WHO regional technical briefing: strengthening palliative care in the WHO European Region
Palliative care has been recognized as an integral part of universal health coverage and, along with prevention, promotion, treatment and rehabilitation, as a key strategy for achieving and maintaining population health. The inclusion of universal health coverage in its European priorities for the next five years enables WHO to highlight the need for palliative care and provides the opportunity to support authorities in Member States to develop palliative care as part of public health. Consistent with this commitment to palliative care development, the WHO Regional Office for Europe organized a technical briefing on palliative care. The technical briefing, which was developed in collaboration with experts from a range of organizations and academic institutions with expertise in palliative care, aimed to support and strengthen the development of palliative care in countries of the WHO European Region. This report sets out a summary of presentations at the briefing.
Meeting report

WHO regional technical briefing: strengthening palliative care in the WHO European Region

Virtual meeting hosted by the WHO Regional Office for Europe,
29 November 2021
Background

Palliative care has been recognized as an integral part of universal health coverage and, along with prevention, promotion, treatment and rehabilitation, as a key strategy for achieving and maintaining population health. Palliative care is a crucial part of integrated, people-centred health services at all levels of care and should be available to all who need it regardless of age or diagnosis. The WHO European Region has a rapidly ageing population with an increasing number of people with noncommunicable diseases. It is estimated that 5 million people in the Region need palliative care each year and of these, 65% have no access to palliative care services.

Developing and integrating palliative care requires both a primary health care and a public health approach that maximizes the level and distribution of health and well-being across the whole of society through multisectoral policy and action. This is a part of the WHO European Programme of Work (EPW), which runs from 2020 to 2025. The EPW commenced in 2020, the year when the COVID-19 pandemic impacted on all health services across the European Region. Over the last 18 months, citizens from every country in the Region have been affected by the pandemic and health service capacity has been stretched. During this time, WHO acted swiftly and decisively to deal with the crisis. The pandemic has highlighted the need to ensure that palliative care is available to all who need it. Providing end-of-life care has been challenging throughout the pandemic, and the skills and experience of those working in palliative care have been highlighted.

World Health Assembly resolution WHA67.19 highlights the need to strengthen palliative care through the development of national palliative care policies, access to essential medicines for pain and other symptoms, education and training in palliative care for all health-care staff, and the integration of palliative care services into existing health-care systems in the WHO European Region. The inclusion of universal health coverage in its European priorities for the next five years enables WHO to highlight the need for palliative care and provides the opportunity to support authorities in Member States to ensure that palliative care is developed as part of public health.

Consistent with this commitment to palliative care development, the Regional Office organized a technical briefing on palliative care. The technical briefing was aimed at those responsible for palliative care at national level in Member States’ ministries of health, decision-makers and those responsible for the development of national policy. In addition, WHO country representatives and those active in the development of palliative care in Member States were invited to attend. The technical briefing was developed in collaboration with experts from a range of organizations and academic institutions with expertise in palliative care.

Aim and objectives

The aim was to support and strengthen the development of palliative care in countries of the WHO European Region.

The objectives were to:

- establish key emergent palliative care needs in the Region;
- monitor and identify palliative care service development;
• identify opportunities for strengthening palliative care as an integrated component of health services delivery and as part of universal health coverage;

• establish and support implementation of WHO palliative care tools;

• highlight WHO publications on palliative care, including guidelines on the development and implementation of palliative care, palliative care for children, access to essential medicines for pain and symptom management and the newly published palliative care indicators; and

• review available and emerging research and evidence on models of development, provision and integration of services in palliative care, including financing.

The agenda for the meeting is shown in Annex 1 and the participants are listed in Annex 2.
Satish Mishra, Regional Advisor on Disability, Rehabilitation, Long-term Care and Palliative Care, WHO Regional Office for Europe, opened the technical briefing by explaining that the aim was to support and strengthen the development of palliative care in countries of the WHO European Region. The first part of the briefing would provide an overview of palliative care in the Region and at global level, before four palliative care clinicians and leaders shared their experiences of country-specific development of palliative care.

Dr Natasha Azzopardi Muscat, Director of the Division of Country Health Policies and Systems, WHO Regional Office for Europe, then officially launched the meeting. She stated that palliative care services have been among the most utilized during the COVID-19 pandemic and that strengthening palliative care systems should remain a priority for health policy agendas.

