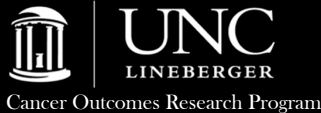


# Patient-Reported Outcomes (PROs) in Cancer Care

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Summer, 2020

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## Learning Objectives

- Describe what patient reported outcomes (PROs) are and how are they used in cancer care
- Describe the clinical outcomes PROs can improve when completed remotely outside the clinic (at home) and in clinic
- Apply understanding of PROs via an implementation case study at NC Cancer Hospital

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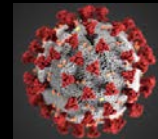
## Part I:

### PRO Background



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## COVID-19 and PROs



**Management of cancer and health after the clinic visit: A call to action for self-management in cancer care**

Doris Howell, Deborah K Mayer, et al.

*JNCI: Journal of the National Cancer Institute*,  
djaa083, <https://doi.org/10.1093/jnci/djaa083>

Published: 11 June 2020

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## PRO Measurement

- Patient-Reported Outcome measure (PRO):  
Measurement based on report that comes directly from patient about status of patient's health condition **without amendment or interpretation of patient's response**
  - New FDA guidance in 2020



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## Common PROs and PREMs

### PROs

- Symptoms
- Functional status
- Quality of life
- Self-efficacy for managing condition



### PREMs

- Satisfaction with care
- CAHPS



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## Example PRO Items

Welcome **jaynedoe** Home Log out

Please think back over **the past 7 days**: Page: 2 of 5 Progress:

**How OFTEN did you have ARM OR LEG SWELLING?**

**What was the SEVERITY of your ARM OR LEG SWELLING at its WORST?**

**How much did ARM OR LEG SWELLING INTERFERE with your usual or daily activities?**

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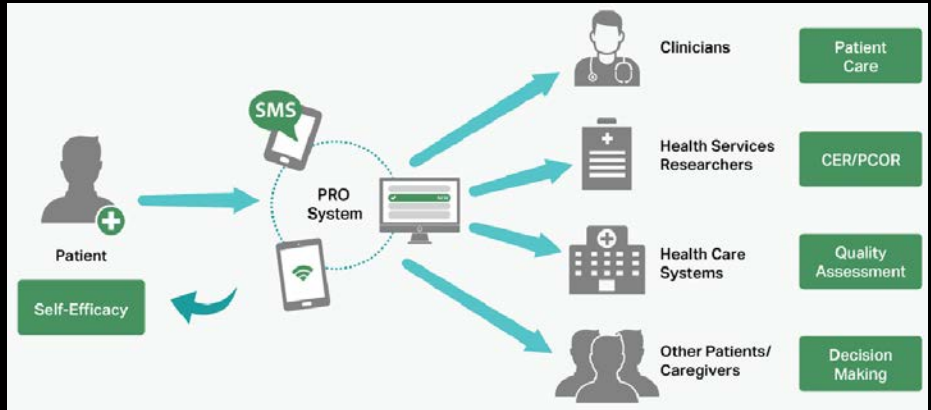
## PHQ-9 Items

Over the last 2 weeks, how often have you been bothered by any of the following problems?  
(use “~” to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself	0	1	2	3

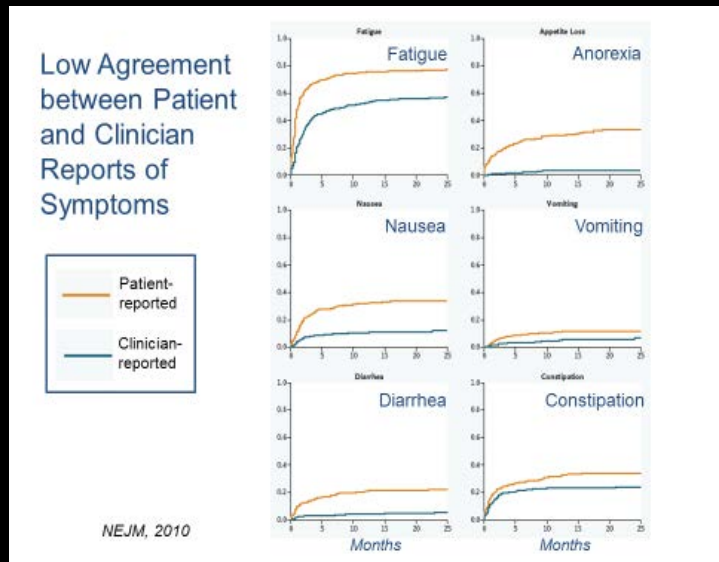
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# PRO Uses in Healthcare



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# Why Are PROs Important in Health Care?



