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*Leila Paukkonen*

# PATIENT PARTICIPATION, ADHERENCE, AND ACTIVATION FOR SELF-MANAGEMENT AMONG ADULT PATIENTS WITH MULTIMORBIDITY IN PRIMARY HEALTHCARE SETTINGS

*UNIVERSITY OF OULU GRADUATE SCHOOL;*
*UNIVERSITY OF OULU,*
*FACULTY OF MEDICINE*

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# PATIENT PARTICIPATION, ADHERENCE, AND ACTIVATION FOR SELF-MANAGEMENT AMONG ADULT PATIENTS WITH MULTIMORBIDITY IN PRIMARY HEALTHCARE SETTINGS

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## *Abstract*

The purpose of this study was to describe and explain patient participation, adherence, and activation for self-management among adult primary healthcare (PHC) patients with multimorbidity, and the associations between these and patient-related factors, and subsequently to produce a schematic model to describe this phenomenon based on the findings.

The study consisted of three phases including four original publications (I–IV) and this summary which also presents additional results. In the first phase, the Patient Participation in Rehabilitation Questionnaire (PPRQ) was translated into Finnish and further tested using psychometric assessment in a cross-sectional study (n=88, I). Basic and multivariate methods were used to perform statistical analysis. In the second phase, a cross-sectional descriptive correlational study was conducted to explore patient participation (n=125, II), adherence (n=124; III), and activation for self-management (n=122, IV) among adult PHC patients with multimorbidity, associations between these and patient-related factors (II–IV, Summary). The data were collected using several instruments, such as the PPRQ, the Adherence of People with Chronic Disease Instrument (ACDI), and the Patient Activation Measure (PAM®). Data were analysed using statistical analyses such as descriptive analysis (II–IV), correlations (III, Summary), t-test or ANOVA (II, IV, Summary), General linear model (II, IV), Binary logistic regression (III, IV) and Multivariable linear regression analysis (Summary). In the third phase, the schematic model was produced to describe the studied phenomenon (Summary).

The results supported the validity and reliability of the PPRQ instrument in Finnish PHC settings. Patients generally perceived patient participation as highly important but their accounts of the extent to which this had been realised in healthcare encounters varied. Most patients had good adherence to care regimens, but adherence to healthy lifestyle behaviours was more frequently inadequate. Significant explanatory factors for adherence were energy and will-power, motivation, results of care, sense of normality, fear of complications and additional diseases, and support from nurses, physicians, and family and friends. Patient activation varied. Patients with low activation (47%) had significantly poorer perceptions related to self-management, adherence to several self-management elements, patient participation and HRQoL. There were statistically significant positive associations between patient participation, adherence, and activation, and they and their specific elements were associated with various patient-related factors. The results reflect the complexity of self-management in the context of multimorbidity, where patient participation, adherence, and activation are pivotal factors, as also shown by the model, emphasizing the importance of a holistic approach and collaboration between patients and professionals in healthcare encounters to promote multimorbidity management.

*Keywords:* chronic conditions, health behaviours, healthcare encounters, multimorbidity, patient activation, patient adherence, patient participation, primary healthcare, self-management

**Paukkonen, Leila, Potilaan osallisuus, sitoutuminen ja aktivaatio omahoitoon aikuisilla monisairailla perusterveydenhuollon potilailla.**
Oulun yliopiston tutkijakoulu; Oulun yliopisto, Lääketieteellinen tiedekunta
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## *Tiivistelmä*

Tutkimuksen tarkoituksena oli kuvailla ja selittää potilaan osallisuutta, hoitoon sitoutumista ja aktivaatiota omahoitoon monisairailla perusterveydenhuollon potilailla, näiden yhteyttä toisiinsa ja potilaaseen liittyviin tekijöihin; ja tämän perusteella tuottaa skemaattinen malli kuvaamaan tätä ilmiötä.

Tutkimus koostui kolmesta vaiheesta sisältäen neljä alkuperäisjulkaisua (I–IV) ja yhteenvedon lisätuloksineen. Ensimmäisessä vaiheessa potilaan osallisuusmittari (PPRQ) käännettiin suomeksi ja sen psykometriset ominaisuudet arvioitiin poikkileikkaustutkimuksella (n=88, I). Tilastollisina menetelminä käytettiin perus- ja monimuuttujamenetelmiä. Toisessa vaiheessa tutkittiin potilaan osallisuutta (n=125, II), hoitoon sitoutumista (n=124; III) ja aktivaatiota (n=122, IV) sekä näiden yhteyttä toisiinsa ja potilaaseen liittyviin tekijöihin (II–IV, yhteenveto) aikuisilla monisairailla perusterveydenhuollon potilailla kuvailevalla korrelaatio poikkileikkaustutkimuksella. Aineisto kerättiin muun muassa Potilaan osallisuus (PPRQ), Kroonisesti sairaan potilaan hoitoon sitoutuminen (ACDI) ja Potilaan aktivaatio -mittarilla (PAM®). Aineisto analysoitiin tilastollisilla menetelmillä, kuten kuvaileva tilastoanalyysi (II–IV), korrelaatio (III, yhteenveto), t-testi, ANOVA (II, IV, yhteenveto), lineaarinen malli (II, IV), binaarinen logistinen regressio (III, IV) ja lineaarinen monimuuttuja regressioanalyysi (yhteenveto). Kolmannessa vaiheessa tuotettiin skemaattinen malli kuvaamaan tutkittua ilmiötä (yhteenveto).

Tulokset tukivat PPRQ-instrumentin validiteettia ja reliabiliteettia suomalaisessa perusterveydenhuollon kontekstissa. Potilaat pitivät osallisuutta tärkeänä, mutta näkemykset sen toteutumisesta terveydenhuollon kohtaamisissa olivat vaihtelevia. Useimmat potilaat olivat sitoutuneet hoitoonsa hoito-ohjelmien osalta, mutta terveellisten elämäntapojen noudattaminen oli usein riittämätöntä. Tilastollisesti merkitseviä hoitoon sitoutumista selittäviä tekijöitä olivat energisyys ja tahdonvoima, motivaatio, hoidon tulokset, normaaliuden tunne, komplikaatioiden ja lisäsairauksien pelko, ja tuki hoitajilta, lääkäreiltä sekä läheisiltä. Potilaan aktivaatio oli vaihtelevaa. Potilaat, joilla oli alhainen aktivaatio (47 %), sitoutuivat huonommin useisiin omahoidon elementteihin, heillä oli huonommat käsitykset omahoidosta, osallisuudesta sekä alhaisempi terveyteen liittyvä elämänlaatu. Potilaan osallisuus, sitoutuminen ja aktivaatio olivat tilastollisesti merkitsevästi positiivisessa yhteydessä toisiinsa, ja ne, sekä niihin sisältyvät eri elementit, olivat yhteydessä erilaisiin potilaaseen liittyviin tekijöihin. Tulokset heijastavat omahoidon monimutkaisuutta monisairastavuuden kontekstissa, jossa potilaan osallisuus, sitoutuminen ja aktivaatio ovat keskeisiä, kuten myös malli kuvaa, korostaen kokonaisvaltaisen lähestymistavan sekä potilaan ja ammattilaisen välisen yhteistyön merkitystä terveydenhuollon kohtaamisissa monisairastavuuden hallinnan edistämiseksi.

*Asiasanat:* krooniset tilat, monisairastavuus, omahoito, perusterveydenhuolto, potilaan aktivaatio, potilaan hoitoon sitoutuminen, potilaan osallisuus, terveydenhuollon kohtaaminen, terveyskäyttäytyminen

*To my children*

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November Leila Paukkonen

# List of abbreviations and symbols

| | |
|---|---|
| ACDI | Adherence of People with Chronic Disease Instrument |
| ANOVA | Analysis of Variance |
| AUDIT-C | Alcohol Use Disorders Identification Test -Consumption |
| BMI | Body Mass Index |
| BTS | Bartlett’s Test of Sphericity |
| CI | Confidence Interval |
| CINAHL | Cumulative Index to Nursing and Allied Health Literature |
| CTT | Classical Test Theory |
| EFA | Exploratory Factor Analysis |
| FFH | Fisher-Freeman-Halton Exact Test |
| FIT index | Frequency Intensity Time -index |
| HCPs | Healthcare professionals/ providers |
| HRQoL | Health-related Quality of Life |
| KMO | Kaiser-Meyer-Olkin test |
| MD | Mean Difference |
| MEDLINE | Medical Literature Analysis and Retrieval System Online |
| MeSH | Medical Subject Heading |
| OECD | The Organization for Economic Co-operation and Development |
| OR | Odds Ratio |
| PAF | Principal Axis Factoring |
| PAM | Patient Activation Measure |
| PC | Primary Care |
| PHC | Primary Healthcare |
| PPRQ | Patient Participation in Rehabilitation Questionnaire |
| SD | Standard Deviation |
| SE | Standard Error |
| SPSS | Statistical Package for the Social Sciences |
| STROBE | Strengthening the Reporting of Observational Studies in Epidemiology |
| TENK | Finnish Advisory Board on Research Integrity |
| THL | National Institute for Health and Welfare, Finland |
| WHO | World Health Organization |
| WMA | World Medical Association |
| $\chi 2$ | Chi-squared test |

# List of original publications

This dissertation is based on the following publications, which are referred to throughout the text by their Roman numerals (I–IV):

I Paukkonen, L., Kankkunen, P., Kreuter, M., & Pietilä A-M. (2019). Patients' perceptions of participation: Pilot validation study of the FI-PPRQ questionnaire in Finnish primary healthcare settings. *Nordic Journal of Nursing Research*, 39(3), 117–126. https://doi.org/10.1177/2057158518815992

II Paukkonen, L., Oikarinen, A., Kähkönen, O., & Kyngäs, H. (2021). Patient participation during primary health-care encounters among adult patients with multimorbidity: A cross-sectional study. *Health Expectations: An international journal of public participation in health care and health policy*, *24*(5), 1660–1676. https://doi.org/10.1111/hex.13306

III Paukkonen, L., Oikarinen, A., Kähkönen, O., & Kyngäs, H. (2022). Adherence to self-management in patients with multimorbidity and associated factors: A cross-sectional study in primary healthcare. *Journal of Clinical Nursing*, *31*(19–20), 2805–2820. https://doi.org/10.1111/jocn.16099

IV Paukkonen, L., Oikarinen, A., Kähkönen, O., & Kaakinen, P. (2022). Patient activation for self-management among adult patients with multimorbidity in primary healthcare settings. *Health Science Reports*, *5*(4), e735. https://doi.org/10.1002/hsr2.735

This summary also includes previously unpublished results.

# Contents

# 1 Introduction

Chronic conditions are common and increasing worldwide. These conditions are characterised by their long-lasting and persistent effects (WHO, 2016). In Finland, the number of people with at least one chronic disease is higher than in the EU on average (OECD, 2021c). Even though some risk factors of these conditions, such as smoking, have decreased in recent decades, the development has not been favourable in all areas and particularly obesity continues to increase alarmingly (Tolonen et al., 2022). There are also pronounced regional (THL, 2023) and sociodemographic differences in morbidity and risk factors (Parikka et al., 2020; Finnish Government, 2021). Further, many people with chronic conditions do not have a single condition but instead have multiple conditions also referred to as multimorbidity; the co-occurrence of two or more chronic conditions – either physical, mental, or both – in an individual. The estimated prevalence of multimorbidity is around 30% in the population, while the prevalence increases strongly with age and more than half of people over 65 have multimorbidity. However, a substantial number of young and middle-aged adults live with multimorbidity (Cassell et al., 2018; Nguyen et al., 2019), and this is more common in people with socioeconomic deprivation and poor lifestyles. People with multimorbidity face multiple adverse outcomes including decreased perceived health, functional ability and quality of life, as well as increased treatment burden, polypharmacy, safety incidents, acute morbidity, and premature mortality (Hajat & Stein, 2018; Xu et al., 2017). Multimorbidity is a major driver of healthcare utilisation and costs, particularly in primary healthcare but also across the health system (Cassell et al., 2018), also incurring costs to society (Tran et al., 2022).

Primary healthcare plays an important role in managing patients with multimorbidity while also coordinating their care with the secondary care they often need (WHO & UNICEF, 2018; WHO, 2016). However, shortcomings have been detected in identifying patients with multimorbidity and meeting their care needs (National Audit Office of Finland, 2017; Wallace et al., 2015). This may indicate that some service use may result from a failure to sufficiently meet patients' needs. Moreover, not only have patients with multimorbidity faced difficulties in getting optimal care (Ørtenblad et al., 2018; van der Aa et al., 2017) but providers have also experienced challenges in caring for them (Ploeg et al., 2017; Whitehead et al., 2021). Indeed, multimorbidity poses a great challenge for health systems as it increases the complexity of care, exacerbated by prevailing single disease-oriented health systems, while striving to provide optimal healthcare services in resource-constrained environments (Academy of Medical Sciences, 2018). The relevance of this issue in Finland is emphasized by the ongoing health and social services reform that aims to ensure equal and high-quality services according to individual needs and reduce inequality in health and well-being (Finnish Government, 2023) at a time of increasing demand for healthcare (THL, 2022b).

The patient's role has changed significantly over the last few decades; currently, patients are expected to be active partners in, rather than passive recipients, of their care. This shift results from changes in society and the healthcare system, such as a move away from paternalism, and an emphasis on individual rights along with the increasing burden of chronic conditions, in which case the role of self-management by patients in their everyday circumstances is essential (Ocloo & Matthews, 2016; WHO, 2013c). However, self-management in the context of multimorbidity is often complex, necessitating the management of demanding medical needs along with competing, potentially conflicting priorities, and care regimens. Therefore, receiving support from HCPs is an essential part of self-management. The inherent complexity of multimorbidity further highlights the need for patient-centred care implemented by professionals (Gobeil-Lavoie et al., 2019; Wallace et al., 2015).

In this study, the key role of the patient and the impact of the patient–professional collaboration on this role are examined through the concepts of patient participation, adherence, and activation for self-management. Participation in care lies at the core of patient-centred care and the collaboration between HCPs and patients. Adherence is an active, responsible process of care, in which patients work to maintain their health in close collaboration with their care providers (Kyngäs, 1999); including the extent to which the patient follows agreed recommendations regarding their care (WHO, 2003). Patient activation describes the patient's knowledge, skills, and confidence, and their beliefs about the importance of their own role in managing their health and healthcare (Hibbard et al., 2004, 2005). While the concepts have been otherwise studied quite extensively, they have been little studied in patients with multimorbidity, and not together like in this study. Further, while multimorbidity has been recognised as a priority in global health research (Academy of Medical Sciences, 2018), research evidence remains limited on high-quality care and effective interventions, including self-management support, to improve outcomes for patients with multimorbidity (Academy of Medical Sciences, 2018; *Multimorbid patient. Current Care Guidelines*, 2021), Thus, this study aims to provide new knowledge contributing to the understanding of the studied issues and to produce information that can be utilised in care and in developing the care for patients with multimorbidity.

# 2 Patient participation, adherence, and activation for self-management among patients with multimorbidity

This theoretical chapter provides an overview of the theoretical background of this study focusing on the main concepts and based on previous scientific knowledge and other important publications. The information was gathered during the whole research process with respect to the ongoing phase of the study and supplemented for this summary. For this purpose, several database searches were conducted in the PubMed, Scopus, and CINAHL databases focusing on the following concepts of interest: *multimorbidity, patient participation, patient adherence, patient activation, self-management,* and *primary healthcare.* Further, the search term '*concept*' was used in conjunction with other main research concepts to focus on the theoretical basis of each concept. The searches were designed with the expert assistance of a university librarian and conducted in various combinations using appropriate Medical Subject Headings (MeSH), keywords and/or subject terms, and further search terms and constraints appropriate for each database. Examples of the searches performed are shown in Table 1. The selection of published articles was based on first screening the titles, the abstracts, and finally the full texts. Manual searches were also performed on the references of selected articles and the articles referring to them to complement the literature search (Aromataria & Munn, 2020; Polit & Beck, 2018). Other sources included the web pages of the International Research Community on Multimorbidity (IRCMo), the World Health Organization (WHO), and the Finnish Institute of Health and Welfare (THL).

In this study, the term "patient" is used consistently throughout the text as it has become inseparably established in the phrases used in this study, such as "patient activation" and "patient participation". However, it was recognized that other terms, such as client or person, are also preferred in referring to users of various outpatient healthcare services, and it has also been argued whether there are differences between these concepts, especially in the interpretation of the roles and mutual relationships between service users and healthcare providers (Costa et al., 2019; Jackson et al., 2016). The term "patient" is used without taking a stance in this debate. A patient is a healthcare client who uses healthcare services (Act on the Status and Rights of Patients 1992/785) because of health problems (THL, 2021a). Further, the term "primary healthcare" is used consistently when referring to it as the context of this study, while the term primary care is also used in accordance with original sources. Although these terms are often used interchangeably, Primary healthcare (PHC) encompasses a broader concept than primary care (PC), which is an element within PHC used to describe service provision to patients by healthcare professionals (HCPs) (WHO & UNICEF, 2018).

**Table 1. Examples of literature searches performed in this study; subject, database, search terms, and the results obtained.**

| Subject | Database used: Search term | Items found |
|---|---|---|
| Patient participation, activation, and adherence in patients with multimorbidity | Scopus: (TITLE-ABS-KEY (patient* W/2 activat*) AND TITLE-ABS-KEY ((patient* W/2 participat*) OR (patient* W/2 involv*) OR (consumer* W/2 participat*) OR (consumer* W/2 involv*)) AND TITLE-ABS-KEY (adherence OR compliance OR concordance) AND TITLE-ABS-KEY (“multi-morbid*” OR multimorbid* OR “multiple chronic condition*” OR “Multiple Chronic Health Condition*” OR “multiple chronic dis*” OR “multiple chronic illness*” OR “Multiple Chronic Medical Condition*”) | 2 (2019)<br>5 (2022) |
| Patient participation OR patient activation OR adherence in patients with multimorbidity | PubMed: (((patient activation[Text Word]) OR ((“Patient Compliance”[Mesh]) OR (Adherence[Text Word] OR compliance[Text Word] OR concordance[Text Word]))) OR ((“Patient Participation”[Mesh]) OR (patient participation[Text Word] OR patient involvement[Text Word] OR consumer participation[Text Word] OR consumer involvement[Text Word]))) AND ((((“Multimorbidity”[Mesh]) OR “Multiple Chronic Conditions”[Mesh])) OR (multi-morbid*[Text Word] OR multimorbid*[Text Word] OR multiple chronic condition*[Text Word] OR Multiple Chronic Health Condition*[Text Word] OR multiple chronic dis*[Text Word] OR multiple chronic illness*[Text Word] OR Multiple Chronic Medical Condition*[Text Word])) | 532 (2019)<br>847 (2022) |
| Patient participation OR patient activation OR adherence in patients with multimorbidity | Scopus: (TITLE-ABS-KEY (patient* W/2 activat*) OR TITLE-ABS-KEY ((patient* W/2 participat*) OR (patient* W/2 involv*) OR (consumer* W/2 participat*) OR (consumer* W/2 involv*)) OR TITLE-ABS-KEY (adherence OR compliance OR concordance) AND TITLE-ABS-KEY (“multi-morbid*” OR multimorbid* OR “multiple chronic condition*” OR “Multiple Chronic Health Condition*” OR “multiple chronic dis*” OR “multiple chronic illness*” OR “Multiple Chronic Medical Condition*”) | 852 (2019)<br>1,359 (2022) |
| …in PHC | as above plus AND TITLE-ABS-KEY (“primary care” OR “primary health care” OR “primary healthcare” OR “community Health Services”) | 197 (2019)<br>316 (2022) |

| Subject | Database used: Search term | Items found |
|---|---|---|
| Patient activation for self-management | Scopus: (TITLE-ABS-KEY (patient* W/2 activat*) AND TITLE-ABS-KEY ("self-management" OR "self-care") | 452 (2019)<br>703 (2022) |
| …in patients with multimorbidity in PHC | as above plus TITLE-ABS-KEY ("multi-morbid*" OR multimorbid* OR "multiple chronic condition*" OR "Multiple Chronic Health Condition*" OR "multiple chronic dis*" OR "multiple chronic illness*" OR "Multiple Chronic Medical Condition*") AND TITLE-ABS-KEY ("primary care" OR "primary health care" OR "primary healthcare" OR "community Health Services") | 5 (2019)<br>15 (2022) |
| Adherence as concept | Scopus: (TITLE-ABS-KEY (adherence OR compliance OR concordance) W/2 concept* | 910 (2019)<br>1,108 (2022) |

## 2.1 Multimorbidity as a significant public health problem

Multimorbidity is usually defined as the coexistence of "two or more chronic health conditions" in a single individual (Academy of Medical Sciences, 2018; NICE, 2016; WHO, 2016). Also, the term "multiple chronic conditions" is used synonymously with "multimorbidity", which is currently on its way to becoming the most frequently used term, even though it is relatively new and was only assigned as a Medical Subject Headings (MeSH) term in January 2018. Multimorbidity refers to a state in which all conditions are of equal importance, and none are considered an index condition that is the specific focus of attention. By contrast, the related term "comorbidity" refers to the presence of additional disease(s) in relation to one leading index condition in an individual. Thus, individuals with comorbidity also have multimorbidity but the reverse does not apply (Nicholson, Makovski, et al., 2019). There are also other related terms such as "frailty" and "complexity" that have even been used interchangeably with multimorbidity, at least until recently, even though they have a difference in content. Frailty refers to a dynamic and multidimensional clinical condition of increased vulnerability (Villacampa-Fernández et al., 2017) and while most (72%) frail individuals are also multimorbid, only 16% of individuals with multimorbidity have frailty (Vetrano et al., 2019). Complexity, in turn, refers to the overall impact of different conditions on an individual, which is influenced not only by health-related characteristics, but also by biological, socioeconomic, environmental, cultural, and behavioural characteristics. So, multimorbidity is one aspect of complexity (Zullig et al., 2016).

The definition of multimorbidity as "the simultaneous presence of two or more chronic conditions" needs some refinement. First, although the most common cut-off count of conditions has been determined as two or more, it has also been defined as at least three and even more, and some studies additionally take into account the severity of the conditions (Chua et al., 2021; Ho et al., 2021; Johnston et al., 2019; Willadsen et al., 2016). Second, there is need to define what is meant by chronic conditions. The World Health Organization (WHO, 2002) has defined chronic conditions as health problems that require ongoing management over a year or more. According to this definition, the term "chronic conditions" encompasses but also expands beyond the traditional chronic "noncommunicable diseases", such as heart disease, diabetes, and cancer, and also includes persistent communicable conditions such as HIV/AIDS, certain mental disorders such as depression and schizophrenia, and ongoing physical or structural impairments not defined as diseases. However, there is no single standard definition for chronic conditions and there is debate about what constitutes chronic conditions (Bernell & Howard, 2016; Goodman et al., 2013). Accordingly, there is no generally accepted consensus for the conditions included in multimorbidity (Fortin et al., 2017; Hafezparast et al., 2021; N'Goran et al., 2016) and thus chronic conditions accepted for multimorbidity vary (Ho et al., 2021; Johnston et al., 2019; Xu et al., 2017). Some definitions also include longstanding behavioural health problems or risk factors, such as obesity and substance misuse (NICE, 2016; Willadsen et al., 2016) while others do not. One of the existing definitions also accepts acute conditions in addition to chronic conditions (Le Reste et al., 2015). In this study, multimorbidity is defined according to the definition of the Academy of Medical Sciences, which has recommended the adoption of a uniform definition consistent with that adopted by the World Health Organization (WHO, 2016). According to this, multimorbidity involves the co-existence of two or more chronic conditions, each one of which is either: a physical non-communicable disease of long duration (such as cardiovascular disease, diabetes, asthma, or cancer), a mental health condition of long duration (such as a mood disorder), and/or an infectious disease of long duration, such as HIV or hepatitis C (Academy of Medical Sciences, 2018).

### *2.1.1 Epidemiology of multimorbidity*

The prevalence rates of multimorbidity varied considerably across studies, as measuring these is not straightforward and depends on which conditions are included (i.e. the used definition of multimorbidity and the often used restrictions on predefined conditions included in the study), the examined population, sample, and setting (general, PHC etc.) and the method used to measure multimorbidity (survey data, medical records etc.) (Griffith et al., 2019; Holzer et al., 2017; Johnston et al., 2019; Lefèvre et al., 2014). However, regardless of variations in the estimated prevalence, multimorbidity is indisputably common among adult populations worldwide in high-, middle-, and low-income countries (Hajat & Stein, 2018; Nguyen et al., 2019; WHO, 2016). According to large studies conducted in PHC populations, about one in four have multimorbidity (Barnett et al., 2012; Cassell et al., 2018) while a recent systematic review and meta-analysis suggested that this is even more common; about one third of the world population in community settings is affected by multimorbidity (Nguyen et al., 2019). A Finnish study using data from a national healthcare register found a prevalence of 38% in the adult population (Palomäki et al., 2022). In addition, the prevalence of multimorbidity has been on the rise (Bisquera et al., 2021; Buttorff et al., 2017; Lebenbaum et al., 2018; Van Oostrom et al., 2016) and is predicted to further increase (Canizares et al., 2018; Head et al., 2021); this is particularly the case with severe multimorbidity (four or more concurrent conditions), which is projected to double between 2015 and 2035 (Kingston et al., 2018).

### *Potential determinants of multimorbidity*

Several biological, socioeconomic, psychological, and behavioural factors have been linked to the risk of developing or exacerbating multimorbidity. These factors can be non-modifiable (e.g., age and gender) or modifiable (e.g., socioeconomic and lifestyle-related health behaviours). The possible investigated determinants are outlined below, but as the mechanisms underlying the development of multimorbidity are complex, interrelated, and multilevel, it is important to note that there is still a need for more knowledge (Academy of Medical Sciences, 2018; Kudesia et al., 2021).

**Age and gender** influence multimorbidity. The prevalence of multimorbidity undoubtedly increases substantially with age (for example Kudesia et al., 2021; Nguyen et al., 2019; Xu et al., 2017) as does the number of related conditions (Barnett et al., 2012; Orueta et al., 2014; Schiøtz et al., 2017). However, even though age is a salient risk factor for the development and progression of multimorbidity, it is important to pay attention to the fact that multimorbidity does not only occur in the elderly, but a substantial number of young and middle-aged adults live with it, too (Head et al., 2021; Ryan et al., 2018; Sakib et al., 2019).

Actually, due to the age structure, the absolute number of people with multimorbidity is reportedly higher in those aged below 65 than in the older population (for example Adams, 2017; Gruneir et al., 2016; Nicholson, Terry, et al., 2019; St Sauver et al., 2015). Moreover, multimorbidity has been found to begin at a younger age these days than in previous decades (Canizares et al., 2018; Head et al., 2021; Katikireddi et al., 2017; Van Oostrom et al., 2016; Vos et al., 2022). The most typical related conditions vary based on age as well as gender and interactions between these factors (Agur et al., 2016; Schäfer et al., 2012; Schiøtz et al., 2017; St Sauver et al., 2015) and studies suggest that, as a result, physical–mental multimorbidity constitutes a greater proportion of overall morbidity in younger patients (Cassell et al., 2018; McLean et al., 2014) and in women (Agur et al., 2016; Barnett et al., 2012; Cassell et al., 2018). Also, the overall prevalence of multimorbidity is suggested to be higher in women than in men (Agur et al., 2016; Buttorff et al., 2017; Cassell et al., 2018; Head et al., 2021; Larsen et al., 2017; Orueta et al., 2014; Sakib et al., 2019; Vos et al., 2022) and although contradictory results also exist (de Souza et al., 2021; St Sauver et al., 2015), systematic reviews have confirmed this result (Johnston et al., 2019; Marengoni et al., 2011; Nguyen et al., 2019; Violan et al., 2014). In Finland, 31% of men and 44% of women aged 18–64 years and 77% of men and 79% of women aged 65–85 years are multimorbid (*Multimorbid patient. Current Care Guidelines*, 2021).

**Socioeconomic status (SES) factors,** such as low income, wealth, education, and occupational position, and living in a deprived area are well known to be associated with a higher prevalence (Agborsangaya et al., 2012; Barnett et al., 2012; Cassell et al., 2018; Garin et al., 2016; Ingram et al., 2021; Larsen et al., 2017; Mondor et al., 2018; Orueta et al., 2014; Palladino et al., 2016; Pathirana & Jackson, 2018; Schäfer et al., 2012) as well as an increased risk of developing multimorbidity, both in terms of a greater burden and an earlier onset (Canizares et al., 2018; Dugravot et al., 2020; Jackson et al., 2015; Khanolkar et al., 2021; Mounce et al., 2018; Sakib et al., 2019; Singer et al., 2019). In people with low SES, the prevalence of multimorbidity in middle age is comparable to people with high SES about 10–15 years older (Barnett et al., 2012; Puth et al., 2017). The pathways between socio-economic disadvantages and multimorbidity are diverse and partly unknown (Academy of Medical Sciences, 2018) but differences in multimorbidity between SES groups have been suggested to be partly explained by the different distribution of lifestyle-related health behaviours in different SES groups (Barnett et al., 2012; Katikireddi et al., 2017; Kivimäki et al., 2020; Wikström et al., 2015).

