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### **D11 Practical Guide on Home Health COPD**

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## Colophon

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## Table of Contents

Acronyms .....	2
Introduction .....	3
Purpose of this document .....	3
Background .....	3
Methods .....	5
What is home health COPD? .....	6
The chronic care model .....	7
The Guided-Care model .....	7
The Home Based Chronic Care Model .....	8
Integrated Care .....	8
Pulmonary rehabilitation .....	9
Disease management .....	9
Evidence for home health COPD .....	11
The Chronic Care Model .....	11
The Guided-Care Model .....	12
The Home Based Care Model .....	12
Integrated Care .....	12
Pulmonary Rehabilitation .....	13
Disease management .....	14
Which patients may benefit from home based COPD care? .....	15
Establishment of a home health service for COPD patients - Organisational and structural considerations .....	18
Integrated care programmes .....	21
Conceptual basis .....	21
Constructing integrated care programmes: building blocks .....	23
Constructing integrated care programmes: detailing tasks and roles .....	25
Conclusions and recommendations .....	32
The outlook for integrated care .....	33
References .....	35

## Acronyms

BPMN	Business Process Model Notation
CCM	Chronic Care Model, developed by Wagner, E.H.
CMS	Centres for Medicare and Medicaid Services
COPD	Chronic Obstructive Pulmonary Disease
EAP	Primary Care Team (Catalan: Equip d'Atenció Primària)
HADS	Hospital Anxiety and Depression Scale
HBCCM	Home based Chronic Care Model
HRQL	Health Related Quality of Life
ICCC	Innovative Care for Chronic Conditions, framework developed by WHO
IJIC	International Journal of Integrated Care ( <a href="http://www.ijic.org">www.ijic.org</a> )
MeSH	Medical Subject Headings. Thesaurus of the National Library of Medicine. <a href="http://www.nlm.nih.gov/mesh/meshhome.html">http://www.nlm.nih.gov/mesh/meshhome.html</a>

## **Introduction**

### **Purpose of this document**

This document has been prepared in the context of the Homecare project<sup>1</sup> and constitutes one of the deliverables included in project's work package 3 "Guide on Home Health for HF and COPD".

As implicit in its title, the document aims at having a practical and up-to-date value. To do so, it builds on state-of-the-art knowledge in the field, leading-edge running experiences and current debates, to identify and highlight those approaches that can be seen as best practices at present. These have been then distilled into practical items that could be easily adopted by health managers and professionals.

The document focuses on COPD as a condition. However, the reader should be aware that current approaches to the management of COPD tend to maximise commonalities across different chronic conditions that are usually concurrent in an individual. This can ultimately affect the components of services that are part of the envisioned care pathway. Whereas an effort has been made to keep the focus on the selected disease, i.e. COPD, this overlapping or mix of different conditions is apparent in different parts of the document.

Finally, the document includes a brief outlook on the future of integrated care services for chronic conditions, inspired by the new system medicine approaches. While this has no immediate implications at the moment, many of their aspects are to shape-up new ways of confronting these services.

### **Background**

Chronic obstructive pulmonary disease (COPD) is not only a leading cause of morbidity and mortality worldwide but it also imposes a major burden on health care systems [1, 2]. While recent years have witnessed a progress in our understanding of the mechanisms of the disease and better treatment strategies have been made available [2], COPD patients, notably those that are most severe, often suffer from exacerbations that require hospital admissions. Thus, COPD as a main diagnosis ranks among the first five common causes of unplanned hospital admission and together with heart failure (a highly prevalent co-morbidity in these patients) counts for up to 80% of the cases in those patients with multiple readmissions over 1 year [3].

These undesirable clinical results and the accompanying impact on health care resources can be explained to a degree because of the co-morbidities present in these patients together with, in many cases, a complex social environment that usually lacks the required social support [4]. While these might be seen as aspects that are not under the direct responsibility of health professionals (or the health sector in general), failure to pay appropriate attention to them is a major contributor to the observed unacceptable rates of readmission [5].

Actually, and as it is discussed in other parts of this document, the need for better strategies for the management of chronic patients emerged in the late 90's following the work of Wagner et al [6-8] that was later adopted by WHO in the form of a policy framework to develop new ways of providing care services in chronic patients [9]. These new perspectives inspired researchers and health policy makers to explore new organisational formats to obtain

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better outcomes in these patients, not only in terms of avoiding institutional care but also aiming at preventing relapses and increase quality of life. This translated into different organisational proposals (day-case units, early discharge pathways, home hospitalisation...) and the introduction of new components in the care chain (patient empowerment, carer empowerment, case managers, ICT supported remote monitoring...) [10-15]. The term “Integrated care” was coined to reflect this comprehensive vision becoming an umbrella where a range variety of services could be included [16-18], as it is discussed in the next section.

Home-based care or home hospitalisation is a short-term high-intensity intervention mainly applied to severe exacerbated COPD patients discharged from emergency room or after a short hospital stay. It is carried out by specialised personnel as an alternative to conventional admission. This intervention has proved to be an interesting alternative in COPD patients [5]. Among others, main benefits of this format include: a) a reduction of the risk of hospital acquired infections; b) a decrease in the number of hospital beds allocated to this patients, and c) increased comfort for the patient that stays at home. Safety and efficacy of this service modality has also been demonstrated [5, 19, 20].

However, not all COPD patients are equally eligible for this modality and it seems necessary to limit its use to a well-selected group of patients. Also, from a patient-centric perspective, best results can only be achieved if an overarching integrated care strategy is adopted. This typically involves a multidisciplinary team of professionals from different institutions / levels of care that are coordinated by a case manager. Patients and their carers play a more active role in this model. Quite often, the level of coordination required along with the execution of tasks is supported by information and communication technologies. These integrated care strategies for COPD patients hold the potential to move care beyond the management of crisis to early detection and prevention.

In this document, we present a suitable approach to such overarching strategy. This is mostly based on the work in this field carried out in Hospital Clinic Barcelona since 2000. But the model has also been tested in other settings through different research projects. Notably, the case of the design of a new integrated care model for a urban area in Barcelona is described (see pages 15 and following ones)

## **Methods**

In order to elaborate this document, a literature review has been carried out to identify those studies that focused on COPD and home health care (or any of the other terms discussed in section “What is home health COPD?” in page 6 and following ones). Articles published in English or Spanish (or including an abstract in any of these two languages) and published in the last 5 years have been considered.

Because of the intended practical nature of the document, data from currently running services and pilots has been used whenever such information was available to the researchers, even if it had not been officially published. In these cases, permission for using the information in this document was requested.

One of such cases corresponds to the work done at Hospital Clínic de Barcelona, since year 2000 to develop integrated care services for COPD patients. The conceptual framework used in these services, along with the learning process that has been followed, inspires many parts of this document. Some of the professionals that are involved in the current service and that were part of the development team have agreed upon discussing some of the facts and approaches described in this document.

## What is home health COPD?

In this section, we discuss some of the names that are being used to describe the provision of services for COPD patients that are predominantly delivered at home. Actually, this is a difficulty that clinicians, researchers, policy makers or citizens must face, forcing them to navigate through different terms that essentially refer to the same type of services.

It must first be noted that “Home health” is not a MeSH term and it only appears as a part of the terms “Home Health Agencies” or “Home Health Care Agencies” or “Home Health Aides”. This possibly reflects the particularities of the American market for the provision of care services at home. Thus, for Medicare “home health care” encompasses a wide range of health care services that can be given at patient’s home. From an organisational perspective this includes skilled nursing care services provided part-time or intermittently as well as other types of interventions like physical therapy, occupational therapy, and speech therapy. The possibility of including social support is also contemplated. All these services are usually provided by home health care agencies. Importantly, Medicare only covers this home health care for patients that are homebound.

In contrast “home care”, not only includes the entries mentioned in the previous paragraph but also includes a variety of other related terms. According to MeSH, the scope of “Home care services” is: “Community health and nursing services providing coordinated multiple services to the patient at the patient's homes. These home-care services are provided by a visiting nurse, home health agencies, hospitals, or organized community groups using professional staff for care delivery. It differs from home nursing which is provided by non-professionals”.

This latter clarification is relevant in our case since MeSH excludes professionals in the case of home nursing services: “Home nursing” is “Nursing care given to an individual in the home. The care may be provided by a family member or a friend. Home nursing as care by a non-professional is differentiated from home care services provided by professionals: visiting nurse, home health agencies, hospital, or other organized community group”

So, “home care” would be a preferable term in our case to “home health” since it seems to better capture the idea of coordination in the services provided at home by a diversity of professionals. However, many authors have preferred to use terms that better recall the organisational aspects.

Thus “integrated care” exists in MeSH under the form of “Delivery of Health Care, Integrated” and corresponds to “A health care system which combines physicians, hospitals, and other medical services with a health plan to provide the complete spectrum of medical care for its customers. In a fully integrated system, the three key elements - physicians, hospital, and health plan membership - are in balance in terms of matching medical resources with the needs of purchasers and patients”. This is a far more detailed explanation that, however, does not mention the location (in our case, the home) where the care takes place.

Another term frequently used is “Patient care management”. In MeSH this term includes the previous one as a subheading. It is a general term that refers to “Generating, planning, organizing, and administering medical and nursing care and services for patients”.

One can easily see that there is a certain degree of commonalities among all the terms presented. The concepts of planning, coordination and organisation are present, explicitly or implicitly in all of them. Differences are only found in the set of actors involved, the context where the service is provided or its nature. To have a better understanding of this, so that we

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can distil the best options, it is necessary to review with some detail some of the historical developments in the integrated home care domain.

### The chronic care model

Historically, it was the work of Wagner et al in the 90's the first one establishing a new approach to chronic conditions by conceptualising the chronic care model (CCM) [22]. The CCM model is based on the following components that work together to optimise care delivery: (1) Self-management support, (2) delivery system design, (3) decision support, and (4) clinical information systems. These components require positive interactions between community resources and policies and healthcare organisations (Figure 1).

