**Appendix: Myeloproliferative Neoplasms Research Questionnaire Indonesia**

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| **A: PHYSICIAN DEMOGRAPHICS & CASELOAD** |

Our survey today is focused on BCR-ABL1-negative myeloproliferative neoplasms (MPN) including essential thrombocythemia (ET), myelofibrosis (MF), polycythemia vera (PV)**.** Please only consider these patients when answering the survey questions.

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| Q1 | Does your centre have a stem cell transplant program?  **Please select one only**   |  |  |  | | --- | --- | --- | | Yes | **1** | **CONTINUE** | | No | **2** | |
| Q2 | 1. In an average month, approximately what persentage of all the patients you see (i.e. in and out-patients) are haematology cases? 2. Of the Haematology cases you see in an average month, what percentage do you see on an outpatient basis   **Please enter a percentage between 0 and 100 for each**   |  |  |  |  | | --- | --- | --- | --- | | a) Haematology cases (in and out-patients) | % | **1** | **CONTINUE** | | b) Haematology cases, on an outpatient basis | % | **2** | |
| Q3 | Thinking about all the MPN patients you see and treat (ET, MF and PV), what percentage of your MPN patients:   1. are **referred to you** from each of the following? 2. **do you refer on** to each of the following?   **Please enter a percentage between 0 and 100**     |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | |  | a) MPN patients referred to you from the following: |  | b) MPN patients you refer on to the following: |  |  | | No referral / not referred on | % | No referral / not referred on | % | **1** | **CONTINUE** | | Primary care physician | % | Primary care physician | % | **2** | | Hematologist-oncologist | % | Hematologis -oncologist | % | **3** | | Other specialists | % | Other specialists | % | **4** | | TOTAL | **100%** |  | **100%** |  | |
| Q5 | On a scale from 1 (not at all) to 7 (extremely), how important is discussion with other Specialists (e.g., Pathologist, Clinical Laboratory, Molecular Biologist etc.) before making a treatment decision?  **Please select one only**   |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | |  | | Not at all important | | |  | Extremely important | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | Discussion with other Specialists | **A** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |

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| **B: PATIENT DISEASE BURDEN** |

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| Q6 | **Please enter a percentage between 0 and 100 for each**   |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | |  | | ET |  | MF |  | PV | | At diagnosis, what percentage of your ET patients do you choose to observe instead of recommending drug treatment? | **1** | % | At diagnosis, what percentage of your MF patients do you choose to observe instead of recommending drug treatment? | % | At diagnosis, what percentage of your PV patients do you choose to observe instead of recommending drug treatment? | % | | What percentage of your ET patients have a history of thrombotic events? | **2** | % | What percentage of your MF patients have a history of thrombotic events? | % | What percentage of your PV patients have a history of thrombotic events? | % | | What percentage of your ET patients also have splenomegaly? | **3** | % | What percentage of your MF patients also have splenomegaly? | % | What percentage of your PV patients also have splenomegaly? | % | |
| Q9a | **At the first time your patient comes to visit you**, what percentage of your MPN patients do you estimate have symptoms vs. no symptoms?  **Please enter a percentage between 0 and 100 for each**   |  |  |  |  | | --- | --- | --- | --- | |  | | MF | PV | | No symptoms | **1** | % | % | | Symptoms | **2** | % | % | | TOTAL | | **100%** | **100%** | |
| Q9b | What percentage do you observe have symptoms vs. no symptoms in **all your MPN patients that you currently follow/monitor?**   |  |  |  |  | | --- | --- | --- | --- | |  | | MF | PV | | No symptoms | **1** | % | % | | Symptoms | **2** | % | % | | TOTAL | | **100%** | **100%** | |
| Q11a | What are the top 3 symptoms you most often hear about from your MF patients?  **Please rank the top 3 symptoms, where 1 is most often heard about**   |  |  |  | | --- | --- | --- | |  | | MF | | Abdominal pain | **2** |  | | Blood clots | **3** |  | | Dizziness/vertigo/light-headedness | **9** |  | | Facial flushing | **10** |  | | Fatigue or tiredness | **11** |  | | Filling up quickly after eating (early satiety) | **13** |  | | Hypertension | **14** |  | | Itching (pruritis) | **17** |  | | Nosebleeds | **20** |  | | Numbness/tingling in hands or feet | **21** |  | | Problems with headaches | **23** |  | | Redness, throbbing and burning in the hands or feet | **25** |  | | Stroke | **27** |  | | Tinnitus | **28** |  | | Other, please specify | **99** |  | |
