

## Questionnaire on Quality of Life of Chinese CML Patients

Tyrosine kinase inhibitors (TKIs) have dramatically changed the history of chronic myelogenous leukemia (CML) treatment. Most of patients can achieve the survival as long as the healthy people, if they receive the proper treatment and standard monitoring. Lifelong TKI medication is still the well-known recommended treatment for CML in the world and stopping TKI therapy is only restricted in clinical trials. However, the decline of quality of life caused by TKI side effects has aroused more and more attention of doctors and patients. In order to know the side effects of TKI medication in Chinese CML patients, their impacts on quality of life and the patients' common concerns, this questionnaire is designed to help doctors make better therapy for Chinese CML patients.

I. Fill in the blank and choose the best answer

Name: \_\_\_\_\_ (optional)                      Date of filling \_\_\_\_\_

1. Gender: A. male    B. Female
2. Age: \_\_\_\_\_
3. Habitual residence: \_\_\_\_\_ (City) \_\_\_\_\_ (Province)
4. Census register: A. Non-agricultural registered    B. Agricultural registered
5. Marital status: A. Married    B. Single    C. Divorced    D. Widowed
6. Educational background: A. Elementary    B. Junior high    C. Senior high    D. Bachelor    E. Master/Doctor
7. Do you have other complications? (multiple choices) A. hypertension    B. Diabetes  
C. Coronary heart disease    D. Cerebrovascular disease    E. Liver disease    F. Chronic pulmonary disease    G. other tumor    H. thrombus    I. peptic ulcer    J. kidney disease  
L. others \_\_\_\_\_
8. Other medications \_\_\_\_\_
9. When were you diagnosed with CML? \_\_\_\_ (Year) How old when you were diagnosed? \_
10. Your disease phase when diagnosed with CML: A. chronic    B. accelerating    C. blast
11. Which therapy did you receive after diagnosis?  
A. interferon    from \_\_\_\_\_ (year) to \_\_\_\_\_ (year)  
B. hydroxycarbamide    from \_\_\_\_\_ (year) to \_\_\_\_\_ (year)

- C. chemotherapy from \_\_\_\_\_(year) to \_\_\_\_\_(year)
- D. bone marrow transplantation from \_\_\_\_\_(year) to \_\_\_\_\_(year)
- E. others\_\_\_\_\_, from \_\_\_\_\_(year) to \_\_\_\_\_(year)
12. When did you start TKI treatment? \_\_\_\_\_(month) \_\_\_\_\_(year)
13. Which TKI did you take?
- A. Glivec (Novartis) B. Generic imatinib (GeNiKe, Xinwei)
- C. Indian generic imatinib D. Tasgina (Novartis)
- E. Sprycel (Bristol-Myers Squibb) F. Generic dasatinib (Yinishu)
- G. Indian generic Dasatinib H. Ponatinib (American branded drug)
- I. Others\_\_\_\_\_ (please list)
14. Which TKI are you taking now?
- A. Glivec (Novartis) B. Generic imatinib (GeNiKe, Xinwei)
- C. Indian generic imatinib D. Tasgina (Novartis)
- E. Sprycel (Bristol-Myers Squibb) F. Generic dasatinib (Yinishu)
- G. Indian generic Dasatinib H. Ponatinib (American branded drug)
- I. Others\_\_\_\_\_ (please list)
15. Duration of TKI therapy \_\_\_\_\_ (years) \_\_\_\_\_ (months) (If it is less than 1 year, please calculate it by months.)
- \_\_\_\_\_ (medication), taking from \_\_\_\_\_ (month) \_\_\_\_\_ (year) to \_\_\_\_\_ (month) (year)
- \_\_\_\_\_ (medication), taking from \_\_\_\_\_ (month) \_\_\_\_\_ (year) to \_\_\_\_\_ (month) (year)
- \_\_\_\_\_ (medication), taking from \_\_\_\_\_ (month) \_\_\_\_\_ (year) to \_\_\_\_\_ (month) (year)
16. Your current disease phase: A. chronic B. accelerating C. blast
17. Your current responses:
- A. Ph+ chromosome ☐positive ☐negative
- B. BCR-ABL gene ☐positive ☐negative
- C. Unsatisfactory response or progression
18. Your satisfaction of CML control with TKI therapy:
- A. Very satisfied B. satisfied C. unsatisfied D. quite unsatisfied
19. Is your work influenced by CML and the treatment? A. Yes B. No
20. Now your TKI cost-sharing resource is:
- A. out-of-pocket spending:
- ☐PAP(patient assistant program)3+9 ☐PAP3+12 ☐medical insurance
- ☐bear the cost 100% without any assistance or reimbursement
- B. cost free ☐ clinical trials ☐special assistant program ☐ reimbursed by the work unit
21. Total TKI cost per year \_\_\_\_\_ (RMB)

