervening in the care chain (patients, carers, professionals...) were identified and considered in the intervention.</td>
</tr>
<tr>
<td>5</td>
<td>Intervention design</td>
<td>19</td>
<td>The intervention was designed and implemented in consultation with the target population (patients, carers and professionals).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>20</td>
<td>There was a clear description of the patients, carers and professionals’ specific role and/or contribution at each point in the care chain.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>21</td>
<td>Organisational structures supporting patient empowerment were clearly defined and described (i.e. responsibility assignments, flows of communication and work and accountabilities).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>22</td>
<td>Patient and stakeholder participation/involvement was planned and programmed (activation, tracking systems, formal commitments, contracts or agreements regular mechanisms for communicating are established).</td>
</tr>
<tr>
<td>6</td>
<td>Leadership</td>
<td>25</td>
<td>There was a clear leadership commitment, and the responsibilities of the different partners and the relationships among them were well defined.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>26</td>
<td>The leader was a person of reference/“champion” for the involved stakeholders with experience, trajectory and connections to the relevant networks.</td>
</tr>
<tr>
<td>7</td>
<td>Multi-stakeholder</td>
<td>27</td>
<td>The principal actors in each setting were involved in the planning and implementation of the project.</td>
</tr>
<tr>
<td>Driver-ID</td>
<td>Driver</td>
<td>Item-ID</td>
<td>Item</td>
</tr>
<tr>
<td>-----------</td>
<td>--------</td>
<td>---------</td>
<td>------</td>
</tr>
<tr>
<td>8</td>
<td>Adequacy, capacity and resources</td>
<td>28</td>
<td>All the actors intervening in the care chain to empower patients were identified/ considered (health authorities, health administration, health professionals, communities...) and their support was secured.</td>
</tr>
<tr>
<td>8</td>
<td>Adequacy, capacity and resources</td>
<td>30</td>
<td>The project leaders and all others involved in the project were adequately qualified to accomplish their tasks.</td>
</tr>
<tr>
<td>9</td>
<td>Information systems</td>
<td>31</td>
<td>The allocation of funding and resources were specified in regards to stability and commitment.</td>
</tr>
<tr>
<td>9</td>
<td>Information systems</td>
<td>32</td>
<td>The provision of resources covers all the elements of the intervention (addressed to patients, professionals and carers) and justifies sufficiency for the described tasks.</td>
</tr>
<tr>
<td>9</td>
<td>Information systems</td>
<td>33</td>
<td>Organisational structures were clearly defined and described (i.e responsibility assignments, flows of communication and work and accountabilities).</td>
</tr>
<tr>
<td>9</td>
<td>Information systems</td>
<td>34</td>
<td>The information generated by the intervention was systematically registered and integrated within the regular circuits of health care information in place (electronic health record, patient file, clinical notes...).</td>
</tr>
<tr>
<td>9</td>
<td>Information systems</td>
<td>35</td>
<td>The architecture of the information system allowed professionals and patients Personal Health Care Information access and management (including Health Care Record, patient file, and clinical notes, open health information, decision support for patients and professionals).</td>
</tr>
<tr>
<td>9</td>
<td>Information systems</td>
<td>36</td>
<td>The intervention included tools and social networks allowing communication among different stakeholders (patients and professionals).</td>
</tr>
<tr>
<td>10</td>
<td>Interaction with care delivery system</td>
<td>37</td>
<td>The intervention was inserted in the existing organization of care consistently over time.</td>
</tr>
<tr>
<td>10</td>
<td>Interaction with care delivery system</td>
<td>38</td>
<td>The intervention addressed the patient’s transition across different levels of care ensuring communication and cooperation between professionals, centres, programmes or services.</td>
</tr>
<tr>
<td>10</td>
<td>Interaction with care delivery system</td>
<td>39</td>
<td>The intervention sought linkage and coordination between community services and health care delivery system to empower patients.</td>
</tr>
<tr>
<td>11</td>
<td>Ethical considerations</td>
<td>41</td>
<td>Rights on information access and right to refuse to be informed or treated were respected and enhanced.</td>
</tr>
<tr>
<td>11</td>
<td>Ethical considerations</td>
<td>42</td>
<td>The intervention’s objectives and strategy were transparent to patients /carers involved and professionals.</td>
</tr>
<tr>
<td>11</td>
<td>Ethical considerations</td>
<td>43</td>
<td>Potential burdens, including harm of the intervention for patients were addressed.</td>
</tr>
<tr>
<td>12</td>
<td>Evaluation</td>
<td>45</td>
<td>There was a validated method and/or tools for regular evaluation in place for assessing the progress and/or impact of the implemented intervention on patient/user empowerment.</td>
</tr>
<tr>
<td>12</td>
<td>Evaluation</td>
<td>46</td>
<td>Information /monitoring systems were in place to regularly deliver data aligned with evaluation and reporting needs.</td>
</tr>
</tbody>
</table>
The evaluation framework included assessment of all relevant outcomes: quality of life, costs, service/system utilization, self-management, patient’s experience, professional satisfaction, shared-decision making and education/knowledge.

The evaluation results were relevant and linked to the stated goals and objectives.

The results of evaluation were linked to actions to reshape the implementation accordingly.

The continuation of the project was ensured through ownership and/or institutional anchoring.

The intervention promoted alliances, collaborative framework with other stakeholders.

There was an analysis of requirements for potential scalability such as patient characteristics, (i.e. stage of disease/dependence of patients and, other characteristics of importance for the elements of patient empowerment i.e education-knowledge, shared decision-making and self-management).

There was an analysis of requirements for potential scalability such as patient’s support i.e. community resources, patient networks.

There were specific knowledge transfer strategies in place (evidence into practice).

Table 2. No consensus drivers and items for interventions’ assessment obtained in round 1

<table>
<thead>
<tr>
<th>Driver-ID</th>
<th>Driver</th>
<th>Item-ID</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>Sustainability</td>
<td>50</td>
<td>The continuation of the project was ensured through ownership and/or institutional anchoring.</td>
</tr>
<tr>
<td>51</td>
<td>Sustainability</td>
<td></td>
<td>The intervention promoted alliances, collaborative framework with other stakeholders.</td>
</tr>
<tr>
<td>14</td>
<td>Scalability</td>
<td>54</td>
<td>There was an analysis of requirements for potential scalability such as patient characteristics, (i.e. stage of disease/dependence of patients and, other characteristics of importance for the elements of patient empowerment i.e education-knowledge, shared decision-making and self-management).</td>
</tr>
<tr>
<td>55</td>
<td>Scalability</td>
<td>56</td>
<td>There was an analysis of requirements for potential scalability such as patient’s support i.e. community resources, patient networks.</td>
</tr>
<tr>
<td>3</td>
<td>Defined intended</td>
<td>3</td>
<td>Key elements of the intervention embraced patient-centred care seeking education-knowledge as stated effect.</td>
</tr>
</tbody>
</table>
The objectives showed alignment with adopted guidelines, programmes and policies, and a relevant scope for expansion.

The practice follows a strategic framework, seeking to develop a systemic vision of the implications of empowering patients for the organization.

The intervention was tailored to the health system organizational characteristics and socioeconomic environment.

There was a baseline assessment of the situation (including team and other stakeholders readiness to engage) used to better shape the intervention according to the established ‘departing point’.

A comparison to existing alternatives of intervention was carried out including impact on different dimensions of patient empowerment (i.e. Self-management, shared decision making, education-knowledge and value concordance).

A comparison to existing alternatives of intervention was carried out including impact in terms of health care utilization (e.g. visits, hospitalizations, treatments, tests...).

The concept included a SMART specification of the intervention aims and objectives (Specific/Measurable/Acceptable for the target population/Realistic/Time-framed).

The needs of the intervention’s target group/s in the setting were adequately identified and considered (a comprehensive assessment of patients/users/professionals specificities has been carried out).

Methods used for selection of target population/were described, documented and suitable to their characteristics.

The design thoroughly described the methodology of intervention: recruitment, location, concrete activities and timeframe (sequence, frequency, duration).

Community engagement was planned and organised to include relevant stakeholders from the local civil society (i.e main town halls, NGOs, business, individuals....).

The institutional leadership was aligned with the scope of the implementation.
### Online Round 2 (R2)

Round 2 was launched in December 14th 2015 and closed on January 18th 2016. The initial number of European experts invited to join the second round panel was 21. **Twenty** of them completed the questionnaire in this round: men=12 (60%) and women=8 (40%), the age-range included 20% within 25-34 years old, 10% ages 35-44, 15% ages 45-54, 35% ages 55-65 and 15% >65 years old.

They came from different countries in Europe (Belgium, France, Germany, Ireland, Netherlands, Slovakia, Spain, Sweden and United Kingdom); covering a variety of health system models as well as diverse individual expertise (academic, clinician, policy). Their common feature was holding knowledge and experience in the field of organizational interventions focused on dealing with chronic patients with multiple conditions.

In relation to the **eighteen** items where the panel reached not agreement in the first round, **one** were deemed relevant and retained for discussion at the face to face meeting (table 3).

<table>
<thead>
<tr>
<th>Driver-ID</th>
<th>Driver</th>
<th>Item-ID</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Multi-stakeholder</td>
<td>29</td>
<td>Social support (in terms of gaining the support of stakeholders outside the health system) is arranged.</td>
</tr>
<tr>
<td></td>
<td>involvement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Ethical considerations</td>
<td>40</td>
<td>Conflict of interests among stakeholders and individuals involved were analysed.</td>
</tr>
<tr>
<td>12</td>
<td>Evaluation</td>
<td>44</td>
<td>The evaluation process involved the engagement of stakeholders, including those participating in program operation, those served or affected by the program; and primary key users/participants.</td>
</tr>
<tr>
<td>13</td>
<td>Sustainability</td>
<td>52</td>
<td>The financial viability of the intervention was guaranteed in the long term.</td>
</tr>
<tr>
<td>14</td>
<td>Scalability</td>
<td>53</td>
<td>There was an analysis of requirements for potential scalability such as adaptability and perceived challenges for healthcare organization/governance (trialability, stepwise introduction, technology support requirements...).</td>
</tr>
</tbody>
</table>

Table 3: Driver and items assessed as relevant in round 2
The evaluation process involved the engagement of stakeholders, including those participating in program operation, those served or affected by the program; and primary key users/participants.

The other seventeen items were considered unclear or no relevant; therefore they were discarded from the list (table 4).

Table 4: Drivers and items discarded in round 2

<table>
<thead>
<tr>
<th>Driver-ID</th>
<th>Driver</th>
<th>Item-ID</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>Evaluation</td>
<td>44</td>
<td>The evaluation process involved the engagement of stakeholders, including those participating in program operation, those served or affected by the program; and primary key users/participants.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Driver-ID</th>
<th>Driver</th>
<th>Item-ID</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Defined intended effect</td>
<td>3</td>
<td>Key elements of the intervention embraced patient-centred care seeking education-knowledge as stated effect.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5</td>
<td>The objectives showed alignment with adopted guidelines, programmes and policies, and a relevant scope for expansion.</td>
</tr>
<tr>
<td>2</td>
<td>Theory grounds of intervention</td>
<td>7</td>
<td>The practice follows a strategic framework, seeking to develop a systemic vision of the implications of empowering patients for the organization.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9</td>
<td>The intervention was tailored to the health system organizational characteristics and socioeconomic environment.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10</td>
<td>There was a baseline assessment of the situation (including team and other stakeholders readiness to engage) used to better shape the intervention according to the established ‘departing point’.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12</td>
<td>A comparison to existing alternatives of intervention was carried out including impact on different dimensions of patient empowerment (i.e. Self-management, shared decision making, education-knowledge and value concordance).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>13</td>
<td>A comparison to existing alternatives of intervention was carried out including impact in terms of health care utilization (e.g. visits, hospitalizations, treatments, tests...).</td>
</tr>
<tr>
<td>3</td>
<td>Aims and objectives</td>
<td>14</td>
<td>The concept included a SMART specification of the intervention aims and objectives (Specific/Measurable/Acceptable for the target population/Realistic/Time-framed).</td>
</tr>
<tr>
<td>4</td>
<td>Target group / population addressed</td>
<td>16</td>
<td>The needs of the intervention’s target group/s in the setting were adequately identified and considered (a comprehensive assessment of patients/users/professionals specificities has been carried out).</td>
</tr>
</tbody>
</table>
Driver-ID | Driver | Item-ID | Item
---|---|---|---
| | | 17 | Methods used for selection of target population/were described, documented and suitable to their characteristics

| 5 | Intervention design | 18 | The design thoroughly described the methodology of intervention: recruitment, location, concrete activities and timeframe (sequence, frequency, duration).
| | | 23 | Community engagement was planned and organised to include relevant stakeholders from the local civil society (i.e main town halls, NGOs, business, individuals,...).

| Driver-ID | Driver | Item-ID | Item
---|---|---|---
| 6 | Leadership | 24 | The institutional leadership was aligned with the scope of the implementation.
| 7 | Multi-stakeholder involvement | 29 | Social support (in terms of gaining the support of stakeholders outside the health system) is arranged.
| 11 | Ethical considerations | 40 | Conflict of interests among stakeholders and individuals involved were analysed.
| 13 | Sustainability | 52 | The financial viability of the intervention was guaranteed in the long term.
| 14 | Scalability | 53 | There was an analysis of requirements for potential scalability such as adaptability and perceived challenges for healthcare organization/governance (trialability, stepwise introduction, technology support requirements...).

From the **thirty eight** items agreed as relevant in the previous round, **thirty five** rated in the area of high priority and **three** were assigned a low priority on the second round. They were kept for discussion at the face to face meeting. The scores obtained for each item and the corresponding drivers are summarised in table 5.
Table 5: Relevant drivers and items for intervention’s assessment ordered by their average priority scores obtained from round 2.

Note: Category coloured in yellow corresponds to no consensus item obtained in round one and subsequently selected as relevant in the second round, and categories coloured in pink correspond to the item assigned low priority in the second round ranked by priority weight.

