Palliative care

Palliative care programme 2014-2020
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Colophon

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Progress requires research and development. ZonMw funds health research and stimulates use of the knowledge developed to help improve health and healthcare.

ZonMw’s main commissioning organisations are the Ministry of Health, Welfare and Sport and the Netherlands Organisation for Scientific Research.

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Summary

In June 2014 the Ministry of Health, Welfare and Sport commissioned ZonMw to develop a proposal for a palliative care programme. This ZonMw programme, Palliative care is part of the National Palliative Care Programme (NPPZ), which also includes regional palliative care partnerships. In response to the commission, ZonMw submitted an Outline NPPZ on 30 July 2014. The Ministry officially endorsed the outline on 23 September, requesting that it be worked up to a full programme proposal.\(^1\) ZonMw presented the full proposal to the Ministry on 3 February and received the Ministry’s approval on 14 April 2015.\(^2\)

The basic vision of the programme is that palliative care should be based on the needs and wishes of patients\(^3\) and their families, should be part of regular healthcare provision and should be arranged as close to home as possible.

The ZonMw programme Palliative care aims to achieve a noticeable improvement in palliative care over the coming years for patients and their families. Though the palliative care currently on offer is good, there is room for improvement. Provision is for example still driven too much by the supply side, and standards and accessibility vary.

Programmatic approach: broad and open

Investment in a programmatic approach should ensure that this goal is achieved. The approach will be broad and open. It will be broad in the sense that it will invest in projects combining practice, training and research. Attention will also be focused on the development of products for use in practice and training. The open approach will give people in the final phase of life and their families, and also volunteers and care providers an important role in defining priorities in the programme and assessing the social relevance of applications. The open approach will also be reflected in a willingness to incorporate and prioritise problems encountered in practice. As a result, priorities may change during the programme. The programme committee will therefore amend the programme’s priorities every two years on the basis of the results achieved and the current situation. It will do so in close consultation with the partnerships, people in the palliative phase and their families and other stakeholders.

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\(^1\) Ministry of Health, Welfare and Sport, letter no. 649409-124497-LZ
\(^2\) Ministry of Health, Welfare and Sport, letter no. 731025-133839-LZ
\(^3\) Patient in this context is defined as anyone who is in the palliative phase. These people are not always patients. However, in the interests of readability, and because these people often are patients in the context of this programme, we have elected to use the word ‘patient’.
in the National Palliative Care Programme. There will also be scope to respond on an ad hoc basis to new issues that need to be addressed quickly.

This programme document is based on the NPPZ matrix, which encompasses three activities: ‘research’, ‘training’ and ‘care practice’, as well as four themes: ‘awareness and culture’, ‘organisation and continuity of care’, ‘care innovations and standards’ and ‘patient participation and support’ (see figure 1). These themes refer to aspects of palliative care that stakeholders have highlighted as essential to its quality.

This document describes the themes and the problems associated with them, as well as potential for improvement. The topics and priorities in the programme are described in the sections on the individual themes. The topics focus on improving practice, training or the development of knowledge, and an indication is given as to where priority will lie over the next two years. Priorities have been set largely on the basis of the goals described in the Ministry of Health, Welfare and Sport’s letter of 11 December 2013 and the outcomes of expert meetings held in autumn 2014. Where possible, the priorities for this programme are described in the sections on the different themes from the perspective of patients and their families. As announced in the outline, the baseline situation with regard to these topics and priorities will be defined at the outset so that improvements can be monitored.

It will take more than this programme to further raise standards of palliative care in the Netherlands. The programme must therefore tie in well with national policy and the activities of regional partnerships. To ensure this is the case, the Ministry of Health, Welfare and Sport has established a broad-based steering group, and specific goals for palliative care in 2020 will be set out. The results of the programme will therefore be consolidated on a broader basis and recommendations for improvements to palliative care that fall fully or partially outside the remit of the programme will be taken up by the appropriate organisation.

A knowledge synthesis will be performed when the programme is launched. It will outline what we already know, and what activities are already underway concerning the topics to which the priorities refer. The synthesis will allow objectives and programming to be rendered more specific.

The Palliative care programme has a budget of 51 million euros. It will run from 2014 to 2020. The first investments have already been made, with the establishment and expansion of regional partnerships and the launching of a palliative care website administered by Agora.
Submission of applications will start in spring 2015. The budget for the first year is eight million euros, including the final round of the Palliative Care Improvement Programme, which encourages the implementation of best practice.

The ultimate goal of the programme is for joint efforts to be made to substantially reduce problems in palliative care, using the input and knowledge of the entire field. Good initiatives have also been developed that represent permanent investments in clear improvements to training, research and practice in the field of palliative care.

1. Introduction

1.1 Commission

For over a decade, the palliative care domain has been working to achieve a comprehensive supply of palliative care and a policy on this type of care. A report on the financing and organisation of palliative care (Financiering & organisatie van palliatieve zorg: De pioniersfase voorbij?, Palliactief, 2011) draws attention to a number of points, including:

- The needs of patients and their families must play an important role. Quality of life and dignity are key. This also includes bereavement counselling.
- Physical, psychological, social and spiritual factors must be taken into account and support offered in these areas. Patients must have as much control as possible over the final phase of their life.
- Care providers must arrange palliative care as close to home as possible.
- Extra consideration must be given to informal carers.
- Palliative care should be part of regular healthcare provision.

In a letter to parliament of December 2013 on investing in palliative care State Secretary for Health Martin van Rijn pointed out that these principles are not yet regarded as self-evident in day-to-day practice. Over the next few years, therefore, the Ministry plans to invest in a new National Palliative Care Programme. The national programme encompasses the ZonMw programme Palliative care and regional partnerships/consortia in which the Palliative Care Centre of Expertise (EPZ) and other regional players will together establish a context in which practical research and professional development can take place. In June 2014 the
Ministry of Health, Welfare and Sport invited ZonMw to draw up a programme proposal for the comprehensive development of research, training and care.

1.2 Background to the document

The programme is based on the NPPZ matrix containing the three activities ‘research’, ‘training’ and ‘care practice’ (previously known as ‘implementation’), and the four themes ‘awareness and culture’, ‘organisation and continuity of care’, ‘care innovations and standards’ (previously ‘innovative interventions in care’) and ‘patient participation and support’ (previously ‘patient/family participation appropriate to patient’s abilities’). The matrix was developed in 2013 by members of the Palliative Care Core Group, on the initiative of the Netherlands Federation of University Medical Centres (NFU), and the categories have since been altered slightly (see section 2.2, figure 1).

