

The Unmet Needs of Alaska's Cancer Survivors

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Alaska Division of Public Health

Prevention Promotion Protection

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Institutional Review Board

These public health surveillance activities were reviewed by the University of Alaska Anchorage and Alaska Area Institution Review Boards and determined “Not Research”

Overview

Define “cancer survivors”

Review what we know (and don't know) about cancer survivors

Describe the Needs Assessment

Explore the initial findings

Identify next steps



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Cancer Survivors

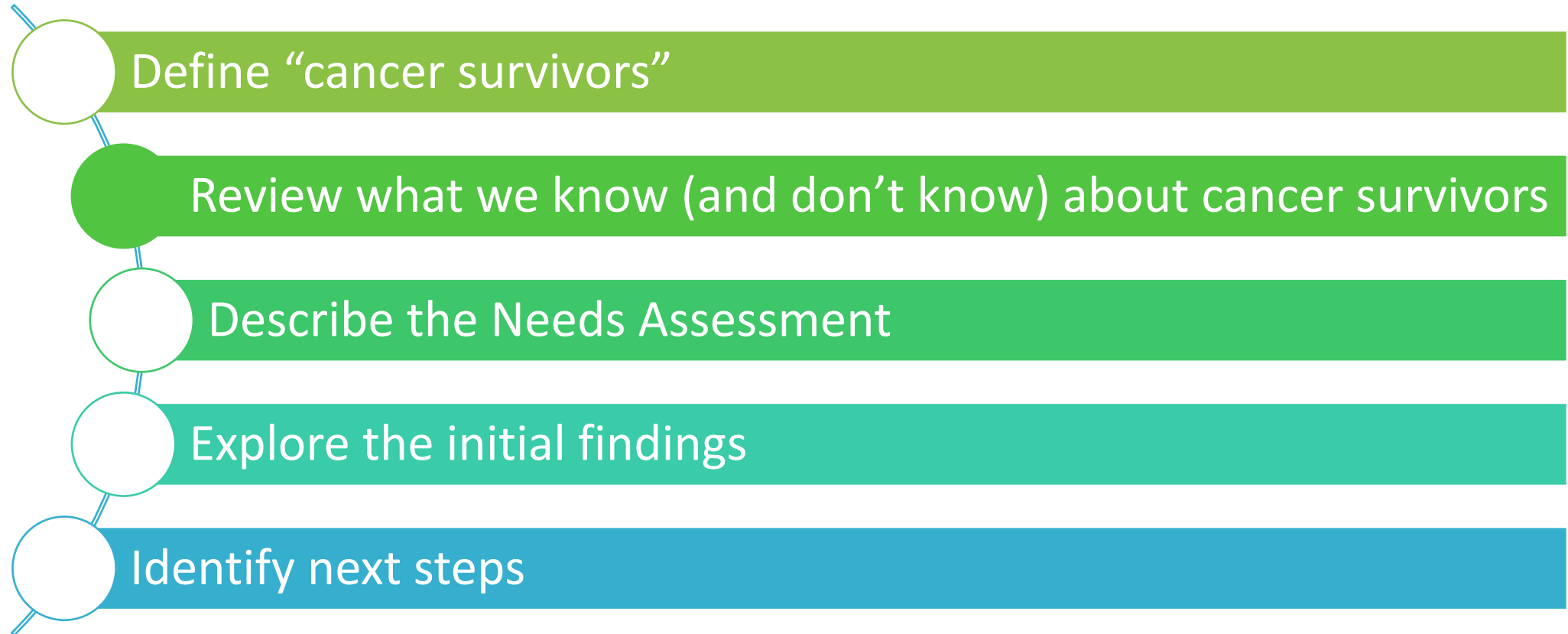
- A person is considered to be a survivor from the time of diagnosis until the end of life¹
- Unique challenges as a result of diagnosis and treatment
- Approx. 31,000 survivors in Alaska²
- Population will continue to grow with advances in early detection and treatment



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Overview



What we know from

Behavior Risk Factor Surveillance System

Alaska's Cancer Survivors need...

- Improved Care Coordination and Follow-up
 - Less than half were given a summary of their cancer treatment to share with their primary care provider
 - About 70% report it's been over a year since their last check-up
- Support for Healthy Living
 - 11% currently smoke
 - Two-thirds overweight or obese
 - Twice as likely to report health alcohol use compared to those never diagnosed with cancer
 - More likely to have other chronic conditions like diabetes and heart disease

What we know from

2010 Breast Cancer Survivor Needs Assessment

Alaska's Breast Cancer Survivors...

- Satisfied with their treatment and services
- Many reported enduring physical problems
 - (e.g. hot flashes, memory loss)
- Many reported emotional difficulties
 - (e.g. worries about sexuality, stress)
- Few reported daily living problems
 - (e.g. financial, employment)

What we know from

2014 Prostate Cancer Survivor Needs Assessment

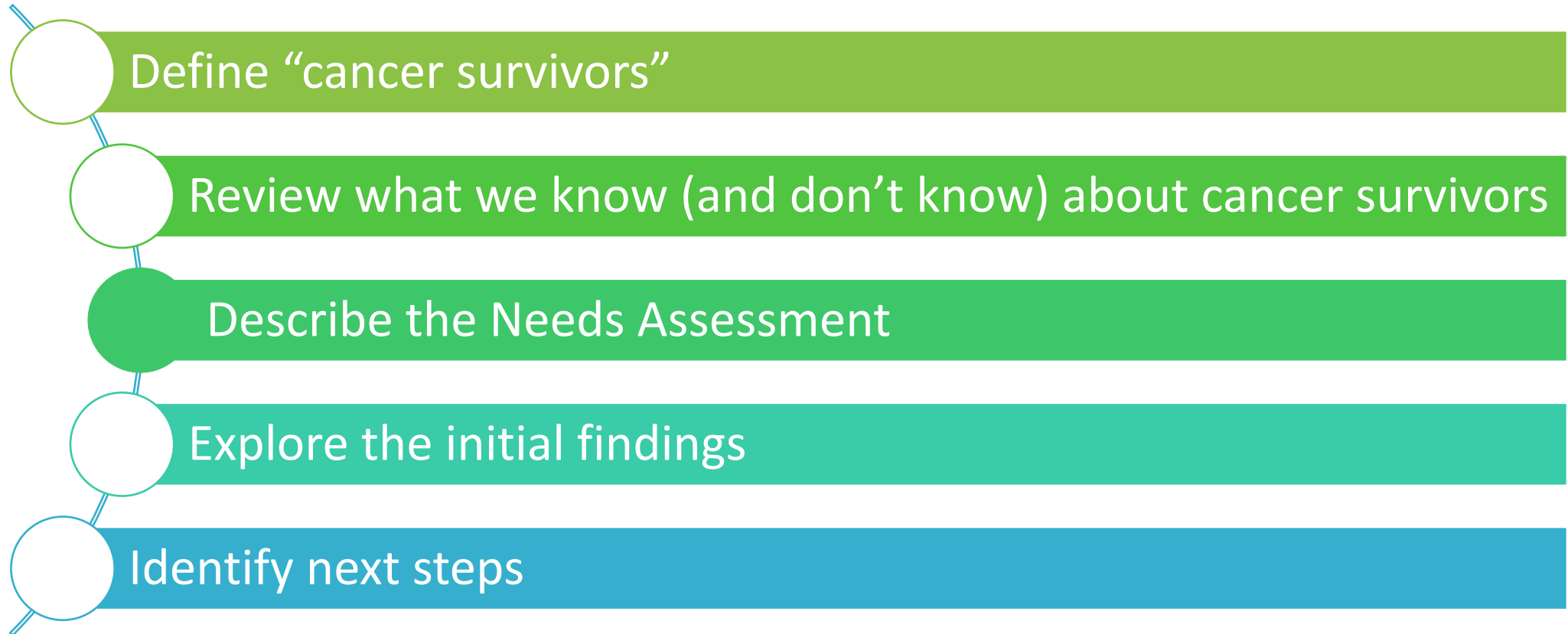
Alaska's Prostate Cancer Survivors...

