Healthcare
Fact Check

BertelsmannStiftung

SPOTLIGHT HEALTHCARE 10 | 2015
Data, analysis, perspectives

Palliative care

Available services do not (yet) meet patient needs – Expansion requires clear regulatory strategy

- Most Germans would prefer to die at home, but nearly one in two dies in hospital
- Far fewer persons die in hospital in Baden-Wuerttemberg than in North Rhine-Westphalia or Berlin
- Local care structures have a significant influence on whether or not patients die in hospital
- Only one in three patients receives adequate palliative care at the end of his life
- Palliative care is received mainly by patients suffering from cancer
- Outpatient care most closely meets the preferences of the population and should therefore be expanded

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Seriously ill and dying persons need comfort, care, and support. Most people would like to spend their last days in a trusted and familiar environment. But nearly half of Germany's population dies in hospital and only one in five at home. According to the German Society for Palliative Medicine, about 90 percent of the dying need special care. But many either receive this care very late or not at all.

Healthcare Fact Check by Bertelsmann Stiftung has carried out the first systematic investigation into the actual state of palliative care in Germany. Here, considerable regional variations are in evidence – not only amongst the 16 federal states, but also amongst the 402 urban and rural districts.

Most Germans would prefer to die at home, but nearly one person in two dies in hospital

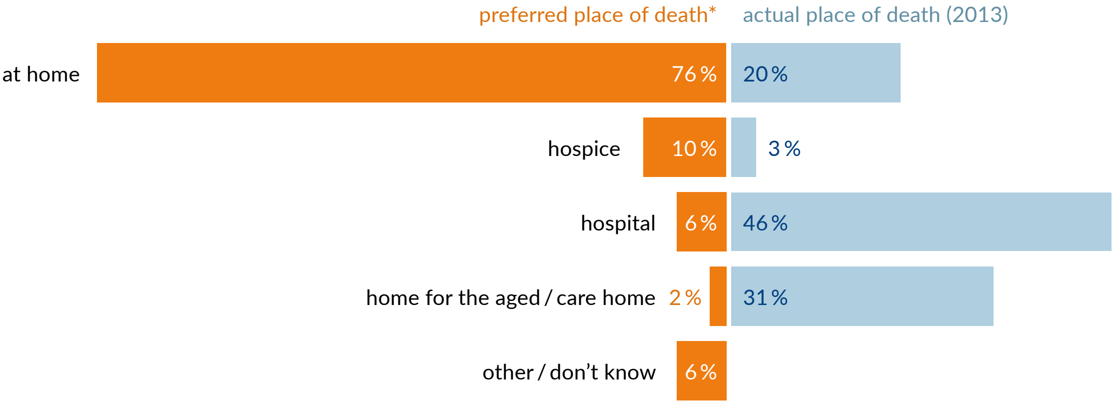
According to a representative survey carried out for Healthcare Fact Check, 76 percent of German citizens would prefer to die at home, ten percent would choose a hospice, two percent a care home, and six percent would opt for a hospital (Fig. 1). But in practice, a hospital is the place where almost half of the over 64s in Germany end their days. Also, more and more patients die in care homes, often after only a brief stay there.

A key criterion determining the quality of care at the end of a person's life is the fulfilment of the patient's wish to spend his final days in the comfort of his own home. And the new hospice and palliative care law picks up this notion: the aim is to strengthen hospice and palliative care so that anyone, wherever he spends the final phase of his life, can receive the same quality of care and attention at the end.

The importance of hospitals as a place to die varies from region to region

Healthcare Fact Check has conducted the first detailed study into the importance of hospitals as a place to die and has detected considerable regional variations: Whereas in Baden-Wuerttemberg only 41 percent and in Schleswig-Holstein 42 percent of the elderly die in hospitals, in North Rhine-Westphalia and Berlin, this figure is 49 percent. If the lower hospital death rate observed in Baden-Württemberg were achieved throughout Germany, 37,000 more people could spend their last days in the familiar surroundings of their own home. At district level, the importance of hospitals as a

Preferred and actual place of death



* n=1,010, survey period: October 2015

Figure 1 | Sources: TNS Emnid, Prof. Wolfgang M. George (partly estimates), Healthcare Fact Check 2015 | BertelsmannStiftung

