

In Advance

D3.4 – Description of InAdvance Needs Assessment Intervention

**WP3 – Intervention modelling through equitable multilevel
needs assessment**

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List of acronyms	
PC	Palliative Care
RCT	Randomised Controlled Trial
COPD	Chronic Obstructive Pulmonary Disease
CONSORT	Consolidated Standards Of Reporting Trials
GOLD	Global Initiative for Chronic Obstructive Lung Disease
mMRC	Modified British Medical Research Council
CAT	COPD Assessment Tool
NAT:PD	Needs Assessment Tool: Progressive Diseases



1. Executive Summary

This report is developed to illustrate the needs assessment intervention process to provide pathways for early identification of patients who have the potential to benefit from early palliative care (PC) input.

D3.3 identified PC needs of patients living with advanced non-malignant diseases. One of the common themes identified across 5 clinical sites (UK Leeds/Highlands_COPD; Spain/Portugal_multimorbidity; Greece_COPD, frailty and heart failure) was the uncertainty and poor prognosis of non-malignant diseases, often leading to delayed identification of PC needs. Early identification and holistic needs assessment with optimised clinical pathways were concluded as the priority that needs to be addressed in the following clinical trials.

Due to a varying degree of health systems and clinical pathways for advanced patients in each site and different health conditions that each site focused on, a generic needs assessment tool is agreed to be used as the primary intervention to identify patients and their carers PC needs. This proposed intervention will then be tested and compared with usual care in a randomised controlled trial (RCT). Patients who are over 65, at the severe stage of their diseases, cognitively intact with no experience of specialist PC or current involvement in other research project are eligible to take part in this trial. If there are carers (either informal or professional) providing care and support for patients, one of them can be nominated by patients to participate in the study. The outcome of the needs assessment on patients and/or carers will trigger a management plan and PC pathway: either specialist PC where needs are met within hospice settings or generalist PC where needs are met within primary care settings.

Upon the completion of outcome assessment for the primary intervention, each site may start the test of secondary interventions proposed to support timely PC input depending on local pathways and resources. UK (Leeds/Highlands) and Spain focus on self-management support and patient-centred care, whereas Portugal and Greece on PC interventions supported by technologies developed in Work Package 4.



2. Introduction

The majority of patients with non-malignant diseases who are at the end of life are either under-identified or under assessed [1]. Our work so far carried out has suggested that there is still a lack of evidence on the implementation of early identification, holistic needs assessment and mapped PC pathways to provide early symptoms management and support to patients and their families.

An intervention itself aiming to either identify advanced patients early or assess their holistic needs is not sufficient to achieve early PC input. It is also necessary to understand patients' clinical pathways and what services are available for them in each setting so that patients' needs can be met by optimising available treatments and resources in caring for advanced patients.

This report aims to describe the needs assessment intervention and how it can be delivered in each of the clinical sites involved in the InAdvance project.

3. Methods

3.1 Design

According to needs identified and clinical pathways in each site, an intervention process was proposed based on the CONSORT (Consolidated Standards of Reporting Trials) flow diagram [2] aiming to 1) identify patients who are at the advanced stage of their diseases, 2) assess potential PC needs of patients and their carers, and 3) decide clinical pathways to address the identified needs.

Due to a varying degree of integrated palliative and disease-specific care services for patients among clinical sites, two versions of the intervention process were designed to make sure that it fits the current health system and clinical pathways. Figure 1 shows the process designed for the UK (Leeds and Highlands) Spain and Greece, and Figure 2 Portugal.



