

FACCT
FOUNDATION FOR ACCOUNTABILITY

A person-centered view of consumer information in the health care marketplace

**FTC/DOJ Joint Hearings on Health Care
and Competition Law and Policy**
June 12, 2003

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Foundation for Accountability

FACCT activities and role

- Developed quality measures:
 - Chronic illness
 - Child and adolescent health
 - End of life care
- Consumer Information Framework
 - *The Basics*
 - *Staying Healthy*
 - *Living with Illness*
 - *Getting Better*
 - *Changing Needs*
 - Adapted by NCQA, National Quality Report, states

FACCT activities and role

- Emphasis on consumer information access:
 - Health plan comparison report formats, decision models (FEHB)
 - *CompareYourCare* web sites
 - Personal Health Record design
 - Data Resource Center

FACCT consumer research

- Over 100 focus groups across all segments
- Surveys of 100,000+ people
- In-depth interviews
- Annual consumer leadership conference

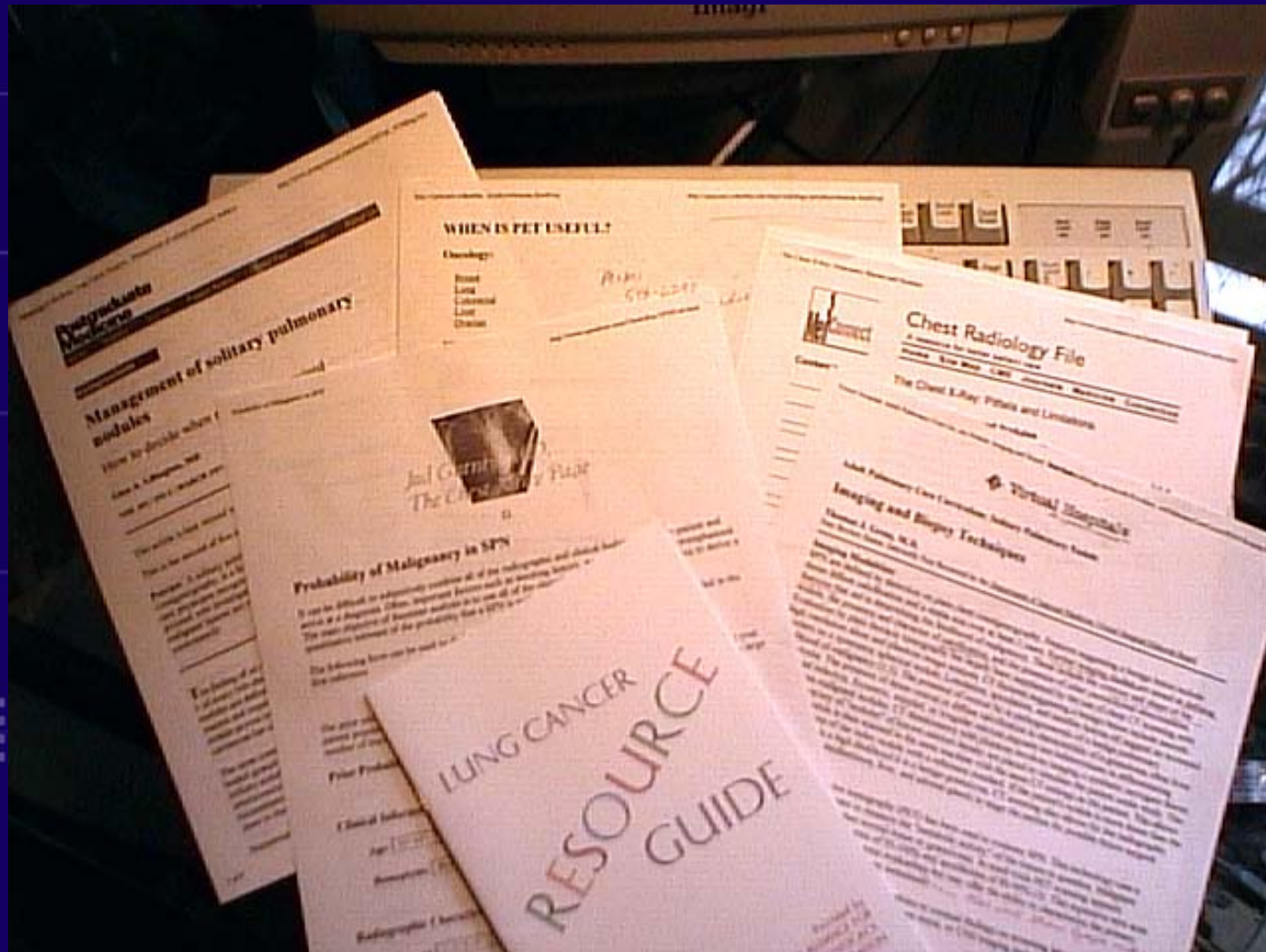
FACCT perspective

- Purchasers and professional disciplines have defined quality information channels (plan, group, nursing home, hospital, physician, CHF, pneumonia, etc.)
- Quality information for marketplace decisions should be driven by *patient and family information requirements*
- Three stories ...

Grandma Lou & family



Gayle's Research



What decision is being made?

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PubMed Nucleotide Protein Genome Structure PopSet Taxonomy OMIM Books

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1: Eur Respir J 1996 Mar;(3):410-4 Related Articles, **NEW Books**, LinkOut

Evaluation of the solitary pulmonary nodule by positron emission tomography imaging.

Bury T, Dowlati A, Paulus P, Corhay JL, Benoit T, Kayembe JM, Limet R, Rigo P, Radermecker M.

Dept of Pneumology, CHU Liege, Belgium.

Current noninvasive imaging methods are not sufficiently reliable for accurate detection of malignancy in most solitary pulmonary nodules (SPNs). Positron emission tomography (PET) using 18-fluorodeoxyglucose (FDG), showing increased FDG uptake and retention in malignant cells, has proved useful to differentiate malignant from benign tissue and could, therefore, contribute to the evaluation of the SPN. We