Mystery of The Blue Highway
Engaging Community in Research

John M. Westfall, MD, MPH
Director – High Plains Research Network
Associate Den for Rural Health
University of Colorado Denver

Bridging the Causeway: A Center for Healthcare Policy and Research Symposium
UC Davis Center for Healthcare Policy and Research
Mystery of the Blue Highway

“It is inherently improbable that an academic researcher can ask a clinical question that matters to a patient.”
What’s wrong with our medical research?

• Inventing a new medicine or treatment is just the starting point for improving the health of an individual patient.
• The magnitude and nature of the work required to translate findings from human medical research into valid and effective clinical practice, have been underestimated.
• Balas and Boren estimated that it takes an average of 17 years for only 14% of new scientific discoveries to enter day-to-day clinical practice.
• McGlynn et al. reported that Americans only receive 50% of the recommended preventive, acute, and chronic health care.
  – For example, just over 50% of eligible Americans have received appropriate colorectal cancer screening.
  – While the beneficial effect of beta-blockers in acute myocardial infarction was discovered 25 years ago, the variation in use is still great, and beta-blockers are widely underutilized.
What’s wrong with our medical research?

• The detours, speed traps, roadblocks and potholes that limit the movement of treatments from bench to bedside are numerous and common

• limited external validity of randomized controlled trials
• diverse nature of ambulatory primary care practice
• difference between efficacy and effectiveness
• paucity of successful collaborative efforts between academic researchers and community physicians and patients
• failure of the academic research enterprise to address needs identified by the community
What’s wrong with our medical research?

- Graham reported that patient-specific factors greatly affect physicians’ treatment of heart failure and pointed out that imprecise definitions, reliance on single measures, and organizational factors limit the validity of heart failure treatment guidelines.

- O’Connor et al. reported the evidence-based clinical practice guideline on upper respiratory infections was generally unhelpful because only 13% of the patients with upper respiratory symptoms were actually eligible for adherence to guideline care.

- Katz found that guidelines for treating unstable angina likely do not decrease unnecessary hospitalizations and might actually increase admission to limited ICU beds.
After initial widespread encouragement of tPA for acute ischemic stroke several studies reported significant deviation from national treatment recommendations leading to unacceptably high complication rates.

- PSA Screening
- Vioxx
- Etc.
What’s wrong with our medical research?

• Frequently, the major questions that need to be answered to close the gaps between scientific discovery and wide-spread use in primary care are not prioritized by funders or undertaken by academic researchers.

• Innumerable studies have been done on hypertension, and hypertension treatment guidelines are routinely updated and distributed.

• Fundamental questions about how to implement these recommendations in primary care remain unresolved.
  – What is the incremental benefit to lowering the blood pressure an additional 10 points by adding another medicine?
  – What are the additional risks?
  – Patients want to know if the benefit is worth the costs of taking yet another pill.
The Mysteries

• Mystery #1 –
  – Why can’t our best discoveries make their way to our practicing physicians, their exam rooms, and their patients?

• Mystery #2
  – Why isn’t our research relevant to our community?
Mystery of the Blue Highway

• Mystery #3 –
  – The mystery of practice-based research
  – Engaging practicing doctors

• Mystery #4 –
  – The mystery of participatory research
  – Engaging community members
The Mystery of Practice Based Research

Engaging doctors, nurses, and practices in research
Kerr White Boxes - 1960

Traditional Medical Research Occurs in
this itsy-bitsy little box

White KL, William TF, and Greenberg BG.
In an average month: KW Boxes 2000

- 1000 people
- 800 have symptoms
- 327 consider seeking medical care
- 217 visit a physician’s office
- 113 visit primary care physician’s office
- 65 visit CAM provider
- 21 visit a hospital outpatient clinic
- 14 receive home health care
- 13 visit an emergency department
- 8 are in a hospital
- <1 is in an academic health center hospital

New Ecology of Medical Care - 2000
Practice-based Research Networks

Engaging physicians and medical practices along the blue highways
FEAR

UNTIL YOU HAVE THE COURAGE TO LOSE SIGHT OF THE SHORE, YOU WILL NOT KNOW THE TERROR OF BEING FOREVER LOST AT SEA.

www.despair.com
Practice-Based Research Networks

- A group of clinicians, practices or institutions that wish to work together, over time, to ask and answer clinical questions
  - A network has life beyond a single study
- Come in many flavors/missions
- Have variable governance
- Use variable methods to develop studies
Who can be the members?