Figure 1 Intervention process_in Leeds, Highlands, Spain and Greece

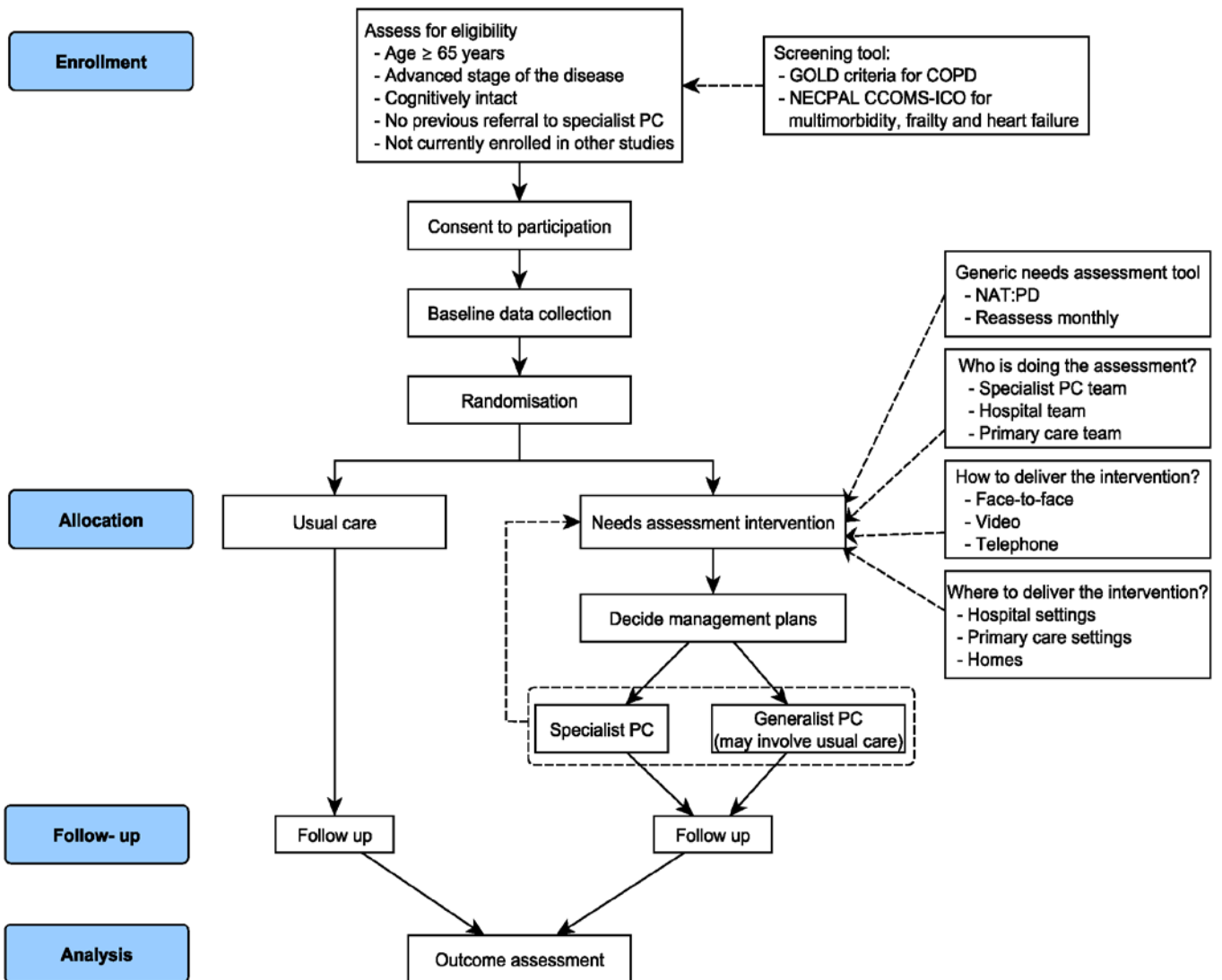
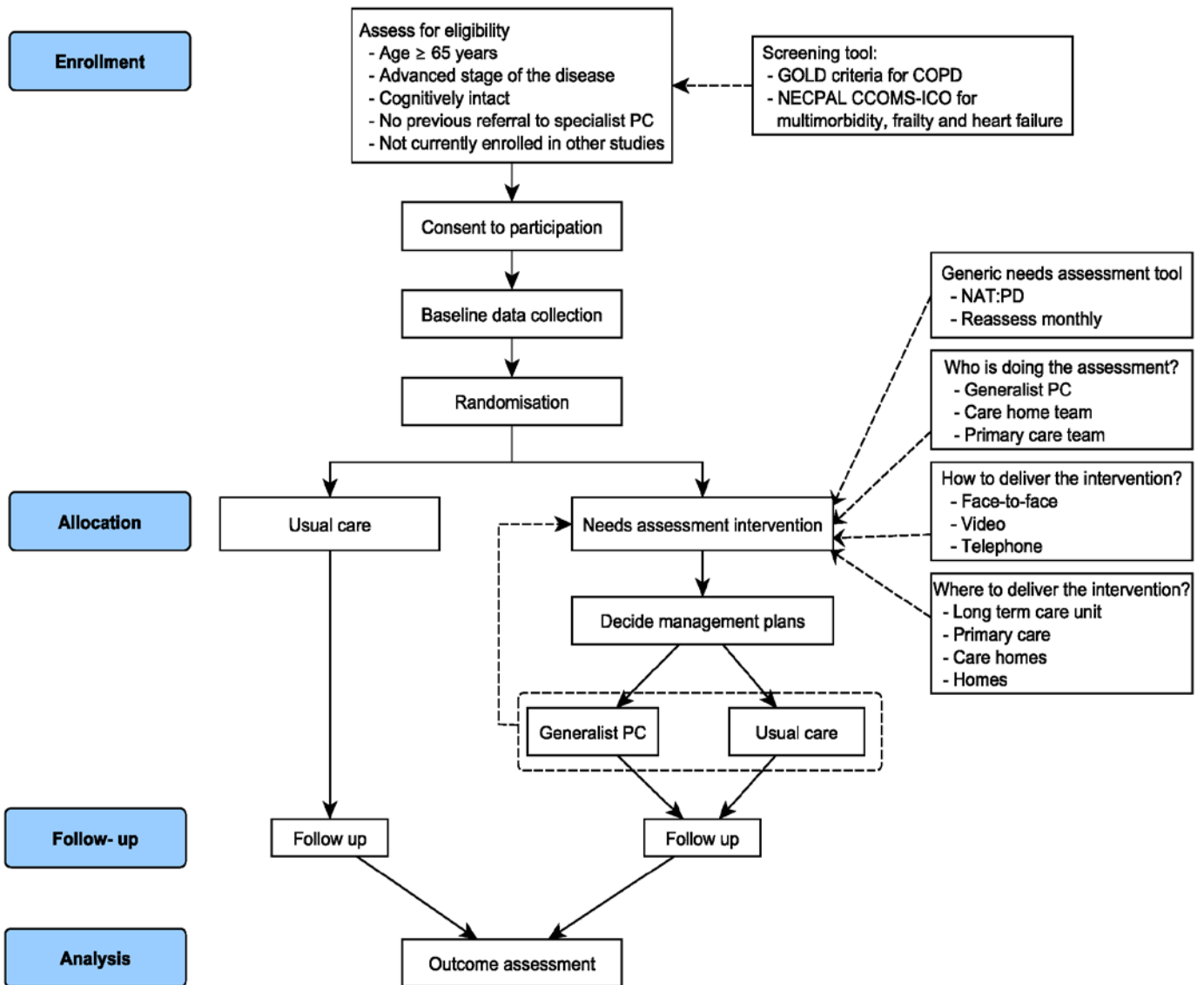


