Integrating Patient-Reported Outcomes in Electronic Health Records: Presentation of a Users’ Guide and Discussion of Standardization

May 25-26, 2017
Hyatt Regency Crystal City

Claire Snyder, PhD, Principal Investigator
Albert Wu, MD, MPH, Co-Principal Investigator

Funded by the Patient-Centered Outcomes Research Institute
Wedding Day
Multi-Purpose PROs

Assess PROs

Inform Quality Improvement

Evaluate Care Quality

Use in Clinical Practice
Measure once, cut twice—adding patient-reported outcome measures to the electronic health record for comparative effectiveness research

Albert W. Wu*, Hadi Kharrazi, L. Ebony Boulware, Claire F. Snyder

Departments of Health Policy & Management and Medicine, Johns Hopkins University, Baltimore, MD, USA
Accepted 19 April 2013
Multi-Purpose PROs

- Assess PROs
- Evaluate Care Quality
- Inform Quality Improvement
- Use in Clinical Practice
Clinician & Patient View Report

Comments View All

Is there one problem in particular you'd like your doctor or nurse to address during your next visit?

I am having trouble doing the things I need to do.

Enter any other comments or questions for your doctor or nurse.

It's helpful answering these questions.

The results for the most recent and four previous surveys are graphed below. Graphs highlighted in yellow represent either a significant worsening or a score that is likely to be a problem. For a summary of the items in each score, click What is this? For an explanation of the scoring, click Score meaning. For suggestions for how to address potential problems, click What can I do?

Table Chart

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<tr>
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<td>54.3</td>
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<td>Comments</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
Review of Electronic Patient-Reported Outcomes Systems Used in Cancer Clinical Care

By Roxanne E. Jensen, PhD, Claire F. Snyder, PhD, Amy P. Abernethy, MD, Ethan Basch, MD, Arnold L. Potosky, PhD, Aaron C. Roberts, Deena R. Loeffler, MA, and Bryce B. Reeve, PhD

Lombardi Comprehensive Cancer Center, Georgetown University Medical Center, Washington, DC; The Johns Hopkins University School of Medicine and the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, Baltimore, MD; Duke Comprehensive Cancer Center, Duke University Medical Center, Durham; Lineberger Comprehensive Cancer Center, University of North Carolina, Chapel Hill, NC; and Health Outcomes Group, Memorial Sloan-Kettering Cancer Center, New York, NY

Abstract

**Purpose:** The use of electronic patient-reported outcomes (PRO) systems is increasing in cancer clinical care settings. This review comprehensively identifies existing PRO systems and explores how systems differ in the administration of PRO assessments, the integration of information into the clinic workflow and electronic health record (EHR) systems, and the reporting of PRO information.

**Methods:** Electronic PRO (e-PRO) systems were identified through a semistructured review of published studies, gray literature, and expert identification. System developers were contacted to provide detailed e-PRO system characteristics and clinical implementation information using a structured review form.

**Results:** A total of 33 unique systems implemented in cancer clinical practice were identified. Of these, 81% provided detailed information about system characteristics. Two system classifications were established: treatment-centered systems designed for patient monitoring during active cancer treatment (n = 8) and patient-centered systems following patients across treatment and survivorship periods (n = 19). There was little consensus on administration, integration, or result reporting between these system types. Patient-centered systems were more likely to provide user-friendly features such as at-home assessments, integration into larger electronic system networks (eg, EHRs), and more robust score reporting options. Well-established systems were more likely to have features that increased assessment flexibility (eg, location, automated reminders) and better clinical integration.

**Conclusion:** The number of e-PRO systems has increased. Systems can be programmed to have numerous features that facilitate integration of PRO assessment and routine monitoring into clinical care. Important barriers to system usability and widespread adoption include assessment flexibility, clinical integration, and high-quality data collection and reporting.
• Helps clinicians and researchers interested in implementing PRO assessment to aid patient care

• Includes
  – Considerations
  – Options
  – Resource requirements
  – Relative advantages and disadvantages

Available at:
Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations

Claire F. Snyder · Neil K. Aaronson · Ali K. Choucair · Thomas E. Elliott · Joanne Greenhalgh · Michele Y. Halyard · Rachel Hess · Deborah M. Miller · Bryce B. Reeve · Maria Santana

Accepted: 18 October 2011
© Springer Science+Business Media B.V. 2011

Abstract
Purpose While clinical care is frequently directed at making patients “feel better,” patients’ reports on their functioning and well-being (patient-reported outcomes [PROs]) are rarely collected in routine clinical practice. The International Society for Quality of Life Research (ISOQOL) has developed a User’s Guide for Implementing Patient-Reported Outcomes Assessment in Clinical Practice. This paper summarizes the key issues from the User’s Guide.