| Q11b | What are the top 3 symptoms you most often hear about from your PV patients?  **Please rank the top 3 symptoms, where 1 is most often heard about**     |  |  |  | | --- | --- | --- | |  | | PV | | Abdominal pain | **2** |  | | Blood clots | **3** |  | | Dizziness/vertigo/light-headedness | **9** |  | | Facial flushing | **10** |  | | Fatigue or tiredness | **11** |  | | Filling up quickly after eating (early satiety) | **13** |  | | Hypertension | **14** |  | | Itching (pruritis) | **17** |  | | Nosebleeds | **20** |  | | Numbness/tingling in hands or feet | **21** |  | | Problems with headaches | **23** |  | | Redness, throbbing and burning in the hands or feet | **25** |  | | Stroke | **27** |  | | Tinnitus | **28** |  | | Other, please specify | **99** |  | |
| Q13 | On a scale from 1 (not at all) to 7 (a great deal), to what extent do the following symptoms have a major negative effect on MF patient quality of life?  **Please select one per row**     |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | |  | | Not at all | | |  | A great deal | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | Abdominal pain | **2** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Blood clots | **3** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Dizziness/vertigo/light-headedness | **9** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Facial flushing | **10** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Fatigue or tiredness | **11** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Filling up quickly after eating (early satiety) | **13** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Hypertension | **14** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Itching (pruritis) | **17** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Nosebleeds | **20** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Numbness/tingling in hands or feet | **21** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Problems with headaches | **23** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Redness, throbbing and burning in the hands or feet | **25** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Stroke | **27** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Tinnitus | **28** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Other, please specify | **99** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q14 | On a scale from 1 (not at all) to 7 (a great deal), to what extent do the following symptoms have a major negative effect on PV patient quality of life?  **Please select one per row**     |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | |  | | Not at all | | |  | A great deal | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | |  | **2** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Blood clots | **3** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Dizziness/vertigo/light-headedness | **9** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Facial flushing | **10** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Fatigue or tiredness | **11** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Filling up quickly after eating (early satiety) | **13** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Hypertension | **14** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Itching (pruritis) | **17** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Nosebleeds | **20** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Numbness/tingling in hands or feet | **21** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Problems with headaches | **23** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Redness, throbbing and burning in the hands or feet | **25** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Stroke | **27** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Tinnitus | **28** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Other, please specify | **99** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q15a | Which three symptoms do you perceive your MF patients would most want to resolve?  **Please rank the top 3 symptoms, where 1 is most important to resolve**   |  |  |  | | --- | --- | --- | |  | | MF | | Abdominal pain | **2** |  | | Blood clots | **3** |  | | Dizziness/vertigo/light-headedness | **9** |  | | Facial flushing | **10** |  | | Fatigue or tiredness | **11** |  | | Filling up quickly after eating (early satiety) | **13** |  | | Hypertension | **14** |  | | Itching (pruritis) | **17** |  | | Nosebleeds | **20** |  | | Numbness/tingling in hands or feet | **21** |  | | Problems with headaches | **23** |  | | Redness, throbbing and burning in the hands or feet | **25** |  | | Stroke | **27** |  | | Tinnitus | **28** |  | | Other, please specify | **99** |  | |
