Submission from the Irish Hospice Foundation

From:

To:

5 attachments

APPENDIX A PALLIATIVE CARE IN THE ACUTE HOSPITAL SYSTEM.docx

APPENDIX B - IHF - THE STRATEGIC IMPORTANCE OF PALLIATIVE CARE.pdf


Public-Consultation-on-the-White-Paper-on-UHI-IHF-FINAL.docx

UHI Unit,
Department of Health.

I am pleased to submit the Irish Hospice Foundation’s response to the public consultation process on the White Paper on Universal Health Insurance. Our submission is contained in the consultation document and in a number of appendices which are attached.

Our major concerns relate to the lack of clarity about how palliative care will be financed across all care settings, how inequities in service provision and infrastructural deficits will be addressed.

The Irish Hospice Foundation urges the Government to recognise palliative care as an essential and needed health care service and that ensuring equitable access to, availability of and usage of quality palliative care services is a fundamental component, and part of the definition, of universal health coverage.

We would recommend a specific and focused in-depth consultation – as proposed in the White Paper - on the role of and future funding of palliative care services and the care of people at end of life to achieve clarity on the appropriate funding for service provision and development of the sector before UHI is implemented. The Irish Hospice Foundation would welcome and participate in such a process.

Please consider this email as part of submissions.

Kind regards,

[Signature]

Advocacy Coordinator
Irish Hospice Foundation
Morrison Chambers
Please make a gift to our Nurses for Night Care
DONATE NOW

Find out more about Nurses for Night Care

The Irish Hospice Foundation | Morrison Chambers | 32 Nassau Street | Dublin 2
Tel: +353(0)1 6793188 | Fax: +353(0)1 6730040 | www.hospicefoundation.ie

Scanned by The Email Laundry
http://www.theemaillaunder.com
Public Consultation on the White Paper on Universal Health Insurance

The information collected from the submissions made through this consultation process will be used for the purposes of informing the policy development of Universal Health Insurance. With reference to the Data Protection Act, 1988 and the Data Protection Amendment Act, 2003, the Department of Health will be producing a report on the consultation process, and information provided may be included in this report. Please note that all information and comments submitted to the Department of Health for the purpose of this consultation process are subject to release under the Freedom of Information Acts 1997 and 2003.
1 Personal Information

1.1 Are you completing this document:

- In a personal capacity
- *As an authorised representative of an organisation/body, expressing the views of that organisation/body.

1.2 Name:* [Signature]

1.3 Organisation: (mandatory if you select the second option at 1.1) Irish Hospice Foundation (IHF)

1.4 Please classify your organisation type: (mandatory if you select the second option at 1.1)

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Options</td>
<td>Options</td>
<td></td>
</tr>
<tr>
<td>Health Insurer or Other Insurer</td>
<td>Public Interest Group</td>
<td></td>
</tr>
<tr>
<td>Public Health Service Organisation / Provider</td>
<td>Patient Interest Group</td>
<td></td>
</tr>
<tr>
<td>Private Health Service Organisation / Provider</td>
<td>Regulatory Body</td>
<td></td>
</tr>
<tr>
<td>Union</td>
<td>Representative Body</td>
<td></td>
</tr>
<tr>
<td>Educational Sector</td>
<td>*Other (Development and Advocacy Organisation)</td>
<td></td>
</tr>
</tbody>
</table>
2 Overview

The White Paper on UHI sets out the policy vision for the most radical ever reform of our health system. The major overhaul of the system will see a move away from a two-tier unequal health system to a single-tier system where access is based on need and not on income.

The key features of the UHI policy are:

- Everyone will have mandatory health insurance and their choice of insurer.
- Everyone will be entitled to the same package of care, which will include primary and acute hospital services, including acute mental health services. There will be no distinction between ‘public’ or ‘private’ patient; access to treatment will be on the basis of medical need, rather than ability to pay.
- Health services which will continue to be government funded and available outside of the UHI package include social and continuing care services, non-acute mental health services and certain social inclusion services.
- Citizens will be given a number of protections under UHI: they will be able to switch insurer annually, they will have the right to renew their policy and they will be charged the same premium for the same policy irrespective of age or risk profile.
- Citizens will also be afforded financial protection. The Government is committed to paying or subsiding UHI policy premiums for those who need support through the new National Insurance Fund.

