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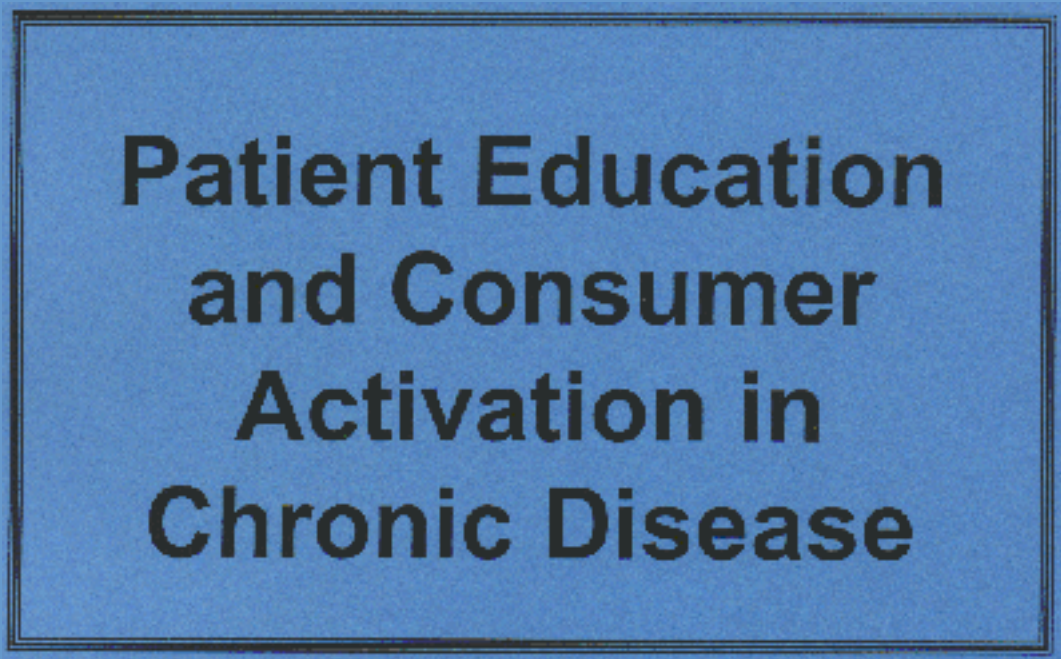
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## MEETING PROCEEDINGS



**Patient Education and  
Consumer Activation in  
Chronic Disease**  
July 6-7, 2000

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## Patient Education and Consumer Activation in Chronic Disease

The Robert Wood Johnson Foundation

July 6-7, 2000

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Clinicians, policymakers, and others are increasingly interested in finding ways to encourage individuals with chronic conditions to become more actively engaged in their health and health care. The prevalence of chronic conditions is increasing as the population ages and evidence indicates that people with these conditions—including arthritis, diabetes, and others—have better health outcomes if they participate actively in choices about their health.

In July 2000, the Foundation convened a panel of experts representing clinicians, patient advocates, and researchers with experience in the fields of patient and provider education, physician-patient relationships, health behavior change, and new information technologies. The charge to the panel was to identify a range of strategies and tactics to help individuals with chronic conditions become more active participants in their health and health care. While there is a broad range of behaviors in "activated consumers," there is no one agreed upon definition.

Participants said the current health care delivery system remains resistant to these ideas in many ways, but that discontent with the current status of health care may prove to be a powerful motivator for change. Social and technological trends generally support patients' efforts to actively manage their own health and health care, but not all groups have access to needed resources or are ready to take on this responsibility.

Participants identified three groups of patients with chronic conditions that might especially benefit from efforts to promote active participation in health and health care:

- 1) those with resources who are on the cusp of becoming active in their health due to their developmental, social, and economic status; 2) those who have few resources and may require significant help in becoming actively engaged; and 3) those who are especially vulnerable to the problems that accompany a passive approach to health and health care.

Participants identified a range of possible intervention points, including micro-level strategies, which target patients and clinicians; mid-level strategies, which target local institutions and community-based groups; and macro-level strategies, which target big institutions and social forces. There was agreement that interventions across all levels will be necessary in order to help large numbers of individuals with chronic conditions become active participants in their health and health care. No single strategy will work.

