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)

Ronan Le Calloch,1,2 Karine Lacut,3,4,5 Christelle Le Gall-Ianotto,6 Emmanuel Nowak,3 Morgane Abiven,3 Adrian Tempescul,2,7 Florence Dalbies,2,7 Jean-Richard Eveillard,2,7 Valérie Ugo,6 Stéphane Giraudier,9 Gaëlle Guillerm,2,7 Eric Lippert,10 Christian Berthou2,7 and Jean-Christophe Ianotto2,4,7

1Service de Médecine Interne-Maladies du Sang-Maladies Infectieuses (MIIS), CHIC de Quimper; 2Fédération Inter Hospitalière d’Immunologie et Hématologie de Bretagne Occidentale (FIHBO); 3CIC 1412, INSERM, Brest; 4EA3878 G.E.T.B.O, Université de Bretagne Occidentale, Brest; 5Département de Médecine Interne et Pneumologie, CHRU de Brest; 6Laboratoire Interactions Epithélium-Neurones, EA 4685, Université de Bretagne Occidentale; 7Service d’Hématologie Clinique, Institut de Cancérologie et Hématologie, CHRU de Brest; 8Laboratoire d’Hématologie, CHU d’Angers; 9Laboratoire d’Hématologie, Hôpital Saint-Louis, AP-HP, Paris and 10Laboratoire d’Hématologie, CHRU de Brest and Equipe ECLA, INSERM U1078, Université de Bretagne Occidentale, Brest, France

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Correspondence: jean-christophe.ianotto@chu-brest.fr
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: ______

12. Do you sometimes forget to take this medication?     NO □

13. 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 □
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

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

Are you monitored or treated for:

High blood pressure    High cholesterol    Diabetes

Please specify your:

Weight    Height    BMI:

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.