

# ISSUE BRIEF

## Shared Accountability in Family Medicine: Physician and Patient Perspectives

Prepared by PatientsLikeMe, Inc. (PLM) and the American Academy of Family Physicians National Research Network (AAFP NRN) with funding from the Robert Wood Johnson Foundation Grant #73040

### EXECUTIVE SUMMARY

The goal of this study was to explore patient and provider perspectives on shared accountability for health care outcomes in the primary care setting. To achieve this goal, two independent online focus groups were held: one with patients (23 participants) and one with physicians (17 participants).

Qualitative data collected via the online focus group revealed six themes that characterize the patient perspective of shared accountability. Among patients, these include communication as a shared responsibility, personal advocacy, coordinating and controlling personal information, primary care providers as “chief,” distinct roles for each member of the care team, and viewing outcomes as a process rather than a change in health status. Among physicians, the perspectives include the importance of bidirectional communication, accountability demonstrated in patient activation, accountability to “show up and be present,” challenges in balancing patient management and roles within a healthcare system and feeling a sense of responsibility of outcomes that they may not totally control. Physicians generally see themselves as fully responsible for clinical aspects of care, but also as teachers who support patients taking personal accountability, following care plans and making healthy lifestyle choices.

Quantitative data collected via the online focus groups revealed that there is a high level of mutual alignment of perspectives about responsibilities in the care relationship between primary care patients and physicians. Two areas of difference were noted in that patients rate themselves higher than physicians rate patients in: (1) remaining healthy and (2) the amount of time it takes to recover and return to normal activities after an illness.

Recommendations include: (1) improving communication and educational skill training for physicians; (2) improving patient communication by offering education and support; (3) recognizing the ongoing and iterative nature of treatment planning; and (4) the importance of contextualizing “best” patient care in light of non-medical factors.

### RATIONALE AND STUDY DESIGN

#### Rationale

Accountability for health care outcomes is shared by providers, patients, and the system in which they operate.<sup>1</sup> A 2014 report by the American College of Cardiology/American Heart Association Task Force on Performance Measures recommended that shared accountability (among patients, clinicians, and health systems) be considered in the reporting and analysis of performance measures.<sup>1</sup> This group of providers and researchers suggested that patients ideally should be accountable for the following: being aware of what to watch for; contacting their clinicians when symptoms arise; learning about their condition and what they can do to improve their health; implementing agreed-on treatment plans and lifestyle changes; and following up with their clinicians to assess outcomes and adjust their treatment plan.

However, patient and provider perspectives on accountability for health outcomes are usually not included in performance measurement development. This omission hampers including features of the care relationship that matter to both and it decreases understanding of the mutually reinforcing roles that the patient/provider dyad relationship must have to be effective. To achieve favorable outcomes, patients must work within systems and with providers to take actions for which they are accountable.<sup>2</sup> Outcomes are important indicators of the success, but without shared accountability for health care, achievement of these outcomes is difficult.

## Study Design

To more fully understand the concept of accountability in attaining desired health care outcomes, we conducted a mixed method study to separately elicit perspectives from both patients and physicians. Using a matched domain approach, each stakeholder group – patient and physician – answered questions that elicited their views on the same issue relevant to accountability. Having both the patient and physician perspectives permit comparison and allow for the identification of areas where shared accountability between groups does and does not align.

To collect and compare perspectives, we utilized QualBoard® version 3.0, a proprietary software platform for qualitative data collection and analysis owned by 20/20 Research, Nashville, TN. The project design had two key components to achieve the study's aims: (1) an asynchronous, online focus group with patients, and (2) a parallel asynchronous online focus group with family medicine physicians. Both focus groups were held over five days, and participants were able to save progress, as well as log in and out at any time during the five-day period. A moderator from the PLM research team led the discussion in the patient group, asking follow-up questions for clarity around participant responses. A moderator from the AAFP NRN research team led discussion for the participating physicians.