Methods Using the literature, an ISOQOL team outlined considerations for using PROs in clinical practice; options for designing the intervention; and strengths, weaknesses, and resource requirements associated with each option.

Results Implementing routine PRO assessment involves a number of methodological and practical decisions, including (1) identifying the goals for collecting PROs in clinical practice, (2) selecting the patients, setting, and timing of assessments, (3) determining which questionnaire(s) to use, (4) choosing a mode for administering and scoring the questionnaire, (5) designing processes for reporting results, (6) identifying aids to facilitate score interpretation, (7) developing strategies for responding to issues identified by the questionnaires, and (8) evaluating the impact of the PRO intervention on the practice.

Conclusions Integrating PROs in clinical practice has the potential to enhance patient-centered care. The online version of the User’s Guide will be updated periodically.
Topics Covered

1. Identifying the goals for collecting PROs in clinical practice
2. Selecting the patients, setting, and timing of assessments
3. Determining which questionnaire(s) to use
4. Choosing a mode for administering and scoring the questionnaire
5. Designing processes for reporting results
6. Identifying aids to facilitate score interpretation
7. Developing strategies for responding to issues identified by the questionnaires
8. Evaluating the impact of the PRO intervention on the practice
Multi-Purpose PROs

- Assess PROs
- Evaluate Care Quality
- Use in Clinical Practice
- Inform Quality Improvement
Aggregate Data Across Patients

Survey Name: Prostate Cancer Questionnaire

**Henry Hamilton**

Survey Name: Prostate Cancer Questionnaire

**Beth Wilson**

Survey Name: Prostate Cancer Questionnaire

**Chris Miller**

Survey Name: Prostate Cancer Questionnaire

**Jodi Anderson**

Survey Name: Prostate Cancer Questionnaire

A highlighted graph represents either a significant worsening or a score that is likely to be a problem.

Physical Functioning (0 = Bad, 100 = Good)

Mental Functioning (0 = Bad, 100 = Good)

Urine Functioning (0 = Bad, 100 = Good)

Sexual Functioning (0 = Bad, 100 = Good)

Pain (0 = Less pain, 10 = More Pain)

Sphincter Functioning (0 = Bad, 100 = Good)

Hormonal Functioning (0 = Bad, 100 = Good)
Quality Reporting to Compare Providers

Percentage

Our Practice | Practice A | Practice B | Practice C
---|---|---|---
Worst Pain ≥4 | 10 | 20 | 50
≥ Moderate Nausea | 20 | 30 | 80

Legend:
- Worst Pain ≥4
- ≥ Moderate Nausea
Patient-Reported Outcome Performance Measures in Oncology

By Ethan Basch, MD, Claire Snyder, PhD, Kristen McNiff, MPH, Rebecca Brown, Suzanne Maddux, RN, Mary Lou Smith, JD, MBA, Thomas M. Atkinson, PhD, Doris Howell, PhD, RN, Anne Chiang, MD, William Wood, MD, MPH, Nathan Levitan, MD, Albert W. Wu, MD, MPH, FACP, and Monika Krzyzanowska, MD

Lineberger Cancer Center, University of North Carolina, Chapel Hill, NC; Johns Hopkins School of Medicine, Baltimore, MD; American Society of Clinical Oncology, Alexandria, VA; Research Advocacy Network, Plano, TX; Memorial Sloan Kettering Cancer Center, New York, NY; Princess Margaret Hospital, Toronto, Ontario, Canada; Yale Cancer Center, New Haven, CT; University Hospitals Seidman Cancer Center, Cleveland, OH; and Dana-Farber/Harvard Cancer Center, Boston, MA

Multi-Purpose PROs

Inform Quality Improvement

Assess PROs

Use in Clinical Practice

Evaluate Care Quality
How do we turn PROMs into remedies?
An interpretable PROM for breast reconstruction?  
The Breast-Q.

