

# Development of an evidence-based reference framework for care coordination with a focus on the micro level of integrated care: A mixed method design study combining scoping review of reviews and nominal group technique

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#### **Title**

Development of an evidence-based reference framework for care coordination with a focus on the micro level of integrated care: a mixed method design study combining scoping review of reviews and nominal group technique.

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#### **CRediT** authorship contribution statement

Françoise Colombani: term, conceptualization, investigation, data curation, writing original draft, visualization, project administration, funding acquisition. Gaëlle Encrenaz: investigation, resources, data curation. Matthieu Sibé: term, conceptualization, methodology, funding acquisition. Bruno Quintard: term, conceptualization, methodology, funding acquisition. Alain Ravaud: term, conceptualization, funding acquisition. Florence Saillour-

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#### **Conflict of Interest statement**

The authors declare that they have no competing interests.

#### **Ethics and consent form**

The EPOCK study protocol was approved on 26 July 2017 by institutional review boards and Ethics Committees (Comité de Protection des Personnes [CPP] du Sud-Ouest et Outre-Mer III number: 2017-A02049-44) and registered in *clinicaltrials.gov* (registration number: NCT03350776).

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The EPOCK study protocol has been peer-reviewed (expert jury) by the funding body (originality of the study, study design, data collection, type of analysis planned) and published by Colombani *et al.* in BMC HSR 2019.

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#### **ABSTRACT**

**Background**: Because of the limits in conceptualisation of care coordination linked to the large array of care coordination models and definitions available, a care coordination framework is needed with a particular focus on the *micro* level.

**Objective**: To develop an evidence-based reference framework for person-centred care coordination interventions based on international validated definitions.

**Methods**: This two-step mixed-methods study included first, a scoping review of reviews focus on the impact of care coordination interventions and then, a nominal group technique. The scoping review aimed at identifying the components of the four dimensions of the framework (contexts, activities, actors and tools, and effects). The nominal group technique was to select the relevant components of the dimension 'activities' of the reference framework.

**Results**: The scoping review selected 52 articles from the 1,407 retrieved at first. The nominal group selected the 66 most relevant activities from the 159 retrieved in the literature (28 activities of care organisation, 24 activities of care, and 14 activities of facilitation).

**Conclusion**: This operational framework focused on care coordination at the micro level, is a useful and innovative tool, applicable in any clinical condition, and in any health care system for describing, implementing and evaluating care coordination programmes.

## Highlights

• This review provides a new operational evidence-based framework for care coordination.

 Comprehensive and specific characterisations of care coordination activities were performed.

• Interventions effects were evaluated using patients', caregivers', professionals', and healthcare system perspectives.

 Innovative tools were used to describe, implement and evaluate care coordination interventions.

# Classification and keywords

Care coordination

Continuity of patient care [MeSH term]

Theoretical framework

Consensus [MeSH term]

Models, Organisational [MeSH term]

Scoping review

#### INTRODUCTION

#### Care coordination: a worldwide public health priority

Because of the growing ageing population and the increasing number of people diagnosed with chronic conditions, coordination of care has become a crucial issue in care systems worldwide (1–4). Lack of care coordination has been associated with poor symptom control, medical errors, and high costs (5–9). Therefore, care coordination has been recognised as a key element of high-quality health care delivery and a global priority for improving patient healthcare (10,11). However, trials evaluating the impact of care coordination interventions have shown discordant results, highlighting the heterogeneity of the interventions tested (12–16) and revealing high variability of interventions components, related to a lack of underlying conceptualisation (17,18). In addition, interventions are rapidly evolving with new technologies.

#### Care coordination: a poorly defined complex concept

During the past decade, various models of coordinated care have been widely applied and documented across a variety of settings, which has resulted in an array of care coordination definitions and conceptual frameworks (19,20). These models provide conceptual support for many types of care coordination interventions, ranging from individual case management (21), through disease management population-based programmes (22–24), to fully integrated care systems (*i.e.* chronic care model) (25–27). This model evolution has led to a more comprehensive integration of patient context, environment, capacity and involvement in care, as well as population-based issues (28). Based on these models, care coordination was considered at three levels (29): the *micro* level (clinical) refers to the delivery of health care to individual patients (coordination of person-focused care); the *meso* level (organisational)

refers to inter-organisational relationships to deliver comprehensive service to a defined population (coordination of population-based care and health care services); and the *macro* level (system) refers to health and social system (governance, financing and policy) (22,29–31).

The core reference model is case management, focused on individual patient-centred care needs (19). The case management model was first described in the 1950s and was designed for people with complex needs (*e.g.* people with mental disorders or elderly dependent people) (24). This model introduced a new profile for professionals as 'case managers', consisting mainly of specialised nurses. Case management is schematically based on the quality improvement cycle (*i.e.* 'plan-do-check-act') (21). Each step corresponds to a specific stage of patient case management (23): detection of a complex situation, assessment of the situation, consultation between professionals and the patient to consider care planning intervention priorities, identification of stakeholders and implementation interventions, monitoring of the effectiveness of interventions, and reassessment of the situation. The level of management for each case is adapted according to the complexity of the patient's condition, as well as the duration and intensity of the need for support (24).

From the concept of case management, the disease management model was developed in the 1980s for patients with a well-defined disease (32). This approach is based on coordination tools (*e.g.* decision making algorithms, a structured information system, and patient education) and professional networks adapted to the specific disease (33). Subsequently, the population health management model emerged, integrating both concepts of case management and disease management. This originated from a population-based health programme that aimed to improve care at a lower cost (*i.e.* Kaiser Permanente model) (34,35). Using an information system, people are classified into three distinct groups according to their clinical situation and the importance of their care needs (*Kaiser Pyramid*).

The chronic care model was developed specifically for chronic diseases. Considering the context of care, this model is aimed at integrating informed and active patients into the management of their disease with a proactive and multidisciplinary team of healthcare professionals (36,37). New generations of chronic care models consider broad determinants of health and focus on a system of coordinated interventions across different levels of care (19) through the Innovative Care for Chronic Conditions Framework (World Health Organisation) that is focused on health policies and organisations, as well as resources in the community (38).

In addition to the diversity of these models, several definitions of care coordination coexist. A literature review conducted by Armitage *et al.* revealed approximately 175 overlapping definitions and concepts of care coordination, indicating the absence of a consensus definition (19,39,40). Furthermore, the Agency for Healthcare Research and Quality (AHRQ) has identified more than 40 definitions of care coordination, which has been used to establish a common definition of care coordination (40). Currently, the diversity of existing models, considerable variability among practices, lack of working definitions and shifts in underlying concepts have led to increasing difficulty with regard to the standardisation, replication, transposition and evaluation of coordinated care (41,42). Many authors have acknowledged the lack of effective care coordination and the need to standardise interventions (43–45).

Several integrated care coordination frameworks for multimorbidity (*i.e.* the Integrated Team Effectiveness Model [ITEM], the Development Model for Integrated Care [DMIC], the Rainbow Model of Integrated Care [RMIC], the SELFIE framework or JA-CHRODIS) (46,47,29,31,48–50) have been developed and have provided useful tools concerning care coordination conceptualisation. They cover all dimensions of care coordination but one of the main gaps of these care coordination frameworks is the limited guidance provided on how to

implement care coordination in health systems (50). These models explore the *macro* and *meso* levels, but do not provide sufficient information concerning the *micro* level regarding detailed activities to be carried out with patients, detailed information on actors and tools used to perform person-centered care coordination, or the overall effects of care coordination. In addition, some frameworks tend to combine care coordination activities with tools and actors in the same component, whereas it would be appropriate to individualise them. To the best of our knowledge, there is no comprehensive care coordination framework at the *micro* level that accurately integrates coordination activities.