Palliative care should be available at all levels of care for everyone who needs it, but data from the recently published WHO Global Atlas of Palliative Care show that of the nearly 5 million people who die each year in the European Region, only a third have access to palliative care.

In 2014, the World Health Assembly resolution on strengthening palliative care committed to supporting the integration of palliative care in every country’s health system. This has been reinforced in the European Region by the firm commitment in the EPW to leave no one behind. Palliative care should not be an afterthought. The way we care for the most vulnerable is a yardstick of the way our societies function. The three overarching priorities of the EPW – moving towards universal health coverage, protecting people against health emergencies, and ensuring healthy lives and well-being for all at all ages – need to include palliative care as an integral part of their focus. To support this effort, the Regional Office has prioritized palliative care for the coming months and has strengthened its capacity with experts working on palliative care to provide better support to countries.
**Presentations**

**Satish Mishra** summarized recent progress on palliative care in the Region. Palliative care improves the quality of life of patients, families and caregivers who are facing challenges associated with life-threatening illness. Early delivery of palliative care services reduces unnecessary hospital admissions, burdens on health services and socioeconomic costs. Each year an estimated 40 million people in the Region – 78% of whom live in low- and middle-income countries – need palliative care, but only 35% of them will have access to palliative care services.

The Regional Office has been working on a range of initiatives to support Member States, including pursuing closer technical cooperation and support, providing advice to Member States on palliative care policies and services, promoting capacity-building activities and working with the WHO collaborating centres on palliative care in Europe. This support is augmented through the wide provision of WHO technical tools on palliative care.

**Tomas Zapata, Regional Adviser on Health Workforce and Service Delivery, WHO Regional Office for Europe,** spoke about the development of health-care services and the impact on provision of palliative care. Health needs in Europe are changing. Populations are ageing and, coupled with a rise in noncommunicable diseases, this has led to an increase in the number of people with life-limiting conditions requiring palliative care.

Many countries in the Region are not able to respond to the increasing demand for palliative care services. To address this issue, it is essential that services are realigned, with education and planning prioritized to ensure the health workforce has the requisite skills, knowledge and motivation to provide high-quality palliative care and health-care workers are available in the right places and in the right numbers.

The main message of the Global Strategy on Human Resources for Health (Workforce 2030) is that the health workforce is central to health systems. Supporting countries in properly planning and developing the health workforce is critical to achieving universal health coverage. In 2017, the United Nations High-level Commission on Health Employment and Economic Growth stated that investing in health and care workers is a positive move that has high returns to the economy and society. This is an important message to use when advocating for strengthened palliative care services with senior policy-makers and politicians.

It is important to consider the wider health and care workforce, not just traditional health workers like doctors, nurses, midwives and pharmacists, but also those working in the social sector and social workers, whose key roles have been highlighted during the COVID-19 pandemic. This wider health and care workforce also plays a key role in the provision of palliative care services. Palliative care is about professionals – physicians, nurses, paramedics, pharmacists, physiotherapists, support workers – working as a team. They all play an important role in providing a multidisciplinary approach to care.

This year, 2021, is the International Year of Health and Care Workers. This special year has been used to advocate for increased investment to further develop palliative care services in the Region and to protect and value the health workforce. The nature of palliative care can pose psychological and emotional challenges for workers, and it is important to ensure that measures are in place to protect their physical and psychological well-being.
Palliative care services are provided in a wide range of settings, from home to hospital. Evidence shows that most people prefer to have the final stages of their life at home. Meeting this need requires that sufficient primary health care workers are trained to provide home services and that services are in place quickly for more complicated cases.

A patient focus that reflects needs and increasing demands is required to develop health services in Europe, with palliative care services included in local and national policies. This will require adequate investment in financial and human resources. There can be no universal health coverage without palliative care.

Marie-Charlotte Bousseau, WHO headquarters, addressed how palliative care can be improved globally and described some WHO technical reports and ongoing work. She emphasized that palliative care addresses need across disease groups and works on the basis of early identification of need, not just end-of-life care.