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## How Long Do Patients Have to Talk?

ORIGINAL RESEARCH

### Eliciting the Patient's Agenda- Secondary Analysis of Recorded Clinical Encounters

Naykky Singh Ospina, MD, MSc<sup>1,2</sup>, Kari A. Phillips, MD<sup>3</sup>, Rene Rodriguez-Gutierrez, MD, MSc<sup>2,4,5</sup>, Ana Castaneda-Guarderas, MD<sup>6</sup>, Michael R. Gionfriddo, Pharm D, PhD<sup>7</sup>, Megan E. Branda, MS<sup>8,9</sup>, and Victor M. Montori, MD MSc<sup>2</sup>

- Analyzed recorded consultations
- 112 patients and 66 physicians between 2008-15
  - Specialty care: 51 visits, primary care: 61 visits
- Median encounter: 30 min (range: 4 - 80 min.)

Singh Ospina, et al. JGIM 2019;34(1):36-40.

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## How Long Do Patients Have to Talk?



Clinician interrupted after median of **11 seconds**  
(interquartile range 7-22 s)

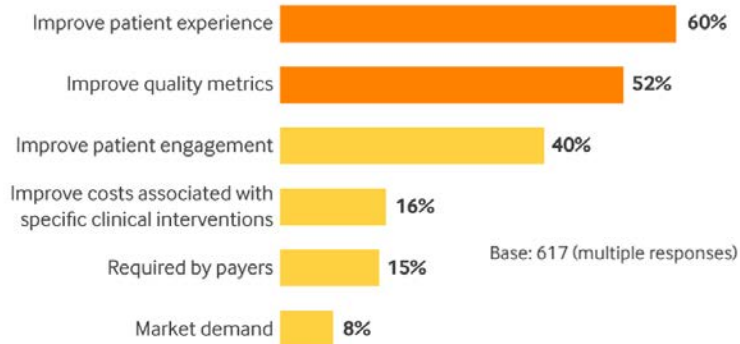
Singh Ospina, et al. JGIM 2019;34(1):36-40.

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## Why are Health Systems Interested in PROs?

### Better Patient Experience and Quality Are the Top Reasons to Collect and Use PROMs

What are the top two reasons for health care organizations to collect and use Patient-Reported Outcome Measures (PROMs)?



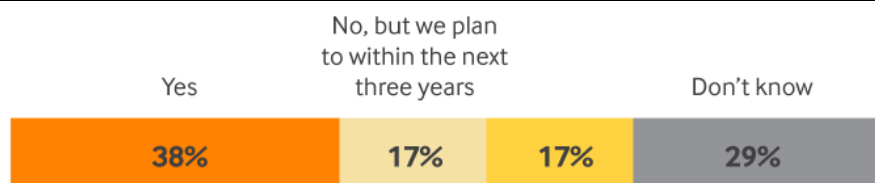
Base: 617 (multiple responses)

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

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## PRO Usage in Clinics Growing

Does your organization use a Patient-Reported Outcome Measures (PROMs) system?



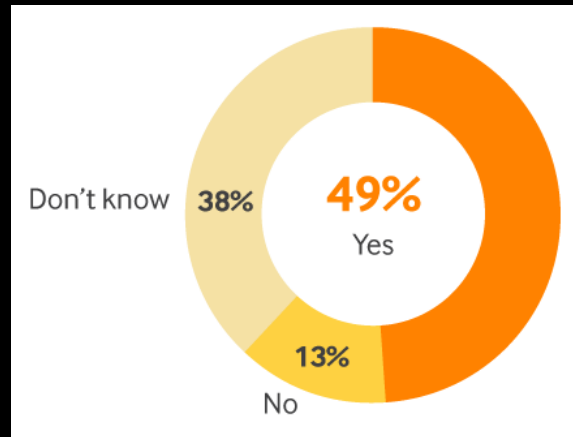
No, and we have no plans to do so

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

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## Among Sites Using PROs, Worth it to Implement?

