

# Assessing self-care behaviours in people living with myeloproliferative neoplasms: A research study by the Italian Patient Association (AIPAMM)

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## INTRODUCTION

People with myeloproliferative neoplasms (MPN) are recommended to engage in daily behaviours to maintain their health condition stable (**self-care maintenance**), monitor symptoms and clinical parameters (**self-care monitoring**), and deal with the situation when more severe symptoms occur (**self-care management**).

## AIMS

The Italian association of MPN patients (AIPAMM) started a research initiative to:

- (1) develop and validate a self-report **questionnaire measuring self-care behaviours** in MPN patients;
- (2) test its psychometric properties;
- (3) describe the level of self-care in MPN patients;
- (4) evaluate the associations between self-care and the socio-demographic and clinical characteristics of the participants, including symptom burden, quality of life, patient engagement, self-efficacy, and information sources.

## METHODS

This is a **multicentric cross-sectional validation study** conducted in **Italy**. After two focus groups with 10 MPN patients and a literature review, we developed a 31-item questionnaire measuring self-care behaviours: the **Self-Care in MyeloProliferative Neoplasms Inventory (SC-MPNI)**, which yielded good content validity. The self-care components are represented in Figure 1.

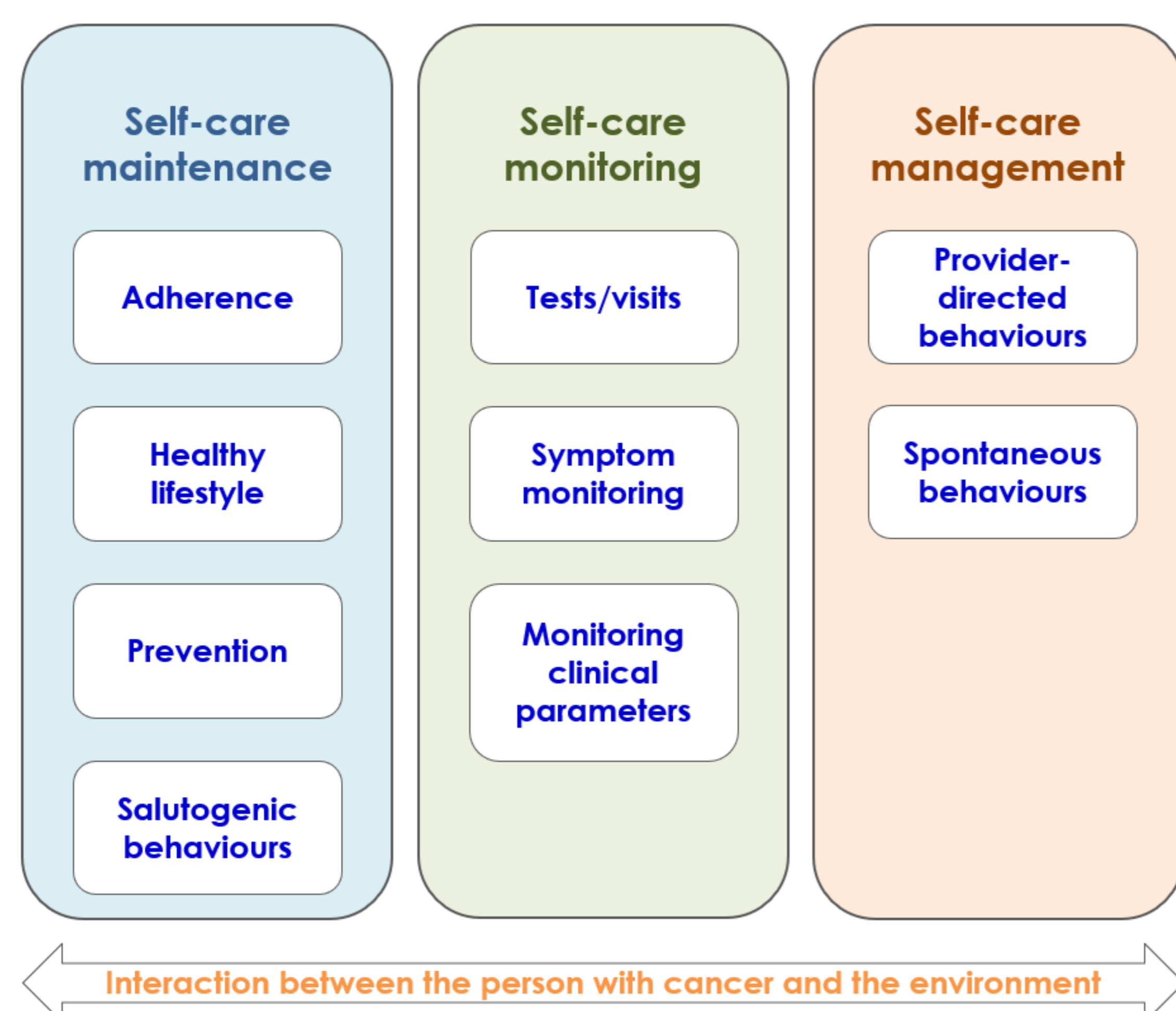


Figure 1. Self-care components

## RESULTS

The Ethics Committee of each of the **9 centres** approved the study. Enrolment started on November 2021 and it will consist of **375 adult patients with MPN** across Italy: 125 with essential thrombocythemia, 125 with polycythaemia vera, and 125 with myelofibrosis.

