Better implementation of improvements in chronic care

European experts' views on future research and development
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Executive summary

1.1 Introduction

We know more about the effectiveness of chronic care itself than we know about how to implement these effective practices and care models. The result of this mismatch is that too often the implementation of inherently good innovations fails. Luckily, this is recognised as a problem and we are beginning to use methods which combine implementation with research so that we can more quickly improve care and learn about what works best for whom and where. This report presents a synthesis of what a diverse group of experts across the European Union see as research priorities to speed up and spread improvements to chronic care.

It will contribute to the future EU Research Agenda and also seeks to stimulate research funding for rigorous and timely implementation research in chronic care. But it is also of immediate use to improvers and researchers across Europe for the insights and discussions about implementation, chronic care and improvement science and practice.

1.2 What is the problem the report addresses?

There is an increase in knowledge both in chronic health conditions and in changes that are effective for improving care, self-care and prevention. Significant suffering could be avoided by making more use of knowledge we already have about which interventions are effective. Significant savings, also, in costs could be made by using what we know from research about the costs and return on investment of these interventions.

Implementation research can help speed and spread the use of these proven effective changes by practitioners’ organisations, patients and citizens. Implementation research is the systematic study of how best to enable people and organisations to carry into their daily routines new proven ‘better ways’ of working and self-care (‘improvements’). It also involves understanding the surrounding conditions that may help or hinder people to take-up these new better ways.

The project reported here was not to discover which treatments, care and support models or prevention approaches were most effective, or to explore which research into promising treatments is needed. Rather, it was to find out the best ways to implement these effective interventions: which kind of research is most needed about how to ‘take-up’ (‘implement’) the developing body of knowledge about intervention effectiveness and cost in everyday practice and in people’s everyday lives? Methods to enable take-up are many and various – one example is to change the way services are paid, so as to give more incentives to make use of a proven effective service delivery method to support people with a chronic illness and prevent avoidable hospital admission.

A second part of the project was to establish a network to implement already proven chronic care improvements in each EU country, as well as a cross-European network to share implementation experiences and insights. The details of this are provided in another project report available from the ‘EU implement’ website (Bongers et al., 2015).
1.3 Methods

A systematic approach was used to gather and prioritise the views of experts across Europe. The method used a) experts from a range of stakeholder groups following the Triple Helix Plus, b) who used a systematic and ‘iterative approach’ to assess priorities, and c) were allowed to revise their priorities after online debates with each other and feedback from the project team. A summary of the methods and a more elaborate description of the results are presented in other reports (Bongers et al., 2015; Øvretveit et al., 2015).

1.4 Main findings

With a first group of 25 international experts we developed a list of 18 priority subjects for implementation research. These research subjects are listed in the report below and fully elaborated in the main report (Bongers et al., 2015). The list served as a starting point for the development of the research agenda using the iterative method described above. This method enabled a large group of 389 European experts to agree on the top priorities for research into implementation of chronic care improvements as. All of the subjects were scored by 389 experts as a priority for research.

The top-3 subjects for future implementation research in chronic care are:
1. Adoption or ‘take-up’
2. Measuring and evaluating implementation effectiveness
3. Patient empowerment for implementation

Close to this top 3 subjects follow ‘Skills, education and training’, ‘Reducing burden of treatment’ and ‘Information and communication technology’.

Those implementation research subjects rated as lowest priority were:
16. Simulating implementation, before actual introduction
17. Laws, regulations and standards in chronic care
18. Scientific research methods for knowledge about implementation

Also here, the differences in ranking are small and the bottom 3 are close to other subjects. The reason for these small differences in mean rankings is that all research subjects are important to almost all respondents, who found it hard to really prioritise.

Statistical analysis showed that priority was not significantly affected by the country or stakeholder group from which the expert came.
1.5 Further analysis of experts’ views

The full reports of Bongers et al. (2015) and Øvretveit et al. (2015) give:
- The descriptions of each of the 18 subjects which experts scored and prioritised for implementation research, with examples,
- The distribution of the 389 experts by country and by the eight stakeholder categories from the Triple Helix Plus,
- The prioritisation of the research subjects by the 389 European experts,
- Details of the degree of agreement between experts and other details,
- Discussion and observations by the research team.

This book summarises these subjects and presents further proposals for an EU Agenda on implementation research for chronic care improvements.

1.6 Conclusions and proposal for the EU Research Agenda

Implementation experts across Europe agreed on 18 subjects where research could facilitate faster and wider implementation of proven improvements to chronic care and self-care. A large expert group came to some consensus on the top priorities for an EU Agenda for implementation research in chronic care. We advise the EU to start with the first six subjects for implementation research in chronic care improvements, and to establish a European collaborative with the eight stakeholder groups from the Triple Helix Plus. This networking strategy (social innovation) will create the necessary structures to further develop and complete the research agenda in the second and third round, thus covering all research subjects.

The structured discussion and debate between experts about why particular subjects should be priority for implementation research revealed that experts sometimes differ in the criteria they use to prioritise. Also, there are different views on the likely practical value of more implementation knowledge for significant reductions in the suffering of patients and today’s waste of resources, in their own country and elsewhere in the EU.

This study thus provides guidance to the EU and other funders of research interested in supporting practical research that will reduce suffering and waste in chronic care, through accelerated system-wide implementation of the continuously growing body of knowledge. It provides help to researchers in choosing implementation research as a field for greater attention, and introduces subjects within this field which a wide sample of EU experts from different stakeholder groups consider to be urgently needed to address across Europe.
People in European countries are growing older and suffer increasingly from heart failure, diabetes, asthma and other chronic health conditions.
Introduction and methods

2.1 Introduction

People in European countries are growing older and suffer increasingly from heart failure, diabetes, asthma and other chronic health conditions - which can also include cancers. These common health conditions are more frequently experienced by more European citizens, may not be curable and may persist for the rest of one's life. In addition to the human suffering caused, this is placing an increasing burden on families, health care services, businesses and taxpayers.

Many older people experience two or more long-term illnesses, making care and support even more complex (Coulter et al., 2013) (US DHHS, 2010). Clinical coordination is often unsatisfactory or even harmful, and becoming ever more difficult. In part this is because a greater variety of services is being offered and used by people with long-term conditions, with growing numbers of service suppliers and start-ups coming from outside of the health sector. In part the coordination issues are caused by constraints to data exchange, which hinders the potential for better access to needed information that more Electronic Health Records and interconnectivity can provide.

Research has discovered interventions that are effective, and some that are cost-effective, for prevention, diagnosis, treatment, care coordination and self-care. These ‘chronic care improvements’ include changes to support self-care, and changes that improve the care provided to patients by practitioners, service organisations and close caregivers. These improvements apply to chronic care in all fields of health care, including home-care, general care, specialised and hospitalised care, and psychiatric care.

The ‘take-up’ or ‘adoption’ of these improvements by care providers and others has been slow and variable, as well as the take-up of support for self-care by people with chronic illnesses. Some research exists into effective implementation strategies and methods, but this research is limited and often not known or used, even by those actively implementing improvements. The focus of the study reported here was on implementation of these improvements.

The purpose of the IMPLEMENT project was to discover which research is most needed in the future to speed and spread the ‘take-up’ of these improvements, and to establish a European network to carry out and apply the research.

