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# Patient engagement support for older adults: Development and implementation of an intervention in an integrated-care context


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# Abstract

*Background:* With the increase in the number of older adults and chronic diseases, current health care practice is challenged. One solution is to engage older individuals more in their own care. Despite the high-relevance of this theme, literature on patient engagement support for older adults is limited and in its infancy.

*Aims:* The main purpose of this thesis was to contribute knowledge about how patient engagement support can be provided to older adults, by describing the contents of interventions aimed at patient engagement for older adults in published studies, developing a patient engagement intervention and studying its early-stage implementation.

*Methods:* The Medical Research Council (MRC) Framework was used to assist the research. First, a systematic review of the literature was performed to describe the contents in interventions reported in RCTs focused on patient engagement and similar terms where the average age of the participants were 60 years or more (Chapter 2, study 1). Then, a qualitative study with focus groups involving healthcare professionals and individual interviews to older adults was conducted to develop and validate an individual patient engagement intervention for older adults (Chapter 3, study 2). Finally, a qualitative study of a participatory process with data collected through multiple sources was accomplished to explore the early-stage implementation of the developed intervention in one Italian integrated-care organization (Chapter 4, study 3).

*Results:* The systematic review found that the affective/emotional dimension was less used than the educational/cognitive and behavioural dimensions among the 35 interventions focused on patient engagement and involving older adults. One tenth of the studies combined all three dimensions, and almost half focused on one dimensions only, mainly the cognitive one. It also revealed that studies mainly focusing on the affective/emotional dimension were different from studies mainly focusing on the cognitive and behavioural dimensions. The findings from the systematic review were used, together with a theory of patient engagement and practical considerations, to develop a draft of a brief individual patient engagement intervention for older adults (*PHEinAction*). The views of healthcare professionals and older adults were used to refine and finally endorse it, making it potentially implementable in clinical practice. Examples of refinements made were a greater clarification and structuring of materials, or a greater graduation of exercises basing on engagement positions. The final version of *PHEinAction* consisted of two face-to-face one hour individual sessions one month apart, plus a set of personalized home-based exercises aimed to facilitate a range of affective/emotional, behavioural, cognitive changes for patient engagement. Finally, the qualitative study of the participatory process for the early-stage implementation of *PHEinAction* in one Italian integrated-care organization observed how the existing patient education practice of inpatient,

outpatient and territorial settings differently challenged the implementation. A certain degree of flexibility of *PHEinAction*'s contents and procedures was required to meet these challenges.

*Conclusion*: In the literature, interventions focused on patient engagement had different contents from interventions focusing on adherence, and they tended to pay more attention on behavioural and cognitive dimensions than on affective/emotional ones. *PHEinAction*, the brief individual intervention for patient engagement support, could be developed to balance affective/emotional, cognitive, and behavioural dimensions and adjusted to make it potentially implementable in clinical practice. The participatory early-stage implementation of *PHEinAction* within the integrated-care organization was partially possible in different care settings with some adjustments, allowing for a deployment of *PHEinAction* in the rest of the organization and in other care contexts.

*Implications*: *PHEinAction* shows promise as an intervention to improve patient engagement in older adults. However, more research is needed, especially focusing on long-term implementation studies and, most of all, evaluation of effects with experimental studies. The key most effective ingredients of the intervention should also be evaluated.

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# Introduction

With the increase of the aged population and the related growth of chronic conditions in the later life, engaging individuals in their health and care management has becoming a key priority to allow care processes maintaining quality and efficacy without losing in sustainability. The first Chapter of the thesis describes this social background and the evolution of the patient's role in healthcare, by then highlighting the implications that these changes are leading for individuals and healthcare services. The main gaps in literature concerning making individuals engaged in care are underlined. Gaps that, if we look specifically to older adults, become particularly needy of attention.

The thesis started from these gaps and aimed to contribute knowledge about how patient engagement support can be provided to older adults, by describing the interventions' contents in published studies, developing a patient engagement intervention and studying its implementation. A theory of patient engagement drove the research throughout.

Chapter 2 reports the systematic literature review of interventions reported in RCTs focused on promoting patient engagement among older adults, so to describe and classify their contents. From this first study, it was found that interventions for older adults focused on patient engagement had different contents from generic interventions focused on patient adherence. Furthermore, they tended to pay more attention to the behavioural and cognitive dimensions than the affective/emotional dimension. It was also found that studies mainly focusing on the affective/emotional dimension were different from studies mainly focusing on the cognitive and behavioral dimensions, and it was discussed the specific potential that the affective/emotional dimension could have for older adults. The study also identified unique components used within interventions reported in patient engagement studies on older adults.

Then, in Chapter 3, the study about the development and qualitative validation of an individual intervention for patient engagement support of older adults (*PHEinAction*) is described. In this second study, the PHE theory was used to guide, together with the literature retrieved in the study 1 and practical considerations, the initial development of *PHEinAction*. Through a refinement process with group discussions and repeated interviews involving healthcare professionals and older adults, aspects which made it better implementable in clinical practice were identified. The final intervention, which emerged from this process, consisted of two face-to-face one hour individual sessions one month apart, plus a set of personalized home-based exercises aimed to facilitate a range of emotional, behavioural, cognitive changes for patient engagement. The participants endorsed the final version of *PHEinAction*. In particular, professionals endorsed

having written guided materials for the intervention and that it was a brief intervention, whereas older adults liked the possibility of having a dedicated individual moment for sharing and reflecting on their engagement journey and experience. Specific contents particularly appreciated were the sharing of assessment results from the scales, goal setting/planning, and the opportunity to have different affective/emotional, cognitive, behavioural dimensions covered.

Chapter 4 describes the final study of the research, which explored the early-stage implementation of *PHEinAction* in one Italian integrated-care context. In this regard, a participatory process with a triangulation of qualitative data from workshops, participant observations and shadowing, artefacts analysis and interviews with professionals of an integrated-care organization was performed. This third study observed how the early-stage implementation of *PHEinAction* into the existing patient education practice of an integrated-care organization was challenged by having educational practices consistently differing among inpatient, outpatient, and territorial settings. The different responsibility, contents, and focus of patient education had an impact on the experiences that professionals had when implementing *PHEinAction* into their existing educational practice. These experiences, in turn, enlightened the solutions enacted during the participatory process to promote the intervention implementation. In this process, a certain degree of flexibility of *PHEinAction*'s contents and procedures was required.

Chapter 5 finally discusses patient engagement support to older adults and the possibility of implementing it in healthcare practice in light of the main findings of the studies presented in this thesis and of relevant findings from other published studies. It also offers a discussion of the key methodological issues of the research presented in this thesis. The thesis ends with a brief reflection on the future implications of the work for research and practice.

# Chapter 1

## Background and research aims

In this Chapter, an introduction to the field of the thesis and a presentation of the knowledge gap it contributes to is provided. I will start presenting how the demographic changes in contemporary society are posing major challenges to the health system. I will then offer an overview of how the patient's role in healthcare evolved across the last years. The movement towards an active role of individuals in care resulted in concrete implications for better care management for both individuals and healthcare services. I will then highlight the main problems related to the application of making individuals engaged in care. Problems that, if we look specifically to older adults, become particularly needy for attention. I will finally explain the objectives and design of this thesis, which aimed to contribute knowledge about how patient engagement support can be provided to older adults. It is only at the end that I will present the theory of patient engagement that drove the research.

## 1.1. Background

### 1.1.1. One of the major challenges to the health system: Ageing of the population

"Today, for the first time in history, most people can expect to live into their 60s and beyond" (United Nations Department of Economic and Social Affairs, 2009). Most of the scientific literature and global policies start with this or similar statements, as a leading point for orienting scientific, social and political efforts and resources towards addressing the challenges of an ageing population (Beard et al., 2016; WHO, 2016). It is not only that life expectancy is increasing worldwide, but also that fertility rates are markedly decreasing, making the ageing of the global population one of the major challenges that our societies should contend with: In 2015, one in eight people was aged 60 years or over; by 2030, older persons are projected to account for one in six people globally; by 2050, one in every five people will be aged 60 years or over (United Nations, 2015). Even if this is a global phenomenon, it is especially in the high-income countries that this process is more pronounced. Italy has the third position of the world's most aged population, with 28% of citizens were aged 60 years or over in 2015 (United Nations, 2015). And among European countries, it is the one having the largest proportion of older citizens (EC, 2017). The ageing of the population has a double face: it is a success and triumph for our societies, but it also leads to profound economic, social, and political implications (WHO, 2016).

The burden of these implications relies on one key factor: whether older citizens live their later years in good health. Evidences on the health of older citizens are not consistent, but they all report that the number of diseases tends to increase with increasing age (Beard et al., 2016). Health problems in old age are expected to steadily rise in the next years, more or less in line with the increase in the older population (Mathers & Loncar, 2006). It is estimated that in almost 50 years from now, the Italian population will remain the same in numbers, but older citizens will double (ISTAT, 2015). This means that chronic health problems are likely to steadily increase. In Italy, 39,1% of the total population lives now with at least one chronic condition (ISTAT, 2011). In particular for the older age group, three classes of diseases globally dominate mortality and health burden: cardiovascular, chronic pulmonary, and oncological diseases (Beard et al., 2016).  Furthermore, the diseases often add up, with half of older people having more than one disorder at the same time (Prince et al., 2015). Chronic diseases have been found to be the most important reason for healthcare utilization, and thus the most relevant expenditure item for contemporary health systems (Yach, Hawkes, Gould, & Hofman, 2004). This is because they have to be managed over the lifetime (Lorig & Holman, 2003).

Consequently, there are and there will be increased needs for healthcare use due to chronic conditions and age, especially in high-income countries (WHO, 2015). The overall described situation puts pressure on the limited resources of health systems and asks for innovative sustainable solutions in the management of chronic health problems in the later age (de Bruin et al., 2012).

### 1.1.2. The evolving role of "patients" in healthcare: From passive recipients of care to active constructors of health trajectories

New ways of interaction between healthcare providers and citizens have been said to be needed to efficaciously and sustainably manage the care of chronic conditions (Bergeson & Dean, 2006). For a long time, the patient has been considered a carrier of the disease, and the doctor the main actor able to influence the care process. It is only in the last decades that the role of patients in the care process has been valued towards a more and more positive, proactive, resource-oriented vision of the person in healthcare (Bardes, 2012; Kaba & Sooriakumaran, 2007; Stewart et al., 2005). Giving (back) to persons a greater role in healthcare has been suggested to be probably the only solution to allow a sustainable management of chronic conditions (Epstein, Fiscella, Lesser, & Stange, 2010; Michie, Miles, & Weinman, 2003).

There is a plethora of terms to refer to individuals playing a starring role in their care process (Grande, Faber, Durand, Thompson, & Elwyn, 2014; Hibbard & Mahoney, 2010; Menichetti, Libreri, Lozza, & Graffigna, 2016). Different labels have been introduced in the last years to gradually denote their more and more active role in healthcare (patient compliance, patient adherence, patient participation, patient involvement, patient empowerment, patient activation, patient engagement). These concepts have been considered a possible strategic operationalization of the overarching approaches healthcare systems can assume in the relationship with the "patient" (disease-centred, patient-centred, person-centred, citizen-centred) (Pulvirenti, McMillan, & Lawn, 2014). Furthermore, these concepts evolved over time, from the most historical ones such as patient compliance and adherence to the most recent and lasting one of patient engagement (Menichetti et al., 2016).

To present and make an overview of these terms and overarching approaches, I have made a simplified classification that is presented in Figure 1.1. This is a result of my personal perspective on the literature on the evolving role of "patients" in healthcare. Key references are provided in the Figure to support the classification. The Figure will guide the structure of the next paragraphs, where I am going to present details about these approaches and terms. The perspective assumed to present this overview focused on the patient's individual role in healthcare and on how patients exchange with the health system (individual level).

**Figure 1.1.** Overview of the terms (in brackets) and overarching approaches defining the evolving role of "patients" in healthcare, considering their focus, vision, setting and type of exchange



| | Focus | Vision | Setting | Exchange |
|---|---|---|---|---|
| Citizen-centered (engagement) | wellbeing (Dahlberg et al., 2009) | consumeristic (Dahlberg et al., 2009) | life (Nelligan et al., 2002) | collaborative (Millenson, 2017) |
| Person-centered (activation, empowerment) | health (Starfield, 2011) | bio-psycho-socio-spiritual (De Maeseneer, 2012) | home (Zhao, 2017) | enabling (Health Foundation, 2014) |
| Patient-centered (involvement, participation) | illness (Balint, 1964) | biopsychosocial (Engel, 1977) | clinical visit (Bauman et al. 2003) | dialogical (King and Hoppe, 2013) |
| Disease-centered (adherence, compliance) | disease (Green, 2002) | biomedical (Larsen and Lubkin, 2009) | body (Larsen and Lubkin, 2009) | paternalistic (Kaba and Sooriakumaran, 2007) |

### 1.1.2.1    Disease-centred

The first conceptual area (the blue circled one in Fig. 1.1) is the *disease-centred* approach in healthcare, with *patient adherence* and *patient compliance* as main terms. The *disease-centred* approach sees the disease as a scientifically measurable deviation from a biological standard and as a pathophysiologic process, and considers this deviation the main and only focus of healthcare (Tinetti et al., 2016). According to this approach, professionals have to fix a broken human body, as a mechanic has to repair pieces of a damaged car. The professional-patient relationship consequently became lopsided, with the healthcare professional being the only one having the scientific knowledge and the power to diagnose, care and cure the disease and the patient being a passive and powerless recipient of care (Kaba & Sooriakumaran, 2007). Clinical consultations are thus characterized by directive and paternalistic tones and styles, making this traditional model also doctor-centred.

According to the literature, the two terms *patient compliance* and *patient adherence* reflect with different nuances a *disease-centred* approach to care (Bissonnette, 2008; Vermiere, Hearnshaw, Van Royen, & Denekens, 2001). *Patient compliance* has been defined as "the extent to which a person's behaviour coincides with medical advice" (Haynes, 1979), i.e. portraying a concept of the patients' job as behave accordingly to what the healthcare professional decides. This is exemplified in Vermiere's review of studies using the term *patient compliance* (Vermiere et al., 2001), where it was found that the patient was given a passive unequal role and expected to submit to doctors' prescriptions. It was also found a negative attitude towards patients, with the main focus of compliance research being on non-compliance, where patients are seen as disobeying the advice of their healthcare providers (Delamater, 2006).

The term *patient adherence* was introduced in research and policy documents to diminish the attribution of power only to the physician and surpass the undertone of paternalism which the term compliance brings (Bissonnette, 2008; Vermiere et al., 2001). The term *patient adherence* most commonly refers to "the extent to which patients follow the instructions they are given for prescribed treatments", as stated in Bissonnette's study revising literature on the concept of adherence (Bissonnette, 2008). Here, the patient's job is portrayed as agreeing to follow what the healthcare professional has decided. Consequently, it implies that patients have a role in agreeing with treatment recommendations, and there is emphasis on their right to make a decision about whether or not to follow recommendations (Robinson, Callister, Berry, & Dearing, 2008).

The concepts of compliance and adherence share a focus on how patients behave regarding medical prescriptions. They both concern with the individuals' performance on the recommended

care process which is strongly based on the expert medical knowledge. They thus reflect an unbalanced power relationship where professionals prescribe/educate and patients behave accordingly. Even if it has been suggested *patient adherence* being more *patient-centred* than compliance (Robinson et al., 2008; Vlasnik, Aliotta, & DeLor, 2005), both have been considered implying a *disease-centred* perspective and not giving value to the dynamic nature of adherence behaviours (Bissonnette, 2008).

### 1.1.2.2   *Patient-centred*

A second conceptual area (the yellow one in Fig. 1.1) reflects a *patient-centred* approach and includes terms like *patient involvement* and *patient participation.* Different events led to a *patient-centred* approach in healthcare: From the new definition of health proposed by the WHO that emphasized health being much more then the only absence of disease (WHO, 1948), to the Engel's biopsychosocial model, to which is particularly ascribed the crisis of the *disease-centred* model (Engel, 1977, 1997). According to these changes, patients started being considered not only a disease-carrier requiring diagnosis and treatment but also individuals who live with the disease (Bardes, 2012). In this perspective, how patients experience the disease (the illness) is also an important focus of clinical consultations, because it is accordingly to that experience that patients will behave (Eisenberg, 1977). If clinicians are, thus, the scientific experts of the disease, patients are the lay experts of their illness, with all the feelings and emotions, thoughts and knowledge, values and preferences, desires and expectations that they bring to the clinical visit (Marvel, Epstein, Flowers, & Beckman, 1999).

Stewart's work on *patient-centred* medicine is an example of how this approach can be understood in clinical practice and which can be the principles and components of a *patient-centred* approach in healthcare (Stewart et al., 2013). These include validating the patient's experience, considering the broader context in which the illness is experienced, working towards mutual understandings between doctor and patient, engaging in health promotion, taking a partnership approach to the doctor–patient relationship and being realistic about goals. If, generally, there seems to be a substantial agreement in literature about these *patient-centred* pinnacles - also demonstrated by the Institute of Medicine report of 2001 and by the WHO policy document of 2007 calling for patient-centeredness in care -, there is much more debate about what patient-centeredness really means for practice (De Maeseneer et al., 2012; Epstein & Street, 2007; Starfield, 2011; Zhao, Gao, Wang, Liu, & Hao, 2016). For Bauman et al. (Bauman, Fardy, & Harris, 2003) and Barry et al. (Barry & Edgman-Levitan, 2012), a similar approach is clearly about the doctor-patient encounter.

The same main focus applies for the concepts of *patient involvement* and *patient participation* which – from an individual-level perspective - mostly deal with the doctor-patient relationship in the healthcare process. Indeed, the two terms *patient involvement* and *patient participation* are interchangeably used to denote the dyadic informational and relational efforts in clinical encounters to improve shared decisions in healthcare (Entwistle & Watt, 2006; Guadagnoli & Ward, 1998; Sahlsten, Larsson, Sjöström, Lindencrona, & Plos, 2007; A. Thompson, 2007). Shared decision-making is the ideal goal of this dyadic exchange, the optimal process where relational efforts resulting from patient involvement and participation should be placed (Charles, Gafni, & Whelan, 1997; Elwyn et al., 2012). The attention is thus circumscribed to the negotiation of medical decisions during the clinical exchange between the patient and the healthcare professional. The setting is bounded to the clinical consultation, the time restricted to the process of decision making, and the focus is in between the doctor and the patient.

Even if these clear boundaries, a democratization of the doctor-patient exchange within the process of decision making could be envisaged in these terms. As in the *patient-centred* vision of healthcare, patients' expectations and needs for care are considered, and, even if boarded into the clinical visit, they open to the psychosocial world of patients (Murray, Charles, & Gafni, 2006).

### 1.1.2.3   *Person-centred*

A third more recent conceptual area (the grey one in Fig. 1.1) concerns a *person-centred* approach and includes the two terms of *patient empowerment* and *patient activation*. The *person-centred* approach focuses on the totality of the person, within a holistic bio-psycho-socio-spiritual framework (De Maeseneer et al., 2012; Starfield, 2011; Wong & Cloninger, 2010; Zhao et al., 2016). By looking at patients not only as individuals with a disease but also as persons living a complex health trajectory, it implies an attention to the health of persons rather than to the disease only. Persons are thus considered much more than their symptoms: What happens to them outside the clinical consultation becomes crucial to help them caring for themselves in their daily life (Wong & Cloninger, 2010). This means, for healthcare professionals, not only assessing symptoms and prescribing pills, but also helping the person to live well and increasing his/her ability to make self-directed choices to do what provides lasting satisfaction and meaning (Wong & Cloninger, 2010). Therefore, there is a greater emphasis on the spiritual, evolutionary, life-course perspective on the individual (Zhao et al., 2016), valuing the existential needs of persons (De Maeseneer et al., 2012). The context of care is expanded to the persons' home, and the time of care augmented to a care over time (Starfield, 2011; Zhao et al., 2016).

As reflected by the concepts of *patient empowerment* and *patient activation,* the focus in this conceptual area is on persons' capabilities and strengths for influencing their health. Indeed, on one hand, *patient empowerment* indicates a boosting individual/relational process/result for enabling persons self-managing their care (Anderson & Funnell, 2010; Bravo et al., 2015; Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016). There are many definitions of *patient empowerment*, and most of them conceive in some way persons as self-determining agents with some control over their own health and healthcare (Anderson & Funnell, 2010; Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008; McAllister, Dunn, Payne, Davies, & Todd, 2012). Therefore, this concept has been considered close to the tenets of self-determination (Ryan & Deci, 2000) and self-regulation (Leventhal, Leventhal, & Contrada, 1998) theories, which both value the natural intrinsic motivation of individuals to improve their own wellbeing.

*Patient activation*, as introduced by Hibbard in 2004, has been defined as "the knowledge, skills and confidence a person has in managing their own health and health care" (Hibbard, Stockard, Mahoney, & Tusler, 2004). A theory has been built to explain how persons can gradually become activated towards care, following four sequential levels of increasing knowledge, confidence, skills to manage the disease condition towards a greater activation (Hibbard & Mahoney, 2010; Hibbard et al., 2004). The Patient Activation Measure (PAM) has been also developed to detect these four activation levels (Hibbard et al., 2004).

For both the concepts, an underlying attention on individuals' acquirements can be acknowledged: autonomy, power and influence for *patient empowerment,* and knowledge, skills and confidence for *patient activation*. These concepts are intimate to a *person-centred* approach to care, where the doctor-patient exchange is supportive of new acquirements, the setting enlarges to the autonomous home care of individuals, and health-management issues are also considered.


### 1.1.2.4  Citizen-centred

The fourth conceptual area (the orange one in Fig. 1.1), is the most overarching one and reflects a *citizen-centred* approach to care, with *patient engagement* as the most lasting core concept. The *citizen-centred* approach - which can be placed near the *consumer-centred* one, mostly retrievable in the grey literature (Australian Commission on Safety and Quality in Health care, 2016; "Demonstrating Value Key to Consumer-Centered Healthcare," n.d.) - preserves all the above-mentioned visions and embraces a consumeristic vision of healthcare (Fox & Ward, 2006; Hibbard & Mahoney, 2010a; Lober & Flowers, 2011). It highlights the consumeristic and managerial approach to the citizens exchange with the healthcare system and reconceives individuals not only as empowered and activated persons for better self-care, but also as consumers able to influence

and shape what is offered by the health system (Cooper, Bryer, & Meek, 2006; Nykänen & Seppälä, 2012).

This vision values and strengthens citizens/consumers' role in being active constructors of their own health and life trajectories (Woolf, Dekker, Byrne, & Miller, 2011). Citizens bring expectations for shaping not only care processes but also their health trajectory towards a better quality of life. Patient journeys become crucial to look at patients in an integrated way, considering the possible turning points and exchanges that they could experience during their journey and that pinpoint possible co-constructive occasions (Trebble, Hansi, Hydes, Smith, & Baker, 2010). The engagement of citizens as collaborators, co-producers of their care experience is thus emphasized. Consumers can have a potential productive and constructive role within a fair, balanced, and mutual exchange with the healthcare system (Doherty & Mendenhall, 2006; Gilardi, Guglielmetti, Marsilio, & Sorrentino, 2016; Millenson, 2017). In this potential co-productive and collaborative exchange, the value of care depends on the encounter and negotiation between the demand and the supply (Mead & Bower, 2000). New priorities take centre stage: customer satisfaction, broad range of alternatives, choice, and unimpeded access to goods and services. According to this approach, providers will be drawn into a new partnership with patients who are more responsible for their own care (Chewning & Sleath, 1996).

In line with this approach, *patient engagement* has been introduced as an umbrella term, reflecting a holistic vision of individuals which takes into account different care dimensions (Graffigna, Barello, & Triberti, 2016; Higgins, Larson, & Schnall, 2017; Menichetti et al., 2016). It encompasses all the previous mentioned conceptual levels and their central concepts (Fig. 1): from involvement in care for partnering with providers (patient involvement, patient participation), to increasing the power, confidence and skill levels of individual patients (patient activation, patient empowerment) for the purposes of maximizing – among the other outcomes - treatment uptake (patient compliance, patient adherence) (Barello, Graffigna, Vegni, & Bosio, 2014; Higgins et al., 2017).

Definitions of *patient engagement* highlight a vision of patients as citizens ("the demand") who proactively interact with a health system ("the supply") (Graffigna et al., 2016), and include the increased responsibility of individuals for creating care occasions with the healthcare organizations and the local health services (Gruman et al., 2010). The *Patient health engagement (PHE)* theory, which will be presented in detail at the end of this Chapter (section 1.4), has been developed to explain how people can become engaged (or not) in the care process, explaining the process of patient engagement as being a dynamic multifaceted journey featured by four main possible engagement positions (Graffigna, Barello, Bonanomi, & Lozza, 2015; Graffigna, Barello,

Libreri, & Bosio, 2014). In this theory, the emphasis is on the psychosocial process of adjustment by the individuals to a health condition, so that they are able to integrate the illness experience into their life trajectory in a way that is meaningful for them (Graffigna et al., 2014). When citizens are engaged, it is not only that they are able to care for their health, but also that they proactively interact with the healthcare system and contribute to meaningful and positive health trajectories.

The attention pointed to the potential role of citizens as co-constructors of care and to the emotional elaboration of their role as persons with a health condition that can contribute to a healthy society reflect a conceptualization of *patient engagement* as within a *citizen-centred* approach to care (Gilardi et al., 2016; Graffigna et al., 2016). This is probably because the roots of the word engagement date back to the organizational and marketing literature, which conceives individuals as consumers/citizens (Bakker & Demerouti, 2008; Schaufeli & Bakker, 2003).

### 1.1.3. The main implication for individuals of having a greater role in care: taking care of one's own health

From the proposed overview of the main approaches and concepts for designing the citizens' role in healthcare, it is possible to observe how, gradually, we are moving towards a greater consideration of the individual in the care process (Menichetti et al., 2016). This has several implications for how care is managed and delivered (Bodenheimer, Wagner, & Grumbach, 2002). Having an active role in the care process has generally implied for individuals to start taking care for their health (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Taking care of own health has been generally referred to as self-management or, broadly, self-care (Bodenheimer, Lorig, et al., 2002), meaning the "day-to-day tasks an individual must undertake to control or reduce the impact of disease on physical health status" (Clark et al. 2003, p. 5).

Self-care is not an on/off process, but rather an inevitable aspect on one's life. Individuals self-manage their health condition daily, they take decisions on what to eat, how much to move, and if to follow the medical recommendations (Lorig & Holman, 2003). The question is how individuals manage their health, rather than if they do it (Bodenheimer, Lorig, et al., 2002). Optimal self-management requires that individuals understand the health condition and manage their care on a daily basis, including taking medications and participating in decision-making with their health providers regarding their disease (Lorig & Holman, 2003). Additionally, people must manage the impact of the chronic condition on their daily life, maintain their general health and avoid risk factors for other health problems, by, for example, eating a healthy diet and participating in regular exercise (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Finally, individuals also need to accomplish with how they psychologically react to the disease condition (emotional self-management) and to their new role as patients (Taylor et al., 2014). The key tasks for optimal self-

management, therefore, include having the confidence to deal not only with medical management, but also with the new role and the emotional management of the health condition (Adams, Greiner, & Corrigan, 2004).

Thus, taking care of one's own health generally involves the concrete tasks that people who have a chronic condition do (Clark, Hampson, Avery, & Simpson, 2004; K. R. Lorig & Holman, 2003). Managing one's own health does not imply being an active patient (Pulvirenti et al., 2014), but it is demonstrated that more active patients have better self-management behaviours (Fowles et al., 2009; Hibbard, Mahoney, Stock, & Tusler, 2007; Mosen et al., 2007; Remmers et al., 2009; Shively et al., 2013).

Thus, if patient/person/citizen centred care are more philosophical approaches to be embraced by the healthcare system, self-management is a more narrow concept involving how people finally behave to manage the disease (Pulvirenti et al., 2014). In the middle, the concepts of involvement, empowerment, activation, engagement and the others can make more, different or better room for a self-determining, self-managing individual (Kidd, Lawrence, Booth, Rowat, & Russell, 2015; Pulvirenti et al., 2014). Among these, probably the concept of patient engagement as outlined in the previous section can make a better room not only for a self-determining, self-managing individual, but also for a collaborative individual able to co-create a new project of health with the healthcare system. However, there is a lack of knowledge of how this can be played out within a clinical setting.

### 1.1.4.  Supporting individuals taking care for their health: the key activities

There is a rich global policy context that endorses how supporting individuals taking care of their health should become a critical component and a normal aspect of long-term care provision (Taylor et al., 2014). Such self-management support or education has been recognized worldwide as a pillar for enabling a high-quality care of chronic conditions (Institute of Medicine, 2003), and an indispensable part of new care models for their sustainable management (Boult & Wieland, 2010; de Bruin et al., 2012). Different policy guidelines and researches outlined the key activities to support individuals taking care for their health (K. R. Lorig et al., 2001; National Voices, 2014; Taylor et al., 2014).

Examples of a self-management support and patient education include providing knowledge and information about the health condition, supporting people adjusting to a life with a health condition through psychological strategies, offering practical support for physical care tailored to the specific health condition, making action plans for health conditions that may deteriorate, comprising self-

monitoring with feedback and practical support with adherence strategies, and including social support as appropriate (Taylor et al., 2014). Evidences showed that, if these activities are tailored to the individuals and their condition, benefits increase (Taylor et al., 2014). Therefore, this support can be conceptualized as the provision of educational and supportive interventions by healthcare providers to facilitate individuals' self-management by helping them develop their personal skills and confidence related to managing, and making decisions about, their own health (The Scottish Government, 2009).

There are a range of studies investigating the effect of interventions aimed at supporting patients, like patient education and self-management support, which have been summarised in reviews (Lagger, Pataky, & Golay, 2010; National Voices, 2014). The evidence base for self-management support is rapidly expanding. Established, generic self-management support programmes are, for example, the Stanford Chronic Condition programme in the United States (Kate; Lorig, 1993), the Flinders programme in Australia (W. Battersby et al., 2008), and the Expert Patient Programme in the UK (Kennedy et al., 2007).

Despite the rich policy context surrounding self-management support, a key challenge remains in how to define the active ingredients and design interventions that consider supporting also the individual's crucial role in maintaining health and promoting care, and aligned with individual's priorities. Indeed, authors suggested that without problematizing the need for centring the care to the individuals' co-leading role – and to their disposition to play such a role - , self-management support risks to be only "a new jargon term for traditional, didactic classroom teaching" (Wagner et al., 2001a).

Researchers complained a lack of details about the contents of interventions for supporting individuals having an engaged role in care, making it difficult to understand what are the elements and ingredients of actions aimed to this goal (Kane et al., 2015). Even if some efforts can be recognized in reviews deepening interventions' contents for patient compliance or patient adherence (Roter et al., 1998; van Dulmen et al., 2007), for the following terms reflecting a patient/person/citizen centred vision (patient involvement, activation, engagement…) efforts are still fragmented. The poor reporting and understanding of ingredients of actions for supporting individuals in care is a problematic area in general (Borek, Abraham, Smith, Greaves, & Tarrant, 2015; Jonkman, Schuurmans, Groenwold, Hoes, & Trappenburg, 2016; Mohler, Bartoszek, & Meyer, 2013), but it is particularly for patient engagement. Indeed, health systems need to embrace it in a concrete way, but research on patient engagement actions is still embryonal and fragmented (Kane et al., 2015; Prey et al., 2014). There is a need for more research detailing the contents of

interventions focused on the concepts emerged after the disease-centred approach, as a mean to advance interventions for supporting patient engagement.


### 1.1.5. Embracing patient engagement within the health system

As a consequence of the evolving role of the patient, the health systems are asked to change the way they provide care to make the patient at the centre of the care process, so as to improve both care quality and efficacy (Bodenheimer, Wagner, et al., 2002; Boult & Wieland, 2010; de Bruin et al., 2012; WHO, 2015). This has been translated into different models of care, and one is the widely-known Chronic Care Model (Bodenheimer, Wagner, et al., 2002; Coleman, Austin, Brach, & Wagner, 2009; Wagner et al., 2001a). This is an integrated approach for the prevention and management of chronic conditions that aims bridging the hospital-home care gaps through a planned collaborative system (Wagner et al., 2001a). But there are also other similar care models and several applications of it, all joined by the goal of rethinking care for a better quality (Boult & Wieland, 2010; de Bruin et al., 2012; Jayadevappa & Chhatre, 2011). All of them stress the need for actions aimed to support individuals in taking an active role in care (Boult & Wieland, 2010; de Bruin et al., 2012; Jayadevappa & Chhatre, 2011).

At the same time, it has been acknowledged that reshaping care delivery and including new ways of interaction with citizens is not a simple task (Fleuren, Wiefferink, & Paulussen, 2004). Difficulties arising from these required changes are reported worldwide (Green, Wendland, Carver, Hughes Rinker, & Mun, 2012). Myriad of obstacles have been identified to interfere on a system level with transforming an organization into one that truly embraces a patient-centred care (Moretz & Abraham, 2012). Also on an individual level, obstacles are present (Locatelli et al., 2015). This is exemplified in the conduct of patient education: healthcare professionals have difficulty in performing it in a way that is not spontaneous and unplanned, without making inconsistent and vague goals (Hult, Lindblad Fridh, Lindh Falk, & Thörne, 2009). Research indicated that most healthcare professionals are unfamiliar with patient education methods, lack competence, and have inadequate education and training in patient education (Friberg, Granum, & Bergh, 2012; Lelorain, Bachelet, Bertin, & Bourgoin, 2017). This happens despite patient education not being a new practice for healthcare professionals (Hoving, Visser, Mullen, & van den Borne, 2010). When asked to introduce new self-management support or education actions, healthcare professionals can be also reluctant or fearful to change their practice (Blakeman, Macdonald, Bower, Gately, & Chew-Graham, 2006; Greaves & Campbell, 2007; Kennedy et al., 2014). They can further complain the lack of support and flexibility to assess and respond to individuals' needs in a person-centred manner, or the lack of procedures and guidance to deliver

education as an integrated part of routine practice (Blakeman et al., 2006; Greaves & Campbell, 2007; Kennedy et al., 2014). Even more, introducing patient engagement support – and not only self-management or patient education– could become even more challenging, because a more complex effort. Barriers have been reported standing in the way of healthcare providers promoting patient engagement through individual approaches (Dentzer, 2013; Longtin et al., 2010; Moore et al., 2016). Examples of these are their reluctances to give up traditional roles and to change their practice, lack of communication training, personal beliefs and resistances, or complaint that time simply lacks (Dentzer, 2013; Longtin et al., 2010; Moore et al., 2016). National guidelines have been produced to drive similar changes (National Institute for Health and Care Excellence, 2014). However, as similar changes depend on the specific situations within the single contexts (Moore et al., 2016), transferring evidence to practice for a greater role of individuals in care is still far to be accomplished (Grol & Grimshaw, 2003). Therefore, research is needed to understand how to most effectively embed and sustain patient engagement support within the "real-world" setting of healthcare professionals' clinical practice.

## 1.1.6.  Patient engagement in the elderly: The main challenges

As described above, it is possible to observe how the ageing of the population and the raise of chronic conditions corresponded to a change in the approach to individuals' role in the care process. The new concepts that nurtured in the last years for denoting a more and more active role of individuals in the care process, however, challenge individuals, and also the health systems.

Managing a chronic condition is per se a difficult task for individuals, but that can become considerably harder for older individuals. It is not only that older individuals have often to live their later years of life managing a chronic condition, but also that they have usually deal with multiple health problems with overlapping symptoms impairing their lives (Stamm, Pieber, Crevenna, & Dorner, 2016). Particularly at a later age, the ability to carry out the usual activities of daily living and to adapt to manage one's life decreases due to the deterioration of the physical and cognitive condition (Stamm et al., 2016). There are also the social difficulties to consider, with the reduction of social relationships after the retirement and possible friends or relatives' losses, further challenging the functional status (Shankar, McMunn, Demakakos, Hamer, & Steptoe, 2017). For these reasons, later life can become a challenging period also for the psychological health of individuals, with lowered wellbeing and increased depression and distress being often reported (Steptoe, Deaton, & Stone, 2015).

Altogether, these physical, psychological, social aspects can impact on the ability of older adults to manage their own health and care on an ongoing basis (Blakemore et al., 2016; Chubak et al.,

2012; Gallagher, Donoghue, Chenoweth, & Stein-Parbury, 2008). Studies demonstrated that older persons are generally poorly activated towards care (Blakemore et al., 2016; Chubak et al., 2012; Gleason, Tanner, Boyd, Saczynski, & Szanton, 2016; Rolin, Bartels, Aschbrenner, & Cimpean, 2013). This can have a ripple effect on the physical and mental health status of older individuals in its turn (Hibbard & Greene, 2013). Thus, the ability to self-care by assuming an active role in care is particularly a key point in the management of health issues in later age (WHO, 2015). Older adults are the ones most needy for support for maintaining an active role in caring for themselves (Oliver, 2016). This is not only a need, but actually an active request of older adults. Literature reported how older individuals are willing to play a role in decisions about their health (Belcher, Fried, Agostini, & Tinetti, 2006; Ladin et al., 2016; Teh et al., 2009). Furthermore, for older adults, engagement does not have to be limited to clinical encounters. Rather, engagement for them implies being valued and assisted to make sense of their experiences of care within an overall sense of life purpose towards a greater exchange with the health context (Foss, 2011; J. Thompson, Tiplady, Hutchinson, Cook, & Harrington, 2017). Engaging older adults in their care can have important effects on their functional status, on the healthcare quality, the adherence to medications, and the enactment of healthy self-management behaviours (Greene, Hibbard, & Tusler, 2005; Skolasky et al., 2011).

At the same time, older adults particularly are not supported to take a leading role in care (Belcher et al., 2006; Dyrstad, Laugaland, & Storm, 2015). They are, indeed, traditionally seen as unable to autonomously manage their health condition and needy for somebody else taking care for them (Ward, 2000). As a consequence, they are commonly treated in a paternalistic passivizing way and their role as main actor of the care process is often not recognized (Kane & Kane, 2005). Therefore, the gap between what is needed and asked by individuals and what is offered by healthcare providers in terms of engagement in care becomes wider when individuals are older (Ladin et al., 2016; Ward, 2000). Complex barriers in the delivery of interventions to promote patient engagement among older adults have been reported, not restricted to a difficulty in informing them about their care management but including also restricted and fragmented care due to negative preconceptions associated with old age (Belcher et al., 2006; Sachs, Stocking, & Miles, 1992; Selman et al., 2016). Optimizing care for older people has been usually considered a responsibility of aged care services. This even if older people are now the principal users of health services (Gething, 1999). Therefore, the attention on how to manage this complex target group usually lacks in the health services.

