



How to involve patients and the public in guideline development: the G-I-N PUBLIC toolkit

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Agenda



- I. G-I-N and G-I-N PUBLIC Background
- II. G-I-N Public Toolkit: A Framework of Public and Patient Involvement
- III. Participation: Recruitment and Support of Patients and Public in Guideline Development
- IV. Consultation: Public Consultation Strategies
- V. Communication: Patients' Versions of Guidelines
- VI. Pilot Program at Kaiser Permanente



Guidelines International Network G-I-N

Working Group:

G-I-N PUBLIC

www.g-i-n.net/activities/gin-public

- Established to support patient & public involvement (PPI)
- Made up of Guideline developers, researchers patient/public representatives
- Goal: to produce “Toolkit”; workshops; publications

Toolkit Launched in Berlin 2012



Why Patient Involvement?

- Why Involve Patients?
- Why Develop a Tool Kit?
- Why Now?

Why Now?

- Recommended standards issued by Institute of Medicine (IOM) suggest that guideline development groups include patients and consumers in their guideline development process (IOM of the National Academies, 2011).



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Involvement Strategies

- Participation
 - Exchange of information between clinical practice guideline (CPG) developers and the public
 - Patient representative(s) in guideline development groups
- Consultation
 - Collection of information from patient/public
 - Focus groups, workshops, surveys, literature searches, interviews
- Communication
 - Information to patients/public for individual clinical decisions
 - Patient versions of guidelines, dissemination and implementation, patient decision aids.

Toolkit Chapters



Participation

- How to recruit and support patient/public members
- How the Chair can facilitate PPI
- Involving patients and the public in guideline dissemination

Consultation

- How to conduct public and targeted consultation

Communication

- How to develop Patient versions of guidelines
- How guidelines can support patient involvement in the clinic

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Participation...

Role of Patient/Public Members

- Need for clarity on role and expectations
- Decide if full member or assigned a specific tasks?
- All members of the group involved in same work
- All members have equal status
- Represents patient perspectives (not just a token representative)



What experience, knowledge and skills are needed?



- Relevant experience of the condition
- Understanding of issues that matter to people with the condition – as a patient, care giver or employee of a patient organization
- Ability to provide a balanced view on patient issues
- Good communication and team working skills
- Time and commitment to attend meetings, do background reading and comment on draft documents

Participation...

Nomination or Open Recruitment?

- Advantages and disadvantages of both methods – lack of research on which produces the best result
- Method of selection should be transparent and accepted as legitimate



Participation...

Open Recruitment (Example)

National Institute for Health and Care Excellence (**NICE**) uses an open recruitment process:



- Advertise on website, patient group websites and newsletters, clinical networks, Twitter, etc...
- Role description and person specification
- Applications assessed against these criteria
- Telephone interviews with shortlisted people

Participation...

Nomination (Example)



The **German Agency for Quality in Medicine (AQuMed)** uses a formal nomination process:

- AQuMed informs patient umbrella organizations when a new CPG will be developed
- Patient organizations nominate up to 5 patients and/or representatives
- AQuMed has no influence on nomination
- Nomination is documented transparently in the methods section of each guideline

Participation...

Support

- Practical support
- Physical adjustments
- Compensation (honorarium, gift cards, etc...)



