



## **D8.2– Guidelines for the implementation of evidence-based palliative care interventions**

**WP8 – Policy recommendations and clinical guidelines**

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## Introduction

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illnesses. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems – physical, psychological, social, or spiritual – experienced by adults and children living with life-limiting health problems. It promotes dignity, quality of life and adjustment to progressive illnesses, using best available evidence.

Palliative care services should:

- Identify patients who could benefit from palliative care.
- Assess (and reassess) the needs of these patients and their caregivers.
- Provide the necessary care (relieve symptoms, address spiritual, psychological and social needs, clarify the patient's values and determine culturally appropriate goals of care).
- Prepare for and provide end-of-life care.
- Provide bereavement support.

The InAdvance project sought to explore early integration of palliative care and timely identification of the needs of older people with complex chronic non-cancer conditions. For that, personalised pathways were created to respond to both patients' and relatives/carers' needs at physical, emotional, social and spiritual levels.

## Guideline development

These guidelines were developed using qualitative and quantitative evidence from the InAdvance project to promote patient centred pathways of early palliative care.

The guidelines were initially drafted by the NHS Highland clinical team. There followed two rounds of review by clinicians and service managers from the Medical Research Institute of Hospital La Fe (HULAFE), Santa Casa da Misericórdia da Amadora (SCMA) and Aristotle University of Thessaloniki (AUTH). After two rounds of review there was consensus on all clinical recommendations.

Following presentation of the guidelines at a subsequent consortium meeting, with representation from HULAFE, SCMA and AUTH, there was also consensus on which pieces of evidence (both quantitative and qualitative) from the whole InAdvance project should be used to help support the recommendations.

### *Recommendations:*

#### **Identification of older people with complex chronic conditions who may benefit from palliative care**

1.1 Older people with complex, chronic life-limiting conditions should be identified earlier. This will enable them to access palliative care, aimed at maximising their quality of life, even as they receive treatments with the primary aim of prolonging life.

1.2 Existing tools that assess disease severity can aid the identification of patients who may benefit from palliative care.

1.3 Multi-disciplinary team (MDT) review is recommended to ensure suitable patients are identified.

1.4 Patients and professionals need education to overcome the stigmas that still inhibit patients being 'labelled as' or identifying as palliative.

1.5 Computer assisted decision making aids may help more accurate prognostication and patient identification in the future.

#### **Assessing holistic needs**

2.1 Older people with complex, chronic life-limiting conditions should have an initial holistic needs assessment. The Needs Assessment Tool: Progressive Disease (NAT:PD) can be used to assess the range of physical and psychological needs of patients and caregivers, together with the ability of the caregiver to care throughout the disease process. It is effective and well tolerated. It is most useful when narrative information is recorded in addition to the tick-boxes.

2.2 Health and social care staff who use the NAT:PD should have appropriate training and support.

2.3 The holistic needs assessment should be repeated periodically to ensure that new or changing needs are identified and timely support is offered.

#### **Responding to the needs that have been identified. The delivery of palliative care**

3.1 The patient and/ or caregiver needs will be physical, psychological, social, financial, spiritual and informational. Addressing these needs will require excellent communication and coordination between services, including health care, social care and other community services. The MDT responsible for the patient should meet to formally coordinate the response to the identified needs.

3.2 Service providers should be aware of the needs of older people with complex, chronic life-limiting conditions and develop services that can address their needs if these services do not already exist. There should be a formal process for unmet needs to be fed back to health and social care commissioning bodies.

3.3 Older people, and their carers, often have informational needs. It is important that information is provided to them when they need it and in a way that they can easily access and understand.

## **Preparing for end-of-life care**

4.1 Older people should be offered the opportunity to be involved in their own advance and anticipatory care planning. Should they wish this, they will require information about how their disease will progress and what the realistic treatment and care options will be for them in the future.