Number of operations

Equal in shape + size (unclothed)

Equal in size (unclothed)

Breasts ‘lined up ’unclothed

Shape when clothed

Slide courtesy of John Browne, PhD, University College – Cork
Multi-Purpose PROs

- Assess PROs
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Multi-Purpose PROs

Inform Quality Improvement

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Use in Clinical Practice
Aggregate Data Across Patients

Survey Name: Prostate Cancer Questionnaire

Henry Hamilton

Beth Wilson

Chris Miller

Jodi Anderson
Describing Impact of Treatment

This figure describes the physical function of patients who undergo this procedure on average. Scores of 0 represent poor physical function, and scores of 100 represent good physical function. On average, patients who undergo this surgery have a score of 30 before the procedure. Immediately following the procedure (1 week after surgery), their function has decreased a little to a score of 25. However, physical function then improves over the next 3 months to achieve a score of 50, with a little additional improvement to 55 at the point 6 months after surgery.

The general population of a similar age has a physical function score of 60.

Thus, on average, this procedure improves patients’ physical function substantially, but not quite to the level of the general population.
Advances in the Use of Patient Reported Outcome Measures in Electronic Health Records

Including Case Studies

Albert W. Wu, MD, MPH
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Roxanne E. Jensen, PhD
Lombardi Comprehensive Cancer Center
Georgetown University, Washington, DC

Claudia Salzberg, MS
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Claire Snyder, PhD
Johns Hopkins University School of Medicine, Baltimore, MD

In support of the PCORI National Workshop to Advance the Use of PRO measures in Electronic Health Records
Atlanta, GA. November 19-20, 2013
<table>
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<th>#</th>
<th>System Affiliation (Name)</th>
<th>Initial Population</th>
<th>Multiple Sites/Clinics</th>
<th>Multiple Populations</th>
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<tbody>
<tr>
<td>1</td>
<td>Epic Systems Corporation (MyChart, EpicCare)</td>
<td>Epic Users</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>3</td>
<td>Cleveland Clinic (Knowledge Program)</td>
<td>Neurological Disorders</td>
<td>Y</td>
<td>Y</td>
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<td>2</td>
<td>Dartmouth Spine Center</td>
<td>Spine</td>
<td>Y</td>
<td>Y</td>
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<td>4</td>
<td>Group Health Cooperative (Health Profile e-HRA)</td>
<td>General</td>
<td>Y</td>
<td>N</td>
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<td>Cincinnati Children’s Hospital</td>
<td>Rheumatology</td>
<td>Y</td>
<td>Y</td>
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<td>6</td>
<td>Kaiser Permanante Colorado (PATHWAAY)</td>
<td>Older Adults</td>
<td>Y</td>
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<tr>
<td>7</td>
<td>Essentia Health (MN Community Measurement)</td>
<td>Depression</td>
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<td>8</td>
<td>University of Pittsburgh Medical Center</td>
<td>Primary Care</td>
<td>Y</td>
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<td>9</td>
<td>Duke University (Patient Care Monitor)</td>
<td>Cancer</td>
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<td>GI Disorders</td>
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<td>HIV</td>
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Rationale

• Increasing interest in the topic of PROs in EHRs
  – PCORI-sponsored meeting reviewing the use of PROs in EHRs (November 2013)
  – NIH collaboratory meeting on barriers to routine collection of PROs for EHRs (January 2015)

• Need for:
  – Guidance on the steps involved in integrating PROs in EHRs
  – Opportunity for voluntary consortia to collect PRO-EHR data to enable pooling
Project Goals

• Provide practical guidance on how to implement PROs in EHRs
• Facilitate formation of consortia that will voluntarily collect PROs using standardized approaches to enable data pooling
Project Phase 1: Planning

- Formed a Steering Group to advise on the overall project plan
- Developed strategy for meeting long-term goals
- Identified questions to be addressed in the PRO-EHR Users’ Guide
- Circulated question list for comment
- Outlined next steps
Steering Group