#### The EPOCK research programme

In the context of increasing cancer incidence and cancer survivorship (51,52), many national strategic cancer plans have identified cancer care coordination as a priority for health service improvement. In the United States, Canada, and Northern Europe, *cancer navigation* programmes were introduced in the 1980s and 1990s by Freeman, with the initial aim of reducing health inequalities (53), then reducing cancer-related morbidity and mortality (54) and finally offering patients a complete continuum of support in terms of care throughout their lifespan (55). For 20 years, France has implemented a cancer care coordination national programme. There are two distinct levels regarding the structure of cancer care in France: a collective level focused on the organisation and structuration of care coordination, and an individual level focused on patient-centred care. At the collective national level, the French National Cancer Institute (56) has been created to implement National Cancer Plans (*macro* level). At regional and local collective levels (*meso level*), Regional Cancer Networks and Cancer Care Coordination centres are responsible for organising, structuring, and evaluating cancer care in healthcare facilities with regard to the authorisation of, and delivery system for, cancer treatments (57). In addition, at the individual level (*micro level*), various new

professions involved in the coordination of patient care have been implemented empirically since the 2000s without underlying conceptualisation. Some have been focused on healthcare pathways from hospital to ambulatory care and others on treatments. This heterogeneity, particularly among nurses involved in coordination from hospital to ambulatory care, hampers readability, action comprehension, and mission definition, thus causing difficulty in the evaluation of cancer care coordination intervention (20).

Although there is a widely recognised need to improve care coordination for people with cancer (8,9,20), efforts have been hampered by the lack of a common conceptual framework concerning care coordination, information regarding the diversity of professional practices and descriptions of care coordination contexts (58).

Thus, we are carrying out the EPOCK mixed-methods research project in France (funded by the Ministry of Solidarity and Health) (59). This project is aimed at developing a reference framework for care coordination interventions, as well as evaluation of practices and working contexts concerning hospital-based cancer care coordination nurses within this reference framework. This project is being carried out in three phases: (1) building a reference framework for care coordination at the patient level in any clinical situation; (2): describing practices, perceptions, and job attitudes related to care coordination models in the context of oncology treatment in France, while considering diversity and heterogeneity; (3) comparing the expected theoretical framework (developed in phase 1) to professional practices for use in proposing a measurement framework for cancer care coordination nursing intervention in France.

This paper presents the results of the first phase of the EPOCK project, which is aimed at building an evidence-based comprehensive framework of care coordination for all types of diseases, focused on the *micro* level of integrated care models (22,29). We focused on the *micro* level to compensate for the lack of a current standard referral system for care

coordination at this level, and to respond to the need for the EPOCK project phase 2 to investigate cancer care coordination activities of delivered by nurses.

#### MATERIALS AND METHODS

The framework developed within the EPOCK project is based on the main dimensions of care coordination that has emerged from the AHRQ care coordination definition (40,60), which encompasses all the underlying models studied in the McDonald *et al.* review and have identified four dimensions: a) contexts; b) care coordination interventions activities (at *macro*, *meso*, *and micro* levels); c) actors and tools; and d) outcomes, classified from three perspectives: patients, professionals, and health system.

#### Study design

We conducted a two-step mixed-method study, overviewed by an interdisciplinary research team (EPOCK team) composed of epidemiologists with expertise in health services research, researchers in management sciences, and researchers in human and social sciences. In Step 1, an international scoping review was performed (according to the PRISMA guidelines for Scoping Reviews) (63) involving reviews that evaluated the impact of care coordination interventions to clarify the concept and identify key components of the four dimensions of the framework. This review of reviews was performed to construct a comprehensive and structured inventory of a wide variety of interventions and their components. We used a scoping review to identify as broadly as possible the components of the care coordination framework (64). In Step 2, a nominal group technique (NGT) (65,66) was implemented to select and prioritise the activities of care coordination interventions most relevant to the AHRQ definition of care coordination and applicable to the healthcare systems of high-income countries, particularly France.

### Step 1: Identification of key components of framework dimensions (scoping review)

The research strategy explored reviews publications in *PubMed, Scopus, and PsycInfo* databases using keywords focused on 'care coordination', 'coordination of care', or 'coordinated care' without additional selection criteria regarding the type of disease (see search strategy on *PubMed* data base in supplementary materials Figure 1).

# In Supplementary Materials Figure 1: Electronic search strategy in PubMed Database

After removal of duplicates, the titles and abstracts were hand-screened for relevance by two reviewers (GE and FC). Screened articles were English and French language reviews published between 1990 and September 2017 that evaluated the impact of care coordination interventions, irrespective of clinical condition, patient population or specific outcomes. Articles were excluded if they did not describe care coordination interventions. Then, the fulltext publications were reviewed manually by two reviewers (FC and GE). Furthermore, a number of articles were added using a snowball approach (articles selected from the reference lists of included publications). Publications considered relevant only by one of the two reviewers were discussed until consensus was reached. The process of synthesising the literature was iterative. Data were extracted from eligible articles according to the scoping review characteristics (year of publication, authors, journal, number and design of included studies and care coordination interventions tested), population, health conditions. The lead author (GE) and the second author (FC) catalogued the different care coordination theoretical models, activities, actors, tools and type of outcomes (by patient, caregivers, health care professional and system perspectives) according to the AHRQ definition. During five meetings of approximately two hours a discussion was held on the synthesis of the essential

elements of care coordination activities to be rated by the NGT. Based on these discussions we refined the framework.

The outcomes of care coordination interventions were assessed on the basis of impact evaluation criteria in retrieved studies. The selected effects of 'outcome' dimensions were those with statistically significant positive results (p < 0.05 was considered statistically significant). Effect criteria were not retained if the review did not indicate the level of significance. In addition, a meta-analysis effect was not recorded if its pooled result was not globally statistically significant. Finally, effect criteria were classified according to the four perspectives of the AHRQ (patients, caregivers, healthcare professionals, and healthcare system).

## Step 2: Selection of the components of the dimension 'activity' (nominal group technique)

The interdisciplinary expert group represented various roles, missions, positions and projections for and in the coordination of care in France, in any clinical setting. We defined three categories of needed experts and chose to select three experts in each category. A total of nine experts were selected including: 1) researchers who have published on care coordination (three experts); 2) policy makers and regulators who have organised care coordination at local, regional and national levels (three experts); 3) patients as experts (67,68) who were trained to support patients (three expert patients). The additional selection criteria for experts were volunteering, absence of conflicts of interest, geographic diversity and parity.

According to the NGT's reference methods (69,70), the three steps of the nominal group meeting were conducted as follows: 1) Group discussion (discussion of items and suggestion of new items) to reach an agreement concerning the activity items proposed by the literature review. 2) Individual ratings of activity items, where each expert anonymously rated

the relevance of each individual item, using a score ranging from 0 (not relevant at all) to 4

(very relevant). A care coordination activity was considered relevant if it met the care

coordination definition (60). 3) Collective discussion of results and suggestions for rewording

or regrouping, further proposals of priorities and reconsiderations of previous discussions.

