An investigation of patient experience with and perception of generic TKIs for the treatment of CML

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INTRODUCTION & AIMS

When new medicines are initially licensed, they can only be produced and marketed by one manufacturer. They are known as 'branded' medicines and are promoted under specific brand names - e.g. Glivec® which is a branded version of imatinib. After a number of years, other companies are given permission to produce their own versions of the branded product. These are known as generic medicines. Several CML medicines (e.g. imatinib, dasatinib) now have generic versions available in many countries. It is expected that over the next few years, more of the tyrosine kinase inhibitors (TKIs) that CML patients take will also become available as generic versions.

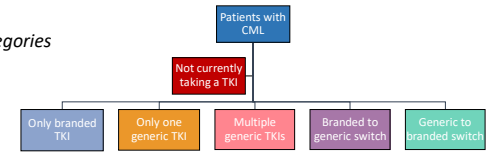
Although, there are potential advantages associated with the introduction of generic medicines in CML (e.g. reduced drug costs), concerns have been raised about differences between branded and generic versions, particularly in relation to tolerability, and also about the level of patient engagement with the process of switching.

The aim of the project was to explore CML patients' existing beliefs, concerns and experiences surrounding generic TKIs.

METHODOLOGY

A survey was designed using an on-line survey platform by a final year pharmacy student at University of Birmingham. Survey logic ensured that different patient pathways were captured (see figure).

Figure 1: Patient categories



Draft survey was reviewed by patient advocates from CML Facebook UK and CML Support prior to launch.

The survey was launched in November 2024 and was promoted by the aforementioned organisations and also by the CML Buster Foundation in the USA.

Survey participants were questioned on their views regarding previous or potential changes from branded to generic and between different generic medicines to treat their CML. Experiences with taking TKIs, particularly related to side effects and adherence were also investigated, alongside interactions and communication with health care professionals in relation to the switching process.

Results were analysed using descriptive statistics and preliminary findings shared via the 3 patient organisations.

RESULTS

Demographics

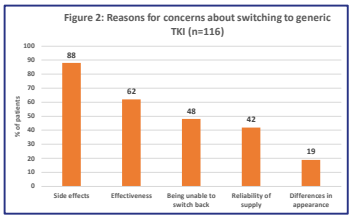
Responses received from 173 patients (72% female) in 16 countries
Majority from United Kingdom (64), then North America (27%).
Most commonly prescribed TKI was imatinib (40%)

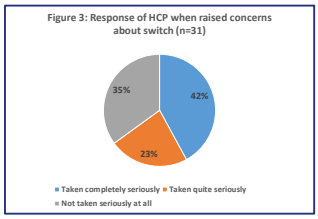
Patient concerns

67% of patients were concerned about switching from branded to generic TKI. 18% stated that they were very concerned and 3% stated that they wouldn't take a generic medicine. Reasons for concerns are presented in figure 2.

Patient experience

79 patients had switched from branded to generic or between generics. Overall, 75% of these patients were NOT told that their medicine was being switched. 66% of patients who switched from branded to generic were not informed and 96% of patients who switched between generics were not informed. Reponses to concerns raised are presented in Figure 3.
Only 4% of patients were provided with written information when they switched from branded to generic TKI.
46% of patients reported a change in side effects following a switch. There were not enough numbers to draw conclusions about the side effect profile of specific generics but overall, patients reported that side effects were more likely to be worse with their current medications than better with their current medication.





PATIENT VIEWS

"TKI is doing its job but I have a much lesser quality of life due to many side effects. Tiredness, aches, pains, cramps, bones locking, blue lips, stomach issues. I wonder about trying another but it's worrying if it's worse. I feel help and advice would be good to help with side effects." *A branded only TKI patient*

"There is so much to take in when you are diagnosed with CML, so many numbers to understand, and panic about! You need your TKI to be consistently good and to literally do what it says on the packet, I don't need at this stage, a different set of sides!" *A generic only TKI patient*

"I think doctors should discuss generics vs name brands with patients." *A generic to generic switch patient*

"Consultants only seem interested in 'the numbers'. Side effects are not really considered, but I am grateful TKIs are available, as I probably would not be here without them." *A branded to generic switch patient*

CONCLUSIONS

- A significant number of patients surveyed were concerned about switching from branded to generic medicine to treat their CML.
- Communication about switches by health care professionals could be improved, particularly in relation to the provision of written information.
- Patients often experienced a change in side effects when switching, particularly when switching from branded to generic TKI.

We hope that the survey results will help to ensure that health care professionals looking after CML patients have a greater awareness of what patients think about this important subject.

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INSTRUCTIONS FOR CML Horizons 2025 POSTERS

The poster template is provided for your convenience. However, you are welcome to design your own. Feel free to be as creative as you like! It would be most suitable to use a vertical setting, as shown in the example. Keep in mind that viewers typically expect information to flow from left to right and from top to bottom. Clarify the poster's sequence or flow with the use of arrows, hands, numbers, or letters. Your information should be labelled with headings and subheadings. This is a chance for you to present an activity, project, or initiative that was developed by your CML patient organization in the period 2024-2025.

REGARDING STYLE

- Size of the poster template: **A1: 59 x 84 cm**
- You can use this poster template, or you can have your own design. Be creative as you like!
- Use at least 36-point font for your text and at least 48-point font for the title. Your font style should be legible also.
- We recommend to use images, tables, photos or graphs. Minimum recommended size is 300 dpi.
- Remember that viewers will typically expect information to flow from left to right and from top to bottom. Use arrows, pointing hands, numbers, or letters to help clarify the sequence or flow of the poster.
- Use headings and subheadings to label your information.

REGARDING CONTENT

- You can present an activity, project, initiative from 2024 & 2025 developed by your CML patient organization.

INSTRUCTIONS FOR CML Horizons 2025 POSTERS

AN IDEAL POSTER SHOULD BE:

- **It is readable**. Putting simply, readability refers to the ease with which the ideas and messages presented in the poster are understood. The text will be more difficult to follow if it contains grammatical errors, misspellings, or complex sentences.
- ***Is it understandable***. A clear and easy-to-read text is essential. Using fonts that are too small for reading a poster from 1 to 2 meters away is a common poster presentation error.
- ***It is well organized.*** By organizing your poster spatially, you can reach 95% instead of just 5% of your audience: this means that the reader will not have to search for information and can spend more time learning about the initiative.
- Concise. There are only 11 seconds for you to catch and maintain the attention of your audience, so make the punch line obvious and concise. Most of your audience is going to absorb only the punch line. Those who are really interested in the topic will seek you out anyway and chat with you!