Ethan Basch, MD, MSc Lineberger Comprehensive Cancer Center at the University of North Carolina-Chapel Hill

Jason Gerson, PhD, Patient-Centered Outcomes Research Institute

Mellanie True Hills, CSP Patient Advocate

Kevin Weinfurt, PhD Duke Clinical Research Institute

Nancy Smider, PhD Epic

Albert Wu, MD, MPH Johns Hopkins Center for Health Services and Outcomes Research

Claire Snyder, PhD Johns Hopkins School of Medicine

Matt Stiefel, MS, MPA Kaiser Permanente Care Management Institute

David R. Hunt, MD, FACS Office of the National Coordinator for Health Information Technology

Erin Holve, PhD, MPH, MPP Department of Health Care Finance in the Government of the District of Columbia

Ashley Wilder Smith, PhD National Cancer Institute

*We appreciate the previous service on the Steering Group of Jamie Skipper, PhD, and Caroline Coy, MPH, from the ONCHIT.
Project Phase 2: Implementation

• Identify Working Group Members
• In-Person Meeting to Discuss Section Outlines
• Develop Draft Sections
• Working/Steering Group Review and Comment on Draft Sections
• Circulate Draft for Comment
• Hold Public Meeting
Extend Deadline
Ctrl+D

Enhance Salary
Ctrl+Y

Find Better Client
Ctrl+Alt+C

Restore Wasted Evenings
Ctrl+W

Save Weekend
Ctrl+S
Users’ Guide to Integrating Patient-Reported Outcomes in Electronic Health Records

Prepared For PCORI By:
Johns Hopkins University, Baltimore, MD

May 2017

Topics Covered

1. What strategy will be used for integrating PROs in EHRs?
2. How will the PRO-EHR system be governed?
3. How can users be trained and engaged?
4. Which populations and patients are most suitable for collection and use of PRO data, and how can EHRs support identification of suitable patients?
5. Which outcomes are important to measure for a given population?
6. How should candidate PRO measures be evaluated?
7. How, where, and with what frequency will PROs be administered?
8. How will PRO data be displayed in the EHR?
9. How will PRO data be acted upon?
10. How can PRO data from multiple EHRs be pooled?
11. What are the ethical and legal issues?
Content

• Considerations involved in integrating PROs in EHRs

• Options offered for each consideration

• Relative advantages/disadvantages described for each option

• Case example descriptions (optional)

• Key information gaps/research questions

• Useful references/resources
Similar to ISOQOL Users’ Guide

- ISOQOL Users’ Guide focuses on use of PROs in Clinical Practice, in general
- PRO-EHR Users’ Guide focuses specifically on integrating PROs in EHRs
- ISOQOL is a collaborating partner

Available at:
AND…you don’t have to pick just one option from each course!
Additional Notes

• Addresses patient-reported outcomes specifically
  – Direct reports of symptoms, functioning, health-related quality of life, and so on using standardized questionnaires
  – Not other types of patient-generated data (e.g., alcohol use) or other sources of patient-generated data (e.g., fitness trackers)
    • Though many of the considerations are the same