Consensus was reached when everyone around the table was in agreement, comments had

been exhausted and everyone agreed on the choices made. We ran two full days NGT at one-

month interval in a central and neutral location.

**RESULTS** 

**Step 1: Identification of key framework components (literature review)** 

Review selection

Our literature search yielded 1,407 potentially relevant publications (609 in *PubMed*, 734 in

Scopus and 64 in PsycInfo). After removal of duplicates (n = 400), as well as exclusion of

editorials, opinions, articles in other languages than English or French and publications that

did not refer to the impact of care coordination interventions (n = 857), 150 publications were

screened on the basis of their title and abstract. Among these 150 articles, 77 revealed an

absence of information concerning many basic elements of care coordination, while 24 full-

text articles were not accessible. The screening process resulted in 52 unique full-text reviews

(n = 49 articles from database searches and n = 3 articles added by the snowball approach)

(see Figure 2 in supplementary materials).

In Supplementary Materials

Figure 2: Scoping review flow chart. EPOCK research project.

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The 52 publications were mainly published in the US (n = 17), Europe (n = 15), Canada (n = 10), and Australia (n = 6). Of the 52 publications, 36 (69%) were systematic reviews, 15 were other reviews (narrative, scoping, integrative or focused), and one was a meta-analysis. Articles identified from the scoping literature review were published during the period from 2000 to 2017, and more than half of the reviews were published after 2013. For each included review, the target populations were outlined (*e.g.* mental health, chronic illness, emergent disease, paediatrics and/or elderly), as were the care coordination conceptual models (*i.e.* models either described in the articles or qualified in accordance with the description of interventions in the article) and the nature of interventions tested (**Table 1**).

Table 1: Listing of reviews included in the scoping literature review.

### **EPOCK Research Project**

#### Components of the framework dimensions

The literature review identified the following components within the four selected dimensions of the framework.

#### a) Contexts

The literature review reported several contexts of care coordination intervention implementation, characterised by the target populations, which differed according to the nature of disease, stage of care process, sociodemographic characteristics of the patients, and type of healthcare system (71):

#### - Diseases and multimorbidities managed by care coordination

Care coordination interventions appeared necessary in the context of complex medical pathways involving many providers in the management (72,73) of people with multiple comorbidities (73) (including chronic diseases (74–78)) and having frequent use of the health

system (79). The retrieved care coordination interventions most frequently concerned the following diseases: cancer at different points in management (*i.e.* screening, announcement, post-treatment phase (80) and link between primary care and oncology services (81,82)); after a cardiovascular accident (76,83–85); in the context of dementia (86–88), diabetes (76,83,89), asthma (83,90), rheumatoid arthritis (76,83), or chronic obstructive pulmonary disease (76); after a spinal cord injury(91); and in the context of mental health and addictions (83,92,93).

#### - At each step of the care process

The retrieved interventions were required at specific stages of the care pathway and care transitions, regardless of the health problem encountered, such as in emergency departments (90,94) and to provide transitions between general and specialised medicine (95). Thus, many articles concerned transitions of healthcare services within the hospital, from intensive care units to general wards (79,90,96), including city-hospital transitions (79,84,95,97,98).

 Sociodemographic and economic characteristics of patients benefitting from care coordination

These interventions had also been tested or implemented in patients with different life-stage situations such as paediatric patients (90,99–101), pregnant patients (73,102,103), elderly patients (97,104–106), or those in end-of-life care (83,107). In addition, these interventions could have been implemented for specific population groups such as those from resource-limited countries (108), refugees (109), or those living in rural areas (102).

#### - Healthcare system characteristics

These contexts included variables related to the organisation and funding of health systems and their regulation across different countries: funding and financial incentives (79,83) and system re-design (83,90,110), flexible general practitioners funding (102), investments in practice infrastructures (102), pay for performance approaches with new rules for scope of practice (*e.g.* involving non-traditional providers in patient care) (83), physician payment for

time spent coordinating (83), reduction of patient financial barriers (109), and lack of insurance or under-insurance (83).

#### b) Activities of care coordination interventions

Care coordination interventions consisted of several types of activities that have been grouped by EPOCK team into three main categories: a) organisation of care, b) care, and c) facilitation. Each major category was divided into several types of activity as presented in **Table 2**.

# Table 2: Classification and description of care coordination activities identified in the literature review. EPOCK Research Project

#### c) Actors of care coordination

The retrieved care coordination interventions could be implemented by several types of actors: dedicated professionals, multidisciplinary teams and other actors.

#### **Dedicated professionals**

Many terms retrieved in the review referred to individuals dedicated to the coordination of care: care coordinators (79,101,103,111), care coordination counsellors, nurse care coordinators (111), nurse coordinators (85), key workers (71,92), patient navigators (79), care navigators (83,97), care managers (111), case managers, nurse case managers (79,90,111,112), nurse practitioners (111), lay navigators, liaison nurses (84,113), counsellors (88), hospital-based case managers (97), social workers or community health workers (78,79,88,111,114), care networks (106), nursing homes (91,110,114) or municipality home visitors (intervention-focused municipality employees) (115).

#### *Multidisciplinary teams* (79,83)

These teams generally involved two or more professionals from different specialties or professions who provided care to a patient or a group of patients. Teams consisted of health care personnel from different fields (i.e. mixed skills) (116). Examples included a case management team approach (79) with local community mental health teams that integrated health and social care professionals; a case management team with a registered nurse and physiotherapist who performed a comprehensive patient assessment and developed a goaldirected, individualised care plan in consultation with the patient, health professionals, family and caregivers (79); a senior social worker and a chief professional nurse who acted as main care coordinators (79); care coordinators and clinical pharmacists working with study teams who interacted with patients daily throughout their hospital stay and following discharge (via post-discharge phone call) (79); a typical group meeting (with primary care physician and nurse) that patients attended monthly as needed (79); an intensive case management approach involving a social worker, psychologist, psychiatrist, nurse, and occupational therapist (79); and patients in an assertive community rehabilitation programme who received support from a team including a psychiatrist, nurse, social workers, vocational counsellor and a support worker for those with mental illness who were available 24 hours per day, 7 days per week (79,83,95).

A multi-disciplinary team of medical staff members from various fields were likely to manage all aspects of patient care, share information and thus provide more coordinated care (79,83). Other types of teams were also retrieved, including a *peer-support group*, commonly described for patients with type 2 diabetes or for children and families (71,117). Additionally, general practitioners in multidisciplinary teams were identified as a specific actors in the coordination of care (82). Collaboration of case managers with general practitioners is a key component of *case management* (110). Regular communication between case managers and

family physicians is essential for patient-centred care targeting vulnerable populations (110,118).

#### d) Tools

Care coordination actors use numerous tools to perform their activities. They have been classified according to their contributions to care coordination activity facilitation (*e.g.* information communication technology tools, medical services, and long-term support services), decision making (*e.g.* multidisciplinary meetings, case conferences, referral systems, care plans and guidelines) and evaluation (*e.g.* professional feedback methods) (Supplementary Materials Table A).