Thus, if we focus specifically on the vulnerable age group with demanding healthcare needs of older adults, we can find increasing care gaps, particularly for allowing older adults being engaged

in care. This makes engagement of older individuals a research area that requires high attention, particularly for implementable deployments able to support an engaged role of them in care. Despite the high-relevance of this theme, literature on patient engagement of older adults is limited and in its infancy. Studies that embraced a wider perspective on patient engagement all concerned with exploring experiences of (not) engagement of older patients (Barello et al., 2015; Ladin et al., 2016; J. Thompson et al., 2017). There is a need for studies exploring how patient engagement support can be provided to older persons within the "real-world" setting of healthcare professionals' clinical practice.

## 1.2.  Research aims

The main purpose of this thesis was to contribute knowledge about how patient engagement support can be provided to older adults, by describing the interventions' contents in published studies, developing a patient engagement intervention and studying its implementation.

In details, this thesis aimed to:

- Describe patient engagement interventions' contents delivered to older adults (Chapter 2 – study 1);

- Describe the development and qualitative validation of an individual intervention for supporting patient engagement of older adults, called *PHEinAction* (Chapter 3 – study 2);

- Investigate the early-stage implementation of *PHEinAction* into the existing patient education practice of different care services of an Italian integrated-care organization (Chapter 4 – study 3).

## 1.3.  Overview of the research design

The Medical Research Council (MRC) Framework was used to assist the research, as phased approach aimed to provide a guidance for the development and evaluation of complex interventions (Campbell et al., 2000; 2007; Craig et al., 2008). This framework was selected because of its robust research background and methodological basis, as well as for its relevance for the research purpose (Campbell et al., 2000; 2007; Craig et al., 2008). According to this framework, some key phases should accompany the development, evaluation, and implementation of complex interventions. In Figure 1.2, the key steps of the MRC Framework that were accomplished in the present research project are reported. It, indeed, helped defining how to proceed and structure the research work.

**Figure 1.2.** The MRC Framework's steps implied in the PhD research project

| | | | |
|---|---|---|---|
| **Development** | 1 | The first step includes identify the existing evidence and what it is already known about similar interventions. The framework suggests conducting systematic reviews for this aim. | Study 1 |
| | 2 | The second step features drawing on existing evidence and theory to develop a theoretical understanding of the likely process of change enacted by the intervention. | Study 2 |
| | 3 | The third step involves modelling and progressively refine the intervention design. | |
| **Feasibility** *and piloting* | 4 | The fourth step regards assessing feasibility of implementation of the intervention in the real-word setting. | Study 3 |
| | 5 | Piloting is thereafter suggested as fifth step, as a scale model of the planned evaluation. This step falls outside the research project. | X |

*Evaluation (outside the research project)*

*Implementation (outside the research project)*

The research aims were, thus, addressed with three connected studies adopting different research methodologies, divided in three main sequential research phases:

1. Development Phase I

Study 1: A systematic review of the literature to describe the contents in interventions reported in RCTs focused on patient engagement and similar terms where the average age of the participants were 60 years or more

2. Development Phase II

Study 2: A qualitative study with focus groups involving healthcare professionals and individual interviews to older patients to develop and validate a patient engagement intervention for older adults

3. Implementation Feasibility Phase III

Study 3: A qualitative study of a participatory process to explore the early-stage implementation of the developed intervention in one Italian integrated-care context with multiple sources of information

## 1.4.  Theoretical framework for the thesis

The present project started from and built on the work on a theoretical framework of patient engagement (PHE theory) developed from experiences of patients affected by chronic conditions of their engagement in care (Barello et al., 2015; Barello & Graffigna, 2015; Graffigna et al., 2015, 2014). This theoretical framework supported the entire research project described in this thesis.

Here, I first present a cross-disciplinary overview of the concept of "engagement", focusing then on the label "patient engagement" within the health science discipline. I finally report details on the definition and theory of patient engagement that has been used for this thesis (the PHE theory).

### 1.4.1. Engagement

If we look at the concept of "engagement" in itself, it is possible to observe how in literature it has been applied to several contexts (marketing, social, educational, healthcare). The origin can be traced to the organizational context, with the contributes of Kahn (1990) and Shaufeli (2013) on work engagement. The word engagement has been criticized for being no more than old wine in new bottles as its core attributes remained barely the same across contexts (Jeung, 2011). Definitions of terms like student/work/brand/patient engagement (Appleton, Christenson, & Furlong, 2008; Graffigna et al., 2016; Hollebeek, 2011; Little & Little, 2006; W. Schaufeli, 2013) have several commonalities which have led to engagement being defined as: (i) an "umbrella term", but with a final meaning that is more than the sum of the concepts embraced, (ii) tri-dimensional, incorporating emotional, cognitive and behavioural elements, (iv) reflecting a psychosocial dynamic and processual experience, (v) being context-dependent, (vi) developing within a two-way relational interaction.

### 1.4.2. Patient engagement

Looking at the healthcare context specifically, different researchers wrote about what patient engagement is (Carman et al., 2013b; Coulter, 2006; Graffigna et al., 2014; Higgins et al., 2017; Holmes Rovner et al., 2010; James, 2013). Angela Coulter's well-known definition focuses on the relationship between individuals and healthcare providers: They work together to "promote and support active patient and public involvement in health and healthcare and to strengthen their influence on healthcare decisions, at both the individual and collective levels." (Coulter, 2006).

Carman refers to patient engagement speaking about "patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system— direct care, organizational design and governance, and policy making—to improve health and health care" (Carman et al., 2013a). Then, the Center for Advancing Health's engagement behaviour framework focuses on the behaviours, defining engagement as "actions people take for their health and to benefit from healthcare" (Holmes Rovner et al., 2010). In Julia James' article, patient engagement has been defined as "a broader concept [compared to patient activation] that combines patient activation with interventions designed to increase activation and promote positive patient behaviour, such as obtaining preventive care or exercising regularly." (James, 2013). Therefore, the recent Higgins' review of patient engagement concepts defined it as "the desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual, in cooperation with a healthcare provider or institution, for the purposes of maximizing outcomes or improving experiences of care", highlighting how it is shaped by the relationship between the patient and the provider and the environment in which the healthcare delivery takes place (Higgins et al., 2017).

Finally, Graffigna et al. (2014, p.87) contributed with a definition which is claimed to present a concrete idea of patient engagement, also aligned with the attributes of the concept of engagement presented in the section 1.4.1:

*"patient engagement is a multi-dimensional psychosocial process resulting from the conjoint cognitive, emotional, and behavioural enactment of individuals toward their health condition and management"*.

This definition values the complexity of the patient engagement experience (it is a multidimensional process), with embedded emotional, cognitive and behavioural aspects. It also highlights the dynamicity of the process of engagement, featured by the interlace of psychosocial experiences that, therefore, embrace interactions between the individual and the other actors of the healthcare context.

## 1.4.3. The Patient Health Engagement (PHE) theory

Based on the above definition of patient engagement (Graffigna et al., 2014), a processual theory of patient engagement, called the *Patient Health Engagement (PHE)* theory (Graffigna et al., 2015), has been developed to explain how people can become engaged (or not) in the care process. This theory was based on results from several qualitative studies with different populations of Italian patients (Barello et al., 2015; Barello & Graffigna, 2015; Graffigna et al., 2014).

The emphasis in this theory is on the psychosocial process of adjustment by the individuals to a health condition so that they are able to integrate the illness experience into their life trajectory in a way that is meaningful for them (Graffigna et al., 2014). This requires processing their role as a patient in different ways, not only attributable to the cognitive and behavioural dimensions of care but concerning also the emotional dimension and the ability of individuals to give meaning to their disease and care (Carman et al., 2013a; Graffigna et al., 2014; Gruman et al., 2010). When individuals are engaged, it is not only that they are able to care for their health, but also that they proactively interact with the healthcare context and contribute to meaningful and positive health trajectories. Recent studies demonstrated how a similar conceptualization of patient engagement is able to moderate and boost the activation level of individuals and their adherence to health behaviours (Graffigna, Barello, & Bonanomi, 2017; Graffigna, Barello, Bonanomi, & Riva, 2017).

In particular, it explains the process of patient engagement as being a dynamic emotional, cognitive, behavioural journey featured by four main positions of engagement: blackout, arousal, adhesion, and eudaimonic project. These positions describe specific experiences and needs for care. In Figure 1.3, the theoretical model of patient engagement as presented in literature is reported (Graffigna et al., 2014).

**Figure 1.3.** The patient engagement process as described by the PHE theory (Graffigna et al., 2014)



THE PROCESS OF PATIENT ENGAGEMENT
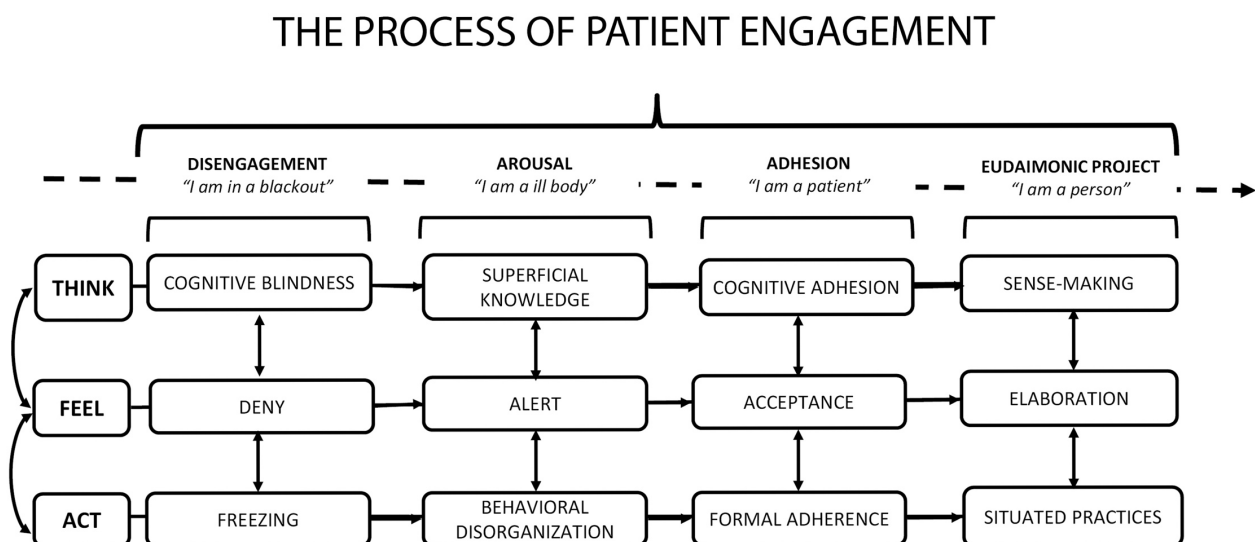
### 1.4.3.1.   Blackout

Individuals in a blackout position feel unable to manage their health condition and are upset, cognitively and behaviourally frozen (Fig. 1.3). This is a typical position of just diagnosed patients

or where the disease condition is particularly challenging, making them vulnerable. Discouragement, and sometimes anger, is typical when being in this experiential position, and the experience reported is generally of crumbling of certainties. They thus tend to delegate to others their care, and feel not responsible for their health, not able to contribute. Individuals perceive their health as out of their control, and they thus experience an emotional, cognitive and behavioural block ("*blackout*"). They describe themselves as suspended, not being still completely aware of what it is happening around and inside them. They have poor knowledge on the disease condition and have difficulty in decrypt all the information received. Furthermore, they feel behaviourally locked and unable to autonomously manage the disease. Due to the traumatic experience of the disease condition, their resources and energies are generally focused on the disease, omitting the other spheres of life.

### 1.4.3.2.   Arousal

Individuals can then experience an arousal position in which they perceive anxiety and worry for their condition, enacting disorganized behaviours to manage their disease. Even if a starting awareness and understanding of the new health condition ripened, individuals in arousal still struggle to accept the new condition as part of their daily life. As a consequence, they live in a state of emotional alert, which lead them to focus on physical symptoms lived as potential signs of relapses or worsened condition. They describe themselves as in alarm, leading to negative experiences and dysfunctional reactions. They are informed about their health condition, but their knowledge is fragmented and their behaviours are disorganized.

### 1.4.3.3.   Adhesion

In an adhesion position, individuals learn to manage their health condition and are "good" patients, but only formally adherent to health prescriptions. This experiential position is featured by better structured and consistent knowledge on the health condition and on how to manage it, as well as by behavioural skills that they had acquired or developed to properly follow the medical recommendations. Individuals have psychologically accepted the health condition, and they feel confident on their ability to deal with the challenges related to the health condition. Emotionally, they overcame the stress and the negative feelings featuring the other positions, and they feel having accepted and elaborated their health condition and their condition as « patients ». However, they are not completely autonomous when managing their disease, and might have problems when

contextual situations change. They formally adapt to the therapeutic plan, but they still do not have interiorized fully the rationale for this plan and for prescriptions. As such, adherence to medical recommendations is merely formal, and they perceive themselves as formal executors of prescriptions. Even if they are "good" patients and they are able to properly interact with the health system and manage the health condition, they do not perceive themselves as the crucial actor of the care process. Their daily organization to manage their health condition is consolidated but still dependent from medical prescriptions.

### 1.4.3.4.    Eudaimonic project

In a eudemonic project position - with the term eudaimonic being used in psychology as a construct of wellbeing, meaning personal growth, meaning and a fully functioning life (Ryan & Deci, 2001) -, after having become aware of the health condition and learned efficacious strategies to manage medical recommendations, individuals matured having an active role in reaching a good full quality of life which overcome the boundaries of the health condition. They have indeed elaborated that their identity and role as patients is only one of the multiple roles they can enact in their life. The health condition is perceived as less totalizing, and the health sphere as only one of the multiple life spheres. Individuals in this position are able to positively integrate their health condition into their life plans. As such, they are focused on re-project themselves and their life according to the requirement of the health condition, perceiving themselves as leading actors and co-producers of wellbeing trajectories. They are proactive, also for what concerns their efficacy in reaching information on their health condition. This helps them giving sense to their care experience. The acquired and interiorized knowledge on their health condition allows them understanding the rationale behind the medical recommendations, and thus managing self-care behaviours also when life contexts change. Strategies for self-care are aware, embodied, and situated.

### 1.4.4.  The PHE Scale

A 5-items unidimensional validated self-report scale (PHE-Scale) has been validated strongly rooted in this theory, showing the ability to detect these four main patient engagement positions along the care process (Graffigna et al., 2015). The items of the PHE-scale were developed based on the findings from the literature review and from interviews with chronic patients, and then tested on an Italian sample of chronic patients. The analysis showed that the PHE Scale has good

psychometric properties with good correlation with concurrent measures of patient activation (PAM Scale) and reliability. The Scale has been suggested to be a useful tool for tailoring interventions and for assessing changes after patient engagement interventions (Graffigna et al., 2015).

# Chapter 2

# What are the contents of patient engagement interventions for older adults? A systematic review of randomized controlled trials

In this Chapter, I will report the scientific literature on the interventions for patient engagement support of older adults.

As previously described, despite the high-relevance of patient engagement support for older adults, literature is limited and in its infancy. In the previous Chapter, I have highlighted the need for research detailing the contents of interventions studies focusing on the concepts emerged after the disease-centred approach, as a mean to further advance interventions for supporting patient engagement. Here, I will describe the study that answers to this research gap, by describing and analysing the intervention contents reported in RCTs on patient engagement support for older adults. This involved conducting a systematic review, and classifying interventions' contents according to three levels of analysis: (i) the components used by patient engagement interventions for older adults (micro-level), (ii) the combination of cognitive, behavioural and affective/emotional dimensions within interventions and the differences among interventions according to these combinations (meso-level), (iii) the main cognitive, behavioural and affective/emotional focus of the interventions and the differences among the studies having a different focus (macro-level).

The final result of this literature review is an analysis of interventions' contents for older patient engagement, starting from the minimal units of interventions and building on them to observe how these have been combined within interventions. I will finally discuss the results comparing them with those of studies that classified interventions' contents with a disease-centred approach.

## 2.1.  Introduction

In the Background of this thesis (Chapter 1), I showed how the increase of older adults and of chronic conditions are creating significant demands on healthcare services (Prince et al., 2015). I also described how making older individuals protagonists of their own health and care management has been argued to be a key strategy (Boyd et al., 2005; World Health Organization-WHO, 2013; World Health Organization, 2010). I have retraced the steps of the focus paid to the individuals' role in care. Historically, the focus has been on making patients comply and adhere to medical recommendations and treatments (Vermiere et al., 2001). In the last years, concepts like patient participation, involvement, empowerment, activation, or engagement have become more common (Finset, 2017). Patient engagement has been described as an umbrella term for all these new concepts, reflecting a multi-dimensional psychosocial process where the individuals play an active role, and are supported by the health care, on a cognitive, emotional, and behavioural level (Graffigna et al., 2014; Higgins et al., 2017; Hurley, Keenan, Martsolf, Maeng, & Scanlon, 2009).

I have also highlighted how, observing the literature, it is unclear whether supporting compliance/adherence behaviours or processes like patient engagement means changing the contents of the interventions delivered to older adults. The first question that, thus, raised from the literature was: does the change in the terms used mean a shift in contents of the interventions? It is also unclear whether the contents of such interventions follow the care needs of an increasingly older population. Therefore, a second questions raised: does targeting older patients have specific effects on the interventions delivered?

Following the division in emotional, cognitive, behavioural dimensions as expressed by the concept of patient engagement was considered useful to track interventions' contents. Indeed, a similar classification would have allowed observing how and how much contents delivered in clinical practice considered the complexity of the patient engagement experience and were aligned with a shift in concepts.

Researching the literature, it was possible to observe how a similar classification was already adopted in literature to characterize interventions supporting a patients' role in care. However, all of the identified studies focused on patient compliance/adherence. The first  of these reviews was published in 1998 by Roter et al. (Roter et al., 1998). They developed a definition grid to classify interventions for patient compliance according to three main dimensions: educational (in following articles renamed "cognitive", see (De Bleser, Matteson, Dobbels, Russell, & De Geest, 2009; Fogarty et al., 2002)), behavioural, affective/emotional (and combinations of these). They also

defined specific components within each dimension. Other reviews on patient adherence interventions followed, using the same or slightly modified versions of the Roter study's classification criteria (Chong, Aslani, & Chen, 2011; De Bleser et al., 2009; Fogarty et al., 2002; Galo, Mehat, Rai, Avina-Zubieta, & De Vera, 2016; Low, Williams, Manias, & Crawford, 2015; Omran, Guirguis, & Simpson, 2012a; Sapkota, Brien, Greenfield, & Aslani, 2015). Seen together with a review of reviews on medication adherence (van Dulmen et al., 2007), it was found that interventions combining cognitive, behavioural, affective/emotional dimensions showed the best outcome. However, most interventions were cognitive, understood as providing knowledge (Roter et al., 1998). The affective/emotional dimension was the less covered one. None of these studies looked specifically at older people. It remained questionable how such a difficult target could have been made capable of the tasks associated with the complex care responsibility they have (Greene et al., 2005), and which interventions' contents needed to be considered for engaging this target group in care.

No reviews were found classifying the contents of interventions in studies focusing on the concepts emerged after the disease-centred approach and targeting older people. It is thus an open question whether such interventions have different contents and whether targeting older patients has consequences for the contents delivered. Describing and evaluating the components of the interventions can help to pave the way toward more efficient interventions (Borek et al., 2015; Lokker, McKibbon, Colquhoun, & Hempel, 2015). Consequently, a review of RCTs (especially those targeting older persons) with such a focus is needed, as first step to explore existing evidence on patient engagement interventions for older adults.

## 2.2.  Aim

The overall aim of the study here reported was to conduct a systematic review to describe the contents of interventions used in publications reporting RCTs focused on patient engagement where the average age of the participants was 60 years or older and to compare interventions and studies according to the cognitive, behavioural and affective/emotional dimensions.
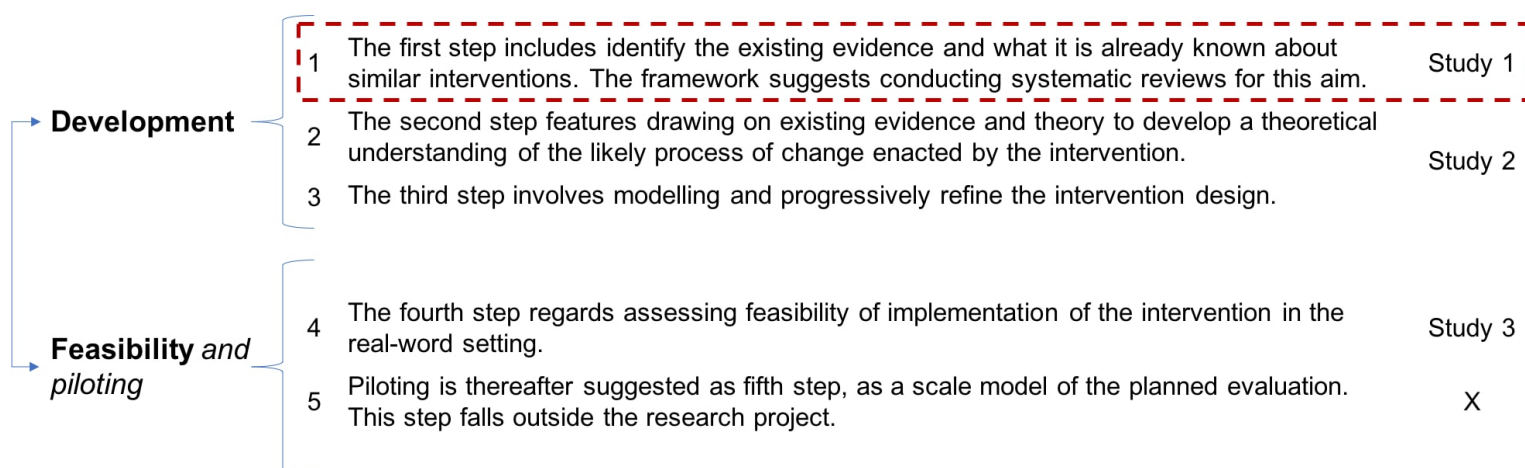The specific aims of this study were to describe the:
   o   Type and frequency of components used by patient engagement interventions for older adults (micro-level)
   o   Differences among interventions using different combinations of cognitive, behavioural and affective/emotional dimensions (meso-level)
   o   Differences among the studies having a main focus on the cognitive, behavioural and

affective/emotional dimensions (macro-level)

This study covered the first point of the MRC Framework (Figure 2.1), focused on exploring what it is already known about similar interventions, i.e. patient engagement intervention for older adults.

**Figure 2.1.** MRC Framework's point covered by the study 1

| | | | |
|---|---|---|---|
| **Development** | 1 | The first step includes identify the existing evidence and what it is already known about similar interventions. The framework suggests conducting systematic reviews for this aim. | Study 1 |
| | 2 | The second step features drawing on existing evidence and theory to develop a theoretical understanding of the likely process of change enacted by the intervention. | Study 2 |
| | 3 | The third step involves modelling and progressively refine the intervention design. | |
| **Feasibility** *and piloting* | 4 | The fourth step regards assessing feasibility of implementation of the intervention in the real-word setting. | Study 3 |
| | 5 | Piloting is thereafter suggested as fifth step, as a scale model of the planned evaluation. This step falls outside the research project. | X |

## 2.3.  Methods

A systematic review of RCTs was performed. A broad search strategy, followed by a step-by-step screening of articles through a funnelling approach, was purposively used.

Systematic reviews seek to systematically search, collate and synthetize all relevant research evidences that fits specific eligibility criteria to answer a particular research question (Higgins and Green, 2009). Differently from scoping reviews, they are guided by specific aims, as well as they consider the means (the quality) used to obtain results and generally synthetize results in a quantitative way (Mora et al., 2015). The advantages of systematic reviews are to draw together all known knowledge on a topic area. The suggested disadvantages include providing insights about effectiveness rather than seeking answers to more complex, but still well-narrowed, search questions; for example, what are the characteristics that make a particular intervention effective over another (Granth and Booth, 2009).

For these reasons, considering the research aim, a systematic review was performed and the methods used for retrieving, selecting and synthetizing data were based on PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Moher D, Liberati A, Tetzlaff J, 2009). However, as the focus of this review was on contents rather than on outcomes

of studies, some aspects of the PRISMA statement were not applicable (see Additional file 1 for PRISMA checklist) and some changes into the criteria for conducting systematic reviews on interventions' effectiveness (Higgins and Green, 2009) were made (i.e., broad search strategy).

### 2.3.1. Eligibility criteria

Studies eligible for inclusion had to:

(i) include the searched terms relevant for patient engagement (see the section 2.3.3. "Search" for details) in the title/abstract/keywords;

(ii) have individual patients as the main target of the intervention;

(iii) have a sample where the average age was 60 years or older;

(iv) be RCTs;

(v) be full-text retrievable peer-reviewed articles;

(vi) be reported in a major European language.

Studies were excluded if they:

(i) concerned engaging patients in the research or intervention itself;

(ii) investigated the effect of drugs, surgery and other similar medical therapies;

(iii) focused mainly on patient adherence/compliance to treatments;

(iv) reported on interventions mainly targeting caregivers, healthcare professionals, or the healthcare system organization.

### 2.3.2. Information sources

The first search was conducted on the July 15, 2016 and updated January 26, 2017, using the PubMed, CINAHL, Cochrane, and PsychInfo databases. This search was supplemented by reviewing reference lists from included studies.

### 2.3.3. Search

The search strategy included the labels most recently used related to the concept of patient engagement (Menichetti et al., 2016), giving the following search in PubMed; ("patient engagement" OR "patient activation" OR "patient empowerment" OR "patient involvement" OR "patient participation") AND ("intervention*" OR "trial*" OR "program*"). The search was restricted to the title/abstract/keywords. No years, language or documents' type restrictions were applied in the search.

## 2.3.4.  Study selection and data collection

Data extraction and selection was performed by one researcher (me), and followed a structured process: a) extraction of articles' data (title, authors, journal, year, keywords, abstract, country) into an Excel database, b) removal of duplicates through the Excel function "remove duplicates" after having cleaned titles for punctuation marks, c) first manual screening of articles to select those targeting the individual patient and being RCTs, and to exclude those referring to engage patients in research/intervention, and testing medical therapies by signing yes/no/unclear and providing written justification, d) research of the full texts of the articles that passed the first screening step or that needed further evaluation, e) second manual screening to identify the studies with a sample age of 60 or more years and not focusing mainly on adherence/compliance and to further check inclusion/exclusion criteria.

The studies' authors were contacted to get a copy of the full text only when it was not otherwise available.

## 2.3.5.  Data items

For each study the following variables were systematically extracted (detailed description for some of the variables below): (i) study characteristics (country of the first author, study design and number of arms, control group type, number of participants in the control and experimental group, (risk of bias, see the separate section)), (ii) participants-related aspects (diagnosis, mean age, number of males and females), (iii) intervention-related aspects (group/individual, type of provider, type of theory used for developing the intervention, use of technologies, personalization of contents, components used, the dimension(s) (cognitive/behavioural/affective) used in the intervention, the main dimension (cognitive/behavioural/affective) used in the study at large), and (iv) outcomes-related aspects (overall effect on the main outcomes of the study).

Personalization of contents was any study using words such as "personalized", "targeted", "tailored" or "individually adapted" to indicate that the intervention was personalized to the individual participant.

Components used were the interventions' minimal units of action (e.g., techniques, activities, materials). These were first identified and then classified according to the categorization of Roter et al. (1998) into three dimensions: cognitive (if they had a knowledge-based pedagogic emphasis, with verbal sessions or written teaching designed to convey information); behavioral (if they were

targeting, shaping, or reinforcing specific behavioral patterns); and affective (if they tried to influence engagement through appeals to feelings and emotions or through social relationships and support). In the cases in which the included strategies were not mentioned in the categorization of Roter et al. (1998), articles using the same classification system were used to solve doubts and define in which dimension the component had to be included (Chong et al., 2011; De Bleser et al., 2009; Fogarty et al., 2002; Galo et al., 2016; Low et al., 2015; Omran et al., 2012a; Sapkota et al., 2015). In cases in which it was not possible to categorize the components based on this literature (e.g., for motivational interviewing), classification was determined by consensus among the authors after discussion in a research group on patient education and participation consisting of nine researchers with different educational and professional backgrounds.

The dimension(s) (cognitive/behavioural/affective) used in the intervention was classified, as described above, according to which dimensions the identified components in the interventions fell into. Thus, an intervention could be classified as cognitive, behavioural, affective/emotional or a combination depending on whether the components identified were classified in one or several dimensions.

The main dimension (cognitive/behavioural/affective) used in a given study was classified by counting the number of components within each dimension. The study was designed as cognitive, behavioural or affective/emotional based on which dimension had the highest number of components. In cases in which two dimensions had an equal number of components, the main focus of the intervention was decided by consensus among the authors after the studies having been discussed in a research group on patient education and participation consisting of nine researchers with different educational and professional backgrounds.

The overall effect was classified according to the defined primary outcome in each study. For studies with more than one main outcome, three categories were defined: 1) positive (articles reporting positive significant effects on all the main outcomes stated), 2) partial (articles reporting positive significant effects on some of the main outcomes stated), 3) negative (articles not reporting positive significant effects in none of the main outcomes stated). The proportion positive and partial outcomes is reported.

## 2.3.6. Risk of bias assessment

The risk of bias was only used to characterize the different studies (i.e. as a data item). It was evaluated using the Downs and Black checklist for quality assessment, which is a well-established standardized tool with good psychometric properties (Downs & Black, 1998). This checklist with 27 questions allows an overall score for study quality to be reported (maximum score of 32) based on scores for reporting (11 as maximum score), external validity (3 as maximum score), internal validity concerning intervention and outcomes (7 as maximum score), internal validity concerning confounding (6 as maximum score), and the power of the study (1 question, 5 as maximum score).

### 2.3.7.  Data analyses and synthesis

Characteristics were reported with descriptive analyses (n, frequency, median, range). The mean sample age including standard deviation for groups of studies was weighted for the sample size of the different studies (Bland & Kerry, 1998). To compare interventions (research question two, meso-level), a descriptive comparison was made. To compare interventions according to whether they included one, two or more dimensions, as well as for comparing studies (research question three, macro-level), parametric (one-way analysis of variance with Tukey post-hoc test) and non-parametric (Chi-squared test, Fisher's exact test) analyses were performed using Excel or the IBM Statistical Package for Social Science version 24.0 (IBM Inc. Armork, NY).

## 2.4.  Results

A total of 2680 potentially relevant articles were identified, which, adding the records identified from reviewing reference lists of included studies, led to 2749 articles totally screened (Figure 2.2). After assessment of 305 full-texts articles, 35 were finally included.

**Figure 2.2.** Search flow
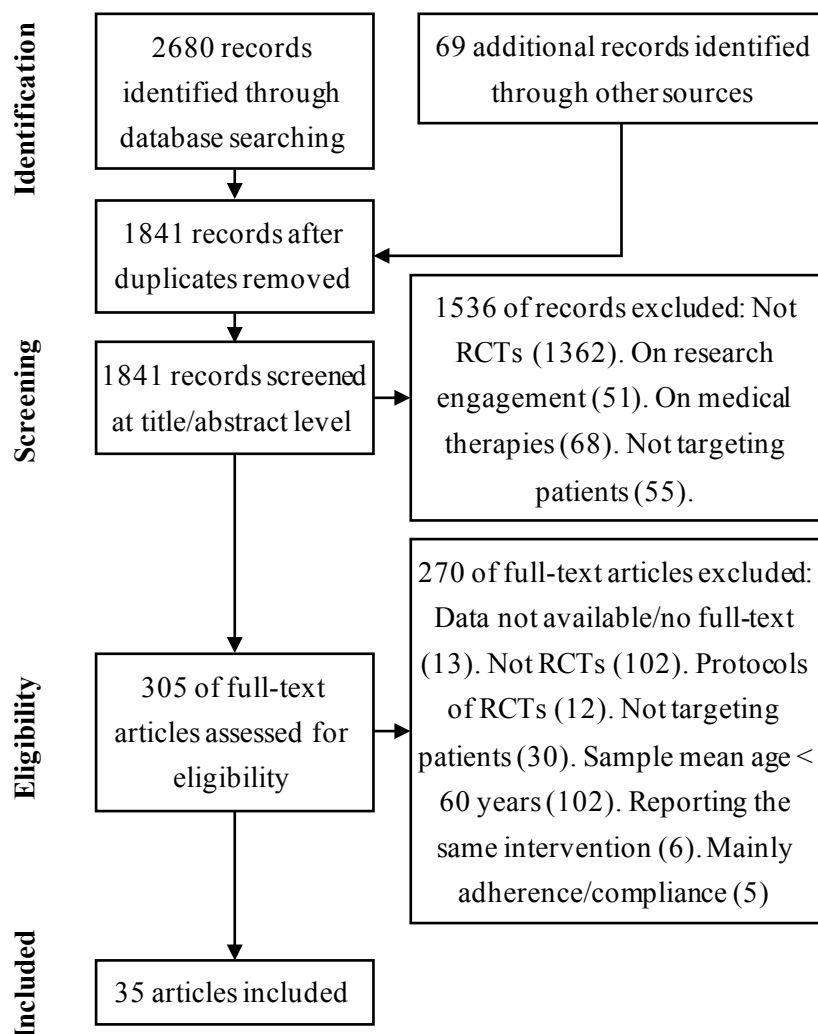


Of the 35 included studies, 25 (71%) were published in the last four years. Six (17%) studies adopted a cluster RCT design and six (17%) included more than two intervention arms. Most frequently (n=22; 63%) intervention conditions were compared with treatments as usual, nine (26%) studies used attention control conditions (e.g., advice, printed materials, general education), two (6%) waiting-list and one (3%) established gold standard intervention.

In 21 (60%) studies, the intervention was theory-driven, in most of the cases by the patient activation theory of Hibbard et al. (n=4, 19%), by the social cognitive theory of Bandura (n=4, 19%), or by the self-determination theory of Ryan and Deci (n=4, 19%). Individual sessions were used by the majority of studies (n=25, 71%) and almost half of studies (n=16; 46%) personalized interventions' components to patients' needs and characteristics. Nurses were the most frequent provider (n=12; 34%), and training of the provider was done in 12 (34%) studies.

## 2.4.1.  Risk of bias

In this review, the risk of bias was used to compare studies. The methodological quality of included studies had a median score of 21 (range 12 to 27). The most common methodological weaknesses were the lack of attempts to blind study participants to the intervention arm, to measure adverse events potentially impacting to the intervention, and to select samples representative of the population. Studies succeeded in clearly describing the main findings of the study and the characteristics of the patients included.

## 2.4.2.  Micro-level: Type and frequency of components

Table 2.1 summarizes the type and frequency of components used in patient engagement interventions for older people, categorized according to the three dimensions, cognitive, behavioural and affective/emotional. A total of 20 unique components were identified, totalling 112 components used in the 35 studies giving an average of 3.2 components for each study (range 1 to 9). Behavioural and cognitive components accounted for 45.5% each (n=102), while 9 % (n=10) of the components were affective/emotional. Cognitive components were mainly written informational materials (brochures, leaflets, workbooks) or verbal education sessions and accounted for 29% each (n=30), but also provision of assessment of physical or mental symptoms to improve patients' awareness and information on their physical and mental health status (n=13, 25%). Among the behavioural components, goal setting exercises, action planning, and question-asking encouragement were the most adopted with 16% each (n=24). Finally, affective/emotional components were mostly positive thinking exercises (n=3, 30%), but also motivational interviewing techniques, personal/contextual resource mapping exercises, and relaxation exercises were used accounting for 20% each (n=6).

**Table 2.1.** Type and frequency of interventions' components categorized according to the three cognitive, behavioural and affective/emotional dimensions (N=112)

| Dimensions | Type of components | Frequency (% of sub-total) | |
|---|---|---|---|
| **Cognitive** | Informational workbooks/leaflets | 15 | (29) |
| | Verbal education | 15 | (29) |
| | Sharing of assessment results | 13 | (25) |
| | Informational audio-visual materials | 6 | (12) |
| | Educational simulation scenario | 2 | (4) |
| | *Sub-total* | *51* | 100 |
| **Behavioural** | Goal setting | 8 | (16) |
| | Action planning | 8 | (16) |
| | Question asking | 8 | (16) |
| | Self-monitoring | 6 | (12) |
| | Provider's feedbacks on behaviours | 5 | (10) |
| | Problem solving | 4 | (8) |
| | Coaching from provider (face-to-face/phone-based) | 3 | (6) |
| | Goal values elicitation | 3 | (6) |
| | Skills building training | 3 | (6) |
| | Reinforcement | 3 | (6) |
| | *Sub-total* | *51* | 100 |
| **Affective/ Emotional** | Positive thinking | 3 | (30) |
| | Internal/external resource mapping | 2 | (20) |
| | Motivational interviewing | 2 | (20) |
| | Relaxation | 2 | (20) |
| | Friends/familiars support | 1 | (10) |
| | *Sub-total* | *10* | 100 |
| ***Total*** | | ***112*** | |

## 2.4.3. Meso-level: Comparison of interventions according to the combination of dimensions used

In Table 2.2, the characteristics of the studies for interventions using the cognitive, behavioural or affective/emotional dimensions, or a combination of these, is provided. Most interventions with a single-focus (focusing only on one dimension) were classified as cognitive (n=11; 31%). One intervention was solely affective/emotional (3%). Eighteen (51%) interventions covered more than one dimension, most frequently combining cognitive and behavioural dimensions (n=13, 37%). Four studies (11%) covered all the three dimensions, but none combined cognitive and affective/emotional dimensions.

