6 Societal relevance: link between health care problems and research, dissemination, impact and valorisation

Research on the utilization of research has shown that mere dissemination of results is not enough. Interaction between policy makers and researchers, at individual and institutional level, is a key element in research utilization. NIVEL therefore invests in interaction with policy makers and other stakeholders. At the same time, dissemination is important. The internet is very helpful in disseminating research. Examples of more focused ways of dissemination are feedback reports and invitational conferences. NIVEL research has an impact on health care, as we have shown throughout this report by brief narratives on utilization in national governmental policies, professional guidelines, advisory bodies etc. Valorisation of NIVEL research is not meant in the restricted sense of making money out of products and services resulting from research, but the use of products in the public domain.

Societal relevance is difficult to define and there are no generally accepted indicators of societal quality of research. NIVEL has in the past contributed to the Dutch debate on societal quality of research. Interaction is a key factor in research utilization, not only when research is finished, but importantly also in the phase of defining research problems and designing research. ‘Productive interactions’ is the key concept in an international project, called SIAMPI: Social Impact Assessment Methods through Productive Interactions. The Dutch part of this project is led by the Netherlands Academy of Arts and Sciences (KNAW). For this project NIVEL was asked to be one of the ‘cases’ in the field of health (services) research. We have taken this opportunity to have an external assessment of the societal quality of NIVEL research (just as we have an external assessment of scientific quality). We use the draft report of this part of the SIAMPI project as background to this chapter. We take examples from stakeholder interviews and the internet visibility analysis of NIVEL research from the SIAMPI report.

We have organised this chapter in sections around four phases of research-policy interaction and research utilization:
- the link between problems in the health care sector and research (which is the relevance of research in a restricted sense);
- dissemination of results (which is a condition for the use of research);
- impact (which is the actual utilization of research findings);
- and valorisation (which is the structured use of products that were developed on the basis of research).

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See for example Bensing et al., 2003.
From policy issues in the health sector to research

Figure 6.1 shows the interactions between health services research and the health care sector, in the problem definition phase, in the phase when research is conducted (e.g. through multiparty committees), and in the concluding phase (dissemination and impact). Health services research is driven by policy issues and practical problems in the health care sector. These problems need to be translated into research questions, and the research has to be sensitive to the problems in the health care sector. This translation is facilitated by interaction between researchers and policy makers.

At the individual project level, we try to get in touch with policy makers and stakeholders as much as possible. At the level of the institute this is done by an annual round of consultations with stakeholders in the health care sector, including the MoH. In 2009, 29 meetings were organised as part of the yearly round of consultations. In addition, the Societal Advisory Board also helps in converting the problems in the sector into research questions.

Within the context of the SIAMPI project interviews with stakeholders were held. They were asked to state how they rated different aspects of NIVEL’s work.

Table 6.1 Stakeholders’ evaluation of aspects of NIVEL research

<table>
<thead>
<tr>
<th>NIVEL research is …….</th>
<th>N</th>
<th>Average score (range 1-10)</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Original in its research questions</td>
<td>17</td>
<td>5.7</td>
<td>2.0</td>
</tr>
<tr>
<td>Applicable</td>
<td>16</td>
<td>8.3</td>
<td>1.1</td>
</tr>
<tr>
<td>Reliable</td>
<td>17</td>
<td>8.5</td>
<td>0.9</td>
</tr>
<tr>
<td>Topical</td>
<td>15</td>
<td>7.6</td>
<td>1.6</td>
</tr>
<tr>
<td>Insightful</td>
<td>17</td>
<td>7.8</td>
<td>0.8</td>
</tr>
<tr>
<td>Authoritative</td>
<td>16</td>
<td>7.6</td>
<td>1.7</td>
</tr>
<tr>
<td>Innovative in its methodology</td>
<td>16</td>
<td>8.0</td>
<td>1.1</td>
</tr>
</tbody>
</table>

Source: SIAMPI.