Hospice and palliative care

The central goal of hospice and palliative care is to maintain or improve the quality of life of patients with serious or life-threatening conditions and to help these patients and their relatives cope with the burdens of a disease. Hospice and palliative care aim to alleviate suffering, reduce physical pain and provide psychosocial and spiritual support. This kind of assistance and support is to enable more patients to die in their familiar surroundings. Especially the hospice movement has promoted the considerable progress in the care and support of terminally ill patients. It has helped to raise public awareness about issues of death and dying as part of life and to bring more attention to the psychosocial needs of seriously ill patients and their relatives. A well-coordinated cooperation between health, nursing and hospice care services also helps to avoid unnecessary medication in the last phase of life.

place to die shows even greater variations: In the district of Freudenstadt/Baden-Wuerttemberg, only 33 percent of persons aged 64 and older die in hospital, whereas this figure is 60 percent in Landshut/Bavaria. In about 30 of the 402 German districts, the percentage of older people who die in hospital has been below 39 percent for a number of years; in more than 60 districts, on the other hand, it is over 50 percent (Fig. 2).

Number of patients who died in hospital as a percentage of all deceased patients aged 65 years and over, 2011 to 2013

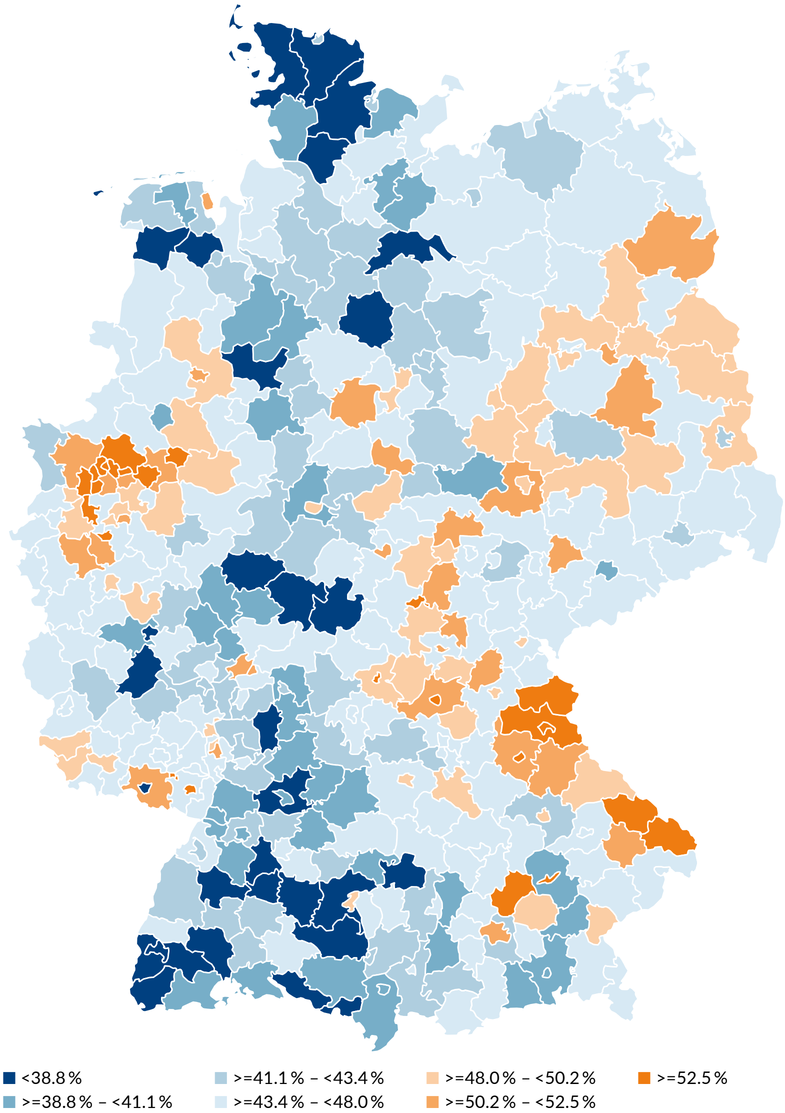


Figure 2
Source: Destatis, calculation IGES, Healthcare Fact Check

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Care structures have a major effect on where people die

The federal states, regional associations of statutory health insurance physicians, and main health insurance funds set very different priorities in outpatient and inpatient care at the end of a person's life. For example, the number of beds in hospices per million inhabitants is 12 in Bavaria and 56 in Berlin and the number of beds in palliative wards is 19 in Berlin and 46 in Saarland.