Figure 2 Intervention process_in Portugal



3.2 Setting

The intervention will be tested in an RCT across five sites with patients living with different diseases including:

- Leeds and Highlands focusing on severe COPD;
- Spain and Portugal on multimorbidity;
- Greece on COPD, frail patients with heart failure.

3.3 Enrollment

3.3.1 Eligibility

Patients who are aged 65 years old and over and live with advanced diseases will be approached. Eligible patients for the trial also need to be cognitively intact to be able to provide their consent. Patients who are diagnosed with cancer, have been referred to specialist PC services or are currently enrolled in other studies will be excluded.

Advanced status of the diseases are identified using the following tools:

- COPD (Leeds, Highlands and Greece): The Global Initiative for COPD (GOLD) system (that uses a combined symptoms assessment based on the Modified British Medical Research Council (mMRC) or COPD assessment test (CAT) scale) will be used to assess the severity of the disease to identify patients with severe and very severe COPD and those who are in Group C and D with high risk [3].
- Multimorbidity (Spain and Portugal), frailty and heart failure (Greece): the NECPAL CCOMS-ICO© 3.1 (2017) tool [4] will be used which is primarily based on the NECPAL parameters to identify the severe stage of diseases.

Carers will be identified by patients who take part in this study. Carers who are aged 18 or over, provide frequent care for patients and cognitively intact are eligible to participate in this study. Only one carer (informal or professional) can be nominated by patients.

3.3.2 Randomisation

Eligible patients will be invited to provide their written consents, after which research nurses/researchers will collect baseline data before the randomisation process.

3.4 Allocation

Patients will be randomised to receive either usual care or needs assessment intervention. The NAT: PD (Needs Assessment Tool: Progressive Disease) [5] will be used to assess the needs of patients and their carers. For patients recruited in



the UK (Leeds and Highlands), their generalist PC services may be delivered as part of the usual care.