Stakeholders, furthermore, expect NIVEL to produce applicable, reliable and methodologically innovative research. Stakeholders do not expect innovative research questions. This reflects the fact that the research questions of health services research are derived from problems in the sector and not generated within discipline-related research.
In drafting the new covenant with the MoH for the period 2012-2017 we have prepared an overview of the match between policy information needs of the MoH and research conducted by NIVEL. We have used three sources of policy needs: for short-term policy requirements we used the yearly policy agenda; for long-term policy requirements we used the societal challenges that were defined by the MoH some years ago and the long-term (so-called ‘daring’) goals that are currently being developed within the MoH.

| Match between NIVEL research and short and long-term policy needs of the MoH: examples from yearly policy agendas, MoH defined societal challenges and long-term goals |
| Policy agenda curative care: removal of benzodiazepines from insured package. |
MoH decision no longer to reimburse benzodiazepines from 1 January 2009. Research based on data from LINH, Dutch Health Care Consumer Panel and National Panel of Chronically Ill and Disabled to monitor effects. |
| Policy agenda long-term care: improving palliative care. |
Development of an indicator set to measure the quality of palliative care. Examples of indicators are the percentage of patients in moderate or severe pain and assessment by patients of the expertise level of carers. |
| Policy agenda quality and safety: patient rights |
Research on patients who filed a complaint with their hospital or care organisation. Complainants expect a prompt and adequate response from the health care providers involved, but the latter usually do not react. |
| Societal challenge: Living longer in health – stimulate participation in society |
Development of a participation index for chronically ill people, disabled people and people with an intellectual disability. Evaluation of Wmo (Social Support Act ). |
| Societal challenge: anticipating changing health care demand – more knowledgeable health care users |
Contrary to the common belief, the relationships between GPs and patients with hypertension have not become more equitable. Rather, the communication pattern of GPs has become more task-oriented and less personal. |
| Long-term (daring) goals: governance based on trust |
NIVEL monitors public trust in health care since 1997. The results are used in the Dutch Health Care Performance Report (RIVM). |
| Long-term (daring) goals: the Netherlands – the healthiest country |
Research into the integration of prevention into care: introduction of special prevention consultations with GPs, overweight prevention by dieticians, attention to physical activity in health care (‘activity prescriptions’) |
| Long-term (daring) goals: caring – no longer a physically demanding occupation |
Research on the role of new technology (such as video monitoring) and acceptance among patients and caring professions. |

**Dissemination**
The starting point for the dissemination of research results to policy makers, other stakeholders and the general public is making the research results public. Nowadays the preferred medium is via downloadable reports on the NIVEL website. More focused dissemination is realized through presentations to policy makers and through invitational conferences.

**Website**
All NIVEL research reports and publications are downloadable to make them more accessible. Table 6.2 shows the most frequently downloaded reports during the review period.
### Table 6.2 Top five of downloaded reports in the period 2004-2009

<table>
<thead>
<tr>
<th>Translated title of report</th>
<th>Frequency of downloads</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiences of insurees with health care and insurers</td>
<td>6,378</td>
</tr>
<tr>
<td>Guideline on the prevention and treatment of intertrigo in large skin folds</td>
<td>4,857</td>
</tr>
<tr>
<td>Quality of care for elderly persons with psychogeriatric problems in nursing homes and homes for the elderly</td>
<td>1,585</td>
</tr>
<tr>
<td>Individual professionalization of nurses in occupational training and daily practice</td>
<td>1,071</td>
</tr>
<tr>
<td>Monitor palliative care</td>
<td>872</td>
</tr>
</tbody>
</table>

The website is also the core medium for presenting news items based on recent research. We started to publish short news items on the website in 2003 (and on the international website in 2007). On average every week one-and-half new items are presented on the home page of the website. The news items have an uniform structure of a few introductory lines with a ‘read more’-button, leading to approximately one page of text and the link to the research report on which the news item was based. In addition, NIVEL provides short news items in a format that can be read on a I-Phone or Blackberry to over 3,000 subscribers.