The ethical duty to provide palliative care services is clear. Lack of access to palliative care violates the human rights principle of beneficence and non-maleficence and has been identified as an act of torture. All health-care workers have a duty of care to patients until the end of life. National policies must be in place to allow the provision of palliative care across ages and disease groups.

World Health Assembly resolution WHA67.19 focuses on the need to adopt a primary health care approach to strengthening palliative care. The approach should be centred on the needs and expectations of people and integrated at all levels of care, starting at primary care level, to ensure palliative care is part of universal health coverage.

One of the barriers countries sometimes face is limitation on accessing controlled medicines. Domestic laws and national regulations need to be in place to ensure not only safe use of controlled medicines, but also equitable access to them.

Historically, palliative care has been linked to specific programmes such as those for people with cancer. This model now requires some modification. The old model was described as an umbrella with key components on policy, access to drugs and education. A new WHO technical report launched in October 2021 proposes a more complex model of palliative care that is based on a house (Fig. 1).

The aim is to ensure palliative care focuses on people and not specific diseases. It highlights the need to empower people and communities to participate in palliative care from an early stage and identifies the important role of palliative care research in supporting evidence-based practice. This practical tool can be adapted to specific settings to identify current status and challenges. A companion document sets out how the quality-of-care concept can apply to palliative care and provides concrete ideas on how to better organize palliative care services in countries.

WHO has provided guidance to countries over the years, some focused on how to strengthen palliative care services at primary care level and some related to palliative care in the context of humanitarian emergencies, which has been central to advice provided by WHO to countries on the clinical management of people with COVID-19.
New technologies are now being used to strengthen palliative care. A WHO study in different regions showed very clearly that technologies like mobile phone apps can be very useful in facilitating communication between palliative care teams and family caregivers at home.

**Julie Ling, Consultant Technical Officer Palliative Care, WHO Regional Office for Europe**, highlighted some key elements in the development of palliative care provision. She provided a brief history of the development of palliative care in Europe, from the pioneering work of Dame Cicely Saunders in the United Kingdom during the 1960s, through to WHO’s first guidelines on pain in 1982, the formation of the European Association for Palliative Care in 1988, WHO formally recognizing palliative care as a specialty in 1990 and the development of services across many European countries during the 1990s. The European Association for Palliative Care Atlas of Palliative Care in Europe 2019 highlights inequities between and within countries in the European Region, with better access to palliative care services available in western Europe.

Key elements used to measure palliative care include:

- national policy (strategy, funding, standards, representation in ministry of health);
- education (specialization, inclusion in undergraduate programmes, professorships);
- medicines (opioid consumption, access and prescribing);
- service provision (specialist palliative care services and beds, support teams); and
- professional activity (national associations, directories of services and practitioners, published scientific articles).
The inclusion of palliative care in national health policies or having a specific palliative care policy or strategy is significant in the development of palliative care. Funding models vary. The availability of ring-fenced funding for palliative care is important. In many countries, not-for-profit organizations are involved in the provision of palliative care services. It is important that they are included in the development of palliative care strategies and policies.

Education is a key element in the development of palliative care. Inclusion in the undergraduate programmes of nurses, doctors and allied health professionals increases awareness of palliative care needs and improves levels of service delivery. It is also important to ensure that postgraduate-level educational opportunities are available to enable professionals to specialize in palliative care. Academic posts should also be developed in palliative care, including professorships, as they enhance the development of the specialty.

Access to essential medicines for the control of pain and other symptoms is crucial. Despite substantial evidence to support the use of morphine and other opioids for the management of pain and other symptoms, these are not always available. Barriers to access include a lack of legislation, limited knowledge regarding prescribing practice, limited access, restrictive prescribing and prohibitive costs for patients and their families. Out-of-pocket expenditure for patients is a further barrier in some countries. Availability and costs of such drugs and who is able to prescribe them is important.

Access to palliative care in a range of settings is important and includes acute hospitals, hospices, older people’s care settings and children’s hospices, as well as services in the community and in people’s homes. Palliative care puts the patient and the family at the heart of care and most people say they would prefer to die at home. To ensure services are able to provide care in the patient’s location of choice, it is important to invest in workforce and service provision in that setting.

National palliative care associations can advocate for palliative care development and national palliative care service directories enable people to locate services they need.