The White Paper seeks to further develop the above features of the model by setting out a blueprint of how our future health services will be funded, organised and delivered. On that basis this consultation document sets out a number of key questions under the following four headings:

- Proposed Organisation and Delivery of the UHI Model
- Policy and Operational Aspects of the Subsidy System
- Regulation of Healthcare Providers and Purchasers
- Funding of the UHI model and the Overall Health System

You are invited to give your views, in writing, on some or all of the issues raised. Please provide your response to the questions in each relevant box. If you have no views to offer on a particular area, simply leave the box blank. There will be an opportunity at the end of this document for other observations/comments you may have on any aspect of the White Paper or to forward an email attachment.

Thank you for giving us your views.
3 Proposed Organisation & Delivery of the UHI Model

3.1 When the UHI system is in place, health insurers will be responsible for purchasing care on behalf of the population. Do you have any views on safeguards that should be built into this system, e.g. timely access to care, geographic limits etc.?

Safeguards should ensure timely access to healthcare based on need, in the home where appropriate, or as close to home as possible. There should be a system in place to recognise people with palliative care needs and ensure their priority access to the services they need.

3.2 Do you have any views on the role of the National Insurance Fund in (a) directly financing certain services and (b) being responsible for the financial support payments system?

It should plan for the taking over the funding of essential services such as the Irish Hospice Foundation’s Nurses for Night Care which is provided free to patients and is currently completely funded by the IHF.

3.3 How, in your view, can integration between health services outside of UHI and those in the standard UHI package best be achieved?

Palliative care is currently funded and sited in the Acute Hospitals Directorate. There is an urgent need for clarity and coherence about the alignment of and funding of palliative care within the new structures.

It is proposed that specialist palliative care (SPC) will be sited in the social and continuing care financial stream, separate to UHI, but SPC and generalist palliative care (GPC) are both applicable in the acute hospital sector across all diagnostic groups and none. SPC healthcare professionals are in most acute hospitals. How will their service be funded? We would be concerned that patients admitted to the acute hospital sector under UHI would be denied palliative care because the funding stream is different. Evidence shows that 30% of patients in acute hospitals are in their last year of life. There is no clarity on how patients can move from one funding stream to another within a service. Palliative care should be an integral part of care in all settings. PLEASE SEE APPENDIX A (ATTACHED) ON THE IMPORTANCE OF PALLIATIVE CARE IN THE ACUTE HOSPITAL SECTOR.
3.4 What should be the priorities for phasing the delivery of the UHI model i.e. with full implementation by 2019?

Palliative care, both specialist and generalist, should be a priority component of all care streams from the outset. In particular, as it is an integral part of care for the dying, it needs to be integrated and funded properly to address these needs in addition to episodic control of complex symptoms at all stages in the trajectory of chronic conditions in all care settings.

3.5 Do you have any views on the role of supplementary insurance under the new system?

All patients requiring palliative care should be able to access all components of this vital service based on their need and not on their level of insurance or supplementary insurance cover.

3.6 The White Paper sets out a proposed values framework to guide the work of the Commission in assessing what services should be included under UHI and the overall health system. Do you have any views on this values framework?

Palliative care – specialist and generalist - should be regarded as an essential service and included in the values framework. We believe that palliative care should be recognised as an essential and needed health care service and that ensuring equitable access to, availability of and usage of quality palliative care services is a fundamental component, and part of the definition, of universal health coverage.

SEE APPENDICES B – The Strategic Importance of Palliative Care within the Irish Health Service (IHF) and D “Palliative Care: A needed and essential service within universal healthcare” (Worldwide Palliative Care Alliance) ATTACHED
4 Policy & Operational Aspects of the Subsidy System

4.1 Do you have any views on how the subsidy system for UHI should operate i.e. how can we ensure that it protects those on low incomes?

4.2 The White Paper notes that the financial subsidy system will be provided on a means tested basis. Do you have any views on whether this assessment should be solely based on income or if other factors such as assets should also be included?