<table>
<thead>
<tr>
<th>Driver-ID</th>
<th>Driver</th>
<th>Item-ID</th>
<th>Item</th>
<th>Priority weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Defined intended effect</td>
<td>1</td>
<td>Key elements of the intervention embraced patient-centred care seeking self-management improvement as stated effect.</td>
<td>156</td>
</tr>
<tr>
<td>2</td>
<td>Theory grounds of intervention</td>
<td>2</td>
<td>Key elements of the intervention embraced patient-centred care seeking shared decision making as stated effect.</td>
<td>158</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td>4</td>
<td>The objectives showed alignment with patient preferences and values.</td>
<td>166</td>
</tr>
<tr>
<td>4</td>
<td>Target group / population addressed</td>
<td>6</td>
<td>The intervention was aligned with a comprehensive approach to patient’s empowerment.</td>
<td>155</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td>8</td>
<td>The intervention was based on the patient’s and/or carer’s specific values, preferences, beliefs, needs, capacities, circumstances and wishes.</td>
<td>162</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11</td>
<td>The intervention considered health professionals’ needs in terms of enhancing/acquiring the right skills, knowledge and attitudes to foster patient empowerment (i.e. Self-management, shared decision making, education-knowledge and value concordance).</td>
<td>155</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td>15</td>
<td>All actors intervening in the care chain (patients, carers, professionals...) were identified and considered in the intervention.</td>
<td>149</td>
</tr>
<tr>
<td></td>
<td></td>
<td>19</td>
<td>The intervention was designed and implemented in consultation with the target population (patients, carers and professionals).</td>
<td>160</td>
</tr>
<tr>
<td></td>
<td></td>
<td>20</td>
<td>There was a clear description of the patients, carers and professionals’ specific role and/or contribution at each point in the care chain.</td>
<td>155</td>
</tr>
<tr>
<td></td>
<td></td>
<td>21</td>
<td>Organisational structures supporting patient empowerment were clearly defined and described (i.e. responsibility assignments, flows of communication and work and accountabilities).</td>
<td>150</td>
</tr>
<tr>
<td></td>
<td></td>
<td>22</td>
<td>Patient and stakeholder participation/involvement was planned and programmed (activation, tracking systems, formal commitments, contracts or agreements regular mechanisms for communicating are established).</td>
<td>151</td>
</tr>
<tr>
<td>Driver-ID</td>
<td>Driver</td>
<td>Item-ID</td>
<td>Item</td>
<td>Priority weight</td>
</tr>
<tr>
<td>-----------</td>
<td>-------------------------------</td>
<td>---------</td>
<td>----------------------------------------------------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>6</td>
<td>Leadership</td>
<td>25</td>
<td>There was a clear leadership commitment, and the responsibilities of the different partners and the relationships among them were well defined.</td>
<td>156 155</td>
</tr>
<tr>
<td>6</td>
<td></td>
<td>26</td>
<td>The leader was a person of reference/&quot;champion&quot; for the involved stakeholders with experience, trajectory and connections to the relevant networks.</td>
<td>153 156</td>
</tr>
<tr>
<td>7</td>
<td>Multi-stakeholder involvement</td>
<td>27</td>
<td>The principal actors in each setting were involved in the planning and implementation of the project.</td>
<td>160 153</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td>28</td>
<td>All the actors intervening in the care chain to empower patients were identified/considered (health authorities, health administration, health professionals, communities….) and their support was secured.</td>
<td>154 155</td>
</tr>
<tr>
<td>8</td>
<td>Adequacy, capacity and resources</td>
<td>30</td>
<td>The project leaders and all others involved in the project were adequately qualified to accomplish their tasks.</td>
<td>157 154</td>
</tr>
<tr>
<td>8</td>
<td></td>
<td>31</td>
<td>The allocation of funding and resources were specified in regards to stability and commitment.</td>
<td>151 152</td>
</tr>
<tr>
<td>8</td>
<td></td>
<td>32</td>
<td>The provision of resources covers all the elements of the intervention (addressed to patients, professionals and carers) and justifies sufficiency for the described tasks.</td>
<td>153 154</td>
</tr>
<tr>
<td>8</td>
<td></td>
<td>33</td>
<td>Organisational structures were clearly defined and described (i.e responsibility assignments, flows of communication and work and accountabilities).</td>
<td>148 147</td>
</tr>
<tr>
<td>9</td>
<td>Information systems</td>
<td>34</td>
<td>The information generated by the intervention was systematically registered and integrated within the regular circuits of health care information in place (electronic health record, patient file, clinical notes…).</td>
<td>152 155</td>
</tr>
<tr>
<td>9</td>
<td></td>
<td>35</td>
<td>The architecture of the information system allowed professionals and patients Personal Health Care Information access and management (including Health Care Record, patient file, and clinical notes, open health information, decision support for patients and professionals).</td>
<td>148 146</td>
</tr>
<tr>
<td>9</td>
<td></td>
<td>36</td>
<td>The intervention included tools and social networks allowing communication among different stakeholders (patients and professionals).</td>
<td>133 134</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Driver-ID</th>
<th>Driver</th>
<th>Item-ID</th>
<th>Item</th>
<th>Priority weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>Interaction with care delivery system</td>
<td>37</td>
<td>The intervention was inserted in the existing organization of care consistently over time.</td>
<td>146</td>
</tr>
<tr>
<td>10</td>
<td></td>
<td>38</td>
<td>The intervention addressed the patient’s transition across different levels of care ensuring communication and cooperation between professionals, centres, programmes or services.</td>
<td>162 154</td>
</tr>
<tr>
<td>10</td>
<td></td>
<td>39</td>
<td>The intervention sought linkage and coordination between community services and health care delivery system to empower patients.</td>
<td>154</td>
</tr>
<tr>
<td>Driver-ID</td>
<td>Driver</td>
<td>Item-ID</td>
<td>Item</td>
<td>Priority weight</td>
</tr>
<tr>
<td>-----------</td>
<td>-------------------------</td>
<td>---------</td>
<td>----------------------------------------------------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>11</td>
<td>Ethical considerations</td>
<td>41</td>
<td>Rights on information access and right to refuse to be informed or treated were respected and enhanced.</td>
<td>164</td>
</tr>
<tr>
<td></td>
<td></td>
<td>42</td>
<td>The intervention’s objectives and strategy were transparent to patients/carers involved and professionals.</td>
<td>163</td>
</tr>
<tr>
<td></td>
<td></td>
<td>43</td>
<td>Potential burdens, including harm of the intervention for patients were addressed.</td>
<td>163</td>
</tr>
<tr>
<td>12</td>
<td>Evaluation</td>
<td>44</td>
<td>The evaluation process involved the engagement of stakeholders, including those participating in program operation, those served or affected by the program; and primary key users/participants.</td>
<td>143</td>
</tr>
<tr>
<td></td>
<td></td>
<td>45</td>
<td>There was a validated method and/or tools for regular evaluation in place for assessing the progress and/or impact of the implemented intervention on patient/user empowerment.</td>
<td>152</td>
</tr>
<tr>
<td></td>
<td></td>
<td>46</td>
<td>Information/monitoring systems were in place to regularly deliver data aligned with evaluation and reporting needs.</td>
<td>153</td>
</tr>
<tr>
<td></td>
<td></td>
<td>47</td>
<td>The evaluation framework included assessment of all relevant outcomes: quality of life, costs, service/system utilization, self-management, patient’s experience, professional satisfaction, shared-decision making and education/knowledge.</td>
<td>153</td>
</tr>
<tr>
<td></td>
<td></td>
<td>48</td>
<td>The evaluation results were relevant and linked to the stated goals and objectives.</td>
<td>158</td>
</tr>
<tr>
<td></td>
<td></td>
<td>49</td>
<td>The results of evaluation were linked to actions to reshape the implementation accordingly.</td>
<td>162</td>
</tr>
<tr>
<td>13</td>
<td>Sustainability</td>
<td>50</td>
<td>The continuation of the project was ensured through ownership and/or institutional anchoring.</td>
<td>148</td>
</tr>
<tr>
<td></td>
<td></td>
<td>51</td>
<td>The intervention promoted alliances, collaborative framework with other stakeholders.</td>
<td>150</td>
</tr>
<tr>
<td>14</td>
<td>Scalability</td>
<td>54</td>
<td>There was an analysis of requirements for potential scalability such as patient characteristics, (i.e. stage of disease/dependence of patients and, other characteristics of importance for the elements of patient empowerment i.e education-knowledge, shared decision-making and self-management).</td>
<td>142</td>
</tr>
<tr>
<td></td>
<td></td>
<td>55</td>
<td>There was an analysis of requirements for potential scalability such as patient’s support i.e. community resources, patient networks.</td>
<td>144</td>
</tr>
<tr>
<td></td>
<td></td>
<td>56</td>
<td>There were specific knowledge transfer strategies in place (evidence into practice).</td>
<td>136</td>
</tr>
</tbody>
</table>
• Comments provided by the experts

In both first and second round, experts were invited to add any driver they thought relevant or missing. They were also encouraged to provide comments to individual items, drivers, or the general model. Though no additional items were suggested during this process, experts’ comments proved very informative as to how they were facing their task and the conceptual difficulties they identified in the process.

One of the issues that can be gathered from those comments is the importance of having a strategy framework to empower patients in the organization. However, there is concern that the vision of the organization might lose the patient’s focus, towards the organization’s objectives and results:

[“I agree with a framework strategy, but I disagree with the development of a systemic vision. The most important reason is that you will easily lose focus on individual patients and shift towards result on an organizational level”]

In relation to education and knowledge, though it is well supported if centred on patient’s needs, its impact on empowerment is questioned:

[“…education-knowledge should be based on what a patient wants to know. Just testing the education-knowledge could give a positive result, but doesn’t necessarily mean that it has an effect on empowerment!”]

Another topic of importance for the experts is leadership within an organization. Some experts expressed concern about too much valuing leadership in a practice. It is also argued the importance of others “champions” in the organization that can influence the outcome of the intervention.

[“…leaders only contribute marginally to effective implementation”]

[“The leader would necessarily have to be a champion, would not it? What is important is that there are other champions in the network that will have an influence on the outcome.”]

The lack interaction among different levels of care was stressed by some experts

[“The linkage between the health and social are vital. There is a deficiency in practice with separate departments, budgets, etc.”]

Some others emphasised that enhancing the information systems to foster communication across services.

[“… seems to be obligatory… information flows are undoubtedly vitally important.”]
Some expert also revealed the difficulty of evaluating interventions to empower patients throughout usual measurement systems:

[“Difficult to measure empowerment through the traditional way, putting a number is unrealistic”].

Along the comments, they also mentioned the importance to be clear and concise about what information has to be collected and the difficulty that may encounter to obtain it:

[“...whenever talking about information collection, it needs to be carefully designed so that the information collected is only what is meaningful and important to evaluate the project, and does not represent an excessive burden on the people who have to record it.”]

And some others highlight that, stakeholders involved in the intervention, especially patients, should also be engaged in the evaluation process:

[“... of course users/patients have to be involved in the evaluation.”]

Along the same lines other participant supported the idea of adding patients’ perspective to the intervention evaluation

[“...it is also important that “self-management improvement” and “shared decision-making” are evaluated according to patients’ perspective (what matters for the patient) over and above what matters for the healthcare system or professionals. This selection of what matters most is what will make the outcome patient centred in a meaningful way”].

And the main outcomes should be also put on patients’ experiences and outcomes:

[“...main focus should be on the health care providers and patients, their experiences and patient outcomes”].

Related to sustainability and despite is not always seen as priority, some experts emphasized that should be taken into account when the intervention is designed:

[“Sustainability is a phase that is not always in the centre of our attention. I think it should be, to embed the intervention”].

Others argued that it is not always possible to foreseen sustainability of a practice and that some of them could not be affordable in the present but may result in costs reductions in the long term.

[“Ideally there should be an idea of sustainability, but it has to be recognised that this is not always feasible or at least it cannot be foreseen in advance”].
“... of course financial viability is crucial, but by improving quality of care and experience of care, reduction of costs is imminent. The thing is that an intervention could be part of an investment in health. In other words it could be part of reducing costs in the long term whilst be financially unviable at present times”.

All these concerns were addressed and dealt with during discussions at the face to face meeting.

- **Face to face**

The expert meeting to refine and prioritize criteria to assess interventions on patient’s empowerment took place on 18th and 19th February 2016 in Brussels.

**Eleven** out of the twenty experts that completed the 2nd round were able to attend. They were 6 women and 5 men. The range of countries represented (Brussels, France, Ireland, Netherlands, Slovenia, Spain, and United Kingdom) still showed a good sample of the variety of health systems in Europe. The range in expertise was also covered with academic, clinician, advocate, patient’s associations and policy representatives.

In order to ease discussions at the meeting, the initial 13 criteria obtained in the second online round (table 5) were further elaborated by the CHRODIS Delphi Team to identify redundancies. Thus, a proposal for merging criteria and reallocating categories was presented to the expert panel and thoroughly discussed at the meeting. The experts finally agreed on 7 criteria made up of 28 categories and weighted categories composing each criterion as well as the final list of criteria. Table 6 shows the final list of categories, criteria and their weights agreed by the expert panel.

The following paragraphs provide details on the decisions made by the panel to achieve this final output on the basis of the results obtained from the 2 online rounds (reflected in table 5).

Criterion 1 “**Defined intended effect**” and criterion 2 “**Theory grounds of intervention**” were merged into a new one renamed “**Goals, scope and mechanisms**”

Categories 1 and 2 were combined as follows:

*The intervention actively promotes patient empowerment by using appropriate mechanisms to embrace patient empowerment (e.g. self-management support, shared decision making, education-information or value clarification, etc).*

Categories 4, 6 and 8 were also merged resulting in:

*The intervention is aligned with patients and/or carers specific values, preferences, beliefs, needs, capacities, circumstances and/or expectations.*
Category 11 was rephrased changing health professionals to all stakeholders as the subjects which need patient empowerment knowledge to be covered:

*The intervention considered all stakeholders’* needs in terms of enhancing/acquiring the right skills, knowledge and behaviour to promote patient empowerment (*Patients, carers, health and care professionals, policy makers, etc.*).

Criterion 4 “Target group/population addressed”, criterion 5 “Intervention design” and criterion 7 “Multi-stakeholder involvement” were merged into a new criterion named “Care intervention design” and composed by 5 categories redacted as follows:

- The intervention was co-designed and implemented with the target population (patients, carers and professionals).
- All relevant stakeholders (patients, carers, professionals, community groups, statutory bodies, etc.) were considered and key stakeholders identified.
- There was a clear description of the patients, carers and professionals’ specific role and their contribution was appropriately planned, supported and resourced.
- Organisational structures supporting patient empowerment were clearly defined and described (i.e. responsibility assignments, flows of communication and work and accountabilities).
- Key stakeholders (other than target population) were involved in the design and implementation of the intervention.

Criterion 6 “Leadership”, criterion 8 “Adequacy, capacity and resources” and criterion 9 “Information Systems” were merged into a new one renamed “Leadership, Capacity and Communications”. Experts preferred the term leadership to leader as they objected the individual nature of the later. They stressed the difference between a leader and a champion, and different opinions were sustained about the importance of the champions endorsing patient empowerment interventions. As a part of information systems, good internal communication was pointed out and the access to the information, not only for professionals but also for patients.

The new criterion was finally composed by 6 categories redacted as follows:

- There was a clear commitment to the intervention from the leadership of the organisations.
- Leadership of the intervention exhibits commitment to patient’s empowerment and is both credible and effective.
• All team members involved had appropriate capacities, experience, training and support to accomplish their tasks.
• The provision of resources covers all the elements of the intervention and is sufficient for the described tasks.
• The information generated by the intervention was systematically recorded and is accessible to professionals and patients and when appropriate embedded in existing information systems.
• The intervention included an effective mechanism for internal communication.

Criterion 10 “Interaction with care delivery system” was renamed as “Interaction with the health and care delivery system” as it is a more accurate and comprehensive name. Experts remarked that there could be very good practices that don’t cover the whole care pathway or the different levels of care so they rephrased the three existing categories into two new ones discarding the concept of inserting the practice in the system:

• The intervention considers creating effective linkages with all relevant parts of the health and care system.
• The intervention enhances and supports the patients’ and/or carers’ ability to effectively interact with the health and care system.

Criterion 11 “Ethical considerations” was barely changed. Experts discussed category 41 and discarded the idea of patients refused to be informed. They discussed about patients and carers right to be informed, and specify that their rights should include decision about their care and issues regarding confidentiality. The three categories making up the criterion resulted as follows:

• Patients’ and/or carers’ rights to be informed, to decide about their care, participation and issues regarding confidentiality were respected and enhanced.
• The intervention’s objectives and strategy were transparent to all involved stakeholders.
• All the potential burdens, benefits and harms of the intervention were addressed for both patients and/or carers.

Criterion 12 “Evaluation” was renamed as “Evaluation and Monitoring” as they were regarded as two different concepts needed to be considered separately.