Agenda
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Speakers</th>
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<tr>
<td>8:30-9:30</td>
<td>Breakfast/Registration</td>
<td>Group</td>
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<tr>
<td>9:30-10:00</td>
<td>Welcome and Orientation to Project</td>
<td>Claire Snyder, PhD Johns Hopkins School of Medicine</td>
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<td>Albert Wu, MD, MPH Johns Hopkins Bloomberg School of Public Health</td>
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<tr>
<td>10:00-10:20</td>
<td>1) What strategy will be used for integrating PROs in EHRs?</td>
<td>Roxanne Jensen, PhD Georgetown Lombardi Comprehensive Cancer Center</td>
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<td>Rachel Hess, MD, MS University of Utah</td>
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<td>10:20-10:40</td>
<td>2) How will the PRO-EHR system be governed?</td>
<td>Greg Pawlson, MD, MPH P&amp;M Healthcare Insights</td>
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<td>Erin Holve, PhD, MPH, MPP Department of Health Care Finance, Government of D.C.</td>
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<td>10:40-11:00</td>
<td>3) How can users be trained and engaged?</td>
<td>Galina Velikova, MBBS, PhD Leeds Institute of Cancer and Pathology, University of Leeds</td>
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<td>Carolyn Kerrigan, MD, MHCDS Dartmouth-Hitchcock Medical Center</td>
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<td>11:00-11:40</td>
<td>PANEL 1 DISCUSSION</td>
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<td>11:40-12:40</td>
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<td>What populations and patients are most suitable for collection and use of PRO data, and how can EHRs support identification of suitable patients?</td>
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<td>5)</td>
<td>Which outcomes are important to measure for a given population?</td>
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<td>1:20-1:40</td>
<td>6)</td>
<td>How should candidate PRO measures be evaluated?</td>
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<td>1:40-2:00</td>
<td>7)</td>
<td>How, where, and with what frequency will PROs be administered?</td>
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<td>2:00-2:40</td>
<td>PANEL 2 DISCUSSION</td>
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<td>2:40-3:00</td>
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<td>Break</td>
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<td>3:00-3:20</td>
<td>8) How will PRO data be displayed in the EHR?</td>
<td>Arlene Chung, MD, MHA, MMCi University of North Carolina-Chapel Hill</td>
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<td>Andrea Hartzler, PhD GroupHealth Cooperative</td>
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<td>3:20-3:40</td>
<td>9) How will PRO data be acted upon?</td>
<td>Neil Wagle, MD, MBA Partners Healthcare</td>
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<td>Ethan Basch, MD, MSc Lineberger Comprehensive Cancer Center at the University of North Carolina-Chapel Hill</td>
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<td>3:40-4:00</td>
<td>10) How can PRO data from multiple EHRs be pooled?</td>
<td>Dean Sittig, PhD University of Texas Health Science Center at Houston</td>
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<td>Adam Wright, PhD Harvard Brigham &amp; Women’s Hospital</td>
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<td>4:00-4:20</td>
<td>11) What are the ethical and legal issues?</td>
<td>Danielle Whicher, PhD, MHS Patient-Centered Outcomes Research Institute</td>
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<td>Joseph Ali, JD Johns Hopkins Berman Institute of Bioethics</td>
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<td>PANEL 3 DISCUSSION</td>
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<td>5:00-5:15</td>
<td>Wrap-Up and Plan for Tomorrow</td>
<td>Claire Snyder, PhD</td>
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<td>Albert Wu, MD, MPH</td>
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<td>8:00-8:10</td>
<td>Introduction to the Day</td>
<td>• Albert Wu, MD, MPH Johns Hopkins Bloomberg School of Public Health</td>
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<td>• Claire Snyder, PhD Johns Hopkins School of Medicine</td>
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<td>8:10-8:25</td>
<td>PCORNet Common Data Model</td>
<td>• Keith Marsolo, PhD Cincinnati Childrens’ Hospital</td>
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<td>8:25-8:50</td>
<td>Case 1 – PaTH CDRN PRO Data Collection</td>
<td>• Harold Lehmann, MD Johns Hopkins</td>
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<td>8:50-9:20</td>
<td>Case 2 – EASI-PRO I Access to Seamless Integration of PROMIS</td>
<td>• Justin Starren, MD, PhD Northwestern University</td>
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<td>9:20-9:50</td>
<td>Case 3 – Shrine i2b2</td>
<td>• Adam Wright, PhD Brigham and Women’s Hospital</td>
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<tr>
<td>9:50-10:20</td>
<td>Case 4 – Get Real Health</td>
<td>• Eugene Nelson, PhD Dartmouth</td>
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<tr>
<td>10:20-10:50</td>
<td>Discussion</td>
<td>• Group</td>
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<td>10:50-11:00</td>
<td>Break</td>
<td>• Group</td>
</tr>
<tr>
<td>11:00-12:00</td>
<td>Small Groups</td>
<td>• Group</td>
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<tr>
<td>12:00-1:00</td>
<td>Report Back (Box Lunch)</td>
<td>• Group</td>
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And They Provided Patient-Centered Care Happily Ever After