Participants identified four possible general approaches to improving the level of participation and engagement that individuals with chronic conditions can bring to their health and health care. These approaches included:

- **Undertake activities that would result in systems and policy changes.**
- **Target a single community or series of communities as a laboratory to develop tools and evaluate successful projects that could be disseminated later.**
- **Provide the best available interventions to Medicaid and uninsured populations.**
- **Focus on health care providers (physicians, in particular) as the nexus within which active participation by consumers is most likely to be fostered.**

Participants also identified a series of potential activities to pursue in order to increase people's participation in their health and health care:

- **Conduct qualitative research to find out what language resonates with consumers and their families.** Use these findings to develop a communications/media campaign that encourages individuals and their families to become active participants in their health and health care. Promote use of language and messages by the media (print, mass electronic, and Web-based), consumer groups, professional societies, health plans, employers, and insurers.
- **Invest in activities that draw on the current evidence base for promoting active participation and engagement among consumers.** For example, disseminate information on effective interventions through demonstration projects. Look at a variety of outcomes (quality, implementation requirements, and costs) with different target populations. Create a central knowledge resource to increase the robustness, utility, and use of available approaches. Package evidence-based approaches to meet the needs of the different configurations of health care delivery (e.g., physicians, health plans, and community organizations), promote their use, and make them widely available.
- **Support organizations for people with chronic conditions.** Find ways to help them to: 1) attract new members; 2) become a strong voice (individually and collectively) for change in health care delivery; and 3) gain access to the best available information on medicine and self-management techniques. Work with these organizations to help them to develop Web-based and other tools that expand their reach, and allow them to interact more effectively with individuals with chronic conditions and their families.
- **Develop system-level incentives to increase the value that health care purchasers and plans place on active participation by consumers in their health care.** For example, explore the use of performance indicators and accreditation standards as incentives for purchasers and plans to institute

interventions to increase patient self-management and consumer participation. Develop and promote outcome standards that are relevant to successful management of chronic conditions.

- **Target people who are on the "cusp" of needing to be active consumers of health and health care.** For example, individuals approaching age 60 represent a large target population. Focusing first on those who are literate and Web-savvy, who have a consumer orientation in matters other than health, and who feel entitled to adequate health care may work to form a critical demand for health system change.

Participants also identified a host of research questions necessary to further define what motivates individuals with chronic conditions to become active participants in their health and health care.

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Clinicians, policymakers, and others are increasingly interested in finding ways to encourage individuals with chronic conditions to become more actively engaged in their health and health care. Evidence over the past decade has demonstrated that people who take an active role in their health experience better health outcomes. Research has also shown that a variety of programs and techniques can help people learn to be better "self-managers" of their own health care—improving the way they function with a variety of chronic conditions, including diabetes, arthritis, and asthma. At the same time, with advances in biomedicine and an aging population, increasing numbers of people survive heart attacks and other acute health threats only to face the challenges of living with heart failure and other chronic conditions. With the rise of consumerism, some patients' traditional relationship with their health care providers has shifted—from one best characterized as "enlightened paternalism" toward an ideal of shared decision-making that sees patient and provider as partners. The rise of managed care and other fiscal forces have also combined to erode the trust that patients once placed in health care providers and institutions. Collective consumer action can also be a potential driver for better quality of care. And as employers move from "defined-benefit" plans—which offer employees a selection of insurance options—to "defined-contribution" plans—which provide employees with premium dollars to spend as they choose—increasing numbers of consumers are facing the challenge of shopping for health care coverage for the first time.

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In July 2000, The Robert Wood Johnson Foundation assembled a panel of experts to explore ways to encourage individuals with chronic conditions to become more actively engaged in their health and health care. The experts represented a range of stakeholders, including clinicians, patient advocates, consumers, and researchers with experience in the fields of patient and provider education, health behavior change, and new information technologies. (For a roster of participants, see Appendix A.) The group was not asked to reach consensus on any of the issues discussed, but instead to identify a range of strategies to increase the level of participation and engagement that individuals with chronic conditions bring to their health and health care.

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## The Context of Consumer Activation in Chronic Conditions

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Prior to the meeting, participants completed a brief questionnaire designed to elicit their current thoughts on patient education and consumer activation and provide a context for further discussions. (See Appendix B for a complete summary of the survey results). The questions probed how individuals, health care providers, the structure and financing of health care, and social trends and new technologies can encourage or discourage individuals from actively participating in their own health and health care.