| Q15b | Which three symptoms do you perceive your PV patients would most want to resolve?  **Please rank the top 3 symptoms, where 1 is most important to resolve**   |  |  |  | | --- | --- | --- | |  | | PV | | Abdominal pain | **2** |  | | Blood clots | **3** |  | | Dizziness/vertigo/light-headedness | **9** |  | | Facial flushing | **10** |  | | Fatigue or tiredness | **11** |  | | Filling up quickly after eating (early satiety) | **13** |  | | Hypertension | **14** |  | | Itching (pruritis) | **17** |  | | Nosebleeds | **20** |  | | Numbness/tingling in hands or feet | **21** |  | | Problems with headaches | **23** |  | | Redness, throbbing and burning in the hands or feet | **25** |  | | Stroke | **27** |  | | Tinnitus | **28** |  | | Other, please specify | **99** |  | |
| Q17 | On a scale from 1 (not at all) to 7 (very much), to what extent do you think MF patients may feel/experience the following because of their condition (and not because of their treatment):  **Please select one per row**     |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | |  | | Not at all | | |  | Very much | | | Don’t  know | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | **1** | | **Physical well-being** | | | | | | |  | | Physically fit | **1** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Nausea | **6** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Trouble meeting the needs of the family | **7** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Pain | **8** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | **2** | | **Social/family well-being** | | | | | | |  | | Family acceptance of their illness | **1** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Satisfaction with their sex life | **2** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Avoiding social interactions | **3** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | **4** | | **Functional well-being** | | | | | | |  | | Able to work (including from home) | **1** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Acceptance of their illness | **2** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Able to sleep well | **3** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Contentment with their quality of life | **4** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Able to eat well | **5** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | **5** | | **Financial well-being** | | | | | | |  | | Loss of income | **1** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Concern about cost of their care/treatment | **2** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Inability to pay for their care/treatment | **3** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q18 | On a scale from 1 (not at all) to 7 (very much), to what extent do you think PV patients may feel/experience the following because of their condition (and not because of their treatment):  **Please select one per row**     |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | |  | | Not at all | | |  | Very much | | | Tidak  Don’t  know | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | **1** | | **Physical well-being** | | | | | | |  | | Physically fit | **1** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Nausea | **6** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Trouble meeting the needs of the family | **7** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Pain | **8** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | **2** | | **Social/family well-being** | | | | | | |  | | Family acceptance of their illness | **1** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Satisfaction with their sex life | **2** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Avoiding social interactions | **3** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | **4** | | **Functional well-being** | | | | | | |  | | Able to work (including from home) | **1** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Acceptance of their illness | **2** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Able to sleep well | **3** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Contentment with their quality of life | **4** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Able to eat well | **5** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | **5** | | **Financial well-being** | | | | | | |  | | Loss of income | **1** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Concern about cost of their care/treatment | **2** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Inability to pay for their care/treatment | **3** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q19a | On a scale from 1 (no impact) to 7 (significant impact), to what extent does their condition impact negatively on activities of daily living for a **newly diagnosed patient**?  **Please select one**   |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | |  | No impact | | |  | Significant impact | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | MF | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | PV | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q19b | On a scale from 1 (no impact) to 7 (significant impact), to what extent does their condition impact negatively on activities of daily living for a **patient whose disease is under control**?  **Please select one**   |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | |  | No impact | | |  | Significant impact | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | MF | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | PV | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q21 | Please state your level of agreement with the following statements?  **Please select one per row**     |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | |  | | **1** | **2** | **3** | **4** | **5** | |  | | Strongly disagree | Somewhat disagree | Somewhat agree | Strongly agree | Don’t  know | | Even mild to moderate symptoms can have a negative impact on the quality of life for patients with MPN | **A** | ○ | ○ | ○ | ○ | ○ | | An MPN patient’s quality of life is not significantly affected unless splenomegaly is severe | **B** | ○ | ○ | ○ | ○ | ○ | | I am comfortable assessing my MPN patients’ symptoms | **C** | ○ | ○ | ○ | ○ | ○ | |

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| **C: PATIENT MANAGEMENT AND TREATMENT DECISIONS** |

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| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Q22 | Which classification/clinical guidelines do you use the most often for diagnosing MPN?  **Please select one only**   |  |  |  | | --- | --- | --- | | World Health Organization (WHO) | **1** | **CONTINUE** | | National Comprehensive Cancer Network (NCCN) | **2** | | European Society Medical Oncology (ESMO) | **3** | | Other, please specify | **99** | |
| Q23 | Which of the following tests do you request to make a diagnosis of MPN?  **Please select all that apply**   |  |  |  | | --- | --- | --- | | Complete blood count | **1** | **CONTINUE** | | Peripheral blood smear | **2** | | Comprehensive metabolic panel | **3** | | Serum erythropoietin (EPO) | **4** | | Serum iron | **5** | | Bone marrow biopsy | **6** | | BCR-ABL1 mutation testing | **7** | | JAK2 V617F mutation testing | **8** | | Cytogenetic testing / karyotyping | **9** | | Other, please specify | **99** | |
| Q24 | What percentage of all your symptomatic patients undergo each of the following diagnostic tests?  **Please enter a percentage between 0 and 100 for each**     |  |  |  |  | | --- | --- | --- | --- | | Bone marrow biopsy | % | **1** | **CONTINUE** | | BCR-ABL1 mutation testing | % | **2** | | JAK2 V617F mutation testing | % | **3** | |
| Q25a | Out of all the reasons why symptomatic patients do not undergo bone marrow biopsy, what are the top five reasons?  **Please rank the top 5 reasons, where rank 1 is the most common reason**   |  |  |  |  | | --- | --- | --- | --- | | Patient request |  | **1** | **CONTINUE** | | I am not aware of the test |  | **2** | | Procedure is difficult to do |  | **3** | | Turnaround time for results is too long |  | **4** | | I do not find the results to be that useful |  | **5** | | Inability to accurately determine the results |  | **6** | | Lack of hospital infrastructure/equipment |  | **7** | | Cost/coverage |  | **8** | | Other, please specify |  | **99** | |
| Q25b | Out of all the reasons why symptomatic patients do not undergo JAK2 V617F mutation testing, what are the top five reasons?  **Please rank the top 5 reasons, where rank 1 is the most common reason**   |  |  |  |  | | --- | --- | --- | --- | | Patient request |  | **1** | **CONTINUE** | | I am not aware of the test |  | **2** | | Procedure is difficult to do |  | **3** | | Turnaround time for results is too long |  | **4** | | I do not find the results to be that useful |  | **5** | | Inability to accurately determine the results |  | **6** | | Lack of hospital infrastructure/equipment |  | **7** | | Cost/coverage |  | **8** | | Other, please specify |  | **99** | |
| Q27 | On a scale from 1 (not at all) to 7 (extremely), how important are the following tests to make a diagnosis of MPN?  **Please select one only**   |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | |  | | Not at all | | |  | Extremely | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | Bone marrow biopsy | **A** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | JAK2 V617F mutation testing | **B** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q28 | Do you classify your MPN patients according to prognostic risk category?  **Please select one only**   |  |  |  | | --- | --- | --- | | Yes | **1** | **CONTINUE** | | No | **2** | |
| Q29 | Which prognostic assessment do you utilize the most for MPN?  **Please select one only**   |  |  |  | | --- | --- | --- | | International Prognostic Scoring System (IPSS) | **1** | **CONTINUE** | | Dynamic International Prognostic Scoring System (DIPSS) | **2** | | Dynamic International Prognostic Scoring System Plus (DIPSS+) | **3** | | Other, please specify | **99** | |
