Primary Care Research: No Longer Lost in Translation

James W. Mold, MD, MPH
George Lynn Cross Emeritus Research Professor
Department of Family and Preventive Medicine
University of Oklahoma Health Sciences Center
Objectives

1. Define the scope of primary care research

2. Explain several ways that applied research is different from basic research and clinical trials and some of the methodological implications of those differences

3. Give an example of each of the following types of primary care research:
   a. Theoretical and methodological research
   b. Health care research (attributes research)
   c. Clinical research
   d. Health systems research (D&I, policy research)

4. Help you to think differently/more clearly about the role and importance of primary care research

5. Encourage you to become a contributor (researcher, advocate, participants, etc.)
Legitimacy of Primary Care

• A waste of your intelligence and training. Nothing but runny noses and sore throats

• Too difficult for anyone to do well. Way to too much information to master (even for you).

• An essential component of a high functioning health care system. Associated with:
  – Reduced mortality/increased life expectancy
  – Increased perceived health status
  – Increased patient satisfaction
  – Reduced disparities (access and outcomes)
  – Reduced cost
Primary Care

“the provision of integrated, accessible health care services by clinicians that are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing within the context of family and community”

A function with specific attributes.
The only medical specialty area defined by processes rather than clinical content

Donaldson MS, Yordy KD, Lohr KN, and Vanselow NA (Editors). Primary Care: America's Health in a New Era. Committee on the Future of Primary Care, Division of Health Care Services, Institute of Medicine; National Academies Press, Washington, DC, 1996
Secret Sauce

Accessibility
  First contact
  Accommodation

Coordination
  Internal
  External

Sustained Care
  Longitudinality
  Continuity

Comprehensiveness

Partnership with Patients
  Relationship
  Decision-making
  Advocacy

Person-centeredness
  Whole person care
  Family context
  Community context

Accountability
  Integration
Paucity of Relevant Information

What is amazing is that primary care is so effective given how little we know about what we are doing.

Note: Think of all of the practical questions you were asked by family members during your training for which you could find no good answers. (Why are my feet and hands always cold? Why do I sweat so much at night? Why can’t I smell things as well as I used to?)

Nearly all of the research-based information we rely upon has been derived from studies conducted by subspecialists in academic settings on atypical patients. That we are as effective as we are is a tribute to the largely experiential wisdom passed on by generations of generalist physicians and their patients.
Legitimacy of Primary Care Research


- Basic Research
  - T1
- Human Research
  - T2
- Practice

We’ve discovered and developed it and proved that it works. Now... Just do it!
Basic Research

Human Research

Practice-and Community-Based Research

Theory and Methods
Attributes/Processes
Clinical Care
Health System Development

Urgency

- Escalating costs
- Depersonalization (e.g. fragmentation)
- Corporatization
- Ever increasing pharmaceutical industry influence
- Genomics
- Artificial intelligence

- The wisdom of GPs is being lost through retirement, death, and external financial and political pressures.
- Primary care is looking increasingly like subspecialty care (e.g. problem-oriented rather than person-focused)
Primary Care Research

“research directed toward the better understanding and practice of the primary care function” to improve the lives of patients, families, and communities

1. Theoretical and methodological research
   a) Conceptual models
   b) Research methods

2. Health care research
   a) Attributes and processes of care
   b) Clinical research

3. Health systems research (education/training; D&I; policy)
   a) Dissemination, implementation, and diffusion research
   b) Educational and resource development research
   c) Health system organization and policy research

Applied

• Goal-directed/Relevant
  – Intended to improve outcomes meaningful to patients, practices, communities, or society
  – Collaborative

• Timely
  – Aligned with ongoing development efforts (R&D)
  – Results available in real time

• Practical
  – Broadly implementable and useful
  – Financially feasible for practices and patients
Context Matters

- Population
  - Community
  - All those with symptoms and concerns
  - Those who seek care
  - Those seen in primary care
  - Those with certain clinical challenges
- Health care setting
  - Phone, office, urgent care, home, NH, ED, hospital
- Patient context (individualized interventions and/or outcomes)
- Family context
- Community context
- Practice context (e.g. financially viable)

