

“Patients’ Views about Patient Engagement and Representation in Healthcare Governance”

DeCamp, Dukhanin, Hebert, Himmelrich, Feeser, & Berkowitz

APPENDIX B. Qualitative Codes with Example Quotations

PRIMARY CODE	SECONDARY CODES	EXPLANATION/KEY QUOTE
<p>A patient representative is important</p>	<p>Offers general patient input</p>	<p>“The BR [beneficiary representative] balances the other board members.”</p> <p>“Different perspectives are important—MDs tend to be a clannish lot.”</p> <p>“[A] patient on board indicates recognition of need to communicate in plain language.”</p> <p>“Patients know best what their needs and concerns are. It would be paternalistic to have a board without patients.”</p> <p>“Just having a general patient present is important.”</p> <p>“A patient representative ideally presents a view that is germane and shared by patients in general.”</p> <p>“I believe a patient’s input is very important to any decision regarding patient care. Patient knows best.”</p> <p>“Without one or more patients on the board the other members have little idea of the experience of actual patients.”</p> <p>“A layperson patient is prob[ably] more sensitive to what is needed rather than a physician [or healthcare] professional.”</p> <p>“A patient representative is more likely to consider the implications on patient financial burdens.”</p>
	<p>Is critical to the success of the ACO</p>	<p>“Any program needs end user direction if it’s to be a success. ... You need to have pt [patient] input if you truly want to make it work. ... Also, use their voice to help you market the program.”</p>

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		“A patient will bring a valuable different perspective to deliberations, which should strengthen the program and enhance its success.”
	Having some representation is better than none	“Any representation is better than none.”
	Helps represent my needs	“Having a patient on the board somewhat increases the likelihood my needs may be represented.”
	Improves trust	“Having patients on the board makes an organization more trustworthy.”
Expressing skepticism about patient representation, in concept or in practice	Representatives may be unable to influence the board	<p>“I believe the patient would be bullied by the professionals.”</p> <p>“I like that you’ve included a patient but I’m not convinced they hold much sway when it’s 12 to 1.”</p> <p>“Patient input should be welcomed even sought. ... Don’t believe one patient on board would do the trick or make meaningful difference.”</p> <p>“I’m sure there would be meetings without patients in attendance where things would be said and done unbeknown to them the patient committee.”</p>
	The representative is chosen for public relations purposes	<p>“Was the patient handpicked to give the board the kind of answers they want?”</p> <p>“One patient has no benefit, except to make the process look more inclusive.”</p>
	A patient representative may be overly self-focused	<p>“The patient could influence based on their diagnosis unwittingly or on purpose.”</p> <p>“Probably impossible to represent needs of all. One only is not good enough—great chance that his/her personal issues predominate.”</p>
	One patient cannot represent all patients	<p>“How would this person know the thoughts and concerns of thousands of other patients?”</p> <p>“Each patient will have individual care bias or preferences.”</p>

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		<p>“A subgroup of multiple patient types could focus needs as one patient with one health issue might not be the broad perspective needed.”</p>
	Being on a board is not something for a patient to do.	<p>“This sounds like something professionals should decide.”</p>
	It would be better to spend resources elsewhere	<p>“I wish you would put all this money and effort into improving the equipment and helping the great doctors you have.”</p> <p>“My doctor and others have done a great job. I see no need for this administrative burden.”</p> <p>“Sounds like a lot of bureaucracy.”</p> <p>“I think this is a total waste of time since my experiences indicate the primary concern is for money.”</p>
	As an individual, I do not need this.	<p>“As a health care professional, I did not see a need for myself to access these on a regular basis.”</p> <p>“It doesn’t affect me so I don’t care.”</p> <p>“When your [sic] sick these stuff is meaningless to you, just busy work.”</p> <p>“In the past my opinions have not mattered, why now?”</p>
Keys to success	Success depends on who the patient representative is	<p>“[The] patient rep is really only valuable if she/he communicates to other patients what is going on and will take issues from patients to the board. That is difficult.”</p> <p>“Can she/he be able to enhance the individual director’s awareness of the concerns of patient care recipients’ needs within the context of the professional and legal environment that care is provided?”</p> <p>“It just makes sense to have a patient on the board. Of course she needs to be someone who is also knowledgeable about health care systems.”</p>