- Individual Clinicians –
- Practices – all clinicians within a practice agree to join (CaReNet)
- Institutions – such as a hospice or a rural hospital (PoPCRN and High Plains Research Network)
  - Hospitals
  - Nursing homes
  - Home health
  - Public health dept
Minimal Governance/Support Needs

- Director/ Research Director
- Network coordinator (consistency for members)
- Communication system (newsletter, web, e-mail)
- Name/ Logo (identity)
- Recruitment process (brochure, contacts)
- Application process
- Collect basic practice/ member data
Storms on the Blue Highways
Typical Governance/Support

- Board of Directors/Steering Committee – made up of clinicians, perhaps community members
- Regular meeting for members (Annual Convocation)
- PRAs to get work done
- Community Advisory Council/Board
  – Community members
What’s possible?

• Descriptive studies of beliefs (provider or patient/client)
  – All member types can perform

• Cross-sectional Descriptive studies of care
  – All member types can perform

• Participatory Research
What’s Possible?

• Quasi-experimental methods
  – More difficult when only select members of a group participate

• Longitudinal descriptive studies
  – All member types may be able to participate but depends on research methods

• Randomized Control Trial
  – Difficult when only selected members participate
Blue Highways on the NIH Roadmap

BENCH

Basic Science Research
Preclinical Studies
Animal Research

TRANSLATION TO HUMANS

T1
Case Series
Phase 1 and 2 Clinical Trials

BEDSIDE

Human Clinical Research
Controlled Observational Studies
Phase 3 Clinical Trials

T2
Guideline Development
Meta-analyses
Systematic Reviews

TRANSLATION TO PATIENTS

T2
Practice-Based Research
Phase 3 and 4 Clinical Trials
Observational Studies
Survey Research

T3
Dissemination Research
Implementation Research

TRANSLATION TO PRACTICE

PRACTICE

Clinical Practice
Delivery of Recommended Care to the Right Patient at the Right Time
Identification of New Clinical Questions and Gaps in Care

• Practice-based research fits well with the vision of the NIH Roadmap to “develop new partnerships of research with organized patient communities, community-based health care providers … who care for sufficiently large groups of patients interested in working with researchers to quickly develop, test and deliver new interventions”

• Practice-based research may be an essential component of successful CTSA/CTSI
What’s it really take

http://www.dot.ca.gov/interstate/images/YoloCauseway_1915.jpg
What’s it really take?

• Time
  – Windshield time
  – Cold calls

• Hot tamales and bit-o-honey
  – And diet pepsi

• The First idea
  – Your idea
  – Their idea
What’s it really take?

- Trust
- Cold Calls
- Rejection insurance
  - Or counseling
- An eager student
- Know one or 2 doctors
What’s it really take?

- You have to leave your office.
- Get in your car
- Drive to an office
- Say hello
- Take some candy
- Ask a question
- Start a conversation
- Make a friend
ACHIEVEMENT
You can do anything you set your mind to when you have vision, determination, and an endless supply of expendable labor.

www.despair.com
• Who are your doctors?
• Where are your practices?
“On the old highway maps of America, the main routes were red and the back roads blue. Now even the colors are changing. But in those brevities just before dawn and a little after dusk – times neither day nor night – the old roads return to the sky some of its color. Then, in truth, they carry a mysterious cast of blue, and it’s that time when the pull of the blue highway is strongest, when the open road is a beckoning, a strangeness, a place where a man can lose himself.”

William Least Heat-Moon in Blue Highways
The Mystery of Participatory Research

Engaging the community
I’m the researcher, where’s the fire?
Participatory

- Community-based Participatory Research (CBPR) is an emerging model of research within primary care.
- This model has been described as “systematic investigation, with the collaboration of those affected by the issue being studied, for the purpose of education and taking action or effecting social change.”
- CBPR is participatory, cooperative, and a co-learning process for researchers and community members.
- number of parallels between community-based research and efforts to create healthy communities.
Participatory Research

• ground-up rather than top-down approaches,
• recognizing the limitations of expert knowledge and narrow single discipline approaches to complex human problems.
• “democratic participatory processes and social learning” about the meaning of health and other concerns in order to promote change.
• strengths of people and communities, including, their capacity for problem-solving.
• driven by community priorities, rather than those of outside experts.
• no cookbook or recipe, either for “doing” community-based research or “creating” a healthy community.
CBPR is a partnership
- Community members bring individual expertise
- Researchers bring expertise
- This collaboration is synergistic
- Your research will be better,
  - will matter more,
  - and will be more fun.
HPRN C.A.C.
HPRN Mission Statement