Due to the variety of combinations of dimensions, the decision was made not to do any statistical comparison but rather to describe the differences. Interventions including the affective/emotional dimension were more frequently based on a theory (Table 2). The 60% (n=3) of behavioural only interventions and the 55% (n=6) of cognitive only interventions personalized some of the interventions' contents, but also half (n=2) of those including all the three dimensions had a personalization of contents (Table 2). All affective/emotional only interventions (n=1) and all behavioural plus affective/emotional interventions (n=1) used individual sessions and trained the providers. Finally, behavioural plus affective/emotional interventions had older samples and had a higher proportion of females. Cognitive-only interventions, meanwhile, had the least risk of bias. Behavioural plus affective/emotional (n=1, 100%) and behavioural only (n=4, 80%) interventions reported more positive or partial results on the main outcomes.

When comparing the interventions including only one dimension (n=17, 49% of the studies) with those with two or more (n=18; 51% of the studies) (data not shown in table), there were some differences that were noticeable, though not statistically significant. The mean age of the sample in the one-dimension sample was lower (64 vs. 70 years for two or more dimensions, $p = 0.08$). Also for the other variables there were observed differences – but not statistically significant - between the interventions with one compared to two or more dimensions covered; individual sessions (56% vs. 44% respectively, $p=0.155$), delivering training to providers (58% vs. 42%, $p=0.316$), being theory-based (43% vs. 57%, $p=0.315$), and being personalized to the patients' needs and characteristics (56% vs. 44%, $p=0.311$). Also, interventions covering one dimension reported more positive or partial effect on the main outcomes compared to those ones covering two or more dimensions (59% vs. 41%, $p=0.2$).

**Table 2.2.** Description of study characteristics for each of the different types of combination of the cognitive (C), behavioural (B) and affective/emotional (A) dimensions (n=35)

| Study characteristic | Dimensions | | | | | | | Total |
|---|---|---|---|---|---|---|---|---|
| | **C** | **B** | **A** | **C + B** | **C + A** | **B + A** | **C + B + A** | |
| Number of studies (n, %) | 11 (31) | 5 (14) | 1 (3) | 13 (37) | 0 (0) | 1 (3) | 4 (11) | *35 (100)* |
| Main targeted health problem (n; %) | osteoporosis (2;18), diabetes (2;18), multi-morbidity (2;18) | cardiovascular (2;40) | periodontist (1;100) | cardiovascular (4;31); diabetes (4;31) | - | generic (1;100) | cardiovascular (2;50) | *cardiovascular (9; 26%)* |
| Number of Participants (median; range) | 138 (52-7749) | 210 (26-500) | 56 (-) | 146 (60-4804) | - | 59 (-) | 207 (64-587) | *138 (26-7749)* |
| Average sample age (weighted mean; SD) | 67 (8,9) | 63 (12,2) | 62 (11) | 66 (6,6) | - | 78 (9,3) | 66 (10,9) | *68 (8,4)* |
| Proportion of females (median %, range) | 47 (22-100) | 58 (36-75,3) | 52 (-) | 44 (0-65,9) | - | 71 (-) | 66 (34-89) | *47 (0-100)* |
| Individual (n, %) | 10 (91) | 3 (60) | 1 (100) | 9 (69) | - | 1 (100) | 1 (25) | *25 (71)* |
| Personalization (n, %) | 6 (55) | 3 (60) | 0 (0) | 5 (38) | - | 0 (0) | 2 (50) | *16 (46)* |
| Most frequent provider (n; %) | technology (5; 45) | nurse (2; 40) | counsellor (1; 100) | nurse (6; 46) | - | nurse (1; 100) | multiple | *nurse (12; 34)* |
| Training of provider (n; %) | 3 (27) | 3 (60) | 1 (100) | 3 (23) | - | 1 (100) | 1 (25) | *12 (34)* |
| Theory-based (n, %) | 5 (45) | 3 (60) | 1 (100) | 8 (62) | - | 1 (100) | 3 (75) | *21 (60)* |
| Positive + partial effect (n, %) | 6 (55) | 4 (80) | 0 (0) | 4 (31) | - | 1 (100) | 2 (50) | *17 (49)* |
| Risk of bias score (median) | 22 | 20 | 21 | 20 | - | 17 | 20,5 | *21* |
| References | (Chaboyer et al., 2016; Denig, Schuling, Haaijer- | (Lenze et al., 2012; Safford et al., 2015; Sit et al., 2016; | (Brand, Bray, Macneill, Catley, & | (Beyth, Quinn, & Landefeld, 2000; Blackberry et al., 2013; | | (Crawford Shearer, Fleury, & | (Kate Lorig, Ritter, Villa, & Armas, 2009; Ryvicker, | |

| Ruskamp, & Voorham, 2014; Eikelenboom et al., 2016; LeBlanc et al., 2015; O'Donnell, Alvarez-Iglesias, McGuire, & Dinneen, 2016; Poureslami, Kwan, Lam, Khan, & Fitzgerald, 2016; Senesael, Borgermans, Van de Vijver, & Devroey, 2013; Tannenbaum, Martin, Tamblyn, Benedetti, & Ahmed, 2014; Wehbe-Janek, Hochhalter, Castilla, & Jo, 2015; Wolinsky et al., 2016) | Thiboutot et al., 2013; Walczak et al., 2017) | Williams, 2013) | Desbiens et al., 1998; Figar et al., 2006; Fonda, McMahon, Gomes, Hickson, & Conlin, 2009; Hochhalter, Song, Rush, Sklar, & Stevens, 2010; Maindal, Carlsen, Lauritzen, Sandbaek, & Simmons, 2014; Nguyen et al., 2013; Rygg, Rise, Grønning, & Steinsbekk, 2012; Schmidt et al., 2015; Shearer, Cisar, & Greenberg, 2007; Shively et al., 2013; van Tol-Geerdink et al., 2016) | Belyea, 2010) | Feldman, Chiu, & Gerber, 2013; Tan, Chan, Wang, & Vehviläinen-Julkunen, 2016; Vahedian-Azimi et al., 2016) |
|---|---|---|---|---|---|

## 2.4.4. Macro-level: Comparison of the studies according to the main dimension used

In Table 2.3, the characteristics of the studies after they had been categorized as mainly focusing on cognitive, behavioural or affective/emotional dimensions are reported. There was a statistical difference ($p<0.05$) between the studies focusing on the different dimensions for four of the 12 variables included. The weighted mean age of the sample was different ($p<0.001$), with those studies focusing mainly on the affective/emotional dimension having older participants compared to those included by studies mainly focusing on the cognitive (diff 5.2 years, 95%CI 2.1 to 8.3, $p<0.001$) and behavioural (diff 6.6, 95%CI 3.5 to 9.7, $p<0.001$) dimensions. Significant differences were also observed for the proportion of males and females, with the proportion of females in the affective/emotional interventions being higher than the proportion of females in the behavioural and cognitive interventions ($p < 0.001$). The studies focusing mainly on the affective/emotional and behavioural dimensions more frequently included additional dimensions compared to cognitive interventions ($p = 0.019$). Finally, there were differences in the methodological quality, with studies mainly focusing on the cognitive dimension having a lower risk of bias compared to those ones focusing on the other two dimensions ($p = 0.048$).

For the other variables, the differences were not statistically significant. The observed differences showed that the studies focusing mainly on the affective/emotional dimension targeted generic population of patients, used a multi-professional team to deliver the intervention and gave these providers training to a larger degree. The affective/emotional studies tended to include less participants and they were all theory-driven. Almost half of the overall studies reported positive or partial significant change in the main outcomes after the intervention, and 67% (n=2) of studies focusing mainly on the affective/emotional dimension reported positive/partial improvements, but differences among interventions' type were not statistically significant.

**Table 2.3.** Characteristics of the studies focusing mainly on the cognitive, behavioural or affective/emotional dimensions (n=35)

| Study characteristics | Total | Main dimension focused on | | | p-value |
|---|---|---|---|---|---|
| | | Cognitive | Behavioural | Affective | |
| Number of studies | *35* | *16* | *16* | *3* | |
| Main targeted health problem (n; %) | cardiovascular (9; 26%); diabetes (8; 23%); multi-morbidity (4; 9%) | cardiovascular (4; 25%); diabetes (2;13%); osteoporosis (2;13%) | diabetes (6; 38%); cardiovascular (5; 31%); cancer (2; 13%) | Generic (1; 33%), multi-morbidity (1; 33%), periodontics (1; 33%) | 0.157[c] |
| Number of Participants (median; range) | 138 (26-7749) | 189 (52-7749) | 178 (26-652) | 59 (56-64) | 0.266[a] |
| Sample mean age (weighted mean; SD) * | 68 (8,4) | 67 (7,9) | 65 (9,8) | 72 (8,6) | <0.001[a] *** |
| Proportion of females (median %, range) * | 47 (0-100) | 44 (0-100) | 46 (1-76) | 71 (52-89) | <0.001[b] *** |
| Included more than one dimension (n; %) * | 18 (51%) | 5 (31%) | 11 (69%) | 2 (67%) | 0.019[c*] |
| Individual (n; %) | 25 (71%) | 13 (81%) | 10 (63%) | 2 (66%) | 0.477[c] |

| | | | | | |
|---|---|---|---|---|---|
| Personalization (n; %) | 16 (46%) | 6 (38%) | 9 (56%) | 2 (66%) | 0.533[c] |
| Most frequent provider (n; %) | nurse (12; 34%) | technology (5; 31%) | nurse (8; 50%) | multiple/nurse/counsellor (1; 33%) | 0.164[c] |
| Training to provider (n; %) | 12 (34%) | 5 (31%) | 5 (31%) | 2 (66%) | 0.522[c] |
| Theory-based (n; %) | 21 (60%) | 9 (56%) | 9 (56%) | 3 (100%) | 0.406[c] |
| Positive or partial effect on the main outcomes (n; %) | 17 (49%) | 9 (56%) | 6 (38%) | 2 (67%) | 0.362[c] |
| Risk of bias (median, range) * | 21 (12-27) | 22 (16-27) | 20 (12-23) | 20 (17-21) | 0.048[a]* |
| References | (Beyth et al., 2000; Chaboyer et al., 2016; Denig et al., 2014; Desbiens et al., 1998; Eikelenboom et al., 2016; Figar et al., 2006; LeBlanc et al., 2015; Lo et al., 2011; O'Donnell et al., 2016; Poureslami et al., 2016; Senesael et al., 2013; Tannenbaum et al., 2014; Vahedian-Azimi et al., 2016; van Tol-Geerdink et al., 2016; Wehbe-Janek et al., 2015; Wolinsky et al., 2016) | (Blackberry et al., 2013; Fonda et al., 2009; Hochhalter et al., 2010; Lenze et al., 2012; Kate Lorig et al., 2009; Maindal et al., 2014; Nguyen et al., 2013; Rygg et al., 2012; Ryvicker et al., 2013; Safford et al., 2015; Schmidt et al., 2015; Shearer et al., 2007; Shively et al., 2013; Sit et al., 2016; Thiboutot et al., 2013; Walczak et al., 2017) | (Brand et al., 2013; Crawford Shearer et al., 2010; Tan et al., 2016) | |

[a]ANOVA test (note: for sample age, tests were based on mean and SD weighted for sample size)
[b]Chi-squared test
[c]Fisher's exact test
*p<.05; **p < .01; ***p< .001

## 2.5. Discussion

This review explored the contents of interventions delivered for older adults focusing on patient engagement. Overall findings showed that the affective/emotional dimension was the least used. One tenth of the studies focused on all the affective/emotional, behavioural, cognitive dimensions, while almost half focused on one dimensions only, usually the cognitive dimension.

Broadly speaking, the findings in this review, even though it only included studies focused on patient engagement for older people, were close to those found in earlier reviews focusing on patient adherence/ compliance (Chong et al., 2011; De Bleser et al., 2009; Galo et al., 2016; Omran, Guirguis, & Simpson, 2012b; Roter et al., 1998; Sapkota et al., 2015). Reviews on help delivered to individuals following medical prescriptions also found that the cognitive dimension was the most frequently used (Galo et al., 2016; Omran et al., 2012b; Roter et al., 1998; Sapkota et al., 2015), while the affective/emotional dimension was the least used (Chong et al., 2011; De Bleser et al., 2009; Galo et al., 2016; Roter et al., 1998; Sapkota et al., 2015). Thus, it appeared that studies focusing on patient engagement have contents similar to those of studies focusing on adherence.

However, when looking more closely at the identified components, the picture changed. In the present review, the described behavioural components generally require the active commitment of patients to health goals (goal setting, action planning). In previous literature on adherence/compliance, behavioural components frequently featured simple stimuli to generate better behavioural responses (reminders, packaging, follow-ups, monitoring devices) (Roter et al., 1998; Chong et al., 2011; Low et al., 2015; Orman et al., 2012). Furthermore, specific and detailed affective/emotional components (positive thinking, resource mapping, relaxation exercises) have been envisaged within patient engagement interventions (Crawford Shearer et al., 2010; Kate Lorig et al., 2009; Tan et al., 2016). In the literature on adherence, only generic affective/emotional components, such as social support, counselling, and communication, were mentioned (Roter et al., 1998; Orman et al., 2012; Chong et al., 2011). This showed that one should look at the detailed components when comparing interventions with different aims. It also suggested that not only has the use of terms like patient engagement become more frequent (Finset, 2017), but it has also been accompanied by a change in the contents, resulting in increased use of components with greater complexity. Neither this study nor earlier reviews (Chong et al., 2011; Omran et al., 2012a; Roter et al., 1998). can however prove and deepen these changes in interventions' contents, as there are too few details on the specifics of the interventions. A plausible explanation of these observed changes may be in the accumulating evidence from behaviour change interventions (Nigg & Long, 2012). Another possible explanation may be in the type of theories adopted to drive the patient engagement interventions. These theories generally suggest greater attention toward the active role of the patient and are more complex and able to embrace different care dimensions (Bandura, 1986; Hibbard & Mahoney, 2010), compared, for example, to the basic behavioural theories driving patient adherence interventions (van Dulmen et al., 2007). At the same time, the theories reported here (Bandura, 1986; Hibbard & Mahoney,

2010), tend to cover the behavioural and cognitive care dimensions rather than the affective/emotional dimension.

In this review, studies focusing mainly on the affective dimension were found to differ from those focusing on the other two dimensions. One particular finding was that studies focusing on emotions had a higher proportion of females. One explanation for this finding may be that women are more willing than men to "open their hearts" and expose their inner feelings (Barrett, Lane, Sechrest, & Schwartz, 2000; Timmers, Fischer, & Manstead, 1998). Moreover, studies focusing on emotions were those with older samples. This might reveal an aspect specific to patient engagement interventions devoted to older patients: they stress and appeal to the emotional dimensions of care to a greater extent to enhance older patients' engagement in care. Since it is demonstrated that older patients in particular can benefit from interventions appealing to emotional and social aspects of care for ageing healthily and successfully (Depp, Vahia, & Jeste, 2010; Fuller & Larson, 1980; Scheibe & Carstensen, 2010), interventions for patient engagement involving older adults in particular should pay more attention to this dimension and include it in educational and behavioral support practice.

While this review did not focus on the effects of the interventions, it is interesting to observe that the literature on patient adherence / compliance interventions has repeatedly demonstrated a better effect of interventions including all three dimensions (cognitive, behavioural and affective/emotional) (Chong et al., 2011; Dolder, Lacro, Leckband, & Jeste, 2003; Low et al., 2015; Roter et al., 1998; Sapkota et al., 2015). Although these reviews did not control for the length and intensity of the interventions, their findings make it relevant to ask whether interventions focusing on patient engagement, and particularly those including older adults, would benefit from including all the three dimensions. Since the studies surveyed, both in our findings and in the literature on patient adherence/compliance interventions, showed a difficulty in including the affective dimension, further research should investigate whether and how interventions can address patients' emotional experience together with behavioural and educational efforts. This is also supported by literature reporting that emotions are important for enhancing patient activation and adherence by improving patients' psychological care experience (Graffigna, Barello, & Bonanomi, 2017; Graffigna et al., 2015). In psychology, emotions are stressed as crucial facets and outcomes of identity changes and self-processes (Cast & Welch, 2015; Kiefer & Muller, 2003; Stets, 2005), such as those required as a result of receiving a diagnosis and being a "patient" (Graffigna et al., 2014). They are also highlighted as influencing individuals' desire to make decisions for their health and

self-determination (Hermann, Trachsel, Elger, & Biller-Andorno, 2016; Levit, Balogh, Nass, Ganz, & Institute of Medicine (IOM), 2013). For example, the emotional repercussions of a diagnosis can prevent patients from engaging in effective communication with their clinicians (Graham, Mancher, Wolman, Greenfiled, & Steinberg, 2011).

## 2.6. Limitations

The first limitation of this review concerns the potential exclusion of relevant articles. This could be due to incomplete search terms and a lack of clear presentation of whether the interventions were aimed at improving patient engagement.

Regarding the search strategy, adding other terms like "self-management", "self-care" or "patient-centered" may have allowed for the retrieval of other relevant articles. I chose not to do so in order to only select interventions for patient engagement and similar terms. This choice may have excluded other relevant articles, but it allowed me to detect only studies explicitly focused on patient engagement, which was the aim of this study.

Furthermore, only one researcher performed the screening (me). I acknowledge that as a result some borderline articles may have been lost. However, it is unlikely that having only one researcher performing the screening would have influenced findings of this study. Indeed, the screening followed a detailed list of exclusion/inclusion criteria defined together with my supervisors, with the main reason for exclusion (i.e., not being a RCT) being easily detectable. Doubts and borderline cases were solved through discussion with my supervisors. Reasons for exclusion were tracked. Finally, the screening was done twice, and checks on the screening process were made by my supervisors.

The second limitation was in the categorization of the interventions' contents. This is a known limitation (Hoffmann et al., 2014) of all reviews of this type, and further studies should follow to deepen the applicability of the adopted classification criteria. Categorization of articles was performed by one researcher (me) for the micro level of analysis (interventions' components), as the other levels built on it and did not require evaluation by a researcher (except for a few cases that were discussed by a group of nine researchers and then evaluated by my supervisors). Being aware that having only one researcher categorizing articles would result in limited findings, it was enacted a procedure to increase the reliability of the classification. I defined how to classify interventions' contents basing on a structured classification grid (Roter et al., 1998) and previous studies applying it (Chong et al., 2011; De Bleser et al., 2009; Fogarty et al., 2002; Galo et al., 2016; Low et al., 2015; Omran et al., 2012a; Sapkota et al., 2015). All doubts were discussed with my supervisors.

Furthermore, a multidisciplinary research group on patient education and participation was involved to classify a sample of tricky interventions and to discuss classification criteria. For example, in the previous literature, motivational interviewing was sometimes considered behavioral (Sapkota et al., 2015) and sometimes emotional/affective (Chong et al., 2011). Extracts from articles discussing motivational interviewing were evaluated by the group of nine experts. Therefore, decisions were based on what was described in the articles. Following this procedure, the approach was finally considered emotional/affective.

As the classification was based on what described in the articles, and as these were all studies of RCTs, focusing on RCTs and using a quantitative approach may have limited the possibility to deeply describe the interventions' contents. At the same time, it allowed to describe and detect differences among patient engagement intervention contents reported in studies with the strongest type of evidence and at an advanced stage of research on patient engagement interventions. Another limitation concerned the adoption of specific classification criteria for interventions' contents (Roter et al., 1998). Even though Roter's criteria have been adopted by different studies (Chong et al., 2011; De Bleser et al., 2009; Fogarty et al., 2002; Galo et al., 2016; Low et al., 2015; Omran et al., 2012a; Sapkota et al., 2015), they still require evaluation. Other taxonomies classifying interventions' active ingredients have more universal agreement (Hoffmann et al., 2014; Michie et al., 2013). However, they usually consider only one level of analysis and do not allow one to grasp the overall behavioral, cognitive, emotional/affective nuances of interventions, which are useful to indicate the type of support needed.

## 2.7.   Conclusion

Interventions focused on patient engagement and targeting older adults had contents that differ from those of interventions focusing on adherence, and they tended to pay more attention to behavioral and cognitive dimensions than to affective/emotional ones. Moreover, studies focusing mainly on the affective/emotional dimension differed from studies focusing mainly on the cognitive and behavioural dimensions, and older patients can particularly benefit from interventions including the affective/emotional dimension.

Future research on patient engagement promoting interventions among older adults should investigate the role of the affective/emotional components; the balance of emotional, cognitive, behavioural dimensions; the relationship between concepts, theories and interventions; and the applicability of classification criteria to report interventions' contents.

# Chapter 3

# "PHE in Action": Development and validation of a patient engagement intervention for older adults

As described in the previous Chapter, there are some interventions reported in literature aimed at supporting patient engagement of older adults. However, as argued, what already exists does not perfectly fit with patient engagement as understood from the Patient Health Engagement (PHE) theory. This chapter describes the development and qualitative validation of an individual intervention for supporting patient engagement of older adults, called *PHEinAction.* I will report the three main research steps that were performed to try to address this aim: (i) develop a first version of the intervention as a concept of contents and procedures, (ii) discuss it with healthcare professionals and older patients to make it fit their reality, (iii) test the final version of the intervention with new groups of health healthcare professionals and older patients to learn more about how *PHEinAction* is perceived and validate it. Details about the main refinements made leading to the final intervention will be reported between the steps (ii) and (iii).

## 3.1. Introduction

In the Chapter 1, I described how older individuals are particularly needy for self-management support (Oliver, 2016). Making them partners in care has been highlighted as a highly-relevant task for this, a task that should be the heart of health care all along (Dentzer, 2013; Laurance et al., 2014). Patient engagement has been indeed demonstrated to improve activation levels of patients (Graffigna, Barello, & Bonanomi, 2017; Graffigna, Barello, Bonanomi, et al., 2017) and, thus, - amongst the other benefits - to result in good self-management behaviours (Fowles et al., 2009; Hibbard et al., 2007; Mosen et al., 2007; Remmers et al., 2009; Shively et al., 2013). Patient engagement is used in different ways in literature (Finset, 2017), and authors have complained a lack of a common and clear theoretical ground (Barello et al., 2014; Grande et al., 2014). To date, the PHE theory is the one providing a clear definition of patient engagement able to value the first-person psychosocial processes to participate in health and care activities (Graffigna et al., 2015). This theory has been deeply described at the end of Chapter 1.

However, a gap was observed between the way patient engagement is conceptualized and what is delivered in clinical practice. This is probably for what highlighted in the Chapter 1 concerning

patient engagement being a challenging task, particularly for older individuals, because of the preconceptions, physical and mental inabilities, social barriers that can obstacle a resourceful proactive vision of the elderly in healthcare (Belcher et al., 2006; Dyrstad et al., 2015; Oliver, 2016). The research field of patient engagement support in healthcare setting is particularly underdeveloped for older adults (Kane and Kane, 2001; Elliott et al., 2016).

A need was detected for making the concept of patient engagement really viable for clinical practice of older patients. Despite the potential for the PHE theory to open up concrete insights for action, a lack was observed for making this theory a viable road- with the word "viable" meaning also sustainable, a paramount aspect to consider when driving changes (Dombrowski et al., 2016; Wiltsey Stirman et al., 2012) -. It was thus suggested to translate the PHE theory into an intervention protocol deliverable to older individuals in healthcare professionals' practice.

## 3.2. Aim

The purpose of the study presented in this Chapter was to describe the development and qualitative validation of an individual intervention for supporting patient engagement of older adults, called *PHEinAction.*
The specific aims of this study were:

- o to develop a conceptual draft of contents and procedures for *PHEinAction*;
- o to refine the conceptual draft of the *PHEinAction* intervention according to the reality of healthcare professionals and older individuals;
- o to investigate how healthcare professionals and older individuals perceived the final version of *PHEinAction.*

The study covered the second and third points of the MRC Framework (Figure 3.1), that was presented in the Chapter 1, section 1.3.

**Figure 3.1.** MRC Framework's points covered by the Study 2
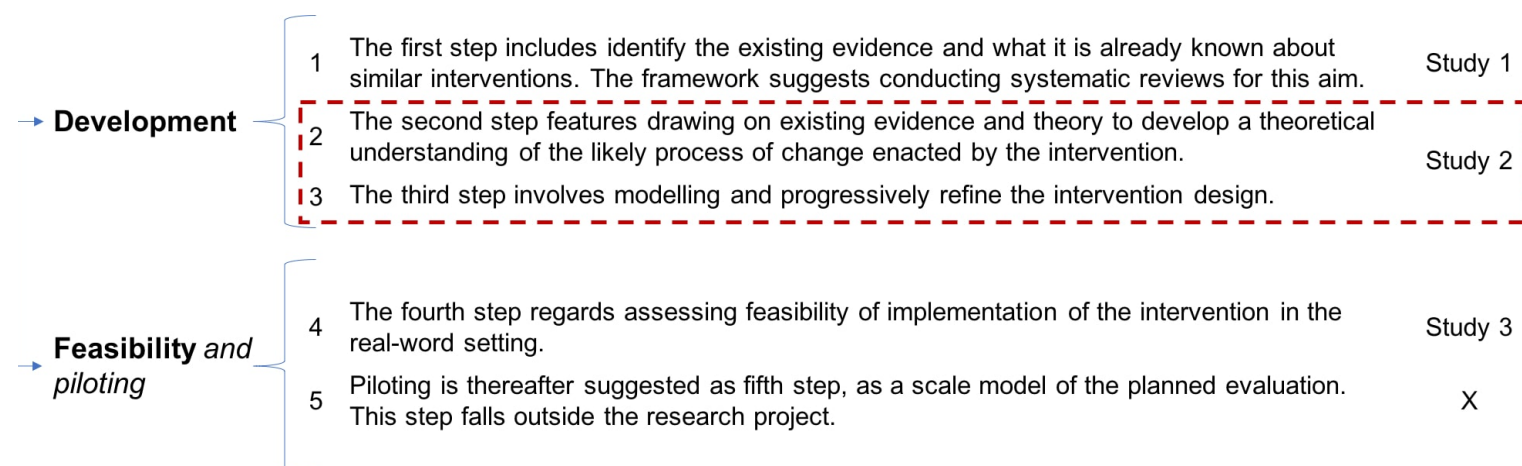


## 3.3. Methods

The development and validation process involved three different methodological steps, also summarized in Figure 3.2:

(i) operationalizing the PHE theory into concrete action lines, and using the literature on older patient engagement and practical considerations to identify the contents and procedures that can be used to support the action lines (conceptual development step)

(ii) presenting the draft of *PHEinAction* to healthcare professionals and older individuals respectively and asking them about their views and suggestions for changes (refinement step)

(iii) presenting and discussing the final version of *PHEinAction* to healthcare professionals and interviewing older individuals who have tested it about their perceptions (validation step)

**Figure 3.2.** Overview of the research steps, tasks and methods of the study 2
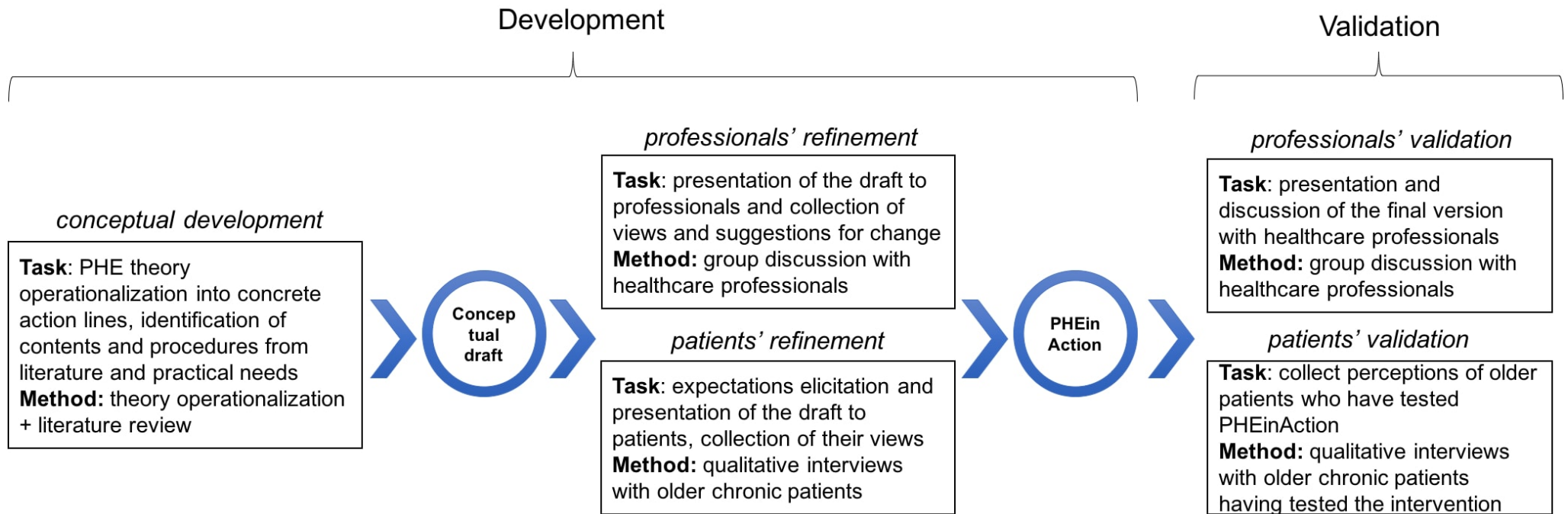
In the conceptual development step, the PHE theory was operationalized in concrete action lines and literature reviews allowed retrieving interventions' contents and procedures that were selected, also basing on practical considerations, to support the action lines. This allowed a conceptual draft of intervention's contents and procedures to be drawn. At this point, healthcare professionals and older individuals were separately but in parallel involved. A first round of group discussions with healthcare professionals was performed to present the conceptual draft, and collect views and suggestions for changes. A second round of new group discussions with healthcare professionals was then, after having revised the intervention, run to validate the final version. Repeated qualitative semi-structured interviews were conducted with older individuals, before and after participating in an intervention test during which they were asked to explicit their thoughts and views on the intervention's contents and procedures (in Table 3.2 is reported the semi-structured track of interviews). Repeating interviews before and after the intervention testing allowed discovering different perspectives on patient engagement support, unbiased from the intervention participation before and focused on the intervention contents and procedures after. The last patients were engaged in a presentation and testing of the final revised version of the intervention.

The choice of using different qualitative methods was guided by the desire of valuing, on one hand, common healthcare professionals' thinking and group interactions enriching data (Asbury, 1995; Krueger & Casey, 2000), and, on the other hand, in depth perceptions of older individuals with verbal and non-verbal data from a relaxed place where they could freely express themselves (M. Murray & Chamberlain, 1999). A detail of the methodological aspects is reported in Table 3.1.

**Table 3.1**. Methodological aspects for the intervention development and validation

| Step | Activity | Aim(s) | Methods |
|---|---|---|---|
| **"Conceptual development step"** | Theory operationalization + literature review + conceptual desk work | to develop a conceptual draft of contents and procedures for *PHEinAction* | 1. Operationalizing the PHE theory into concrete action lines 2. Literature review: systematic review (see Chapter 1 for details) + ad hoc searches to cover all the action lines from the PHE theory (search augmented to articles not on older patients and ad hoc searches for less covered action lines) 3. Selecting of interventions' components from literature on patient engagement supporting the concrete action lines as from the PHE theory 4. Defining the interventions' procedures basing on literature on patient engagement and practical needs |
| **"Professionals' refinement step"** + **"Professionals' validation step"** | Qualitative study with group discussions involving healthcare professionals | (i) to refine the conceptual draft of the *PHEinAction* intervention according to the reality of healthcare professionals (ii) to investigate how healthcare professionals perceive the final version of *PHEinAction* | - <u>Participants</u>: 6 groups with 8-15 healthcare professionals (n=80) purposively selected from a North-Italian healthcare organization located in one of the areas of Italy with the oldest population and trained in patient engagement theories and measures - <u>Procedures of group discussions </u>(approx. length: 2-3 hours): (i) presentation of the conceptual draft for the interventions contents (Figure 3 and 4), with examples on components; (ii) general open discussion on the inputs presented + small-group discussion for views basing on practice and suggestions for change of components; (iii) presentation of a draft of intervention's procedures (Figure 5), (iv) general open discussion on the inputs presented + small-group discussion on the inputs presented for views basing on practice and suggestions for change of procedures (refinement step). After the first three groups, the intervention was refined. Therefore, the final intervention was presented to the last three groups and overall perceptions on it were collected. - <u>Data analysis</u>: The transcripts and materials produced during group discussions were red several times. Initial codes for meaningful discourse's parts were then signed by one researcher (me). During the coding process, similar codes were collapsed into common subthemes. Subthemes were then discussed with other researchers to figure out the main underlying themes of discussion (Braun and Clarke, 2006). Common themes of discussion among groups were extracted with relevant quotes, and organized basing on the type of feedbacks provided (on intervention's procedures or contents) |

| **"Patients' refinement step" + "Patients' validation step"** | Qualitative study with repeated qualitative semi-structured interviews with older chronic individuals | (i) to refine the conceptual draft of the *PHEinAction* intervention according to the reality of older individuals | - <u>Participants</u>: 8 purposively selected persons >65 years-old affected by at least one chronic condition. Participants were purposively and sequentially recruited by an external researcher through community senior or medical centres or associations. |
| --- | --- | --- | --- |
| | | (ii) to investigate how older individuals perceive the final version of *PHEinAction* | - <u>Procedures</u>: (i) preliminary qualitative semi-structured interview lasting about 30 minutes before the involvement in a simulation of the intervention to collect expectations, (ii) participation in intervention (participants were informed that the intervention would have been refined basing on their feedbacks and invited to explicit thoughts/views on it), (iii) second interview lasting about 60 minutes just after the second session (1 month after the first interview and session) in which the patients' perceptions on the intervention's participation were collected. Interviews were conducted by an external researcher. Table 2 reports the semi-structured track of the 2 interviews. The intervention was revised after the first 5 patients, the final version was presented to the last 3 patients.<br>- <u>Data analysis</u>: Procedures followed to identify main themes within interviews were close to those described for group discussions. |

**Table 3.2.** Semi-structured tracks of older patients' interviews

**First interview**

| *Area* | *Exemplificative questions* |
| --- | --- |
| Experiences and interests for engagement support | • In your experience, what would help one in being more engaged in managing his/her health and care? What would help you?<br>• Would you be interested in participating in initiatives aimed to foster your engagement in health and care management? Why would you engage in such an effort? |
| Expectations for a patient engagement intervention | • What characteristics should have an intervention to engage you in managing your health and care?<br>• Which contents and which way of delivery would you prefer? |

**Second interview**

| *Area* | *Exemplificative questions* |
| --- | --- |
| Patients' perceptions about their participation in the intervention | • Could you describe what happens in the sessions?<br>• How did you feel when you participate in the intervention?<br>• If you had to describe what the intervention meant to you, what would you say? What images/metaphors come to your mind? |
| The intervention effects on the daily life and on health management | • In your opinion, how the intervention improved your engagement and attitude towards managing your health and care? How did it affect your daily life?<br>• If you think about your way of managing your health and care, what aspects of the intervention have contributed to it? How?<br>• If you think about your daily life and lifestyle, what aspects of the intervention have contributed to them? How? |
| Intervention satisfaction and feedbacks | • How would you rate and define your satisfaction towards the intervention? What aspects satisfied you more? What satisfied you less? Why?<br>• What were the obstacles and difficulties?<br>• What would you change or improve? |

## 3.4. Results

The findings from the development, divided in the conceptual development and refinement steps, and validation phases are presented in the following sections.
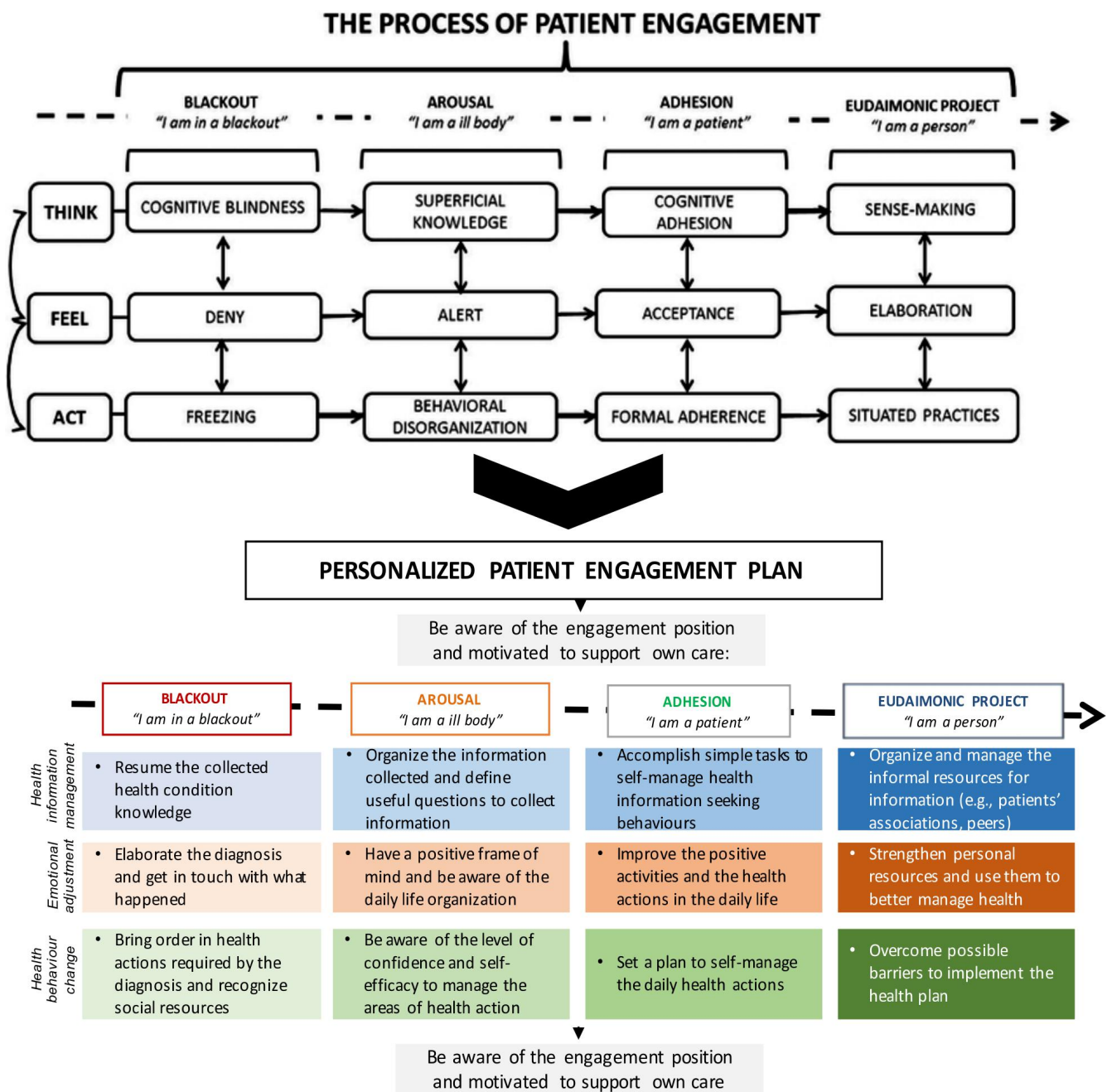
### 3.4.1. Conceptual development: towards a draft of PHEinAction

This section describes the operationalization of the PHE theory into concrete action lines, and the use of the literature on patient engagement and of practical considerations to identify the contents and procedures that were used to support the action lines, so to develop a conceptual draft of contents and procedures for *PHEinAction.*

#### *3.4.1.1. From the PHE theory to concrete action lines*

As previously described (Chapter 1, section 1.4), the conceptualization of patient engagement as from the PHE theory depicts a process with four main possible positions of engagement unveiling specific emotional ("feel"), cognitive ("think"), and behavioural ("act") experiences and, thus, possible needs for support. The PHE scale allows detecting these four positions, and so their unique experiences and needs. Personalization of a possible engagement pathway on these four positions detected through the PHE scale was thus considered fundamental. This was not only considered a way to target actions to patients' positions and needs, but also as a mean to promote awareness in the patient of his/her engagement experience and motivate a possible change towards a proactive and co-authorial role in care. Promoting patients' awareness and motivating them to change were considered important starting goals to be covered in first instance, so to take patients on board in a personalized engagement plan working on emotional, cognitive, behavioural dimensions. At the same way, re-adopting the PHE scale to make the patient aware of possible progresses/difficulties after having worked on such dimensions was considered useful, as (possible) final step for a patient engagement intervention. Thus, basing on the PHE theory (Graffigna et al., 2015) and on previous foundation literature (Barello et al., 2015; Barello & Graffigna, 2015; Graffigna et al., 2014, 2016), a first matrix of action areas for the different engagement positions considering the emotional, cognitive, and behavioural dimensions to be enacted after a starting "awareness and motivation" stage and to be revised with a final "awareness and motivation" stage was drafted (Figure 3.3).