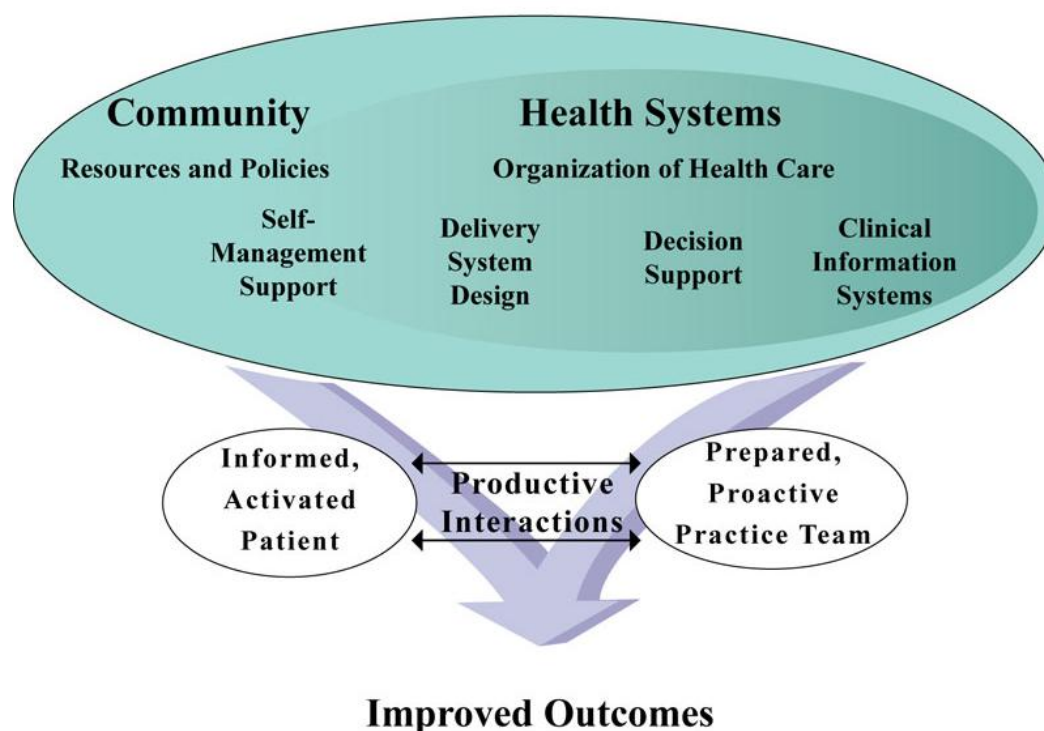


Figure 1 The Chronic Care Model as proposed by Wagner et al (Developed by the MacColl Institute)

The model was soon adopted by WHO to develop the Innovative Care for Chronic Conditions framework (ICCC) [23], thus drawing world-wide attention to the problem of chronic conditions. Neither the CCM nor the ICCC provide precise descriptions about how interventions should be designed. Rather they are inspiration for a new approach. This threw a wealth of health professionals and institutions into a race to put the model into practice. In this process two sub-models have emerged that are of interest in our case: The Guided-Care model and the Home-based Chronic Care Model.

### The Guided-Care model

The Guided-Care model, created by Boult and colleagues, combines the rationale of the CCM with a set of selected successful innovations in chronic care [24]. The goals of the Guided-Care model are to be: effective in practices throughout America, financially sustainable,

attractive to physicians and nurses, valuable to health care organizations, and popular with patients and caregivers. In spite of this American focus, some of points of the Guided Care model are interesting: Firstly, it relies on a specifically trained nurse that acts in support to three to four primary care physicians. Secondly, the support provided consists of eight different services: (1) comprehensive assessment at the patient's home; (2) elaboration of a patient's individualised care guide; (3) proactive monitoring of the execution of the individualised care guide; (4) patient's coaching using motivational techniques; (5) patient's empowerment on chronic disease self-management; (6) Education and support to carers; (7) helps in the coordination of transitions between health care providers and (8) facilitates access to community services. The Guided-care model has been mostly applied in the States and, as discussed in the next section, its take-up by the health professional community is unclear.

### The Home Based Chronic Care Model

The home based chronic care model (HBCCM) is possibly closer to the original Wagner's design but has been expanded on the basis of experience gathered in Centres for Medicare and Medicaid Services (CMS), team-work and coordination concepts and stressing the patient empowerment component [25]. The resulting model is based on four pillars: (1) A high-touch delivery system, including: comprehensive assessment, face to face visits, telehealth nurse interactions and proactive planned visits; (2) Theory-Based Self-Management that involves: Health coaching, self-efficacy improvement, health literacy and principles of adult education; (3) Specialist oversight to ensure alignment with evidence-based guidelines, to coach and guide staff and partner with physician specialists; and, (4) Use of technology in the form of telehealth, dashboards, registries, and solutions for data exchange among providers. As in the previous case, adoption of HBCCM is uncertain.

### Integrated Care

However, most authors and researchers have named their experiences as integrated care, at times qualifying it with indications corresponding to the settings or the actors involved. A simple search in Pubmed using the search string: {integrated care} or {integrated home care} or {integrated health care} or {integrated healthcare} retrieves 863 references, with {integrated care} alone corresponding to 507 references (59%). This shows the acceptance of the term among the community of health professionals. In the absence of a standard definition, the one adopted by the International Journal of Integrated Care (IJIC) seems appropriate:

“(…) integrated care is a coherent set of methods and models on funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long-term problems cutting across multiple services, providers and settings. The result of such multi-pronged efforts to promote integration for the benefit of these special groups is called ‘integrated care’ [27].

The definition is interesting since it implies that those planning and providing services must impose the user's perspective as the organising principle of service delivery. A further differentiation between a ‘process – integration’ (e.g. as a result of creating a team, pathway or merger) – and ”outcome – integrated care” (e.g. care experience and outcomes, cost-effectiveness) is helpful [28,29].

### Pulmonary rehabilitation

Pulmonary rehabilitation has been defined by the American Thoracic Society and European Respiratory Society as: “an evidence-based, multidisciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities. Integrated into the individualized treatment of the patient, pulmonary rehabilitation is designed to reduce symptoms, optimize functional status, increase participation, and reduce health care costs through stabilizing or reversing systemic manifestations of the disease” [30]. Thus pulmonary rehabilitation is an important therapeutic option in COPD patients and includes comprehensive assessment, education, exercise training, and psychosocial intervention. The gains observed in the patients receiving pulmonary rehabilitation are attributed to the reduction of the impact of the systemic manifestations of the disease and frequent co-morbidity. Pulmonary rehabilitation also leads to substantial reductions in subsequent health care utilization [31].

Thus, pulmonary rehabilitation is seen as a fundamental part of the treatment of stable COPD patients. A recent Cochrane review also suggests, albeit some methodological limitations of the studies analysed, that it could also be effective and safe for those patients that have recently suffered an exacerbation of the COPD: reduction of hospital admission and mortality and improvement of health related quality of life [32].

Wouters et al highlight the fact that pulmonary rehabilitation programmes for COPD patients are usually organised as temporary interventions in a highly fragmented delivery care system. They argue that, ideally, pulmonary rehabilitation needs to be considered as an essential part of an individualized, integrated care process, organized from the vantage point of the patient and the patient’s health continuum. In this process, aspects such as partnering and communication skills are crucial drivers, together with an appropriate assessment of patients’ needs, for the success of the programme. For the authors, this calls for more integrated structures with all the range of professionals’ expertises [33].

### Disease management

Disease management has been proposed as a better approach to enhance the quality and cost-effectiveness of health care for chronic conditions. Ellrodt et al define it as “an approach to patient care that emphasises coordinated, comprehensive care along the continuum of disease and across health care delivery systems” [34]. Core components of disease-management include patient counselling and education and coordination and standardisation of care, but the following are also part of the model: inclusion of population identification criteria, the use of evidence-based guidelines, multidisciplinary teams, patient self-management education, evaluation of processes and outcomes measurement and routine reporting and feedback [35].

Disease-management programmes reported in the literature have usually targeted cardiovascular diseases, chronic respiratory diseases, diabetes and depression [35,36] and systematic reviews carried out suggest that they are effective both when addressing a single condition or a number of them (co-morbidity) [37]. This evidence seems to be less clear in the case of COPD [38,39].

In disease management, a reallocation of professionals’ roles might take place with a special emphasis in the role of nurses and the new demands that these new organisation modalities imply [40]. Jónsdóttir has analysed the specific role of nursing care in the chronic phase of COPD to investigate if there was a need for changing nurses’ practices [41]. The author noticed that nursing care in stable COPD patients is mainly seen as composed of home-based respiratory care, self-management educational programmes and telephone service with

influences of specialisation in respiratory nursing care on patients' outcomes as an emphasis as well. Family focus was not found in any of the studies analysed. The author claims the importance of an appropriate basis for nursing care in COPD patients that is to be evidence based, comprehensive, family-centred, focused on health and the health experience and be situated within the service system. However, the author's focus remains limited to nursing care, without mentioning the role of other professionals.

## **Evidence for home health COPD**

In spite of a welcome tendency to accept integrated care services as an adequate option for COPD patients, not all the interventions investigated have been able to demonstrate positive results. This apparent lack of certainty might also explain the slow adoption of these care modalities. Some authors have also stated whether we might not even be in front of an uneasy truth: can well-coordinated care actually avoid the progression of chronic conditions, including COPD? [42]

However, common sense seems to be in favour of it and what might be needed are more efforts to design better and more effective services that can be properly assessed in a more robust manner. Something that emerges as a frequent comment in all the reviews done so far is the great heterogeneity of modalities of interventions, the varied contexts of use, the diversity of professionals and the huge differences in the design of the studies carried out.

In spite of these difficulties, across the different studies it is possible to identify several characteristics that are part of effective home health programmes (or, in a wider sense, integrated care programmes). These characteristics include: (1) the use of individualised case management; (2) personal contact with patients; (3) a focus on hospital discharges as key opportunities to improve health outcomes; and (4) helping patients to use effective treatments by reducing patient cost sharing for these treatments. On the other side, common barriers mentioned are: (1) Financial incentives and payment systems.