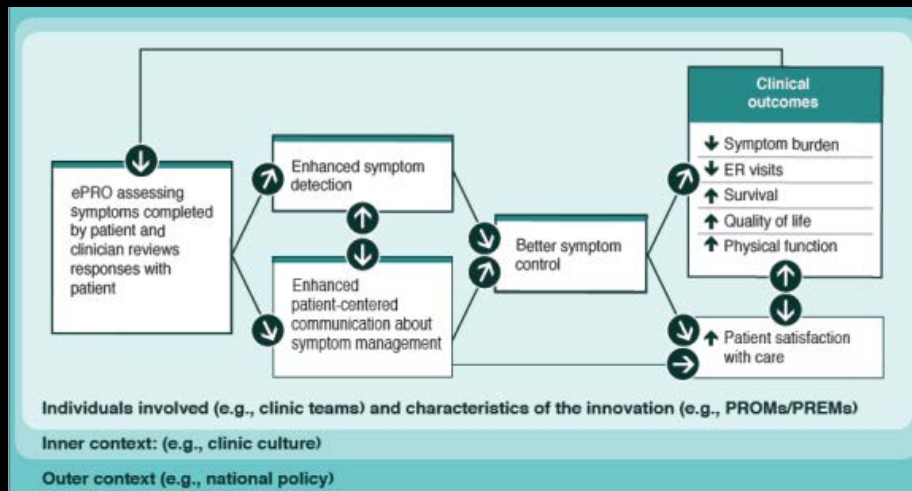
Is the effort involved in collecting, processing, and implementing PROMs worth the result?



NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

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## How do PROs Improve Outcomes?



Stover, 2020

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## Part II:

### Remote PROs outside the clinic



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### PRO Randomized Trial at MSK

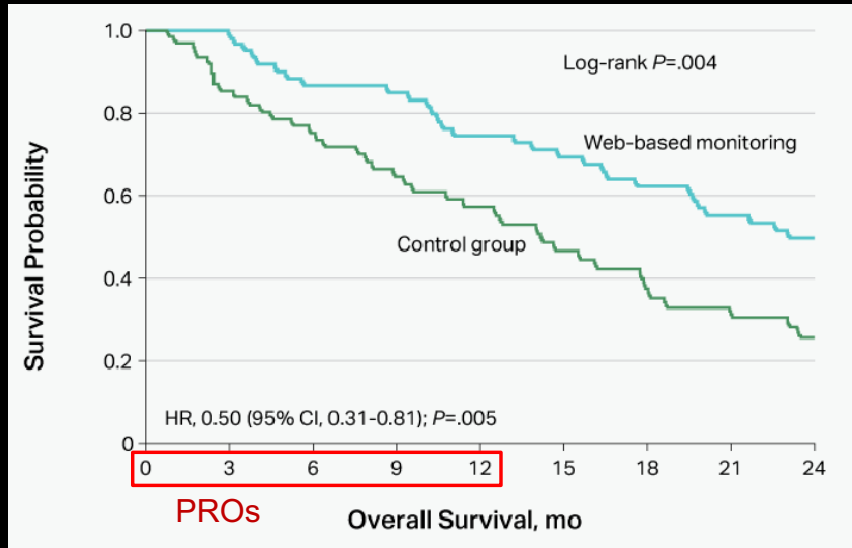


#### PRO Intervention Group:

- Remained on chemo longer (8.2 v 6.3 months)
- More likely to survive at 1 and 5 years
- Less likely to visit ER: 35% v 41%

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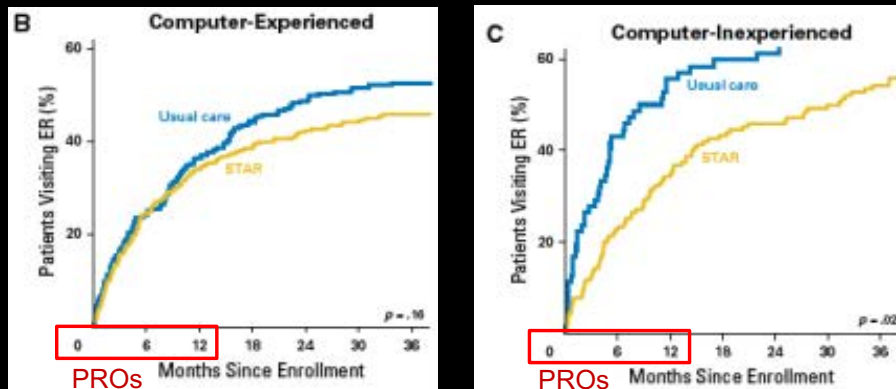
## PROs Improve Survival



Basch E, et al. JAMA. 2017;318(2):197-198.

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## PROs Improve ER Rates



Basch E, et al. JCO. 2016;34(6):557-565.