**Figure 3.3.** Operationalization of the PHE theory (Graffigna et al., 2015) into concrete action lines

## THE PROCESS OF PATIENT ENGAGEMENT

|  | BLACKOUT<br>"I am in a blackout" | AROUSAL<br>"I am a ill body" | ADHESION<br>"I am a patient" | EUDAIMONIC PROJECT<br>"I am a person" |
|---|---|---|---|---|
| THINK | COGNITIVE BLINDNESS | SUPERFICIAL KNOWLEDGE | COGNITIVE ADHESION | SENSE-MAKING |
| FEEL | DENY | ALERT | ACCEPTANCE | ELABORATION |
| ACT | FREEZING | BEHAVIORAL DISORGANIZATION | FORMAL ADHERENCE | SITUATED PRACTICES |

### PERSONALIZED PATIENT ENGAGEMENT PLAN

Be aware of the engagement position and motivated to support own care:

|  | BLACKOUT<br>"I am in a blackout" | AROUSAL<br>"I am a ill body" | ADHESION<br>"I am a patient" | EUDAIMONIC PROJECT<br>"I am a person" |
|---|---|---|---|---|
| Health information management | • Resume the collected health condition knowledge | • Organize the information collected and define useful questions to collect information | • Accomplish simple tasks to self-manage health information seeking behaviours | • Organize and manage the informal resources for information (e.g., patients' associations, peers) |
| Emotional adjustment | • Elaborate the diagnosis and get in touch with what happened | • Have a positive frame of mind and be aware of the daily life organization | • Improve the positive activities and the health actions in the daily life | • Strengthen personal resources and use them to better manage health |
| Health behaviour change | • Bring order in health actions required by the diagnosis and recognize social resources | • Be aware of the level of confidence and self-efficacy to manage the areas of health action | • Set a plan to self-manage the daily health actions | • Overcome possible barriers to implement the health plan |

Be aware of the engagement position and motivated to support own care

In detail, acting on the emotional enactment dimension was understood as supporting the emotional adjustment to the disease condition, by helping patients expressing the psychological impact of their disease and other stresses and by activating and strengthening their skills and inner resources to regain a positive and satisfactory life trajectory. Then, acting on the cognitive enactment dimension was understood as supporting the ability to collect, organize, and understand health information, both formal and informal. Finally, the behavioural enactment dimension was understood as supporting health behaviour changes for managing the health condition, and in particular helping patients setting

a health plan with sustainable goals coherent with recommended self-care actions and sustaining the self-efficacy for implementing the new situated practices into the daily life context.

### 3.4.1.2. *Identifying literature interventions' contents supporting the action lines*

The operationalization of the PHE theory leaded to define concrete action lines, broadly divided in: 1. awareness and motivation to change support, 2. emotional support, 3. cognitive support, 4. behavioural support. Interventions' components used in literature on patient engagement interventions were selected to fill them in (Table 3.3). Basing on how the theory was operationalized, some components from literature before recognized as pertaining to one dimension were moved if they were considered supporting another one. For example, "question asking", that in the systematic review was considered a behavioural component, was here considered a component supporting the cognitive dimension of patient engagement, because a way to collect information. Furthermore, some components were selected to support the starting and final "awareness and motivation support" stages.

**Table 3.3.** Main interventions' components from literature considering the main theory's action lines

| Action lines | Included components from systematic review | Added components from further searches | Excluded (with reasons) |
|---|---|---|---|
| Emotional support, understood as supporting the emotional positive elaboration of the disease condition | • Positive thinking/positive psychology exercises<br>• Internal resource mapping | • Expressive writing | • Relaxation (chosen expressive writing for a better fit with the theory dimension's goal) |
| Cognitive support, understood as supporting the ability to collect, organize, and understand health information | • Question-asking (moved from behavioural to support information seeking)<br>• Informational workbooks/audio-visual materials (adaptation: to be designed by patients themselves to make it feasible for a generic intervention)<br>• External resource mapping | | • Verbal education (unfeasible for a generic intervention)<br>• Educational simulation scenario (unfeasible for a generic intervention) |

| Behavioural support, understood as supporting health behaviour changes | • Friends/familiars support (moved from emotional to support the behavioural dimension)<br>• Goals setting<br>• Action planning<br>• Problem solving<br>• Skills building training |
| --- | --- |
| Awareness and motivation to change support | • Motivational interviewing (from the emotional dimension)<br>• Sharing of assessment results (from the cognitive dimension)<br>• Coaching from provider (face-to-face/phone-based) (from the behavioural dimension)<br>• Reinforcement (from the behavioural dimension)<br>• Goal values elicitation (from the behavioural dimension) |

For the emotional dimension support, components selected from scientific literature to support the emotional adjustment to the disease condition with a positive integrated outlook were expressive writing exercises, positive psychology exercises, and exercises to map internal resources (Table 3.3). In particular, the "relaxation" component extracted from literature was considered only partially fitting the "emotional adjustment support" goal, because focused on management of consequences of stress but not on elaboration of a stressful event. Therefore, expressive writing was selected from focused literature searches on interventions helping patients emotionally adjust to a stressful condition (Baikie & Wilhelm, 2005; Merz, Fox, & Malcarne, 2014) to better cover the specific goal of "emotional adjustment support".

Looking into the cognitive dimension support, the main literature components selected to support the patients' ability to collect, organize and understand health information were question-asking exercises, informational materials to strengthen and organize the information on the disease, and exercises to map external resources for collecting information (Table 3.3). Some of the components adopted in literature were considered unfeasible because requiring to deliver disease-specific contents. For the same reason, informational materials were considered feasible only if drafted by patients themselves basing on their unique knowledge on their disease.

Considering the behavioural dimension support, goal setting and goal planning exercises were then included, as well as problem solving and skills training activities, and identification of social supporters for enacting positive health behaviour changes (Table 3.3).

Finally, some components were selected for supporting the "awareness and motivation" line (Table 3.3). This was the case of motivational interviewing, sharing of assessment results, face-to-face/phone-based coaching, reinforcement, goal values elicitation. Motivational interviewing strategies (exploration of values/motivations for change, setting of achievable goals, elicitation of personal resistances and rolling with them, pointing for the positive changes) were implemented in both the starting and final "awareness and motivation" action lines. The same was made for sharing of assessment results which was considered a key component to personalize goals and components as well as to help patients and providers being aware of the engagement position and progresses. In the starting step, goal values elicitation was included and, in the lasting step, reinforcement and positive feedbacks on progresses were particularly valued. A brief phone-based coaching encounter for motivating patients in changes was considered useful to be inserted along the intervention to sustain motivation of participants and collect difficulties. In Figure 3.4, the resulting map of the selected intervention's components is provided as following the PHE theory's action lines.

**Figure 3.4.** A map of the selected interventions' components organized following the action lines based on the PHE theory (preliminary version)
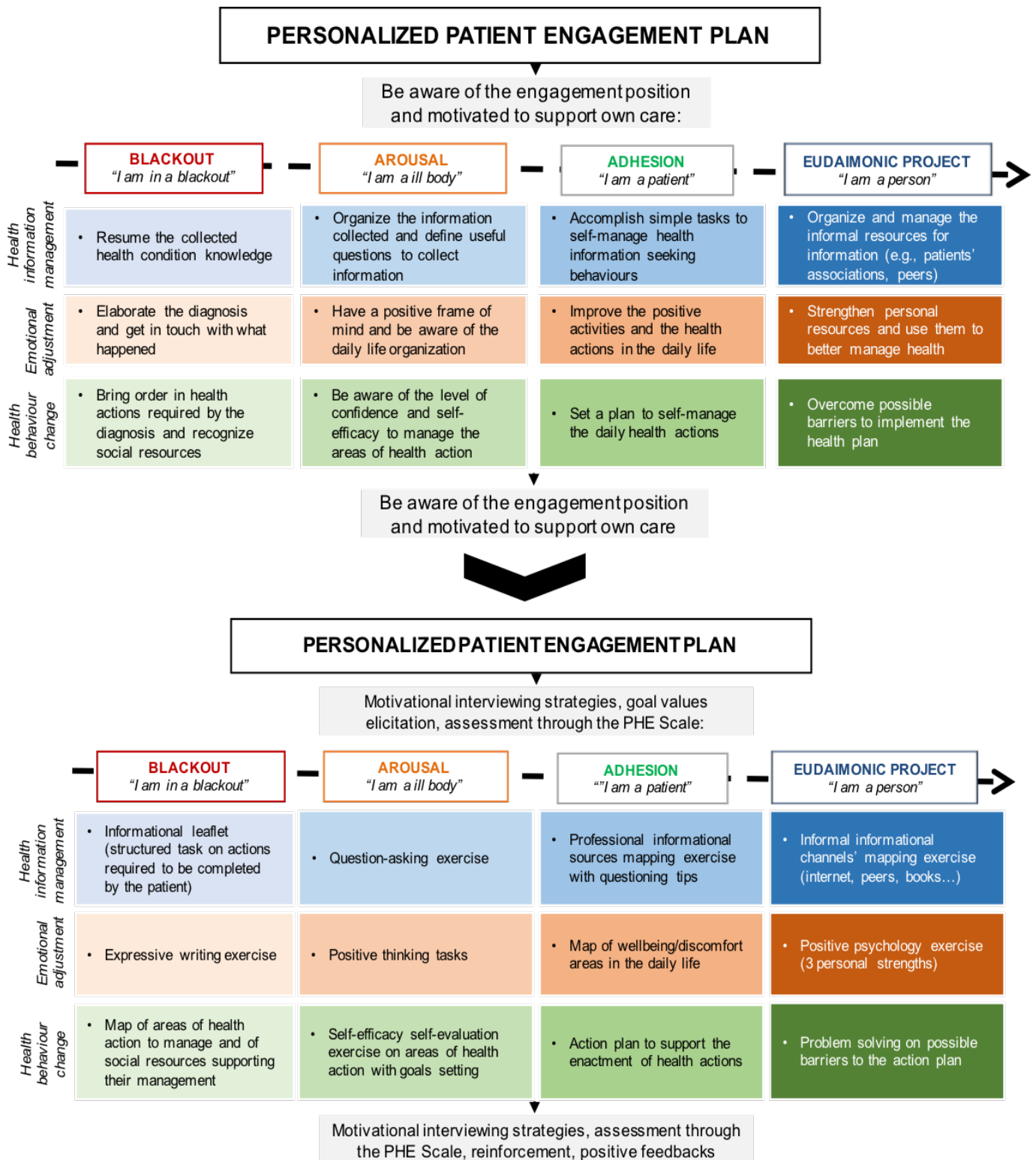
### 3.4.1.3.    Identifying interventions' procedures from literature and practical considerations

Practical aspects concerning the need to make the intervention feasible to be implemented in a clinical setting (inpatient, outpatient or territorial settings) were taken in consideration when shaping intervention's procedures. These key needs concerned the intervention to be:

o   brief,

o   delivered by healthcare professionals already working into a clinical context (and, thus, probably already delivering patient education) and not necessarily with psychological competencies,

o   usable by individuals affected by different type of health problems (primarily chronic conditions).

From the systematic review (Chapter 2), it was also possible to observe how individual sessions were mostly implemented throughout interventions for older patient engagement. For these reasons, individual, face-to-face sessions complemented with structured home-based exercises, not on care contents but on patients' ability to manage care contents, were selected. Indeed, it was observed that all the components for supporting the emotional, behavioural, cognitive dimensions could have been autonomously managed by patients and that, on the contrary, components selected to support the "awareness and motivation" line could have required the presence of a provider. Therefore, to make the intervention brief and easily deliverable, the intervention was divided between home-based and face-to-face parts.

The following intervention procedure was, thus, selected:
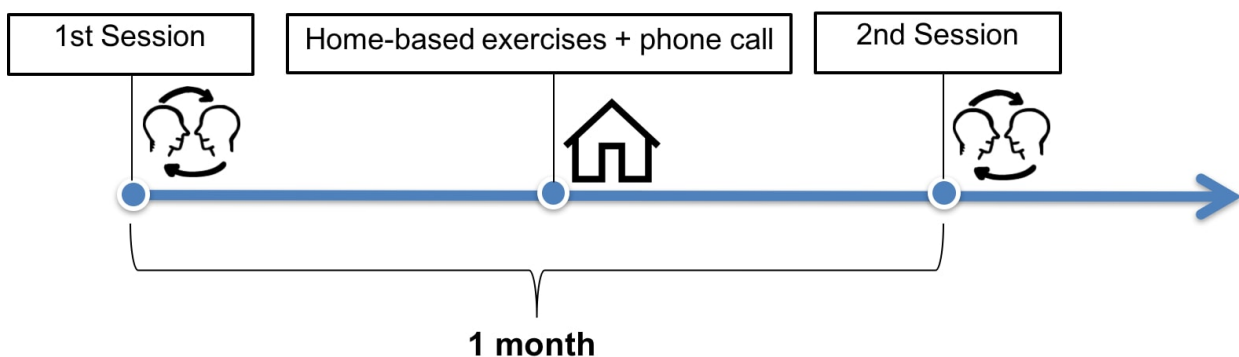


### 3.4.1.4.    "PHEinAction": The conceptual draft of the intervention

The draft of the intervention included a first session aimed to: (i) promote a greater awareness of individuals on their engagement in the health condition management, (ii) define an action plan to

foster engagement changes, (iii) sustain a process of motivation to change towards a proactive and co-authorial role in care. It featured the assessment and sharing of assessment results by adopting the PHE scale, the setting of goals for engagement and of achievable actions, the exploration of values/motivation to change as well as of possible resistances, and the sharing of interventions' exercises to be used by patients at home basing on assessment results and defined goals. Interventions' components matching the theory's action lines for emotional, behavioural and cognitive support were constituted as a multifaceted package of home-based exercises comprising 12 components (3 exercises -1 emotional, 1 cognitive, 1 behavioural - for every of the four engagement positions) (Figure 3.4). Indeed, for every dimension, components were personalized to each of the four PHE positions, yielding four different paths of training gradually demanding (for example, individuals in position of arousal were asked to complete also the exercises for the previous blackout position, and exercises were more demanding for them), so to enhance flexibility and personalization of the intervention. Components were translated into practical examples using the program MS Office PowerPoint, basing on a personal interpretation of details provided in literature.

A brief phone-based coaching encounter was also included for checking for difficulties and to maintain motivation of individuals. Then, a second session was inserted to share exercises and provide feedbacks on them, to point for and reinforce the positive changes, to assess and share assessment results, and to eventually set a new engagement goal and plan.

A distance of one month between the first and the second session was hypothesized to be a good possible length for enacting the plan without losing in participants' motivation. Figure 3.5 provides details about the procedures and the sessions' goals of the preliminary version of the intervention.

**Figure 3.5.** The "PHEinAction" pathway: intervention's procedure and main goals (preliminary version)
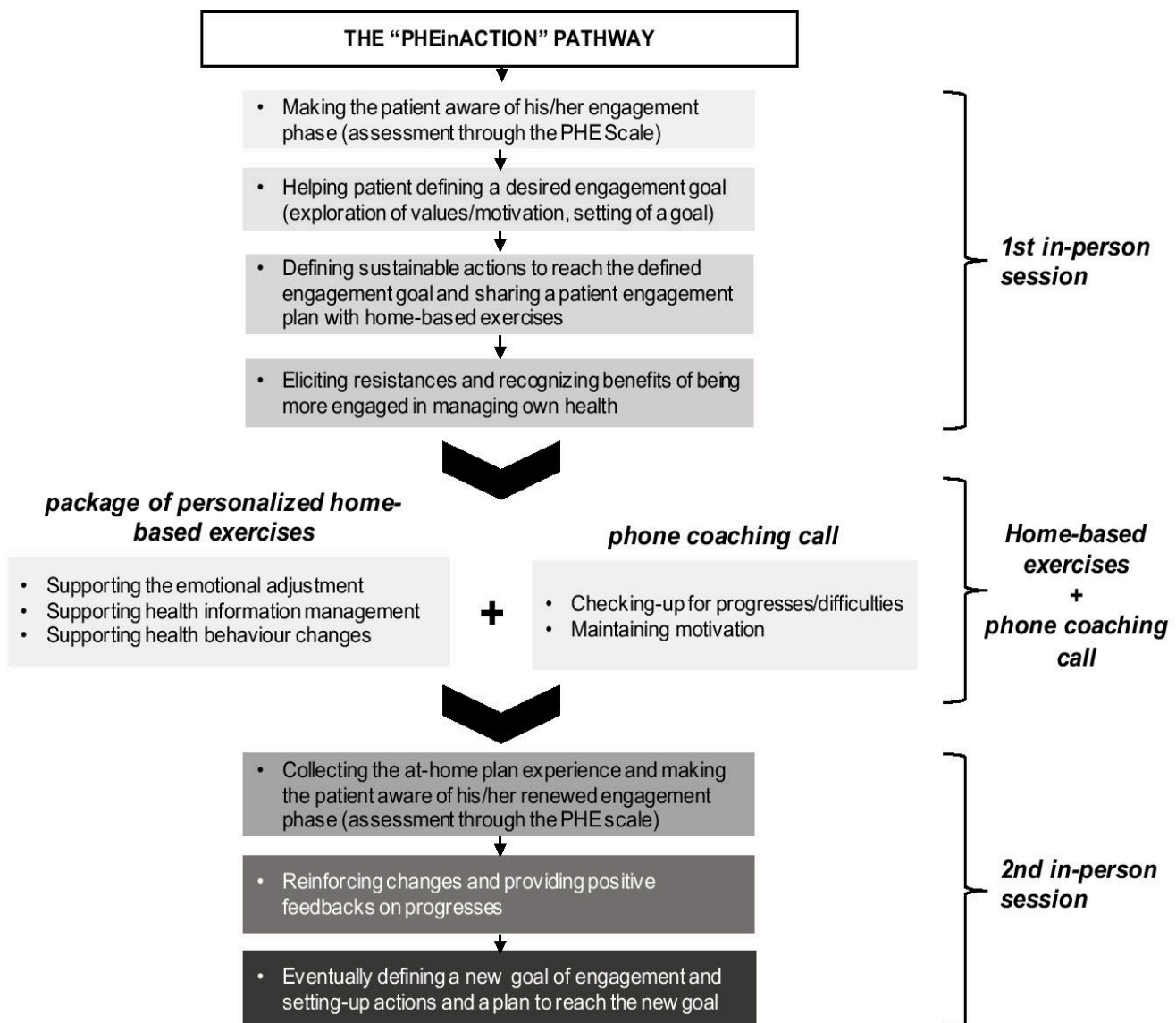


### 3.4.2.     Refinement: towards a final version of PHEinAction attuned to professionals' and older patients' reality

In this section, professionals' and older patients' views and suggestions for changes on the draft of contents and procedures of *PHEinAction* are described. These led to refine it according to their reality. First, healthcare professionals' views and suggestions for change are reported. Then, older patients' views on the intervention's contents and procedures are summarized. In particular, common themes discussed during groups and interviews are reported. Quotes to support findings are provided throughout. In the case of group discussion with healthcare professionals, it was not possible to detail participants' data on quotes (gender, type of profession, years of experience).

### 3.4.2.1.    Professionals' refinement

Overall, six groups with 8-15 healthcare professionals each were performed (n=80). These were mostly nurses (n=62), but also therapists (n=15), physicians (n=2), and psychologists (n=1). Professionals worked in different care settings: home-based/territorial care (n=34), ambulatory (n=24), inpatient care (n=17), administration services (n=5). Professionals working in the home-based/territorial care had mostly to deal with generic clinical conditions, whereas those ones working in the ambulatories or the hospital with specific clinical conditions (i.e., cardiovascular patients, chronic kidney disease patients, …). Most of them were women (65%) with a mean age of 46 years old (range: 29-62) and with a mean number of years of work experience of 22 years (range 1-38). Data here presented particularly concern the first three groups, to which the preliminary draft was presented to collect focused feedbacks on contents and procedures.

### 3.4.2.1.1.    Feedbacks on contents

When asked to discuss the draft of action lines (Fig. 3.3) and intervention's components (Fig. 3.4), professionals generally provided positive comments. They liked the idea of having covered different emotional, cognitive, behavioural dimensions, as well as of having a pathway personalized to the engagement positions. Some specific suggestions were collected for the different components.

Emotional components were particularly discussed by professionals, who perceived them as close to narrative-based medicine and useful to collect aspects of the patients' experience normally not explicitly considered. Some of them reported to use some narrative tasks, similar to diaries or expressive writing exercises, for hospitalized older patients in the final stages of the disease, or to elicit personal resources to motivate patients self-manage their disease condition (*"We already ask patients – especially those particularly impaired – to write their experience and how they are feeling, like a diary…I didn't know this could be already part of an intervention")*. However, they found difficult to elicit emotional openness among their older patients, as well to manage it after ("*I really don't know if people will be willing to write this things by their own"; "these exercises open too much! It's not our duty managing these things, it's yours [referring to us as psychologists]")*. Particularly for the emotional components, having them home-based was considered useful to facilitate a better disposition of patients to freely write about themselves, and so as writing and not speaking, even if this would have limited the usability to the more literate patients (*"yes, probably having it in a written format and also not to be done together would help…but some of my patients need support in reading and writing, they would not surely be able to do this")*. It was then agreed

that components, especially the emotional ones, needed a tailoring to the patient's needs. Narrative components covering the adjustment process to the disease condition were considered more suitable to patients in blackout or arousal, and more active components eliciting positive views on the disease condition to patients in adhesion or eudaimonic project. Some emotional components were discussed in detail, such as how to design the "expressive writing task", in order to make it feasible and, at the same time, not too open in eliciting negative feelings. If some professionals preferred making it a drawing task for the potential that images and metaphors can have in expressing feelings and for making it more accessible to low literate patients, others suggested following the standard expressive writing procedure with a writing task. The specific classical opening task was also discussed, and it was suggested to change it to make it simpler and not too scary. The "positive thinking tasks" were discussed too, especially if making them a structured diary exercise and if asking patients to do it daily/weekly/freely.

Considering cognitive components, professionals agreed in having exercises complementary to contents provided in patient education, even if they were worried of not having then the time to manage the educational disease-specific contents ("*I understand that doing this is important, but I have primarily to pass specific messages, can't take the time for these things*"). Also in this case, having the burden of procedures alleviated by home-based exercises reassured them, despite the worries for the lack of autonomy of some of their patients. More in detail, they liked the idea of putting on the table the difficult aspect of the informal informational sources, such as the internet and the television programs. Considering this, they appreciated the possibility to explore in an indirect way (without directly asking to patients but leaving them the space to sign and discuss these aspects during encounters) other sources of information used by patients ("*it's always difficult to manage the information patients collect outside the clinical encounters, it happens that they arrive already at the encounter with a lot of confused information, most of the times from unclear sources… it's good that this aspect can be putted on the table*"). They also appreciated starting by asking to patients what they already knew about the disease, and it was discussed if it was better to have it as an open or a structured task. The most discussed exercise was the "professional sources mapping exercise with questioning tips", considered not so useful and confusing.

Then, some of the professionals, especially those ones working in the territory, reported to already use most of the behavioural components in their practice, but without having structured materials ("*I usually do most of the things you described, but I do them without thinking…having a guide could help me better organizing my actions*"). It was recognized the need to define gradual steps in the behavioural plan, and that patients in a blackout position would have benefitted more from a behaviours recap exercise whereas patients in an adhesion or eudaimonic project position from

concretely enacting a behavioural plan. Some overlaps between the home-based behavioural components and what proposed during the sessions were reported.

Finally, considering the first session, they suggested to include a preliminary step to collect the patient story (*"It's true that we already know most of our patients, but it's not the rule and usually in the first moment we collect some information on the patient"*). The moment where assessment results were shared was valued as a core moment for the intervention, and complementing the PHE scale with the PAM scale (Chapter 1, section 1.1.2.3) was consider useful to deepen the concrete cognitive and behavioural difficulties of individuals (*"It seems to me that this moment of sharing assessment results is the first engagement action, because it allows patients becoming aware and acknowledge their engagement experience and their areas of needs, as well as it elicits the misalignments in perceptions"*). Most of the attention was paid on that moment and on how to manage it: *"how can we manage the scoring and the restitution at the same time?"*, *"This is a crucial moment, we need to share results with patients but it's difficult to find the right words"*, *"Can I help the patient completing the questions? What do I have to do?"*, *"Isn't embarrassing for the patient answering the question in front of me? How do I know that what he says is true?"*. No specific feedbacks were provided for the second session, that was perceived as quite similar to the first one.


### 3.4.2.1.2.    Feedbacks on procedures

Considering the draft of intervention's procedures (Fig. 3.5), professionals appreciated the idea of a brief structure and the possibility to have a part of the intervention to be completed by patients at home (*"Is useful to give to the patient some at-home exercises, it could be a way for the patient to bring patient engagement into the home walls"*), even if for some patients this could have been a problem (*"don't know if patients will then complete the exercises alone…and most of patients will have difficulty in doing them without someone supporting them"*). They did not question the overall possible procedure, but provided general feedbacks on the main aspects of the intervention. In particular, they proposed having better structured materials also for the face-to-face sessions and not only for the home-based exercises (*"This flow could be a guide for our exchanges with the patient"*; *"This can help having a guide for my communication with the patient...I already ask to my patient his story, but with a written material I can remember what to do and have some practical tool"*). Furthermore, they suggested to better work on how the intervention would have been presented to patients, to make a similar work understandable. In this sense, they suggested using metaphors and images to simplify it (*"We deal with patients that are really older and most of the times they do not use the Italian language by the dialect. The more we are able to use images to explain things the*

*more it helps patients understanding materials"; "It's important to find a way to explain this work to patients in a simple way, maybe by using some metaphor to explain what will happen in the sessions easily".* Finally, the temporal distance between one session and another, as well as the introduction of a phone call in between, were questioned by participants. They reported worry for having so structured times, and not all of them considered the time of one month feasible (*"it's impossible for me to schedule since the very beginning a second moment after 1 month", "can't we do also the second session by phone?"*). At the same time, it was agreed that living the patient, after the first session, with a scheduled visit would have reduced possible drop-outs.

### 3.4.2.2. Patients' refinement

Eight participants older than 65 years accepted to participate in this refinement phase. Most participants were women (72%), affected primarily by type 2 diabetes (57%). Most had an elementary education (57%) and indicated that they were married (71%). All of them were retired. Three participants were overweight, but none of them was a smoker. Almost all (n=7) participants had multiple diseases and comorbidities, mainly with cardiovascular disorders. For further details about the characteristics of participants, see Table 3.4.

**Table 3.4.** Characteristics of participants (n=8)

|  |  | *mean (SD)/ n (%)* |
| --- | --- | --- |
| Age |  | 73 (4) |
| Gender |  |  |
|  | Male | 2 (25%) |
|  | Female | 6 (75%) |
| Education (years) |  | 8 (4) |
| Diagnosis |  |  |
|  | Type 2 diabetes | 4 (50%) |
|  | Cardiovascular disease | 2 (25%) |
|  | Chronic respiratory disease | 1 (12,5%) |
|  | Inflammatory bowel disease | 1 (12,5%) |

### 3.4.2.2.1.    Expectations for a patient engagement intervention

Results from the first interviews' round revealed that participants reported interest in participating in an intervention designed to engage them in their health and care management, with different motivations (*"to become calm, I'm too anxious when I manage my health,"*- Int. 5, F, 70 years-old - *" "to succeed in changing my lifestyle according to my health condition,"* - Int. 6, F, 68 years-old - and *"I'm really upset, I need to understand what it is happening to me and reorganize my life"* - Int. 2, F, 69 years-old-). They did not have particular expectations for a patient engagement intervention (*"I don't really know what to expect!"* - Int.1, F, 77 years-old)., but they recognized that a similar work would have suited much more their needs if provided in the hospital and from a healthcare professional. Most of them (57%) preferred an individual intervention, because of the embarrassment to discuss personal life aspects with other people and in order to benefit from a personalized pathway.

### 3.4.2.2.2.    Feedbacks on contents

The responses to the intervention's contents were generally positive. Older participants reported some difficulties in reporting the main points of their illness journey, and most of the times the help of researchers was searched. They appreciated the use of the scales and the moment when results were shared, recognizing themselves in the map designed to resume the four engagement positions. This moment helped them in seeing different possible experiential trajectories. Defining a possible engagement goal was sometimes difficult, but with the help of the researcher all the participants were able to settle affordable goals (*"I'm in between arousal and adhesion, probably if I'll leave my constant worry for symptoms behind I will feel much more in this way, in adhesion"* - Int. 2, F, 69 years-old -). Setting specific objectives to reach the engagement goal was considered useful for them, and in that moment eliciting resistances/motivations was helpful to strengthen the decision to enact changes. Understanding the package of exercises was not always simple for older patients, it was clear that they had the possibility to use them at home, but not so clear why. After having used them, some reported a poor comprehension of words reported in exercises or of tasks explained (*"I only completed the elementary degree so some words are difficult to me to understand"*, Int. 5, F, 70 years-old). Some of exercises were perceived repetitive, and thus boring sometimes (*"sometimes home-works appeared repetitive and I would have benefitted by more concise exercises"*, Int. 6, F, 68 years-old), also because some of them reported having already implemented some home-made strategies. These were, for example, strategies for retaining and organizing information, i.e. having a diary on the disease, recording medical visits, using reminders (*"I've already a system to organize all the*

*health issues of me and my wife, it's like a book where I take note of what doctors say and where I point out my symptoms and doubts, I'm also used to benefit from taking notes during medical visits"*, Int. 7, M, 69 years-old*)*. In these cases, the participants were asked to show their self-made materials in order to take suggestions for possible adaptations of the intervention's exercises. Finally, looking at the way the exercises were perceived and then completed, it was clear that some of them were not auto-explicative and needed a revision.

### 3.4.2.2.3.    Feedbacks on procedures

Participants appreciated the possibility of having a dedicated individual moment for sharing their health and care experience. Most of them reported that it was the first time they had the opportunity of reflecting on these aspects in a protected space (*"it's the first time I can think on these things and take a moment for reflecting on how things are going"*, Int. 4, F, 70-years-old). Some of them also stated that they would have preferred having had this opportunity a long time before, and with one of their healthcare professionals as provider (*"of course…this would have been much more better when they diagnosed me diabetes, if one of the professionals would have offered this to me it would have been much better"*, Int.1, F, 77 years-old). When home-based exercises were presented, they were suspicious and resistant in having a part of the intervention to be done alone in their home, also for the fear of being judged and for doing things "right" (most of them asked *"Have I done things right?"*)*. However, adherence to the home practice was high, and all participants used all of the provided instruments and engaged in a sustained effort to pursue their health goals. When asked to explain why, most of them reported that their efforts were for contributing to a research and hoping to help with their efforts other people. Finally, when asked to report how they perceived the intervention, most of them used images and words pertaining to the natural field, like *"having planted something in my ground that it's flowering"* (Int. 4, F, 70-years-old) or *"it was like a flowered field with the sun…this pathway made me serene" (*Int. 1, F, 77 years-old).

### 3.4.2.3.    Summary of refinements made leading to the final PHEinAction Intervention

According to the main feedbacks provided by professionals and patients, the draft of intervention's contents and procedures was refined, leading to the final intervention.

In general, after group discussions with healthcare professionals, the main changes to the preliminary intervention concerned: (i) a better gradualness of components basing on patients' engagement positions, (ii) the adaptation of components basing on experiences and suggestions from clinical practice, (iii) the improvement and simplification of instruction and of graphic of exercises, (iv) the

simplification of some of the passages, (v) the introduction of a starting moment collecting the patient's story, and (vi) a better structuring of the "sharing of assessment results" moment of the first session. In general, a better structured written guidance for all procedures was considered, as well as the need to train the providers. Since feedbacks were positive, changes were not made to the general procedures of the intervention.

Overall, basing on older patients' feedbacks, the following aspects were changed: (i) the adoption of a metaphor from the natural field to explain the intervention's purpose and contents to participants, (ii) the revision of some of the materials to make them more comprehensible, (iii) the removal of some exercises and their replacement with new ones to avoid repetitiveness. No changes were made to the intervention's procedure (presence of in-person sessions and home-based exercises, being individual, comprising at least two in-person moments, being provided by a healthcare professional).

### 3.4.2.3.1.    Refinements to procedures

The overall intervention's procedures drafted in the conceptual development step were maintained. It was confirmed that the two face-to-face sessions had to be considered the minimal units of action for a patient engagement change, with further "units of actions" to be suggested basing on professionals' evaluations and/or in critical points of the care process to sustain the change process.

After patients' involvement in the preliminary intervention, it was observed that the length of the first session was approximately around 60 minutes, and the one of the second session of approximately 40 minutes. The two sessions required a place feasible for an exchange on private themes – such as the ones related to individual's health and health management -, as much as possible protected from interruptions and with at least two chairs and one table to work on the materials. It required the materials to be printed and brought during the sessions.

The following aspects of the intervention's procedures and contents were changed or implemented:

- All the intervention was protocolled and detailed materials were created to guide the intervention delivery, both for the sessions and the home-based exercises. In particular, materials comprised a PDF manual for the two face-to-face sessions, and a package of numbered exercises created with MS PowerPoint. The full package of materials was not attached as Appendix due to the high number of pages, but it is freely available upon request.

- The materials of the sessions and of the home-based exercises were made friendly to be understood by older patients, i.e. a big format for letters was chosen and few words were complemented by images.

- A metaphor was used to explain the intervention. The first session was explained as a moment for taking stock of the situation and planting a seed of the engagement pathway for a happy

role in healthcare. Instruments were represented as a suggestion of care actions that patients can do to fertilize and nurture the seed, so to make the engagement plant grow up (Figure 3.6) ("this first session it's like planting a seed, which needs in the following weeks multiple cares to grow up: care for the roots (emotional exercises), care for the tree trunk (cognitive exercises), care for the branch (behavioural exercises)").

**Figure 3.6.** Example of the "explanation of instruments" material



### 3.4.2.3.2. *Refinements to contents*

The main goals of the first session (promoting a greater awareness of individuals on their engagement in the health and care management, defining an action plan to foster engagement changes, and sustaining a process of motivation to change towards a proactive and co-authorial role in care) were maintained, so as the ones of the second session. However, the two sessions were better structured to help their delivery:

- A first moment of collection of the patient's story was introduced, through a patient's journey map. This first step was included considering professionals' feedback about the need to support patients rethinking and resuming their healthcare journey, by highlighting its main turning points (Figure 3.7). The purpose was to help individuals measure with the health condition, and professionals recollect an anamnesis of the lived healthcare journey of patients, so to facilitate a better empathy with the patient's perspective and needs. A first-version of this map was created and revised thanks to patients' feedbacks (Figure 3.7).

**Figure 3.7.** Example of the "patient's journey map" material (from the first to the final version) (original version)
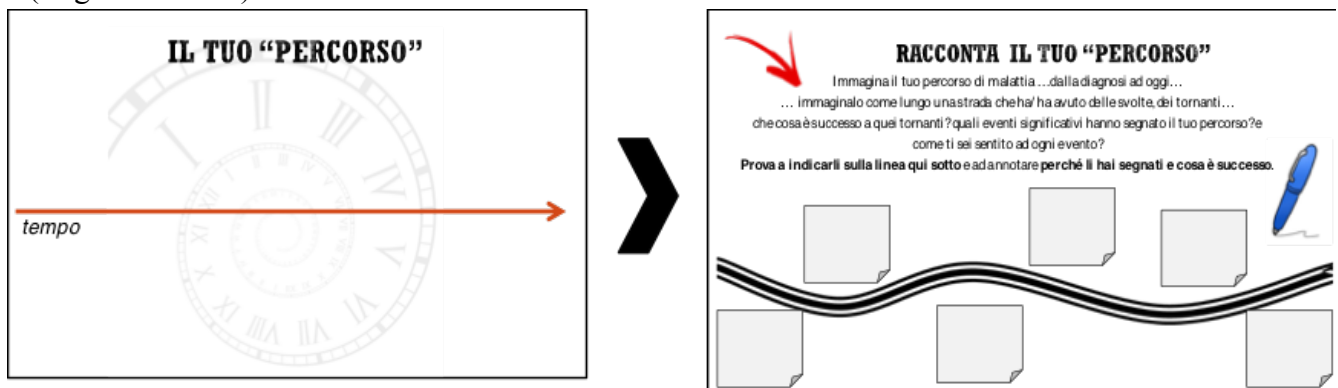


- The assessment and sharing of the starting position of engagement of participants through the PHE Scale was better structured and it was stressed the value of this moment not only as a "diagnostic" moment, but most of all as an opportunity to make patients and professionals aware of the actual patient's role and experiential position in the care journey, due to the possibility to visualize it (Figure 3.8). This moment was conceived as a first opportunity of engagement, by improving the awareness of patients and the alignment between professionals' thoughts and patients' experience, as well as by motivating patients in a possible decision to take a proactive role in the care management. It was also defined to complement the PHE Scale with the PAM scale to have detailed suggestions on cognitive and behavioural dimensions.