To provide excellent rural health care by translating the best scientific evidence into every-day clinical practice. The HPRN provides approved Continuing Medical Education, system-wide interventions aimed at quality improvement, and feedback reports on outcomes of interest to physicians, other providers, hospital administrators, and patients.
High Plains Research Network

- 16 counties
- 30,000 miles²
- 150,000 people
- 16 hospitals
- 50 practices
- 125 physicians, PA, NPs
- 75-300 miles from HPRN headquarters
The C.A.C. Mission Statement

The High Plains Research Network Community Advisory Council was developed in response to a growing awareness of the importance of involving communities in research.

We believe it is essential to include the consumer and patient, that is - potential study participants, in the generation of research ideas, review of research protocols, and promotion of subject recruitment.

The guiding principle of the CAC is to help inform and guide research in real patient experience and assure information garnered returns to and improves the quality of health care in individual rural communities.
CONSISTENCY
It’s Only a Virtue if You’re Not a Screwup.
www.despair.com
Community members

Maret Felzien and Ned Norman
   Farmer/rancher, community college English teacher
Mike Hernandez
   English teacher at prison
Mary Rodriguez
   Home visitation paraprofessional
Kathy and Steve Winkleman
   Elementary school teacher and farmer/rancher
Shirley Cowart
   Retired school administrative assistant
Sergio and Nora Sanchez
   Hardware store owner and dental assistant
Carly Schrade
   High School Student
Karyssa Schuppe
   High School Student
What’s it really take?

• Time
  – Windshield time
  – Cold calls
  – Friend of a friend of a friend

• Coffee Cake and Betty Eastin
  – And coffee (the stronger the better)

• The First idea
  – Your idea
  – Their idea
What’s it really take?

• Trust
• Cold Calls
• Rejection insurance
  – Or counseling
• An eager student
• Patience
LOSING
If at First You Don’t Succeed, Failure May Be Your Style.
www.despair.com
What’s it really take?

• You have to leave your office.
• Get in your car
• Drive to a home
• Say hello
• Take some coffee cake
• Ask a question
• Start a conversation
• Make a friend
What’s it really take

• Resource needs. Remember that both you and the community members have resource needs
  – Travel time
  – Space to meet
  – Teleconference
  – Compensation
    • Honoria
    • Mileage and meal reimbursement
    • Lodging
    • Email
Successful behaviors

- “The Community is always right!”
  - Ann Macaulay
  - Listen to your community members
- Teach your community partners about research
  - Research methods
  - Financing research
  - Bring your community partners to your meetings and convocations
- Involve community members early in reviewing methods, data, results,
- Have community members write articles and present
What our C.A.C. members want

• A sense that they are doing something important. Something that matters
• Movement – projects must move forward
• Results – our C.A.C. want to see the data
• The CAC expects us to do our job and get fulfill our promises and obligations
• The guiding principle of the CAC is to help inform and guide research in real patient experience and assure information garnered returns to and improves the quality of health care in individual rural communities.
Some attributes of the High Plains C.A.C.

• Ongoing, enduring
• Fluid, adaptable
• Participants, not necessarily representatives
• Diversity in age, gender, ethnicity, education, geography, employment……..
• No set requirements for level & type of involvement
Where is your community?

Who are your community members?
The Seventh Mystery

What happens when you engage practices and communities?
The Sixth Mystery

“There is nothing like looking, if you want to find something. You certainly usually find something, if you look, but it is not always quite the something you were after.”

-J.R.R. Tolkien
Medical Mistakes Survey

- Stemmed from Applied Strategies in Patient Safety (ASIPS) project
- ASIPS aimed to increase error reporting by primary care clinicians, analyze causes and effects of errors, and reduce incidence of errors
- Funded by AHRQ
- Medical Mistakes Survey conducted by C.A.C.
Medical Mistakes Survey

• The CAC:
  – Developed anonymous survey instrument with guidance from ASIPS research team.
  – Conceived of distribution method (survey inserted in local newspapers).
  – Identified four communities and coordinated ads of upcoming survey with local newspapers.
  – Participated in the qualitative review of 170 reported errors
  – Read surveys, made comments, identified themes, quotes
  – Assisted in manuscript preparation – co-author
  – Co-presented at national meeting
• 284 surveys returned
• 170 identified an error
• We identified about 58 errors using Victorroff and Pace Taxonomy
• What did respondents report as harm?
• CAC members participated in the qualitative review of 170 reported errors
• All CAC members read surveys, made comments, identified themes, quotes, ideas,
• Helped write paper, presented at NAPCRG
Patient Safety event