Discussion questions covered the same topics, however were adapted for the specific audience (i.e. patients or physicians). The discussion guide was drafted from a literature review and consultation with experts, including researchers and physicians. The questions were a mix of open-ended questions and quantitative, multiple-choice questions about various aspects of healthcare and health outcomes. Discussion topics included the patient's role in their health care, their interest in playing an active role in their health care, confidence and empowerment, shared decision-making, role of the primary physician and other providers, and access to services. Multiple choice questions were derived from Porter's (2010) outcome measure hierarchy and covered patient perspectives on shared accountability for achieved or retained health status, recovery, sustained health, recurrence, and care-induced illness.<sup>3</sup> The discussion guide for patient and provider focus groups included the following sections:

- Role responsibilities of the patient
- Expectations for patient role in healthcare
- Patient empowerment by provider
- Role of primary care/family medicine physician
- Access to services/systems
- Other roles involved in shared accountability
- Perceptions of burden of accountability for outcomes
- Perceptions of ideal patient accountability role expectations

## Analytic Plan

**Quantitative Analysis.** Patients (n = 23) and physicians (n = 17) were each given a survey with 22 questions to determine their views on patient and physician responsibility. Each question had a scale from 1 = “not at all” to 5 = “completely responsible.” Aggregate data (i.e., response counts for each scale item in each question) for both surveys were provided for analysis. To determine any differences between patients' and physicians' perceived responsibilities, t-tests were conducted ( $\alpha = 0.05$ ). The responses for each question were determined to be approximately normally distributed within the scope of the sample size and response scale. (See section “Comparative Quantitative Results” below for more information.)

**Qualitative Analysis.** Discussion text was analyzed using the immersion/crystallization method.<sup>4</sup> Based on this method, analysis was conducted in two phases. First, transcripts were read in full by each researcher, who independently listed key themes that occurred for each discussion question (immersion). Second, the research team reviewed themes as a group to allow the most fundamental elements of the themes to emerge. Third, the patient team (PLM) and physician team (AAFP NRN) met to discuss and refine the final list of key themes that crystallized out of the process. Themes were then described in depth to elucidate findings.

## PARTICIPANT PROFILES

See Table 1 below for a profile of the demographics of both patient and physician participants.

**PLM Patients:** PLM patients with diagnoses of major depressive disorder, diabetes, arthritis, and/or multiple sclerosis were invited to participate. Additional inclusion criteria for participation were: (1) being 18 years of age or older, (2) having a primary diagnosis of one of the four conditions, and (3) having primary residence in the United States. Demographic and clinical characteristics were collected from patients via self-report in the first module, including treatment background and disease severity. Participants were highly health literate (96% extremely or quite a bit confident in filling out medical forms). Likewise, most were very or completely confident that they could be responsible for their health and health care (87%). This highly engaged group also shared their perspectives on the extent to which they believe responsibility for different outcomes of health care should be shared by patients and physicians.

**AAFP Physicians:** The AAFP NRN solicited member physicians to participate in the study via email correspondence. The goal was to recruit 15 physicians given the funding available for remuneration. Recruited physicians were drawn from a pool of AAFP NRN members with the goal of having geographic diversity and varied location type (e.g., rural/frontier, suburban, urban). All of the participants provide clinical care  $\geq$  35 hours per week. Positive response was swift, and 17 physicians were recruited to participate in the QualBoard<sup>®</sup> activity. Demographics were collected from physicians during their recruitment and enrollment phase.

**Table 1. Participant Characteristics**

Physician Participants (n=17)		Patient Participants (n=23)	
<b>Sex</b>		<b>Sex</b>	
Female	5 (29%)	Female	19 (83%)
Male	12 (71%)	Male	4 (17%)
<b>Age (Average)</b>	48 years (range 34-65)	<b>Age (Average)</b>	52 years (range 22-75)
<b>Race</b>	Not collected	<b>Race</b>	
		White	21 (91%)
		Black	1 (4%)
		No response	1 (4%)
<b>Ethnicity</b>	Not collected	<b>Ethnicity, Hispanic</b>	1 (4%)
<b>Practice ownership</b>	30% are sole or partial owners	N/A	
<b>Practice size (physicians, any specialty)</b>	Average=10 (min=1; max=70)	<b>Education Level</b>	
		High school or less	0 (0%)
		Some college	9 (39%)
		College graduate	10 (43%)
		Post graduate	4 (17%)
<b>Practice area location type</b>		<b>Health Conditions*</b>	
Rural/frontier	5 (29%)	Arthritis	15 (65%)
Suburban	11 (65%)	Major depressive disorder	11 (48%)
Urban	1 (6%)	Type 2 diabetes	8 (35%)
		Type 1 diabetes	1 (4%)
		Multiple sclerosis	4 (17%)
<b>Years practicing post-residency 5 or fewer</b>		<b>Has a primary care physician</b>	23 (100%)
11-20 years	5 (29%)		
21+ years	6 (35%)		
	6 (35%)		