| Q30 | Why don’t you classify your MPN patients at time of diagnosis according to prognostic risk category?  **Please select one only**   |  |  |  | | --- | --- | --- | | I am not familiar with the prognostic assessments available | **1** | **CONTINUE** | | I am familiar but do not find the prognostic assessments useful | **2** | | I am familiar and think they are useful but do not have the time to make individual assessments | **3** | | Other, please specify | **99** | |
| Q31 | Which of the following best describes how you assess MPN patient symptoms during an average patient visit?  **Please select one only**   |  |  |  | | --- | --- | --- | | Listen to the patient; if it’s bothering them they will mention it | **1** | **CONTINUE** | | Proactively ask the patient how they are feeling | **2** | | Specifically ask about most important symptoms | **3** | | Have patient fill out some type of symptom check list and review each symptom | **4** | | Other, please specify | **99** | |
| Q32 | Which of the following best describes how you discuss the symptoms that the MPN patient might experience during an average patient visit?  **Please select one only**   |  |  |  | | --- | --- | --- | | Run through a full and comprehensive list of symptoms | **1** | **CONTINUE** | | Outline the symptoms they are most likely to experience | **2** | | Mention the top, most bothersome symptoms that they may experience | **3** | | I don’t discuss symptoms with my patients | **4** | | Other, please specify | **99** | |
| Q33 | How frequently do you assess symptom presence or severity in your MPN patients?  **Please select one only**   |  |  |  | | --- | --- | --- | | Never | **1** | **CONTINUE** | | Sometimes | **2** | | Every visit | **3** | |
| Q34 | What tool(s) or approaches do you use to assess symptom severity in your MPN patients?  **Please select all that apply**   |  |  |  | | --- | --- | --- | | Validated assessment forms | **1** | **CONTINUE** | | Your own rating | **2** | | Significance of impact on their activities of daily living | **3** | | Other, please specify | **99** | |
| Q35 | What percentage of your MPN patients recognize their symptoms as being related to MPN?  **Please select one only**   |  |  |  | | --- | --- | --- | | None | **1** | **CONTINUE** | | Few | **2** | | Some | **3** | | Almost all | **4** | | All | **5** | | Don’t know | **99** | |
| Q36 | What do you look for when assessing disease progression in your patients?  **Please select all that apply**   |  |  |  |  | | --- | --- | --- | --- | |  | | **B [SHOW IF S5 CODE 2 >0]** | **C [SHOW IF S5 CODE 3 >0]** | | MF | PV | | Change in haematocrit | **1** | □ | □ | | Change in white blood cell counts | **2** | □ | □ | | Change in platelets | **3** | □ | □ | | Change in haemoglobin | **4** | □ | □ | | Change in status or severity of symptoms | **5** | □ | □ | | Change in spleen size | **6** | □ | □ | | Hydroxyurea dose increase | **7** | □ | □ | | Frequency of phlebotomy treatments | **8** | □ | □ | | Increasing blasts | **9** | □ | □ | | Increasing weight loss | **10** | □ | □ | | Progression of condition | **11** | □ | □ | | Presence of a new symptom | **12** | □ | □ | | Other, please specify | **99** | □ | □ | |
| Q37a | Which 3 symptoms of MF would you most likely decide to recommend a drug treatment for?  **Please rank the top 3 symptoms, where 1 is most likely to recommend drug treatment for**   |  |  |  | | --- | --- | --- | |  | | **B [SHOW IF S5 CODE 2 >0]** | | MF | | Anaemia | **3** |  | | Marked leukocytosis | **4** |  | | Day or night sweats | **5** |  | | Unintentional weight loss | **6** |  | | Fever | **7** |  | | Symptomatic splenomegaly | **8** |  | |
| 37b | Which 3 symptoms of PV would you most likely decide to recommend a drug treatment for?  **Please rank the top 3 symptoms, where 1 is most likely to recommend drug treatment for**   |  |  |  | | --- | --- | --- | |  | | **C [SHOW IF S5 CODE 3 >0]** | | PV | | Anaemia | **3** |  | | Marked leukocytosis | **4** |  | | Day or night sweats | **5** |  | | Unintentional weight loss | **6** |  | | Fever | **7** |  | | Symptomatic splenomegaly | **8** |  | |
| Q38 | Which of the following treatments have you ever given to your patients?  **Please select all that apply**   |  |  |  |  | | --- | --- | --- | --- | |  | | **B [SHOW IF S5 CODE 2 >0]** | **C [SHOW IF S5 CODE 3 >0]** | | MF | PV | | Aspirin | **1** | □ | □ | | Antihistamines | **2** | □ | □ | | Bone marrow transplant or stem cell transplant | **3** | □ | □ | | Phlebotomy | **4** | □ | □ | | Removal of spleen | **5** | □ | □ | | Antidepressants | **6** | □ | □ | | Anabolic steroids | **7** | □ | □ | | Corticosteroids | **8** | □ | □ | | Epoetin alfa injection | **9** | □ | □ | | Hydroxyurea | **10** | □ | □ | | Ruxolitinib | **11** | □ | □ | | Lenalidomide | **13** | □ | □ | | Thalidomide | **14** | □ | □ | | Anticoagulants/blood thinners | **15** | □ | □ | | Interferon | **16** | □ | □ | | Anagrelide | **17** | □ | □ | | Busulphan | **18** | □ | □ | | Transfusion | **20** | □ | □ | | Radiation therapy | **21** | □ | □ | | Androgens | **23** | □ | □ | | Iron preparations | **24** | □ | □ | | Psychological therapy | **25** | □ | □ | | No treatment / Watch and Wait | **26** | □ | □ | | Other, please specify | **99** | □ | □ | |