This document reports the findings and analyses of the first part of the project, which was to seek experts’ views about the gaps in knowledge about implementation that are hindering the take-up of these improvements. A second part of the project was to establish a cross-European network to share experience.
### 2.2 Triple Helix Plus

The Triple Helix thesis is that the potential for innovation and economic development in a Knowledge Society lies in a closing working between University, Industry and Government (three key stakeholder groups, hence “Triple Helix”) to make apply knowledge (Etzkowitz & Leydesdorff, 1997). From this perspective implementation can gain from many perspectives and experience. Knowledge can be gathered from experts that work as policy makers, business people or professionals in healthcare. Perhaps even more important are patients and their informal care givers (often relatives). Hence, IMPLEMENT developed a Triple Helix Plus with eight stakeholder groups (see Figure 1).

<table>
<thead>
<tr>
<th><strong>Triple Helix</strong></th>
<th><strong>Plus</strong></th>
<th><strong>Main examples</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Triple Helix</strong></td>
<td><strong>Government / Policy</strong></td>
<td>Government</td>
</tr>
<tr>
<td></td>
<td><strong>Industry / Business</strong></td>
<td>Industry</td>
</tr>
<tr>
<td></td>
<td><strong>University / Research</strong></td>
<td>Research institutions</td>
</tr>
<tr>
<td><strong>Plus</strong></td>
<td><strong>Practice</strong></td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Professional</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Healthcare institutions</td>
</tr>
<tr>
<td><strong>Combined perspectives</strong></td>
<td>Professional and research institutions</td>
<td>Professional and healthcare institutions</td>
</tr>
</tbody>
</table>

**Figure 1** | The Triple Helix Plus stakeholder groups

Some people have a dual role in the Helix. Healthcare professionals may carry out research in addition to their clinical work, or have a managerial role as well in their healthcare institution. Examples of people in each stakeholder group include:

<table>
<thead>
<tr>
<th><strong>Triple Helix Plus</strong></th>
<th><strong>Main examples</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient perspective (Practice)</td>
<td>Representative of a patients organisation, an actual patient (practical knowledge)</td>
</tr>
<tr>
<td>Professional perspective (Practice)</td>
<td>A doctor or nurse working in clinical practice</td>
</tr>
<tr>
<td>Healthcare institutional perspective (Practice)</td>
<td>A manager of a healthcare service</td>
</tr>
<tr>
<td>Governmental perspective (Policy)</td>
<td>A policy advisor</td>
</tr>
<tr>
<td>Industrial perspective (Business)</td>
<td>A manager in a technology business, a manager in an insurance company, CEO of a medical devices manufacturer, manager in a pharmaceutical company</td>
</tr>
<tr>
<td>Research institutional perspective (Research)</td>
<td>A university researcher, a researcher employed by a research organisation or consultancy</td>
</tr>
<tr>
<td>Professional and a research institutional perspective</td>
<td>A university researcher with a clinical qualification</td>
</tr>
<tr>
<td>Professional with a healthcare institutional perspective</td>
<td>A manager who is also a clinician</td>
</tr>
</tbody>
</table>
Building the bridge between the worlds of formal experts (‘Triple Helix’) and core users (‘Plus’), the manifest and tacit knowledge of all stakeholder groups is indispensable in making inventions work in daily practice. Where the manifest knowledge may find its way into scientific publications, tacit knowledge only can be made explicit by working with the holder of the knowledge.

### 2.3 Theoretical assumptions

This research was based on assumptions about why research for improving chronic care is challenging to implement. The theoretical and methodological backgrounds are described in detail in the grant proposal (IMPLEMENT, 2013a) and in the scientific protocol for the project (IMPLEMENT, 2013b).

In summary, these assumptions are:

1. The more effective interventions are those that involve a number of stakeholders: for example, ‘transitions’ interventions (e.g. from hospital to primary care), or some or all elements of the Chronic Care Model (Coleman et al., 2009).

2. Implementation requires a number of stakeholders to make changes in order to establish the improvement in routine, daily practice, and in the daily life of people with long-term conditions.

3. Stakeholders from different stakeholder groups have different views about which knowledge would be of most use to assist them in implementation, and which is missing.

4. Stakeholders in one EU country are likely to have views about gaps in needed knowledge about implementing these improvements that are different to the views of those in another country.

5. A systematic review of research into implementation methods is needed but was too time-consuming and resource-intensive for the short period allowed for this project if it was to inform the imminent EU Research Agenda-building process. Furthermore, this would not necessarily reveal what the stakeholders who were implementing changes, viewed as the missing knowledge.
## 2.4 Definitions used in this publication

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic health condition</td>
<td>A health condition that lasts a year or more and requires on-going medical attention and/or requires limiting the activities of daily living.</td>
</tr>
<tr>
<td>Co-morbidity or multiple morbidity</td>
<td>More than one co-existing illness, which may include chronic disease or may refer to one or more chronic disease co-existing with trauma or a disease which may be curable.</td>
</tr>
<tr>
<td>Context or conditions for implementation</td>
<td>Influences which may help or hinder actions to enable the take-up of a new way of doing something but which are not direct implementation actions.</td>
</tr>
<tr>
<td>Intervention</td>
<td>The new ‘better way’ to be taken up by people or organisations.</td>
</tr>
<tr>
<td>Implementation</td>
<td>Enabling people or organisations to take up and adopt a new way of doing something.</td>
</tr>
<tr>
<td>Improvement</td>
<td>A change that makes things better in some respect for someone (noun). Also, an activity intended to bring about an improvement, sometimes by using systematic quality or safety methods (verb).</td>
</tr>
<tr>
<td>Implementer</td>
<td>A person who enables people to take up a new better way.</td>
</tr>
<tr>
<td>Implementation research</td>
<td>The systematic study of how best to enable people and organisations to carry into their daily routines new proven ‘better ways’ of working and self-care (‘improvements’).</td>
</tr>
<tr>
<td>Practitioner</td>
<td>A clinician or health professional who practices an occupation or profession that can include management practitioners. A practitioner can be an implementer also.</td>
</tr>
<tr>
<td>Triple Helix Plus</td>
<td>The eight stakeholder groups within (the research field of) chronic care.</td>
</tr>
</tbody>
</table>

*Figure 3 | Terms and definitions*
2.5 Methods

The details of the methods to gather and define priorities for implementation research are described in the full reports (Bongers et al., 2015; Øvretveit et al., 2015).

Collecting and processing the data has been done by deploying the ExpertLens method (Dalal et al., 2011). This is a validated online elicitation method, aiming at closing the gap between the practical constraints of project budgets and time lines, and the methodological challenges associated with eliciting opinions of large, diverse, and distributed groups.

In summary, the method involved the following phases:

**Phase 1 | Selection of experts to be surveyed**
Forming one group called an 'Expert Panel' (N=25), and recruiting another wider group called 'ExpertLens Group' (N=300+), who then prioritised the research subjects.

**Phase 2 | Gathering research subjects**
In this round, 25 experts were interviewed individually using an ‘open interview’ approach (Bongers et al., 2015). Beforehand, instructions have been sent (IMPLEMENT, 2013b), asking respondents to focus on needed implementation research for a range of chronic care interventions. These interviews were recorded, transcribed and summarised by the researcher. The summary was checked by each expert. The interview summaries were analysed to merge the matching and overlapping topics and subjects of the experts into meta ‘research subjects’, using standard qualitative coding methods. This phase discovered what the ‘Expert Panel’ members considered to be the research most needed to speed and spread implementation of chronic care improvements.

**Phase 3 | Prioritise research subjects by ‘ExpertLens method’**
This phase surveyed the wider ExpertLens group in three rounds, to discover which of the 18 research subjects they thought were the highest priority for future research to speed and spread implementation of chronic care improvements. At the start 496 experts across the 28 EU countries were invited to participate. In the first round, 389 experts filled in the survey for preliminary ranking of the research subjects. After feedback to all participants about the overall priority scores, round 2 started the asynchronous and anonymous online discussion between experts (226 actually took part in these discussions; see Bongers et al., 2015). In round 3, the experts were surveyed again to allow them to confirm or revise or their priorities (196 respondents, with 101 adjusting their answers). This resulted in the final ranking of all research subjects.