**Lifestyle-related health behaviours,** such as physical inactivity, unbalanced diet, tobacco use, and harmful alcohol consumption are known key behavioural risk factors for several single chronic conditions that individuals can personally influence (The Finnish Medical Society Duodecim, 2017; WHO, 2013b). There is also evidence that these factors appear to increase the risk of multimorbidity and the development of a new chronic condition in people who already have multimorbidity (Chudasama et al., 2020; Dhalwani et al., 2017; Freisling et al., 2020; Katikireddi et al., 2017; Licher et al., 2019; Mounce et al., 2018; Wikström et al., 2015). According to a Finnish study, the most prominent factors for multimorbidity among initially disease-free population were smoking, physical inactivity, and obesity (Wikström et al., 2015). Particularly accumulating unhealthy behaviours seems to correlate with an increased risk (Dhalwani et al., 2017; Fortin et al., 2014; Freisling et al., 2020; Wikström et al., 2015). Correspondingly, healthier lifestyle behaviours have been associated with spending a greater part of life without diseases and a longer life expectancy (Licher et al., 2019), the latter both across individual risks and combined in those with and without multimorbidity (Chudasama et al., 2020).

**Physical inactivity** was associated with the presence of multimorbidity in several studies (Cimarras-Otal et al., 2014; Keats et al., 2017; Roberts et al., 2015; Vancampfort, Koyanagi, Ward, et al., 2017), but some studies found no association in all age and gender groups (Cimarras-Otal et al., 2014) or at all (Fortin et al., 2014). However, several longitudinal studies have confirmed that low physical activity is associated with an increased risk of multimorbidity (Dhalwani et al., 2016, 2017; Freisling et al., 2020; He et al., 2021; Jackson et al., 2015; Mondor et al., 2018; Mounce et al., 2018; Ryan et al., 2018; Singer et al., 2019; Wikström et al., 2015; Xu et al., 2018) and the progression of multimorbidity over time (Mounce et al., 2018; Ryan et al., 2018; Wikström et al., 2015; Xu et al., 2018) although not in all studies (Canizares et al., 2018; Katikireddi et al., 2017). Also, sedentary behaviours beyond low physical activity have been found to be determinants of multimorbidity (Canizares et al., 2018).

**Unhealthy diets** have been shown to be associated with multimorbidity (Dekker et al., 2019; Kyprianidou et al., 2020; Roberts et al., 2015). Further, there is evidence that those with a poorer diet have a higher incidence (Dhalwani et al., 2017; Freisling et al., 2020) and risk of developing multimorbidity (Katikireddi et al., 2017; Ruel et al., 2014; Zhang et al., 2022). Poor eating habits, combined with low levels of physical activity, are also the main risk factors for **overweight or obesity** (WHO, 2000). Overweight and obese individuals are much more likely to be multimorbid than those in a normal weight range (Bisquera et al., 2021; de Souza et al., 2021; Fortin et al., 2014; Katikireddi et al., 2017; Lebenbaum et al., 2018; Roberts et al., 2015). Further longitudinal studies have confirmed the connection between overweight/obesity and the development and/or progression of multimorbidity (Ashworth et al., 2019; Booth et al., 2014; Jackson et al., 2015; Kivimäki et al., 2017; Mounce et al., 2018; Ryan et al., 2018; Shang et al., 2020; WikströTablesm et al., 2015). A recent birth cohort study found that more obese individuals, especially in younger age groups, develop multimorbidity at an earlier age than those of normal weight (Canizares et al., 2018). Another large cohort study in PHC estimated that a third of multimorbidity was attributable to overweight and obesity (Booth et al., 2014). Again, studies have suggested that the rising obesity epidemic may be a significant contributor to the increase in multimorbidity (Bisquera et al., 2021; Booth et al., 2014; Lebenbaum et al., 2018).

**Tobacco use** (current and/or past) has also been showed to be associated with multimorbidity (Agborsangaya et al., 2012; Andersén et al., 2021; Ashworth et al., 2019; Fortin et al., 2014; Roberts et al., 2015) although one study found this association only in men (Fortin et al., 2014). However, a study conducted in Finland showed that there was around 2.5-fold increase in the risk of multimorbidity associated with smoking in both men and women (Wikström et al., 2015) and several other longitudinal studies have confirmed the connection between tobacco use and the development/ progression of multimorbidity (Canizares et al., 2018; Jackson et al., 2015; Mounce et al., 2018; Shang et al., 2020; Xu et al., 2018). Also, **harmful alcohol consumption** was associated with a higher likelihood of multimorbidity both in cross-sectional (Bisquera et al., 2021) and longitudinal studies (Jackson et al., 2015), although one study that measured alcohol use only as frequency found no connection (Singer et al., 2019). Further while some studies revealed no association with multimorbidity based on smoking (Dhalwani et al., 2017) or alcohol consumption alone (Dhalwani et al., 2017; Freisling et al., 2020), they showed this association when combined with other risk factors (Dhalwani et al., 2017; Freisling et al., 2020). For example, when smoking was combined with obesity and physical inactivity, the risk increased by four times (Dhalwani et al., 2017).

**Existing conditions** seem to increase the risk for other conditions, some of them increasing the risk more potently than others. Further, studies have found that some conditions cluster together more than would be expected by random chance, but the clusters (or patterns) found are myriad and their compositions vary greatly (Busija et al., 2019; Prados-Torres et al., 2014). However, diabetes, heart disease, hypertension, and depression seem to be the epicentre (Kudesia et al., 2021; Xu et al., 2017; Zemedikun et al., 2018) as well as a starting point for many multimorbidity disease clusters, depression being a common starting condition in younger individuals (Kudesia et al., 2021; Xu et al., 2017). Further, mental and physical conditions seem to have bidirectional relationship; Individuals with certain mental conditions, mostly depressive symptoms or depression, were significantly more likely to have physical conditions than the general population (Filipčić et al., 2020; Kivimäki et al., 2020; Prados-Torres et al., 2014; Xu et al., 2019) and, on the other hand, an increased number of chronic conditions was associated with an increased risk for mental health conditions (Barnett et al., 2012; Read et al., 2017; Schiøtz et al., 2017; Xu et al., 2019). The link between mental health and physical health is complex, but it is suggested to partly be due to underlying mediating factors, such as social and lifestyle-related behavioural factors along with a physiological mechanism (Kivimäki et al., 2020; Ohrnberger et al., 2017; Singer et al., 2019).

**A lower sense of control and more negative attitudes toward life and health** seem also to be linked to the increased risk of multimorbidity. A lower sense of control i.e., the extent to which individuals feel that life events are outside their control has been found to be associated with a higher likelihood of developing or worsening multimorbidity (Mounce et al., 2018; Singer et al., 2019). A recent study found that more negative attitudes towards life and health are associated with accelerated multimorbidity development independent of demographic, clinical, social, personality, and lifestyle factors both with and without multimorbidity at baseline (Calderón-Larrañaga et al., 2019). Also, **loneliness,** i.e., an individual's perceived subjective discrepancy between one's desired and actual relationships (smaller quantity and/or poorer quality than preferred), a well-known risk factor for multiple individual chronic conditions (Yanguas et al., 2018), has been found to be associated with multimorbidity in several population health survey studies (de Souza et al., 2021; Kristensen et al., 2019; Stickley & Koyanagi, 2018). This association is also observed with just physical multimorbidity and has been found to be stronger in younger people (Stickley & Koyanagi, 2018) and confirmed by the findings of a longitudinal study (Singer et al., 2019) and a recent systematic review (Hajek et al., 2020). The explanations for this association are varied and even unknown, but it has been suggested that they are related to complex biological, social and lifestyle-related behavioural factors and causality probably occurs in both directions (Hajek et al., 2020; Singer et al., 2019; Yanguas et al., 2018).

### *2.1.2 Challenges and complexity of multimorbidity*

**Patients with multimorbidity are a highly heterogeneous group** with varied physical and mental conditions. There are huge variations in how these conditions are combined, what are the severity, progression, outcomes, and care needs of these conditions and how they impact the individual patients in their unique and changing circumstances. Thus, the effect of multimorbidity on patients varies considerably, and even the same combination of conditions may have different implications for different patients. However, in general, multimorbidity has major negative and probably interacting consequences on patients, their care, carers, and healthcare systems and the whole society, from both human and economic perspectives (Academy of Medical Sciences, 2018; Muth et al., 2019; Wallace et al., 2015; WHO, 2016).

**Multimorbidity has a negative impact on outcomes related to the patient's health and life.** Patients with multimorbidity are more likely to have poor perceived health, i.e., the subjective experience of their health in general (Jylhä, 2009; OECD, 2021a), than others with no or only one chronic condition (Arokiasamy et al., 2015; Marques et al., 2018; Mavaddat et al., 2014; Palladino et al., 2016). There is also evidence that multimorbidity negatively influences patient's health-related quality of life (HRQoL), i.e., the subjective assessment of health-related well-being (Agborsangaya et al., 2013; Brettschneider et al., 2013; Li et al., 2016; Makovski et al., 2019; Ryan et al., 2015; Wang et al., 2017) as well as the quality of life (QoL) i.e., the overall subjective well-being encompassing physical, emotional, and social functioning (Garin et al., 2016; Kanesarajah et al., 2018; Makovski et al., 2019; Wikman et al., 2011; Williams & Egede, 2016). Multimorbidity is also associated with reduced functional ability (Arokiasamy et al., 2015; Buttorff et al., 2017; Garin et al., 2014; Jindai et al., 2016; Palladino et al., 2016; Stenholm et al., 2015) and increased disability (Rizzuto et al., 2017; Williams & Egede, 2016). Functioning and disability exist on a continuum; Functioning refers to people's ability (physical, psychological, and social) to cope with the day-to-day activities they find necessary and meaningful in the environment in which they live, while disability refers to difficulty performing activities considered necessary to engage in everyday life (Jindai et al., 2016; THL, 2021c). Multimorbidity also increases the odds of perceived anxiety (Vancampfort, Koyanagi, Hallgren, et al., 2017) and perceived stress i.e., perceiving one's life as unpredictable, uncontrollable, and overloaded (Prior et al., 2016). Further, by causing reduced ability to work, sick leaves, and early retirement, multimorbidity increases work-life problems (Cabral et al., 2019). It is also associated with a higher incidence of acute morbidity (Foguet-Boreu et al., 2014), which was also clearly demonstrated by the COVID-19 epidemic (Chudasama et al., 2021) and premature mortality/reduced life expectancy (Dugravot et al., 2020; Gallo et al., 2016; Jani et al., 2019; Rizzuto et al., 2017).

**Patients with multimorbidity experience increased treatment burden** i.e., the impact of the 'work of being a patient' on functioning and general well-being defined as the aggregate weight of the actions and resources patients devote to their healthcare (Sav et al., 2016; Tran et al., 2015), or the effort required to self-manage medical conditions (Duncan et al., 2018). Treatment burden is a relatively new concept without a single standard definition (Alsadah et al., 2020), but it is important to note that it is distinct from disease burden i.e., the effect of the disease on an individual. The treatment burden that patients with multimorbidity face can be comparable to the disease burden itself (Tran et al., 2015) and may have negative effects on the patient's care and quality of life (Duncan et al., 2018; Herzig et al., 2019).

**Polypharmacy is strongly associated with multimorbidity.** This result is consistent despite various definitions used for polypharmacy, i.e., the use of multiple medications to treat health conditions (Calderón-Larrañaga et al., 2012; Hopman, Heins, et al., 2016; Masnoon et al., 2017; Monterde et al., 2020; Vos et al., 2022; WHO, 2019). The most widely used definition may be the concomitant use of ≥5 medications daily (Masnoon et al., 2017; WHO, 2019) but polypharmacy has also been defined as the use of eight or more (Monterde et al., 2020) or ten or more drugs during the year (Hopman, Heins, et al., 2016). Polypharmacy is known to be associated with many problems such as drug-drug and drug-disease interactions, medication non-adherence, and adverse drug events (Vos et al., 2022; WHO, 2019). Indeed, **patients with multimorbidity are more likely to experience an increased number of adverse drug events** (Calderón-Larrañaga et al., 2012; Panagioti et al., 2015) **as well as other safety incidents** (WHO, 2016) such as complications, infections and care failures (Panagioti et al., 2015).

**Patients with multimorbidity are more likely to use an increased number and variety of healthcare services.** Indeed, multimorbidity is a major driver of healthcare utilisation, particularly in PHC (for example Bähler et al., 2015; Cassell et al., 2018; Monterde et al., 2020; Stafford et al., 2018; Van Oostrom et al., 2014; Wallace et al., 2015) where it is related to more than half of consultations (Cassell et al., 2018; Salisbury et al., 2011), but it also affects the whole healthcare system, including secondary care (Bähler et al., 2015; Palladino et al., 2016), hospitalizations (Buttorff et al., 2017; Gruneir et al., 2016), and unplanned emergency admissions (Palladino et al., 2016; Stafford et al., 2018). **Multimorbidity management has also considerable financial implications** both for patients (Larkin et al., 2021) and healthcare systems, while costs often increase exponentially with an increase in the number of chronic conditions (Bähler et al., 2015; McPhail, 2016; Orueta et al., 2014; Stafford et al., 2018; Wang et al., 2018). Multimorbidity also increases social care utilisation (Henderson et al., 2021; Kasteridis et al., 2015; Monterde et al., 2020) and costs (Kasteridis et al., 2015).

**Patients with multimorbidity have more complex care needs.** Multimorbidity requires addressing, prioritising, and finding a balance between multiple conditions and multiple care regimens. Furthermore, it contributes to clinical complexity due to interactions of conditions, interactions of treatments (pharmacological and others), and interactions between the conditions and treatments. Treating one condition may worsen another (Muth et al., 2014; Wallace et al., 2015). Further, the currently available health services (also applies in PHC) are not well adapted to multimorbidity but are, instead, typically organised around a single disease model (reinforced by care, workforce, education, research, care guidelines etc.), which ensures high professionalism in single-disease care but causes fragmentation in the treatment of patients with multimorbidity (Calderón-Larrañaga & Fratiglioni, 2019; Palmer et al., 2018). Clinical guidelines, commonly used to help make decisions about appropriate care, are created largely for individual conditions and rarely address multimorbidity. Similarly, randomised controlled trials (RCTs) usually routinely exclude patients with multimorbidity to limit sample variability. As such, applying multiple single disease-oriented care guidelines may be impractical, inappropriate, or even harmful, leading to highly demanding care (Buffel Du Vaure, Dechartres et al., 2016; Stoll et al., 2019; Uhlig et al., 2014). Further, patients are typically cared for by multiple specialists, perhaps different providers for each condition and perhaps in different settings, so it is also common for care to be fragmented (Rijken et al., 2016; National Audit Office of Finland, 2017; Wallace et al., 2015).

**Managing multimorbidity has been found challenging by the patients with multimorbidity, HCPs working with them, and patients' family caregivers** (Gill et al., 2014; Ploeg et al., 2017)**.** All these parties have also faced many common challenges, including care management difficulties, a lack of coordination, and poor communication between both HCPs as well as HCPs and patients (Gill et al., 2014). HCPs have described that multimorbidity poses challenges in their work and is associated with feelings of complexity (Cottrell & Yardley, 2015; Coventry et al., 2014; Gill et al., 2014; Kenning et al., 2013; Ploeg et al., 2017; Sinnott et al., 2013; Sondergaard et al., 2015; Stokes et al., 2017; Whitehead et al., 2021), uncertainty (Bower et al., 2013; Cottrell & Yardley, 2015; Kenning et al., 2013), and enforced compromises (Cottrell & Yardley, 2015). In addition, the patient and HCPs did not always share a common understanding of care, its priorities, and goals (Cottrell & Yardley, 2015; Kuluski et al., 2013; Morris et al., 2011; Sathanapally et al., 2020) which causes discrepancies between the expectations of the HCPs and those of the patient (Cottrell & Yardley, 2015). Further, studies mapping the experiences of patients have identified several difficulties related to the healthcare process e.g., contradictory (Morris et al., 2011; Sav et al., 2013) or insufficient information about patients' conditions and treatment options (Adeniji et al., 2015; Koch et al., 2015; Morris et al., 2011; Sav et al., 2013; van der Aa et al., 2017), a lack of holistic care, counselling (van der Aa et al., 2017), decision-making support (Gill et al., 2014; Ploeg et al., 2017), coordination (Gill et al., 2014; Maeng et al., 2012; Ploeg et al., 2017; Schiøtz et al., 2016), and continuity of care (Salisbury et al., 2011; Sav et al., 2013; Schiøtz et al., 2016; van der Aa et al., 2017) along with poor communication and a lack of respect (Adeniji et al., 2015; Gill et al., 2014; van der Aa et al., 2017). Further, these problems faced by patients have been found to make them feel confused and disempowered (Cottrell & Yardley, 2015; Grant et al., 2013). So, the problems faced by patients may be due to the severity or nature of their conditions and care, but they are often also related to the organisation of the healthcare system and their interaction with it (Doessing & Burau, 2015; Duguay et al., 2014; NICE, 2016). On the other hand, some studies suggest that increased interactions with health services in these patients might also increase the chances of receiving effective care (Panagioti et al., 2015; Ricci-Cabello et al., 2015; Zulman et al., 2014), indicating a potential for high-quality care that should definitely be considered.

### 2.1.3 Self-management as a key to managing multimorbidity

The care of chronic conditions is an ongoing, often lifelong, task, and while chronic conditions can rarely be cured, they can be controlled and the goal of their care is minimizing troublesome symptoms, slowing down disease progression, preventing the onset of additional illnesses, and achieving the best possible functional ability and quality of life despite existing conditions (Barlow et al., 2002; Grumbach, 2003; WHO, 2002). With its wide range of services provided by healthcare professionals centred around clinical encounters, PHC is seen as an optimal context to deliver care for chronic conditions and multimorbidity as it often serves as the first point of contact and a place for coordinating and referring patients to the necessary care provided in special/secondary care services (Barnett et al., 2012; Hansen et al., 2015; Smith et al., 2021; WHO, 2016). Indeed, PHC aims to maximize health and well-being through care by focusing on people's needs and preferences throughout their life course as closely as possible in people's everyday environments (WHO & UNICEF, 2018). However, patients are in contact with their healthcare providers for a fraction of their lives while the rest of time, the care is only under the direct control of the patients themselves and based on the measures that patients take in their everyday lives (Bayliss et al., 2007; Bodenheimer et al., 2002). As a result, ensuring patients' ability to self-manage their conditions is of paramount importance to the effective management of conditions and to improve the overall health of the population.

### *Self-management as concept*

In general, self-management refers to the day-to-day management of chronic conditions by individuals throughout an illness (Lorig & Holman, 2003). However, self-management is a broad concept with numerous definitions and no universal standard definition (Matarese et al., 2018; Miller et al., 2015; Van De Velde et al., 2019). The term "self-care" is also often used to refer to self-management. However, while some overlap between these related concepts exists, they also differ: self-care is defined as actions performed by all individuals to take care of their health with a focus on prevention and maintenance, and it is considered unavoidable but inherently involving choice. Meanwhile, self-management is used for actions performed by patients with chronic condition(s) with a focus on controlling and coping, and inherently involving essential and inevitable actions (Grady & Gough, 2014; Jones et al., 2011; Matarese et al., 2018; Richard & Shea, 2011; Sadler et al., 2014). According to the existing definitions of self-management, it is characterised as a dynamic, ongoing process that requires the patient's ability, confidence, and responsibility, and further, specific behaviours that patients perform to influence their health and well-being (Barlow et al., 2002; Lorig & Holman, 2003; Miller et al., 2015; Richard & Shea, 2011; Udlis, 2011; Van De Velde et al., 2019), aiming to minimize the impact of chronic condition(s) on physical health status and functioning, and to enable coping with the psychological effects of the illness and maintaining a satisfactory quality of life (Barlow et al., 2002; Grady & Gough, 2014; Lorig & Holman, 2003).

Further, while self-management is admittedly what the patient does to manage their condition(s), and is thus affected by the characteristics of the patient, patients do not self-manage in isolation, and support from loved ones is recognized as important. Further, support from HCPs is seen as a central part of self-management (Barlow et al., 2002; Bodenheimer et al., 2002; Jones et al., 2011; Lorig & Holman, 2003; Miller et al., 2015; Richard & Shea, 2011; THL, 2021b; Udlis, 2011). Self-management support is a person-centred collaborative approach for facilitating and maintaining appropriate effective self-management by the patient (Jones et al., 2011; Mills et al., 2017), which is recognised as a core component of care for people with chronic conditions (Muth et al., 2019; Taylor et al., 2014). Further, it is known that patients themselves have interpreted self-management in terms of the quality of the relationship with HCPs, including a collaborative partnership and tailored support (Sadler et al., 2014). A recent concept analysis of self-management emphasises that while self-management requires the patient to actively participate in and take responsibility for their care process, it also entails openness to ensure a reciprocal partnership with healthcare providers and social support (Van De Velde et al., 2019). As such, the realisation of patient participation, which lies at the core of collaboration between HCPs and patients in care, can be seen as the basis of successful self-management. Again, patient adherence to self-management is intertwined with the care process, as adherence refers to the extent to which the patient follows care recommendations that have been agreed upon in close collaboration with HCPs (Kyngäs et al., 2016; Lyu & Zhang, 2019; WHO, 2003). In this study, self-management is defined according to the concept analysis mentioned above (Van De Velde et al., 2019) as “the ability of an active, responsible, informed and autonomous individual to live with the medical, role and emotional consequences of their chronic condition(s) in partnership with their social network and the healthcare provider(s).”

### *Self-management in the context of multimorbidity*

Self-management in the context of multimorbidity is more complex than in the case of a single condition. Life-long self-management required even by a single condition on a daily basis can be challenging, and the presence of two or more conditions makes management a more burdensome and complicated, yet even more imperative, process (Bratzke et al., 2015; Garnett et al., 2018; Gobeil-Lavoie et al., 2019; Hopman, Schellevis, et al., 2016; Liddy et al., 2014). This often necessitates the management of complicated, demanding medical needs along with competing, potentially conflicting priorities, and care regimens for conditions (Gobeil-Lavoie et al., 2019; Wallace et al., 2015). Further, due to the nature of chronic diseases, exacerbations and remissions of each of the conditions may alternate, and any condition can affect the patient more or less at a given time. As a result, self-management necessitates the prioritization of care and involves a need to repeatedly reorganize one's everyday life (Duguay et al., 2014; Slightam et al., 2018). Self-management can be particularly challenging when patients' conditions are unrelated to each other and require different treatment measures (discordant multimorbidity, such as physical-mental multimorbidity), which may impair and complicate the management considerably. Meanwhile, in cases where a patient's conditions are interrelated, sharing similar origin and/or management strategies (concordant multimorbidity), care strategies can overlap, which may improve the effectiveness of patient care and help patients in the self-management process (Academy of Medical Sciences, 2018; Zulman et al., 2014).

Self-management typically involves a range of tasks or behaviours, such as following care regimens that may include taking medications as prescribed, self-monitoring conditions and treatments, choosing proper treatment options, and organising and attending healthcare appointments, which typically includes coordinating care between different providers and multiple appointments as well as executing lifestyle changes and/or maintaining a healthy lifestyle (Bayliss et al., 2007; Bodenheimer et al., 2002; THL 2022a). Four main behavioural risk factors shared in the field of chronic diseases, i.e., tobacco use, unhealthy diet, physical inactivity, and the harmful use of alcohol (WHO, 2013b), are also risks for good care and prognosis of multimorbidity as well as for developing a new chronic condition in people who already have a multimorbidity. They should therefore be avoided. As such, self-management represents a significant burden for patients, demanding a lot of their time and energy (Duguay et al., 2014; Duncan et al., 2018; Sav et al., 2013; Tran et al., 2015). For example, an analysis of the potential workload of patients with multimorbidity applying the most recent clinical guidelines for adults with prevalent chronic conditions in PHC found that (depending on the concomitant chronic conditions) patients with three chronic conditions would have to: take 6–13 medications per day, visit a health caregiver 1.2–5.9 times per month, and spend 49.6–71.0 hours per month on average on health-related activities. Moreover, the potential workload increased greatly with an increasing number of concomitant conditions, growing to 18 medications per day, 6.6 visits per month, and 80.7 hours per month spent on health-related activities for patients with six chronic conditions; this results in workloads so laborious that may be unrealistic to adhere to (Buffel Du Vaure, Ravaud et al., 2016).

The main patient-related factors influencing self-management, according to the experience reports of both patients and HCPs, were capacity, motivation, and responsibility (Coventry et al., 2014; Kenning et al., 2013). Many patients have further stressed the need for appropriate, individualized support from HCPs and close friends and relatives (Freilich et al., 2020; Koch et al., 2015; Liddy et al., 2014; Slightam et al., 2018) to improve their motivation, and understand and manage these issues in their daily lives (Coventry et al., 2014; Gill et al., 2014; Kenning et al., 2013; Morris et al., 2011; van der Aa et al., 2017). For some, life with multimorbidity is more normal and for others, it significantly complicates their patient journey, self-management, and everyday life (Coventry et al., 2014; Duguay et al., 2014; Kenning et al., 2013; Ørtenblad et al., 2018; Slightam et al., 2018). HCPs have also detected that patients have struggled to self-manage their conditions, to varying degrees, and further found it challenging to support patients to achieve good self-management (Coventry et al., 2014; Freilich et al., 2020; Kenning et al., 2013; Whitehead et al., 2023).

Indeed, while self-management has been recognized to play a central role in managing multimorbidity, embracing the approaches to support it is needed (Academy of Medical Sciences, 2018; Muth et al., 2019; NICE, 2016; Poitras et al., 2018; WHO, 2016; Wilson et al., 2016). Again, while self-management has been studied quite extensively with a focus on individual diseases, there is a need for research focusing on multimorbidity. A recent systematic review (Dineen-Griffin et al., 2019) and a cross-country comparative document analysis (O'Connell et al., 2018) on self-management support strategies or frameworks for PC found that there was a notable gap in studies regarding a focus on multimorbidity. Also, a large systematic review of interventions for patients with multimorbidity in PC or community settings found only 17 randomised controlled trials (RCTs), five of which were patient-oriented self-management support-type interventions, but the effectiveness of these interventions was sparse (Smith et al., 2021).

### 2.1.4 Patient-centred approach as a requirement in the care of patients with multimorbidity

Research information on high-quality care and effective interventions to improve outcomes for patients with multimorbidity, including self-management support, remains limited (Academy of Medical Sciences, 2018; *Multimorbid patient.*

*Current Care Guidelines*, 2021; Smith et al., 2021; Xu et al., 2017). However, according to literature, implementing individualized patient-centred care has been frequently suggested to enable meeting the care needs of patients with multimorbidity when delivering care, as well as handling the pitfalls of managing multimorbidity. Various terms have been used to refer to this kind of care, including patient/person-focused/-oriented, holistic, or whole-person care and it has been further seen as a particularly proper approach in PHC (Academy of Medical Sciences, 2018; Buja et al., 2018; Calderón-Larrañaga & Fratiglioni, 2019; Kuipers et al., 2019; Muth et al., 2019; Poitras et al., 2018; Savitz & Bayliss, 2021; Sturmberg et al., 2021; Valderas et al., 2019; Wallace et al., 2015; WHO, 2016, 2018a; Wilson et al., 2016). Patient-centred care is not a new approach; there have been suggestions that it should be adopted by HCPs for decades (Dwamena et al., 2012; Langberg et al., 2019; WHO, 2013c). However, a tangible need for it has received stronger and more recent emphasis in the context of multimorbidity. A care approach that considers the individuality and overall situation of the patient has also been mentioned in care guidelines (*Multimorbid patient. Current Care Guidelines*, 2021; NICE, 2016) and models for patients with multimorbidity (Fortin & Stewart, 2021; Leijten, Struckmann, et al., 2018; Mercer et al., 2016; Palmer et al., 2018; Salisbury et al., 2018; van der Heide et al., 2018). Such an approach is also aligned with patients' perceptions that continuous care and a holistic approach used by HCPs are vital to good care (Butterworth et al., 2019; Cottrell & Yardley, 2015; Freilich et al., 2020; Leijten, Hoedemakers, et al., 2018; van der Aa et al., 2017).