3.4.1 Intervention

The NAT: PD is a tool (free to use) developed to be used in both generalist and specialist settings that can assist in matching the types and levels of need experienced by patients with progressive chronic diseases and their carers with health professionals to address those needs. It can also facilitate decision-making on PC referrals to ensure that the identified needs can be better managed with appropriate services and support. It is recommended that assess the needs of patients and carers on a monthly basis or when their situation or functional status changes. The tool has been validated in non cancer patients, including chronic heart failure [6, 7] and interstitial lung disease [8]. The generic version was developed based on both of these tools with very similar categories and descriptors. Permission to use and translate the NAT: PD into other languages has been provided by the developer. Please find the NAT: PD in Appendix 1.

The NAT: PD is a one-page assessment tool that consists of 21 items divided into four sections: 1) priority referral for further assessment; 2) patient wellbeing; 3) ability of caregiver or family to care for the patient; and 4) caregiver wellbeing. The level of concern is scored for each item as none, some or severe.

In each clinical trial, the NAT: PD will be delivered by:

- Leeds: COPD nurses, community matrons or consultants in the chest clinic;
- Highlands: COPD nurses and/or primary care team and/or hospice team and/or physiotherapists and/or occupational therapists.
- Spain: the Unit of Telemedicine and Hospital at Home and the case manager nurses.
- Greece: clinical team in the Hippokrateio University Hospital, Thessaloniki.
- Portugal: multidisciplinary team comprising social and healthcare professionals with complementary backgrounds, either at the care homes or at home.

The NAT: PD will be delivered either face-to-face or remotely via telephone or video, taking into consideration patient's preferences and/or ability to visit the healthcare facility or respecting social distancing protocols established by national/regional health authorities under the current COVID-19 pandemic. Researchers involved in this project at each clinical site should deliver a short session on how to use of the NAT: PD prior to the trial to ensure that the interventions will be delivered consistently in a standard approach.

3.4.2 Management plans

Based on the outcomes of the NAT: PD, in agreement with patients, patients will be provided with specific management plans and pathways to address their identified needs depending on the local resources. Decisions made on referrals or care pathways will be recorded on the NAT: PD form.



For patients recruited from UK (Leeds and Highlands), Spain and Greece, patients will be referred to the local specialist or generalist PC services, whereas patients from Portugal will be referred to local generalist PC or usual care depending on the outcome of the NAT: PD. Table 1 presents services offered for patients under each management plan.

Table 1 Service provision for specialist and generalist PC referrals

	Specialist PC	Generalist PC
UK (Leeds/Highlands)	Day services; specialist domiciliary care; inpatient unit who work towards complex symptom control and psychological support delivered by multidisciplinary team.	Primary care; district nurses; community respiratory service who work towards optimising disease specific needs and providing core level PC but are not led by a specialist level palliative care service multidisciplinary team.
Spain	Case management programme, hospital at home unit.	Primary care services as front-line health care providers.
Portugal	No PC specialised service adopted.	Complex symptom control will be delivered by a multidisciplinary team who have been educated in PC including primary care (GP and nurses); social care services, psychology and physiotherapy
Greece	No PC specialised service adopted.	Intend to form a special group of different specialities that will support the PC scheme including primary care services: GP, home aid (nurses, social services).

3.5 Follow up

Participants in both arms will be followed up every month and their needs will be reassessed using the NAT: PD at monthly basis.

3.6 Outcome assessment

Outcome measures will be assessed according to the trial protocol. More details about the outcome assessment are provided in the Deliverable 6.1 (Trial Evaluation Framework).

3.7 Secondary interventions

The trial to test and evaluate the secondary interventions will start upon the completion of outcome assessment for the primary intervention. A range of secondary interventions is proposed in each clinic site based on local pathways and resources, most of which will be supported by technology. Types of technology used are summarised as below:



- **Leeds/Highlands:** Available platform to provide support for patients and carers remotely, such as Zoom or MS Teams. No application of technology proposed in WP4.
- **Spain:** Improving patient-centred care within current clinical pathways. No application of technology proposed in WP4.
- **Portugal:** predictive analytics model; mobile app such as Adhera to improve monitoring and reassessment, deliver contents and promote behaviour change.
- **Greece:** AI-based behaviour change intervention using wearables; mobile app to collect self-reported outcomes and deliver educational resources.

Specific interventions are described in the following.