| Q39 | What percentage of the patients you currently manage are receiving each of the following treatments?  **Please enter a percentage between 0 and 100 for each**   |  |  |  |  | | --- | --- | --- | --- | |  | | **B [SHOW IF S5 CODE 2 >0]** | **C [SHOW IF S5 CODE 3 >0]** | | MF | PV | | Aspirin | **1** | % | % | | Antihistamines | **2** | % | % | | Bone marrow transplant or stem cell transplant | **3** | % | % | | Phlebotomy | **4** | % | % | | Removal of spleen | **5** | % | % | | Antidepressants | **6** | % | % | | Anabolic steroids | **7** | % | % | | Corticosteroids | **8** | % | % | | Epoetin alfa injection | **9** | % | % | | Hydroxyurea | **10** | % | % | | Ruxolitinib | **11** | % | % | | Lenalidomide | **13** | % | % | | Thalidomide | **14** | % | % | | Anticoagulants/blood thinners | **15** | % | % | | Interferon | **16** | % | % | | Anagrelide | **17** | % | % | | Busulphan | **18** | % | % | | Transfusion | **20** | % | % | | Radiation therapy | **21** | % | % | | Androgens | **23** | % | % | | Iron preparations | **24** | % | % | | Psychological therapy | **25** | % | % | | No treatment / Watch and Wait | **26** | % | % | | Other, please specify | **99** | % | % | |
| Q40 | **Please enter a percentage between 0 and 100**     |  |  |  |  | | --- | --- | --- | --- | | What percentage of your PV patients require treatment in addition to their phlebotomy treatments to control their condition? | % | **1** | **CONTINUE** | | What percentage of your PV patients refuse or cannot tolerate phlebotomy? | % | **2** | |
| Q42 | What reasons do your PV patients give for not wanting to continue with their phlebotomy?  **Please select all that apply**   |  |  |  | | --- | --- | --- | | Frequency of visits are convenient | **1** | **CONTINUE** | | Treatment is painful | **2** | | Felt worse after phlebotomy | **3** | | Too long distance to travel to clinic | **4** | | Fear of needles | **5** | | Lack of IV access | **6** | | Other, please specify | **99** | | No reasons are given | **98** | |
| Q43 | On a scale from 1 (not at all) to 7 (a great deal), to what extent do you feel that phlebotomy treatments are a burden to your PV patients?  **Please select one only**   |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | |  | | Not at all | | |  | A great deal | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | Phlebotomy burden to PV patients | **A** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q44 | What percentage of your PV patients develop/show inadequate efficacy or intolerance to hydroxyurea?  **Please enter a percentage between 0 and 100**     |  |  |  | | --- | --- | --- | | % | **1** | **CONTINUE** | |
| Q45a | Other than a cure, what is your most important treatment goal for therapy for MF?   |  |  |  | | --- | --- | --- | |  | | MF | | Symptom improvement | **1** |  | | Prevention of vascular/thrombotic events | **2** |  | | Anaemia treatment | **3** |  | | Reduce blood transfusions | **4** |  | | Healthy blood counts | **5** |  | | Reduce frequency of phlebotomy treatments | **6** |  | | Haematocrit levels less than 45% | **7** |  | | Reduction in spleen size | **8** |  | | Better quality of life | **9** |  | | Slow/delay progression of condition | **10** |  | | Thrombocytopenia treatment | **11** |  | | Other, please specify | **99** |  | |
| Q45b | Other than a cure, what is your most important treatment goal for therapy for PV?  **Please rank the top 3 goals, where 1 is most important**   |  |  |  | | --- | --- | --- | |  | | PV | | Symptom improvement | **1** |  | | Prevention of vascular/thrombotic events | **2** |  | | Anaemia treatment | **3** |  | | Reduce blood transfusions | **4** |  | | Healthy blood counts | **5** |  | | Reduce frequency of phlebotomy treatments | **6** |  | | Haematocrit levels less than 45% | **7** |  | | Reduction in spleen size | **8** |  | | Better quality of life | **9** |  | | Slow/delay progression of condition | **10** |  | | Thrombocytopenia treatment | **11** |  | | Other, please specify | **99** |  | |
| Q46 | In what circumstances would you change drug therapy for your patient?  **Please select all that apply**   |  |  |  |  | | --- | --- | --- | --- | |  | | **B [SHOW IF S5 CODE 2 >0]** | **C [SHOW IF S5 CODE 3 >0]** | | MF | PV | | Lack of efficacy | **1** | □ | □ | | Inconsistent HCT control | **2** | □ | □ | | Disease progression | **3** | □ | □ | | Side effects | **4** | □ | □ | | Change in blood counts | **5** | □ | □ | | Cytopenia | **6** | □ | □ | | Patient preference | **7** | □ | □ | | Cost/coverage | **8** | □ | □ | | Change of symptoms | **9** | □ | □ | | Other, please specify | **99** | □ | □ | |