A patient-oriented approach refers to an approach in which service providers perceive patients as individuals with active agency, organise their activities based on patients' needs and resources, and enable patients to act as equal partners with experts and professionals (Key Concepts of the Health and Social Services Reform glossary, THL, 2021a). Two distinct kinds of expertise are needed to facilitate this: the expertise of the HCPs and the expertise of patients about their specific context; collaboration is essential to reconciling these key areas of care, consultation, and the real world in which patients live their lives (Bayliss et al., 2014; Valderas et al., 2019). The idea of co-production has also emerged in the context of patient-centred care: a view of health services continually shaped and reshaped by HCPs and patients together (Batalden et al., 2016; OECD, 2021b). Again, patient-centred care that involves collaboration between HCPs and patients is also closely related to aspects of continuity of care that encompass three types: relational, informational, and management continuity (Haggerty et al., 2013; WHO, 2018). These approaches emphasize the importance of assessing the patient's outcomes and experiences gathered from patients from patient-reported measures (PRMs) (Forestier et al., 2019; Kingsley & Patel, 2017; OECD, 2019, 2021b), the use of which has been argued to be critical to achieving high-performing health systems that are responsive to the needs of patients with multimorbidity (Calderón-Larrañaga & Fratiglioni, 2019; Valderas et al., 2019).

Paradoxically, due to its complexity, the presence of multimorbidity also makes it difficult for HCPs to provide patient-centred continuous care (Kuipers et al., 2021; Sinnott et al., 2013; van der Heide et al., 2018). So far, interventions related to this topic have not been particularly effective in this complex patient population (Fortin et al., 2022; Mann et al., 2019; Salisbury et al., 2018; Smith et al., 2021). In this study, the central role of the patient and collaboration between patients and HCPs are examined through the concepts of patient participation, adherence, and activation. Additionally, while all these concepts are used related to the meaning of providing patients with a key role in managing their own health and healthcare (Finset, 2017; Fumagalli et al., 2015; Menichetti et al., 2016), they also differ, as they characterize different aspects of the patient's role in the care process and further self-management but nevertheless, they all offer the patient's perspective.

## 2.2 Patient participation in chronic care

### *2.2.1 Patient participation as a concept*

Patient participation lies at the core of patient-centred care and collaboration between HCPs and patients. While it is a commonly used and widespread concept, there is no single general definition for it (Cahill, 1996; Castro et al., 2016; Kvæl et al., 2018; Melin, 2018; Nilsson et al., 2019; Sahlsten et al., 2008; Thórarinsdóttir & Kristjánsson, 2014). There are also many related or parallel concepts and terms for patient participation, such as patient involvement (Cahill, 1996; Castro et al., 2016; Halabi et al., 2020; Melin, 2018; Thompson, 2007; Thórarinsdóttir & Kristjánsson, 2014), patient empowerment (Castro et al., 2016; Halabi et al., 2020; Kvæl et al., 2018; Melin, 2018; Thompson, 2007), patient engagement (Higgins et al., 2017; Kvæl et al., 2018; Melin, 2018), patient enablement (Fumagalli et al., 2015), patient partnership (Cahill, 1996; Gallant et al., 2002; Halabi et al., 2020; Thórarinsdóttir & Kristjánsson, 2014), collaboration (Cahill 1996), and patient centred(ness)/patient-centred care (Castro et al., 2016; Kvæl et al., 2018; Langberg et al., 2019; Thórarinsdóttir & Kristjánsson, 2014). However, while these concepts are even at times used interchangeably, most of them also have some differences (Fumagalli et al., 2015; Halabi et al., 2020; Kvæl et al., 2018). The meaning and the relationship between the presented concepts also vary according to the source considered. For example, while patient involvement is often considered a synonym for patient participation (Castro et al., 2016; Higgins et al., 2017; WHO, 2013a), it is also perceived as an integral part of patient participation along with partnership (Thórarinsdóttir & Kristjánsson, 2014) or as a prerequisite for patient participation (Cahill, 1996) and vice versa (Thompson, 2007). Further, patient participation is seen as a way to promote patient empowerment (Castro et al., 2016; Sahlsten et al., 2008), but empowerment is also presented as an antecedent for patient participation (Fumagalli et al., 2015). Moreover, patient participation is a strategy used to achieve patient-centred care (Castro et al., 2016; Kvæl et al., 2018) and a true partnership between HCPs and patients (Cahill, 1996).

However, despite the variety in definitions, the generally recognized attributes of patient participation include an established collaborative relationship; exchanges of information, knowledge, and power between the patient and HCPs; and mutual engagement in diverse activities, such as care planning and decision-making (Cahill, 1996; Kvæl et al., 2018; Sahlsten et al., 2008; Thórarinsdóttir & Kristjánsson, 2014). A framework analysis of person-centred patient participation presented that patient participation manifests itself via three intertwined phases, human connection, information processing, and action, and should be based on patients' experiences, values, preferences, and needs, and place respect and equality at the centre (Thórarinsdóttir & Kristjánsson, 2014). Mutual communication elements are integral to patient participation as communication is a key tool and component in patient participation (Millar et al., 2016; Thórarinsdóttir & Kristjánsson, 2014). Again, a patient's way of communicating in healthcare encounters has been considered to reflect their active participation. This active participation manifests as providing information, asking questions (information seeking), and expressing opinions, preferences, and views (assertive utterances, expression of concern) (Cegala, 2011; D'Agostino et al., 2017; Street & Millay, 2001). Patient participation is thus a broad, multidimensional, and multilevel concept covering the reciprocal process where the patient and HCP(s) act and influence each other's actions. In this study, patient participation is considered to emphasize patients' rights and possibilities to participate in and influence their own care in collaboration with HCPs, including reciprocal relationships, information processing, and actions.

### *2.2.2 Meaning and realisation of patient participation*

Patient participation is based on ethical principles such as autonomy, integrity, justice, and dignity, and a key justification for participation is the individual's right to influence matters that concern one's life and receive services and care that correspond to one's needs and values (WHO, 1994, 2013c). It is also a highly valued goal and principle in itself, i.e., an intrinsic value (Kitson et al., 2013; Modigh et al., 2021). Patient participation is high on the political agenda (Finnish Government, 2021) and several Western countries have also passed legislation to support it. In addition, a good realisation of patient participation has been found to produce many positive benefits for patients, the results of care, and the care process (Modigh et al., 2021) as well as to play an empowering and therapeutic role (Tambuyzer et al., 2014), enhancing satisfaction, motivation, and empowerment (Sahlsten et al., 2008), confidence (Millar et al., 2016), an ability to take more responsibility (Luhr, Holmefur, et al., 2018), and engage in self-management activities (Longtin et al., 2010; Luhr, Holmefur, et al., 2018), and prevent medical errors and increase patient safety (Longtin et al., 2010; WHO, 2013a). Further, the patient's active participation may lead to better outcomes, such as enhanced reciprocal communication between patient and HCPs (Cegala et al., 2007; Cegala & Post, 2009), remembering treatment recommendations (Richard et al., 2017). and adherence to behavioural treatment and follow-up appointments (Cegala et al., 2000). From the point of view of the healthcare system, patient perceptions of the realisation of patient participation serve as a quality indicator and may further improve it (Tritter, 2009; WHO, 2013a).

However, although the importance and significance of participation have been internationally acknowledged, realising patient participation in everyday practice is challenging (Angel & Frederiksen, 2015; Halabi et al., 2020; Millar et al., 2016; Thórarinsdóttir & Kristjánsson, 2014; Weiste et al., 2020). It is a complex phenomenon that emerges in social interaction, and thus all parties, including patients, HCPs, and organisational factors, influence its process. Previous studies have found that patient participation may involve patient-related factors such as sociodemographic characteristics and health condition (Angel & Frederiksen, 2015; European Commission, 2012; Halabi et al., 2020; Lalani et al., 2019; Longtin et al., 2010). Poor health and serious illness are likely to hinder actual participation, even if they do not affect the desirability of participation (Angel & Frederiksen, 2015). It may also be limited by patients' perceived ability and willingness to participate, as well as feeling unclear about their expected role (Angel & Frederiksen, 2015;

European Commission, 2012; Halabi et al., 2020; Longtin et al., 2010) and low patient activation (Henselmans et al., 2015). Patients' preferences may also vary over time and from situation to situation and activity to activity. For example, it is possible that some patients are not interested in an active role in decision-making, yet still value information relevant to it (European Commission, 2012; Longtin et al., 2010; Thórarinsdóttir & Kristjánsson, 2014; Xie et al., 2014).

In healthcare encounters, HCPs play a pivotal role in ensuring patient participation and sometimes patients have perceived personnel behaving in a way that limits their participation, such as a paternalistic attitude, lack of individual recognition, respect of autonomy, or lack of adequate time and communication (Eldh et al., 2008; European Commission, 2012; Halabi et al., 2020; Henselmans et al., 2015; Thórarinsdóttir & Kristjánsson, 2014). Patients have mentioned respect and equality as necessary preconditions of participation (Eldh et al., 2010; Luhr, Holmefur, et al., 2018; Thórarinsdóttir & Kristjánsson, 2014; Weiste et al., 2020) and further emphasized the importance of accessing adequate information and knowledge (Eldh et al., 2010; Luhr, Holmefur, et al., 2018; Melin, 2018; Thórarinsdóttir & Kristjánsson, 2014). However, the latter does not just concern receiving information, but also includes building the necessary skills and knowledge through cooperation, mutual dialogue, and getting heard (Eldh et al., 2010; Melin, 2018; Thórarinsdóttir & Kristjánsson, 2014) and encouraged by HCPs. For patients, this entails being "seen and heard" as an individual from a holistic perspective (Eldh et al., 2010; Lindberg, Kreuter, Taft, et al., 2013; Thórarinsdóttir & Kristjánsson, 2014). Implementing patient participation requires HCPs to collaborate with patients, including recognizing the importance and meaning of patient participation, which may require them to adapt to a new role and allocate resources, such as time and skills, for its implementation. Patient participation must be considered in the context, and both patients and HCPs are determined by the context in which they operate, but also construct the shape of this context (Angel & Frederiksen, 2015; Kvæl et al., 2018).

It appears that patient participation has often been studied in separate, limited areas, which is also confirmed by the results of recent reviews on patient participation reporting that most studies just focus on decision-making (Allen et al., 2019; Kylén et al., 2022; Modigh et al., 2021) or care planning (Kylén et al., 2022; Modigh et al., 2021). Patient participation is at times even merely perceived as a concept limited to decision-making (Allen et al., 2019; Kylén et al., 2022; Modigh et al., 2021). Again, there is a lack of validated instruments for measuring patient participation as a whole (Mavis et al., 2015; Phillips et al., 2016), particularly in outpatient settings (Kylén et al., 2022). Further, research on patient participation in patients with multimorbidity is scarce, as the review studies also show (Allen et al., 2019; Kylén et al., 2022; Modigh et al., 2021).

## 2.3 Patient adherence to self-management

### *2.3.1 Patient adherence as a concept*

Patient adherence can be defined as the extent to which a patient's behaviour, such as taking medication and following a diet, corresponds to what has been agreed with HCPs (Lyu & Zhang, 2019; WHO, 2003). However, it is a multidimensional concept for which there is no single commonly accepted definition. Several related concepts and terms have been introduced and are used to refer to the concept such as compliance (Bissonnette, 2008; Friberg & Hansson Scherman, 2005; Gardner, 2014; Kyngäs et al., 2000; Snowden et al., 2014; WHO, 2003), concordance, co-operation and therapeutic alliance (Bissonnette, 2008; Friberg & Hansson Scherman, 2005; Gardner, 2014; Snowden et al., 2014; WHO, 2003). Therapeutic alliance and co-operation focus more on the relationship and interaction between the patient and HCP while adherence and compliance refer more to the outcomes of this interaction (Friberg & Hansson Scherman, 2005; Kyngäs et al., 2000). Compliance, the oldest of these concepts, reflects the extent to which a patient follows orders decided and given by healthcare providers. Meanwhile, adherence places emphasis on cooperation and a shared understanding between HCPs and the patient, and thus focuses on active patient participation while choosing the most suitable treatment (Gardner, 2014; WHO, 2003). Moreover, compliance is seen as a dichotomous concept, whereas adherence has been more appropriately conceptualized as a continuum of behaviours ranging from full non-adherence to partial and full adherence (Gardner, 2014). As such, the shift from compliance to adherence reflects a fundamental change in understanding the relationships between patients and HCPs and the nature of adherence. The newest and still evolving concept is concordance (Snowden et al., 2014), which is more focused on the relationship between patients and professionals, while adherence is more of a behavioural process (Bissonnette, 2008; Gardner, 2014). In this study, adherence is defined as an active, intentional, and responsible process of care, in which the patient works to maintain their health in close collaboration with their healthcare providers (Kyngäs, 1999; Kyngäs et al., 2016), including the extent to which the patient follows agreed-upon recommendations regarding their care, as well as general recommendations related to leading a healthy lifestyle (WHO, 2003).

### 2.3.2 Meaning and realisation of patient adherence

Patient adherence to self-management is essential for maintaining optimal health, avoiding troublesome symptoms and even life-threatening complications, slowing down the progression of diseases, and preventing the onset of additional diseases (Bayliss et al., 2007; Bodenheimer et al., 2002). Further, poor adherence has numerous negative consequences for both individuals and societies due to reducing the effect of treatment (Dimatteo et al., 2002; Sav et al., 2015; WHO, 2003) and increasing morbidity, mortality, and healthcare visits and costs, which could be largely avoided by good adherence (Martin et al., 2005; WHO, 2003).

Adherence to self-management is a complex process driven by several complex factors (Dimatteo et al., 2002; Fernandez-Lazaro et al., 2019; Maffoni et al., 2020; Martin et al., 2005; Vermeire et al., 2001; WHO, 2003). In addition to patients' social and economic factors, other patient-related factors such as resources, knowledge, beliefs, and perceptions, as well as condition-related factors (level of disability, co-morbidities etc.), therapy-related factors (complexity, long duration etc.), and health system-related factors (patient-provider partnership, system's ability to establish self-management capacity etc.) may be influencing and interacting (Martin et al., 2005; WHO, 2003). These factors highlight the fact that the burden and complexity of multimorbidity in itself as well as its care contain features that may reduce patients' adherence to care. Previous systematic reviews on medication adherence in patients with multimorbidity have shown this variability and an abundance of factors associated with adherence (Foley et al., 2021; Maffoni et al., 2020). Further, it is important to note that nonadherence can be either intentional or unintentional, either of which may be influenced by workload and capacity imbalances (Giardini et al., 2018; Tran et al., 2015).

The Theory of Adherence of People with Chronic Disease developed by Kyngäs (1999) presents factors associated with adherence from the patient's point of view. These are energy and willpower (in contrast with fatigue), motivation, the experienced results of care, a sense of normality, fear of complications and additional diseases, and support obtained from physicians, nurses, and friends and relatives. While this theory was originally developed among young people with diabetes, it has since been modified and used among different patient groups with varied ages and health conditions in varied healthcare settings. Previous studies gathered among adult patients with specific chronic conditions have found that the factors explaining adherence to care included motivation (Kääriäinen et al., 2013; Kähkönen et al., 2015), the results of care (Lunnela et al., 2011), sense of normality (Kääriäinen et al., 2013), and support from physicians (Lunnela et al., 2011), nurses (Kähkönen et al., 2020; Lunnela et al., 2011), and next of kin (Kähkönen et al., 2020).

Adherence is known to be deficient in patients with chronic conditions (Fernandez-Lazaro et al., 2019; WHO, 2003). In patients with multimorbidity, the findings regarding the prevalence of medication adherence and non-adherence have varied considerably (Foley et al., 2021; Kim et al., 2018). However, the study assessing guideline-concordant care among this patient population found that patients adhered to the care recommended by clinicians on average more than 90% of the time; adherence was high when it came to medications and follow-up tests, but lower regarding lifestyle changes (Cohen-Stavi et al., 2020).

There is a considerable need for more research on adherence and factors influencing it in patients with multimorbidity (Granata et al., 2020; Yang et al., 2022). It is known that there is no single intervention strategy that can improve adherence in all patients and that interventions should be patient-oriented (Martin et al., 2005; WHO, 2003), signalling a need for introducing multifaceted and tailored approaches and interventions to enhance adherence in multimorbid populations (Foley et al., 2021; Granata et al., 2020; Maffoni et al., 2020; Yang et al., 2022). Further, previous studies using the ACDI instrument have not yet focused on patients with multimorbidity.

## 2.4 Patient activation for self-management

### *2.4.1 Patient activation as a concept*

Patient activation describes the individual’s knowledge, skills, and confidence in managing their own health and healthcare. It refers to the degree to which the individual understands they must play an active role in managing their health and health care, and the extent to which they feel able to fulfil that role (Hibbard et al., 2004, 2005; Hibbard & Greene, 2013). Patient activation is related to, but different from, a few other concepts such as self-efficacy, patient engagement, empowerment (Fumagalli et al., 2015; Hibbard & Gilburt, 2014) readiness to change, and health literacy (Hibbard & Gilburt, 2014). First, it is a more generalized concept than self-efficacy and readiness to change that are used in relation to a specific designated behaviour, such as a healthy diet (Hibbard & Gilburt, 2014). Further, although all these include patients' judgments regarding their capability to perform a set of self-management activities, patient activation also includes making judgments about skill building and the actual execution of those behaviours (Moore et al., 2016). Patient engagement is, in turn, usually considered a broader concept that includes patient activation (Fumagalli et al., 2015; Hibbard & Gilburt, 2014; Hibbard & Greene, 2013). Further, while patient activation weakly correlates with the skills-based concept of health literacy, it is different and separate (Hibbard & Gilburt, 2014; Nijman et al., 2014; Smith et al., 2013), as patient activation is related to the behavioural and cognitive attitude of a patient in their care management (Graffigna et al., 2015). Patient activation has been conceptualized as involving four sequential stages: (1) patients believe they have important roles to play in managing their conditions, (2) they possess the knowledge needed to manage their health, (3) they take action, using their skills and behavioural repertoire to maintain their well-being, (4) finally, they stay on the course under stress (Hibbard et al., 2004; Skolasky et al., 2011). In this study, patient activation is defined as the patient's knowledge, skills, and confidence, and beliefs about the importance of their role in managing their own health and healthcare (Hibbard, 2005).

### *2.4.2 Meaning and realisation of patient activation*

According to the construct of patient activation, more highly activated individuals believe that their role in managing their own health is important and feel more in charge of it, and they have the knowledge and confidence necessary to act appropriately and carry out behaviours to maintain or improve their health (Hibbard et al., 2005, 2004). Accordingly, previous empirical studies conducted among patients with diverse chronic condition(s) have linked patient activation to many positive health behaviours (Greene & Hibbard, 2012; Hibbard et al., 2015), such as following medication guidelines, and monitoring their condition (Marshall et al., 2013; Rask et al., 2009), adherence to medications (McCusker et al., 2016), physical exercise (McCabe et al., 2018; McCusker et al., 2016; Skolasky et al., 2011), a healthy diet (Hibbard et al., 2017), not smoking (Greene & Hibbard, 2012; McCabe et al., 2018), declining healthcare task difficulty over time (Boyd et al., 2014), as well as seeking and using health information (Nijman et al., 2014). Correspondingly, low activation was associated with worse self-management performance (Regeer et al., 2021; Zimbudzi et al., 2017). Additionally, studies have also found that higher activation further predicts positive clinical outcomes such as better blood pressure control (Greene & Hibbard, 2012; Sacks et al., 2017), glycaemic control (Sacks et al., 2017), and a lower body mass index (BMI) (Bos-Touwen et al., 2015; Korpershoek et al., 2016; McCabe et al., 2018). Lower patient activation is, in turn, found to be associated a with lower perceived overall health (Gerber et al., 2011; Hendriks & Rademakers, 2014; Tusa et al., 2020), health-related quality of life (HRQoL) (Blakemore et al., 2016; Magnezi et al., 2014; Overbeek et al., 2018; Schmaderer et al., 2016; Zimbudzi et al., 2017), depression (Blakemore et al., 2016; Bos-Touwen et al., 2015; Magnezi et al., 2014; Schmaderer et al., 2016), and anxiety (Korpershoek et al., 2016; Schmaderer et al., 2016). Activation also seems to be linked to experiences of diverse positive and negative emotions in daily life related to illness (Graffigna et al., 2017) and managing health (Hibbard & Mahoney, 2010). A systematic scoping review confirmed that diverse psychosocial and psychological factors, such as satisfaction with social roles, fatigue, illness perception, and optimism, play important roles in patient activation (Golubinski et al., 2020). Patient activation has also been found to be higher in those with better social support (Blakemore et al., 2016).

Further, in patients with chronic condition(s), patient activation has been found to be related to a more positive healthcare experience (Alexander et al., 2012; Graffigna et al., 2017; Greene et al., 2013; Wong et al., 2011) and to taking a more active role during healthcare encounters (Deen et al., 2011; Hibbard, 2009) as well as reporting fewer care-coordination problems (Maeng et al., 2012) and perceived barriers during medical consultation (Henselmans et al., 2015). Further, high patient activation is associated with lower healthcare utilisation (Barker et al., 2018; Greene & Hibbard, 2012; Kinney et al., 2015; Mitchell et al., 2014) and costs (Hibbard et al., 2013).

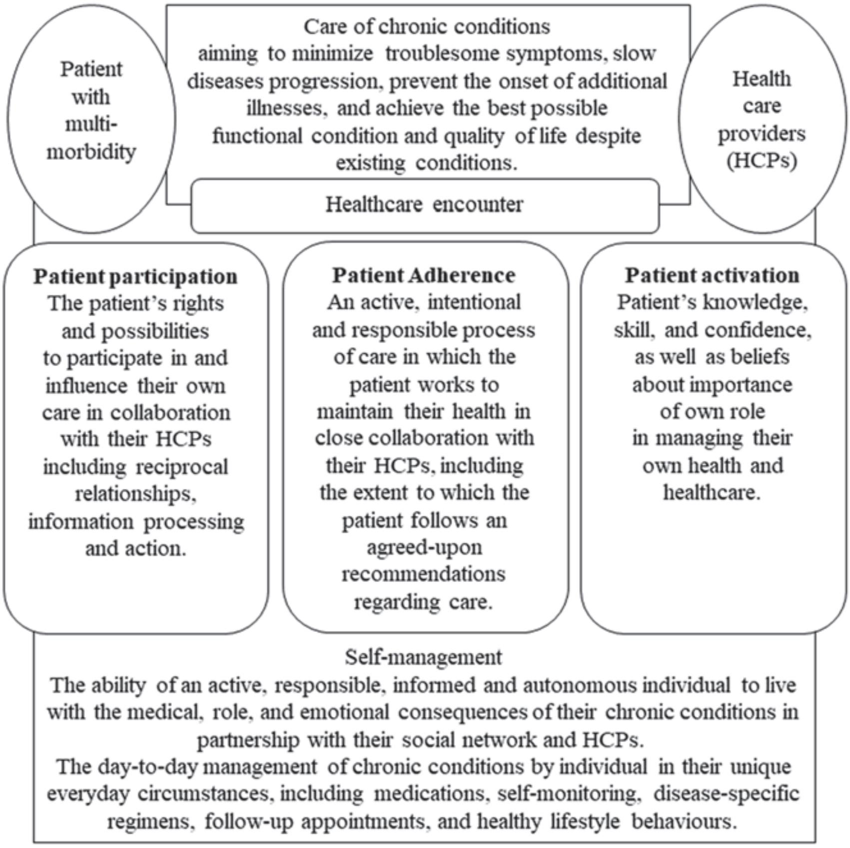
Patient activation is a central concept in a consumer-driven healthcare approach and chronic care models (Hibbard & Greene, 2013). Further, its use has been suggested to advance the science of self-management of chronic conditions, also in nursing science (Moore et al., 2016) and it has been identified as a potential key enabler of personalized care and supporter of self-management by the National Health Services (NHS) England (NHS England, 2018). Previous studies have also found that patient activation is modifiable and can also increase with intervention (Shively et al., 2013). In particular, interventions tailored according to patients' activation levels have previously been shown to be effective. However, research is needed on how PAM-tailored interventions can be integrated into clinical practice and guide patient-clinician interaction in ways that improve the quality of patient care (Kearns et al., 2020). Again, while patient activation has been quite widely studied in different healthcare contexts and populations with varied chronic conditions, studies focusing on it among patients with multimorbidity are still scarce. Studies focused on multimorbidity (Blakemore et al., 2016; Schmaderer et al., 2016; Skolasky et al., 2011) or that cover multimorbidity linked to a specific disease(s) of interest (Bos-Touwen et al., 2015; Zimbudzi et al., 2017) have suggested that activation levels vary considerably and that there may be some demographic, clinical, and psychosocial factors that are associated with low activation.

## 2.5 Summary of the literature

A review of previous literature shows that multimorbidity is a considerable challenge for patients, HCPs, and healthcare systems, as well as societies, due to its high and rising prevalence, care complexity, and great impact on patients' care outcomes and lives while striving to provide optimal healthcare services within resource-constrained environments. Patients with multimorbidity usually have more complicated health and care needs, and they are likely to need health services more frequently and with a more varied array compared with others without multimorbidity and to account for a high proportion of healthcare resources. As the care of patients with chronic conditions is mostly realised by the actions patients take in their everyday lives, multimorbidity entails a high demand for patients' ongoing self-management. However, in the context of multimorbidity, self-management can be challenging and burdensome, requiring patients to pay attention to multiple medical needs along with competing and potentially conflicting priorities and regimens as well as coordination of care between different providers. Challenges in managing multimorbidity are caused by the complexity of the different conditions and that of their care as well as complex interactions between patients and HCPs, exacerbated by a single-disease-oriented healthcare system. However, to be successful, self-management requires the patient to actively participate in and take responsibility for their care, but it also entails ensuring a reciprocal partnership with HCPs. As such, it is important to together consider the patient's perceptions of both their ability and the cooperation with HCPs for self-management to improve the care of these patients.

In this study, the central role of the patient with multimorbidity and the patient-professional collaboration supporting this role are examined through the concepts of patient participation, adherence, and activation for self-management. (Figure 1)

Factors important for patient participation include ensuring that patients feel “seen and heard” by HCPs as whole persons as well as patients recognizing their own role. Again, patient adherence to self-management is intertwined with the care process, while it refers to the extent to which the patient follows care recommendations that have been agreed upon in close collaboration with HCPs. Patient activation includes knowledge, skills, and confidence, as well as an understanding of one’s own role in managing one’s health and healthcare. Even though patient participation, patient adherence, and patient activation have each been found to be central to care and its outcomes, especially in patients with chronic conditions, these are difficult to achieve in practice and are related to many factors. Furthermore, these concepts are all also central to be considered by HCPs for providing patient-centred care, for which there is a high demand in the care of patients with multimorbidity, while also including opportunities to support the patients’ own active role. However, each of these concepts has been little studied in relation to multimorbidity and, furthermore, they have not been studied together as in this study. So, there is an urgent need to gain evidence of patient participation, adherence, and activation in patients with multimorbidity and examine all these processes together. Moreover, while multimorbidity is recognized as a priority for global health research and even though research on multimorbidity has increased greatly in the past decade, there is still little research on care, including self-management, and effective interventions for patients with multimorbidity. Further, as much of the management of multimorbidity takes place in PHC settings, it is important to focus research in this context. As such, research is needed to contribute to understanding these issues and further develop the care for patients with multimorbidity.



Care of chronic conditions aiming to minimize troublesome symptoms, slow diseases progression, prevent the onset of additional illnesses, and achieve the best possible functional condition and quality of life despite existing conditions.

**Patient participation** The patient's rights and possibilities to participate in and influence their own care in collaboration with their HCPs including reciprocal relationships, information processing and action.

**Patient Adherence** An active, intentional and responsible process of care in which the patient works to maintain their health in close collaboration with their HCPs, including the extent to which the patient follows an agreed-upon recommendations regarding care.

**Patient activation** Patient's knowledge, skill, and confidence, as well as beliefs about importance of own role in managing their own health and healthcare.

Self-management

The ability of an active, responsible, informed and autonomous individual to live with the medical, role, and emotional consequences of their chronic conditions in partnership with their social network and HCPs.

The day-to-day management of chronic conditions by individual in their unique everyday circumstances, including medications, self-monitoring, disease-specific regimens, follow-up appointments, and healthy lifestyle behaviours.

**Fig. 1. Main concepts of the study and their context based on literature.**

# 3 Purpose, aim and objectives

The purpose of this study was to describe and explain patient participation, adherence, and activation for self-management among adult primary healthcare (PHC) patients with multimorbidity, and the associations between these and patient-related factors, and subsequently to produce a schematic model to describe this phenomenon based on the findings. The aim was to provide new knowledge contributing to the understanding of these issues and to produce information that can be utilised in care as well as in developing the care provided to patients with multimorbidity. The study consists of three phases, each with specific main objectives that are described below.