The WHO Assessing the development of palliative care worldwide: a set of actionable indicators document provides a means for countries to check how their health systems are functioning against internationally agreed indicators and presents support for advocacy for the development of more services and greater funding. It also enables countries of similar size and population to compare their performance.

Julia Downing, Chief Executive Officer, International Children’s Palliative Care Network (ICPCN), provided an update on children’s palliative care and described some of the tools and guidelines the ICPCN has been using in partnership with WHO.

A child is part of a family and should be cared for within the family context, beginning when illness is diagnosed right through to death and bereavement. Around 7% of people who need palliative care globally are children. While the overall percentage might be small, the number of children and families around the world who are affected is large. About 2.8% of the global total of children needing access to palliative care are in the European Region.

The ICPCN estimates that over 21 million children around the world need access to palliative care, with more than 8 million requiring specialist service provision. Work is underway with a team from the Lancet Commission and the WHO Global Atlas to revise these figures, but there is a clear and definite need for access to palliative care for children around the world.
Only an estimated 5–10% of children globally who need palliative care receive it. Access to palliative care services for neonates is even lower. Inequities in access to children's palliative care services are seen in Europe, but mapping carried out by the ICPCN in 2011 and 2019 showed growth in the provision of children's palliative care services across the Region. Despite this, the need to develop these services further and ensure access to suitably trained paediatric palliative care professionals remains. Children's palliative care should have a voice at national and regional levels and all children in Europe who need palliative care should be able to access it.

In Europe and across the globe, even when cure is theoretically possible, it may not be a realistic option. This may be due to the uneven distribution of services, children presenting late with cancers and other potentially curable conditions and the expense to families of accessing care or services that are not available close to the child’s home.

Lack of awareness of the need for palliative care for children and the technical skills and expertise required to provide it need to be addressed. All paediatric nurses and paediatricians should be trained in children's palliative care. People providing palliative care for adults may be nervous about the use of strong analgesics such as opioids, and this anxiety is heightened in paediatric palliative care. Effective training, backed up by solid evidence and the availability of medicines, is required to ensure professionals can manage medication confidently, competently and safely.

The ICPCN has a memorandum of understanding with WHO and is keen to work with WHO across Europe on the development of palliative care for children. ICPCN also works with the Worldwide Hospice and Palliative Care Alliance, the International Association of Hospice and Palliative Care and other regional organizations to support the development of palliative care, specifically for children, and leads advocacy work around palliative care nursing.

ICPCN is part of the Global Initiative for Childhood Cancer and its CureAll Framework, ensuring that children's palliative care is included in the framework, contributing to various documents and materials coming from the initiative, supporting focus countries and working with the nurse specialist group. Palliative care, of course, is not just for children with cancer, but services for children with cancer is a key part of ICPCN’s work.

WHO and ICPCN have worked on guideline development and dissemination, notably the guidelines on the management of chronic pain in children. Work to develop best practice guidelines and other materials is ongoing, as are contributions to e-learning materials and indicators for palliative care.
Country experiences

Martin Loučka, Director, Centre for Palliative Care, presented on palliative care services in Czechia. The Czech Republic Hospice Movement started in 1993 and the first inpatient hospice unit opened in 1995, very much emulating the United Kingdom model of standalone inpatient hospice facilities. The first community hospice care service started in 2004 and palliative care consultant teams in hospitals were introduced in 2011. Reimbursement for inpatient hospices was developed soon after the first hospices started delivering services (1998), but reimbursement for home palliative care services was not introduced until 2018, causing delay in the development of home and community palliative care services across the country.

The establishment of a postgraduate specialty for physicians in palliative medicine, which has been available since 2004, was a huge milestone. Palliative care is nevertheless a second-level specialization, so physicians first have to specialize in fields like internal medicine, paediatrics or general practice. Physicians are finding it more and more attractive to undertake specialization in palliative medicine but there are insufficient numbers of mentors for them, with only a few centres equipped to provide the requisite education and experience.

Current provision of specialized palliative care services includes 17 inpatient hospice facilities (totalling 500 beds) and 45 home hospice care services. Many of these are small local services, however, providing capacity for only 30–40 patients per year.

Only 15 of around 200 hospitals have palliative care consultant services, and palliative care programmes are not present in all university hospitals. A few hospitals have a palliative care inpatient unit (sometimes called a hospice in the hospital) because they are reimbursed through the same scheme as inpatient hospice facilities outside of the hospital system.