Complex and messy, but still very much research
Practice-Based Research Networks

- Networks of practices helping to improve primary care through systematic R&D across multiple projects over time.
- 183 PBRNs registered with AHRQ
  https://pbrn.ahrq.gov/pbrn-registry
- The Oklahoma Physicians Resource/Research Network
  www.okprn.org
  501c3 non-profit, 145 practices/245 clinicians, 50% rural
  Connections to AMC: listserv, projects, ClinIQ
PBRNs in North Carolina

• Duke Primary Care Research Consortium
  PCRC  https://medicine.duke.edu/divisions/general-internal-medicine/research/duke-primary-care-research-consortium

• UNC Practice Based Research Network
• NC Family Medicine Research Network
• NC Child Health Network
• Eastern Carolina Association for Research and Education
• Mecklenburg Area Partnership for Primary Care Research
• Consortium for Southeastern Hypertension Control
Delivery of Preventive Services

Related primarily to the survival goal

- Arguably the most important goal of health care
  - Best predictor of preference for survival over quality of life is greater disability (cross-sectional and longitudinal)
  - Our most important responsibility

Cost and time are important

- Cost is lower when services are individualized/prioritized
  - Effectiveness may also be increased (e.g. better adherence)
- Primary prevention (e.g. increasing physical activity) tends to be much more effective than secondary and tertiary prevention, but it requires more time, skill, and family and community support systems
Delivery of Preventive Services

Strategies known to be effective in primary care:

- Wellness visits
- Standing orders
- Recall and reminder systems

Delivering preventive services in primary care at current clinician/patient ratios and staffing levels is virtually impossible based upon time constraints

Delivery of Preventive Services

Motivational Issues

• Clinicians
  – Primary and secondary prevention are not problem solving
  – Perceived lower reimbursement rate for time involved
  – Poor alignment of effort and reward (e.g. CRC screening)
  – Benefits to patients hard to quantify
  – Requires system development and delegation

• Patients
  – Benefits vague and far in the future
  – Inconvenience, discomfort, cost
Delivery of Preventive Services

Conceptual issues

• Problem-oriented care (care organized around dx/rx) vs. goal-directed care (care organized around achieving meaningful outcomes)


• Primary care vs. primary health care (role/responsibility of primary care within communities)
Methodological Challenges

• Understanding current best indigenous practices and establishing longitudinal partnerships with practices
  – Existing processes and tools
  – Current benchmarks and aspirations
• Developing and testing of dissemination and implementation strategies
  – Distinguishing improved care vs. improved documentation
• Developing and validating decision support tools
  – Measurement of survival/life expectancy
• Developing and testing of new care processes and management systems
• Moving target
  – Health systems, EHRs, HIEs, guidelines, payment models
  – >50% of practices experience major disruptions/year
“Best Practices Research”

1. Understand the process
   • Components (wellness visits, prompts, standing orders)
2. Identify exemplars for individual components
3. Figure out what the exemplars know/do
   • Principles (focus on 5-6 key services; annual visit)
   • Techniques (standing orders with oversight)
   • Scripts (directive, simplified, regret)
4. Combine best practices into a cohesive method
5. Test the combined method in a cRCT

High performing practices focus on 5 or 6 high priority preventive services, limit options, delegate to nurses with oversight, and deliver firm messages

Adding additional MA helps, but integration matters
Implementation Research

• Cluster RCTs, and stepped wedge studies to test the acceptability, effectiveness, and cost of:
  a) Performance feedback/benchmarking
  b) Academic detailing
  c) Decision aids
  d) Practice facilitation
  e) IT support
  f) Local learning collaboratives
  g) Traditional learning collaboratives

To help practices implement new approaches

“Best” combination is a+b+c+d+e
Development - IT

• Decision support tool (Preventive Services Reminder System) for MAs/nurses/clinicians
  – Preventive services due based upon age, gender, certain risk factors, contraindications, and previous services printed at time of visit (registry)
  – Effective when used, but too many tasks, too few staff
  – CCR insufficient link to EHRs

• Personal health record (Wellness Portal) for patients
  – Patient view of same data
  – Ability to enter risk factors, and update services received
  – Effective for motivated patients (e.g. me)
  – Practice reinforcement and assistance important
  – HIEs won’t allow patient input
Development - IT

• Individual prioritization tool (Health Planner)
  – Comprehensive health risk appraisal (HRA)
  – Proportionate hazards model using population stats adjusted for individual risk factors mitigated by risk reduction strategies
  – Diseases included as risk factors so includes tertiary prevention
  – Estimated life expectancy, disability-free life expectancy, real age, wellness score, max. possible life extension
  – Prioritized list of recommended preventive services and size of benefit
  – Validated against two available cohorts
Your estimated "RealAge" is: 93.0 years. This means that although your calendar age is 79 years, your body is as "old" in terms of risk, as that of an average 93.0 year old in your peer group (same age, gender, and ethnicity).