Phase I; Psychometric assessment of the PPRQ instrument

1. To assess the validity of the Finnish version of the Patient Participation in Rehabilitation Questionnaire (PPRQ) instrument *(Publication I)*
2. To assess the reliability of the PPRQ instrument *(Publication I)*
3. To assess the suitability of the PPRQ instrument for Finnish PHC settings *(Publication I)*

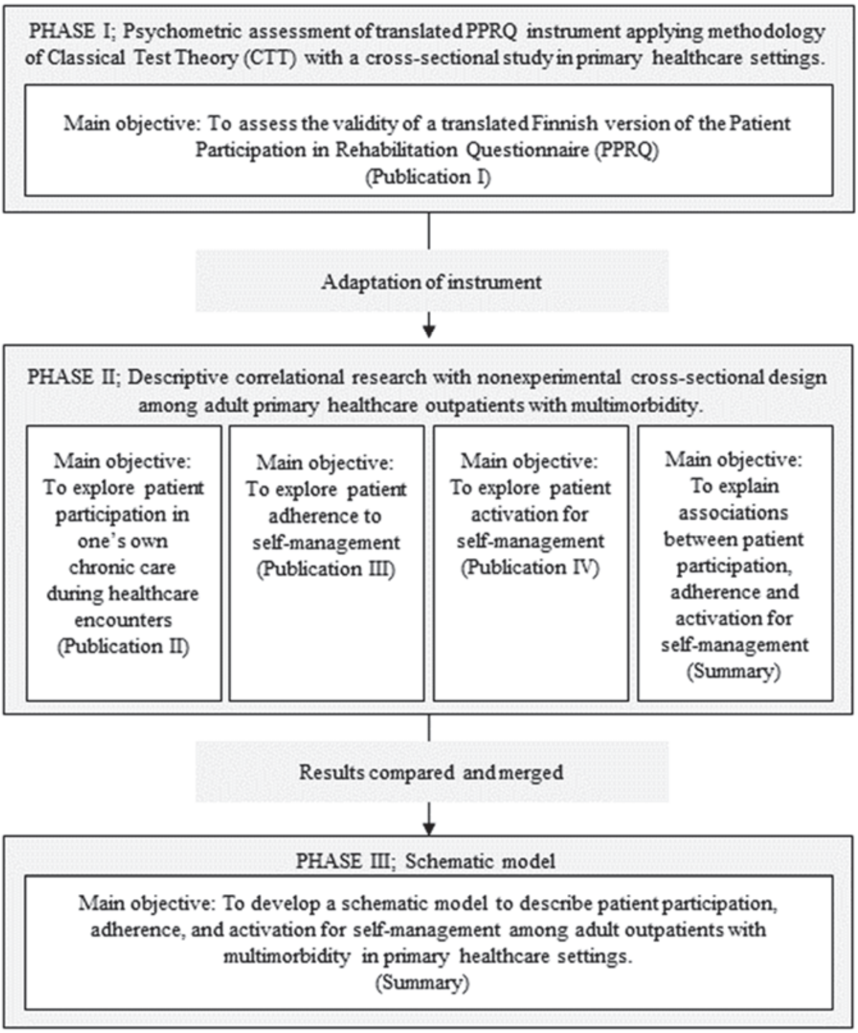
Phase II; Descriptive correlational research among adult patients with multimorbidity

1. To explore and describe patient participation *(Publication II),* patient adherence *(Publication III),* and patient activation for self-management *(Publication IV)*
2. To identify and describe factors associated with patient participation *(Publication II),* patient adherence *(Publication III)*, and patient activation for self-management *(Publication IV)*
3. To examine factors explaining patient participation *(Publication II),* good adherence to self-management *(Publication III)*, and level of patient activation *(Publication IV)*
4. To determine associations between patient participation, adherence, and activation for self-management *(Summary)*

Phase III; Schematic model
To develop a schematic model to describe patient participation, adherence, and activation for self-management among adult patients with multimorbidity in PHC settings *(Summary)*

# 4 Materials and methods

This study consisted of three phases. The results were reported in four publications (I–IV). In addition, previously unpublished results are presented (Summary). The process of the study is presented in Figure 2 and in more detail in Table 2.



PHASE I; Psychometric assessment of translated PPRQ instrument applying methodology of Classical Test Theory (CTT) with a cross-sectional study in primary healthcare settings.

Main objective: To assess the validity of a translated Finnish version of the Patient Participation in Rehabilitation Questionnaire (PPRQ) (Publication I)

Adaptation of instrument

PHASE II; Descriptive correlational research with nonexperimental cross-sectional design among adult primary healthcare outpatients with multimorbidity.

Main objective: To explore patient participation in one's own chronic care during healthcare encounters (Publication II)

Main objective: To explore patient adherence to self-management (Publication III)

Main objective: To explore patient activation for self-management (Publication IV)

Main objective: To explain associations between patient participation, adherence and activation for self-management (Summary)

Results compared and merged

PHASE III; Schematic model

Main objective: To develop a schematic model to describe patient participation, adherence, and activation for self-management among adult outpatients with multimorbidity in primary healthcare settings. (Summary)

**Fig. 2. Study process.**

**Table 2. The phase, report, data, participants, and data analysis of the study.**

| Phase<br>Report | Data | Participants | Data analysis |
|---|---|---|---|
| Phase I<br>Publication I:<br>Patients' perceptions of participation: Pilot validation study of the FI-PPRQ questionnaire in Finnish primary healthcare settings. | a) Translation process: Translation reports, the reports of multidisciplinary PHC group.<br>b) Instrument validation process: Translated PPRQ questionnaire | b) Adult PHC patients: "key clients" and patients undergoing rehabilitation (n=88). | Descriptive statistics, floor and ceiling effects, Cronbach's alpha coefficients, item-total, interitem, and subscale-scale correlations, Multitrait multi-item scaling analysis, Exploratory factor analyses (EFA) with the Kaiser-Meyer-Olkin (KMO) test and Bartlett's Test of Sphericity (BTS) |
| Phase II<br>Publication II:<br>Patient participation during primary health-care encounters among adult patients with multimorbidity: A cross-sectional study | Questionnaire; Main instrument: PPRQ. | Adult PHC outpatients with multimorbidity (n=125) | Descriptive statistics, Cronbach's alpha coefficients, a Chi-squared test (χ2 test), Fisher-Freeman-Halton exact test, independent samples t-tests, One-way analysis of variance (ANOVA), Kruskal-Wallis test, a general linear model: univariate and multivariate models |
| Phase II<br>Publication III:<br>Adherence to self-management in patients with multimorbidity and associated factors: A cross-sectional study in primary healthcare | Questionnaire; Main instruments: ACDI, AUDIT-C, FIT index of Kasari, and single-item measures of diet and use of tobacco. | Adult PHC outpatients with multimorbidity (n=124) | Descriptive statistics, Cronbach's alpha coefficients, Spearman's Rank Correlation Coefficient with 95% Confidence interval (by Bootstrap estimation), Chi-squared test (χ2 test), Fisher's exact test, Fisher-Freeman-Halton Exact test, Binary logistic regression analysis (with Odds ratios with 95% Confidence interval) |
| Phase II<br>Publication IV:<br>Patient activation for self-management among adult patients with multimorbidity in primary healthcare settings | Questionnaire; Main instrument: PAM. | Adult PHC outpatients with multimorbidity (n=122) | Descriptive statistics, Cronbach's alpha coefficients, independent samples t-test, One-way analysis of variance (ANOVA) with the Tukey test for post hoc comparisons, Chi-squared test (χ2 test), Effect size (Cohen's d or Cramer's V), A general linear model: multivariate models, Binary logistic regression analysis (with Odds ratios with 95% Confidence interval) |

| Phase<br>Report | Data | Participants | Data analysis |
|---|---|---|---|
| Phase II<br>Summary:<br>Associations between patient participation, adherence, and activation | Questionnaire; Main instruments: PPRQ, ACDI and PAM | Those patients of phase Two for whom valid PPRQ, ACDI, and PAM instruments were available (n=100) | Descriptive statistics, Pearson correlation coefficients, Multivariable linear regression (with the coefficient of multiple determination (R2)), independent samples t-test, and mean differences (with 95% CI), Effect Size (Cohen's d) |
| Phase III<br>Summary:<br>Schematic model | Study results obtained in phase II | | |

## 4.1 Phase I (Publication I)

Phase I was conducted to test the Participation in Rehabilitation Questionnaire (PPRQ) instrument in Finnish PHC settings: The Swedish PPRQ instrument was translated into Finnish and the validity, reliability, and suitably of the translated instrument were further tested by subjecting it to psychometric assessment (DeVellis, 2016) with a cross-sectional study conducted among PHC patients.

### *4.1.1 Instrument and its translation process*

PPRQ was originally developed in Sweden for patients with a spinal cord injury to measure their perceptions of patient participation in care and rehabilitation, based on a qualitative interview study with this patient group (Lindberg, Kreuter, Taft, et al., 2013). The PPRQ instrument includes 23 items covering five dimensions: respect and integrity (six items); planning and decision-making (four items); information and knowledge (four items), motivation and encouragement (five items); and involvement of family (four items). Respondents rate each item both in terms of perceived importance and the extent to which patient participation was realised by HCPs in their care using a five-point Likert scale (1–5) with importance ranging from not at all important to extremely important, and realisation from never to always. The respondents assess their care regardless of its duration and refer to all the personnel involved in their care during that period (Publication I). The instrument has shown good reliability. Lindberg et al. reported an internal consistency of coefficient alphas of 0.78–0.88 for importance and 0.89–0.91 for realisation among patients, and 0.72–0.88 and 0.89–0.95 among family members, respectively (Lindberg et al., 2014; Lindberg, Kreuter, Person, et al., 2013).

Permission to translate and use the Finnish version of the PPRQ was obtained from the developers of the original instrument (Lindberg, Kreuter, Person, et al., 2013). The original Swedish version of the PPRQ was translated into Finnish using forward and backward translation (Gray & Grove, 2021; Schwartz et al., 2014). Final revisions of the Finnish version were completed by researchers of the study. For this study, one item associated with the 'respect and integrity' subscale in the original PPRQ was deleted because it was inappropriate for the outpatient context. Thus, the modified instrument consists of 22 items (Publication I). Finally, prior to using the translated instrument, it was approved by the developers of the original PPRQ instrument.

### *4.1.2 Sample and data collection procedures*

The data was gathered from PHC patients with varied conditions using a lot of healthcare services from six units of appointment services and two rehabilitation wards in one municipality between June and October 2016. Patients under 18 years of age or unable to complete the questionnaire due to language or cognitive barriers (according to professionals working with them and familiar with this study) were excluded from the study. The participant recruitment process was planned in collaboration with a chief nurse. Prior to data collection, the researcher briefed HCPs in face-to-face meetings in each unit involved in the study to establish the arrangements. HCPs were instructed to distribute questionnaires to patients at the end of their care period together with return envelopes and detailed written information including the purpose and objectives of the study, assurance of anonymity, confidentiality, and the voluntary nature of participation as well as the researchers' contact details (Publication I).

### *4.1.3 Data analysis*

Statistical analysis was performed using IBM SPSS for Windows (versions 23.0, 27.0; IBM Corporation). The rates given to individual respondents and total respondents to the importance and realisation of participation were evaluated separately. Descriptive statistics were used to characterise the sample in terms of participants' demographic characteristics and measured or calculated variables. A half-scale method was used to impute missing values (Publication I). Cronbach's alpha coefficients were calculated before imputation. The distributions of some of the data did not meet the normality criteria for parametric tests (according to Kolmogorov–Smirnov tests and visual inspection of the data), so nonparametric tests were used. The level of statistical significance was set at $p<0.05$ (Gray & Grove, 2021). Floor and ceiling effects were assessed against the recommendation of 15% (Terwee et al., 2007).

The reliability of the instrument was evaluated by internal consistency, assessed by Cronbach's alpha and correlation coefficients (corrected item-total, interitem, average interitem, and subscale-scale correlations). Cronbach's alphas were calculated also following the deletion of items to identify items that should potentially be excluded. Cronbach's alpha coefficients ≥0.70 and corrected item-total and inter-item correlations in (sub)scale ≥0.3 (DeVellis, 2016; DeVon et al., 2007) were considered acceptable. The average interitem correlation was expected to be 0.15–0.50 if ideal (Clark & Watson, 2019).

The construct validity and structure of the PPRQ were assessed by subjecting the realisation ratings to exploratory factor analyses, EFA (DeVon et al., 2007; Streiner et al., 2015). EFA was performed using principal axis factoring (PAF) with varimax rotation to obtain the simplest factor solution. EFA was used to study what theoretical constructs (factors) underlie a given dataset and the extent to which these constructs represent the original variables, without wanting to assume the factorial structure by limiting the number of factors in advance (DeVon et al., 2007; Yong & Pearce, 2013). Values for the Kaiser-Meyer-Olkin measure of sampling adequacy and Bartlett's Test of Sphericity test were set at >0.6 and $p<0.05$, respectively. Based on the Kaiser Criterion, factors with eigenvalues greater than 1 were extracted for rotation. The threshold value for primary factor loadings was set at 0.35 or higher (Clark & Watson, 2019; Yong & Pearce, 2013).

The instrument's item convergent and discriminant validity were tested by multitrait multi-item scaling analysis. This method extends the logic of the multitrait-multi-method technique (DeVon et al., 2007; Streiner et al., 2015) from the level of traits to the level of items. A matrix of correlations was created by computing correlations of each item with their corresponding subscale, corrected for overlap, and all other subscales. Item convergent validity was judged to have been confirmed if correlations between items and the corresponding subscales exceeded 0.40. Item discriminant validity was considered to have been confirmed if the correlations between items and the corresponding subscales were significantly higher (by more than two standard errors) than the correlations between the items and the other subscales (Karlsson et al., 2000; Ware & Gandek, 1998).

## 4.2 Phase II (Publications II–IV, Summary)

Phase II was conducted to investigate the patient participation, adherence, and activation for self-management among adult patients with multimorbidity and to explain the relationships between these three and selected patient-related factors. The cross-sectional study design was used because it allowed the examination of factors simultaneously related to the phenomena at a given time. Further, the between-subjects design incorporating comparisons of different groups of patients was used to enhance interpretability (Gray & Grove, 2021; Polit & Beck, 2018).

### *4.2.1 Sample and data collection procedures*

The participants were adult PHC patients with multimorbidity who visited PHC facilities for chronic condition management. The eligibility criterion for participation was multimorbidity i.e., the coexistence of two or more chronic conditions, which fall under the following classifications: physical non-communicable disease of long duration, mental health conditions of long duration and/or infectious diseases of long duration (Academy of Medical Sciences, 2018). Participants were also required to be at least 18 years old and have sufficient Finnish language skills to complete the questionnaire. The convenience sampling strategy (Polit & Beck, 2018) was used to form the sample of patients who attended a consultation at the time of data collection, which took place between November 2019 and May 2020 and was implemented across all primary health centres in one medium-sized municipality in Finland. Sample sizes were calculated by power analysis using effect size estimations for main outcomes based on previous information of PPRQ, ACDI and PAM with a power level of 0.8 (80%) and level of significance ($\alpha$) 0.05 (Gray & Grove, 2021) with the help of a statistician (Publications II–IV). In addition, for multiple regression, the sample size needed was set based on the ratio of predictor variables to the total number of cases (Polit & Beck, 2017): N should be greater than 50 plus 8 times the predictors (Tabachnick & Fidell, 2012) i.e., 74–122 depending on the case.

Data were gathered directly from patients in natural real-world settings using patients' self-reports as these are known to be strong in terms of directness and versatility and as such a suitable method of data collection considering the nature of the information needed (Polit & Beck, 2017). The participants' recruitment process was planned in collaboration with a service manager of primary health services. Prior to the data collection, all service managers of the participating health centres, who would later distribute information about the study within their units, were briefed on the study by a researcher in a face-to-face meeting. Written instructions were also provided. Personnel were instructed to distribute paper-and-pencil format questionnaires to any patients satisfying the eligibility criteria. The questionnaires included detailed written information about the study's purpose and objectives, as well as the researchers' contact information and a return postal envelope. Patients could complete the questionnaires at home and were asked to return the questionnaire within two weeks. The COVID-19 pandemic emerged shortly after the start of the data collection process and made it challenging to collect data for the study.

### 4.2.2 Collected data, used instruments, and their scoring

Data were collected on patient participation, adherence, activation, active participation, and health behaviours (physical activity, diet, alcohol consumption, use of tobacco). Data were also collected on the patients' assessments of their health-related quality of life, perceived health, perceived functional ability, and perceived loneliness, and sufficiency of close friends and relatives. Information on the chronic conditions constituting multimorbidity, weight and height, and sociodemographic factors was also surveyed. Numerous different instruments and variables were used to collect these data (Table 3). Permission for using all the instruments, and, if necessary, modifying them, was obtained from the copyright holders.

**Table 3. Summary of the information gathered for Phase II of study.**

| Instrument / content | Specific content and dimensions (items) | Number of items | Answering |
|---|---|---|---|
| PPRQ | Patient participation; Two domains (importance and realisation) with the following dimensions on both: Respect and integrity (4); Planning and decision making (4); Information and knowledge (4); Motivation and encouragement (5); Involvement of family (2) | 19 | 5-point Likert scale Each item is assessed in relation to both importance and realisation. |
| Active participation | Asking questions and expressing views/opinions | 2 | 4-point Likert scale |

| Instrument / content | Specific content and dimensions (items) | Number of items | Answering |
|---|---|---|---|
| ACDI | Adherence to care regimens (11): Medications, Monitoring, General regimens, Diet, Co-operation, Responsibility, Willingness. Affecting factors (27): Energy and willpower, Motivation, Results of care, Sense of normality, Fear of complications and additional diseases, Support from physicians, nurses, and family and friends | 38 | 4-point Likert scale |
| PAM-13® | Patient activation (one dimension): Patient's knowledge, skill, and confidence in managing their own health and healthcare. | 13 | 4-point Likert scale and an additional "not applicable" option |
| FIT Index of Kasari | Frequency, intensity, and time of physical activity | 3 | 5- or 4-point ordinal scales |
| AUDIT-C | Alcohol consumption; frequency, typical quantity, frequency of heavy drinking | 3 | 3-point ordinal scale |
| Tobacco use | Tobacco use and method | 2 | 3-point ordinal scale |
| Diet | A healthy and varied diet | 1 | 5-point ordinal scale |
| Perceived health | Self-rated general health | 1 | 5-point Likert scale |
| Perceived functional ability | Self-rated general functional ability | 1 | 5-point Likert scale |
| 15D | Health-related quality of life (15 dimensions): Mobility, Vision, Hearing, Breathing, Sleeping, Eating, Speech, Excretion, Discomfort and symptoms, Depression, Vitality, Usual activities, Mental function, Distress, Sexual activity | 15 | 5-point ordinal scale |
| Loneliness | Perceived loneliness | 1 | 3-point ordinal scale |
|  | Sufficient number of close friends and relatives | 1 |  |
| Multimorbidity | Type and number of conditions | A multiple-choice template listing 26 chronic conditions, open-ended question |  |
| Body weight and height | BMI: Body weight in kilograms divided by height in meters squared (kg/$m^2$) | 2 | open space |
| Socio-demographic information | Year of birth (age), Gender, Education, Employment status, Marital status, living situation (household arrangements) | 6 | open-ended or multiple-choice |

**Patient Participation in Rehabilitation Questionnaire (PPRQ)** is described in Publication I. Based on this study, and other studies conducted in different contexts

(Lindberg et al., 2014; Melin & Årestedt, 2020), PPRQ was assessed as suitable for patients with multimorbidity, as it evaluates patients' perceptions of key aspects of participation in care (respect and integrity, planning and decision-making, information and knowledge, motivation and encouragement and involvement of family) without being disease-specific; further, there is no participation instrument for this group. PPRQ measures patients' perceptions of the importance and degree to which PP was realised by professionals. After Phase I, a few changes were made to the questionnaire, including removing one item from the *Respect and Integrity* subscale and two items from the *Involvement of Family* subscale, as it was not considered valuable to retain these items (see more in discussion). Permission for these changes was obtained from the developers of the original PPRQ instrument (Lindberg, Kreuter, Person, et al., 2013), who have also continued to develop the instrument and whose results also support the changes made now (Melin & Årestedt, 2020). The PPRQ instrument used at this phase contained 19 items covering the same five dimensions as the original instrument. Cronbach's alpha coefficients calculated in this study were good at 0.7 or higher for all subscales in both domains (importance, realisation), and for the instrument as a whole at 0.91 and 0.95, respectively. (Publication II, Summary)

**Active Participation.** The approach used to measure active participation was derived from previously published studies and based on the extent to which patients ask questions and express their views/opinions (Cegala, 2011; D'Agostino et al., 2017; Street & Millay, 2001). The respondents were asked to assess their behaviour in healthcare encounters with HCPs treating them (nurses, doctors, etc.) regarding their condition and care using two single statements: I ask questions (about the things I want to know about, I do not understand, that need clarification, etc.) and I express my views/opinions. The respondents answered the questions on a 4-point Likert scale (1–4) ranging from fully disagree to fully agree. (Publication II)

**The Adherence of People with Chronic Disease Instrument (ACDI)** is based on the theory of adherence of chronically ill patients developed by Kyngäs (1999). While, the instrument was originally developed for young people with diabetes and later adjusted and validated to measure the adherence of young people with several chronic diseases (Kyngäs et al., 2000), it has been subsequently used, modified and validated in several studies in patients with various chronic diseases and ages (Kääriäinen et al., 2013; Kähkönen et al., 2015, 2020; Oikarinen et al., 2018, 2023) and frequent attenders (Hirsikangas et al., 2016; Kivelä et al., 2020). The instrument includes 11 items intended to measure adherence and 27 items used to measure related factors (Table 3). Respondents rate each item using a 4-point

Likert scale (1–4) ranging from strongly disagree to strongly agree. Scores, generated as mean sum variables, were categorised into three classes: poor (<3), adequate (3≤ mean <3.5), and good (≥3.5). In terms of factors affecting adherence, values ≥3 (agree or strongly agree) and <3 (disagree or strongly disagree) indicated positive and negative responses, respectively. Cronbach's alpha coefficient for internal consistency was good in previous studies (Kääriäinen et al., 2013; Kivelä et al., 2020) as well as in this study at 0.75 to the 11 adherence to care regimens items, 0.71 to the three adherence to medication items, 0.87 to the related factors 0.87, and 0.90 to the instrument as a whole. (Publications II–IV, Summary)

**Patient Activation Measure (PAM®)** is a generic instrument for patient activation developed by Hibbard and colleagues in 2004, and supported by patient activation theory (Graffigna et al., 2017; Hibbard & Mahoney, 2010). The first version of PAM included 22 items (Hibbard et al., 2004) but, in 2005, the same group of researchers created and validated a shorter version of PAM including 13 items (Hibbard et al., 2005). PAM is widely used in research and has also been adopted as a PROM measure by the National Health Service (United Kingdom) and the National Institute of Health (United States). The present study used the Finnish-language version of PAM-13, available under licence from Insignia Health (Portland, OR, USA). It is a one-dimensional instrument containing statements about the patient's knowledge, skills, and confidence in managing their health while measuring a latent construct, patient activation. Respondents judge each item using a 4-point Likert scale (1–4) ranging from 'strongly disagree' to 'strongly agree', with an additional 'not applicable' option. The total score is calculated for all the items (theoretical minimum-maximum: 13–52) and then converted into a PAM score of 0–100 (provided by Insignia Health) with higher scores indicating higher activation. The PAM score can be further categorized into one of four progressively higher levels of activation: Levels 1 ("Disengaged and overwhelmed"), 2 ("Becoming aware, but still struggling"), 3 ("Taking action"), and 4 ("Maintaining behaviours and pushing further") that correspond to scores of <47.1, 47.1–55.1, 55.2–67.0 and >67.1, respectively (Hibbard & Gilburt, 2014). Activation levels can again be dichotomized into low (levels 1 and 2) and high (levels 3 and 4) activation according to previous studies (Aung et al., 2015; Zimbudzi et al., 2017). According to the guidelines of PAM, respondents must answer between 10 and 13 questions (N/A responses are considered missing) to obtain a valid PAM score. Also, because PAM is a Guttmann-like scale characterized by increasing difficulty as the survey progresses, uniform response patterns without variation are often considered unreliable and invalid and are therefore excluded. Cronbach's alpha values for PAM were in a Finnish validation study 0.87 (Riippa et al., 2014), in a validation study in patients with multimorbidity 0.87 (Skolasky et al., 2011) and in this study 0.84, indicating that the instrument exhibits good internal consistency. (Publications II–IV, Summary)

**FIT (Frequency, Intensity, Time) Index of Kasari** is the instrument for assessing general physical activity developed by Kasari in 1976. Since then, it has been used in numerous research studies (Grant et al., 2014; Uutela et al., 2018). A Finnish version of the instrument is generally available and also used in clinical practice for patients with chronic conditions, such as asthma, COPD, and diabetes. The instrument is based on three parameters: the frequency of exercise ("How often do you exercise?"), the intensity of exercise ("With what intensity do you usually exercise?"), and time spent exercising ("How long do you usually work out?"). For frequency, there is a 5-point Likert-type scale (from once per month or less to at least 6 times per week). For intensity, there is also a 5-point scale (from light aerobic activity to high intensity), and for time spent exercising, there is a 4-point scale (less than 10 minutes to >30 minutes). The FIT index is scored by multiplying scores obtained for each of these three parameters, so the scores range from 1 to 100, with scores of ≤36, 37–63, and ≥64 indicating low, moderate, and high physical activity levels, respectively. 12 points or below is considered to indicate a sedentary lifestyle (Uutela et al., 2018). In this study, the Cronbach's alpha coefficient was 0.77. (Publications III, IV)

**Diet quality** was assessed using a single question: "How varied is your diet overall?" This single-item measure, which is also in ongoing use in the National Health and Nutrition Examination Survey (NHANES) conducted among the U.S. population (Hecht et al., 2020) has demonstrated a good construct validity by showing a strong and consistent relationship with self-reported dietary habits, biomarkers of dietary intake, and diet-related health outcomes (Loftfield et al., 2015) and has proven to be a valid and useful proxy for more burdensome measures of overall diet quality and deemed particularly appropriate in differentiating those with a poor or good diet (Adjoian et al., 2016; Hecht et al., 2020). This question invites Likert-type responses with a 5-point scale ranging from highly varied to highly unbalanced. The two highest response categories on a scale were considered to describe healthy dietary adherence, consistent with previous research (Hecht et al., 2020). (Publications III, IV)

**The Alcohol Use Disorders Identification Test-Concise (AUDIT-C)** is an alcohol screening instrument used widely to assess hazardous alcohol consumption both in research and in clinical practice. It is a modified version of the 10-question

AUDIT instrument developed by the WHO (2001) including the first three questions of the instrument. Each question has 5 response alternatives which are rated on a scale from 0 to 4 points. Points are summed up on a range from 0 to 12, in which a score of 0 reflects no alcohol use. Scores of 3 and under for men and 2 and under for women are considered to indicate low-risk consumption, points above this indicate some degree of risk, while scores of 6 or more indicate a high risk in both genders (Bradley et al., 2009). However, in international studies, these thresholds for risky use have varied slightly. According to the Finnish Current Care Guidelines (*Alcohol abuse. Current Care Guidelines*, 2015), screening thresholds for problematic alcohol consumption are ≥6 for men and ≥5 for women. These thresholds were used in this study to allow comparison. In this study, the Cronbach's alpha was 0.91. (Publications III, IV)

**Tobacco use** was assessed with two questions: "At the present time, do you smoke cigarettes?" and "Do you use other tobacco products (snuff, chewing tobacco etc.)?" The response alternatives for both were: not at all, occasionally, and daily. (Publications III, IV)

**15D**© is a generic, comprehensive self-administered measure of HRQoL developed by Sintonen (Sintonen, 2001). It is originally in Finnish but has also been translated into several languages. It has been proven valid and reliable in numerous studies (*15D-instrument net.*) and compares favourably with other generic HRQoL instruments (Richardson et al., 2016). 15D consists of 15 different dimensions (Table 3), each of which has five structured, ordinal-level response options (1= best possible situation, 5= worst situation). From each dimension, the respondent chooses the level that best describes their present health status. The score is then summed up into a 15-dimensional description of the patient's health status, which can be used both as a profile (15D profile) and a single index score (the 15D score). These are constructed on a scale from 0 to 1 using the variables for which the original ordinal numbers of the levels (1–5) are replaced by level values produced by the assessment system. The 15D score represents the overall HRQoL ranging from 0 (being dead) to 1 ('full' HRQoL= no problems in any dimension) (*15D-instrument net*). The scoring algorithm for this study was provided by the instrument administrator. In this study, the Cronbach's alpha coefficient was 0.87. (Publication IV)

**Perceived health** (also known as self-perceived/self-rated health) is a one-question indicator used globally reflecting the individual's subjective overall perception of their general health. It has been proven to be a reliable and valid tool serving as an independent predictor for healthcare needs and use, morbidity, healthy life expectancy, and mortality (Bowling, 2005; Jylhä, 2009; OECD, 2021a). The response alternatives provided for the question ‘How is your current health in general?’ were as follows: ‘good’, ‘quite good’, ‘moderate’, ‘quite poor’, and ‘poor’. These responses were also further classified as good (good, very good), moderate, and poor (quite poor, poor) consistently with the FinTerveys2017 and FinSote studies of the Finnish Institute for Health and Welfare (Koponen et al., 2018; Parikka et al., 2020). (Publications II–IV)

**Perceived functional ability** was assessed using one question that adopts the same ideology as the measure of perceived health. The response alternatives provided for this question, “How is your current functional ability in general?”, were as follows: ‘good’, ‘quite good’, ‘moderate’, ‘quite poor’, and ‘poor’ (Halonen et al., 2017). These responses were also further classified as good (good, very good), moderate, and poor (quite poor, poor). (Publications II–IV)

**Loneliness** was measured with two single questions. First, the respondents were asked the question ‘Do you suffer from loneliness?” This single-question measure has been used in several studies and has been reported to have good validity (Henriksen et al., 2019; Yanguas et al., 2018). It was also used as a standard for validating the two most used larger loneliness scales, as it correlated well with both (Henriksen et al., 2019). The response alternatives provided for this question were: ‘not at all’, ‘sometimes’, and ‘often’. In addition, the respondents were asked: ‘Do you have sufficiently close friends and relatives?’, with the response alternatives: ‘Yes, sufficiently’; ‘Not sufficiently’; ‘Not at all’. (Publications II–IV)

**Multimorbidity and a healthy weight.** The type and number of chronic conditions constituting multimorbidity were assessed using a form listing 26 chronic conditions. Respondents could select any combination of chronic conditions from the list and add other chronic diseases not mentioned in the list. The aim was to form a comprehensive understanding of conditions as recommended in the literature (Ho et al., 2021; Johnston et al., 2019). The suitability of freely listed conditions for constituting multimorbidity was checked before including the conditions in the respondent’s total number of conditions. Height and weight information was collected to allow calculation of respondents’ BMI and to further determine obesity (≥30), overweight (25–29.9), normal weight (18.5–24.9), and underweight (<18.5) (*Obesity (children, adolescents and adults). Current Care Guidelines*, 2023; WHO, 2000). Obesity was not included in a respondent’s total number of conditions constituting multimorbidity; instead, obesity or overweight were considered separately.