Overall, participants did not locate primary responsibility for consumer activation in individuals themselves, but in the context of the environment in which they live. They agreed that it would be a difficult task to raise people's participation and engage them in their health and health care. No one strategy will work for everyone. Participants also stressed that consumers lack role models that can provide them with guidance in knowing what to do when confronting a chronic condition. In addition, while participants noted that physicians frequently interact with patients in ways that discourage the development of a partnership, they recognized that the relationship between patients and their health care providers can be a critical nexus in the drive to engage consumers to take a more active role in their health and health care. Physicians and the marketplace respond largely to contingent reinforcers, participants observed. As one participant said: "Money reinforces a lot of bad health care practices."

A number of people mentioned difficulties with language—specifically, that terms like "consumer activation" and "self-management" are not readily accessible to consumers nor necessarily meaningful or desirable to other health care stakeholders. These terms are loaded with meanings that may be irrelevant and counterproductive. Plan managers and health care providers, for example, may see an "activated" consumer as meddlesome or a malcontent. Focus on "chronic conditions," rather than chronic "disease" or "illnesses," one participant advised. Participants urged that more work be done to explore the specific language used to describe the "positive participation" in health and health care that is targeted here.

Several other contextual points were raised during discussion at the meeting, including:

- **Consumer engagement and participation should be viewed on a continuum.** Some patients take a passive approach to their health, while others may take a more active interest. With some patients, this will change over time. Other patients will be more active managing one part of their health regimen and more passive about other parts. The success of any efforts to engage and activate consumers will rest on a program's ability to meet patients where they are at a particular point in time. The concept of "mandatory autonomy"—that everyone must be an active consumer—is inappropriate. Not everyone will be comfortable with the idea of managing his

or her own health. Respect for the patient's decision—whether he or she chooses to actively manage or remain less engaged—is paramount.

- **Interventions must be adapted for various segments of the population.** Little is known about what messages will be appropriate, what interventions will be most effective, and which replication strategies should be employed in various subgroups of the population, including people with low-literacy skills, those from disadvantaged backgrounds, or those from minority cultures.
- **Empowering consumers may have unforeseen consequences.** "Consumers given power may not accept what our vision of health and health care includes," one participant said. Health care historically has followed a paternalistic model. "Do we want a power shift? Are we willing to live with the consequences? What are the unintended consequences of a fully empowered patient population?"

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Participants discussed vignettes of three fictional people in order to explore how one might work to promote active engagement and participation in health care among those with chronic conditions. The three vignettes described:

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- Howard Matthews, a 50-year-old divorced Wisconsin picture framer, who is 50 pounds overweight, complains of back pain and headaches, and has a family history of heart disease. He currently belongs to an HMO but has not seen a doctor for seven years.
- Gloria Garcia, a 32-year-old single mother from the Bronx who is currently on public assistance, has no physical health complaints, but complains of chronic fatigue and "the blues." Her 11-year-old son has recently been diagnosed with type-2 diabetes. Her mother and sisters live close by.
- Walter Wilson, a 73-year-old retired black man who has cataracts and an arthritic hip but is otherwise in good health and continues to serve as a church deacon. He and his wife (who has high blood pressure) receive Medicare and have a Medigap policy, but generally don't see a doctor unless something is "really wrong."

In one view, Howard represents "low-hanging fruit"—an individual who could be readily identified by his HMO and targeted with interventions to combat his known risk factors. Gloria, and her diabetic son, in contrast, may be seen as the most vulnerable, with no medical safety net even as she displays obvious signs of depression that may presage other medical problems. Finally, Walter can be seen as a member of an age-defined group, in this case the elderly, who remains relatively active yet vulnerable as accumulating chronic conditions take their toll on his daily functioning.

One participant asserted that Howard would not be so readily engaged in his health care. He has no computer, does not go to the doctor, and his 4-person employer is probably not the place for a work-site health intervention. Walter and his wife, who remain active and involved in their church, may be more accessible, the participant said.

Another participant suggested targeting the most vulnerable—including people with low-literacy skills, Medicaid recipients, and other disadvantaged groups—and provide them with the tailored, direct support they would need to become actively engaged with their health. Success would signal that active engagement in health is possible for all members of a society.

