**Appendix: Myeloproliferative Neoplasms Research Questionnaire Indonesia**

|  |
| --- |
| **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.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| 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** | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

 |

|  |
| --- |
| **B: PATIENT DISEASE BURDEN** |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 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 | TidakDon’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’tknow |
| 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** | ○ | ○ | ○ | ○ | ○ |

 |

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

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 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** | □ | □ |

 |

|  |
| --- |
| **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 SebutkanOther, 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**