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		<p>“A representative of the patients have to have a lot of knowledge about the health issues. It is hard to find one.”</p> <p>“Unless the patient is a doctor that understands medical terms and decisions, it makes no difference.”</p> <p>“It would be a rare set of health pros who would listen. It would be a rare individual who could influence doctors or has the skills to be useful.”</p> <p>“The patient representative should be a strong advocate for patients. not a silent representative”</p> <p>“It should be a patient who rates their health as fair or poor. How would a patient in very good health know how the services are working?”</p> <p>“Have an amateur on the board to ask questions doctors take for granted.”</p>
	<p>Patient representatives should reflect diversity</p>	<p>“Using this space to request that you ensure that the board is culturally diverse. Very important to me.”</p>
	<p>Patient representatives should be representative of the population served</p>	<p>“In general any board should be representative to some degree of those governed.”</p> <p>“You need a valid statistical cross section of patients on the board.”</p>
	<p>There should be more patient representatives</p>	<p>“Suggestion: Have 2 patient members, 1 female and 1 male, to better represent patient needs.”</p> <p>“There should be another patient and at least 2 nurses ... so it can actually make good changes to managing care.”</p> <p>“It is important that there is more than 1 patient. There should be</p>

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		<p>patients of different economic backgrounds to give their outlook on what may be needed.”</p> <p>“Just one? How about a patient board that sends reps to advisory board?”</p> <p>“I think there should be one permanent member with continuity to be familiar with issues and one or two more rotating because one member alone cannot be representative of the whole population of patients.”</p> <p>“Have a patient committee of some kind with its own chairperson. ... I’m sure there would be meetings without patients in attendance where things would be said and done unbeknown to the patient committee.”</p>
	<p>Patients should choose the beneficiary representative</p>	<p>“Member should be a delegate from [a patient council].”</p>
	<p>Ensure full participation</p>	<p>“Patient on board needs to be a full participant and contribute to discussions.”</p> <p>“I would hope that the consumer be given full consideration and not [be] a token.”</p> <p>“The importance of the patient member is determined by the board’s response to the member’s comments. It can be helpful or just a token.”</p>
	<p>Rotate members after fixed term</p>	<p>“Rotate patients on board after fixed term to get other input.”</p> <p>“Patients are picked annually. Other patients of different medical needs should serve.”</p> <p>“Each patient has different needs this person should be changed for each meeting.”</p>

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	Transparency	<p>“Patients need transparency from the board. Communication of board activities is important.”</p> <p>“Could we get anything like a summary of board actions or decisions?”</p>
	Ensure the patient representative connects with patients	<p>“A patient representative ideally presents a view that is germane and shared by patients in general.”</p>
Things patients want to know	How was the representative selected?	<p>“How is [the] Medicare patient selected? Any other qualifications?”</p> <p>“Board member selection process needs to be transparent.”</p>
	What are the representative’s qualifications?	<p>“What are the qualifications of this patient and how much this patient knows about all the medical problems.”</p> <p>“Is it a token patient? Is the patient bright? Are they paid?”</p> <p>“Having one patient is good, but who is this patient? What influence does he/she have on the board?”</p> <p>“What types of medical issues does the patient represent?”</p>
	What does the board do?	<p>“How does the board’s decision concern medical treatment I receive?”</p> <p>“How much influence power does the board have to effect change?”</p> <p>“It does not mean a lot to have a patient voice on the board, though at this point I’m not clear how what the board decides affects me.”</p>
	Who is on the board?	<p>“I would like more info on all board members.”</p> <p>“I am curious to know how board breaks down. How many doctors vs. practice leadership vs. health executives? If the dominance is the latter, I have less faith in board decisions.”</p>
	How can I connect with the representatives?	<p>“How would we communicate with our patient rep?”</p> <p>“How does the board get feedback from patients?”</p>

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		“A newsletter from the BAC might be interesting and useful and let the BAC members know that they are being recognized.”
	How is agenda decided?	“How is the meeting agenda selected / decided?”
	Are meetings open to the public?	“Are meetings open to public?”
	I would like more information in general	“More information is needed.”
Not coded		