#### **In Supplementary Materials**

# Table A: Presentation of care coordination tools retrieved in the literature review:

#### **EPOCK Research Project**

#### e) Effects of care coordination (Table B in supplementary materials).

Effects of care coordination interventions could be assessed in 39 international reviews from among the 52 publications. Notably, 45 types of effects (165 outcomes) were statistically significant. The following effects were retrieved: a) patient perspective (*e.g.* patient engagement, patient satisfaction, patient experience, quality of life, patient knowledge, social integration, morbidity and mortality), b) caregiver perspective (*e.g.* family burden, caregiver satisfaction and caregiver quality of life), c) professional perspective (*e.g.* communication among healthcare providers, communication between patients and professionals, guideline

adherence, care appropriateness, decision support, referral and professional quality of life), and d) health care system perspective (*e.g.* health services use, primary care use, transitions between primary care and hospital, costs and efficiency) (**Table B in Supplementary Materials**).

#### **In Supplementary Materials**

Table B: Statistically significant effects of care coordination interventions identified by the scoping review. EPOCK research project

#### Step 2: Selection of activities (nominal group technique)

In total, 66 activities in three categories were finally selected by the experts after voting and final discussion phases: category 1 (care organisation activities) included 28 activities; category 2 (care activities) included 24 activities; and category 3 (facilitation) included 14 activities (**Table 3**).

Table 3: Final selection of activities items after voting and discussion by the nominal group technique: EPOCK research project

Among the 159 types of care coordination intervention activities initially retrieved in the scoping review, 29 were removed from the framework and 10 others were added to the framework by the experts after the first step of the nominal group process (in Supplementary materials Table C).

#### **In Supplementary Materials**

# Table C: Nominal group technique selection process of activities items retrieved in the scoping review. EPOCK Research Project

The main categories of care coordination activities excluded by the experts in the first round of the nominal group were related to:

- Care implementation activities (such as monitoring delivery services, executing care plans and implementing care packages) and activities related to medical treatment such as (prescription of medication, reviewing drugs and medication conciliation), which were not specific to care coordination functions, but were focused on provision of care;
- Outdated terminologies found in the literature, such as 'Advocacy, advocate for the patient, or speak on behalf of families in an advocacy manner' (71,75,93,97,103,115,119), 'doctor-patient relationship' and 'patient engagement' (a preferred phrase was 'establish liaison or collaboration with the patient');
- Activities not strictly specific to care coordination interventions such as activities related to specific categories of professionals (such as *triage*, *transportation assistance and making travel arrangements*) or activities related to health care providers (such as *psychological support*). By unanimous agreement, the experts also recommended exclusion of activities related to 'psychological support', 'emotional support', 'family support', and 'proactive support'. They considered these activities to be related to the specific roles of health care professionals (including nurses) and not as specific care coordination intervention tasks. The experts considered 'psychological support' to be a consequence of the regular link created by care coordination

- interventions. The experts preferred 'assist in the transition from hospital to home' and 'act as a point of reference for all enquiries related to the patient';
- Activities related to 'gatekeeper funds' or 'considering the costs of different care options' were regarded as a 'societal issue to be addressed by social security institutions'. These activities were replaced with 'consider the excess to be paid by the patient during care planning';
- Evaluation activities as clinical *audits* because these were considered 'collective coordination', rather than 'individual or clinical coordination'.

Among the remaining 130 activities, the experts further discussed changing the terminology for 44 activities, then ranked and combined 76 activities into 15 grouped categories (**Table 3** and all experts' choices in **Supplementary materials Table C**). The experts emphasised the importance of identifying the most complex situations at all levels (*e.g.* medical, social, psychological and environmental) and the patients with the least access to primary care. They also highlighted the importance of including two other stakeholders in the care process: 'patients as care providers' (patients could be trained to support patients; expert discussions focused on the importance of considering patients' experiential knowledge and the 'lay knowhow') and relatives who are often excluded. During the discussion of care planning activities, the concepts of 'consent to care' and the 'right to oblivion' were addressed. Experts therefore prioritised patient involvement activities and shared decision making.

Experts combined medical, cognitive, behavioural and psychosocial patient needs assessment. They emphasised the importance of assessing care coordination needs. In addition, the experts recommended adding activities related to the assessment of relatives' personal and environmental resources. Experts ranked the concept of 'empowerment' as the most important element of care activities. They indicated that care coordination activities should focus on 'assessing education need or suggesting patient education' rather than

'educating patients'. In addition, the experts changed the phrase 'enhancing adherence' to 'support and monitor patient adherence'. The expert group considered 'communication as the core of the coordination professions'. They combined 23 elements related to communication, information management, and information sharing into seven activities. They also proposed adding three activities related to analysis of practices, analysis of the patient experience of care coordination and participation in the evaluation of the traceability of information.

The final constitutive elements of the care coordination framework (**Figure 1**) were: a) contexts (individual, organisational and collective); b) 66 care coordination activities at an individual level (28 care organisation activities, 24 care activities, and 14 facilitation activities); c) actors (dedicated professionals or multidisciplinary teams) and tools (facilitation, decision support, and evaluation tools); d) 165 effects of care coordination (grouped into 45 categories) classified according to patients, caregivers, professionals and healthcare system perspectives.

Figure 1: Overall reference framework structure for care coordination interventions.

EPOCK research project

#### **DISCUSSION**

#### Result synthesis

Our study proposes an innovative and operational framework of care coordination at the *micro* level, applicable in any clinical condition (*e.g.* multimorbidity, multiple chronic conditions, physical or mental illness and long-term care) and many organisational contexts. The EPOCK framework provides new knowledge concerning the components of all dimensions of the coordination of care at the patient level (*i.e.* contexts, activities, actors and

tools, and effects). In particular, the dimension 'activities' constitutes major information for the operationalisation of the framework, as well as the effective and efficient implementation of care coordination. To the best of our knowledge, this framework provides a structured synthesis of the overall effects of care coordination that has not been previously published and answers many questions concerning the effectiveness of care coordination.

In the absence of a current standard referral system for care coordination intervention at the *micro* level, the EPOCK framework could be a very useful and innovative tool for describing, implementing, and evaluating care coordination intervention programmes. It could facilitate effective implementation of care coordination, preparation of teaching materials for training in care coordination, and robust development and evaluation of care coordination interventions. This framework can be implemented in high-income countries and re-examined in the context of local organisations, because care coordination intervention is based on key universal elements that extend beyond the characteristics of a specific country's healthcare system.

#### Comparison with the literature

As suggested by Peterson *et al.* (50,120), more than 35 frameworks on care coordination have been developed but remained mostly theoretical. Few of them have been implemented in health care systems and few have led to the implementation of interventions to improve care coordination. In addition to AHRQ's care coordination framework (40), a number of these integrated care models consider the micro level: the Integrated Team Effectiveness Model (ITEM) (46), the Development Model for Integrated Care (DMIC) (47,121), the Rainbow Model of Integrated Care (RMIC) (29,122,123), the Sustainable intEgrated chronic care modeLs for multimorbidity: delivery, Flnancing, and performancE (SELFIE) (49) and JA-CHRODIS (concerning chronic diseases and healthy ageing across the life cycle) (48). However, the EPOCK framework focuses on the details of care coordination activities (what

Peterson et al. call the 'type of coordination') allowing for greater precision and ability to implement coordination interventions on-the-ground. Our classification provides a more specific and operational approach by differentiating activities (practices), actors, tools and effects. Few other models provide such detailed analysis at micro level and for some frameworks, we can observe a mix between components (activities, tools and effects). For example, some frameworks have suggested 'Case management' at the micro level, but without detailing what this encompasses (in cluster 2 'delivery system' of DMIC, in the micro level of RMIC). Or, they consider 'continuity of care' (listed in SELFIE and in RMIC) and 'Client satisfaction' (RMIC) at the micro level, whereas these elements seem to refer to the effects of care coordination. Other frameworks such as DMIC provide very detailed elements for each of its components (89 elements grouped in a nine cluster-model) (121). However, the three levels of the integrated care models seem to be mixed among the nine clusters and activities of care coordination retrieved in EPOCK seem to overlap several clusters. This could make the implementation of such a model quite difficult in practice. For example, clusters '1: patient-centeredness', '4: quality care' and '7: roles and tasks' could correspond to the micro level of the integrated care models and to some EPOCK activities; other clusters mix the different macro, meso and micro levels (clusters 6, 8 and 9).

