



A Tool Preparing Patients with Stage III Non-Small Cell Lung Cancer for Shared Decision Making: Validating Acceptability and Usability

Avalere Health | An Inovalon Company
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Background

Gaps in Preparing for Stage III NSCLC Treatment Decision Making

After diagnosis, adults with stage III non-small cell lung cancer (NSCLC) face an overwhelming range of decisions, many of which are preference-sensitive. Patients often report poor communication with their clinicians, including limited discussion and consideration of their treatment preferences^{1,2}.

Few existing tools and resources available to elicit patient preferences, needs, and goals³

Lack of consideration of patient preferences in treatment decision making²

Patients play smaller role in treatment decision making than preferred^{2,4,5,6}

Time constraints and technical medical terminology impede patient-provider communication¹

- 1 National Learning Consortium. "Shared Decision Making." https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf. Accessed October 29, 2019.
- 2 Perloff T, Ciupek A, Rigney M, King JS. An Exploration of Supportive Care in Lung Cancer Survivorship. Lung Cancer Alliance, Abstract 0583. <https://go2foundation.org/wp-content/uploads/2017/09/MASCC-on-An-Exploration-of-Supportive-Care-in-Lung-Cancer-Survivorship.pdf>.
- 3 Schmidt K, Damm K, Prezler A, Golpon H, Welte T. Preferences of lung cancer patients for treatment and decision making: a systematic literature review. Eur J Cancer Care. 2015; 25 (4): 580-591.
- 4 Buzaglo J, Gayer C, RajivMallick, Charap E, Ferris A, et al. Understanding the experience of living with non-small-cell lung cancer (NSCLC): a qualitative study. J Comm and Supp Onc. 2014; 12 (1): 6-12.
- 5 Silvestri G, Pritchard R, Welch GH. Preferences for chemotherapy in patients with advanced non-small cell lung cancer: a descriptive study based on scripted interviews." BMJ. 1998; 317: 771-775.
- 6 LUNGeivity. Reaching the unreached: results of a pilot study. <https://lungevity.org/sites/default/files/file-uploads/reaching-the-unreached-122316.pdf>. Updated December 2016. Accessed October 29, 2019.

Preparation for Shared Decision Making Tool Development Process

- 1 To improve experience, engagement, and value for patients in preparing them to communicate effectively with clinicians, Avalere used a human-centered design approach to develop the preparation for shared decision making (PFSDM) tool.
- 2 Avalere adapted the tool from the PFSDM tool in breast cancer that was developed and validated by Avalere in 2019¹.
- 3 Tool development included in-depth interviews with patients diagnosed with stage III NSCLC (n=14).
- 4 Avalere also conducted in-depth interviews with 2 medical oncologists, 1 radiation oncologist, 4 social workers, and 1 nurse navigator, all of whom treat patients with stage III NSCLC.
- 5 Following interviews with patients and care team members, we integrated feedback into the tool and finalized the prototype for validation.

¹ Masi D, Gomez-Rexrode A, Bardin R, Seidman J. The “preparation for shared decision-making” tool for women with advanced breast cancer: qualitative validation study. J Participat Med. 2019; 11(4): e16511.

The Tool Has 5 Sections to Help Patients with Stage III NSCLC Prepare for Treatment Decisions

Timeline to Expect as You Plan Your Care

Supports patients with Stage III unresectable NSCLC understand the broad phases of their care experience and key decision points

Other Goals and Needs to Discuss With Your Family & Care Team

Supports patients think through their personal preferences (goals, expectations, needs) ahead of their treatment planning visit

Questions to Answer for Your Oncologist⁸

Supports patients share their care-related preferences with their care teams ahead of their treatment planning visit

Questions to Ask Your Oncologist & Care Team

Guides the patient-clinician conversation during the treatment planning visit, based on the patient and family's preferences

Resources That May Be Helpful for You

Provides patients with national resources to access financial assistance, support groups, nutrition services, and clinical trial information





Methods

Study Process

The study objective was to validate the PFSDM tool for acceptability and usability among patients with stage III NSCLC.

We used a recruitment service to identify interviewees, and conducted 20 1-on-1, semi-structured interviews with adults diagnosed with stage III NSCLC.

Interview questions were designed to elicit feedback on patients' perceptions of the tool's acceptability and usability using eight themes:

understandability, clarity of information, amount of information, suitability for decision making, usefulness, relevance of information, value, and formatting.