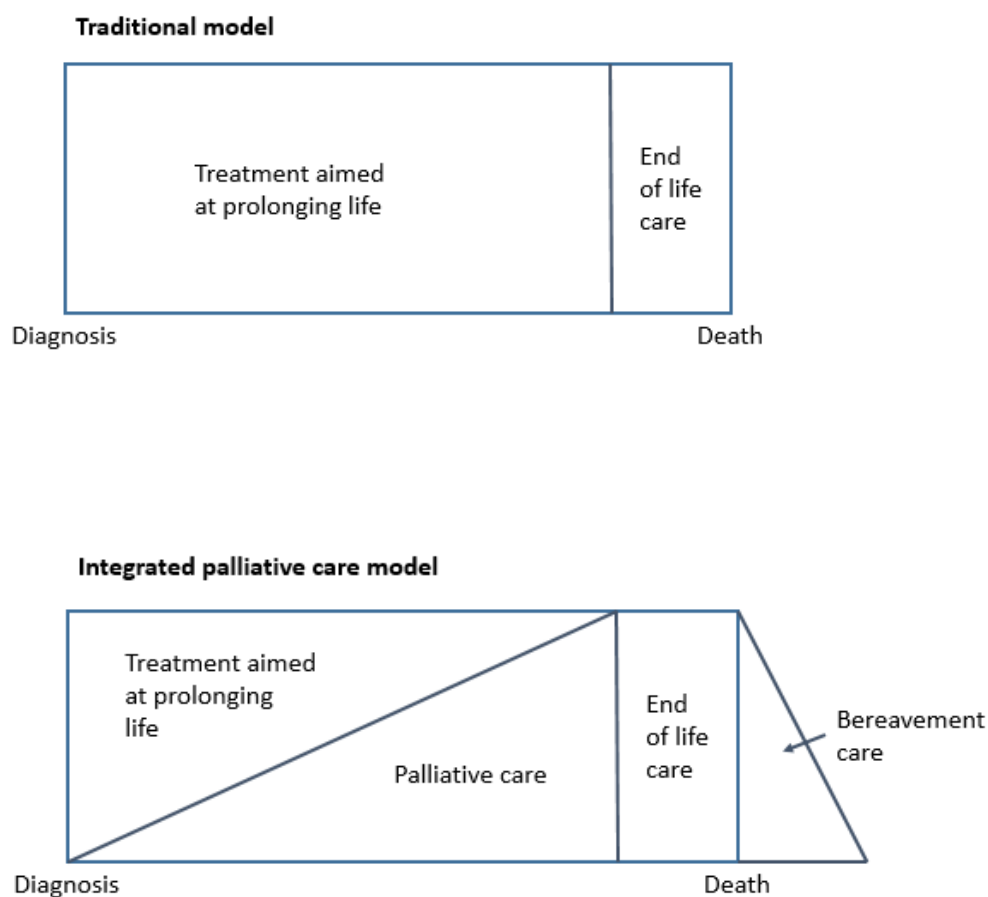


## Identification of older people with complex chronic conditions who may benefit from palliative care

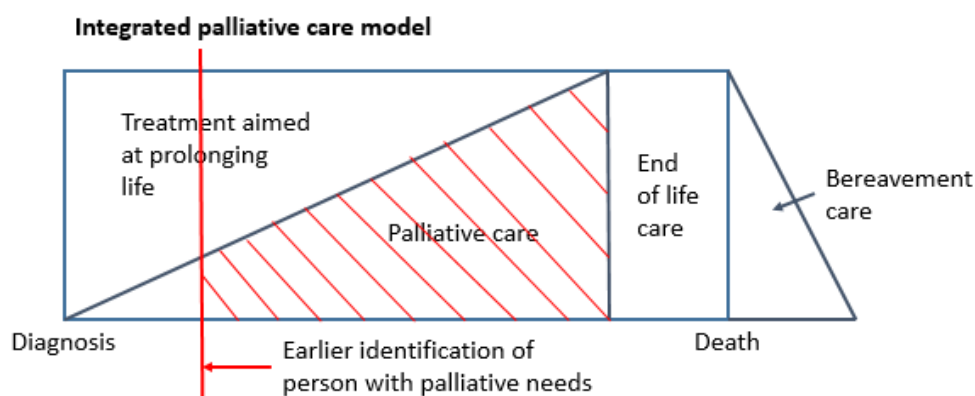
### **Recommendation 1.1**

People need to be identified as potentially having palliative needs before any care can be offered. Most patients who are identified as palliative, and who therefore have access to palliative care services, continue to be younger cancer patients. Older people with complex, chronic life-limiting illnesses are often overlooked, or only identified when they already have a very high burden from their disease or when they are dying. Integrated palliative care seeks to identify and address palliative needs from earlier in the disease process. This can be alongside treatments with the primary aim of disease modification and prolonging life. See figure 1.

Figure 1.







Earlier identification of older people with palliative care needs will increase the demands on these services and service providers will need to have strategies to respond to this.

### **Recommendations 1.2 and 1.3**

There currently is no universally agreed screening tool to identify people who may benefit from palliative care.

InAdvance: site visit evidence.