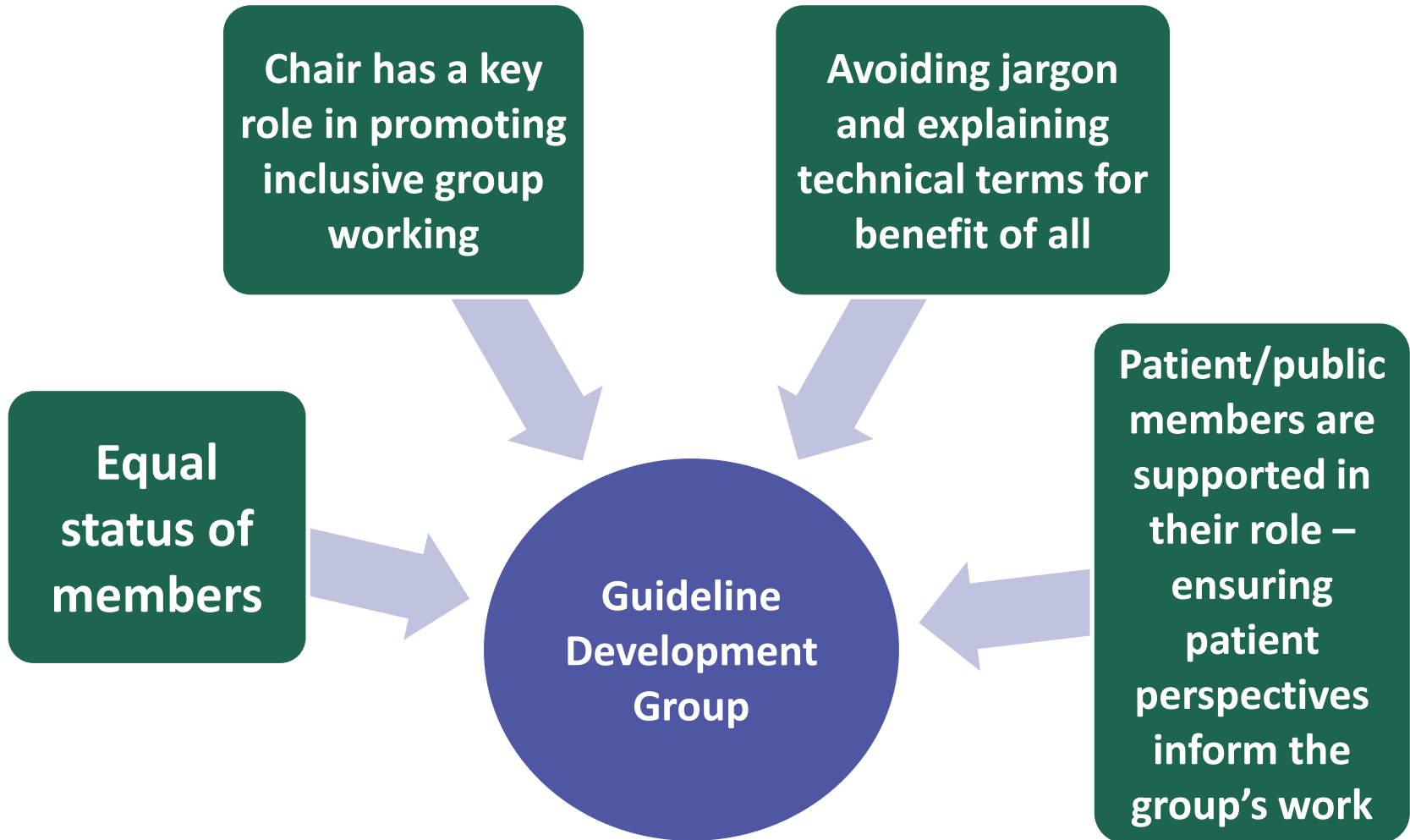
Participation... Training



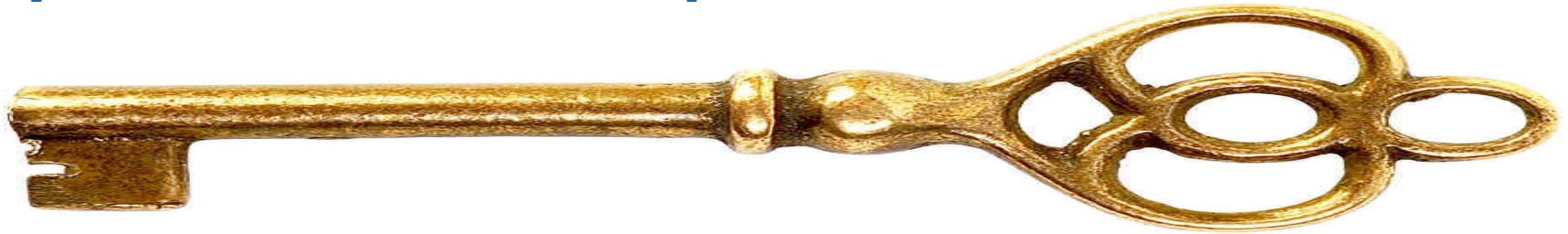
- Training in methods of EbM and guideline development
- Training techniques include:
 - Tailored in-house programme
 - External training course
 - Online learning e.g. Cochrane Collaboration's consumer learning on evidence-based healthcare:

<http://training.cochrane.org/consumers>

Inclusive Working Group



Keys to Success: Participation



- Clarity on what is expected of patient & public members
- Effective recruitment processes
- Equality of status on guideline groups & good chairing
- Induction, training, support & financial compensation
- Evaluation and refinement of processes

Voices of Experience



“Those of us with the condition are the REAL experts on how it feels. Others, no matter how brilliant, cannot have that insight” **(Patient member, guideline group)**



“I am even more convinced that development of guidelines must involve the people that the care, treatment or system is for” **(Chair, guideline group)**

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Consultation Defined...

- Consultation refers to the process of collecting information from patient and public stakeholders to inform guideline development and implementation. ~Boivin et al.

Consultation ensures:

- that issues important to patients, families and care givers are considered during the guideline development process.
 - that the CPG is relevant and acceptable to patients, care givers, and to specific groups
-
- Feedback paves the way for acceptance, implementation and dissemination of the guideline



Open and/or Targeted Methods of Consultation

	OPEN	TARGETED	OPEN & TARGETED
Ways	Public posting of draft documents & questions	<ul style="list-style-type: none"> • By invitation to all relevant stakeholders 	Public posting of draft documents /questions & targeted invitations
Potential advantages	Transparency and opening up process to all	<ul style="list-style-type: none"> • More effective in generating responses • Finding individuals or groups and invite them to contribute • Volume of feedback manageable 	Combines openness and transparency with reaching all relevant stakeholders
Potential disadvantages	<ul style="list-style-type: none"> • High volume of feedback • Inadequate feedback 	<ul style="list-style-type: none"> • Important viewpoints overlooked or avoided • Invited organizations not interested or able to respond timely 	High volume of feedback

Key Points In Time for Consultation to Occur...

#1: Setting the Guideline Scope

- Open or targeted consultation
- Wiki sites
- Focus groups & surveys
- Qualitative research
- Peer review



#2: Review of Guideline Draft

- Open or targeted consultation
- Focus groups
- Peer review

#3: Entire Guideline Development Process

- Structured feedback from patient organization
- Systematic search of qualitative studies



How to Deal With Comments



- Confirm receipt of comments to the commentator
- Document transparently all comments received
- Document rationale if recommendations have been modified after consultation

Key messages: Consultation



- Effective consultation adds value to the process of guideline development and can enhance implementation (ownership)
- Requires transparency and inclusion of all relevant stakeholders
- Can be conducted at all key stages, with a diversity of methods
- Requires additional time and resources, which need to be factored in from the start

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Patient Versions of Guidelines = Improved Communications

Shared decisions based on the same body of evidence builds a trusting relationship...



Patient Versions of Guidelines...

...foster Guideline Implementation.



Quality Demands...

are addressed with patient versions of guidelines...

- ✓ No influence by financial or intellectual interest;
- ✓ Joint editing of clinicians and patients/consumers
- ✓ Systematic search and assessment of the evidence
- ✓ Communicate levels of evidence /strength of recommendations
- ✓ Convey a realistic idea of the condition
- ✓ Description of all treatment options with their risks and benefits
- ✓ Patient-centred outcomes
- ✓ Risk communication
- ✓ Address uncertainties
- ✓ Readable, understandable and accessible

Challenges: Health Literacy Levels

Different levels of health literacy require different formats:



Communication

Sharing Decisions...