We used template analysis to code transcripts, using 19 codes decided a priori, allowing for additional codes to emerge. Two researchers double-coded 4 interviews, ensuring interrater reliability >75% and reconciled differences, subsequently independently coding the remaining interviews (n=16).

Validation Theme/Subtheme Definitions

Themes

Acceptability⁹

Usability^{10,11}

Subthemes

- Understandability – Whether patients understand how to use the tool
- Clarity of Information – Whether the information in the tool is clear to patients
- Amount of Information – Whether the amount of information in the tool is acceptable
- Suitability for Decision Making – Whether the tool helps to prepare for decision making & facilitate conversation with providers

- Usefulness – Whether and how the tool will be used by patients
- Relevance of Information – Whether the information included in the tool is relevant to patients with Stage III NSCLC
- Value – Whether and how the tool is valuable to patients
- Formatting – Whether the tool is attractive and readable to patients

⁹ O'Connor AM, Crane A, User Manual - Acceptability, 2002.

https://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Acceptability.pdf. Updated 2002. Accessed February 6, 2020.

¹⁰ Timmerman J, Tonis T, Dekker-van M, Weering M, Stuiver M, et al. Co-creation of an ICT-supported cancer rehabilitation application for resected lung cancer survivors: design and evaluation, BMC Health Serv Res. 2016; 16: 155.

¹¹ Chenel V, Mortenson W, Guay M, Jutai JW, Auger C. Cultural adaptation and validation of patient decision aids: a scoping review. Patient Prefer Adherence. 2018; 12: 321-332.





Results

Overall Study Findings and Patient Demographics

Overall, we found patients reported positive acceptability and usability, with positive statements about the tool across all 8 themes and 1 emergent sub-theme (overall usefulness)

Of the 20 Interviewees:

- 13 (65%) were female
- 12 (60%) were 55-64 years old
- 18 (90%) identified as white
- 16 (80%) had less than a college degree
- 9 (45%) reported less than \$50,000 total household income over past 12 months



The most commonly reported insurers were Medicare (n=8) and insurance through employer* followed by Medicaid (n=4), self-purchased insurance (n=), and other government programs (e.g., TRICARE) (n=3)

Summary of Validation Findings for the Tool Overall (1 of 2)

Across 20 interviews, where discussed, there were 18 positive and 0 negative statements about overall understanding, indicating high acceptability

Theme/Subtheme	Code	Number of Utterances
Acceptability		
Understandability (n=18)	Patient understands the tool overall	18
	Patient does not understand the tool overall	0
Clarity of Information (n=16)	Clear overall	14
	Not clear overall	2
Amount of Information (n=50)	Sufficient information	15
	Not enough information	2
	Appropriate length	17
	Too long/short	0
Suitability for Decision Making (n=16)	Helps prepare for decision making	16
	Does not help prepare for decision making	0

* An utterance signifies a remark made by a patient (e.g., In 20 interviews, 18 patients said something positive about the understandability of the tool). Each patient may contribute more than one utterance. Therefore, some totals are greater than 20.