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## UNC's National PRO Trial

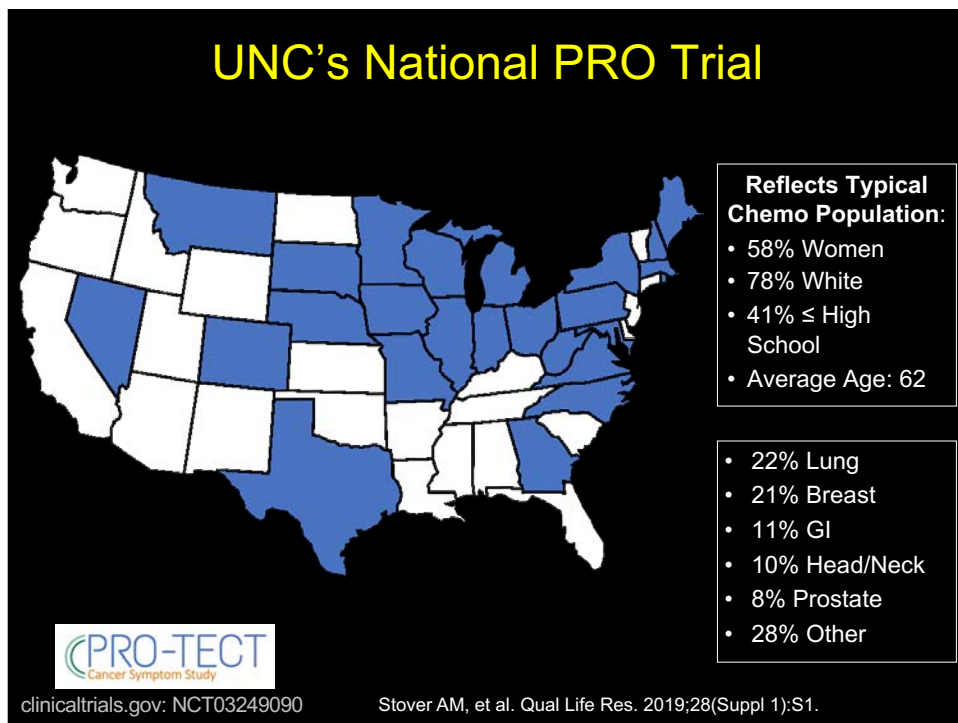


- 52 community cancer centers randomized to usual care or home PROs with alerts to clinicians
- All adult patients receiving chemotherapy
- 1,200 patients enrolled
- Follow up continues up to 12 months

Stover AM, et al. Qual Life Res. 2019;28(Suppl 1):S1.

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## UNC's National PRO Trial



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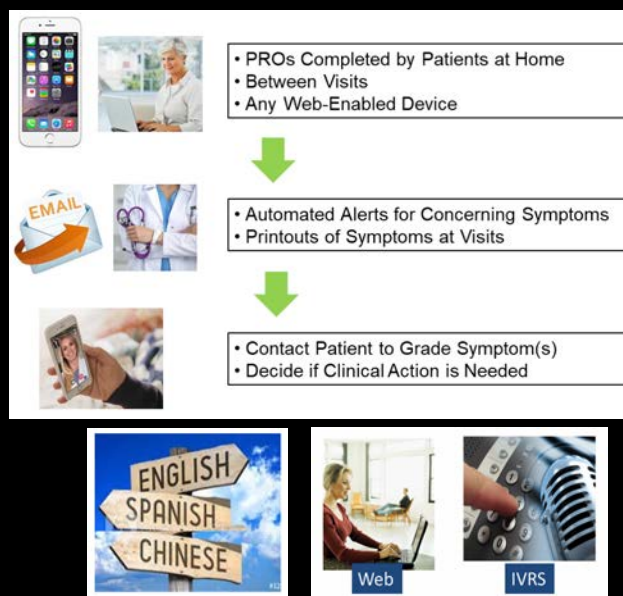
## Symptoms Assessed in PRO-TECT

Symptom
Pain
Diarrhea
Constipation
Nausea, Vomiting
Physical Function
Eating/Drinking
Fatigue
Insomnia
Dyspnea
Depression
Falls

Stover AM, et al. Qual Life Res. 2019;28(Suppl 1):S1.

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## Intervention Arm



Stover AM, et al. Qual Life Res. 2019;28(Suppl 1):S1.