In this section we review some of the current evidence existing around home health care for COPD patients. For the sake of clarity, the section is organised following the same subheadings of the previous section.

### The Chronic Care Model

Adams et al carried out a systematic review of the chronic care model applied to COPD patients with the goal to see if the benefits reported in other conditions, such as heart failure, could be also documented for COPD [39]. The studies selected by the authors had to contain interventions with CCM components that had been measured by a comparison group or before/after the intervention. The authors observed that symptoms, quality of life, lung function, and functional status were not significantly different between the intervention and control groups. However, the use of institutionalised resources (emergency/unplanned visits, hospital admissions) was lower in those patients receiving at least 2 CCM components. Equally, they observed a shorter length of stay in the group receiving an intervention with at least 2 CCM components, when compared with the control groups.

Clark et al elaborated a narrative review of intervention studies in COPD patients in relation to: a) clinical, psychosocial, and educational interventions for COPD patients and their outcomes, and b) what type of interventions could be associated to what type of outcomes [43]. They additionally compared these interventions to the ones applied in patients with asthma. Their findings suggested that the use of health care resources was the outcome that most benefit from interventions specifically designed to enhance disease management by patients. The impact on quality of life was modest and was weak for all the other outcomes considered.

The study from Steuten et al focused on the cost-effectiveness of multi-component COPD programmes without differentiating between model approaches (e.g. CCM, disease management, pulmonary rehabilitation, etc.) but describing the process and the intermediate

and end results of care [44]. Steuten's group found that provision of self-management education and increased disease specific knowledge were linked to better outcomes but this was not the case for other components of the process explored. It seemed that programmes containing 3 or more components as a part of the intervention scheme had the potential to decrease the risk of readmissions. The evidence about programmes saving money was inconclusive.

### The Guided-Care Model

In a cluster-randomised study, Boulton and collaborators investigated the effect of guided care teams on the use of health services in 850 older patients with co-morbidities [45]. The nurse provided eight services among those that are part of the guided care approach: comprehensive assessment, evidence-based care planning, monthly monitoring of symptoms and adherence, transitional care, coordination of health care professionals, support for self-management, support for family carers, and enhanced access to community services. The authors only observed a reduction in the use of services provided by home health agencies whereas the use of all the other resources monitored (emergency departments, hospitals, skilled nursing facilities, primary care physician services, and specialty physician services) remained the same, at least, in the short term.

Marsteller et al report on the appraisal of primary care physicians about the Guided-Care Model for chronically ill older patients [46]. The authors run a cluster-randomised controlled trial among 14 primary care teams for a period of 3 years. The results showed that physicians in the Guided-Care model group were more satisfied with patient/family communication and their knowledge of the clinical characteristics of their chronically ill older patients but no other significant differences were found.

The same group of researchers complemented the previous work by looking at the perceptions of patients and their relatives that were receiving services under the Guided-Care modality [47,48]. The chronic patients treated in the same primary care facilities were surveyed by telephone using the Patient Assessment of Chronic Illness Care (PACIC). In the case of the carers, they were surveyed for depressive symptoms, strain, quality of care recipients' chronic illness care and personal productivity. The authors found that Guided-Care improved self-reported quality of care in the patients and also the perception of the carers about the quality being provided, but no changes were found in any of the other variables explored.

### The Home Based Care Model

Apart from the authors that have first described this adaptation of Wagner's CCM, the literature search carried out did not find articles investigating this specific format and its impact on care.

### Integrated Care

A number of studies have been done demonstrating the benefits of an integrated care in COPD patients. Thus, Hernández et al [5] demonstrated in a prospective study that a group of exacerbated COPD patients enrolled in an integrated care program for 8 weeks showed: a reduced number of emergency room visits, better health related quality of life and a decrease of 38% in the direct costs incurred. They did not find significant differences in the readmission rate of the patients, although a trend towards a reduction was observed. Additionally, the group of patients in the integrated care programme showed, after 8 weeks

better knowledge of the disease, better use of inhalers and better performance of respiratory rehabilitation exercises.

The same group ran a similar study focussing on the prevention of exacerbations in stable COPD patients [11] following a group of patients for an entire year demonstrating that, at the end of the study, up to 5 out of ten patients in the integrated care programme were free from readmission while only 3 out of ten had not required admission in the control group.

Other groups have corroborated these results. Thus, Bakerly et al [49] using a similar approach in an early discharge programme for exacerbated COPD patients demonstrated savings of 27% (GBP600) in the integrated care group that also showed shorter lengths of stay. The same group reports on an extended integrated care programme for COPD patients, covering also the initial diagnosis phase and highlights positive findings in increased number of diagnoses, reduced unplanned admissions and reduced length of hospital stay [50].

### Pulmonary Rehabilitation

A revision of the components of comprehensive care of patients with COPD from a pulmonary rehabilitation perspective was carried out by Zu Wallack et al [51]. The authors carried out a first examination of published clinical trials, meta-analyses, and national guidelines or statements on pulmonary rehabilitation. The resulting document was then presented to a panel of pulmonary specialists and primary care physicians. This panel was requested to use this information to elaborate key messages that could assist in the implementation of guideline-based care mainly in primary care settings. The consensus reached by the panel pointed out the components of comprehensive pulmonary rehabilitation for COPD that has to include: patient education, exercise training, psychosocial support, and nutritional intervention – oxygen supplementation should be evaluated. The panel highlighted the importance of delivering all these components in an integrated fashion also at primary level even if most of these programmes were hospital-based. If a comprehensive programme was not possible then, at least elements of this care should be provided to individual patients.

The panel also stressed the fact that pulmonary rehabilitation was erroneously considered as an indication for patients with an advanced condition. Instead they highlighted the importance of indicating it on all patients who, in spite of optimal medical therapy, remain symptomatic or show a decreased functional status. In support of this strategy, they highlighted the impact of pulmonary rehabilitation programmes in increasing exercise capacity, reducing breathlessness, improving health-related quality of life and decreasing use of health care resources. Improvements can actually be of greater magnitude than those achieved with pharmacologic therapy. Pulmonary rehabilitation did not appear to have direct effect on usual pulmonary function tests and the authors hypothesised that it works, in part, through reducing non-pulmonary co-morbidity.

Following these observed benefits, the GOLD guidelines indicate that pulmonary rehabilitation must be offered to all COPD patients of stage II or greater [52]

Ambrosino et al have recently reviewed the existent evidence on the benefits of pulmonary rehabilitation [53, 52] that are to support this GOLD recommendation. In their study the authors focused on the different outcomes that are of interest in COPD patients and whether pulmonary rehabilitation had a positive impact on them. Thus, exercise tolerance, disease symptoms, health-related quality of life and need of health care were all positively changed by a pulmonary rehabilitation programme. Survival rates seemed to be also positively affected although by an indirect mechanism. But they also found that up to one third of patients did not benefit from pulmonary rehabilitation without being able to identify any predictors of success

of failure. In spite of this, they recommended to use pulmonary rehabilitation as a part of the comprehensive treatment of these patients.

### Disease management

In 2008, Peytremann-Bridevaux conducted a systematic review to assess the effectiveness of COPD disease-management programs [35]. The authors included programmes with: patient education, 2 or more different intervention components, 2 or more health care professionals actively involved in patients' care, and intervention lasting 12 months or more. Programmes that were only hospital based or those targeting palliative care were excluded. Clinical impact was studied for all cause mortality, lung function, walking distance (exercise tolerance), health related quality of life, symptoms, number of exacerbations, and use of health care resources. The authors found that disease management programmes improved the tolerance to exercise, decreased the risk of hospitalisation and improved, albeit moderately, the health related quality of life. No impact was observed in all-cause mortality.

A similar study was carried out by Lemmens et al who examined the effectiveness of multiple interventions, provided within a disease management approach, in contrast to usual care in the case of asthma and COPD [54] and analysed data on quality of life and health care utilisation. They complemented this analysis with a qualitative assessment of the effects of the different types of interventions. The authors grouped the interventions studied in “double interventions” (including patient-related actions and organisational ones) and “triple interventions” (that in addition to patient and organisation were also targeting professionals) but for the rest the entire set differed in their designs, outcomes, and settings. The results showed that quality of life was improved significantly and that those patients that were in a programme of “triple intervention” had less chance of at least one hospital admission compared with usual care. However, this benefit was not observed in the case of emergency department visits. No changes were seen in clinical outcomes (symptoms, lung function). Finally, the qualitative analysis of the process demonstrated more satisfaction and a sense of improvement. The authors concluded that, in spite of the limited amount of evidence, the positive impact in quality of life and reduction in the use of institutional resources (hospitalisation) were promising enough to recommend it.

De Bruin et al were less optimistic in a recent study that complements the previous one with information in the domain of healthcare expenditures of disease management programmes [55]. The programmes studied had to contain two or more of the components of the CCM and were not restricted to COPD but also included diabetes, depression and heart failure. There was a substantial variation across all the studies in the designs of the interventions and the characteristics of the economic evaluations. The authors, while acknowledging the progressive implementation of these modalities of programmes, concluded that evidence is still weak and there is a need for better designed studies.

## **Which patients may benefit from home based COPD care?**

From the revision of the evidence carried out, it seems that from the pure perspective of the disease condition, COPD patients are to benefit from a comprehensive care approach even at mild stages of the disease. This is what actually is reflected in the guidelines issued by the GOLD initiative when it is recommended considering pulmonary rehabilitation in patients with stage II or greater of the disease, a point also supported by different studies [51,52].

However, this is still insufficient to determine how care components should be provided. To guarantee that the service provided matches the needs of the patients we need to know how patients can be grouped into homogenous clusters that are eligible for a similar level of service provision. If we manage to do so, then patients can be allocated to specific care pathways that could help as a way to normalise care and might also facilitate the coordination across health care agencies and professionals.