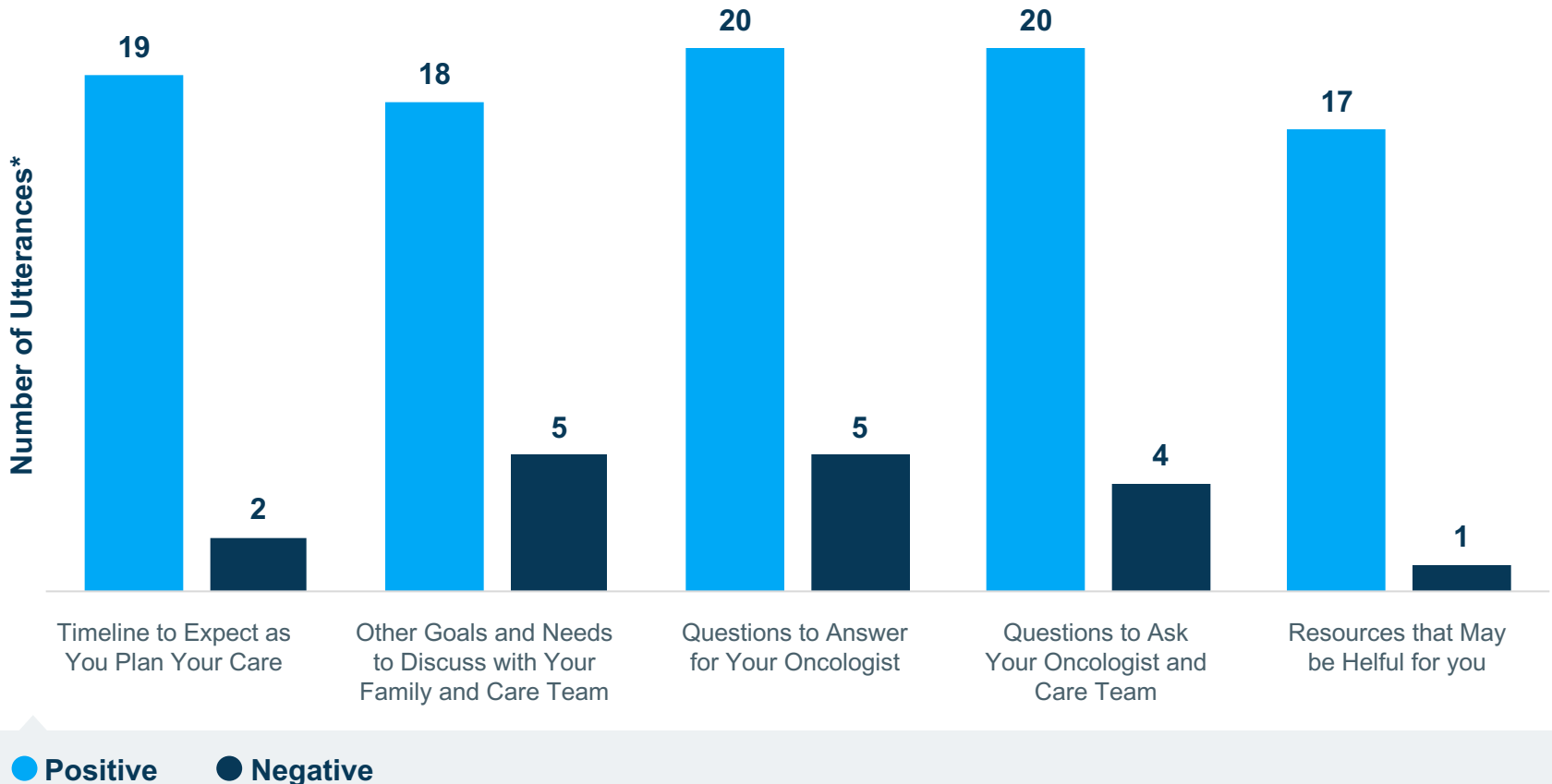
Summary of Validation Findings for the Tool Overall (2 of 2)

Across 20 interviews, where discussed, there were 16 positive and 0 negative statements about overall usefulness, indicating high usability among this sample

Theme/Subtheme	Code	Number of Utterances
Usability		
Usefulness (n=16)	Useful overall	16
	Not useful overall	0
Relevance of Information (n=23)	Relevant to patients with NSCLC	15
	Not relevant to patients with NSCLC	0
	Relevant to recently diagnosed patients with NSCLC	8
	Not relevant to recently diagnosed patients with NSCLC	0
Value (n=25)	Wish they had tool at diagnosis	12
	Did not wish they had tool at diagnosis	1
	Recommend tool to others	12
	Do not recommend tool to others	0
Formatting (n=19)	Overall positive formatting	16
	Overall negative formatting	3

* An utterance signifies a remark made by a patient (e.g., In 20 interviews, 18 patients said something positive about the understandability of the tool). Each patient may contribute more than one utterance. Therefore, some totals are greater than 20.

