

Cancer Research: Leveraging PCORnet[®] Infrastructure, Tumor Table, and Synoptic Data

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Presentation materials: https://redcap.link/LEC2026_cancer_research

Outline

- Success stories
- Data resources
- Next steps: GPC as a cancer research network

Share Thoughts on Breast Cancer

Original Article | Published: 05 June 2019

The association between cancer care coordination and quality of life is stronger for breast cancer patients with lower health literacy: A Greater Plains Collaborative study

Epidemiology | Open Access | E

Upper extremity cancer treatment clinical research network

Bradley D. McDowell , Jennifer Klemp, Anne Blaes, Andrea A. Cohee, Amy Trentham-Dietz, Sailaja Kamaraju, Julie L. Otte, Sarah L. Mott & Elizabeth A. Chrischilles

Supportive Care in Cancer 28, 887–895 (2020) | [Cite this article](#)

Elizabeth A. Chrischilles , Danielle Riley, Elena Letuchy, Linda Koehle

Brian Gryzlak, Neil Segal, Bradley McDowell, Brian Smith, Sonia L. Sugg, Lizarraga

Breast Cancer Research and Treatment

Breast Oncology | Published: 12 July 2020 | Sarah H. Nash^{1,2}  | Elizabeth Verhage¹ | Bradley D. McDowell² | Joan Neuner³  | Elizabeth Chrischilles^{1,2} | Ingrid M. Lizarraga^{2,4} | Mary Schroeder⁵

Surgical Decision-Making Surrounding Contralateral Prophylactic Mastectomy: Comparison of Treatment Goals, Preferences, and Psychosocial Outcomes from a Multicenter Survey of Breast Cancer Patients

Ingrid M. Lizarraga MBBS, Mary C. Schroeder PhD , Ismail Jatoui MD, PhD, Sonia L. Sugg MD, Amy Trentham-Dietz PhD, Laurel Hoeth & Elizabeth A. Chrischilles PhD

Brief Report

Annals of Surgical Oncology 28, 8752–8765 (2021) | [Cite this article](#)

Parental Status in Treatment Decision Making among women with Nonmetastatic Breast Cancer

Patricia I. Jewett ¹, Rachel I. Vogel ^{2,3}, Mary C. Schroeder⁴, Joan M. Neuner⁵, and Anne H. Blaes^{6,7}

ACTA ONCOLOGICA, 2017
VOL. 56, NO. 12, 1690–1697
<https://doi.org/10.1080/0284186X.2017.1374555>

 Taylor & Francis
Taylor & Francis Group

ORIGINAL ARTICLE

 Check for updates

Preferences and actual chemotherapy decision-making in the greater plains

Multicenter Study > *Support Care Cancer*. 2019 Mar;27(3):857–865.

doi: 10.1007/s00520-018-4370-3. Epub 2018 Jul 31.

Julie L. Otte^c
Medical Center,

Variation in coordination of care reported by breast cancer patients according to health literacy

Body Weight and Breast Cancer Treatment Experiences: Results From the Share Thoughts on a Breast Cancer Study

T Greenlee³, Laurel Hoeth⁴,
Iowell⁷, Lee G Wilke⁸.

Economic status with receipt of neoadjuvant chemotherapy

Joan M. Neuner , Amanda Kong, Ann Blaes, Danielle Riley, Elizabeth Chrischilles, Alicia Smallwood, Ingrid Lizarraga & Mary Schroeder

Breast Cancer Research and Treatment 173, 179–188 (2019) | [Cite this article](#)

Factors associated with genetic testing in a cohort of breast cancer survivors

Anne H Blaes MD, MS¹  | Patricia I Jewett PhD¹  | Kathleen McKay PhD¹ |
Danielle Riley MS² | Ismail Jatoui MD³ | Amy Trentham-Dietz PhD⁴ |
Elizabeth Chrischilles PhD² | Jennifer R Klemp PhD, MPH⁵

NET-PRO

Using a participation monitoring database to enhance recruitment in a rare cancer population

Michael A. O'Rorke^{1,2} , Brian M. Gryzlak¹, Tao Xu¹, Bradley D. McDowell², Rhonda R. DeCook¹, Nicholas J. Rudzianski¹, Kimberly C. Serrano¹, Abigayle M. Wehrheim¹, Udhayvir S. Grewal³, Chandrikha Chandrasekharan⁴, Joseph S. Dillon³, Thorvardur R. Halfdanarson⁵, Michael J. Schnell⁶, Carrie L. Witter⁶, T. Clark Gamblin⁷, Syed Kazmi⁸, Lindsay G. Cowell⁹, Tobias Else¹⁰, Heloisa P. Soares¹¹, Vineeth Sukrithan¹², Sravani Chandaka¹³, Hanna K. Sanoff¹⁴, Fiona C. He¹⁵, David A. Geller¹⁶, Robert A. Ramirez¹⁷, Mei Liu¹⁸ , William Lancaster¹⁹, Josh A. Mailman²⁰, Heather Moran²¹, Maryann Wahmann²², Elyse Gellerman²³ and Elizabeth A. Chrischilles^{1,2}

Assessing Patient Characteristics in Neuroendocrine Tumor Research: A
NET-PRO Study to SEER Population-Based Data

In press, *Endocrine*

JOURNAL ARTICLE ACCEPTED MANUSCRIPT

Quality of life and care experiences in a US multi-institutional neuroendocrine tumor cohort

Michael A O'Rorke, PhD , Tao Xu, PhD, Rhonda R Decook, PhD, Bradley D McDowell, PhD, [Brian M Gryzlak, MSW, MA](#), Nicholas J Rudzianski, BS, Kimberly C Serrano, BA, Abigayle M Wehrheim, BS, Udhayvir S Grewal, MD, Chandrikha Chandrasekharan, MBBS ... [Show](#)