Medical mistake
Colon Cancer Boot Camp:

• Learned all about colon cancer – epidemiology, screening methods, current literature on screening rates and barriers

• Read “Tipping Point” to become familiar with social trends and marketing

• Brainstormed what to tell folks and how to tell ‘em

CDC Grant for Colorectal Cancer Screening
Intervention Development

- Met quarterly for face-to-face meetings
- Held conference calls every two weeks (30-45 minutes)
- Many emails and individual phone calls!
CRCS Project Title

- Do we have to use *coloRECTAL*?*
- What is “screening”?*

**TESTING TO PREVENT COLON CANCER**

*Interventions Aimed at Increasing Colorectal Cancer Screening Among Men and Women in Rural Colorado*
The Message

- Colon cancer is the second leading cause of cancer death in the United States
- Colon Cancer is preventable
- Testing is worth it
- Talk to your doctor about testing to prevent colon cancer
The Dissemination

- Newspaper articles by local doctor
- Newspaper story about local person
  - Cancer survivor
  - Community member who was tested
  - Family member
- Advertisement with each message and local person in the ad
- Community talks by physicians and community members
- “Farm Auction” Flyer
- Travel Mugs provided by HPRN practices
  - “Got Polyps?”
Colon Cancer is Preventable.

Pass this card along.

Make an appointment with your doctor to talk about colon cancer testing, take this card to your appointment, and receive a FREE travel mug (while supplies last).

- Colon cancer is the second leading cause of cancer death in the U.S.
- It is preventable.
- Testing is worth it.
- Talk to your doctor today.

THIS MESSAGE BROUGHT TO YOU BY THE JOINT PLANNING COMMITTEE, HIGH PLAINS RESEARCH NETWORK.
Farm Auction

ask your doctor about Colon Cancer

Did you know that... colon cancer is the second leading cause of cancer death in the U.S., colon cancer is preventable... colon cancer testing is worth it... you should talk to your doctor about testing today!

Tractors, Combine, Trucks Pickups and Cars

Your risk for colorectal cancer may be higher than average if you or a close relative have had colorectal polyps or cancer or if you have inflammatory bowel disease.

Regular screening for polyps using sigmoidoscopy or colonoscopy can prevent cancer and save your life.

Talk to your doctor!

Machinery

Colon cancer occurs when polyps (small growths in the colon) start to grow abnormally. Not all polyps will develop into cancer, but nearly all colon cancers come from polyps.

Removal of polyps prevents the chance that one might become abnormal and develop into colon cancer.

Talk to your doctor!

Miscellaneous

• Most colon cancers develop from polyps in the colon.
• An estimated 105,000 new colon cancer cases will be diagnosed this year in the U.S. 16,000 new cases will be in Colorado.
• Each week, about 6 women in Colorado die from colon cancer compared to about 8 women dying from breast cancer.

Talk to your doctor!

Farm and Shop Items

Colorectal cancer is cancer that occurs in the colon or rectum, the colon is the large intestine or large bowel. The rectum is the passageway connecting the colon to the anus.

Several different screening tests can be used to test for polyps or colorectal cancer. Each can be used alone. Sometimes, they are used in combination with each other.

Fecal Occult Blood Test or Stool Test—A test you do at home using a test kit you get from your healthcare provider. You put stool samples on test cards and return the cards to the doctor or lab. This test checks for occult (hidden) blood in the stool.

Flexible Sigmoidoscopy—A test in which the doctor puts a short, thin, flexible, lighted tube into your rectum. The doctor checks for polyps or cancer in the rectum and lower third of the colon. Sometimes this test is used in combination with the fecal occult test.

Colonoscopy—This test is similar to flexible sigmoidoscopy, except the doctor uses a longer, thin, flexible, lighted tube to check for polyps or cancer in the rectum and the entire colon. During the test, the doctor can find and remove most polyps and some cancers.

Double Contrast Barium Enema—A test in which you are given an enema with a liquid called barium. The doctor takes x-rays of your colon. The barium allows the doctor to see the outline of your colon to check for polyps or other abnormalities.

Talk to your doctor!