### *4.2.3 Data analysis*

The statistical analyses were performed using IBM SPSS for Windows (version 27.0; IBM Corporation). Some of the entered data was reverse scored (scores given to the items were reversed by software commands so that the responses scoring higher for all items in the scales indicated higher agreement/level). The data were also classified for some analyses and new variables were also calculated based on the data. Descriptive statistics were used to describe the sample characteristics as well as collected and calculated variables. Visual inspection of the data (histograms and boxplots) and tests of normality were used to evaluate outliers and a normal distribution of data. Pairwise deletion was used to handle missing data in analyses. For all analyses, $p<0.05$ was considered significant (Gray & Grove, 2021; Polit & Beck, 2018). (Publications II–IV, Summary)

#### *Patient participation among patients with multimorbidity (Publication II)*

To explore factors associated with patient participation, the statistical significance of differences in means of patient participation between varied patient groups was assessed using the independent-samples t-test (t-test) for dichotomous categorical patient variables and one-way analysis of variance (ANOVA) for variables with more than two categories. Mean differences between the groups were calculated on each of the five subscales of patient participation and concerning both the importance and realisation of patient participation separately. When differences in active participation were assessed, a Chi-squared test ($\chi2$ test) or Fisher-Freeman-Halton exact test (FHH) was used for categorical variables while a Kruskal-Wallis test (nonparametric data) or ANOVA (parametric data) was used for continuous variables. A general linear model was used to examine which factors explain patients' perceptions of patient participation. First, a univariate model was calculated for each explanatory variable and the total score of both importance and realisation of patient participation. This was done to determine univariate associations, not as a selection method for candidate variables for multivariate models, as that kind of univariable selection may be misleading (Sun et al., 1996). The used explanatory variables were age, gender, education, number of conditions, perceived health, perceived functional ability, patient activation, adherence to care regimens, and active participation. Then, all variables were integrated into a multivariate model. As certain substantial correlations were observed between variables, two multivariate models were presented for both domains of patient participation (Tabachnick & Fidell, 2012).

### Patient adherence among patients with multimorbidity (Publication III)

To test the significance of associations between patient-related factors and good adherence $\chi 2$, Fisher's exact, or FHH exact test was used, as appropriate. This was applied to identify sociodemographic and health-related factors associated with adherence to the studied self-management elements. Binary logistic regression analysis was used to identify potential explanatory factors for the respondents' adherence in terms of *the theory of adherence of people with chronic diseases* with the calculation of Odds Ratios (OR) between explanatory factors and adherence to self-management elements. Relations between the elements of self-management were assessed by Spearman's rank correlation coefficients. Correlation coefficients of $<0.3$, 0.3–0.5, and $\geq 0.5$ were respectively regarded as indicating a weak, moderate, and strong correlation (Gray & Grove, 2021).

### Patient activation among patients with multimorbidity (Publication IV)

To investigate factors associated with patient activation, the statistical significance of differences in PAM means between varied patient groups was evaluated using t-tests and ANOVA with the Tukey test for post hoc comparisons. Differences between low and high activation of patients in self-management behaviours and related perceptions were explored using a t-test when comparing means and a $\chi 2$-test when comparing categorical variables. For these comparisons, the effect size, the magnitude of association, was assessed by Cohen's d and Cramer's V, as appropriate (Tabachnick & Fidell, 2012). The resulting interpretations were as follows: For Cohen's d, 0.2 small, 0.50 medium, 0.80 large; for Cramer's V, 0.10 small, 0.30 medium, 0.50 large (Ellis, 2010). Further, binary logistic regression analysis with the calculation of Odds Ratios (OR) was used to identify effects between patient activation (low and high) and self-management behaviours and related perceptions. In addition, because PAM scores were previously found to be associated with some patient-related factors (perceived health, loneliness, and obesity), the association of patient activation level with self-management behaviours and perceptions was also calculated by adapting these factors in a linear model. Differences in HRQL between low and high activation of patients were determined using the t-test. Again, as HRQoL is known to be related to age, gender, and disease count (Makovski et al., 2019), the association of activation level with HRQoL dimensions was also calculated by adjusting these factors in the linear model.

### *Associations between patient participation, adherence, and activation (Summary)*

The Pearson correlation coefficient was used to assess the correlations between the scores of PPRQ, PAM, and ACDI. Multivariable linear regression with multicollinearity statistics (tolerance and Variance Inflating factor (VIF)) was used to assess a simultaneous linear relationship of these variables. An inspection of histograms of the standardized residuals was used to verify their assumption of normality, and additionally, the normal distribution of residuals was tested by Kolmogorov-Smirnov and Shapiro-Wilk W test (Gray & Grove, 2021). A t-test was also used to compare differences between respondents' PAM, PPRQ, and ACDI scores with different levels of each other. Comparisons were made using known cut-off points for good values for the PAM and ACDI instruments. Since there is no cut-off point for the PPRQ instrument, these were created using an upper quartile (75% percentile). The effect size was also determined for all comparisons of mean differences using Cohen's d (Ellis, 2010).

## 4.3 Phase III (Summary)

In this phase, the schematic model to describe patient participation, adherence, and activation for self-management among adult patients with multimorbidity in PHC settings was developed based on the empirical results obtained in the preceding Phase II of this study. The schematic model, also called a conceptual map, is a visual summary of complex ideas i.e., a description of the phenomenon, the concepts associated with it, and the relationships between them (Gray & Grove, 2021; Polit & Beck, 2018). The model was constructed based on the interpretation of results by merging the results of publications II–IV and by limiting the study results to focus on research concepts – not to describe numerous dimensions (subscales) of concepts that were also examined in this study – and relationships of those concepts (i.e., propositions) to ensure clarity and usefulness and to highlight the most important issues related to the phenomenon.

# 5 Results

## 5.1 Characteristics of study samples

The data of Phase I consists of responses from 88 PHC patients. More than half of the patients (59%) were treated in a rehabilitation ward and 41% attended a consultation in appointment services. The patients' ages ranged from 24 to 90 years, with a mean of 69 years (SD 15.9). Almost equal numbers of respondents were women (52%) and men (48%). About one third of them had completed primary education, one third secondary education, and one third tertiary education. More detailed characteristics of the participants are presented in Table 1 in Publication I.

In Phase II, the data consist of responses from 125 patients with multimorbidity who attended PHC consultations for chronic condition management. Their ages ranged from 38 to 93 years, with a mean of 68.5 years (SD 10.7). Well over half (59%) of the respondents were women. Just under a third (29%) had only completed primary education, 20% had secondary education, and half (51%) had tertiary education. The participants had 2–13 chronic conditions which constituted their multimorbidity. Severe multimorbidity i.e., four or more simultaneous conditions was detected in 55% and physical-mental in 15% of participants. The conditions were diverse, while the most common types of chronic physical conditions were hypertension (74% of the sample), diabetes (63%), coronary artery disease (27%), asthma (27%), and arrhythmia (24%). The most common mental health condition was depression reported by 10% of the participants. In addition to the conditions mentioned above, 42% of the participants were obese, 34% had overweight, while 17% were at a normal weight. More than half (53%) felt that their general health was moderate or worse, and correspondingly, slightly less than half (46%) felt this way regarding their functional ability. Participants' health-related quality of life (by the 15D) was also significantly lower (p=0.000) than in an age- and gender-standardized comparison population sample (National Institute for Health and Welfare (THL), Report 68/2012). Perceived health, perceived functional ability, and HRQoL were all statistically significantly inverse related to the number of conditions. Of the respondents, 41% reported suffering from loneliness sometimes or often. In addition, just over a quarter reported they do not have enough close friends and relatives. Loneliness, perceived inadequacy of the number of loved ones and poor perceived functional ability were statistically significantly more frequent among those with physical-mental multimorbidity.

## 5.2 Psychometric properties of Finnish PPRQ (Publication I)

### *Item-level analysis*

Means of items in the importance domain ranged between 3.82–4.51. In about half of the items, the responses were distributed over the entire scale (1–5). The means of items in the realisation domain ranged from 2.71 to 4.02. In all the items, the responses were distributed over the entire scale (1–5). Cronbach's alpha coefficients were not improved by removing any items in either domain. Corrected item-total correlations ranged from 0.486 to 0.742 for the importance domain, and from 0.476 to 0.774 for the realisation domain. See more in Appendix 1.

### *Construct validity*

**Factor structure.** To examine the PPRQ's construction and construct validity, the EFA was performed by Principal Axis Factoring (PAF) with varimax rotation to obtain the simplest factor solution for the realisation domain. The distributions of variables met the normality requirements (Kolmogorov–Smirnov statistic: 0.2, $p>0.05$). Moreover, the results of the Kaiser-Meyer-Olkin measure of sampling adequacy and Bartlett's Test of Sphericity showed that the correlation matrix had acceptable covariance and factorability (0.847 and $p<0.001$, respectively). Factor loadings were from 0.374 to 0.916. Based on the Kaiser Criterion (eigenvalues >1) five factors were retained, which collectively explained 70% of the total variance (Publication I). Communalities were good, ranging from 0.445 to 0.943. A largely corresponding set of items for the subscales of participation were identified as in the initial development and tests of the original PPRQ. The four items were loaded slightly more strongly to a different factor than in the original measurement. However, because they theoretically fit both factors, the structure of the original instrument was retained in this phase. The convergent and discriminatory validity testing also supported the original structure, see below.

**Convergent and discriminant validity**. A multitrait multi-item scaling analysis was used to test the convergent and discriminant validity of the instrument's items for rating respondents' perceptions of the realisation of participation. The coefficients of correlation between items and corresponding subscales (after correcting for overlap) ranged from 0.55 to 0.88, well above the 0.40 threshold for adequate item convergent validity. Item discriminant validity was also good: all items except one correlated more strongly with the corresponding subscales than with the other subscales and this exception (one of 88 comparisons) correlated equally strongly with the corresponding subscale and another subscale.

### Reliability

Internal consistency was assessed by calculating Cronbach's alpha coefficients and correlation coefficients between the instrument's items and subscales for both domains. Cronbach's alphas for the subscales ranged from 0.76 to 0.89 for the importance domain and from 0.84 to 0.92 for the realisation domain. Thus, all the alpha values exceeded the threshold of 0.7, so indicating that the scales had adequate internal consistency. Moreover, none of the items indicated the need to be modified as alpha coefficients were not significantly improved by removing any of them. Intercorrelations of items within subscales were also good: The correlation coefficients ranged from 0.25 to 0.69 for importance and from 0.43 to 0.84 for the realisation domain ($p<0.001$), and only one (of 76) was $<0.3$. The correlation coefficients between subscales ranged from 0.56 to 0.82 for the importance and from 0.33 to 0.74 for the realisation domain ($p<0.001$).

### Scores of PPRQ

The mean total PPRQ for the importance ratings was 4.07 (SD 0.63). The focus of the responses was on response alternatives deemed highly important (min–max 2.43–5.00, $Q_1, Q_3$: 3.59, 4.62). *Information and knowledge* was considered the most important dimension (mean 4.33, SD 0.58, median 4.50, min–max 2.75–5), while the *involvement of family* was assessed as the least important (mean 3.91, SD 0.89, Median 4.00, min–max 1.24–5). There were no minimum responses for subscales, but the frequencies of maximum responses ranged from 10.5% to 23.5%, indicating a moderate ceiling effect for three subscales: respect and integrity, information and knowledge and the involvement of family. (Publication I)

The mean total PPRQ of the realisation scores was 3.46 (SD 0.78) The range of means was rather wide (min–max 1.45–5.00, $Q_1, Q_3$: 2.91, 4.00). *Respect and integrity* was considered the best-realised dimension (mean 3.83, SD 0.85, median 4.00, min–max:1–5) while the *involvement of family* was rated with the lowest score (mean 2.81, SD 1.31, median 2.5, min–max 1–5). Frequencies of floor and ceiling responses for subscales ranged from 0% to 16.3% and 4.5% to 8.8%, respectively, indicating a slight floor effect for one subscale i.e., the involvement of family. (Publication I)

## 5.3 Patient participation during healthcare encounters among patients with multimorbidity (Publication II)

### *Active participation and associated factors*

Almost all the respondents agreed that they had asked certain questions about their condition and care during healthcare encounters; more specifically, 46% of the respondents fully agreed, 52% agreed, and only a few per cent disagreed with the statement. Regarding getting to express their views and opinions, 23% of the respondents fully agreed, 59% agreed, and 18% disagreed with the provided statement. However, both items have several missing cases, i.e., 9% and 10%, respectively. Neither active participation factor was associated with the number of conditions, sociodemographic factors, perceived health or functional ability, or loneliness. Instead, the factors showed an association with patient activation and adherence (p=0.004, p=0.026, and p=0.003, p=0.055, respectively). Further, the perceived importance of patient participation implemented by HCPs was significantly positively associated with asking questions (p=0.001) and expressing views/opinions (p<0.0001) (Tables 4 and 5). The associations of active participation to the dimensions of patient participation are explored further on in this section.

**Table 4. Associations of fully active participation with patients' perceptions of patient participation implemented by HCPs. Asking questions.**

| Variable | AP[1] for asking questions Mean (SD) | Not AP for asking questions Mean (SD) | Mean difference (95% CI[2]) | p-value[3] | Effect Size[4] (95% CI) |
|---|---|---|---|---|---|
| PP[5] for importance | 4.47 (0.43) | 4.19 (0.46) | 0.28 (0.11–0.44) | 0.001 | 0.624 (0.246–1.001) |
| PP for realisation | 3.82 (0.72) | 3.55 (0.74) | 0.27 (-0.01–0.54) | 0.055 | 0.364 (-0.008–0.735) |
| Patient activation | 60.49 (13.69) | 52.29 (12.03) | 8.19 (2.87–13.52) | 0.004 | 0.640 (0.217–1.059) |
| Patient adherence | 3.69 (0.24) | 3.51 (0.40) | 0.18 (0.06–0.30) | 0.003 | 0.525 (0.149–0.898) |

[1] active participation i.e., those who fully agree with the statement, [2] Confidence Interval,

[3] p-value < 0.05 is significant,

[4] Cohen's d, Interpretation: 0.20 small effect size, 0.50 medium effect size, 0.80 large effect size,

[5] patient participation. Used test: Independent samples T-test.

**Table 5. Associations of fully active participation with patients' perceptions of patient participation implemented by HCPs. Expression opinions.**

| Variable | AP[1] for expressing opinions Mean (SD) | Not AP for expressing opinions Mean (SD) | Mean difference (95% CI[2]) | p-value[3] | Effect Size[4] (95% CI) |
|---|---|---|---|---|---|
| PP[5] for importance | 4.61 (0.32) | 4.23 (0.47) | 0.37 (0.18–0.57) | < 0.0001 | 0.844 (0.395–1.300) |
| PP for realisation | 3.84 (0.86) | 3.63 (0.69) | 0.21 (-0.12–0.53) | 0.210 | 0.282 (-0.159–0.722) |
| Patient activation | 61.24 (14.92) | 54.31 (12.28) | 6.93 (0.84–13.02) | 0.026 | 0.531 (0.063–0.996) |
| Patient adherence | 3.71 (0.33) | 3.56 (0.35) | 0.15 (-0.00–0.30) | 0.055 | 0.434 (-0.010–0.875) |

[1] active participation i.e., those who fully agree with the statement, [2] Confidence Interval,

[3] p-value < 0.05 is significant,

[4] Cohen's d, Interpretation: 0.20 small effect size, 0.50 medium effect size, 0.80 large effect size,

[5] patient participation. Used test: Independent samples T-test.

### *Patients' perceptions of importance and the extent to which patient participation was realised by HCPs*

The mean reported importance of patient participation was 4.32 (SD 0.46, 95% CI 4.24–4.40, min–max 3.15–5.00). Most of the respondents (79%) assessed participation to be very or extremely important ($4 \leq \text{mean} \leq 5$). The dimension concerning the importance of patient participation that received the highest rating was *Information and knowledge* (4.58, SD 0.41), while the *Involvement of family* was assessed as the least important dimension (3.77, SD 1.34). The mean values of the other dimensions were as follows: *Respect and integrity* 4.39 (SD 0.57), *Morivation and Encouragement* 4.33 (SD 0.48), and *Planning and decision-making* 4.23 (SD 0.61). (Figure 3)

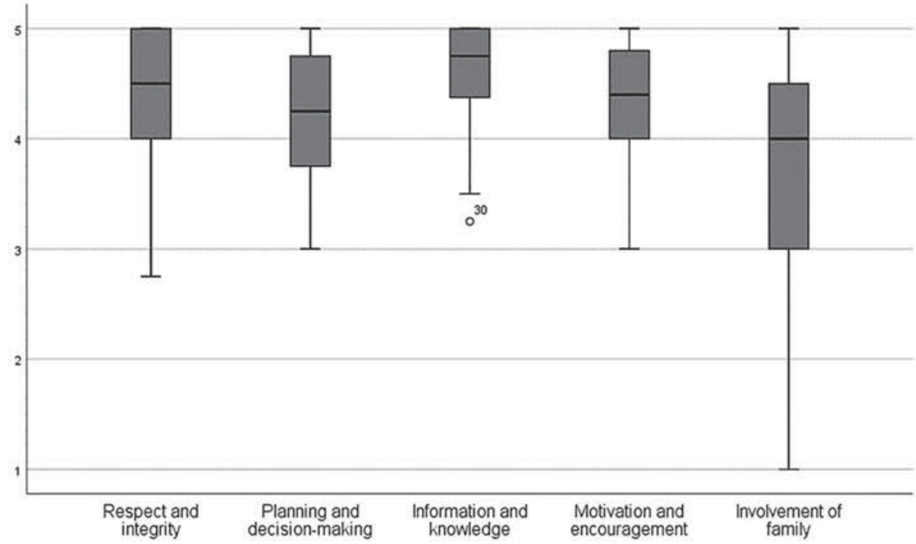


**Fig. 3. The dimensions of the importance of patient participation. Note the interpretation of the scale: 1= not at all important, 2= slightly important, 3= important, 4= very important, 5= extremely important.**

The mean of the realisation of patient participation was 3.67 (SD 0.73, 95% CI 3.54–3.79, min–max 1.68–5.00) on a scale in which a score of 3 indicated "sometimes" and a score of 4 indicated "often". About a third (32%) of respondents found that participation had been implemented somewhere between "often" and "always" (4≤ mean ≤5). The dimensions concerning the realisation of patient participation that received the highest ratings were *Respect and integrity* (3.97, SD 0.80) and *Information and knowledge* (3.92, SD 0.77), whereas *Involvement of family* received the lowest ratings (2.53, SD 1.34). The mean values of *Planning and decision-making* and *Motivation and encouragement* were 3.72 (SD 0.86) and 3.62 (SD 0.86), respectively. (Figure 4)

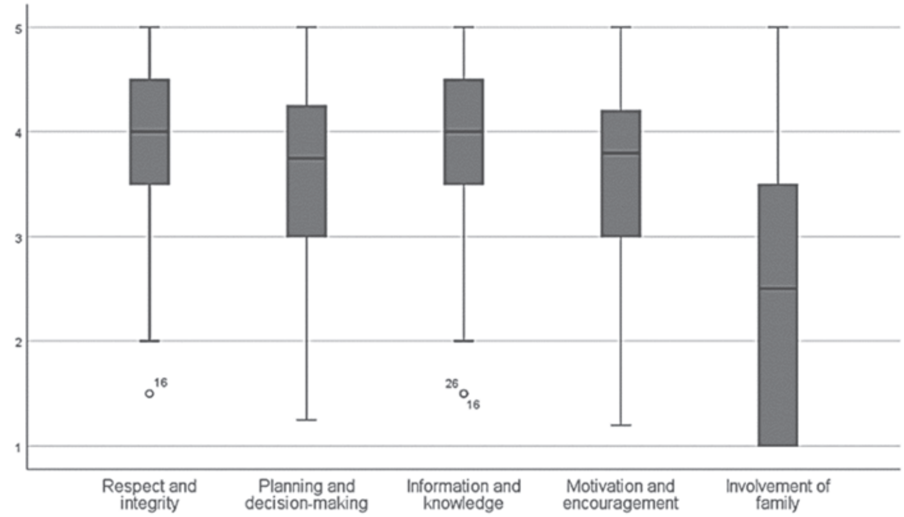


**Fig. 4. The dimensions of realisation of patient participation. Note the interpretation of scale: 1= never, 2= seldom, 3= sometimes, 4= often, 5= always.**

### *Associations of patient-related factors with dimensions describing the importance of participation*

Age, gender, perceived health, perceived functional ability, patient activation, and active participation were significantly associated with the scores of various subscales related to the importance of patient participation. *Respect and integrity* was associated with age (p=0.028), perceived health, and functional ability (p=0,002, both), patient activation (p=0.013), and the manner of expressing opinions (p=0.010). *Planning and decision-making* was associated with gender (p=0.020), patient activation (p=0.003), and asking questions and expressing opinions (p=0.010, p<0.001, respectively). *Information and knowledge was* associated with gender (p=0.002), patient activation (p=0.023), and asking questions (p=0.012), *Motivation and encouragement* was associated with gender (p=0.003), perceived health, and perceived functional ability (p=0.035, p=0.007, respectively), patient activation (p<0.001), and asking questions and expressing opinions (p=0.009, p=0.002, respectively). The *Involvement of family* was associated with gender (p=0.005), patient activation (p=0.028), and asking questions and expressing opinions (p=0.039, p=0.003, respectively). Higher scores were given by younger and female patients, patients with high activation levels, good perceived health, and good functional ability and who fully agreed with items concerning asking questions and expressing views/opinions.

### *Associations of patient-related factors with dimensions describing the realisation of participation*

The number of conditions, perceived health, perceived functional ability, patient activation, adherence, and active participation significantly influenced and were associated with the scores of various subscales related to the realisation of patient participation. *Respect and integrity* was associated with perceived health and functional ability (p=0.025, p=0.015, respectively), *Planning and decision-making* was associated with the number of conditions (p=0.006), patient activation (p=0.002), and asking questions (p=0.042), *Information and knowledge* was associated with perceived health and functional ability (p=0.026, p=0.006, respectively), patient activation (p=0.001), and adherence (p=0.033), *Motivation and encouragement* was associated with perceived health and functional ability (p=0.010, p=0.004, respectively), patient activation (p<0.001), and adherence (p=0.030). The *Involvement of family* was associated with patient activation (p=0.005) and expressing views and opinions (p=0.034). Higher scores were reported by patients with 4–5 conditions, good perceived health and functional ability, high patient activation level, good adherence, and those who fully agreed that they asked questions and expressed opinions during care encounters.

### *Factors explaining patients' perceptions of patient participation*

**Importance of patient participation as a whole.** The general linear model revealed that gender (p=0.002), perceived health (p=0.048), perceived functional ability (p=0.052), patient activation (p<0.001), adherence (p=0.032), and active participation as well as asking questions (p=0.005), and expressing views/opinions (p<0.001) were significant explanatory factors for the importance of patient participation in the univariate analyses. Female patients considered participation as more important than male patients. Patients with good perceived health and functional ability gave the highest scores for the importance of patient participation, followed by patients with poor perceived health and functional ability, while patients with moderate perceived health and functional ability rated the importance of patient participation the lowest. Also, patients who fully agreed with the provided statements concerning active participation related to asking questions and expressing opinions found participation implemented by HCPs more important compared to other patients. Again, patient activation and adherence were both positively associated with the perceptions of the importance of participation. In the case of multivariate analysis, because perceived health and perceived functional ability, as well as asking questions and expressing views/opinions, were strongly correlated with each other, these variables were included in different multivariate models. The multivariate models, which were adjusted for all other variables included in the model, showed that in Model 1 ($p<0.001$) including eight factors, the factors that significantly explained the perceived importance of patient participation were gender ($p=0.002$), perceived health ($p=0.006$), patient activation ($p=0.034$), and asking questions ($p=0.019$), and the model explained 36.8% of the variance for the importance of patient participation. In Model 2 ($p<0.001$) including eight factors, gender ($p=0.001$) and expressing views/opinions ($p=0.002$) remained significant and explained 36.8% of the variance for the importance of patient participation.

**Realisation of patient participation as a whole.** The general linear model revealed that patient activation ($p<0.001$), adherence ($p=0.048$), perceived health ($p=0.032$), and perceived functional ability ($p=0.007$) were significantly associated with the realisation of patient participation in univariate analyses. Patients with higher activation and adherence felt that the implementation of patient participation was better. Patients with good perceived health and functional ability reported the highest extent of the realisation of participation, while patients with poor perceived health had the worst experiences of patient participation. Two multivariate models, which both included eight variables and were adjusted for other variables in the model, revealed that patient activation ($p<0.001$) significantly explained the realisation of patient participation. Model 1 ($p=0.008$) explained 27.6% and Model 2 ($p=0.004$) explained 29.6% of the variation in the realisation of patient participation.

## 5.4 Patient adherence to self-management among patients with multimorbidity (Publication III)

**Adherence to care regimens** measured by the ACDI (mean 3.60, SD 0.35, 95% CI 3.53–3.66, min–max 2.64–4.00, on a theoretical scale of 1.00–4.00) revealed that about three quarters (73.4%) reported good adherence (mean $\geq 3.5$), and 17.7% reported adequate ($3 \leq$ mean $<3.5$), and 8.9% poor adherence (mean $<3$). The factors found to be significantly associated with adherence were marital status, perceived sufficiency of the number of loved ones, and patient activation level: good adherence in this respect was less frequent among respondents who were single (p=0.012), reported having an insufficient number of loved ones (p=0.026), and a low level of patient activation (p=0.004). In relation to **adherence to medication** (mean 3.78, SD 0.40) most patients (81.5%) reported good adherence, while 14.5% and 4% respectively reported adequate and poor adherence. Factors associated with medication adherence were marital status (p=0.020) and sufficiency of the number of loved ones (p=0.023) in line with the overall adherence to care regimens.

**Physical activity** measured by the FIT index (mean 32.01, SD 19.24, 95% CI 28.52–35.50, min–max 1–64, on theoretical scale 1–100) indicated that 60% of participants had low activity (classified as sedentary and having some activity, 21% and 39%, respectively), 27% had moderate activity, and 9% high activity. Half (50.8%) of the participants engaged in physical activity for at least 10 minutes at least three times a week, and the rest rarely. Physical activity was significantly associated with the patient's living situation, and levels of adequate activity (moderate and high) were highest for the group living with a spouse or partner (p=0.041). The number of patients' chronic conditions was also significant: participants with 2 or 3 conditions were more frequently adequately active than those with 4 or more conditions (p=0.014). High patient activation level (p=0.005) and good perceived health and functional ability (p<0.0001 and 0.001, respectively) were positively associated with adherence to physical activity, and the frequency of physical activity (i.e., the scores were higher for respondents who engaged in physical activity at least three times a week than for those who exercised rarely).

Regarding the **variety of diet**, 58.5% considered their diet as highly or quite varied. Adherence to a varied diet was significantly associated with age, being more common among patients aged 65–74 years than in either younger or older age groups (p=0.018). It was also significantly associated with education level, being more common among participants with tertiary education than those with a lower level of education (p=0.017). Similarly, patients with enough loved ones (p=0.012), with good perceived health and functional ability (p<0.0001 in both cases) and high patient activation (p=0.002) reported eating a variety of foods more frequently than those without a sufficient number of loved ones, poorer perceived health and functional ability, and low patient activation.