**Figure 3.8.** Example of the "engagement pathway" material (original version)
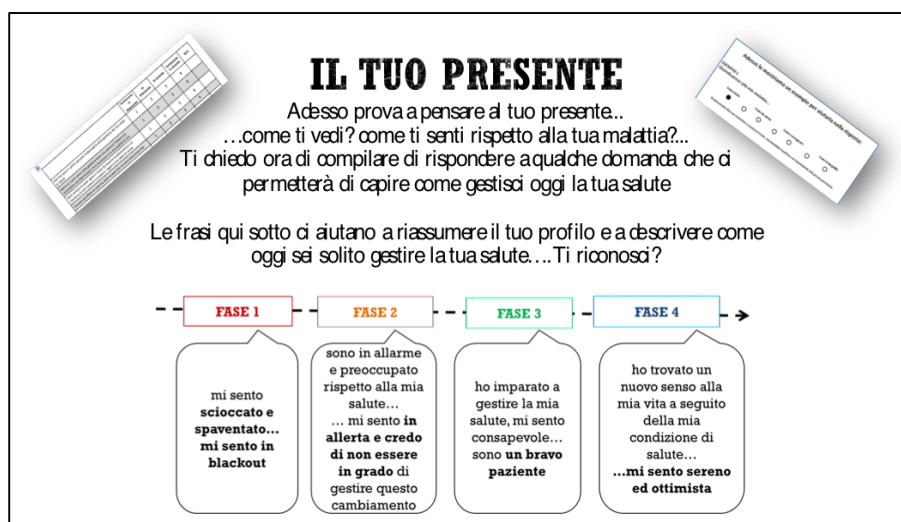
- The moment of definition of a purpose of engagement and of manageable actions to sustain this purpose was better explained to make it affordable. In details, the desirable engagement goal was conceived to be the "destination" of the engagement pathway. The definition of the concrete simple actions (the milestones) able to sustain reaching the destination was stressed to allow perceiving the destination tangible and reachable. It was also conceived as a possible self-determination moment for the patient, as well as an opportunity to negotiate with the professional the milestones and make them aligned with the care pathway. It was also stressed the importance of eliciting, during this moment, the possible advantages and resistances of reaching the goal/the destination, so to motivate individuals in enacting the change and to roll with the personal barriers towards the change.

- The value of the end of session was enhanced. It was decided to close the session with a codified contract moment to formalize what shared during the meeting and to elicit the real motivation of patients in following the defined engagement plan. Materials developed thus helped remember professionals to simply ask, for example: Are you in? How much are you willing to proceed? This was for giving patients the possibility to explicit their intention and motivation to proceed/not proceed, limiting the risk of future resistances/renounces. It was then decided to include a section for the next appointment to allow clarifying the times for the activity and helping patients feeling not alone in the engagement pathway.

After patients' and professionals' feedbacks, home-based exercises were also better structured and clarified, as well as it was as much as possible enhanced their graduation basing on the specific needs of every engagement position. Then, the different exercises finally required an increasingly challenging effort basing on the engagement position: patients in blackout were not asked to "do" something, but to "express" their feelings/thoughts/behaviours. Figure 3.9 shows the evolution from the starting map of exercises to the final one. Figure 3.10 provides some examples of how exercises were refined after professionals' and patients' feedbacks. Table 3.5 reports the final detailed package of home-based exercises, with the key components, aims and procedures of instruments for the three dimensions.

**Figure 3.9.** Evolution of the home-based exercises from the preliminary to the final version
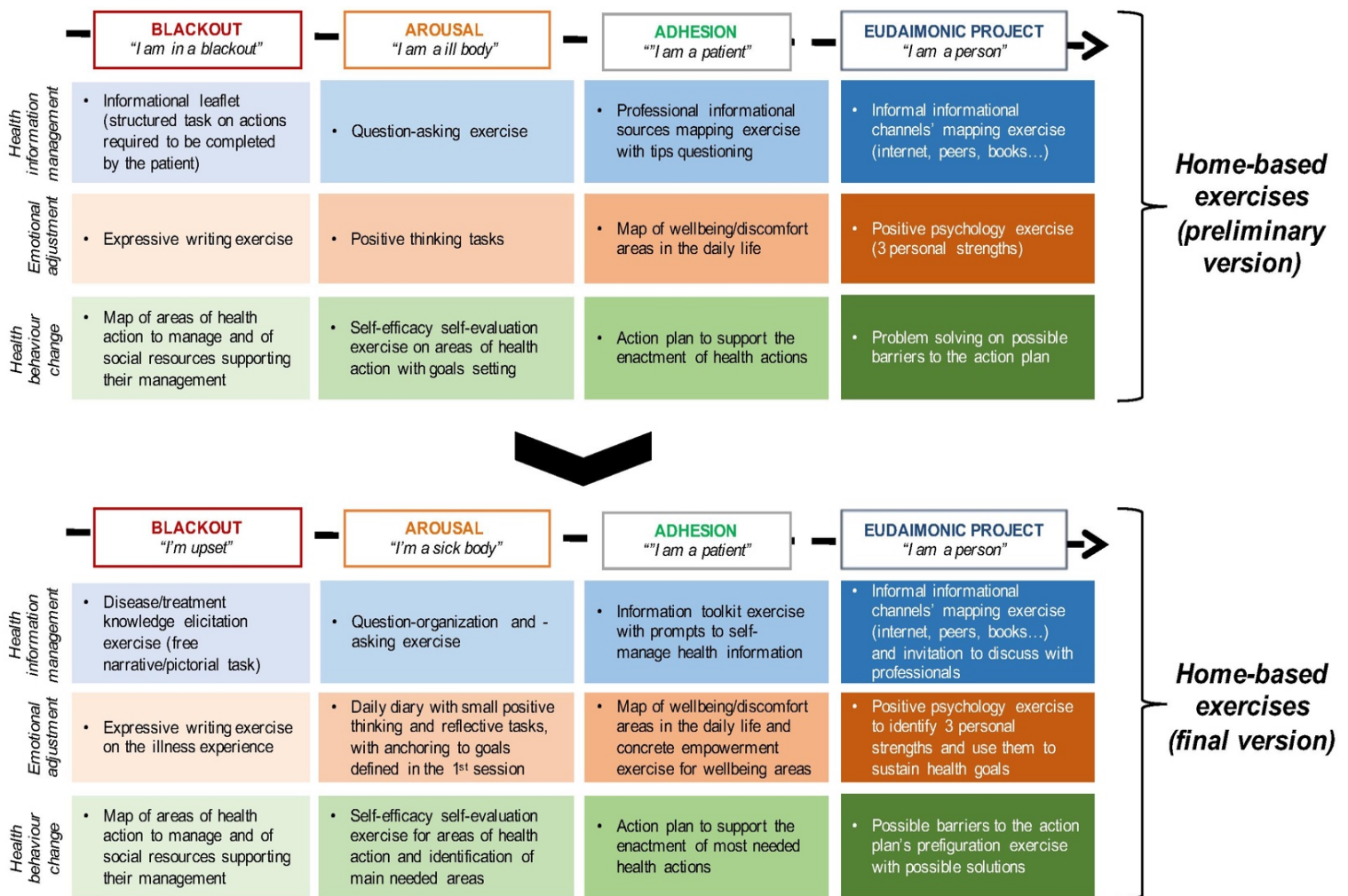
**Figure 3.10.** Screen shots of the evolution of selected exercises after professionals' and patients' feedbacks (original versions)

**Table 3.5.** "PHEinAction" home-based exercises, aims and procedures (final version)

| Dimensions | Aims | Exercises |
|---|---|---|
| *1. Emotional adjustment* | • To foster a process of adjustment to the diagnosis and to the patient's role<br><br>• To activate and strengthen skills and inner resources of the patient | 1) Expressive writing exercise on the illness experience;<br>2) Daily diary with small positive thinking and reflective tasks;<br>3) Map of wellbeing/discomfort areas in the daily life and empowerment exercise of wellbeing areas;<br>4) Positive psychology exercise to identify 3 personal strengths and apply them to better manage health |
| *2. Health information seeking and use* | • To improve health information seeking/use processes<br><br>• To sustain the adoption of external resources | 1) Disease/treatment knowledge elicitation exercise (free narrative/pictorial task);<br>2) Question-organization and -asking exercise;<br>3) Information toolkit exercise with prompts to self-manage health information;<br>4) Informal informational channels' mapping exercise (e.g., internet, peers, books…) and invitation to discuss it with professionals |
| *3. Health behaviour change* | • To sustain the plan and organization of health behaviours<br><br>• To improve self-efficacy in managing health | 1) Map of areas of action that patient needs to manage (diet, physical activity, medications…) and of social resources supporting the management of these areas;<br>2) Self-evaluation exercise concerning self-efficacy level for every area of action that patients need to manage and identification of reasons for self-evaluation and main needed areas;<br>3) Action plan to support the enactment of most needed health actions;<br>4) Possible barriers to the action plan's prefiguration exercise with possible solutions |

### 3.4.3. Qualitative validation of the final version of PHEinAction

This final section reports the perceptions of healthcare professionals and older patients on the final version of *PHEinAction*, which resulted from having presented and discussed it with the last group of professionals and from having interviewed older patients who have tested it. As perceptions of professionals and patients were in general positive, no further changes were made to the intervention.

#### 3.4.3.1. Professionals' validation: perceptions on the final version

In general, no major issues were raised when the final version of contents and procedures was presented. Professionals liked the idea of an intervention able to support patients and professionals in an engagement journey through simple and concrete steps and to structure contents and procedures (*"It's easier to follow the program if exercises and procedures are well described"*). They also endorsed the graduation of exercises. Worries for the range of materials and components to be managed were reported throughout the groups (*"There are a lot of things to consider! Things can be too complicated to manage"*). Some of professionals reported a "*worry for not being appropriate enough*", especially considering the need to manage the possible experiences and emotions opened by the scales and the exercises. It was, however, agreed that, compared to other interventions, there was an effort to reduce and simplify contents and procedures for clinical practice, and no concrete suggestions were provided to help simplifying the work without losing in contents. They generally perceived the framework of action valuable, and the components a useful way to support the actions defined. In particular, they were reassured by having something "*that comes from research*", and by using components supported by the scientific literature (*"All the proposed exercises are reported in literature and have a solid background, this helps"*). The possibility of the intervention to consider different dimensions was particularly appreciated (*"I think that the most valuable aspect of the intervention could really be that it allows working on different aspects of the patient's experience"*). If the match between components and engagement positions was generally supported, professionals perceived some difficulties in dividing components for the three emotional, cognitive, and behavioural dimensions. Overlaps between components' dimensions were reported, and it was agreed that the division of intervention's components in the three dimensions served much more as a guide for developing an equally balanced intervention than as a strict procedure (*"I cannot see how this component can be only cognitive, I think that it's good to know that we should work on different aspects but of course components are not so divided among dimensions"*). Procedures and flow of sessions were also generally endorsed, even if worries for managing proposed times and proposing the intervention to patients with low literacy and from difficult socio-economical situations were reported throughout.

### 3.4.3.2. Patients' validation: perceptions on participating in the intervention

After having tested the intervention, patients felt in general it useful for them and aligned with their needs. They reported to benefit from reflecting on their health condition with a new perspective (*"I already knew all these things, but I kept them insight myself and gave no importance to them, with this intervention I eviscerate them and thus I faced them"*, Int. 1, F, 77 years-old; *"it is now for me like some light into the fog is appearing...and this light changes your perspective...it is like I'm realizing some things"*, Int. 2, F, 69 years-old). Even it was challenging sometimes for them to reflect on their health condition and to take a moment for taking stock on how they were managing their health condition, it was satisfying for them participating in the intervention (*"It was important to me because I slowed down and I reflected on my situation, it was difficult but important and satisfactory"*, Int. 6, F, 68 years-old). Some changes in their approach to health issues were actually enacted by some of the participants (*"it was useful for me to manage my emotions and my anger...it helped me"*, Int. 5, F, 70 years-old; *"I want to thank you because I never thought to be able to do something to better manage my health"*, Int. 2, F, 69 years-old).

## 3.5. Discussion

This Chapter described the development and qualitative validation of an individual intervention for supporting patient engagement of older adults, called *PHEinAction*. This intervention aimed to sustain patient engagement of older populations by valuing the emotional, cognitive, behavioural dimensions of the care experience. It resulted from a match among a theory of patient engagement, scientific literature, practical considerations, and healthcare professionals' and older patients' feedbacks. A final qualitative validation step allowed to endorse the final version of intervention's procedures and contents. The intervention still requires implementation in clinical practice, as well as piloting and formal evaluation.

Generally, professionals and patients appreciated that the developed intervention was able to: (i) consider emotional, cognitive, behavioural dimensions, (ii) personalize the overall pathway to patients' needs for engagement, (iii) feature easy-to-follow written materials. Considering the first point, as already stated in the previous Chapter, literature stressed the importance of fully supporting patients cognitively, behaviourally, emotionally to enhance care outcomes. As showed in Chapter, few interventions reported in literature are also able to do this. Considering the second point, personalization to patients' individual characteristics in healthcare interventions is more and more highlighted in literature (Eikelenboom et al., 2016; Evers et al., 2012; Simmons, Wolever, Bechard,

& Snyderman, 2014), and professionals' and patients' feedbacks reflected this attention. Finally, making procedures and contents of interventions clear and easy-to-follow is actually a key aspect in the delivery and evaluation of intervention to allow implementation and replication (Borek et al., 2015; Hoffmann et al., 2014).

At the same time, some limitations on *PHEinAction*'s contents and procedures were pointed out. First, the intervention was developed for patients affected by different chronic conditions. The choice of developing a generic intervention was taken due to the underlying philosophy of the PHE theory and practical needs, but is also supported by literature showing how generic interventions can be even more valuable than disease-specific ones (Ghahari, Packer, Boldy, Melling, & Parsons, 2015; van Houtum, Rijken, Heijmans, & Groenewegen, 2015). No differences in the fruition of the intervention among the different clinical conditions were reported by patients, nor by professionals. At the same time, it remained questionable if adjusting it to specific clinical conditions and complement it with disease-specific contents could make it more precise and thus enhance its auspicated benefits.

Then, the intervention was designed to be devoted to individual older patients. As supported in literature, sustaining patient engagement requires action also devoted to the other actors of care, such as caregivers and professionals (Bright, Kayes, Worrall, & McPherson, 2015; Pelletier & Stichler, 2014). Indeed, giving support and engaging families and caregivers could help ensure high-quality care at home (Donelan et al., 2002), strengthening the engagement of patients and supporting them when directly engaging them is hindered by physical or contextual barriers. Similarly, complex programs that train clinicians to embrace requests of patients for engagement and, even more, enable patients to become partners in their care management could make patient engagement more effective. The role of healthcare professionals in advancing patient engagement have been increasingly emphasized too (Gilardi et al., 2016), as they play a crucial role in guiding patients on their care journey (Greene & Yedidia, 2005; Killaspy et al., 2015).

Even more, the study did not allow to evaluate possible aspects of care that can impact on the intervention delivery, such as the moment when the intervention is proposed along the care journey. Literature suggested that the period just after diagnosis can represent an optimal window to deliver interventions, as it allows a process of adjustment to be started (Ridder, Geenen, Kuijer, & Middendorp, 2008). This and similar aspects should be tested by further studies.

Finally, as the intervention mixed autonomous and shared activities, questions might arise on the extent to which having home-based activities could be a delegation of work to the patient. Indeed, if on one hand professionals appreciated this unburden, patients reported some difficulty in understanding and completing some of the tasks. Even if home-based exercises were thought to be

an occasion of personal space for patients for reflecting on their experience to be later discussed together with the professional, the extent to which this work division might change patient-professional relationship and workloads remains unclear. Furthermore, having home-based exercises requires patients not having cognitive impairments and having minimum literacy skills, such as being at least able to read and write. This could limit the adoption of the intervention from particularly disadvantaged and vulnerable populations. These are limitations consistently reported in literature on self-management support for older adults (Foster et al., 2003; Parsons, Bury, Hurst, Magee, & Taylor, 2010; Redman, 2011). There is literature which suggested to explicitly address the community context to engage disadvantaged populations too (Eakin, Bull, Glasgow, & Mason, 2002; Larson, Schlundt, Patel, Goldzweig, & Hargreaves, 2009). Within the community context, familiars and caregivers can have an important role for sustaining impaired health conditions (Queen, Butner, Berg, & Smith, 2017; Sadak, Korpak, & Borson, 2015). This indicates that further work to adapt *PHEinAction* to caregivers, or to engage caregivers too in the intervention, could be valuable.

## 3.6. Limitations

The main pitfalls in focus group rely on having censored or conformed discussions (Carey & Asbury, 2012), but also on having comments prompted by the specific group, and thus not consistent and reliable, or on making hard protecting confidentiality of what said (Carey, 2016). It was tried to build homogeneous group of participants as coming from the same healthcare organization. However, groups were open to professionals from different positions and from different care services. This was done to explore different professional positions and services on the intervention under discussion (Clavering & McLaughlin, 2007). It might have however lead some participants conform to opinions of most influential persons. It cannot be excluded that disagreements among participants or resistances to openly express opinions with other colleagues might have limited discussion. Resistances to freely discuss with conductors might have been too, as participants might have perceived the proper (or easier) response to be providing positive feedbacks, because of the involvement of the researchers as conductor and as intervention developers. For this, participants were informed that their opinions were important to adapt the intervention, and it was valued building trust and rapport with them by providing a careful introduction to the study. Then, participants received formative credits for their participation. Not all professionals were, therefore, necessarily interested in the subject, allowing having different perspectives on the intervention. The majority of professionals were female nurses. There might have been an unbalanced gender balance in favour of women, because of the gender-specificities of the nursing profession, at least in Italy.

For interviews, the main problems are on power and data authenticity (Nunkoosing, 2005). The problem of power and (dis)equalized authorities in favour to the interviewer is generally considered inevitable during interviews (Nunkoosing, 2005). It was tried to clarify with participants their key role as main holders of knowledge before starting interviews. Participants were also allowed to choose if being interviewed in their homes or in the University. Similarly, to sustain collection of free data, and thus authentic, the researcher performing interviews was external to the research. She was solicited to participate during interviews and collaborate with participants to build a comfortable environment and construct a knowledge with them (Nunkoosing, 2005). It is also worth to notice that patients were recruited from territorial services and, even if it was tried to include patients with different diagnosis, age, gender, length from diagnosis, it was difficult to engage men, just diagnosed patients, or patients in charge to different healthcare services. All of them participated on a volunteer basis, and have thus an interest in the theme. All these aspects might have restricted patients' voices to a specific group of patients.

## 3.7. Conclusion

A brief individual intervention for patient engagement support resulted from a conceptual work on literature and the PHE theory, taking also into consideration practical needs of clinical settings. The intervention was refined with and endorsed by healthcare professionals and older patients, making it potentially implementable in clinical practice. Further work is needed to tackle issues related to its delivery and implementation within healthcare professionals' existing clinical practice.

# Chapter 4

# Exploring the early-stage implementation of PHEinAction in an Italian integrated-care context: A qualitative study of a participatory process

In this chapter, I will present the final empirical investigation in this thesis: The early-stage implementation of *PHEinAction* in an Italian integrated-care context. This completes the study on how to promote patient engagement support to older adults, by providing knowledge about how the implementation of the *PHEinAction* intervention is experienced in different clinical settings. The context for this investigation was especially relevant as it involved different care settings within the same organization which had been undergoing a re-organization of services towards a long-term integrated care particularly aimed at improving care for older patients. It is also relevant that this Italian integrated-care organization, as part of this re-organization process, stated that it aimed to be open to engage (older) patients more actively in their care and to have a citizen-centred approach. A participatory process was thus enacted, engaging staff at the organization in on-going discussion alongside the researcher-based activities on the implementation of *PHEinAction*. In this chapter, I will report on the investigation of the participatory process used during the early-stage implementation. This involved investigating, through a triangulation of multiple sources of information – workshops, interviews, observations, artefacts analysis: (i) the usual patient education practice enacted by three different care settings of the organization; (ii) the early-stage (first six months) experiences that different care settings had when implementing *PHEinAction* in the usual patient education practice; (iii) the early-stage solutions defined with professionals to promote the implementation of *PHEinAction* in the organization. I will end this chapter by discussing the findings in light of how *PHEinAction* can offer an opportunity for enacting service changes in the direction of giving citizens a more engaged role in the care process, and the challenges it gives to the healthcare professionals and the healthcare organization itself.

## 4.1. Introduction

As highlighted in the Chapter 1, embracing patient engagement within the healthcare system is seen as an indispensable part of care for persons with chronic conditions (Finset, 2017).

In the same Chapter, I described how, at an individual level, embracing patient engagement support means not only working with the individual to sustain self-care behaviours but also helping him/her taking on an engaged role in care (Fiandt, 2006; Kidd et al., 2015; Pulvirenti et al., 2014). As a consequence of this new possible role of the patient, the healthcare systems are asked to change the way they provide care to make the patient at the centre of the care process (Bodenheimer, Wagner, et al., 2002; Boult & Wieland, 2010; de Bruin et al., 2012; WHO, 2015).

Therefore, at a system level, embracing patient engagement means rethinking the way care is provided to include actions for supporting patients in taking an active role in care, but also to continuously support them along the care trajectory (Bodenheimer, Wagner, et al., 2002; Boult & Wieland, 2010; de Bruin et al., 2012; World Health Organization, 2008). This has been translated into different models of care (Boult & Wieland, 2010; de Bruin et al., 2012; Jayadevappa & Chhatre, 2011; Wagner et al., 2001b), joint by an effort to improve the quality of chronic care by ensuring "a continuum of preventive and curative services, according to clients' needs over time" (World Health Organization, 2008).

I have also showed (Chapter 1) how reshaping care delivery and including new ways of interaction with patients is not a simple task (Fleuren et al., 2004). Obstacles have been identified to interfere on a system level with transforming an organization into one that truly embraces a citizen-centred care (Moretz & Abraham, 2012). Also on an individual level, obstacles are present for supporting individual patients and changing professional practice in order to implement individual support into existing workflow (Fleuren et al., 2004; Harris, Williams, Dennis, Zwar, & Davies, 2008; Kennedy et al., 2014; Locatelli et al., 2015).

Examining the active and planned efforts to implement newly-developed interventions in healthcare contexts, and identifying solutions to overcome obstacles and sustain the implementation, is essential to avoid current and future pitfalls and problems, and to help proceeding with future studies that can better examine effectiveness (Elwyn, Légaré, Weijden, Edwards, & May, 2008; Gagliardi & Brouwers, 2015; Grol & Grimshaw, 2003). Implementation of new interventions is actually a main concern within health science research (Finch et al., 2013; Grol & Grimshaw, 2003; McEvoy et al., 2014; Nilsen, 2015). This literature have mostly focused on the course of action when the new intervention is still being implemented from time (Moullin, Sabater-Hernández, Fernandez-Llimos, & Benrimoj, 2015; Rise, Solbjor, & Steinsbekk, 2014).

Only one study has been retrieved focusing on the early-stages of the implementation process (Gilmore, Vallières, McAuliffe, Tumwesigye, & Muyambi, 2014). In this study, the importance of an early-stage evaluation of users' experiences with newly initiated interventions' implementation is

highlighted for providing valuable, timely feedback that could contribute to long-term implementation success or failure (Gilmore et al., 2014). Furthermore, broadly looking into the implementation research literature, greater attention has been paid on final users/patients' acceptability (Sekhon, Cartwright, & Francis, 2017). However, in the early implementation stages much attention needs to be paid on providers/professionals, as they have a key role in the innovation implementation and delivery (Gilmore et al., 2014). Participatory methods have been particularly stressed to be used when implementing interventions in healthcare organizations (Leykum, Pugh, Lanham, Harmon, & McDaniel, 2009). Indeed, they enable more lasting organizational changes through the participation of those individuals who are most involved in the local processes of care (Leykum et al., 2009).

Particularly in integrated-care contexts, where different cultures and practices should work closely together, attention during implementation needs to be placed not only on the organization itself, but also on the different single care settings. Indeed, the diverse care services of the organization could differently challenge the effort of improving care by changing existing practice. These challenges can also increase when the care is provided to older patients dealing with chronic conditions (Boult & Wieland, 2010; Sendall, McCosker, Crossley, & Bonner, 2016). The different communities of practice represented by the different care settings within an integrated-care organization have the potential to create knowledge, skills, and best practices relevant for the implementation and an broader audience (Li et al., 2009). Accounting for them and for their experiences with the implementation can highlights pitfalls and solutions that can have an important influence on implementation outcomes (Chaudoir, Dugan, & Barr, 2013). These are usually not grasped by frameworks used in implementation science for studying the normalization of new practices in healthcare organizations (Nilsen, 2015).

A need was identified to get a deeper understanding of how new interventions for patient engagement support, such as the *PHEinAction* intervention, can be implemented. This could have provided knowledge about areas it might influence, such as reconfiguring existing relationships, communication and practices, as part of the process of becoming embedded into routine educational practice. The setting is also important, and no studies were identified looking at the early-stage implementation in healthcare organizations where educational practice can differ from one service to another and that, dealing with particularly difficult and vulnerable populations such as older patients, need to align and connect care practice.

## 4.2. Aim

The main aim of this study was to investigate the early-stage implementation of an individual patient engagement support intervention for older adults (*PHEinAction*) into the existing patient education practice of different care services of an Italian integrated-care organization.

The specific objectives of this study were:

(a) to describe the usual patient education practice of three care settings and identify their organizational and cultural key differences;

(b) to describe the experiences that different care settings had when implementing *PHEinAction* and investigate how the experiences can be understood in the light of the settings' organizational and cultural key differences in patient education;

(c) to describe the solutions to promote the *PHEinAction* implementation and investigate how the solutions can be understood in the light of the settings' key experiences with the implementation.

The study covered an early stage of the fourth point of the MRC Framework (Figure 4.1), aimed to understand implementation feasibility of a new intervention in the real-world setting (details are reported in Chapter 1).

**Figure 4.1.** MRC Framework's point covered by the study



**Development**

1. The first step includes identify the existing evidence and what it is already known about similar interventions. The framework suggests conducting systematic reviews for this aim. — Study 1

2. The second step features drawing on existing evidence and theory to develop a theoretical understanding of the likely process of change enacted by the intervention. — Study 2

3. The third step involves modelling and progressively refine the intervention design.

**Feasibility** *and piloting*

4. The fourth step regards assessing feasibility of implementation of the intervention in the real-word setting. — Study 3

5. Piloting is thereafter suggested as fifth step, as a scale model of the planned evaluation. This step falls outside the research project. — X

## 4.3. Methods

### 4.3.1. Design

This was a qualitative study in a public integrated-care organization located in the North of Italy. It was used a participatory approach, engaging staff at the integrated-care organization in on-going discussion alongside the researcher-based activities. Multiple sources of information were collected

during the early stages of the implementation process. The term early-stage implementation refers to this study investigating the activities from the proposal of the implementation of the intervention to the first six months of a participatory process with workshops and other activities. The data included were collected from December 2016 to June 2017.

There is literature discussing the bounds and differences among collaborative approaches in research (e.g., participatory action research, action research, co-operative inquiry, participatory research, participatory rural appraisal) (Cargo & Mercer, 2008a; Cornwall, A. and Jewkes, 1995; Dalton et al., 2008). It is also discussed which aspects can make a study participatory (George, Daniel, & Green, 2006; Jagosh et al., 2015). In this study, participatory research, which is a collaborative, cyclical and reflective inquiry approach, was used as an inspiration because it focuses on planning and conducting the research process with those people whose life-world and meaningful actions would be impacted by the intervention implementation (Cargo & Mercer, 2008b; Cornwall, A. and Jewkes, 1995). It is an approach widely used in different disciplines, including organizational psychology, as it values the coequal role of organization members for participating in the inquiry and it allows to account for the matters of real concern of members involved (Gorli, Nicolini, & Scaratti, 2015; Ivaldi, Scaratti, & Nuti, 2015; Meredith & Wallerstein, 2013; Sorrentino, Guglielmetti, Gilardi, & Marsilio, 2015). Having this perspective strengthened the focus on working collaboratively with local healthcare providers and on engaging them in the research process, thus also empowering them in the implementation. Another aspect is the focus on work with different care settings and to value the contextual-specific social practice in complex systems such as healthcare organizations (Leykum et al., 2009). For these reasons, this approach has been suggested to be a particularly appropriate one for use in implementation research of new interventions in healthcare organizations (Leykum et al., 2009). It, consequently, was chosen to strengthen the role of the participants in the early-stage implementation of the *PHEinAction* intervention.

## 4.3.2. Context

The Italian integrated-care organization were the study was conducted is the "Azienda Sanitaria Universitaria Integrata di Trieste" (ASUITs), that is a public healthcare organization within the wider Regional and National Healthcare System. It is located in Trieste, Italy, and covers a territory of 211,82 kmq with an overall population of 236.186 persons. Almost 30% of the population living in Trieste is older than 65 years (the Italian average is approx. 20%). The area is also famous for having the greatest number of centenarian citizens in Italy. Therefore, the organization has to manage patients who are often in their old age. Historically, the healthcare organization of Trieste was the one starting the movement to close – or, better, to open – the psychiatric hospital in 1978, and the one beginning

the legislation (Legge Basaglia) that improved the management of mental health patients in Italy. After this experience, the organization has been pioneer of different movements towards a better democratization of healthcare services, such as the recent one against healthcare services' restraining (see the website: https:// triesteliberadacontenzione.wordpress.com for an example of the activities promoted by the organization). Following this constant effort of improving a collaborative culture in care, the organization was one of the first in Italy implementing an integrated-care model for better assisting the citizens living in the area. In May 2016, the organization changed its name and status after the fusion between the "Azienda per l'Assistenza Sanitaria n.1 Triestina – an outpatient hospital service – and the "Azienda Ospedaliero - Universitaria Ospedali Riuniti" – an inpatient University hospital service -. The organization was, thus, reorganized to integrate different inpatient, outpatient and territorial care services.

During this reorganization process, the healthcare organization, and particularly two medical and one nursing director, searched for possible tools to support the integration of services towards a better engagement of patients. They asked the Catholic University and the research group on consumer health engagement to provide training on the theoretical principles and measures of patient engagement. They also expressed an interest of having practical strategies for promoting patient engagement in the organization.

As first concrete step of the collaboration, in 2016, before the implementation study, it was defined to offer to groups of 10-25 employees a pre-defined training of two days on patient engagement theoretical principles and measures (PHE and PAM theories and scales, see Chapter 1 for information, but not specifically about *PHEinAction* as it was not already fully developed at that time). In total, during the 2016, almost 100 professionals participated in this training, that was considered part of the formative activity offered by the organization and for whom professionals received formative credits. For further information on the first steps of this training activity see Barello's study (Barello et al., 2016). Participants of this training activity were mostly nurses, as during the collaboration the nursing direction took the leadership on the project and identified a key nursing figure to lead the activities locally. Apart from professionals working in the administrative and academic sectors of the organization, participants of this training activity who had a direct clinical activity with patients were working in different care services: inpatient/hospital, ambulatory, home-based/territory.

The context offered by this organization represented, thus, an interesting opportunity for the aims of this study, for several reasons: (i) the organization was located in an area with a particularly older population, (ii) the organization comprised different care services with different organizational and cultural educational and care practices (with the main ones being: hospital, ambulatory, territorial

services), (iii) the organization was dealing with themes related to the integration of care and the engagement of citizens in care, (iv) the organization already embraced the theoretical principles of patient engagement – and, particularly, in the perspective of the PHE theory - and some of the professionals working in the organization were already trained on it, and were thus ready for starting implementing some changes such as the implementation of *PHEinAction*.

### 4.3.3. Study sample

The study followed two sampling logics: 1) a selection of prototypical clinical services for the analysis of current educational activities and of the applicability of *PHEinAction*; 2) a selection of employees including persons in management positions for the analysis of patient education and implementation experiences within the organization.

**Clinical services.** For the clinical services, the aim was to purposefully include one specific clinical service within each of the main activity area of the organization (inpatient, ambulatory, territory). Selection was also based on the type of patients referred to the services. It was indeed defined to select services caring for patients affected by chronic conditions and, generally, having an old age. At the same time, variation in the type of chronic problems treated by services was preferred. Services were suggested basing on these criteria by the site collaborators.

- A cardiovascular inpatient unit was selected for representing the inpatient setting because a prototypical example of how the first emergency care is provided to patients, usually older, who are then followed by other outpatient services in the long-term.
- The pre-dialytic ambulatory was chosen for representing the ambulatory setting because being a central small junction between the acute or primary care and the ambulatory or territorial care (depending from the treatment chosen).
- The healthcare nursing service (home-based nursing service and a nursing clinic) of the territorial District 1 was selected for the territorial setting because providing ambulatory/home-based care to people affected by different healthcare problems, generally vulnerable, and living in an area of Trieste covering also rural territories.

These services were also selected as patients with cardiovascular diseases, needing a dialytic treatment, or those from the community who ask support to the healthcare nursing service are often older and require long-term care.

**Individual employees.** For the individual employees, the aim was to recruit key informants of the different care settings of the organization. For the three specific settings chosen, two key informants

were purposively selected for their key role in the educational practice of the setting, as suggested by the site collaborators, and for their motivation in implementing the intervention (Patton, 2002). Besides them, other professionals working in other care services of the organization and having participated in the previous training were purposively selected. The aim of augmenting recruitment to professionals from other care settings was to enrich data as it gave additional information of other settings of the organization which helped improve the understanding of the three clinical settings chosen. It also contributed to spread of experiences from the three clinical settings to other settings of the organization, especially during the workshop activities.

The recruitment of the professionals from other care settings was done by asking the site collaborators for possible key stakeholders in the implementation and / or persons being interested to take part in the implementation phase in their respective services.

### 4.3.4. Study procedures

For the enrolment of clinical services, a meeting was organized with the directors/coordinators and the first line professionals of the services, if not already involved in the research. During this meeting, the study's aims and procedures were explained, and permission to collect data and consent to participate in the study were obtained.

After having obtained consent from the services to collect data, participant observations, shadowing, and semi-structured interviews were performed. All the services consented to participate, but it was not possible to perform observations of educational practice sessions and shadowing in the healthcare nursing service due to limitation in the field access.

For the enrolment of individual employees, professionals were invited to attend a first meeting at the end of December 2016 in which the *PHEinAction* intervention was presented (as resulting from the refinement and validation process described in the Chapter 3), information on the study was provided, study procedures and aims were shared, and written consent was obtained from interested professionals. Data collection with participant observations, informal interviews and documents/artefacts analysis started with that meeting (Figure 4.2). Hence, professionals who finally accepted to participate were open to the possibility of implementing *PHEinAction*, and they started thinking of it from that meeting. At the moment where the first workshop was held (after almost 1 month, at the end of January 2017), they had different degrees of experiences with the *PHEinAction* implementation, with almost all of them not having yet tried to use it in the day-to-day clinical routine. Therefore, working from this time frame seemed appropriate to capture usual practice, as well as participants' experiences of shifting from usual practice to usual practice with *PHEinAction* added.

Twenty-six individuals finally accepted to participate. These were mostly motivated professionals, as their participation was voluntary, and were generally female (n=23) nurses (n=22) with coordinating/leading roles (n=12) within different services of the organization: (a) hospital inpatient service (n=5), (b) ambulatory/outpatient care service (n=3), (c) territorial service (n=13). One of them was project manager for the training activities, two worked in the university departments of the organization. Finally, two professionals worked in the nursing direction of the organization, and one of these had a key role in managing the research activities locally.

### 4.3.5. Data collection

As illustrated in Figure 2, qualitative data were collected through different sources: (1) participant observations and shadowing; (2) interviews; (3) documents and artefacts analysis; (4) workshops. This triangulation of techniques was applied to grasp the early stages of the implementation from different perspectives and to ensure a deep understanding and involvement of the single-care settings involved in the research. In particular, data collection followed two parallel lines: Data collected through observations, interviews and artefacts analysis were used during workshops to reflect on them together with participants, and to define with participants the next relevant steps for the research. For this reason, I will start by explaining how data from observations, interviews, artefacts analysis were collected. I will end with workshops, which worked as a tool to reflect on the data collected and enrich them with overall participants' perspectives.