The AHRQ framework (*Care Coordination Measures Atlas*) has been developed mainly to identify and evaluate the effects of care coordination. This framework is organised through key domains (*i.e.* goals, mechanisms and effects) involving the combination of coordination activities and broad approaches in the domain 'mechanisms'. The AHRQ framework does not focus on a complete listing of care coordination activities, but considers broader approaches to understand more fully variations in the effects of care coordination. While the AHRQ grouped together 'case management' and 'disease management' into a single dimension ('care management'), EPOCK regards care coordination at the individual

level as 'case management'. The EPOCK framework proposes a complete and specific list of care coordination activities, excluding activities that can be carried out by other professions (*e.g.* patient education, medication management, reconciling discrepancies in medication use and psychological support).

The SELFIE framework has been built around the *micro*, *meso* and *macro* levels and grouped according to six World Health Organisation components used to describe and compare health systems: service delivery, leadership and governance, workforce, financing, technologies and medical products, and information and research (49). The JA-CHRODIS identified 16 components of integrated care in four domains (delivery of system design, decision support, self-management support, and clinical information system) for patients with multiple chronic conditions or frailty, all of which are covered in the SELFIE framework (48,49).

The existing models are mainly oriented toward the *macro* and *meso* levels of integrated care, and combine actors, tools and activities into similar dimensions with a more global approach. These models underline the 'need for care coordination' and 'having a named coordinator' without providing a precise description of the specific care coordination activities to be carried out. Similar to the existing models, the EPOCK framework is applicable to multimorbidity. By providing accurate information concerning the 'activity' dimension of care coordination, the EPOCK framework complements these two models at the *micro* level. For example, regarding the component 'Coordination tailored to complexity' listed in the SELFIE *micro* level, EPOCK provides more details in activity categories '1.1 Case identification' (identify patients with complex needs who are not in contact with health services)' and '2.2 Comprehensive needs assessment and patient monitoring'.

In addition, all activities identified in the EPOCK framework consist of pragmatic and practice-oriented actions, which can be translated into measurable care coordination indicators

(124). The EPOCK framework separates the dimension 'activities' from the dimensions 'actors' and 'tools' of care coordination, as in the AHRQ model, although this separation is absent from other frameworks (47–49,122). Thus, the EPOCK framework could provide greater clarity with regard to the description of coordination intervention, and more precise information to ensure careful evaluation of care coordination interventions. In their latest review, Duan-Porter *et al.* recommend for future research to better define the 'core' intervention components and describe local adaptations, particularly in multi-site studies, which is in line with the objective and results of the EPOCK project (129). Furthermore, the EPOCK framework development process led to an evidence-based list of care coordination effects. This selection was based on systematic criteria applied in the selected studies and resulted in the selection of solely statistically significant effects. These short-listed outcomes could be used to evaluate more accurately the impact of care coordination, independently of clinical or organisational contexts.

#### Strengths and limitations

In contrast to other thematically related articles on building theoretical frameworks, our study used an evidence-based consensus method (including expert patients) to produce structured and explicit outputs, combined with a scoping review of interventions reviews. These methods helped to identify, broadly and comprehensively, existing dimensions of care coordination interventions (activities, actors and critical outcomes). We opted to carry out a scoping review as we sought to be more sensitive than with a systematic review (which is more specific) in order to clarify working definitions and conceptual boundaries of care coordination interventions, to describe fully all the detailed elements of the framework, and to inform and guide the process of selection and prioritisation ensured by the nominal group technique (125,126). However, our scoping review did not explore all sources of data (grey

literature, conference abstracts, or consulting of experts) that may have increased our risk missing relevant studies. In addition, independent data extraction by two review authors was not feasible due to the large number of included reviews (and is not recommended in methods guidance for scoping reviews) (127). Nevertheless, two authors independently screened and selected reviews, thus minimising the likelihood of omitting eligible reviews. Furthermore, the retrieval process was sufficiently broad to ensure collection of a large and comprehensive body of description of care coordination interventions related to complex contexts, activities, actors, tools and outcomes. To address any variation or investigate any conflicting results, further analyses of the care coordination effects would probably require a systematic review or even a meta-analysis.

Because the term 'care coordination' was not identified as a Medical Subject Headings (MeSH) term, care coordination was often approached by combinations of other terms such as 'comprehensive care', 'care integration', 'continuity of care', or 'integrated care'. However, these terms were not specific to care coordination and might have introduced confusion concerning the definition of care coordination. To avoid making any *a priori* assumptions regarding the definition of care coordination, we chose (for the research equation) to include only terms that specifically contained the word 'coordination' or 'coordinated'. Therefore, some articles may have been missed. Moreover, this first step was a prerequisite for conducting a structured consensus method that allowed refinement of the results and completed notions that could not have been identified by the literature review. The review team included a researcher with methodological expertise in conducting systematic reviews, policy makers, and care coordination practitioners. We limited the search to the period from the early 1990s onwards, which enabled us to identify all but the very small minority of reviews conducted prior to that time (59). In addition, we limited our research to the end of September 2017 because the EPOCK project phase one had to be completed in 2018 in order

to keep the project on schedule. The same search and selection process was reproduced between October 2017 and June 2021. We then selected 23 eligible articles for full-text analysis. This extension did not identify any new emerging themes but highlighted the importance of the issue of 'relationship in coordination' or 'relational coordination' (mode of communication, informal relationships, mutual respect, relationships built on trust) (20,50,123,128). This component was in line with the following activities previously retrieved in the scoping review, selected and modified by the experts and selected by the experts: '1.3.a. Engage/involve patient (shared decision making)', '2.1.a. Establish and sustain collaboration with patient', '2.1.d. Sustain relationship with patient for better therapeutic adherence', '2.2.a. Determine patient's decision-making capacity', '2.2.c. Consider patient preferences, expectations, and resources to assist in adjustment of care delivery', '2.3.a. Patient empowerment', '2.3.h. Support patient in expressing needs'.

Several consensus methods were considered by the EPOCK research group. We chose the NGT rather than the Delphi technique because this method was the most appropriate for achieving our objectives. Direct verbal exchanges between experts were encouraged to facilitate addition of elements, enable discussion of possible rewording, and allowance of idea generation. The NGT provides group dynamics on the basis of direct interactions among experts, and yields a *consensus* by giving equal weight to each participant's input. This process yields more ideas than a conventional unstructured group meeting in which normal group interactions constrain the freedom of expression or in a Delphi technique which uses self-completed e-mailed questionnaires with individual feed-backs (130). The NGT group size should not exceed five to nine participants to minimise the risk of a dominant participant influencing the discussion (69,70). In addition, the profiles of the experts were sufficiently varied to allow each to express his or her skills. In addition, four researchers were in charge of moderating and facilitating the group to ensure equitable distribution of speaking time.

