

Turning Patient Questions into Research Projects: Creating Evidence that Matters to Patients

Patient Engagement Studio

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Background



- In order to generate research that has more relevance to patients, we “flipped” the research process by inviting patients to raise questions that matter to them.
- We used this approach with 2 groups of patients with diabetes.
- One could also use a hypothetical disease to demonstrate the method, i.e. unclear test results that might indicate a pancreatic disorder (Cioffi, 1994)

Question Generation Process

- Participants discuss what they “wonder” about based on their personal experience with diabetes
- Typical “wonderings” include:
 - Mysteries of Health: What has happened to me and why?
 - Mysteries of the Medical World: What are you going to do to me and why? Will it hurt?
 - Mysteries of the Future: When will I know the results of this test? What can I do to help myself? What will you do to help me?
 - 150 “wonderings” questions were framed using concept maps.
- Patients converted top questions using the PICOT model (Population, Intervention, Comparison, Outcome, and Timeframe)

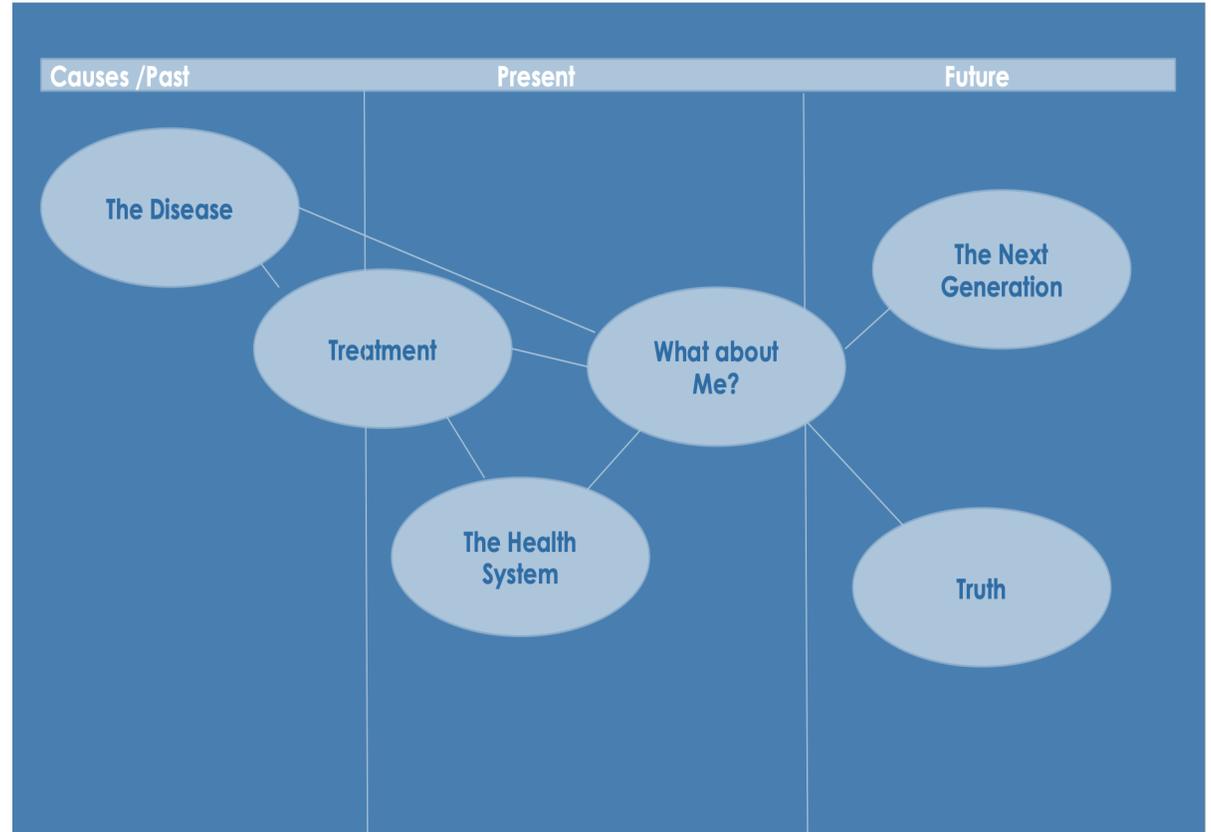


Figure. Concept Map of Patient “Wonderings”

Patients then cast votes with stickers and play money to rank order their questions.

Final Steps

Ranking of questions

QUESTION	Sticker vote	Cash distribution	Rank
Is diabetes reversible, giving hope?	17	\$42,500	1
Will education influence future consequences?	16	\$28,050	2
What is the relative genetic vs cultural contribution to disease?	12	\$24,960	3
What would be the impact of a multimedia campaign?	12	\$20,060	4
Do lifestyle discussions produce negative emotions?	8	\$13,370	5
How can physicians be better trained in communication?	7	\$9,000	6

Implementation strategies

- Patients “pitch” final ideas to researchers in seminar sessions
- Internal seed grant applications
- Interfacing with student-led projects
- Manual of all training materials available from the authors and as supplemental material
- Contact: wagnerpj@greenvillemed.sc.edu