In spite of the potential difficulty in defining such groups, this can actually be the cornerstone to success [57]. The challenge is to decide on the criteria that allow us to perform this clustering or stratification, its accuracy to allocate patients and the adequacy of the care pathways that are to be applied to the patients.

It is at this stage, when the comprehensiveness of patient assessment becomes crucial and when the role of co-morbidities and other factors modulating risk of worsening or complications (such as poor social support) become more relevant. We have seen before that not all expected outcomes are equally achieved by the different modalities of care considered. It seems reasonable, then, to limit our objectives to those parameters that evidence shows that can be positively impacted.

However, the review carried out has not been very precise in identifying operational criteria for this stratification. A study done in Barcelona, provides a more specific picture to proceed with an initial criteria [58]. This study had as a goal to set the basis for the deployment of territorial care for some chronic conditions. By territorial care it was meant a concerted actuation of the different health care agencies and professionals in the territory considered “Eixample esquerra” (Catalan for “left Eixample” an urban sector for healthcare in Barcelona). The team of professionals that focused on COPD elaborated a proposal to ensure a more effective management of exacerbated COPD patients after discharge. The intended goals were:

- Reduction in the number of hospital admissions and/or emergency room department visits after discharge.
- Increased compliance with the prescribed treatment (usually with the support of structured educational programmes)

Secondary goals include:

- Increased coordination across levels of care
- Reduction of repeated tests
- Identification of frail patients

In principle, all exacerbated patients that were discharged from the hospital were eligible for the pilot if they lived in the defined territorial area. However, the following exclusion criteria were applied:

- Living in a nursery home
- Not accepting the modality of service offered

- No telephone at home

Approximately, 15% of the total numbers of patients eligible were excluded because of any of these reasons.

The patients that were included in the pilot were then assessed with regard to their frailty, distinguishing among three groups:

- Group A, COPD patients with no risk factors
- Group B, COPD patients with the following criteria:
  - two or more comorbidities and/or Chalon index greater than 2
  - Anxiety (HADS>6);
  - Staying indoors (at home) more than 50% of the time;
  - Staying indoors all the time and carer with the same age
  - Medication: more than 4 pills a day
  - In need of social support
  - In need of some type of cure
- Group C, COPD patients with the following criteria:
  - two or more hospital admissions and/or emergency room visits in the last year
  - home oxygen treatment
  - patients with non-invasive mechanical ventilation
  - patients with complex treatments at home
  - patients receiving palliative care.

It was estimated that up to 20% of the patients would correspond to group A, 45% in group B and 35% in group C.

What is important is that each of these 3 groups was allocated to a specific set of interventions, as described below:

#### *Intervention in group A*

Only usual care is provided in this group. This usual care includes the action corresponding to the “pre-Alt”. This means that the discharge report is made available to the primary care physician responsible for the patient upon patient discharge from hospital. Apart from this, it corresponds to primary care professionals to decide on any future intervention or follow-up.

#### *Intervention in group B*

In those patients assigned to group B, the following interventions are planned:

- Communication to primary care physician upon discharge (pre-Alt programme, as described in the previous group)
  - The primary care team (composed usually by a primary care physician and a primary care nurse) visits that patient at his/her home within the first week of discharge (preferably within the first 72 hours following discharge). During this visit the following tasks are carried out: a) standardised assessment of the patient status; b) basic educational intervention; c) elaboration of a list of problems and solutions proposed; and d) elaboration of an individualised care plan.
  - Follow-up visits: These are scheduled according to the individualised care plan and patient needs (it includes visits to primary care center and home visits done by the nurse and doctor)
  - Telephone follow-up by primary care nurses according to the established protocol and with goal of providing therapeutic education and early identification of worsening.
-

These calls take place every 15 days till the end of the follow-up period (3 months). The patient can always get in touch with the primary care center by phone.

- Specialist's visit (at primary care settings, if the patient can move): This visit takes place at the end of the established follow-up period, i.e. 3 months after discharge
- At the end of the 3 month follow-up period, the team decides whether the patient can be moved to group A or must go to group C.

#### *Intervention in group C*

- Home visit by a nurse of the hospital, during the first 72 hours following discharge. During the visit, the following tasks are carried out: a) standardised assessment of the patient status; b) basic educational intervention; c) elaboration of a list of problems and solutions proposed; d) elaboration of an individualised care plan and e) control of oxygen saturation and, if needed, other tests are performed.
- Weekly home visits if required during the first month of follow-up. This weekly visit is initially scheduled in the individualised care plan.
- Telephone follow-up by hospital based specialised nurses according to the established protocol and with goal of providing therapeutic education and early identification of worsening. These calls take place every 15 days during the 2<sup>nd</sup> month of follow-up. The patient can always get in touch with the specialised nurse by phone.
- Specialist outpatient visit at the end of month 3 following discharge.
- The primary care team can, if needed, support hospital specialised team during the home visits or phone follow-up.
- Tele-monitoring of the patient (questionnaires / vital signs) can be performed if indicated.
- Diagnostic tests, if needed can be performed at home (blood gases tests, pulse-oximetry, forces spirometry, blood tests...)
- At the end of the 3<sup>rd</sup> month, the patient can be derived to group A or B if needed.

## **Establishment of a home health service for COPD patients - Organisational and structural considerations**

In the previous section we have described a plan that is to be followed in an urban area of Barcelona to address a home health service for COPD patients following an exacerbation. This plan should be seen as a first attempt to connect specific groups of COPD patients to a level of service provision in the particular case of home health after discharge. We have seen that there were some initial requirements regarding how patients were identified as eligible for the service and also how we could then categorise these patients in homogeneous groups that we could treat following similar care plans. Albeit these care plans can be personalised at each individual patient level, it is important to have the notion that similar patients tend to behave and evolve in a similar way. This is an aspect that, if managed properly, has a significant potential to better allocate expenditures in a given number of patients. In turn, this might facilitate planning and promote service sustainability. Importantly, though, these home health services have to be seen as one possibility among the list of other services (institutional based or home based) that are available to these patients. Home health is not a replacement but an alternative in some cases for the right type of patients.

In the Barcelona case described, the organisational components that were taken into account in setting up the home health services were the following:

- Programme registries: including all the patients that have been accepted into the programme. These registries allowed keeping track of patients admitted into the programme and/or discharged from it.
- Specific training and education for primary care nurses.
- Development of the specific intervention protocols and required clinical instruments (e.g. questionnaires to be used)
- Installation of required information and communication systems to support coordination and control.

### *Specific training and education*

The need for specific training and education of the professionals that are part of home health delivery teams is almost universally recognised by all the authors. It can be seen as a part of the wider concept of inter-professional collaboration. Intervention based on inter-professional collaboration are strategies run in healthcare settings to improve work interactions and processes between two or more types of healthcare professionals with the ultimate goal of achieving better health outcomes. While a relatively recent Cochrane review found indications that they can have positive benefits in health care, the evidence is weak at the moment [59].

It is difficult to find articles or reviews specifically addressing the needs for education and training in home health services. One of the few available corresponds to the work done by Howarth et al [60]. In their investigation the authors underlined the importance of focusing on six themes: a) Team work considered an essential skill and directly related to patient safety; b) Communication, required to ensure effective collaboration with a focus on respect to other team members; c) role awareness, implies a good understanding of the tasks and responsibilities of each of the members of the team; d) professional and personal development, to ensure that professionals in integrated care are equipped with the necessary competences to deliver the required services; e) practice development, to better balanced

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changes across levels in the demand of care services (e.g. shorter stays at hospitals might mean a transfer of complex patients to primary care); and f) leadership and partnership working, skills on group leadership and positive attitudes to develop a framework for trusted partnership. All these elements should be part of the education and training of health professionals working in the domain of integrated care and the authors pointed out the need for collaboration among higher education institutions and health and social care agencies.

Other authors basically support this approach. Ehrlich et al acknowledges that integrated care relies on difficult concepts such as partnerships, networking, collaboration, knowledge transfer, person-centred practice and self-management support and the literature is scarce about how this should be implemented by professionals [61]. The leading role of nurses in integrated care is seen as almost natural due to their long tradition as integrators of different care services and this should be specifically promoted [62]. Nevertheless, Hewison et al warn about the actual role of the leadership and advocates for ensuring that organisations are equally ready for new practices [63].

In a study evaluating and developing inter-professional working among health and social care staff in the UK, particularly in relation to the intermediate care of older people found that there was no research about interventions used to develop inter-professional working [64].

The urgent need for a reorganisation of medical professions to be more aligned with the changing health needs and potential strategies for better management has been highlighted by Ploch et al [65]. The authors encourage adopting a population based approach (focusing on complex chronic diseases) as a first step to then reorganise specialties around the needs of these patients and eliminate work that can be done in other levels of care or by the patients themselves. This should translate into new curricula for medical professions. Garson is even more explicit and directly proposes an entire new model for education seeing in it the unique alternative to the almost certain failure of Western health care systems to keep sustainable in the future [66].

#### *Development of specific intervention protocols*

The type of interventions to be carried out in the case of COPD patients has been established by the GOLD guidelines [52] but the actual format on how this should be delivered is a point of discussion.

The review done by Steuten et al pointed out that increased provision of patient self-management education and improved disease-specific knowledge seemed to be interesting in specific intervention protocols but they also noticed that an intervention with 3 or more components of the CCM was more likely to reduce the need for rehospitalisation [44]. A richer framework to redesign this intervention is presented in pages 21 and following.

