

**“Did you ever, even once, use cannabis for any reason?”:
Designing questions on cancer patients’ cannabis use for twelve
different surveys**



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5/13/2022
AAPOR 2022



Background

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- Needed to design a set of core items that would work for all twelve grantees
- Using the same set of core items would allow for pooled analyses
- Pooled analyses = larger sample size, more representative, multiple areas of the country
- Ability to compare states with different legalization status

Constraints

- Had limited time due to contract constraints
- Few existing surveys studying cannabis use among cancer patients specifically
- Some grantees had already put together draft questionnaires with different items on the same topics
- Grantees wanted to ask additional questions outside the core
- Some could link administrative data (e.g., electronic health records) for demographic and health information while others could not

Core Components of Survey

Current and past use of cannabis

Frequency and duration of use

Mode(s) of use

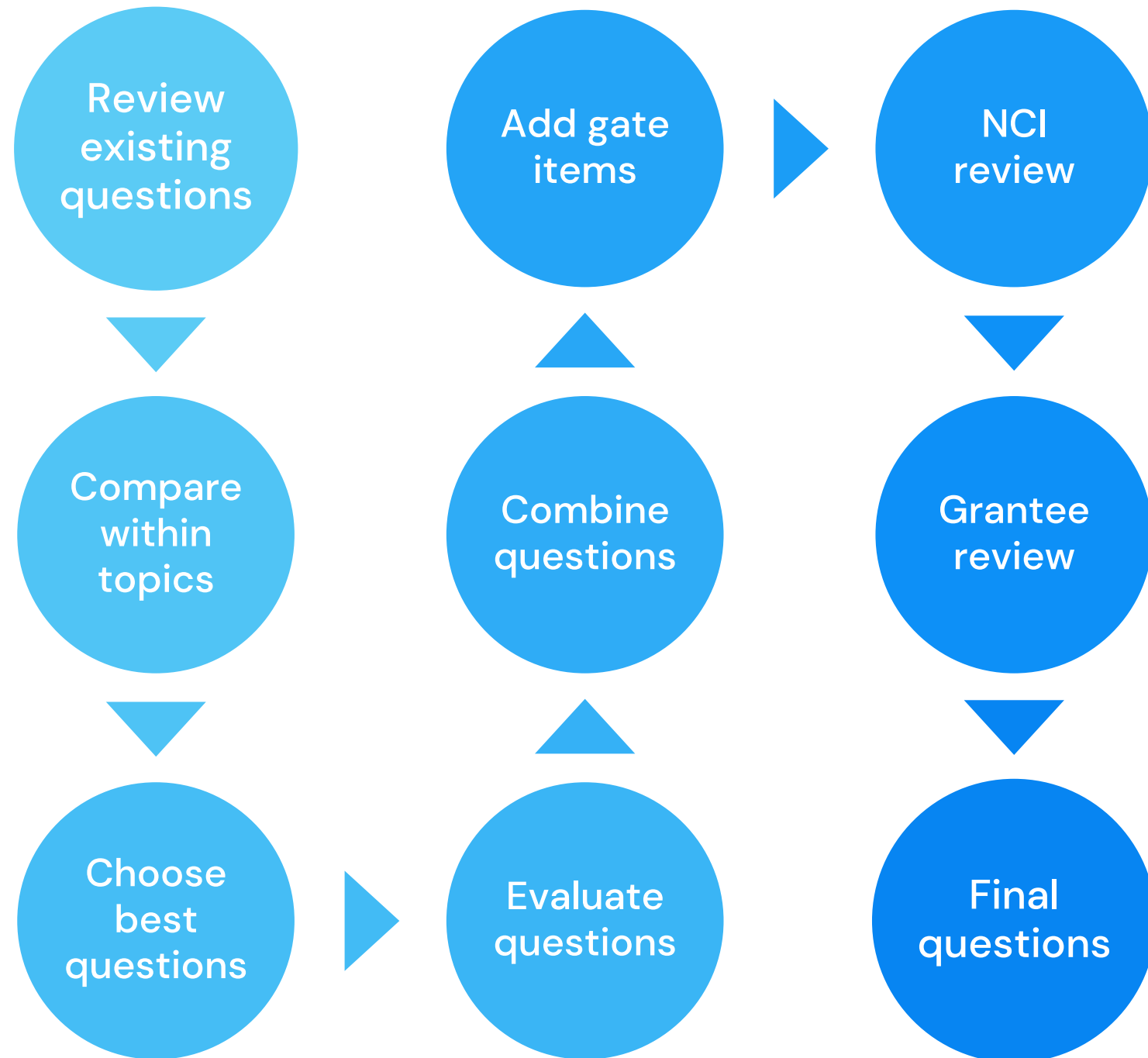
Therapeutic reasons for use

Perception of benefit or harm

Discussion of use with clinical providers

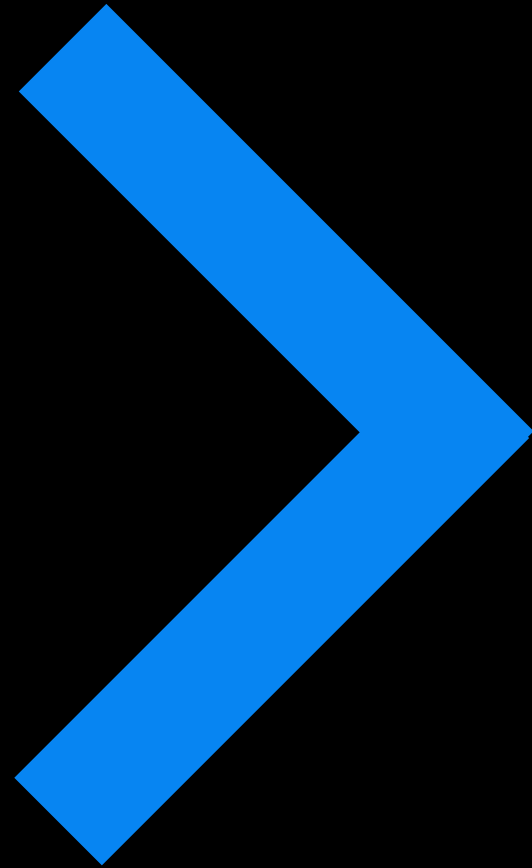
Recommended use by clinical provider

Process



Considerations

- Designed questions to be versatile so grantees could add their own questions without disrupting flow
