P2.15.05: A Shared Decision Aid for First-Line Treatments of ALK+ Advanced Non–Small Cell Lung Cancer: A Patient-Centered Approach

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*At time of study and analyses.

BACKGROUND

There are multiple first-line (1L) anaplastic lymphoma kinase (ALK) tyrosine kinase inhibitor (TKI) treatment options for ALK+ advanced non–small cell lung cancer (aNSCLC), and treatment risk-benefit profiles vary in ways that are important for patient decision-making. Further, there is some uncertainty about treatment outcomes due to a lack of head-to-head trials. Under these conditions, choosing a treatment may be challenging for patients.

Results from multiple patient preference studies in ALK+ aNSCLC demonstrate patient preference for efficacy over adverse events and the willingness for tradeoffs.[1-3] These studies also reveal the heterogeneity in preferences across patients, which underscores the importance of supporting patients' treatment choices and their participation in shared decision-making.

The objective of patient decision aids (DAs) is to improve knowledge, reduce decisional conflict/regret, and support values-concordant decisions. DAs are especially useful for preference-sensitive, uncertain decisions when several treatment options are available.[4,5]

OBJECTIVE

Engage with patients and oncologists to develop the first digital DA (with a values clarification activity [VCA]) for newly diagnosed patients with ALK+ aNSCLC to support shared decision-making discussions with their oncologists regarding 1L TKI selection.

METHODS

The study included 25 participants. Formative qualitative research was conducted to inform the content and design of a DA, and user testing was used to refine the DA.

Formative Qualitative Research

- Eleven patients and 3 oncologists participated in 60-minute, 1-on-1 virtual interviews that used a semistructured, think-aloud format with targeted questions on draft content and concepts for the DA.
- Patients with ALK+ aNSCLC were recruited in partnership with 2 collaborating patient advocacy groups (PAGs): ALK Positive and GO2 for Lung Cancer.
  - Patient eligibility criteria: aged 18 years or older, recent (within approximately the last 12 months) diagnosis of ALK+ aNSCLC, ability to participate in a discussion in English, and access to a computer/laptop.
- Participating oncologists were recruited by study team oncologists.
  - Oncologist eligibility criteria: Currently care for patients with ALK+ aNSCLC, ability to participate in a discussion in English, and access to a computer/laptop.
- Transcripts were analyzed using an Excel-based matrix.

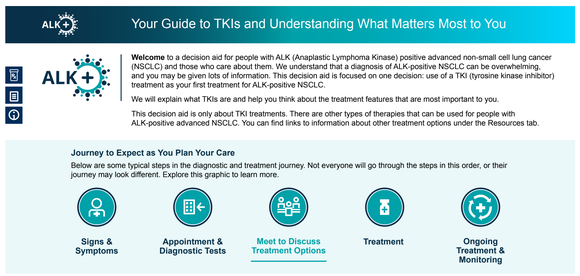
DA Content

- DA content was informed by the results of clinical trials, input from clinical experts on the study team, and feedback from 4 patient advisors.
- DA content was refined after concept interviews.
- A beta version of the DA was prepared for user testing.
- The DA comprises the following main sections (**Figure 1**):
  - Introduction and description of a typical patient journey
  - Descriptive information (education) about TKIs focused primarily on the similarities and differences between the main features of available treatment options
  - Links to existing educational resources, provided by collaborating PAGs
  - A quantitative VCA (best-worst scaling [BWS][6] in which users indicate most and least important treatment features with attributes informed by a prior preference study[1]
  - An individualized report with a treatment attribute priority list
  - Common questions about TKI treatments for ALK+ aNSCLC
  - A space for the user to record their questions

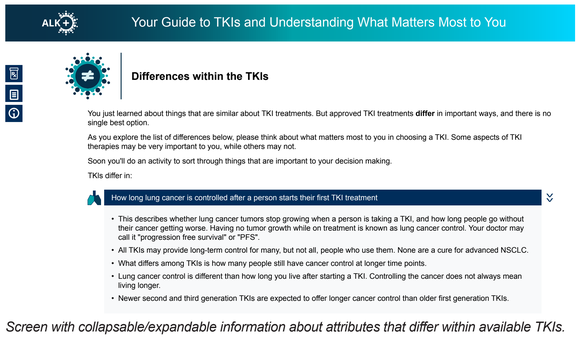
User Testing Interviews

- Seven patients participated in 60-minute, 1-to-1 virtual interviews in which they shared their screen while exploring the beta version of the DA and answered targeted questions related to user experience, information seeking, navigability, engagement with the VCA, and other features. Participants also completed the Preparation for Decision Making scale.[7]
- Patients with ALK+ aNSCLC were recruited via the same methods as outlined above, and the same eligibility criteria were applied.

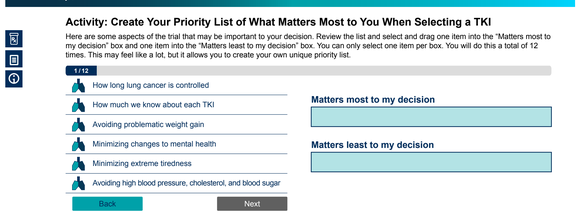
Figure 1. Select Screenshots From Decision Aid



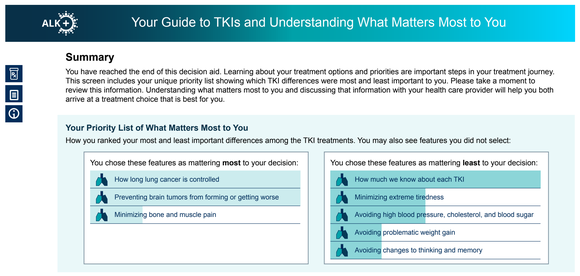
DA landing page with introduction and patient journey.