Categories 45 and 46 were merged into one, and categories 44, 47, 48 and 49 were rephrased
The final 5 categories resulted as follows:

- There was a stated method and information system for regular monitoring and evaluation the progress (formative) and/or impact (summative) of the implemented intervention.
- The evaluation framework includes assessment of all relevant outcomes including those selected by patients and/or carers.
- The evaluation results were relevant and linked to the stated goals and objectives.
- There is a process in place to reshape the implementation according to the evaluation results.
- The evaluation process and dissemination of the results involved relevant stakeholders.

Finally, criterion 13 “Sustainability” and criterion 14 “Scalability” were merged into a single criterion renamed “Sustainability, Scalability and Transferability” to keep coherence with previous Delphi processes. The two categories making up Scalability were merged into one. Also Category 31 and category 37 (from other criteria) were included and discussed as part of this new criterion.

The new criterion “Sustainability, Scalability and Transferability” resulted in four categories rephrased as follows:

- The continuation of the project has been ensured through institutional anchoring and/or ownership by the relevant stakeholder or communities.
- Human and financial resources for the long term future of the project have been identified and action has been taken to secure them.
- Advocates or champions for the continuation of the project have been identified and nurtured (e.g. patients and carers’ groups, community leaders, policy makers, organisations leaders, professionals, etc).
- There is an analysis of requirements for potential scalability and transferability.

Once the work on new specification was completed, and categories in each criterion were weighted, experts weighed the 7 criteria by distributing 100 points among them. The highest weight was assigned to the criterion: “Care intervention design” (19% of the total score of a practice), while the criteria with the lowest score (11% of total score each) were: “Interaction with the health and care system”, “Ethical considerations” and “Sustainability, Scalability and Transferability”. Category and criteria weights are detailed in table 6.
Table 6: Final set of weighted criteria recommended for evaluating patient’s intervention with chronic diseases ranked by criteria weight.

<table>
<thead>
<tr>
<th>NEW Criteria name</th>
<th>Criteria Weight</th>
<th>Categories</th>
<th>Category Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core intervention design</td>
<td>19</td>
<td>The intervention was co-designed and implemented with the target population (patients, caregivers and professionals). All relevant stakeholders (patients, caregivers, professional, community groups, statutory bodies, etc.) were considered and key stakeholders identified. There was a clear description of the patient’s care and professional specific role and their contribution was appropriately planned, supported and resourced. Organisational structures supporting patients’ empowerment were clearly defined and described (i.e. responsibility assignments, roles of communication and roles and accountabilities). Key stakeholders (other than target population) were involved in the design and implementation of the intervention.</td>
<td>30</td>
</tr>
<tr>
<td>Goals, scope and mechanisms</td>
<td>17</td>
<td>The intervention actively promotes patients’ empowerment by using appropriate mechanisms (e.g. self-management support, shared decision making, education-information, value clarification, etc.) The intervention is aligned with patients’ and/or caregivers values, preferences, beliefs, needs, capacities, circumstances and/or expectations. The intervention considered all stakeholders’ needs in terms of enhancing acquiring the right skills, knowledge and behaviour to promote patient empowerment (patients, caregivers, health and care professionals, policy makers, etc.).</td>
<td>40</td>
</tr>
<tr>
<td>Leadership, Capacity and Communication</td>
<td>17</td>
<td>There was a clear commitment to the intervention from the leadership of the participating organisations. The category of the intervention exhibits commitment to patients’ empowerment and is both credible and effective. All team members involved had appropriate capacities, experience, training and support to accomplish their tasks. The prevention of resources covers all the elements of the intervention and is sufficient for the described tasks. The information generated by the intervention was systematically recorded and is accessible to professionals and patients, and where appropriate embedded in existing information systems. The intervention included an effective mechanism for internal communication.</td>
<td>40</td>
</tr>
<tr>
<td>Evaluation and monitoring</td>
<td>14</td>
<td>There was a stated method and information system for regular monitoring and evaluation of the progress (formative and/or impact) of the implemented intervention. The evaluation framework includes assessment of all relevant outcomes including those selected by patient and/or caregivers. The evaluation results are relevant and linked to the stated goals and objectives. There is a process in place to reshape the implementation according to the evaluation results. The evaluation process and dissemination of the results involved relevant stakeholders.</td>
<td>25</td>
</tr>
<tr>
<td>Interaction with the health and care system</td>
<td>11</td>
<td>The intervention considers creating effective linkages with all relevant parts of the health and care system. The intervention enhances and supports the patient’s and/or caregiver’s ability to effectively interact with the health and care system.</td>
<td>30</td>
</tr>
<tr>
<td>Ethical considerations</td>
<td>11</td>
<td>Patients and/or caregivers’ rights to be informed, to decide about their care, participation and issues regarding confidentiality, were respected and enhanced. The intervention’s objectives and strategy were transparent to all involved stakeholders. All the potential burdens, benefits and harms of the intervention were addressed for both patients and/or caregivers.</td>
<td>30</td>
</tr>
<tr>
<td>Sustainability, scalability and transferability</td>
<td>11</td>
<td>The continuation of the project has been ensured through institutional anchoring and/or ownership by the relevant stakeholders or communities. Human and financial resources for the long-term future of the project have been identified and action has been taken to secure them. Advocates or champions for the continuation of the project have been identified and nurtured (e.g., patients and caregivers’ groups, community leaders, policy makers, organisations leaders, professional, etc.). There is an analysis of requirements for potential scalability and transferability.</td>
<td>22</td>
</tr>
</tbody>
</table>

Total must equal 100
ANNEX 1: List of Sources

1. PRACTICE APPRAISAL: FRAMEWORKS

   a) EU level


   ▪ EIP-AHA B3 Maturity Model. AA5 Patient / User Empowerment dimensions.


   ▪ SUCCEED tool

   ▪ European Quality Instrument for Health Promotion (EQUIHP)

   ▪ Empathy. Empowering patients in the management of chronic disease.


   b) International experience


   ▪ Preventing and Managing Chronic Disease: Ontario’s Framework

   ▪ Assessment of Chronic Illness Care (ACIC): A Practical Tool to Measure Quality Improvement — MacColl Institute for Healthcare Innovation (USA)

   ▪ Patient assessment of chronic illness care (PACIC and PACIC plus)—MacColl Institute for Healthcare Innovation (USA)

   ▪ CDC Program Performance and Evaluation Office (PPEO) – Program Evaluation Steps
· Quint-essenz: Swiss quality criteria for health promotion and prevention programmes
  www.quint-essenz.ch

· CDC’s Framework for Program Evaluation in Public Health, steps and standards.

**WHO:**

· Coulter A, Parsons S and Askham J. Where are the patients in decision-making about their own care? World Health Organization and World Health Organization, on behalf of the European Observatory on Health Systems and Policies. (2008)

· NCD report 2010

· Cost of scaling up action against NCD 2011

· Best buys to prevent NCDS: Discussion Paper Prevention and control of NCDS: Priorities for investment 2011

· Draft comprehensive global monitoring framework and targets for the prevention and control of NCD 2013

WPS collaborators and associated partners- National GP assessment frameworks revised were: Bulgaria, Cyprus, Estonia, Germany, Greece, Iceland, Ireland, Italy, Lithuania, Netherlands, Norway, Portugal, Spain and UK.

**2. INNOVATION**


- WHO Innovative Care for Chronic Conditions: Building blocks for action 2012

- PAHO Innovative Care for Chronic conditions: Organizing and Delivering High Quality Care for Chronic Non communicable Diseases in the Americas 2013-Eng

- Excellent Innovation for Ageing a European guide for the Reference sites of the European Innovation Partnership on Active and Healthy Ageing


- Margolis et al Collaborative Chronic Care Networks (C3Ns) to Transform Chronic Illness Care. Pediatrics 2013;131;S219


- RESINDEX model Regional Social Innovation Index 2013. Innobasque - 2013

- OECD Innovation strategy 2010


3. SCALABILITY

- DG SANCO y DG CONNECT European scaling up strategy for Reference Sites EIP AHA 2014


4. IMPLEMENTATION


ANNEX 2: Summary of Evidence

This document is intended to provide a view of the foundations for the list of drivers and items submitted to experts in the first online round. It summarises the specific contribution of each of the sources analysed and retained as relevant during the literature review (to see a complete list of the sources consulted, please, refer to the document “list of sources”). There main bodies of information is made up of the conceptual models, assessment tools, frameworks and procedures identified at national and international level Europe focused on patient’s empowerment interventions with chronic conditions.

1. PRACTICE APPRAISAL: TOOLS AND FRAMEWORKS

a) EU level

| DOCUMENT: SUCCEED. A quality Improvement Tool for HIV Prevention Projects |
| Summary |
| Succeed is a tool designed to help HIV prevention projects, assess their objectives, and analyse their ability to meet them with sound, high quality activities. |
| The SUCCEED tool allows project personnel, and important stakeholders, to review their own work and improve it while its implementation. Succeed is based on scientific research about success factors in the field of health promotion. It has been specifically adapted for its use in HIV prevention. It can be used to review existing interventions or a draft of a new one, using a straightforward questionnaire to capture critical data points about the quality of the project. |
| The questionnaire broadly addresses three widely-recognized work aspects on quality improvement: Structure, Process and Results. Each part has several sections in which one can choose the questions that apply to the project in order to be assessed. At the end of each section, you can develop and document your own recommendations and actions for improvement. |
| The SUCCEED tool has been conceived primarily as a self-diagnostic approach to quality improvement. |

Contribution to CHRODIS GP assessment dimensions
Two new domains were added from this tool:

**Ethical implications of the project**

**Sustainability of the project.** *(This item will be stated from the result of the programme assessment)*

It also contributes to the reinforcement of the following “criteria”:

- **Theory grounds** (well specified and measurable main goal and sub-goals)
- **Expected size of the effect**
- **Time Schedule**
- **Leadership** (and responsibility)
- **Key population and target population**
- **Community linkages**
- **Financing and sources of funding**
- **Participation and commitment**
- **Mapping of relevant stakeholders**
- **Impact of the implementation in current organization**
- **Specific knowledge transfer strategies planned or already in place**
- **Regularity of monitoring reports and consequences derived from assessment**
- **Evaluation framework assessing process and outcomes**

**Regarding participation:**

- Do you know if the stakeholders feel they are active participants in the project?  
- Does the project track the extent of stakeholder participation?  
- Have stakeholders made formal commitments about their participation in the project?  
- If yes, can you list the commitments made by the various stakeholders?  
- Are there contracts or agreements between the project sponsor and the stakeholders *(e.g. between the project sponsor and an implementing partner)*?  
- Are there regular mechanisms for communicating with stakeholders?  
- Has the project analyzed potential obstacles and/or opponents to its work?  

**Other comments**

Although the SUCCEED tool has been specifically adapted for its use on HIV prevention programs implementation, it is usually considered as a good self-assessment framework for organizations with the intention of implementing broader promotion and prevention programs.
### Summary

The EQUIHP has been developed as a European consensus tool, facilitating the assessment and improvement of quality in health promotion. It is based on the review of existing tools and European consensus. EQUIHP consists of two components: a Scoring Form (checklist) and a User manual (guideline).

The criteria are clustered into four topics, identifying the areas that are considered essential to achieve quality for effective health promotion: (I) the framework of health promotion principles, (II) aspects regarding project development and implementation, (III) aspects regarding project management, and (IV) sustainability. For each of these areas or ‘clusters’, a number of criteria have been formulated, as well as indicators to measure these criteria.

It is a tool for quality development and assurance of health promotion projects. It can be used throughout the process of planning, implementing and/or assessing a project.

The aim is to obtain more uniformity in quality indices and to facilitate cross-national comparisons and collaboration in enhancing quality in health promotion projects.

This approach embraces the principles of health promotion, including a positive and comprehensive approach to health, attention for the broad determinants of health, participation, empowerment, equity and equality.

### Contribution to CHRODIS GP assessment dimensions

This document provided us with the theoretical framework (health promotion principles) used for structuring the general domains of analysis into a comprehensive map of areas and assessment criteria. Domains and subdomains of analysis were arranged to meet this working frame.

The 4 areas mentioned above, and most of the criteria configured in those ‘clusters’ were matched with the domains previously identified, positioning them into a broader context.

The final structure of the questionnaire includes:

<table>
<thead>
<tr>
<th>Domain</th>
<th>Topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>I - Framework of health promotion principles</td>
<td>Analysis, Aims &amp; objectives, Target group(s), Intervention (strategies and methods) // Implementation strategy, Evaluation</td>
</tr>
<tr>
<td>II - Project development &amp; implementation</td>
<td></td>
</tr>
<tr>
<td>III - Project management</td>
<td>Leadership, Capacity and resources, Participation &amp; commitment, Dissemination // Knowledge transfer</td>
</tr>
</tbody>
</table>
Integration or interaction with the healthcare system

Community linkages // Networks
Ethical implications
IV- Sustainability

Participation & commitment
The ways in which various parties will be involved and committed to the project is clearly outlined. The following indicators will help you to determine the level of participation and commitment:

1. Has the way in which collaboration and synergy (networking) will be obtained been clearly specified?

2. Have the internal and external partners been identified who are required for adequate support and commitment at each stage of the project?

3. Will working methods be used that take into account the different perspectives and contributions of different partners?

4. Is the participation foreseen in the organisation of the project (e.g., steering/advisory committee)?

5. Have the potential opponents and obstacles of the project been identified?

6. Will participation of internal and external partners be formalised via agreements?

Other comments

The user manual includes a Glossary of terms as an annex which we used to complement our own glossary of terms.

Besides, as a part of the Scoring Form (checklist), we found the scale used to evaluate each indicator as ‘achieved’, ‘partially achieved’ and ‘not achieved’, appealing.

DOCUMENT: Empathy Empowering patients in the management of chronic diseases

Summary

EMPATHiE Project has analysed patient empowerment (PE) for patients with chronic diseases. The results of this project include a catalogue of best practices in PE, that has found four types of promising strategies established effective practices (such self-management support and patient education); recent innovative practices (such as virtual interactive platforms and tele-monitoring through smart-phones); shared decision making practices and systemic changes regarding the model of care (such as the chronic care model).

Contribution to CHRODIS GP assessment dimensions
### Interventions
- self-management
- education or health literacy
- multidimensional interventions
- SDM

### Outcomes
- Patient Empowerment related measurements
- Patient perception/satisfaction
- Professional perception/satisfaction
- Quality of life
- Clinical outcomes
- Use of health services (ER, Cost, time...)
- Patient-provider relationships

### Settings
- clinical encounter
- web-based, paper
- Local, institutional, national, international
- Primary care

### Multimorbidity /co-morbidity
Continuity of care (a proper coordination between levels of care) workflows include multiplicity of scenarios, the participation of different professional groups and the sequential nature of the proceedings, in order to address health care processes integrally.
- Care pathways for multimorbid patients
- Adapting evidence for individual comorbidity cases
- Facilitators/Barriers for co-morbid patient empowerment  better motivation to change lifestyle; professional fragmentation; different conditions are treated separately; teamwork professionals

### Patient centred care/ Patient Empowerment Dimensions
- considering patient needs and preferences
- Support autonomy
- Support ownership
- Create strengths and resources (salutogenic approach ?)
- Access to information and health literacy covering all aspects of health, including prevention, treatment options, evidence-base for different treatments, and lifestyle advice.
- ensuring that health professionals have the right skills, knowledge and attitudes to practice patient-centred healthcare
- Self-management supported by technology
- Transparent quality data for patient choice

### Other Comments
**Summary**

The HSPM collects information on European NHS in different areas. The information on patient empowerment has been reviewed. It mainly focuses on patient’s rights regarding information, choice, public participation, compensation.