In over a quarter of all urban and rural districts, there are neither hospices nor palliative wards nor any special facilities for outpatient palliative care. For the patients and their relatives, but also for providers of palliative care in these white areas on the care map, this can mean travelling considerable distances – and may affect the decision whether a person dies in hospital or at home.

Furthermore, outpatient hospice services staffed by volunteers and professional teams of specialized outpatient palliative care (spezialisierte ambulante Palliativversorgung – SAPV) providers vary from region to region. In Baden-Wuerttemberg, there are 28 outpatient hospice services per million inhabitants, about three times as many as in Brandenburg, Berlin and Hamburg. In Lower Saxony and

Percentage of hospital deaths, number of days spent in hospital and number of palliative care physicians

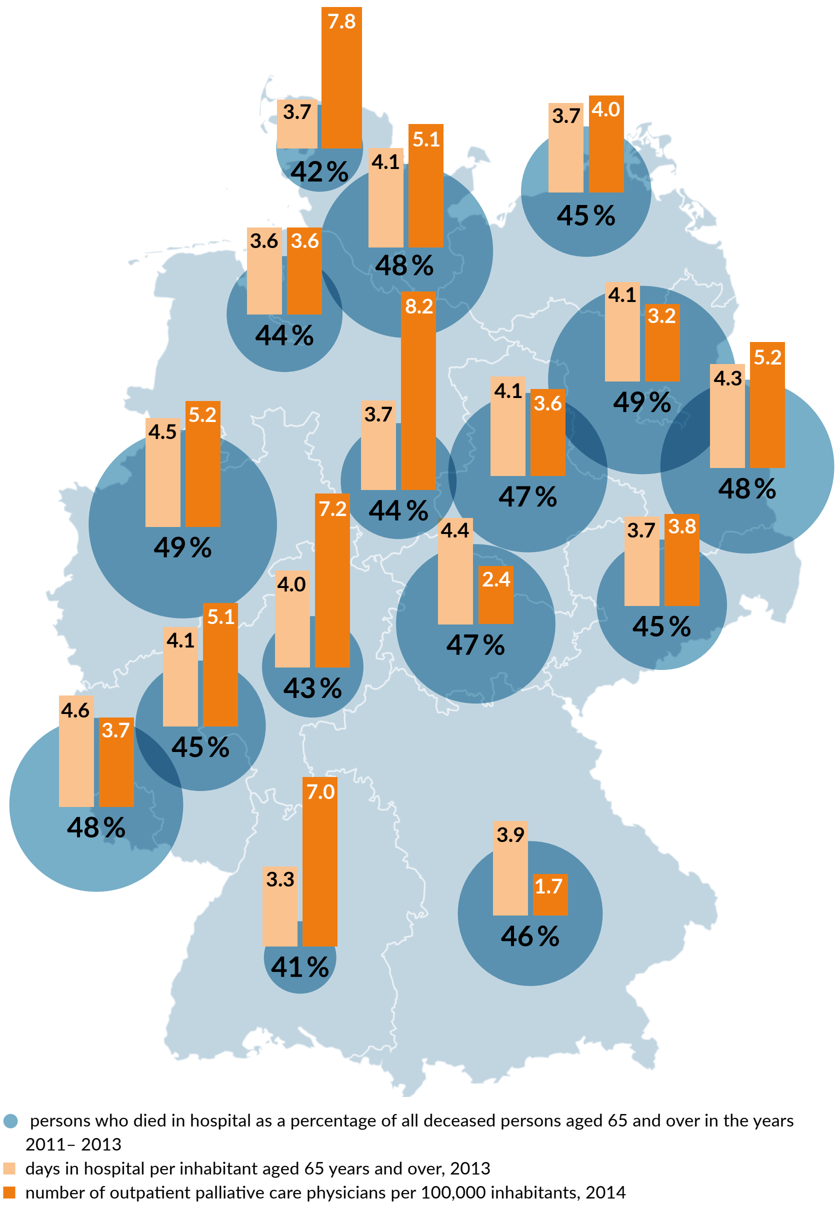

Figure 3 | Source: GBA, Destatis, calculation IGES, own graphics, Healthcare Fact Check 2015

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Saarland there are more than six SAPV teams per million inhabitants, whereas in Rhineland-Palatinate there is statistically less than one SAPV team per million inhabitants.