- Together clinicians and patients will make evidence based decisions based on one guideline.
- To enhance implementation, decision support tools will be directly linked to guideline content
- Other tools will be developed for use during patient encounters at the point of care (one tool for both clinicians *and* patients)

Key messages: Communication



- Patient versions of guidelines support the patient-doctor-relationship and shared decision making
- Patient versions of guidelines should meet the following criteria: transparency in terms of funding and COI; understandability, reliability, availability
- Communication to patients must be tailored to their needs and abilities (health literacy)
- Decision aids directly linked to the guideline and for use within consultation are needed

Barriers.....



Toolkit – What Next?



A Living Document!

- Dissemination & Evaluation
- Writing Toolkit Part Two

<http://www.g-i-n.net/activities/gin-public/toolkit>

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Patient and Public Involvement in Guideline Activities: A collaborative quality improvement pilot

Carrie M Davino-Ramaya and Krishnan Ramaya

Agenda

Introduction: Kaiser Permanente and Pacific University collaboration:
background and outcomes of interest

Part 1: Gauging organizational interest & focus group recruitment

Part 2: Focus Group Curriculum

Part 3: In progress: High risk/underserved Focus Group Activities

Conclusion and Exit Survey

Pacific University & Kaiser Permanente Collaboration



- Kaiser Permanente (Northwest region) and Pacific University became community partners in wellness:
 - Objective: To pilot a program of patient and consumer engagement in guideline activities.
- Why now: Why not now?? The recommended standards issued by Institute of Medicine (IOM) suggests that guideline development groups include patients and consumers in their guideline development process (IOM of the National Academies, 2011).

Patient and Public Involvement in Guideline Activities

Outcomes of Interest for our quality improvement pilot included:

- Address high-priority topics identified from survey results
- Increase knowledge of clinical practice guidelines
- Empower consumers/patients to have informed discussions with their health care providers.
- Create informative and actionable support tools for high risk/underserved populations (work in progress)



Patient and Public Involvement in Guideline Activities

Part 1: Gauging organizational interest, focus group recruitment, identifying target population and survey

Part 1: Pre-focus group survey

Gauging organizational interest & focus group recruitment

- Identify target population:
 - Employee (non faculty) of PU; N = 445
 - All staff are required to carry health insurance
- Survey Respondents:
 - A total of 91 respondents (20.4%) of which
 - 84 out 91 completed the survey (~19% response rate)
- Participation Incentive: random drawing.
 - Five cash awards of \$25 each.



Visits to Health Care Provider :



3. In the last one year I visited a health care provider (doctor/nurse)

		Response Percent	Response Count
1 time		19.3%	17
2 -3 times		37.5%	33
3 or more times		37.5%	33
I did not visit my health care provider		5.7%	5
answered question			88
skipped question			3

32-Question Survey: Demographic results:



Gender:	28.4% Male (25)	71.8% Female (63)		
Age:	18-24= 4.5%	25-36 =28.4%	37 to 48 = 28.4%	49-64 = 34.1% (4.6 undisclosed)
Ethnicity	White, Non- Hispanic=88.6	Hispanic = 3.4	Asian = 4.5	Multi Racial = 2.3 (1.2 Undisclosed)
Education	4yr coll grad 39.8%	> 4yr masters/doc 36.4%	2 yr coll 21.6	HS or GED 1.1

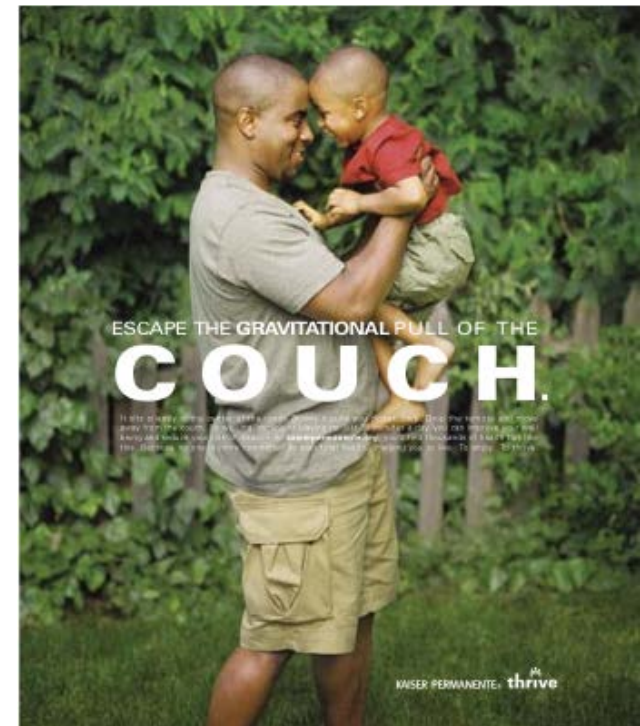
Of the 30 conditions listed below, which of the following are important to you and your family?