- Satisfied with screening and diagnostic services, provider communication
- Over 80% reported treatment side effects
 - (e.g. urinary issues, fatigue)
- No differences for those treated in AK v. Outside
- Most common sources of information about treatment were provider (89%) followed by websites (53%)

What we don't know

- Specific information needs
- Specific medical care coordination or access issues
- Which factors are impacting quality of life
- Which emotional and relationship issues need support

Overview



Cancer Program Objectives

1. Identify the unmet needs of Alaska's cancer survivors
2. Increase awareness of unmet needs
3. Identify opportunities for improvement
4. Develop recommendations for individuals, public health and community organizations, and health care providers

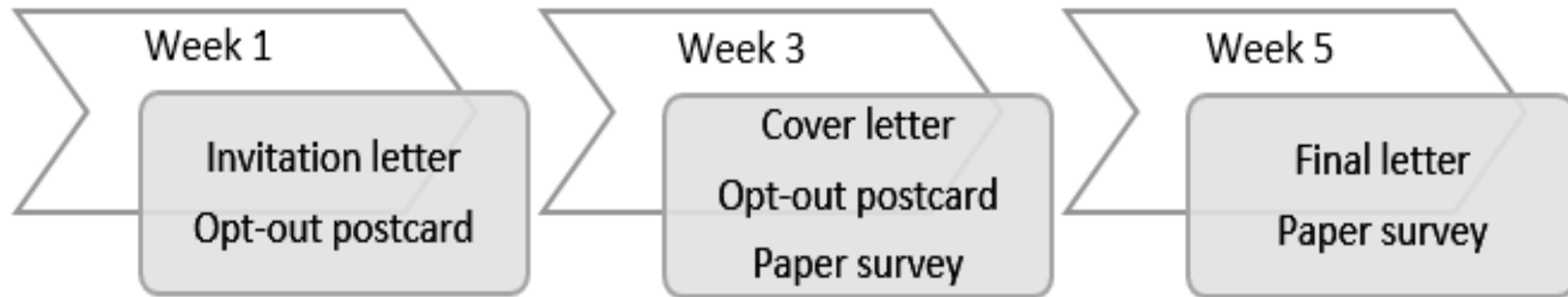
Methods: Sample

- Eligibility criteria: Alaska residents identified in state Cancer Registry with current address
 - Diagnosed between 2004-2016
 - Age 18 or older at time of diagnosis
 - Not deceased
- A sample of 200 per calendar year of diagnosis was drawn (N=2,600)

Methods: Data Collection

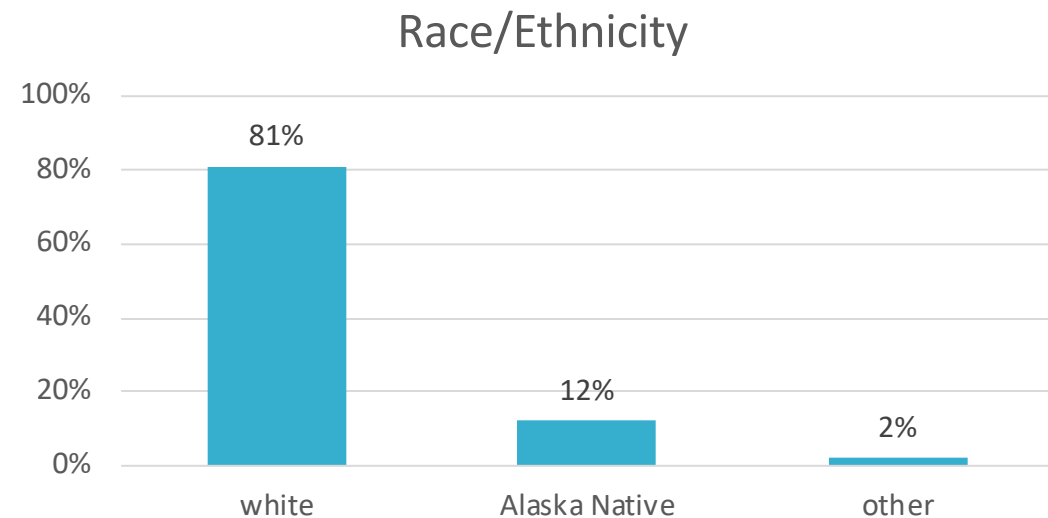
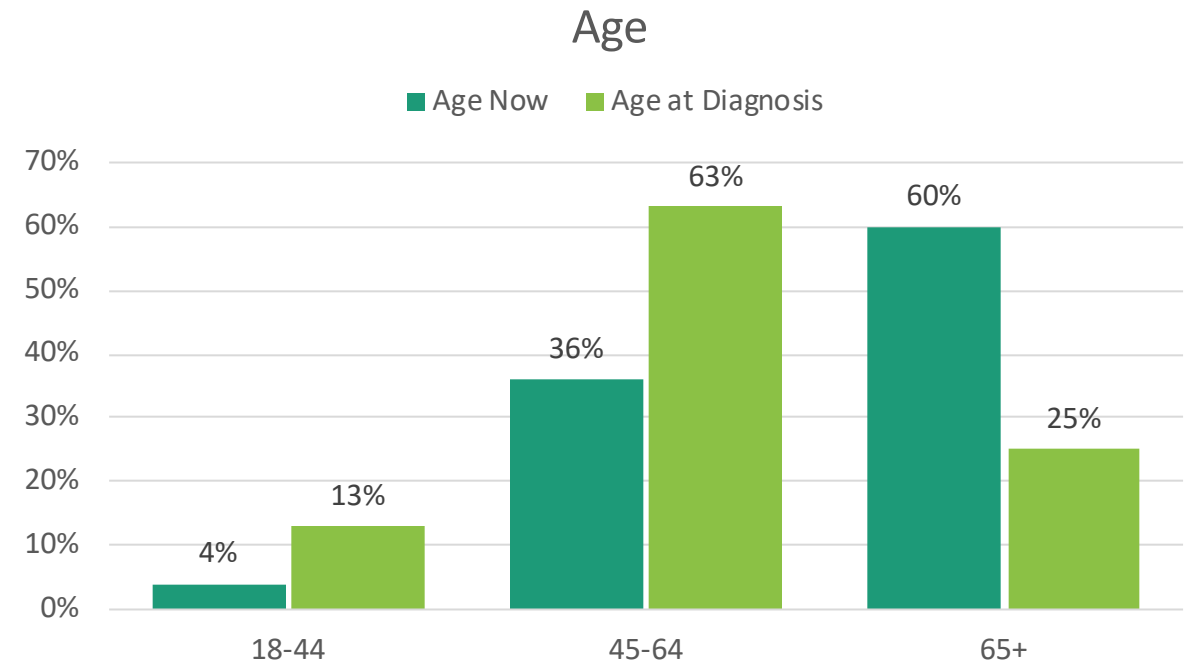