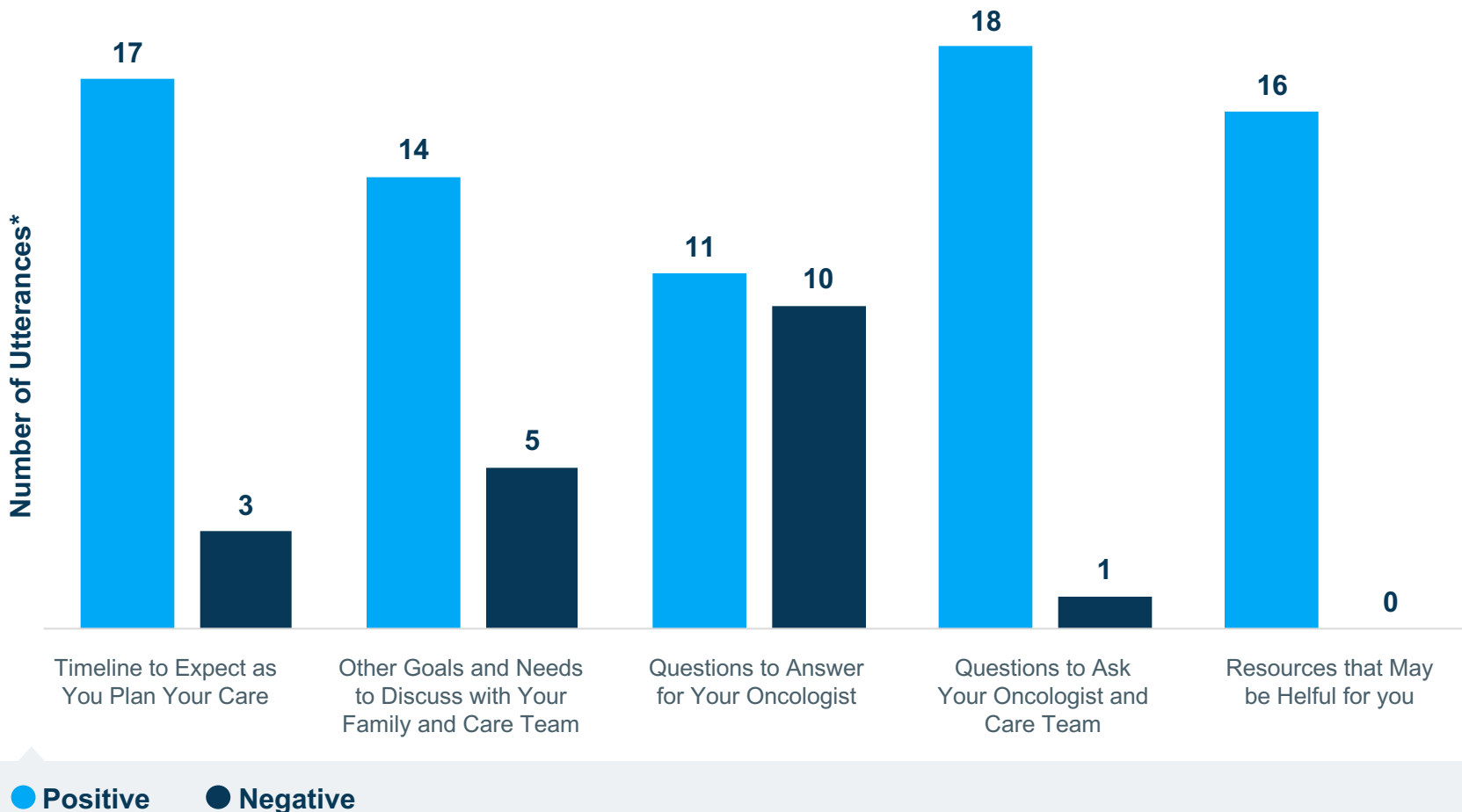
Validation Findings for Usefulness Subtheme by Section of Tool



* An utterance signifies a remark made by a patient (e.g., In 20 interviews, 18 patients said something positive about the understandability of the tool). Each patient may contribute more than one utterance. Therefore, some totals are greater than 20.

Validation Findings for Understandability

Subtheme by Section of Tool



* An utterance signifies a remark made by a patient (e.g., In 20 interviews, 18 patients said something positive about the understandability of the tool). Each patient may contribute more than one utterance. Therefore, some totals are greater than 20.



Patient Quotes for Usability from Validation Interviews



“Every doctor’s office should have [the tool] when [the patients] first get diagnosed. They should have this. I can’t say enough about it.”

“If I had this tool, it would have made me feel more comfortable about what to ask, what to look forward to, and what upcoming events are going to be like.”



“Looking at this, it gives me answers to things that I can sit and talk with [my family] about and think about who I can get support from.”