The programme builds on existing documents, including the White Paper on Palliative Care (Palliative Care Core Group, 2011), the Knowledge Agenda (ZonMw, 2012), the Palliative Care Module (coordinating platform for healthcare standards and quality institute, Ministry of Health, Welfare and Sport), an NFU memorandum from 2013 (Als je niet meer beter wordt; aanzet tot het nationaal programma palliatieve zorg), an NFU booklet on the National Palliative Care Programme (NFU, 2013), an NHG position paper on general practitioners and palliative care (2009), Palliatieve Zorg in beeld (IKNL, 2014), a document describing plans to set up a National Palliative Care Programme, version 1.0 (Ministry of Health, Welfare and Sport, October 2014), and the document Niet alles wat kan hoeft. Passende zorg in de laatste levensfase (steering group on appropriate end-of-life care, draft, December 2014).

In September and November 2014 six expert meetings were held to identify the problems associated with each theme and the potential for improvement. The expert meetings also determined which problems and potential improvements deserved priority. The objectives of the programme over the coming two years will reflect these priorities. The expert meetings were attended by professionals involved in research, training and care, and by patient groups; two of the meetings on special groups were attended only by experts.

4 Kerngroep Palliatieve Zorg: Agora, Palliactief, Associatie van zelfstandige high-care hospices, Expertisecentra Palliatieve Zorg (EPZ)/NFU, Stichting Fibula, IKNL, PalHag/NHG, VPTZ, V&VN Palliatieve Zorg, Zorginstituut Nederland
1.3 Budget and duration

The programme has a budget of 51 million euros, and will run from 2014 to 2020. The budget for the first year is eight million euros. Monitoring will continue to the end of 2021, when a final evaluation will also be conducted.

1.4 Structure of the document

This programme document first describes the mission and design of the programme, considering the collaboration with other parties in the National Palliative Care Programme and how this programme’s remit relates to other programmes (section 2). Section 3 then describes the themes and the programme goals and priorities associated with them. Finally, section 4 considers all factors related to the management and organisation of the programme.

2. Programme

2.1 Mission of the ZonMw programme

The goal of this ZonMw programme is to bring about noticeable improvements in palliative care for patients and their families. We define ‘noticeable’ as meaning that the care caters better for the needs and wishes of people in the final phase of life and their families. This improvement is to be achieved through new initiatives in research, practice and training. The quality of attention focused on people in the final phase of life and their families will have risen. All stakeholders in the palliative care field and the public should also be showing substantially more interest in the subject of ‘discussing end-of-life issues’ and the associated care needs.

This programme bases its description of palliative care on the WHO definition (2002): ‘palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’ (WHO 2002). A life-threatening illness is defined as an incurable disease. This includes most types of cancer, and also other...
types of illness, such as metabolic disorders, COPD, cardiovascular disease, ALS and dementia.

The basic vision of the programme is that palliative care should be based on the needs and wishes of the patient. Palliative care should be arranged on the basis of this, as part of regular healthcare provision, and as close to home as possible.

2.2 Programme design

A broad approach has been chosen for this programme to allow room for all kinds of projects that accelerate *improvements in care practice* that will be noticeable to patients. This is based on the notion that improvements will not come about for patients, their families, volunteers and care providers if knowledge is developed only through research. On the other hand, practical initiatives will not easily emerge from local activities if they are not supported by evaluation, further development and dissemination. In short, the programme will provide room for projects that combine practice, training and research in a whole range of ways. This might include projects experimenting with new forms of care, implementing best practice or initiating collaboration.

This is not to say that every project must include research, training and practice in equal proportion. The prospect of achieving a noticeable improvement in care for patients and their families is the basic principle, and it is on this basis that the best plan of action will be proposed for each project, depending on the issue. This might result in a practice-oriented study with an equal proportion of practice and research activities, but it might also be that a fundamental research question first has to be addressed before any progress can be made towards improvements in practice.

A lot of knowledge already exists and many examples of best practice are already being applied. This programme wants to bring together this knowledge and best practice and spread it throughout the country, allowing us to make improvements more quickly, and prevent the wheel from continuously being reinvented. Conversely, the programme will also be critical as regards interventions or methods that do not appear to work, or whose effect is unclear. Just as implementation can constitute an improvement, so can discontinuing an ineffective practice.
Besides practice and research, the programme will also fund projects for the purpose of training, such as the development of teaching material, learning modules and interactive forms of working. Reports from the field suggest that care providers are not always equipped with enough knowledge and skills to provide good palliative care. This programme intends to improve this situation. The idea is also to provide recent knowledge and insights to incorporate into basic training and refresher training. To ensure this happens, the programme will include measures to encourage the transfer of knowledge developed in each project to the training sector. It should however be noted that this is no simple matter. A plan of action will be needed to ensure that the training courses of both basic training and retraining and refresher courses are structurally fed with newly developed knowledge. After the programme is launched a plan of action will be worked out, based on the principles that palliative care should be a self-evident part of all appropriate basic training and refresher training courses and that training is also a part of practice (lifelong learning).

The programme is to have an open character to allow it to respond as well as possible to topical issues. The programme will not therefore be set in stone. We will remain in discussion with patients and stakeholders from care practice, research, training and policymaking throughout the programme. The leaders of projects funded by this programme will play an important role, as they are in the best position to know what knowledge is available on the four themes, and what developments are occurring. During the course of their project they will be able to help update the current state of knowledge. There will be scope for rapid response in the event of situations that must be addressed as a matter of urgency. The programme will evaluate the state of knowledge every two years, and adjust the programming if necessary.

The programme will follow the NPPZ matrix, using training, research and care practice projects to address the main themes requiring improvement in palliative care. These ‘themes’ – ‘awareness and culture’, ‘organisation and continuity of care’, ‘care innovations and standards’ and ‘patient participation and support’ (see figure 1) – were defined by members of the Palliative Care Core Group at the instigation of the NFU (NFU, 2013), and provide a basis for the improvement of palliative care. Each theme is seen as an appropriate area of focus in good palliative care. The themes and how they relate to the Palliative care programme are explored in further detail in section 3.
2.3 Parties and allocation of responsibilities

The ZonMw programme *Palliative care* is designed to be a stimulator for palliative care across the board, including not only knowledge development and dissemination, but also collaboration between many parties that together should be able to structurally improve palliative care in the Netherlands. This collaboration will receive a boost from the new regional partnerships/consortia coordinated by the Palliative Care Centres of Expertise (EPZ/NUF), Palliative Care Networks and IKNL cancer centre. However, existing partnerships and parties already active in palliative care can also contribute to improvements. The main initiatives will be coordinated by a broad-based steering group established by the Ministry of Health, Welfare and Sport, which will consolidate results from the programme on a broad basis. This will ensure that recommendations for improvements to palliative care that do not fall within the remit of the programme are taken up by the right organisation. These parties’ main roles, responsibilities and activities for the programme are described below.