Priority rating of each research subject in all rounds was based on the same scoring method: ‘Extremely high priority’ (score=2), ‘High priority’ (score=1); ‘Low priority’ (score=-1); ‘Extremely low priority’ (score=-2) and ‘No opinion’ (score=0).
We need research into methods and mechanisms through which chronic care improvements are adopted or ‘taken up’ by practitioners, health care services and patients.
Building the EU Agenda for implementation research in chronic care

3.1 Subjects for implementation research in chronic care

The initial list of 18 implementation research subjects is given below. This was the list and some of the explanation given to the wider group of experts for them to score the priority of the subject in terms of which knowledge was most needed to speed and spread chronic care improvements.

More details of the explanation given in the online survey for the experts are given in Bongers et al. (2015). Below we give only full details of the explanation for the first subject of ‘Adoption or take-up’. This is to illustrate the type of elaboration under each subject given to explain to experts the subject to be prioritised. For the other 17 subjects we only give the abbreviated definition of the subject, without the full explanation and the list of research questions for each subject.

3.1.1 Implementation – general

1 | Adoption or ‘take-up’
We need research into methods and mechanisms through which chronic care improvements are adopted or ‘taken up’ by practitioners, health care services and patients.

Explanation of this subject:
In (optimal) practice, healthcare improvements are developed with the end-user and implementation stakeholder requirements in mind. The resulting (optimally satisfying the requirements) healthcare improvement is expected to be adopted rapidly. In practice, we see that the adoption is slow - if at all. We need to know more about which methods and mechanisms work or do not work for different chronic care improvement changes to be adopted by different people in different situations.

Adoption or take-up refers to the many phases from initial change to embedded, sustained change.

Research questions within this subject:
• Which are the underlying causes of failure of different implementation approaches, for several improvements in chronic care?
• Which combinations of methods and strategies are effective for enabling the take up of different improvements by several parties in different situations, and are any generally effective for all?
• For which improvements is it useful to separate ‘implementation’ as one part of an intervention and for what improvements is it useful to view implementation as an integral part of an intervention? What are the advantages and disadvantages in doing so?
• Which methods or strategies have been successful and which not?
• Which communication methods and media are most effective for different chronic care improvements?
• How do these methods, mechanisms and structural factors differ in effectiveness for implementing different chronic care improvement, in different situations, in different EU countries?

For the other subjects we only give the abbreviated definition of the research subject.

2 | Simulating implementation
Research into methods to allow management of a healthcare organisation rapidly to simulate or model the impact of various improvement implementation scenarios.

3 | Skills, education and training
Research in improving the education and training of stakeholders, to support future implementation processes.

4 | Pathways
Research in how patient-pathways can more effectively enable implementation.

3.1.2  Patients and participation

5 | Reducing burden of treatment
Research into ways to reduce the burden of treatment to patients.

6 | Patient empowerment for implementation
Research into enhancing the implementation of healthcare improvements, at the stakeholder participation level.

7 | Co-designing implementation
Research into cost-effective co-design in planning implementation and in developing improvements in chronic care.

8 | Stakeholder endorsement and sustained use
Research into the features of chronic care improvements and implementation strategies, which predicts whether stakeholders will sustain the chronic care improvement.

3.1.3  Context

9 | Reimbursement
Research in which reimbursement methods would most encourage implementing chronic (integrated) care improvements.

10 | Financing systems for implementation
Research into financing systems, other than reimbursement arrangements, which will pay for implementation and for changes in arrangements to allow implementation of chronic care improvements.
11 | Laws, regulations and standards
Research into the new or changed laws, regulations and standards to ensure privacy, security and patient control of this information, to be able to implement improvements that call for easy exchange of personal health information between those necessary for care.

12 | Information and communication technology
Research in how ICT can enable the implementation of improvements to chronic care.

13 | Coordination and alignment between levels and sectors
Research into different sectors and organisations, in how to optimise chronic care delivery by coordinating the organisation of health care.

14 | Match of implementation to intervention and context
Research in how implementation strategies can be best matched to the context within which they are carried through.

3.1.4 Research methods and use of research

15 | Measuring and evaluating implementation effectiveness
Research into measuring and evaluating the effectiveness of implementation strategies for different improvements, for different patients, in different situations.

16 | Partnership Research
Research into research and practice partnerships, which can make research more relevant and contribute more to wide-scale implementation of chronic care improvements.

17 | Scientific research methods for knowledge about implementation
Research into research methods, which give rigorous and relevant knowledge about approaches for implementing chronic care improvements.

18 | Policy informed by research for implementation
Research into better ways to review, synthesise and present evidence of chronic care improvements and of implementation approaches for policy makers to be able to make more effective policy, which enables implementation.

3.2 Response to ExpertLens survey
At the start, 496 experts were invited to fill in the questionnaire. Of these 496 invitees, 389 ExpertLens participants (78.4%) filled in one or more questions in the first round of the IMPLEMENT Questionnaire. Of these 389 respondents, 226 (58%) used the online discussion forum to discuss with other experts the priority they had scored to the research subjects. This group of 389 respondents is the study group for which we present our results. The full list of names with background, organisation, country and Triple Helix Plus category of the ExpertLens participants is given in Bongers et al. (2015).
Because the ExpertLens method requires discussion to reach consensus, those doing so need to have seen all the research subjects before they contribute to this forum. Therefore, only the ExpertLens participants who completed 100% of round 1 were invited for this round (330). The total response for this second round consists of 226 ExpertLens expert participants (68.5%).

During the final round, the 330 ExpertLens participants who completed 100% of round 1 were asked to verify or change ('validate') their answers. A total of 196 ExpertLens participants (59%) validated their answers. Of these 196 people, we found 101 (51.5%) changed one or more of their previous answers about priority of research subjects.

The total group of participants is spread over the EU, but not all EU countries have been reached (see figure 5 and 6). The top 3 of countries that represent a large share of the ExpertLens expert-participants are The Netherlands, Spain and Romania.
The spread of ExpertLens participants over Triple Helix Plus categories and EU regions is shown below in Figure 7. Respondents in the category ‘professional and research institutional perspective’ represent a large share of experts surveyed (24%), together with category ‘research institution’ (24%). This is probably a consequence of using a ‘snowball’ method to gather ExpertLens participants by building on experts’ suggestions for other experts to invite, and for which they probably used their own networks, for example knowing other expert colleagues in medical universities.