4.3 Some members of the population currently have entitlements under various schemes e.g. medical cards, GP visit cards, Long term illness scheme etc. Do you have any views on how these benefits may best be delivered when UHI is introduced?

Medical Cards are currently available without means test to people with a prognosis of six months or less. This entitlement to comprehensive medical and community care supports should not diminish or reduce under UHI.
5 Regulation of Healthcare Providers & Purchasers

5.1 Do you have any views on the proposed system of regulation of healthcare providers and health insurers? Are there any areas you would like to see strengthened?

We would like there to be patients representation on any such regulatory body.

5.2 Do you have any views on how the management of contractual disputes regarding health insurance might be best achieved?

The burden of administration should never fall on the patient.

5.3 Do you have any views on what economic regulation mechanisms should be applied to ensure good governance and financial management of health services?
6 Financing of UHI and the Overall Health System

6.1 Do you have any views on the proposed new financing model for UHI i.e. a blend of premium income, direct taxation and out of pocket payments?

There must be clarity on how the transition will work and a clear road map for the future funding.

6.2 Do you have any views on the use of co-payments for services?

Palliative care should be provided without the requirement for co-payments as currently exists. The Worldwide Palliative Care Alliance recommends that governments should ensure that households with people who require palliative care, particularly during the last years of life, should not have to pay out of pocket financially for palliative care services. The government should equally ensure that households with people that require palliative care are not subject to financial pressure because of the usage of unnecessary and futile treatments. (SEE APPENDIX D WITH THIS DOCUMENT)

6.3 Do you have any views on the cost control measures that have been set out in the White Paper? Are there other cost control measures that could be implemented?

6.4 In your view, how best can the regulatory systems set out in the White Paper provide the state with sufficient means to safeguard the financial sustainability of the health system and secure ongoing affordability of UHI policy premiums?
6.5 Do you have any views on how the regulatory and administration costs of the system might be minimised?
7 Additional Comments / Observations

Should you wish to provide comments on any other aspects of the White Paper please do so in the box below or attach a document in the email response.

Palliative care is not mentioned at all in the White Paper and in the accompanying document (Background Policy Paper on Designing the Future Health Basket) it is unclear exactly how palliative care will be financed across all settings: i.e. Specialist In-Patient Units (Hospices); the Community (home, long-stay residential settings and Level Two hospice beds in community settings) and the Acute Hospital Sector. There must be clarity on how this essential service can be delivered and funded in an integrated way across all care settings.

If Primary Care is to be funded under UHI and palliative care funded under social and continuing care how will this integrate with palliative care services delivered by primary care healthcare professionals and allied health professionals? Currently 90% of care in the last year of life is delivered by primary care professionals. If this care is funded under UHI how will primary healthcare professionals be paid for their palliative care of patients in the community?

We are concerned about how current SPC services will be maintained and the future development of this sector be advanced while there is no clarity on the funding stream. Currently there are areas of the country (Midlands, South East, North East) with no specialist in-patient beds. Patients in these areas have no access – and therefore less choice – in where they are cared for and die. Research (“Access to Specialist Palliative Care Services and Place of Death in Ireland” APPENDIX C to this document) shows that where there is no SPC unit cancer patients are more likely to be admitted to and die in the acute hospital sector. There is no clear and shared understanding about how the hospice services in the poorly developed areas will be able to improve their situation. If there is competition between hospital groups will there also be competition between hospices and will this further entrench the inequity that currently exists?

The current budget (2013) for palliative care is €73 million. Evidence suggests that up to €1.3 billion is spent each year on end of life care and this spending is largely unplanned.

How will funding for palliative care under either/both UHI and direct funding under social and continuing care support strategic development of SPC services and infrastructure?

Finally we would recommend a specific and focussed in-depth consultation – as proposed in the White Paper – on the role of and future funding of palliative care services and the care of people at end of life to achieve clarity on the appropriate funding for service provision and development of the sector before UHI is implemented. The Irish Hospice Foundation would welcome and participate in such a process.