#### *Information and communication technologies*

ICT is a needed allied and generally the enabler of integrated care interventions. The goals are generally twofold:

- To facilitate organizational interoperability among professionals, healthcare/social care providers and citizens.
- To facilitate the exploitation and management of knowledge about the characteristics of integrated care processes. This should make it possible to design better processes and tools to support the professionals

To cover these goals, ICT should be able to address the following functionalities:

- a) EHR (Electronic Health Record): A longitudinal record storing the following information for each subject of care: demographics; anamnesis, vital signs, visit evaluation, prescribed exams and their results; personalized care plan; medication lists, etc.... The EHR maintains the centralized repository for all patient-specific data, tagged to allow selective access from all participating actors.
- b) CSCW (Computer Supported Cooperative Work): This functionality is responsible to support workflows and cooperative activities among the participating actors, based on the personalised care plan.
- c) CRM (Customer Relationships Management): This functionality is basically a call center support system, with extensions to manage multichannel communication flows (email, SMS, etc.). It is also responsible for handling alerts and notifications, both towards users of the platform and external users/organizations.
- d) Education or e-Education: This functionality supports the management of educational content, its storage and retrieval for the education of patients and also professionals.
- e) Mobile solutions (Mobile/Home devices interface and tools): This functionality should handle the performance of vital sign measurements from remote medical devices.
- f) Administration and security: This includes the set of tools for the administration of the ICT solution and those that ensure security (identification, authorization, data integrity, and auditability)
- g) External Interfaces: Interoperability standards and interfaces to allow communications with external systems (clinical and/or administrative)

*Estimated impact on use of health care resources*

Taking as a reference the 3 categories considered in the Barcelona study, a estimation was made using 2010 figures of the expected impact in terms of use of health care resources.

Thus, patients allocated to group A, should not require any additional resources to the ones already consumed.

In the case of patients allocated to group B and for a follow-up duration of 3 months, costs were expected to rise by 3 times at the primary care side. This was the consequence of the extra activity required. In terms of cost per patient, it means that we would move from the current 84 Euro to 248 Euro.

## Integrated care programmes

### Conceptual basis

The model of integrated care for chronic patients developed in Hospital Clínic in Barcelona targets different types of conditions (COPD, congestive heart failure, diabetes...) and under different service modalities (e.g. home hospitalisation or early discharge during acute exacerbations, prevention of unplanned admissions, wellness and rehabilitation...).

Under this model a set of programmes, also known as care pathways, have been developed. A programme can be seen as a set of normalised actions as well as evaluation tools that target precise service objectives. Programmes are based on a process model (and in the health domain are necessarily inspired by clinical guidelines), but as it is discussed later, they do not necessarily represent the entire process (or the entire guideline). Depending on the patient's risk profile, each individual will be assigned to a particular programme as represented in Figure 2.

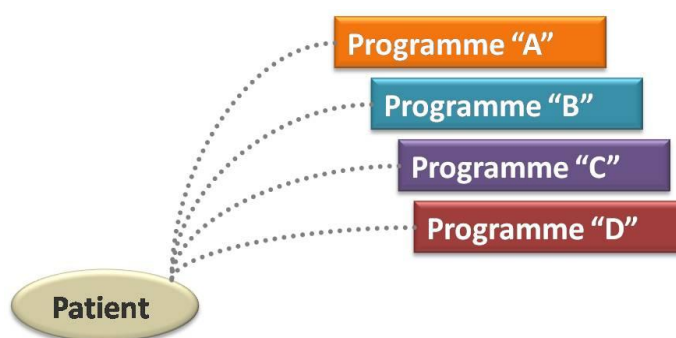


Figure 2 Allocation of a patient to an integrated care pathway. Each pathway reflects a level of intensity in the services provided that should match the specific patient's needs.

This concept of programme has been adapted from Marc Berg who was the first author describing it and is represented in Figure 3 [67].



Figure 3 A significant number of patients can be allocated to integrated care if we have the tools to categorise them according to the level of service required (Adapted from Marc Berg, see text, percentages are indicative only)

According to Berg, patients can be grouped in homogeneous groups considering different aspects that are relevant in terms of the level of health care / social care services they require. If these groups are done in the proper way, then we can redesign services in a more integrated fashion for the "integrated care group" by: 1) normalising the work practices; 2) redefining

the roles of the professionals in these work practices; and 3) better allocating the resources available.

There are important advantages in the three central elements of this redesign of services. Firstly, the normalisation of practices is clearly supported by the increasing presence of evidence-based guidelines in the routines of health professionals' practices (arguably, this is less the case in the social care domain). One of the important advantages in normalising practices is related to its potential to reduce the variability of the care provided. This might be an especially interesting issue if care is being provided by different professionals across different levels of care and/or health agencies. As it will be discussed later on, this process of service redesign does not necessarily mean that the entire guideline of a particular disease must be normalised. Rather it is a matter of selecting a segment of the entire guideline (i.e. a part of the process of the disease or its evolution) that is of interest in our case because we can handle it in a more cost-effective way by applying an integrated care approach.

Secondly, by reconsidering a segment of the care process that is of our interest and looking in detail at the tasks that are part of it, we have the chance to consider the allocation of roles and responsibilities. This should not be necessarily seen as having nurses doing the job of doctors. Rather, it is a matter of thinking about the new tasks in the context of the care trajectory and then deciding about the professional that can execute it in a more cost-effective manner. This might require the creation of new professionals or roles. Two clear examples of this situation are: 1) case-managers, as skilfully trained nurses that have responsibility on the execution of the overall patient trajectory and are also the contact point for the patients, and 2) patients and carers that are considered as another actor in the entire trajectory, with duties and responsibilities in ensuring that health goals are achieved.

Finally, once our care process is in order and we have also managed to assign professionals to individual tasks as well as defining the overall governance of the trajectory then we can easily plan in advance the resources that we might need or, looking at it from another angle, how we can make the most with the resources available. This is not the usual case in most health care settings when course of action is decided at each patient-professional encounter.

Integrated care programmes that have been redesigned following the guiding principles mentioned above have an additional benefit as was also pointed out by Berg: Not only it is easier to apply information and communication technologies to the programmes, but the application of technology has a transforming / disruptive effect in the entire programme and in the relationship and actions of participants (Figure 4) [67].

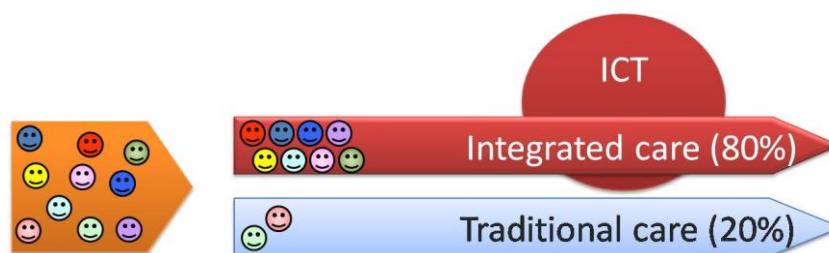


Figure 4 Transforming effect of applying information and communication technology to integrated care programmes. (Adapted from Marc Berg, see text, percentages are indicative only)

## Constructing integrated care programmes: building blocks

The construction of integrated care programmes can be facilitated if we divide them in five building blocks or phases that generally correspond to different events in a time axis. Each of these building blocks includes a well-defined set of tasks to be carried out and usually a limited number of actors. These building blocks, if properly designed, should render outcomes that are relevant or are needed for execution of the next phase. Figure 5 illustrates this set of building blocks.

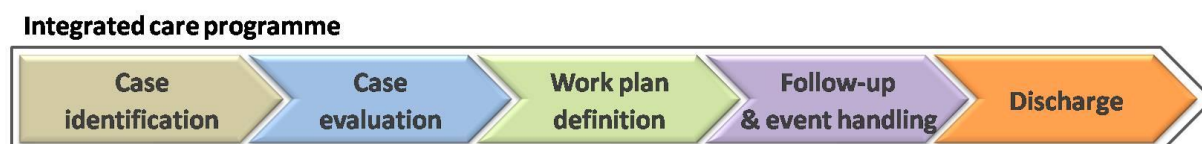


Figure 5 Building blocks of an integrated care programme. Each block renders results needed for the subsequent one.

We will first describe what is meant in each building block and we will later examine an example of integrated home hospitalisation care in COPD patients that have been designed following this model.

It is important to note that while the descriptive part can be generalised to all settings, particular examples always imply a customisation to the specific location where the programme is to be used. The latter should be kept in mind: when designing a programme, the tasks to be included in each of the blocks and the role of the actors depend on local characteristics such as: type of services available, professionals skills, levels of care that are accessible, tradition of relationship among actors, information technologies and possibilities of sharing information, etc. Failure in making a proper contextualisation of the integrated care programme can result in poor performance and outcomes.

### *Case identification*

This is the entry level for the integrated care programme. It concerns the detection of those individuals that might be eligible for a given integrated care programme. This phase does not necessarily involve the professionals that are part of the programme, or, at least, not in direct tasks.

In this phase, professional working at institutional facilities (e.g. at hospital wards, acute & emergency departments, day-case facilities, out-patient clinics, GP's surgeries, etc.) identify a patient as potentially eligible for an integrated care approach. This implies that they have the skills to recognise some of the key elements that will be further assessed by the integrated care team. These professionals then refer the patient to the integrated care team so that a proper assessment can be done.

As said before, the integrated care team is indirectly involved in this phase since they should elaborate and communicate an executive list of the characteristics that qualify eligible patients. Professionals working in the areas mentioned should be aware of the basic inclusion criteria to the programme to consider referring the patient.

### *Case evaluation*

Patients referred to the integrated care programme as potential candidates are assessed by members of the integrated care team. This task can be assigned to the integrated care case manager (be it a nurse, a doctor or another professional), albeit there might be other

possibilities (e.g. a combination of a case manager nurse and a consultant specialist). The evaluation of the patient should not be limited to the main health problem. Rather a comprehensive approach should be adopted including: co-morbidities, social aspects, patient education and informal carer support. In addition to regular clinical information, instruments monitoring quality of life and dependence are to be used at this stage (e.g. HRQL questionnaires, HADS scores ...)

This phase has only two possible outputs: a) the patient meets the required criteria and therefore is admitted to the integrated care programme; or b) the patient does not meet the required criteria and it is rejected and management is returned to the facility/level of care that made the referral.

#### *Work plan definition*

The evaluation of the patient done in the previous phase, in addition to verifying the criteria for including the patient in the programme, also provided a profile of the patient in terms of care needs. In this phase, this information is used by the case manager to select an existing programme that might be suitable for addressing these needs.