<table>
<thead>
<tr>
<th>Triple Helix Plus category</th>
<th>Western Europe</th>
<th>Southern Europe</th>
<th>Eastern Europe</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient (Practice)</td>
<td>12</td>
<td>8</td>
<td>7</td>
<td>27</td>
</tr>
<tr>
<td>Professional (Practice)</td>
<td>19</td>
<td>16</td>
<td>27</td>
<td>62</td>
</tr>
<tr>
<td>Healthcare institution (Practice)</td>
<td>11</td>
<td>7</td>
<td>3</td>
<td>21</td>
</tr>
<tr>
<td>Government (Policy)</td>
<td>17</td>
<td>7</td>
<td>4</td>
<td>21</td>
</tr>
<tr>
<td>Industry (Business)</td>
<td>10</td>
<td>10</td>
<td>2</td>
<td>27</td>
</tr>
<tr>
<td>Research institution (Research)</td>
<td>15</td>
<td>24</td>
<td>14</td>
<td>80</td>
</tr>
<tr>
<td>Professional and research institution</td>
<td>42</td>
<td>22</td>
<td>25</td>
<td>92</td>
</tr>
<tr>
<td>Professional and healthcare institution</td>
<td>45</td>
<td>22</td>
<td>16</td>
<td>55</td>
</tr>
<tr>
<td>No answer</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>175</td>
<td>116</td>
<td>98</td>
<td>389</td>
</tr>
</tbody>
</table>

Figure 6 | The spread of ExpertLens participants by EU regions (N=389)

Figure 7 | ExpertLens participants by stakeholder group and EU region (N=389)
If we look at the spread of the Triple Helix Plus categories over the whole of the EU, we get this view:

![Pie chart showing the spread of 389 ExpertLens experts by stakeholder group (Triple Helix Plus category)]

**Figure 8 |** The spread of 389 ExpertLens experts by stakeholder group (Triple Helix Plus category)

### 3.3 Experts' views on research priorities

This section presents the final rating of priority by experts of the implementation research they thought most needed to speed and spread the take-up of improvements in chronic care in Europe. Noteworthy is that all subjects on the list were rated as a priority, as the totals scores for each subject had a mean priority above 0.

#### 3.3.1 The Top 3 and Bottom 3 priorities for implementation research

Figure 9 on the next page gives details of the overall rating of the 18 research subjects, ranked from highest to lowest.
<table>
<thead>
<tr>
<th>Priority</th>
<th>Research subjects</th>
<th>Mean score</th>
<th>Degree of agreement on the priority given to this research subject</th>
<th>Total score</th>
<th>Number of respondents on this subject</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Adoption or 'take-up'</td>
<td>1.262</td>
<td>0.374</td>
<td>491</td>
<td>389</td>
</tr>
<tr>
<td>2</td>
<td>Measuring and evaluating implementation effectiveness</td>
<td>1.185</td>
<td>0.893</td>
<td>391</td>
<td>330</td>
</tr>
<tr>
<td>3</td>
<td>Patient empowerment for implementation</td>
<td>1.181</td>
<td>0.795</td>
<td>399</td>
<td>338</td>
</tr>
<tr>
<td>4</td>
<td>Skills, education and training</td>
<td>1.177</td>
<td>0.64</td>
<td>420</td>
<td>357</td>
</tr>
<tr>
<td>5</td>
<td>Reducing burden of treatment</td>
<td>1.073</td>
<td>0.939</td>
<td>366</td>
<td>341</td>
</tr>
<tr>
<td>6</td>
<td>Information and communication technology</td>
<td>1.027</td>
<td>0.893</td>
<td>340</td>
<td>331</td>
</tr>
<tr>
<td>7</td>
<td>Pathways</td>
<td>0.997</td>
<td>0.794</td>
<td>349</td>
<td>350</td>
</tr>
<tr>
<td>8</td>
<td>Coordination and alignment between levels and sectors</td>
<td>0.912</td>
<td>1.056</td>
<td>302</td>
<td>331</td>
</tr>
<tr>
<td>9</td>
<td>Financing systems for implementation</td>
<td>0.813</td>
<td>0.889</td>
<td>270</td>
<td>332</td>
</tr>
<tr>
<td>10</td>
<td>Reimbursement</td>
<td>0.729</td>
<td>1.322</td>
<td>242</td>
<td>332</td>
</tr>
<tr>
<td>11</td>
<td>Partnership Research</td>
<td>0.709</td>
<td>1.204</td>
<td>234</td>
<td>330</td>
</tr>
<tr>
<td>12</td>
<td>Match of implementation to intervention and context</td>
<td>0.697</td>
<td>1.002</td>
<td>230</td>
<td>330</td>
</tr>
<tr>
<td>13</td>
<td>Policy informed by research for implementation</td>
<td>0.688</td>
<td>1.158</td>
<td>227</td>
<td>330</td>
</tr>
<tr>
<td>14</td>
<td>Co-designing implementation</td>
<td>0.685</td>
<td>1.017</td>
<td>230</td>
<td>336</td>
</tr>
<tr>
<td>15</td>
<td>Stakeholder endorsement and sustained use</td>
<td>0.674</td>
<td>0.965</td>
<td>225</td>
<td>334</td>
</tr>
<tr>
<td>16</td>
<td>Simulating implementation</td>
<td>0.615</td>
<td>1.054</td>
<td>225</td>
<td>366</td>
</tr>
<tr>
<td>17</td>
<td>Laws, regulations and standards</td>
<td>0.607</td>
<td>1.245</td>
<td>201</td>
<td>331</td>
</tr>
<tr>
<td>18</td>
<td>Scientific research methods for knowledge about implementation</td>
<td>0.585</td>
<td>1.18</td>
<td>193</td>
<td>330</td>
</tr>
</tbody>
</table>

Mean score = total score/number of respondents who scored the research subject
Degree of agreement on the priority given to this research subject = degree of consensus amongst the participants about the research subject
Total score = sum of given scores (2 till -2) to the research subject
Number of respondents on this research subject (n)

**Figure 9** | Rating of research subjects, ranked from highest to lowest by the mean score

The implementation research subjects that experts scored as highest priority for future research are:
1. Adoption or ‘take-up’
2. Measuring and evaluating implementation effectiveness
3. Patient empowerment for implementation

Close to this top 3 follow 'Skills, education and training,' 'Reducing burden of treatment' and 'Information and communication technology.'
The implementation research subjects rated as lowest priority were:
16. Simulating implementation, before actual introduction
17. Laws, regulations and standards in chronic care
18. Scientific research methods for knowledge about implementation

Also here, the differences in ranking are small and the bottom 3 are close to other subjects. The reason for these small differences in mean rankings is that all research subjects are important to almost all respondents, who found it hard to really prioritise.

Figure 10 below shows the priority scores for each research subject.
3.3.2 Means don’t tell the whole story

More telling than the mean scores, are the variations in scores between the respondents. Figure 11 shows the degree of agreement between the experts. We see that the most important subject ‘Adaptation or take-up’ not only has the highest mean score but also the highest degree of agreement (i.e. the lowest variance). The top 3 consensus on research subjects is formed by the topics that have the lowest variance, or in other words: the experts agree most on the priority of these subjects (respectively ‘Adoption or take-up’, ‘Skills, education and training’ and ‘Pathways’). This way it is also possible to show the top 3 research subjects with the least agreement. These topics have the highest variance, in other words: the experts disagree relatively most on the priority of these subjects (respectively ‘Reimbursement’, ‘Partnership Research’ and ‘Laws, regulations and standards’).

Figure 11 | Strength in agreement for all research subjects (N=389)
3.3.3 How strongly do the experts (dis)agree?

Figure 12 below shows the strength of agreement for the top 3 prioritised research subjects.

These research subjects have the lowest variance (the experts agree most on the priority of these subjects) (Figure 13).

Neither country nor stakeholder group significantly affects the priority of the research subjects. However it needs to be noted that, within this general rank order prioritisation, the perspectives and countries/areas most represented do influence the total scores.
3.3.4 Further details on prioritising tendencies per country or stakeholder group

The rest of this section describes the more detailed analyses we did to find how much ranking of priority differed by stakeholder group and by region of the EU from which the expert came. Since the perspectives and countries/areas most represented do have some influence on total scores, we clustered all countries to three European areas, but there is still a biased representation (e.g. 175 participants from Western Europe, 98 participants from Eastern Europe). Also, the stakeholder perspectives are not ‘equally balanced’. There were proportionally fewer Patient, Healthcare, Industry and Government stakeholders participating.