In 2007 NIVEL’s new international site was launched, specifically targeting our international research activities. Apart from (international) dissemination of NIVEL research, the site contains a section on expertise and experts to promote the acquisition of international funding and the creation of new partnerships. Like our national website, the international website features small news items; in 2009 every two weeks a new item was posted.

NIVEL keeps close track of user statistics such as overall page views and visits (figure 6.2).

![Figure 6.2 Number of overall page views, visitors and visits on the NIVEL-website in 2004-2009](image)

* No information is available on the number of visits to www.nivel.nl in 2004.

Most of the page views can be traced back to universities, representing both students and university employees. Nearly equal numbers originate from government organisations and other research institutes. To assure the quality of website publications, web texts are based on research reports that have been reviewed by the peer review committee, while the web texts themselves are reviewed by a small committee (the internet editorial committee).
Presentations
On average twice a week (103 times in total) a presentation was given to an audience of policy-makers or other societal stakeholders in 2009; this represents a doubling of the number since 2003 (48 times in total). These presentations are part of dissemination efforts, but of course they also contribute to the other phases in the research-policy interaction.

Invitational conferences
In a number of research projects, an invitational conference is part of the project. The aims of these conferences are to discuss policy implications of research with stakeholders, to discuss best practices or to reach consensus on an issue. They are an important link between research, the health care field and policy makers. The number of organised invitational conferences varies strongly between years, with an average of five invitational conferences for 2004-2009 (see also table 4.3).

Societal impact
When dissemination of research leads to uptake by policy makers or others a next step towards research impact has been taken. We look here at how often our research is cited in government documents, how often our research is mentioned in newspapers (and thus made available to a broader general public) and how often our website reports are cited by other websites.

Citations in government documents
These are the counterpart of citations in scientific articles. The database ‘Opmaat’ contains governmental sources such as official letters and ministerial policy memos. The number of times NIVEL was mentioned in governmental files has been benchmarked against other organisations. We have compared NIVEL, the Trimbos Institute (research in mental health and addiction), Prismant (former hospital institute), and NIZW (development and support in care and welfare, now Vilans/NJI/Movisie). NIVEL performs relatively well compared to these institutes with a health care related societal mission. In 2005, 2007, 2008 and 2009 NIVEL is mentioned in ‘Opmaat’ more than a hundred times. The organisations that we use as comparison to NIVEL, differ in size. This partly explains the differences.

Table 6.3 Number of times the name of an institute was mentioned in ‘Opmaat’, in absolute numbers

<table>
<thead>
<tr>
<th>Year</th>
<th>NIVEL</th>
<th>Trimbos</th>
<th>Prismant</th>
<th>NIZW*</th>
</tr>
</thead>
<tbody>
<tr>
<td>2004</td>
<td>76</td>
<td>50</td>
<td>55</td>
<td>96</td>
</tr>
<tr>
<td>2005</td>
<td>120</td>
<td>50</td>
<td>43</td>
<td>122</td>
</tr>
<tr>
<td>2006</td>
<td>94</td>
<td>75</td>
<td>46</td>
<td>121</td>
</tr>
<tr>
<td>2007</td>
<td>116</td>
<td>83</td>
<td>56</td>
<td>200</td>
</tr>
<tr>
<td>2008</td>
<td>115</td>
<td>94</td>
<td>41</td>
<td>176</td>
</tr>
<tr>
<td>2009</td>
<td>132</td>
<td>130</td>
<td>47</td>
<td>215</td>
</tr>
</tbody>
</table>

* Since 2007: Vilans, NJI and Movisie.