After selecting a suitable programme, the case manager in coordination with other members of the team elaborates the individual care plan for the patient. This plan includes the set of tasks as well as its scheduling: the regime of visits by nurses and/or doctors, the need for education sessions, frequency and type or monitoring sessions (if needed) and other logistics (i.e. oxygen at home) or services that might be needed.

It is at this stage where certain aspects, such as existing co-morbidities or social issues, should be addressed by complementing the “normalised” trajectory and personalising it for the specific patient. For instance, an exacerbated COPD patient that also suffers from diabetes might temporarily be moved from oral antidiabetic drugs to an insulin regime to have better control of the levels of glucose while in treatment with oral corticosteroids. This might require the incorporation of the diabetes nurse to perform some checks at regular intervals (i.e. scheduled tasks in the programme for this nurse and/or for the patient).

#### *Follow-up*

This phase corresponds to the actual execution of the individual plan and may vary in duration, depending on the specific programme and also on the patient’s evolution.

During this period, the case manager, the team of involved professionals, the patient and the carer (if needed) execute the set of scheduled tasks. The case manager acts as the coordinating agent and ensures that the programme is being followed in an appropriate way.

Should the patient have any demand or unplanned need, the case manager is the one that will provide the answer to it, requesting help from other professionals or health care agencies if needed. If the patient worsens, the case manager and the rest of the team can reassess his/her status and decide that new interventions or increased frequency in the existing ones are needed and, thus, readapt the programme as necessary. If this is insufficient or if, as a result of the worsening, the patient does not longer meet the criteria that correspond to the current integrated care program then he/she has to be discharged from the programme.

#### *Discharge*

Discharge occurs when the patient does not longer meet the inclusion criteria for the specific programme he/she had been allocated.

A variety of causes can lead to the patient being discharged from a programme. This can be the result of a change in the health or social condition (e.g. the main health problem worsens, a stroke episode, a change of carer) or other causes (e.g. patient moving to another area). Discharge may or may not imply referral of the patient to institutional care. Thus, there will be patients that might need readmission at the hospital, whereas others will be moved to a programme of higher intensity (e.g. including daily hospital nurse home visits).

The contrary, moving a patient from a high intensity to a low intensity programme, is also possible. Thus an exacerbated COPD patient that first required hospital admission can be early discharged home under a home hospitalisation programme. Once the episode of exacerbation is over, the patient can be moved to a home based programme to prevent future exacerbations and improve quality of life. The following figure describes this wider patient trajectory (Figure 6).

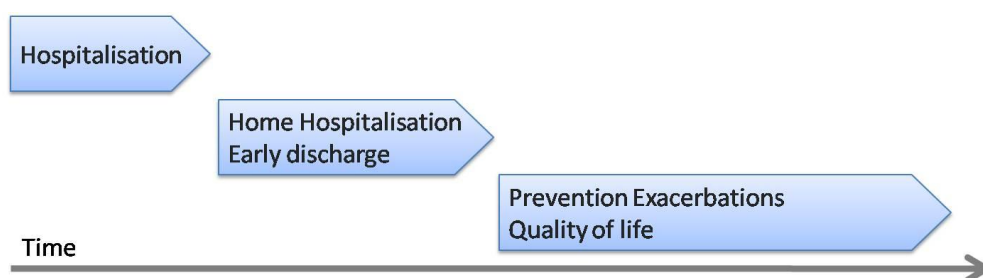


Figure 6 Example of a COPD patient’s wider trajectory: Exacerbation is treated first at the hospital and then discharged home under a home hospitalisation programme. Once the patient is stable, a home based prevention of exacerbations programme is used.

### Constructing integrated care programmes: detailing tasks and roles

While the division in five building blocks is a useful aid to advance in the construction of integrated care programmes, it is still a skeleton that must be filled in with the detailed tasks and a mechanism to allocate these tasks to the different actors.

#### *Business Process Modelling Notation*

In our experience developing the integrated care model at Hospital Clínic in Barcelona, we have found it useful to use a workflow-like formalism known as BPMN (Business Process Modeling Notation).

BPMN is a tool created for the business domains. However, even a quick look at the short description that appears on its webpage (<http://www.bpmn.org/>) reveals its potential utility in the health care sector: “A standard Business Process Modeling Notation (BPMN) will provide businesses with the capability of understanding their internal business procedures in a graphical notation and will give organizations the ability to communicate these procedures in a standard manner. Furthermore, the graphical notation will facilitate the understanding of the performance collaborations and business transactions between the organizations. This will ensure that businesses will understand themselves and participants in their business and will enable organizations to adjust to new internal and B2B business circumstances quickly.”

This is very much the exercise that we need to do when designing integrated care programmes across levels of care. In our experience, this is a tool that can be understood and used by different actors, that requires no (or very little) learning effort, and facilitates the understanding of how decisions flow, how information is handled, the tasks that are to be

carried out and the actors responsible for them. Additionally, it is helpful in provoking the redesign of current care practices by making explicit what areas are in need of redesign. Also it is excellent in grouping activities along care paths or trajectories.

The example below (Figure 7) illustrates the use of BPMN in a very simple process. This example has been extracted from the document “Introduction to BPMN” by Stephan A. White and can be found on the BPMN website.

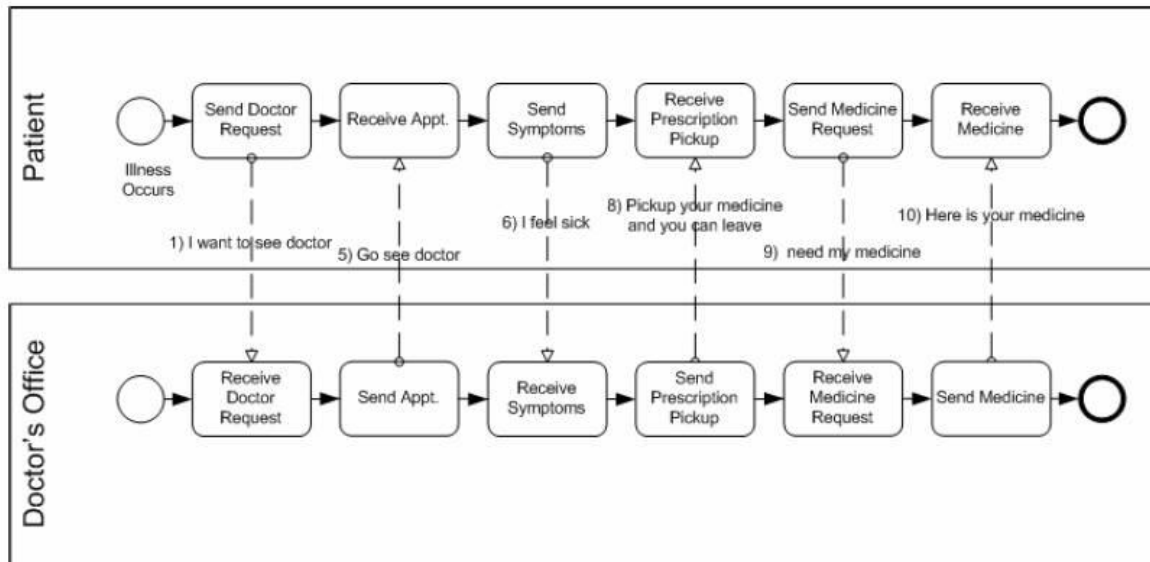


Figure 7 Example of a simple BPMN chart applied to the health care domain. Each actor is represented by pools or lanes, whereas tasks are represented by a rectangle with rounded corners.

We have applied this formalism to the elaboration of the integrated care programmes for different types of services including home hospitalisation in COPD patients. This is the one shown Figure 8 that represents the current programme in use by the integrated care at our hospital<sup>2</sup>.

<sup>2</sup> N.B.: This programme has inspired the intervention in group B described in section “Which patients may benefit from home based COPD care?” on page 17, that is to be seen as a more advanced one and better linked to other actors, notably, primary care.