Collectables

People who have polyps or colorectal cancer don’t always have symptoms, especially at first. Someone could have polyps or colorectal cancer and not know it. If there are symptoms, they may include:

Bleeding or on your stool (bowel movement).

Stomach aches, pain, or cramps that happen a lot and you don’t know why.

A change in bowel habits, such as having stools that are narrower than usual.

Loosing weight and you don’t know why.

If you have any of these symptoms, talk to your doctor. These symptoms may be caused by something other than cancer. However, the only way to know what is causing them is to see your doctor.

Talk to your doctor!

Auctioneers:
The Joint Planning Committee, High Plains Research Network

Talk to your doctor!

Bridging The Causeway
Did it work?

• Reach
  – 68% of a random sample of community members had seen at least one of the materials
  – the more products seen the more likely they were to report plans to get tested

• Outcome
  – 27% increase in plans to get tested
  – 9% increase in any test
  – 15% increase in endoscopy screening
    • 9% increase in our control communities
    • however, the control communities were “contaminated”
    • Up to 40% of the control community respondents also reported seeing our products
  – Follow-up “card-study” in practices this month

• When the community likes something they share it
What else have they done?
HPRN for rural health care

by Shirley Cowart

What is HPRN?
The High Plains Research Network (HPRN) is a community-based research program designed to promote a positive attitude toward health issues in rural northeastern Colorado. With community support, the mission of the Network is to “provide excellent health care by translating the best scientific evidence into everyday practice.” The High Plains Research Network itself feels it is essential to include the consumer and/or patients in creating research ideas, reviewing research protocol and ideas for future research that would benefit the communities involved.

In 1996, the Department of Family Medicine at the University of Colorado-Greeley rubber-stamped the founding of the Network, and a meeting was held with the leadership at the University of Colorado- Denver and the University of Colorado-Greeley. It was a huge success. Now, the Network is a state-of-the-art research facility, with a strong focus on improving the health care of rural patients.

The guiding principal of the HPRN is to help inform and direct research in a real patient experience, and assure that this information returns to the community to improve the quality of health care in our area.

Some of the accomplishments of the research include an increased understanding of the role of hospital transfers in the care of rural patients suffering from heart attacks, improved access to health care for Hispanic community members in the study area, an assessment of the knowledge and attitudes towards palliative care by health care professionals, and a better understanding of why ECG (electrocardiogram) in each hospital in northeast Colorado and several of the medical offices in the network.

You are important. Your input is important whether or not you have health care issues at this time. Further information, surveys and/or articles will follow periodically to inform the public concerning the progress of the High Plains Research Network.

***

I like the dreams of the future better than the history of the past.

—Thomas Jefferson

***

Impress Mom With Beautiful
HPRN responding to health care needs in Northeastern Colorado

Have you ever wondered if health care in Logan County is as good as it could be? High Plains Research Network wants to prove that it is.

The High Plains Research Network (HPRN) is a community-based research program designed to promote a positive attitude toward health issues in rural northeastern Colorado.

With community support, the mission of the Network is to "provide excellent health care by translating the best scientific evidence into everyday practice." The researchers involved with HPRN feel it is essential to include the consumer and/or patient in creating research ideas, reviewing research protocol, and eliciting ideas for future research that will benefit the communities involved.

Some of the accomplishments of the research include an increased understanding of the role of hospital transfer in the care of rural patients suffering from heart attacks, improved access to health care for Hispanic community members in Yuma County, an assessment of the knowledge and attitudes towards palliative care by health care professionals, and a better understanding of why providers make particular medical decisions in patients with diabetes.

HPRN has also provided state-of-the-art electrocardiograph machines (ECG) in each hospital in northeastern Colorado and several of the medical offices in the network.

In 1996, the Department of Family Medicine at the University of Colorado formed the High Plains Research Network in collaboration with the medical communities within nine counties (Phillips, Morgan, Sedgwick, Washington, Yuma, Kit Carson, Cheyenne, Lincoln, Logan) in rural northeast Colorado. HPRN is directed by Dr. Jack Westfall, an Associate Professor at the University of Colorado Health Sciences Center.

Being a native of Yuma, and a family doctor at the Plains Medical Center in Limon, Dr. Westfall is familiar with the medical services and care available to the northeastern Colorado counties included in the network area.

Informing and directing research in a real patient experience are the guiding principles of HPRN. A subsequent goal is to return this information to the community to improve the quality of health care in our area.