Leeds and Highlands, UK

To explore the feasibility and acceptability of delivery “living well” course remotely using available technologies e.g. Zoom, MS Teams. Patients will receive this intervention at their own homes. Possible sessions of the course include:

- Introduction/ hopes/ fears/ goal setting
- What is COPD?
- What is breathlessness? How to manage my breathlessness
- Exercise and pulmonary rehabilitation
- Day to day life. Goal setting, activities of daily living
- Finances
- How to speak to your doctor
- Planning for the future
- Funerals, wills, power of attorney

It is planned to deliver one session each week by presenters/ facilitators from a faculty including COPD specialist nurses, respiratory physiotherapists, hospice physio and occupational therapists, respiratory consultant, palliative medicine consultant, citizens advice bureau, funeral director. Each session will be approximately one-hour long with up to 18 participants. These sessions will be recorded so patients can revisit. If necessary, this remote course can be repeated every 12 weeks.

Spain

Tasks developed for the secondary intervention will focus on improving patient-centred care within current clinical pathways.

- Implement the NECPAL CCOMS-ICO® tool, after the first clinical needs assessment, to support clinical decision making related to the selection of the most appropriate management plan.
- Create and distribute welcome packs for patients, relatives and carers. Those documents will provide information related to the Hospital at Home Unit, case management programs, clinical teams, consultation times, clinical and social services and contact information, along with guidelines for the patients’ follow-up.



- Provide physical therapy support when needed to improve symptom management among advanced chronic patients and their overall QOL (functional and psychosocial well-being).
- Provide psychological treatment to patients and relatives, such as problem-solving or talking therapies, to improve symptom management and reduce the overall symptom or grief burden.
- Provide social workers' assistance, if necessary, to help patients and relatives with assessment, family dynamics, counselling, or liaison with social resources.
- Establish standardized action protocols to manage complicated situations such as comfort care options, treatments (CPR, ventilation, artificial nutrition and hydration...) or therapeutic intensities.
- Provide support Caregiver's support kits containing a collection of practical caregiving information as well as material to encourage you to take care of themselves
- Establish standardized and personalized follow-up programs aimed at patients and caregivers reinforcing several issues such as symptom assessment, clinical swing phase changes, caregivers' skills and caregiver well-being.
- Introduce a fast track program between CM programs.

Portugal

Three types of secondary interventions will be tested.

- An early/timely referral to National PC Network, supported by a Predictive Analytics Model, that will take in account the patient's health condition progress and the waiting time for bed vacancy in the National PC Network. This information will be delivered to the health professionals through the dashboard.
- A capacity building strategy leveraged on three actions below, delivered by a MDT composed of health professionals, psychologists and social workers. This could be supported by Adhera to deliver contents and promote behaviour change.
 - o A "Health Promotion Programme" for older adults and relatives focusing on behavioural change toward a healthy and active lifestyle. This action will build capacity on nutrition, exercise, and health, either physical, emotional and mental.
 - o A "Carers' Campus" to build capacity on acts of care and self-care, on ICT usage and behavioural and relational skills like communication, conflict management, resilience and decision making. This action will be delivered both for formal and informal carers and patients in a B-Learning format to better serve their needs.
 - o A "Loss&Grief Support Programme" delivered by professionals that will be trained on how to help relatives cope with emotions and attitudes related to loss and grief.
- Two stages of early PC intervention delivered by a MDT:
 - o The 1st stage is a rapprochement to PC that is meant to be delivered on an "equilibrium phase" where the condition is either stable or progressing slowly. This action is delivered both at care homes and home services and



implies a 1-month cycle monitoring on day 1 and 7 to continually reassess the patient's needs.

- The "In advance" stage is a more intensive approach to PC that is to be delivered after the referral to the PC Network, while the patient waits at the care home for the vacancy. This action implies continuous monitoring/reassessment every 3 days possibly through the dashboard.

Greece

To test technology and digital tools that are developed to support patients, caregivers and health professionals. Users will be recruited from the same pools used in the needs assessment intervention. Participants involved in needs assessment intervention will be invited to take part in the technology intervention should they wish to. The sample size will be smaller with no control group. These digital tools, assessed through a smartphone, will be easy to use, supporting all three aforementioned user groups (patients, caregivers and health professionals) and promote PC strategies.