- Survey design and content – largely based on published tools³⁻⁴
 - Paper survey, 4 pages, 41 questions
 - Demographics, source of care
 - Self-reported current *needs*; support *received* for needs since diagnosis
- Recruitment – strictly voluntary, no incentive (Sep-Nov 2019)



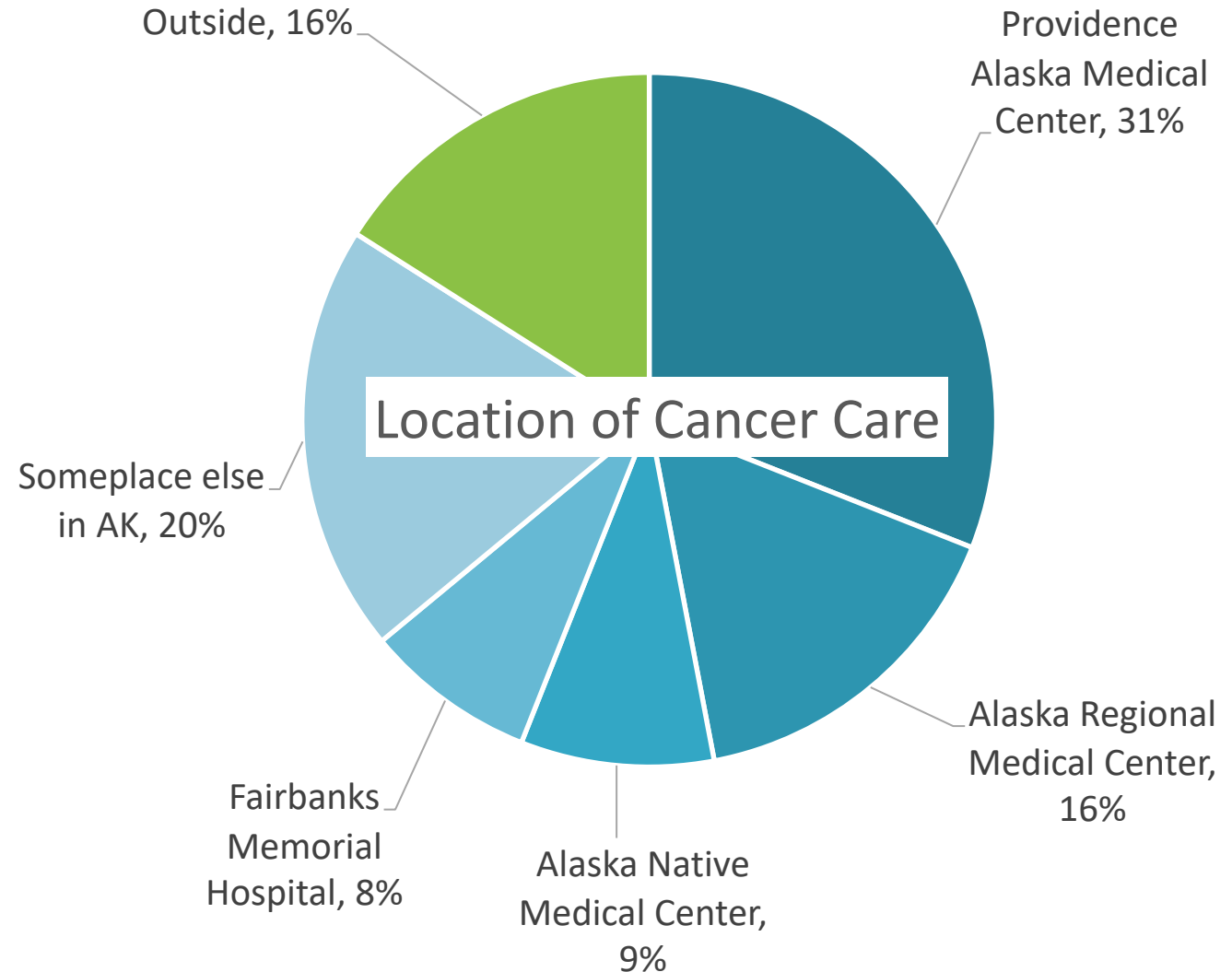
Respondents

- 329 surveys returned (13% response rate)
 - 240 opt-out cards received
 - 19 undeliverable or deceased
 - 2,012 no response
- Gender: 60/40% female/male, <1% non-binary