Newspaper coverage
The way to create an impact on the general public is through the mass media, but this also constitutes an indirect way to reach policy makers. NIVEL invests in bringing research results to the attention of the media. A clipping service scans the Dutch newspapers for the name NIVEL, which provides a count of the number of times NIVEL or NIVEL research is mentioned in newspapers. The number of newspaper clippings containing the word NIVEL remained fairly stable from 2004 to 2009 varying between 405 (2004) and 469 (2007).
The number of newspaper clippings has been benchmarked against other organisations by using an open access database containing quality Dutch newspapers (since 2006 the ‘Krantenbank plus’). Among these institutes NIVEL does quite well (table 6.4).

Table 6.4 Number of times the name of an institute was mentioned in ‘Krantenbank (plus)’, in absolute numbers

<table>
<thead>
<tr>
<th>Year</th>
<th>NIVEL ¹</th>
<th>Trimbos</th>
<th>Prismant</th>
<th>NIZW ²</th>
</tr>
</thead>
<tbody>
<tr>
<td>2004</td>
<td>60</td>
<td>128</td>
<td>23</td>
<td>50</td>
</tr>
<tr>
<td>2005</td>
<td>63</td>
<td>68</td>
<td>13</td>
<td>21</td>
</tr>
<tr>
<td>2006</td>
<td>68 (73)</td>
<td>89 (102)</td>
<td>18 (18)</td>
<td>23 (25)</td>
</tr>
<tr>
<td>2007</td>
<td>95 (105)</td>
<td>120 (153)</td>
<td>14 (17)</td>
<td>51 (65)</td>
</tr>
<tr>
<td>2008</td>
<td>68 (97)</td>
<td>95 (142)</td>
<td>11 (13)</td>
<td>49 (70)</td>
</tr>
<tr>
<td>2009</td>
<td>85 (105)</td>
<td>109 (152)</td>
<td>8 (8)</td>
<td>36 (54)</td>
</tr>
</tbody>
</table>

¹ Numbers differ from the total number of clippings because ‘Krantenbank’ only includes quality newspapers. Krantenbank Plus contains quality newspapers and free papers (Metro, Spits, Dag (2007-2008) and NRC.Next. Since 2006 the number of times an institute is mentioned in Krantenbank Plus is provided between brackets.

² Since 2007: Vilans, NJI and Movisie.

Websites citing the NIVEL website

Apart from our own website, NIVEL contributes to other websites. These include the website of the National Care Compass (Nationaal Kompass Volksgezondheid) and KiesBeter.nl developed by RIVM. KiesBeter.nl contains information to facilitate the general public in choosing a health care provider and health care insurance. NIVEL has developed survey instruments to measure patients’ experiences with their health care providers and insurance (the so-called Consumer Quality Index or CQ-index). The results are published on KiesBeter.nl.

Within the SIAMPI project, a contextual response analysis was performed on the visibility via internet of reports and documents from NIVEL’s national databases and panels and a number of projects. Other websites – belonging to various domains – use information from NIVEL databases/panels and projects. This analysis was split up between five domains of responding websites: General/other, Government and politics, Health and health care, Science, and Communication and dissemination.

According to the SIAMPI report, this analysis reveals receptiveness in a much wider circle than stakeholders directly involved in research projects, and shows indications of use in specific domains of health care (health care authorities), policy making (local authorities) or science and also indications of use in a more general audience of media, knowledge platforms and bloggers. The databases, panels and projects analysed have different internet profiles. Some are more often traced back to web sources from ‘science’, others to ‘health and health care’. The most striking finding, however, is that the domain ‘Government and politics’ apparently generated relatively few internet responses about NIVEL research. This is probably related to the way in which government uses internet. Visibility of government use is clearer in the database of official documents, presented in table 6.3.