Multi-disciplinary team (MDT) members were able to identify patients using their own knowledge of the patients, or clinical data that had already been recorded to assess disease severity. Most diseases have severity scoring tools (COPD, heart failure, frailty). These patients had not been identified by 'normal' care illustrating the need for regular MDT discussions specifically aimed at identifying potential palliative patients.

### **Recommendation 1.4**

There is evidence that lack of knowledge about palliative and end-of-life care amongst the public and professionals is a barrier to understanding what treatment and care options are available and is a barrier to accessing appropriate care. It is revealing that the professionals on the Clinical Research Ethics Committee who reviewed the InAdvance study had reservations about the possible harms of the word palliative being used in patient information sheets.

InAdvance: focus groups with patients (n=66), carers (n=28) and professionals (n=63).

Real or perceived stigma around the term palliative care was identified as a barrier to initiating conversations and starting appropriate advance care planning.

In Spain patients generally had poor knowledge of what palliative care was with healthcare professionals equating palliative care with end-of-life care and feeling death was a taboo subject.

In Greece both patients and healthcare professionals described palliative care as being an unknown concept.

In the UK, the term 'palliative care' was considered a major barrier to palliative care conversations. Most of the patients, and some health care professionals, believed palliative care was only for dying cancer patients.

In Portugal patients expressed the need for more information about palliative care, and carers wanted more education on palliative care and death.

### **Recommendation 1.5**

There are several electronic tools/ apps/ programmes that can use population based electronic health data to produce prognostic estimates. These tend to have similar sensitivity and specificity. More work needs to be done to establish if they can add value to routine clinical practice. Lack of validation in different population groups or health care settings and compatibility issues with different health care electronic records systems are barriers to their wider use.

InAdvance: frailty and mortality prediction models.

The digital records of 19,753 >65 year old (mean age 80.75) hospitalised patients were analysed using machine learning to develop mortality and frailty prediction models. The 1-year mortality prediction model achieved a AUC ROC of 0.87. The frailty predictor (either not frail or vulnerable vs frail or very frail) achieved a AUC ROC of 0.89. There was minimal correlation between these models suggesting they are complementary. There is potential that these models could be used to highlight patients who are at increased risk of dying and or becoming more frail, and thus prompting assessment and advance care planning. The results need to be externally validated in other patient populations and health care systems.

The predictive models are available as an online clinical support system for academic use until they are further validated - Palliative Care Models Webapp (Demo Aleph). <http://demoiapc.upv.es/>

AUC ROC = Area Under the Curve Receiver Operating Characteristic

### **Assessing holistic needs**

#### **Recommendation 2.1**

Older people with complex, chronic life-limiting conditions have multiple needs, and many of these have not previously been picked up by their health and social care

professionals. These needs must be identified and communicated before an appropriate plan of care can be developed with the person, taking into account their priorities and wishes.

InAdvance: descriptive data from the NAT:PDs

Data from the initial needs assessments of 179 patients (from Spain, Portugal, Greece and the UK) reveal that unresolved symptoms are common and include: physical 72%, psychological 50%, spiritual 27%, financial 20% and sexual functioning/ relationships 11%.

Carers (n=154) also described having concerns: distress about patient's physical symptoms 52%, difficulty coping 44%, difficulty providing physical care 40%, difficulty managing medications and treatment 26% and financial or legal concerns 16%.

InAdvance: focus groups with patients (n=66), carers (n=28) and professionals (n=63).

Both patients and carers identified their needs to be informed and supported for their physical, psychosocial and financial functioning. Receiving consistent support by health professionals, accessing individualised and consistent care and having the option for home-based services were seen as facilitators for having their needs met. Lack of effective communication or regular follow up were felt to be barriers.

InAdvance: site visit evidence.

Focus groups with the healthcare professionals (n=24) who were involved in the study in all four clinical sites.

There was consensus across all four sites that the NAT:PD was an acceptable and effective way to identify patient and carer needs. It was felt to be a useful addition to current practice and there was optimism that it could lead to better coordination of care for patients.

## **Recommendation 2.2**

Appropriate training and support is needed for the professionals who are using the NAT:PD. This will be needed to ensure the assessments are being done thoroughly and information is being recorded accurately. The professional will need to be able to deal with strong emotions and difficult conversations with the patient and their carer, and deal with how these emotions may affect themselves. They also need to be aware of local referral pathways and how to escalate particularly important concerns. In practice, well trained interviewers elicited much more information that could be recorded on the NAT:PD tick-box form. This information was often very important and consideration will need to be given in how it is recorded and communicated.