The normal distribution of data was tested by the Kolmogorov-Smirnov test, showing that the dependent variables are non-normally distributed. Therefore, we used the Kruskal-Wallis H to test group differences (European Area, Triple Helix Plus category, Scientist/Non-Scientist). Not all of these background variables were found to be significant (see appendix M in Bongers et al., 2015). This again confirms the importance the experts attach to all research subjects.

Figure 15 reveals that priorities differ for different stakeholder groups. Noteworthy, our Plus-variant provides different rankings than the original Triple Helix approach would have done. We feel that our broader stakeholders’ approach works out better for chronic care and sheds some new light on the research priorities.

Among the stakeholder groups, patients put relatively more emphasis on implementation research for ‘Patient empowerment for implementation’, ‘Reducing burden of treatment’ and ‘Pathways’. Professionals (Triple Helix Plus categories ‘Professional’ and ‘Professional & Research’) highly prioritise ‘Skills, education and training’ and ‘Reducing burden of treatment’ and professionals with a research role highly rank ‘Measuring and evaluating implementation effectiveness’. For scientists ‘Measuring and evaluating implementation effectiveness’ could slightly be more important, whereas non-scientists prioritise ‘Patient empowerment for implementation’ higher. And finally, respondents from the business sector and the Healthcare institutional perspective (managers) score other subjects in their top 3: ‘Coordination and alignment between levels and sectors’ and ‘Information and communication technology’.
In the same way we analysed differences between EU regions, but the differences are less pronounced than those for the stakeholder groups (see figure 16). The Eastern European experts’ ratings are different from those of experts from the other EU regions. They emphasise more on ‘Skills, education and training’, this is even their prime priority against a 4th place in the overall prioritisation. Furthermore, Eastern Europe puts relatively more emphasis on ‘Reimbursement’, ‘Laws, regulation and standards’ and ‘Partnership research’, but less on ‘Patient empowerment for implementation’, ‘Information and communication technology’ and ‘Measuring and evaluating implementation effectiveness’ which scored in the top 3 amongst the other participants. The explanation for this difference could be the over-representation of professionals in the Eastern European respondents.

<table>
<thead>
<tr>
<th>Research Field</th>
<th>Research subject</th>
<th>Practice</th>
<th>Policy</th>
<th>Business</th>
<th>Research</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Patient</td>
<td>Profes-</td>
<td>Health-</td>
<td>Profes-</td>
<td></td>
</tr>
<tr>
<td>General</td>
<td>Adoption or ‘take-up’</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Simulating implementation</td>
<td>16</td>
<td>12</td>
<td>15</td>
<td>14</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Skills, education and training</td>
<td>5</td>
<td>3</td>
<td>9</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Pathways</td>
<td>3</td>
<td>5</td>
<td>6</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Patient</td>
<td>Reducing burden of treatment</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Patient empowerment for implementation</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Co-designing implementation</td>
<td>13</td>
<td>15</td>
<td>12</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td>Context</td>
<td>Stakeholder endorsement and sustained use</td>
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<td>13</td>
<td>15</td>
<td>12</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Reimbursement</td>
<td>8</td>
<td>10</td>
<td>8</td>
<td>16</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Financing systems for implementation</td>
<td>10</td>
<td>11</td>
<td>7</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Laws, regulations and standards</td>
<td>11</td>
<td>17</td>
<td>11</td>
<td>15</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Information and communication technology</td>
<td>6</td>
<td>6</td>
<td>3</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Coordination and alignment between levels and sectors</td>
<td>13</td>
<td>8</td>
<td>1</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Match of implementation to intervention and context</td>
<td>14</td>
<td>14</td>
<td>14</td>
<td>17</td>
<td>7</td>
</tr>
<tr>
<td>Research</td>
<td>Measuring and evaluating implementation effectiveness</td>
<td>8</td>
<td>7</td>
<td>10</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Partnership research</td>
<td>12</td>
<td>9</td>
<td>13</td>
<td>13</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Scientific research methods for knowledge about impl</td>
<td>15</td>
<td>18</td>
<td>17</td>
<td>18</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Policy informed by research for implementation</td>
<td>7</td>
<td>16</td>
<td>16</td>
<td>11</td>
<td>10</td>
</tr>
</tbody>
</table>

* The priority has been determined through the mean (the higher, the higher is the priority)
** Due to the number of respondents, this prioritisation must be considered indicative
For this breakdown the 4 who did not fill in their expertise category were excluded for that reason therefore the expert categories add up to 385

Figure 15 | Ranking of priority overall by each stakeholder group
Western and Southern Europe have the same top 3, but in different order. Furthermore, Southern Europe only stands out with relatively more emphasis on 'Simulation implementation', but less on 'Reimbursement'.

<table>
<thead>
<tr>
<th>Research Field</th>
<th>Research subject</th>
<th>Priority* per European area</th>
<th>Western Europe</th>
<th>Southern Europe</th>
<th>Eastern Europe</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>Adoption or ‘take-up’</td>
<td></td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Simulating implementation</td>
<td></td>
<td>18</td>
<td>10</td>
<td>14</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Skills, education and training</td>
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<td>4</td>
<td>4</td>
<td>1</td>
<td>4</td>
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<tr>
<td></td>
<td>Pathways</td>
<td></td>
<td>7</td>
<td>8</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Patient</td>
<td>Reducing burden of treatment</td>
<td></td>
<td>6</td>
<td>5</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Patient empowerment for implementation</td>
<td></td>
<td>2</td>
<td>2</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Co-designing implementation</td>
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<td>11</td>
<td>11</td>
<td>18</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Stakeholder endorsement and sustained use</td>
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<td>12</td>
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<td>16</td>
<td>15</td>
</tr>
<tr>
<td>Context</td>
<td>Reimbursement</td>
<td></td>
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<td>18</td>
<td>7</td>
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<td>Financing systems for implementation</td>
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<td>9</td>
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<tr>
<td></td>
<td>Laws, regulations and standards</td>
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<td></td>
<td>Information and communication technology</td>
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<td>5</td>
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<td>Coordination and alignment between levels and sectors</td>
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<td>8</td>
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<td>11</td>
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<tr>
<td></td>
<td>Match of implementation to intervention and context</td>
<td></td>
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<td>12</td>
<td>15</td>
<td>12</td>
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<tr>
<td>Research</td>
<td>Measuring and evaluating implementation effectiveness</td>
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<td>1</td>
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<td></td>
<td>Partnership research</td>
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</tr>
<tr>
<td></td>
<td>Scientific research methods for knowledge about implementation</td>
<td></td>
<td>15</td>
<td>14</td>
<td>17</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Policy informed by research for implementation</td>
<td></td>
<td>14</td>
<td>15</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>Number of respondents who scored the research subject (n)</td>
<td></td>
<td></td>
<td>175</td>
<td>116</td>
<td>98</td>
<td>389</td>
</tr>
</tbody>
</table>

* The priority has been determined through the mean (the higher, the higher is the priority)

Figure 16 | Ranking of priorities by each of the three EU regions

3.4 Overall priority ranking stands firmly

For the purposes of this study, which is to substantiate decisions about future EU-wide funding of research for improvements, the overall prioritisation is more important than any particular emphasis given by experts in one country or stakeholder group. For example, research subject 6, which is ‘Patient empowerment for implementation,’ and which was the third highest ranked subject for research, is the subject that patients in all countries scored as high priority, but also many other stakeholder groups scored it highly, hence resulting in it being ranked 3rd out of the 18 subjects.
There is considerable knowledge about which changes are effective for improving chronic care. There is a lack of knowledge about how effectively to implement these changes.
Proposal for EU Research Agenda

4.1 Conclusions

In all European countries, more citizens are experiencing chronic health conditions, and often more than one condition at the same time. In addition to the human suffering caused, this is placing an increasing burden on families, health care services, businesses and taxpayers.