Another way of quantifying the use of NIVEL research on the web is to analyse how often the news items on the NIVEL website are cited by other websites. We noticed that many of our news-items were relayed by a number of other websites, thus increasing the exposure without a parallel increase of the amount of visitors to our own website. To be able to monitor the intensity of web citations of NIVEL research we constructed an indicator which is comparable to the H-index used in bibliometric research on scientific quality of researchers and research groups. This H-index denotes the number of website items cited by the same number of other websites. In 2009, 26 of our website news items were cited at least 26 times by other websites.
Figure 6.3 Internet response to NIVEL panels and databases per domain

- Second Dutch National Survey of General Practice
- LINH: Netherlands Information Network of General Practice
- Dutch Health Care Consumer Panel
- LIPZ: National Information Network of Allied Health Care
- Panel of People with an Intellectual Disability
- Continuous Morbidity Registration Centres

Source: SIAMPI.

Figure 6.4 Internet response to publications of projects

WET 002: Evaluation of Health insurance reform
COM 002: Communication with elderly patients during nursing encounters preceding chemotherapy
MIG 002: Asylum seekers, refugees and their children: an epidemiological study of health problems, needs and looking for help
CHR 007: Monitor Societal participation of the chronically ill and disabled
GGZ 006: Capacity and referrals in primary mental health care
CHR 022: Monitor Life and health care situation of people diagnosed with asthma or COPD
COM 007: Communication and role delineation in paediatric oncology: a multi-perspective view on policies, preferences, and practices
RAM 008: Quick scan Education, training and exercises in preparing for emergency health services after disasters

Source: SIAMPI.
Examples of societal impact of NIVEL research
Current consensus in the health research community is that the actual impact of research is best illustrated by narratives of how research is used. To date there is no quantitative approach that captures research impact in a systematic way. Inbetween the chapters of this Self-Evaluation we have presented key examples of the impact of NIVEL research. Box 6.1 gives an overview of these and other examples.

### Box 6.1 Examples of the societal impact of NIVEL research

<table>
<thead>
<tr>
<th>Examples presented in this report:</th>
<th>Other Examples:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>International and Migrant Health</strong>&lt;br&gt;Case: Assessment of primary care in Central and Eastern Europe and Central Asia&lt;br&gt;The state of primary care is studied on the basis of a format developed by NIVEL in cooperation with WHO Europe. Reports are published by WHO Europe in English as well as in the national language and launched at a policy round table with stakeholder representatives.</td>
<td><strong>Maternity Care and Reproductive Health</strong>&lt;br&gt;Case: Monitoring Midwifery Care and Maternity Care Assistance&lt;br&gt;This study addressed the shortage of midwives and maternity care assistants, leading to high workload and to the reduction of maternity care assistance. The results have contributed to policy decisions to reduce workload/caseload for midwives.</td>
</tr>
<tr>
<td><strong>Communication in Health Care</strong>&lt;br&gt;Case: VOICE - Communicating with older cancer patients&lt;br&gt;The project aimed at improving the way oncology nurses inform older patients with cancer about chemotherapy. We have translated the results into a new educational model and training programme for cancer nursing, increasingly used in Dutch hospitals.</td>
<td><strong>Pharmaceutical care</strong>&lt;br&gt;Case: Professional Level of Pharmaco-therapeutical Audit Meeting groups (PTAMs)&lt;br&gt;NIVEL studied the professionalization of PTAMs, local peer review groups of GPs and pharmacists, aiming at quality improvement in prescribing. The levels of cooperation of PTAMs have been used by insurance organisations in contracts with GPs.</td>
</tr>
<tr>
<td><strong>Organisation and quality of health care</strong>&lt;br&gt;Case: Adverse events in hospitalized patients: incidence and causes&lt;br&gt;Our research on patient safety, the first to confirm the extent of the problem, is seen as a milestone in Dutch health care. The position of the MoH is that preventable adverse events cannot be tolerated. All parties in health care back the report and have developed an “action plan” to tackle the problem.</td>
<td><strong>General Practice Care</strong>&lt;br&gt;Case: Embedding prevention in the general practice care setting&lt;br&gt;Integration of disease prevention, especially at population level, in general practice has been controversial for many years. We have studied the conditions for a more positive attitude of GPs towards preventive services: focus on high-risk groups and sufficient supporting personnel.</td>
</tr>
<tr>
<td><strong>Monitoring the Health Effects of Disasters</strong>&lt;br&gt;Case: Health effects of the fireworks disaster in Enschede&lt;br&gt;NIVEL has monitored health problems after several disasters and environmental incidents, using EMD information from general practices. This has supported national, regional and local policies during many years of managing the mental and physical health consequences for survivors.</td>
<td><strong>Mental Health and Primary Care</strong>&lt;br&gt;Case: Monitoring Primary Mental Health Care&lt;br&gt;The problem-solving capacity of primary care is being enhanced by the introduction of practice nurses for mental health care. Our research contributed to the task description for these new professionals in primary care.</td>
</tr>
<tr>
<td><strong>Patient Perspective and Demand led Health Care</strong>&lt;br&gt;Case: Development and use of the Consumer Quality Index&lt;br&gt;NIVEL had and still has a pivotal role in the development and use of the CQ-index. CQ-index information is used by patient organisations, insurers, managers and professionals, and the Ministry of Health.</td>
<td><strong>Professions in Health Care and Manpower Planning</strong>&lt;br&gt;Case: Manpower planning for medical professions&lt;br&gt;NIVEL has developed a stock and flow model to support the planning of the required number of doctors in training to meet projected demand. Our work is used by the Capacity Body in advising the MoH and the MoE.</td>
</tr>
<tr>
<td><strong>Needs and Health Care Demands of People with Chronic Illness or Disability</strong>&lt;br&gt;Case: Financial compensation for the higher health care costs of people with chronic illness or disability</td>
<td><strong>Evaluation of Health Law</strong>&lt;br&gt;Case: Evaluation of the Health Insurance Act&lt;br&gt;The introduction of the 2006 Health Insurance Act was relatively smooth. The short term evaluation provided</td>
</tr>
</tbody>
</table>
We have conducted several studies on the use of tax-relief by people with a chronic illness or disability to compensate for higher health-related costs. The results have been frequently used to respond to parliamentary questions.