Some patient driven interventions have been implemented at national level

**Information**

- Telephonic Information for patients (UK) or carers (Austria)
- Health information online (Austria)
- Integrated Patient Handbook contains information about patient’s right to health care services, treatments, provided health care services and other benefits, prescribed medicines and on the financing of the treatment.

- Right to refuse to be informed
- Right to inspect or copy patient file
- Right to be informed of diagnosis, prognosis, treatment (some include treatment alternatives) (some countries oral and written)

- Transparency portals, waiting list information
- Patient offices (Denmark) for information on the system, counselling, complains

**Choice:** mainly choosing GP

**Public participation**

- Patient Associations are consulted by the Gov. Health Department
- Patient inclusion in administration boards (hospitals, elders’ homes). (Belgium, France)
- Umbrella patient association [www.leciss.org](http://www.leciss.org) (France) Danish Patient (Denmark)
- National/local Patient forums
- NSUE [http://www.nsue.ie/](http://www.nsue.ie/) users participate in the redefinition of mental health services (Ireland)

**Contribution to CHRODIS GP assessment dimensions**
Summary

Good Practices following the integrated care model (an European adaptation of the Chronic Care Model) https://webgate.ec.europa.eu/eipaha/infographics/B3.jpg

Contribution to CHRODIS GP assessment dimensions

Best practices that included patient empowerment

Apps where patients introduce their medical data and they receive tailored healthy living advices. Training programmes to support patients and carers and develop support tools for self-management and patient involvement

continuity of care projects changing work processes or integrating information of different providers sometimes including patients

care outside the hospital for chronic patients with all or some of the following elements:

care coordination: to ensure attention to patient needs, plan and brig data to the clinical team

Tele-monitoring: can be preventive or for acute periods.

In some cases consists in periodical calls to patients to collect basic vitals (that have been measured at home), survey data about health and lifestyle and receiving advice to promote autonomy

In some others, call centre for specific conditions where patients can call with doubts or seeking help in acute episodes

some require monitorization technology as portable electrocardiograms

Access to Personal Health Records for self-monitorization, linked to tailored learning resources and remote assistance

Community care: mainly in care homes


b) WHO

DOCUMENT: Coulter A, Parsons S and Askham J. Where are the patients in decision-making about their own care? World Health Organization and World Health Organization, on behalf of the European Observatory on Health Systems and Policies. (2008)

Summary

Strategies for promoting an active role for patients should pay attention to health literacy, shared decision-making and self-management. A number of interventions have been shown to be effective in building health literacy, promoting patient involvement in treatment decisions and educating patients to play an active role in self-management of chronic conditions. These interventions include:

• written information that supplements clinical consultations
Carrying out health care tasks, looking for ways to inform and empower patients need to agree on clear goals and a coherent strategy, with actions targeted at macro (national), meso (regional) and micro (organizational) levels. This coherent strategy requires a whole-system approach, in which support for patient involvement is built into the following types of initiatives:

- Patients’ rights or charters;
- Regulatory requirements for provider organizations, including financial incentives and contracts;
- Procedures for professional regulation, including patient feedback on interpersonal skills and quality of care;
- Provision of health information materials, web sites and portals;
- Training health professionals in communication skills; self-care education and support integrated into all levels of health delivery; and specific aids and techniques to help patients play a more active role.

The goal of self-management support is to enable patients to perform three sets of tasks (11): 1. Managing their illness medically – for example, taking medication or adhering to a special diet; 2. Carrying out normal roles and activities; and 3. Managing the emotional effect of their illness.

### Contribution to CHRODIS GP assessment dimensions

Educating patients about self-management can improve their knowledge and understanding of their condition, coping behaviour, adherence to treatment recommendations, and sense of self-efficacy and symptom levels. Computer-based self-management education and support help to increase a patient’s knowledge and self-care ability and help improve social support, leading to better health behaviour and a better outcome. Self-management initiatives appear to work better when integrated into the health care system, instead of being organized separately. The role of health professionals in guiding patients through the process is critical to successfully implementing these initiatives.

Implementation: it requires a whole-system approach. Governments, health authorities or payers looking for ways to inform and empower patients need to agree on clear goals and a coherent strategy, with actions targeted at macro (national), meso (regional) and micro (organizational) levels. This coherent strategy requires a whole-system approach, in which support for patient involvement is built into the following types of initiatives:

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- Web sites and other electronic information sources
- Personalized computer-based information and virtual support
- Training for health professionals in communication skills
- Coaching and question prompts for patients
- Decision aids for patients
- Self-management education programmes.

It focuses on strategies to improve:

- Health literacy
- Treatment decision-making
- Self-management of chronic conditions.

The Chronic Care Model developed by Ed Wagner and his colleagues in the United States has been highly influential internationally (10).
Summary

This report was prepared by the WHO Secretariat under Objective 6 of the 2008–2013 Action Plan for the Global Strategy for the Prevention and Control of NCDs. It focuses on the current global status of NCDs and will be followed by another report to assess progress in 2013.

Contribution to CHRODIS GP assessment dimensions

Self-care programmes are seen as a vital form of prevention in those at high risk and in improving outcomes in people with NCDs. They have also been shown to reduce demand on health services and thereby cut costs of care (44). Self-care is defined by WHO as including “activities that individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting illness and restoring health”. Techniques and approaches used in self-care programmes include the “patient as the expert” approach, nurse-led programmes, home self-monitoring techniques and programmes using new information technologies, such as mobile phones, computer networks, web-based tools and telemedicine. In general, self-care programmes aim to increase the interest and involvement of people in their own care, and by doing so, empower them to manage their condition. They use educational or self-management interventions to improve patients’ management of their conditions. These interventions are designed to impart knowledge and skills to enable patients to participate in decision-making, to monitor and control the disease and to change behaviour. Published literature demonstrates that patient education for self-care can provide benefits in terms of knowledge, self-efficacy and health status (45). Although the amount of scientific enquiry into the direct associations between increased health literacy and improved health outcomes on NCD-related health outcomes is scant, the impact of health education, an important component of self-care, is known (46), particularly in smoking cessation interventions directed towards individual smokers through individual and group counselling and mass education (47, 48). The effectiveness of individual patient education in the management of diabetes has also been reported to be positive (49) but it is not yet supported by quality evidence (50).
The review of this report did not add any additional information.

c) WP5 collaborators and associated partners: National GP assessment frameworks revised

The objective of CHRODIS WP 5 (Objective № 2 in CHRODIS work programme) is to promote the exchange, scaling up, and transfers of highly promising, cost-effective and innovative health promotion and primary prevention practices.

In order to achieve this aim, WP5 developed the questionnaire on “Good practice in the field of health promotion and primary prevention” to get an overview of existing mechanisms and policies and to identify where good practice exists and where needs lie in the participating EU countries.

Responses to this questionnaire have constituted WP5 partners Country Reviews and describe how health promotion and primary prevention is currently being delivered in different countries and also set the stage to help partners identify promising practices being applied in their own countries.

Evidence extracted from the specific country responses are separately analysed in the following items

Contribution to CHRODIS GP assessment dimensions

From this questionnaire, a new domain have been added:
- Integration and/or interaction with Health delivery system and Community linkages

Development or reinforcement of the following “criteria”:
- Estimated size of effect, effectiveness and economic analysis within section Analysis
- Dissemination, scaling up and knowledge transfer
- Equity approach in target population
- Definition of Integration and/or interaction with Health delivery system
- Capacity and resources: data collection systems, personal training, financing and Budget impact
- Leadership and Evaluation
**Summary**

Bulgaria implemented a comprehensive national health strategy which entails different policies and guidelines in the field of CVD, stroke and Diabetes:

- National Program for Prevention of Chronic Non-communicable Diseases 2014-2020
- Better Healthcare Concept
- Health Strategy for Disadvantaged Ethnic Minorities
- National Strategy for Poverty Reduction and Social Inclusion Promotion 2020
- National Strategy for Long-term Care
- National Plan to Promote Active Aging among Elderly in Bulgaria (2012-2030)

The above-stated policies include monitoring and evaluation frameworks, timeframes for implementation and target indicators.

Health inequalities and the socio-economic gradient are addressed in the following policies:
- National Strategy for Poverty Reduction and Social Inclusion Promotion 2020

The target group of older population (65 and over) is specifically addressed in the updated version of the National Strategy for Demographic Development in Republic of Bulgaria (2012-2030), National Plan to Promote Active Aging among Elderly (2012-2030), and National Strategy for Long-term Care.

**Criteria to CHRODIS GP assessment dimensions**

Criteria reflected in the Bulgarian health strategy:

- Comprehensiveness
- Alignment with other strategies
- Aims & Objectives (Bulgaria’s approach follows a clear structure
- Multi-stakeholder approach
- Empowerment (e.g. “enhancing the capacity of the community in the health field”)
- Indicator “community linkage” (“Improving the network in support of health formed by local institutions, NGOs and individuals.”)
- Equity approach (Commitments and strategies addressing health inequities and supporting socially vulnerable populations)
**Summary**

Cyprus implemented a national health framework through the MoH which entails a strategic plan on Diabetes, currently under revision.

Policy development included the participation of stakeholders who were able to set specific goals and describe the mechanisms to facilitate the implementation of the strategy. These stakeholders are also responsible to implement the strategy.

**Contribution to CHRODIS GP assessment dimensions**

Criteria reflected by the Cypriote approach:
- Comprehensiveness (e.g. through Health in all policies)
- Multi-Stakeholder Approach / Inter-sectoral work
- Equity
- Evidence / Context analysis

**Indicators:**
- Health Impact Assessment
- Theoretical basis of the programme

**Other comments**

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**Summary**

Estonia has electronic database for health-promoting activities (Created by the National Institute for Health Development 2010)

http://www.terviseinfo.ee/et/toeovahendid/toovahendid/tervist-toetavate-tegevuste-andmebaas

(Before that electronic database Institute published annually a book with some of the selected best practices).

Prevention activities should be described by the target, location, and time. Activities can be searched by keyword or filter field.

All inserted activities are revised by health promotion specialist, to evaluate evidence base, and whether the action is justified by the need and methodology.
There is a need to develop special criteria to evaluate the “best practices” in that database. It has no proper assessment tool. At the moment there exists only a possibility to “like” the activities to signal either you like it or not.

## Contribution to CHRODIS GP assessment dimensions

The following categories are applied in the database and included in the template (criteria/indicators in italic)

<table>
<thead>
<tr>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Target group</td>
</tr>
<tr>
<td>Main target group</td>
</tr>
<tr>
<td>Main target group stratification</td>
</tr>
<tr>
<td>Main target age</td>
</tr>
<tr>
<td>Main target gender</td>
</tr>
<tr>
<td>Planned target area:</td>
</tr>
<tr>
<td>Actual presence of how many target persons</td>
</tr>
<tr>
<td>Description</td>
</tr>
<tr>
<td>Objectives</td>
</tr>
<tr>
<td>Methodology</td>
</tr>
<tr>
<td>Evidence</td>
</tr>
<tr>
<td>Evaluation of performance</td>
</tr>
<tr>
<td>Reporting on results</td>
</tr>
<tr>
<td>Final recommendation for the practice</td>
</tr>
<tr>
<td>Budget and partners</td>
</tr>
</tbody>
</table>

## Other comments

## DOCUMENT: Questionnaire WP5 Questionnaire on Good practice in the field of health promotion and primary prevention. Question II- Germany

### Summary

Information provided through Work Package 5 partner Germany.

The cooperation network “Equity in Health” is a nation-wide strategy to tackle health inequities with a database for “Best Practice” Interventions as the core of the activities.

The presented concept follows the overarching aim to identify good practices in health promotion especially among socially disadvantaged and/or vulnerable groups.

## Contribution to CHRODIS GP assessment dimensions

The following criteria have been taken into account:

- Target Group Orientation
- Innovation and Sustainability (this is a joint criteria in the German concept. The criteria were separately included in the template)
| Low Threshold Participation Empowerment Integrated Action Concept and Networking Documentation and Evaluation |
|---|---|---|---|---|
| Included but in different context: Concept and Statement of Purpose (dissolved within the dimension “Concept and Design -> Criteria Aims and Objectives”) Intermediary Concept (indicator of criteria “Scalability”) Setting Approach (indicator under criteria “target group”) Quality Management (subsumed in “Evaluation”) Cost-Benefit Ratio (used as indicator, not a criteria on its own) |

**Other comments**

**DOCUMENT: WP5 Questionnaire on Good practice in the field of health promotion and primary prevention. Question II- Greece**

**Summary**

There is no national mechanism or criteria to identify good practice and no good practice databases in Greece.

The Centre for Health Services Research at the University of Athens uses and advocates for the European Quality Instrument for Health Promotion (EQUIHP) - however it has not been adopted yet at a central level for the evaluation processes of the funded projects.

**Contribution to CHRODIS GP assessment dimensions**

See SoE on EQUIHP

**Other comments**
**Summary**

Iceland implemented a national health strategy which is implemented through the development and provision of guidelines.

Iceland’s public health guidelines follows a life cycle perspective and provides guidelines and information on selected topics for different steps in the life cycle, e.g. healthy ageing.

Topics for public health practices for older people include:

- Health and wellbeing
- Alcohol and drug abuse and older people
- Mental health and older people
- Health of older people
- Exercise and older people
- Nutrition and older people
- Violence and the prevention of accidents and elderly people
- Dental care and older people
- Nursing and residential - numbers

In addition to domestic research and experiences, health promotion and primary prevention practice initiated by the health sector is usually based on guidance and recommendations published by e.g. WHO, EU and the Nordic council of ministers.

**Contribution to CHRODIS GP assessment dimensions**

The Public Health Fund of Iceland defines criteria for the funding of public health programmes ([http://lydheilsusjodur.sidan.is/content/files/public/uthlutunarreglur.pdf](http://lydheilsusjodur.sidan.is/content/files/public/uthlutunarreglur.pdf) – translation below through Google Translate).

Criteria which were included in the criteria template (Criteria and Indicators in italic):

Projects those are consistent with the policies and programs of the government in public health (Alignment/Comprehensiveness).

The value and importance of the project for public health (Relevance)

Gender and residence distribution. (Equity: Gender, Rural&urban)

Applications for funding for projects must be professionally processed and based on the results of research or equivalent professional data (Evidence base).

Projects must have clear objectives and the projected results (Aims and Objectives).

Provision of a manner in which performance will be assessed (Evaluation, Effectiveness)

Furthermore the following funding priorities of the City of Reykjavik prevention fund have been taken into account in the template:

([http://reykjavik.is/sites/default/files/2013_reglur_forvarnarsjods.pdf](http://reykjavik.is/sites/default/files/2013_reglur_forvarnarsjods.pdf))

- Strengthening social capital in neighbourhoods in the city (Empowerment)

Systematic collaboration of residents, organizations and businesses for the benefit of preventive and social capital (Scalability: Community linkages/Networks)
Projects that meet the goals set by the City Council, such as the prevention strategy goals of the City (Concept and Design: Comprehensiveness)

Other comments

Further funding criteria which were not included in the template because they are too specific for funding mechanisms rather than related to actual good practice identification:

- Applications must be accompanied by budget.
- Grants are generally awarded to companies, organizations and public authorities.
- Individuals are normally only awarded grants for research projects.
- Normally does not exceed the amount allocated to the project by the local or institutions than their own contribution.
- If the applicant has previously received a grant for a project must be submitted for the final report, if continuing work involved shall be available for a progress report on implementation of the project.
- Allowances are higher than 500.000kr. are normally paid in two instalments and subsequent Things only from progress reports and other requested data.
- Do support the general management of institutions or organizations or to purchase furniture or other furnishings.
- No grants are given to conferences.
- No grants are given to projects that are profit applicant.
- Application and supporting documents should be sent within the period mentioned in the ad.
- Applications received after the scheduled deadlines are not taken into consideration.