APPENDIX D (ATTACHED) is a recently published paper from Palliative Worldwide Palliative Care Alliance (WPCA) on ‘Palliative care: a needed and essential service within universal health coverage’
APPENDIX A
Why does end of life and palliative care in acute hospitals matter so much?

The acute healthcare system is the bedrock of the Irish Healthcare system. Any element of a national healthcare system that cares for a significant proportion of the population, expects client numbers to continue to grow, and commands a significant direct and indirect budget, must plan effectively for the future delivery of services. The management of our approach to death, dying and bereavement within our acute health service matters – not only to patients but to the health system as a whole.

Why

- Death is a natural life experience which affects a significant proportion of the population – 29,000 people die in Ireland each year, and up to 290,000 are newly bereaved.
- We know that up to 30% of patients in every acute hospital are already in their last year of life. Very recent research from 10,743 inpatients in 25 Scottish teaching and general hospitals showed that 10% of in-patients had died by 30 days and 28.8% by one year.
- Of the many people who die in Ireland, the large majority of them wish to die at home. However, the reality is that approximately two-thirds die in hospitals and 43% die in acute hospitals.
- While the state budget for specialist palliative care currently (2012) stands at €78 million, international evidence suggests that in reality 10%-15% of national healthcare spending goes on care at the end of life. In Ireland, this would be about €1.3 billion. With careful attention, better patient and service outcomes can be achieved for this expenditure. For the acute hospital sector this spending represents xx ...
- Specialist palliative care services play a critical role in the development and provision of care for people with life-limiting illnesses in acute care settings, which makes it an important component of the overall acute health service. There is a growing body of evidence to support – both from a cost containment and a quality perspective – the role of specialist palliative care in the provision of complex care hospitals.
- Anticipating needs and planning for palliative care can assist in preventing inappropriate emergency admissions to expensive care settings such as acute hospitals, and can facilitate discharge and the provision of care closer to home, in line with patient preferences. A study commissioned by the Health Service Executive (HSE) found that 40% of patients being cared for in hospitals could be more appropriately cared for elsewhere. The national audit of end of life in Irish

1 Central Statistics Office figures, 2012
4 Prospectus Consulting. Acute Hospital Bed Capacity Review, 2007 plus additional results from Audit on Edil if life in Acute Hospitals [insert full reference]
Hospitals (2010: IHI & HSE) provided supporting evidence in this regard.

- **Public interest** in end-of-life issues is increasing and is likely to result in more public demand that everyone should be able to have a 'good death'. More importantly, where death and bereavement are approached poorly by staff is a key component of many hospital complaints.

---

5 The Irish Hospice Foundation’s Forum on End of Life in Ireland enjoyed significant public engagement during its period of public consultation in 2009-2010

6 Ombudsman report.
APPENDIX A

Why does end of life and palliative care in acute hospitals matter so much?

The acute healthcare system is the bedrock of the Irish Healthcare system. Any element of a national healthcare system that cares for a significant proportion of the population, expects client numbers to continue to grow, and commands a significant direct and indirect budget, must plan effectively for the future delivery of services. The management of our approach to death, dying and bereavement within our acute health service matters – not only to patients but to the health system as a whole.

Why

- Death is a natural life experience which affects a significant proportion of the population – 29,000 people die in Ireland each year, and up to 290,000 are newly bereaved.
- We know that up to 30% of patients in every acute hospital are already in their last year of life. Very recent research from 10,743 inpatients in 25 Scottish teaching and general hospitals showed that 10% of in-patients had died by 30 days and 28.8% by one year.
- Of the many people who die in Ireland, the large majority of them wish to die at home. However, the reality is that approximately two-thirds die in hospitals and 43% die in acute hospitals.
- While the state budget for specialist palliative care currently (2012) stands at €78 million, international evidence suggests that in reality 10%-15% of national healthcare spending goes on care at the end of life. In Ireland, this would be about €1.3 billion. With careful attention, better patient and service outcomes can be achieved for this expenditure. For the acute hospital sector this spending represents ...
- Specialist palliative care services play a critical role in the development and provision of care for people with life-limiting illnesses in acute care settings, which makes it an important component of the overall acute health service. There is a growing body of evidence to support – both from a cost containment and a quality perspective – the role of specialist palliative care in the provision of complex care hospitals.
- Anticipating needs and planning for palliative care can assist in preventing inappropriate emergency admissions to expensive care settings such as acute hospitals, and can facilitate discharge and the provision of care closer to home, in line with patient preferences. A study commissioned by the Health Service Executive (HSE) found that 40% of patients being cared for in hospitals could be more appropriately cared for elsewhere. The national audit of end of life in Irish Hospitals (2010; IHF & HSE) provided supporting evidence in this regard.
- Public interest in end-of-life issues is increasing and is likely to result in more public demand that everyone should be able to have a ‘good death’. More importantly, where death and bereavement are approached poorly by staff is a key component of many hospital complaints.