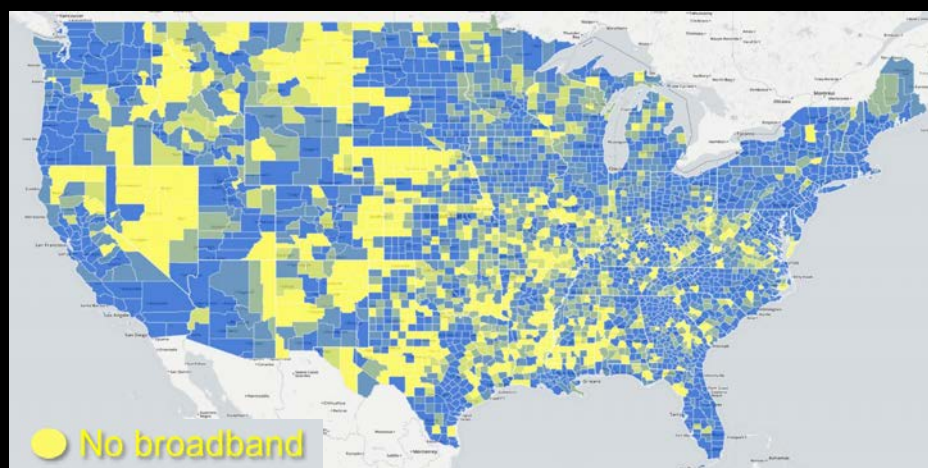
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39%

Stover AM, et al. Qual Life Res. 2019;28(Suppl 1):S1.

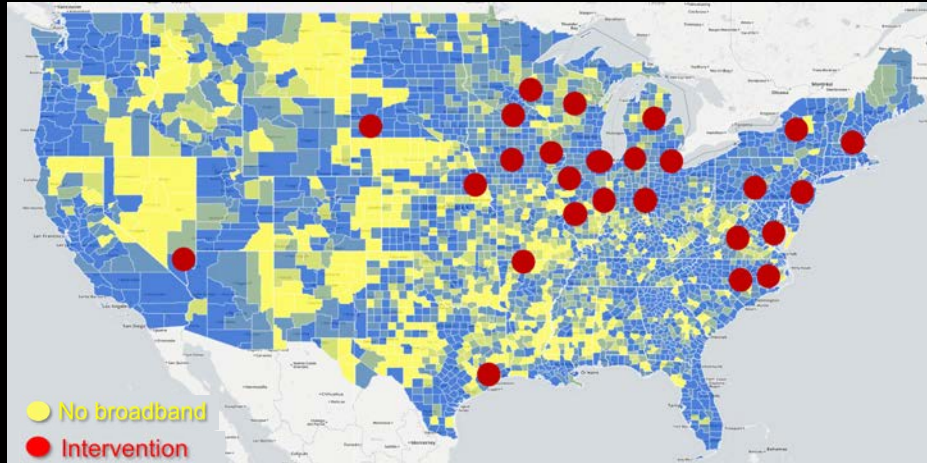
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## U.S. Broadband Access



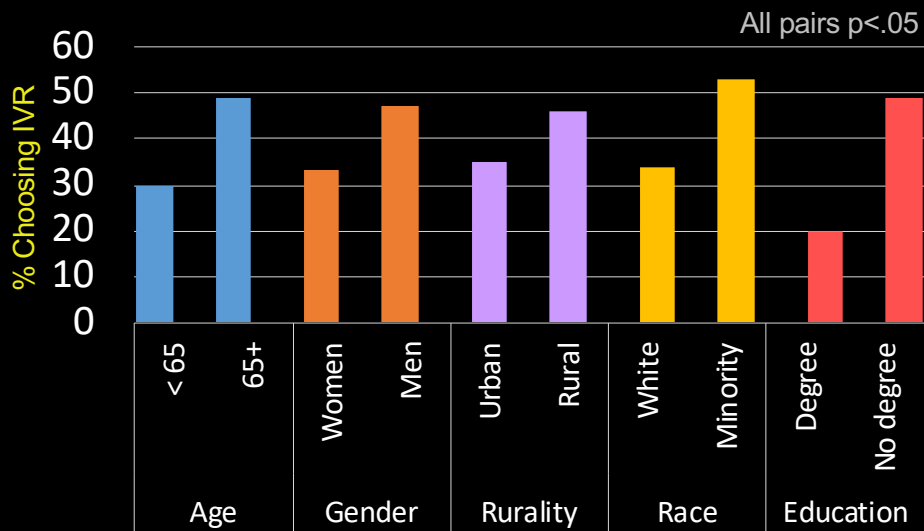
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## U.S. Broadband Access: 26 Intervention Sites



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## At-Risk Populations More Likely to Choose IVR

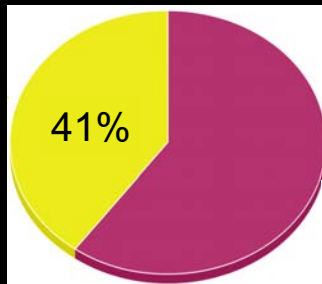


Stover AM, et al. Qual Life Res. 2019;28(Suppl 1):S1.