**Figure 4.2.** Overview of the data collection flow and of the main activities in the early-stage implementation phase
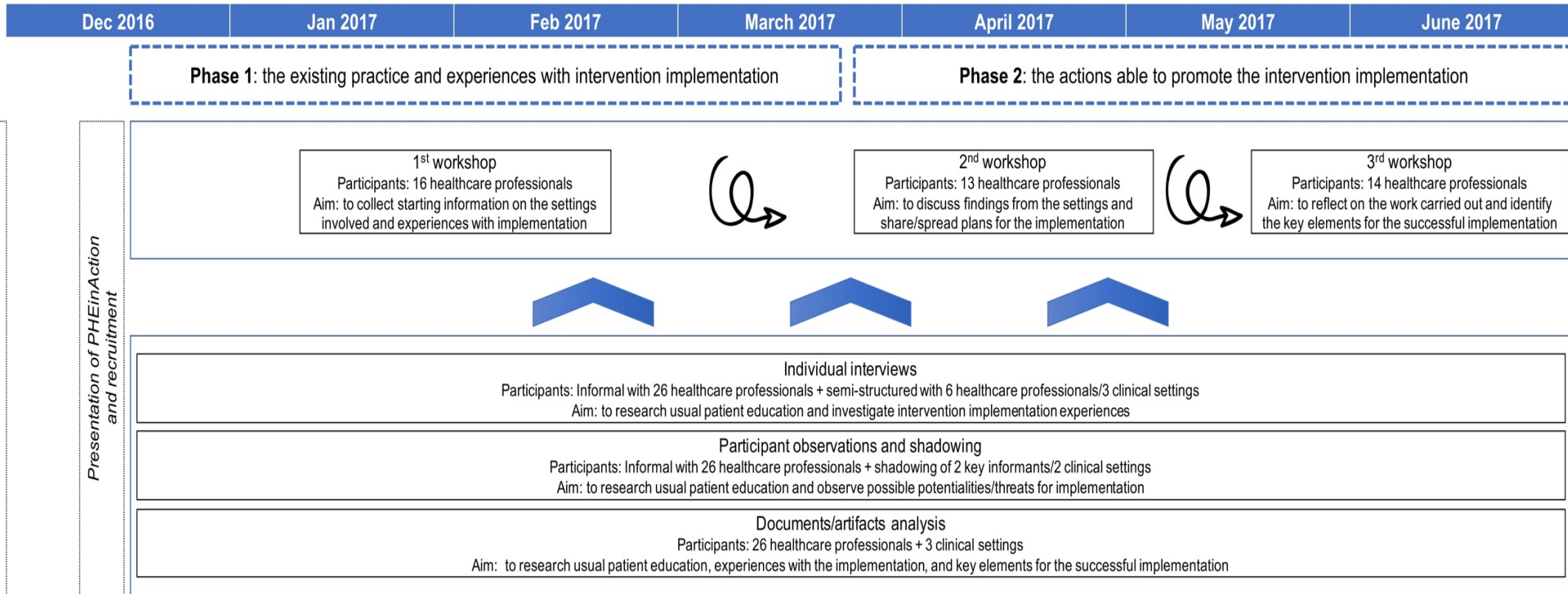
### 4.3.5.1.   Participant observations and shadowing

Participant observations were conducted over the study period in the different clinical (i.e., cardiology inpatient unit, pre-dialytic ambulatory, healthcare nursing service of the territorial district 1, meeting halls of other clinical units) and formative (i.e., building and halls for training activities) settings of the organization. Observational data collection activities included participation in the team meetings, the observation of the contexts and of the exchanges between the researchers and the professionals and among the professionals, the medical and nursing handovers in the three specific care settings, the observation of the routine care and of the educational practices in the clinical settings. Therefore, they were performed in places and times defined by the research activity. They were also performed in places and times chosen by the researchers within the clinical settings for being the most relevant units of analyses (basing on what collected during interviews) to deeply observe specific clinical contexts.

Narrative field notes of these observations were taken following a grid of observation, that was gradually refined basing on the on-going observations and interactions with the context. The final structured grid was organized to collect descriptive, methodological, emotional, and theoretical notes on patient education and implementation spaces/places, times, actors, routines/ behaviours, exchanges/ interactions/ conversations, artefacts/ materials (Gobo, 2001). Observational data collection aimed at capturing (1) how professionals performed their educational activity and organized it in relation to other professionals and settings, (2) how professionals started organizing the *PHEinAction* implementation, (3) whether overt threats, difficulties, barriers, or collaboration, knowledge-sharing, and overt facilitators occurred, (4) what consequences to educational care occurred, (5) which solutions and deployments were enacted for facilitating the implementation.

Shadowing key professionals was also held by two researchers in two of the three specific settings to enrich and complement data on usual patient education practice (Gobo, 2001; McDonald, 2005; Spradley, 1980). The goal was to gain a concrete understanding of the patient education-related workflows, to ground analyses in the actual day-to-day work of the first line professionals working in the specific care settings, and to illuminate potentially important differences in workflow among different clinical settings. In particular, professionals were shadowed for a full day when they were performing their usual educational and clinical activity. Field notes were taken at the end of the day. This type of approach would have also deepened the understanding of issues identified through other forms of data collection. In particular, shadowing was strictly entwined with semi-structured interviews performed with the two key professionals in the three clinical settings and with the observations done in the care settings.

### 4.3.5.2. Interviews

Informal conversations and semi-structured interviews were performed with the professionals who participated in the study. These were entwined and worked synergistically with participant observations and shadowing, each influencing the other's choices. For example, basing on semi-structured interviews, the most relevant units of analyses for observations for every setting were defined, and basing on participant observations the track for semi-structured interviews was developed. Concerning informal conversations, during the course of the study there were frequent face-to-face or telephonic/ e-mail interactions between the researchers and the professionals. For example, there were different calls and e-mails where the interventions' role in workflows and the implementation problems were discussed with the professionals, as well as the research's procedures, the data, and the choices made. Narrative field notes of these interactions were taken to appoint the main points of conversation, and e-mails were saved.

Individual semi-structured interviews were also conducted with two key stakeholders for each of the three purposively selected care settings (a. cardiology inpatient unit, b. pre-dialytic ambulatory, c. healthcare nursing service of the territorial district 1) (Creswell, 1998). Interviews lasted about one hour and followed a semi-structured track developed by the researchers basing on the observations performed. The first part aimed to collect information about the usual patient education practice (examples of questions: "Can you describe the usual patient education workflow?", "What are the main actors involved?", "Can you give me some example of educational exchanges and contents?", "What in your opinion works in the existing patient education practice?", "What can be improved?"). The second part aimed to discuss the experiences of the professionals with the *PHEinAction* implementation and elicit possible solutions for promoting it (examples of questions: "In your opinion, what are the main advantages of including a similar intervention in your patient education practice?", "How do you imagine to graft *PHEinAction* onto your daily practice?", "What are your main barriers/resistances/worries on implementing *PHEinAction*?", "What could be the possible solutions/strategies to overcome these barriers?").

### 4.3.5.3. Documents and artefacts analysis

Over the course of the study, there were different occasions where, during formal data collection activities or complimentary research activities, attention was paid on collecting documents and artefacts from the field or concerning the exchanges with the participants. In particular, public

documents (such as pictures, articles, documentaries, educational material, books) that were used by participants for patient education, or concerning the organization and its care settings, were collected. All these written artefacts were, eventually, printed and collected to be part of the data analysis process.

### 4.3.5.4.  Workshops

Three subsequent workshops were conducted with the overall group of healthcare professionals involved in the *PHEinAction* implementation. These workshops aimed to discuss the data collected in the three specific care settings and along the process, so to reflect on them and on possible similarities/differences with other care contexts. Indeed, during workshops, data collected from the different sources on the educational practice, the experiences with the *PHEinAction* implementation, and the possible strategies and recommendations for the implementation were constantly shared and discussed. This was done to enrich data from the specific settings with the experiences and perspectives of the professionals working in other care contexts. In this way, data were widened and spread to other care settings of the organization. Workshops also worked as an instrument of the participatory process to co-define together with participants the next research and implementation steps. Indeed, the aims and activities performed during the workshops were defined basing on the needs/suggestions collected during the process, and contracted together with participants during the workshops.

Workshops lasted about three hours each and were held by two research psychologists experienced in leading group processes. A total of 26 individuals participated in one or more of the workshops, due to not all of them having the possibility to attend all the workshops.

The first workshop (n=16) was held at the beginning of the participatory process (month 1, end of January 2017) and aimed to discuss and deepen the usual patient education practice performed by participants in their day-to-day activity, as well as to reason on the feasibility of adding *PHEinAction* into it.  The second workshop (n=13) was held at the midpoint of the research (month 3, end of March 2017) and aimed to discuss three prototypical example of how the *PHEinAction* intervention could have been embedded into the existing patient educational practice of different care settings, as from interviews and observations. These examples were used as starting point of discussion on similarities/differences to the other care settings involved in the workshops. Finally, the third workshop (n=14) was held at the end of the research (month 6, June 2017) and aimed to review and reflect on the work carried out by presenting a synthesis of the main findings from the participatory process. It also aimed to identify and plan the key elements for the successful implementation of *PHEinAction* in the usual patient education practice.

## 4.3.6.  Data analysis

There were two main parts of the data analysis' work: the analysis performed along the process to discuss the data with the participants and those ones that leaded to the final results.

In both the cases, a thematic analysis using a deductive open coding approach of the observational field notes, artefacts, and interviews' and workshops' transcripts was carried out (Braun & Clarke, 2006).

Along the process, data from the different sources were iteratively and interactively used for data collection and constantly cross-checked in order to triangulate findings together with participants during workshops. Data were sequentially analysed, and data analysis proceeded together with data collection. Indeed, data progressively obtained were reported and discussed together with participants during workshops so to ensure a constant reflective and interpretative process on them. In particular, there were two times during the research process (before workshops 2 and 3) where a summary of the findings emerging from data collection was written to check data with participants. Before the second workshop, the data collected in the first workshop and during the observations and the interviews on the patient education in different care contexts and on the experiences with the implementation were synthetized. Transcripts were read several times, and a written summary with figures was created to simplify workflows. These materials were firstly shared with participants involved in the interviews and the observations to check them and collect their feedbacks. Then, the figures were presented during the second workshop to the overall group of professionals to discuss and build on them. Then, again, before the last workshop, all the data previously collected were read several times. Emerging themes, patterns, categories, and anomalies in the data were identified, with a particular attention on the possible solutions enacted during the process to overcome the barriers. These were discussed with another researcher and grouped into main themes. Tables were created to visualize the main findings, and these were presented to participants during the last workshop to check their validity and to identify additional data that might have challenged the preliminary analyses.

For the final organization of findings, all data collected along the research process were re-read, and it was built from the point of analysis and abstraction reached during the process. Indeed, a particular attention was paid to the syntheses of findings discussed with the participants during the workshops. These were enriched with participants' feedbacks and cross-checked with the overall amount of data. All the analytic steps at this stage were discussed with two other researchers for a deep interpretation

of findings, and for an organization of findings consistent with the research aims and the data collected.

Quotations from the workshops and the interviews are inserted in the results section to illustrate findings throughout.


## 4.4. Results

The following sections provides a summary of the findings from the research, that were divided in three main sections according to the main aims: (a) the usual patient education practice of three care services and their organizational and cultural key differences; (b) the experiences that different care settings had when implementing *PHEinAction* and their investigation in the light of the settings' organizational and cultural key differences; (c) the solutions to promote the *PHEinAction* implementation and their investigation in the light of the settings' key experiences with the implementation.

Thus, every section starts with a descriptive part and ends with an analytic part, where findings from the previous descriptive parts are merged and synthetized. In particular, the qualitative conceptual model developed from the first section of results on organizational and cultural key differences in usual patient education practices is used to enlighten the findings of the later section on professionals' experiences with the implementation. Then, the same model enriched with the experiences with the implementation is used to read the findings of the last section on the actions performed to promote the *PHEinAction* implementation.


### 4.4.1. Using the stethoscope on usual patient education

In this section, a description of the usual patient education practice enacted in the three clinical settings is provided, with a final qualitative conceptual model with the key organizational and cultural aspects explaining the main differences in patient education among the three care settings. This section particularly reports for the data collected during the participant and unstructured observations and the interviews with professionals. In the territorial setting where focused observations were unfeasible, data are complemented with extracts from workshops.


#### 4.4.1.1.  Setting 1: The cardiology inpatient unit

**Setting.** As observed, the cardiology inpatient unit is located outside the city of Trieste, in the second floor of the Cattinara Hospital. The unit comprises almost 15 double rooms, for a total of 30 beds.

All the rooms are located around a central area, where there is an open reception with computers, an open area for professionals with faucets, cabinets for bags and a blackboard for tracking visits, a central corridor with some chair and elevators, and a utility room. The corridors of the square where rooms of patients are located have monitors outside every room to track the clinical parameters of patients, and areas with chairs. Two corridors from the rooms' square allow moving into the other sections of the hospital (Figure 4.3). In these two corridors are located the rooms for professionals: the nurses room where the handover took place, the physicians room, the kitchen room, and two other rooms for the coordinators of the unit. Rooms for patients have a bathroom with shower, the possibility to watch pay TV, a bid window in front of the door, and two beds with bedside tables. Usually, patients stay in the clinic for 3-5 days.

**Actors.** As reported by the professionals, there are at least three professionals (two nurses, one physician, sometimes a therapist) managing one patient in one day, and at least 25 patients recovered. It was also reported that nurses have in charge almost ten patients, with shifts from 6 am to 1 pm and from 1 pm to 8 pm. The professionals reported that the main actors for patient education are the patient and the nurse. Sometimes – especially during the discharge – also caregivers are involved. As observed, physicians give starting instructions and manage the medical aspects of care, and delegate to the nurse a deep exploration of therapies, care, lifestyle information. The professionals interviewed reported that the therapists (mostly physiotherapist) are also involved to start rehabilitation with physically-compromised patients.

**Educational practices.** It was observed that every time of the day is scheduled with structured activities: washing patients, serving foods and pills, visits of the doctor and the nurse, handover, special medications, contact with familiars and with other units, discharges. In this daily schedule, the professionals said that the educational/informational flow is most of the times irregular and interrupted ("*it's a daily on spot work*"), due to exacerbated times and urgency ("*forced speed doesn't allow us to be on patient education*"). They then reported that encounters between the nurse and the patients are casual, and rarely structured ("*the intensity and quality of information during the hospitalization is left chance, basing on the length of hospitalization but also basing on the single professional*"). Information are given when the patient asks for, during the visits and the discharge, or in casual moments of the day. As stated by the professionals interviewed, the most relevant moment for educating/informing the patient is the discharge, that usually takes not more than ten minutes and aims to leave the patient with key information on the care process ("*discharge is the most important moment for patient education, because you verify the outcome or the crash of the information you gave*"). Consequently, patient education is generally information, as labelled and described by the professionals, with the patient sitting in the bed and the doctor or the nurse providing key information

on the setting, the disease, the therapies, the lifestyle ("*I think that if the patient knows what he has and why he takes these pharms I've done my part in patient education*" or *"...for example, today I gave 3 simple information to one patient and in my opinion this was enough for her"*). In other cases, the educational work consists in detecting at risk situations, helping the patient become aware of risky behaviours, finding an alliance in deciding to activate external resources, as the two professionals interviewed described. It was observed and reported that education on specific aspects is provided only in special circumstances: when the patient is particularly confused and the nurse choose to provide a deeper education. In these situations, always at the bed of the patient, the nurse tries to educate the patient by explaining how the disease and the therapy work and how the patient can manage them. An effort was reported to try to adapt the educational exchange and the contents to the needs and characteristics of the patient. Education was reported to be highly personalized, being the exchanges with the patient the main benchmark for deciding which type of information to give, when and how ("*basing on the exchange with that patient we understand how many information we have to give, which type of information"). As from the professionals' statements, it is the single professional who took the responsibility for answering to the patient's questions and for managing education/information efforts ("*there is somebody who doesn't feel safe in giving information and dealing with questions, so maybe sneaks out of the drips and beds*"). The professionals working in this setting also reported that "*patients will continue to be cared out of here by our system*", as there is a "*trust also in the good willingness of others*" for delivering patient education. It was then observed that the educational handover to the other colleagues is provided during the handover moment, in the middle of the day. All the nurses participate and there is an exchange of information – also of detected informational/educational needs -  with the other colleagues.

**Artefacts.** Observations revealed that there is an educational schedule for nurses to track the type of information/education given, usually compiled at the beginning and at the end of the hospitalization. This schedule comprises basic information on the patient's starting level of information, risk factors and information provided during the hospitalization. Informational leaflets are hanged on the walls of the hallway (Figure 4.4), but rarely actively used by professionals and patients.

**Figure 4.3.** Setting 1: One of the hallway of the cardiology inpatient unit



**Figure 4.4.** Setting 1: Informational leaflets in the central hallway of the cardiology inpatient unit

### 4.4.1.2.   Setting 2: The pre-dialytic ambulatory

**Setting.** As described by the professionals and testified by the artefacts collected, the multi-professional ambulatory for the dialytic treatment decision-making is part of the simple Unit "Clinic for the Chronic Kidney Disease", in the main building of the "Ospedale Maggiore" located in the centre of Trieste. The professionals reported that the ambulatory manages patients with severe chronic kidney disease (stage 4 or 5 from the NKF-DOQI classification) when they are probably needing to start a substitute treatment in the following 6-12 months. Also, they described how their patients are referred from the Divisional Ambulatory, from the Nephrology ward, from the Day Hospital, from other healthcare structures, or from the general practitioners. It was observed that the ambulatory does not have a clear location, being in the same floor of the Ambulatory for chronic kidney disease treatments and comprising the two rooms of the doctor and the sanitary assistant. These rooms are located near the waiting room, just before the dialysis area.

**Actors.** The professionals described that, usually, the ambulatory receives 100 patients in one year, and four main professionals are involved in the care of patients: One doctor and one sanitary assistant (located in the ambulatory), and one dietician and one social assistant (on spot presence, located outside the building and working also in other clinical services). The nurses of the hospital and of the territory are also involved, but as external resources. The two main actors for patient education are the clinician and the sanitary assistant with a nursing expertise, as from the professionals' accounts. Working together with the other colleagues to educate patients was reported by the doctor and the sanitary assistant as crucial ("*group discussion with the other colleagues caring for our patients it's very important for us, because in this way we can share our experiences and have a wide picture of one's life*"). At the same time, also collaborating with the other clinical settings was perceived by them important because "*otherwise you lose a well-done job and patients feel confused if they feel treated in one way in one context and in another way in the following one*". However, intra- and inter-collaboration was reported by the professionals as hard to reach, and the responsibility for patient education was described to be mostly in charge of the small group of professionals working in the ambulatory.

**Educational practice.** The professionals of this setting described the patient education speaking about an optimal model of management of the patient education, as a guiding light for their practice, and comparing their real practice with this ideal model. This model helped them in having a clear roadmap for patient education. They described how the first encounter with the patient is managed by the clinician, and this is mostly an anamnestic and assessment meeting, with clinical examinations. The role of this encounter in patient education is to provide initial information about the evolution of the disease and about the need for a treatment, and then to refer to the sanitary assistant for logistic

aspects, education on treatment options (i.e., haemodialysis, peritoneal dialysis, kidney transplant) and decision-making, to the social assistant for managing practical life aspects, and to the dietician to start a dietary program ("*the doctor is the first junction for patient education and activates all the other professional figures*"). From the perspective of the clinician, the educational work in this encounter is even much more preponderant than the clinical one ("*actually the clinical aspect of my job is quite marginal, it is the educational aspect that is much more preponderant*"). Other meetings follow this first encounter. These are also done by the sanitary assistant who manages part of the patient education process, together with the logistic aspects, before the patient is referred to the dialytic ambulatory when he/she has decided the treatment. The sanitary assistant reported managing the encounters (from 1 to 6) by telephone or in presence. The first encounter is always a face-to-face encounter, and sometimes it involves also familiars or caregivers. Observations revealed that this encounter is managed in a comfortable room divided in two areas: a sitting area with four chairs and one low table, and a clinical area with one personal computer on a desk and two chairs (Figure 4.5). It was observed that the sanitary assistant chooses which area of the room to use basing on the preferences and characteristics of the patient, as also confirmed by the sanitary assistant. Although professionals reported that the ambulatory follows a clear roadmap to manage the encounters with the patient, education provided was described to be personalized to the clinical and psychological condition of patients ("*the education and information we give can't be standardized but must be suited to the physical and psychological condition of the patient*"). "*Giving patients generic information about the disease, assessing and helping them in recognizing and communicating symptoms, providing information and support about the treatment decision, explaining pros and cons of every option and mapping the different professional resources as well as the clinical pathway they could follow*", these were all aspects featuring the encounter managed by the sanitary assistant and the usual patient education practice as described from the professionals of the pre-dialytic ambulatory. "*Social resources as well as individuals' needs and preferences are also considered to orient them in choosing one dialytic treatment before another*", showing how the attention is on the patient rather than on the ill body only. It was also observed that active strategies – e.g., showing to the patient the dialytic room and how dialysis works - are used by the sanitary assistant to educate patients in eventually managing the treatment and in choosing among the treatment options.

**Artefacts.** During the encounter, the painting on the room's wall illustrating the dialytic treatment as well as informational brochures and leaflets on the disease and treatments are actively used to educate and inform patients, as reported from observations. It was also observed that a standardized schedule is used by the sanitary assistant to collect information, and to help professionals remember which type of information and support to give to the patients.

**Figure 4.5.** Setting 2: The sanitary assistant room of the pre-dialytic ambulatory



### 4.4.1.3.  Setting 3: The healthcare nursing service of the territorial district

**Setting.** As reported by the professionals and enriched by materials on the setting available on the website of the organization, the healthcare nursing service of the territorial district is comprised within the District 1 of the healthcare company. The District aims to take care of the healthcare and socio-sanitary problems of people living in the north-west area of Trieste, as well as in three constituencies and three other municipalities of the territory (approx. 60.000 citizens). As the webpage of the setting states, the nursing service of the sanitary territorial district aims to provide a networked nursing service for people living in the area, working together with local communities, general practitioners and the hospital in-patient and out-patient services. It offers a particular attention to vulnerable persons. Professionals described how the service provides home-based or ambulatory care to people with different healthcare and socio-sanitary problems, with most of them being older individuals with mobility problems or ulcers. These problems are often due to other pre-existing clinical conditions (i.e. diabetes) which are not properly cured because of socio-economic difficulties and led to secondary health problems (i.e. diabetic foot), as from the professionals' statements. Patients are generally referred from the general practitioners, but also from the specialists of the hospital services. The service is indeed reported by PHEfessionals to be an important hospital-territory junction ("*none of the older patients leave the hospital without being hooked by our service*"). During meetings performed in the District, it was observed that the main building of the service is located in

the centre of Trieste and comprises a floor with an open waiting room and several offices. The setting also comprises the home of individuals, as stated by the professionals ("*in the concierge care you are the one that gets in patients' context; you can also create a personalized care plan in your office, but then you need to see the evidence at the patient's home*").

**Actors.** The interviewed professionals reported that only nurses work in this service, and they have a one-to-one relationship with the individuals in charge. They reported to have a strict collaboration with general practitioners, that are updated on the care process and are often required to evaluate the medication prescriptions. A dietician is also involved in the service to help patients settling new dietary plans. Education of the single patient is thus a matter of the referred nurse, who becomes "*the reference point for the patient*", and usually involves also familiars and caregivers, as from professionals' interviews. The professionals who worked in this setting stated that being the main reference point for the patient impacts on the type of relationship with the patient and, thus, on the education delivered ("*in our work we are usually involved in symbiotic relationships with our patients*").

**Educational practice.** In this setting, the professionals reported enacting a whole clinical and educational taking over, starting from the very first meeting. The first meeting (usually lasting 60 minutes) is the occasion not only to know the sanitary history of the patient, but also to enter into setting up a complex individualized support plan, with multiple steps to be enacted to help patients understanding their problem and how to manage it ("*Most of the times our patients do not understand which is the problem, we need to educate them step by step and to know them very deeply*"). In this context, individual patient education is called by professionals with a clear well-defined name: "therapeutic education", meaning for them an educational plan for informing, educating, and activating patients in self-managing the disease condition. This plan was described as including - in addition to practical clinical activities, i.e. medications, exams, treatment administration - also the definition of individualized goals and tasks for the individual to manage this plan at home ("*we deal with therapeutic education, but with EKG, intravenous therapy, ostomy management, medications and a lot of other things as well. We make an individualized caring and educational plan, that sometimes is a long-term plan*"). Even if clinical activities are described to be a relevant part of the work of the nurses of this service, the health problem is treated by addressing both clinical and pedagogic needs ("*the ulcer is the last thing, you need to look, support and point out all the rest*"). This is also because health problems are usually considered by professionals the result of a psycho-social background that need to be taken in charge ("*it's not that I see the ulcer and I stop there, I need to go beyond because the ulcer is the tip of the iceberg. We need to have a full knowledge of our patient – social, psychological, sanitary – to understand how the health issue happened and to sustain*

*the educational process*"). During the workshops, the professionals of this service reported how the plan also integrates different available resources. Indeed, being the home the main setting for patient education, therapeutic education also features the contextual and social resources/obstacles for realizing this plan. They reported that relatives and caregivers are most of the times engaged in it. Consequently, the perspective raised by therapeutic education in this setting is of providing education not only to a patient but to an individual that has a specific name, history, and own context. Professionals described that, after the first meeting, patients are usually seen from one to three times a week, for months. Here, skills building, problem solving and goal planning strategies are relevant for professionals, as from their words, to support clinical activities and educate patients. Some of them also reported asking individuals to complete daily diaries or to take pictures of the health problem ("*it happens that I ask to the patient to write what he has done during the day, symptoms, medications…this helps me a lot, and also patients are happy when they see that the problem improves. Sometimes I also ask to take pictures of how the medication evolves*"). The professionals reported to have a high sense of responsibility for patient education ("*most – if not all - of the nursing activity is strictly related to therapeutic education*"), and to feel to be the ones with the strictest contact with their patients ("*we almost live their life with them*") and the central cells of a whole capillary territorial network ("*we are lucky because in the home-based care context we all invest on therapeutic education*", and "*there is this common ground for a whole caring idea in the District*"). The professionals of this setting were also the ones that mostly reported a need for defining and structuring educational workflows transversal to every clinical context ("*what it lacks is a standard procedure, that is common for everybody. We have a strong idea and philosophy for therapeutic education in the Districts, but then the way it is applied changes a lot from one person to another*").

**Artefacts.** The nurses working in this context reported to usually adopt informational leaflets or workbooks to support the educational practice.


### 4.4.1.4. The key organizational and cultural differences in patient education across the care settings: A conceptual model

From the description of the three settings, a model with three key aspects (or axes) was made to help connoting the patient education practice in the three settings:

1. Contents of patient education (information vs. therapeutic education) (black axis),

2. Perceived responsibility for patient education (low vs. high) (green axis),

3. Focus of patient education (disease vs. person) (orange axis).

Using these 3 axes, a conceptual model was qualitatively draw up to give a graphical presentation of how patient education was enacted in the different care settings (Figure 4.6). In particular, words used by professionals to describe patient education were used as main anchorages for defining the poles of the axes, and observations were used for labelling the axes of the conceptual model.

**Figure 4.6.** The conceptual model with three key axes explaining the organizational and cultural key differences in the usual patient education practice across the three care settings
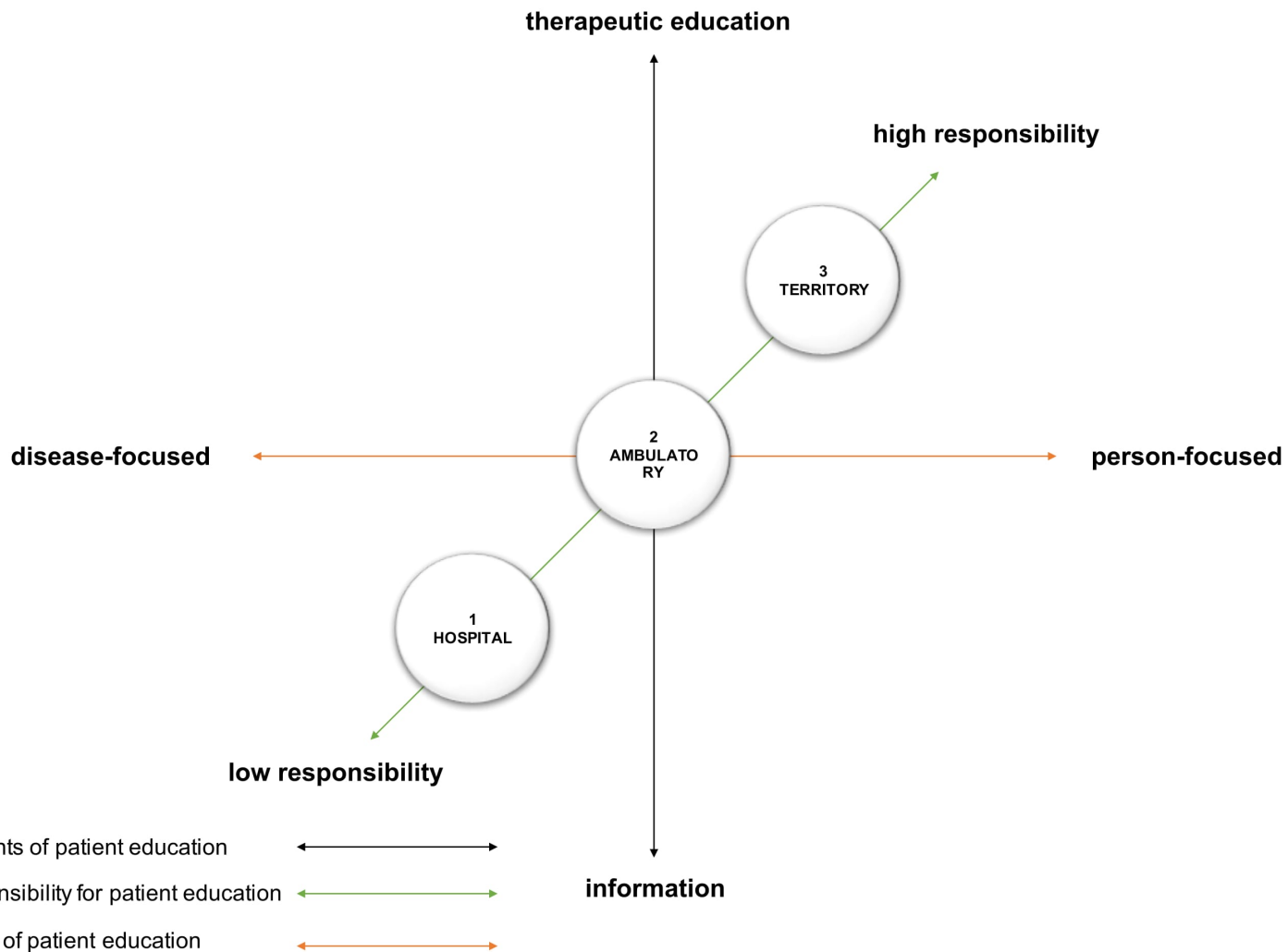


The three settings seemed to firstly diverge for the type of educational contents provided (black axis in Fig. 4.6). Education provided in the inpatient unit was mostly described in terms of providing information and knowledge to patients, with the main concern of professionals was to give patients unstructured and basic information on the disease and therapies ("*my duty is to explain to the patient what he/she has to do and not to do, maybe are only four things but they have to be clear*"). From the other side, education provided in the daily environment of the territorial service went beyond

informing the patient; professionals of this setting reported an idea of patient education as "therapeutic education" (as they referred to patient education using this specific label), with the support of different social, medical, emotional patients' skills through structured strategies (see the previously described adoption of daily diaries or pictures of medications). In the middle, as described before, education provided in the ambulatory had a strong information component but also included an educational part to help individuals in self-managing the decision-making process and the possible treatment options. Thus, a first axis could be recognized speaking of the "contents of patient education", as the three settings used different labels for describing patient education: "information" (setting 1), "education" (setting 2), or "therapeutic education" (setting 3).

The perceived responsibility for delivering patient education was then a second aspect making settings differ (green axis in Fig. 4.6). In the inpatient unit, patient education was mostly seen as a challenging personal initiative ("*we usually think that patient education is a somebody else responsibility, but of course it is ours too*"), whereas in the other settings higher degrees of sense of responsibility emerged. In the second outpatient setting, individual patient education was indeed reported being an important part of the clinical work (ambulatory context: "*actually the clinical aspect of my job is quite marginal, it is the educational aspect that is much more preponderant*"), and in the third territorial setting it was reported as a fundamental aspect of one's professional life permeating all the work activity ("*most – if not all - of the nursing activity is strictly related to therapeutic education*"). This was probably due to perceive being the central educational cells of a whole territorial system, the ones leaving in a strict contact with patients ("*we almost live their life with them*"). Therefore, a second axis labelled "responsibility for patient education" helps showing how patient education is differently taken in charge from professionals in the three settings, from settings perceiving low levels of responsibility towards patient education (setting 1) to settings perceiving higher degrees of responsibility (settings 2 and 3).

Finally, the three settings appeared differing for the main focus of patient education (orange axis in Fig. 4.6). If, in the inpatient unit, the focus of patient education was mostly on the disease and therapies, in the ambulatory attention was paid also to the way patients adjust to the disease condition and to their illness experience ("*individuals' needs and preferences are also considered*"). Finally, in the territorial district, the entire home of the patient was reported to be at the centre of care, being the care system that needs to adapt their practice to the home of the patient, not the opposite. Thus, a fourth axis named "focus of patient education" can be envisaged differently connoting the three settings, from a focus on the organic disease (context 1) to a focus on the person in the daily life environment (context 3).

## 4.4.2. The experiences with the PHEinAction implementation

In this section, the main experiences with the intervention implementation are reported. In each setting, three common themes are outlined concerning the experiences that different care settings had when implementing *PHEinAction:* the implications for the professionals' workplace, the implications for the teamwork, the implications for the interactions among settings.

The presentation of the findings was enriched with excerpts from the observation field notes, the interviews and the workshops' transcripts, which provided first-hand descriptions of participants' on-going experiences with the proposed change. The workshops and the informal conversations allowed to complement data on the single selected care settings with those ones on the other similar settings. As the data collected in this study came from a sequential on-going process involving different care settings with different speeds with the implementation, data evolved over time. If in the first phases data accounted more for the participants' expectations/thoughts on the possible implementation, in the lasting phase they concerned more the concrete experiences of implementation. In particular, data here reported accounted for the first phase of data collection (Figure 4.2). Some relevant data from the second phase – and particularly from the 2nd workshop – were also used for describing the on-going experiences of implementation within the settings.

The reactions to the *PHEinAction* implementation were in some cases the result of how the professionals perceived *PHEinAction* and experienced it during the implementation. The perceptions related to *PHEinAction* of the group of professionals involved in this study were close to those ones reported at the end of the Chapter 3 (section 3.4.3.1). During the collection of the experiences of use of *PHEinAction,* some specific aspects emerged and perceptions become deeper during time. In particular, the professionals experienced the opportunity offered by the scales and the exercises to collect and give space to the patients' voices and emotions, as well as the possibility to define specific goals of care. Professionals also reported that "*the intervention needs time to be managed and fully understood*", and that "*it works at a different level compared to our educational practice, it's probably complementary because it's more a support to the process of identity elaboration of one's health condition and to how care can be properly managed, but we still need to provide specific information to our patients*".

### 4.4.2.1. Setting 1: The inpatient units

**The implications for the professionals' workplace.** The professionals working in the inpatient units of the organization and involved in the research were the ones that most reported seeing in the

intervention implementation an occasion to work on and get back the relational, empathic and emotional components of their care profession, often leaved behind in these settings to follow the strict daily schedule and the technical care activities ("*it's a way to regain our professional identity, especially in the inpatient settings where times are strict, we are becoming more and more technician and we frequently loose the emotional component of our work: this intervention helps us to focus on that again*"). Therefore, the *PHEinAction* intervention was coherent with an often-lost part of their professional identity that values the openness to a meaningful relationship with the patient rather than work technicalities. For them, this was mostly related to the possibility of having something concrete – such as the scale and the exercises – that opens to the patients' voice and experience, without only focusing on the disease ("*if we see the patient only as a disease nothing is getting resolved, we must see all the whole person, and this work helps me*"). An example of how the intervention worked for these professionals as a tool for opening to the patient's voice, was the effort of the nurses in the cardiology inpatient unit to align the goal setting activities proposed in the intervention with their specific clinical goals (""*concerning health goals, we always make such goals from our professional perspective, and of course it's important to start listen to the health goals of our patients that can be different*"). By regaining the relational and empathic dimension of their profession, some of the professionals working in the inpatient units reported during workshops and interviews feeling to have the possibility to gain back an important part of their work ("*thanks to what I'm seeing and experiencing in this intervention, I'm recovering the heart of my work*"). As the professionals were aware that their educational efforts were mostly informational and fragmented, the intervention was an occasion for them to better organize their current processes of care and to optimize existing practices, helping structuring unstructured and implicit practices ("*this is really the occasion to standardize our practice, that is often implicit and vague*"). At the same time, making live together the need for a focus on the organ care with the desire for looking patients in the eyes was perceived challenging by professionals in terms of skills, times and practical resources. Indeed, during the workshops they reported a difficulty in taking together the intervention with the usual activities they had to continue: "*our priority still remains transmitting specific information to the patients, helping them in managing the experience of care is surely important but it risks to lead us away from our work priorities*". During the interviews in the cardiology unit, the intervention's procedures and workflow were complained to be too long, demanding and complex for the work speeds of inpatient settings ("*it seems to me too long, I need something easier, there are too many papers and I'm not able to assess patients so many times, I need a one-shot thing*"). Compatibility and consistency of the workflow of *PHEinAction* with the existing procedures was also reported as being a difficult aspect, especially for the structured times and for the amount of materials to be organized and

managed. They thus reported a need to exploit their already-in-use practices and materials – such as the educational schedule of the cardiology inpatient unit – and embed the intervention in them. The same was complained for the spaces available for delivering the sessions, being the bed of the patient the most common space for education and requiring the intervention an intimate environment. Also in this case, during the interviews, the professionals started reasoning on how to use at best what they had, by for example closing the curtain that divides one bed to another or by sitting on a chair when speaking to the patient.

**The implications for the teamwork.** In the cardiology unit, it was observed how the strong camaraderie among nurses and the need to work side by side with doctors made the buy-in of the other colleagues extremely important for implementing the intervention. Indeed, even if at least two key professionals for setting were identified and involved in the implementation process, these were not enough in the inpatient units for allowing a sustainable change. The poor awareness and involvement of the other colleagues, and the consequent lack of an intra-group supportive climate for the intervention ("*I know that we will be considered the scribbles of the group*"), enhanced the perception of these professionals of being alone and with too many changes at too many levels to manage and implement for the poor resources committed to the change ("*I don't like that we are feeling a little bit alone, abandoned by the system*"). As they had to deal with limited practical resources, and emergencies did not allow coordinators supporting extra activities, engaging the most direct heads and supervisors was considered almost vital to not risk being stigmatized for investing time and resources on the project ("*we need to engage other professionals from our context, as our head nurses because without them in the boat we don't go very far*"). They felt the need of collecting objective data on their work and efforts so to buy their deans in, and being inside a research project was helpful for them in this way ("*knowing that we are within a research project and that this will hesitate in something scientific is really motivating, I really appreciate this*").

