A Streamlined Care Pathway Model

Incorporating the WELCOME System as a Tool of Care

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WELCOME

Wearable Sensing and Smart Cloud Computing for Integrated Care to COPD Patients with Comorbidities

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Project Partners: EXODUS (GR), CSEM (CH), KINGSTON (UK), AUTH (GR), INVENTYA (UK), CAU (DE), ROYAL COLLEGE OF SUR (IR), SMARTEX (IT), CIRO+ B.V. (NL), Kristronics GmbH (DE), UNIVERSADE DE COIM (PT), Croydon Health Servi (UK)
## Contributors

<table>
<thead>
<tr>
<th>Name</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reem Kayyali</td>
<td>KINGSTON</td>
</tr>
<tr>
<td>Shereen Elnahhani</td>
<td>KINGSTON</td>
</tr>
<tr>
<td>Inez Frerichs</td>
<td>CAU</td>
</tr>
<tr>
<td>Nikki Davies</td>
<td>CROYDON</td>
</tr>
<tr>
<td>Eleni Perantoni</td>
<td>AUTH</td>
</tr>
<tr>
<td>Shona D’Arcy</td>
<td>RCSI</td>
</tr>
<tr>
<td>Anouk Vaes</td>
<td>CIRO+</td>
</tr>
<tr>
<td>John Chang</td>
<td>CROYDON</td>
</tr>
<tr>
<td>Martijn Spruit</td>
<td>CIRO+</td>
</tr>
<tr>
<td>Nada Philip</td>
<td>KINGSTON</td>
</tr>
<tr>
<td>Roshan Siva</td>
<td>CROYDON</td>
</tr>
<tr>
<td>Evangelos Kaimakamis</td>
<td>AUTH</td>
</tr>
<tr>
<td>Ioanna Chouvarda</td>
<td>AUTH</td>
</tr>
<tr>
<td>Barbara Pierscionek</td>
<td>KINGSTON</td>
</tr>
<tr>
<td>Norbert Weiler</td>
<td>CAU</td>
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## Peer Reviewers

<table>
<thead>
<tr>
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<th>Organization</th>
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<tr>
<td>Andreas Raptopoulos</td>
<td>EXUS</td>
</tr>
<tr>
<td>Anouk Vaes</td>
<td>CIRO+</td>
</tr>
<tr>
<td>Pantelis Natsiavas</td>
<td>AUTH</td>
</tr>
<tr>
<td>Paulo de Carvalho</td>
<td>COIMBRA</td>
</tr>
<tr>
<td>Evangelos Kaimakamis</td>
<td>AUTH</td>
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## Revision History

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Executive Summary

Successful COPD management requires a multidisciplinary approach. Current evidence shows that improvement in quality of life and reduction in healthcare costs can be achieved by integrating care via telehealth.[1,2] Maintaining adherence and lifestyle management is another important aspect of chronic obstructive pulmonary disease (COPD) follow-up.

This task as part of the WELCOME EU project aimed to map current COPD care pathway in 5 European countries (Germany, Greece, Ireland, Netherlands & UK) and identify how telehealth can integrate it.

Healthcare professionals from 5 collaborative partners were interviewed using a qualitative, semi-structured 2 stages email interview.

Lack of communication among different healthcare providers managing COPD and co-morbidities is a common feature of the studied care pathways. GPs/family doctors are responsible for liaising between different teams/services, apart from Greece where this is done through pulmonologists. Ireland and the UK are the only countries with services for patients at home to shorten unnecessary hospital stay.

In all countries, the lifestyle management service provided is similar with no specific tools used to enhance patients’ adherence. Furthermore, no specified role/training exists for informal carers (partners, family & friends).

Service and professional integration between care settings using a unified system targeting COPD and co-morbidities is a priority. An outline of how this can be achieved using the WELCOME telehealth care system was proposed.
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1 Introduction

WELCOME (Wearable Sensing and Smart Cloud Computing for Integrated Care to COPD Patients with Co-morbidities) aims to develop an integrated care approach for continuous monitoring and detection of worsening events for patients suffering from COPD with chronic heart failure, diabetes, anxiety and depression as comorbidities. This system will be validated in five countries; Greece, UK, Ireland, Germany and Netherlands.

Countries often have different care pathways for long term conditions and thus respond in different ways to similar problems. [3] Determining similarities and differences, using international comparative research, can improve health and the functioning of health services. [4]

As part of the WELCOME project, the care pathway for patients with COPD was compared between five countries: England, Ireland, Netherlands, Greece and Germany. The purpose was to explore the similarities and differences in diagnosis, follow-up and services provided to patients to manage COPD. Such information will enable the design of a unified WELCOME telehealth system that can be integrated in COPD patients’ care pathway in each of the EU countries acting as pilot sites.
2 Method

Healthcare professionals from 5 collaborative partners were interviewed using a qualitative, semi-structured 2 stages email interview. The interview schedule is provided in appendix A. The interview aimed to elicit the current care pathway for COPD patients with co-morbidities in the hospital setting, community setting in terms of guidelines used, adherence and lifestyle measures provided, training and education etc. In the first stage, questions listed in Appendix A were sent to each of the five centres. Follow-up questions were sent as appropriate to further explore the care pathways. The follow up questions for each of the clinical sites are available in Appendix B.

2.1 Data analysis

The received data were read and entered into an MS Excel spread sheet to compare each question reply from different centres (Appendix C). Similarities and differences were concluded, and follow up question were designed accordingly. Follow up answers were also entered into the same spread sheet. The final version was analysed to illustrate the care pathways. Diagrammatical presentation of each care pathway was produced (Appendix D).
3 Results and Discussion

The current COPD care pathway for each country is attached in Appendix D. The care pathway for COPD patients starts at the general practitioner (GP) in UK, Netherlands and Germany, while in Greece and Ireland it starts from the Hospital (or secondary care).

The diagnostics parameters, normal ranges, therapeutic targets and alerts values for COPD patients are only slightly different between the five countries. UK and Ireland follow NICE COPD guidelines (CG101), the Netherlands follows ATS/ERS (American Thoracic Society [http://www.thoracic.org/clinical/copd-guidelines] /European Respiratory Society [http://ersnet.org/news/item/4401-new-clinical-recommendations-for-diagnosing-and-treating-copd.html]) and Chronic Obstructive lung Disease GOLD [http://www.goldcopd.org/Guidelines/guidelines-resources.html] guidelines, while Greece follows GOLD. In Germany, they use their national guideline for the Management of COPD and the Disease management programmes on COPD which are issued by the statutory health care insurance funds.