Other participants recommended concentrating on where the opportunities present themselves, for example:

- where channels of communication are already in place, such as through existing consumer groups, health plans, senior centers, or religious

organizations;

- with consumers who have experience as active participants in other domains but who have yet to turn this experience toward health and health care;
- with people who will, for reasons of health risk or development, soon develop chronic conditions.

Another view argued against trying to set priorities among the three groups. "The lesson of these three stories is the ecological framework of empowerment," one participant said. "We need to have overlapping circles that can hit people where they are." While Howard may not be well connected, Gloria is involved in a larger family network and strategies that go beyond the individual might be effective for her. Meanwhile, Walter and his wife are involved in an even larger circle, and by persuading them to become more active participants in their health care, others may follow.

"We need to go beyond the individual to the co-worker and the family," one participant said. "You can influence a lot more behavior when you talk about the larger group."

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Participants said that targets for change exist at multiple levels. One can view the patient/self manager at the center surrounded by a series of concentric circles that depict those who can influence the patient's health and health care choices. These circles of influence might include: 1) the family; 2) health care providers; 3) the community, real or on-line; 4) health plans; 5) business and industry; and 6) state and local government and other policy-makers. Each of these entities represents a potential target for change. Strategies need to be identified at every level and articulated across all of these levels.

Participants disagreed over the assertion that physicians represent a point of leverage in more actively engaging patients with chronic conditions in their health care. Several noted that the typical 10- to 15-minute primary care visit is geared toward delivering acute care for well-defined conditions. Whereas physicians can be effective in "priming the pump" to get patients to consider quitting smoking, for example, they frequently do not have the time, training, or expertise to help patients become active managers of their health. One physician/participant took a dimmer view. "Most of the comments I've heard [today] are talking about the trees, but the forest is dying," he said. "It is not just a matter of changing the physician-patient interaction, it's the whole climate of health care that needs to change. Physicians are concerned about reimbursement and their [loss of] power. [Consumer activation] is not on their radar screen." But another physician/participant expressed optimism that doctors will see efforts to engage patients as a positive way to reclaim their relationship with their patients.

Participants also saw promise in partnerships with "trusted" institutions that may have an "intensity of interest" in these ideas. Many function as information intermediaries to their constituents, who might otherwise not have access to the information and tools necessary to become active managers of their health and health care. These groups might include:

- schools
- senior centers
- religious organizations
- disability/disease organizations
- consumer organizations
- employers

Engage established community and employer coalitions, rather than trying to set up new ones, participants advised. Bear in mind that many consumer groups have a protective function that focuses on defending their members' rights rather than trying to motivate them to take an active role in their health. And understand that community groups may be weary of taking on responsibilities that they perceive as health care system delivery problems. "People keep asking the black churches to do

it," one participant said.

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Throughout the meeting, participants discussed a range of strategies to help individuals with chronic conditions become more actively engaged in their health and health care. These strategies may be grouped as micro-level strategies, mid-level strategies, and macro-level strategies.

**Micro-level strategies target individuals, their families, and their health care providers. These strategies focus on:**

- How to create systems and incentives that support patients and health care providers who are trying to help patients become more active participants and managers of their own health and health care.
- How to use the Internet today (which is largely text-dependent), and how to use the Internet of tomorrow (which will have greater video and information-tailoring capabilities) to reach individuals and create virtual communities of like-minded people.

**Among the micro-level strategies discussed:**

- Find out what information, messages, and assistance people with chronic conditions need in order to become more active participants in their health. For example, patient education classes and performance measures on health care providers or HMOs are available, but do patients really need, want, or use them?
- Build on the experience, wisdom, and energy of consumer groups by working with them to develop Web-based and other tools to expand their influence among people with chronic conditions and their families.
- Engage health care providers, who have direct access to patients. Whereas physicians and nurses may be pressed for time, most want to do the right thing. Seek ways to reach health care providers earlier, in schools and residencies as they train, as well as in mid-career, with evidence-based tips and training to help them work more effectively as partners with their patients.
- Experiment with mechanisms to shift health care purchasing power from third parties to first parties (consumers). Give people back the premium money and allow them the opportunity to take charge and see how they do. Or find a situation where this is taking place and track it.
- Make information on quality, performance, and accreditation available. It may have a bigger effect on chronically ill people than it has had on the general public. Turn practice guidelines into performance measures and inform patients of what they should expect. Patient expectations/demand may be effective in moving providers.
- Demystify the process of medical decision-making and make it more transparent and available to consumers. Consumers and health care providers alike may not realize the extent to which there are no "right" answers.