There is considerable knowledge about which changes are effective for improving chronic care, for enabling self-care and preventing onset or deterioration of chronic health conditions and co-morbidity. There is a lack of knowledge about how effectively to implement these changes. Research can help find ways to enable people to ‘take-up’ the proven ‘new better ways’ through evidence-based implementation strategies and policies, organisational structures and processes, multidisciplinary practices and patient empowerment.

We adopted a systematic online method, called ExpertLens, to find out what research is most needed, working with European experts (389 persons), covering eight stakeholder groups informed by the Triple Helix Plus approach. This varied stakeholder orientation proved fruitful for better understanding evidence-based and more implicit or ‘tacit’ knowledge from daily practice. The experts agreed on and prioritised 18 subjects for implementation, where research could help faster and wider implementation of proven improvements and innovations to chronic care and self-care. Of these 18, the following implementation subjects scored as highest priority for future research:

1. Adoption or ‘take-up’ of improvements and innovations
2. Measuring and evaluating the effectiveness of implementation
3. Patient empowerment for implementation

Close to this top 3 subjects follow ‘Skills, education and training,’ ‘Reducing burden of treatment’ and ‘Information and communication technology’.

The implementation research subjects rated as lowest priority were:
16. Simulating implementation, before actual introduction
17. Laws, regulations and standards in chronic care
18. Scientific research methods for knowledge about implementation

We observed that the differences in ranking between the 18 research subjects are small and the bottom 3 are close to the other subjects. The reason for these small differences in the rankings is that all research subjects were considered important to almost all respondents, who found it hard to really prioritise. In other words: the 25 Expert Panel members have given priority to 18 research subjects that is shared by the large ExpertLens community.
In the next section we propose an EU Agenda for the most important implementation research subjects in chronic care. Next, we discuss the possible impact and consequences for the Research Agenda of different stakeholder proportions and perspectives in the Triple Helix Plus.

4.2 Proposal for an EU Agenda for implementation research for faster system-wide improvements in chronic care

4.2.1 Discussion

All subjects for implementation research in chronic care improvements were recognised by many experts, who found it difficult either to add a new subject or to prioritise the subjects proposed. Differences in ranking were small (which is quite surprising, given the large numbers of respondents) and mostly not significant between stakeholder groups in the Triple Helix Plus. Extending the original Triple Helix of three parties (research, policy and business) to our broader version with patients, professionals and managers in health care, revealed more practice based needs for further implementation research. To give an example: the traditional Triple Helix approach would not have ranked ‘Adoption or take-up’ and ‘Measuring and evaluating implementation’ in the top 3 of most important research subjects. Respondents from business would have put ‘Information and communication technology’ second and ‘Reimbursement’ third, but ‘Skills, education and training’ on place nine. Government representatives would have added ‘Coordination and alignment between levels and sectors’ on the third place, and would have put ‘Information and communication technology’ on place 14 (all other stakeholder groups rank this subject much higher, ranging from second to sixth place). Both government and industry would not have ranked ‘Measuring and evaluating implementation effectiveness’ in the top 5; it is the second priority for the extended Triple Helix Plus approach.

On the other hand, in the Triple Helix Plus there is a strong indication that ‘Patient empowerment for implementation’ and ‘Adaptation or take-up’ really belong to the top 3 priority subjects for future implementation research. Rankings between 3 and 6 are less decisive. But again, all subjects have been scored and hardly any score differences were significant, so we advise the EU to work with all subjects and also explore to make them more tailor-made to stakeholder groups or regions like Eastern Europe. Not all stakeholder groups have evenly strong interests in all subjects and there are differences in the phase in which the several parties and healthcare systems or countries are in regard to their development of systemic integrated chronic care. This is demonstrated by the low rankings and ranking differences for subjects like ‘Reimbursement’, ‘Laws, regulation and standards’ and ‘Co-designing implementation’.

So, we propose to develop an EU Agenda for implementation research for chronic care improvements that should not exclude any of the 18 subjects (see paragraph 3.1), but tailor them a bit more to the needs and experience-phases of the different stakeholder groups and EU regions. But this should be done without losing the real essence of multi-interdisciplinary work that is at the core of chronic care and implementation research.
All stakeholder groups are interdependent in the Triple Helix Plus and need to work together in new forms of co-design. Using this concept of social innovation and co-creation in multi-stakeholder settings, it may be wise to build up the EU Agenda in two or more rounds. We propose to start a first round with the first six relatively high priority subjects that follow from this report. This first round will help to further enforce and facilitate the networks of experts we brought together. This networks needs to develop further towards international collaborations for systematic implementation research in chronic care across Europe. Then, a second round for the next group of research subjects can be launched, professionalising and speeding up the implementation and improvement cycles in care practices. Perhaps a third round will be needed to take up the remaining research subjects. We advise to reconsider and refine the total list of subjects after each round, as we gain more insights and experiences from multi-stakeholder collaboration along the road towards systemic implementation of chronic care improvements across Europe.

4.2.2 Priority subjects

Adoption or ‘take up’
Research into methods and mechanisms through which chronic care improvements are adopted or ‘taken up’ by practitioners, healthcare services and patients. In (optimal) practice, healthcare improvements are developed with the end-user and implementation stakeholder requirements in mind. The resulting (optimally satisfying the requirements) healthcare improvements are expected to be adopted rapidly. In practice, we see that the adoption is slow – if at all. We need to know more about which methods and mechanisms work or do not work for different chronic care improvements changes to be adopted by different people in different situations.

- Which are the underlying causes of failure of different implementation approaches in chronic care?
- Which combination of methods and strategies are effective?
- For which improvements is it useful to separate or include ‘implementation’ as an integral part of an intervention?
- What are the advantages and disadvantages in doing so? What methods or strategies have been successful and what not?
- Which communication methods and media are most effective for adoption by different parties of different chronic care improvements?
- How do these methods mechanisms and structural factors differ between types of change induced by a chronic care improvement, in different situations, in different EU countries?

Patient empowerment for implementation
Research into enhancing the implementation of healthcare improvements, at the patient level. There are different ways to empower patients, with one or more chronic conditions, for implementing improvements. Empowering patients in certain ways can provide incentives to providers, to adopt improvements to chronic care. One way is to provide patients with information about how well different providers care for patients with chronic care, and to give patients choice of provider. Another is to do more to enable self-care and informal care from relatives and neighborhood as method of implementation.
What types of patient empowerment would most effectively contribute to implementing improvements in chronic care?

What is the role of self-management in implementation of improvements in chronic care?

What strategies can we define to enhance self-management as part of the implementation process?

How can we measure self-managed adherence in a treatment plan?

What feedback mechanisms/interventions can be included to enhance motivation?

Is there an association between engagement, sustainment and the level of provided instruction and training?

Measuring and evaluating implementation effectiveness

Research into measuring and evaluating the effectiveness of implementation strategies for different improvements, for different patients, in different situations. This research subject is not about measuring care outcomes, but about methods for measuring the impact of implementation approaches and for evaluating them. Quantitatively proving the value of novel care delivery in chronic care is difficult, due to a lack of effective outcome measurements. Hence, we do not know the effectiveness of delivered chronic care for patients. There is a lack of a systematical collection of this type of data - together with a lack of pro-active research leading to feedback towards the effectiveness of healthcare delivery strategies and improvements.

Which effective research methods and tools are currently in use for effective measurement?

