

## Non-adherence to treatment with cytoreductive and/or antithrombotic drugs is frequent and associated with an increased risk of complications in patients with polycythemia vera or essential thrombocythemia (OUEST study)

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**Supplementary Figure 1:** Non-adherence questionnaires for patients with myeloproliferative neoplasms taking oral or subcutaneous cytoreductive drugs.

**QUESTIONNAIRE FOR  
ORAL ADMINISTRATION**

**1-IDENTIFICATION**

**Please specify your:**

Initials Surname \_\_\_ First name \_\_\_ Age \_\_\_ years Sex F  M

**Date of questionnaire completion:** \_\_\_/\_\_\_/\_\_\_

**Do you live:** Alone  With other(s)

**Do you live:** In a town or city  In the country

**In your family, have any close relatives ever had blood clots?**

NO  YES

If YES, what type? Stroke  Myocardial Infarction   
Deep Vein Thromb.  Pulmonary embolism   
Other

**Have you ever had a blood clot before your illness was discovered (Polycythemia vera or Essential thrombocytosis)?**

NO  YES

If YES, what type? Stroke  Myocardial Infarction   
Deep Vein Thromb.  Pulmonary embolism   
Other: \_\_\_\_\_

**Do you smoke?** NO  YES

**Are you monitored or treated for:**

High blood pressure  High cholesterol  Diabetes

**Please specify your:**

Weight \_\_\_\_\_ Height \_\_\_\_\_ **BMI:** \_\_\_\_\_

**2-YOUR MEDICATION**

**1. What medication are you currently on?**

Hydrea  Vercyte  Xagrid  Jakavi

**2. What quantity of this medication is prescribed by your doctor?** \_\_\_ pills/week

**3. How long have you been on this medication for?**

Over a year  Less than a year

**4. Before starting this medication, did you take any of the following?**

Hydrea YES / NO Vercyte YES / NO

Xagrid YES / NO Pegasys/ViraferonPEG (Injection) YES / NO

**5. Is your medication prepared in advance?**

NO  The night before  Pill organiser box (weekly)

**6. Is your medication prepared by a nurse?**

NO  YES

**7. Do you have someone who helps you to take/not forget your medication?**

NO  A nurse  A friend/relative

**8. Do you take your medication at a fixed time?**

NO  YES

**9. If YES, how is it distributed throughout the day?**

\_\_\_ pills in the morning (\_\_\_ am) \_\_\_ pills at noon (\_\_\_ pm)  
\_\_\_ pills in the evening (\_\_\_ pm)

**10. Who determined this schedule?**

Your doctor  Your pharmacist  Yourself

**11. Are you on medication to thin your blood?**

NO  YES

Aspirin  Clopidogrel  Ticlopidin  Warfarin   
Other: \_\_\_\_\_

Do you sometimes forget to take this medication? NO  YES

**12. If you are currently on any other medication, how many other pills do you take each day?**

\_\_\_ pills in the morning \_\_\_ pills at noon \_\_\_ pills in the evening

**3-MEDICATION ADHERENCE**

**13. Do you take your medication reluctantly?**

NO  YES

**14. Have you ever forgotten to take it? (If the answer is NO, go directly to question 23).**

NO  YES

**15. If YES, have you forgotten to take it during the past year?**

NO  YES

**16. If YES, have you forgotten to take it during the past 3 months?**

NO  YES

**17. If you have forgotten to take it during the past 3 months, was this:**

Rarely?  Regularly (every month)?  Frequently (every week)?

**18. Over the past month, on how many days do you think you forgot to take your medication?**

Less than 3 days     7 days or less     More than 7 days

**19. Why do you not take your medication as prescribed? (tick as many answers as relevant)**

Forgetfulness                       Deliberate   
Busy                                       Professional reasons   
Supply problem                       Side effects   
Tablet size                               Number of daily intakes   
My blood test results are back to normal     Holidays/travel

**20. Do you think that forgetting to take your medication could affect its effectiveness?**

NO                                       YES

**21. If you forget to take your medication, do you make up for it by increasing the following dose?**

NO                                       YES

**22. Since you began your treatment, do you know if your haematological disorder has evolved?**

NO                       YES                       Date: \_\_\_\_\_

From ET:    to Polycythemia vera     Myelofibrosis

From PV:    to Myelofibrosis

**23. Have you had a blood clot since you have been under haematological supervision?**

NO                       YES                       Date: \_\_\_\_\_

If YES, what type?    Stroke     Myocardial Infarction   
Deep Vein Thromb.     Pulmonary embolism   
Other

**QUESTIONNAIRE FOR  
SUBCUTANEOUS ADMINISTRATION**

**1-IDENTIFICATION**

**Please specify your:**

Initials Surname \_\_\_ First name \_\_\_ Age \_\_\_ years Sex F  M

**Date of questionnaire completion:** \_\_\_/\_\_\_/\_\_\_

**Do you live:** Alone  With other(s)

**Do you live:** In a town or city  In the country

**In your family, have any close relatives ever had blood clots?**

NO  YES

If YES, what type? Stroke  Myocardial Infarction   
Deep Vein Thromb.  Pulmonary embolism   
Other