**Nine** Italian haematological centres and AIPAMM are currently recruiting. Each centre is expected to enrol 30 patients. Participants are asked to fill in a **paper-and-pencil questionnaire** to assess self-care and other study variables (Figure 2). during their hospital outpatient visit or sent it at home via mail. The expected results are related to the validation tests of the self-care questionnaire, according to the COSMIN criteria.

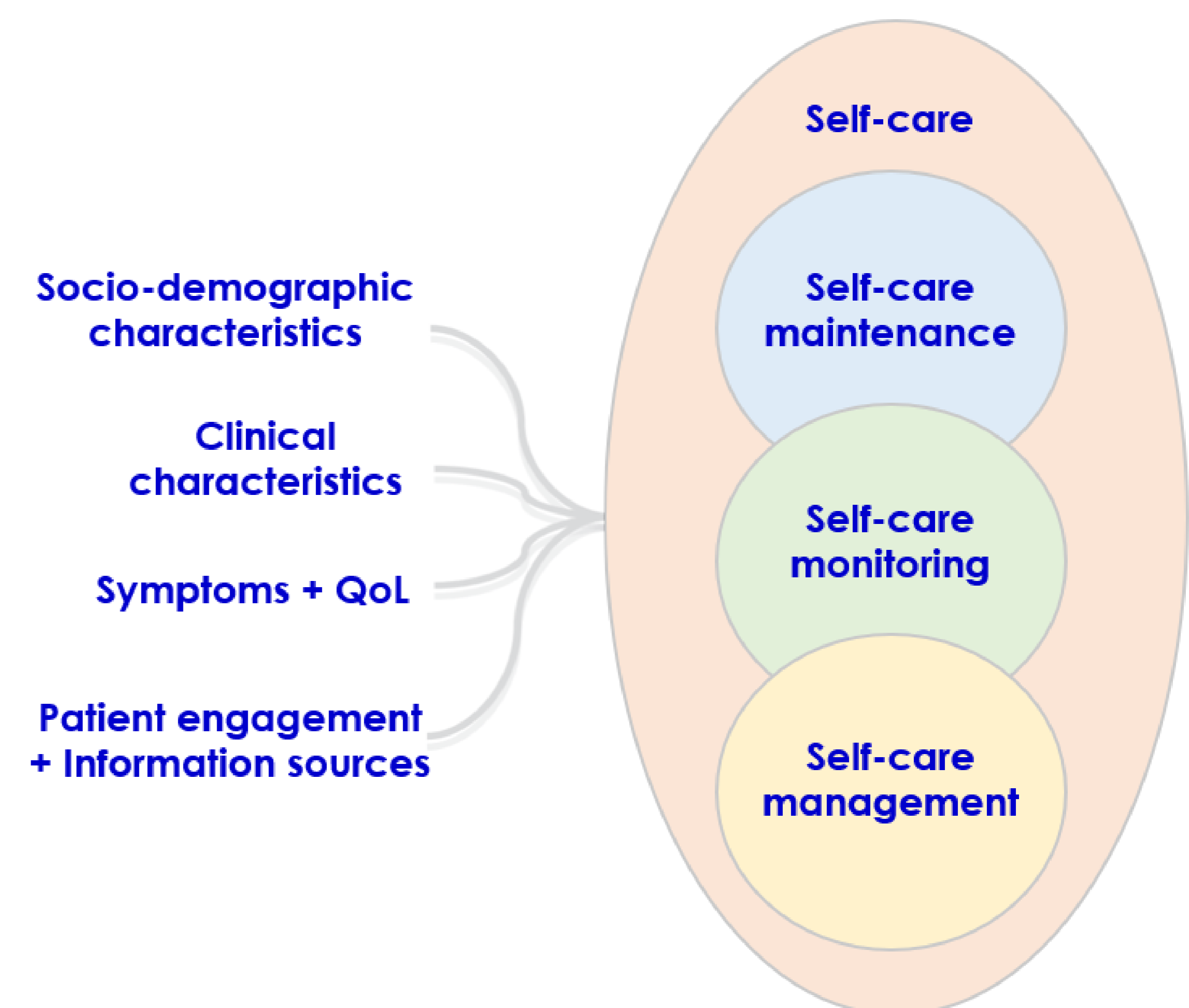


Figure 2. Study variables

## CONCLUSIONS

This study will contribute to **assessing the self-care level in people with MPN**. Moreover, the information on the influencing factors will support innovative **interventions to promote self-care**, which is crucial to reduce cardiovascular events and be medically fit to undergo hematopoietic stem cell transplantation.

## REFERENCES

- 1) Biagioli, V., Drury, A., Wells, M., Eicher, M., & Kelly, D. (2021). Self-care and cancer: Comment on Riegel et al. (2020) 'Characteristics of self-care interventions for patients with a chronic condition: A scoping review'. International Journal of Nursing Studies, 115, 103877. doi: 10.1016/j.ijnurstu.2021.103877