- High Blood Pressure 44.3%
- High cholesterol 34.1%
- Back Pain 30.7%
- Diabetes 28.4%
- Depression 28.4%
- Obesity 23.9%



From the following 5 conditions, select the health topics that you are most interested in learning about?

- Diet and exercise 76.1%
- Obesity and weight loss 38.6%
- High Blood Pressure 22.7%
- High Cholesterol 18.2%
- Diabetes 10.2%
- Others 20.5%



(Defining CPGs within the survey)

- **Clinical practice guidelines are recommendations for health care providers (doctors, nurse, etc) to follow in caring for patients with specific conditions. They are based upon the best available research evidence and practice experience. Select all that apply to you:**

- | | |
|--|-------|
| • I have never heard of CPGs | 42.4% |
| • Health care provider has shared CPGs with me | 35.3% |
| • Interested in learning more about CPG | 28.2% |
| • CPGs would help me to be more informed of my HC issues | 25.9% |
| • Would like to participate in a focus group to develop CPGs | 23.5% |

- Guidelines for patients are designed to help people and the general public learn about treatment information in easy to understand language. They are meant to help you when you talk to your doctor about health issues and treatment options that are best for you and/or your family. Select all that apply to you:
 - I would like more information in a CPG regarding:
 - Nutrition 81.2%
 - High BP 40.6%
 - Obesity 30.4%
 - Flu shots 21.7%
 - Vaccines 27.5%



Select all that you believe guidelines for patients will provide you and your family:

- Guidelines for patients can translate information that doctors use to help you and your family understand treatment options for many illnesses. 69.4%
- Guidelines for patients empower you to discuss treatment choices with your doctor or other health care provider. 67.1%
- Guidelines for patients contain the best available information to help you make informed health care decisions for you and your family. 69.4%
- Guidelines for patients are written with input from the general public to reflect values and preferences of you and your family 25.9%

Incentives to Participate:

- Two focus group session with 11 participants
- Back-to-back sessions on 2 separate days.
- Upon completion of the two-hour focus group, \$75 honorarium was given as compensation.



Additional Survey Questions:

- Dental
- Health plan
- Times accessed services per year
- Flex spending accounts
- General Health Status
- Main university job
- Self gauged knowledge of health issues
- Quality of Life
- Where do you access health information
- Exercise
- Evaluation of written material received from clinician





Patient and Public Involvement in Guideline Activities

Part 2: Focus Group Curriculum

Clinical Guideline Selected:



- Guideline full title:
 - *Adult Weight Management: Clinical Recommendation*
 - The evidence based recommendation is intended to assist health professionals in the screening, evaluation, and management of overweight and obesity in adults.
 - Selected based upon survey responses

Part 2: Focus Group Curriculum

- Level setting: an important objective was to “clearly” define:
 - Patient and Public Involvement (IOM & Health Care Reform)
 - Evidence-based Medicine (Judicious use of....)
 - Clinical Practice Guidelines
- We asked:
 - At the beginning of focus group we asked how many people had heard of evidence based medicine?
 - After completing the focus group we asked how their understanding of evidence based medicine changed?
 - Initially thought that the doctor knows everything; that the doctor learned everything from texts books during medical school
 - Not aware that there is a rigorous methodological process for EBM
 - Not aware that patient perspective and values were part of EBM