**Alcohol use** by AUDIT-C (mean 2.10, SD 2.75, 95% CI 1.60–2.59, min–max 0–12, on theoretical scale 0–12) indicated that two thirds (68%) of the respondents had low alcohol consumption (46% did not consume alcohol at all) and a third (32%)

consumed more than recommended limits, with 15% falling into the category of high-risk alcohol use. Alcohol consumption was significantly related to age, the number of chronic conditions, and gender. The proportion of participants with a low level of alcohol consumption grew with increases in age ($p=0.003$) and the number of conditions ($p=0.014$). Women were also more likely to report low alcohol consumption than men ($p=0.003$). All these variables remained significant factors for low alcohol consumption even when they were adjusted to each other in a multivariable binary regression analysis. Age and gender were also associated with risky use of alcohol, which was found to be inversely related to age ($p=0.042$) and higher among men than women (30% and 5%, respectively, $p<0.001$).

**The use of tobacco** (smoke or smokeless) was reported by 12.9% of the respondents, 10.5% daily. The use of tobacco was also significantly associated with age: adherence to the non-use of tobacco increased with the age of the stratified groups ($p<0.001$). The results also showed that employment status was associated with the use of tobacco, but this was due to the employed respondents being younger on average compared to other participants, as demonstrated by a loss of significance for employment status in multivariable binary regression analysis adjusted for age. The use of tobacco was also more common among those reporting perceived inadequacy of the number of loved ones than among those who reported having enough loved ones ($p=0.026$).

**Simultaneous adherence** to all examined five specific elements of self-management was present in less than one in five of the respondents (17%) while 24% adhered to four elements and 23% adhered to three. The respondents were considered to meet the required adherence to physical activity if it was at least moderate, to a healthy varied diet if it was at least quite variable, to avoiding harmful alcohol use if their alcohol consumption was at a low level (including those who not use it at all), and to avoiding tobacco products if these were not used at all, and to care regimens if adherence to these was at a good level. Again, some significant correlations between the examined elements were detected: adherence to care regimens had a moderate positive correlation with a varied diet ($r=0.351$, $p<0.01$) and a weak positive correlation with physical activity ($r=0.254$, $p<0.01$). In addition, physical activity had a weak negative correlation with the use of tobacco ($r=-0.212$, $p<0.05$), which in turn had a weak positive correlation with the use of alcohol ($r=0.210$, $p<0.05$).

### *Factors explaining patient adherence using the Theory of Adherence of People with Chronic Disease*

Most participants in this study felt that they had enough energy and willpower (as opposed to fatigue) (78%) and motivation (85%) to care for themselves. Most (92%) also perceived positive results of care and that caring for oneself is related to positive feelings (83%, corroborating the sense of normality in care). In addition, 80, 69 and 87% felt that they obtained sufficient support from their family and friends, physicians, and nurses, respectively. However, most (69%) also had fears of complications and additional diseases.

The significant factors for good adherence to healthcare regimens detected in this study were the results of care (OR 7.90, p=0.004), support from physicians (OR 5.14, p<0.001) support from nurses (OR 4.70, p=0.005), motivation (OR 3.96, p=0.008), sense of normality in care (OR 3.16, p=0.021), and support from family and friends (OR 2.75, p=0.031). Significant factors for good adherence to medication detected were having no fears of complications and additional diseases (OR 5.82, p=0.022), support from physicians (OR 4.99, p=0.001), and motivation (OR 4.36, p=0.007). Regarding physical activity, significant explanatory factors for its frequency were support from nurses (OR 4.10, p=0.040) and support from physicians (OR 2.35, p=0.038). Significant explanatory factors for a varied diet were motivation (OR 4.97, p=0.004), sense of normality in care (OR 4.46, p=0.004), support from family and friends (OR 3.89, p=0.004), having energy and willpower to care for oneself (OR 3.71, p=0.004), and support from physicians (OR 3.01, p=0.006).

## 5.5 Patient activation for self-management among patients with multimorbidity (Publication IV)

### *Patient activation status and associated factors*

The mean PAM score was 56.12 (SD 12.82, 95% CI 53.65–58.58) based on a theoretical point scale of 0–100. The distribution of PAM levels was as follows: 23% of participants were at level 1, 24% were at level 2, 46% were at level 3, and 7% were at level 4. Thus, 47% of participants exhibited low activation (levels 1 and 2) and 53% exhibited high activation (levels 3 and 4). See Table 6.

Higher PAM scores were significantly associated with better perceived health (p=0.019), functional ability (p=0.016), and vitality (p=0.001). Additionally, non-obese participants had higher PAM scores (mean 60.04) than obese participants (mean 54.63, p=0.032). There were also significant differences in PAM scores based on psychosocial variables: patients with a perceived sufficient number of close friends and relatives had higher PAM scores (mean 58.14) than those who deemed the number of loved ones as insufficient (mean 51.78, p=0.031), and participants who felt lonely reported lower activation (mean 52.99) than those who did not (mean 58.91, p=0.025). However, the patient's number of chronic conditions was not related to patient activation. The only socio-demographic factor significantly associated with the PAM score was old age; the oldest participant group (over 75 years) had lower activation than the others (mean=51.75; mean=58.20, p=0.035).

**Table 6. The levels of patient activation and their interpretation (Hibbard 2014) (CC BY licensed image publication IV © 2020 Authors).**

| PAM level | | PAM Score | Interpretation | Proportion in this study |
|---|---|---|---|---|
| Low | level 1 | <47.0 | *Disengaged and overwhelmed.*<br>Individuals tend to be passive and feel overwhelmed by the task of managing their own health. They may not understand their role in the care process and may not yet believe that the patient's role is important. | 23% |
| | Level 2 | ≥47.1 and ≤55.1 | *Becoming aware, but still struggling*<br>Individuals may lack the knowledge and confidence required in managing their health. | 24% |
| High | Level 3 | ≥55.2 and ≤67.0 | *Taking action*<br>Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours. | 46% |
| | Level 4 | ≥67.1 | *Maintaining behaviours and pushing further.*<br>Individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors. | 7% |

PAM= Patient Activation Measure; Theoretical range of PAM score 0–100

### *Differences between patients with low and high activation*

**Differences in perceptions related to self-management**. The low and high activation groups differed significantly in several factors relating to the perceptions of self-management: the high activation group had more positive perceptions in terms of having energy and motivation (p=0.001, t-test), feeling a sense of normality (p<0.001, t-test), and having less fear of complications and additional diseases (p=0.029, t-test). Patients with low activation felt less support from physicians and nurses compared to patients with high activation (p=0.001; p<0.0001, t-test, respectively). Further, there was a significant difference in the odds ratio of good energy and motivation (OR 5.39, p<0.001), good sense of normality (OR 3.50, p=0.004), and good support from physicians (OR 5.46, p<0.001), from nurses (OR 6.40, p<0.0001), and from family and friends (OR 2.62, p=0.020), and having no fear of complications and additional diseases (OR 3.84, p=0.050) between high- and low-activation patients.

**Differences in self-management behaviours.** The self-management elements associated with patient activation level were physical activity, diets, and adherence to care regimens. Patients with low patient activation had significantly lower physical activity based on the FIT index than those with high activation (mean=27.8; mean=39.6, p=0.002, t-test); The result also remained significant (p=0.015) even when adjusted for obesity, loneliness, and perceived health in the same model, and were more likely to have sedentary lifestyles or engage in only some physical activity (73.8%) compared to those with high activation (45.3%, p=0.004, $\chi 2$). Patients with low activation were more likely to eat an unbalanced diet (55.3%) than those with high activation (24.5%, p=0.002, $\chi 2$), and followed agreed dietary instructions less frequently than those with high activation (p=0.007, $\chi 2$). Finally, the low activation group reported lower adherence to care regimens than the high activation group (means 3.4 and 3.7, p=0.001, t-test). This result was revealed to be significant even when adjusted for obesity, loneliness, and perceived health in the same model (p=0.006). Further, there was a significant difference in the odds of engaging in moderate-to-high physical activity (OR 3.41, p=0.006), having a varied diet (OR 3.81, p=0.002), following a diet according to agreed instructions (OR 3.33, p=0.008), and having good adherence to care regimens (OR 3.82, p=0.006) in patients with high activation compared to patients with low activation.

**Differences in HRQoL.** HRQoL also differed significantly between the activation groups; more specifically, the low activation group had a significantly worse HRQoL (p=0.001). HRQoL dimensions with statistically significant between-group differences were breathing (p=0.033), speech (p=0.035), usual activities (p=0.011), mental function (p=0.014), depression (p=0.004), distress (p=0.025), vitality (p=0.001), and sexual activity (p=0.003). These differences remained statistically significant after adjusting for age, gender, and number of conditions. After adjusting for loneliness and obesity, the statistically significant between-group differences were HRQoL total (p=0.015), mental function (p=0.021), depression (p=0.014), distress (p=0.042), vitality (p=0.003), and sexual activity (p=0.004).

## 5.6 Associations between patient participation, adherence, and activation (Summary)

There was a statistically significant positive linear correlation between patient participation, patient adherence, and patient activation, as assessed as values of PPRQ, ACDI, and PAM, respectively. The correlation coefficient ranged from 0.21 to 0.44, so the effect varied from small to medium, while patient activation had a stronger correlation with others (Table 7).

**Table 7. Pearson's correlations between patient participation (PPRQ scores for importance and realisation), patient activation (PAM) and patient adherence (ACDI).**

| Variable | PP[2] for importance r (p-value) | PP for realisation r (p-value) | Patient activation r (p-value) | Patient adherence r (p-value) |
|---|---|---|---|---|
| PP for importance | 1 | 0.26 (.008) | 0.36 (<0.001) | 0.23 (0.021) |
| PP for realisation | 0.26 (0.008) | 1 | 0.44 (<0.00001) | 0.21 (0.033) |
| Patient activation | 0.36 (<0.001) | 0.44 (<0.00001) | 1 | 0.39 (<0.0001) |
| Patient adherence | 0.23 (0.021) | 0.21 (0.033) | 0.39 (<0.0001) | 1 |

[2] patient participation

Further, multivariable linear regression was used to assess the simultaneous linear relationship of patient participation (PPRQ scores) and patient adherence (ACDI) to patient activation (PAM). According to the results, the model was significant ($p < 0.001$). Multicollinearity was not found, as tolerance and VIF were $> 0.03$ and $< 1.2$, respectively. A histogram of the standardized residuals was symmetric and bell-shaped, showing that the assumption of normal distribution was likely to be true. This was also confirmed by the Kolmogorov-Smirnov test ($p > 0.05$). The coefficient of multiple determination ($R^2$ i.e., proportion of variance in dependent variable attributable to independent variables) was .327, and thus together, adjusted for each other patient participation for importance (p=0.021), patient participation for realisation ($p < 0.001$) and adherence (p=0.002), explained 33% of the value of patient activation (Table 8).

**Table 8. Multivariable linear regression; Patient activation as dependent and patient participation and adherence as explanatory variables.**

| Dependent variable | Explanatory variables | Adjusted β[1] (95% CI[2]) | Standardized β coefficients | p-value[3] |
|---|---|---|---|---|
| Patient activation | PP[4] for realisation | 6.12 (2.89–9.36) | 0.330 | <0.001 |
| | PP for importance | 5.98 (0.90–11.06) | 0.206 | 0.021 |
| | Patient adherence | 9.91 (3.64–16.18) | 0.274 | 0.002 |
| | | | | Model p<0.001; R2[5]=.327 |

[1] β= Regression coefficient; Adjusted for other variables included in the model, [2]Confidence Interval,

[3] p-value <0.05 is significant, [4] patient participation, [5] R2= Coefficient of multiple determination

According to the results, patient participation, activation, and adherence were associated with one another; more specifically, patients with higher patient participation, patient activation, and patient adherence also reported higher degrees of the other areas; there were also statistically significant differences between almost all PAM, PPRQ, and ACDI scores of participants compared with the different levels of each area, except between adherence and patient participation for realisation. Comparisons were made using known cut-off points of good values for the PAM and ACDI instruments. As there is no cut-off point for the PPRQ instrument available, these were created using upper quartiles (Q3). All differences between group means had noteworthy effect sizes. (Tables 9, 10, 11 and 12)

**Table 9. Comparisons of patient participation and patient adherence for patients with different levels of patient activation.**

| Variable | Patient activation high Mean (SD) | Patient activation low Mean (SD) | Mean difference (95% CI[1]) | p-value[2] | Effect Size[3] (Cohen's d) |
|---|---|---|---|---|---|
| PP[4] for importance | 4.47 (0.41) | 4.15 (0.44) | 0.32 (0.15–0.49) | 0.000 | 0.741 (0.333–1.145) |
| PP for realisation | 3.95 (0.68) | 3.41 (0.63) | 0.54 (0.28–0.80) | 0.000 | 0.824 (0.413–1.231) |
| Patient adherence | 3.70 (0.27) | 3.44 (0.40) | 0.25 (0.12–0.39) | 0.001 | 0.735 (0.327–0.327) |

[1] Confidence Interval, [2] p-value <0.05 is significant,

[3] Interpretation for Cohen's d: 0.20 small effect size, 0.50 medium effect size, 0.80 large effect size,

[4] patient participation. Used test: Independent samples T-test.

**Table 10. Comparisons of patient participation and patient activation for patients with different levels of patient adherence.**

| Variable | Patient adherence good Mean (SD) | Patient adherence not good Mean (SD) | Mean difference (95% CI[1]) | p-value[2] | Effect Size[3] (Cohen's d) |
|---|---|---|---|---|---|
| PP[4] for importance | 4.38 (0.44) | 4.16 (0.45) | 0.21 (0.01–0.41) | 0.036 | 0.479 (0.032–0.925) |
| PP for realisation | 3.77 (0.70) | 3.48 (0.69) | 0.29 (-0.02–0.60) | 0.067 | 0.417 (-0.030–0.861) |
| Patient activation | 58.89 (13.03) | 49.76 (11.21) | 9.13 (3.51–14.74) | 0.002 | 0.727 (0.270–1.309) |

[1] Confidence Interval, [2] p-value <0.05 is significant,

[3] Interpretation for Cohen's d: 0.20 small effect size, 0.50 medium effect size, 0.80 large effect size,

[4] patient participation. Used test: Independent samples T-test

**Table 11. Comparisons of realisation of patient participation, patient activation, and patient adherence for patients with different levels of importance of patient participation.**

| Variable | Importance of PP ≥ Q3[1] Mean (SD) | Importance of PP < Q3 Mean (SD) | Mean difference (95% CI[2]) | p-value[3] | Effect Size[4] (Cohen's d) |
|---|---|---|---|---|---|
| PP[5] for realisation | 4.00 (0.60) | 3.59 (0.72) | 0.42 (0.11–0.73) | 0.009 | 0.611 (0.155-1.065) |
| Patient activation | 63.37 (10.30) | 53.98 (13.21) | 9.39 (3.72–15.06) | 0.001 | 0.749 (0.288-1.206) |
| Patient adherence | 3.70 (0.32) | 3.53 (0.37) | 0.16 (0.00–0.33) | 0.046 | 0.461 (0.008-0.911) |

[1] upper quartile, [2] Confidence Interval, [3] p-value <0.05 is significant,

[4] Interpretation for Cohen's d: 0.20 small effect size, 0.50 medium effect size, 0.80 large effect size,

[5] patient participation. Used test: Independent samples T-test

**Table 12. Comparisons of importance of patient participation, patient activation, and patient adherence for patients with different levels of realisation of patient participation.**

| Variable | Realisation of PP[1] ≥ Q3[2] Mean (SD) | Realisation of PP < Q3 Mean (SD) | Mean difference (95% CI[3]) | p-value[4] | Effect Size[5] (Cohen's d) |
|---|---|---|---|---|---|
| PP[5] for Importance | 4.51 (0.32) | 4.26 (0.47) | 0.26 (0.09–0.43) | 0.003 | 0.588 (0.121–1.053) |
| Patient activation | 63.42 (11.89) | 54.21 (12.80) | 9.20 (3.35–15.05) | 0.002 | 0.731 (0.259–1.199) |
| Patient adherence | 3.68 (0.29) | 3.54 (0.38) | 0.14 (-0.03–0.30) | 0.106 | 0.382 (-0.081–0.843) |

[1] patient participation,[2] upper quartile, [3] Confidence Interval, [4] p-value <0.05 is significant,

[5] Interpretation for Cohen's d: 0.20 small effect size, 0.50 medium effect size, 0.80 large effect size,

Used test: Independent samples T-test

## 5.7 Schematic model

Based on the empirical results of this study a schematic model of patient participation, adherence, and activation for self-management among adult patients with multimorbidity in PHC settings was produced. The model is a visual summary describing this phenomenon, the concepts associated with it, and the relationships between them. The model was constructed based on the interpretation of results by merging the results of publications I–IV and limiting the study results to focus on research concepts and their relationships – not to describe numerous dimensions (subscales) of concepts that were also examined in this study – to ensure clarity and usefulness, and to highlight the most important issues related to the phenomenon. The conceptual definitions of the concepts used are presented in the theoretical part of the study, and their operationalization emerges in the methodology section according to the instrument used to measure this. The main concepts of the model are patient participation, patient adherence, and patient activation. It also includes patient-related factors i.e., sociodemographic factors (age, gender, education, employment status, marital status, living situation) and health-related and psychosocial factors i.e., multimorbidity (number of conditions and type of conditions leading to either physical, physical-mental, or mental multimorbidity), HRQoL, perceived health, functional ability, and loneliness. The model also includes patients' self-management related factors i.e., explaining factors in the Theory of Adherence of People with Chronic Disease by Kyngäs (energy and willpower, motivation, results of care, sense of normality, no fear of complications and additional diseases, support from physicians, from nurses, and from friends and relatives). The results of this study showed that patient participation, adherence, and activation for self-management were interrelated and further, each of them was related to many patient-related factors. Patients' perceptions related to their self-management as well as perceived health, functional ability and loneliness proved to be important factors in this model. Thus, the model shows that multiple factors can shape patient participation, patient adherence, and patient activation for self-management, illustrating that self-management is a complex and constantly evolving process in the context of multimorbidity (Figure 5).

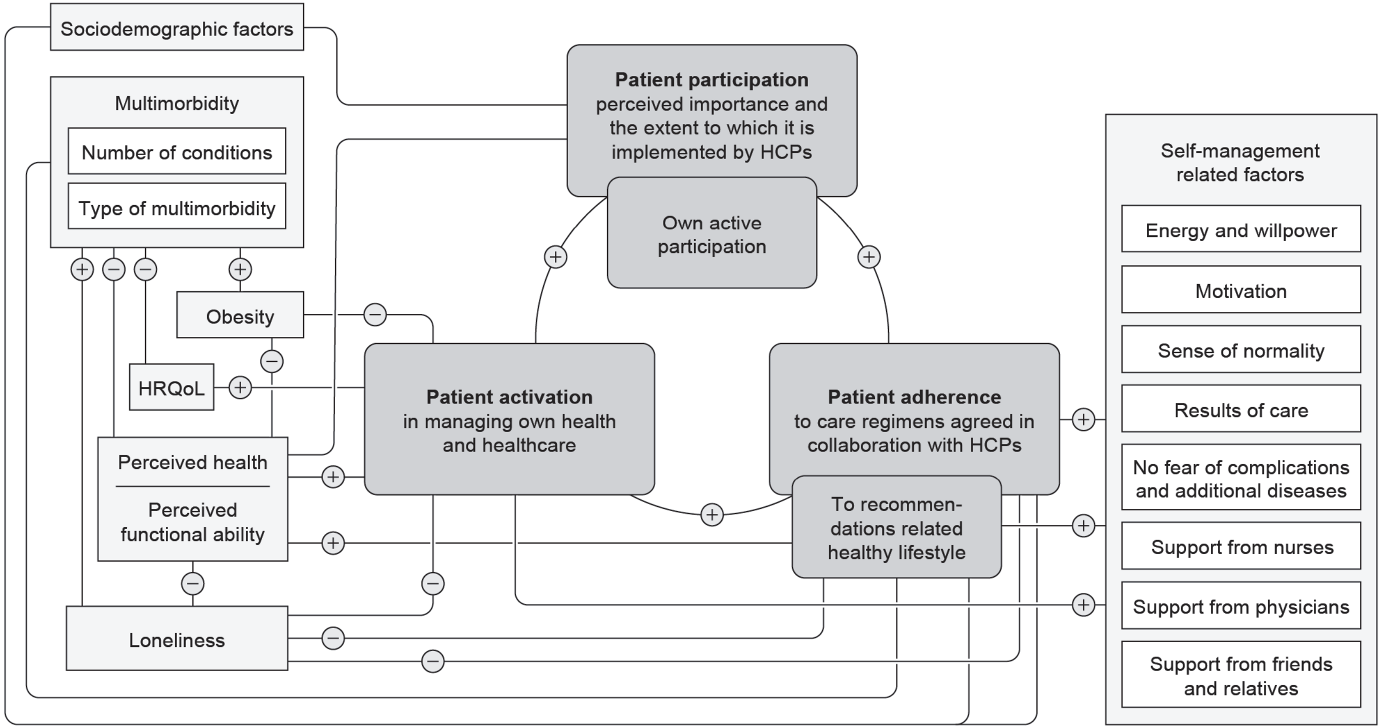


**Fig. 5. Patient participation, adherence, and activation for self-management among adult PHC patients with multimorbidity; Schematic model. A positive connection is marked with a + and negative with a – sign. The absence of a sign indicates that the relationship is present, but the nature of the relationship varies.**

## 5.8 Summary of the main results

The main results of the study are:

- The PPRQ instrument had good reliability and validity for assessing the respondents' perceptions of participation in terms of importance and the extent to which participation was realised by HCPs in PHC settings while providing information about the core dimensions of participation, namely respect and integrity; planning and decision-making; information and knowledge; motivation and encouragement; and the involvement of family.
- PPRQ scores in PHC patients showed that perceptions related to participation were individual and varied, also by the dimensions. However, on average, the focus of the responses was on alternatives that indicated that they were perceived as very important; there was more variation in the responses regarding realisation, ranging from the alternative 'always' to 'seldom, if ever'. These results were similar in both phases of the study.
- *Information and knowledge* and *Respect and integrity* scored the highest for the importance of patient participation, while the *Involvement of family* was assessed as the least important dimension, showing also greater variation than other dimensions. These results agree in both phases of the study.
- In terms of the perceptions of the extent to which patient participation was realised by HCPs, the *Respect and integrity* and *Information and knowledge* dimensions received the highest whereas the *Involvement of family* received the lowest averages. These results were similar in both phases of the study.
- Most patients with multimorbidity agreed that they tended to have active participation to some extent by asking certain questions and expressing views/opinions about their condition and care during healthcare encounters; this was significantly positively associated with patient activation, adherence, and the perceived importance of patient participation.
- Each of the five dimensions of patient participation in both domains (importance, realisation) was significantly associated with several patient-related factors, which, however, varied depending on the dimension under consideration.
- Factors that significantly explained perceptions of the importance of patient participation in univariate models were gender (female), perceived health (good), functional ability (good), patient activation (higher scores), patient

adherence, (higher scores), active participation (the highest level), while in multivariate-adjusted models, the explanatory factors were gender, perceived health, functional ability, and patient activation and active participation (the direction of the variable for greater importance remained same as in the univariate models above). Together, these factors explained about 37% of the variance.

- Factors that significantly explained perceptions for the realisation of patient participation in the univariate models were: perceived health (good), functional ability (good), patient activation (higher scores), and patient adherence (higher scores), while in multivariate-adjusted models, patient activation remained an explanatory factor, explaining about 29% of the variance on its own.
- The majority of patients (73%) reported good adherence to care regimens. The factors that were significantly associated with adherence were marital status, perceived sufficiency of the number of loved ones, and patient activation level; good adherence was less frequent among respondents who were single, who found that they had an insufficient number of loved ones, and who had a low level of patient activation.
- Adherence to behaviours related to a healthy lifestyle (physical activity, a varied diet, avoiding tobacco use and harmful alcohol use) proved to be variable and a minority of the respondents had good adherence to all of them. Significant weak to moderate correlations were found between some of these behaviours. Factors that were significantly associated with them were: age (diet, alcohol use, tobacco use), gender (alcohol use), education level (diet), living situation (physical activity), number of conditions (physical activity, alcohol use), perceived health (physical activity, diet), perceived functional ability (physical activity, diet), perceived adequacy of the number of loved ones (diet, tobacco use), and patient activation (physical activity, diet). Regarding these elements, there was variation in the groups (e.g., age group) in which adherence was poor. However, poor perceived health and functional ability, an insufficient number of loved ones and low patient activation were systematically linked to poor adherence.
- Significant explanatory factors for adherence included energy and willpower, motivation, results of care, sense of normality, fear of complications and additional diseases, and support from nurses, physicians, and family and friends, in line with the Theory of Adherence of People with Chronic Diseases. Positive perceptions and having no fears were associated with good adherence.

- The mean PAM score was quite low (56.12 on a scale of 0–100). It was significantly associated with age, obesity, and perceived health, functional ability, vitality, loneliness, and the adequacy of the number of loved ones; the oldest patient group (75 years or older), obese participants, those with poor perceived health, functional ability, and vitality, as well as those who felt lonely and felt they had an insufficient number of loved ones more frequently reported lower patient activation.
- Patients with low (47%) and high (53%) patient activation differed significantly in adherence to several self-management elements, perceptions related to self-management and HRQoL; patients with low activation had poorer adherence to care regimens, diet, and physical activity, perceived lower energy, motivation, sense of normality, felt less support from physicians, nurses, family and friends, and had more fears of complications and additional diseases as well as lower HRQoL.
- Patient participation, patient adherence, and patient activation have several significant associations with one another, such as intercorrelations and differences in means at their different levels.
- The schematic model provides a visual summary of the studied phenomenon i.e., patient participation, adherence, and activation for self-management among adult PHC patients with multimorbidity, while illustrating that these concepts were related to each other and further to many patient-related factors. Thus, in terms of patient participation, adherence, and activation, self-management is a complex, evolving process in the context of multimorbidity.

# 6 Discussion

In this chapter, the main results of the study are first discussed in context compared to previous literature. Subsequently, the evaluation of the reliability and validity, and the ethical considerations of this study are discussed. Finally, the implications of the study, suggestions for future research as well as conclusions are presented.

## 6.1 Discussion of the main results

### *Validation of the Finnish version of PPRQ in measuring patient participation*

It was important to conduct a validation study before using the PPRQ instrument more widely because it was both translated from another language and used for the first time in the Finnish PHC context. However, the legitimate use of previously validated instruments lays a stronger foundation than the use of instruments that have not been previously tested (Gray & Grove, 2021; Polit & Beck, 2017). The methodology applied for psychometric testing in this study was based on CTT because it is long-established, widely used, and primarily based on evidence from correlations and descriptive statistics (Clark & Watson, 2019; DeVellis, 2016; Petrillo et al., 2015).

Instrument validity, the degree to which an instrument is measuring the construct it is intended to measure, is a broad task. First, because no statistical test exists for determining content validity, the extent to which an instrument's content captures the theoretical construct, it was verified that the development of the original PPRQ instrument was based on qualitative research works, confirming content validity (DeVellis, 2016; Gray & Grove, 2021). Second, validity was assessed via construct validity, i.e., an instrument's adequacy in measuring the focal construct, as it is an especially relevant way to pursue validity, especially for instruments for abstract constructs measured by self-reporting tools, such as the PPRQ. This study tested construct validity using both item convergent-discriminant validity with the results supporting the validity of the instrument, and structural validity, i.e., the extent to which evidence supports hypotheses about the dimensionality of a construct (Polit & Beck, 2017). The latter was tested using factor analysis, namely EFA. The use of Confirmatory Factor Analysis (CFA) was only considered justified at a later point once there was a stronger prior theory regarding the structure of the data (DeVon et al., 2007; Yong & Pearce, 2013). Also, the criterion validity, more specifically concurrent validity, would have complemented the results of instrument validity testing, but this could not be performed because there was no measure or "gold standard" available as a criterion, as is often the case with abstract constructs (Kimberlin & Winterstein, 2008; Polit & Beck, 2017).

EFA yielded a five-factor solution that corresponded well with the five dimensions of participation identified in the development and tests of the original instrument (Lindberg et al., 2014; Lindberg, Kreuter, Taft, et al., 2013). However, four items loaded slightly more strongly on factors that did not match the corresponding dimension in the original instrument and one item also showed a fairly similar loading (i.e., cross-loading) on a factor other than the original one. In these kinds of cases, both theory and measurements must be assessed at the same time in construct validation and the final factor model must be determined based on its relevance to the logical and conceptual meaning (Polit & Beck, 2017; Streiner et al., 2015). This also applies in cases where cross-loading is detected, in which cases it is worth considering whether it is a good idea to include or exclude the item (Yong & Pearce, 2013). In this study, any discrepancies were theoretically understandable, considering the essence of patient participation (see more in Publication I). As a result, although some discrepancies were obtained with EFA, the structure of the original PPRQ was applied in further analyses and interpretations, and the results supported the reliability of the instrument, as described in the following paragraph.