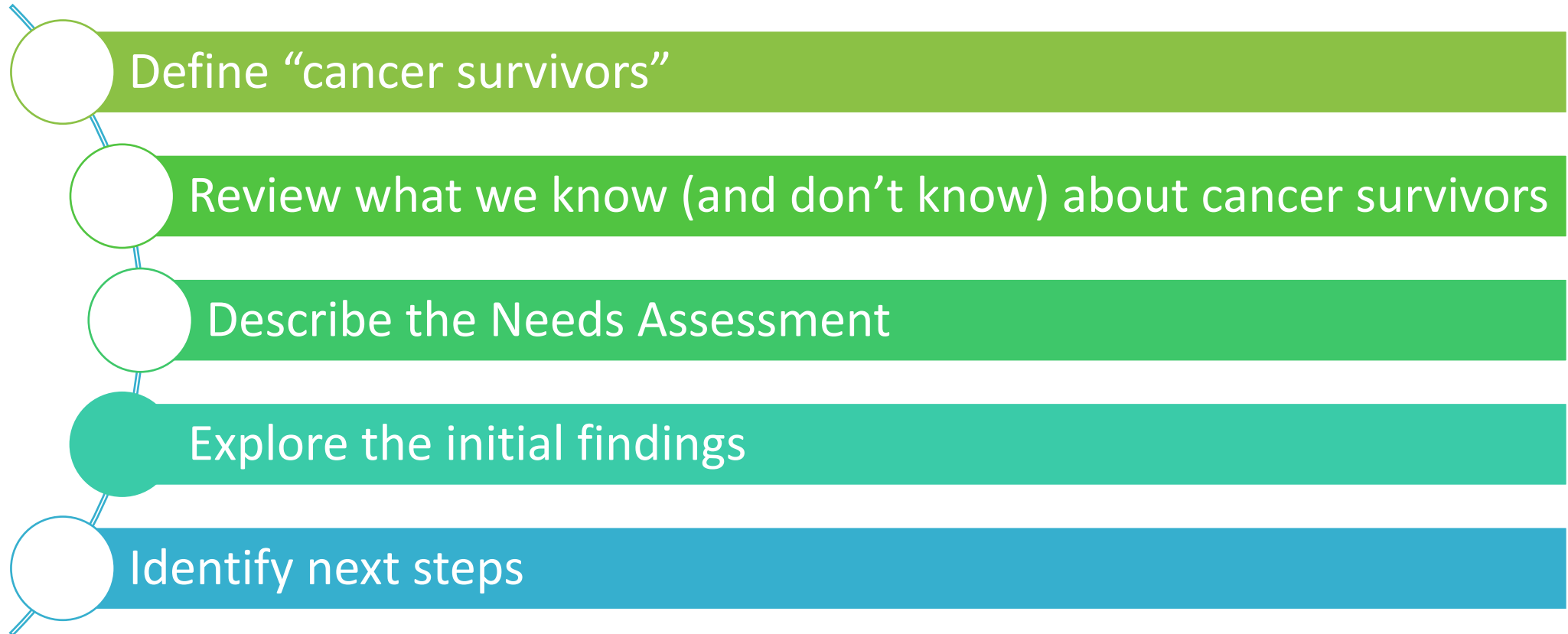


Respondents

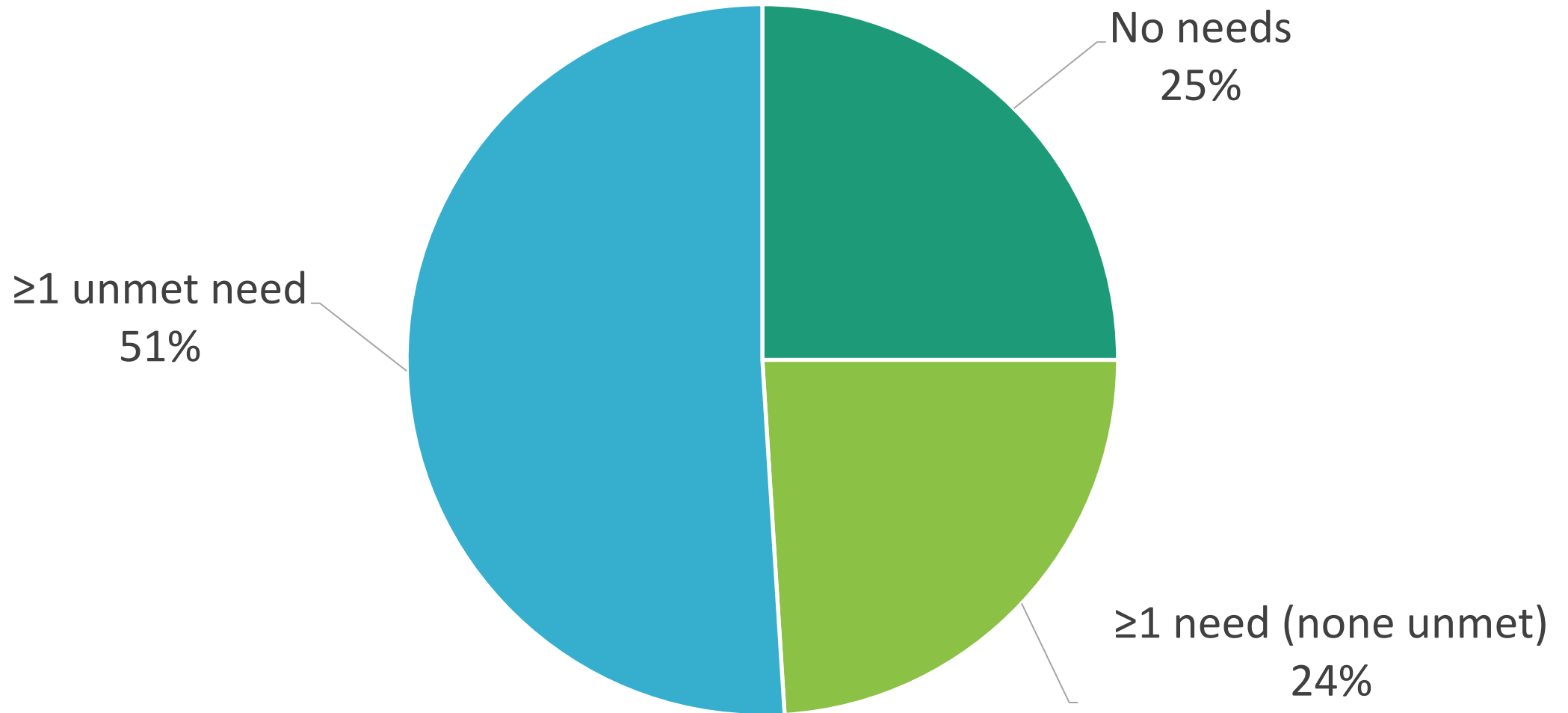
- Average 9 years since first diagnoses
- More than half diagnosed within past 10 years
- Most received the majority of their care in Alaska