The ability of people in the Northeastern Plains of Colorado to make decisions about research in their community is both recognized and respected. Your input is important whether or not you have health care issues at this time.

Further information, surveys and/or articles will follow periodically to inform the public concerning the progress of the High Plains Research Network. Your Logan County members of HPRN Advisory Council are Maret Felzien and Ned Norman.

(By Maret Felzien, a Logan County member of the HPRN Advisory Council.)
Patient safety study leads to upcoming rural medical survey

By Shirley Cowart
HPRN CAC member

Have you or a loved one ever personally experienced a medical mistake? In 1998, the Institute of Medicine issued a report that indicated that 98,000 people die each year from medical errors. While most of decreasing these errors.

Participants in this ASIPS project included the High Plains Research Network (HPRN), a rural integrated primary care research network in the nine counties of northeast Colorado and the Colorado Research Network (CareNet), a practice-based research net...
• Improving Physical Activity among rural community members with arthritis
  – Mary Christenson, PhD Student
  – C.A.C. ad hoc committee on arthritis
  – Local medical providers
• Methamphetamines
  – Working on ideas and funding
• Underinsured
  – Practice-based survey of patients
  – Reviewed and pilot tested the survey instrument
- Asthma Toolkits
  - Practice Toolkit
    - Spirometer
    - On-site training (3 visits)
  - Patient Toolkit
    - Peak-flow meter
    - Action Plan
    - Voice Reminder system sign up
    - Educational materials
      - Customized for eastern Colorado by the C.A.C.
  - Outcomes
    - Improved asthma control and decreased acute visits
What else have they done?

• Presented posters and workshops at NAPCRG, AHRQ National PBRN Conference, and the Federal of PBRNs Annual Meeting
• Co-authored papers for peer-reviewed publication
• Participated in local, regional, and state health meetings and events.
• Planned new and exciting research and community health programs.
The Final Mystery

Pandemic Flu along the Blue Highway

• What happens when you really engage practicing doctors, nurses, and their office staff in research?
• What happens when you really engage community members in research?
The Final Mystery

The theatre has been closed because of the Plague.

That great medical discovery has not really worked out so well in your practice.

Excerpt from Shakespeare in Love
HENSLOWE is making his way from the theatre to the market place when FENNYMAN and LAMBERT appear at either shoulder and propel him back the way he came.

FENNYMAN
   This time we take your boots off!

HENSLOWE
   What have I done, Mr. Fennyman?

FENNYMAN
   The theatres are all closed by the plague!

HENSLOWE
   Oh, that.

FENNYMAN
   -by order of the Master of the Revels!
HENSLOWE
Mr. Fennyman, let me explain about the theatre business (they stop)

HENSLOWE (Cont'd)
The natural condition is one of insurmountable obstacles on the road to imminent disaster. Believe me, to be closed by the plague is a bagatelle in the ups and downs of owning a theatre.

FENNYMAN
So what do we do?
HENSLOWE
Nothing. Strangely enough, it all turns out well.

FENNYMAN
How?

HENSLOWE
I don't know. It's a mystery.
How does it all work out so well when we really engage practices and communities along the blue highways?

I don’t know, it’s a mystery
Thank you

- Linda Zittleman, HPRN Research Coordinator
- Christin Sutter, HPRN Research Field Associate
- Susan Gale, HPRN Research Field Associate
- Community Advisory Council Members
- Docs, PAs, NPs, Nurses, practice staff in the HPRN
- Numerous other folks in the Department of Family Medicine and the University of Colorado Denver School of Medicine

Bridging The Causeway
The Yolo Causeway was originally built in 1916 linking Davis and Sacramento.

In 1928 the Causeway was made a part of the re-routed Lincoln Highway, the first blue highway across America. Later, the causeway became a part of US Highways 40 and 99W.

The current causeway was built in 1962 and renamed the "Blecher-Freeman Memorial Causeway" after two California Highway Patrol officers who were shot to death in 1978 by an armed felon after a highway stop near the causeway.

The causeway is composed of two bridges connected by an earth fill segment. The easternmost of the two bridges is the longer of the two and traffic reporters will sometimes refer to the two structures as the "long bridge" and the "short bridge".
The end
While practice-based research may indeed provide an appropriate setting for randomized controlled trials, such trials do not take full advantage of the strength of practice-based research.

The benefit of practice-based research goes beyond the simple notion of access to large numbers of patients.