**The implications for the interactions among settings.** Despite the professionals working in these settings reported the educational work being mostly in charge to other care settings, they were also aware to be the starting point of care able to give the first imprinting to the self-care activities of patients. Therefore, even if they felt the *PHEinAction* starting session as feasible and useful to be performed during the hospital stay, they also recognized during workshops a difficulty in proceeding with the second sessions and the need to collaborate with the other services to hand the patients' care and the patient engagement support over ("*I see in that a possibility of discussion and connection among colleagues*"). The difficulty in having structured procedures defined from above to connect different care contexts and build integrated workflows so to hand the work over was reported to be the first reason of possible failure of the implementation process ("*it happened that I started*

*PHEinAction with a patient who was referred to the territory, but there was nobody in the territory that continued my work and I felt passing the patient into the dark, and so all died there*"). In this, during the workshops, the professionals complained a difficulty in communicating with the settings organized in a different way ("*it's difficult because we have very different languages, it seems that the hospital and the territory speak completely different languages*").

### 4.4.2.2. Setting 2: The ambulatories

**The implications for the professionals' workplace.** The professionals from the other settings looked at the setting offered by the ambulatories as the optimal one for the *PHEinAction* implementation, because of the possibility of having rooms, relaxed times, and a visit schedule compatible with the intervention's workflow ("*probably in the ambulatory it's easier to implement the intervention, they don't deal with strict times and emergency, and they have their own spaces for seeing patients*"). This was not always confirmed by the professionals working in this setting, which complained a difficulty in having protected spaces, without distractions. However, the professionals working in the pre-dialytic ambulatory confirmed that time was a good resource for implementing *PHEinAction*, as their schedule allowed them to perform long consultations with their patients ("*which is our biggest resource at the moment? Time! We are lucky that we are a small ambulatory and we can dedicate time to our patients*"). Furthermore, patients attending the ambulatories were also considered – generally by all professionals - the ones in a good phase of the care journey for being involved in patient engagement support, because "*they are neither in an acute phase where managing the disease is a priority neither in a particularly impaired phase where autonomous activities of daily living are limited, thus limiting the possibility to propose the intervention*".

Then, the professionals working in this setting reported to be accustomed to explore patients' priorities and needs, their activity was aligned with the activities proposed by *PHEinAction* ("*I do not perceive at all this proposal as off from our reality and what we do*"). In one of the ambulatory involved, the bariatric surgery ambulatory, this alignment facilitated the *PHEinAction* implementation, as it was the setting that most easily and rapidly succeeded in embedding it into practice. This was also a consequence of dealing with individuals already motivated to change, as perceived by the professionals working in the territory who reflected on the bariatric surgery ambulatory experience: "*in bariatric surgery you have a target that is already motivated, patients who arrive to surgery have already done a personal motivational path, so it becomes easier to propose the intervention to them.*" However, in other ambulatories such as the pre-dialytic one, the same alignment slowed down professionals' motivation to change their already existing practice, as some of them did not see a specific need for improvement. This slow-down was reported to be also a

consequence of the lack of patients' motivation, as from the words of the professionals working in this setting: *"one has to be willing to put himself out there to move a change… the work with a person that is not willing to change is superficial, waiting for the right time to hang him up for a change."*

**The implications for the teamwork.** In the ambulatories, it was observed a greater feasibility to start implementing the intervention also if few professionals were involved. A certain autonomy in the work of the single professionals was observed in the pre-dialytic ambulatory, and confirmed by other outpatient professionals (*"we are like a production line, everyone is a piece of a chain"*). Therefore, the main point for the professionals working in the ambulatories was to identify the key professional for providing the intervention. For example, the professionals of the pre-dialytic ambulatory questioned themselves about the competencies that the provider of *PHEinAction* needed to have. Particularly at the beginning when they had no experience with the intervention, they were worried to tread on the work of the Service of Psychology of the healthcare organization. Teamwork reasons mostly sustained the motivation of these key professionals for implementing *PHEinAction.* In the pre-dialytic ambulatory, it was, for example, a way for the sanitary assistant to acquire a greater role in the team, and to better interact with the medical professionals, as revealed by the interviews and the informal conversations (*"I'd like having more patients referred by the doctor, and so if he will refer to me patients for the intervention it would be good for me"*). In the bariatric surgery ambulatory, the key nurse involved in the implementation reported that most of her colleagues were not aware of the work she was doing, but the doctors who were doing the visits with her were giving her space for recruiting patients. Therefore, in both the settings, it was observed an openness from the medical and the nursing disciplines to the intervention implementation, also as a way to improve teamwork collaboration. This was also demonstrated by the fact that these settings particularly complained the need of multi-disciplinary group activities (*"what we need is a multi-disciplinary group, so we can share what we are doing with the other colleagues"*).

**The implications for the interactions among settings.** Differently from the inpatient settings where being the starting care point limited the possibility of implementation and asked for trans-setting solutions, in the ambulatory setting the need to work closely with the other settings for the intervention implementation was less evident, as from the on-going observations and the informal conversations. Indeed, even if the professionals in this setting recognized the need to better interact with the inpatient and territorial services (*"probably the point that still don't work is the collaboration with the nursing territorial service, we tried to work in this sense but it's difficult"*), this interaction was not reported to be particularly crucial for implementing *PHEinAction,* except for transmitting information on the patient engagement changes observed during the intervention to other settings or to collect follow-up measures (*"I'd like to know if what I do will produce some changes in the long-*

*term, so probably I'd need to contact the colleagues of the other services, but we don't have a clear procedure for this and you never know who will take in charge your patient").*

### 4.4.2.3. Setting 3: The territorial services

**The implications for the professionals' workplace.** During the workshops, the professionals from the territorial services revealed that the most important aspect for them affecting the *PHEinAction* implementation concerned the complex care needs of their patients and the need to consequently adapt the intervention's contents and procedures (*"our main point is that we already know that this [intervention] cannot work in this way for our patients, but we really trust in finding a way feasible to our setting to engage them"*). On one hand, the professionals felt the problem of engaging their patients in care and of findings tools and solutions for it as highly relevant for their practice (*"we are fatigued but we really feel this problem, there are persons with chronic conditions who do not listen to our advises, so surely this is a problem we need to try to solve"*). On the other hand, they highlighted how it was hard for them to engage in the intervention all their patients (*"we deal with patients that are neither able to read, and also if they are able to read they show difficulties in correctly completing the scales already, some of them are not able to write or they speak only in dialect"*). Indeed, they reported to deal with patients with a tendency of disguising their health behaviours (i.e., diabetes), or with patients with advanced age and low socio-economical background. During the workshops and the informal conversations, an often-reported obstacle in this setting to the *PHEinAction* implementation was represented by the lack of patients' motivation to participate and change (*"there are a lot of patients that are not motivated to engage in it. In some way, these work is useful for patients that are already motivated to change"* or *"we need to refer to a population of individuals that are often not motivated, and they are also used to be not listened because they manage a chronic disease from a long time"*). During the interviews, the professionals also described how, even if some of the patients accepted to participate, resistances (fears, embarrassments) emerged in writing or telling their experience, and this impaired the intervention delivery and the relationship with the patient (*"one was even scared of seeing that he had to write or tale something of him"* or *"sharing something intimate in writing is embarrassing and open to resistances"*). This was referred to be the result of the close intimate relationships with the patients in charge, as the professionals reported to be afraid to propose something that could create discomfort to them and to their patients. For example, during the workshops and the interviews, they reported a difficulty in identifying eligible patients without introducing a sort of subjective screening procedure and without opening to possible errors (under- or over-estimation of the patient's ability) able to create uncomfortable situations in the relationship and thus become counterproductive (*"it is very difficult to have clear in*

*mind which patients to involve, I can proceed basing on my evaluation, but I often realize that my evaluations are not always correct…it happened that I engaged a patient that then I saw he was not able to do the tasks and this became frustrating*"). At the same time, having objective instruments like the scales for grasping the patients' experience was reported by some of them during the workshops to be a good way to objectively bring to light possible misperceptions of the professional on the patient ("*it helps objectifying your misperception of the patient, it makes your thought scientific*"). Therefore, even if the scales and the sharing of assessment results were considered valuable for this, the other aspects of the intervention were difficult to implement in their practice, as stated during one of the workshops ("*the biggest thread is knowing already that we need to adapt the intervention to our practice, it is too demanding for us as it is now*"). During informal conversations, they asked, for example, to work on caregivers, or to start implementing only the scales, or to adapt materials to what already in use in their practice. In general, during the workshops, the professionals from the territory complained the lack of specific contents on the disease, as well as of a linear simple pathway that could be applied to all the persons ("*we need a linear pathway that we can apply and that suits all, these exercises and tools are too demanding for the type of patients we have*").

**The implications for the teamwork.** Most of the professionals from the territory involved in the implementation were nursing directors from different territorial services, who were asking to frontline the nurses of their team to implement the intervention in their practice. The disciplinary alliance in the territorial services and the involvement of the directors in the implementation process were both aspects observed during the informal meetings with the territorial teams as able to facilitate the implementation. Furthermore, none of the professionals working in the territory reported specific teamwork reactions to the *PHEinAction* intervention proposal, which mostly concerned on the contrary the relationship with the service users or with the other care services and the organization.

**The implications for the interactions among settings.** The professionals from the territory were the ones that mostly complained, during informal exchanges, the burden of managing the demand of new cultural changes from the organization in the direction of a better integration of services. During the workshops, they reported to feel struggling in managing the tip of the iceberg (i.e., the *PHEinAction* implementation) when they were actually dealing with an overall iceberg of change ("*I'm a little bit discouraged, because it's true that this is a cultural change for the overall company, but we need to start using this as first step for a wider change, maybe by delimiting the setting of action*"). In this setting, the main reasons for decelerations in the implementation process concerned the limited staff resources, and the number of things to change during the specific moment of life of the organization, as reported in the field notes taken during the informal exchanges. The burden was probably related also to the fact that these professionals' thoughts on the intervention implementation were mostly in

the direction of using it to integrate care services. Indeed, during the implementation process, they particularly reasoned on how to create *PHEinAction* pathways across care services. They asked for defining top-down organizational procedures to support the implementation within an integrated-care context. For example, in the 2<sup>nd</sup> workshop, one of the territorial nursing directors proposed: "*all the patients we can't ensure to continuously take charge of – as individuals and as service – should be excluded, because giving the scales without doing nothing after it's useless*", and some of them stated that: "*single-context patient engagement pathways are pointless broken off pathways*".

### 4.4.2.4. The key experiences with the intervention implementation in the light of the settings' organizational and cultural key differences in patient education

As professionals were asked to add *PHEinAction* to their educational practice, the organizational and cultural key differences in patient education practice among the care settings (section 4.4.1.4, Figure 4.6) had a key role in explaining the different experiences with the implementation in the settings (sections 4.4.2.1, 4.4.2.2, 4.4.2.3). Therefore, the 3-axes conceptual model from the section 4.4.1.4 made for explaining the settings' organizational and cultural key differences in patient education (Figure 4.6), was used to investigate the experiences of implementation of *PHEinAction*, as described in the previous paragraphs. The conceptual model and the axes were thus here used to understand the described experiences, that were synthetized into macro-themes and qualitatively projected into it (Figure 4.7). A particular attention was placed on the challenging experiences, those ones that were reported to hinder the implementation. For example, as in the ambulatory setting no particular challenging experiences were collected for the "focus of patient education" axis, these were not projected and reported in the Figure 4.7.

**Figure 4.7.** The key experiences with the implementation in the light of the settings' organizational and cultural key differences in patient education
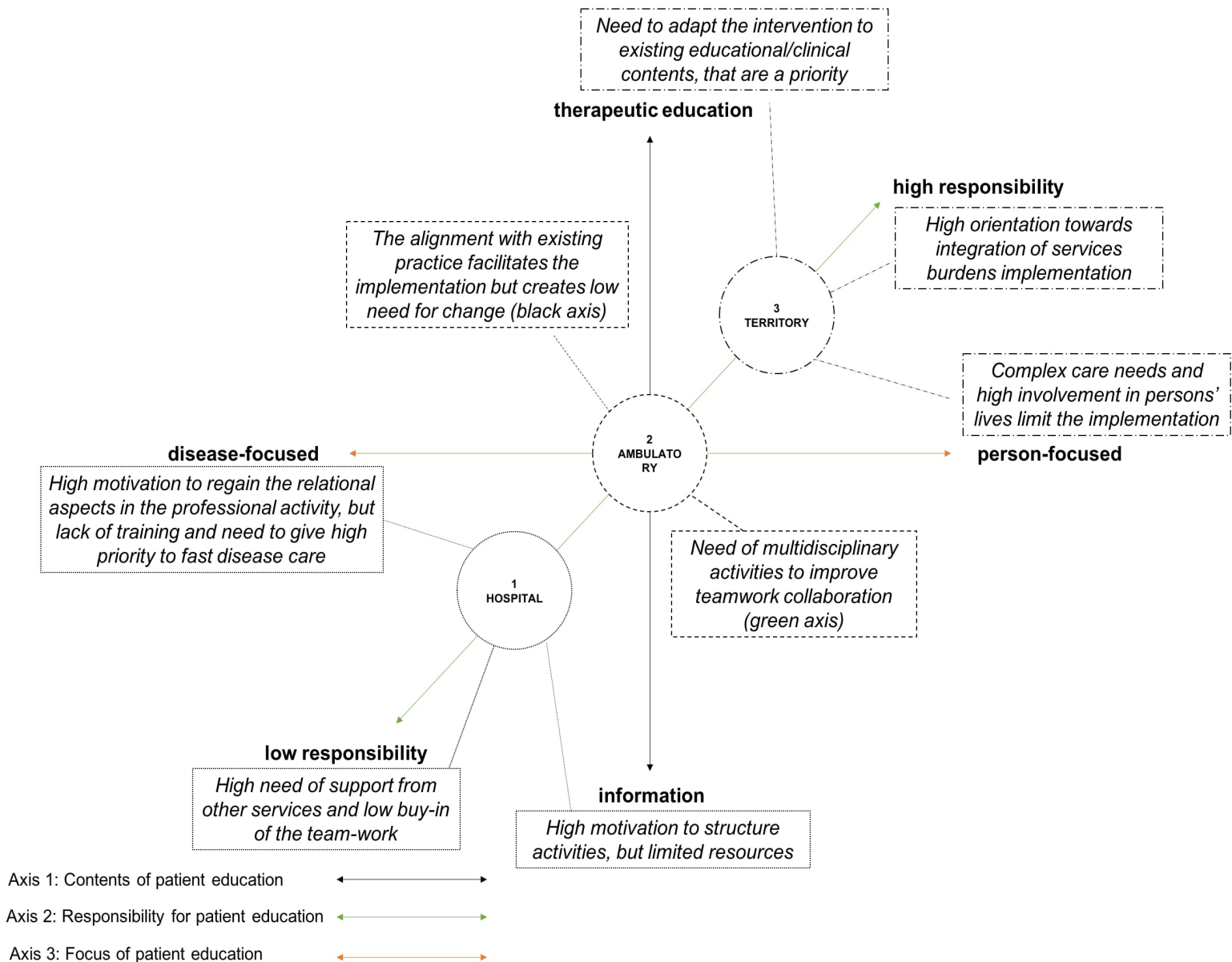


Following the first axis on the contents of patient education (the black one), an "information" pole features inpatient settings mostly intent on providing information, which were also those ones with a high motivation to better structure and strengthen their educational activities, but complaining the limited facilities, times, spaces for doing this. At the opposite of the axis, the territorial settings with an idea of patient education as "therapeutic education" referred a need to give priority to this strong idea, mostly related to the disease-related contents, and align the intervention to it with substantial changes. Then, in the middle, the "educational" contents provided in the ambulatory were reported to be particularly aligned with those ones offered by *PHEinAction,* and, if in some of these services this facilitated the implementation, in others lowered the motivation to change existing practice.

Therefore, the main features of this axis that can help explaining the experiences of the professionals mostly related with the goals and the structuring of the educational activities, and highlighted the threats from both the poles of the axis for the implementation.

Looking at the second axis on the perceived responsibility for patient education (green axis), settings with low perceived responsibility such as the inpatient ones were triggered in the implementation by the need of involving the other care services and the poor buy-in of the different professionals of the teamwork, whereas settings with higher degrees of responsibility for patient education stressed more the potential of multidisciplinary teamwork activities for sustaining the implementation (setting 2), or, finally, the challenge and burden of reasoning towards an integration and collaboration across care services, also in the implementation (setting 3).

Then, in the first pole of the third axis on the focus of patient education (orange axis), the inpatient settings with a focus on the disease were generally also those ones seeing in the intervention the opportunity to see at patients not only as carriers of a disease but also as persons, but also requiring training for managing relational aspects of care and complaining a difficulty in giving priority to the disease care and, in addiction, find time to support more deeply the patient. On the opposite pole, settings with a focus on the whole person complained the complexity of the individual in charge and the deep personal involvement in individuals' lives as relevant aspects affecting the implementation. In the middle, patient-focused settings were those ones that mostly reported a good balance between the difficulty in being involved in a relationship with the patient and the burden that a high involvement could bring, and where the type of approach to the patient was considered helpful for the implementation.

### 4.4.3. The solutions to promote the PHEinAction implementation

From the participatory process, and particular during the last phases, different practical solutions were identified and enacted to promote the *PHEinAction* implementation. Different aspects were deemed as critical for the implementation by the professionals, from the difficulty in anchoring the intervention to the existing workflows and practices, to the need of buy-in the other colleagues within the workplace, from the wider request of a deeper involvement of the organization in facilitating the exchanges among services, to the general lack of structural and financial facilities. At the time of the last workshop, only two settings had started with a systematic implementation of *PHEinAction* in their educational practice (the bariatric surgery ambulatory and the cardiology inpatient unit), for a total number of 36 patients involved. Most of the other settings made tentative to use it in their practice, but without enacting a systematic plan of implementation. Then, few settings did not either

try to use it, but implemented some part of it, such as the assessment of patient engagement through the scales and the sharing of assessment results.

Therefore, the research group and the professionals agreed during the second research phase to develop a series of artefacts and enact a series of actions that met the needs of all stakeholders to enforce the implementation. In this section, the concrete actions performed and the artefacts developed are reported. Even if some of these were tailored to the single settings, the type of actions, the artefacts, and the tools created were transversal to the settings.

### 4.4.3.1. The PHEinAction pathways

The first action taken by the professionals and the researchers was the co-design of *PHEinAction* pathways where *PHEinAction* was entwined into the existing educational practice of the single settings. In all the settings, this was perceived as a helpful deployment to anchor the intervention to the existing workflows and practices, so to capitalize on existing practice, complement the activities of the intervention with the educational/informational ones, and make the *PHEinAction* procedures suitable to existing workflows. This was a sartorial work, which took different shapes in the different settings to become successful ("*we are aware that we have to do a sartorial and context-tailored work*"). In this sartorial work to adapt the intervention to the usual educational practice, the main point was defining the existing educational turning points and anchor the intervention turning points to them. In particular, two aspects were particularly discussed with the professionals for designing the *PHEinAction* pathways: the patients' eligibility criteria and the starting point of the first session. Considering the co-definition of exclusion/inclusion criteria for patients eligible for the intervention, it was particularly defined to exclude: (i) not individually in charge patients, (ii) patients not in charge for at least one month (in the hospital context this was changed in: patients for whom it is impossible to plan a discharge and not available for a second phone contact after one month), (iii) patients with cognitive impairments, (iv) patients not able to read, write, or understand Italian. Then, another crucial effort was defining the best starting point to manage the first session ("*defining yet the best moment for the first session means having already done half the work, then all will happen accordingly*"). In the inpatient setting the first session was generally linked to the discharge meeting – so to leave the hospitalization days to the first evaluation of eligibility and recruitment -. In the ambulatory setting it was anchored to the first visit of the nurse or of the sanitary assistant – after a first referral/recruiting moment during the first medical visit-. Finally, in the territorial settings it was decided to implement it after some meetings, so to have established a relationship with the patient and to not burden too much the clinical and educational activities of the first encounters. Figure 4.8 provides an example of the *PHEinAction* pathway co-defined with the pre-dialytic ambulatory.

**Figure 4.8.** An example of PHEinAction pathway defined with the pre-dialytic ambulatory
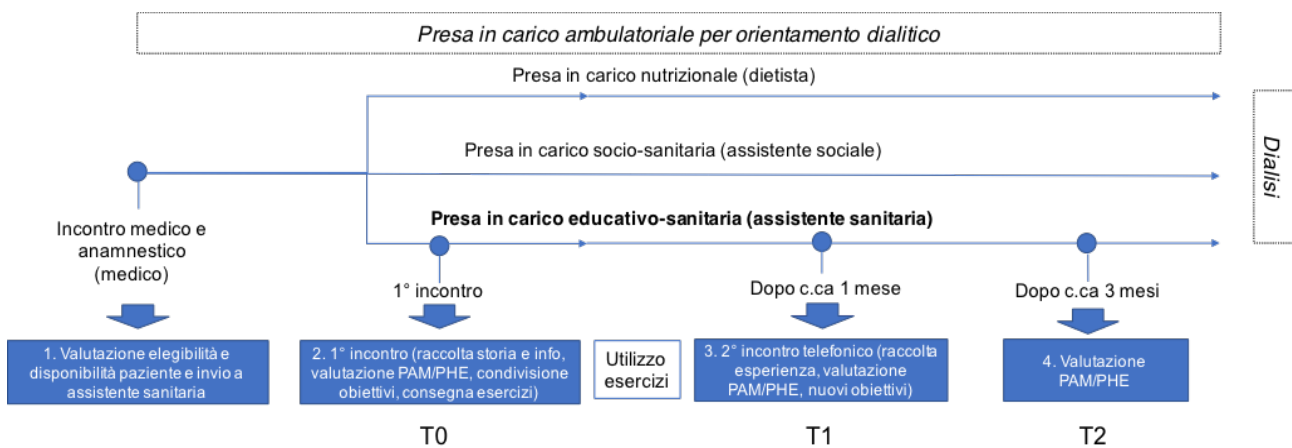


Inside these pathways, some adaptations of the *PHEinAction* intervention's procedures and contents (i.e., by also involving caregivers, by making the second session telephone-based, by merging some components of the intervention with other already in use) were enacted to meet the needs of the single settings. Then, specific outcome measures for the single settings were defined to evaluate the intervention, basing on the clinical characteristics of the patient in charge to the settings. For example, in the inpatient settings it was particularly valued the importance of including clinical measures and the satisfaction of patients for the care received, whereas in the territorial settings it was also proposed to include measures on professionals' outcomes.

Even if the specific *PHEinAction* pathways were considered a useful deployment for beginning the implementation and collect first pilot experiences ("*in this way we can assure as a small reserve of positive experiences that can allow having first data about our patients and about ourselves*"), it was agreed with the professionals, especially during the second and the third workshop, that a further step would have been connecting these pathways and creating integrated *PHEinAction* pathways. In particular, it was discussed how to proceed in this sense and if to implement the adoption of the scales throughout the care and propose the intervention only in the more favourable settings/care moments. This idea particularly matched the difficulty of the territorial services in using the intervention, which considered to implement only the assessment through the scales and the sharing of assessment results as first engagement step feasible also for particularly complex patients.

### 4.4.3.2.    The PHEinAction artefacts

Other actions detected and enacted during the second phase of the participatory process were the design or adaptation of existing artefacts to support the intervention implementation and its insertion in the existing practice.

A first artefact was the design of a leaflet and informed consent form to propose the intervention and explain it to patients in an easy way. This was also a way to facilitate professionals in having clear the aims of the intervention, and to share procedures and information for the management of possible pitfalls.

Then, a second artefact consisted in the development of an educational sheet with information on *PHEinAction,* or the revision of that one already in use in some of the settings. In particular, this was proposed in some of the settings (particularly, the inpatient and the territorial ones) to facilitate the recording of the key information on the education provided and on the *PHEinAction* patient's pathway, as well as to share this data with the other colleagues or with the other settings. This educational sheet included clinical and socio-demographic information on the patient, the summary scores of the PHE and PAM scales (and others relevant for the settings) in the different time points, the inclusion/exclusion from the intervention with reasons, the type of support provided (information, education, emotional support, behavioural support, PHEinAction), the main support mean (verbal, written), the clinical goals and those co-defined with the patient.

A third artefact was the definition of common procedures for not motivated patients. During the last workshops, it was co-decided to draw a checklist of possible strategies to manage not motivated patients, to be evaluated case by case. Among these strategies, it was included the possibility of using only the scales (with the sharing of assessment results, as mandatory step), to adopt motivational interviewing strategies (and, thus, widen the participation in the motivational interviewing training offered by the organization to the employees), to monitor the patient and wait for a good moment to propose the intervention, or to involve/target caregivers.

Finally, in some settings, it was proposed to better structure the disease-specific educational materials in a way that could have better suited the *PHEinAction* intervention. For example, in one inpatient and one territorial setting, it was developed a checklist with the key clinical actions/goals for the main health problems professionals had to manage, to be shared with patients and to be actively used during the *PHEinAction* sessions to facilitate the goal setting and planning activity, as well as the health information management.

### 4.4.3.3. The patient engagement seminar

During the second workshop, the participants agreed to organize a sensitizing moment for intra- and inter-group colleagues – an awareness-raising seminar on patient engagement - where to report the work done, the reason why they participated in the project, and the available data about the intervention. This was held at the end of the research process, at the sixth month. It was a one-day seminar that was open to all the interested person of the organization (it involved more than 50

professionals with different roles in the organization) and to all citizens. All settings involved in the research presented their activities connected to the project and the implementation of *PHEinAction*. Oral sessions also involved relevant key stakeholders of the organization, such as the nursing director, who were invited to open the seminar so to strengthen the motivation of professionals and to sustain the organization's commitment to the proposed change ("*all these formative moments can be tiles of a cultural change strategy if we involve the key actors*" – project coordinator -).

Similar moments were defined to be useful also in the future to raise awareness among colleagues and facilitate the implementation. In particular, it was stressed the relevance during these meetings to strengthen the involvement of professionals from different disciplinary backgrounds, in particular medical doctors and therapists.

### 4.4.3.4.  The on-going training and the peer group supervision

A process of on-going training was required by the participants, particularly for improving their communication skills, their leadership, and the capability to work with caregivers in particularly compromised situation where proposing the intervention was considered not feasible. In particular, the training offered by the organization on communication/motivational strategies (i.e., motivational interviewing) was used as a useful occasion to complement the relational skills required by the intervention. Then, the organization approved two different training activities: (i) a leadership and employee engagement training to strengthen professionals' capability to promote their role and the change within the organization, (ii) a caregiver engagement training to build, with professionals, key strategies to involve caregivers in the care process.

Finally, constant encounters among the professionals for peer supervision were organized to support the capabilities and skills of the professionals in the delivery of *PHEinAction*. These were occasions to discuss how to manage materials and to share the practical experiences collected during the implementation process ("*you need specific skills to manage this, it's good to know that we can have a space where we can discuss our difficulties and learn from the experiences of each other*" – territory, nurse - or "*it's important we continue to ensure some moments where we can consolidate what we have learned and done in the field*" – hospital, nurse-).

### 4.4.3.5.  The actions for promoting the implementation in the light of the settings' key experiences with the implementation

In this last section of results, the model developed to investigate the patient education practice in the different care contexts and enriched with the experiences of professionals with the implementation (Figure 4.7) is used to understand the solutions enacted to promote the intervention implementation

in the organization. Indeed, these were the result of the key challenging experiences with the implementation, that were in their turn a result from the different patient education practices in the care settings. In Figure 4.9, the solutions defined are qualitatively projected into the conceptual model to understand them in the light of the settings' key experiences with the implementation. The final resulting map is, thus, the step-by-step result of the participatory process, from the patient education practice, to the experiences with the *PHEinAction* implementation in the educational practice, to the solutions enacted to promote the implementation.

**Figure 4.9.** The actions for promoting the *PHEinAction* implementation in the light of the settings' key experiences with the implementation
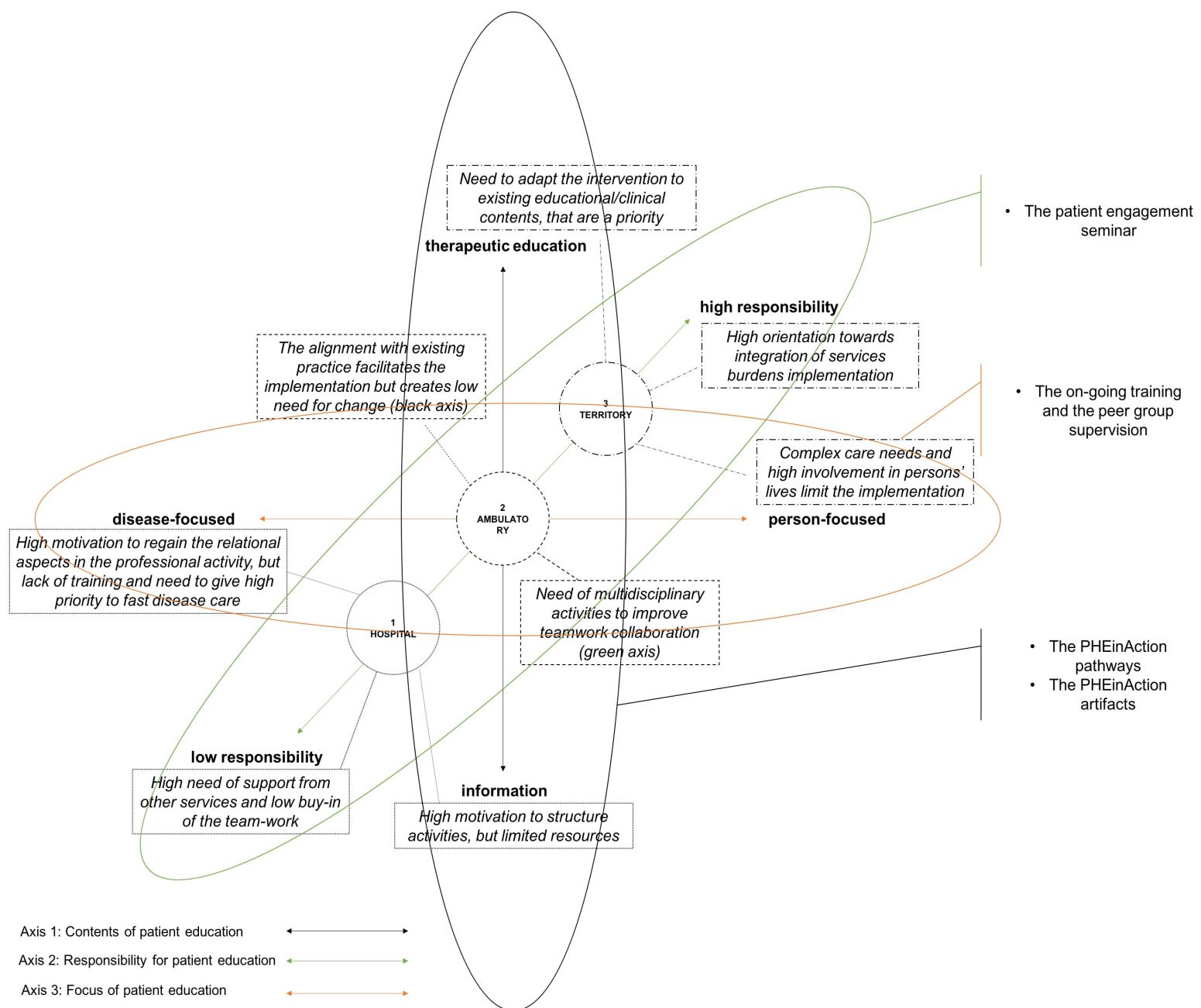
The first action concerned the co-design of *PHEinAction* pathways and artefacts with the different care settings. These were both a response to the need across settings to align the *PHEinAction* contents and procedures with what already in practice, in the direction of a better structuring and exploiting of existing activities or either of an adaptation and integration of the intervention to educational materials and activities. Therefore, they concerned the experiences of implementation positioned on the axis on contents of patient education.

Then, the patient engagement seminar was the result of the experiences across settings concerning the need to improve the buy-in of the other intra- and inter-group colleagues and to strengthen the commitment of the organization by valuing the on-going work of participants ("*I think that if we structure a moment where we tell to our colleagues what we have done and the results obtained we could engage much more persons*" –hospital, nurse -). Therefore, this action related to the experiences with the implementation anchored to the perceived responsibility for patient education axis.

Finally, both the on-going training and the peer group supervision were actions thought to sustain the skills and capabilities of professionals to manage the complexity brought by the individual patient and the relational aspects of care required by *PHEinAction*, or to provide additional resources for this. They answered to the needs of inpatient settings to regain the relational aspects of care through *PHEinAction* and receive training for this, but also to the needs of territorial settings to share good practices for managing *PHEinAction* with complex patients or to work with caregivers in compromised situations. Thus, these actions concerned mostly the experiences located on the orange axis, on the focus of patient education.

## 4.5.  Discussion

The main findings of this study were how the patient education differed across settings and how this influenced both the experiences and the type of solutions related to the early-stage implementation of *PHEinAction*.

The first aspect that made settings diverge was the type of contents provided in patient education. There were settings mostly delivering information to the disease condition, others also supporting patients take appropriate actions, or those that reported a more comprehensive idea of patient education as "therapeutic education". In literature, focusing the education on disease-specific information and technical skills is reported to be anchored to a traditional concept of patient education, whereas supporting self-management education also needs complementary activities so to teach to patients medical, social, and emotional problem-solving skills (Bodenheimer, Lorig, et al.,

2002; Corbin & Strauss, 1988; K. R. Lorig et al., 2012). The different types of education are usually reported to be driven by an historical transformation from traditional medically-dominated to contemporary health-oriented care approaches (Bodenheimer, Lorig, et al., 2002; D. Roter, 2000; D. L. Roter, Stashefsky-Margalit, & Rudd, 2001) (see also Chapter 1 for a thorough examination of the topic). In light of this literature, findings of this study revealed how care settings with a longer history, such as the inpatient hospital wards (Moore et al., 2016), tended to show an anchorage to traditional patient education. In this study, whilst these settings showed a desire to deepen and widen their educational practice, they also lacked of the contextual and cultural conditions for enabling this shift. On the opposite, care settings that had a more recent history and concretely reflected the last century change from institutional to community care, such as the territorial services (Means, Richards, & Smith, 2008), revealed a greater orientation to the patient education approaches and contents most recently advocated (Bodenheimer, Lorig, et al., 2002; D. Roter, 2000; D. L. Roter et al., 2001). These new approaches and contents were however lived as of high-priority from territorial services and still required support for a complete implementation. This could have impeded their openness to further complementary activities.

Then, a second aspect that explained the differences among settings was the focus of patient education. Settings ranged from those ones that needed to focus mostly on the disease care because of emergency situation, to those ones that needed to help patients managing their health condition in their daily life environment and, thus, to look at them as persons by transcending traditional medical borders. A gradient in the educational practice, from disease-focused to person-focused, was revealed by findings. These focuses reflect specific care approaches, as reported in the Chapter 1. According to Bodenheimer's explanation of the relationship between educational care approaches and contents of patient education (Bodenheimer, Lorig, et al., 2002), the focus/approach of patient education lies on a different practical level compared to the previous one on the contents. Indeed, even if these aspects are conceptually related, the focus/approach of patient education affects not so much the concrete activities that professionals do, as the essence of the patient-professional interaction (Bodenheimer, Lorig, et al., 2002). Consequently, it concerns professionals' identity within the workplace (Sluss & Ashforth, 2007). This is also revealed by the enactment of solutions working on strengthening employees' capabilities to manage the complexity of the interaction with the patient. In recent essays on collaborative health (Godlee, 2017; Millenson, 2017), it is argued that the challenges for implementing actions that require a greater partnership with patients and to see them as persons mostly rely on shrinking professionals' power and importance. In these essays, a specific attention is paid on the resistances from the medical profession, traditionally the one that has a power role in the interaction with the patient. It is worth noticing that findings of this study reflected mostly

the experiences of the nursing profession. The nurses were indeed the professionals most involved in the studied implementation period. They were also those ones that took the leadership on the project from the very beginning. Findings of this study showed how the intervention was perceived by some of them as an opportunity to clarify and empower their key role in the care process and in the organization. In literature, the nursing profession is reported to strive particularly for optimal nurse-patient relationships, by having a strong orientation towards others-oriented values and caring styles (Carpenter, 1995; Fagermoen, 1997). At the same time, the nursing profession has to deal with stereotypes issues, self-branding efforts, and poorly-defined roles (K. Fletcher, 2007; Hoeve, Jansen, & Roodbol, 2014; Roberts, 2000). This makes nurses particularly open to promote new changes within the workplace (Needleman & Hassmiller, 2009; Shirey, 2006). There are also researches revealing how promoting quality care involves a reorganization of inter-professional roles in care teams, and particularly of nurse-doctor boundaries (Gilardi, Guglielmetti, & Pravettoni, 2014). Therefore, the proposal of the intervention could have been perceived as an occasion for a better professional self-branding in the interaction with the patient, and also within the care teams and the healthcare organization (K. Fletcher, 2007; Hoeve et al., 2014). This aspect requires a greater exploration and a focus on the inter-professional dynamics that the intervention proposal might open within care teams. Further research should also follow to better explore the potential key role of nurses for enabling healthcare organizations embracing patient engagement support.

A third aspect that made settings vary was the perceived responsibility for providing patient education. This impacted on the experiences with the implementation and, particularly, on the interactions with the other settings and within the workplace. Inpatient settings revealed to rely on the other care settings for providing complete patient education. Outpatient settings felt the relevance and the burden of providing a comprehensive support to patients and of creating a continuous network among services. Indeed, the division in disciplinary nucleus in the territorial services required a cross-services alliance. Then, in the ambulatory the responsibility for patient education was perceived as to be distributed among the different professionals working in the same work-team. Therefore, every setting depicted a different picture of their educational role in the organization (delegating to the outside, focused on the teamwork, supporting a cross-services network). In literature, it has been repeatedly said that no one service can adequately respond to the diverse needs of the healthcare consumer (Glasby & Dickinson, 2014). Therefore, networking, collective leadership and partnership working mechanisms are usually required to unlock cultural changes (West, Eckert, Stewart, & Passmore, 2014; Woods, Policy, & Evaluation, 2001). Similarly, in the present study, the different perceived roles in patient education among settings opened to different needs related to implementing

the intervention, all asking for a mutual buy-in and commitment from the organization, as showed by the awareness-raising actions.