1 Central Statistics Office figures, 2012
4 Prospectus Consulting, Acute Hospital Bed Capacity Review, 2007 plus additional results from Audit on Edi
5 life in Acute Hospitals [insert full reference]
6 The Irish Hospice Foundation’s Forum on End of Life in Ireland enjoyed significant public engagement during its period of public consultation in 2009-2010
7 Ombudsman report.
Worldwide Palliative Care Alliance (WPCA) position paper on 'Palliative care: a needed and essential service within universal health coverage'

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Palliative care: a needed and essential service within universal health coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Author</td>
<td>Claire Morris, Stephen Connor, Liz Gwyther</td>
</tr>
<tr>
<td>Publication Date</td>
<td>May 23 2014</td>
</tr>
<tr>
<td>Audience</td>
<td>Palliative care personnel, national governments, international organizations</td>
</tr>
<tr>
<td>Circulation List</td>
<td>Regional and National hospice and palliative care Associations</td>
</tr>
<tr>
<td>Summary</td>
<td>This discussion document identifies how palliative care is a needed and essential health care service and a core component of universal health coverage. The document highlights WPCA's position on the positioning of palliative care with UHC, the monitoring of UHC and the recommendations for action by policy makers at the national, regional and international level.</td>
</tr>
<tr>
<td>Contact Details</td>
<td><a href="mailto:info@theWPCA.org">info@theWPCA.org</a></td>
</tr>
<tr>
<td>Review Date</td>
<td>May 2016</td>
</tr>
</tbody>
</table>

Introduction
The Worldwide Palliative Care Alliance (WPCA) is an international NGO focusing exclusively on hospice and palliative care development worldwide. Its members are national and regional hospice and palliative care organisations and affiliate organisations supporting hospice and palliative care. Our vision is a world with universal access to hospice and palliative care.

The WPCA strongly supports the ethos and principles of universal health coverage and calls on policy makers to ensure that equitable access to, availability and usage of palliative care is included in all plans to progress towards universal health coverage.

Summary of recommendations
The WPCA recommends that policy makers at the national, regional and at the global level should:

1. Recognise palliative care as an essential and needed health care service and that ensuring equitable access to, availability of and usage of quality palliative care services is a fundamental component, and part of the definition, of universal health coverage.

2. Ensure country level action plans to move towards universal health coverage include explicit actions, and allocated budget, to achieve equitable access, availability and usage of quality palliative care services for all those that need them as part of a minimum set of services.
3. Ensure that households with people who require palliative care, particularly during the last years of life, should not have to pay out of pocket financially for palliative care services.

4. Ensure that households with people that require palliative care are not devastated financially because of the usage of unnecessary and futile treatments.

5. Include a tracer indicator on palliative care as a core component of the monitoring framework to track progress on universal health coverage. This recommended tracer palliative care indicator is ‘Morphine Equivalent Consumption of strong opioid analgesics per capita’.

6. Encourage comprehensive indicator sets to be developed at the country level to monitor the availability of holistic palliative care looking at health care policy, service provision, education and medications. The indicator set should look at appropriate disaggregation to ensure equity of access as well as including impact measurements.

7. Support universal health coverage as a core component of the post 2015 development agenda and ensure that palliation is included as a key tracer indicator to ensure healthy, long lives with good quality of care throughout the life course.