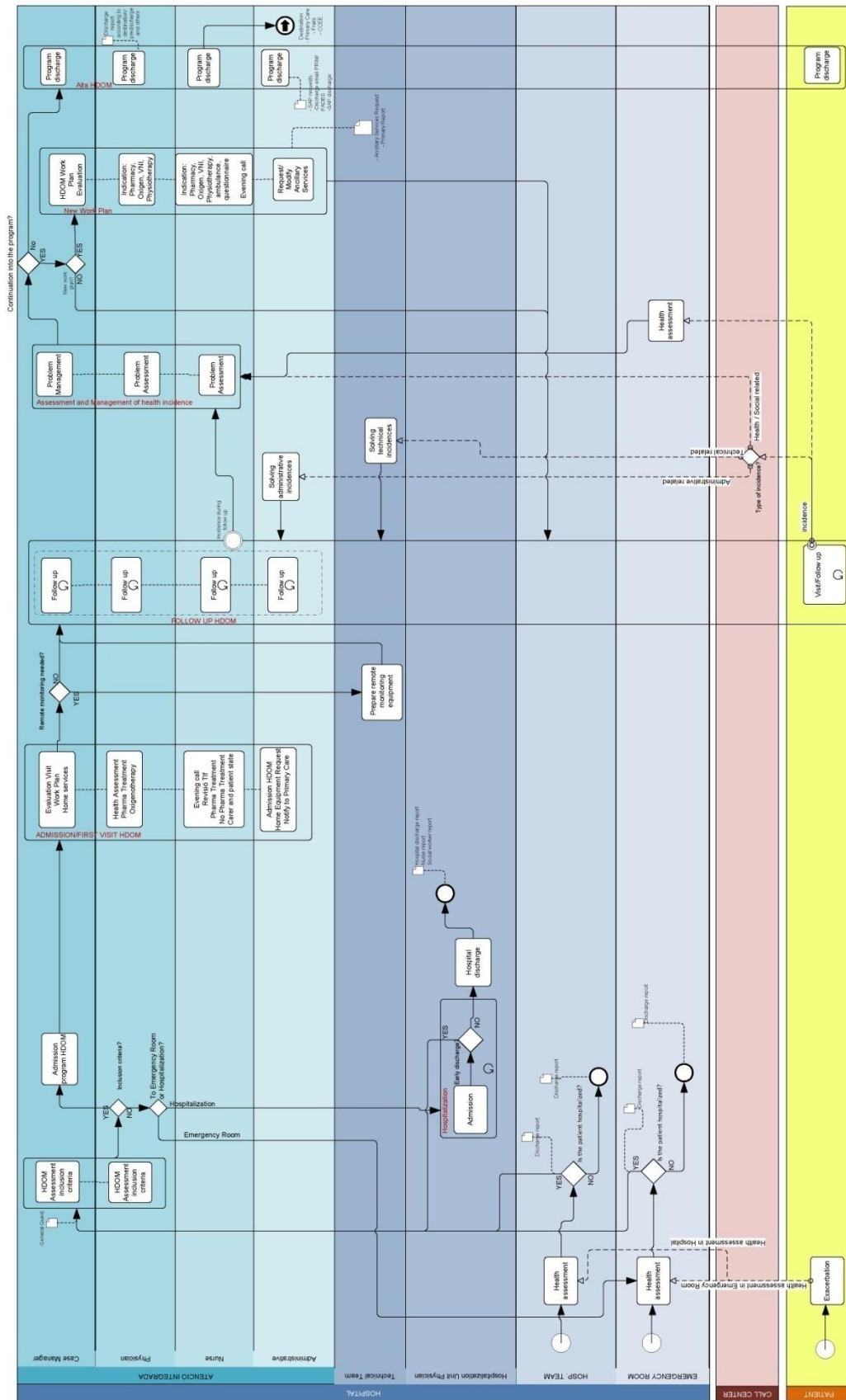


Figure 8 BPMN for Home Hospitalisation of exacerbated COPD patients (Graphic elaborated for the Nexes project CIP-PSP EU Grant 225025)

The different main building blocks mentioned before can be recognised in the previous chart but, for the sake of clarity, they are highlighted below (Figure 9)

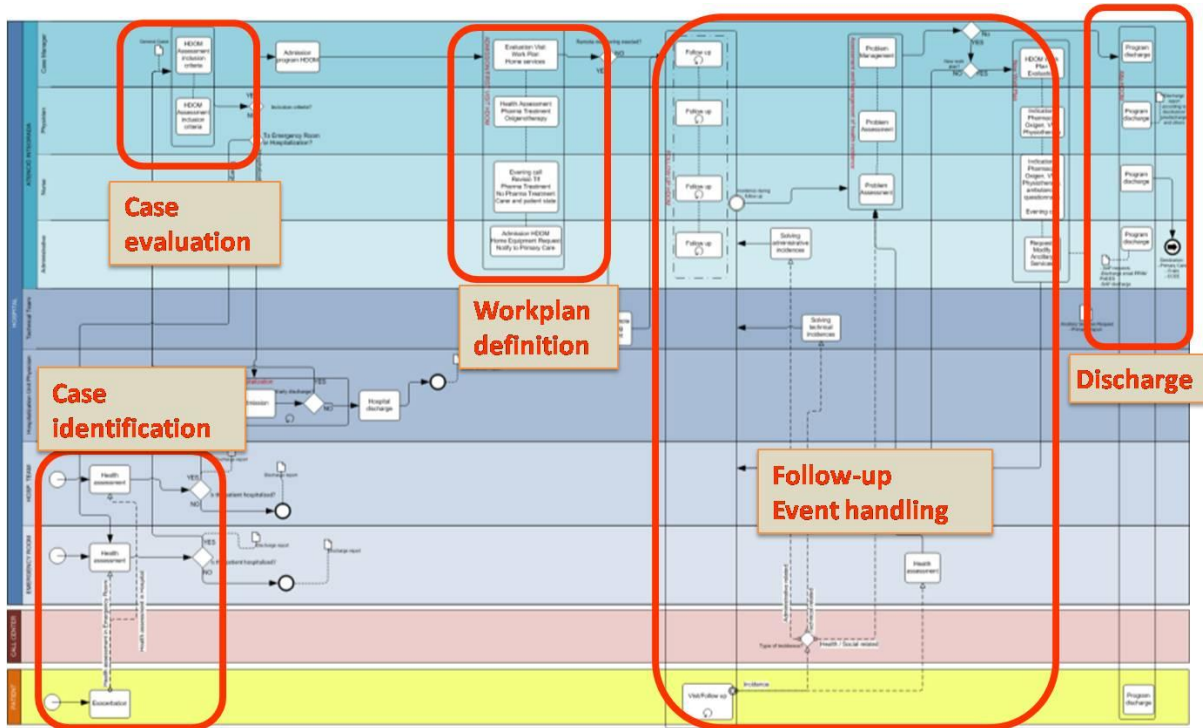


Figure 9 BPMN for Home Hospitalisation of exacerbated COPD patients. The main process blocks are highlighted. (Graphic elaborated for the Nexes project CIP-PSP EU Grant 225025)

Let's see two detailed examples that illustrate the representation of tasks and professionals involved.

The exacerbation of the patient's condition is the event that triggers the entire programme. This patient is seen either at the Emergency Room department or at the Day-Case facility of Hospital Clinic. These are institutional resources that are not part of the programme. However, the professionals working there are aware that integrated care programmes supporting COPD patients are available, provided they meet certain inclusion criteria. After performing a basic check, the patient can then be referred to the integrated care team for a more accurate evaluation. Figure 10 zooms in on this part of the programme.

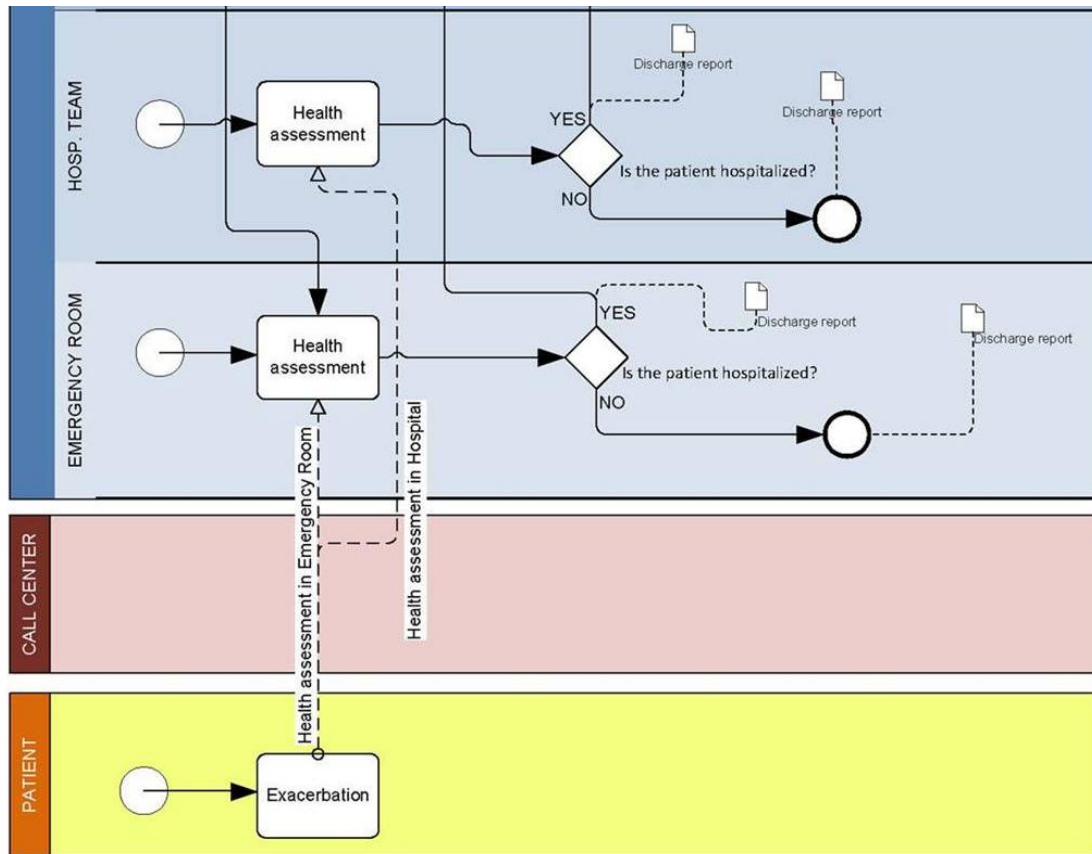


Figure 10 Zoom in on the phase of case identification in the case of the home hospitalisation programme for COPD patients. The pools and lanes show the participating actors in this phase: patient, emergency room team / hospital team (at day-case facilities). (Graphic elaborated for the Nexes project CIP-PSP EU Grant 225025)

A second example corresponds to the definition of the work plan that involves the different professionals at the integrated care unit. Thus the case manager is the one that performs the evaluation visit at home (in our case in the first 24 hours), plans the schedule of the home visits of the case and decides on the home services that might be needed. The specialist or physician is the one that performs the health visit and prescribes the treatment (medicines, oxygenotherapy...). The nurse will be responsive for the evening call where he/she will check that discharge from hospital to home was safely done. Also he/she will check about any doubts regarding treatment or any other special needs and also assess the state of the carer. Finally, the administrative staff will be responsible for the administrative admission of the patient into the programme and for sending a notification to the primary care physician and the request for home oxygen to the company supplying it.