- Gate items designed to be flexible – could make it so that everyone is asked certain questions or limit it to certain groups
- Lots of opinions!



Lessons Learned

- Start questionnaire development early
- Provide a structured forum for feedback
- Utilize subject-matter expertise
- Be flexible and adaptable throughout



Survey Items

Overview

- Final set of survey items included 37 core measures (not accounting for “select all” questions)
- Estimated about 9 minutes for all items (4 Qs/min)
- Most were required, 4 were optional
- Provided grantees with final document including:
 - File specifications and variable formats/labels
 - The exact text of questions and response options
 - Skip patterns

Defining Cannabis

- CBD-only products included in the formal definition of cannabis for the core measures.
- Grantees are welcome to ask their own additional questions with narrower definitions.
- Standardize the definition of cannabis/marijuana across all questionnaires
- Definition of cannabis should be explicitly mentioned at the beginning of each questionnaire, or at the beginning of the section(s) about cannabis use

When we use the term 'cannabis' we are referring to any:

- *Marijuana*
- *Cannabis concentrates*
- *Edibles, lotions, ointments, tinctures containing cannabis*
- *CBD-only products*
- *Pharmaceutical or prescription cannabinoids (e.g., dronabinol, nabilone, Marinol, Syndros, Cesamet)*
- *Other products made with cannabis*