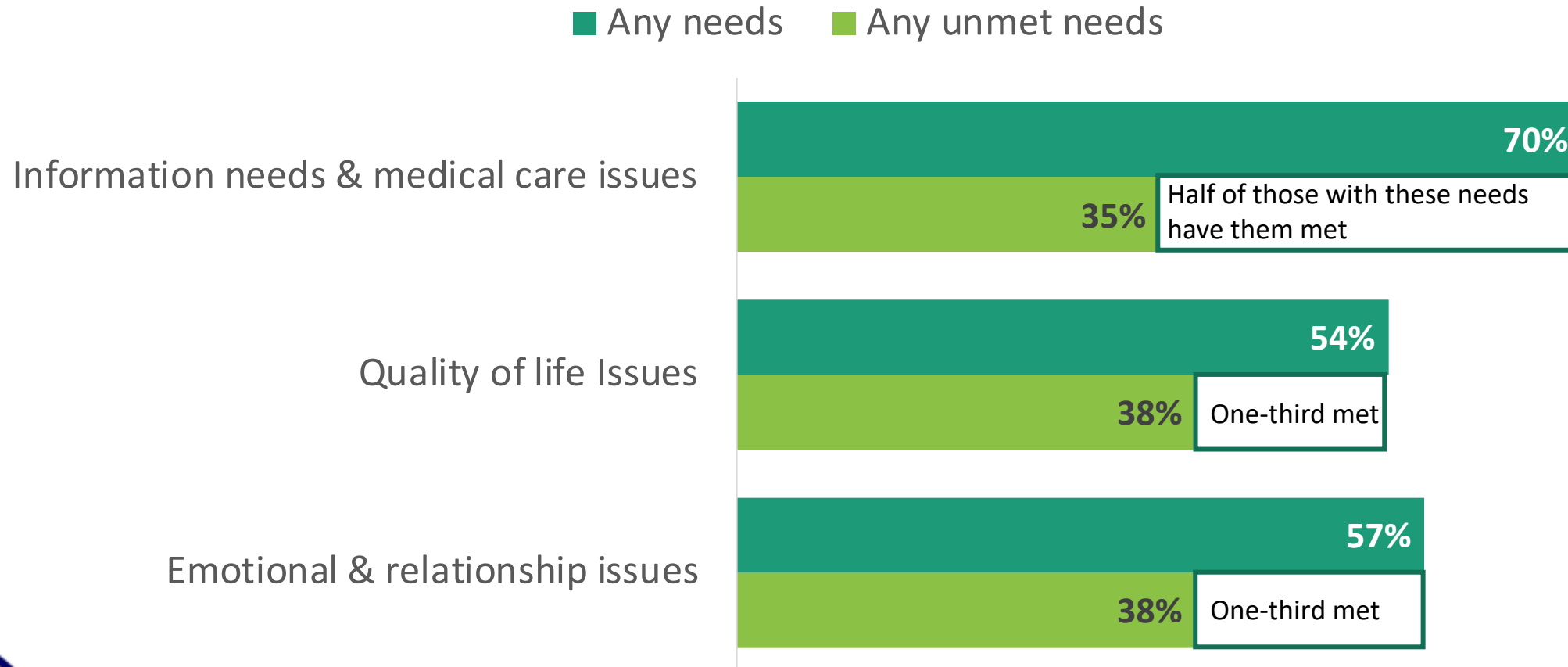
Overview



Findings



Types of Needs



Overall Rank

Most highly ranked needs (met or unmet)

| Survey need item: <i>In the last month I need...</i> (total N= 329) | Total Need (%) |
|--|-------------------|
| 1 - To know that all my doctors talk to each other to coordinate my care | 57.1 |
| 2 - To feel like I am managing my health together with the medical team | 56.6 |
| 3 - Local health care services that are available when I require them | 54.9 |
| 4 - The very best medical care | 53.0 |
| 5 - Help to manage concerns about the cancer coming back | 44.6 |
| 6 - Help to reduce stress in my life | 43.8 |
| 7 - Any complaints regarding my care to be properly addressed | 38.5 |
| 8 - Up to date information | 37.1 |
| 9 - Information provided in a way that I can understand | 35.0 |
| 10 - Emotional support to be provided for me | 33.0 |

Most highly ranked UNmet needs

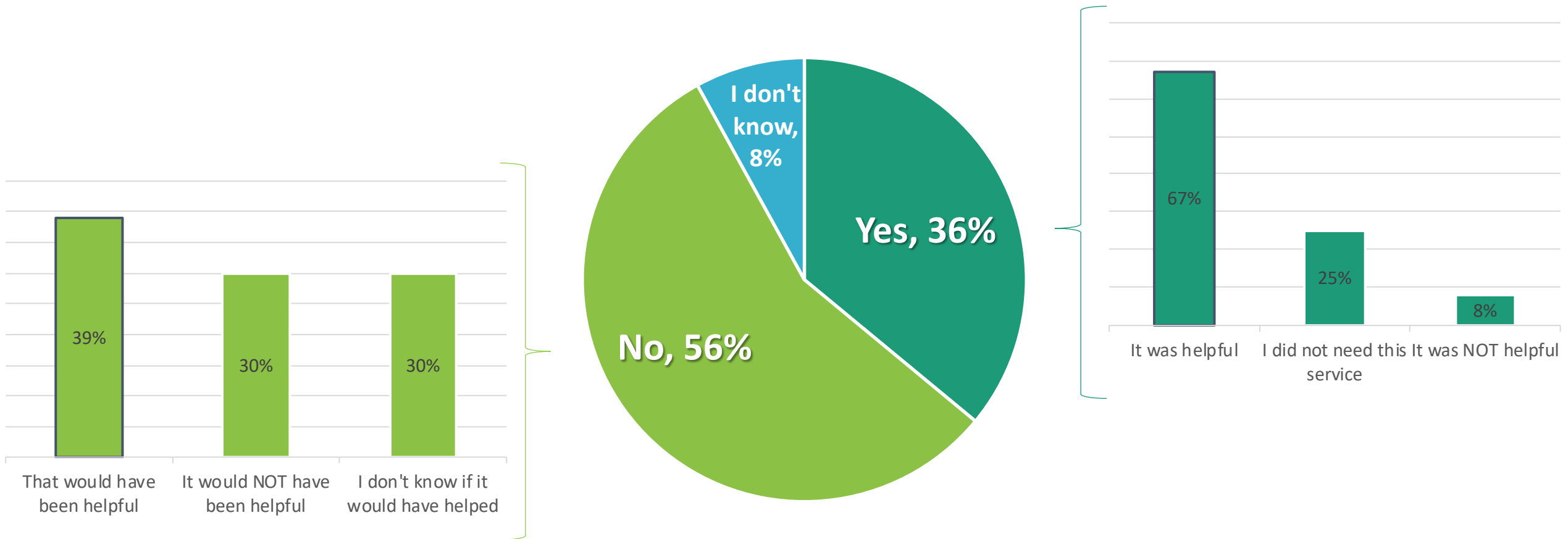
| Survey need item: <i>In the last month I need...</i> (total N= 329) | Unmet Need (%) | Total Need (%) | Overall Rank |
|--|-------------------|-------------------|-----------------|
| 1 - Help to reduce stress in my life | 27.0 | 43.8 | #6 |
| 2 - To know that all my doctors talk to each other to coordinate my care | 24.6 | 57.1 | #1 |
| 3 - Help to manage concerns about the cancer coming back | 24.5 | 44.6 | #5 |
| 4 - Access to complementary and/or alternative therapy services | 20.1 | 31.8 | |
| 5 - Help to adjust to changes to the way I feel about my body | 19.9 | 28.0 | |
| 6 - Help to find out about financial support and/or government benefits to which I am entitled | 19.9 | 25.5 | |
| 7 - Help to address problems with my/our sex life | 19.8 | 26.3 | |
| 8 - An ongoing case manager to whom I can go to find out about services whenever they are needed | 19.8 | 25.0 | |
| 9 - Help to manage ongoing side effects and/or complications of treatment | 19.6 | 32.9 | |
| 10 - To feel like I am managing my health together with the medical team | 17.9 | 56.6 | |