- Keep abreast of changes in technology. Personal pagers, Palm Pilots, and the Internet promise new ways to reach and maintain contact between patients and the health care system.

**Mid-level strategies** involve local groups and institutions, as well as expanded social networks of individuals and small employers. These strategies focus on finding local institutions and community-based groups that have an intense interest in helping patients become more willing and able to manage their own health and health care.

**Among the mid-level strategies discussed:**

- Involve trusted institutions, such as religious organizations, networks of senior centers, and patient advocacy and disability groups. Their strong ties and intensity of interest might render them willing to serve as channels and vehicles for conveying messages, information, or role models in support of active participation in health and health care.
- Work with national business coalitions and regional coalitions to reach employers who might find common ground with their employees around a consumer activation agenda.

**Macro-level strategies involve social forces and institutions (such as the media, the government, or the insurance industry). These strategies focus on:**

- Social marketing and media advocacy campaigns to change public expectations and demand and encourage participation. This will require assessing the nature of the audience and the channels of communication available to deliver messages promoting active participation in health and health care.
- Parallel strategic efforts to make the case to providers, plans, and other decision-makers that active participation by patients in health and health care can yield positive benefits to each.

**Among the macro-level strategies discussed:**

- Within the health care system, focus on system-level change. Chronic disease management is a team effort that requires systematic support for effective delivery. Whereas staff-model HMOs are well poised to deliver such care, they are not likely to gain in prominence. Identify where in existing health systems the same incentives lie for plans, providers, and patients. How can these be brought together to promote change?
- Experiment with fiscal incentives and new modes of reimbursement, such as reimbursing providers for chronic disease outcomes rather than actual services delivered.
- Look to other social movements, such as civil rights, for techniques in galvanizing support for widespread change.
- Do not depend on the written word to encourage and support active participation by consumers in health and health care. Use television and radio,

including entertainment shows and local news, where 25% of content is health related.

- Provide role models for active participation in health. Find out from consumers what they think an active, engaged consumer looks like. Work to raise the visibility of such role models in the media, in chronic disease self-management programs, and other venues.
- Define what quality health care should look like for people with chronic conditions and use a variety of channels (voluntary health organizations, government resources, and the media) to target it to people with chronic conditions and their families in order to create demand.
- Create off-the-shelf tools that health plans can use to establish their own chronic disease self-management programs. Similarly, package physician-delivered health behavior interventions as practice tips and make them widely available.
- Make use of the existing public health infrastructure when possible and appropriate.
- Find ways to involve pharmaceutical companies on issues of common concern.

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Participants identified four possible general approaches to improving the level of participation and engagement that individuals with chronic conditions bring to their health and health care. These approaches included:

- **Focus on activities that would result in system-level and policy change via the development and careful dissemination of information and other tools that would have a multiplicative effect.** The intervention should be built around a coherent strategy that builds on readily identifiable opportunities (for example, a particular target group or disease) and fills clear gaps.
- **Focus on a single community or several communities as a laboratory for change.** Care should be taken to make clear how such an initiative differs in substance and scope from previous community interventions funded by foundations and the government.
- **Focus on providing the best available interventions to Medicaid and uninsured populations.** How will services/resources be sustained beyond the project's lifetime? How will demand for patient activation be maintained in the future?
- **Focus on health care providers, (physicians, in particular) as the nexus within which consumer activation is most likely to be fostered.** How can such messages be delivered effectively alongside other issues competing for attention?