The follow-up care services (e.g. pulmonary rehabilitation (PR)) differ largely between countries. In UK, the follow-up is provided by GP visits, community services, hospital chest clinics and special clinical teams. The follow-up care services involve GPs, specialists (consultants in UK), physiotherapist and nurses. The special clinical team members, which operate through local respiratory teams, are hospital based but provide services in the community.

UK is the only country to provide community services. These include the respiratory teams and community matrons providing specialist input and basic support including respiratory teams’ clinics, PR and smoking cessation. Such services are funded by the National Health Service (NHS) in the UK and they are free to all patients.

In Ireland an outreach team consisting of a respiratory consultant, a practice physiotherapist and nurses provide an early supported discharge, assisted discharge, PR, and transitional care program for inpatients. For outpatients a service in a respiratory COPD clinic and a PR program is available. The outreach program is funded by the Health Service Executive (HSE) that operates in Ireland and patients do not have to pay for such services.

In Netherlands, the follow-up of patients takes place in primary or secondary care. GPs are involved in the prevention, diagnosis and treatment and follow-up care of COPD and they have a gate-keeping role. The gate-keeping principle determines that hospital care and specialist care (except emergency care) are only accessible upon referral from a GP. Specialist care involves referral to centres like CIRO+ (Centre of expertise for chronic organ failure) where services like PR get provided. In Greece, there are no special services provided for outpatients with no role of primary care.

The follow-up parameters are similar and include spirometry tests, body mass index (BMI), blood gases and oxygen saturation. Follow-up occurs via face-to-face appointments, the frequency of which depends on patients’ needs in both Germany and Netherlands, but it is performed annually in UK, and biannually in Greece and Ireland.

In UK and Ireland, there are currently special schemes to support patients at home. In UK, telehealth service is being provided to COPD patients along with facilitated discharge, management plans for some patients and rescue packs. In Ireland, early supported discharge, assisted discharge, and transitional care programs are used to support patients at home, but only if the patients meet the inclusion criteria.
Co-morbidities:
The management pathways of COPD with co-morbidities (namely diabetes, heart failure, and mental conditions) were also compared. In the five countries, the same management of COPD is followed even if the patients are being diagnosed with co-morbidities. Each co-morbidity is managed independently following its own national guidelines and providing its own services (e.g. clinical teams...).

It is noticeable that the different diagnosed condition services don’t communicate with each other directly. In all countries, the GP is mainly responsible for liaising and referring patients between these services and clinical teams, except for Greece where this is done through the pulmonologist.

Pharmacist Role:
The role of pharmacist is similar in these countries and is limited to check inhaler techniques and compliance to inhaled medication.

Adherence and Lifestyle:
The services being provided for lifestyle management is similar between the five countries. Smoking cessation, advice on annual flu vaccination, advice on importance of PR and referral to dieticians are example of such services.

The patients’ adherence to therapy is monitored differently. In Greece, the pulmonologist monitors the adherence by questionnaires and demonstration with the devices. In UK, the adherence is monitored mainly by the appropriate teams running PR and smoking cessation. In Netherlands the patients’ adherence is done during group sessions (training, education, smoking cessation). No specific services are available in Ireland to monitor adherence to therapy. In all countries, there is no specified role or training for the informal carer (partners, family, and friends).

Figure 1 shows the proposed model for the integration of telehealth in the care pathway. The proposal is for a patient-centred telehealth system which will integrate the fundamental elements of care provided by the multidisciplinary healthcare team into a unified holistic system targeting COPD and its co-morbidities. The aim of the system is to provide better communication between healthcare providers, patients and informal carers resulting in streamlined patient care. The system will allow sharing of information; clinical parameters, recent change in prognosis, hospitalisation information etc between all the HCPs involved in patient care including the informal cares and the patients themselves. This will allow for joined up care between different sectors/teams removing the need for this to be done by a GP or a pulmonologist. This should enable accessibility to up-to-date information, hence allowing for timely and holistic care being provided with less chance of error. The information shared will include current medicines and past medical and current history of the patient as being monitored regularly etc. All information will be stored in the secure cloud system proposed by WELCOME allowing different level of accessibly to data by the HC team, the patient and their carer.

The system proposed will also enable real time communication between the patient and an assigned HCP and will provide patient with updates and alerts about their condition at home, hence empowering them to be in charge of their own care and allowing for early detection of deterioration.
Figure 1: Sample Integration of telehealth into care pathway. HCP=healthcare professional

This schematic presentation proposes a patient-centred telehealth system which integrates care provided by the multidisciplinary healthcare team allowing for information to be shared by different care providers including informal carers, hence providing integrated and streamlined care to patients.
4 Conclusions

The care pathway for COPD and co-morbidities in the 5 European countries where the WELCOME system will be validated was identified. It was evident that the care is not integrated but rather provided separately by each HCP with GPs or pulmonologist acting as the coordinators of information/care between the different HC team. The system proposed will allow for patient data to be shared securely between HC providers and settings hence ensuring that each is accessible to up-to-date patient information and that care of patient is streamlined and integrated regardless of how many co-morbidities they have. This should allow for potential errors to be reduced as each HCP will be accessible to the recent clinical parameters for the patient as being monitored at home without any delay.

Despite the differences in care pathways between the counties in terms of services offered and the coordination of care provided, it was evident that the diagnostic and follow up parameters were largely similar and that the main guidelines used stemmed from GOLD, this outlines the feasibility of a unified telehealth integrated system that can be applied within the EU. A diagrammatical proposal outlining how telehealth can integrate care of COPD patients with co-morbidities at service and professional level was outlined.
Bibliography


Abbreviations

- GP: General Practitioner
- PR: Pulmonary Rehabilitation
- HSE: Health Service Executive
- BMI: Body Mass Index
- HCP: Health Care Professional
Appendix A. Interview questions

WELCOME – WP2

Clinical and end-users requirements - Observational Study

1. COPD General:
   1.1. What is the percentage/prevalence of COPD patients with co-morbidity (ies) in each centre?

   Please answer questions 2 to 8 for an uncomplicated COPD patient. Then consider these questions again for the following cases: COPD patient with diabetes, COPD patient with heart failure, and COPD patient with mental conditions. Please provide the clinical diagnostic, monitoring parameters, treatment plan and the healthcare professionals involved in the management of each co-morbidity.