Survivor groups with relatively greater needs

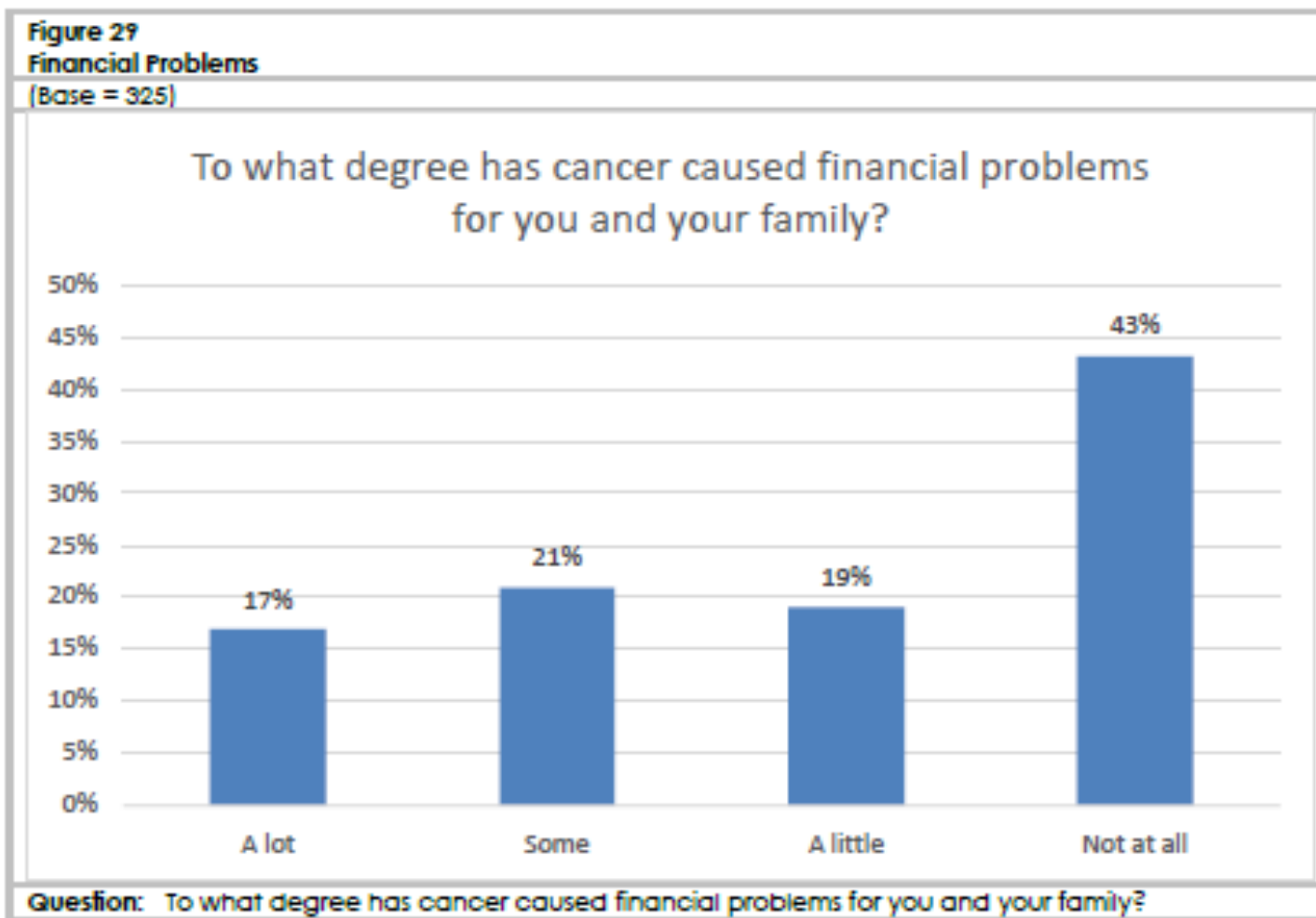
| Statistically significant unadjusted associations ✓✓ p<.05; ✓ p<.10 | Information & Medical Care | Quality of Life | Emotional & Relationship | Total |
|--|----------------------------|-----------------|--------------------------|-------|
| Male | | | | |
| Age group: 18-44 vs. 65+ | | | | |
| Age group: 45-64 vs. 65+ | ✓ | | | |
| Alaska Native | ✓✓ | ✓✓ | ✓✓ | ✓✓ |
| HS or less education | ✓✓ | ✓✓ | | ✓✓ |
| Diagnosis year: 2015-2019 vs. pre-2010 | | | | |
| Diagnosis year: 2010-2014 vs. pre-2010 | | | | |
| Recent care (within last year) | ✓✓ | ✓✓ | ✓✓ | ✓✓ |
| 50+ miles to usual source of care | ✓ | | ✓ | |
| Participated in professional counseling/support group | | | ✓ | ✓ |
| Received help from patient navigator | | | | |

Patient Navigation

Since you were diagnosed with cancer, did you receive support from a patient navigator or case manager?