<b>Primary employer</b> Self-employed, majority practice owner Physicians group (single or multi-specialty) University-owned (public or private) clinic or hospital Private for-profit hospital or health system (“corporately owned”) Private non-profit hospital or health system Federal, state or local government, community board	4 (24%) 2 (12%) 1 (6%) 1 (6%) 8 (47%) 1 (6%)	<b>Confidence filling out medical forms</b> Extremely Quite a bit Somewhat A little Not at all	14 (61%) 8 (35%) 0 (0%) 0 (0%) 1 (4%)
<b>Primary patient care location</b> Privately-owned medical practice Non-profit or public hospital-owned clinics Federally qualified community health center Urgent care facility	(53%) (29%) (12%) (6%)	<b>Confidence to be responsible for health and health care</b> Completely Very confident Somewhat confident A little confident Not at all confident	4 (17%) 16 (70%) 2 (8%) 1 (4%) 0 (0%)
<b>Types of clinical services provided</b> Chronic care management Geriatric medicine Adolescent medicine Care of infants and children Urgent care Hospice/Palliative care Sports medicine Emergency care Newborn/Nursery care Occupational medicine Inpatient care Obstetrics Sleep medicine Intensive care	16 (95%) 16 (95%) 15 (88%) 15 (88%) 10 (59%) 8 (47%) 8 (47%) 6 (35%) 6 (35%) 5 (29%) 4 (24%) 3 (18%) 3 (18%) 2 (12%)		

*\*Note: Percentages do not sum to 100% because participants could select more than one health condition*

## RESULTS: PATIENT PERSPECTIVES

*“Most doctors make their patients feel like pieces of meat on a butcher block, complete with the paper to wrap the meat up. Our medical system does not allow doctors to know their patients, and vice-versa. Doctors are not auto mechanics, and patients are not bad fuel injectors or electrical systems. Patients need to trust their doctor’s knowledge, not just of a particular condition, but of this specific patient as a totality. Mutuality of trust empowers the whole thing.” Patient Participant, Male, Age 59, Multiple Sclerosis*

### Patient Domains

1. Communication was a prominent theme throughout the discussion. Patients described the importance of communication in shared responsibility in two ways: (1) information management and (2) style of the provider. First, participants felt that while it is the patient’s responsibility to be informed about their health condition and treatments, it was the provider’s responsibility to “connect the patient to individuals or sources that explain side effects and symptoms.” Once patients have this information, it becomes their responsibility to contact their provider when their health changes or they have questions. That is, providers should give patients the tools they need to understand and manage their condition, and it is up to patients to take responsibility to apply them appropriately. Second, style or mannerisms in which providers communicate was another critical part of communication, including a sense of humor. Patients reported that they want their providers to connect with them on an individual, human level and to be acquainted with their lifestyle when considering their care plan.

2. Personal responsibility for their health care is valued and desired by patients, who see themselves as their best advocate. In discussions with their providers, they want to feel that they have had true shared decision-making, with the provider offering options, guidance, and support, but with the patient as the final decision maker. However, some mentioned that this responsibility can be overwhelming and frustrating, especially when they have multiple comorbidities or insurance constraints. Patients are less confident in their responsibility for their care in instances where they are unprepared, such as emergencies, or if they are cognitively impaired.
3. Coordinating and controlling their own health information is viewed as a patient responsibility. Patients felt it was their responsibility to keep track of medical records and to know their laboratory test results in order to facilitate communication and participate fully in their care. This includes ensuring that information such as labs, tests, and treatments are shared between specialists and family medicine physicians. Patients felt that providers did not always have the time to review all of their information from specialists or laboratory reports, thus the burden fell on patients to ensure this information was available.
4. Family medicine physicians are the “everything doctor” or “chief” who is responsible for “putting together all the pieces of my puzzle.” This includes being aware of comorbidities, labs, and treatments. Many viewed their physician as responsible for the overall picture of their health whereas issues associated with specific biological systems would go to specialists.
5. There are clear roles for each member on the team. Patients felt their role responsibilities are to select providers and be the ultimate decider on treatment plans. Patients acknowledged their responsibility to take part in their health and assume ownership of certain aspects of their care, but also raised the need to work with a collaborative team of providers. Physicians bring knowledge that patients do not have and their guidance and support aids patients in fulfilling their healthcare responsibilities.
6. Outcomes center on process, not changes in health status. Patients generally viewed outcomes in terms of activities they do to self-manage rather than what researchers typically think of as outcomes. For example, patients described outcomes in terms of whether they had success following a treatment plan or monitoring and reporting symptom changes to their provider. They felt they were only responsible for those outcomes they are able to monitor and report. Further, they identified some outcomes for which they are not responsible, such as accidents or loss of function due to inevitable disease progression.