2. Diagnosis, monitoring and follow-up:
   2.1. What are the diagnostics parameters for COPD patients? (e.g. spirometry, oxygen saturation etc)
   2.2. What are the normal ranges, therapeutic targets and alerts values of these diagnostics parameters?
   2.3. How frequent are the diagnostics parameters measured?
   2.4. What are the diagnostic parameters that are checked regularly? (e.g. oxygen, weight, FEV1, etc)
   2.5. What are the follow-up care services available for COPD patients? (e.g. pulmonary rehabilitation)
   2.6. Who is the team involved in follow-up care?
   2.7. How frequently do follow-up events happen?
   2.8. What is the format of follow up? (e.g. face to face, phone, etc)
   2.9. If a patient is diagnosed with co-morbidity, who offers treatment, follow up?
   2.10. What are the referral procedures for patients with co-morbidities?
   2.11. What types of preventive care is available for COPD patients?
   2.12. Do patients have personal care plans?

3. Guidelines followed:
3.1. Are there any specific guidelines (local and/or national) being followed in the management of COPD and associated co-morbidities? (please provide copies)
3.2. Are there guidelines/protocols for referral between settings of care?

4. Healthcare professionals and teams
4.1. Who are the HCPs and/or teams involved in the management of COPD?
4.2. What is the role of each professional/team?
4.3. Where does the patient’s care pathway usually start?
4.4. Which HCP do the COPD patients primarily go to for the management of their COPD?
4.5. Who provides the following for COPD patients?
   4.5.1. Diagnosis.
   4.5.2. Treatment.
   4.5.3. Follow-up care in stable patients. (please include extra information e.g. regular screening for depression)
   4.5.4. Follow-up care in acute phases (exacerbations).
   4.5.5. Follow-up care in patients with co-morbidities
   4.5.6. Preventive care.
4.6. What relevant forms of collaboration are available between different healthcare teams (Respiratory Care Team, Diabetes team, CHF team) who are responsible for the management of the patient’s condition?
4.7. Is this integrated through the GP/Family Doctor?

5. Support at home
5.1. Is there any type of telehealth services provided for COPD patients?
5.2. Is there any type of other support provided for COPD patients at home? (e.g. early hospital discharge (hospital at home), rescue packs)
5.3. What home monitoring procedures are used by patients, if any?

6. Support at community
6.1. Are there any community services/teams looking after COPD patients? (e.g. community outreach teams, community health team)
6.2. Who refer the COPD patients to the community services?
6.3. Who leads the community services?
6.4. Which other health professionals are involved in the community services?
6.5. What sort of services is provided by the community teams?
6.6. Where other services are provided in the community?
6.7. Is there a defined role for the informal carer (partners, family, and friends)? (if yes, specify)
6.8. What is the role of social care?

6.9. What roles do pharmacists play in the management of COPD? (e.g. medicine optimisation, medication review, adherence)

7. **Secondary Care**

7.1. What type of services is provided by the hospitals to inpatients? (services specific to COPD care or its co-morbidity e.g. pulmonary rehabilitation, depression assessment, etc)

7.2. What type of services is provided by the hospitals to outpatients? (regular assessments, medication reviews, etc)

7.3. Which health professionals are involved in the hospital care for COPD patients?

8. **Adherence and Life Style**

8.1. Is there any form of advice and/or services being provided for lifestyle management (e.g. Smoking, vaccinations, diet, physical activity, weather pollution...)?

8.2. If yes, what is the standard lifestyle advice/recommendation provided?(please provide guidelines if used)

8.3. How is the patients’ adherence to therapy being monitored?

8.4. What tools (if any) are used to enhance patients’ adherence?

8.5. What tools (if any) are used to enhance patients’ lifestyle (e.g. smoking cessation...)?

8.6. Are there any other services being provided to patients? If yes, what are they?

9. **Training and Education**

9.1 Is there standard training offered to HCP involved in COPD care?

9.2 Is there standard education that gets offered to COPD patients? What does it cover?

9.3 Is there standard training and education offered to informal carers?
Appendix B.  Follow up questions for each clinical site

WELCOME – WP2

Clinical and end-users requirements - Observational Study

UK Follow up Questions

1. Who is the patient first point of contact when having an exacerbation?
2. In question 2.9
   a. Could you please specify what you mean by “Primary Care” is? Is it only GPs or does it include other HCP
   b. Who conduct the CBT, how is depression/anxiety diagnosed and how frequent COPD are screened for mental illnesses (depression and anxiety)?
3. What effect will the new NHS structure have on this pathway? The new structure talks about local services and no more primary and secondary care.
4. In question 3.1, do you mean NICE guidelines?
5. In question 3.2, could we have a copy of the new local pathway?
6. In question 4.1
   a. Where is the CRT team based? (Hospital, GP practice, other)
   b. Where is the Chest Clinic based?
7. In question 4.2, do the same consultants work in Chest Clinic and the CRT? or are those different?
8. In question 5.1 could we have more details about the current Telehealth service? is it for patients with only COPD, or for COPD and co-morbidities.
9. In question 5.3, is Telehealth considered as a standard of care, or is it being provided selectively?
10. In question 6.4, we assume that this includes physiotherapist?
11. In question 6.6
    a. Where is PR being provided for patients and by which HCPs?
    b. Where is Smoking Cessation being provided for patients and by which HCPs?
12. In question 7.1, could we have more details about COPD bundle and Facilitated Discharge.
13. In question 8.3, who is part of the PR team?

Co-Morbidities

In order to have a better understanding of the management of COPD with co-morbidities, could you please answerer the following questions:
1. For EACH of the three most common co-morbidities, heart failure, diabetes, and Mental disorders (depression and anxiety), could we have the:
   a. Clinical diagnostic and monitoring parameters used
   b. Clinical guidelines used
   c. Frequency of follow-up
   d. Other specialised teams available for the management of each co-morbidities

2. What role does the CRT team play in the management of the co-morbidities? Is it only for the management of COPD, or do they liaise and refer patients to other teams?