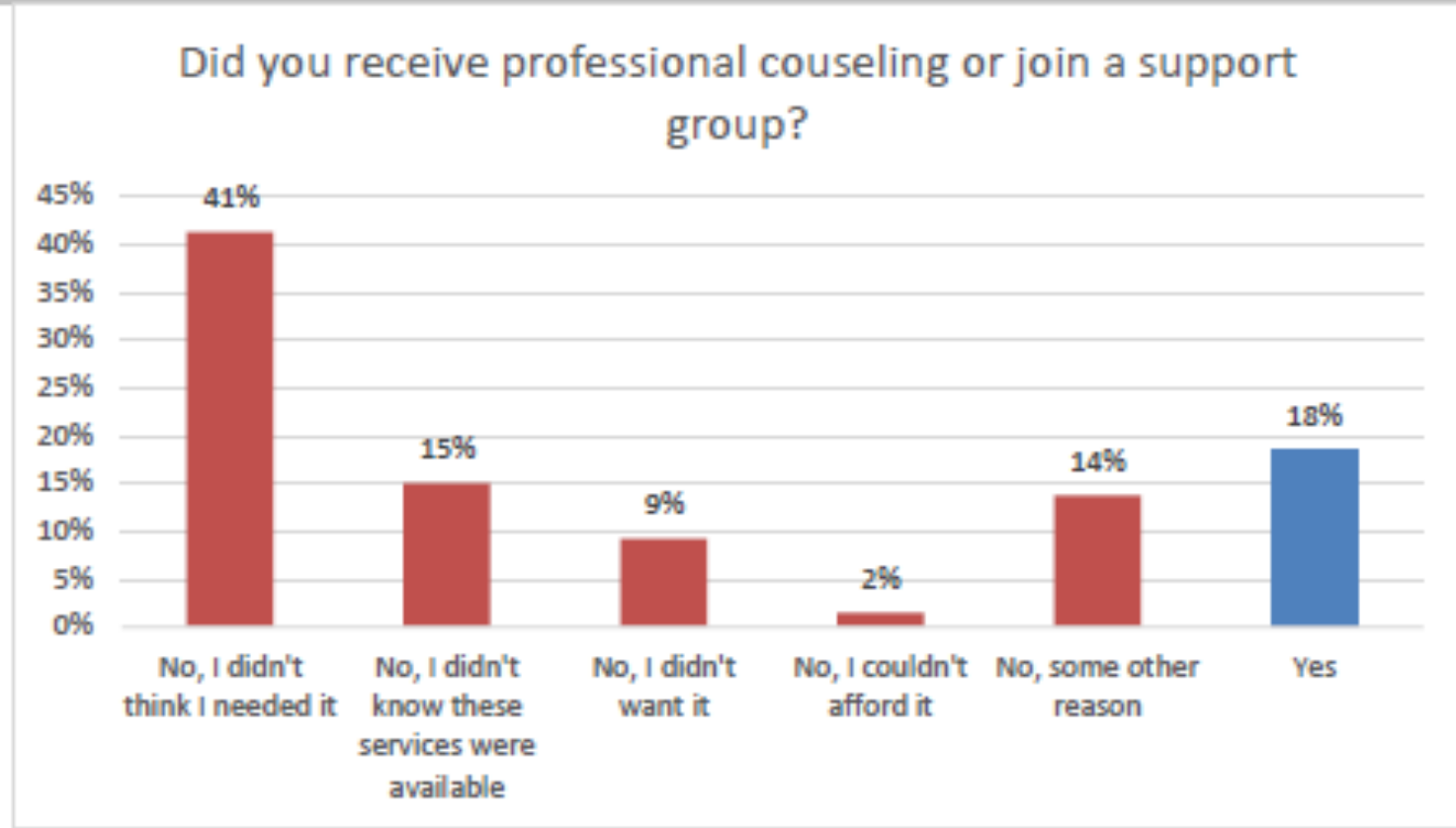
Financial Problems



Support Group Utilization

Figure 28
Professional Counseling or a Support Group

(Base = 324)



Question: After your cancer was diagnosed, did you received professional counseling or join a support group to help you cope?

Initial findings

- Information and Medical Care needs are the most frequently endorsed in a population that's at least 3 years post-diagnosis
- Quality of Life Needs and Relationship & Emotional Needs are less endorsed but also less likely to be met

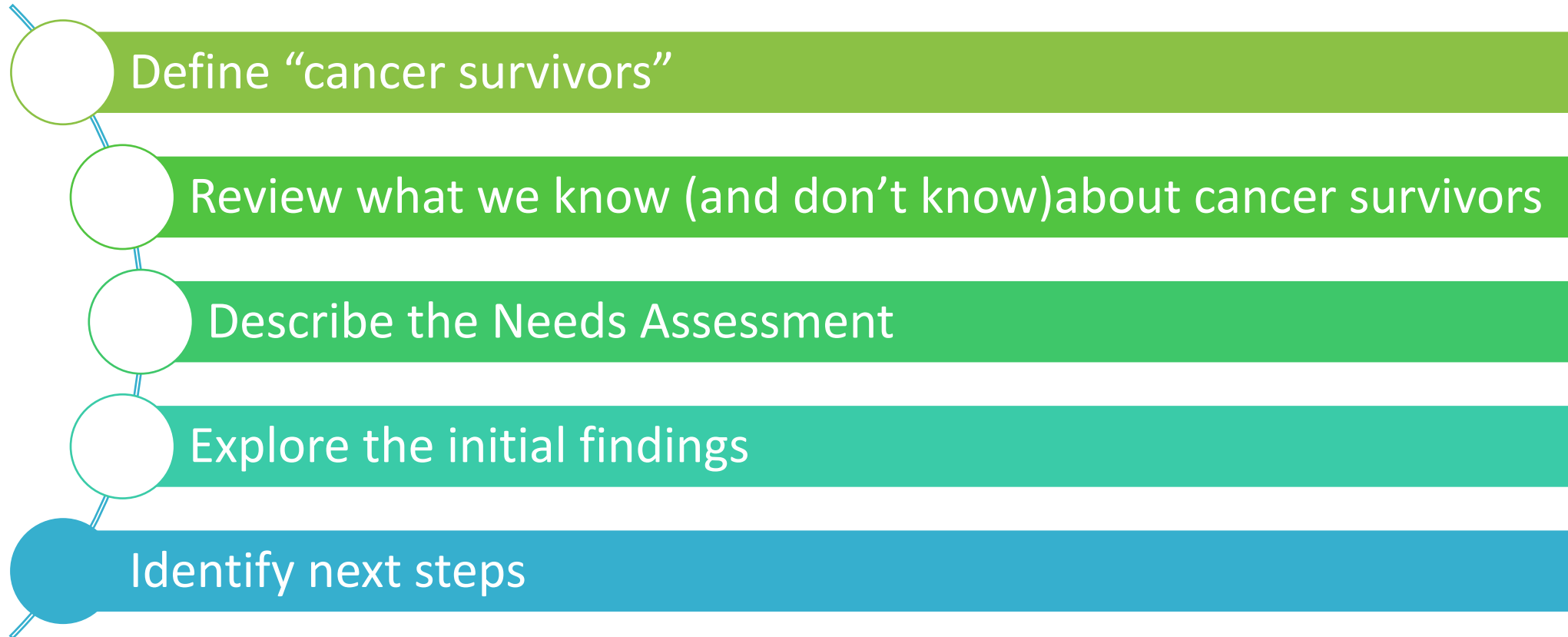
Initial findings

- Survivors who have greater needs are those who are:
 - Still receiving care/treatment
 - Alaska Native
 - High school educated or less
- Distance from care, time since diagnosis, support group/counseling utilization, patient navigation don't appear to impact these measured needs

Initial findings

- The majority of survivors did not receive patient navigation
 - The majority of those who received it, found it helpful
 - Many of those who did not receive it, think it would have been helpful
- The majority of survivors had financial problems as a result of their cancer
- Few Alaskan survivors use professional counseling or support groups
 - Mostly because they don't think they are needed

Overview



Cancer Program Objectives

1. Identify the unmet needs of Alaska's cancer survivors ✓
2. Increase awareness of unmet needs
3. Identify opportunities for improvement
4. Develop recommendations for individuals, public health and community organizations, and health care providers

Next Steps

- Validation against Cancer Registry data
- Further analysis (multivariate, comparison to non-responders)
- Dissemination
- Program planning

Thank You

Technical Advisory Team

- Judith Muller, MHA, ANTHC Cancer Plan
- Sarah Nash, PhD, Alaska Native Tumor Registry
- Andrea Fenaughty, PhD, State of Alaska, Chronic Disease Epi
- Rosa Avila, PhD, Alaska Cancer Registry
- David O'Brien, PhD, Alaska Cancer Registry
- Julia Dilley, PhD, Program Design and Evaluation Services

Alaska Cancer Partnership, Survivorship Work Group

References

¹National Cancer Institute. NCI Dictionary of Cancer Terms. Available at <https://www.cancer.gov/publications/dictionaries/cancer-terms>

²An estimated 31,000 people were diagnosed in Alaska but may no longer reside in this state. Estimate based on linear trend projections from 2018. Unpublished data. Anchorage, Alaska: Health Analytics and Vital Records Section, Division of Public Health, Alaska Department of Health and Social Services; July 18 2019.

³Hodgkinson K, Butow P, Hunt GE, Pendlebury S, Hobbs KM, Lo SK, et al. The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CaSUN (Cancer Survivors' Unmet Needs measure). *Psychooncology*. 2007;16(9):796-804.