Your Wellness Score is: 56.2 A score from 90-100 means "average" health. Less than 90 shows worse than average, while over 100 indicates better than average health.

Your main health strengths are:
(assuming a fully completed HRA)

You do not smoke, drink too much, or abuse drugs
You do not need medical attention too often
You always buckle your seatbelt
Your risk of injury from various activities is low
You seem to be in a good psychological health
You have multiple inherited (family) risk factors. Your risk of injury from a car accident is elevated. You are due for several preventive services.

Maximum **health benefit** that can be gained when all services are completed or maintained:

**4.85 additional years of life**

Preventive services **ranked** in a decreasing order of health benefit:

<table>
<thead>
<tr>
<th>Preventive Services</th>
<th>Share of Benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Link to Resources</td>
<td>Physical activity improvement</td>
</tr>
<tr>
<td>Link to Resources</td>
<td>Weight control</td>
</tr>
<tr>
<td>Link to Resources</td>
<td>Blood sugar control</td>
</tr>
<tr>
<td>Link to Resources</td>
<td>Stress reduction</td>
</tr>
<tr>
<td>Link to Resources</td>
<td>Adjusting sleeping time</td>
</tr>
<tr>
<td>Link to Resources</td>
<td>Blood pressure control (~130/85)</td>
</tr>
<tr>
<td>Link to Resources</td>
<td>Healthier diet</td>
</tr>
<tr>
<td>Link to Resources</td>
<td>Annual flu shot</td>
</tr>
<tr>
<td>Link to Resources</td>
<td>PAP smear</td>
</tr>
<tr>
<td>Link to Resources</td>
<td>Folic acid supplementation</td>
</tr>
<tr>
<td>Link to Resources</td>
<td>Pneumonia vaccination</td>
</tr>
<tr>
<td>Link to Resources</td>
<td>Sun exposure protection</td>
</tr>
</tbody>
</table>
Method: 4 clinicians/50 patients each (N=200) randomized to two 2 PCP/100 patient groups

1. Patients completed baseline HRA, given results, encouraged to have Wellness Visit
2. Patients completed baseline HRA, not given results, encouraged to have Wellness Visit

All patients completed HRA again at one year

Outcome measures included:

a) Rates of various preventive services received/documentated
b) Up-to-date rate
c) CAHPs Patient-centeredness measure
d) Change in estimated life expectancy
## Participants

<table>
<thead>
<tr>
<th>Patient Characteristics</th>
<th>Control (N=98)</th>
<th>Intervention (N=102)</th>
<th>Significance (P)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (years)</td>
<td>59.9±10 a</td>
<td>60.4±11 a</td>
<td>0.36</td>
</tr>
<tr>
<td>Females</td>
<td>65%</td>
<td>72%</td>
<td>0.07</td>
</tr>
<tr>
<td>Non-Caucasians</td>
<td>8%</td>
<td>5%</td>
<td>0.07</td>
</tr>
<tr>
<td>At least a high school education</td>
<td>94%</td>
<td>95%</td>
<td>0.52</td>
</tr>
<tr>
<td>Household income &lt; $40K per year</td>
<td>9%</td>
<td>12%</td>
<td>0.22</td>
</tr>
<tr>
<td>Number of chronic conditions</td>
<td>2.7</td>
<td>3.2</td>
<td>0.06</td>
</tr>
<tr>
<td>Active smokers</td>
<td>11%</td>
<td>15%</td>
<td>0.20</td>
</tr>
<tr>
<td>Self-rated overall health (0 to 4 scale)</td>
<td>2.76±0.8 a</td>
<td>2.61±0.8 a</td>
<td>0.12</td>
</tr>
<tr>
<td>Self-rated satisfaction with life (1-10 scale)</td>
<td>7.57±2.1 a</td>
<td>7.48±1.9 a</td>
<td>0.32</td>
</tr>
<tr>
<td>Average number of office visits per year</td>
<td>3.4</td>
<td>4.95</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>
The mean increase in Estimated Life Expectancy (ELE) across the intervention population was 6 months higher than in the control group (13 vs. 7 months; P<0.001).
Development - Organizational