Practice-based research also provides the laboratory for observational studies, physician and patient surveys, secondary data analysis, and qualitative research.

Well positioned to conduct translational research, practice-based research is not synonymous with translational research.

Practice-based research may be the best setting for studying the process of care and the manner in which diseases are diagnosed, treatments initiated, and chronic conditions managed.

It is in practice-based research where effectiveness can be measured, where new clinical questions may arise, where readiness to change and adopt new treatments can be studied and addressed, where patient knowledge and preferences are encountered and managed, and where the interface between a patient and their doctor can be explored and medical care improved.

Practice-based research is the final common pathway for improving individual patient care and outcomes.
CBPR in PBRNs in the U.S.

Survey to all identifiable PBRNs in the United States
We asked if and how the PBRN met the description established by AHRQ
  “…mechanism(such as a community advisory board) is in place to solicit advice/feedback from the communities of patients served by PBRN clinicians.”
This was used as a baseline example to stimulate respondents to describe their activities.
46 responses from 65 (71%) total identified PBRNS

20 reported they do not meet the AHRQ description
26 report they do meet the AHRQ description
What types of community/patient involvement?

Community boards for health clinics
Clinician board of directors/advisors
_A patient on our board
Community advisory board that meets regularly to discuss current projects provide input
CAB reviews all network studies, developing their own study for the PBRN to conduct
Future plans

First we need to get a physician advisory group
Obtaining expert advice on CBPR
Planning stages
2-3 patients will be selected to be on the advisory committee
“virtual advisory board” meet by conference call 2 times per year.
Barriers

Our network is too young
Difficult to find times to meet
Money and time for travel
Our network covers hundreds of miles so difficult to get together
Data sharing (HIPPA)
Multiple languages among our patients
National representation is difficult for our network
Is the CAC Participatory Research?

Participatory Research Continuum

Pure Participatory Research
• community comes up with the idea
• community members “do the work”
• researchers help guide research

Participatory PBRN
• Partnership on project ideas
• Sometimes the $ determines the project
• Community members are experts
• Researchers are experts
• Community members assure that research relates to the community
• Shared work load.
• Community in advisory role

I don’t know, this is all a big experiment
When CBPR met PBRN

What is Community-Based Participatory Research?

Can you mix participatory Research and Practice-based research?

What did we do in the High Plains Research Network?

CAC

How do you get started?
Our charge

...inform and guide the research in real patient experience and assure information garnered returns to and improves the quality of health care in individual rural communities.
Accomplishments to date…

Held 5 working meetings

Hosted many experts to bring us to speed

Published 3 articles in regional newspapers:
- Introduction to HPRN and the CAC
- Palliative Care study report
- Medical Harm Survey
Not to mention, we have...

Sent 2 members to National Rural Health Assoc. Conference
Sent 1 to Rural Philanthropy Days
Sent 1 to Drug Endangered Children Conference
Endorsed Colorectal Cancer Screening Project grant, and
Are prepared to be active members on JPC for CRCS
We have also....

Given input on the format of medical harm survey

Organized media effort for survey

Distributed the medical harm survey through newspapers and community connections.
Medical Mistakes Survey:

Community members’ perspectives of harm from medical mistakes
Anonymous Patient Report

Reporting Hotline: 1-866-000-0000 (Toll Free)

1. Describe what happened.

2. Please describe how you think the patient was harmed.

3. Who was involved in this event? (select all that apply)
   1. Doctor
   2. Nurse
   3. Office Staff
   4. Specialist
   5. Laboratory
   6. Pharmacist
   7. Hospital Management/Patient Representative
   8. Lawyer
   9. Other ____________________________

4. Who have you talked to about this? (select all that apply)
   1. No one
   2. Family/Friends
   3. Doctor
   4. Nurse
   5. Other Office Staff
   6. Hospital Management/Patient Representative
   7. Lawyer
   8. Pharmacist
   9. Other ____________________________

5. Where did this happen? (select all that apply)
   1. Local doctor's office
   2. Local Hospital
   3. Urban/Suburban hospital
   4. Pharmacy
   5. Any urban/suburban doctor's office
   6. Other ____________________________

6. How old was the patient at the time this happened?
   _____ Years Old (if an younger than 1 year old, enter 0)

7. What is the patient's gender?
   1. Male
   2. Female

Medical Mistakes Survey

The High Plains Research Network (HPRN) of the University of Colorado Department of Family Medicine in collaboration with the HPRN Community Advisory Council is conducting a research study that aims to learn more about patients' definitions and experiences with medical mistakes. Medical mistakes can be serious (such as a mistake during surgery that may require additional surgery) or not so serious (such as not getting your test results back). We hope that those who have experienced a medical mistake would take the time to fill out this form and send it back to us.