Definitions

Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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. In many settings, palliative care also provides a more holistic response also looking at addressing social, economic, legal and human rights support.

Universal Health Coverage is defined as ensuring that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, which are of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.

Background

Universal health coverage is a concept that has been increasingly recognised and adopted by national governments in the last 50 years. It embodies three inter-related concepts focussing on equity of access to needed health care services for all those that need them, irrespective of their ability to pay; that the quality of health services is good enough to ensure the improvement of health of those receiving the services; and financial risk protection to ensure that the cost of using care does not put people at risk of financial hardship.

In order to achieve universal health coverage, it is not simply possible for financial risk protection measures to be put place, e.g. insurance schemes and the abolition of user fees. In addition, quality health services must be available, equitable and accessible and these need to be funded and utilised.

The concept and approach of palliative care is fully aligned with the principles of UHC bringing together coverage, quality, equity and financial protection.

---

Palliative care within universal health coverage

Palliative care has been recognised as a needed and essential health service as part of universal health coverage by the World Health Organization. It is recognised as a fundamental component of health care by the World Health Organization for people living with and affected by many non-communicable and communicable diseases and improves quality of life. In addition, there is a strong argument that palliative care, including access to opioid medications, is a basic human right.3

However, there is still work to be done to review how progress in relation to universal health coverage impacts on the availability, accessibility and usage of palliative care for all people who need it. A significant challenge is looking at how universal health coverage and palliative care are monitored at the national level.

Universal health coverage does not mean that every needed health service will be immediately accessible to everyone who needs it when they need it but will rely on country prioritisation in relation to the health needs in their country and the budgetary and resource constraints. This relies on decisions around what a minimum set of health services are as progress is achieved towards UHC. Palliative care is rarely been prioritised as part of a minimum set of health services. Yet, countries such as Uganda show that progress in increasing the accessibility, availability and usage of palliative care is not dependent on high resources4. The WPCA reiterates that palliative care is not a luxury only available for high resource health systems but a human right; and an essential and needed service which can be made available within a health system at relatively low cost and should be part of a minimum set of services.

Coverage of palliative care and progress on UHC

To date, monitoring of UHC largely relies on countries self-declarations of achieving universal health coverage and is weighted towards financial protection measures for the whole population rather than the availability or usage of services. The availability and accessibility of a ‘basic minimum package’ of services can always be increased, as can the financial protection available, thereby progressive realisation is a key factor of UHC.

Currently, there are a number of countries that claim to have UHC. This claim is often based on a system having been put in place that financially protects users to access a minimum set of health care services. Palliative care is rarely if ever included in this minimum set of services, although access to essential medicines required for palliative care may be included.

It is clear when comparing the availability of palliative care services and the consumption of morphine that progress in achieving universal health coverage does not include the development of palliative care services within the country.

---

4 Committee on Economic, Social and Cultural Rights (CESCR) General Comment 14, para. 25.
Mexico – Mexico declared itself as achieving UHC when it completed the implementation of Seguro Popular scheme, which provided health insurance for the entire population who were not previously covered by the formal social security system. This does not mean however that all health care services are available for all the population groups that need them. In relation to access to palliative care, Mexico is classified in group 3a in the ‘Mapping the development of palliative care report’ which indicates only isolated provision of palliative care services. There is currently (2014) a campaign to change restrictive opioid laws in Mexico to improve access to opioid medication to help people who suffer needlessly.

Thailand – Thailand has been one of the notable and well discussed examples of progress in universal health coverage with a universal coverage system to reach the entire population implemented in 2002. A review of the Thai system showed that health insurance (paid entirely from general government revenues) for the poor and the informal sector increased their access to the services they needed and improved financial risk protection. It required a multi-pronged approach including ensuring essential medicines were available and retaining health care workers. However, in relation to palliative care, Thailand is also only ranked as having isolated provision across the country (group 3a in Global Atlas of palliative care at the end of life), highlighting that the majority of the population will not have access to palliative care services.