The AI-based behaviour change intervention is going to be delivered as follows:

- Patients undergoing this intervention will be provided with a wearable (it could be either commercial -i.e. fitbit, polar- or medical degree -i.e. Actigraph-wristband) and a mobile app. The wearable will gather biometric information (physical activity and sleep quality). The mobile app will gather psychometric information through validated questionnaires (mental wellbeing, symptoms, etc) and other valuable information related to lifestyles such as nutrition habits, smoking habit, social interactions and treatment adherence. Information regarding in-app behaviour is also gathered by the app, including user ID (random alphanumeric code), password for accessing the app, number of sessions (number of times the user opens the app), length of the sessions, time spent on each of the sections of the app, ratings given to the recommendations and educational contents, whether the mobile has or not enabled push notifications, answers to the quizzes (educational contents), and whether the user has read or not each of the educational pills. On the other hand, the app will deliver a behaviour change intervention aiming at fostering adherence towards healthier lifestyle habits through:
 - Delivery of AI-based personalized motivational messages built upon clinically validated recommendations extracted from regarded clinical guidelines and conformed according to the I-Change behaviour change theory [9] to optimize its impact.
 - Delivery of scientifically grounded educational resources to improve disease self-management making use of a spaced learning methodology and a gamification approach to ensure incremental retention while minimising the perceived mental fatigue by the patient.
- Caregivers will be provided with a mobile app with the same functionality that the patients' one but adapted to the role of caregiver (i.e. motivational messages and educational resources will deal with topics closer to the caregivers such as grief and empathy).
- Clinical researchers will have access to a web application where they will be able to access all the information being gathered on the patient and caregiver



sides, so they can take this information into account to personalise the care pathway during follow-up consultations if needed.

- Both patients and caregivers will have access to e-forums and chat rooms where they will connect and exchange experiences and tips. Both patients and caregivers will have access to virtual patient and scenarios (mobile app) that will train them to better handle their health issues and maintain their wellbeing.
- Health professionals will attend live sessions improving their empathy and communication with their patients. Resulting from these sessions, Virtual Patient scenarios will be created to train more doctors online and improve their skills in PC.

3.8 Limitations

Potential sources of bias may exist in this trial, concerning allocation concealment, imbalance in baseline prognostic variables, no blinding, the application of intention to treat analysis. Details on how to handle these potential limitations can be found in the trial protocol.

4. Conclusion

This report is developed to illustrate the needs assessment intervention process to provide pathways for early identification of patients who have the potential to benefit from early PC input. The NAT: PD will be used to assess patients and their carers PC needs, the outcome of which will trigger a specific management plan and PC pathway to address the identified needs, in agreement with patients, depending on the local health care services and resources.

This proposed intervention process will then be tested and compared with usual care in an 18-month RCT in 5 clinical sites, which protocol is explained in the Deliverable 5.1 (“Final version of the Trial operation Protocol”).



5. References

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Appendix 1. Needs Assessment Tool: Progressive Disease (NAT: PD)

NEEDS ASSESSMENT TOOL: PROGRESSIVE DISEASE (NAT: PD) USER GUIDE

Purpose of the NAT: PD

- Used in both generalist and specialist settings, the Needs Assessment Tool: Progressive Disease (NAT: PD) can assist in matching the types and levels of need experienced by people with progressive chronic diseases (eg cancer, heart failure, COPD) and their caregivers with the most appropriate people or services to address those needs.
- In generalist settings (eg general practice, oncology and cardiology), the NAT: PD can be used to determine which needs may be met in that setting and which needs are more complex and may be better managed by specialists.
- In specialist settings (eg specialist palliative care services), the NAT: PD can assist in determining when complex needs have been met and act as a discharge planning tool, or to identify the need for ongoing support.
- The NAT: PD is an important tool for facilitating communication between primary and specialist care providers about patient needs and actions taken to address these.

Completing the NAT: PD

The NAT: PD is a one-page assessment tool that can be completed by health professionals across a range of disciplines. When completing the NAT: PD, the following steps should be followed:

1. **ASSESS** patient/caregiver level of concern FOR EVERY ITEM, using the response options: "none", "some/potential for" or "significant".
2. **CONSIDER** the range of issues within each domain that apply to a person at this stage of their illness. Prompts are provided on a separate page to help you.
3. **ACT** on each need where you identified some concern ("some/potential for" or "significant"). Your actions may include: directly managed by you, managed by another member of your care team, or referral to someone outside your care team. Record your action on the NAT: PD.
4. **REFER** if required by completing the referral section at the bottom of the tool, ensuring that information regarding the type of referral, the priority of the referral and client knowledge of the referral is included.
5. **INFORM** other members of the care team of the outcomes of the needs assessment by:
 - a. Filing one copy of the NAT: PD in the patient's medical file.
 - b. Sending a copy to the person's GP/oncologist/cardiologist/other specialist.
 - c. If a referral is required, forwarding a copy to the referee.
6. **REASSESS** needs by completing the NAT: PD approximately monthly or when the patient's or family's situation, or functional status changes.