- Agora is ZonMw’s partner for communications and dissemination of knowledge on palliative care. Agora will also coordinate other parties involved in disseminating information, making knowledge available and providing the link to the welfare field. ZonMw has provided a grant for the launch of a broad-based palliative care website.
- The Palliative Care Core Group can advise ZonMw, and will act as a focus group of parties that promote palliative care in the Netherlands (Agora, Palliactief, Association of Independent High-care Hospices, Palliative Care Centres of Expertise (EPZ/NFU), Stichting Fibula, IKNL, PalHag/NHG, VPTZ, V&VN Palliative Care). Agora will supply the group’s chair.

- Consortia are partnerships that will translate NPPZ topics into regional practice and, conversely, provide input for changes to priorities. The Palliative Care Centres of Expertise, Palliative Care Networks (NPZ) and IKNL cancer centre will participate in the consortia. The most relevant care providers and organisations in each region will be involved, including general practitioners, hospices, nursing homes, home care organisation, hospitals, volunteers and patients’ associations. The consortia will form a nationwide network for the optimisation and coordination of palliative care throughout the Netherlands, allowing improvements to be achieved for all people in the final phase of life.

- The Palliative Care Centres of Expertise (EPZ/NFU) will make new knowledge and professional and scientific expertise available for improvements to care practice. They will do so by such means as scientific and practice-based research, development and improvement of care products, evaluation studies and training activities. They will also be able to advise their own and other regions on the basis of their particular specialist knowledge.

- Regional Palliative Care Networks, represented by Stichting Fibula, will be an important link at regional level, highlighting problems in care practice and linking the care and welfare sectors. The networks will be responsible for regional coordination of care between institutions and organisations, making clear what care is available in the network’s area, and implementing new products/methods. They will help raise awareness of palliative care.

- IKNL cancer centre will play a role in the sharing and implementation of knowledge, alongside Agora. They will organise a comprehensive nationwide system of consultation, professional development and refresher training.

- The steering group consists of administrative representatives of NFU, IKNL, Agora, the National Health Care Institute (ZIN), GP association NHG, ZonMw, several professional organisations, insurance companies and welfare organisations. It will advise parties as necessary to achieve improvements in the broad field of palliative care.

- The Ministry of Health, Welfare and Sport is ZonMw’s commissioning organisation, and will have observer status in ZonMw’s programme committee.
The Ministry is responsible for national policy and the legislation needed to achieve national objectives.

- The National Health Care Institute will be responsible for identifying and recording best practice in palliative care and for any guidelines produced as a result of the Palliative care programme. The institute advises the government on the scope of the statutory healthcare insurance package (which includes palliative care) and authorises guidelines.

Relevant parties in the training sector will be described in the separate training plan.

2.4 Collaboration in the programme

One important task for ZonMw will be to ensure that issues impacting on palliative care are included in the programme. We will also foster collaboration within and between the consortia. Tackling the topics in this programme will require close collaboration between all involved. The programme also has its limitations. Creating the conditions for new knowledge to be implemented is for example beyond the scope of the programme. This means that when a problem requires a response all those mentioned above will have to provide input in terms both of technical expertise and of process.

It is expected that the majority of grant applications will be submitted by the consortia, or by consortium partners. However, the programme is also open to other applicants, on condition that they liaise with the consortia. As we have said, most grant applications are likely to come from parties involved research, training and practice who are already collaborating in consortia. It is incidentally also possible that an EPZ might take up certain issues together with a network outside the region because its research is more closely related to the issue. Equally, regional networks might seek collaboration with an EPZ outside their own region because it is a more obvious choice given its focus on a specific issue or knowledge of a particular target group.

2.5 Remit in relation to other ZonMw programmes

The programme ties in with other ZonMw programmes such as the Palliative Care research programme, which is already complete, and the ongoing programmes Quality of Care, the National Care of the Elderly Programme and Memorable. The Palliative Care Improvement
Programme will be completed in the framework of this programme. *Palliative care* will collaborate with other ZonMw programmes wherever there is overlap in terms of focus on specific groups (e.g. people with learning disabilities, people with dementia and elderly people).

### 2.6 Internationalisation

The Netherlands offers high standards of palliative care compared with other countries (*Palliatieve Zorg in beeld*, 2014). The *Palliative care* programme is designed to foster scientific collaboration with international experts in this field to enable the Netherlands to retain this international position. The programme will also stimulate other international initiatives, including the sharing of practical experience and best practice, and international comparative studies.

### 3. Structure and content of the programme

This section examines the four themes, exploring the problems experienced and the potential for improvement. As described above, this programme will take the main issues encountered in practice as a basis for improvement, to ensure that by the end of the programme palliative care caters better for the needs and wishes of people in the final phase of life and their families. Given this fact, this section is necessarily subject to change. After all, today’s issues might not be so pressing in a few years’ time. The main topics are described in this section, along with the programme’s envisaged priorities. Some of them can already be specified in some detail, while others are merely presented by way of guidance. The topics relate to improvements in practice, training or the development of knowledge. A list of topics that will be given priority over the next two years is given at the end of each section. These priorities are based largely on the outcomes of the expert meetings held in autumn 2014. After the launch of the programme the knowledge already available will be identified, and used as a basis to flesh out the details of the objectives and programming for 2015-2016.

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5 ‘Ranking end-of-life care across the world’ gives the Netherlands a score of 6.3, putting it in seventh place. The highest score in the ranking is 7.9, and the lowest 1.9. Great Britain, Australia, New Zealand, Ireland, Belgium and Austria all score higher than the Netherlands. (Economist Intelligence Unit. The Quality of Death. Ranking end-of-life care across the world. A report commissioned by the Lien Foundation. Singapore 2010).
3.1 Awareness and culture

According to the WHO definition palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO 2002). This seems like quite a specific definition, but in practice it is not always clear when it is appropriate to start referring to the palliative phase. This is largely because palliative and curative care are not always strictly separate phases in the disease process. The model by Lynn and Anderson (figure 2) shows that the palliative phase can commence quite early in the course of a life-threatening illness. According to care providers, in most cases this model effectively represents what they encounter in practice. However, in view of this gradual transition, the boundary between curative and palliative can easily become blurred.