DOCUMENT: WP5 Questionnaire on Good practice in the field of health promotion and primary prevention. Question II- Ireland

Summary

Ireland developed and implemented a comprehensive policy framework for health promotion and primary prevention which is aligned with the basic principles of the Ottawa charter.

Policies include
Healthy Ireland (HI) framework
Tobacco control
Special Action Group on Obesity (SAGO)
Physical activity
National strategies, e.g.
Building Healthier Hearts
Changing Cardiovascular Health
National positive ageing strategy

On the implementation level this entails approaches like
The Health Promoting School Initiative
The Health Promoting Health Services
The Healthy Cities Project
Currently there is no systematic approach to collating and evaluating good practice on a national level in Ireland. However, in 2013/2014 the HSE undertook an auditing exercise to collect information on all ongoing projects directly funded by the HSE relevant to health promotion and disease prevention. It is intended that this audit will inform a more systematic approach to good practice review in Ireland in the future’.

Contribution to CHRODIS GP assessment dimensions

A special focus from the Irish partners was put on the Gender aspects in health care and health promotion.

Further basic principles and rules of action from the Irish approach considered in the template entail:

Setting approach
Identifying and addressing the social determinants of health
Equity
Gender
Comprehensiveness

Other comments

DOCUMENT: Questionnaire WP5 Questionnaire on Good practice in the field of health promotion and primary prevention. Question II-Italy

Summary

Information provided by ISS (Istituto Superiore di Sanita ) and MINSAL (Ministry of Health)

Good Practice Criteria provided through a proprietary evaluation framework “Pro.Sa”¹

“Pro.sa” is grounded on the theories of evidence and best practices translation and exchange (knowledge translation and exchange), among different actors (practitioners on health promotion and prevention, stakeholders, decision makers). Through Pro.Sa database the project manager can submit his project to be evaluated as Good Practice. Two independent readers, properly trained in the use of the assessment tool and experts in the field of health promotion, read the project and give it a scaled score. The focus on good practices aims at:

highlighting strength factors for the effectiveness of an intervention; promoting sustainability and transferability in other settings or contexts; building a professional network (community of practice) in the field of health promotion and prevention

¹ http://www.retepromozionesalute.it; http://www.guadagnaresalute.it/progetto/progettoProsa.asp
### Contribution to CHRODIS GP assessment dimensions

The following Good Practice criteria from ProSa were taken into account for the template (Criteria/Indicator):

- Working group (multidisciplinary, multi-sector, including representatives of target groups)
- *Multi-Stakeholder Approach*
- *Equity in health*
- *Empowerment*
- *Involvement/Participation*
- *Setting*
- *Theoretical models and theories of design and behaviour change*
- *Evidence of effectiveness and good practice examples*
- *Context analysis*
- *Determinants analysis*
- *Context and determinants analysis*
- *Resources, time and limits*
- *Partnership and alliances*
- *Objectives*
- *Process evaluation*
- *Evaluation*
- *Interventions/activities description*
- *Output and outcome evaluation*
- *Evaluation*
- *Sustainability*
- *Communication*
- *Documentation*

### Other comments


### DOCUMENT: WP5 Questionnaire on Good practice in the field of health promotion and primary prevention. Question II- Lithuania

#### Summary


Implementation follows action plans as issued by the Ministry of Health through Ministerial orders, e.g.
The main national health policy in Lithuania is the “Resolution for Lithuanian health program approval 2014-2025”. It aims to achieve that the population is healthier and lives longer, improves population health and reduces health inequalities by 2025.

It entails the following purposes and tasks:

- To create a safer social environment, reduce health inequalities
- To reduce poverty and unemployment
- To reduce socio, economic population differentiation at country and community levels
- To create healthy occupational and living environment
- To create safe and healthy working conditions, increase the safety of consumers
- To create favourable conditions for leisure
- To reduce road accidents and injuries
- To reduce pollution of air, water, soil and noise
- Formation of healthy lifestyle and its culture
- To reduce alcohol and tobacco use, prevent diversion of drug and psychotropic substances use and their accessibility
- To promote habits of healthy nutrition
- To develop habits of physical activity
- To ensure high quality and efficient health care needs of the population
- To ensure the sustainability and quality of the health system by developing evidence-based health technologies
- To develop the health infrastructure and improve the quality of healthcare, safety, accessibility and to patient-centred care
- To improve maternal and child health
- To strengthen chronic non-communicable diseases prevention and control
- To develop Lithuanian electronic health system
- To maintain the health care during the crisis and emergency situations

**Contribution to CHRODIS GP assessment dimensions**

Principles related to Good Practice criteria in the template:

- *Comprehensiveness*
- *Alignment*
- *Context and determinants analysis*
- *Aims and Objectives*
- *Equity*
- *Socioeconomic status, Education level and Vulnerable social groups*
<table>
<thead>
<tr>
<th>DOCUMENT: WP5 Questionnaire on Good practice in the field of health promotion and primary prevention. Question II- Norway</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Summary</strong></td>
</tr>
</tbody>
</table>
| Norway developed and implemented a comprehensive policy framework with a Public Health Act from 2012 at its core.  
The purpose of this act is to contribute to societal development that promotes public health and reduces social inequalities in health. Public health work shall promote the population's health, well-being and good social and environmental living conditions, and contribute to the prevention of mental and somatic illnesses, disorders and injuries. The act establishes a new foundation for strengthening systematic public health work in the development of policies and planning for societal development based on regional and local challenges and needs. It also provides a broad basis for the coordination of public health work across various sectors and actors and between authorities at local, regional and national level.  
A dedicated Good Practice Database does not exist. However, basic criteria within the existing policy and implementation framework were identified and included in the Good Practice template. |
| **Contribution to CHRODIS GP assessment dimensions** |
| The following principles of the Norwegian approach were reflected in the criteria of the template:  
  *Comprehensiveness*  
  *Health in all policies*  
  *Alignment*  
  *Equity*  
  *Gender*  
  *Socioeconomic status*  
  *Multiple stakeholders*  
  *Sustainable development*  
  *Participation*  
  Principles not reflected in criteria  
  *Precautionary principle (“do no harm”)*  
  *Diametral to the purpose to identify good practice* |
| **Other comments** |
### Summary

**Information in the questionnaire through Work Package 5 partners from Portugal:**

Direcção - Geral de Saúde (DGS)
Instituto Nacional de Saúde (INSA)

Portugal implemented a national health plan, which is specified through nine national health programs and in particular for cardiovascular disease and stroke, a National Programme for Cardio-Cerebrovascular Diseases exists.

Criteria to identify good practices are used for the assignment of funding mechanisms.

### Contribution to CHRODIS GP assessment dimensions

The following criteria have been taken into consideration:

- Project area facing health strategies and objectives (Alignment)
- Quality of methods proposed
- Post-funding sustainability of the project
- Potential for translation of the intervention or project
- Participative methodology with involvement of several stakeholders and or target groups
- Budget appropriateness in the face of expected work to be done and results

### Other comments

Criteria not taken into consideration:

- Expected situation improvement in a before-after evaluation with adequate methodology

Because: Lack of feasibility and applicability to health promotion programmes

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### Summary

**Information in the questionnaire provided by Spanish partners in WP 5:**

Consejería de Sanidad y Servicios Sociales, Comunidad Autónoma de Cantabria
Consejería de Salud y Bienestar Social de la Junta de Andalucía
Fundación Progreso y Salud
Instituto de Salud Carlos III
Ministerio de Sanidad, Servicios Sociales e Igualdad

Spain established a structured procedure to identify good practices across the National Health
System (NHS). The procedure is embedded within different “Health Strategies of the NHS”.

The procedure entails inclusion criteria for programmes/practices:

- Adequacy (it covers the factors and issues considered in the Strategy)
- Relevance (its objectives correspond with the needs and characteristics of the population at which are aimed at or a regulatory rule)
- based on the best evidence available (efficacy proven)
- potential evaluation possible (registry systems in place)
- Sustainability (being implemented for at least one year and funding in place).

### Contribution to CHRODIS GP assessment dimensions

Prioritization criteria entailed in the approach include:

- Evaluation/ Effectiveness
- Efficiency: economic evaluation performed.
- Equity: it is evaluated the existence of an equity approach incorporated in the situation analysis and in the formulation of the different actions taking into account the different needs of population groups. Participation of the target population on different stages and intersectoral work are also considered here.
- Feasibility: it is suitable for transferability.
- Strategic adequacy: it is aligned with the main national and international strategies on the field.
- Comprehensiveness: it takes on two or more risk factors/health determinants.
- Ethical issues: potential conflicts of interest of the different actors involved are being considered.

### Other comments

### DOCUMENT: WP5 Questionnaire on Good practice in the field of health promotion and primary prevention. Question II- the Netherlands

**Summary**

The RIVM (National Institute for Public Health and the Environment) Centre for Healthy Living (CGL) supports the delivery of efficient and effective local health promotion by clearly presenting available interventions, planning instruments, communication materials and links to relevant Dutch knowledge and support organizations on the portal Loketgezondleven.nl. This portal also presents information on the quality, effectiveness and feasibility of health promotion interventions.

**Database with life style interventions**

Organizations working in the field of health promotion interventions can request for including their intervention in the database with health promotion (lifestyle) interventions. Every organization with a grant for research or implementation of a lifestyle intervention needs to enter their intervention in the database of Loketgezondleven.nl.

**Procedure for selecting best practices**

To identify and select best practices, the Centre for Healthy Living developed an assessment system
for interventions, i.e. the Dutch recognition system. The aim of the recognition system is to gain a better view into the quality and effectiveness of health promotion interventions and to increase the quality of professional practice in health promotion. Organizations are supported to submit an intervention using a standard submission form.

The registration desk of the Centre for Healthy Living checks the criteria for inclusion, the completeness and quality of the submitted forms provides and gives initial feedback to improve the submission if necessary. They also check the relevance of the intervention. Then there are two types of assessment possible:

- An assessment of the description of the objective, target group, approach and boundary conditions by professional practitioners or other experts from the sector concerned. This happens in the form of a peer review by practice panels. Based on this, interventions can receive the assessment ‘Well Described’.

- An assessment of the theoretical basis and/or effectiveness of the intervention by an independent expert committee. Interventions that are assessed as good by the Recognition Committee receive a recognition ‘Theoretically Sound’ or ‘Effective’ There are several subcommittees for different types of interventions, for example youth health care and health promotion for adults and elderly.

- For both types of assessment, an evaluation for Feasibility is also possible, i.e. strong and weak features with respect to the feasibility of the interventions. Interventions that are assessed to be feasible are easy to adapt to another context.

**Contribution to CHRODIS GP assessment dimensions**

| The Dutch system includes the following criteria (criteria/indicator in template) |
| Manual of intervention available (Documentation) |
| Process evaluation |
| Two way assessment: |
| Description of the project / ‘well described’ |
| Theoretical basis of the project |
| Transferability (‘Feasability’) |
| Effectiveness |
| Relevance |

| Other comments |
| Criteria not included in the template: |
| Material for the next 2 years available |
| Contact person |
| too specific for the purpose of the template |
In the United Kingdom, health promotion and chronic diseases overarching policy development for the four constituent home countries (England, Scotland, Wales and Northern Ireland) takes place within the Departments (Ministries-equivalent) of Health for each country. As a result there are variations from home country to home country. Policies are initiated, developed and approved centrally, with input from regional and local health authorities/boards and from patient groups such as Diabetes UK and from clinicians and academics with an interest in the areas concerned.

Implementation is at a regional and local level. Recently, In England, local government has become involved with public health, including prevention of diseases. The delivery of prevention policies is made by clinicians, social workers and others.

PHE is therefore the national-level body setting the policy and strategic direction of public health and promotion, while, the delivery became a legal duty of local authorities in April 2013. Overall, public health is the duty of local authorities, while it used to be a combination of local health bodies and local authorities.

The UK developed an extensive range of clinical and best practice guidelines through the national body “NICE” on topics like

- Lifestyle and wellbeing
- Diabetes and other endocrinal, nutritional and metabolic conditions
- Cardiovascular conditions
- Health inequalities
- Value for money

The following principles of the UK’s system have been adopted for the template on Good Practice criteria:

- Comprehensiveness, Alignment, Several risk factors addressed at the same time, Evaluation
- Cost effectiveness, Risk assessment, Multi-/Intersectoral approach, Partnerships and alliances
- Equity, Documentation, Evidence base, Theoretical mode, Health Impact Assessment, Aims and Objectives, Community linkage /Networks, Sustainability

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5 [https://www.nice.org.uk/advice/LGB4/chapter/introduction](https://www.nice.org.uk/advice/LGB4/chapter/introduction)
6 [https://www.nice.org.uk/advice/LGB10B/chapter/introduction](https://www.nice.org.uk/advice/LGB10B/chapter/introduction)
d) International experience

**DOCUMENT:** Canadian best practice portal (http://cbpp-pcpe.phac-aspc.gc.ca/)

**Summary**

The Canadian Best Practices portal was originally launched in 2006 and supported by the Centre for Chronic Disease Prevention (CCDP) within the Public Health Agency of Canada. The portal includes a searchable list of Best Practice Interventions relevant to chronic disease prevention and health promotion.

The aim of the Best Practices Intervention Section is to provide decision-makers with access to published information about proven best practices.

The Best Practice Interventions include interventions, programs/services, strategies, or policies which have demonstrated desired changes through the use of appropriate well documented research or evaluation methodologies and have the ability to be replicated and the potential to be adapted and transferred.

For the practice to be included in the portal and be considered a Best Practice must satisfy five required criteria:

- The Type of intervention is appropriate
- Evaluation of the intervention
- Impact
- Replicability and adaptability
- Source

**Contribution to CHRODIS GP assessment dimensions**

Reinforcement of the following “criteria”:

- Ethical implications
- Interventions must have been developed free of commercial interests that may compromise integrity
- Analysis: the practice is based on a systematic analysis of the health problem and its determinants
- Addresses health determinants
- Focuses on a population health
- Evaluation framework assessing process and outcomes

**Other comments**

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www.chrodis.eu
## Contribution to CHRODIS GP assessment dimensions

<table>
<thead>
<tr>
<th>Productive interactions and relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed, activated individuals &amp; families</td>
</tr>
<tr>
<td>Activated communities &amp; prepared, proactive community partners</td>
</tr>
<tr>
<td>Self-management Supports</td>
</tr>
<tr>
<td>Clients are part of care team and engaged in shared decision making</td>
</tr>
<tr>
<td>Individuals empowered to be self-managers</td>
</tr>
<tr>
<td>Self-management support services organized for clients</td>
</tr>
<tr>
<td>Shared clinical guidelines</td>
</tr>
</tbody>
</table>

**Follow-up**

Innovative Patient Interactions: regular group-classes (vs 15 min. visits)

Telephone contact has been found to be effective, and is low-cost

Managing and preventing chronic disease successfully requires regular, ongoing contact with clients

**Care Planning, Care Paths and Care Management:**

- Periodic planned visits between clients and their care team that focus solely on clients’ chronic conditions, have been found to improve health outcomes and reduce the number of specialty and acute care visits.
- Patient-centred care plan tailored to the client’s specific needs, capacities, circumstances and wishes.