Currently, fewer than 5% of patients who die in Czechia are supported by specialized palliative care services, but progress is being made. Hospices are being funded mainly by nongovernmental organizations (NGOs) and charities. This has many benefits, but also some disadvantages: for instance, it means hospices remain outside the mainstream health-care system. Working cooperatively with hospices as NGOs is not easy for hospitals and the health-care system.

The Czech Society for Palliative Medicine, established in 2008, is a strong advocate for palliative care, particularly as the society is involved in the development of all legislation and policies relevant to palliative care. The Avast Foundation has financed pilot projects in most areas of palliative care and the Ministry of Health has been able to consider how to make the models sustainable in the health-care system.

Most of the public do not understand exactly what palliative care can offer them. Communication about these issues is challenging for clinicians and families. There is no national palliative care plan adopted by the Government, which hinders the adoption of a systematic approach to developing palliative care and restricts the ability to mount a coordinated public information campaign.

Around 93% of patients in hospices have a cancer diagnosis. It is very difficult to navigate patients with other diagnoses through the health-care system to enable them to access palliative care at the right time – this is an area that requires further work. Thought also needs to be given to the distinction between general and specialized palliative care. Palliative care provided by general practitioners (GPs)
is challenging, with many GPs unsure of their roles. The risk is that this leads to providers of specialist palliative care taking care of people who do not need their services. It is very important to develop general and specialized palliative care at the same time.

Christoph Ostgathe, Professor and Head of Department of Palliative Medicine, Erlangen University, provided details on the development and provision of palliative care in Germany, focusing on policy, patient care, research and education. Palliative care is very well developed in Germany, but not everything is perfect.

In 2015, the issue of assisted dying was discussed intensively in Germany. A law on palliative care was enacted shortly after, mandating palliative care as a medical treatment freely available to every insured patient (effectively 100% of patients). The aim is to ensure that people with life-limiting conditions and their families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis – a high aspiration that has not yet fully been met. Palliative care is nevertheless well integrated in society and health care; a charter for care of the dying is now in place and has been developed into a national strategy.

The scientific association for palliative care – the Deutsche Gesellschaft für Palliativmedizin – was founded in 1994. It currently has more than 6000 members, most of whom are doctors, but also including nurses and other members of multiprofessional teams.

The country’s population of around 80 million is served by 338 inpatient palliative care units in hospitals, 252 hospices, 309 home-care teams and 69 hospital support teams for adults. With around 2000 hospitals in Germany, the numbers are comparatively low (probably due to unsolved issues regarding financing mechanisms). Palliative care for children is available across the country through 18 hospices, 49 home-care services and three hospital programmes.

Around 12 000 doctors – 4% of all physicians in Germany – have undertaken postgraduate education in palliative care at least at basic level. Nurses are also very active participants in palliative care training, with about 30 000 (1.5% of all nurses) being trained to date. More than 1300 volunteer hospice teams are in place, with 120 000 volunteers in hospice and palliative care services. Clinical care is based on evidence-based guidelines, including guidelines on care of patients with incurable cancer that were developed at national level – much of the evidence base for these guidelines is also relevant to the support of non-cancer patients.

The standard is to have one home-based palliative care team for every 250 000 inhabitants. The teams are consultant-led and are multidisciplinary: besides doctors and nurses, at minimum a psychologist, social worker or spiritual carer should be part of the team, but the multidisciplinary element of home-based palliative care is underdeveloped at this point. The teams work closely with GPs and volunteer services.

Academic development has been very active over the last two decades since the first chair in palliative medicine was appointed in 1999. There are now 10 professors of palliative medicine for adults, two for children and two for palliative/spiritual care. Universities in the eastern part of the country still do not have palliative care chairs but one professorship of palliative medicine will be established in Berlin soon. A research roadmap has been developed by the National Academy of Sciences and a major research grant scheme from the Ministry of Research and Education has been in place since 2015. A mandatory course in palliative medicine has been part of the curriculum for all undergraduate medical students at Erlangen University since 2012.
Ongoing problems include issues around financing, with hospital support teams being particularly underfunded and health insurance companies being somewhat reluctant to finance these services fully. As a result, only 3% of hospitals have hospital support teams; government action is needed in this area to achieve the baseline aim of every person who is in need of palliative care having access to it.