The results obtained in this study indicated adequately good reliability of the PPRQ. Cronbach's alpha coefficients for all subscales (0.76–0.92) and the instrument for both domains (0.94 and 0.95) were all well above the generally accepted limit of 0.70 (DeVon et al., 2007; Gray & Grove, 2021; Polit & Beck, 2018), indicating good internal consistency (capturing consistency across items of the subscale/instrument), while for subscales of this kind of newly-created instrument, coefficients of 0.60–0.69 would have also been considered acceptable (Gray & Grove, 2021). These results were congruent with the Cronbach's alphas of the original PPRQ calculated in previous studies (Lindberg et al., 2014; Lindberg, Kreuter, Person, et al., 2013). Further, if all the items of the (sub)scale measure the same concept, they would be expected to correlate well with one another, suggesting congruence with the underlying construct. Intercorrelations of items within subscales ranged from 0.25 to 0.84, while almost all correlation coefficients fell between the recommended range of 0.30 and 0.70 (DeVon et al., 2007; Polit &

Beck, 2017). One of the correlations was lower than 0.03 for importance while four items exceeded the ideal value for the realisation domain; three of the items in the family involvement subscale exceeded 0.80, indicating that some associated items are very narrowly focused, possibly overlapping (Streiner et al., 2015). All corrected item-total correlations (the consistency of an item with the total score) were over the recommended limit (DeVellis, 2016; Streiner et al., 2015).

The scores obtained with the PPRQ instrument in this study were broadly consistent with previous findings obtained using the original PPRQ (Publication I). The biggest differences were detected in the mean scores of the realisation ratings in the family involvement subscale. These were probably due to contextual and/or cultural differences. In PHC in Finland, the participation of family members is not as well-established as in the care of patients with spinal cord injuries in the original study.

The results obtained in this study show that the Finnish PPRQ, after minor modification, has adequate reliability and validity in the studied context and is suitable for use among PHC patients to provide information about the various core aspects of participation. The instrument can be used to measure patients' perceptions of both the importance and realisation of participation in care: more specifically, the importance ratings allow patients to depict their personal preferences and expectations, while realisation ratings reflect patients' perceptions of the extent to which the patient participation is realised and supported by HCPs in healthcare encounters.

### *Patient participation in their own care for managing chronic conditions during healthcare encounters among patients with multimorbidity*

The study among patients with multimorbidity revealed that the respondents consider patient participation implemented by HCPs a very important aspect. This is an important finding and consistent with previous findings in chronic PHC patients (Luhr, Eldh, et al., 2018; Paukkonen et al., 2018). However, perceptions of the extent to which participation was realised showed substantial variation, with responses ranging from always to seldom, if ever. Previous studies have also shown that there are shortcomings in the implementation of patient participation as perceived by patients (Henselmans et al., 2015; Protheroe et al., 2013). This may be because patient participation is known to be challenging to achieve in general, while it is also individual, situational, and context-specific (Angel & Frederiksen, 2015; Thórarinsdóttir & Kristjánsson, 2014), and the complexity of the care of multimorbidity is likely to make it more complicated, despite being even more imperative.

The respondents' assessments of both the importance and realisation of participation demonstrated some variability, and some dimensions were rated higher than others; *information and knowledge* and *respect and integrity* were considered the most important and best-implemented dimensions of participation. This result is also consistent with the result of Phase I (Publication I). This is notable because the starting points for participation include the recognition of individuals' autonomy and respect for them as individuals and further a prerequisite for adequate information exchange, which remains the basis for building more patient participation (Kvæl et al., 2018; Tambuyzer et al., 2014; Thórarinsdóttir & Kristjánsson, 2014). Particularly, patients with multimorbidity have a major need for information, and the information they receive can be confusing and even contradictory when several HCPs are involved in their care (Adeniji et al., 2015; Morris et al., 2011; van der Aa et al., 2017). Further, in terms of importance, patients in this study also rate the *motivation and encouragement* dimension very highly, which emphasizes the significance of support provided by HCPs for coping and other emotional areas. Previous studies have highlighted the importance of patients' perceived motivation for self-management and their related support needs (Bratzke et al., 2015; Coventry et al., 2014). *The involvement of family* was perceived as the least important area and received the most varying importance ratings. This may be explained by the fact that not all patients have families and some do not want to involve their family members in their care. However, there was also the biggest gap between the perceived importance and realisation of this subscale. These same results were also revealed in Phase I of the study (Publication I). Thus, attention should be paid to the possibility for family members to participate if the patient so wishes. The importance of family-centred care (Kokorelias et al., 2019) and the involvement of family as a central component of patient participation is known (Kvæl et al., 2018; Melin, 2018) and highly recognized in managing patients with multimorbidity (Giunta et al., 2022; Leijten, Struckmann, et al., 2018; Palmer et al., 2018; WHO, 2016) but it is also known that family participation is not always an easy task (Kuipers et al., 2019).

Various patient-related factors were found to be associated with the perceptions of patient participation implemented by HCPs. Statistically significant associations were found for all dimensions in both domains, while the associated factors varied depending on the dimensions and domains (see more in Publication II). This variation may reflect the multilevel and multidimensional nature of participation.

Age showed an effect on the importance of the respect and integrity dimension, which was consistent with previous study findings in primary care settings indicating that younger patients were more critical and had higher expectations of their own involvement (European Commission, 2012). Gender was found to be associated with patients' perceptions regarding the importance of participation but did not affect the perceptions on the extent to which patient participation was realised. In this study, female patients gave significantly higher scores to almost all subscales for the importance of patient participation than male patients, and the female gender was also further found to be a significant exploratory factor for the total importance of participation in both univariate and multivariate analyses. These results are in line with previous findings (among varied settings of patients) indicating women are more likely to perceive patient participation as important (Melin & Årestedt, 2020; Paukkonen et al., 2018), have a stronger preference for it in medical decisions (Hamann et al., 2007; Say et al., 2006), are more interested in health-related information (Ek, 2015), and demonstrate a more active attitude towards treatment than men (Chylińska et al., 2017).

Perceived health and functional ability were found to significantly impact patients' perception of both the importance and realisation of participation. Patients with poor perceived health and functional ability felt patient participation to be implemented more poorly by HCPs, shown statistically in the *respect and integrity, information and knowledge* and *motivation and encouragement* dimensions. This may suggest that patients with multimorbidity who have severe problems in their health and/or functional ability feel that their need for respect, access to information, and encouragement is not adequately addressed. They may also have higher expectations, possibly due to their greater health needs. A previous study reported somewhat similar results; that is, patients, with one or more chronic conditions with poor perceived health had a more negative experience of interacting with and developing a relationship with HCPs (Gulliford et al., 2011). Moreover, a large general sample study showed that respondents with poor perceived health rated the communication of HCPs (i.e., listening to, explaining, respecting, spending enough time, and being involved in decisions) lower than other patients (Rutten et al., 2006). Further, poor perceived health has also been found to predict lower overall satisfaction with healthcare as determined by the results of a systematic review (Batbaatar et al., 2017).

Again, patients' perceptions of the importance of patient participation as well as the extent to which it was implemented by HCPs were found to have associations with patient activation, adherence as well as active participation by patients. These results are discussed later in the section *Relationships between patient participation, adherence, and activation.*

### Patient adherence to self-management among patients with multimorbidity

The findings reveal that adherence to care regimens was generally moderately good among the multimorbid patients. Adherence to medication and attendance of healthcare follow-up appointments was particularly high, in accordance with previous findings in a study examining multimorbid patients' adherence (Cohen-Stavi et al., 2020). This is important, as many multimorbid patients are usually receiving polypharmacy, and the co-occurrence of many chronic conditions is considered a risk for good adherence to medications. However, studies have resulted in highly varied rates of medication adherence or non-adherence, and it is also worth noting that there are many current methods for assessing these topics along with varied study settings, which both complicate the attempts to compare the results of different studies. The recent systematic review of medication non-adherence among patients with multimorbidity confirms this heterogeneity while the range of non-adherence among all reviewed studies was 7.0–83.5% (Foley et al., 2021). On the other hand, it is also possible that as multimorbid patients have numerous healthcare contacts, they receive overlapping care, especially in cases where their conditions are interrelated and share similar management strategies (Zulman et al., 2014), which may help them to adhere to medications and other care regimens. This notion is corroborated by a previous study conducted among Finnish frequent healthcare attendees, most of whom had at least one chronic disease, which found a similarly high rate of adherence to care regimens as in this study (Hirsikangas et al., 2016).

The results of this study also show that several factors were associated with adherence to care regimens. Good adherence to both overall care regimens and medications was less frequent among respondents who were single and respondents who expressed having an insufficient number of close friends and relatives. Further, support from family and friends, and nurses and physicians was also a significant explanatory factor for adherence to care regimens, while support from physicians was a significant explanator of medication adherence. This finding is consistent with previous findings that patients' perceived healthcare provider's relational quality is positively associated with greater medication adherence and their ability to self-manage and experience less treatment burden (Eton et al., 2017). Previous studies using the same theory of adherence as this study have also found that the significant explanatory factors for adherence of patients with varied chronic conditions included support, results of care (Lunnela et al., 2011), sense of normality (Kääriäinen et al., 2013), and motivation (Kääriäinen et al., 2013; Kähkönen et al., 2015), all of which proved to be explanatory factors in this study. Poor adherence to medications was also found to be more common among patients who had fears of complications and additional diseases, so identifying them would be important. Moreover, fears were very common in the focal population; about 70% of respondents reported having fears compared to 46% of coronary heart disease patients treated with a percutaneous coronary intervention previously surveyed by Kähkönen et al. (2018). Finally, this study also revealed that patient activation was significantly associated with adherence to care regimens, which is discussed later.

In terms of adherence to healthy behaviours (physical activity, varied diet, avoiding use of tobacco, and harmful use of alcohol) about a fifth had good adherence to all the above. Some correlations were found between these behaviours, namely, the use of tobacco correlated positively with the use of alcohol and low physical activity. This is consistent with previous findings that showed that lifestyle-related health risk factors cluster somewhat (Noble et al., 2015). Again, this study also found a correlation, albeit only a weak one, between adherence to care regimens and both a healthy diet and physical activity. So, it was noted that adherence to self-management among patients with multimorbidity is clearly not an ‘all or none’ phenomenon, and even if commitment is good in one component, it may be lacking in another. A multimorbid patient’s adherence to a healthy lifestyle is important not only for managing current conditions but also for the prevention of secondary conditions. There is evidence that unhealthy behaviours appear to increase the risk of new chronic conditions (Chudasama et al., 2020; Katikireddi et al., 2017; Licher et al., 2019; Mounce et al., 2018), particularly when combined (Dhalwani et al., 2017; Freisling et al., 2020; Wikström et al., 2015). There are also promising indications that multidomain intervention could reduce the risk of developing new chronic disease(s) in patients with multimorbidity (Marengoni et al., 2018). Additionally, recent studies have found that an overall healthy lifestyle largely counterbalances the negative association between multimorbidity and life expectancy, and engaging in a healthier lifestyle, in particular abstinence from smoking, can increase life expectancy by up to 7 years (Chudasama et al., 2020). These results show that health behaviours should indeed be studied together and not just separately. Again, results suggest that it would be important to invest in lifestyle guidance for patients with multimorbidity as part of supporting their self-management, especially since these issues are known to entail central self-management problems as defined by the patients themselves (Hessler et al., 2019).

The level of engagement in physical activity varied among the multimorbid patients; six out of ten reported low activity and a fifth a sedentary lifestyle. Physical activity was negatively correlated to the number of conditions, perceived health, and functional ability, consistent with a previous study that found an inverse relationship between physical activity and perceived health and functional limitations (Cimarras-Otal et al., 2014). Again, previous findings have shown that many patients with multimorbidity experience a variety of challenges to exercise (Jäger et al., 2022). Multimorbidity can restrict physical activity and exercise, and some exercises may have to be adapted to suit those with chronic conditions but it is nonetheless important to find appropriate individual ways to engage in physical activity and understand the role it plays for health. The results of this study indicate that patients' knowledge and understanding of the importance of their role in their care can promote physical activity, as this was positively associated with patient activation. This result is supported by another finding of the study that frequent physical activity (at least three times per week) was associated with support from nurses and physicians. As physical activity is a key form of prevention and care of chronic conditions (Pareja-Galeano et al., 2015; Pedersen & Saltin, 2015; *Physical Activity. Current Care Guidelines*, 2016) and a recent systematic review suggested that exercise therapy appeared to be a safe and beneficial intervention to improve both physical and psychosocial health in people with multimorbidity (Bricca et al., 2020), HCPs should clearly encourage patients to engage in physical activity, for example using counselling and exercise prescription as a tool. Even moderate exercise has been found to be beneficial and associated with longer life expectancy (Chudasama et al., 2019). Physical activity also reportedly contributes to improvements in perceived health and life satisfaction, the factors known to be negatively associated with living with multimorbidity (Marques et al., 2018). Again from a preventive point of view, an inverse dose-response association has been found between levels of physical activity and multimorbidity, and compared to a physically inactive group, the odds of multimorbidity were reduced by 39% in even the moderate activity group (Dhalwani et al., 2016).

Regarding a varied diet, 58% of respondents reported that their diet was very or quite varied. This was significantly associated with several patient-related factors. First, having a varied diet was more common among patients with tertiary education, in accordance with findings of a Finnish national health survey that indicated that highly educated citizens had better eating habits than those with a lower level of education (Koponen et al., 2018). It was also more common among patients with high patient activation in accordance with previous findings regarding cancer patients (Hibbard, Mahoney, et al., 2017). By contrast, an experience of an insufficient number of loved ones, and poor perceived health and functional ability were negatively associated with a varied diet. This may have been at least partly because patients with poor perceived health and functional ability may be more frequently too overwhelmed by their situation or circumstances to take care of healthy eating on a daily basis. The results of the study also showed that energy and willpower, motivation to care for oneself, feeling normality in care, and support from physicians, family, and friends are explanatory factors for a varied diet. Thus, targeted support and guidance to make maintaining a balanced diet as natural and easy as possible in everyday life, considering possible limitations of patients' health and living conditions, could be extremely helpful.

Poor eating habits, combined with low levels of physical activity, are the main risk factors for being overweight or obese. Obesity is a major risk factor for noncommunicable chronic conditions (*Obesity (children, adolescents and adults). Current Care Guidelines*, 2023) and is strongly associated with multimorbidity (for example Andersén et al., 2021; Booth et al., 2014; Canizares et al., 2018; Freisling et al., 2020; Mounce et al., 2018) in keeping with the results obtained here: almost half of the respondents in this study fell into this category, compared to around 25% of the total adult Finnish population (Koponen et al., 2018) while less than a fifth of the participants were of normal weight. However, obesity is projected to increase in Finland (Tolonen et al., 2022). Again, more obese individuals, especially in younger age groups, have been detected to develop multimorbidity at an earlier age than those of normal weight (Canizares et al., 2018). Obesity also increases the risk of multimorbid people developing a new disease (for example (Freisling et al., 2020). These results confirm the importance of required weight management support in PHC.

Alcohol consumption was found to be quite dichotomous; while almost half of the respondents did not consume it at all, a third consumed more than recommended limits, 15% being assigned to the risky use category. Alcohol consumption was significantly associated with age and gender, being lower among women and older age groups, in accordance with the findings of a comprehensive Finnish national health survey (Koponen et al., 2018). Men and younger participants were also more likely to be risky users of alcohol; 30% of men (slightly more than the proportion in the national sample), but just 5.4% of women were in this category. These results are also consistent with international findings obtained among the multimorbid population that alcohol use is more common in young males (Bisquera et al., 2021; Violan et al., 2014). However, a positive finding in this study was that the proportion of participants with low consumption of alcohol increased with the number of conditions even when adjusted with age and gender. About 13% of respondents used tobacco (smoke or smokeless) and its use was significantly associated with younger age and perceived inadequacy of close friends and relatives. In this study, the proportion of daily smokers was pretty much the same as in the Finnish population among the over-65s, but the proportion of under-65s in this study was about 24%, corresponding to 12% of the population (Jääskeläinen & Virtanen, 2021). Adherence to the avoidance of tobacco use as well as harmful alcohol use was therefore far from ideal. Thus, finding ways to reduce rates of risky alcohol consumption and tobacco use would be very beneficial.

### *Patient activation for self-management among multimorbid patients*

The mean patient activation score for the studied population was quite low, 56.1 on a scale of 1–100 (Cuevas et al., 2021; Hibbard et al., 2005), perhaps due to the characteristics of the study population that are connected to low activation (discussed below). However, it was consistent with a previously reported value for multimorbid older adults (Skolasky et al., 2011). The proportions of low (levels 1 and 2) and high (levels 3 and 4) activation in this study were 47% and 53%, respectively, which were also consistent with the rate found in the above-mentioned study. However, in this study, the proportion of participants exhibiting the highest level of activation (four) was very low (7%). Similar results were also reported previously for patients with selected chronic conditions (Bos-Touwen et al., 2015) and in older patients with complex medical needs (Gerber et al., 2011) and frailty (Overbeek et al., 2018). This is noteworthy in terms of e.g. healthcare resources because while multimorbid patients are known to be major users of healthcare resources (McPhail, 2016; Palladino et al., 2016), patient activation in patients with chronic condition(s) is found to be inversely associated with healthcare costs (Hibbard et al., 2013; Lindsay et al., 2018) and utilisation across the whole health economy (Barker et al., 2018; Kinney et al., 2015; Mitchell et al., 2014), as their use is found be lowest at activation level four (Deeny et al., 2018; Mitchell et al., 2014).

Numerous studies in different contexts have investigated the patient's sociodemographic factors as factors related to activation. However, there are variable and conflicting results, which may be due to differences in study samples. In this study, only the association related to sociodemographic factors was concerned with age; lower patient activation was associated with old age, in keeping with previous findings in multimorbid patients (Blakemore et al., 2016) and in patients with comorbid diabetes and chronic kidney disease (Zimbudzi et al., 2017). However, mixed results were obtained in several studies on chronic populations: some found an association with age (Barker et al., 2018; Hendriks & Rademakers, 2014; Korpershoek et al., 2016) but others did not (Graffigna et al., 2017; McCabe et al., 2018). However, previous findings have shown that patient activation scores are even moderately correlated with socio-economic status (Hibbard & Gilburt, 2014) and that patients' sociodemographic characteristics (age, gender, education, and income) explained only 5–6% of the variation in PAM scores (Greene et al., 2005).

In the studied population, PAM was apparently unrelated to the number of chronic conditions, which is consistent with previous findings in adults with multimorbidity (Skolasky et al., 2011). However, perceived health and functional ability were both significantly associated with patient activation: patients with lower activation scores reported worse perceived health and worse perceived functional ability. Lower self-rated health (based on diverse metrics) was also previously associated with low activation in multimorbid patients (Bos-Touwen et al., 2015; Schmaderer et al., 2016; Skolasky et al., 2011). The HRQoL analysis performed here reinforced the finding that patients with low activation have significantly more difficulties with vitality and mental function and feel more depressed and distressed than high activation patients. The relationship between health outcomes and activation is presumably complex. It was speculated that the direction of the causal relationship between patient activation and health is likely to go in both directions, also suggested by Hibbard and colleagues (Hibbard et al., 2017) meaning that those with low patient activation are at risk for poor self-management and health outcomes, but also that those patients who are overwhelmed by their illness or circumstances, for example, those with poor perceived health, are likely to find self-managing of their conditions on a day-to-day basis as more difficult, and as a result, they score low in patient activation.

Another factor that was found to be significantly associated with patient activation in this study was obesity: obese participants had lower activation than their non-obese counterparts. This is consistent with previous study reports showing that lower activation is associated with obesity/higher BMI in patients with chronic condition(s) (Bos-Touwen et al., 2015; Korpershoek et al., 2016;

McCabe et al., 2018; Rozjabek et al., 2020). These results come from cross-sectional studies, but there is also longitudinal evidence that higher patient activation acted as a predictor of not developing obesity or moving into a normal BMI range (Sacks et al., 2014). This result is consistent with another result of this study i.e., patients with low and high activation also exhibited significant differences in self-management behaviours: low activation participants were significantly less likely to have a balanced diet and comply with dietary instructions, and had lower frequencies of physical activity than those with high activation. These findings are consistent with previous results suggesting that healthy eating (Hibbard, Mahoney, et al., 2017) and physical activity are associated with activation (McCabe et al., 2018; Skolasky et al., 2011). As such, patient activation may potentially be incorporated into a single tool to address the challenges of inadequate physical activity and diet as well as overweight and obesity.

In this study, perceived loneliness was found to affect patient activation. More specially, feelings of loneliness and insufficient close relationships with others were more common among patients with lower patient activation. As far as known, this association has only been studied a little before, Previously, loneliness was found to be associated with low patient activation among military veterans with depression (Teo et al., 2018). However, these results are in line with previous findings that social support, as measured in various ways (Blakemore et al., 2016; Bos-Touwen et al., 2015), and satisfaction with one's social role (Schmaderer et al., 2016) were positively associated with patient activation in patients with a chronic condition(s). However, living alone, or one's living situation in general, was not associated with patient activation, in keeping with previous findings (Blakemore et al., 2016). Further, according to this study patients with high activation felt more supported by their family in their self-management, consistent with previous findings in an older adult population with functional difficulties (Gleason et al., 2016). These findings confirm the importance of taking patients' perceptions of their social relationships into account for self-management, particularly because these issues were also found to have numerous connections to the adherence to self-management in this study, as previously discussed, and as loneliness is known to be associated with multimorbidity (Hajek et al., 2020; Stickley & Koyanagi, 2018).

This study also examined patients' perceptions relating to self-management at different levels of patient activation. Highly activated participants had significantly more positive perceptions of having energy and motivation to care for themselves, as well as feeling a sense of normality in care; meaning, for example, that they more often felt that self-management produces well-being and is a natural part of their daily routine. Meanwhile, low-activation patients more frequently agreed that they did not follow recommended treatment guidelines because the guidelines did not fit their lifestyle. This is consistent with previous reports that patients with low activation may not consider their role in the care process to be important and are more likely to have low confidence in their ability to self-manage and to feel overwhelmed as a result (Hibbard, Greene, et al., 2017). Patients with low activation had more fears of complications and additional diseases which may reflect a lack of knowledge and control over one's situation among these patients.

However, studies have found that change in patient activation is possible and that increases in activation are actually likely to be greater and easier to achieve for patients who are starting at a low level (Hibbard et al., 2015; Hosseinzadeh et al., 2022; Regeer et al., 2021). Especially interventions tailored according to patients' activation level, ensuring that the level of support provided is appropriate to the needs of the individual, have previously been shown to be effective (Cuevas et al., 2021; Hibbard & Mahoney, 2010). It is important to proceed in suitable and sufficiently small steps with those with low activation; experiences of success in self-management, even small, can build positive emotions and confidence and initiate positive progress, while too much information or too many demands can overwhelm individuals, while for patients with higher activation, more complex information and interventions can be provided (Hibbard, 2017; Hibbard & Mahoney, 2010). However, it should be noted that activation can also decrease; the onset of a new disease or complications may render a patient's good knowledge and confidence insufficient in a new situation where more support is temporarily needed (Rijken et al., 2014). In addition, it is important to consider how to best integrate support into routine healthcare and clinical practice, as separate interventions are more likely to engage those who already have high activation (Hibbard & Gilburt, 2014) but according to the results of this study, the patient's adherence to PHC follow-up visits was high.

### *Relationships between patient participation, adherence, and activation*

In this study, multimorbid patients with high activation had better adherence to care regimens and several healthy lifestyle behaviours. Patient activation had also a strong relationship with patient participation; patients with high activation provided positive ratings on all the subscales related to the importance and realisation of participation. Patient activation was also revealed to be an explanatory factor for patients' perceptions of patient participation in multivariate models. These findings are supported by previous reports according to which patient activation is linked to patients' experiences of health services. In patients with chronic condition(s), patient activation was found to be negatively associated with perceived barriers during medical consultation (Henselmans et al., 2015) and positively associated with perceived care experience (Greene et al., 2013), quality of chronic illness care (Gerber et al., 2011; Skolasky et al., 2011), quality of the patient–physician relationship (Alexander et al., 2012; Graffigna et al., 2017), interpersonal exchanges with physicians (Alexander et al., 2012; Wong et al., 2011), and fairness in the treatment process (Alexander et al., 2012). These results also coincide with the finding of this study that patients with high activation felt that they received more support for their self-management from their HCPs.

The better care experiences found among patients with high activation may be explained by highly activated patients finding encounters more approachable and feeling that it is easy for them to operate in healthcare encounters. In addition, they are probably more adept and take more urgent action to get their HCPs to meet their needs (Alexander et al., 2012). As a result, their experiences related to patient participation implemented by HCPs were also more positive. These conclusions, in turn, are also supported by the findings of this study that patients with more active participation, i.e., those who ask questions and express their opinions more often, were also more often those with high patient activation and adherence and also perceived patient participation as more important. These findings are further corroborated by previous studies (in general or community health samples) that showed that more activated patients are more persistent in asking questions when not understanding something (Hibbard, 2009) and prefer and take more active roles in their medical decisions (Deen et al., 2011). Further, previous studies have presented that, among patients with high activation and proactivity, the healthcare interactions were also more productive. This was seen as the result of a transaction between patients and HCPs (Greene et al., 2013).

Indeed, previous studies based on researchers' observational findings, have found that PHC patients with higher active participation (i.e., who actively communicate with HCPs) received care that was more informative and was communicated in a more patient-centred way (Cegala et al., 2007; Cegala & Post, 2009). On the other hand, HCPs' patient-centred communication style increased patients' active participation (Cegala, 2011). However, previous findings have shown that the risks for patient participation include patients' disagreeing opinions (European Commission, 2012) and concern of coming off as too "bothersome" as well as lack of time (Henselmans et al., 2015). Again, while there have been encouraging experiences of interventions to increase patients’ active participation with HCPs, they have also brought out the reciprocal interaction while suggesting that both sides may have to be included to influence patient-centred care outcomes (D’Agostino et al., 2017). A previous study showed that practitioners’ trust in their patients’ role in self-management was positively associated with collaborative and partnership-building behaviours, and again improvements in their patients’ level of patient activation (Alvarez et al., 2016). A longitudinal study among patients with diabetes or cardiovascular disease also showed that the relationship between patients’ experiences of collaboration with HCPs in the shared decision-making process and patient activation was positive and bidirectional, though dominated by baseline patient activation (Poon et al., 2020). It is also important to pay attention to previous findings showing that the patient-assessed quality of received care had a stronger effect on care outcomes in patients with low activation than in patients with high activation among patients with type 2 diabetes, which indicates that good quality of care is particularly beneficial for patients with low patient activation (Aung et al., 2015, 2016).

Again, this study also suggests that participation and adherence processes play an important role in patient activation; according to this study, just the values of participation and adherence could explain 33% of the values of patient activation, while in a previous study in patients with chronic condition(s) (Bos-Touwen et al., 2015) they could explain 16% with 9 explanatory variables (age, BMI, educational level, financial distress, physical health status, depression, illness perception, social support, and underlying chronic disease) and another study in multimorbid patients could explain 17% in the PAM score with seven variables (age, depression, health literacy, HRQoL, social support, number of conditions, perceived impact of multimorbidity) (Blakemore et al., 2016). In this study, there was also a statistically significant positive linear correlation between patient participation, patient adherence, and patient activation. However, these varied from small to medium indicating that these concepts are related but clearly separate. To sum up, as regards the relations between these concepts, patient activation has a great impact on patient participation and adherence. Further, it is likely that patient participation, if perceived as appropriate by the patient, serves as a tool to achieve patient activation and adherence. Again, adherence to recommended care regimens may create a sense of control over one’s health, which may further foster patient activation and again the ability and courage to take an active role in health encounters. This makes adherence not just the end result of the process, but a part of it.

### *Discussion of the schematic model*

In phase III, the schematic model was constructed to describe to studied phenomenon i.e., patient participation, adherence, and activation for self-management among adult PHC patients with multimorbidity. The model has been formed deductively based on the results of an empirical quantitative study, while the used cross-sectional design also allowed for examining the factors simultaneously related to the phenomenon at a given time. Again, the study was built on relevant scientific literature and careful design, and while the phenomenon as a whole is new and unexplored, the main concepts used in this model have been studied quite extensively in the past in varied settings, forming a background and understanding for the study. Further, some parts of the study were developed deductively through the ideas of an existing theory i.e., the Theory of Adherence of People with Chronic Disease originally developed by Kyngäs (1999). This study tested if the concepts identified by the theory to affect adherence to self-management (propositions) also apply to patients with multimorbidity. Further, these same concepts were used to lay the data for studying patient activation and it was studied if these factors affect patient activation as well (Kyngäs et al., 2020; McKenna et al., 2014; Polit & Beck, 2017). In this study, no hypotheses were used; instead, research questions were introduced, which can also be used to test a theory, especially within a correlational design like in this study (McKenna et al., 2014). Indeed, one strength of the model is its background in quantitative research, enhancing its clarity. Again, based on the interpretation of the results, by limiting the research results to focus on key research concepts and proposals, the model attempts to be clear and useful and clarify the most important issues of the phenomenon, without losing too much of its complexity.