If you fill out this form, please do not include your name or any names of medical providers that may have been involved. We are not a reporting agency and as such will not try to remedy the situation. We only want to be able to describe what people are experiencing. We will keep any information that you provide strictly confidential and we will not be able to link the information back to you. If you have any questions about this survey or how the information will be used you can contact the principal investigator, Dr. Jack Westfall, at 303 724 9712. This study has been reviewed by the Colorado Multiple Institutional Review Board (#04-0601).

1. Have you or a family member experienced a medical mistake?
   □ No  □ Yes  □ If yes, who?  □ Self  □ Family Member
   Please summarize what happened.
   ______________________________________________________________________
   ______________________________________________________________________
   ______________________________________________________________________

2. Do you feel that you or the family member was harmed by this medical mistake? (There are many ways one can be harmed, for example, physically, emotionally, and other ways.)
   □ No  □ Yes
   If yes, how were you harmed?
   ______________________________________________________________________
   ______________________________________________________________________
   ______________________________________________________________________

3. Who have you or your family member talked to about this? (Please check all that apply)
   [ ] No one
   [ ] Hospital Management
   [ ] Nurse
   [ ] Family/Friends
   [ ] Patient Representative
   [ ] Other, please specify ______

4. Who was involved in this event? (Please check all that apply)
   [ ] Doctor
   [ ] Laboratory
   [ ] Office Staff
   [ ] Nurse
   [ ] Pharmacy
   [ ] Radiology
   [ ] Specialist
   [ ] Hospital Staff
   [ ] Other, please specify ______

Please continue on other side
Medical Mistakes Survey —
Coming in next week’s newspaper

Have you experienced a medical mistake?
If you answered “YES”, you may be eligible to fill out our Medical Mistakes Survey. The High Plains Research Network (HPRN) at CU Department of Family Medicine in collaboration with the HPRN Community Advisory Council is conducting a research study that aims to learn more about patient safety in rural communities.
If you are at least 18 years of age, read and write English and have experienced a medical mistake, you are eligible to complete an anonymous survey to help us learn more about patients’ definitions of harm and experiences with medical mistakes.

For questions, please call Becky at the High Plains Research Network 303 724-9716 or email becky.vanvorst@uchsc.edu. COMIRB #04-0601 P.I. John Westfall MD, MPH.

Please watch for the GREEN survey in next week’s paper!
Resident to be surveyed on medical issues

By Michael Becker
mbecker@journal-advocate.com

Residents of eastern Colorado will soon be surveyed for a study on medical issues — and the study hopes to determine just exactly what "harm" is. Maret Feltz, a member of the advisory board of the High Plains Research Network, said the study follows on a study done by Dr. John Westfall, a family physician in Limon and director...
Medical Harm Survey
270 returned surveys
155 reported errors

½ report for themselves, ½ for a family member
To patients, what is medical harm?

Wrong thyroid med dosage=
  Caused stress and additional blood tests
Erroneous “suspicious” mammogram=
  Extremely emotional
Incorrect labeling on cough med=
  None, but close call
Incorrect prescription for MRI not CAT scan
  Stress, fatigue and a day lost for 2 people
What is next for CAC?

Interpret the Medical Harm Survey results for the communities and for action items

Provide earnest work on CRCS project

Explore the impact of methamphetamine abuse in NE Colorado
HPRN CAC

Who are you?
Why are you on the CAC?
What is the purpose of the CAC?
What did you expect from the CAC?
Describe your experiences on the CAC over the past year and a half?
What might you tell folks considering starting a CAC?
Rural Colorado
What’s wrong with medical research?

• The Family Practice Inquiries Network (FPIN) has begun soliciting clinical questions from practicing physicians with the intent to find practical, relevant answers to these questions.
• Arising from the everyday clinical practice of medicine in primary care offices, these questions address common issues that seek to bridge the gap between recommend care and actual care.
• Unfortunately, these questions are infrequently addressed by academic and industry trials which focus their attention and resources on discovering new medicines and treatments.
• FPIN may be an important source for clinical questions for future funding initiatives.
HUMILIATION
THE HARDER YOU TRY, THE DUMBER YOU LOOK.

www.despair.com