InAdvance: site visit evidence

There was consensus across all four clinical sites that staff need training and support to effectively use the NAT:PD.

Best practice: when a need is elicited when using the NAT:PD, details about that need should be recorded. The completed NAT:PD form with any additional information attached should be forwarded to the multidisciplinary team with the responsibility for responding to the needs.

### **Recommendation 2.3**

People with complex chronic illnesses may have palliative needs for many years. These needs will change over time. Routine reassessment of their needs will allow their care to be adapted to their new circumstances. There is no evidence to support how frequent these reassessments should be.

InAdvance: site visit evidence

There was no consensus among the clinicians doing the study about how frequently the NAT:PD should be repeated, but most felt that either six monthly or annual review would be appropriate, with sooner review should there be a significant change in the patient's clinical or social circumstances.

Some sites had introduced monthly follow-up contacts to try to identify changes earlier.

## **Responding to the needs that have been identified. The delivery of palliative care**

### **Recommendation 3.1**

Holistic needs assessments consistently demonstrate that people with physical illnesses do not just have physical problems, but have significant psychological, social and spiritual issues. No one person in the multi-disciplinary team is likely to be able to address all these needs. Care will need to be delivered by multiple individuals or agencies. Coordination of this care will be necessary to make sure it is efficient and effective.

InAdvance: focus groups with healthcare professionals n=24

Portugal. Significant lack of resources, but existing resources could be better coordinated. The NAT:PD could help to standardise patient assessment and help promote cultural change within the health and care systems as patients' priorities are brought to the fore.

Spain. To meet patients' needs there needs to be better communication between primary and secondary care and better coordination of services. It was also noted that the needs identified through the NAT:PD should promote better care coordination.

Greece. Minimal existing palliative care services, but staff want to be able to deliver appropriate, good quality palliative care. The need for education and service development was emphasised.

Scotland. The NAT:PD results were uncovering previously unidentified needs and challenging healthcare professional assumptions. The multidisciplinary panel that reviewed each patient's NAT:PD promoted more cross-disciplinary working and better coordination of care.

InAdvance: descriptive data from the NAT:PDs

Data from the initial needs assessments of 179 patients (from Spain, Portugal, Greece and the UK) reveal that unresolved symptoms are common and include: physical 72%, psychological 50%, spiritual 27%, financial 20% and sexual functioning/ relationships 11%.

Carers (n=154) also described having concerns: distress about patient's physical symptoms 52%, difficulty coping 44%, difficulty providing physical care 40%, difficulty managing medications and treatment 26% and financial or legal concerns 16%.

Patients often had unmet information needs: treatment options 33%, medical/ health/ support services 32%, social/ emotional issues 31%, diagnosis 19%, prognosis 18%, financial/ legal issues 13% and advanced directive/ resuscitation 3%.

Carers had similar information needs: medical/ health/ support services 32%, diagnosis 31%, social/ emotional issues 30%, treatment options 29%, prognosis 21% and financial/ legal issues 8%.

InAdvance: site visit evidence

Best practice:

in Scotland, the results of each patient's NAT:PD were reviewed by a clinical panel consisting of a COPD specialist nurse, physiotherapist and doctor (both palliative care). Options to address any unmet needs were discussed and communicated with the patient. This promoted the identification (if not already done) of the most appropriate lead professional for that patient. That person could then better coordinate existing services and arrange suitable follow-up.

In Spain the MDT met to formally discuss each NAT:PD and agree a personalised care plan with onward referral for more specialist input if required.

InAdvance: living well course.

The 'Living Well course' was developed to try to address some of the information needs that had been identified through the initial NAT:PD interviews. It was delivered remotely using Zoom and consisted of nine one hour sessions, hosted by Highland Hospice with in-house technical and administrative support. Patients in the InAdvance study were contacted by telephone and invited to participate in the course. These patients either had COPD or heart failure. Each session was facilitated by a member of the course faculty. Participants were encouraged to interact and were given opportunities to guide the topics discussed. Each session included time to do some guided exercise. Topics covered included: What is COPD/ heart failure?, What is breathlessness?, Exercise and pulmonary rehabilitation, Conversations about advance care planning, Funerals and wills, Financial questions and Goal setting in day-to-day life.

Patients felt the remote delivery was acceptable, the format encouraged participation and discussion, the content was interesting and relevant, and the technical support was very useful.

The clinicians who delivered the course felt it complemented existing services and resources, was a useful use of their time, that the sessions were easy to deliver remotely but that technical support was essential.