Provision of services is inconsistent throughout the country, with an imbalance between rural and urban areas. New models of care for rural areas and development of telemedical approaches to delivery of services are required.

Diana Nevronova, Chief Specialist on Palliative Care, Ministry of Health, described how palliative care began to develop in the Russian Federation in the 1990s, when a two-year course on palliative care was introduced in St Petersburg. The first hospice was opened in Leningrad in 1990, followed by openings in Moscow and other places. At that time, the British–Russian Hospice Society charitable organization was established to promote palliative care and provide professional support to hospices in the country. The Russian VERA Hospice Charity Fund started its work in autumn 2006 and the Hospice Care Professional Association was formed in 2014.

The population of the Russian Federation is around 146 million, of whom about 27 million are under 18 years. Around 1.2 million adults and 82,000 children are in need of palliative care.

Prior to 2011, there was no regulatory framework on palliative care for non-cancer patients. Access to opioids was impeded by complicated procedures for prescription, storage and administration of opioids and an acute lack of some non-invasive opioids, including oral morphine. There were no hospices for cancer patients or children and no outreach services in most regions. Knowledge on palliative care in the medical community was poor, with few educational opportunities, limited research activity and a lack of volunteers.

In 2011, Federal Law No. 323-FZ on the Basics of Health Protection of Citizens in the Russian Federation established palliative care as a comprehensive approach to care. Now, palliative care is subdivided into primary and specialized medical care, with an important aspect being the development of home care. Patients, relatives, families, social service institutions and NGOs are involved. The Ministry of Health regulated palliative care services further in a decree in 2019. The decree specified use of the Supportive and Palliative Care Indicators Tool (SPICT™) and set out rules for the interface of services with NGOs, social institutions and other palliative care agents. Palliative care was to be provided not only to patients with cancer, but also those with other progressive diseases.

Presently, the country has 41 hospices, more than 1000 palliative care doctors, 786 outreach teams and almost 15,000 beds, with 704,000 people having received palliative care (around 500,000 at home). The number of palliative care beds has increased tenfold since 2011, but provision of beds per 10,000 population varies across the country, from 3.67 in the Southern Federal District to 0.62 in the North Caucasus Federal District. Outreach home-visiting services have grown from 30 in 2012 to 510 in 2021.

The list of non-invasive opioid drugs in 2007 was limited. In 2016, the Government produced a roadmap on improving the availability of narcotic (opioid) and psychotropic drugs for medical use that aimed to expand the range of narcotic medications used to relieve pain (including medications for children) and improve the availability and quality of pain relief. The roadmap also helped health workers to define clinical indications for pain relief methods and drug therapy, including narcotic and psychotropic drugs.
Since 2018, the Government has provided subsidies from the federal budget (totalling 4.07 billion roubles (US$ 55 million) annually) to the budgets of subnational bodies to support the development of palliative care. These funds have enabled procurement of medical devices and drugs (including painkillers) and provision of vehicles for palliative care home visits. Additional funding has enabled the development of services throughout the Russian Federation.

Palliative care is now included as a mandatory component of professional standards for doctors. The requirement for continuous education programmes for physicians in palliative care has led to some medical universities establishing training courses. Online learning modules in areas such as chronic pain syndrome and organizing palliative care are available on the Ministry of Health website. The Hospice Care Professionals Association holds annual education forums and conferences supported by regional governments that bring together physicians, nurses, caregivers and social workers, and two medical journals focus on palliative care.

The Government founded the Federal Research Centre for Palliative Care at Sechenov Medical University in 2019. The Centre conducts comprehensive monitoring of palliative care provided throughout the country and develops technical and clinical recommendations. It is monitored by the Federal Centre of Palliative Care.

In 2020, a WHO-supported training course on preparing palliative care teachers for university medical faculties was launched. The two-week course (run initially online due to the COVID-19 pandemic) comprises theory and teaching practice and is open to faculty of all nine medical universities in the country.