**Have you ever had a blood clot before your illness was discovered  
(Polycythemia vera or Essential thrombocytosis)?**

NO  YES

If YES, what type? Stroke  Myocardial Infarction   
Deep Vein Thromb.  Pulmonary embolism   
Other

**Do you smoke?** NO  YES

**Are you monitored or treated for:**

High blood pressure  High cholesterol  Diabetes

**Please specify your:**

Weight \_\_\_\_\_ Height \_\_\_\_\_ **BMI:** \_\_\_\_\_

**2-YOUR MEDICATION**

**1. What medication are you on?**

Pegasys  ViraferonPEG

**2. What dosage of this drug are you prescribed and how often is it administered?**

\_\_\_\_\_ micrograms / \_\_\_\_\_ days

**3. How long have you been on this medication for?**

Over a year  Less than a year

**4. Before starting this medication, did you take any of the following?**

Hydrea YES / NO Vercyte YES / NO Xagrid YES / NO

**5. Who gives you the injections?**

A nurse  Yourself  A friend/relative

**6. Administration of the medication:**

Do you have your injection at a fixed time? NO  YES

At what time of day?

Morning  Noon  Evening

At what time? \_\_\_\_ am/pm

**7. Who determined this time?**

Your doctor  Your pharmacist  Your nurse  Yourself

**8. Do you take Paracetamol before the injection?**

NO  YES

**9. Are you on medication to thin your blood?**

NO  YES

Aspirin  Clopidogrel  Ticlopidin  Warfarin

Other: \_\_\_\_\_

Do you sometimes forget to take this medication? NO  YES

**10. If you are currently on any other medication, how many other pills do you take each day?**

\_\_\_\_ pills in the morning      \_\_\_\_ pills at noon      \_\_\_\_ pills in the evening

**3-MEDICATION ADHERENCE**

**11. Do you take your medication reluctantly?**

NO  YES

**12. Have you missed or postponed any injections over the past 6 months? (If the answer is NO, go directly to question 19)**

NO  YES

**13. If YES, did you do so:**

Regularly?  Rarely?

**14. If YES, did you miss or postpone at least one injection a month?**

YES  More

**15. Why do you not take your medication correctly? (tick as many answers as relevant)**

Forgetfulness  Deliberate  Busy   
Professional reasons  Supply problem  Side effects   
Number of injections  My blood test results are back to normal   
Holidays/travel

**16. Do you think that forgetting to take your medication could affect its effectiveness?**

NO  YES

**17. If you forget to take your medication, do you make up for it by increasing the following dose or by reducing the time between injections?**

NO  YES

**18. Since you began being supervised, do you know if your haematological disorder has evolved?**

NO  YES  Date: \_\_\_\_\_

From ET: to Polycythemia vera  Myelofibrosis

From PV: to Myelofibrosis

**19. Have you had a blood clot since you have been under medical supervision?**

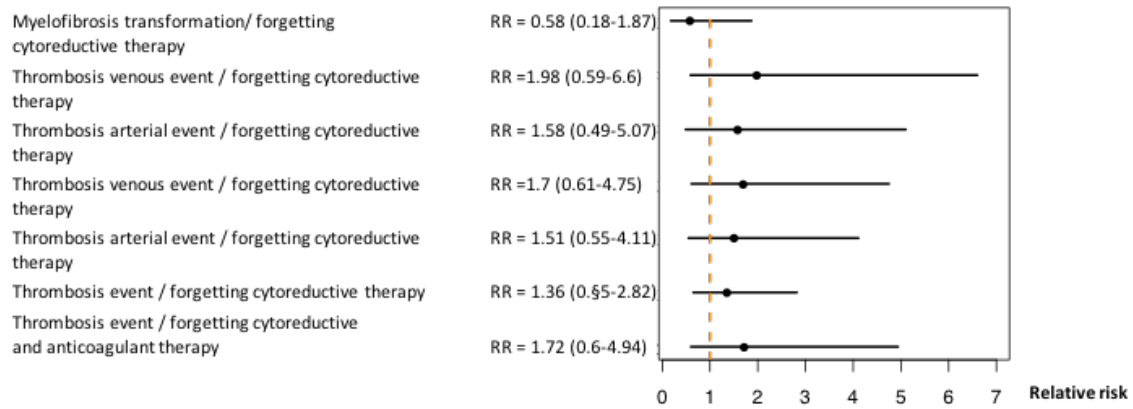
NO  YES  Date: \_\_\_\_\_

If YES, what type? Stroke  Myocardial Infarction

Deep Vein Thromb.  Pulmonary embolism

Other

**Supplementary figure 2A:** Evaluation of the relative risk (RR) of an arterial and / or venous thrombotic event as a function of the forgetfulness of the cytoreductive and / or antithrombotic treatment as well as the risk of transformation into myelofibrosis for the patients treated for polycythemia vera.



**Supplementary figure 2B:** Evaluation of the relative risk (RR) of an arterial and / or venous thrombotic event as a function of the forgetfulness of the cytoreductive and / or antithrombotic treatment as well as the risk of transformation into myelofibrosis for the patients treated for essential thrombocythemia.

