National Coalition for Cancer Survivorship (NCCS)

Webinar: Redefining Functional Status (RFS) Project Findings

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Presented by:

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Impacting Policy - Empowering Survivors - Transforming Care

Survivors, Not Victims

What does "living well" with cancer mean to you?

Provide your answer in the chat box

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Cancer Quality Measurement

- Focused on process – did the patient get the right test, right treatment, right procedure?
- Limited outcome measures – avoidable hospitalizations and emergency department visits
- What would quality measurement look like if it reflected what patients and caregivers say matter the most to them?

Measuring Functional Status

- Patient-centered measure development project to define cancer outcome measure(s) in this critical area, using the Principles of Patient-Centered Measurement
- Original Title: *Return to Functional Status (RFS): Patient-Led Cancer Outcome Measurement*
- Funded by the American Institutes for Research (AIR), with support from the Robert Wood Johnson Foundation (RWJF): Pilot projects to implement Principles of Patient-Centered Measurement

High Level Project Steps

Convened diverse committee of 10 cancer survivors, as well as Technical Expert Panel (TEP)

Solicited input from cancer survivors through various social media platforms

Developed conceptual definition of ‘return to functional status’ by cancer patients and survivors

Evaluated existing validated surveys for best alignment with the conceptual definition

Developed patient-centered specifications for RFS outcome measures (PRO-PMs)

Sufficiently detailed to allow for testing and validation in a subsequent initiative

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Project Committees

- RFS Committee
  - Members invited to reflect a diverse range of experiences
  - Charged with leading development of the RFS measure by defining the concept (via structured RAND Delphi approach); reviewing and contributing to the development of patient-centered specifications
- Clinical/methodologist panel
  - Members who are experienced in cancer patient-reported outcomes, functional status research, measurement methodology, and implementation / clinical workflow
  - Charged with making recommendations to the RFS Committee and project team on methodologic and implementation issues

RFS Committee

- Rebecca Esparza
- Betsy Glosik
- Matt Goldman
- Candace Henley
- Allen Hirsch
- Kirby Lewis
- Allison Rosen
- Susan Strong
- Desiree Walker
- Dan Weber

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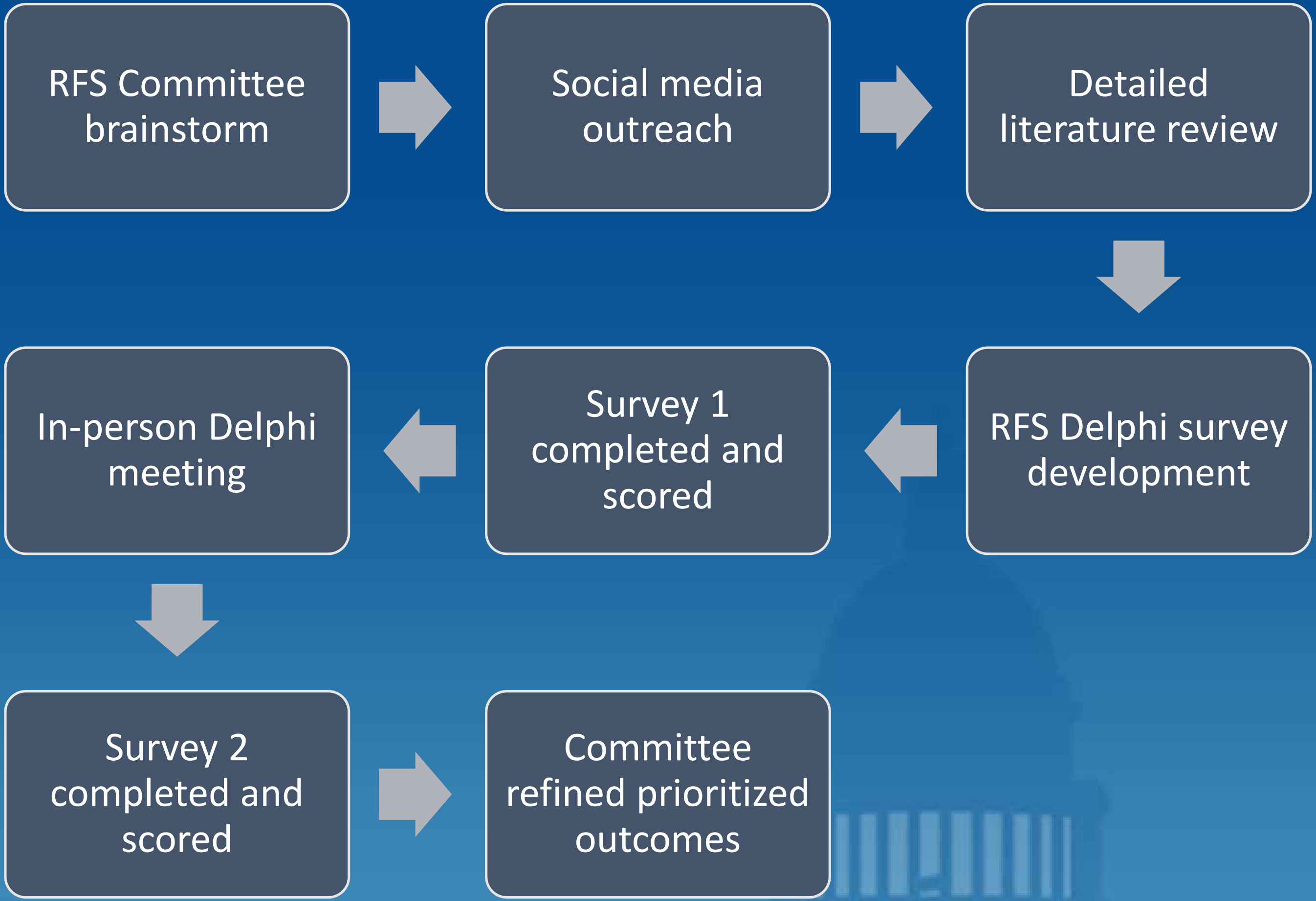
Conceptualization