**Enhanced Health Promotion and Prevention**

Outreach, Population Needs-Based Care and Cultural Sensitivity: culture and Social Determinants of Health

Sharing access to Electronic Medical Records with clients has also been shown to increase clients’ ability to self-manage chronic conditions and take charge of their health.

Public Participation Strengthening community action also involves mobilizing individuals and families to participate in organized community action.

**Enhancing Local knowledge, Skills and Resources**

### Other Comments
## DOCUMENT: Assessment of Chronic Illness Care (ACIC)

### Summary

The content of the ACIC was derived from specific evidence-based interventions for the six components of the Chronic Care Model (community resources, health organization, self-management support, delivery system design, decision support and clinical information systems). Like the Chronic Care Model, the ACIC addresses the basic elements for improving chronic illness care at the community, organization, practice and patient level.

The ACIC provides subscale scores corresponding to each of the Chronic Care Model elements, as well as an overall score.

### Contribution to CHRODIS GP assessment dimensions

From this tool, new domains or specifications have been added:

- Community linkage between the health delivery system (or providers) and the Community (Linking Patients to Outside Resources, Partnerships with Community Organizations)
- Self-Management Support. Effective self-management support can help patients and families cope with the challenges of living with and treating chronic illness and reduce complications and symptoms.
- Patient’s participation in the programme and to consider their empowerment as a final aim of the programme
- The need of evidence based resources available for professionals and patient’s
- Assessment and Documentation of Self-Management Needs and Activities
- Self-Management Support
- Addressing Concerns of Patients and Families
- Effective Behaviour Change Interventions and Peer Support
- Decision Support: Informing Patients about Evidence based Guidelines
- Delivery System Design. Evidence suggests that effective chronic illness management involves more than simply adding additional interventions to a current system focused on acute care: appointment system, follow up, Planned Visits for Chronic Illness Care, continuity of care.
**Summary**

This CDC evaluation framework gives public health professionals a starting point for evaluating public health programs. The evaluation includes six ordered steps that can be used as a starting point to tailor an evaluation for a particular public health effort, at a particular point in time. In general, the earlier steps provide the foundation for subsequent progress.

Engage stakeholders, including those involved in program operation; those served or affected by the program; and primary key users of the evaluation.

Describe the program, including the need, expected effects, activities, resources, stage, context and logic model.

Focus the evaluation design to assess the issues of greatest concern to stakeholders while using time and resources as efficiently as possible. Considering the purpose, users, uses, questions, methods and agreements.

Gather credible evidence to strengthen evaluation judgements and the recommendations that follow. These aspects of evidence gathering typically affect perceptions of credibility: indicators, sources, quality, quantity and logistics.

Justify conclusions by linking them to the evidence gathered and judging them against agreed-upon values or standards set by the stakeholders. Justify conclusions on the basis of evidence using these five elements: standards, analysis/synthesis, interpretation, judgement and recommendations.

Ensure use and share lessons learned with these steps: design, preparation, feedback, follow-up and dissemination.

Attached to this, there is a document of evaluation standards (CDC), setting 30 standards assessing the quality of evaluation activities determining whether a set of evaluative activities are well-designed and working to their potential. These standards, adopted from the Joint Committee on Standards for Educational Evaluation, answer the question, "Will this evaluation be effective?"

The 30 standards are organized into the following four groups:

Utility standards, ensuring that an evaluation will serve the information needs of intended users.

Feasibility standards, ensuring that an evaluation will be realistic, prudent, diplomatic and frugal.

Proprietary standards, ensuring that an evaluation will be conducted legally, ethically and with due regard for the welfare of those involved in the evaluation, as well as those affected by its results.

Accuracy standards, ensuring that an evaluation will reveal and convey technically adequate information about the features that determine worth or merit of the program being evaluated.

**Contribution to CHRODIS GP assessment dimensions**

Development or reinforcement of the following “criteria”:

Quality Management // Evaluation of the program (project):
Consulting insiders and outsiders
Taking special effort to promote the inclusion of less powerful groups or individuals
Coordinating and including stakeholder input throughout the evaluation design, operation and use
Identification of the purpose of evaluation (who and how the evaluation results are to be used)
Intervention & Implementation strategy:
Characterizing the set of needs addressed
Listing specific expectations as goals with explicit criteria of success
Clarifying by an explicit logic model the relationships between program elements and expected changes
Assessing the program’s maturity or stage of development
Integration of the program (project) with other ongoing efforts
Integrated action concept and networking: systematic networking to exchange information, mutual support and cooperation
Quality management: framework to be tested on a regular basis for potential improvements:
Choosing indicators that meaningfully address evaluation questions
Description of practical methods for sampling, data collection, data analysis, interpretation and judgement
Existence of written protocols or agreements that summarize the evaluation procedures
Existence of clear roles and responsibilities for change management of the program (project)
when critical circumstances change
Safeguarding the confidentiality of information and information sources
Using appropriate methods of analysis and synthesis to summarize findings
Interpreting the significance of results for deciding what the findings mean
Considering alternative ways to compare results with program objectives (comparison groups, past performances)
Recommending actions or decisions that are consistent with the conclusions and limiting conclusions to situations, time periods, persons, contexts, and purposes for which findings are applicable
Dissemination and knowledge transfer:
Providing continuous feedback to stakeholders regarding interim findings, provisional interpretations and decisions to be made that might affect likelihood of use
Scheduling follow-up meetings with intended users to facilitate the transfer of evaluation conclusions into appropriate actions or decisions
Disseminating both the procedures used and the lessons learned from the evaluation to stakeholders, using tailored communication strategies that meet their particular needs

| Other comments |

Although there is framed into the context of a meta-evaluation of the assessment process; this document also includes a reference to a ‘Checklist for ensuring effective evaluation reports’ adapted from Worthen BR, Sanders JR, Fitzpatrick JL. Program evaluation: alternative approaches and practical guidelines. 2nd ed. New York, NY: Addison, Wesley Logman, Inc. 1997.
This checklist has been also reviewed in order to address in our evaluation model to some of those recommendations.
**DOCUMENT: Quint-Essenz. Quality criteria**

**Summary**

Quality system Quint-essenz ([www.quint-essenz.ch](http://www.quint-essenz.ch)) has been funded and developed by Health Promotion Switzerland. Part of their work has been developing set of criteria for systematic project quality assessment, specifically for intervention projects in health promotion and prevention. It has been developed in partnership with scientist and practitioners.

Its objectives are:

- To systematically reflect and evaluate intervention projects during their different phases.
- To identify strengths and potential for improvement.
- To determine priority areas where improvement in the project is necessary.
- To set goals for quality and to define measures for improvement.

The core of the system constitutes 24 quality criteria that are corroborated in terms of indicators which identify strengths and weaknesses, determine priority areas and define measures for improvement and make project’s qualities visible.

An initial assessment is needed to determine which criteria and indicators are the most relevant for a project at a specific point in time (project design, implementation or valorisation). To assess each phase-specific indicator on a scale from minus to maximum.

**Contribution to CHRODIS GP assessment dimensions**

Development or reinforcement of the following “criteria”:

Equity approach: considerations of gender, social status, cultural and linguistic diversity. Quint essenz includes this criterion in project design, implementation and evaluation. **FEASABILITY**

Reinforcement and social resources.

The project aims at empowering individuals and groups to take responsibility for their own health and for the conditions that are conducive to a health-promoting lifestyle.

The project aims to strengthen the 'sense of coherence' (meaningfulness, manageability, comprehensibility).

It is explicit which resources are to be strengthened for which kind of individuals or groups.

Assessment: The needs of the target group(s) of the intervention and other stakeholders in the setting are adequately considered.

An assessment of advantages and disadvantages for the stakeholders in the setting has been carried out.

The needs of the various stakeholders and target groups have been researched and documented.

The needs of the various stakeholders and target groups are adequately considered.

Participation and commitment of stakeholders and/or target groups:

- The principal actors in each setting are involved in the planning and implementation of the
- The project's structure is adequate and comprehensible for all concerned.
- The project leaders and all others involved in the project are adequately qualified to accomplish their tasks.

Evidence of the health problem addressed and need of the programme
Practice shows alignment with broader health programme or national strategies.
Contextual conditions as part of the systematic analysis of the health problem addressed.
Potential for conflicts of interest in the project environment
Project’s objectives state clearly the desired effect on the various target groups

Intervention strategies and methods:
- Justification for proposed procedures
- Time Schedule
- Availability of necessary resources
- All the resources needed for the programme are in the budget

Community linkages/Network: The project is making the most of possible networking opportunities in order to achieve its objectives.

Evaluation:
- The project is managed by periodical target-performance comparisons.
- The evaluation contributes to the best possible management of the project and allows a conclusive assessment of the project.
- The project’s objectives have been reviewed and they have been attained.

Dissemination, scaling up and knowledge transfer:
- All the important aspects of the project have been documented in a comprehensible manner.
- Sustainability: The project aims at long-term changes.
- Results and experiences from the project are disseminated and made available in a purposeful manner.

Other comments

In the map of dimensions these criteria have not been considered:

Attribution of indicators to specific project phases: Project Design (PD), Implementation (IM), Valorisation (VA).

The communication processes within the project structure are adequate. The project management and the team are motivated to work in the best possible way.
2. INNOVATION


**Summary**

The concept of patient-centeredness has gained in importance over recent decades, including its growing importance on a health policy level. However, many different definitions and frameworks exist. This renders both research and implementation into clinical practice difficult. This study aimed at assessing how German researchers conceptualize patient-centeredness, how they translate the German equivalent into English, and what they consider the most important references on the topic.

**Contribution to CHRODIS GP assessment dimensions**

see table below
Summary

Existing models of patient-centeredness reveal a lack of conceptual clarity. This results in a heterogeneous use of the term, unclear measurement dimensions, inconsistent results regarding the effectiveness of patient-centered interventions, and finally in difficulties in implementing patient-centered care. The aim of this systematic review was to identify the different dimensions of patient-centeredness described in the literature and to propose an integrative model of patient-centeredness based on these results.

Contribution to CHRODIS GP assessment dimensions
see table below

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Brief description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principles</td>
<td>A set of attitudes towards the patient (e.g. empathy, respect, honesty) and oneself (self-reflectiveness) as well as medical competency</td>
</tr>
<tr>
<td>Clinician-patient relationship</td>
<td>A partnership with the patient that is characterized by trust and caring</td>
</tr>
<tr>
<td>Patient as a unique person</td>
<td>Recognition of each patient's uniqueness (individual needs, preferences, values, feelings, beliefs, concerns and ideas, expectations)</td>
</tr>
<tr>
<td>Biopsychosocial perspective</td>
<td>Recognition of the patient as a whole person in his or her biological, psychological, and social context</td>
</tr>
<tr>
<td>Enablers</td>
<td></td>
</tr>
<tr>
<td>Clinician-patient communication</td>
<td>A set of verbal and nonverbal communication skills</td>
</tr>
<tr>
<td>Integration of medical and non-medical care</td>
<td>Recognition and integration of non-medical aspects of care (e.g. patient support services) into health care services</td>
</tr>
<tr>
<td>Teamwork and teambuilding</td>
<td>Recognition of the importance of effective teams characterized by a set of qualities (e.g. respect, trust, shared responsibilities, values, and visions) and facilitation of the development of such teams</td>
</tr>
<tr>
<td>Access to care</td>
<td>Facilitation of timely access to healthcare that is tailored to the patient (e.g. decentralized services)</td>
</tr>
<tr>
<td>Coordination and continuity of care</td>
<td>Facilitation of healthcare that is well coordinated (e.g. regarding follow-up arrangements) and allows continuity (e.g. a well-working transition of care from inpatient to outpatient)</td>
</tr>
<tr>
<td>Activities</td>
<td></td>
</tr>
<tr>
<td>Patient information</td>
<td>Provision of tailored information while taking into account the patient's information needs and preferences</td>
</tr>
<tr>
<td>Patient involvement in care</td>
<td>Active involvement and collaboration with the patient regarding decisions related to the patient's health while taking into account the patient's preference for involvement</td>
</tr>
<tr>
<td>Involvement of family and friends</td>
<td>Active involvement of and support for the patient's relatives and friends to the degree that the patient prefers</td>
</tr>
<tr>
<td>Patient empowerment</td>
<td>Recognition and active support of the patient's ability and responsibility to self-manage his or her disease</td>
</tr>
<tr>
<td>Emotional support</td>
<td>A set of behavior that ensures physical support for the patient (e.g. pain management, assistance with daily living needs)</td>
</tr>
</tbody>
</table>

doi:10.1371/journal.pone.0107828.t003

Summary

Intervention review

Personalised care planning is a collaborative process used in chronic condition management in which patients and clinicians identify and discuss problems caused by or related to the patient’s condition, and develop a plan for tackling these. In essence it is a conversation, or
series of conversations, in which they jointly agree goals and actions for managing the patient’s condition.

19 studies involving a total of 10,856 participants.: diabetes (12), mental health (3), one on heart failure, one on end-stage renal disease, one on asthma, and one on various chronic conditions.

**Contribution to CHRODIS GP assessment dimensions**

**Patient-focused interventions:**
- information materials or decision aids for patients (Protheroe 2010)
- computer-based interventions to help patients identify and achieve behavioural goals (Glasgow 2004)
- suggested lists of questions the patient can ask to prompt the clinician to involve them more actively in decisions about their care (Shepherd 2011)
- health coaching and motivational support to help patients clarify objectives, solve problems and achieve behavioural goals (Frosch 2011)
- patient-held records for summarising personal goals and test results (Dijkstra 2005)

**Clinician-focused interventions:**
- specific training programmes in shared decision making, care planning and/or motivational interviewing (Kennedy 2005)
- guidelines and feedback emphasising the need to elicit patients’ preferences during care-planning consultations (Wensing 2003)
- algorithms embedded in clinical record systems to guide the care-planning process (Ell 2010)

**Interventions designed to influence the behaviour of both clinicians and patients:**
- brief tools for use within care-planning consultations to guide the discussion about options and agreed actions (Elwyn 2012a)
- an electronic or printed template for documenting jointly-agreed actions for use in monitoring and follow-up (Ross 2004).

**Primary outcomes**
1. Changes in health and well-being, including each of the following three dimensions measured separately: i) physical health ii) psychological health iii) subjective health status.
2. Changes in patients’ self-management capabilities or indicators relevant to those capabilities

**Secondary outcomes**
1. Changes in health-related behaviours: diet, exercise, smoking, use of relaxation techniques, self-management actions, condition-relevant self-monitoring, adherence to
2. Changes in use of formal health services: number and length of hospital admissions, number of outpatient, emergency department, or primary care visits, and, where recorded, effects on the costs of care.


**Summary**

The objective of our study was to examine various existing chronic disease models, their elements and their role in the management of Diabetes, Chronic Obstructive Pulmonary Disease (COPD), and Cardiovascular diseases (CVD).

**Contribution to CHRODIS GP assessment dimensions**

Chronic Care Model (CCM) (20 articles), Improving Chronic Illness Care (ICIC) (1), and Innovative Care for Chronic Conditions (ICCC) (4), Stanford Model (SM) (1) and Community based Transition Model (CBTM) (1).