• WCC/immunization problem as example of bigger challenges
  – Poor alignment and relationships between primary care and public health including biases and prejudices
  – Difficulty aligning funding streams (public/private)

• Community Coalitions
  – Present in nearly all 77 counties
  – Supported by public health

Creation (through certification process) of county health improvement organizations (CHIOs)
The Oklahoma Primary Healthcare Extension System

Federal Funding
- Oklahoma Universities
- Oklahoma Foundation for Medical Quality

Oklahoma’s Academic Health Centers

State Funding
- Oklahoma Department of Health
- Oklahoma Department of Mental Health
- Oklahoma Center for Healthcare Improvement

Public Health
- Community Service Council of Greater Tulsa

Mental Health
- Local Public Funding
- OPCA, OAFP, OACP, OAP, OOA, OSMA

Hospital
- Area Health Education Centers

Primary Care
- OPCA, OAFP, OACP, OAP, OOA, OSMA

Coop. Extension
- Alignment Collaboration Visibility Credibility Innovation Resources

Public Health
- Public Health Institute of Oklahoma

Social Services
- Community Service Council of Greater Tulsa

County Health Improvement Organization

Resource Development
Community-Based Preventive Services Delivery Model

Rationale

• Shared/collective priority (public and private)

• Misalignment of effort and rewards
  – Financial (e.g. colonoscopy, mammography, DEXA)
  – Quality metrics (e.g. immunizations/WCC)

• Poor coordination
  – Multiple separate, poorly coordinated funding sources both public and private
  – Difficulty combining public and private funds
  – Multiple different health systems
Community-Based Delivery Model

Method:

• Three rural counties entered sequentially (yrs 1, 2, 3)
• Community-based Wellness Coordinators paid to use basic PSRS linked to HIE to update information and advise and refer patients to 10 preventive services in accordance with PCP preferences
• Rates of delivery of services determined for baseline year and compared to intervention year
• Costs and revenues associated with specific services during baseline year compared to intervention year for PCPs and hospitals

Results available for first county
# Community-Based Delivery Model

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Outreach Effort</th>
<th>Denominator</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adoption</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary care practices</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Hospitals</td>
<td>1</td>
<td>1(+1)</td>
</tr>
<tr>
<td>Health Depts.</td>
<td>(1)</td>
<td>1</td>
</tr>
<tr>
<td><strong>Implementation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PCPs</td>
<td>3 full/3 partial</td>
<td>6</td>
</tr>
<tr>
<td>Hospitals</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Health Depts.</td>
<td>(1)</td>
<td>(1)</td>
</tr>
<tr>
<td><strong>Reach</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Population</td>
<td>9138 records</td>
<td>15,000 pop.</td>
</tr>
<tr>
<td>Contacted</td>
<td>5034</td>
<td>22% up to date</td>
</tr>
<tr>
<td>Services Discussed</td>
<td>7776</td>
<td>2/person</td>
</tr>
</tbody>
</table>
## Effectiveness