3. Apart from the GP and Hospital, who else is involved in the management of COPD patients with heart failure, diabetes, and/or Mental disorders.(e.g. nurse, dietician, physiotherapist)

4. In particular, how is depression and anxiety being assessed and screened in COPD patients?
WELCOME – WP2

Clinical and end-users requirements - Observational Study

Germany Follow up Questions

1. Where are the Specialist/Consultant based (i.e. Hospital or community)?
2. Is there any form of interaction/liaison between the different Specialists/Consultants? or is the communication only made through GP?
3. Is there a specific Specialist/Consultant for mental illnesses (depression and anxiety) or is it done by the GP?
4. How frequent is the patient being assessed for depression and anxiety?
5. What does the Respiratory Team consist of? Where is it based? Who refer patient to the team?
6. For EACH of the three most common co-morbidities, heart failure, diabetes, and Mental disorders (depression and anxiety), could we have the:
   a. Clinical diagnostic and monitoring parameters used
   b. Clinical guidelines used
   c. Frequency of follow-up
   d. Other specialised teams available for the management of each of the co-morbidities
7. What role does the Respiratory Team play in the management of the co-morbidities. Is it only for the management of COPD, or do they liaise and refer patients to other teams?
8. Which Health Care Professionals are involved in the Rehabilitation?
WELCOME – WP2

Clinical and end-users requirements - Observational Study

Greece Follow up Questions

1. In question 2.5, which health care professionals are involved in the outpatients clinics? Who refer the patients to these clinics? (Hospital, pulmonologist...)

2. In question 2.7, will the frequency of the follow-up events be different between stable and complicated patients i.e. according to clinical need?

3. In question 2.10, if the patients had one/more co-morbidity:
   a. are there any special outpatients clinics for the co-morbidities? (diabetes, heart failure, and depression)
   b. If yes, which health care professionals are involved in these outpatients clinics? Is there a form of communication between the different outpatients’ clinics?
   c. Who refer the patients to these clinics?

4. In question 4.5.3, would the pulmonologist perform all the follow up checks, or is there another HCP involved?

5. In question 5.1, is there currently any type of telehealth services available to COPD patients?

6. In question 6.7, is there a defined role for the informal carer (partners, family, and friends)? (if yes, specify)

7. In question 6.8, what is the role of social care?

8. In question 6.9, what roles do pharmacists play in the management of COPD? (e.g. medicine optimisation, medication review, adherence)

9. In question, 8.1, 8.2 who provide the lifestyle management?

10. In question 8.3, who monitor adherence to therapy?

11. In question, 8.4, what tools (if any) are used to enhance patients’ adherence?

12. In question 8.5, what tools (if any) are used to enhance patients’ lifestyle (e.g. smoking cessation...)?

Co-Morbidities

1. For EACH of the following co-morbidities: heart failure, diabetes, and Mental disorders (depression and anxiety), could we have the:
   a. Clinical diagnostic and monitoring parameters used
   b. Clinical guidelines used
   c. Frequency of follow-up

2. Who else is involved in the management of COPD patients with heart failure, diabetes, and/or Mental disorders (e.g. nurse, dietician, physiotherapist)
3. In particular, how is depression and anxiety being assessed and screened in COPD patients?
Netherlands Follow up Questions

1. In question 2.3, as follow up, how frequent are diagnostics parameters measured? (annually, biannually)
2. In question 4.3, could the GP directly refer the patient to the CIRO+?
3. In question 5.1, what about primary and secondary?
4. For EACH of the three most common co-morbidities, heart failure, diabetes, and Mental disorders (depression and anxiety), could we have the:
   a. Clinical diagnostic and monitoring parameters used
   b. Clinical guidelines used
   c. Frequency of follow-up
   d. Other specialised teams available for the management of each co-morbidities
Clinical and end-users requirements - Observational Study

Ireland Follow Up Questions

1. In question 2.2, what are the normal ranges, therapeutic targets and alerts values of these diagnostics parameters?
2. Is there any other form of liaison between the different Specialist/Consultant?
3. What does the Outreach Team consist of? where is it based? who refer patient to the team?
4. For EACH of the three most common co-morbidities, heart failure, diabetes, and Mental disorders (depression and anxiety), could we have the:
   a. Clinical diagnostic and monitoring parameters used
   b. Clinical guidelines used
   c. Frequency of follow-up
   d. Other specialised teams available for the management of each co-morbidities
5. What role does the Outreach Team play in the management of the co-morbidities. Is it only for the management of COPD, or it liaise and refer patients to other teams
6. Which Health Care Professionals are involved in the Rehabilitation?
Appendix C. Response to interview questions from each of the WELCOME’s pilot countries

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<thead>
<tr>
<th>COPD General:</th>
<th>Greece</th>
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<th>Ireland</th>
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<td>1. What is the percentage/prevalence of COPD patients with comorbidities in each centre?</td>
<td>Measured prevalence 0.7%. Average comorbidities approximately 4 comorbidities/patient (other population evidence).</td>
<td>97.7% of all patients has one or more comorbidities and 53.5% has four or more comorbidities (based on a recent study performed in CIRO+).</td>
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| 2.1 Diagnostics parameters for COPD patients? (e.g. spirometry, oxygen saturation etc) | Spirometry: oxygen; ABG: chest x-ray | - Lung function  
- Arterial blood gas, oxygen saturation  
- Physical functioning (cardiopulmonary exercise test, constant work rate test, 6-minute walking test, skeletal muscle function test) (during all tests: Borg symptom scores for dyspnea and fatigue, heart rate, oxygen saturation; during CPET and CWRT: blood pressure, ECG, ventilation)  
- Body composition (dual x-ray absorptiometry scan, body mass index)  
- Psychological functioning (Hospital Anxiety and Depression Scale)  
- Health status (St. George Respiratory Questionnaire, Clinical COPD Questionnaire)  
- Self-reported and objectified co-morbidities | Heart failure: patient history, physical examination, echocardiography, chest radiography, ECG  
Diabetes: patient history, physical examination, blood glucose, glycated haemoglobin  
Psychosocial disorders: patient history, depression questionnaire, indirectly through the degree of respiratory failure (conventional pulmonary function testing, oxygen saturation, blood gas analysis). |
2.2. What are the normal ranges, therapeutic targets and alerts values of these diagnostics parameters?

**2.2 The normal ranges, therapeutic targets and alerts values of these diagnostics parameters are the ranges of the scientific societies.**

2.2. As per BTS Guidelines COPD requires obstructive ratio (<0.7). Severity stratified by percentage predicted FEV1.

Target aims: reduce symptoms and exacerbations. In severe disease, if SpO2 <90%, suggest arterial blood gases.