Moreover, the multidisciplinary composition of the expert group (*i.e.* patients, researchers, professionals, policy makers and payers) and a broad geographical representation (five French regions) of experts ensured a high level of consensus.

The participation of expert patients in the nominal group was a major advantage. Based on their personal experience, those experts selected more specific care coordination activities by removing activities related more to other professions than to coordination. For example, 'emotional support' (75) was retrieved from the literature search, but was excluded from the reference framework because care coordination was presumed to refer patients to dedicated supportive care professionals.

In addition, patient contributions (based on the Montreal model developed in 2010) (131–133) in this research enriched the discussion so that patient needs could be accurately addressed. Patient contributions provided considerable guidance in the discussions and strengthened the role of patients in the 'activities' dimension of the framework. The experts emphasised the need to include the Patient Engagement Capacity Model (110) in any care coordination framework because identifying elements within interconnected domains (*i.e.* person, environment, or behaviour) may improve health workers' abilities to facilitate patient engagement and patient access to integrated care systems.

Finally, the experts suggested involving patient experts as much as possible in healthcare organisation transformation initiatives, in accordance with the Collaborative chronic care network model (134).

#### **Implications**

The EPOCK reference framework could be used in several domains. First, it could be used in care coordination practices to develop position profiles, job descriptions and best practice guidelines for care coordination workers, and to develop criteria for evaluating practices

among care coordination professionals and work environments. It could also be used to build a wide range of teaching materials and training programmes, from undergraduate to post-graduate programmes and lifelong learning courses. Second, it could be used in public health and health system organisation (measurable indicators) to develop care coordination evidence-based clinical and performance measurable indicators. In addition, care coordination activities identified in the reference framework could be used to design specifications for the development of care coordination tools (*e.g.* information communication tools) and their evaluation. Third, it could be used in health services research to build qualitative study tools needed to analyse the practices of care coordination nurses in various clinical contexts, and could help in comparisons of care coordination intervention programmes among contexts.

#### **Conclusions**

This study contributed to the conceptualisation of care coordination interventions from a patient-centred care perspective, in the absence of an existing evidence-based reference framework for care coordination interventions at the *micro* level. The EPOCK reference framework could reduce variability in practices by developing job descriptions and training programmes for future care coordination professionals, thereby increasing the quality and safety of care. This framework could provide key elements for effective implementation of care coordination intervention, and for designing further medico-economic evaluation of the impact of coordination interventions.

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## **TABLES and FIGURES**

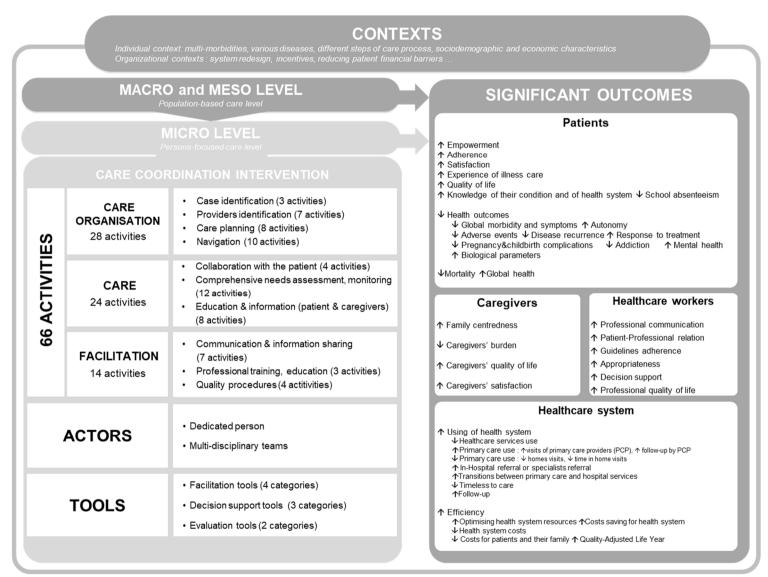


Figure 1: Overall reference framework structure for care coordination interventions. EPOCK research project

Table 1: Listing of reviews included in the scoping review. EPOCK Research Project

Author	Year	Journal	Country	Method	No. of reviews	Target population	Interventions tested
Au	2011	Mathematica Policy Research	US	Systematic review	46	Adults with disabilities	CM (community-based) by nurses or MDT
Baysari	2015	IMIA Yearbook of Medical Informatics	Australia	Systematic review	34	Elderly; mental illness (young patients)	CM
Beswick	2005	Journal of Advanced Nursing	UK	Systematic review	23	Cardiac rehabilitation	CM (community and hospital based) by nurses or social workers or lay volunteers
Bloemen- Vrencken	2005	Spinal Cord	Netherlands	Systematic review	24	Spinal cord injury	CM (community and hospital-based) by nurses or MDT
Borycki	2015	IMIA Yearbook of Medical Informatics	International	Focused review	na	Emergent disease (Ebola)	DM
Britton	2004	The Cochrane Collaboration	Australia	Systematic review	1	Elderly patients with delirium	CM with multidisciplinary teams
Burke	2014	BMC Health Services Research	US	Systematic review	66	Transition of care from hospital to community/all conditions	CM (community and hospital-based) by nurses or transition coach or MDT
Ciapponi	2017	Cochrane Database of Systematic Reviews	International	Systematic review	51	Low-income countries	CM (community and hospital-based) by nurses or midwives or lay health workers or physicians or MDT
Cohen	2011	Archives of Pediatrics and Adolescent Medicine	Canada	Systematic review	35	Children with special health care needs	CM (community and hospital based) by nurse or physician or MDT
Edelstein	2016	Child: Care, Health and Development	Canada	Scoping review	49	Children with complex needs	CM (community-based) by nurse or social workers
Ehrlich	2009	Health and Social Care in the Community	Australia	Conceptual review	20	Chronic disease	CM (community based) with MDT; DM
Eklund	2009	Health and Social Care in the Community	Sweden	Systematic review	9	Frail elderly people living in the community	CM (community and hospital based) by nurse or social workers or MDT
Ganz	2008	Seminars in Oncology Nursing	US	Review of reports	na	Childhood cancer survivors	CM (hospital based) by nurse; DM
Gardiner	2012	British Journal of General Practice	UK	Systematic review	22	Palliative and end-of-life care	CM (community and hospital based) by nurse
Gardner	2014	BMC Health Services Research	Australia	Review	na	Diabetes	CM (community and hospital based) with MDT
Gurse	2006	Journal of the American Medical Informatics Association	US	Systematic review	44	Surgical oncology, internal medicine, general surgery, trauma residents	CM (hospital-based) with MDT
Health Quality Ontario	2013	Ontario Health Technology Assessment Series	Canada	Systematic review	11	Transitions in care/outpatients with chronic disease in the community	CM (community and hospital based) with MDT
Hillis	2016	International Journal of Integrated Care	Ireland	Systematic review	37	Children with complex care needs	CM (Community and hospital-based) by nurse or MDT
Holland	2007	Home Health Care Services Quarterly Journal	US	Review	6	Transitions in care/any conditions	No intervention tested
Hollowell	2011	BMC Pregnancy and Childbirth	UK	Systematic review	36	Antenatal care programmes for	CM (community and hospital-based) by nurse or midwives or MDT