The different pictures for responsibilities in patient education might have been related to the specific phase of life of the organization, where a re-organization of services was recently required. The polarization of views on patient education responsibilities might have been a reaction to the organizational change towards an integration of services. As suggested in literature, the phase of integrated-care development can impact on implementation experiences and rates (Minkman, Ahaus, & Huijsman, 2009). It would be thus interesting to further research a possible relation between the phases of development of the integrated care service and the intervention implementation rates. In general, it remains an open question how the experience of transition to an integrated service had impacted on the experience of implementation of *PHEinAction*, as literature worldwide reports how similar changes are challenging for the healthcare organization (Maruthappu, Hasan, & Zeltner, 2015; Wensing, Wollersheim, & Grol, 2006).

Overall, the findings raised the question about the readiness of the different care services for patient engagement support. Indeed, results showed how settings presented different pros and cons for the *PHEinAction* implementation, and differently embraced *PHEinAction*. The openness of the territorial service to a person-/citizen-centred approach and its marked responsibility for patient education with therapeutic education contents would have made thought to a greater readiness of this setting for patient engagement support compared to the inpatient setting and its constant speed-up workflow. However, the territorial services were the ones that mostly reported a difficulty in passing to a systematic implementation, and none of these services started adopting *PHEinAction*. In literature, the few studies that contrasted care services for implementation challenges reported that inpatient services were the ones showing the greatest difficulty with the implementation due to decreased length of stay, inadequate staffing, and the acute nature of the illness (C. Anderson, Deepak, Amoateng-Adjepong, & Zarich, 2005; Moore et al., 2016). In this study, challenges were mostly on the territorial service and the ambulatory one was, at the opposite, perceived as the optimal setting for implementing *PHEinAction*. It could be deduced that there are settings, such as the ambulatories, that are readier than others for implementing patient engagement support and that can represent first starting cells for change. As results differed from main literature findings and few studies were advised in literature deeply discussing this aspect, the different readiness of care settings for patient engagement support still requires attention. It also remains to investigate how settings of an integrated-care service could work to support and mutually benefit from a similar practice.

Professionals, indeed, highlighted the need to proceed horizontally across services with the implementation. In the effort of integrating so different care and educational settings, it remains an open question if and how a patient engagement support intervention can represent a tool to facilitate interactions across services. It remains also arguable if it should be all over implemented or if one setting should be selected to implement it, following the trajectory of the disease rule (i.e., "giving the right treatment to the right patient at the right time") (Redekop & Mladsi, 2013). As professionals stressed the need to provide a continuous care, further efforts should be paid to study if there are components of the intervention that should be included throughout care settings – such as the monitoring through the scales and the sharing of assessment results -.

It is also noteworthy of the work in the early-stage implementation had an impact on *PHEinAction*. It was revealed a need for a certain flexibility in the *PHEinAction*'s contents and procedures. This consequently opened up reflections and hypothesis for changes, which can be summarized as follows:

1) the integration between the support on the process of care offered by *PHEinAction* and disease-specific educational/informational contents,

2) the streamline of multiple materials without losing in the relational experience needed by *PHEinAction*,

3) the identification of the minimal indispensable components of action for patient engagement,

4) the introduction of complementary tools to facilitate the *PHEinAction* adoption.

Considering the first point, the study better clarified the relationship between what offered by *PHEinAction* and what offered by usual patient education. *PHEinAction* mostly focused on supporting the management of the care process, and thus the care experience. The existing patient education mostly focused on supporting the efficacious delivery (and sometimes management) of care contents, and thus the care knowledge. In this relationship, the indispensable priority for professionals was reported to be on the care knowledge. Therefore, *PHEinAction* should represent something to be added on this priority. Additional times and resources should be considered when implementing it. Otherwise, further efforts should be placed to enhance the perceived potential of *PHEinAction* in optimizing and organizing the provided care knowledge.

Second, even if professionals experienced the intervention as able to structure their relational work, they also pushed towards a streamline of procedures. For example, some of them asked to perform sessions by telephone or send exercises by e-mail. This opened a reflection on the possibility of *PHEinAction* to be supported by technological tools. In literature, the provision of interventions for

patient engagement support through technologies is debated, with literature generally supporting it but within a patient-professional relationship  (S. L. Craig & Calleja Lorenzo, 2014; Graffigna, Barello, & Bonanomi, 2017). The impact that delivering some of the *PHEinAction* components through technologies could have on the relationship with the patient, which was perceived as an important aspect of *PHEinAction*, need further research.

Then, the participatory process allowed to reveal, especially in settings dealing with complex patients, what constituted the key components of *PHEinAction* that could and should be provided widely as from the professionals' experiences with the implementation: the assessment through the scales and the sharing of assessment results. These components were considered able to move a first patient engagement change, and feasible to be included throughout the care and across the settings. There is literature valuing the importance of promoting awareness of activation/engagement levels among patients through assessments (Kidd et al., 2015). It needs further investigation the possibility to include only this component, and if this is able to improve patient engagement outcomes yet compared to the overall *PHEinAction* intervention.

Finally, the participatory process resulted in concrete solutions for promoting the implementation. In particular, *PHEinAction* required a process of adjustment to the single settings and to support professionals on how to embed it. It also required the implementation of complementary training activities to sustain its adoption and promotion in new care settings. These could represent additional tools that need to be implemented and studied together with *PHEinAction.*

## 4.6.   Limitations

A selection bias of professionals might have limited findings of this study. Professionals involved had a previous experience with the theme, as they participated in a previous training on patient engagement theories and measures. They participated on a volunteer basis, and so they were probably the most motivated professionals and those most willing to proceed with the implementation. This might have restricted findings to a specific group of professionals, with a low concern but with a moderately good experience. At the same time, research activities were open to include further participants, and there was a constant effort from researchers and key local stakeholders to engage professionals along the process. For example, a mailing list was created and e-mails with updates where sent monthly, with the opportunity for all participants to intervene.

Also, as both researcher and developer of the intervention, my role in the participatory process could have introduced a bias and have limited participants in freely expressing their views concerning the intervention.

Finally, in this study, involvement of participants was in the implementation process rather than in the research. Having involved them in the research, by for example co-designing the research purpose with the organization, involving professionals in the research choices and in the data analysis – and not only checking analyses with them - (Anne George, Mark Daniel, & Green, 2006), would have probably increased participants' buy-in to the research too, as sustained by previous literature (Cargo & Mercer, 2008a; Leykum et al., 2009; Macaulay et al., 2011). Furthermore, even if there is literature supporting the importance of involving patients in the research for better research quality and relevance (Sophie Staniszewska, Brett, Mockford, & Barber, 2011), in this study only professionals were involved. This limited the findings to healthcare professionals' voices, and might have reduced relevance of *PHEinAction* implementation issues for patients.

## 4.7.  Conclusion

The findings of this study revealed how the existing patient education practice of different clinical care services of an Italian integrated care organization differed in contents, perceived responsibility, and focus area of patient education. These key aspects had an impact on the experiences that professionals had when implementing a new brief individual intervention for patient engagement such as *PHEinAction* into their existing educational practice. These experiences, in turn, enlightened the solutions suggested and enacted during the participatory process to promote the intervention implementation. The work carried out with a small group of professionals made a base for identifying the key aspects and actions that could allow a greater deployment of *PHEinAction* in the overall organization. In this process, a certain degree of flexibility of *PHEinAction*'s contents and procedures was required. Despite this, it remains still an open question if the *PHEinAction* intervention will be normalized into practice.

# Chapter 5

# Discussion and implications

In this final Chapter, I will first provide a final discussion of findings that will go beyond the single aspects discussed within the studies. It will, indeed, discuss some key topics which emerged across the research project and its three studies. Basing on the findings of this thesis and other relevant literature, I will discuss the role of psychology in driving medical practice towards patient engagement support for older adults. I will argue how supporting older patients to be engaged in care involves supporting the healthcare professionals and the overall healthcare organization too.

Then, I will provide a discussion of the main methodological issues of the research presented in this thesis. At the end of each study (Chapters 2, 3, 4), I have highlighted the key methodological limitations that might have affected the findings. In the second section of this Chapter, I will point out the major issues that might have affected the research findings throughout. Firstly, I will discuss how the MRC framework has been applied in this research, and how this might have impacted on the research results. Then, I will discuss the choices made to ensure that findings were sound for older patients. Finally, I will discuss my role in the research, and how my role might have affected the findings throughout.

After a brief conclusion, I will conclude with a reflection on the future implications of the work for research and practice.

## 5.1.  Discussion of findings

### 5.1.1. The role of psychology and emotions for promoting patient engagement among older adults

This thesis started from a knowledge gap in the scientific literature about how patient engagement support can be provided to older patients, recognizing several challenges that promoting patient engagement could have for older patients and for the healthcare professionals caring for them (Chapter 1, section 1.6).

It was developed an intervention (Chapter 3, study 2) that differed from usual educational interventions aimed to provide disease-anchored knowledge or strengthen specific patients' skills (Guilbert, 2000; D. L. Roter et al., 2001). It represented something to be added into clinical practice and complementary to the educational care, using psychosocial levers to support a positive care journey (Chapter 4, study 3). This opens a first point of reflection onto how psychology, as a

discipline of the understanding of the human being's mind, might offer theories and constructs able to direct interventions' contents for promoting patient engagement that work on a different dynamic processual level compared to educational practice provided by healthcare professionals (Guilbert, 2000; D. L. Roter et al., 2001). In particular, it points out the role of organizational psychology, as applied psychological discipline of the understanding of the human being's subjectivity and inter-subjectivity in organizational contexts and processes, within the medical field, for a greater engagement of health and care consumers.

In literature, overall, psychological interventions applied to the medical field usually pertain the clinical psychology field and target the psychological consequences (depression, anxiety, stress) of having a specific disease (Chew et al., 2015; Harvey, 2015; Rees, Bennett, West, Davey, & Ebrahim, 2004; Smith, Sonego, Ketcheson, & Larson, 2014). These treatments are provided by a clinical psychologist or a mental health specialist, and mostly concern the individual psychopathological aspects that patients bring into the care process (American Psychological Association, 2013; Roditi & Robinson, 2011; Wahass, 2005). The psychological health of individuals decreases with age (Steptoe et al., 2015). Therefore, in the old population, psychological interventions particularly target mental health issues and are provided by mental health specialists in parallel to clinical activities (Naylor et al., 2012). There are then organizational psychology interventions within the medical field, usually aimed to promote healthy workplaces by improving the psychological conditions of employees and of the system (de Jonge, Vlerick, Büssing, & Schaufeli, 2001; Holzhausen, Maaz, Cianciolo, ten Cate, & Peters, 2017; Ruotsalainen, Serra, Marine, & Verbeek, 2008).

*PHEinAction*, by having the goal of supporting individuals taking a co-authorial role in care, differed from the usual educational practice provided by healthcare professionals (Guilbert, 2000; D. L. Roter et al., 2001) (see also Chapter 4, study 3), and also from the psychological support provided within the medical setting by clinical psychologists (Castelnuovo, 2010). Educating individuals, providing knowledge to them, and, also, helping them in managing the psychological and psychopathological reactions of a diagnosis is fundamental (American Psychological Association, 2013; Guilbert, 2000; Roditi & Robinson, 2011; D. L. Roter et al., 2001; Wahass, 2005). At the same time, accompanying individuals in a new co-authorial role in care required looking at "patients" from a different perspective - an organizational psychology one -, applying it to support the individual patient, and adding it to what already in practice to fill the patient engagement need and gap. With *PHEinAction,* an organizational psychological understanding of individuals' engagement towards care - as identity change from a patient to a healthcare teamwork's partner -, was used to help medical professions supporting the patient engagement goal and taking on board an often neglected but fundamental part of the healthcare teamwork. This highlights the possibility, in front of a goal such as patient

engagement, to imagine new roles for the psychological profession within the medical field. Psychology might serve as a driving force for patient engagement interventions' contents to be used by medical professions to support an active patients' role in the care process (Shahin, 2008). Organizational psychology, in particular, might serve as a guide for reshaping the role of the "patient" – and, consequently, of the healthcare professional - within the healthcare system, towards a greater co-authorial role and identity in the care process, with the new rights, duties, and tasks that this change can lead.

Furthermore, compared to the reviewed literature (Chapter 2, study 1), *PHEinAction* was intended to balance behavioural, cognitive, emotional components (Chapter 3, study 2). This was done, particularly, by giving space to the emotional dimension, often overlooked in the older patient engagement literature (Chapter 2, study 1). The second key point of reflection offered by the studies 1 and 2 (Chapters 2 and 3) concerned the relevance of including this dimension for supporting patient engagement, particularly among older adults. Theories aimed to motivate/empower/activate individuals in managing their health (Bravo et al., 2015; Prochaska & Velicer, 1997; Skolasky et al., 2011) have, generally, poorly considered the emotional dimension. In psychology, emotions represent a core aspect to understand human beings (Clore, 2012; Izard, 1991). They are, in particular, crucial as facets and outcomes of identity changes and self-processes (Cast & Welch, 2015; Kiefer & Muller, 2003; Stets, 2005). These can be the reasons why they were underlined during the research for having a key role in moving individuals in engaging in the identity changes required by patient engagement. The psychological perspective that supports the PHE theory (Chapter 1) fostered the inclusion and operationalization of this dimension in *PHEinAction*. Therefore, psychology might provide a specific guidance for supporting a dimension crucial for older patient engagement (Depp et al., 2010; Fuller & Larson, 1980; Scheibe & Carstensen, 2010).

### 5.1.2. Supporting healthcare professionals to promote patient engagement among older adults

*PHEinAction* was thought to be an individual intervention to be used by healthcare professionals. Implementing it in the care practice required an uptake from healthcare professionals too and asked to revise usual educational care. Not only, it also asked to revise usual professional-patient interactions, and, consequently, the individuals' identity and role expectations.

In literature, different aspects have been reported to be important in determining if and how the engagement of patients is supported by healthcare professionals. Examples of these are healthcare professionals' professional identity (Hoeve et al., 2014), their engagement in work and their organizational commitment (Gowen, Mcfadden, Hoobler, & Tallon, 2006; Shanafelt, Dyrbye, &

West, 2017; Shimazu & Schaufeli, 2008), the set of relational skills they have (Lawn et al., 2009), and their openness to give patients a central role in the care process (Alvarez, Greene, Hibbard, & Overton, 2016; Playle & Keeley, 1998). All these aspects played a role for implementing *PHEinAction* in clinical practice (Chapter 4, study 3). Professionals involved in the study 3 (Chapter 4) had a strong commitment to a change towards patient engagement, and it was highlighted how they perceived *PHEinAction* as a mean to strengthen their role within the workplace and their work engagement. At the same time, in the study 3 (Chapter 4), it was observed a need to support healthcare professionals too in implementing the proposed change. They also provided some suggestions for the type of support needed to properly deliver *PHEinAction.*

In particular, the emotional components included in *PHEinAction* and the relational skills required by *PHEinAction* were a particular reason for discussion and concern among healthcare professionals (Chapters 3 and 4, studies 2 and 3). Even if healthcare professionals liked that *PHEinAction* helped them protecting the relational aspects of their work (Chapters 3 and 4, studies 2 and 3), they complained a difficulty in using *PHEinAction* without having a specific training on non-technical skills (Chapter 4, study 3). There is increasing literature about the relevance of non-technical skills, such as relational and emotion-management ones (Birks & Watt, 2007; Dyche, 2007; McQueen, 2004). At the same time, in literature, primary concerns in medical education regard training healthcare professionals in managing the technical dimension of their profession (Vogel & Harendza, 2016). Relational and emotion-management skills' training risked, thus, to remain ancillary. The findings of this research, together with those from the literature, pointed for a need of training in the medical field for relational and emotion-management skills, so to promote patient engagement support too (Birks & Watt, 2007; Dyche, 2007; McQueen, 2004). If we consider that patient engagement requires a change in identities and roles within the healthcare exchanges, the complained need for this type of skills may also be read as a symptom of emotional and cultural resistances towards changing power roles. In literature, it is complained that patient engagement efforts focusing only on individual patients tend to ignore the nature of roles and relationships between professionals and patients (Alexander, Hearld, Mittler, & Harvey, 2012). The quality of the interpersonal exchange between professionals and patients can shape the behaviours and attitudes of patients in ways that support or discourage their active role in care (Alexander et al., 2012; R. M. Anderson & Funnell, 2005; Martinez, Schwartz, Freres, Fraze, & Hornik, 2009; Mattingly, Tom, Stuart, & Onukwugha, 2017). Aspects like the patients' satisfaction towards the interaction with the professional (Bowman, Herndon, Sharp, & Dignan, 1992) or the quality of the professional-patient exchange (Street, 2016) might require attention in the long-term implementation and evaluation of *PHEinAction*. Even more, the type of relational and emotion-management training required by patient engagement support

might require not only training professionals on medical communication aspects, but most of all supporting them in reorganizing their identity, role, and agency within a new type of interaction with their patients.

*PHEinAction* could be not only a way to concretely support patient engagement with specific exercises, but also a mean to open patients and healthcare professionals to a new partnership where patients can play a starring role. As reported in the Chapter 1, older patients are particularly not supported to take a leading role in care (Belcher et al., 2006; Dyrstad et al., 2015), despite they are willing to play it (Belcher et al., 2006; Ladin et al., 2016; Teh et al., 2009). Literature reported how older patients are traditionally seen as unable to autonomously manage their health condition and needy for somebody else taking care for them (Ward, 2000). For these reasons, restricted and fragmented care due to negative preconceptions associated with old age can be provided to them (Belcher et al., 2006; Sachs et al., 1992; Selman et al., 2016). Therefore, there are cultural issues surrounding patient engagement support among older patients. The results from the studies 2 and 3 (Chapters 3 and 4) of this research revealed that *PHEinAction* was lived by professionals as a mean to have concrete strategies to improve their partnership with older patients. Assessment tools might help avoiding preconceptions and relying on scientific instruments to evaluate them. Sharing the assessment results with patients can allow for a discussion of the role they are willing to play in care, so to avoid biased decisions from the professionals' part on how and how much to engage patients in care.

Finally, it is worth noticing how *PHEinAction* brought healthcare professionals to imagine new partnerships with their colleagues within the teamwork and the healthcare organization. In the study 3 (Chapter 4), it has been highlighted how implementing *PHEinAction* opened a reflection into the inter-professional dynamics that a similar change may bring. It was an occasion for the nurses working in the integrated-care organization to empower their key role, mostly in response to the power role of the medical profession. And also, it was an occasion for the different professionals and the different care settings to discuss and clarify their background culture, their values, and their role in the care process during a substantial reorganization phase. The *PHEinAction* implementation asked professionals – and researchers too - becoming gradually aware of how the implementation brought into the table also these inter-professional aspects. Therefore, *PHEinAction* was also a mean to open professionals to a new dialogue among them and with other professions. It was an occasion for professionals to start thinking at the possibility of working as an overall team, with inter-professional multidisciplinary opportunity to sustain it (see the "on-going training and peer group supervision" solution described in the section 4.4.3.4 of the Chapter 4). These findings are sustained by literature on inter-professional collaboration for improving care quality (Bodenheimer, Wagner, et al., 2002;

Dougherty & Larson, 2005; McInnes, Peters, Bonney, & Halcomb, 2015; Supper et al., 2015). Other studies, indeed, highlighted how changing perceptions of health professionals and building awareness of each other's roles for a greater collaboration may be facilitated by multidisciplinary activities (Supper et al., 2015; Thistlethwaite, 2012). Furthermore, as there is literature on inter-professional collaboration models and indicators (Bodenheimer, Wagner, et al., 2002; Dougherty & Larson, 2005; McInnes et al., 2015; Supper et al., 2015), assessing and sustaining the inter-professional change level required by *PHEinAction* could be valuable. Patient engagement – even if in the shape of a brief individual intervention – can require going beyond the individual patient and the professional-patient relationship, and promoting new relational dynamics among professionals able to sustain a similar change (Chen, Mullins, Novak, & Thomas, 2016).

### 5.1.3. From the individual to the organization: a shared responsibility for patient engagement support

The introduction of *PHEinAction* in the clinical practice also brought into play the work units within the different care settings and the overall healthcare organization where it was proposed (Chapter 4, study 3). The brief individual intervention for patient engagement support required a buy in from the healthcare organization and its care settings too, even if healthcare professionals were engaged in implementing it.

Indeed, the unique care setting workplaces and their set of professional practices and cultures have been showed in the study 3 (Chapter 4) to shape the way *PHEinAction* was experienced and the actions performed to sustain its implementation. Having sensitized healthcare workplaces and the healthcare organization to patient engagement allowed the implementation process of *PHEinAction* to be started. Literature evidences support the key role of the organizational culture and of the structural and processual features of care models embraced by the healthcare organization in promoting or hindering patient engagement (Bernabeo & Holmboe, 2013; Burns, Bellows, Eigenseher, & Gallivan, 2014; Sorrentino et al., 2015; Swan, 2009). The infrastructures (Burns et al., 2014), the available facilities (Burns et al., 2014; Swan, 2009), how human resources are managed and interact (Gilardi et al., 2014), the care routines and practices (Bernabeo & Holmboe, 2013; Sorrentino et al., 2015), are some examples of elements reported in literature supporting an organizational context oriented to patient engagement and ready to embrace patient engagement support. Introducing patient engagement support into clinical practice implies a redesign of organizational structures, processes and practices (Fugini, Bracci, & Sicilia, 2016). As suggested by Gilardi, a co-production system-level perspective on patient engagement might help unveiling attention onto its organizational and managerial implications, and not limit it only to the individual dimensions (Gilardi et al., 2016).

Engaging patients involves a broad, multilevel approach, even if this is done through a brief individual intervention. The multiple actors that intervene in shaping how patient engagement support is introduced into clinical practice, and that are shaped by it, need to be considered and assessed for a successful change. This multitude of levels that need to be considered when implementing patient engagement support opens also to a reflection about the responsibilities for sustaining patient engagement within healthcare settings. Even if supporting patient engagement through an individual intervention gave emphasis to the individual responsibility of the patient in care process, it does not imply that this responsibility now is up to the patient only. In literature, there are authors that suggest that a shared responsibility is required for patient engagement (Charles et al., 1997; Coulter, 2006). In the case of *PHEinAction* and patient engagement support, this means that the main focus should be placed onto the exchanges between patients and healthcare professionals, and among healthcare professionals, for a better redistribution of roles and responsibilities in the direction of a shared partnership and common buy-in of all the actors involved. Having reflexive spaces within the healthcare organization where professionals can share their individual and professional experience of a similar change, elaborate it, and discuss it with the other colleagues could allow healthcare organizations orienting their workplaces towards patient engagement and managing the pitfalls that a similar innovation can bring to professionals' roles and identities (Levy, 2004; Slade, 2017).

This took a particular importance when care is provided to an older population. The multiple health problems that older patients have often to manage require the presence and interlacement of multiple care actors and services (Stamm et al., 2016). In healthcare organizations dealing with an older population such as the one involved in the study 3 (Chapter 4), integration of care services is required. Therefore, the different care workplaces with their professional practices and cultures might increase the complexity of levels to consider when implementing *PHEinAction* and ask to add further levels of analysis: not only the exchanges among professionals within the workplace, but also the exchanges among different care services and between care services and the healthcare organization.

## 5.2. Discussion of methods

### 5.2.1. The adoption of the MRC Framework and the implications for the research

The UK Medical Research Council's (MRC) for developing and evaluating complex interventions (P. Craig et al., 2008) was chosen to guide the research and the research questions. This was done as the research spanned from developing an intervention to study its early-stage implementation. According to the selected MRC framework, some key phases should accompany the development,

evaluation, and implementation of complex interventions (P. Craig et al., 2008). The first phases of this framework were in particular used to outline the main research questions, and, consequently, to select the methods to answer them: systematic review with qualitative classification and quantitative descriptive analyses (Chapter 2, study 1) and qualitative methods for the *PHEinAction* intervention development, validation (semi-structured focus groups and individual interviews), and implementation (individual interviews, observations, workshops, artefacts analysis) (Chapters 3 and 4, studies 2 and 3). In this section, I will discuss the research choices made in the light of the first steps described by the MRC framework.

The MRC framework is explicitly devoted to complex interventions. Consequently, the first question in the adoption of this framework is: what makes an intervention "complex"? Can *PHEinAction* be considered "complex"? For the MRC framework (P. Craig et al., 2008), the answer on complexity resides in: the number of interacting components; the number and difficulty of behaviours required by those delivering or receiving the intervention; the number of groups or organizational levels targeted by the intervention; the number and variability of outcomes; and the degree of flexibility or tailoring of the intervention permitted. According to this answer, *PHEinAction* fits some of these requirements. It involved a high number of components compared to the similar interventions reviewed in the study 1 (Chapter 2), as well as it required different behaviours and actions and degrees of flexibility in contents and procedures as reported in the studies 2 and 3 (Chapters 3 and 4). However, as *PHEinAction* was delivered in one to one consultations, only one level was directly targeted. Nevertheless, as is shown in the study 3 (Chapter 4), the implementation involved several levels. The number and variability of outcomes still need to be clarified, but the findings in this thesis point to the outcomes having to cover several areas. It is also worth to notice that other studies, which reviewed complex interventions developed with the MRC framework, considered them complex because nonpharmacological but rather educational or psychosocial interventions aimed at changing knowledge, beliefs or behaviours (Redfern, McKevitt, & Wolfe, 2006).

Going deeply into the single steps of the framework, the first one of the MRC "development phase", which concerned identifying "what is already known about similar interventions and the methods that have been used to evaluate them" (Craig et al., 2008, p. 980), guided the first study of this project (Chapter 2). This was a systematic review on RCTs reporting patient engagement interventions for older adults. In this study, the "similar interventions" were those ones reported in studies indexed in the abstract/title with patient engagement or synonymous. In doing this, terms like "self-management" or "self-care" were not considered synonymous, but focusing on a different level of action. Despite this choice was supported by literature (in Chapter 1 there are details about the relationship between terms like patient engagement and terms like self-management), it might have

narrowed the search and excluded other potential similar interventions relevant for developing *PHEinAction*. Furthermore, the choice was restricted to studies using a specific method: only RCTs were included. This was done to start from "the point where it can reasonably be expected to have a worthwhile effect" (Craig et al., 2008, p. 980). Even if studies of RCTs are those ones at the most advanced point of the research and most expected to have a worthwhile effect, this choice was a priori made and might have limited the interventions included as well as the possibility to widely describe methods used to evaluate the interventions. Even more, the goal of the review was placed on identifying and classifying components of interventions, and not on interventions' efficacy. Therefore, the focus on effect highlighted by the framework diverged somewhat from the focus of the review. This was found and discussed also in other studies that used the MRC framework to develop new interventions (Aventin, Lohan, O'Halloran, & Henderson, 2015; Dowding, Lichtner, & José Closs, 2017; A. Fletcher et al., 2016; Lakshman, Griffin, Hardeman, Schiff, & Ong, 2012). Focusing on interventions' contents rather than on their overall effect allowed to disentangle the unique ingredients of interventions, but might have not allowed to start from the most effective evidence base.

The second step of the MRC "development phase", which related to identify the theory for the intervention, was the leading point of the overall research. Thus, the theory was not identified from existing evidence but a priori defined: this second step of the MRC framework was implemented first. This might have limited the research into a specific theoretical framework and influenced openness to other valuable theories. Then, the theoretical understanding of the likely process of change was applied by studying the theory and by a personal interpretation and operationalization of it into concrete action lines. It was not supplemented by new primary research as the theory was already reported and tested. This allowed to start the intervention development from a more advanced point. It might however have made the research dependent on what already knew on the theory, without studying further aspects that may have helped in the development. It is the case of the identification of the specific variables and interactions among them that could have explained more in details the process of change towards patient engagement (Lakshman et al., 2012). However, literature only supports the need to perform the identified steps (P. Craig et al., 2008; Lamont et al., 2016). To the best of my knowledge, there is no research arguing that changing the order of these steps and selecting the theory before identifying existing evidence or defining the likely process of change basing on a theory influenced results.

The third step of the MRC "development phase", which suggested conducting studies to progressively refine the intervention's design and model process and outcomes, was applied in this research by conducting the qualitative refinement and validation study (Chapter 3). Therefore, the process of

progressive refinement of the intervention was based on professionals' and patients' feedbacks trough qualitative researches. This process, thus, focused on qualitative feedbacks to refine contents and procedures. Less attention was paid on possible outcomes or economic evaluations that might have impacted on the following evaluations as suggested by the framework (P. Craig et al., 2008) or performed by other studies (Eldridge et al., 2005; Lakshman et al., 2012). This might be a limitation for the future evaluation of the effects of *PHEinAction*. However, some of the findings of this thesis (Chapter 4, study 3) provided indication for type of outcomes to be considered in the *PHEinAction* evaluation.

Then, the "feasibility and piloting phase" of the MRC, which featured testing procedures, estimating recruitment/retention and determining sample size, was partially applied in the study 3 (Chapter 4). As this phase highlighted the importance of understanding the context in which interventions take place, an exploration of the implementation feasibility of *PHEinAction* was undergone. The third study reported in the Chapter 4 fulfilled only the very starting goal of this MRC phase, as it explored the context, and the experiences of the context, towards the implementation. Thus, it did not consist of a full process evaluation study as suggested by the latest update of the MRC framework (Moore et al., 2015). Consequently, no knowledge was produced to guide a formal evaluation. Implementation feasibility still need to be further studied before passing into the evaluation phase.

## 5.2.2. The validity of the research findings for older adults

The overall thesis focused on a specific population of patients, those of age 60 and older. Throughout the research, there were three key choices that concerned the validity of the research findings for older patients. In this research, the question about the validity of results for an older population is dependent on the selection criteria adopted to identify literature on older patients and to include participants that represent such a target, as well as on the procedures followed to develop the intervention and to ensure that older patients – or professionals caring for them – were properly involved in the research process.

The choice in the study 1 (Chapter 2) of not including in the search strategy terms for the sample age but rather screening articles reporting a sample older than 60 might have given a selection of "generic" interventions, not necessarily targeting older patients. This means that interventions' components retrieved could have been not specifically designed to older patients. This might have limited the validity of the findings of the study 1 (Chapter 2) and of the developed intervention (Chapter 3, study 2) for an older target. At the same time, this choice helped getting a broader picture of patient engagement interventions for older adults and opening to more components, as both

"generic" interventions applied to older patients and elderly-specific interventions were retrieved. Even if some interventions could have been not designed for older patients, they were used and tested with this target, and were, thus, valid to be used with older patients.

Then, the intervention was developed basing on a pre-defined theory. The choice of using a specific theory to drive the research might have impacted on the research in several ways, and some of these are discussed in the previous section 5.2.1. The consequences for older patients are difficult to identify. The research did not deeply explore older patients' needs for patient engagement support, and no studies were conducted to test the validity of the PHE theory for an older target. Having selected a priori a theory and having applied it to a specific age target without making research on it might open doubts about the validity of the research for older patients. It is however worth to notice that the PHE theory was based on qualitative studies among Italian chronic patients (Barello et al., 2015; Barello & Graffigna, 2015; Graffigna et al., 2014). These were not necessarily older. However, most of them were in their older age (Barello et al., 2015; Barello & Graffigna, 2015; Graffigna et al., 2014). It was thus reasonable to assume that it would have been valid for an older population. In the study 2 (Chapter 3), older participants provided feedbacks on the intervention that indirectly qualitatively confirmed the validity of the PHE theory for them. Furthermore, a "generic" theory in terms of age groups allowed to make the intervention valuable for patients with different perceptions of their age, outside their chronological age (Rubin & Berntsen, 2006).

A third choice considered the involvement of the target group in the research. In general, the engagement of patients throughout the research is a theme on the spotlight in literature, as it is anticipated to improve study design, recruitment and dissemination of findings (Domecq et al., 2014; Puts et al., 2017). There are different frameworks to support this in general (Canadian Institutes of Health Research, 2014; PCORI, 2015; S Staniszewska et al., 2017). Some research has been made also for older patients (Backhouse et al., 2016; Dewar, 2005; Marlett & Emes, 2010; Puts et al., 2017). In this research, older patients and healthcare professionals used to care for them were involved in the studies 2 and 3 (Chapters 3 and 4). Involving different type of users (first and final users) in the study 2 (Chapter 3) allowed to have different perspectives on the intervention. Older patients were only involved in the study 2 (Chapter 3), so in a preparatory phase (Shippee et al., 2015), as the early-stage implementation needed to focus on first users (Chapter 4, study 3). Further research should follow and involve older patients in the later execution and translation/dissemination phases (Shippee et al., 2015). The sample's variation of older patients was also limited (women managing their chronic condition from time were mostly involved in the study 2), as it was hard to reach and motivate older patients to participate. This might have limited findings of the research and their validity for older patients. Reaching and involving older patients, and particularly those most vulnerable and hard-to-

reach, is, however, a reported challenge in literature (Liljas et al., 2017). The involvement of healthcare professionals with different degrees of professional experiences and from different care settings helped having a wide range of experiences of care and engagement of older patients (Chapters 3 and 4, studies 2 and 3). Therefore, healthcare professionals provided an indirect but rich of experiences voice of the older patients' needs, helping improving the validity of the findings for older patients.

### 5.2.3.  The role of the researcher in the research process

The final aspect that could have an impact on the research throughout concerned my role in the research. Indeed, I was involved with multiple roles in the research, and my roles and my preconceptions might have impacted on the findings in several ways.

First, being part of the research group that developed the theory used to drive the research and the intervention might have limited the choices made and biased my perspective. This was a not addressable internal bias of the research itself, as also changing theoretical framework would have introduced a bias related to proposing a "contrasting" theoretical model. An outside research group and a co-supervisor from a foreign University were involved to reduce this bias and reflect on the research choices that could have been influenced by this aspect. It is worth to notice that the dependence of research findings from the researchers' perspective is inevitable if we follow, for example, the constructivism approach, as for constructivists knowledge is always socially constructed (Guba & Lincoln, 1989, 1994).

Then, in both the studies 2 and 3, I was involved as researcher, intervention provider (during the qualitative study with patients reported in the study 2, Chapter 3), or intervention developer. Furthermore, I am a psychologist with a clinical background, within a research group in organizational psychology. I have been working for six years inside community and hospital structures to provide educational and/or psychological group/individual support to chronic patients, some of them older, working together with healthcare professionals. The practical experience of support to patients helped me in the operationalization of the theory and in the development of the intervention, as well as in its delivery to older patients and discussion with healthcare professionals. It also helped in the classification of interventions in the study 1 (Chapter 2). The same experience might have, however, blinded me to new approaches and perspectives. The expectations that these different roles might have risen among participants of the studies 2 and 3 might have generated findings aligned with these expectations.

Furthermore, participants might have felt limited in freely expressing themselves with persons involved in the intervention development and in the research. At the same time, the meetings and the group discussions were always managed with at least another researcher, less involved then me in the research. Furthermore, no signs of this possible limitation in the free expression of participants were retrieved in the transcripts. In general, the research involved also other researchers with different backgrounds, and this helped discussing the findings from different perspectives. Also in the classification of interventions in the study 1 (Chapter 2), it was helpful to involve external researchers from different disciplines to contrast classification criteria with mine.

In general, my multiple roles in the research and possible preconceptions were as much as possible considered and acknowledged through a constant reflexive process. This was ensured by involving other researchers in the study: an external researcher was involved for performing the interviews, the focus groups and the workshops were always conducted together with another researcher of my research group, my Italian supervisor followed me throughout the research and discussed with me all the performed steps, my Italian colleagues contributed to reflection on the intervention concept and its evolutions, my Norwegian supervisor helped me in seeing blind points in the choices made, in the analysis and in the reporting of data. Furthermore, intervention's changes made and analysis performed were as much as possible brought into the research field for feedbacks. Reporting of process and findings was as much as possible made transparent to readers at the end too. Choices not related to the research results were included in the study 2 (Chapter 3) (i.e., practical considerations) in order to make clear from where decisions were taken. Verbatim descriptions of participants' accounts were provided to support findings of the studies 2 and 3 (Chapter 3 and 4).

## 5.3. Conclusion

With this thesis, new knowledge about how patient engagement support can be provided to older persons was provided.

The thesis provided knowledge on interventions' contents focused on patient engagement and older adults in published studies: interventions for older persons focused on patient engagement have different contents and unique components from generic interventions focusing on patient adherence. It was also found that a psychological theory of patient engagement (PHE theory) could be used to guide, together with the literature and practical considerations, the development of an individual intervention for patient engagement support of older persons (*PHEinAction*). Healthcare professionals and older patients refined and finally endorsed it. It was then observed how the early-

stage implementation of *PHEinAction* into the existing patient education practice of an integrated-care organization was challenged by having to adapt it to educational practices consistently differing among inpatient, outpatient and territorial settings.

This research opened to a reflection onto the role of psychology - and of organizational psychology particularly - in the medical field for patient engagement support. It also revealed a need to support healthcare professionals and healthcare organizations to promote patient engagement among older adults, and suggestions for doing it were provided.


## 5.4.    Implications for research and practice

For greater translation of research findings on patient engagement support into practice of older adults, future research is needed, going further into the steps of the MRC Framework and integrating/completing those partially made with new methodologies. *PHEinAction* requires further long-term implementation studies and, most of all, evaluation of effects with experimental studies. Further specific considerations for future research on PHEinAction include: (a) expanding feasibility research of *PHEinAction* in additional populations (very old and younger patients; other clinical populations); (b) expanding feasibility research of *PHEinAction* in additional settings (primary care; residential care); and (c) designing innovative research methods focusing on the personal, relational, and organizational resources that may surround patient engagement support and impact on it; (d) defining strategies to assess and increase the buy-in from professionals, patients, and healthcare organizations. Studies on healthcare professionals' training, on caregivers or community engagement support for particularly vulnerable populations, and on organizational changes for patient engagement with a system level perspective could be also valuable to provide knowledge on the theme.

Then, implications for practice of findings of this project include having developed an intervention based on patient engagement theory for older adults to be potentially implementable in different care settings with the adoption of different deployments. The intervention had the advantage for clinical practice to be brief, to be supported by written materials, and to be amenable for use by nurses and other healthcare professions. Contents used in the intervention comprise a range of components that capitalize on scientific literature and professionals' and patients' experience. Among these, sharing of assessment results and goal setting/planning have been particularly stressed by professionals and patients. The intervention also included emotional components, which are less used in literature compared to educational and behavioural ones. The key most effective ingredients of the intervention should be still evaluated, also to decrease complexity of materials and improve its potential for implementation and use. In general, the overall efficacy and effectiveness of *PHEinAction* still need to be documented.

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