Part 2: Focus Group Curriculum

- Worksheet #1: Evaluation of guideline title
- Worksheet #2: Guideline review
- Worksheet #3: Group discussion
- Worksheet #4: Small Group break-out session
- Worksheet #5: Over all comments

Work sheet #1: Evaluation of guideline title

- Asked a series of 12 questions regarding the GL Title
- Awareness of treatment options for weight management
 - Pills, commercial diets, programs, surgery,
- Outcomes desired
 - Improved health/wellness, thin, lean , "SEXY" body
 - Magic Bullet weight loss
 - Losing weight and maintaining weight loss.
 - Better self esteem, more active longer life
- Concern about treatment of side effect
 - Costs, time results, effectiveness, hurting joints, aggravating previous injuries, yo-yo weight, failure, digestive issues, total lifestyle change



Work sheet #2: Guideline Review

- A series of 10 questions were asked about the overall guideline.
- Two questions gleaned highly useful information:
 - What section of the GL raised the most questions and concerns?
 - How can the content be improved?



What GL section raised the most questions/ concerns?

- 50% had a negative reaction to the term “co-morbidities”
- 80% felt a glossary would be helpful (hyperlipidemia vs high cholesterol)
- Little useful information for patients (what is a 1200 cal diet??)
- Lots of passive sentences “is recommended” loses impact
- The term obesity champion is not a good title unless they won a gold medal in weight gain!
- What is a BMI? How is it calculated?
- Too technical and too many jargons and abbreviations
- How does obesity affect BP, Diabetes and cholesterol

How could content be improved?

Here is what they said, loud and clear:

- Seems age and weight parameters are arbitrary. What happens to a person like me who is over weight and over 65?
- Can the guideline state that a plan can be personalized to meet my needs or will I always be considered under the “70 Kilo” Vitruvian man classification?
- Tell us how, tell us why, tell us where, make us accountable and make clinicians just as accountable.



Work sheet #4: Small Group break-out session:
"translate" one section of the CPG in your own words:
Breakout group#1: Clinician Talking Points

Clinician Talking Points Sample script:	Patient and Public Rewritten Version
<p>Getting regular exercise is one of the best things you can do to get more energy, improve your mood, and take care of your overall health.</p> <p>The choice is yours and I'm confident that if you decide to make a healthy behavior change, you will find a way to make it happen.</p>	<p>Getting regular exercise is one of the best things you can do to get more energy, improve your mood, and take care of your overall health.</p> <p>Deleted Second Paragraph!!!!</p> <p>There is good evidence that weight loss is associated with improvement in BP, Diabetes, Cholesterol,</p> <p>I understand it can be difficult to include exercise in a busy schedule. Let's talk about resources that would work for you and then lets sent a goal. We'll decide a good time for you to return.</p>

Work sheet #5: over all comments

- Brief behavioral therapy described as “intensive” but then only 3 sessions are recommended. Really? It took me 30 years to become obese and I can get cured in 3 sessions?
- Physician talking points assume clinician is empathetic to my needs but I find it condescending that a clinician needs prompting to be empathetic
- “The guideline does not provide an opportunity or a reason to establish a physician patient relationship when a doctor says, now go and lose weight and eat right. What the heck does that mean?”
- “I wouldn’t mind a follow up monthly reminder asking how I am doing since I get a ton of follow up calls on all my other care gaps for preventive medicine”



Patient and Public Involvement in Guideline Activities

Exit Survey / Conclusion

Conclusion:

Project Aim:

- To explore the role of consumer engagement in development of guideline support tools

How: Two step process:

- Gauge awareness of the existence of guidelines
- Gauge interest in developing support tools.

Outcome:

- Survey elicited topics and outcomes important to the consumer for inclusion in development of consumer directed guideline support tools.
- Underlying theory: Participation produces consumer focused tools to ultimately assist consumers in being better informed and therefore more directly involved in their health care choices.
- Identifying cultural sensitivities in the development of tools will ensure specific preferences and needs are addressed.
- Secondary outcome might include possible closure of care gaps indirectly related to cultural disparities.

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