## RESULTS: PHYSICIAN PERSPECTIVES

*“Providers have a responsibility to listen; to think and to devise treatment plan options that are potentially achievable within the constraints of a patient’s values, budget (both time and money) and motivation (i.e., patient confidence) and that the plan is achievable. Patients have a responsibility to be honest about limitations regarding values, time, money and motivation; to be open with their provider if suggested treatment options do not honor those limitations”; and to own the actual work of carrying out the agreed-on treatment plan”. Physician Participant, Age 48, Rural/Frontier Practice Setting*

### Physician Domains

1. Communication was a prominent theme throughout the discussion. Physicians recognize that honest and open communication is essential, and that bi-directional communication has to be an ongoing priority for both parties. References were made often to the importance of patients’ telling them the “whole story”, especially when withholding information crucial to diagnosis and action/priority setting was withheld. Communication also was cited in particular when physician participants discussed their role as educators, guides, navigators and teachers. Holding the “answers” to medical questions and being able to translate medical information into simple, straightforward messages to communicate effectively with patients is a high priority for family medicine physicians.

2. Accountability for health outcomes described in terms of patient activation. Family medicine physicians treat accountability often as a shared responsibility that ultimately rests with patients taking action based on their recommendations and a jointly agreed upon treatment plan. Many patients seen routinely in family medicine clinics have chronic disease and often comorbid conditions that exacerbate multiple disease states and their symptoms. Lifestyle modifications along with fidelity to pharmacotherapy and treatment plan details are essential to achieve the highest level of potential response. Realistic expectations dominated the conversation about setting the patient up for achievable results, and physicians underscored the importance of patient commitment and activation to improve or maintain their own health.
3. Shared accountability can mean both showing up and being present. Participants frequently mentioned frustration with patients failing to make their scheduled appointments. As a business, health care delivery and patient scheduling is a complex requirement for handling many individuals' priorities with limited resources. When patients fail (sometimes repeatedly) to arrive on time and ready for their appointment, the entire clinic is impacted negatively. Beyond making it to appointments, physicians also indicate that patients need to be prepared for discussion and decision making; they must be fully present, alert, inquisitive, interactive and attuned to the decisions that need to be made during the time they are together.
4. Personal commitment to meeting the needs of patients is counterbalanced with angst over health system limitations on their effectiveness. The physician participants in this study are wholeheartedly committed to their discipline and to their role as healers in the health care system. That system, however, is seen sometimes as a limitation to their ability to deliver care in ways they believe could be most beneficial to their patients. They cite the amount of time they can spend with individual patients and the requirements of their health system or payers regarding what is reimbursed during an encounter as limiting their capacity to meet patient needs. One participant shared "So many times (health insurance companies) are at odds with the patient requiring (prior authorizations) and denying the medication that we the physicians order in the patient's best interest!...all in the name of profit for the insurance company and shareholders".
5. Physicians use their best professional judgement, but they sometimes feel responsible for outcome failures. While the sequelae of disease may occur even when both physician and patient do everything they can to prevent negative outcomes, physicians perceive that they have a disproportionate responsibility. Respondents stated that "providers are very responsible for making sure the diagnosis was accurate and the recommended treatment is based on solid evidence base medicine" but they also recognize that "environmental factors (social determinants of health; pollution, unavoidable exposure to secondhand smoke, etc.)" impinge on outcomes in critical ways that are outside of their control. Nonetheless, family medicine physicians feel an enormous responsibility toward their patients' outcomes.