performed a prospective study of 50 patients referred to the Pneumology Department with unclear diagnoses of SPN after conventional radiological screening. PET study was performed on each subject before an invasive procedure was proposed. Thirty three patients had a malignant nodule and 17 had a benign nodule. The mean size of malignant nodule was 3 cm (range 1.5-4.5 cm). All showed a marked increase in 18-FDG uptake. The mean size of benign nodule was 1.8 cm (range 0.5-3.5 cm). PET imaging showed the absence of 18-FDG uptake and correctly identified 15 of 17 benign nodules. There was two false-positive cases with a moderate increase in 18-FDG uptake (1 postprimary tuberculosis; and 1 anthracosilicotic nodule with nonspecific inflammation). At present, the sensitivity and specificity of the method are 100 and 88%, respectively. The positive and negative predictive values of PET imaging for SPNs are 94 and 100%, respectively. Our preliminary results demonstrate that PET-FDG imaging is a noninvasive technique, which appears highly accurate in differentiating malignant SPN from benign SPN.

PMID: 8729997 [PubMed - indexed for MEDLINE]

Done Internet

Which hospital should you go to?

Number of lobe resections, New York & Brooklyn, 1999

Hospital	No. of Cases	Hospital	No. of Cases
BELLEVUE HOSPITAL CENTER-NEW YORK	4	METROPOLITAN HOSPITAL CENTER-	3
BETH ISRAEL MEDICAL CENTER-NEW YORK	23	MOUNT SINAI HOSPITAL-NEW	45
BETH ISRL MED CTR/KINGS HWY DIV-BROOKLYN	2	NEW YORK & PRESBYTERIAN	69
BROOKDALE HOSPITAL MEDICAL CTR-	10	NEW YORK & PRESBYTERIAN	57
BROOKLYN HOSPITAL/DOWNTOWN-BROOKLYN	2	NEW YORK DOWNTOWN HOSPITAL-	7
CABRINI MEDICAL CENTER-NEW YORK	11	NEW YORK METHODIST HOSPITAL-	11
CONEY ISLAND HOSPITAL-BROOKLYN	7	NORTH GENERAL HOSPITAL-NEW	4
INTERFAITH MED CTR/JEWISH HOSP-BROOKLYN	1	NY UNIVERSITY MEDICAL CENTER-	50
KINGS COUNTY HOSPITAL CENTER-BROOKLYN	1	ST LUKES ROOSEVELT/ROOSVLT	9
KINGSBROOK JEWISH MEDICAL CTR-	1	ST LUKES ROOSEVELT/ST LUKES	6
LENOX HILL HOSPITAL-NEW YORK	22	ST MARYS HOSPITAL-BROOKLYN	2
LONG ISLAND COLLEGE HOSPITAL-BROOKLYN	8	ST VINCENTS HOSPITAL & MED	6
LUTHERAN MEDICAL CENTER-BROOKLYN	6	UNIVERSITY HOSPITAL OF	3
MAIMONIDES MEDICAL CENTER-BROOKLYN	10	WOODHULL MEDICAL CENTER-	2
MEMORIAL HOSPITAL FOR CANCER-NEW YORK	316	WYCKOFF HEIGHTS MEDICAL CTR-	2