Perceived Benefits

- Do you think that there are any benefits related to cannabis use?
 - Yes
 - No → SKIP PATTERN
- **[If believes there are benefits]** What do you believe are the benefits of using cannabis, even if you've never used it? Select all that apply.
 - Pain management
 - Relief of stress, anxiety or depression
 - Relief from neuropathy (numbness or tingling in your hands or feet)
 - Relief from sweating symptoms (e.g., hot flashes, night sweats)
 - Improved sleep
 - Improved nausea/vomiting
 - Increased appetite
 - Increased energy or reduced fatigue
 - Increased sexual interest or activity
 - Decreased use of other medications
 - Decreased use of illicit substances other than cannabis
 - Managing side effects from cancer treatment
 - Treatment of or cure for cancer
 - Treatment of another medical condition (i.e., seizures, chronic pain)
 - Enjoyment or recreation
 - Other benefits (please specify)

Sources of Information

- (Optional) Where would you be most likely to go if you wanted to learn more about cannabis use and cancer? Select all that apply.
 - Primary care provider
 - Oncologist in charge of your cancer treatment
 - Nurse or physician's assistant involved with your cancer treatment
 - Nutritionist
 - Another cancer patient
 - Friend or family member
 - Cannabis store or dispensary
 - Hospital website
 - Official federal, state, or local government website
 - Pamphlet or handout
 - News or magazine articles
 - Internet search engine (e.g., Google)
 - Social media or blogs (Facebook, Twitter, etc.)
 - Other (please specify)

Comfort Discussing Use

- How comfortable would you feel talking with your healthcare providers about cannabis?
 - Extremely uncomfortable
 - Somewhat uncomfortable
 - Somewhat comfortable
 - Extremely comfortable

Discussions with Providers

- Have you discussed using medical cannabis for your cancer symptoms with a healthcare provider?
 - Yes
 - No → SKIP PATTERN
- (Optional) What type of provider have you talked to about cannabis? Select all that apply.
 - Primary care provider
 - Oncologist involved with your cancer treatment
 - Nurse or physician's assistant involved with your cancer treatment
 - Pharmacist
 - Nutritionist or dietician
 - Another health care professional

Use Before/After Diagnosis

- **Prior to your cancer diagnosis, did you ever, even once, use cannabis for any reason?**
 - Yes
 - No
- **Have you used cannabis at any time since your cancer diagnosis?**
 - Yes → SKIP PATTERN
 - No → SKIP PATTERN
- **Have you considered using cannabis since your cancer diagnosis?**
 - Yes
 - No → SKIP PATTERN

Skip Pattern for Cannabis Users

- The remaining questions are only for those who had used cannabis since their cancer diagnosis.

Core Measures: Current Use

- **[If ever used since diagnosis] Are you currently using cannabis?**
 - Yes
 - No → SKIP PATTERN
- **[If currently using] What is your best estimate of the number of days you used cannabis during the past 30 days?**
 - [RANGE 0-30]

Core Measures: Use During Treatment

- **[If ever used after diagnosis]** Did you use cannabis at any time during your cancer treatment?
 - Yes
 - No → SKIP PATTERN
 - I haven't started treatment → SKIP PATTERN
- **[If used during treatment]** On average, during your cancer treatment, how often do you or did you use cannabis?
 - More than once a day
 - Daily or almost daily
 - A few times a week
 - A few times a month
 - Once a month or less
 - Only tried it once or twice

Core Measures: Use After Treatment

- **[If ever used after diagnosis]** Did you use cannabis at any time after the end of your cancer treatment?
 - Yes
 - No → SKIP PATTERN
 - I haven't finished treatment → SKIP PATTERN
- **[If used after treatment]** On average, after your cancer treatment, how often do you or did you use cannabis?
 - More than once a day
 - Daily or almost daily
 - A few times a week
 - A few times a month
 - Once a month or less
 - Only tried it once or twice

Core Measures: Forms Used

- **[If ever used after diagnosis] At any time since your cancer diagnosis, have you used cannabis in the following ways? Select all that apply.**
 - Smoking such as in a joint, bong, pipe, or blunt
 - Eating it in food such as brownies, cakes, cookies, or candy
 - Drinking it in a liquid such as tea, cola, or alcohol
 - Taking by mouth such as pills, tinctures, or sublingually (under the tongue)
 - Vaping or vaporizing such as in an e-cigarette-like vaporizer or other vaping device
 - Dabbing such as using waxes or shatter
 - Applying topically such as in a lotion, cream, or patch
 - Other (please specify: _____)