Outpatient palliative care physicians make a difference

Whether or not a seriously ill person can be cared for at home in the last stages of life also depends on the number of palliative care physicians in a region. The Fact Check indicates a clear correlation: In Baden-Wuerttemberg, Hesse, Lower Saxony and Schleswig-Holstein, where there is a relatively large number of palliative care physicians, the percentage of older persons who die in hospital is especially low (Fig. 3).

According to the Fact Check studies, the fact that Baden-Wuerttemberg has the lowest number nationwide of over 64s who die in hospital (41 percent) is also due to the circumstance that Baden-Wuerttemberg has a far higher number of physicians with additional training in palliative care medicine and more outpatient hospice services than anywhere else. Outpatient care, too, has been considerably strengthened there in recent years through contracts with general practitioners. Hospital planning, on the other hand, has been somewhat restrictive.

Regional variations in hospital admissions and length of stay

One of the factors determining why hospital death rates vary from region to region is the difference in regional hospital capacities, which can be mapped on the basis of days spent in hospital. This means that in regions in which older people are admitted into hospital more frequently and stay in hospital longer, the hospital death rate is also higher (Fig. 3).

A further analysis of health insurer data on care in the last six months of life showed that dying persons spend an average of 18.6 days in hospital during the last six months of their lives. In North Rhine-Westphalia, Berlin, and Bavaria, where the death rates in hospitals are high, this number is almost 20 days as opposed to only 17 days in Baden-Wuerttemberg and 16 days in Schleswig-Holstein. Longer hospital stays may be a consequence of above-average hospital capacities, but they could also be a sign that outpatient palliative care does not meet the need and that the persons concerned have to rely on inpatient care.

30%
receive palliative care

76%
of Germans would prefer
to die at home

90%
need palliative care

37,000
people per year need
not die in hospital

Palliative treatment in hospitals often misses the goal of discharging patients to die at home

It is not only the length of inpatient treatment in the last months of a patient's life that increases the probability of dying in hospital, but also the type of care. Recent years have seen a strong increase in palliative treatment administered in hospitals (Table 1).

A surprising finding of the Fact Check is that the goal of stabilising seriously ill patients to such an extent that they can be discharged to die at home is frequently not reached, because the percentage of elderly people who die in hospital is related to the extent to which hospitals offer specialised palliative treatment. One reason for this could be that many people are admitted to a palliative ward only shortly before they die. Another reason could be that patients and their relatives shy away from allowing the patient to be discharged shortly before the anticipated end of their life, especially if outpatient palliative care is not particularly well developed in the region concerned. At the same time, a lack of outpatient options may be the reason why patients needing palliative care are hospitalized in the first place and then stay there. However, it is not impossible that hospitals in regions marked by strong local competition are expanding palliative wards and building up inpatient palliative treatment as a new business opportunity.

Frequency of palliative care treatments in hospital, 2011–2013

	number of procedures in thousands		
year	2011	2012	2013
comprehensive palliative care treatment in hospital (8-982)*	59.3	51.8	51.9
specialised comprehensive palliative care treatment in hospital (8-98e)*	–	16.1	23.2
total	59.3	67.9	75.1

*OPS code

Table 1 | Source: Destatis, calculation IGES, Healthcare Fact Check 2015

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Only one in three patients receives necessary palliative care

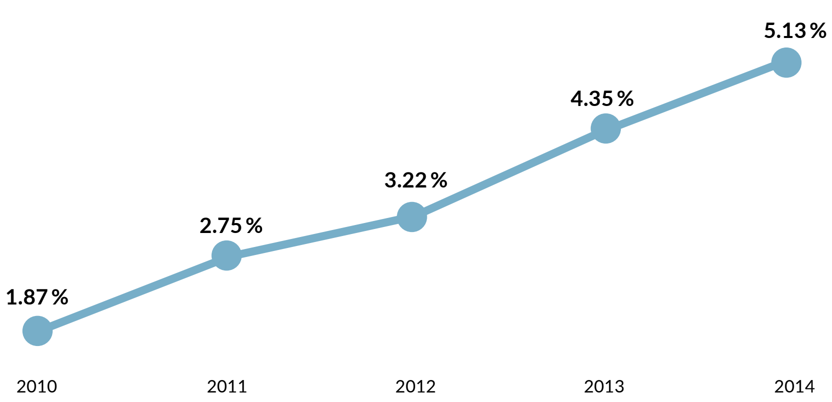
According to the Fact Check studies, only 30 percent of persons who died in 2014 received palliative care. According to the German Society for Palliative Medicine, up to 90 percent of patients need palliative care at the end of their life. This means that only one in three dying persons is receiving the care he needs.