NEEDS ASSESSMENT TOOL : PROGRESSIVE DISEASE (NAT: PD)

COMPLETE ALL SECTIONS

PATIENT NAME: _____

DATE: _____ DIAGNOSIS: _____

PATIENT/ADDRESS LABEL

SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT			
	Yes	No	
1. Does the patient have a caregiver readily available if required?		*	If dotted boxes are ticked, consider assessment by SPCS
2. Has the patient or caregiver requested a referral to a specialist palliative care service (SPCS)?	*		
3. Do you require assistance in managing the care of this patient and/or family?	*		

SECTION 2: PATIENT WELLBEING (Refer to the prompt sheet for assistance)								
	Level of Concern			Action Taken				
	None	Some/Potential	Significant	Directly managed	Managed by other care team member	Referral required (complete referral section below)		
1. Is the patient experiencing unresolved physical symptoms (including problems with pain, breathlessness, sleeping, appetite, bowel, fatigue, nausea, oedema or cough)?								
2. Does the patient have problems with daily living activities?								
3. Does the patient have psychological symptoms that are interfering with wellbeing or relationships?								
4. Does the patient have concerns about how to manage his/her medication and treatment regimes?								
5. Does the patient have concerns about spiritual or existential issues?								
6. Does the patient have financial or legal concerns that are causing distress or require assistance?								
7. Does the patient have concerns about his/her sexual functioning or relationship?								
8. From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?								
9. Does the patient require information about: (tick any options that are relevant)	<input type="checkbox"/> The diagnosis	<input type="checkbox"/> The prognosis	<input type="checkbox"/> Treatment options	<input type="checkbox"/> Medical/health/support services	<input type="checkbox"/> Financial/legal issues	<input type="checkbox"/> Social/emotional issues	<input type="checkbox"/> Advance directive/resuscitation order	<input type="checkbox"/> Other:

COMMENTS: _____

SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR THE PATIENT (Refer to the prompt sheet for assistance)								
Who provided this information? (please tick one) <input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Both	Level of Concern			Action Taken				
	None	Some/Potential	Significant	Directly managed	Managed by other care team member	Referral required (complete referral section below)		
1. Is the caregiver or family distressed about the patient's physical symptoms?								
2. Is the caregiver or family having difficulty providing physical care?								
3. Is the caregiver or family having difficulty coping?								
4. Is the caregiver or family have difficulty managing the patient's medication and treatment regimes?								
5. Does the caregiver or family have financial or legal concerns that are causing distress or require assistance?								
6. Is the family currently experiencing problems that are interfering with their functioning or inter-personal relationships, or is there a history of such problems?								
7. Does the caregiver require information about: (tick any options that are relevant)	<input type="checkbox"/> The diagnosis	<input type="checkbox"/> The prognosis	<input type="checkbox"/> Treatment options	<input type="checkbox"/> Medical/health/support services	<input type="checkbox"/> Financial/legal issues	<input type="checkbox"/> Social/emotional issues	<input type="checkbox"/> Advance directive/resuscitation order	<input type="checkbox"/> What to do in event of patient's death

COMMENTS: _____

SECTION 4: CAREGIVER WELLBEING (Refer to the prompt sheet for assistance)						
Who provided this information? (please tick one) <input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Both	Level of Concern			Action Taken		
	None	Some/Potential	Significant	Directly managed	Managed by other care team member	Referral required (complete referral section below)
1. Is the caregiver or family experiencing physical, practical, spiritual, existential, sexual or psychological problems that are interfering with their own wellbeing or functioning?						
2. Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their own wellbeing or functioning?						

COMMENTS: _____

IF REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE, PLEASE COMPLETE THIS REFERRAL SECTION
1. Referral to: (Name) _____
2. Referral to: (Specialty) <input type="checkbox"/> General practitioner <input type="checkbox"/> Social worker <input type="checkbox"/> Psychologist <input type="checkbox"/> Specialist palliative care service <input type="checkbox"/> Physiotherapist <input type="checkbox"/> Community nurse <input type="checkbox"/> Oncologist <input type="checkbox"/> Cardiologist <input type="checkbox"/> Occupational therapist <input type="checkbox"/> Other: _____
3. Priority of assessment needed: <input type="checkbox"/> Urgent (within 24 hours) <input type="checkbox"/> Semi-Urgent (2-7 days) <input type="checkbox"/> Non-Urgent (next available)
4. Discussed the referral with the client. <input type="checkbox"/> Yes <input type="checkbox"/> No
5. Client consented to the referral. <input type="checkbox"/> Yes <input type="checkbox"/> No
6. Referral from: Name: _____ Position: _____ Signature: _____