Mortality for hospitals > 169 cases: 0.87%
< 37 cases: 3.05%

Recommended HIV/AIDS Quality Measures

• Steps to Good Care

- Screening and referral for mental health and social services
- Anti-retroviral treatment (anti-HIV drugs)
- Prevention of opportunistic diseases
- CD4 counts and viral load testing
- Regular eye exams
- Vaccinations
- Preventive counseling for people at risk of contracting HIV
- Symptom management

Access, Experience of Care and Satisfaction

- Access to social and mental health services
- Access to health care and medical services
- Involvement in care and treatment decisions
- Self-management education
- Effective relationships with health care providers
- Planning for care at the end of life

Results of Care

- Days lost from work/school
- Overall health status
- Achieving undetectable viral load
- Effective symptom management

Prioritized HIV/AIDS Quality Measures

	Expert Rank
HIV Treatment: antiretroviral therapy	1
Immune assessment: viral load	2
HIV Treatment: opportunistic	3
HIV Prevention: Immunizations	4
Experience of care: involvement in decision-making	5
Experience of care: access to services	6
Experience of care: access to mental health services	7
Self-management	8
Symptom control	9
Functional status	10
HIV Prevention: Education	11

Prioritized HIV/AIDS Quality Measures

	Expert Rank	Patient Rank
HIV Treatment: antiretroviral therapy	1	5 (tie)
Immune assessment: viral load	2	4
HIV Treatment: opportunistic	3	1
HIV Prevention: Immunizations	4	11
Experience of care: involvement in decision-making	5	2
Experience of care: access to services	6	5 (tie)
Experience of care: access to mental health services	7	8
Self-management	8	7
Symptom control	9	9
Functional status	10	3
HIV Prevention: Education	11	10

HIV/AIDS Focus Groups: 11/98

“I'm not taking any drugs or anything like that and one of my specific reasons for that is that it seems like every time they seem to know what is going on, they come out with a new drug or several new drugs and specifically because I am a young, black, male, in my age group, there is very little research that is being done and as a black male, most of the research that is being done doesn't really affect me because it is for people who are mostly white, mostly between the ages of late 35 and 45 so that pretty much excludes me. So, until there is more research, I just don't feel taking any of the drugs they have to offer.”

Sample Provider Report

Snapshot of Practice #47 PHDS-PLUS Survey Results

Data are for children who enrolled in your practice through the Medicaid PC PLUS program (N=29) and are based on the Promoting Healthy Development Survey PLUS (PHDS-PLUS) conducted by FACCT- Foundation for Accountability in collaboration with the Office of Vermont Health Access (OVHA) in 2000-2001.