Over 24 percent of patients received general out-patient palliative care (allgemeine ambulante Palliativversorgung - AAPV) at the end of their life. This service, which practice-based physicians have been able to bill separately since October 2013, has been used to varying extents: less than 20 percent of dying persons received this care in Berlin, Brandenburg and Bremen, whereas 28 percent of them did so in Lower Saxony and 33 Percent in Bavaria.

In 2014, already more than five percent of dying patients received the more extensive specialized outpatient palliative care services (SAPV). The overall take-up has steadily increased over the last five years (Fig. 4). However, large regional variations exist once again: Between 2010 and 2014, more than eleven percent of patients received SAPV services in Berlin as opposed to barely two percent in Rhineland-Palatinate. Notably, regions with a relatively high level of prescriptions are not limited to big cities such as Hamburg, Frankfurt, and Munich; they also include rural areas such as East Frisia and Uckermark. On the whole, a clear North/South divide is evident.

> »Curative treatment still dominates at the end of a patient's life. Palliative care and accompanying approaches are often not practised at all or implemented too late«
>
> Prof. Lukas Radbruch,
> Director of the Clinic for Palliative Medicine
> at the University Hospital Bonn

Take-up of SAPV in the last year of life*



*number of deceased patients who had received SAPV as a percentage of all deceased patients, in the last year of life

Figure 4 | Source: own calculations (HRI database) | BertelsmannStiftung

Outpatient palliative care services by medical condition

	AAPV*	SAPV**
cancer	64.9 %	88.3 %
circulatory system disorders	29.2 %	9.3 %
neurological disorders	5.6 %	2.2 %
other	0.3 %	0.2 %
total	100 %	100 %

*2014, **2010 – 2014

Table 2 | Source: own calculations (HRI database) | BertelsmannStiftung

A large number of patients who receive palliative care are cancer patients (Table 2). Cancer patients account for 68 percent of all patients receiving general outpatient palliative care, and 88 percent in the case of specialised care. Patients with other life-threatening conditions such as heart, lung or kidney failure or neurological disorders have so far only rarely had access to palliative care. This may be due to the lack of local capacity or because the physicians and relatives concerned with these diseases do not often enough think of palliative care as a possible form of treatment.

Palliative care often starts too late, which can result in unnecessary treatment

Advanced care planning and beginning palliative care in due time can avoid unnecessary and debilitating treatments in the final stages of a person's life. For example, the Fact Check shows that ten percent of patients who have not received SAPV underwent chemotherapy right into the last month of their life, whereas this figure was only seven percent in the case of cancer patients receiving SAPV.

However, about 40 percent of patients did not receive SAPV services until the last month of their life. Twelve percent of patients did not have palliative care prescribed until the last three days of their life. Many palliative care treatments designed to maintain the quality of life are no longer possible if prescribed at such a late stage.

> »There is an urgent need to strengthen general outpatient palliative care. Otherwise, it threatens to remain a ›roof without walls‹.«
>
> Dr. med. Birgit Weihrauch,
> former Chair of the German Hospice and Palliative Care Association

Patients and relatives prefer palliative care to be administered at home

The Fact Check also studied the nature of what patient-oriented palliative care should provide. Above all, patients and their relatives want reliable, continuous and competent care – to be carried out as much as possible in the comfort of the patient’s own home and adapted to individual needs, which may change during the course of the illness. At this difficult time, they expect their wishes to be treated with respect and without hectic.

The four Fact Check studies show that there is a range of good care services available but that these are mainly taken up separately. There is a need for a “facilitator” to coordinate the various care options. The persons concerned clearly prefer the family doctor to assume this role, since this physician is familiar with the patient’s social environment and is easily accessible. The role of the “facilitator” can, however, also be taken on by practice staff, a nurse or a palliative care service. In order to better accommodate the patient’s wishes, it is therefore crucial to strengthen outpatient care still further.

About this Healthcare Fact Check

The Fact Check is based on four studies:

1. Deaths in hospitals – regional variations and influencing factors (Karsten Zich, IGES Institute)
2. Structures and regional variations in hospice and palliative care (Heiner Melching, German Society for Palliative Medicine)
3. Too much curative care – too little palliative care? Analysis of selected end-of-life treatments (Prof. Lukas Radbruch, University Hospital Bonn)
4. Requirements placed on patient-oriented outpatient palliative care (Prof. Nils Schneider, Hannover Medical School)

The studies are based predominantly on special evaluations by the Federal Statistical Office, data from the hospice and palliative medicine portal of the German Society for Palliative Medicine, and calculations of the German Health Risk Institute (HRI). Because of the lack of quality data in the area of nursing and hospice care, this Healthcare Fact Check focuses mainly on the area of palliative care.