The boundary between curative and palliative is even more difficult to define if the disease process cannot readily be predicted and/or is generally changeable. The course of certain oncological diseases is relatively predictable, generally consisting of a more or less stable phase followed by a fairly short period of sudden and rapid decline. The process is however much less predictable when it comes to a number of chronic non-oncological diseases, such as COPD, and may include a number of severe episodes (IKNL, 2014). The progression of the disease is also difficult to predict in certain patient groups, which means that a linear model does not always adequately reflect practice.⁶

Despite the fact that it is not easy to coordinate treatment plans between care providers, they all need a good description of the palliative phase so that they can clearly discuss the matter when people enter this phase. Palliative care wants to help ensure that, by 2020, all care providers actually or potentially involved in palliative care have a clear and workable definition of palliative care at their disposal that includes particular measures for special groups and takes account of differences in the progression of diseases. Such a definition is a prerequisite for good communication. Section 3.4 (on patient participation and support) looks in more depth at communication and the associated goals and priorities.

⁶ The special groups referred to in this document are children, people with dementia, members of ethnic minorities, people with learning disabilities, mental health service patients and homeless patients.
A large proportion of the public believe that the treatment of illness should mainly be about ensuring the patient does not die (‘giving up is not an option’). Though this view must of course be respected, it leaves little room—even for terminal patients—simply to accept and submit to a disease and the approaching end of life. The focus must shift more to quality of life and patient choices, and to promoting the idea it can also be appropriate not to embark on or to discontinue a therapy focused on cure or prolongation of life (*Niet alles wat kan hoeft*, 2015). This also allows more scope for the use of palliative care.

It is not easy for the general public, and certainly not for people in the final phase of life, to discuss the palliative phase, and negative thoughts about dying tend to dominate. This is a social issue, a matter of helping people to approach the subject as a more normal topic of conversation. Making it easier to discuss this phase can help people think about how they might want to arrange for this phase of their life or how they might support a relative in this phase. It is hoped this programme will help open up the subjects of palliative care and the palliative phase for discussion. This priority is also discussed in section 3.4, ‘patient participation and support’.

To achieve this goal, we need knowledge of cultural factors that help to determine how people regard the palliative phase, besides other factors like age and personal views. Knowledge of diversity in views, needs and wishes is also needed in order to provide appropriate care (*NFU*, 2013). At present we have only limited knowledge of this diversity of
perception in the four dimensions (physical, psychological, social and spiritual).\footnote{Stof in de Wind. Tradities bij overlijden van allochtonen in Nederland. Rabbi Lody B. van de Kamp, Varina Thon-a-Ten (eds.), Ibrahim Spalburg (1995)} It is important that we learn more about this, especially with reference to special groups (Van de Kamp, Thon-a-Ten and Spalburg, 1995).

This social issue cannot be resolved overnight, but it would at least help if care providers could communicate about the palliative phase in a way that was appropriate to the personal perceptions of the individual in question. To do so they will require knowledge, and also communication skills and experience. The goal of this programme is for everyone involved in care to have a good basic knowledge of palliative care. This can be achieved by, among other things, ensuring that by 2020 knowledge of the meaning and diverse perceptions of the palliative phase is included in all the relevant training courses. We propose that, besides knowledge transfer, particular efforts be made to ensure that trainees learn communication skills and receive on-the-job training. Social and community worker trainers have the required expertise to teach communication techniques, and could be called upon to help achieve this aim.

The above paragraphs are about awareness and perceptions of the concept of the palliative phase and palliative care. However, this theme also encompasses awareness and recognition of the point at which a person enters the final phase of life, or when marked physical changes occur during this phase. Methods are being developed that will help care providers identify these points. One example is the Delirium Observation Screening Scale. For good palliative care there has to be agreement as to which signals are to be picked up and how, and what action should be taken in response. There is still much to be gained in this area.

The point of recognition on which specific attention will be focused in this programme is the point at which the final phase of life actually becomes imminent. Recognising this moment is so important because it gives patients and their families the opportunity to think about the arrangements they would like to make for this phase. Once this is acknowledged care can be tailored to it, by transferring the patient from secondary to primary care, for example. With some diseases, this point is fairly obvious. In other diseases, however, many of which are associated with comorbidity, this moment is much more difficult to recognise. Recognition
can also be difficult in certain special groups. Nevertheless, care providers, patients and their families all need this point to be identified.

The Palliative Care Module 2013 included Murray’s ‘surprise question’, which can help care professionals recognise the final phase of life by asking themselves whether they would be surprised if the patient died within a year. If the answer is no, it is time to discuss the matter with the patient. It remains difficult to draw conclusions about life expectancy in individual cases. Though the surprise question is already in use, it is not used systematically, and it has turned out to be a less than ideal approach, particularly in the case of special groups and cases where the progression of the disease takes unexpected turns. It could also be that the time horizon of a year is not appropriate to all groups. It is not for example clear what is the appropriate time horizon for children, though experts agree that it is not the same as in adults.

Furthermore, little is known about what impact recognition of the end of life by the care professional has on the quality of care provided. Are patients indeed transferred to primary care providers at this point – if appropriate – and are things then discussed with patients and their families? The aim of this programme is to build upon the surprise question approach, to develop another method to use alongside it or to replace it, to guarantee that people are informed in time when they are entering the final phase of life. It is also expected that use of the surprise question or a variation on it might lead to more frequent and more appropriate transfer from secondary to primary care.

Informing patients and their families about the situation is an important aspect of awareness and culture. Given the large degree of overlap with the theme of patient participation and support, the method of informing patients and families is explored further in section 3.4.

**Goals and programming 2015-2016**

The goals adopted for this theme with the aim of improving palliative care by 2020 are:  

1. Public awareness of palliative care to be enhanced and it should become normal to consider the end of life.
2. Awareness of palliative care among care providers to be enhanced and it should become normal to consider the question of whether treatment should be continued.

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8 The goals are a more detailed version of the broad goals and principles set out in the Letter to the House of 11 December 2013, with additional information from the expert meetings organised by ZonMw. These broad goals have not yet been finalised and will be adopted this spring by the steering group established by ZonMw.
Not all topics described in this section can be taken up immediately in the programme. The following topics will have priority in 2015-2016, based partly on the two goals mentioned above:

- All care providers involved in palliative care should have a clear and workable definition of palliative care, with specific details applying to special groups, and taking into account the diversity in the progression of diseases.
- There should be an increase in knowledge of how people regard and perceive the palliative phase, with a particular focus on special groups.
- All relevant training courses should cover the concept of palliative care and the diverse perceptions of it. Training should focus on communication techniques and on-the-job training as well as transferring knowledge.
- Professionals should have a tool, the ‘surprise question’ (adapted if necessary) or another form of assistance to help them recognise the point at which the end of life becomes imminent. This tool will have to be adapted to suit certain diseases and special groups.
- We should have an idea of the implications of recognising the point at which the end of life becomes imminent for the provision of information to the patient and their family and for transfer from secondary to primary care.