						deprived and vulnerable women	
Huffman	2014	Psychosomatics	US	Systematic review	67	Psychiatric disorders	CM (community and hospital-based) by nurse or depression care manager or intervention internist or MDT
Huntley	2013	Family Practice	UK	Systematic review	11	Elderly	CM (community and hospital-based) by nurse or MDT
Joo	2014	International Nursing Review	US	Integrative review	18	Any conditions	CM (community-based) by nurse
Joo	2015	International Nursing Review	US	Systematic review	7	Substance abuse population	CM (community-based) by non-specific case managers
Joo	2017	International Nursing Review	Korea	Systematic review	10	Chronic illness	CM (community and hospital-based) by nurse or community health workers or pharmacist case manager or MDT
Joshi	2013	International Journal for Equity in Health	Australia	Narrative review	25	Refugees	CM (community-based) by nurse or other health professionals or MDT (included interpreters and bilingual staff, health visitors, students and ethnic health workers)
Katz	2012	Annals of Emergency Medicine	US	Systematic review	23	Emergency department	CM (community and hospital-based) by nurse
Khanassov	2016	Annals of Family Medicine	Canada	Systematic review and meta- analysis	54	Dementia	CM (community-based) by nurse or MDT
Knapp	2013	International Journal of Geriatric Psychiatry	UK	Systematic review	85	Dementia	CM (community-based)
Koch	2012	International Journal of Geriatric Psychiatry	UK	Review	7	Dementia	CM (community-based) by nurse or social worker or counsellor
Kringos	2010	BMC Health Services Research	Netherlands	Systematic review	85	Primary care	No intervention tested
Kroll-Desrosiers	2016	Women's Health Issues	US	Systematic review	33	Pregnancy	CM (community and hospital-based) by nurse or MDT
Lion	2014	Care Management Journals	US	Systematic review	15	Chronic illness in adults and children	CM (community and hospital-based) by nurse or MDT
Lukersmith	2016	International Journal of Integrated Care	Australia	Scoping and mapping review	79	Brain injury, diabetes, mental health conditions, spinal cord injury	CM (community-based)
Manderson	2012	Health and Social Care in the Community	Canada	Systematic review	15	Chronic disease in older adults (transitional care)	CM (community and hospital-based) by nurse or case manager
Martin	2016	Journal of Allergy and Clinical Immunology	US	Review	9	Children with asthma care transitions in emergency department	CM (community-based and hospital-based)
Mcdonald	2007	Agency for Healthcare Research and Quality Publication	US	Systematic review	75	Any conditions	CM (community and hospital-based) with MDT
Mehrotra	2011	The Milbank Quarterly	US	Narrative review	na	Any conditions	CM (community and hospital-based) with MDT
Olds	1997	Public Health Nursing	US	Review	na	Pregnancy and post- partum in rural area	CM (community-based)
Ouwens	2005	International Journal for Quality in Health Care	Netherlands	Systematic review	13	Chronic illness	CM (community and hospital based) by nurse or MDT
Powell Davies	2008	The Medical Journal of Australia	Australia	Systematic review	80	Primary care	CM (not specified) with MDT

Rigby	2015	IMIA Yearbook of Medical Informatics	EU and Australia	Review	na	Any conditions	Population health management (Kaiser Permanente)
Salter	2010	International Journal of Nursing Studies	Canada	Systematic review	10	Post-stroke	CM (community-based) by nurse or social worker or family support organiser
Shojania	2006	JAMA	Canada	Meta-analysis	69	Type 2 diabetes	CM (hospital-based) by nurse or MDT
Sisler	2016	Canadian Family Physician	Canada	Systematic review	na	After treatment breast cancer	CM (community and hospital-based) with MDT
Snaterse	2016	Heart	Netherlands	Systematic review	18	Secondary prevention of cardiovascular disease	CM (community and hospital-based) by nurse or MDT
Straub	2004	Clinical Obstetrics and Gynecology	US	Systematic review	47	Pregnancy	CM (community and hospital-based) by nurse or midwife or social worker or family worker
Tomasone	2016	ESMO Open	Canada	Systematic review	22	Breast and colorectal cancer	CM (community and hospital-based) by nurse or MDT
Tricco	2014	Canadian Medical Association Journal	Canada	Systematic review	50	Mental illness, chronic medical conditions, homeless	CM (community and hospital biased) by nurse or social worker or 'key worker' or bilingual community health worker or MDT
Van Sluisveld	2015	Intensive Care Medicine	Netherlands	Systematic review	11	Intensive care unit (clinical handover between ICU and general wards)	CM (hospital-based) by nurse or MDT
Veras	2014	Revista de Saúde Pública	Brazil	Systematic review	12	Frail older adults	CM (community and hospital-based) by nurse or social workers or GP or MDT
Wise	2007	AHRQ Publication	US	Review	16	Children with special health care needs	CM (community and hospital based) by nurse or MDT

CM: case management; GP: general practitioner; MDT: multidisciplinary team (with case managers, nurses, physicians, general practitioner, social workers, midwives, pharmacists, community health providers, psychologists, and psychiatrists); na: not available

Table 2: Classification and description of care coordination activities identified in the literature review. EPOCK Research Project

Activity categories	Activity specifications					
1. Organisation of care	1.1 Case identification					
	All activities that identify people for whom the pathway should be coordinated					
	1.2 Specify roles and responsibilities					
	Activities that identify stakeholders involved in patient care and define their specific roles and responsibilities					
	1.3 Care planning and development of care plans					
	Activities that help to define the care plan and monitor its implementation					
	1.4 Navigation					
	Activities that provide connections among care providers or refer patients to appropriate services					
2. Care activities	2.1 Relationships with the patient					
	Activities that focus on the link developed between the person involved in the coordination of care and the patient					
	2.2 Needs assessment, follow-up, and patient monitoring					
	Initial and ongoing assessment of patients' needs (health and social needs).					
	2.3 Patient and family education					
	Patient empowerment, a process through which people gain greater control over decisions and actions affecting their health					
	2.4. Patient and family support					
	Activities related to patient/family support, advocacy activities for patients, and decision-support activities					
	2.5. Implementation of care plans and services					
	Activities related to care plan execution, medical prescriptions, and supportive care interventions					
3. Facilitation activities	3.1. Communication					
	Communication (formal and informal communication) among healthcare stakeholders					
	3.2 Information management					
	All activities related to collection/recording and traceability/historisation of medical information					
	3.3 Sharing information					
	All activities related to transmission and reception of information					
	3.4. Professional training/education					
	Training of coordination professionals and guidance of other professionals by the coordination professional					
	3.5 Quality procedures					
	Use of evidence-based guidelines and practice evaluations					

Table 3: Final selection of activities items after voting and discussion by the nominal group: EPOCK research project