<table>
<thead>
<tr>
<th>Services by Care Delivery Domain</th>
<th>Baseline</th>
<th>Post-Intervention</th>
<th>P</th>
<th>Share of ROI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary Care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking cessation</td>
<td>33%</td>
<td>71%</td>
<td>&lt;0.01</td>
<td>14%</td>
</tr>
<tr>
<td>Adult immunizations</td>
<td>63%</td>
<td>78%</td>
<td>&lt;0.05</td>
<td>3%</td>
</tr>
<tr>
<td>Diabetes management</td>
<td>48%</td>
<td>75%</td>
<td>&lt;0.01</td>
<td>18%</td>
</tr>
<tr>
<td>WCC</td>
<td>51%</td>
<td>60%</td>
<td>&lt;0.05</td>
<td>13%</td>
</tr>
<tr>
<td>Physical activity counseling</td>
<td>27%</td>
<td>38%</td>
<td>&lt;0.01</td>
<td>14%</td>
</tr>
<tr>
<td><strong>Combined</strong></td>
<td>44%</td>
<td>64%</td>
<td>&lt;0.01</td>
<td>62%</td>
</tr>
<tr>
<td><strong>Hospital</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colonoscopy</td>
<td>38</td>
<td>43%</td>
<td>0.07</td>
<td>31%</td>
</tr>
<tr>
<td>Mammography</td>
<td>55%</td>
<td>63%</td>
<td>&lt;0.05</td>
<td>6%</td>
</tr>
<tr>
<td>DEXA</td>
<td>24%</td>
<td>30%</td>
<td>&lt;0.05</td>
<td>1%</td>
</tr>
<tr>
<td><strong>Combined Total</strong></td>
<td>39%</td>
<td>45%</td>
<td>.05</td>
<td>38%</td>
</tr>
<tr>
<td><strong>Combined Total</strong></td>
<td>42%</td>
<td>57%</td>
<td>&lt;0.01</td>
<td>100%</td>
</tr>
</tbody>
</table>
Maintenance

1 of the 3 Health Systems (hospital + 1 practice)

• WC salary plus benefits: Approx. $40,000

• Additional health system revenue: $52,000
  – Hospital: $38,000
  – Practice: $14,000

  – 75% of additional hospital revenue came from colonoscopies, mammographies and DEXAs

Health system decided to pay for the WC post-grant (not ideal).
In second county WCs hired by CHIO
Improving Delivery of Preventive Services

**RESEARCH**

- Existing/Emerging Knowledge
  - Indigenous Knowledge
  - Dissemination & Implementation
  - Validation
  - Field Testing

**DEVELOPMENT**

- Best Practices
- Pilots
- cRCTs
- Validation
- cRCTs
- Stepped Wedge

- PDA-based Reminder System
- PC-Based Reminder System
- Patient Wellness Portal
- Health Planner (HRA)

**Existing/Emerging Tools/Structures**
Improving Delivery of Preventive Services

RESEARCH

Existing/Emerging Knowledge

PSRS-HIE Linkage

Community-Based Delivery System

Cohort Policy CBPR Cost Effectiveness

Existing Organizations CHIOs HRA-HIE Wellness Coordinators

Existing/Emerging Tools/Structures

DEVELOPMENT/POLICY
Planning a Career in Primary Care Research

• What role(s) do you want to play?
• What additional training will you need?
• By what performance measures will you be judged?
• With who will you collaborate?
• Where will your funding come from?
• How much of your time will it take?
Collaboration

• Those who will use the results (e.g., clinicians)
• Those who will be involved in the dissemination and implementation of the results (QI directors, payers, IT vendors, etc.)
• Those who will benefit from the results (e.g. practice staff, patients)
• Clinical content experts (e.g., pulmonologist)
• Methodologists (e.g., epi/biostats/econ.)
• Dissemination/implementation experts
Training

• Fellowship
• Mini-fellowship (e.g. U. of Michigan)
• Public health degree (e.g. MPH, PhD)
• Clinical and Translational Science degree
• Traditional graduate degree program
“Anything worth doing is worth doing for nothing.”

Anonymous

• If the metric is NIH funding, find another institution
• Learn about contracts
• Develop professional relationships with multiple funding organizations
• Don’t chase RFAs
• Become a grant reviewer
• Develop a grant/contract generating team
  – Grant writing expertise
  – Budgetary expertise
  – IRB/regulatory expertise
Time

• 50% protected time minimum
  – 3-5% FTE per grant application
  – 20-50% FTE per major project
  – 1-2% FTE per journal article
  – 10% FTE to develop/direct a PBRN

• Assigned and reliable coverage for patients during protected time

• 10-20% non-clinical, non-research time to manage non-research-related educational and administrative tasks
Objectives

1. Define the scope of primary care research
2. Explain several ways that applied research is different from basic research and clinical trials and some of the methodological implications of those differences
3. Give an example of each of the following types of primary care research:
   a. Theoretical and methodological research
   b. Health care research (attributes research)
   c. Clinical research
   d. Health systems research (D&I, policy research)
4. Help you to think differently/more clearly about the role and importance of primary care research
5. Encourage you to become a contributor (researcher, advocate, participants, etc.)
Primary Care Research: No Longer Lost in Translation

Questions and Comments