Personal Health Record Software for Neuroendocrine Tumors: Patient-Centered Design Approach

[Juan Pablo Hourcade¹](#) ; [Michael O'Rorke^{2,3}](#) ; [Elizabeth Chrischilles^{2,3}](#) ; [Nicholas J Rudzianski²](#) ; [Brian Gryzlak²](#) ; [Kerry Peterman¹](#) ; [Chris Ortman⁴](#) ; [Sam Wolstencroft⁴](#) ; [Margaret Bean⁵](#) ; [Elyse Gellerman⁶](#) ; [Josh A Mailman⁷](#) ; [Maryann Wahmann⁸](#) 

Making progress against rare cancers: A case study on neuroendocrine tumors

[Michael O'Rorke PhD](#) , [Elizabeth Chrischilles PhD](#) , [the NET-PRO Study Investigators](#)

Other Studies

Implementing Cancer Registry Data With the PCORnet Common Data Model: The Greater Plains Collaborative Experience

Bradley D. McDowell, PhD¹ ; Michael A. O'Rourke, PhD² ; Mary C. Schroeder, PhD³ ; Elizabeth A. Chrischilles; Christine M. Spinka, PhD⁴ ; Lemuel R. Waitman, PhD⁵; Kelechi Anuforo, MS⁶ ; Alejandro Araya, MS⁷; Haddyja Jackson Barlocker, MSIS⁸ ; Sravani Chandaka, MS⁹; Lindsay G. Cowell, PhD, MS¹⁰; Carol R. Geary, PhD, MBA, R; Benjamin D. Horne, PhD, MPH, MStat¹³ ; Boyd M. Knosp, MS, FAMIA³ ; Albert M. Lai, PhD¹⁴ ; Vasanthi Ma; Abu Saleh Mohammad Mosa, PhD, MS, FAMIA⁴ ; Phillip Reeder, BS¹⁵; Giyung Ryu, PhD¹⁶; Brian Shukwit, BS⁷; Alexander J. Stoddard, MSc¹⁸; Mahanazuddin Syed, PhD¹⁹; Shorabuddin Syed, PhD²⁰ ; Bradley W. Taylor, MBA¹; Jeffrey J. VanWormer, PhD²¹

Exploration of PCORnet Data Resources for Assessing Use of Molecular-Guided Cancer Treatment

Ryan M. Carnahan, MS, PharmD¹; Lemuel R. Waitman, PhD²; Mary E. Charlton, MS, PhD³; Mary C. Schroeder, PhD⁴; Aaron D. Bossler, MD, PhD⁵; W. Scott Campbell, PhD, MBA⁶; James R. Campbell, MD⁷; Bradley D. McDowell, PhD⁸; Nicholas C. Smith, MS⁹; Brian M. Gryzlak, MA, MSW¹⁰; and Elizabeth A. Chrischilles, PhD¹¹

Design and Rationale of the Outcomes Database to Prospectively Assess the Changing Therapy Landscape in Renal Cell Carcinoma Registry: A Multi-institutional, Prospective Study of Patients with Metastatic Renal Cell Carcinoma

Nrupen A. Bhavsar^{a,b,}, Michael R. Harrison^c, Charles D. Scales^d, Tian Zhang^e, Jesse Troy^b, Kimberly Ward^f, Sarah M. Jabusch^f, Zachary Lampron^f, Daniel J. George^c*

Testing and its Impact on Time to Initial Systemic Therapy in Metastatic Non-Small Cell Lung Cancer

Oyomoare L. Osazuwa-Peters¹, Lauren E. Wilson¹, Devon K. Check¹, Megan C. Roberts², Swetha Srinivasan², Amy G. Clark¹, Jeffrey Crawford³, Elizabeth Chrischilles⁵, Ryan M. Carnahan⁵, W. Scott Campbell⁶, Lindsay G. Cowell⁷, Robert Greenlee⁸, Andrea M. Abbott⁹, Abu S.M. Mosa¹⁰, Vasanthi Mandhadi¹⁰, Alexander Stoddard¹¹, Michaela A. Dinan^{1,4}  

Ancillary Studies Collaboration welcome!

Download “Share Thoughts on Breast Cancer” and NET-PRO Baseline Questionnaires
https://redcap.link/LEC2026_cancer_research



Cancer-Related Data Resources

- PCORnet CDM tables
- Tumor Table
- Synoptic Pathology Reports
- Prospective Data Collection



https://redcap.link/LEC2026_cancer_research



Prospective Data Collection

- Iowa PHR Platform

NET-PRO Step 5: Survey #1

Save and Exit

35%

Thoughts on Neuroendocrine Tumor Diagnosis & Treatment Decisions

Now, we would like to ask you some questions to try to understand how you make decisions about the treatment(s) for your neuroendocrine tumor.

Thinking about all the treatment decisions you made for your neuroendocrine tumor, please mark how much each statement is true for you.

Overall...

I was clear about the best choice for me.	☐ Strongly agree	☐ Agree	☐ Disagree	☐ Strongly disagree	Clear
The decision was easy for me to make.	☐ Strongly agree	☐ Agree	☐ Disagree	☐ Strongly disagree	Clear
I felt that I had enough support and advice to make a choice.	☐ Strongly agree	☐ Agree	☐ Disagree	☐ Strongly disagree	Clear

GPC as a cancer research network

- Lessons learned from previous studies
- Moving forward
 - Engaging researchers and patients
 - Cancer research listserv

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