**CCM: patient driven elements**

core themes

Self-management support: Emphasizes patient’s role in managing health. Established self-management techniques such as mutual goal setting and action planning have focused on various methods of teaching such as group classes, skill development, and various lifestyle behaviors.

Community Involves linking and using community resources that support healthcare effort by clinicians. The use of church-based support groups, local community health programs, clinic based support groups and internet are acceptable community interventions.

Additional themes

Cultural competency

Improving health of people with chronic illness requires transformation of a system to one that is proactive instead of reactive. Roles need to be defined and tasks need to be distributed among team members. Interactions need to be planned to support evidence-based care. More complex patients may need more intensive management for a period of time to optimize clinic care and self-management. Health literacy and cultural sensitivity are two important features and providers are increasingly being called upon to respond effectively to the diverse cultural and linguistic needs of patients (Wielawski, 2011).
ICCC: patient driven elements

Care centered in patients and their families: Management of chronic conditions requires lifestyle and daily behavior change. Focusing on the patient in this way constitutes an important shift in current clinical practice. The present scenario has a patient role as a passive recipient of care, missing the opportunity to leverage what he or she can do to promote personal health. Health care for chronic conditions must be re-oriented around the patient and family.

Support patients in their communities: Patients and families need services and support from their communities. Communities can also fill crucial gap in health services that are not provided by organized.

The other 2 models are not resumed.

How has Self-Management Support been implemented?: It emphasizes patient’s role in managing health. Established self-management techniques such as mutual goal setting and action planning have focused on various methods of teaching such as group classes, skill development, and various lifestyle behaviors (Wagner et al., 1996a, 1996b, 2001, 2002). Personalized healthcare plan, medications, action plan, lifestyle goals and feedback for the providers to deliver tailored feedback have been studied (Pearson et al., 2005; Nutting g et al., 2007; Tracey & Bramley, 2003; Chin et al., 2004; Sperl-Hillen et al., 2004; Ciccone, 2010; Glasgow et al., 2004). Incentives have been offered to increase patients’ participation for self-management programs (Siminerio et al., 2004) Patient education, patient activation/ psychological support (Piatt et al., 2011; Piatt et al., 2010; Siminerio et al., 2006; Piatt et al., 2006; Vargas et al., 2007; Nutting et al., 2007; Schmittdiel et al., 2006; Smith et al., 2008), access to self-management resources and tools (Vargas et al., 2007; Wellingham et al., 2003; Ciccone, 2010; Schmittdiel et al., 2008; Askew, Jackson, Ware & Russell, 2010) and collaborative decision making are some of the other common components of self-management support element of CCM(Pearson et al., 2005). Individuals with chronic diseases are provided with training to improve their skills for blood glucose monitoring (Frei et al., 2010; Schmittdiel et al.,2006), adjusting insulin, and modifying diet and exercise (Schmittdiel et al., 2006), review medical charts (Schmittdiel et al., 2006) and track self-management behavior (Sperl-Hillen et al., 2004) are some of the techniques employed to improve self-management in these individuals. Only one study used Stanford model to improve self-management in chronic disease individuals (Franks, Chapman, Duberstein & Jerant, 2009).

Evidence suggests that the application of CCM principles to health care systems lead to better outcomes for patients with chronic illnesses (Schmittdiel et al., 2006). The principles include (i) first contact (primary care physicians should be patient’s first contact), (ii) continuity includes relationship between the primary care physician and patient should be long term and consistent over time, (iii) comprehensiveness should provide a wide range of preventive and acute care services to meet a large proportion of patient medical records, (v) coordination involves primary care systems to coordinate care across physicians, ideally using electronic information systems and (v) accountability includes primary care physicians to be responsible for patient’s overall health and medical outcomes (Schmittdiel et al., 2008).


Summary

A patient centered e-health management model can improve communication between patient, healthcare professionals in primary care and hospital, can facilitate decision making.

A central concept is personal health system for the patient/citizen and three main application areas are identified. The connected health ecosystem is making progress, already shows benefits in (a) new biosensors, (b) data management, (c) data analytics, integration and feedback.

Contribution to CHRODIS GP assessment dimensions

Future: people will be accessing and controlling their healthcare information

Direct communication with healthcare professionals in timely and contextualized decisions (no SDM)

Life style, prevention, rehabilitation

Enable disease management at home and prevent hospitalization

Ambient assisted living: This category of applications addresses the need for independent living and quality of life among elder population, via multifaceted approaches that include monitoring of activity and vital signs, physical and cognitive training, self-assessment, services for daily life facilitation (e.g. for shopping needs) and social support.

Personal Health Systems; 2 types:
- Portable or wearable
- Intelligent information processing of existent data
- Active feedback to patients from data or healthcare professionals

Such systems can involve the personal health records (PHRs), mobile health and medical apps for patient interaction, decision support for the patient and professional [16], communication tools and social networks [17],

Sensors: devices include a great variety of sensors for measurements

Data management: from personal health record, sensors, patient generated

This includes longitudinal data on symptoms, vital signs and signals, treatment history, lifestyle and behaviour along with contextual and environmental data recorded or inferred by patients and care providers, which can be integrated with the clinical or even molecular data.

Data analytics

Data analysis can produce:
- Represented in status and trends of the patient conditions: intuitive representations for patients.
- Predictive models and decision support systems
- Especially interesting for comorbidity.

**DOCUMENT: WHO Innovative Care for Chronic Conditions: Building blocks for action 2012**

**Summary**

The World Health Organization created this document to alert decision-makers throughout the world about important changes in global health, and to present health care solutions for managing the rising burden. It establish the eight essential elements for taking action as:

1. Support a Paradigm Shift (from acute episodic model to chronic integrated care model)
2. Manage the Political Environment
3. Building Integrated Health Care
4. Align Sectorial Policies for Health
5. Use Health Care Personnel more Effectively
6. Centre Care on the Patient and Family
7. Support Patients in their Communities
8. Emphasize Prevention

This document describes the ‘Innovative Care of Chronic Conditions Framework’ aimed to lead the pathway through innovative ways of addressing the chronic conditions care adapting health policies, systems and models.

It focuses on: Evidence-based decision making, population focus, prevention, quality, integration of care, flexibility and adaptability.
This document provides us with a framework for innovative care for chronic conditions introducing or developing domains such as:

- Innovative Care
- Community Linkages
- Leadership and advocacy
- Self-management and prevention
- Sustainability

Regarding Patient-Centred Approach:
- Lifestyle and daily behavioural change
- Promote patients active role
. Beyond clinic care
. Involve families and communities

Other comments

The proposed framework was used to build up and organize the specific sub-domains included in the Innovation domain.

DOCUMENT: PAHO Innovative Care for Chronic conditions: Organizing and Delivering High Quality Care for Chronic Non communicable Diseases in the Americas 2013-Eng

Summary

The document concludes that the Chronic Care Model should be implemented in its entirety since its components have synergistic effects, where the whole is greater than the sum of the parts. Policy reforms and universal access to care are critical elements leading to better outcomes and reducing disparities in chronic disease care. It is critical to integrate PHC-based chronic care into existing services and programs. Chronic diseases should not be considered in isolation but rather as one part of the health status of the individual, who may be susceptible to many other health risks. A patient-centred care system benefits all patients, regardless of their health conditions or whether his/her condition is communicable or non-communicable. A care system based on the Chronic Care Model is better care for all, not only for those with chronic conditions.

Primary care has a central role to play as a coordination hub, but must be complemented by more specialized and intensive care settings, such as diagnostic labs, specialty care clinics, hospitals, and rehabilitation centres. Finally the ten recommendations for the improvement of quality of care for chronic conditions are:

1. Implement the Chronic Care Model in its entirety.
2. Ensure a patient centred approach.
3. Create (or review existing) multisector policies for CNCD management including universal access to care, aligning payment systems to support best practice.
4. Create (or improve existing) clinical information system including monitoring, evaluation and quality improvement strategies as integral parts of the health system.
5. Introduce systematic patient self-management support.
6. Orient care toward preventive and population care, reinforced by health promotion strategies and community participation.
7. Change (or maintain) health system structures to better support CNCD management and control.

9. Reorient health services creating a chronic care culture including evidence-based proactive care and quality improvement strategies.

10. Reconfigure health workers into multidisciplinary teams, ensuring continuous training in CNCD management.

**Contribution to CHRODIS GP assessment dimensions**

This document provided us with further insights into the development of the Chronic Care Model.

It also enhances the attention to several domains such as:

- Theory grounds (well specified and measurable main goal and sub-goals)
- Key population and target population
- Community linkages
- Patient Participation and commitment
- Mapping of relevant stakeholders
- Impact of the implementation in current organization
- Regularity of monitoring reports and consequences derived from assessment
- Development of integrated health information systems
- Evaluation framework assessing process and outcomes

**KEY ACTIONS FOR SELF-MANAGEMENT SUPPORT**

Ensure patient participation in the process of care;
Promote the use of lay or peer educators;
Use group visits;
Develop patient self-regulatory skills (i.e., managing health, role and emotions related to chronic conditions);
Promote patient communication skills (especially with regard to interactions with health professionals and the broader health system);
Negotiate with patient goals for specific and moderately challenging health behaviour change;
Stimulate patient self-monitoring (keeping track of behaviours);
Promote environmental modification (creating a context to maximize success);
Ensure self-reward (reinforcing one’s behaviour with immediate, personal, and desirable rewards);
Arrange social support (gaining the support of others);
Use the 5As approach during routine clinical encounters (Asses, advise, agree, assist, arrange)

**EXAMPLES OF EFFECTIVE INTERVENTIONS**

- Group based self-management support for people with type 2 diabetes (50)
- Self-monitoring of blood pressure specially adjunct to care (51)
- Patient educational intervention for the management of cancer pain alongside traditional analgesic approaches (52)
- Patient educational intervention using the 5 As for reducing smoking, harmful use of alcohol and
Joint Action CHRODIS

www.chrodis.eu

This document fully endorses the Chronic Care Model committing to its development for structuring a new healthcare system addressing the care of chronic conditions.

**DOCUMENT: Excellent Innovation for Ageing a European guide for the Reference sites of the European Innovation Partnership on Active and Healthy Ageing**

**Summary**

This guide aims to take you on a special journey through Europe: a tour of regions, cities and communities where you can see innovation for active and healthy ageing in real life.

**References sites:** self-assessed innovation cases

**Contribution to CHRODIS GP assessment dimensions**

Integrated flow of information through the healthcare chain increases the discharge rate and enables continuity once the patient is discharged and the municipality/home care takes over the care. The electronic communication also generate cost savings for all the actors involved in the process.

Thanks to the innovation complex patients can be monitored directly from home, with positive impact on their mental health and quality of life.

Thanks to the participation of users in the development and testing phase, companies gain better insight and provide better services.

The best practice relies on rehabilitation after hospital discharge via e-learning and assistive technologies for both the elderly person and their family and carers who receive adapted training in assisting them at home.

The Memory Training (MT) programme aims to maintain, as long as possible, a good quality of cognitive life for the elderly.

The Adapted Physical Activity (APA) contribute:

- Reduce the hospitalization expenditures
- Improve Vitality of citizens though a client oriented and demand driven approach
- Improve inclusiveness (engagement) of citizens and social cohesion
- Improve participation, self-management, autarchy and self-reliance
  supporting patient care near home, avoiding unnecessary hospitalisations and outpatient visits • achieving better outcomes through motivational care planning and improved engagement with patients • promoting self-care and support via information prescriptions, supporting behaviour change


**Summary**

**Contribution to CHRODIS GP assessment dimensions**

What do we mean by quality and what does it really mean to hold all this quality fixed? A particularly attractive definition for thinking about this is from the Institute of Medicine, which defines quality as multidimensional and characterized by care that is safe, timely, effective, efficient, equitable, and patient-centred (recently, this last term of patient-centred has begun to be viewed as too oriented toward sickness as opposed to wellness, so in a spirit of loss aversion is turning toward person-centred).


**Summary**

**Contribution to CHRODIS GP assessment dimensions**

Ten characteristics of a high-performing chronic care system (1) Ensuring universal coverage (2) Provision of care that is free at the point of use (3) Delivery system should focus on the prevention of ill health (4) Priority is given to patients to self-manage their conditions with support from carers and families (5) Priority is given to primary healthcare (6) Population management is emphasised through the use of tools to stratify people with chronic diseases according to their risk and offering support commensurate with this risk (7) Care should be integrated to enable primary healthcare teams to access specialist advice and support when needed (8) The need to exploit the potential benefits of information technology in improving chronic care (9) Care is effectively coordinated (10) Link these nine characteristics into a coherent whole as part of a strategic approach to change Source: Ham [10]
**DOCUMENT:** Margolis et al Collaborative Chronic Care Networks (C3Ns) to Transform Chronic Illness Care. Paediatrics 2013;131;S219

### Summary

### Contribution to CHRODIS GP assessment dimensions

#### Collaborative Chronic Care Networks

All participants in health care (patients and families, caregivers, clinicians, and researchers) care deeply about improving health. What is missing is a system to harness this motivation and focus participants’ collective intelligence toward transforming care and outcomes. What if we could harness the collective intelligence of patients, clinicians, and researchers to create such a system? Wikipedia (the Web-based, collaborative encyclopaedia project), Linux (the open-source computer software operating system), and the open, rapid sharing of data that occurred in advance of publication in the human genome project are just 3 examples of how the production of knowledge, information, and know-how can be distributed over large groups of people, dramatically accelerating the discovery process. These models are transforming how individuals connect, exchange information, and produce knowledge, enabling previously unimaginably large groups of people to join together to make real their shared vision of the future. These models have rapidly achieved unprecedented innovation and performance, in part because they have built systems that allow inherent motivation of like-minded individuals to flourish through a culture of cooperation.4 This form of production has been termed network-based or “social” production.5

Network-based production is particularly suited to complex systems such as health care, precisely because the knowledge, skills, and tools necessary to develop and implement real change are often beyond the capacity of 1 place, person, or organization because the stakeholders in the process (in this case, patients, clinicians, and researchers) are motivated and have skills that can be devoted to the task, and finally because the scientific questions about how to accomplish improvements in health and health care require a multidisciplinary complex systems science perspective. A C3N is a network-based production system for health and health care.

Building community starts with communicating a compelling vision; for the C3N Project, it is improving the health of all patients affected by a chronic illness. The project’s core leadership team of patients, clinicians, and researchers share responsibility for defining this vision and purpose, communicating it, and creating strategies for implementation. Sharing stories is a powerful way to motivate action. A short film about Improve CareNow’s work was created by renowned filmmaker Jesse Dylan, and a diverse group of participants, supporters, and collaborators (including Improve CareNow clinicians and staff, patients and family members, researchers, quality improvement experts, and health care innovators) post their personal stories regularly on LOOP, the official blog of Improve CareNow (http://improvecarenowblog.org/).

http://c3nproject.org/about-c3n-project#challenge
Summary

Contribution to CHRODIS GP assessment dimensions

Adoption of integrated electronic health systems is the beginning of a long care-transformation journey.

Personal Health Navigator. Ejemplo: Geisinger’s “patient-centred medical home” initiative is designed to deliver value by improving care coordination and optimizing health status for each individual. Components designed to create a functional “Personal Health Navigator” for consumers include round-the-clock primary and specialty care access; a GHP-funded nurse care coordinator in each practice site; predictive analytics to identify risk trends; virtual care-management support; a person, called a personal care navigator, to respond to consumers’ inquiries; and a focus on proactive, evidence-based care to reduce hospitalizations, promote health, and optimize management of chronic disease. Other features include home-based monitoring, interactive voice-response surveillance, and support for end-of-life care decisions.