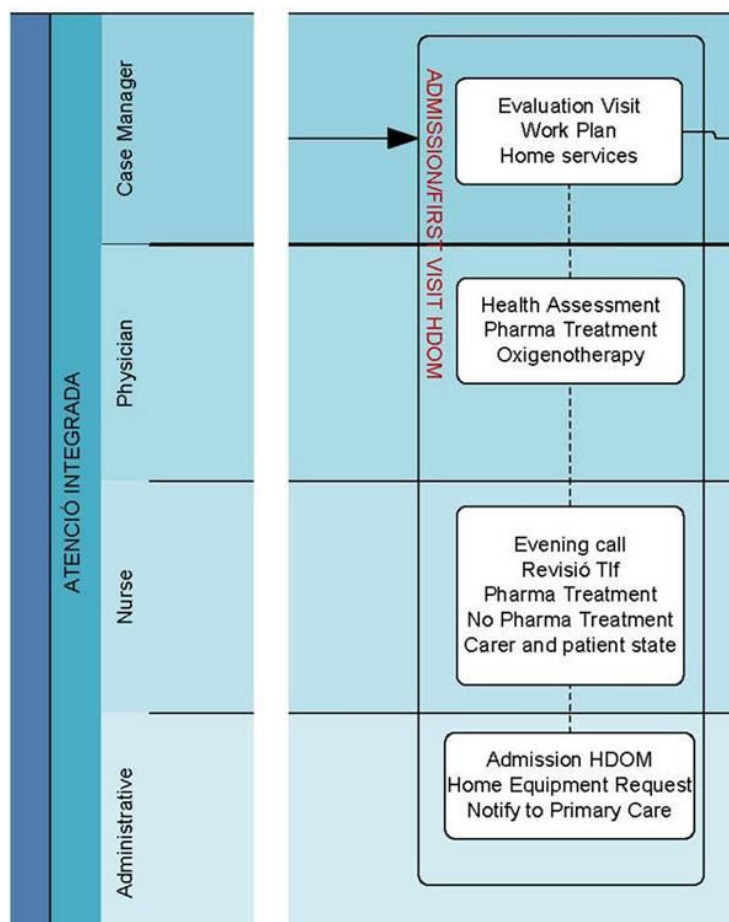


Figure 11 Zoom in on the phase of work plan definition in the case of home hospitalisation programme for COPD patients. The pools and lanes show the participating actors in this phase: the professionals at the integrated care unit. (Graphic elaborated for the Nexes project CIP-PSP EU Grant 225025)

### *Detailing tasks and roles*

The use of BPMN charts is useful to determine the scheduling of tasks and who is the actor doing them. In the case of the tasks, the BPMN representation shows the “containers” where more detail should be incorporated depending on the profile of the patient considered. This detail corresponds to the clinical / social domains of knowledge and should be initially obtained from existing guidelines and/or protocols. However, the particular way of ordering it can be different, as a result of the new organisational model that integrated care represents as well as local traditions.

Let’s see it in a particular example in an exacerbated COPD patient that is being treated in a home hospitalisation programme that follows intervention type B as described in page 16. This patient is supposed to have follow-up visits and follow-up calls, both of them individualised according to the profiles of the patient. Consequently, in this patient the following follow-up has been decided

- Follow-up visits: two weekly. One of them is carried out by the nurse and the other by the nurse and the doctor. The following items will be checked: 1) Risk factors; 2) Co-morbidities; 3) clinical signs and symptoms of respiratory condition (Dyspnoea scale – MRC-, cough, sputum); 4) Physical activity; 5) Adherence to pharmacological and non-pharmacological treatment ; 6) measurement of oxygen saturation and spirometry.

- Follow-up calls: one weekly to check quality of life (EuroQoL, SGRQ) and social issues.

The important point is to decide on how to best allocate the different individual tasks to each of the containers in such a way that the resulting programme can be cost-efficient with respect to current approaches. Most likely, this requires some tries on the different possibilities before finding the most convenient solution.

In this process of finding the combination of services that is more cost-effective, the particularities regarding the local work force are central. Thus, diverse traditions in different locations have resulted in professional profiles that, even with a similar background have dissimilar skills or are assuming different tasks. This means that whereas in location A, a nurse is the one making the weekly follow-up call to check for quality of life; in location B, this is done by the social health professional that provides support at the patient's house every other day.

Similarly, the tradition may advise in favour or against new roles for professionals. For instance, there might be places where delegating in a nurse the role of case-manager might not be easy to accept. Or, in others, general practitioners might not want to take in tasks that they might perceive as corresponding to hospital physicians. In any case, the goodness of the programme designed, apart from its clinical correctness – it should be aligned with current knowledge on the condition – will be determined by its resulting cost-effectiveness. In other words: two programmes targeting the same type of patients can be different in terms of the scheduling of the tasks and the professionals involved but still they can be well-adapted to their surroundings and so, be cost-effective.

## Conclusions and recommendations

Chronic obstructive pulmonary disease (COPD) is a respiratory condition estimated to affect up to 10% of the population older than 40 and it is on the rise. At present, it is the fourth leading cause of death worldwide and projected to be one of the top 5 causes of disease burden globally. Prevalence is higher in man though mortality is similar in both sexes. The condition develops slowly: first symptoms include cough with sputum and shortness of breath (dyspnoea) with wheezing and decreased breath sounds. Patients, notably those more severe, tend to evolve through repeated exacerbations leading to frequent visits to emergency care departments and/or admissions at hospitals and progressive deterioration. Frequent complications include weight loss, pneumothorax, right heart failure and acute or chronic respiratory failure. Together with patients' history, physical examination and chest-X-ray, pulmonary function studies play a key role in diagnose and follow-up of the condition. In spite of the simplicity of spirometry and its reliability, quite often the disease remains undiagnosed during early stages. As a result, patients tend to be elderly.

Treatment of COPD patients is well established. In stable phases treatment goals are: 1) avoid exacerbations and, 2) improve lung and physical function through medications, oxygen therapy, smoking cessation, exercise, enhancement of nutrition, and pulmonary rehabilitation. Regarding medications, inhaled bronchodilators are the main therapy in the management of COPD, including  $\beta$ -agonists, anticholinergics and corticosteroids. In the exacerbations, oral or systemic corticosteroids together with antibiotics and an increase in the doses of short-acting  $\beta$ -agonists are the main options together with supporting measures (additional oxygen supply or ventilation assistance).

However, currently most health systems in Western Europe and developed countries are better designed to handle the exacerbations than the patient as a whole and they repeatedly fail in efficiently preventing such episodes. This is also common for other chronic conditions, such as in the case of congestive heart failure. Moreover, these elder COPD patients tend to suffer from other conditions as well, being heart-related ones the most usual. In an effort to rethink the formats of health care delivery, different proposals have been made following the seminal work of Wagner et al [22] and later developed by WHO in the form of a framework for innovative care of chronic conditions [9]. The last decade has seen the emergence of different applications of these work and framework and has led to a variety of terms that in many cases share significant commonalities, as it has been discussed in pages 6 and following. The evidence available at the moment is of different quality depending on the approach selected. However, it seems that the ideas of greater coordination among professionals and health care agencies and the segmentation of patients in homogenous groups by intensity of services required is reasonable [57]

In this document, albeit entitled home health in COPD, we have adopted an integrated care approach because of its, in our opinion wider, comprehensiveness and applicability to the variety of stages that COPD patients experience, as defined by Kodner [27]:

“(…) a coherent set of methods and models on funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long-term problems cutting across multiple services, providers and settings. The result of such multi-pronged efforts to promote integration for the benefit of these special groups is called ‘integrated care’”

The experience being carried out in Barcelona described in pages 15 and following ones applies this approach to an integrated care home hospitalisation service for exacerbated COPD patients. It proposes the segmentation of patients into 3 groups that are connected to 3 formats of care service delivery. In this approach specialised care and primary care are coordinated and take different responsibilities in the follow-up of the patients, with a certain degree of moving complexity from hospital to the primary care setting. While the individuals tasks are not different from those established in the GOLD guidelines [52], their organisation seems to maximise the cost-effectiveness of the entire process.

This organisation being so crucial to the eventual success of the integrated care approach, we propose the use of certain formalism to not only redesign the process of care but also to have the capability to better analyse the impact achieved and how to modify it if needed. Starting from five basic blocks (case identification, case evaluation, work plan definition, follow-up and discharge) we go into the detail of defining tasks and roles by using a workflow-like formalism known as BPMN. By using this notation, we can fully represent the entire integrated care process, the detail of the tasks and the participation of individual actors. Additionally, we can explicitly introduce checkpoints to evaluate performance, either when applied to an individual patient or to a group of similar patients. Another significant advantage of BPMN is that it helps to make explicit information flows and thus, it can be used for the introduction of ICT technologies supporting the process.

### **The outlook for integrated care**

Our current developments in integrated care programmes have traditionally focused on rather advanced disease conditions, home hospitalisation of COPD patients being a good example. Modalities preventing unplanned hospitalisations have been less frequent although they have also been successfully explored, their long-term sustainability being limited because of the lack of appropriate funding mechanisms.

However, there are authors that are starting to consider that the particular format of service delivery is only one of the aspects that, albeit relevant, might not suffice when sustainability of the health systems is at stake. As we are starting to understand how different conditions influence each other, another crucial facet emerges.

In this respect, we know that NCDs are multi-factorial diseases caused by complex gene-environment interactions (risk factors e.g. tobacco, nutrition) and socio-economic determinants modulated by gender and age. Similar and differential pathways of local and systemic inflammation [68] and bioenergetics [69] are intertwined leading to individual-specific complex biological and clinical phenotypes [70]. Comorbidities (multi-morbidities) are NCD characteristics.

Management strategies using clinical and biological criteria categorizing each NCD separately has been proposed but, even if interesting, they have proved to be insufficient. Recent advances in systems biology and network analysis have opened new avenues to understand mechanisms of co-morbidities of multi-factorial NCDs [69]. The underlying idea would be that, in the case of major NCDs, the complex homeostatic regulatory network is perturbed at different and multiple levels. This perturbation is the expression of an intricate interplay of common and individual-specific biological and clinical phenotypes clustering in co-morbidities. Understanding these interactions is crucial not only to better diagnose and prescribe treatment, but also to envision new formats of service delivery.

We are now in the phase of starting to explore how these tools can be integrated, deployed and validated in real life scenarios for universal adoption. Likely, this should be done in the

context of integrated care modalities, albeit in the long term, the concept of personalized prevention and care might be more appropriate.

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