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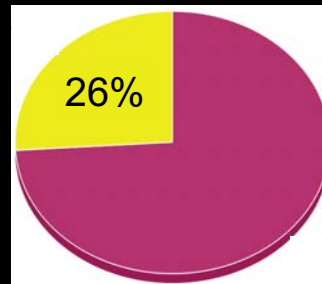
## IVR Patients: More Alerts

Chose IVR



1,835 of 4,573 PROMs triggered alert to nurse

Chose Email



2,089 of 7,968 PROMs triggered alert to nurse

Stover AM, et al. Qual Life Res. 2019;28(Suppl 1):S1.

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## Part III:

### PROs Completed in the Waiting Room and the PRO Rollout at NC Cancer Hospital



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## ESAS in Canadian Oncology Clinics

- In 2007, Cancer Care Ontario implemented PROs in waiting rooms
- Matched each cancer patients to a patient with cancer who did not complete PROs
- Results from 2007-2015
- 128,893 matched patient pairs

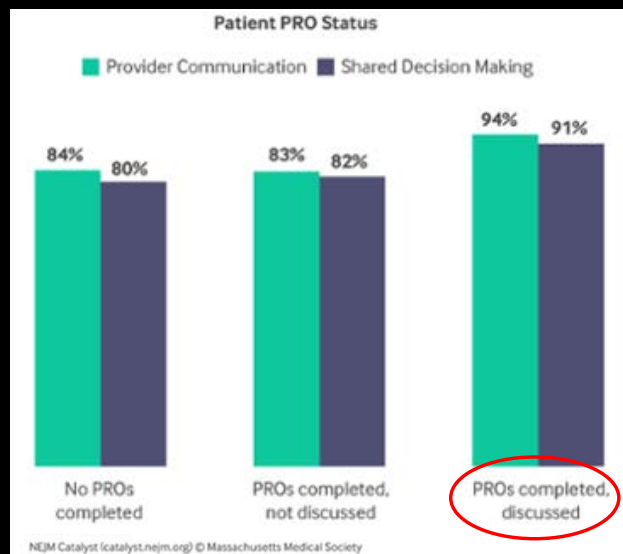
**SUMMARY ANSWER:** Patients exposed to ESAS are 8% less likely to visit the ED and 14% less likely to be hospitalized.

JCO<sup>®</sup> Oncology Practice

Barbera L, et al. JCO OP. 2020;in press. DOI: 10.1200/JOP.19.00660.

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## PROs Improve Satisfaction with Care



- UPMC began collecting PROs in Epic in 2017
- Portal or office-based tablet
- 273 active clinic locations live
- Correlation between discussing PROs and top-box satisfaction scores

Freel, et al. NJEM Catalyst. 2018

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Using an Implementation Science Approach to Implement and Evaluate Patient Reported Outcome Measures (PROM) Initiatives in Routine Care Settings

Angela M. Stover, PhD <sup>1,2\*</sup>  
 Lotte Haverman, PhD <sup>3</sup>  
 Hedy A. van Oers, PhD <sup>3</sup>  
 Joanne Greenhalgh, PhD <sup>4</sup>  
 Caroline M. Potter, DPhil <sup>5</sup>

On behalf of the ISOQOL PROMs/PREMs in Clinical Practice Implementation Work Group <sup>6</sup>

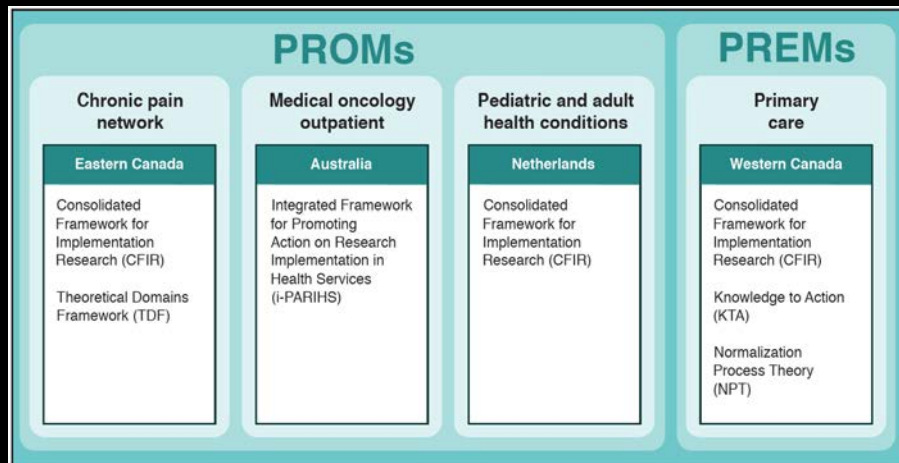


1. Department of Health Policy and Management, University of North Carolina at Chapel Hill, USA
2. Lineberger Comprehensive Cancer Center, University of North Carolina at Chapel Hill, USA
3. Psychosocial Department, Emma Children's Hospital, Amsterdam UMC, University of Amsterdam, NL
4. School of Sociology and Social Policy, University of Leeds, UK
5. Nuffield Department of Population Health, University of Oxford, UK
6. See Appendix 1

Stover et al. Qual Life Res. 2020; in press.