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Participants also identified a series of potential activities to pursue in order to increase people's participation in their health and health care:

- **Use qualitative research to find out what language resonates with consumers and their families.** Use findings to develop a communications/media campaign that encourages individuals and their families to become active participants in their health and health care. Promote use of language and messages by the media (print, mass electronic, and Web-based), consumer groups, professional societies, health plans, employers, and insurers.
- **Invest in activities that draw on the current evidence base for promoting participation and engagement among consumers in their health and health care.** For example, disseminate information on effective interventions through demonstration projects. Look at a variety of outcomes (quality, implementation requirements, and costs) with different target populations. Create a central knowledge resource to increase the robustness, utility, and use of available approaches. Package evidence-based approaches to meet the needs of the different configurations of health care delivery (for example, physicians, health plans, and community organizations), promote their use, and make them widely available. Make strategic use of the electronic media while planning how to prepare for more powerful technologies in the future.
- **Support organizations for people with chronic conditions.** Find ways to help them to: attract new members; become a strong voice (individually and collectively) for change in health care delivery; and gain access to the best available information on medicine and self-management techniques. Work with these organizations to help them to develop tools (especially Web-based) that expand their reach, and allow them to interact more effectively with individuals with chronic conditions and their families. Find information intermediaries who are interested in conveying consumer activation messages. Work with coalitions of community groups that are already in place. Convene other funders and researchers working on attitudes and practices relevant to consumer activation to identify common interests and avoid redundancies.
- **Develop system-level levers to increase the value that health care purchasers and plans place on consumer activation.** For example, explore the use of performance indicators and accreditation standards as incentives for purchasers and plans to institute interventions to increase patient self-management and consumer activation. Develop and promote outcome standards that are relevant to successful

management of chronic conditions.

- **Target people who are on the "cusp" of needing to be active consumers of health and health care.** For example, individuals approaching age 60 represent a large target population. Focusing first on those who are literate and Web-savvy, who have a consumer orientation in matters other than health, and who feel entitled to adequate health care may work to form a critical demand for health system change.

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## Research Needs

Participants also identified a host of research questions necessary to further define what motivates individuals with chronic conditions to become active participants in their health and health care.

For example, in the realm of consumer research, it remains unclear:

- What language will encourage individuals with chronic conditions to become more actively engaged in their health and health care decisions?
- What criteria do consumers use to choose and evaluate health care?
- What do consumers want to receive from their health care and what do they want to know to help them make better choices? (For example, do they care about accreditation?)
- Why do people drop out of the system?

**Among health care purchasers, plans, and providers:**

- What are the incentives and disincentives for health care purchasers, plans, and providers to promote active participation among people with chronic conditions?
- How can the financial and organizational case be made for each group?

**In examining specific interventions to promote consumer activation:**

- What are the benefits and limitations of new technologies for delivering information and support to individuals and families that are managing chronic conditions?
- How can robust self-management interventions best be modified to meet the needs of individuals with different language, literacy, or cultural needs?

**In exploring systems approaches to promoting consumer participation:**

- How can physicians in group practice measure the extent to which health care delivery in that setting supports active participation among people with chronic conditions?
- How can accreditation standards serve as levers to support active participation among people with chronic conditions?

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## Planning Meeting on Patient Education and Consumer Activation in Chronic Conditions

The Robert Wood Johnson Foundation

July 6-7, 2000

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## Planning Meeting on Patient Education and Consumer Activation in Chronic Conditions

The Robert Wood Johnson Foundation

July 6-7, 2000

### Results from a Survey of Participants

Prior to the meeting, participants were asked to answer four questions probing the factors that encourage and discourage patients from actively participating in their health and health care. The four questions were:

1. What factors encourage/discourage individuals to positively participate in their health and health care?
2. What do health care providers do/not do that influences consumer engagement and participation in their health and health care?
3. How do the structure, financing, and delivery systems of health care affect consumer engagement and participation in health and health care?
4. What social norms, trends, and new technologies influence consumer engagement and participation in health and health care?

Following is a summary of their responses:

#### 1) Factors That Facilitate/Inhibit Individuals from Becoming Active Consumers

**Individuals are likely to become active participants for their health because:**

- They prefer to feel well and not to think about their health.
- They have a historical American individualist / consumer approach: "Who will be for me if not me?"
- There is growing suspicion of big science and big medicine (e.g., cloning, genetically modified food).
- Information is available and accessible now more than ever before.
- They have become vigilant because they experience their health care as fragmented or they feel vulnerable to medical errors or poor care due to rationing.

**But human nature gets in the way because:**

- Changing longtime habits and maintaining new behavior is tough and requires daily effort.
- The attraction of immediate gratification and the time horizon for prevention erode motivation for thinking ahead.
- We are vulnerable to the allure of ubiquitous attractive messages that

encourage actions that undermine health.