- Lung function: FEV1/FVC<0.70
- Arterial blood gas, oxygen saturation
- Physical functioning (cardiopulmonary exercise test, constant work rate test, 6-minute walking test, skeletal muscle function test)
- dual x-ray absorptiometry scan:
  - T-score of -2.5 or lower: osteoporosis.
  - T-score of -1.0 to -2.5: osteopenia
- BMI: <18.5 underweight; 18.5-25 normal; 25-30 overweight; ≥30 obese
- Hospital Anxiety and Depression Scale:
  - Range 0-21 for anxiety and depression;
  - normal (0-7), mild (8-10), moderate (11-14) and severe (15-21).
- St. George Respiratory Questionnaire:
  - Range 0-100, with higher scores indicating more limitations;
  - Means (95% confidence intervals) for SGRQ scores in normal subjects with no history of respiratory disease

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<th>Activity Score</th>
<th>Impact Score</th>
<th>Total Score</th>
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<tr>
<td>74 - 46</td>
<td>95 (91-99)</td>
<td>12 (9-15)</td>
<td>9 (7-12)</td>
<td>2 (1-3)</td>
<td>6 (5-7)</td>
</tr>
<tr>
<td>(17-80)</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

2.3. How frequent are the diagnostics parameters measured?

**2.3 The frequency is twice the year**

- All parameters are measured during pre- and post-rehabilitation assessment. If necessary, additional tests will be performed.
- It depends on the clinical status of the patient.
<table>
<thead>
<tr>
<th>2.4. What are the diagnostic parameters that are checked regularly? (e.g. oxygen, weight, FEV1, etc)</th>
<th>2.4 The diagnostic parameters that are checked regularly are weight, BMI, results of spirometry, ABGs, exercise capacity, degree of dyspnoea, treatment effects.</th>
<th>FEV1, FVC and ratio. Blood gases for patient on oxygen therapy BMI</th>
<th>6 monthly check oxygen, weight, FEV1</th>
<th>- Oxygen saturation (during training sessions) - Weight (weekly)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.5. What are the follow-up care services available for COPD patients? (e.g. pulmonary rehabilitation)</td>
<td>2.5 The follow-up care services are the outpatients’ clinics. There are no special services. The patients are informed from the hospital doctors after an admission in the hospital for example, or from the general doctor from the primary health care.</td>
<td>Chest Clinic, CRT, GP follow up, PR, smoking cessation</td>
<td>Rehab, clinic visits</td>
<td>CIRO+ does not provide follow-up care for COPD patients. Follow-up of patients takes place in primary or secondary care.</td>
</tr>
<tr>
<td>2.6. Who is the team involved in follow-up care?</td>
<td>2.6 The team involved in follow-up care is the HCP and physiotherapists</td>
<td>Croydon University Hospital (secondary care), CRT and Primary Care</td>
<td>Clinical Doctor, physio, nurse part of an outreach team</td>
<td>CIRO+ does not yet provide follow-up care for COPD patients. Follow-up of patients takes place in primary or secondary care.</td>
</tr>
</tbody>
</table>

**Respiratory Team:** consist of respiratory physiotherapist, sport (“physical training”) physiotherapist, ergotherapist, nutritionist.
adviser, social care worker. Such a team is typically located in rehabilitation centres. Alternatively and more common, the patient visits these health care providers individually. If the patients require long-term oxygen therapy or non-invasive therapy a respiratory therapist/nurse and the local representative of the producer of this medical technology may also be involved. The GP or the pneumologist refer the patients to the individual providers or to the respiratory team.

2.7. How frequently do follow-up events happen?

2.7 The follow-up events happen twice the year

According to clinical need.

6 months
<table>
<thead>
<tr>
<th>2.8. What is the format of follow up? (e.g. face to face, phone, etc)</th>
<th>2.8 The format of follow up is face to face</th>
<th>Mainly clinics, but also phone calls and home visits if appropriate</th>
<th>face to face</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.9. If a patient is diagnosed with co-morbidity, who offers treatment, follow up?</td>
<td>2.9 If a patient is diagnosed with co-morbidity the treatment and the follow-up is offered by pulmonologist and the relevant specialties coordination.</td>
<td>Primary Care or refer to specialist. Also CBT available for patients with anxiety/depression. GPs, Practice Nurses and Community Matrons We do not do this routinely. If a patients reports or the team feels they are low in mood (we ask the patient if this was the case), we would refer to the CBT team.</td>
<td>GP, and community outreach</td>
</tr>
</tbody>
</table>

The program of all COPD patients consists the same basic elements. Based on their individual needs, additional components are added to the program (e.g. psychological consults, additional consult internist...).

A psychologist or a psychiatrist. (According to the guidelines, the GP should motivate the patient to participate in out-patient teaching courses for COPD patients ( participation at least once in two years is considered meaningful). He also prescribes rehabilitation when necessary. Thus, the GP can indirectly affect the depression/anxiety of his patient because the teaching courses and rehabilitation may improve the quality of life. In the end phase of the disease and/or severe depression and anxiety the GP may prescribe antidepressive drugs and refer the
| 2.10. What are the referral procedures for patients with co-morbidities? | 2.10 The referral procedures for patients with co-morbidities are special tests. There are special outpatient clinics for all comorbidities. 3.2. Only a short medical history, and notes for what every specialist need to do the patient, and with personal communication between the HCPs. The pulmonologist refer the patients to these clinics. | Referral letter to specialist (usually via GP) | Other specialists | Same referral procedures for patients with and without co-morbidities. Patients are referred to CIRO+ by their medical specialist in secondary care. |
### 2.11 What types of preventive care is available for COPD patients?

| 2.11 Hospitals are the types of preventive care which are available for COPD patients | Primary care – flu vaccination, PR, smoking cessation. | Vaccines | Smoking cessation programs, symptom diary/self-treatment action plan for early detection of exacerbations, vaccinations, groups education and individual sessions to increase the patients’ knowledge and to help the patient manage their disease, comorbidities and symptoms and improve their well-being. |

### 2.12 Do patients have personal care plans?

| 2.12 The patients do not have personal care plans | Some patients have management plans for exacerbations. | yes | The program of all COPD patients consists of the same basic elements. Based on their needs and assessment outcome, personalized care plans are developed for each patient (including chest physician, internist, nurse, physiotherapist, dietitian, psychologist, and occupational therapist). |

### 3.1 Are there any specific guidelines (local and/or national) being followed in the management of COPD and associated co-morbidities? (please provide copies)

| The that are followed are the national guidelines (GOLD) | BTS Guidelines. (NICE) | BTS guidelines | ATS/ERS guideline on pulmonary rehabilitation. | Guidelines for the Diagnosis and Therapy of COPD issued by Deutsche Atemwegsliga and Deutsche Gesellschaft für Pneumologie und Beatmungsmedizin National Guideline for the Management of COPD (is currently being updated, the last version was valid till December 2012) Disease management programmes on COPD are issued by the statutory health care insurance funds and in addition National Guideline for |
3.2. Are there guidelines/protocols for referral between settings of care?