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## PRO Case Studies



Stover et al. Qual Life Res. 2020; in press.

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## Common PRO Barriers

- Unsure which PROs to use
- Technology limitations of capturing PROs
  - Displaying results for clinicians in a useful way
  - Not linked to EHR
- Uncertainty about ease and benefit of using PROs
- Perceived increase in workload
- Competing demands within established clinical workflows
- Cost and time to implement



Stover et al. Qual Life Res. 2020; in press.

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## Lessons Learned from Case Studies

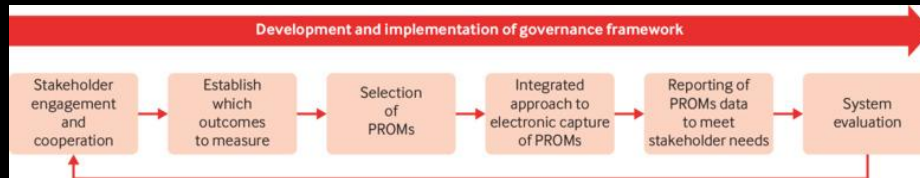
- In cross-study comparisons:
  - Barriers remarkably consistent across care settings
  - Tailor implementation to clinic resources
- PRO clinic initiatives more likely to be more successful if:
  - Purposefully designed integration
  - Substantive engagement with stakeholders (clinicians, patients)
  - Leverage existing EHR technology
  - Clinic evaluates implementation



Stover et al. Qual Life Res. 2020; in press.

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# Steps to Realizing Integrated PRO System

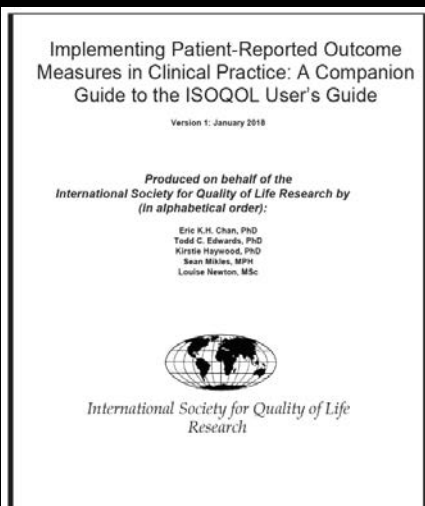
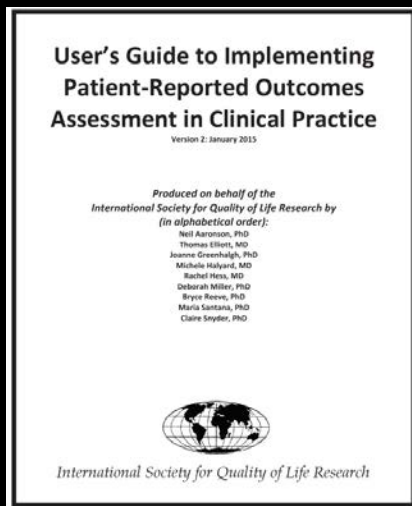


©2019 by British Medical Journal Publishing Group

Melanie Calvert et al.  
BMJ 2019;364:bmj.k5267



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[www.isoqol.org](http://www.isoqol.org)

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## Not All PROs are Free

Examples of proprietary PROs:

- Beck Depression Inventory (BDI)
- Brief Pain Inventory (BPI)
- EQ-5D
- SF-12, SF-36
- Morisky medication adherence scale



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## PROMIS is Free!

**PROMIS**  
Dynamic Tools to Measure Health Outcomes from the Patient Perspective

About PROMIS® | Measures | Science | Software | What's New | Related Resources | PROMIS® For You | Search

### Sample Questions

See samples of actual questions taken from selected physical health, mental health, and social health short forms. [More...](#)

### Twitter

promis@NIA PROMIS - NIH  
Know yourself? PROMIS® Computer Adaptive Test instantly reports on up to 9 different health issues like anger, fatigue. <http://t.co/vN14488>  
3P Oct 29 (2 days ago)  
Re Reply ES Retweet Q Favorite  
promis@NIA PROMIS - NIH  
#Researchers, #Clinicians...what is your preferred format to access research/pubs on Twitter? Presentation, PDF, or Video?  
3P Oct 29 (2 days ago)  
Re Reply ES Retweet Q Favorite