Which novel research methods can we define to fit our needs?

How can we measure effectiveness of improvements through all sectors involved in the delivery of care?

How can we capture outcomes at patient level in an effective way?

Can we adopt a similar model as PROMs in chronic care? Can we identify other monitoring instruments that could fit?

How can we disseminate evidence of effectiveness through all sectors and to involved stakeholders?

Which barriers exist related to the uptake of evidence/expertise by care professionals in healthcare organisations? How can we lift these barriers in future policies and strategies?

Skills, education and training

Research in improving the education and training of stakeholders, to support implementation processes. At present the awareness of implementation and its complexity seems limited by healthcare professionals, managers and researchers. Therefore, we need to determine possible lacks of expertise and resources, and develop educational programs. Besides, we need to define approaches to facilitate effective implementation by these parties.

Which skills, attitudes and knowledge are needed for implementers of improvements in chronic care?

What is the relationship between types of training for implementation for implementers, professionals, and others and the success of implementation of improvements?

Which skills and tools are required for effective implementation project management?

How can we integrate implementation science training in existing curricula for relevant groups of stakeholders?
Reducing burden of treatment

Research into ways to reduce the burden of treatment to patients. Adoption of treatments and lifestyle changes by patients is part of implementing improvement. Often, professionals do not recognise coping and adherence differences between patients. Patients with multiple chronic conditions are prescribed many, sometimes conflicting treatments and lifestyle recommendations. Effective implementation requires professionals individually and together, in co-creation with patients and their informal caregivers, to consider which treatments are most important. This can reduce the burden of treatment, and may require other ways to support patients.

- What is the overall burden of treatment for the patient and informal caregivers for different chronic diseases, and for multiple chronic conditions?
- Which methods can be used by individual practitioners to reduce the burden of treatment, when deciding treatment and recommended lifestyle changes, as well as collectively by all involved in patient care?
- Is any special coordination between caregivers needed for them to ensure the overall burden of treatment and lifestyle?
- Which supports can be used to make it easier for patients and their informal caregivers to follow up treatments and lifestyle changes?
- What is the effectiveness and cost of the methods and supports mentioned above?

Information and communication technology

Research in how ICT can enable the implementation of improvements to chronic care. At present, the potential of ICT is neither used for everyday care nor implementation of improvements. The take up by patients and providers is hindered by poor design, by poor implementation and by the costs of the system and its maintenance. Research is needed to identify best practices, to analyze the benefits, to enable optimal take up and to disseminate results.

- How can we exploit the modern ICT to help us in the implementation of healthcare improvements?
- How can we disseminate best practices of ICT information exchange systems?
- Which barriers exist in the utilisation of ICT information exchange systems in chronic care?
- How can we exploit the modern ICT information exchange systems to help us in the implementation of healthcare improvements?

4.3 Leveraging stakeholder differences in the Triple Helix Plus

Funders and researchers need to recognise that there may be some bias in the results, with some countries and expert groups (e.g. researchers) being over-represented in the survey. For example: there were many experts from The Netherlands (13%) relative to experts from Croatia (0.3%). The method is not intended to give a perfect representation of all experts combined priorities in all EU countries, but to provide a better basis for deciding on future research by using the combined and considered views of 25 (Expert Panel) and 389 (ExpertLens survey) experts across the EU. Besides, it is unclear anyway what should be the ideal representation by country or by stakeholder group (population size? experience with chronic care improvements?).
During the three-stage discussion process of the ExpertLens, many experts from different countries took the opportunity to debate with each other about the reasons for lower or higher research priorities. Experts from countries may vary in the specific implementation research they view as most needed, but there is quite a high level of agreement between countries and types of experts. The discussions give rich data for understanding a range of views across Europe and the rationale and arguments for different types of research and improvement. We further caution funders, policy makers and researchers in interpreting these priorities: it is possible that if all experts all had in mind the same specific chronic care improvement, they may have rated priorities for research for implementation differently than for the implementation research needed for all types of improvement. Further analysis to identify possible disagreements between stakeholder groups may be useful as it may indicate differences between groups, which could be expected and would need to be resolved for cooperative implementation. Also, obtaining more information on the controversies and different views between experts within one group is a useful starting point for research. We did observe some differences in criteria for prioritisation between the experts and saw small changes in the priority scores between round 1 and 3 as a result, but only a few differences between the various subgroups proved to be significant.

Thus, all subjects stayed on the list and no new subjects have been suggested. Therefore, we feel that sampling issues have not jeopardised the overall rating of priorities of the research subjects. The study findings therefore give a rather solid basis, with its limitations, for formulating research funding and for researchers to guide their choice of subjects and to better serve practice and advance knowledge. The following quote of an expert is illustrative of the main opinion in the whole expert panel: “All research subjects that are included in this Discussion Forum are important and should be included in the EU Research Agenda. Priorities are indicative of the needs of each society and nation that is part of the EU. In those nations that are in need of cornerstones and strong foundations for their healthcare system, patient empowerment and acquiring skills through education and training are MOST urgent priorities.”

This study provides guidance to the EU and other funders of research interested in supporting practical research that will reduce suffering and waste through implementing what we already know. It provides help to researchers for choosing implementation research as a field for greater attention and gives the subjects and methods within this field that a wide sample of EU experts from different stakeholder groups consider to be urgently needed.

Far more important however, is the question of how to make possible differences in experience, views and priority criteria between experts, work as a leverage to deepen and broaden our understanding of implementation issues in chronic care. More in particular, there are different views on the likely practical value of more knowledge about the implementation subject for reducing suffering and waste in their countries and elsewhere in the EU. We observed that the Eastern EU Region has somewhat other priorities than the other EU-regions, but until now we do not know which implementation approaches are more effective in some contexts than others (e.g. low resource settings). Likewise, the EU Agenda will help to understand which implementation approaches are more effective for some types of improvements in some contexts than others. These are important matters to keep in mind as the EU works on the proposed future agenda for implementation research in chronic care.
There are practical implications for lower costs and more effective use of time if we employ research rather than anecdote regarding which approach is more effective than another for implementing a particular chronic care improvement in a particular setting. Implementation resources as well as time of providers could be spared by using the most effective implementation approach to implement a proven improvement. Some implementation approaches are more effective than others for implementing a specific improvement, and the effectiveness of an implementation approach may be enhanced or degraded by the wider context within which it is applied. However we note that there is little systematic implementation research evidence for one specific type of improvement, showing which implementation approach may be more or less effective in different contexts. We encourage funders and researchers to consider innovative research methods that enable improvement in practice as equally important as generating valid scientific knowledge. Such research methods and reporting formats are more often than not used outside of the medical field and provide more of the information which implementers in chronic care need, in a more timely and usable way. We encourage questioning whether the balance between rigorous quantitative and quasi-experimental research and other observational and action research methods which provide evidence with higher external validity and more immediate use, at the moment is right in funding for implementation research. There is a need for funding and developing methods for research-practice partnerships for implementation research, which can use both traditional quantitative and quasi-experimental research methods as well as more action research approaches. This would enable implementers to make their intervention more effective during the research (Hasche et al., 2014). There are a few studies emerging that describe how researchers partnered with services to formulate and evaluate adaptions, and some descriptions of this new approach and methods to practice-based research (Hasche et al., 2014; Øvretveit et al., 2014).