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| --- |
| **D: PHYSICIAN PERCEPTIONS** |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Q47 | On a scale from 1 (not at all) to 7 (a great deal), to what extent do your MPN patients want to be involved in decisions regarding their treatment?  **Please select one only**   |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | |  | Not at all | | |  | A great deal | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | **A** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q48 | How often do MPN patients not agree with your primary treatment recommendation?  **Please select one only**   |  |  |  | | --- | --- | --- | | Never | **1** | **CONTINUE** | | Sometimes | **2** | | Often | **3** | |
| Q49 | What are the reasons why patients do not agree with your treatment recommendation?  **Please select all that apply**   |  |  |  | | --- | --- | --- | | Patient financial concerns | **1** | **CONTINUE** | | Patients are inadequately/misinformed | **2** | | Patient concern about treatment side effects | **3** | | Patient concern about frequency / duration of hospital visits | **4** | | Lack of caregiver support | **5** | | Impaired decision making e.g., due to neurological conditions, cultural or language barriers, advancing age | **5** | | Patient has different treatment goals | **6** | | Other, please specify | **99** | |
| Q50 | On a scale from 1 (not at all) to 7 (a great deal), kindly to give rank for each question below  **Please select one only**   |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | |  | Not at all | |  |  |  | A great deal | | |  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | In general, how satisfied are your MPN patients with the individual symptom management? | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | In general, how satisfied are your MPN patients with the overall treatment and management of their condition? | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | In general, how satisfied are you personally with the overall treatment and management of your MPN patient’s condition? | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q53b | Please read the following statements relating to **MF** and indicate your level of agreement?  **Please select one per row**     |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | |  | Strongly disagree | |  |  |  | Strongly agree | | |  | **1** | **2** | **3** | **4** | **5** | **6** | **7** | | Symptoms reduce a patient’s quality of life | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Is a/are blood cancer/s | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | May progress to a more serious condition | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | May increase the risk of heart attacks or strokes | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | The reimbursement of drug treatments plays an important role in the treatment I offer to my patients and/or is accepted by my patients | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q53c | Please read the following statements relating to **PV** and indicate your level of agreement?  **Please select one per row**     |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | |  | Strongly disagree | |  |  |  | Strongly agree | | |  | **1** | **2** | **3** | **4** | **5** | **6** | **7** | | Symptoms reduce a patient’s quality of life | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Is a/are blood cancer/s | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | May progress to a more serious condition | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | May increase the risk of heart attacks or strokes | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | The reimbursement of drug treatments plays an important role in the treatment I offer to my patients and/or is accepted by my patients | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q54 | **Please select one only**   |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | |  | Not at all | |  |  |  | Extremely | | |  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | How much do you feel that your MPN patients understand the treatment goals? | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | How much do you feel that you and your MPN patient agree on the treatment goals? | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q61 | According to you, what are the obstacles to treating MPN in Indonesia?  **Please select all that apply**   |  |  |  | | --- | --- | --- | | Difficult to diagnose | **1** | **CONTINUE** | | Difficult to treat | **2** | | Treatment access/coverage is low | **3** | | Diagnostic test access/coverage is limited | **4** | | MPN patients present late | **5** | | MPN patient prognosis is poor | **6** | | MPN patients often don’t require treatment | **7** | | MPN patients are rare | **10** | | Other haematological conditions have a higher burden of illness | **11** | | Other, please specify | **99** | |