## COMPARATIVE QUANTITATIVE RESULTS

The results of comparison between patient and physician perspectives on the 11 domains are remarkably similar. Only two questions demonstrate statistical difference; physicians underrate the degree to which patients acknowledge their responsibility to remain healthy and for the time it takes to recover from illness and return to normal activities. Given the nature and breadth of these questions, the comparison is remarkable in that it demonstrates that both groups have mutually reinforcing notions about shared accountability for care.

**Table 2. Quantitative Data Analytic Results**

	Patients		Physicians		Differences		t
	M	SD	M	SD	M	SD	
<b>Overall Survival</b>							
Patients responsible for survival from an illness	3.61	0.58	3.47	0.51	0.14	0.78	0.78
Providers responsible for a patient's survival from an illness	3.91	0.29	3.76	0.56	0.15	0.15	1.00
<b>Recovery from Illness</b>							
Patients responsible for the degree to which they recover from an illness	3.87	0.55	3.65	0.61	0.22	0.18	1.21
Providers responsible for the degree to which patients recover from an illness	3.78	0.42	3.71	0.69	0.08	0.19	0.41
<b>Remain Healthy</b>							
<b>Patients responsible for the degree to which they remain healthy</b>	<b>4.26</b>	<b>0.54</b>	<b>3.88</b>	<b>0.49</b>	<b>0.38</b>	<b>0.17</b>	<b>2.28*</b>
Providers responsible for the degree to which patients remain healthy	3.22	0.80	3.24	0.44	-0.02	0.20	-0.09
<b>Amount of Time it Takes to Recover and Return to Normal Activities after an Illness</b>							
<b>Patients responsible for the amount of time it takes to recover and return to normal activities after an illness</b>	<b>3.61</b>	<b>0.72</b>	<b>3.06</b>	<b>0.66</b>	<b>0.55</b>	<b>0.22</b>	<b>2.47*</b>
Providers responsible for the amount of time it takes patients to recover and return to normal activities after an illness	3.22	0.60	2.82	0.64	0.39	0.20	2.00
<b>Errors in Diagnosis</b>							
Patients responsible for errors in diagnosis	2.00	0.67	2.06	0.56	-0.06	0.20	-0.29
Providers responsible for diagnostic errors	4.09	0.67	3.71	0.69	0.38	0.22	1.76
<b>Ineffective Care</b>							
Patients responsible for ineffective care	2.91	1.13	2.41	0.71	0.50	0.31	1.61
Providers responsible for ineffective care	4.09	0.67	3.82	0.73	0.26	0.22	1.19
<b>Side-Effects</b>							
Patients responsible for side-effects	1.87	0.97	1.76	0.44	0.11	0.23	0.46
Providers responsible for side-effects	2.48	1.12	2.82	0.95	-0.35	0.34	-1.02
<b>Complications</b>							
Patients responsible for complications, or undesired problems that occur as a result of a disease or due to disease worsening	2.30	0.93	2.76	0.75	-0.46	0.27	-1.68
Providers responsible for complications, or undesired problems that occur as a result of a disease or due to disease worsening	2.61	0.99	2.65	0.79	-0.04	0.29	-0.13
<b>Costs Associated with Treatment</b>							
Patients responsible for the costs associated with their treatment	2.52	1.38	2.47	0.80	0.05	0.35	0.15
Providers responsible for the costs associated with treatment	3.00	1.31	3.47	0.62	-0.47	0.31	-1.50
<b>Recurrence of a Disease or Symptom</b>							
Patients responsible for a recurrence of a disease or symptom	2.39	0.78	2.65	0.86	-0.26	0.26	-0.98
Providers responsible for a recurrence of a disease or symptom	2.30	0.77	2.71	0.47	-0.40	0.21	-1.91
<b>Long-Term Consequences of Treatment</b>							
Patients responsible for the long-term consequence of treatment	2.70	1.11	2.18	1.02	0.52	0.34	1.52
Providers responsible for the long-term consequences of treatment	2.96	0.93	2.82	0.81	0.13	0.28	0.47