### **Recommendation 3.2**



Holistic needs assessments are likely to highlight needs that are not traditionally addressed by healthcare professionals. There will need to be coordination between health and social care systems. Service planners should also be aware of other available resources, for example local voluntary/community services and on-line materials. The results of holistic needs assessments could be used for service planning, with consistent unmet needs giving evidence of need for change.

**InAdvance: site visit evidence**

The InAdvance clinical sites had very different levels of pre-existing palliative care provision. This ranged from fully integrated palliative care services in Highland, Scotland to no pre-existing palliative care services in Thessaloniki, Greece. Different approaches to service design and delivery will be needed to respond to the palliative care needs of each population, depending on the resources already available.

### **Recommendation 3.3**

People often have questions about their illness and want to be able to be involved in decisions about their current and future care. Conversations about death and dying can be seen as taboo by patients, families and even healthcare professionals. Thought will be needed to ensure information is available in ways that are acceptable, easily accessible and understood. Patients and carers may need health literacy education and extra support to understand any materials they access. This may be particularly true for older people with lower educational attainment. Much information is available on-line, and increasingly healthcare interactions are happening on digital platforms. Older people, particularly those with sensory impairment may find these sources of information difficult to access. We have shown that older people can access information on digital platforms, but that they may need considerable technical assistance to allow this.

InAdvance: Cuidar en casa (care at home) website.

Focus group and NAT:PD evidence showed that informal carers often want more information and support to allow them to confidently provide care. The website was designed to be easily accessible and understood. Information was provided using text, illustrations and videos. The main topics covered were: resources for improving the care-giving role, self-care for the caregiver, information about local services, information about the InAdvance study.

Over 8 months there were 238 visits to the website. Nine caregivers (age range 52-60) participated in a feasibility study to provide feedback. None found the site difficult to use, 8/9 said they'd use the site frequently and all strongly agreed that they would recommend the website to family and friends. Though they all felt confident using the website, 3/9 did feel they might want the support of a person with more technical knowledge.

InAdvance: Living well course.

The living well course was evaluated using an on-line focus group with the patient participants and interviews with the healthcare professionals who had delivered the course. The patients all felt the on-line, remote delivery was acceptable, though several of the participants required significant amounts of technical support. There was even the suggestion that active participation might have been easier than in a face-to-face group.

The healthcare professionals felt it was easy to deliver the course remotely but strongly emphasised how important it was to have had technical support available.

## Preparing for end-of-life care

### **Recommendation 4.1**

End-of-life care discussions can be challenging and are often avoided because of stigma, or because they are perceived as too difficult. Many patients want more information about their illness and welcome the chance to be involved with decisions about their future care. It is interesting to note that just over a quarter of the patients in the study wanted more information about their own diagnosis. There is evidence that well informed patients are less likely to want invasive treatments at the end of life. Preparations for end-of-life are about much more than physical symptoms and hands-on care. There are social, financial and spiritual preparations that can be made if the person has the information required and adequate support.

InAdvance: focus groups with patients (n=66), carers (n=28) and professionals (n=63).

Greece: patients felt they had insufficient information at diagnosis. They frequently have worries about their condition and how it will affect them in the future, particularly financially and becoming more dependent on others.

Spain: patients and carers often felt they had poor knowledge about their condition and its treatment and prognosis. Patients worried about what the future may be like.

Portugal: patients felt they did not know enough about what might happen to them in the future and what their options might be. They also worried about how their families might cope.

Scotland: patients described having inadequate information about their disease (causes, prognosis, treatment strategies) and available services. They wanted more information about how to prepare for the future, how they and their families could get support and financial advice.

InAdvance: evidence from NAT:PDs (Spain, Greece, Portugal and UK n=179)

Patients often had unmet information needs: treatment options 33%, medical/ health/ support services 32%, social/ emotional issues 31%, diagnosis 19%, prognosis 18%, financial/ legal issues 13% and advanced directive/ resuscitation 3%.

Carers (n=154) had similar information needs: medical/ health/ support services 32%, diagnosis 31%, social/ emotional issues 30%, treatment options 29%, prognosis 21% and financial/ legal issues 8%.

InAdvance: Living well course.

Feedback from the participants confirmed that the course content was very relevant to them. This included a session on wills, power of attorney and funeral arrangements. They all indicated that they would want to be involved in planning for their futures and were not frightened to speak about their own deaths. "One of the topics was funerals and future planning. I'd been a bit anxious as to how this would go, particularly remotely. It turned out that the speakers were so comfortable in their field the group freely took part. It was one of the best sessions."