Electronic Health Record access: EHR access is provided to all participants, including physicians, care managers, and consumers. Consumer EHR features include Internet-based lab results display and results trending over time, clinical reminders, self-scheduling, secure e-mail with providers, prescription refills, and educational content.

Summary

It is centred on how to measure Innovation on every different area of progress.

It provides an extensive analysis of the situation of the innovation, measured by proxy indicators across the OECD countries and sectors, addressing the need of more research and measurement in how innovation is implemented and how can we promote it to reach new levels of development.

It proposes a framework for measuring innovation through their derivative products. Also it promotes people participation and addresses the main challenges to tackle in next years.

Contribution to CHRODIS GP assessment dimensions
This document provided us with a main framework for measuring innovation and develops this domain expanding the domains of:

- Innovation
- Sustainability
- Research Implementation
- Innovation measurement as a method to assess its impact on the healthcare systems

### Other comments

### 3. SCALABILITY


#### Summary

The document is focused on development interventions, though the lessons drawn seem more generally applicable to other types of interventions and projects with a vocation to expand and stay in place (such as health promotion and primary interventions in European Member States).

The authors explore the possible approaches and paths to scaling up, the drivers of expansion and of replication, the space that has to be created for interventions to grow, and the role of evaluation and of careful planning and implementation.

They draw a number of lessons for the development analyst and practitioner. More than anything else, scaling up is about political and organizational leadership, about vision, values and mind-set, and about incentives and accountability—all oriented to make scaling up a central element of individual, institutional, national and international development efforts. The paper concludes by highlighting some implications for aid and aid donors.

#### Contribution to CHRODIS GP assessment dimensions

The Domain Scalability has drawn on this document incorporating 3 criteria:

- Size of the population targeted if scaled up
- Analysis of requirements for eventual scaling up: key factors, foreseen barriers and facilitators
- Systematic networking efforts to foster the exchange of information, mutual support and cooperation with other community resources
**Summary**

This document outlines the scaling-up strategy for the good practices identified within the European Innovation Partnership on Active and Healthy Ageing (EIP AHA). It relies on WHO Guide for scaling up (which in turn references the Wolfensohn Center for Development Working Paper 5 included in this summary of evidence).

Beyond the quality of the impact, scale and sustainability. They identify four types of scaling up in terms of structures, programs, strategies or resource bases: quantitative, functional, political or organisational. All these dimension of scaling up are conceived as interrelated since quantitative or functional scaling up requires organisational adjustments and further expansion is triggered by political developments.

The approach proposed in this paper focusses on two key elements – "what to scale up" and "how to scale up". The "what" includes identifying practices, projects and innovations to be scaled up, and the "how" focuses on the methods of going to scale. The latter part also discusses the organisational roles involved in scaling up (who and where) in the European context.

**Contribution to CHRODIS GP assessment dimensions**

The Domain Scalability has drawn on this document incorporating 2 criteria:
- sustainability in the medium term (sufficiency of resources, commitment, ownership and institutional anchoring)
- specific knowledge transfer strategies in place (evidence into practice)

This piece of information also reinforced the other 3 criteria included in the domain:
- size of the population targeted if scaled up
- analysis of requirements for eventual scaling up: key factors, foreseen barriers and facilitators
- systematic networking efforts to foster the exchange of information, mutual support and cooperation with other community resources

**Other comments**
4. IMPLEMENTATION

**DOCUMENT:** Elwyn Glyn, Laitner Steve, Coulter Angela, Walker Emma, Watson Paul, Thomson Richard et al. Implementing shared decision making in the NHS *BMJ* 2010; 341:c5146 [http://www.bmj.com/content/341/bmj.c5146](http://www.bmj.com/content/341/bmj.c5146)

**Summary**

Despite considerable interest in shared decision making, implementation has proved difficult and slow. At least three conditions must be in place for shared decision making to become part of mainstream clinical practice: ready access to evidence based information about treatment options; guidance on how to weigh up the pros and cons of different options; and a supportive clinical culture that facilitates patient engagement. This article outlines some options for creating a sustainable decision support platform for patients that may facilitate a wider adoption of shared decision making in clinical practice.

**Contribution to CHRODIS GP assessment dimensions**

Successful Implementation will require

- available evidence
- adapted into accessible tools (decision aids) both to patients and clinicians
- introduce in the referral care pathway
- a more favourable organizational culture and healthcare professionals
- strong strategic leadership, commissioning high quality content, sustainable funding
Self-management is ‘the tasks … individuals must undertake to live with one or more chronic conditions …[including] …having the confidence to deal with medical management, role management and emotional management of their conditions’. We convened an expert workshop and identified characteristics of LTCs potentially of relevance to self-management and 14 diverse exemplar LTCs (stroke, asthma, type 2 diabetes mellitus, depression, chronic obstructive pulmonary disease, chronic kidney disease, dementia, epilepsy, hypertension, inflammatory arthropathies, irritable bowel syndrome, low back pain, progressive neurological disorders and type 1 diabetes mellitus). For each LTC we conducted systematic overviews of systematic reviews of randomised controlled trials (RCTs) of self-management support interventions (‘quantitative meta-reviews’); and systematic overviews of systematic reviews of qualitative studies of patients’ experiences relating to self-management (‘qualitative meta-reviews’). We also conducted an original systematic review of implementation studies of self-management support in the LTCs. We synthesised all our data considering the different characteristics of LTCs. In parallel, we developed taxonomy of the potential components of self-management support.

We concluded that supporting good self-management is inseparable from the high-quality care all people with LTCs should receive. Supporting self-management is not a substitute for care from doctors and nurses but a hallmark of good care. Providers of services for people with LTCs should consider how they can actively support self-management.

Effective self-management support interventions are multifaceted, should be tailored to the individual, their culture and beliefs, a specific LTC and position on the disease trajectory, and underpinned by a collaborative/communicative relationship between the patient and health-care professional (HCP) within the context of a health-care organisation that actively promotes self-management. Self-management support is a complex intervention and although many components were described and trialled in the studies no single component stood out as more important than any other. Core components include

1. provision of education about the LTC, recognising the importance of understanding patients’ pre-existing knowledge and beliefs about their LTC;
2. psychological strategies to support adjustment to life with a LTC;
3. strategies specifically to support adherence to treatments;
4. practical support tailored to the specific LTC, including support around activities of daily living for disabling conditions, action plans in conditions subject to marked exacerbations, intensive disease-specific training to enable self-management of specific clinical tasks; and
5. social support as appropriate.
Implementation requires a whole-systems approach which intervenes at the level of the patient, the HCP and the organisation. The health-care organisation is responsible for providing the means (both training and time/material resources) to enable HCPs to implement, and patients to benefit from, self-management support, regularly evaluating self-management processes and clinical outcomes. More widely there is a societal need to address public understanding of LTCs. The lack of public story for many conditions impacted on patient help-seeking behaviour and public perceptions of need.

**Contribution to CHRODIS GP assessment dimensions**

<table>
<thead>
<tr>
<th>Self-management support interventions dimensions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Recipients: patients, carers, HCPs, organisations.</td>
</tr>
<tr>
<td>2. Components: education, information about resources, specific action plans and/or rescue medication, equipment, safety netting, regular clinical review, training to communicate with HCPs, training for activities of daily living (ADL), training in psychological strategies, training for practical self-management activities, social support, monitoring with feedback to the patient, practical support with adherence, lifestyle advice and support.</td>
</tr>
<tr>
<td>3. Modes of delivery.</td>
</tr>
<tr>
<td>4. Personnel delivering the support.</td>
</tr>
</tbody>
</table>

Despite intense interest in supporting good self-management among people with long-term conditions (LTCs), it can be difficult for commissioners to identify what works. In addition, although there is a plethora of evidence concerning self-management for some LTCs, many lack a tradition of research explicitly on self-management and, consequently, some patient groups may be overlooked.

We have adopted the definition of self-management proposed by the US Institute of Medicine: Self-management is defined as the tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their condition.

**Phase 1: To agree in discussion with an Expert Advisory Group:**
- Characteristics of LTCs of relevance to self-management
- Components of self-management support interventions to inform a taxonomy
- The selection of exemplar LTCs for detailed investigation in phase 2.

**Phase 2: To undertake meta-syntheses of the evidence around interventions for self-management support in each of the exemplar LTCs from:**
- Published systematic reviews of randomised controlled trials (RCTs) (‘quantitative meta-reviews’)
- Published syntheses of qualitative studies (‘qualitative meta-reviews’).
To conduct an original systematic review of primary studies concerned with the implementation of self-management support interventions in populations with the exemplar LTCs (i.e. Phase IV implementation trials).

To synthesise the resulting meta-reviews and systematic review in an overarching narrative synthesis, to determine what is known about the likely effectiveness of self-management support interventions with respect to health service resource use, health outcomes [including quality of life (QoL), symptoms, biological markers of disease and equity].

Phase 3: To organise a multidisciplinary workshop as a result of the work undertaken in phases 1 and 2 in order to:
- Discuss our findings, and
- Help develop practical recommendations for health service commissioners.

To identify research gaps for future primary research or research synthesis.

Supporting self-management is inseparable from high-quality care for people with long-term conditions

The key theme from all our meta-reviews and the implementation systematic review was that supporting self-management is inseparable from the high-quality care of people with LTCs.

Commissioners and providers of services for people with LTCs should consider how they can promote a culture of actively supporting self-management as a normal, expected aspect of the provision of care.

In our reviews self-management was not a substitute for professional care. Far from feeling abandoned and left to look after themselves, supported self-management empowered patients to access best care and support, though potentially (and paradoxically) reducing health-care resource use, especially in asthma and COPD.

Supported self-management must be tailored to the individual, their culture and beliefs, and the time point in the condition

A recurring theme from the meta-analyses was the importance of tailoring the self-management support to the individual and their condition. There was abundant evidence from the qualitative meta-reviews suggesting that individuals’ existing health beliefs frame their understanding of their condition, and they will tailor medical regimes and self-management strategies to fit into their own lives and beliefs. Quantitative meta-reviews in both T2DM and asthma identified the benefits of providing culturally specific interventions. The nature of the LTC also emerged as an important factor in determining the self-management priorities.

Communication: a common theme in most of the qualitative meta-reviews was the
importance of enhancing communication between HCPs and patients.

Organizational support is needed.

Long-term condition characteristic-specific self-management components must be taken into account

The implementation systematic review suggested that effective interventions were multifaceted and multidisciplinary.

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**DOCUMENT:**


**Summary**

A practical resource for organizations striving to become more patient-centered (in hospitals) with a Self-Assessment Tool to identify and prioritize opportunities for introducing patient centered approaches most frequently cited barriers to implementation of patient-centered care, the foundation for successful implementation.

**Contribution to CHRODIS GP assessment dimensions**

Patient centred care needs organizational culture change

Need to overcome myths about patient centred care including: PCC is costly, there is no evidence, can be unsafe....

Leaders determine, guide and communicate the vision of any organization, and as such, leadership engagement in any organizational culture change initiative is crucial. In their own behaviours and values, leaders set the tone for implementation of patient-centred care.

Walking the talk means communicating openly, soliciting and responding to input from staff, patients, families and others, and ensuring staff members have the resources and flexibility they need to provide patient-centred care.

Physicians must be involved

Board members

Families and patients

Use implementation tools

open and responsive communication
personalization of care 
culturally adapted care 
continuity of care (patient navigators, patient advocates, 
community care 
Technology: data is not enough. Patient centred care technology must: enhance effective communication, promote continuity of care.


Summary

The Health Foundation’s MAGIC (Making good decisions in collaboration) improvement programme began in August 2010 and will run until October 2013. It aims to support clinical teams in primary and secondary care to embed shared decision making (SDM) with patients in their everyday practice. This evaluation covers the first phase of the programme.

The aims of the MAGIC programme are:

- Demonstrate that shared decision making (SDM) can feasibly, affordably and sustainably become a core characteristic of routine clinical care, both within primary and secondary care and at large scale
- Build practical and transferable knowledge about how this can be achieved and what the conditions for success are.

The programme was delivered through activities including:

- skills development and engagement, such as introductory and advanced skills development workshops for participating clinicians
- guidance on developing, adapting and implementing decision support tools
- facilitation and peer support for clinical teams
- Support in involving patients, including setting up patient forums and implementing a campaign – Ask 3 Questions – to ‘activate’ patients (increase their awareness of SDM).

Results:

The evaluation found evidence that the programme has succeeded in building participants’ understanding and awareness of SDM, and developing their skills and confidence to apply the approach in practice. However, it proved difficult to successfully engage a small number of stakeholders, particularly senior clinicians.

Success was more likely where SDM was aligned with broader objectives such as developing
more patient-centred care.

There was widespread use and positive feedback on many of the tools piloted within the programme. This is especially true of brief in-consultation decision support materials (Option Grids, Brief Decision Aids BDAs), which were widely reported as being simple to use, effective in promoting consistent practice across clinical teams, and easy for patients to engage with.

Changes likely to produce a solid foundation for the implementation of SDM include:

- stronger and more widespread efforts to raise patients’ awareness of and capacity to engage with SDM (including support to patient representative groups)
- the creation of mapping tools to enable service managers and commissioners to understand how care pathways can support SDM and where the decision points lie
- the development of national measures that can enable NHS managers to monitor and track patient experiences of SDM and outcomes
- provision of training and development programmes to support SDM, available to clinicians at all levels in the system
- the re-development of NHS and local authority information systems such as GP and NHS trust software systems so that SDM tools and information are readily available to clinicians and to patients, through patient records.

It was exceptional for clinical teams to have started the process of redesigning care pathways or wider systems to support the embedding of SDM prior to the MAGIC programme’s involvement.

Patient awareness and involvement was low when the programme started.

Evaluation participants reported that a key barrier to clinicians taking part in the MAGIC programme was the perception that they were already making shared decisions with their patients and so did not see the need to improve their practice.

The Health Foundation’s recent evidence review notes,14 that initiatives that focus on ‘passive’ information-giving to patients are less likely to be effective than those which seek to actively engage patients with SDM. Raising awareness and changing expectations (described by some participants in the evaluation as the ‘activation’ of patients) was therefore a critical focus of the MAGIC programme.

**Contribution to CHRODIS GP assessment dimensions**

The evaluation found that assessing the baseline or ‘starting point’ of local teams, including their motivation and readiness to engage with SDM, may result in more tailored and therefore more effective approaches to implementation.

Specifically, we looked at the position of teams entering the programme in relation to the following dimensions:

- Attitudes, knowledge and awareness of shared decision making (SDM)
- Readiness of teams to engage in SDM
- Practical experience of using SDM tools, such as decision aids
- Clinical pathways and systems.
The objective of this paper was to review the literature and to scope the field with respect to 2 questions: (1) which ICT interventions have been used to support patients and health care professionals in PCC management of the big 5 chronic diseases? and (2) what is the impact of these interventions, such as on health-related quality of life and cost efficiency?

This scoping review outlined ICT-enabled PCC in chronic disease management. Persons with a chronic disease could benefit from an ICT-enabled PCC approach, but ICT-PCC also yields organizational paybacks. It could lead to an increase in health care usage, as reported in some studies. Few interventions could be regarded as “fully” addressing PCC. This review will be especially helpful to those deciding on areas where further development of research or implementation of ICT-enabled PCC may be warranted.

Contribution to CHRODIS GP assessment dimensions

This document does not add anything additional.