Screen with collapsable/expandable information about attributes that differ within available TKIs.



Example from the BWS VCA where users choose one item from the set and drag to "Matters most to my decision" and one item to drag to "Matters least to my decision."



DA summary printable screen includes BWS VCA results, guidance on interpretation, questions to ask themselves and their healthcare providers, and compilation of user-generated questions.

RESULTS

Table 1 summarizes the characteristics of the 18 patients who participated in the interviews. All patient participants were using 1L ALK TKIs, had a mean age of 46 years (range, 33-76 years), and had been diagnosed 2 to 20 months before the interview.

Table 1. ALK+ aNSCLC Patient Participant Characteristics

Characteristic	Participants (N = 18)
Age, average (range), years	46.4 (33-76)
Time since diagnosis, average (range), months	10.4 (2-20)
Education, n (%)	
High school graduate	1 (6)
Some college or technical school	3 (17)
2-year degree (Associate's or technical school)	1 (6)
4-year college degree	5 (28)
Graduate school degree	8 (44)
Race and/or ethnic identity, n (%)	
Asian (e.g., Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese)	3 (17)
Black, African American, or African (e.g., African American, Ethiopian, Haitian, Jamaican, Nigerian, Somali)	1 (6)
Hispanic, Latino, or Spanish (e.g., Colombian, Cuban, Dominican, Mexican or Mexican American, Puerto Rican, Salvadoran)	3 (17)
Middle Eastern or North African (e.g., Algerian, Egyptian, Iranian, Lebanese, Moroccan, Syrian)	1 (6)
White (e.g., English, European, French, German, Irish, Italian, Polish)	9 (50)
None of these fully describe	1 (6)

Patients responded favorably to the aggregation of information about "similarities" and "differences" on separate screens to highlight differentiators and reduce information overload to learn about TKIs.

Information from patients indicated that:

- The DA is likely to be valuable for newly diagnosed patients seeking information about treatment options.
- Many patients thought that, if they had had this DA upon diagnosis, they would have found it to be informative and empowering and it would have helped them to engage in shared decision-making with their healthcare provider.

Findings indicated that:

- Users perceived the information in the DA to be balanced.
- Users paid attention to cognitively/psychologically challenging concepts and questions.
- Use of the VCA resulted in careful deliberation about ALK TKI features that mattered most and those that mattered least.

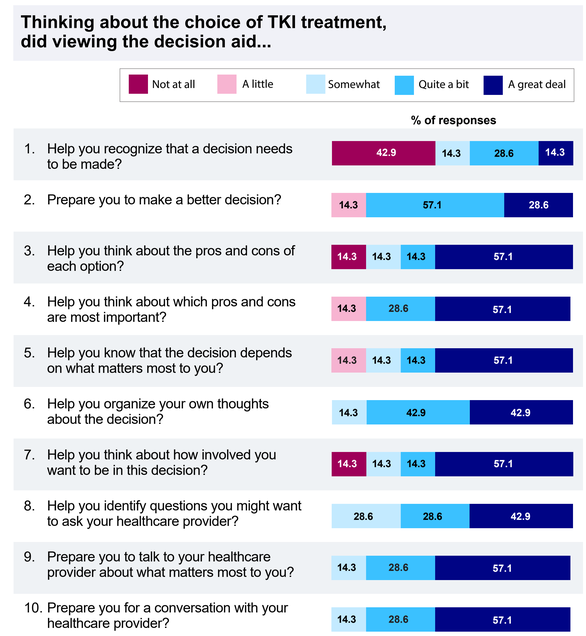
Patients confirmed the importance of individualized reports and user- and pregenerated questions to help guide conversations about treatment choice with healthcare providers.

Oncologists (n = 3; representing 1 community health center and 2 academic centers; currently caring for patients with ALK+ aNSCLC [range, 2-10]) supported the DA's value in helping patients understand treatment options and identify preferences. Suggestions were made to refine content further (e.g., addition of a new similarity item).

In user testing, participants were observed engaging in the desired deliberation during the VCA; participants discussed multiple attributes as important, and they said that selecting the most and least important features was challenging yet meaningful in determining treatment priorities. Participants commented favorably on the simple graphic the activity produced.

Responses of user test participants on the Preparation for Decision Making scale indicated that 9 of the 10 items in the measure rated above the midpoint of the 1-5 scale, with 6 items having median scores of 5 (**Figure 2**).

Figure 2. Summary of Responses to the Preparation for Decision Making Scale by User Test Participants



DISCUSSION

- Participants discussed the value of centralized, patient-friendly information about 1L ALK TKIs that helps patients understand their priorities and supports shared decision-making. Patient participants expressed the desire for such a DA when they were first diagnosed.
- Oncologists also endorsed the DA to provide patients with information about treatment options and support informed decisions.
- User testing interview participants perceived the embedded BWS exercise in the DA to help patients identify treatment priorities.
- Overall, user testers indicated that the DA may help prepare patients for decision-making.

CONCLUSIONS

- The DA was well received by patients with ALK+ aNSCLC and oncologists. Newly diagnosed patients with ALK+ aNSCLC may benefit from the DA to support shared decision-making regarding 1L ALK TKI selection, highlighting the importance of sharing it upon ALK+ aNSCLC diagnosis and before 1L treatment.
- The DA was added to the ALK Positive PAG website (https://alkpositive.org/decisionaids), and will also be disseminated via Go2Lung website in 2025.

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