- New local pathway agreed.

3.2. Are there guidelines/protocols for referral between settings of care?

- No

4.1. The HCPs involved in the management of COPD is the pulmonologist and the physiotherapist

4.1. The HCPs involved in the management of COPD is the pulmonologist and the physiotherapist

- Primary Care, CRT and Chest Clinic CRT team +CC Hospital Based

- Doctor, nurse, physio

- Chest physician

- cardiologist

- internist

- nurses

- physiotherapists

- dieticians

- psychologist

- occupational therapist

- social worker

- medical engineer

A general practitioner can refer a COPD patient to a medical specialist in secondary care, based on the Dutch guidelines. CIRO+ is a tertiary care centre, indicating that it is only accessible by referral of their medical specialist in secondary care.
## 4.2. What is the role of each professional/team?

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chest Clinic</strong></td>
<td>Three consultants. New and follow up patients. MDT with nurses and physio, and Consultant led. Hospital avoidance by case finding, and optimising management via Home Visits and Clinics. Have a COPD Hot Clinic too.</td>
</tr>
<tr>
<td><strong>GP/Practice Nurses</strong></td>
<td>Diagnosing and overall management with annual reviews. Consultants have clinics at the Chest Clinic too.</td>
</tr>
</tbody>
</table>
| **Physio**                                | Rehab. Doctor - chest physician: medical director, optimizing medication, identify comorbidities which might require modifications in the patient’s program, education.  
- Cardiologist (only involved in COPD patients with heart failure): optimizing medication, education.  
- Internist: optimizing medical status (blood glucose, cholesterol, blood pressure, etc.), identify comorbidities which might require modifications in the patient’s program, optimizing medication, education.  
- Nurses: coaching, appropriate use of medication and medication adherence, patient education, improving self-management behaviour, smoking cessation, recognition of early warning signs of exacerbation, education.  
- Physiotherapists: supervising exercise program, stimulating physical activity, learning breathing techniques and airway clearance techniques, relaxation exercises, education.  
- Dieticians: improving nutritional status, lifestyle guidelines and changes, education.  
- Psychologist: counselling, instruction in coping strategies, relaxation exercises, smoking cessation, quality of life, stress management, emotional support, education.  
- Occupational therapist: learning energy saving techniques, identifying patient’s needs and activities that pose difficulties in their daily lives, facilitating independence in activities of daily living and the use of graded therapy programmes to increase activity tolerance/endurance, providing adaptations (grab rails in bathroom, second banister rails, stair lift) and equipment (long handled shoe horns, bathing equipment, walking aids), education.  
- Social worker: assessing needs for home services, helping patients obtain needed benefits, counselling.  
- Medical engineer: performing exercise test, lung function test and body composition test. |
### 4.3. Where does the patient’s care pathway usually start?

The patient’s care pathway usually start at the hospital.

Care pathways for COPD patients start in primary care (GP). The GP refers patients to medical specialist in secondary care according to the Dutch guidelines. If necessary, the medical specialist can refer COPD patients to a specialized rehabilitation centre (tertiary care).

The main coordinator in the management of COPD patients is the GP (or seldom the pneumologist). The individual providers may refer the patients to other providers but this is not typical.

### 4.4. Which HCP do the COPD patients primarily go to for the management of their COPD?

The HCP that the COPD patients primarily go to for the management of their COPD is the pulmonologist.

55% of the COPD patients are treated by their GP and 42% of the COPD patients are treated by their respiratory physician at the hospital.

### 4.5. Who provides the following for COPD patients?

The following for COPD patients is provided by the pulmonologist.

<table>
<thead>
<tr>
<th>4.5.1. Diagnosis</th>
<th>4.5.1 Diagnosis by the pulmonologist</th>
<th>Mainly primary care</th>
<th>GP + hospital</th>
<th>All HCPs.</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.5.2. Treatment</td>
<td>4.5.2 Treatment by the pulmonologist</td>
<td>Mainly primary care</td>
<td>GP + hospital</td>
<td>All HCPs, except medical engineer.</td>
</tr>
<tr>
<td>4.5.3. Follow-up care in stable patients. (please include extra information e.g. regular screening for depression) Mainly</td>
<td>4.5.3 Follow-up care in stable patients: by questionnaires (for depression too), clinical examination, ECG and Doppler (for those with heart failure) etc. The pulmonologist perform the follow-ups checks for the lung diseases. Furthermore, for each comorbidity the follow-up check are performed from the specialists. Mainly primary care</td>
<td>GP</td>
<td>CIRO+ does not yet provide follow-up care for COPD patients. Follow-up of patients takes place in primary or secondary care.</td>
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</tr>
<tr>
<td>4.5.4. Follow-up care in acute phases (exacerbations).</td>
<td>4.5.4 Follow-up care in acute phases (exacerbations) is take place in the hospital by pulmonologist. The pulmonologist perform the follow-ups checks for the Exacerbation: Chest Clinic = first exacerbation and attending hospital. CRT = if patients known to the team – phone calls +/- home visits +/- CRT Out-patient clinic appt. Hospital + outreach</td>
<td>CIRO+ does not yet provide follow-up care for COPD patients. Follow-up of patients takes place in primary or secondary care.</td>
<td></td>
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</tr>
</tbody>
</table>
l lung diseases. Furthermore, for each co-morbidity the follow-up check are performed from the specialists.

| 4.5.5. Follow-up care in patients with co-morbidities | 4.5.5 Follow-up care in patients with co-morbidities is done by the pulmonologist and the specialist for each disease | Mainly primary care | Hospital | CIRO+ does not yet provide follow-up care for COPD patients. Follow-up of patients takes place in primary or secondary care. |
| 4.5.6. Preventive care. | 4.5.6 By spirometry, pulse oximetry, regular follow-up, 6MWT, evaluation of dyspnoea | Mainly primary care | GP | All HCPs, except medical engineer. |
### 4.6

#### What relevant forms of collaboration are available between different healthcare teams (Respiratory Care Team, Diabetes team, CHF team) who are responsible for the management of the patient's condition?