The first two require development and application of knowledge concerning the concept and perception of palliative care. The third involves incorporating this knowledge into training. The last two topics will require research, performed in interaction with practitioners, to find usable methods for identifying points of recognition that lead to improvements in decision-making and action. Given that the surprise question is already used, it is important that past experience of this method be considered in this research.

### 3.2 Organisation and continuity of care

Palliative care is a complex affair. Patients generally have multiple problems requiring a range of care providers, relatives and volunteers. These carers, including the general practitioner, home care service, specialist and the family all take on certain tasks, some more than others. The division of tasks among care providers, family and volunteers is different in every case and also changes during the disease process. The GP may for instance play an increasingly prominent role as the end of life approaches. Volunteers may be called upon
more in order to relieve the burden on informal carers. It might be that the patient is receiving palliative treatment in a large academic hospital but would prefer to continue this in a regional hospital closer to home. In practice it has been found that it is not always possible to provide such complex care 24 hours a day, seven days a week (Palliative Care Platform White Paper, 2011).

In good palliative care, all care providers operate on the basis of the needs and wishes of the patient in all four dimensions. This requires the patient to be actively involved in the care process and how it is arranged. Section 3.4, ‘patient participation and support’, considers how patients, including special groups, can be involved. This section assumes that one care provider takes responsibility for coordination, and this is indeed one of the NPPZ goals for 2020. This does not yet happen automatically, and targeted efforts will be required to ensure that, in principle, care is coordinated by a single care provider. Given the general practitioner’s role in the care process, this task should preferably fall to the GP (NHG position paper, 2009).

In the Netherlands, it is regarded as important that people have the option of dying at home. Among the general public, 73% regard the home as the best place for people in the palliative phase (Van den Acker, Luijkx and Wersch, 2005). To make this possible, all generalist care providers must be capable of providing palliative care, if necessary with the support of specialists. The principle, as set out in the Palliative Care Platform White Paper, that palliative care is primarily generalist care, means that generalists require a high level of expertise. To ensure they attain the required level of expertise, palliative care must become a standard part of basic training and refresher training. This topic touches upon the previous theme of awareness and culture. Collaboration is sometimes less than perfect because care providers do not identify and recognise the palliative phase in the same way, and so sometimes fail to realise that it has commenced. The proportion of ‘unconsciously incompetent’ care providers giving end-of-life care is probably quite high (KWF, 2013). The goal of this programme is for everyone to have a good basic knowledge of palliative care by 2020. One means of achieving this is to ensure that palliative care becomes part of the training of generalists, giving them the opportunity to acquire skills or to call in specialist help when they become ‘consciously incompetent’. The programme hopes in this way to enable more people to die at home.

In practice, it is not always clear who will take on what tasks, or is able to do so. Clear allocation of tasks and collaboration between generalists and specialists, plus national
agreements on this matter, are needed to guarantee 24-hour availability and efficient handovers. The NPPZ wants to ensure that by 2020 there are national agreements about the allocation of tasks and collaboration between generalists and specialists. Experiences with the trial implementation and further development of the Palliative Care Module will play an important role in this.\(^9\)

Another problem in the allocation of tasks is the large supply of residential care providers, including hospitals, hospices, nursing homes and care homes. This sometimes makes it unclear who does what. As a result, regional coverage is not always guaranteed, a situation that will have to improve over the coming years.

It is not always clear to care organisations like nursing homes and institutions for people with learning disabilities how end-of-life care can best be organised. Basic principles of good care include the fact that it should be arranged as close to home as possible and tie in as well as possible with the needs of the patient in all four dimensions. This requires contact with and input from a range of disciplines, the welfare sector, care services for the elderly and after-care. Teams of consultants also play an important role as they can offer their expertise at just the right moment, allowing regular care to proceed. There is no format that care institutions can use to make good palliative care arrangements. After all, such arrangements depend on the institution’s vision and objectives, as well as on the facilities available. This programme does not expect that a single ideal care structure will be developed. However, it does assume that workable forms of organisation will be sought, leading to a set of examples of best practice. These examples should then serve to inspire other institutions.

Palliative care is multidisciplinary and thus involves many handover points. In practice, care does not join up as well as it should and handovers are not as systematic as they should be (NFU, 2013). This applies to handovers between primary and secondary care, and also between GPs, nurses and other local care providers. To address this problem, the concept of the Palliative Home Care Group (PaTZ) has been developed and implemented, on the initiative of a non-profit organisation set up specially for the purpose (Stichting PaTZ), in collaboration with GP association NHG, nursing association V&VN, the palliative care networks, Amsterdam ROS primary care and IKNL. In a PaTZ GPs and district nurses together look at cases in the region where patients require palliative care and, along with external experts, put together a palliative care consultation team and care plan. Research

\(^9\) Palliative Care Module 1.0 (CBO, Oct 2013)
has shown that the PaTZ concept is effective (Van der Plas, 2014). The programme is therefore keen to encourage the establishment of more PaTZ groups.

Another way of coordinating care is the end-of-life care pathway. This is a quality assurance tool that can be used to carefully tailor end-of-life care to the needs and wishes of patients and their families. It describes the care objectives in the final days of life and the multidisciplinary collaboration needed to achieve them. The end-of-life care pathway comprises a care dossier, a checklist and an evaluation tool, and is already used at a number of hospices. Practitioners are aware of and value these and similar methods of collaboration, but point out that they are still too limited in terms of their scale and implementation. Projects that further develop and evaluate these practices, including adapting them for special groups, with a view to introducing them on a national scale, would be highly suited to this programme.

The field needs quality assurance tools: minimum sets of indicators for monitoring care handovers and improving them where necessary. Compiling such a dataset will require research into relevant and distinguishing indicators, into methods for testing whether the criteria are actually met in practice – preferably with the use of IT – and into ways of informing practitioners as quickly as possible if they are failing to meet the criteria.

Goals and programming
The goals adopted for this theme with the aim of improving palliative care by 2020 are:

1. More people able to die at the place of their choosing (generally at home) than in 2014
2. Care arranged as close to home as possible, and primary and secondary care to be more joined up
3. Palliative care to be part of regular healthcare provision, and to be better coordinated with care services for the elderly and the welfare sector, for example
4. Specialist and multidisciplinary knowledge to be made available quickly, with more consideration of the social and spiritual dimensions during the palliative phase

This theme is wide-ranging and requires prioritisation. The following topics will be tackled first in 2015-2016:

- During the course of the programme pilot projects will be conducted to establish a clear method of allocating tasks to generalists and specialists in order to guarantee 24-hour accessibility and effective and efficient handovers among and
between generalists and specialists. National agreements can then be made on the basis of the findings.