Again, this model lends itself to testing, which the newly created model will of course require in the future. For example, the entire model can be tested using a structural equation model (SEM), which enables the examination of relationships including both direct and indirect effects investigating a complex phenomenon (Tabachnick & Fidell, 2012). The results of this study showed that patient participation, adherence, and activation for self-management were related and again they were associated with many patient-related factors. Further, although many direct connections were found between them, it is suggested that they may also act as moderators and/or partial mediators between one another. This means that they can act as a moderating variable (moderator) that affects the strength and direction of two other variables and/or as a mediating variable (mediator) that explains the process through which two variables are related, partially or fully (MacKinnon, 2008). Thus, multiple factors, maybe by interacting, can shape patient participation, adherence, and activation for self-management, and the interplay between them reflecting self-management as a complex and ever-evolving process in the context of multimorbidity.

This model speaks of the importance of a whole-person approach and collaboration between HCPs and patients in care, considering the importance of the roles of both parties in managing multimorbidity, where self-management is key. It is suggested that considering and balancing with these concepts presented in the model may help promote patient-centred care implemented by HCPs and support patients' possibilities to participate and self-manage to the best of their abilities, which may contribute to satisfaction with care, the elimination of excessive treatment burden and well-being. Indeed, patient preferences and needs are central elements of evidence-based practice (EBP) combined with the best research evidence and clinical expertise of clinicians (Gray & Grove, 2021). Further, the concepts and context of this model are related to the nursing metaparadigm foundation elements: human beings, health, environment, and the nursing process (Fawcett & DeSanto-Madeya, 2013; McKenna et al., 2014).

## 6.2 Validity and reliability of the study

In quantitative research, the validity and reliability of the used instruments i.e., the extent to which an instrument actually reflects the examined concept and how consistently the instrument measures it, play a key role in obtaining real results (Streiner et al., 2015). The variables measured in this study were abstract concepts, as is often the case in health sciences, and as such. the use of valid instruments to measure such concepts essential for the quality of research (Gray & Grove, 2021; Kimberlin & Winterstein, 2008). In Phase I, the main objective was validating the instrument, which was done carefully and using multiple analyses. This process is presented in section 4.1, the results in section 5.2 and the obtained findings in section 6.1. In Phase II (Publications II–IV, Summary) several instruments were used. These instruments were selected according to the research objectives, primarily based on conceptual relevance, but their reputation, including validity, was also considered as well as their appropriateness to the research population (Kimberlin & Winterstein, 2008; Polit & Beck, 2017). Cronbach's alpha values were generated for all the instruments and their subscales; the values described sufficiently good internal consistency all over the threshold of 0.7 (Publications II–

IV, Section 4.2.2). However, it is known that there is also disagreement about the ideal values of Cronbach's coefficients in different situations and that it is also affected by the length and dimensionality of the instrument (DeVon et al., 2007; Streiner et al., 2015) as well as a homogeneous distribution of target responses. There is also debate even if the Cronbach's coefficient alpha is the most appropriate to use for a two-item scale as it may underestimate the true reliability of such a scale (Eisinga et al., 2013). However, in this study, the alphas were also deemed good enough for two-item (sub)scales.

The instruments relied on self-reporting, which may introduce some risk of bias. However, their use was justified and necessary because the study largely focused specifically on patients' perceptions related to care and behaviours in their daily life, so there are no acceptable alternative means of measurement for such constructs (Kimberlin & Winterstein, 2008; Polit & Beck, 2017). The respondents were also given written instructions for responding to increase the clarity of each instrument. Further, to ensure that the respondents' assessments accurately reflected their perceptions of patient participation during those encounters, the respondents were instructed to fill out the questionnaire soon after their appointments, thus minimising recall bias, as they could still clearly remember their experience. On the other hand, the respondents had an opportunity to respond at home, at the time most convenient for them. To ensure honesty and minimize social desirability response bias, particularly common in issues related to negative health behaviours, the questionnaires were returned anonymously directly to the researcher (Streiner et al., 2015).

Healthcare personnel recruited the study participants during healthcare encounters with patients, which may introduce some risk of bias. However, the participants were recruited from several health centres and units, and thus by many persons. Phases I and II were conducted in different municipalities, to avoid any overlap in the study participants. Prior to the data collection, the researcher briefed the personnel involved in the study on the research arrangements. Written information was also given and personnel were instructed to distribute questionnaires to all their patients, satisfying the inclusion criteria. Inclusion criteria were set for the study participants before data collection in the study design. The chosen method of data collection, was, however, challenged by the emergence of the COVID-19 epidemic shortly after the start of the data collection of Phase II, because it greatly affected the functioning of healthcare organizations and reduced the number of non-urgent appointments, including those of the studied chronically ill patient population examined. It may also have reduced the willingness of such patients to attend appointments, as they belonged to the risk group for COVID-19. This may partly explain why the sample size remained quite small. It could also be that the patients were unwilling to answer the rather long questionnaire. However, this was taken into account when creating the questionnaire by using competent but as short as possible instruments instead of more burdensome ones whenever possible (Streiner et al., 2015). Again, it is possible that healthier patients participated more frequently in the studies than patients with more illnesses and higher treatment burdens, who may have lacked the energy to participate. Further, as anonymous questionnaires were distributed during consultations in numerous units, and there was no information on how many questionnaires were finally distributed, it was not possible to calculate the overall response rate or perform a nonresponse analysis (Polit & Beck, 2017).

In Phase I, the sample size was assessed to be probably sufficiently large for a pilot study of an instrument that had been previously validated in other settings. However, it was noticed that the sample size of the study can be considered quite small for EFA, which is widely regarded as applicable to datasets describing or collected from large samples. However, the sample sizes suggested for EFA are usually considered either the minimum necessary sample size, N or the minimum ratio of N to the number of variables being analysed and vary widely between sources. They are also controversial (Williams et al., 2010) and research has shown that EFA can also provide acceptable solutions for data concerning or drawn from small samples (de Winter et al., 2009; MacCallum et al., 1999). Furthermore, results obtained by KMO and Bartlett's Test of Sphericity confirmed the suitability of the data for factor analysis. In Phase II, the sample size was calculated to increase statistical conclusion validity by reaching the needed statistical power. This was done through a power analysis based on effect size estimation for main outcomes relying on previous information obtained using PPRQ, ACDI, and PAM (Gray & Grove, 2021) in consultation with a statistician (Publications II–IV). In addition, for multiple regression, the required sample size was based on the ratio of predictor variables to the total number of cases (Tabachnick & Fidell, 2012). In Publication IV, to ensure the validity of PAM, a decision was made to delete all questionnaires with more than three missing responses (N/A responses were also considered missing), or those for which all questions were answered using the same response option (as this can be interpreted as careless responding). Therefore, the sample size for this study was determined by the availability of valid responses. However, a power analysis of PAM using the final sample size of 100 at $\alpha=0.05$ showed that the achieved power was 0.87 for the Chi-squared test ($\chi 2$ test) and 0.95 for ANOVA (for perceived functional ability and perceived health) and was thus well above the threshold of 0.80. Also, statistically significant findings related to those comparisons and associations tested confirm that the sample was sufficient in those respects. However, it is possible that the sample size was not large enough to reveal statistical significance for all single variables that were included (because of their smaller effect size) and that there was not enough diversity in some variables in this study population to support the envisioned statistical analyses (Gray & Grove, 2021).

An attempt was made to select relevant and accurate statistical analyses based on their relevance to meet the purpose of the study also considering the assumptions of used tests. Multivariate analyses were also used, when appropriate, to increase statistical control i.e., the control of confounding variables when studying relationships between variables to increase validity (Polit & Beck, 2017). Statistical results performed with not only p-values but also confidence intervals and effect sizes, including Cohen's d and Cramer's V, as well as Odds ratios and correlation coefficients. The analyses were performed by one researcher, but consultations with the statistician and discussions about results obtained in the research group increased validity.

The EQUATOR (Enhancing the QUAlity and Transparency Of health Research) Network's criteria suitable for this study, namely STROBE guidelines (Von Elm et al., 2007) and checklist for cross-sectional studies were used to support the design, implementation, and reporting of the study. This study uses a cross-sectional design, so deriving causal relationships is not possible. In terms of external validity, the limitation is that the sample of Phase II was collected in one municipality, and it was quite small. Including additional study settings from different geographical areas could have improved the generalizability of the results. However, the sample was based on prior criteria and was representative of the target population. So, despite the limited generalizability, the results are useful, which is supported by the strength of this study i.e., that the data was gathered in real-life circumstances, and it was abundant and versatile, providing information on the care and health of multimorbid patients from a broad perspective.

Several results obtained have some similarities with previous studies in certain parts. However, even though the main concepts of the study have been studied quite extensively in the past, a few studies have examined them together or among patients with multimorbidity, and the whole phenomenon has not been studied before. Therefore, the results of this study could not be fully compared with those reported in a similar previous study. The main concepts of the study are also broad and multidimensional, and there are plenty of both definitions as well as close and parallel concepts for them, which may be used interchangeably but inconsistently in literature. Such inconsistent approaches make the comparison and synthesis of findings from different research efforts challenging.

## 6.3 Ethical considerations

Good research ethics and research practice were followed throughout the research process with the relevant ethical standards of the World Medical Association (WMA, 2013) and responsible research practice guidelines (TENK; Finnish Advisory Board on Research Integrity, 2012). The study was also carried out in compliance with the European Union's General Data Protection Regulation (EU 2016/679) and Finnish legislation, with particular regard to the Medical Research Act 488/1999 and the Data Protection Act 1050/2018. The choice of topic was based on its timeliness, importance, and a clear lack of knowledge, the identified research gap as well as the estimated usefulness of the results. The study was built on relevant scientific literature and careful design. The study was approved by the Institutional Review Boards. Ethical approval from Research Ethics Committees was not required because the study did not involve the collection and storage of data that could be used to identify participants, nor did it involve the recruitment of participants from vulnerable groups or concerns about the harm to patients' integrity (TENK, 2012, 2019; WMA, 2013). All instruments were used and/or modified with their developers' permission, granted via a licence (PAM-13®, Insignia Health, Inc) or registration (15D), as required (TENK, 2012).

All eligible participants were informed and given detailed written information about the study's purpose and objectives, as well as an assurance with regard to anonymity, confidentiality, and the voluntary nature of participation. The researchers' contact information was also provided so prospective participants could ask additional questions. Completing and returning the anonymous questionnaire was considered to imply informed consent for participation in the study (TENK, 2019; WMA, 2013). Minimizing the burden on the participant was considered in the design of the questionnaire and data collection. The data were collected, processed, and stored carefully and without identifying information. No unnecessary personal data was collected (The European Union's General Data Protection Regulation (EU 2016/679), Data Protection Act 1050/2018). Again, the results were presented in a way that protected the possible identification of study participants. Participation in the study did not affect receiving treatment or provide financial advantages (TENK, 2012, 2019; WMA, 2013).

The study is based on working carefully and sincerely throughout the entire process, from study design to data analysis, and reporting of the results, as well as data storage. The STROBE statement's reporting guidelines for cross-sectional studies were followed (Von Elm et al., 2007). The funding bodies of the study had no role in the study, the design of the study, the collection, analysis, and interpretation of data, the writing of the report, or in the decision to submit the article for publication.

## 6.4 Implications of the study

This study produced new knowledge and, in congruent parts, also confirmed existing knowledge. It produced new knowledge about patients' perceptions of the importance and the extent to which patient participation was realised by HCPs, as well as the validity of its instrument in Finnish PHC settings. In addition, the study provided insight into the factors explaining patients' perceptions of patient participation and the extent to which patients with multimorbidity personally actively participate in healthcare encounters. Again, the study provided new knowledge about patients' adherence to self-management and factors explaining it in PHC patients with multimorbidity. It also provided the first indications of specific explanatory factors for good adherence in patients with multimorbidity based on the Theory of Adherence of People with Chronic Disease. Further, this study provided new knowledge about patient activation and associated factors for self-management in patients with multimorbidity in Finnish PHC settings, and differences between patients with low and high activation. Further, the study provided new knowledge about the relationships between patient participation, adherence, and activation and presented a schematic model of patient participation, adherence, and activation for self-management in adult PHC patients with multimorbidity.

This study on patient participation, adherence and activation for self-management was valuable because these concepts have not been studied together like in this study, to the best of our knowledge. Meanwhile, the importance of the patient's active role as well as the provision of patient-centred care and self-management support by HCPs are key themes in contemporary healthcare, especially emphasized in patients with multimorbidity, the priority of global health research. The topic is also in line with the recent international mission of nursing research (ENRF, 2020; NINR, 2022). The study contributes to much-needed understanding from patients' perspective, which is a crucial factor for delivering and developing care to better meet the needs of this population. Again, as the study concerns a serious and increasing public health problem also affecting the broader context outside of healthcare, it has implications for society and health policy, but above all, the study has implications for clinical practice, healthcare management, education, and science, the key themes intertwined to all of which are described below.

Based on the results of this study, attention should be paid to the identification of patients with multimorbidity and their care. About half of patients had low patient activation, meaning a low level of skills, knowledge, and confidence for self-management and there was also room for improvement in adherence to self-management, especially in behaviours related to a healthy lifestyle. Patient participation also needs more attention, as patients perceived it to be very important but that there were shortcomings for realisation in encounters. Patient participation supported by HCPs is an ethical task but also a favourable way to promote patients in taking ownership of their own care as completely as possible according to their abilities. Appropriate support for self-management, including the provision of varied educational and supportive interventions by HCPs, should be emphasised when it comes to care but also in the prevention of new diseases, also considering healthy lifestyles as its key elements and the challenges that may emerge in the context of competing and perhaps conflicting priorities and constraints. Again, it is worth paying attention to the risk that the processing of self-management issues may remain deficient and disorganized, the risk of which is highly increased as the care for multimorbid patients is usually implemented by several parties. However, HCPs working in PHC settings, especially nurses, are well-positioned to support patient participation, adherence, and activation by their actions, and thus enhance the patients' active role. Giving attention to the complexity of multimorbidity, this study highlights the importance of collaboration between patients and HCPs. As Batalden and colleagues (2016) have pointed out, healthcare services are coproduced by HCPs and patients, meaning that "health outcomes are a consequence of the dispositions, capacities, and behaviours of both parties." It is important to make sure that patients benefit from their brief encounters with HCPs; giving further opportunities to utilize any possibly unused potential of self-management, and to leverage self-management in healthcare systems.

In accordance with previous research, this study suggests that a whole-person approach is highly needed in managing multimorbidity. The variety of patients with multimorbidity requires different ways of care delivery and support. Again, this study speaks of the importance of acknowledging the patient's perspective in care to enable the patient-centred care implemented by HCPs and to have the potential to foster self-management and reduce excessive treatment burden. Further, the study reinforces the need and significance of assessing perceptions gained directly from patients themselves by using patient-reported measures (PROs). Indeed, the number of conditions and socio-demographic factors alone did not seem to provide a sufficient picture of the patients' readiness to take an active role in their care and self-management, so measures are needed to produce that missing information. PAM and ACDI instruments are useful for identifying those who are at risk for inadequate self-management and providing, tailoring, and developing the care to meet the patient's needs, and using them as performance indicators for care, alongside PPRQ. The use of PAM can help map the patient's readiness and willingness to manage their own health and adapt their care accordingly, such as through proper information processing, counselling, and setting realistic goals, which helps avoid frustrating and overwhelming situations for both parties. As such, the use of patient-reported measures may serve the purpose of improving an active patient role in care.

Focusing on patient-centred outcomes that are important to, as well as valued by this patient population, is suggested to be particularly important given the inherent complexity of multimorbidity. Based on the results of this study, attention should also be paid both to those with low patient participation, adherence, and activation as well as the patients with poor perceived health and functional ability, and loneliness, because they seem to have a risk for poorer care experiences and self-management. Further, while it is suggested that it is important to identify those patients who have accumulated problems and target them with the extra support they need, it is suggested that it is not enough to direct attention only to those whose situation is already complicated. Instead, there should be efforts to stay ahead of the situation, as prevention and cost-saving interventions may produce better results in those who are not yet at high risk. Further, because the support of loved ones proved to be very important for people with multimorbidity, attention should be paid to the role of loved ones as well as the burden they feel, and the support they need.

Multimorbidity poses challenges to the work of HCPs, requiring extensive expertise in itself in addition to those competencies needed in allowing and supporting patients to take a key role in their care as described above, as well as good interprofessional collaboration, along with good collaboration with patients and their relatives as previously shown. It is therefore suggested that training and education interventions for professionals working in the field of multimorbidity may be useful to promote care that further enables better patient participation and outcomes. The need for this kind of expertise will increase in the future as multimorbidity is set to rise and should be considered in the planning curricula of future healthcare professionals and the field of health service management.

The created novel schematic model is suitable for use as a basis for further utilisation. Overall, more research is needed to understand how best to manage multimorbidity in collaboration between patients and HCPs to promote better self-management and care outcomes.

## 6.5 Suggestions for future research

Based on this study, the suggestions for further research are as follows:

- In this study, patient participation was studied at the level of patient care (micro level). However, patient participation can also take collective forms at the level of the healthcare organization and policy (meso- and macro-level) and result in better systems to support patient participation at the level of individual patients. Therefore, it would be important to also study patient participation at these levels.
- This study did not examine the associations of the background factors of the HCPs involved in the patients' care (demographics, professionality, education, working position etc.) with patient participation, adherence, and activation, so these factors could be explored in future research. Further, HCPs' attitudes, appreciation, and readiness towards the active patient role in their care processes for patient participation, adherence, and activation need to be clarified, and once again, how these factors are related to patient evaluations. In addition to patient-oriented factors, the organisational structures and elements need to be considered when developing the care of multimorbidity, and should also be studied in the future.
- It was found that while patient participation was considered important on average, the perceptions of the extent to which it was realised by HCPs were more varied. This discrepancy in the perceptions, as well as related factors, should be further investigated at the patient level because there was a clear difference in what some patients considered important and what they felt had been realised, while others had more similar experiences of these.
- Energy and willpower, motivation, results of care, sense of normality, fear of complications and additional diseases, and support from physicians, nurses,

and friends and relatives were associated with patient adherence and activation. As a result, it is worth investigating what are the factors associated with these in patients with multimorbidity.

- HRQoL, both total and several of its dimensions, was found to be lower than at the population level, so it is worth investigating this further.
- There is a need for further empirical examination using longitudinal and intervention study designs, also considering the possibilities of digital health solutions and a variety of samples, for example, in young patients with multimorbidity. An even wider use of variables may also be useful in the future, for example, treatment burden as a patient-reported outcome variable.
- There is a need for further research to test and develop the schematic model, including various methods such as mediation and moderation analysis.

# 7 Conclusions

Based on the main findings of the study, the following conclusions are made:

- The PPRQ instrument has acceptable reliability and validity in Finnish PHC settings for measuring patient participation from a patient perspective. It is a useful instrument for assessing patients' perceptions of the importance and the extent to which patient participation was realised in care by HCPs.
- While PHC patients in general perceive patient participation implemented by HCPs as important, there is variation in the perceptions of its realisation by HCPs. There is some variation in these perceptions between the dimensions of patient participation (respect and integrity, planning and decision-making, information and knowledge, motivation and encouragement, and involvement of family) and further, several patient-related factors are associated with those perceptions, reflecting the individual, multilevel, and multidimensional nature of participation. Most patients with multimorbidity perform active participation in healthcare encounters, positively associated with the perceived importance of patient participation, as well as patient activation and adherence.
- Adherence to self-management is clearly not an 'all or none' phenomenon' in patients with multimorbidity: while the majority of patients (three out of four) with multimorbidity have good adherence to healthcare regimes, there was clear room for improvement in their adherence to healthy lifestyle behaviours (physical activity, varied diet, and avoidance of harmful alcohol use and tobacco use). Moreover, although there is some correlation between adherence to some of these elements, only few patients have good adherence to all of them.
- Factors that explain adherence include energy and will-power, motivation, results of care, sense of normality, fear of complications and additional diseases, and support from physicians, nurses as well as friends and relatives, in accordance with the Theory of Adherence of People with Chronic Disease by Kyngäs (1999). Further, adherence is associated with several patient-related factors, with various factors being particularly associated with specific elements of self-management. All this indicates that adherence is a complex process among patients with multimorbidity.
- There is a lot of variation in patient activation and it is associated with several patient-related factors, which indicate that patients' perceptions of their health and psychosocial factors are important for activation. About half of patients

with multimorbidity are at a low level of activation. Patients with low activation have poorer self-management behaviours, perceptions related to self-management, and health-related quality of life.

- Psychosocial factors, such as loneliness, perceived inadequacy of the number of close friends and relatives, and poor perceived health and functional ability play an important role in the self-management of patients with multimorbidity as they have several congruent associations with poorer patient adherence and activation
- Patient participation, patient adherence, and patient activation are related and have several, mostly mutually supportive, associations with each other but each of them is its own special and separate construct.
- The created schematic model describes that patient participation, adherence, and activation are pivotal factors for self-management, while also reflecting their complexity in the context of multimorbidity. The model is ready to be used as a basis for further work.

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# Appendix

Appendix 1 Item analysis of PPRQ instrument for importance and realization domains obtained in Phase I

**Table 13. Item analysis of the PPRQ instrument for importance and realization domains.**

| Item | Importance mean (SD) | min-max | alpha if item deleted | corrected item-total correlation | Realisation mean (SD) | min-max | alpha if item deleted | corrected item-total correlation |
|---|---|---|---|---|---|---|---|---|
| 1 | 4.10 (0.88) | 2–5 | 0.935 | 0.742 | 3.78 (0.94) | 1–5 | 0.944 | 0.598 |
| 2 | 4.20 (0.89) | 2–5 | 0.937 | 0.610 | 4.02 (0.96) | 1–5 | 0.946 | 0.498 |
| 3 | 3.95 (0.98) | 1–5 | 0.936 | 0.689 | 3.75 (1.17) | 1–5 | 0.946 | 0.476 |
| 4 | 4.34 (0.85) | 2–5 | 0.938 | 0.525 | 4.00 (1.01) | 1–5 | 0.943 | 0.597 |
| 5 | 3.96 (1.01) | 1–5 | 0.935 | 0.698 | 3.61 (1.13) | 1–5 | 0.944 | 0.645 |
| 6 | 4.02 (0.93) | 1–5 | 0.935 | 0.714 | 3.38 (1.16) | 1–5 | 0.943 | 0.716 |
| 7 | 4.01 (0.87) | 2–5 | 0.936 | 0.682 | 3.64 (0.97) | 1–5 | 0.942 | 0.743 |
| 8 | 4.08 (0.88) | 1–5 | .938 | 0.566 | 3.43 (1.04) | 1–5 | 0.943 | 0.774 |
| 9 | 4.08 (0.89) | 1–5 | 0.937 | 0.621 | 3.36 (1.13) | 1–5 | 0.945 | 0.619 |
| 10 | 4.51 (0.68) | 3–5 | 0.939 | 0.486 | 3.82 (0.98) | 1–5 | 0.944 | 0.673 |
| 11 | 4.26 (0.79) | 2–5 | 0.937 | 0.576 | 3.67 (1.10) | 1–5 | 0.944 | 0.622 |
| 12 | 4.41 (0.71) | 1–5 | 0.939 | 0.504 | 3.58 (1.12) | 1–5 | 0.943 | 0.680 |
| 13 | 4.11 (0.86) | 2–5 | 0.938 | 0.527 | 3.63 (0.97) | 1–5 | 0.945 | 0.581 |
| 14 | 4.02 (0.97) | 1–5 | 0.937 | 0.614 | 3.42 (1.10) | 1–5 | 0.946 | 0.570 |
| 15 | 4.05 (0.87) | 2–5 | 0.938 | 0.577 | 3.22 (1.04) | 1–5 | 0.943 | 0.687 |
| 16 | 4.29 (0.78) | 2–5 | 0.938 | 0.539 | 3.52 (1,08) | 1–5 | 0.944 | 0.668 |
| 17 | 4.03 (0.81) | 2–5 | 0.937 | 0.644 | 3.35 (1.09) | 1–5 | 0.945 | 0.619 |
| 18 | 3.82 (0.96) | 1–5 | 0.937 | 0.569 | 3.31 (1.00) | 1–5 | 0.944 | 0.621 |
| 19 | 3.82 (1.08) | 1–5 | 0.938 | 0.561 | 2.93 (1.35) | 1–5 | 0.945 | 0.677 |
| 20 | 4.06 (1.07) | 1–5 | 0.935 | 0.652 | 2.83 (1.46) | 1–5 | 0.944 | 0.685 |
| 21 | 3.89 (1.03) | 1–5 | 0.937 | 0.565 | 2.81 (1.48) | 1–5 | 0.945 | 0.638 |
| 22 | 3.88 (1.15) | 1–5 | 0.937 | 0.553 | 2.71 (1.46) | 1–5 | 0.945 | 0.658 |
| Total | 4.07 (0.63) | 2.4–5.00 | 0.940 | - | 3.46 (0.78) | 1.43–5.00 | 0.947 | - |

Likert scale for importance: 1= not at all important, 2= slightly important, 3= important, 4= very important, 5= extremely important

Likert scale for realization: 1= never, 2= seldom, 3= sometimes, 4= often, 5= always

# Original publications

I Paukkonen, L., Kankkunen, P., Kreuter, M., & Pietilä A-M. (2019). Patients' perceptions of participation: Pilot validation study of the FI-PPRQ questionnaire in Finnish primary healthcare settings. *Nordic Journal of Nursing Research*, 39(3), 117–126. https://doi.org/10.1177/2057158518815992

II Paukkonen, L., Oikarinen, A., Kähkönen, O., & Kyngäs, H. (2021). Patient participation during primary health-care encounters among adult patients with multimorbidity: A cross-sectional study. *Health Expectations: An international journal of public participation in health care and health policy*, *24*(5), 1660–1676. https://doi.org/10.1111/hex.13306

III Paukkonen, L., Oikarinen, A., Kähkönen, O., & Kyngäs, H. (2022). Adherence to self-management in patients with multimorbidity and associated factors: A cross-sectional study in primary healthcare. *Journal of Clinical Nursing*, *31*(19–20), 2805–2820. https://doi.org/10.1111/jocn.16099

IV Paukkonen, L., Oikarinen, A., Kähkönen, O., & Kaakinen, P. (2022). Patient activation for self-management among adult patients with multimorbidity in primary healthcare settings. *Health Science Reports*, *5*(4), e735. https://doi.org/10.1002/hsr2.735

Original publications are not included in the electronic version of the dissertation.

1743. Huovinen, Jere (2023) Vitamin D analogue calcipotriol in the local treatment of arthritis : observations from preclinical studies
1744. Kontu, Mikaela (2023) Adolescence and young adulthood risk factors for drug crime offending : a follow up study of former adolescent psychiatric inpatients
1745. Ristaniemi, Jenni (2023) A register-based study of eruption patterns in the maxillary permanent canines and dental developmental abnormalities : features seen in panoramic radiographs and treatment needs in permanent canines
1746. Mustaniemi, Sanna (2023) The roles of maternal characteristics and early-pregnancy serum parameters in gestational diabetes : the Finnish Gestational Diabetes study
1747. Pitkänen, Joel (2023) Morphology of the optic nerve head and the retinal nerve fiber layer and factors affecting them in the Northern Finland Birth Cohort Eye study
1748. Perhomaa, Marja (2023) Imaging of and clinical findings concerning children's non-operatively treated distal forearm fractures, and shaft fractures treated with biodegradable implants
1749. Keskitalo, Eerika (2023) Assessment of prognosis in asbestosis
1750. Kalaoja, Marita (2023) Epidemiological investigations of circulating biomarkers for cardiometabolic diseases
1751. Geneid, Mohamed (2023) The relationship between retinal vessel diameter with retinal nerve fibre layer thickness and optic nerve head parameters : the Northern Finland Birth Cohort Eye study
1752. Hellberg, Iida (2023) 3D quantification of human knee articular cartilage and meniscus microstructures in osteoarthritis
1753. Kaikkonen, Kaisu (2023) Intensified lifestyle intervention with exercise as a treatment of severe obesity and prevention of cardiometabolic risks
1754. Rytky, Santeri (2023) Machine learning applications for multi-scale computed tomography of skeletal tissues
1755. Kerkelä, Martta (2023) Changes in the incidence of mental disorders in Finnish cohorts and the effects of being a participant of the Northern Finland Birth Cohorts
1756. Kauppi, Saana (2023) Comorbidity in atopic dermatitis

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