No collaboration but occasionally liaise with other specialist nurses.

### 4.6 (continued)

- Core team lung failure and heart failure, consisting of chest physician/cardiologist, physiotherapist, nurse, occupational therapist, exercise instructor, dietitian, medical engineer, and psychologist. Key issues: primary rehabilitation process with patient as a partner, provide training for disciplines in CIRO+ and CIRO+-network, contact person for substantive issues for their discipline and the network, create research questions, implement new research in rehabilitation programs.
- Multidisciplinary teams responsible for patient care; after 4 weeks rehabilitation (halfway) each patient is discussed in a multidisciplinary meeting, including the members of each disciplines involved in the treatment of the patient.

The individual providers may refer the patients to other providers but this is not typical. The main coordinator in the management of COPD patients is the GP (or seldom the pneumologist).

The common communication pathway is through the general practitioner. The GP decides whether the patient needs to visit a specialist depending on the current clinical status and receives the feedback from the specialist. Direct communication among the specialists is rare.

### 4.7

#### Is this integrated through the GP/Family Doctor?

Yes

- Multidisciplinary teams responsible for patient care; after 4 weeks rehabilitation (halfway) each patient is discussed in a multidisciplinary meeting, including the members of each disciplines involved in the treatment of the patient.
<table>
<thead>
<tr>
<th>5. Support at home</th>
<th>5.1. Is there any type of telehealth services provided for COPD patients? Yes</th>
<th>There is no support at home. Only for those with oxygen therapy and NIV who are technically supported from provided companies. There isn't any type of telehealth services available to COPD patients</th>
<th>Yes The Telehealth service in Croydon is for all patients who have a LTC.</th>
<th>no</th>
<th>CIRO+ does not yet provide follow-up care for COPD patients.</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.2. Is there any type of other support provided for COPD patients at home? (e.g. early hospital discharge (hospital at home), rescue packs) Facilitated Discharge, management plans for some patients and rescue packs.</td>
<td>Facilitated Discharge, management plans for some patients and rescue packs.</td>
<td>early hospital discharge, rescue packs</td>
<td>CIRO+ does not yet provide follow-up care for COPD patients.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.3. What home monitoring procedures are used by patients, if any? Telehealth and some patients have oxygen saturation probes.</td>
<td>Telehealth and some patients have oxygen saturation probes. It was designed to help reduce hospital admissions so should be selective</td>
<td>None</td>
<td>CIRO+ does not yet provide follow-up care for COPD patients.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Support at community</td>
<td>6.1. Are there any community services/teams looking after COPD patient? (e.g. community outreach teams, community health team)</td>
<td>There is no support at community</td>
<td>CRT and Community Matrons</td>
<td>Outreach team</td>
<td></td>
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<tr>
<td></td>
<td>Community services for COPD patients are limited. Primary care provides services for COPD patients.</td>
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<tr>
<td></td>
<td>- Physiotherapists in community reactivation/maintenance programs.</td>
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<tr>
<td></td>
<td>- Community nursing (home care organisations) is a facility available for patients in their home setting, providing general services such as nursing, medication supervision, washing and dressing. Community nurses with a focus on COPD also provide chronic management services like smoking cessation programmes and disease management.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>6.2. Who refer the COPD patients to the community services?</td>
<td>Primary or secondary care</td>
<td>n/a</td>
<td>Physiotherapist in CIRO+ will refer patients to primary care physiotherapist after their pulmonary rehabilitation. Home care services can be used if needed; the process will be facilitated by the nurse, social worker or occupational therapist.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.3. Who leads the community services?</td>
<td>Nurse Consultant of Long Term Conditions and CRT (if you mean COPD specific)</td>
<td>n/a</td>
<td>Primary/secondary care.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.4. Which other health professionals are involved in the community services?</td>
<td>Other specialist nurses and CRT. The physiotherapy set up is strange in Croydon: we have physiotherapists in the team covering pulmonary rehab (out in the community and not in the patient’s home) and the oxygen service. The Trusts community physios cover mainly general therapies and not respiratory specific.</td>
<td>n/a</td>
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<tr>
<td>6.5. What sort of services is provided by the community teams?</td>
<td>Specialist input by CRT, otherwise District Nursing teams can provide basic support. New Rapid Response team – still in development in the community.</td>
<td>n/a</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>6.6. Where other services are provided in the community</td>
<td>PR and smoking cessation in the community. Plus CRT Clinics in community bases. PR provided Community based SC General practice, pharmacists and the smoking cessation team for more</td>
<td>n/a</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.7. Is there a defined role for the informal carer (partners, family, and friends)? (if yes, specify)</td>
<td>There is no special role for the informal carer.</td>
<td>NO</td>
<td>n/a</td>
<td></td>
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</tr>
<tr>
<td>6.8. What is the role of social care?</td>
<td>To meet social needs.</td>
<td>None</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.9. What roles do pharmacists play in the management of COPD? (e.g. medicine optimisation, medication review, adherence)</td>
<td>The role of the pharmacists is to facilitate the patients with their medicine.</td>
<td>Variable – could check inhaler techniques and compliance to inhaled medication.</td>
<td>Medication review, very limited, pill boxes for tracking medication</td>
<td></td>
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</tr>
<tr>
<td>7. Secondary Care</td>
<td>The type of services is provided by the hospitals to inpatients? (services specific to COPD care or its co-morbidity e.g. pulmonary rehabilitation, depression assessment, etc)</td>
<td>In-patient ward management/case finding COPD Bundle – inhaler checks, refer for PR and smoking cessation Refer for CBT Facilitated Discharge</td>
<td>Pulmonary rehabilitation, smoking cessation, rehab</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.1. What type of services is provided by the hospitals to inpatients? (services specific to COPD care or its co-morbidity e.g. pulmonary rehabilitation, depression assessment, etc)</td>
<td>Treatment in acute phases of the disease, diagnostic facilities, specialist examination, prevention, treatment.</td>
<td>The guidelines recommend a multimodal and multidisciplinary approach to rehabilitation with medical doctors, psychologists, respiratory physiotherapists, sport physiotherapists and nutrition advisers. Social care provider and instructors for the use of medical devices are usually also involved. (Rehabilitation is</td>
<td></td>
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</tr>
</tbody>
</table>
### 7.2. What type of services is provided by the hospitals to outpatients? (regular assessments, medication reviews, etc)

| 7.2 | The type of services is provided by the hospitals to outpatients is the regular follow-up. Out-patient clinics LTOT (long-term oxygen therapy) assessments Pulmonary Function testing | assessments | Diagnostic facilities (regular consultation and assessment), specialist examination, prevention, treatment, follow-up, medication reviews, outpatient rehabilitation programmes. Most of these services are carried out by respiratory nurses. |