Example of Westphalia-Lippe

Since 2009, a palliative care model has been developed in Westphalia-Lippe that differs from that of other federal states. It dispenses with the strict demarcation between AAPV and SAPV. This makes it easier to adapt care to the changing needs of patients. As a rule, the family doctor is the coordinator of care and remains so even if SAPV becomes necessary. About 80 percent of family doctors in Westphalia-Lippe participate in this palliative care model. They are supported by about 260 palliative care physicians and 100 coordinators. In 2014, about 20 percent of patients were cared for in this way at the end of their life. Of these recipients of palliative care, only 8.7 percent died in hospital.

Services for relatives and patients

For relatives and patients, the Healthcare Fact Check provides a service page in the Internet in cooperation with the “Weisse Liste” – a web portal showing quality data for hospitals and physicians. This page explains the differences between the various palliative care options, provides information about legal entitlements and lists advisory offices. A provider search function enables those affected and their relatives to find out about palliative care services in their area.

weisse-liste.de/palliativ-info
(in German only)


Faktencheck Gesundheit

Palliativversorgung
– Modul 1 –
Sterbeort Krankenhaus – Regionale Unterschiede und Einflussfaktoren

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– Modul 2 –
Strukturen und regionale Unterschiede in der Hospiz- und Palliativversorgung

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Palliativversorgung
– Modul 3 –
Überversorgung kurativ – Unterversorgung palliativ? Analyse ausgewählter Behandlungen am Lebensende

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Download the studies (in German) from faktencheck-palliativversorgung.de

Recommendations for action

With the law to strengthen hospice and palliative care, the federal government aims to further develop hospice culture and palliative care overall. Patient preferences are important to the nature and planning of end-of-life care. As the Fact Check shows, most people would prefer to die in familiar surroundings – at home. However, this desire is often thwarted because there is no outpatient palliative care available. Any expansion of hospice and palliative care should therefore take into account the two principles, “outpatient before inpatient” and “general before specialist”, also because in recent years, it is mainly specialist care that has been expanded.

The following recommendations for action are aimed at government, health insurers and service providers with the objective of better respecting the patients’ wishes at the end of their lives and making palliative care available to anyone who needs it.

Strengthen outpatient care

- Palliative care should be more firmly anchored in standard care. The priority should be on expanding easily accessible services of general palliative care.
- General and specialised palliative care should become more interlinked and better coordinated.
- More training for family doctors so that they can recognise the need for palliative care in connection with all diseases and plan end-of-life care in advance.

Complement inpatient care in a rational way

- Despite the density of care achieved, inpatient hospice and palliative care should be expanded in a targeted and needs-oriented way whilst at the same time safeguarding against the development of inpatient overcapacities.
- Palliative care should be possible in all hospital wards. Palliative care officers and palliative advisory services should support this endeavour.
- Hospitals should help palliative patients to be transferred home. This necessitates good discharge management.

Expand information, advice and networking

- The population must receive better information about what palliative care can achieve and what health insurers pay for.
- Health insurers, physicians and nursing care providers should advise patients and relatives early on about local palliative care options.
- Networking and coordination between the service providers involved in palliative care should be promoted.

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SPOTLIGHT HEALTHCARE is an impulse paper drawn up under the program “Improving Healthcare – Informing Patients” of the Bertelsmann Stiftung. It is published several times a year at irregular intervals and deals with the latest topics and challenges in the healthcare system. The Bertelsmann Stiftung is committed to promoting a healthcare system that is based on the needs of the population. Through its projects, it aims to ensure the provision of consistently needs-related and high-quality health care organized on a sound financial basis. Patients should be supported in their role through understandable and objective information.

As part of the program, the project “Healthcare Fact Check” takes a closer look at a specific healthcare topic several times a year. Our studies uncover regional variations. This means that in some areas resources are being deployed unnecessarily and inappropriately. “Healthcare Fact Check” aims to help limited resources to be used more appropriately and ensure that healthcare services are more closely aligned to the actual needs of patients.

Further Information at faktencheck-gesundheit.de