Nursing Care

Case: Moral dilemmas in the daily work of nurses
The Centre for Ethics and Health published a report on moral dilemmas in daily care that nurses and carers are confronted with. The report was largely based on NIVEL research conducted within the Panel of Nurses & Carers.

Allied Health Care

Case: Behavioural graded activity in patients with osteoarthritis
A randomized trial showed that behavioural graded activity is preferable to usual physiotherapy for the treatment of patients with hip osteoarthritis. This evidence has been included in a new version of the national physiotherapy guideline on osteoarthritis.

Valorisation

One aspect of the impact of research results on policy and practice is the utilization of new products, processes and services. This is the definition of valorisation – with the connotation of bringing these products, processes or services to the ‘market’. NIVEL does not produce for the market; the results of research and products based on research are available in the public domain. A number of our products are widely used by other organisations. In a market situation they would probably have been sold. We briefly discuss some examples of valorisation of NIVEL research.

The CQ-index, discussed previously as an instance of the societal impact of our research, is now the standard for measuring patient evaluations of health care in the Netherlands. CQ-index questionnaires are used by other (research) organisations to conduct measurements on a regular basis in several sub-sectors of health care.

VAAM (or Vraag Aanbod Analyse Monitor, in translation Demand-Supply Analysis Monitor) denotes an instrument that enables a diagnosis of the match between primary care supply and the local need for primary care at the level of municipalities and neighbourhoods. VAAM has its own website and is widely used by organisations in health care. This instrument has been developed in cooperation with the NPCF (The Federation of Patients and Consumer Organisations in the Netherlands). VAAM provides insight into:
- demand for care for specific conditions, such as chronic disease and psychosocial problems;
- demand for care for specific services, such as general practices, pharmacies, physiotherapy practices, and primary mental health care;
- demographic data for the municipality or neighbourhood chosen;
- future demand for primary care.