Uganda – Despite the removal of user fees in Uganda, the incidence of catastrophic health expenditure increased from 1996-2006. This is likely due to the use of private providers by the poor. Community Health Insurance (CHI) schemes are only accessible to just 5–10% of the population in the few areas where such schemes operate. Plans are underway to put into place a national health insurance scheme but progress has been challenging. Despite the challenges in progress towards universal health coverage, Uganda is a country with a relatively well-developed palliative care. In the Global Atlas mapping project it is ranked as being fully integrated into health system.

Economic and financial protection
The importance of the inclusion of palliative care within UHC is particularly valid given that one aspect of UHC is to prevent people falling into hardship as a result of their health care requirements. It is well documented that health care costs are extremely high at the end of life. It is also well documented that many health care interventions at this stage can be expensive, unnecessary and futile, often causing increased distress and suffering, in addition to financial hardship. This is burdensome both on the households affected, and the health care system more broadly.

---

6 Connor S R, Sepulveda Bermedo M C (eds.) Global atlas of palliative care at the end of life. [London]: Worldwide Palliative Care Alliance, 2014
8 Connor S R, Sepulveda Bermedo M C (eds.) Global atlas of palliative care at the end of life. [London]: Worldwide Palliative Care Alliance, 2014
10 Connor S R, Sepulveda Bermedo M C (eds.) Global atlas of palliative care at the end of life. [London]: Worldwide Palliative Care Alliance, 2014
11 Kelley, A Out of pocket expenditure in the last 5 years of life Journal of General Internal Medicine February 2013, Volume 28, Issue 2, pp 304-309
It has been shown that good availability and usage of palliative care services at the appropriate time not only improves the quality of care and life of people affected, but also may reduce the cost on households and health systems. In many countries, NGOs provide palliative care free of charge relying on donations from the community and grants from funders to cover the cost of care.

**Monitoring and evaluation of universal health coverage and palliative care**

In order to monitor and evaluate progress towards achieving universal health coverage, and particularly access and coverage of services, it is vital the monitoring frameworks and tracer indicators are selected which cover the full breadth of health care services through promotive, preventative, curative, rehabilitative and palliative care services. A single effective tracer indicator for palliative care is ‘Morphine equivalent consumption of strong opioid analgesics per capita’. The benefits of this indicator are that the data is already collected and there is no additional burden on the country. While the indicator does not measure the holistic and comprehensive nature of the palliative care response, including physical, psychosocial and spiritual care, it does provide a good indicative tracer indicator. This indicator with a different denominator has been accepted by member states and WHO as part of the global monitoring framework on NCDs.

In addition, to a global indicator it is also recommended that national level government develop frameworks to monitor the comprehensive progress in relation to palliative care looking at health care policy, service provision, education and medications. The indicator set look at appropriate disaggregation to ensure equity of access as well as including impact measurements.

**Universal health coverage and the post-2015 agenda**

The WPCA supports the fundamental and vital positioning of UHC within the post 2015 agenda debate. As well as health coverage broadly playing a central role, it is also important that progress is not slowed in relation to achieving universal access to prevention, treatment, care and support (of which palliative care is part) for people living with HIV. In addition, the rapidly expanding issue of NCDs needs to be well included within the post 2015 framework. Palliative care as a cross-cutting issue should be a tracer indicator within the framework under UHC, looking at the availability, accessibility and usage of a needed and essential health service for people with communicable and non-communicable conditions. The availability, accessibility and usage of palliative care may be an indicator of the quality of care being provided within a health system.

**WPCA position statement**

The WPCA believes that UHC is an important and progressive concept in the move towards ensuring healthy, longer lives for people across the globe. The WPCA reiterates that palliative care is a needed and essential health care service and a fundamental component of UHC. Country level action plans on progress towards UHC should include actions towards ensuring palliative care is available, accessible and used by all those that need it. Monitoring of UHC should include a tracer indicator on palliative care, as well as recommending a more comprehensive set of palliative care indicators to be developed, adapted and utilised at the national level. WPCA believes that UHC should be at the core of the health component of the post 2015 development framework. It is a basic right of people living with, and affected by, communicable and non-communicable conditions to have the quality care they need throughout the life course to ensure long, healthy lives. Palliative care is fundamental to achieving this health right.

---