Framework component heading	Final ranking selected elements	Final Ranking priorities*	Votes Mean (SD)	Number of respondent
1. Care organisation				
	1.1.a. Case finding	1	3.71 (0.49)	7
1.1. Case identification	1.1.b. Identify patient with complex needs	2	3.71 (0.49)	7
	1.1.c. Identify patients not in contact with services	3	2.86 (1.07)	7
	1.2.a. Identify participants in care (health and social workers, including patients involved in care)	1	3.86 (0,38)	7
	1.2.b. Specify providers' roles and responsibilities	2	3.86 (0,38)	7
	1.2.c. Negotiate responsibilities	3	2.83 (1.17)	6
1.2. Provider identification	1.2.d. Identify resources (e.g. tools, devices, structures, and financial resources)	4	3.67 (0,52)	6
	1.2.e. Define scope of caregiver engagement	5	3.43 (0.79)	7
	1.2. f. Participate in assessment of patient engagement and its evolution throughout the care pathway	6	3.14(0.69)	7
	1.2.g. Specify fields of competence for each stakeholder	7	3.29 (1.50)	7
	1.3.a. Engage/involve patient (shared decision making)**	1	3.75 (0.46)	8
	1.3.b. Contribute to creation of individual care plans	2	2.75 (1.39)	8
	1.3.c. Contribute to creation of individual health plans	3	2.86 (1.35)	7
	Arrange content of care plan and its implementation with patient	4	2.88 (1.36)	
1.3. Care planning	1.3.e. Plan interventions for patient	5	3.63 (0.74)	8
	1.3.f. Assist and ensure effective intervention planning for patient	6	3.60 (0.55)	5
	1.3.g. Consider excess to be paid by patient during care planning	7	3.50 (0.53)	8
	1.3.h. Contribute to organisation of collective case discussion	8	Item added by experts after voting	
	1.4.a. Liaise with all stakeholders involved in care (including support care professionals) to facilitate appropriate access to medical services and community services	1	4.00 (0.00)	9
	1.4.b. Support family doctor/general practitioner involvement	2	3.78 (0.67)	9
	1.4.c. Liaise with social services	3	3.78 (0.44)	9
	1.4.d. Ensure effective management of transitions throughout care continuum	4	3.75 (0.46)	8
1.4. Navigation	1.4.e. Support patient in accessing social rights and facilities.	5	3.67 (0.50)	9
ŭ	1.4.f. Refer to community resources	6	3.61 (0.49)	9
	1.4.g. Assist in transition from hospital to home	7	3.67 (0.71)	9
	1.4.h. Anticipate barriers to care	8	3.38 (0.74)	8
	1.4.i. Act as a point of reference for all enquiries related to patient	9	3.33 (0.87)	9
	<ol> <li>1.4.j. Alert and respond in case of an unexpected event (crisis intervention)</li> </ol>	10	Item added by experts	

 $<sup>^{\</sup>star}$  Final ranking after voting and final discussion; SD: standard deviation;  $^{\star\star}$  Proposals reworded by the experts

Table 3: Final selection of activities items after voting and discussion by the nominal group: EPOCK research project

(continued) Framework Final ranking Number of Final selected elements priorities Mean (SD) respondents component heading 2. Care 2.1.a. Establish and sustain collaboration with patient 1 3.78 (0.67) 9 2 2.1.b. Mobilise patient resources 3.67 (0.50) 9 2.1 Collaboration with patient 3 2.1.c. Establish therapeutic alliance 2.78 (1.30) 9 2.1.d. Sustain relationship with patient for better therapeutic 4 3.67 (0.50) 9 adherence 2.2.a. Determine patient's decision-making capacity 3.57 (0.53) 2.2.b. Comprehensive understanding of patient and caregiver needs 2 7 (multidimensional needs assessment: health and social 3.57 (0.79) needs) 2.2.c. Consider patient preferences, expectations, and resources to 3 3.57 (0.53) 7 assist in adjustment of care delivery\*\* 2.2.d. Assess patient's personal and environmental situation\*\* 4 3.43 (0.79) Item added by 2.2.e. Assess family's and caregivers' personal and environmental 5 expert after situations voting 2.2 Comprehensive needs 2.2.f. Evaluate available resources and community services 6 2.71 (0.76) 7 assessment and patient 2.2.g. Estimate level of case management support required monitoring 7 3.14 (1.57) 7 throughout patient's care pathway 2.2.h. Symptom monitoring 8 3.29 (0.76) Item added by 2.2.i. Identify intermediate and adverse events throughout patient's 9 expert after care pathway voting 7 2.2.j. Ongoing evaluation and reassessment of needs 10 3.14 (1.57) 2.2.k. Ongoing comorbidity screening 3.00 (0.82) 11 2.2.I. Evaluate quality, relevance, effectiveness, and efficiency of 12 2.43 (1.13) 7 care\*\* 2.3.a. Patient empowerment (reinforce patient's ability to take care of 1 3.71 (0.49) 7 themselves, not simply their illness or treatments)\* 2.3.b. Provide patient with information about the disease and its 2 3.71 (0.49) management 2.3.c. Assess education needs 3 3.57 (0.79) 2.3 Education and 2.3.d. Suggest patient education and self-management programmes 4 3.29 (0.76) information for patient and 2.3.e. Support and monitor patient adherence to treatment 5 3.71 (0.49) caregivers 2.3.f. Provide individualised prevention recommendations 6 3.29 (0.76) 2.3.g. Provide caregivers and family with information\*\* 3.29 (0.76) 2.3.h. Support patient in expressing needs 3.14 (0.69) 7

<sup>\*</sup> Final ranking after voting and final discussion; SD: standard deviation \*\* Proposals reworded by the experts

Table 3: Final selection of activities items after voting and discussion by the nominal group: EPOCK research project

(continued)

Framework component heading	Final selected elements	Final ranking priorities*	Votes Mean (SD)	Number of respondents
3. Facilitation				
	3.1.a. Identify, collect and record information (e.g. medical information, individual preferences, and personal and social circumstances) from patients and their families**	1	4.00 (0.00)	6
	3.1.b. Relay/transfer information to all stakeholders (e.g. healthcare professionals and social workers)**	2	4.00 (0.00)	6
	3.1.c. Inform stakeholders about risk of disruption of patient's journey	3	4.00 (0.00)	6
3.1 Communication and information sharing	3.1.d. Share information with patients and family (ensure information continuity)	4	3.83 (041)	6
	3.1.e. Provide information on coordination of care throughout the journey (collect information, traceability)**	5	3.50 (0.55)	6
	3.1.f. Participate in the updating of information	6	3.50 (0.55)	6
	3.1.g. Follow the updating of information	7	3.33 (0.82)	6
	3.2.a. Assist and inform care professionals and others concerning necessary care and its coordination**	1	4.00 (0.00)	7
3.2 Professional training/education	3.2.b. Contribute to the transmission of knowledge, know-how and experiential knowledge required for appropriate care to all care professionals and others involved in care**	2	3.86 (0.38)	7
	3.2.c. Identify training needs required to ensure coordination of care and health pathways	3	3.71 (0.49)	7
	3.3.a. Encourage and support professionals in the use of evidence-based guidelines**	1	3.57 (0.79)	7
3.3 Quality procedures	3.3.b. Participate in evaluations of practices (e.g. audits and work practice focus groups)	2	3.71 (0.76)	7
o.o adamy procedures	3.3.c. Participate in analysis of patient experience during coordination	3	3.71 (0.49)	7
	3.3.d. Contribute to evaluation of information traceability	4	3.57 (0.79)	7

<sup>\*</sup> Final ranking after voting and final discussion; SD: standard deviation \*\* Proposals reworded by the experts