| Q62 | When thinking about all the patients you currently see in your clinic/practice, on a scale from 1 (least) to 7 (most), where do you rank your MPN patients in terms of clinical and symptom burden?  **Please select one only**   |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | |  | Least burdensome | | |  | Most burdensome | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | MF | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | PV | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |
| Q63a | What do you consider to be the top 5 unmet needs in MF?  **Please rank the top 5 unmet needs, where 1 is the biggest need**   |  |  |  | | --- | --- | --- | |  | | MF | | Ability to accurately diagnose MF | **1** |  | | Early diagnosis of MF | **2** |  | | Effective drugs/therapy | **3** |  | | Cure | **4** |  | | Treatment side effects | **5** |  | | Symptom improvement | **6** |  | | Limit disease progression | **7** |  | | Prevent other disease | **8** |  | | Reduce transfusions | **9** |  | | Decrease/replace phlebotomy treatments | **10** |  | | Access/coverage of genetic testing e.g., JAK2 V617F | **11** |  | | Access/coverage of drugs/therapy | **12** |  | | Treatment cost | **13** |  | | Other, please specify | **99** |  | |
| Q63b | What do you consider to be the top 5 unmet needs in PV?  **Please rank the top 5 unmet needs, where 1 is the biggest need**   |  |  |  | | --- | --- | --- | |  | | PV | | Ability to accurately diagnose PV | **1** |  | | Early diagnosis of PV | **2** |  | | Effective drugs/therapy | **3** |  | | Cure | **4** |  | | Treatment side effects | **5** |  | | Symptom improvement | **6** |  | | Limit disease progression | **7** |  | | Prevent other disease | **8** |  | | Reduce transfusions | **9** |  | | Decrease/replace phlebotomy treatments | **10** |  | | Access/coverage of genetic testing e.g., JAK2 V617F | **11** |  | | Access/coverage of drugs/therapy | **12** |  | | Treatment cost | **13** |  | | Other, please specify | **99** |  | |
| Q64a | What do you consider to be the top 5 solutions to overcoming the unmet needs in MF?  **Please rank the top 5 solutions, where 1 is the biggest priority**   |  |  |  | | --- | --- | --- | |  | | MF | | Improved diagnostic tools with greater specificity | **1** |  | | More effective drug/therapy options | **2** |  | | Drugs/therapy with lower side effect profile | **3** |  | | Nurse support for patients | **4** |  | | Diet/nutritional support for patients | **5** |  | | Peer to peer support for patients | **6** |  | | Psychological support for patients | **7** |  | | Information on MF for patients | **8** |  | | Patient financial assistance | **9** |  | | Improved access/coverage of genetic testing e.g. JAK2 V617F | **10** |  | | Improved access/coverage of drugs/therapy | **11** |  | | Other, please specify | **99** |  | |
| Q64b | What do you consider to be the top 5 solutions to overcoming the unmet needs in PV?  **Please rank the top 5 solutions, where 1 is the biggest priority**   |  |  |  | | --- | --- | --- | |  | | PV | | Improved diagnostic tools with greater specificity | **1** |  | | More effective drug/therapy options | **2** |  | | Drugs/therapy with lower side effect profile | **3** |  | | Nurse support for patients | **4** |  | | Diet/nutritional support for patients | **5** |  | | Peer to peer support for patients | **6** |  | | Psychological support for patients | **7** |  | | Information on PV for patients | **8** |  | | Patient financial assistance | **9** |  | | Improved access/coverage of genetic testing e.g. JAK2 V617F | **10** |  | | Improved access/coverage of drugs/therapy | **11** |  | | Other, please specify | **99** |  | |
| Q65 | Which other Healthcare Professionals are involved in the management and care of MPN patients in your hospital?  **Please select all that apply**   |  |  |  | | --- | --- | --- | | Clinic nurse / nurse practitioner / physician assistant | **1** | **CONTINUE** | | Anatomical Pathology | **2** | | Lainnya, Tolong Sebutkan  Other, please specify | **99** | |
| Q66 | On a scale from 1 (not at all) to 7 (extremely), how important do you feel it is that the following Healthcare Professionals are involved in the management and care of MPN patients?  **Please select one per row**   |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | |  | | Not at all important | | |  | Extremely important | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | | Clinic nurse / nurse practitioner / physician assistant | **A** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Dietician | **C** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Psychologist | **D** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | | Other, please specify | **F** | ○ | ○ | ○ | ○ | ○ | ○ | ○ | |

**END OF QUESTIONNAIRE**