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PROMPT SHEET: ISSUES TO CONSIDER WHEN RATING THE LEVEL OF CONCERN

PATIENT WELLBEING
<p>Physical symptoms</p> <ul style="list-style-type: none"> Does the patient present with unresolved physical symptoms such as drowsiness, fatigue, dyspnoea, vomiting/nausea, persistent cough, pain, oedema, constipation, diarrhoea, sleep problems or loss appetite? <p>Activities of daily living</p> <ul style="list-style-type: none"> Is the patient having difficulty with toileting, showering, bathing, or food preparation? Is there a caregiver to assist the patient? <p>Psychological</p> <ul style="list-style-type: none"> Is the patient experiencing sustained lowering of mood, tearfulness, guilt or irritability, loss of pleasure or interest in usual activities? Is the patient experiencing feelings of apprehension, tension, anger, fearfulness or nervousness, hopelessness or a sense of isolation? Is the patient requesting a hastened death? <p>Medication and treatment</p> <ul style="list-style-type: none"> Is the patient able to manage complex medication and treatment regimes? <p>Spiritual/Existential</p> <ul style="list-style-type: none"> Is the patient feeling isolated or hopeless? Does the patient feel that life has no meaning or that his/her life has been wasted? Does the patient require assistance in finding appropriate spiritual resources or services? <p>Financial/Legal</p> <ul style="list-style-type: none"> Are there financial concerns relating to loss of income or costs of treatment, travel expenses, or equipment? Is the family socio-economically disadvantaged? Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advance care plans? Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these? <p>Sexual</p> <ul style="list-style-type: none"> Does the patient have concerns about his/her sexual functioning or relationship? <p>Health Beliefs, Social and Cultural</p> <ul style="list-style-type: none"> Does the patient or family have beliefs or attitudes that make health care provision difficult? Are there any language difficulties? Does the patient or family require a translator? Is the family preventing information about prognosis from being disclosed to the patient? Is the patient or family feeling socially isolated? Does the family live more than 50km from the primary service provider? Is the patient of Aboriginal or Torres Strait Islander descent? Is the patient over 75 years of age? (NB: older patients are under-represented in SPCs.) <p>Information</p> <ul style="list-style-type: none"> Does the patient want more information about the course and prognosis of the disease and treatment options? Is the patient aware of the various care services available to assist them and do they need assistance in accessing these?
ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT
<p>Physical symptoms</p> <ul style="list-style-type: none"> Are the patient's physical symptoms causing the caregiver or family distress? <p>Providing physical care</p> <ul style="list-style-type: none"> Is the caregiver or family having difficulty coping with activities of daily living or practical issues such as equipment and transport? <p>Psychological</p> <ul style="list-style-type: none"> Is the caregiver or family having difficulty coping with the patient's psychological symptoms? Is the caregiver or family requesting a hastened death for the patient? <p>Medication and treatment</p> <ul style="list-style-type: none"> Is the caregiver or family having difficulty managing complex medication and treatment regimes? <p>Family and Relationships</p> <ul style="list-style-type: none"> Is there any communication breakdown or conflict between patient and family over prognosis, treatment options or care giving roles? Is the patient particularly concerned about the impact of the illness on the caregiver or family? <p>Information</p> <ul style="list-style-type: none"> Does the caregiver or family want more information, eg about the course and prognosis of the disease and treatment? Is the caregiver or family aware of the care services available to assist them and do they need assistance in accessing these? (eg respite, financial and legal services, psychological services, support groups, pastoral care.)
CAREGIVER WELLBEING
<p>Physical and psychosocial</p> <ul style="list-style-type: none"> Is the caregiver experiencing physical symptoms eg fatigue, physical strain, blood pressure/heart problems, stress related illness, or sleep disturbances? Is the caregiver feeling depressed, hopeless, fearful, nervous, tense, angry, irritable or critical of others, or overwhelmed? Does the caregiver have spiritual/existential issues that are of concern? Does the caregiver have concerns about his/her sexual functioning or relationship? <p>Bereavement Grief (pre and post death)</p> <ul style="list-style-type: none"> Is the caregiver or family experiencing intrusive images, severe pangs of emotion, denial of implications of loss to self and neglect of necessary adaptive activities at home or work?

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Further copies are available at: <http://www.newcastle.edu.au/research-centre/cherp/professional-resources>