4.4 Implementation research will benefit social innovation

We advise the EU to combine the Research Agenda for implementation of chronic care improvements with network strategies to foster social innovation in the Triple Helix Plus. Joining forces of all experts across Europe will be a true leverage on behalf of faster and better (research of) implementation of chronic care improvements. To stimulate social co-creation, the EU may consider to actively develop methods for learning and sharing in international expert networks in chronic care, using modern methods for discussion, reflection and consensus building. ExpertLens proved to be a helpful method, but other tools are available or under construction, combining big data developments and internet-based technology and 24/7 knowledge platforms. Thus, the research and implementation cycles will speed up system-wide improvement of chronic care across Europe.

We emphasise the need for novel research methods to produce research more quickly, and to produce research that is of more immediate use by implementers. We believe this study can contribute to reduce suffering and costs more quickly by enabling others to use more effective ways to care and prevent chronic health conditions, especially among the most in need of these interventions.
Health insurer can help to create value based chronic care

Robbert Huijsman and Saliha el Habri (Zilveren Kruis), leader of dissemination

Why did you decide to join this project two years ago?

RH: “Working as a senior manager for Innovation and Quality of care for Zilveren Kruis, the biggest health care insurance company in The Netherlands, I have a particular interest and focus on chronic care. One of the problems in The Netherlands is that the adoption and implementation of proven innovations is slow and that we as insurance companies don’t take an international perspective on innovation and implementation strategies.”

SeH: “In my work as Project manager and in my personal live I have experienced that the current care system does not consider enough what the patient really needs and wants. I am convinced that there is a lot of knowledge and expertise in Europe that could improve this situation. This project gives us more knowledge on the developments in implementation in the field of chronic care in Europe.”

RH: “I agree that we can and must do much better, since growing numbers of ageing, disabled and chronically ill people depend on good chronic care. To realise our ambitions, we need innovation in the whole care continuum or patient journey, in order to achieve tailor-made, effective and cost-efficient chronic care of high quality. For that, and to keep chronic care future-proof, we have to implement effective innovations in chronic care as rapidly and successfully as possible. The challenges are too enormous to do this on our own as an insurance company or country. So, for an insurance company in the Dutch health care system it is very interesting and inspiring to be a participant in this EU project Implement.”
How have you experienced working in this project for the last 2 years?

RH: “Zilveren Kruis has over 5 million insured, a market share of more than 30%. In The Netherlands, healthcare insurers procure all health care needed for their insured by contracting and financing health care suppliers. The goal is to procure the best possible health care with a good balance between quantity, quality and costs of care. Both in the short and long term, to keep a sustainable, accessible, value based health care for all citizens. Being the largest insurance company in The Netherlands we feel a strong responsibility not only for our own participants, but also for a good national healthcare system as a whole.”

SeH: “We need to bundle all international knowledge bases, experiences and networks to develop adequate chronic care for all our citizens. And to be honest, it’s our first European project. Although Zilveren Kruis participates in Eurapco, an alliance of European mutual insurances companies, We were very surprised to learn from the EU Offices that this is the first time ever that a Dutch insurance company participates in such a wonderful EU project. We have enjoyed this project and learned a lot.”

What do you, particularly from your professional/expert point of view, hope what will be done with the outcomes of this project, what will it stimulate, who will benefit and how?

SeH: “We will help to bring the proposed EU Agenda for implementation research in chronic care to realisation. We just cannot wait for the results of these upcoming research lines, as our insured face more challenges every day. Not only the innovation and implementation cycles should gain more speed and usable deliverables, the same holds for the research communities themselves.”

RH: “We are convinced that it will prove to be very awarding to be part of an international network of innovators and implementers in chronic care, to gain rapid accessible knowledge and insights in proven innovations and to learn how to rapidly and successfully implement these innovations system- and nationwide. So, experts in Europe: join forces, speed up the knowledge and valorisation cycles. And become a strong partner in the IMPLEMENT EU Expert Network, it works to achieve better chronic care!”
Why did you decide to join this project two years ago?

“The reason why I have founded this company is because of the vast ‘implementation gap’ between great medical inventions and their use in daily practice. Enormous amounts of money, enthusiasm, creativity go to waste in this gap. The result is that care is less good than it could be and much more expensive than it should be. This is most painfully visible in chronic care. So when I talked with the people that are now my co-consortium members, the link was easily made to the necessity of a Research Agenda for implementation issues in chronic care. For us it is ‘core business’ to improve implementation success, in any way possible. IMPLEMENT is such a way, for the whole of the EU.”

How have you experienced working in this project for the last two years?

“I have experienced these years as inspiring, rewarding... and challenging. The reason why IMPLEMENT has been initiated is because of the barren ground concerning implementation science in chronic care in the EU. This also means that everything had to be built up from – virtually – ‘scratch’. But we made it, and now there is a Research Agenda that will be of influence for the years to come and an EU Expert Network that I am really proud of.”

What do you, particularly from your professional/expert point of view, hope what will be done with the outcomes of this project, what will it stimulate, who will benefit and how?

“I hope that the Research Agenda will be put into practice by the EU, that there will be Calls specifically aimed at implementation research, along the line of the research subjects that we have found and validated. Next, I hope that ANY call that the EU sends out concerning innovations in care, will have an ‘implementation paragraph’ from now on. We have more than enough inventions already; what really counts is using the inventions in daily practice. This and only this will turn these inventions into innovations. And only this will help the patient to have a better life. The EU now can make a difference and take innovation in chronic care to a whole new level. I, together with my company, will gladly be of help to reach this goal.”

We have more than enough inventions already; what really counts is using the inventions in daily practice.
Why did you decide to join this project two years ago?

“Frankly, at first I did not have much faith in the chances for this project to receive EU funding, notwithstanding the necessity for a project like IMPLEMENT. But since the energy between the partners cooperating was so high, I decided to step in anyway. As a researcher I am used to receive funding for research projects. IMPLEMENT rises above this level in the sense that now we wanted to produce a research agenda, a long term guidance for projects in this young and crucial field of research. Next to that, the ambition to have an expert population contribute that not only consists of researchers, but also of all other relevant expertise, really appealed to me. So you can imagine how glad I was to hear that the EU embraced our proposal.”

How have you experienced working in this project for the last two years?

“I have really enjoyed working with a growing number of experts who were willing to put so much time and effort in contributing to the Research Agenda and the Expert Network. These people all are very busy and the questionnaire of the ExpertLens survey was quite large. The lively blog discussions really reflect the great value the respondents attach to the subject of this project. All in all, this dedication of the experts and the good atmosphere in which the consortium partners worked together, made the IMPLEMENT project very rewarding to put effort in. The result is a high quality assessment and a lively network.”

What do you, particularly from your professional/expert point of view, hope will be done with the outcomes of this project, what will it stimulate, who will benefit and how?

“First of all I hope that the current liveliness of the project will continue in the Expert Network. As the EU concerns, I really think that the Research Agenda should be the starting point of an EU funding program that focuses on implementation research in chronic care. The 18 research subjects are supported by a large and comprehensive expert community. They reflect not only the point of view of science, but also the view of patient, professional and policy experts that have contributed to the project. Taking these subjects as guidance for future research safeguards that this research will be useful to daily practice. And that is where the benefits should end up: in improving the daily life of the chronic patient.”

Improving the daily life of the chronic patient

Inge Bongers (Tilburg University), leader of the assessment and its methodology

The Research Agenda should be the starting point of an EU funding program that focuses on implementation research in chronic care.
References


Colophon

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The purpose of the IMPLEMENT project was to discover and disseminate which research is most needed in the future to speed up and spread the `take-up` of improvements in chronic care, and to establish a European network to carry out and apply the research.

This document reports the findings and analyses based on the views of 414 experts throughout the EU concerning the gaps in knowledge about implementation that are hindering the take-up of these improvements in chronic care. The result is a Research Agenda for the EU and for all others interested in improving chronic care.

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