- There are significant environmental barriers (lack of access to safe streets, fresh affordable vegetables) that require enormous energy and commitment to overcome.
- Young people, especially men, feel invulnerable and immortal – and find it difficult to imagine, much less attend to the distant threat of illness.

**Popular American beliefs about the nature of medicine present barriers for many. These beliefs include:**

- There are effective, quick fixes for everything, whether pharmaceutical, surgical, alternative, or now, through genetic manipulation.
- All medicine is scientific and therefore of high quality ("otherwise the government wouldn't let us have it").
- Physicians always know everything.

There is a rich heterogeneity of beliefs about health/medicine/cure that are related to religion, ethnic background, culture, and socioeconomic status, but which are not reflected in the three statements above.

**Other barriers are presented by what it takes to "engage" in health and health care. These include:**

- People rarely think about "health" outside the context of its opposite (illness).
- People are already paying a lot for health care even if they don't use it and have trouble thinking they should "work" at health in light of that investment.
- It is not clear what it means to "engage" effectively in health care – there are no role models and it probably means very different things to different people.
- Doing so may be costly in terms of time, resources, and gaining access.
- Much health and medical information is complex and diffuse and it (appears to) change all the time.
- Finding a clear answer and /or identifying an action plan and maintaining engagement in health and health care is tough, especially when:
  - one is well and health per se is not a high priority or
  - when one is ill and may not have the energy to seek new information and experiment with new relationships.
- Challenging the authority of medicine/doctors in their technical domain requires confidence and a strong sense of efficacy.

**2) How Health Care Providers Encourage/Discourage Active Participation**

**Health care professionals can encourage active participation and engagement in health and health care by:**

- Defining consumer engagement as appropriate and valued.
- Treating patients as part of the treatment team.



- Taking time to answer questions, discuss priorities, explain recommendations, lead collaborative development of (*self* and *medical*) care plans, and arrange follow-up.
- Lowering barriers to entry and on-going communication (ease in use of health care – appointments, communication).
- Maintaining appropriate demeanor and patient-centered communication skills.
- Devoting adequate time to the encounter.
- Explicitly communicating strategies to consumers to improve their health, not just address the current complaint.

**Health care professionals inhibit active engagement in health and health care by:**

- Omitting the practices and skills noted above.
- Protecting historic provider roles and hoarding information, and accepting the power imbalance of the current system.
- Whining about changes to their profession and pointing blame at other stakeholders to explain deficiencies in care and service.
- Failing to acknowledge and take into account the impact of life circumstances on individuals' health and disease prevention and treatment.
- Blaming patients for treatment failure.
- Undervaluing or underestimating patients' knowledge and skills.
- Being intentionally arcane and inaccessible (especially for low literate people).
- Signing health contracts with health plans that cause, or appear to cause, conflicts of interest about health care decision-making.

**3) How the Structure of Health Care Encourages/Inhibits Active Participation**

**The structure, financing, and delivery systems of health care encourage consumer engagement and participation in health and health care by:**

- Ensuring that care is accessible, reliable, vital, and supportive of patient-provider interaction.
- Reimbursing for/covering programs and services designed to enhance and support consumer engagement and participation.
- Making good use of patient-oriented interventions—which include goal setting, problem solving, and shared decision-making—and including providers who are not generally part of the core structure of most medical practices.
- Making available a "one-stop shopping" informational system, through which consumers can gain information about their choices, rights, and responsibilities, a system that provides informational help irrespective of the payer for consumers' health care.

**However, financial arrangements inhibit consumer engagement in health and health care by:**

- Providing financial incentives for only specialty and procedure-intensive medicine and omitting incentives for lower unit cost interventions that effectively support self-management. For example:
- Only paying for people to come in for face-to-face visits.
- Paying more for treatment and care than prevention.
- Not reimbursing or severely limiting reimbursement for non-doc visits and phone calls.
- Failing to reimburse for pro-active follow-up for patient management that is more effective if supported over time (e.g. case management for medication use).
- Implementing payment systems that reward professional process rather than patient outcomes, (e.g., volume over quality incentives).
- Relying on third party payments that sustain the value-exchange disconnect between the provider and recipient of services, causing consumers to devalue health services