[FINDING : Anticipatory Guidance and Parental Education]

Discussions about physical care and injury prevention are more likely to occur than discussions about development and behavior

In your practice:	PHYSICAL CARE such as nutrition, placing young children on their backs to sleep and bedtime routines	INJURY PREVENTION such as how to make the house and car safe for the child - car seats, poison prevention (Syrup of Ipecac) and ways to avoid burns to the child	DEVELOPMENT & BEHAVIOR such as how the child gets along with others, night waking & fussing, language development, toilet training and the importance of reading to the child
All Recommended Topics Discussed: Percent of parents who reported their child's pediatric clinician discussed all aspects of related anticipatory guidance and parental education	37%	62%	52%
Informational Needs Met: Topic(s) of care that parents were MOST likely to report was discussed by their child's pediatric clinician	<ul style="list-style-type: none"> Vitamins & foods the child should eat Importance of breastfeeding Importance of placing child on back when going to sleep* 	<ul style="list-style-type: none"> Using a car seat* 	<ul style="list-style-type: none"> Words and phrases child uses and understands* Behaviors to expect from child as she gets older* Night waking & fussing*
Informational Needs Not Met: Topic(s) of care that parents were LEAST likely to report was discussed by their child's pediatric clinician	<ul style="list-style-type: none"> Things parents can do to help child grow and learn Childcare issues Bedtime routines & number of hours of sleep Issues related to food & feeding Importance of placing child on back when going to sleep* Importance of not putting a child to bed with a bottle 	<ul style="list-style-type: none"> Using a car seat* How to make house safe Syrup of Ipecac 	<ul style="list-style-type: none"> How child responds to caregivers and gets along with others Toilet training Words and phrases child uses and understands* Importance of reading to child How child may start to explore away from parent Behaviors to expect in child as she gets older* Guidance & discipline techniques to use with child Night waking & fussing*

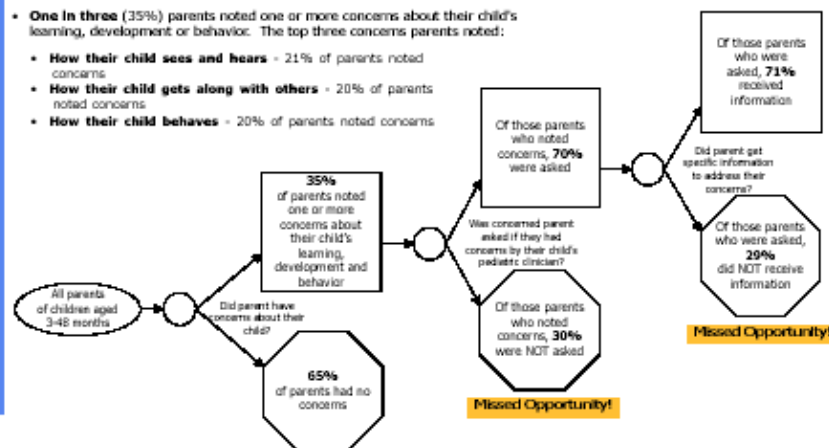
*Pediatric clinicians address this topic with the majority of parents. However, parents who did not discuss this topic with their clinician reported that they wished it had been addressed.

[FINDING : Parental Concerns]

Parents' concerns about their child are often not identified by their child's pediatric clinician. When identified, however, many parents report receiving specific information to address their concerns

In your practice:

- One in three (35%) parents noted one or more concerns about their child's learning, development or behavior. The top three concerns parents noted:
 - How their child sees and hears - 21% of parents noted concerns
 - How their child gets along with others - 20% of parents noted concerns
 - How their child behaves - 20% of parents noted concerns



[FINDING : Maternal Depression]

A significant number of mothers experience symptoms of depression

Mothers who are depressed often are not identified by their child's pediatric clinician

In your practice:

- One in ten mothers (10%) who responded to the survey experience symptoms of depression.
- 62% of mothers were asked about depression by their child's pediatric clinician.
- Statewide: Overall, mothers of children with special health care needs were significantly more likely to report symptoms of depression.

Questions used to screen for depression:

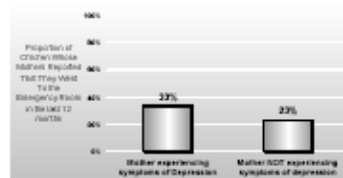
- How many days in the last week have you felt depressed?
- In the past year, have you had two weeks or more during which you felt sad, blue, depressed, or lost pleasure in things that you usually cared about or enjoyed?
- Have you had two or more years in your life when you felt depressed or sad most days, even if you felt okay sometimes?