22. You focus attention on: (multiple choices):

(1) CML knowledge (2) New drug development (3) TKI treatment choice (4) TKI dose adjustment (5) TKI-related side effects (6) Drug interactions (7) Long-term efficacy of TKIs (8) Interpretation of laboratory reports (9) Monitoring methods and significance (10) Fertility (11) Stopping TKIs (12) Quality of generic TKIs (13) Switch between branded TKIs and generics (14) Warnings in the daily life (15) Price reduction of TKIs (16) TKI reimbursement policies

**If you have any of the following symptom(s), please tick the proper degree**

Symptoms	Degree	Discontinue therapy due to symptoms	Needing treatment
Periorbital and lower limb edema	Mild / moderate / severe	Yes / no	Yes / no
Fatigue	Mild / moderate / severe	Yes / no	Yes / no
Chest distress and shortness of breath	Mild / moderate / severe	Yes / no	Yes / no
Hydrothorax and / or ascites	Mild / moderate / severe	Yes / no	Yes / no
Weight gain	Mild / moderate / severe	Yes / no	Yes / no
Weight loss	Mild / moderate / severe	Yes / no	Yes / no
Constipation	Mild / moderate / severe	Yes / no	Yes / no
Palpitation	Mild / moderate / severe	Yes / no	Yes / no
Depression /anxiety	Mild / moderate / severe	Yes / no	Yes / no
Headache	Mild / moderate / severe	Yes / no	Yes / no
Dizziness	Mild / moderate / severe	Yes / no	Yes / no
Tinnitus	Mild / moderate / severe	Yes / no	Yes / no
Insomnia	Mild / moderate / severe	Yes / no	Yes / no
Memory deterioration	Mild / moderate / severe	Yes / no	Yes / no
Conjunctivitis	Mild / moderate / severe	Yes / no	Yes / no
Conjunctival hemorrhage	Mild / moderate / severe	Yes / no	Yes / no
Dry eye	Mild / moderate / severe	Yes / no	Yes / no
Loss of appetite	Mild / moderate / severe	Yes / no	Yes / no
Nausea	Mild / moderate / severe	Yes / no	Yes / no
Vomit	Mild / moderate / severe	Yes / no	Yes / no
Diarrhea	Mild / moderate / severe	Yes / no	Yes / no
Abdominal pain	Mild / moderate / severe	Yes / no	Yes / no
Abdominal distention	Mild / moderate / severe	Yes / no	Yes / no
Hemorrhagic tendency of skin	Mild / moderate / severe	Yes / no	Yes / no
Itchy skin	Mild / moderate / severe	Yes / no	Yes / no
Skin color change	Mild / moderate / severe	Yes / no	Yes / no
Hair color change	Mild / moderate / severe	Yes / no	Yes / no
Alopecia	Mild / moderate / severe	Yes / no	Yes / no

Muscle cramps	Mild / moderate / severe	Yes / no	Yes / no
Musculoskeletal pain	Mild / moderate / severe	Yes / no	Yes / no
Hidrosis	Mild / moderate / severe	Yes / no	Yes / no
(Male) swollen breast	Mild / moderate / severe	Yes / no	Yes / no
(Female) swollen breast	Mild / moderate / severe	Yes / no	Yes / no
(Female ≤50 years) hypemenorrhea	Mild / moderate / severe	Yes / no	Yes / no
(Female ≤50 years) hypomenorrhea	Mild / moderate / severe	Yes / no	Yes / no
(Female ≤50 years) amenorrhea	Mild / moderate / severe	Yes / no	Yes / no
Decrease in sexual desire	Mild / moderate / severe	Yes / no	Yes / no