### Researchers

Provides efficient, reliable, and valid assessments of adult and child (pediatric) self-reported health

- ▶ PROMIS Instruments Selected
- ▶ References
- ▶ PROMIS in Research

### Clinicians

Provides data about the effect of therapy that cannot be found in traditional clinical measures

- ▶ PROMIS for Clinicians
- ▶ Select Publications
- ▶ Computer Adaptive Test (CAT) Demonstration

### Patients

Measures what you are able to do and how you feel

- ▶ More on PROMIS
- ▶ What Patient Reported Outcomes (PROs) are
- ▶ PROMIS Measures

<http://www.healthmeasures.net>

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## NCCH PRO Rollout

- UNC Health multimillion investment in PROs & personnel
- In Feb. 2017, UNC Center for Health Innovation and UNC Health's Information Services Department began joint effort to develop unified strategy
  - Broad organizational support
  - Robust governance process
- New Epic@UNC functionalities:
  - HIPAA-compliant, secure tablet-based ePRO collection
  - Visualizations and decision support for clinicians



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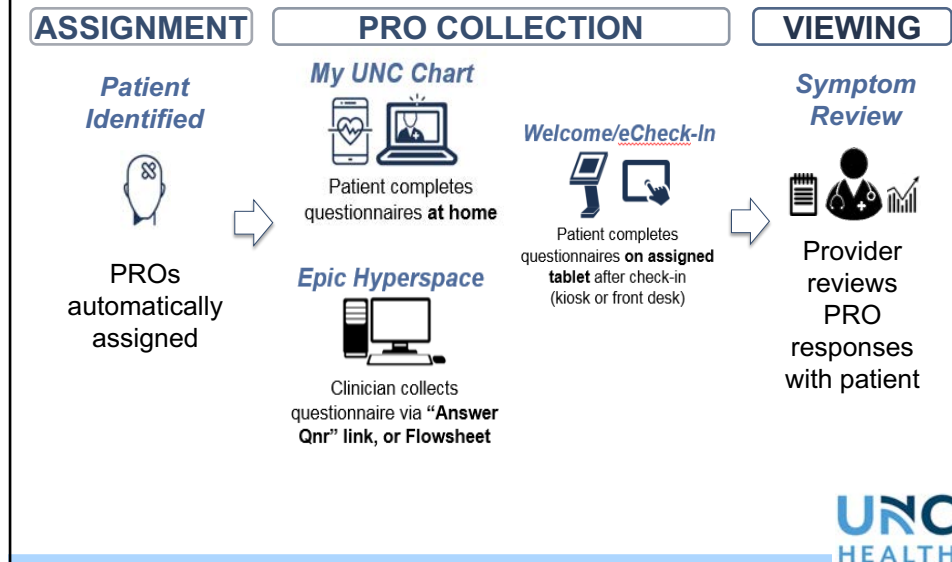
## UNC PRO Rollout Process at a Clinic

- Library of PROs in Epic
- Workflow/PRO needs assessment with coaches
- ISD completes build in Epic
- Tip sheet(s) and decision support available
- Train clinic to use PROs
- PDSA cycles
- Coaches send monthly reports to clinic



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## Epic@UNC MyChart PRO Workflow



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## Take Home Messages

- In cancer care, PROs improve:
  - Communication about symptoms
  - Symptom burden
  - Survival
  - ER rates
  - Satisfaction with care....




....But improved care doesn't happen automatically

- Clinic teams need trained to interpret and discuss PROs with patients during visits
- Get PRO implementation help for clinics

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## Outcomes Breakfast: Every Tuesday

- [unclineberger.org/outcomes](http://unclineberger.org/outcomes)
- Tuesdays at 8am: Carolina Club
- Email Eden Gifford to get on listserv
- @corp\_UNC 



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## References

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- "PROMIS: Dynamic Tools to Measure Health Outcomes from the Patient Perspective," <http://www.healthmeasures.net>
- Singh Ospina, et al. "Eliciting the Patient's Agenda- Secondary Analysis of Recorded Clinical Encounters." JGIM. 2019;34(1):36-40.
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- Stover AM, Haverman L, van Oers H, et al. Using an implementation science approach to implement and evaluate Patient-Reported Outcome Measures (PROM) initiatives in routine care settings. Qual Life Res. 2020; in press
- "User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice" Version 2, International Society for Quality of Life Research (ISOQOL), January 2015. <https://www.isoqol.org/wp-content/uploads/2019/09/2015UsersGuide-Version2.pdf>

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## Questions?

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