Note: Parents are identified as currently experiencing symptoms of depression if they responded positively to at least two of the three questions. (Kemper, AJDC 1992)

In your practice:

- 67% of the mothers who noted symptoms of depression were asked about depression by their child's pediatric clinician.
- Overall, 24% of mothers reported that their child had been to the emergency room in the last 12 months. Mothers experiencing symptoms of depression were more likely to report that their child had been to the emergency room as compared to mothers who are not currently experiencing symptoms of depression (33% vs. 23%).

Mothers Who Are Experiencing Symptoms of Depression Are More Likely to Report That Their Child Went to the Emergency Room in the last 12 months



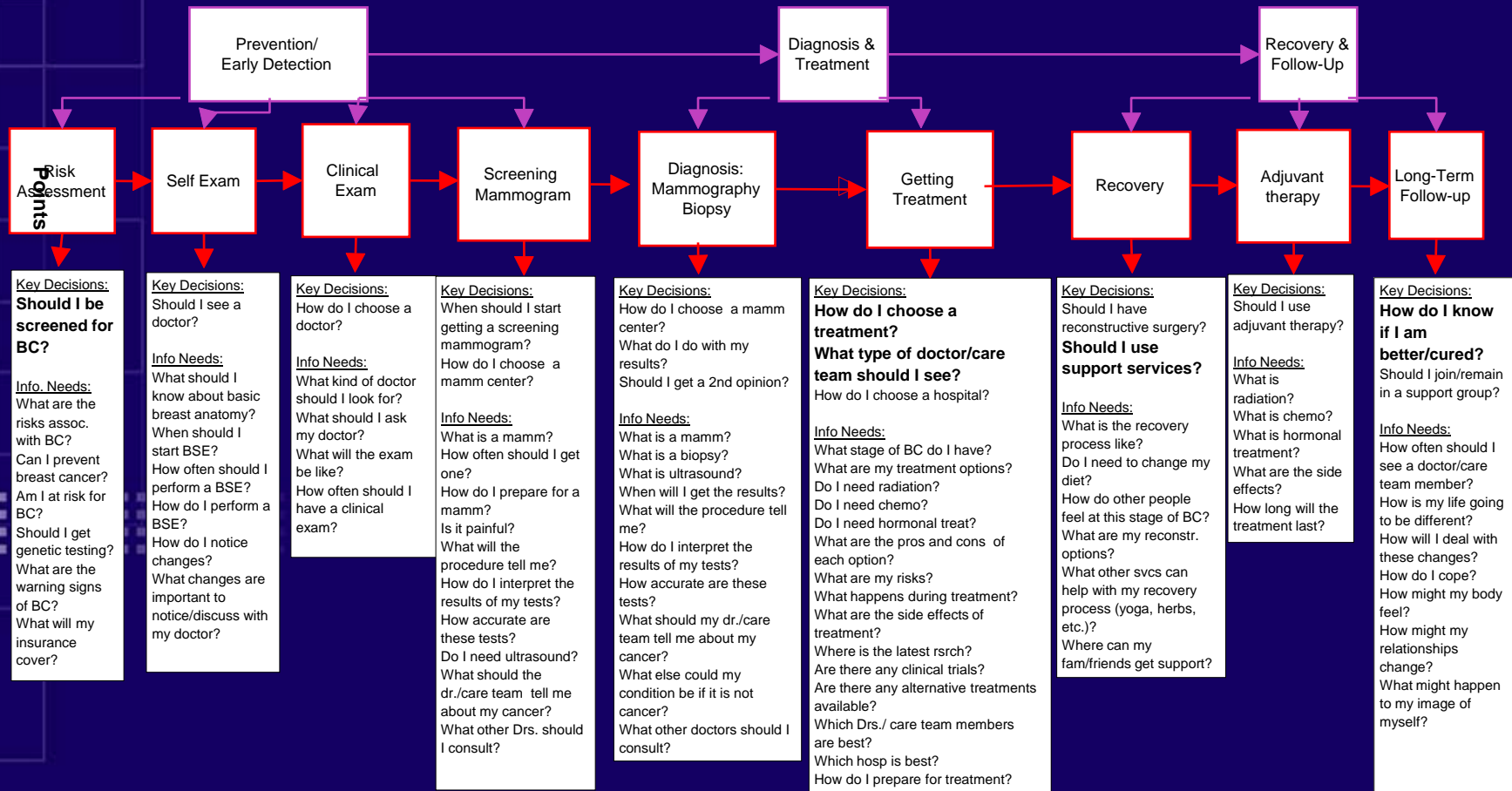
Breast Cancer Decision Map

Possible Connectors:

Nurse (company or office-based), Doctor (company or office-based), letter from healthcare plan, corporate intranet, union, peer/survivor, community groups, special interest groups, syndicated news.