⁴National Center for Health Statistics. Data File Documentation, National Health Interview Survey, 2010. National Center for Health Statistics, Centers for Disease Control and Prevention, Hyattsville, Maryland. 2011.

Back-up slides

Cancer Survivor Unmet Needs (CaSUN) Tool

Information Needs & Medical Care Issues

1. I need up to date information
2. My family and/or partner needs information relevant to them
3. I need information provided in a way that I can understand
4. I need the very best medical care
5. I need local health care services that are available when I require them
6. I need to feel like I am managing my health together with the medical team
7. I need to know that all my doctors talk to each other to coordinate my care
8. I need any complaints regarding my care to be properly addressed
9. I need access to complementary and/or alternative therapy services



Cancer Survivor Unmet Needs (CaSUN) Tool

Quality of Life Issues

1. I need help to reduce stress in my life
2. I need help to manage ongoing side effects and/or complications of treatment
3. I need help to adjust to changes in my quality of life as a result of my cancer
4. I need help with having a family due to fertility problems
5. I need assistance with getting and/or maintaining employment
6. I need help to find out about financial support and/or government benefits to which I am entitled
7. Due to my cancer, I need help getting life and/or travel insurance
8. Due to my cancer, I need help accessing legal services
9. I need more accessible hospital parking



Cancer Survivor Unmet Needs (CaSUN) Tool

Emotional & Relationship Issues

1. I need help to manage concerns about the cancer coming back
2. I need emotional support to be provided for me
3. I need help to know how to support my partner and/or family
4. I need help to deal with the impact that cancer has had on my relationship with my partner
5. I need help with developing new relationships after my cancer
6. I need to talk to others who have experienced cancer
7. I need help to handle the topic of cancer in social and/or work situations
8. I need help to adjust to changes to the way I feel about my body
9. I need help to address problems with my/our sex life
10. I need an ongoing case manager to whom I can go to find out about services whenever they are needed

Example Items

| In the last month... | NO UNMET NEED | | NEED IS CURRENTLY UNMET How strong is your need? | | |
|----------------------------------|----------------------------------|--|---|-------------------------------------|--------------------------|
| | No need, or not applicable | Have need, but need is being met | Weak | Moderate | Strong |
| 1. I need up to date information | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |

Explanation: *This person has needed information following the completion of their cancer treatments and this need is moderately strong.*

Example Items

| In the last month... | NO UNMET NEED | | NEED IS CURRENTLY UNMET How strong is your need? | | |
|---|----------------------------------|--|---|--------------------------|--------------------------|
| | No need, or not applicable | Have need, but need is being met | Weak | Moderate | Strong |
| 2. My family and/or partner needs information relevant to them. | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Explanation: *This person's partner/family has a need for information but this need is currently being met.*

Cancer survivors most highly ranked **met** needs

| Survey need item: <i>In the last month I need...</i> (total N= 329) | Met need (%) | Unmet need (%) | Total need (%) |
|---|--------------|----------------|----------------|
| 1. Local health care services that are available when I require them | 39.1 | 15.8 | 54.9 |
| 2. To feel like I am managing my health together with the medical team | 38.7 | 17.9 | 56.6 |
| 3. The very best medical care | 37.0 | 16.0 | 53.0 |
| 4. To know that all my doctors talk to each other to coordinate my care | 32.5 | 24.6 | 57.1 |
| 5. Any complaints regarding my care to be properly addressed | 22.4 | 16.1 | 38.5 |
| 6. Help to manage concerns about the cancer coming back | 20.1 | 24.5 | 44.6 |
| 7. Up to date information | 19.3 | 17.8 | 37.1 |
| 8. Information provided in a way that I can understand | 18.0 | 17.0 | 35.0 |
| 9. Help to reduce stress in my life | 16.8 | 27.0 | 43.8 |
| 10. Emotional support to be provided for me | 15.3 | 17.8 | 33.0 |

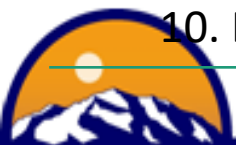


Most highly ranked UNmet needs

| Survey need item: <i>In the last month I need...</i> (total N= 329) | Met need (%) | Unmet need (%) | Total need (%) |
|--|-----------------|-------------------|-------------------|
| 1. Help to reduce stress in my life (met need #9) | 16.8 | 27.0 | 43.8 |
| 2. To know that all my doctors talk to each other to coordinate my care (met need #4) | 32.5 | 24.6 | 57.1 |
| 3. Help to manage concerns about the cancer coming back (met need #6) | 20.1 | 24.5 | 44.6 |
| 4. Access to complementary and/or alternative therapy services | 11.6 | 20.1 | 31.8 |
| 5. Help to adjust to changes to the way I feel about my body | 8.1 | 19.9 | 28.0 |
| 6. Help to find out about financial support and/or government benefits to which I am entitled | 5.6 | 19.9 | 25.5 |
| 7. Help to address problems with my/our sex life | 6.6 | 19.8 | 26.3 |
| 8. An ongoing case manager to whom I can go to find out about services whenever they are needed | 5.2 | 19.8 | 25.0 |
| 9. Help to manage ongoing side effects and/or complications of treatment | 13.4 | 19.6 | 32.9 |
| 10. To feel like I am managing my health together with the medical team (met need #2) | 38.7 | 17.9 | 56.6 |

Most highly ranked needs (met or unmet)

| Survey need item: <i>In the last month I need...</i> (total N= 329) | Met need (%) | Unmet need (%) | Total need (%) |
|---|-----------------|-------------------|-------------------|
| 1. To know that all my doctors talk to each other to coordinate my care | 32.5 | 24.6 | 57.1 |
| 2. To feel like I am managing my health together with the medical team | 38.7 | 17.9 | 56.6 |
| 3. Local health care services that are available when I require them | 39.1 | 15.8 | 54.9 |
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| 9. Information provided in a way that I can understand | 18.0 | 17.0 | 35.0 |
| 10. Emotional support to be provided for me | 15.3 | 17.8 | 33.0 |



Exploring differences by survivor characteristics

- Gender: Male vs. Female (small number non-binary excluded)
- Age group (current age): 18-44 and 45-64 vs. 65+
- Race: Alaska Native/American Indian vs. white (other excluded)
- Education: HS or less vs. any post-HS education
- Diagnosis year: 2015-2019 and 2010-2014 vs. pre-2010
- Survivorship status: current/recent care (currently in treatment, managing as a chronic illness, receiving hospice/palliative care, finished <1 year ago) vs. finished treatment 1+ years ago
- Distance to usual source of care: <50 miles vs. 50+ miles
- Received professional counseling: yes vs. no
- Received help from a patient navigator: yes vs. no/don't know



Methods: Scales and Associations

- No needs=0, met needs = 1, unmet needs = 2
- Summed items within each of 3 domains of needs, and total for all
- Regression models to test for differences across subgroups (only statistically significant differences reported)