**Sheila Payne, Professor in Palliative Care, Lancaster University**, gave a brief overview from the United Kingdom. In a normal year, there are around 0.5 million deaths in a population of just over 68 million, although the rate increased in 2020 due to the pandemic. Main causes of death in the last year were COVID-19, dementia and ischaemic heart disease, and the mean age of death was late 70s for men and early 80s for women. In the past, most people died in hospitals, but this has steadily been decreasing, with home deaths and nursing home deaths rising.

The first strategy for palliative care in England and Wales (there are similar strategies in Northern Ireland and in Scotland) was published in 2004, focusing only on adults with cancer. An end-of-life strategy that covers people dying of all types of conditions in all age groups is now in place.

There are no major distinctions in the United Kingdom between hospice care and palliative care. Over 200 inpatient hospices for adults provide a large range of services, including home care, outpatient clinics, day-care settings to which people can come one day a week to receive support and respite, and bereavement support. These services are free for patients and families, but most are not part of the National Health Service (NHS).

About 40 hospices provide free care for children, parents and their siblings. Provision of direct care is limited, but they offer advice and support for general health-care workers such as GPs and hospital doctors. A mixed funding model is in place, with 80% of hospices for adults receiving some funding contracts from the Government but most being funded from charitable resources.

Hospice and palliative care provision in the United Kingdom has been ranked as world-leading in international evaluations of the quality of dying. Challenges nevertheless remain, particularly in relation to providing palliative care at home, most people’s preferred setting for end-of-life care.
Community nursing services are provided free but are not equally distributed, and some may offer only
day-time services. Social care services are means-tested, so free provision depends on people’s income
and wealth levels.

A range of tools and measures has been developed to improve the quality of home care, including the
Gold Standards Framework. Almost 300 palliative home-care services are provided by hospices and
other charitable organizations. They offer diverse services ranging from telephone support to hands-on
direct provision, and some provide multidisciplinary team support in a service called Hospice at Home,
through which people provide care to patients who are living in their homes.

Deaths in nursing homes are rising. With around 17 000 nursing homes providing care for about
400 000 people (2019 figures), the need for palliative care is likely to increase substantially. The trend is
that increasing numbers of older people who are dying remain in the nursing home to die rather than
being transferred to a hospital. Most nursing homes are run by for-profit organizations and are not part
of the NHS, meaning potential residents must be very poor to qualify for government funding to gain a
place. Staff in nursing homes tend to be poorly paid, lack access to education opportunities and are often
too few in number. Medical care is delivered on a visitation basis by GPs and community nurses who are
funded by the NHS. Specialist palliative care providers and hospices also provide care when required.

Hospitals are funded by the Government through the NHS, paid for through taxation. There are very
few private hospitals and most people do not have private health insurance. All services are provided
free at the point of delivery, but admission to hospital (apart from emergencies) requires a medical
referral, usually from a GP. Palliative care support teams are in place in 334 hospitals.

A large increase in demand for palliative care is predicted, with up to three quarters of all deaths
potentially requiring some type of palliative care intervention provided either by GPs, hospital doctors
or hospices. Provision of hospices varies by region, with wealthier areas having higher concentrations.
Satish Mishra closed the meeting by suggesting the key takeaway messages were the need to ensure that palliative care is available to all who need it, and that while not all people with life-limiting conditions will need specialist palliative care, palliative care can be effectively provided in a range of settings provided people have the right education and training. Palliative care aims to add life to days and not days to life, enabling people to live well until they die. This is something all health-care services in the European Region should aim to provide.
Annex 1

Agenda

**Introduction, welcome and overview**
Satish Mishra/Natasha Azzopardi Muscat (WHO Regional Office for Europe)

**The development of palliative care in the WHO European Region**
Satish Mishra

**Integrating palliative care into national health systems – practical steps**
Tomas Zapata (WHO Regional Office for Europe)

**Overview of palliative care**
Marie-Charlotte Bouësseau (WHO headquarters)

**WHO palliative care tools**
Julie Ling (WHO Regional Office for Europe)

**Children’s palliative care**
Julia Downing (Chief Executive, International Children’s Palliative Care Network)

**Organization and delivery of palliative care – country examples**
Martin Loučka (Czechia)
Christoph Ostgathe (Germany)
Diana Nevzorova (Russian Federation)
Sheila Payne (United Kingdom)

**Conclusion**
Satish Mishra
Annex 2

Participants

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