Core Measures: Form Used Most Often

- **[If ever used after diagnosis] Which one of the following ways do you, or did you, use cannabis most often since your cancer diagnosis?**
 - Smoking such as in a joint, bong, pipe, or blunt
 - Eating it in food such as brownies, cakes, cookies, or candy
 - Drinking it in a liquid such as tea, cola, or alcohol
 - Taking by mouth such as pills, tinctures, or sublingually (under the tongue)
 - Vaping or vaporizing such as in an e-cigarette-like vaporizer or other vaping device
 - Dabbing such as using waxes or shatter
 - Applying topically such as in a lotion, cream, or patch
 - Other (please specify: _____)

Core Measures: Therapeutic Reasons

- **[If ever used after diagnosis] What were your reasons for using cannabis after your cancer diagnosis? Select all that apply.**
 - Pain
 - Mood changes, stress, anxiety, or depression
 - Neuropathy (numbness or tingling)
 - Difficulty sleeping
 - Difficulty concentrating
 - Skin problems
 - Sweating symptoms (e.g., hot flashes, night sweats)
 - Digestive problems (e.g., nausea, vomiting, diarrhea, constipation)
 - Lack of appetite
 - Lack of energy or fatigue
 - Lack of sexual interest or activity
 - Used as a treatment or cure for cancer
 - Used recreationally or for enjoyment
 - Used for a cancer symptom or cancer treatment side effect not listed here (please specify)
 - Other reason (please specify)

Intro to Symptom Improvement Section

- Note: For this series of questions there are two formatting options (single-item and grid).

These next few questions ask about cancer symptoms or cancer treatment side effects, and how your use of cannabis has affected them. If you do not experience these symptoms, please select “I do not have this symptom”.

Core Measures: Symptom Improvement – Grid Option

- [If ever used after diagnosis]** For each of the following symptoms, how much do you think cannabis has worsened or improved it? If you do not experience these symptoms, please select “I do not have this symptom”.

Symptom	Worsened quite a bit	Somewhat worsened	No change	Somewhat improved	Improved quite a bit	I do not have this symptom
Pain						
Stress, anxiety, or depression						
Neuropathy (numbness or tingling in your hands or feet)						
Insomnia or difficulty sleeping						
Loss of appetite						
Digestive problems (e.g., nausea, vomiting, diarrhea, constipation)						
Decline in sexual interest or activity						
Sweating symptoms (e.g., hot flashes, night sweats)						
Fatigue or lack of energy						

Core Measures: Symptom Improvement – Single-item Option

- **[If ever used after diagnosis]** How much do you think cannabis has worsened or improved your pain?
 - Worsened quite a bit
 - Somewhat worsened
 - No change
 - Somewhat improved
 - Improved quite a bit
 - I do not have this symptom

Core Measures: Symptom Improvement – Other

- **[If ever used after diagnosis]** Do you think cannabis has worsened any of your other cancer symptoms or cancer treatment side effects?
 - Yes → Please specify
 - No
- **[If ever used after diagnosis]** Do you think cannabis has improved any of your other cancer symptoms or cancer treatment side effects?
 - Yes → Please specify
 - No

Non-Survey Items

- Date of diagnosis
- State of residence at diagnosis
- Current state of residence
- Cancer type (most recent diagnosis)
- Stage of cancer at diagnosis
- Metastatic cancer diagnosis
- Treatment type(s)
- Treatment completion date(s)



Conclusions

Changes for Next Time

- Add questions on:
 - THC/CBD content of cannabis used*
 - Where patients get their cannabis (e.g., grow it themselves, dispensary, pharmacy, dealer)*
- Make allowances for multiple diagnoses

The next questions ask about your use of cannabis before, during, or after your cancer diagnosis or treatment. If you have had more than one cancer diagnosis, please respond based on your most RECENT cancer diagnosis.

- Test survey questions before fielding



Thank you!

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