\* = p-value < 0.05

## CONCLUSIONS & RECOMMENDATIONS

### Conclusions

1. Both patient and physician participants recognize that a substantial element of shared accountability rests on effective communication. This theme reoccurred across all topical domains and highlights the highly personal interaction required in primary care settings.
2. Broadly, patients feel responsibility about control of information. Awareness and communication, were what patients felt could enable participants to be fully involved in decision-making about their health care.
3. Both groups, but especially patients, highlight how important it is to make sure information is shared among care teams. Are activated patients making up for what the health system lacks? Do patients take for granted that the system (e.g., Electronic Medical Records) is set up in their best interest, or do they recognize that they have to take charge of their health care and health information?
4. Outcomes for patients are not necessarily the same things that physicians or researchers think about. Patients tend to emphasize things like self-management activities and communication with their provider as outcomes in themselves; physicians tend to emphasize clinical status changes as priority outcomes, but they recognize that patients have to engage in their own care goals to achieve improvements.
5. Patients are *unlikely* to blame their providers for poor health outcomes unless they were not engaged in decisions about the appropriate course of treatment. Poor communication or excluding patients from participating and feeling listened to is considered worse than offering an ineffective treatment. Ironically, some physicians think ultimately, they are blamed by patients for poor health outcomes.
6. Patients want to feel both informed and listened to so that their perspective is included in the treatment plan. This includes feeling that their providers understand their individual lifestyle and social circumstances and relate to them on a personal level.
7. Physicians tend to see clear communications and the development of a therapeutic/treatment plan as their responsibility, and once formed, outcomes are largely in the hands of patients. Few physician participants discuss revisiting these plans and addressing why the plan is or is not working and offering corrective actions, even if they actually do this routinely.

### Limitations

Several limitations of this work should be noted. The samples obtained for this study were convenience samples. They may not be representative of the views and experiences of health care delivery as experienced by patients and physicians in general. In addition, the physician sample consisted of only one specialty – family medicine – and may not represent the accountability perspectives of physicians in different medical specialties. Finally, the data in this study is based on self-report and there was no independent verification of the actual contexts in which care took place.

### Recommendations

1. **Improve communication and educational skill training for physicians.**  
Physicians describe their essential role of providing patients with clearly understandable information, but they are not trained to be expert educators. Training that supports effective communication skills and adult (as well as youth) educational techniques and strategies could beneficially be introduced during medical school and residency training. This could include skills in assessing patients' individual circumstances and in engaging patients in the discussion at a personal level to enhance their participation in treatment plans.

2. **Improve patient communication by offering education and support.**

Both patients and physicians feel that patient engagement with their providers is critical to shared accountability. Patients note that managing their information with providers is critical to their ability to engage with their providers and create a shared treatment plan. Patients who do not actively communicate this information with their providers may face a gap in their ability to reach a shared treatment plan. Support materials for patients to aid their communication with providers may help bridge this gap for patients who may not be comfortable with or aware of what information they should be sharing with providers. Furthermore, better preparation by patients in communicating with providers may enhance the quality of care that physicians can provide, and lead to a better understanding of shared goals.

3. **Recognize treatment planning must be ongoing and iterative.**

Patients and physicians jointly agree they must work together to share information and develop a course of action for care. They differ, however, in the degree to which they recognize that they have to refine treatment and iterate the plan as needed. If both parties more aggressively sought to determine if treatment plans were working effectively and made more timely modifications when justified, both parties (and the health system) might be more satisfied with outcomes.

4. **Contextualizing “best” patient care in light of non-medical factors should be promoted and valued.**

Patients point out, and many physician participants agree, that physicians and their care teams should make an effort to understand their patients’ information needs and decision style (e.g., preferred level of involvement) when interacting and deciding on a treatment plan. Furthermore, family medicine physicians report a deep appreciation for the context of their care in their patients’ lives, and they believe they set realistic expectations for care when they are fully informed by the patient about their families, home and built environment, behavioral health and overall quality of life values. Family medicine is a discipline that prides itself on recognizing the social determinants of health and the complexities of whole person care. Patients with positive relationships with their family physician and physicians who report having long term, meaningful relationships with their patients, underscore the mutually satisfying health care relationship that is possible in primary care.

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