Core challenge:

- What does ‘return to functional status’ mean?
- How can the concept be measured to evaluate quality of oncology care?

Project Methodology



RFS Committee brainstorm

Social media outreach

Detailed literature review

RFS Delphi survey development

Survey 1 completed and scored

In-person Delphi meeting

Survey 2 completed and scored

Committee refined prioritized outcomes

Social Media Questions

- What personal/life activities, events or accomplishments do you consider when you think of a cancer survivor living well DURING cancer treatment?
- What personal/life activities, events or accomplishments do you consider when you think of a cancer survivor living well AFTER cancer treatment?
- What are the most important impacts on your quality of life from your cancer or cancer treatment? Did/does your care team help you address these challenges?

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Conceptualization Methodology

RAND Delphi Process

Main steps:

1. Structured survey prepared, informed by literature review, committee brainstorming, social media outreach
2. Structured survey completed by RFS Committee members
3. In-person meeting to review and discuss survey responses; attention to areas of disagreement and uncertainty
4. Survey re-scored by RFS Committee
5. Results and and conclusions reviewed by RFS Committee, minor refinements made

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Expectations Confirmed

- 'We should measure…': Commonly used jargon often lacks meaning
- Putting patients in the driver's seat significantly changes the resulting measures
- Patient committees can be successful in identifying system gaps as measurement priorities
  - *Everyone* brings personal experience to the table
- Gaps in current system are such that measurement alone will be insufficient

Lessons Learned

What we expected…	What we found…
Focus on/measurement of survivors in the post-treatment phase	Commitment to include those receiving extended/chronic treatment as well
Discussions of system gaps	Reality of a system that lacks reliable expectations, norms, infrastructure to provide care that supports RFS
Focus on return to previous activities (e.g. return to work)	A group of prioritized outcomes and set of measures
Concern about appropriate patient responsibility	Concern about appropriate provider accountability

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Selected Results

1. Renaming the concept
2. Prioritized outcomes for measurement of RFS
3. Resulting measure set

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Renaming the Concept

- Immediate feedback from Committee during brainstorming – ‘return to functional status’ is not adequately descriptive
- Following in-depth discussion at in-person meeting, Committee renamed the concept **Redefining Functional Status**

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Prioritized Outcomes

- Overall Quality of Life
  - Physical and mental health
- Physical Function
- Pain Interference
- Fatigue Interference
- Cognitive Function
- Psychosocial Impact

RFS Measure Set

Who is accountable/being measured? Medical oncology teams

Denominator/people for whom quality of care is being assessed? 1) Those who completed chemotherapy; 2) Those who are receiving extended chemotherapy

Process: Survey-based assessment of priority outcomes

Process: Action taken when indicated by survey responses

Outcomes: experience of care (communication re: side/late effects and financial impact)

Outcomes: prioritized patient reported outcomes

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How Survivors Shaped the Project

- ***Name of project:*** changed from "return to functional status" to "redefining functional status"
- ***Composition of committee:*** added committee members with metastatic and chronic cancers
- ***Scope of measurement:*** considered people currently in treatment, as well as people who have completed cancer treatment
- ***Measures specified:*** included process measures for functional status assessment, in addition to outcome measures

> ***"Patient centered measurements are hugely important and I didn't recognize its value prior to participating in this study. Patients aren't always comfortable letting their provider know what they are experiencing and having a quality measurement that allows a patient to share their concerns, issues or changes can overcome the fear of speaking up."***
>
> ***-Matt Goldman, Multiple Myeloma Survivor and RFS Committee member***

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RFS Committee Members

Allison Rosen, Colon Cancer Survivor

Rebecca Esparza, Ovarian Cancer Survivor

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