“When I first got diagnosed, I didn’t know how to even sit down and talk to my girlfriend about it... So, with the tool outlining these questions, I would have been able to sit down and talk with [my loved ones] about it.”





Conclusions

Conclusions and Next Steps

1 Results suggest patients with stage III NSCLC find the PFSDM tool acceptable and usable.

2 Findings indicate patients believe the tool will help them prepare to communicate their preferences with their provider when making decisions.

3 Results will be used to update the tool with patient recommendations and inform future studies evaluating the feasibility of incorporating the tool into the clinical workflow and the tool's impact on clinical outcomes.

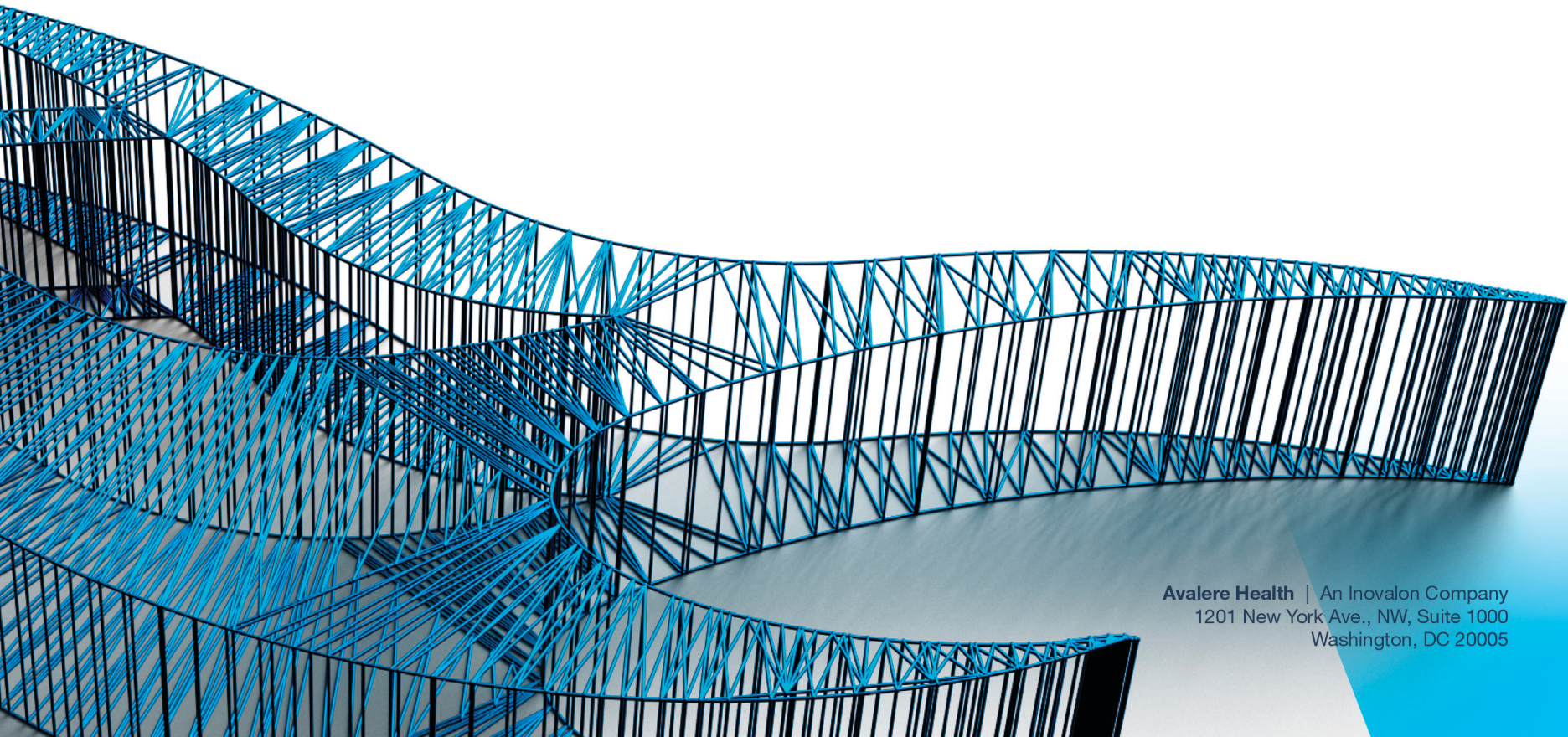


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