- In 2016 an accessible document should be available describing best practice in the organisation of palliative care by care institutions. Further examples will be added during the course of the programme.
- By 2016 a start should be made on the development of a workable national quality assurance tool consisting of a minimum dataset that allows handovers and the continuity of care to be evaluated and improved if necessary. This will then be further developed and implemented.

This theme is ideal for transition experiments, for example to devise and test handover and task allocation arrangements. Such experiments also allow for exploration of the best conditions for enabling care institutions to organise palliative care.

The training sector will have the specific task of developing the expertise of generalists to such an extent that they are all capable of applying a palliative approach. This will require evaluation of the current competence profiles used in each discipline, and the addition of new elements if necessary. It will also require forms of training in which on-the-job training is regarded as normal practice.

### 3.3 Care innovations and standards

In palliative care, innovations concern ways of preventing and relieving pain, early recognition and careful assessment and treatment of pain, and other problems of a physical, psychological, social or spiritual nature.

Symptoms commonly referred to as having a negative impact on quality of life are pain, fatigue, respiratory distress, lack of appetite, anxiety and feelings of depression. Past and current research has focused on ways of identifying and treating these symptoms as well as possible. Interventions generally involve medication, and also radiotherapy and behavioural interventions, for example. Less research has been devoted to interventions in the psychological, social and spiritual dimensions, and any results are less accessible. There has been little research on the spiritual dimension, in particular, and palliative care still involves a lot of improvisation in this respect (Agora, 2009; Puchalski CM, Vitillo R, Hull SK, Reller N, 2014). This has led to an inability among care providers to provide or call in adequate support in these areas. Palliative care will promote the development of interventions
focused on the psychological, social and spiritual domains in order to further improve standards of palliative care. The programme wants to ensure that the supply of support in these areas is regarded as adequate by patients and informal carers.

Pain management will also be a key focus of this programme. The goal is that, by 2020 fewer patients should suffer unnecessary pain or distress, according to reports from patients themselves and from informal carers, than in 2015. Particular attention is required for pain and symptom management in children. There is ground to be made up with this particular group, to ensure that, in the opinion of professionals, the number of interventions for pain and symptom management in children is increased to an acceptable level.

Early recognition of problems is another point requiring attention. Validated tools for this purpose include the Utrecht Symptom Diary, the Delirium Observation Screening Scale and the Distress Thermometer for psychosocial problems. It is proposed that new instruments be developed and widely implemented once their effectiveness has been proven. Benefit could be derived from the further development and use of these tools.

Proven effectiveness is an important criterion for the implementation of care innovations. Effectiveness is often expected to have been proven by means of randomised controlled trials (RCTs). Although this is still the most robust method, it is not always feasible or desirable. For example, in the case of an intervention intended for special groups, it is not always possible to find enough respondents in an acceptable period of time. This programme wishes to see all effectiveness studies present supporting arguments demonstrating that the chosen design has provided appropriate evidence. The design itself will depend on the study.

Fewer interventions are available for special groups, partly because it is difficult to develop valid interventions for them. We have already referred to pain management in children. Ground also needs to be made up in the development and application of interventions in all four domains for other special groups. Sometimes existing interventions can be used, provided they are adapted to the special needs of the group. In other cases, group-specific interventions will need to be developed. We would point out that care providers can draw on each others’ expertise when adapting interventions for special groups. For example, interventions for people with learning disabilities might include elements that are also applicable to people with dementia.
Ideally, interventions of proven effectiveness will be included in guidelines, introduced through training modules and implementation procedures, and then monitored to establish how adequately the guidelines are being applied. It is not currently clear whether enough innovations have been incorporated into guidelines and subsequently applied. There are probably also many examples of best practice that are applied locally, whose effectiveness has not been further investigated. This is a shame, because these examples could be implemented on a broader basis if they proved effective. In this programme, we want to ensure that examples of best practice are implemented, and evaluations or effect studies performed. We will also endeavour to ensure that interventions of proven effectiveness are applied on a large scale. Conversely, any interventions that are found to be ineffective will be discontinued.

Finally, the use of technology can accelerate, simplify and improve the application of care innovations. Technological research – on domotics and IT for communications, for example – is taking off in a big way. As in other care domains, palliative care currently makes insufficient use of these technologies. The problems lie not so much in the development of IT applications, but in the use of and transparency concerning those applications. This issue will require multidisciplinary research to coordinate technological potential and user objectives.

Goals and programming 2015-2016

The goals adopted for this theme with the aim of improving palliative care by 2020 are:

1. Standards of palliative care to have improved
2. Everyone working in care to have a good basic knowledge of palliative care (including the social and spiritual dimensions)
3. Fewer people to suffer unnecessary pain and respiratory distress as they die
4. Knowledge of and organisation of palliative care for special groups (children, mental health service patients, people with learning disabilities, people with dementia, homeless people) to have improved

The theme of care innovations and standards includes many issues and a lot of potential for improvement. The following topics will be given priority:

- Palliative care should be part of ‘generalist’ basic training and refresher training.
- There should, in the view of patients and informal carers, be an adequate supply of interventions targeting the social and spiritual domain.
- Palliative care for children should have caught up in terms of symptom and pain management to the extent that in the opinion of professionals the supply has multiplied.
- More interventions in all four domains available for special groups.
- Examples of best practice should be implemented, where necessary accompanied by evaluations or effect studies, and incorporated into training courses.

This theme encompasses the broad spectrum of development, implementation, evaluation and effect studies, with a focus on implementation. The idea is for a large number of interventions to be put into practice by the end of the programme, and be included in training courses.

Training projects, such as practical initiatives guiding the introduction and implementation of guidelines, are also suitable for this theme.

### 3.4 Patient participation and support

Several references have been made above to the theme of ‘patient participation and support’. Patient participation is of course a part of all themes. However, to ensure it receives the attention it deserves, it has also been included as a theme in its own right.

With reference to awareness and culture we indicated how important it is that palliative care and the end of life become general subjects of discussion for everyone. Only if someone knows properly what is involved, and how people view it, can he or she form their own opinion. Both patients and their families must be encouraged and helped to think about their wishes concerning the end of life in good time, possibly even before the final phase of life, and to discuss it with their friends and relatives and with their care providers.

It is important to find out what precisely people who are in the final phase of life and their families need so that care – including after-care – can be arranged in a way that caters for their needs and wishes as well as possible. It is important that people are well-informed. However, it is not entirely clear what information people need and how it can best be provided. This applies in particular to special groups. In the case of people from ethnic minorities, it might be that the information needs to be translated and adapted to their customs. For people with dementia or a learning disability, written information may not be the
ideal form, and better means of communication will have to be devised. In the case of homeless people, the problem is how to disseminate the information. The aim of this programme is to develop accessible information. It will not be possible to provide enough understandable information for everyone, but the programme will at any rate aim to develop such information for special groups too.