In the context of a large study on patient safety in Dutch hospitals, patient record review methods with trigger lists to detect adverse events were developed. This methodology has been adopted for use by hospitals themselves, with NIVEL providing support and training. Hospitals have now started to use this methodology as part of their safety management system.

NIVEL has developed a ‘deprivation index’ to rate neighbourhoods. The deprivation index is used for additional reimbursement of GPs for their patients living in deprived areas. The deprivation index was also adopted in 2009 by the Royal National Association of Midwives to support midwives delivering services for clients living in disadvantaged areas.
Conclusions
NIVEL invests in making its research responsive to problems in the health care sector, problems faced by policy makers as well as other stakeholders. This takes a large investment in time and energy, but in our evaluation it pays off in terms of the impact of our research. Interaction is the key element to facilitate the translation of problems in the health care sector and in health care policy into research questions, and this interaction increases the chances of future utilization of the research findings. The SIAMPI project tentatively concludes that productive interactions require:
- institutional policy and management;
- involvement of stakeholders in the early stages of research;
- involvement of various stakeholders;
- transparency of involvement of funding agents.
This chapter has shown that NIVEL performs quite well on these conditions. A challenge for the future is to make these interactions even more productive.
A further challenge is to develop a system of monitoring research uptake in policy in a more quantitative way. Up to now, the best we have is the use of narratives of actual research utilization. Finally, valorisation is an area in which we have shown some successes but no systematic investment.
Societal impact: Needs and Health Care Demands of People with Chronic Illness or Disability

Case: Financial compensation for health-related costs of people with chronic illness or disability

**Brief description of the research:**
During the period 2001-2009, NIVEL conducted several studies on financial compensation arrangements by people with a chronic illness or disability. These people often have higher costs of living because of their illness or disability, e.g. higher insurance premiums, co-payments, dietary expenses, energy costs because of specific aids, etc. Tax deduction facilities (within Income Tax Law) have been used to compensate for extraordinary health-related costs. This tax facility was adapted several times during the period 2001-2008, and was finally replaced by a new law (Wtco; January 2009) consisting of a comprehensive system of new - fiscal and non-fiscal - compensation arrangements.

**Policy level:**
Our research has proved to be important for the monitoring and evaluation of financial compensation arrangements at national policy level, in particular income policy for vulnerable citizens, developed by the Ministry of Social Affairs and Employment in collaboration with the Ministry of Health and the Ministry of Finance.

**Policy area:**
Until 2009, extraordinary health-related costs could (partly) be compensated by a tax deduction facility. This facility has been adapted several times in order to make it more tailored to the characteristics of the target groups, to provide better compensation for these groups and to counteract abuse by people who are not chronically ill or disabled. Notwithstanding these adaptations, our studies have demonstrated that underuse by people with chronic illness or disability remained substantial because of the complexity of the arrangement and the need for individual initiative to establish eligibility for compensation. In 2009, the tax facility was partly replaced by compensation arrangements related to social security and the use of long-term care.

**Impact of the research on policy:**
The ministries involved have frequently used our results to respond to parliamentary questions. In response to a resolution (Meurs motion, December 10th, 2009) by the Senate, the Minister of Social Affairs and Employment and the junior Minister of Health have promised to monitor the income effects of the new law – in comparison with the old law - among chronically ill or disabled people. In the minister’s letter to the Senate (EK-31706; 2009-2010), he explicitly referred to NIVEL for monitoring this.

**Use of national information systems:**
For this research we make use of the National Panel of the Chronically Ill and Disabled (NPCD), a nationwide representative prospective panel for studies conducted by NIVEL since 1998. NPCD consists of about 3,800 people who have been diagnosed with a somatic chronic disease or who have moderate to severe levels of physical disability. Its national representativeness is an important characteristic. Moreover, since we have collected data on health related costs and the use of compensation arrangements each year since 1998, data for this research are available from both before and after the transition.