### 7.3. Which health professionals are involved in the hospital care for COPD patients?

| 7.3 | The health professionals who are involved in the hospital care for COPD patients are the pulmonologist and specialist of each comorbidity (cardiologist, pathologist, psychiatrist) | Consultants, ward nursing staff, CRT | GP | Chest physician, respiratory nurse, physiotherapist. If needed, psychologist, dietitian, medical specialist, occupational therapist, social worker, ... |
| 8. Adherence and Lifestyle | 8.1. Is there any form of advice and/or services being provided for lifestyle management (e.g. Smoking, vaccinations, diet, physical activity, weather pollution...)?
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>8.1 Advice being provided for lifestyle management information for smoking, vaccinations, diet, physical activity, weather pollution etc. The pulmonologist provide the lifestyle management</td>
<td>Smoking cessation, advice on annual flu vaccination, advice on importance of PR, referral to dietician if appropriate</td>
</tr>
<tr>
<td>8.2. If yes, what is the standard lifestyle advice/recommendation provided? (please provide guidelines if used)</td>
<td>The recommendation provided is quit smoking, to do vaccination, advices for right diet, training for right therapy The pulmonologist provide the lifestyle management</td>
</tr>
<tr>
<td>8.3. How is the patients’ adherence to therapy being monitored?</td>
<td>Mainly in primary care or appropriate teams (e.g. smoking cessation and PR)</td>
</tr>
<tr>
<td></td>
<td>Presence during group sessions (training, education, smoking cessation) and individual consultations is recorded in their daily schedule. This schedule is checked by the nurse at the end of the day.</td>
</tr>
</tbody>
</table>
8.4. What tools (if any) are used to enhance patients' adherence?

| pulmonologist monitor adherence to therapy | There are not specific tools. | NA | None | Recording daily presence, motivational methods, increase self-management of patients. |

8.5. What tools (if any) are used to enhance patients’ lifestyle (e.g. smoking cessation...)?

| Only smoking cessation | NA | None | Smoking cessation education and consultations (individual and group), activity schedules, symptom diary / self-treatment action plan for exacerbations, weekly weight moments and consultation with dietician. |

8.6. Are there any other services being provided to patients? If yes, what are they?

| Breathe Easy (BLF Local Support Group) | None |

9. Training and Education

9.1 Is there standard training offered to HCP involved in COPD care?

<p>| 9.1 The standard training offered to HCP involved in COPD care are the everyday practice, seminars, national congresses. | No | no | No |</p>
<table>
<thead>
<tr>
<th>9.2 Is there standard education that gets offered to COPD patients? What does it cover?</th>
<th>Booklets (British Lung Foundation) PR have a list of educational input including breathlessness, anxiety and oxygen use.</th>
<th>no</th>
<th>All COPD patients receive basic education sessions, including information on the disease, medication, physical activity, diet, behavioural change, etc. In addition, additional sessions are scheduled to patients with specific need (e.g. obese or underweight patients, oxygen users)</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.3 Is there standard training and education offered to informal carers?</td>
<td>Not specifically to COPD</td>
<td>no</td>
<td>no</td>
</tr>
</tbody>
</table>
Appendix D. COPD Care Pathways in WELCOME’s pilot countries

As is presented in Figure 2 General practitioners are the main point of contact for patients. GP refers the patients to COPD specialists, co-morbidities specialists and hospitals. Patients are referred to specialist care (rehabilitation, ventilation therapy) and respiratory teams through the hospital.
In UK General practitioners (GPs) are the main point of contact for patients (Figure 3). The GP refers the patients to co-morbidities specialists and hospitals. Patients are referred to community services and care teams (local respiratory team, pulmonary rehabilitation and smoking cessation) through GPs and hospitals. Hospitals provide inpatients services (case managements and facilitated discharge) and outpatients’ services.

Figure 3: COPD patients’ Care pathway in UK

CC=Chest Clinic, CRT=Croydon Respiratory Team, PR=Pulmonary rehabilitation, SC smoking cessation
Di= Diabetologists, CA=Cardiologist, PS= Psychiatrist
In Ireland General practitioners (GPs) are the main point of contact for patients (Figure 4). The GP refers the patient to co-morbidities specialists, hospitals and outreach team. Patients could receive inpatients services (early supported discharge and assisted discharge) or outpatients’ services.

Figure 4: COPD patient’s care pathway in Ireland

PR = Pulmonary rehabilitation, SC smoking cessation
DI= Diabetologist, CA=Cardiologist, PS= Psychiatrist

INPATIENTS
Early Supported Discharge
Assisted Discharge
Transitional care program

OUTPATIENTS
Out-patient clinics
Pulmonary rehabilitation
The absence of GP is clear in Greece. As presented in Figure 5 Pulmonologists are the main point of contact for patients. Pulmonologists refer patients to co-morbidities specialist, care teams and hospitals. Hospitals provide inpatients services (pulmonary rehabilitation and depression assessment) and outpatients’ services.

**Figure 5: COPD patients’ care pathway in Greece**

PR = Pulmonary rehabilitation, SC smoking cessation
DI = Diabetologists, CA = Cardiologist, PS = Psychiatrist
Finally in the Netherlands General practitioners (GPs) are the main point of contact for patients and play a gate-keeper role (Figure 6). GP refers the patients to co-morbidities specialists and hospitals. Hospitals provide inpatients services (acute phase of the disease) and outpatients services.

**Figure 6: COPD patients’ Care pathway in the Netherlands**

Di= Diabetologists, CA=Cardiologist, PS= Psychiatrist