This programme will work on the assumption that patients retain as much control as possible over the process and particulars of the care they receive. Care that is designed to maximise their wellbeing in all four dimensions. Experience has shown that patients can best retain control if they manage things in collaboration with their primary care provider. This brings us to the frequently mentioned concept of shared decision-making. It is not clear how best to arrange shared decision-making. It might be that the patient requires extra support in this, using decision models, for example. The programme will aim to develop methods to help care providers put shared decision-making into practice, with the intention of increasing the number of patients and relatives who feel they are seriously involved in the process and the particulars of care in the final phase of life.

This assumes that the patient is willing and able to take a role in shared decision-making. However, this is not so for everyone, and cannot simply be assumed to be the case with special groups. The implications of this for the care provided and those concerned are not clear. This raises questions requiring new knowledge, such as ‘how can the patient be as closely involved as possible?’ and ‘to what extent do the family feel overburdened by responsibility, and how can their load be lightened?’. The goal of this programme is to answer such questions. Other issues which need to be addressed in this connection include the fact that some homeless people avoid care and that children and people with dementia (and sometimes also mental health service patients) cannot take responsibility themselves. Those caring for people with a learning disability sometimes find themselves involved in decisions concerning care, and with ethnic minority patients the language barrier can be a problem.

One method that can be used to support shared decision-making is the advance care planning (ACP) model. The ACP method is a tool that the primary care provider can use to present important issues and choices to the patient and the family, and to discuss them, particularly when the end of life is expected to occur within a year. National pilot studies using the ACP method on a small scale and evaluating it in practice are currently underway. The goal of this programme is to further develop the ACP method over the coming years and
to implement it on a large scale if it proves effective. Effectiveness in this context means the degree to which the method leads to shared decision-making and to better reflection of the needs and wishes of patients.

Relatives often take on a considerable proportion of the care burden. Overload of informal carers is a significant and much-discussed problem, which can lead to crisis situations, and may even necessitate hospitalisation of the patient. The risk of overload is possibly even greater when it comes to special groups, because relatives have an even greater sense of responsibility. More knowledge and use of identification methods and ways of preventing and/or reducing overload are needed. Relatives will also need after-care following the death of the patient.

Finally, this theme also encompasses the question of how best to involve patients in research projects. In other words, not thinking about patients, but with patients. They can be involved in many different ways, in the formulation of appropriate research questions, for example, or in assessing the effectiveness of innovations or helping to develop the training curriculum.

**Goals and programming 2015-2016**

The goals adopted for this theme with the aim of improving palliative care by 2020 are:

1. The needs and wishes of people in the final phase of life and their families are to be the key focus. People in the final phase of life, including special groups, to be more involved as a partner in palliative treatment
2. Informal carers to suffer overload less frequently
3. Deployment of trained volunteers in the final phase of life to be possible in all places where people spend their final weeks

These issues cannot all be tackled simultaneously. The following topics will be given priority:

- Accessible information on end-of-life issues should be freely available to the general public. Specially tailored information should be available for special groups.
- Care providers should have methods to help them put shared decision-making into practice.
- During the programme, knowledge of shared decision-making for special groups, whereby families have a large share in decision-making, should be enhanced.
- The ACP method should be further developed and evaluated during the programme, and then implemented if it proves effective.
- Knowledge of the identification, prevention and reduction of overload in informal carers and of care after death should be increased by this programme.
- Patients and their families should be involved in assessing and implementing research, training and practical projects.

The first five topics require knowledge development. Practically-oriented research projects to further develop and evaluate best practice and current pilot projects concerning shared decision-making and ACP would also be a possibility.

The knowledge developed must be incorporated into training courses. This will include knowledge and understanding of the meaning of palliative care and the end of life, and the acquisition of skills for communicating with patients (and informal carers), to ensure their needs and wishes are respected and taken as the basis for care provision.

The sixth topic constitutes a strong appeal to involve patients and their families in future projects. It should however be noted that this is a vulnerable group and careful consideration must therefore be given to the question of what they can justifiably be asked to do. Involving patients and their families in such a way that maximum account is taken of their perspective with minimum effort on their part will require creativity.
4. Management and organisation

4.1 Phasing of measures to tackle problem areas

It will not be possible to tackle all problem areas at the same time during the programme. Nor will we be able to make equally large improvements in all areas. In some cases there is reason to tackle one thing before something else can be achieved. For instance, research – which can be time-consuming – generally precedes implementation. The logical course of action is thus to flesh out the programme in phases. We have therefore opted to tackle the points for improvement in order of urgency, over three periods: 2015-2016, 2017-2018 and 2019-2020. Every two years the ZonMw committee will adapt its focus if necessary, based on the projects already awarded grants and completed, monitoring information and consultations with the field. NIVEL’s research report on the Palliative Care Improvement Programme will be issued in autumn 2016, and this might give reason to adjust the priorities in 2017-2018. A research/outcome measurement is planned to allow the results of the programme to be determined and any necessary adjustments to be made. This measurement should preferably be based on existing indicators that measure the progress of both the Palliative care programme and the goals of the NPPZ, and monitor improvement processes.

The indicators will be agreed with the consortia and experts on palliative care indicators. An evaluation will be performed after the programme is complete.

4.2 Activities in 2015

The programme will start by filling in the details of the current programming. Experts will be asked to assess the latest situation as regards the topics in this programme, to identify what activities are currently taking place in practice, research and training, and what knowledge is already available. A baseline measurement will be commissioned for the evaluation of the programme in 2021, which will also take account of the evaluation of the Palliative Care Improvement Programme and the objectives of the broader NPPZ programme. This will be performed in combination. Calls for proposals may be issued on the basis of the study of current practice. Where possible, research will comply with the rules concerning open data access (http://wqd.nl/RacPf ).
None of the four themes will be prioritised in the 2015 call, as grant applications may involve more than one theme. The 2015 call will be opened in March. In 2015 grants will be awarded for the establishment of regional partnerships and a knowledge synthesis will be commissioned. The aim is to award the first grants and have the first projects commence in 2015. The final call for the Palliative Care Improvement Programme will also be issued in 2015.