Medium:

Verbal (phone/in person/education programs), Internet, e-mail, print, video/web cast



Are you making an informed treatment decision?

Breast-conserving surgery vs. mastectomy for early stage breast cancer

	<i>BCS Rate</i>	<i>Seen by Medical Oncologist</i>	<i>Never told about BCS</i>
<i>Massachusetts</i>	74%	52%	15%
<i>Minnesota</i>	48%	28%	27%

U.S. needs a modern
information strategy suited to
a modern health care system
and a democratic consumer
culture



Attributes of health system that affect information requirements

- Technical complexity
- Layering of organizations and professionals
- Multidimensional care
 - Appropriate care
 - Education and teamwork
 - Daily living (outcomes)
 - Service quality
- Relationships (not commodities)

Attributes of health system that affect information requirements

- Consumer segmentation
 - Independent active (31%)
 - Doctor-dependent active (31%)
 - Doctor-dependent passive (27%)
 - Uninvolved (10%)
- Transparency
- 3rd party payment
- Mediating decisionmakers
- Trajectory of illness
- Personalization of services
- *No one else will do it for you!*

Solutions to information complexity

- Focus public information on *outcomes*, not process
 - drives innovation
 - drives integration
 - drives person-centeredness
- Mandatory “disclosure”
 - Significant patient participation
 - Voice as well as exit
 - Patients and families as data source
 - Stimulate NHII

Solutions to information complexity

- Distribution as important as “data”
 - Patient-physician agreement
 - Intermediaries
 - Interactive coaching
 - Personalized choice aids (utility based)

Feedback



Appropriate
Care

[Home](#) > [Diabetes Check-up](#) > [About You](#) > [Rate Your Care](#) > [Survey Questions](#) > [Feedback](#)

Appropriate Care: Feedback

Here's how your doctor scores on giving you the tests, screenings, and services you need to help you monitor and control your diabetes.



Take Charge!


Click on the links below to get more feedback on the care you are getting from your doctor and get tips to help you improve your care!

Get More Feedback

- [Blood Pressure Check](#)
- [Cholesterol Check](#)
- [Kidney Disease Test](#)
- [Blood Sugar Testing](#)
- [Eye Exam](#)
- [Foot Care](#)
- [Aspirin](#)
- [Smoking](#)

Things You Can Do

 [Add This Information To My Care Guide](#)

 [View Summary Checklist](#)

 [Go To Care Guide](#)

 [Leave A Note About Your Doctor's Care](#)

[move on](#) 



Summary Checklist



This checklist is based on your answers to the survey questions you just completed.

Take this list with you to your next visit and review your results with your doctor or other health provider. If you can't cover everything on the list in one visit, schedule another visit or ask your doctor if someone else in the office can help you.

		Ask your doctor about ↓
	Appropriate Care	Screenings and tests up-to-date
	Inhaler	✓
	Peak Flow Meter	✓
	Smoking	✓
	Education & Teamwork	Good teamwork!
	Education	✓
	Doing Self Care	✓
	Ease of Self Care	✓
	Day-to-Day Living	Keep up the good work!
	Symptoms	
	Physical and Emotional Health	
	Daily Activities	
	Support & Service	Good support & service!
	Managing Your Care	
	Trust and Caring	
	Customer Service	

Other helpful information available in Your Care Guide

- Your survey questions and answers
- Your personalized feedback
- Quick tips
- Full tips
- Much more!

Before you exit Your Care Guide, be sure to print or download these helpful resources for future use!



Regulatory role

- Information infrastructure critical
 - Information standards
 - Mandatory collection and disclosure
 - Patient centered content
 - Integration, not fragmentation
 - Be wary of commoditization
- Represent patient and family needs - no one else does