**The organization of health care inhibits consumer activation in that:**

- Health care is not organized to produce and maintain an educated, savvy, engaged consumer. The success of most practices and health plans relies on and reinforces a high degree of passivity from patients (e.g., that they only use care when they are sick, and require only the information they are given during an encounter, etc.).
- It is often difficult for consumers to negotiate their way through fragmented uncoordinated care, bouncing among primary and specialty care, mental health and physical health systems.
- There is a lack of coordination between behavioral / risk assessment and tailored interventions and other strategies to support consumer action to prevent and manage disease.
- Inadequate linkages of information and resources among primary and specialty health care providers, patients, and other important players (e.g., community organizations) result in errors, wasted resources, and missed opportunities.
- There are few opportunities (and fewer incentives) for effective training for health care professionals to learn a) to provide appropriate, evidence-based care that encourages and supports patient self-management and b) to refer patients to community organizations and other non-medical providers for intensive and /or ongoing self-management support.

**Current health care market conditions inhibit consumer activation by:**

- Keeping clinical decision-making criteria (e.g. clinical guidelines) of health plans and provider organizations hidden from public view, often based on

questionable assertions of proprietary exclusivity.

- Denying individual consumers any economic /allocations /governance /power (or voice) in the health system; only group purchasers influence provider behavior.
- Supporting an acute care orientation that diminishes the importance of self-care and does not suit the long-term and repetitive needs of chronic conditions.
- Increasing the complexity of access to care.
- Perpetuating the lack of public accountability for the quality of care and complete absence of public expectations for performance.
- Allowing health care plans and practices to reject responsibility for health outcomes.
- Being so turbulent that many complex systems and health care professionals are discouraged from trying anything new.
- Limiting access to the uninsured, a growing group for whom consumer health activation is a critical concern.
- Significantly increasing the churning in doctor-consumer relationships, which in turn undermines patient participation in care, which is built on trust -- trust requires time.

#### **4) How Social Norms, Trends, and New Technologies Influence Participation**

##### **Social norms may encourage engagement:**

- In younger segments of the population, which appear to be comfortable questioning authority and are willing to be more directly involved in decision-making about their lives – this, over time, will enhance consumer/patient involvement.
- New emphasis on consumer activation is spreading as the "Bo Bo" generation assumes leadership in public and private sectors (media, government, etc.).

##### **Social norms may also inhibit consumer engagement:**

- Some Americans—particularly older ones—are reluctant to question their doctor’s medical decision making. Similarly, some doctors (e.g., older ones) are not comfortable sharing decision making with patients.
- The dominance of ‘consumerism’ in all developed countries, and industries creates higher expectations for autonomy, voice, and respect for preferences.

##### **Similarly, a number of trends affect the likelihood of individual participation in health and health care, including:**

- Social ‘leveling’ of attire, popular culture, and educational access reduce consumer comfort with ‘white coat’ professional ethics and increase skepticism about expert authority.
- There is a trend toward doing for yourself things that used to be done by professionals (e.g., financial management /investing, arranging travel) which

may proliferate to health care choices.

- Defined contribution insurance plans (as opposed to defined benefit plans) will accelerate consumer engagement in health as individuals begin to pay out of pocket for more intensive professional services.
- The rise of concern about privacy—a mix of paranoia and real concerns—could seriously limit the free flow of information between consumers and organized health care that is at the heart of real collaboration; in particular it eventually may limit the ability of health care organizations to reach out to patients
- The rise in amount and complexity of available information on every subject, including health, creates a confusing overload and is fomenting a backlash of sorts (e.g., simplicity movement).
- There is a growing expectation of "mandatory autonomy" which characterizes anything less than full autonomy as negligent and irresponsible.
- The proliferation of "legalese" and documentation make many interpersonal and professional exchanges *pro forma* and subject to cynicism.

#### **New technologies offer opportunities for consumer activation:**

- New medical and information technologies permit direct distribution of health services to consumers without participation of traditional stakeholders as well as peer to peer networks of people with shared interests or expertise.
- New technologies can be used to support both provider and patient behaviors: to provide information to inform choices, to support information exchange, and to provide information to support behavioral change.

#### **New technologies also:**

- Create an aura of a technical/pharmaceutical resolution to every problem.
- Cultivate the notion that all patients can have every option of care regardless of societal costs.
- Create a demand for lucrative procedures, services, and drugs.
- Target little information to those who do not constitute a lucrative marketing opportunity.

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