4.3 ZonMw programme committee

The ZonMw board has established an independent programme committee for the Palliative care programme. The committee consists of a chair, eleven members and an observer from the Ministry of Health, Welfare and Sport. Committee members have been appointed in a personal capacity, and do not therefore represent an organisation. When putting the committee together ZonMw looked for members with knowledge of and from universities and other knowledge institutions, and with a broad view of research, training and practice. Knowledge of primary care, hospices, nursing homes and hospitals and patient associations was also considered. The committee members are required to comply with the Conflict of Interest Code (ZonMw, October 2010).

The tasks of the committee have been defined as follows:

- To advise on the programme proposal
- To ensure further prioritisation within themes in each call. The committee may call on the palliative care core group and regional partnerships for advice in this connection
- To take care of programming, assessment of grant applications and definition of priorities
- To contribute to communication

Separate sub-committees or working groups linked to the programme committee will be set up as necessary for training and for implementation. The committee of the ongoing Palliative Care Improvement Programme (VPZ) will operate as a sub-committee until 2016, with two members of the programme committee also participating in the VPZ sub-committee.

The ZonMw board is responsible for adopting the programme proposal for the approval of the Ministry of Health, Welfare and Sport, and for establishing the programme committee.
4.4 Procedure for awarding grants

ZonMw uses standard procedures for the submission and assessment of project proposals. These procedures can be found in the booklet ‘ZonMw procedures’ and are also described in a film on the website. A call will issued each year for projects focused to a greater or lesser degree on research, implementation and education. Calls will either be ‘top-down’ or ‘bottom-up’, at the discretion of the committee. They will range from small projects (some of them implementation projects) to major lines of research designed to deepen knowledge.

Top-down
Contracting projects out to selected parties or awarding a contract to a single ‘preferred partner’ are both forms of top-down commissioning. A targeted commission is a way of responding quickly to a topical issue, allowing ZonMw to retain control. Extra consideration must however be given to the rules concerning VAT and European tendering. Commissions can also be awarded for a knowledge synthesis or an overview of the current state of knowledge.

Bottom-up
In an open or ongoing call, ZonMw receives applications from parties wishing to propose a project in response to the priorities set out in the call. ZonMw defines the framework, and assesses and prioritises applications. This can generate a lot of new ideas.

Assessment
In accordance with the standard procedure, applications are assessed for relevance and quality, plus an extra test of relevance from the patient’s perspective. Research proposals will receive an extra assessment for practical usefulness; practice and implementation proposals will undergo an extra assessment to ascertain whether they include good evaluation and monitoring. Patient panels will perform these extra assessments. The panels will be asked for advice during the assessment of project ideas and grant applications. Their advice will focus on three questions: whether patients were sufficiently involved in drawing up the application; how the results will benefit patients if the application is successful; and whether patients will be sufficiently involved in the execution of the project. This assessment of relevance will be additional to the assessment of relevance by the committee, which concerns the attainment of programme goals, collaboration and consistency in research, training and practice. If the proposal scores well for relevance, its quality will be assessed by
independent reviewers. Patient panels will again be consulted for the assessment of progress reports and final reports.

Adjustment
Representatives of research, training, practice and patients will be invited to give input every two years. The programme committee will adopt a policy for prioritisation/reprioritisation applying for two years. This has already occurred for 2015-2016, and will be followed at the end of 2016 by an update for 2017-2018 and another at the end of 2018 for 2019-2020. ZonMw will issue annual calls, possibly based on the recommendations of the palliative care core group and representatives of national parties involved in palliative care, taking care to ensure consistency between calls.

Communication and implementation plan
A communication and implementation plan will be drawn up in 2015 in collaboration with Agora, under the responsibility of ZonMw. The outline communication strategy will connect with the goals of the Palliative care programme, setting out a framework for 2014-2020. A plan of action for communication will be drawn up each year and implemented by ZonMw and Agora in collaboration with actors from the field.

The keywords in communication will be collaboration, identification and stimulation. The focus will be on achieving the objective: improving the quality of life of people in the final phase of life and their families, preventing fragmentation and improving standards of palliative care in the Netherlands. This is a shared mission.

The primary goal of communication by ZonMw will focus on highlighting the activities and projects in the programme:

1. What kinds of projects have been awarded grants?
2. What progress has been made with these projects?
3. What are the results of these projects, in terms both of process (problem areas and solutions) and of achieving the predefined goals?
4. What contribution have these projects made to improvements in the standard of palliative care?
5. How can the knowledge and skills resulting from the projects best be disseminated among target groups?
6. How can we stimulate the actual use of this knowledge?
Each project may have specific communication goals, some of which will be a response to topical issues. The primary (and probably also the secondary) target group will need to be given information on the programme, the projects and the results. Results will be shared and disseminated on a regular basis.

It is however not only a matter of disseminating information and knowledge. Besides transferring knowledge, others in the field must also be inspired to adapt their attitude and behaviour to achieve improvements in the standard of palliative care. It is important that the knowledge developed be used for the benefit of people in the final phase of life and their families.
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## Timetable

### 2014/2015: preparations

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>June</td>
<td>Outline</td>
</tr>
<tr>
<td>September - November</td>
<td>Expert meetings</td>
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<tr>
<td>November - December</td>
<td>Establishment of programme committee</td>
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<tr>
<td>November – January 2015</td>
<td>Launch of regional partnerships / consortia</td>
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<tr>
<td>December</td>
<td>Draft programme document completed</td>
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<tr>
<td>February – March 2014</td>
<td>Knowledge synthesis</td>
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### 2015 onwards

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>January</td>
<td>Programme committee meetings, max. 4 times a year</td>
</tr>
<tr>
<td>February</td>
<td>VPZ sub-committee meetings, max 3 times a year to 2016</td>
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<tr>
<td>February</td>
<td>Annual presentation of key figures and trends from last call (from 2016)</td>
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<tr>
<td>March - April</td>
<td>Final call for Palliative Care Improvement Programme (once only, in 2015)</td>
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<tr>
<td>March - April</td>
<td>Workshop on writing <em>Palliation</em> grant proposals at approx. 3 locations in NL</td>
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<tr>
<td>March - April</td>
<td>Annual call for proposals for <em>Palliation</em></td>
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<tr>
<td>June</td>
<td>Training meeting (once only)</td>
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<tr>
<td>September</td>
<td>Biennial updates (2016 and 2018)</td>
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<tr>
<td>October</td>
<td>Presentation of key figures and trends from VPZ calls in 2015 (once only); final report in 2016.</td>
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<tr>
<td>November</td>
<td>Biennial contributions to National Palliative Care Conference (in 2016, 2018, 2020)</td>
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<tr>
<td>Spring and autumn</td>
<td>Project leaders’ meeting, twice a year from 2016</td>
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<tr>
<td>December</td>
<td>Completion of VPZ programme in 2016 (once only)</td>
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