

Session Two:

Medicines Matter to the Community

The greatest good for the greatest number of people at the lowest cost, versus “personalized healthcare” where the treatment may be based on an individual genetic profile. How does the community engage in advocacy for treatments that may treat a minority of patients but the benefits are far reaching or curative? What about ethical dilemmas?

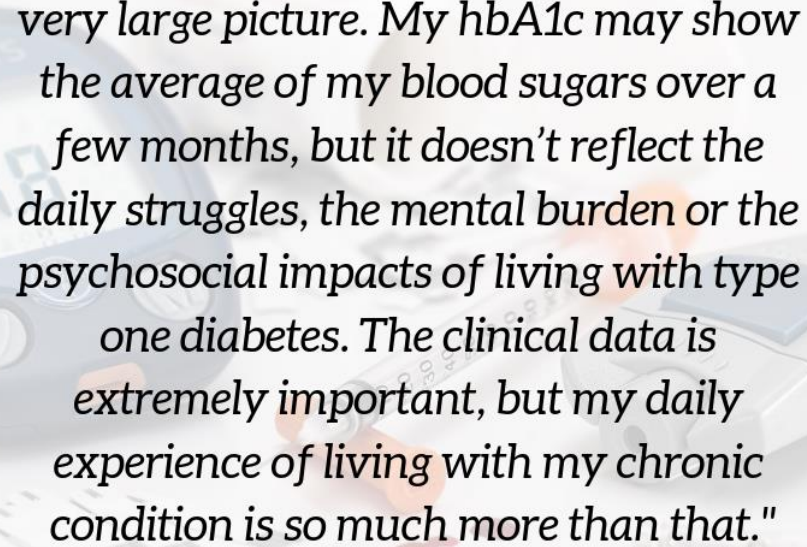
Ann Single / Jessica Bean

Joint Chair, Patient Voice Initiative

Having a voice in healthcare decision making

Living with my disease is not your expertise.



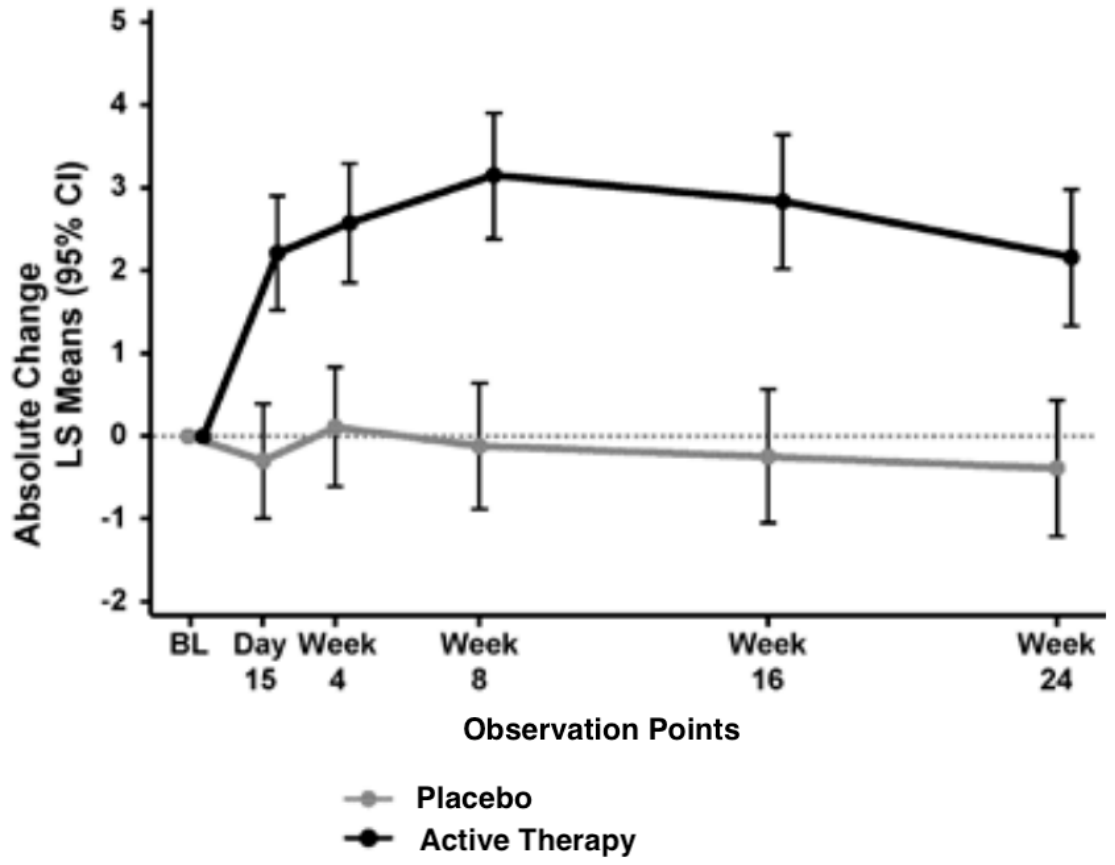


"The clinical data shows one part of a very large picture. My hbA1c may show the average of my blood sugars over a few months, but it doesn't reflect the daily struggles, the mental burden or the psychosocial impacts of living with type one diabetes. The clinical data is extremely important, but my daily experience of living with my chronic condition is so much more than that."

Rachel, T1 Diabetic Patient

Patient Voice Initiative

Pooled Data for Trials 1 and 2



In study data, efficacy of a medicine (in this case a genetic modulator therapy) using a traditional end point might look like this.

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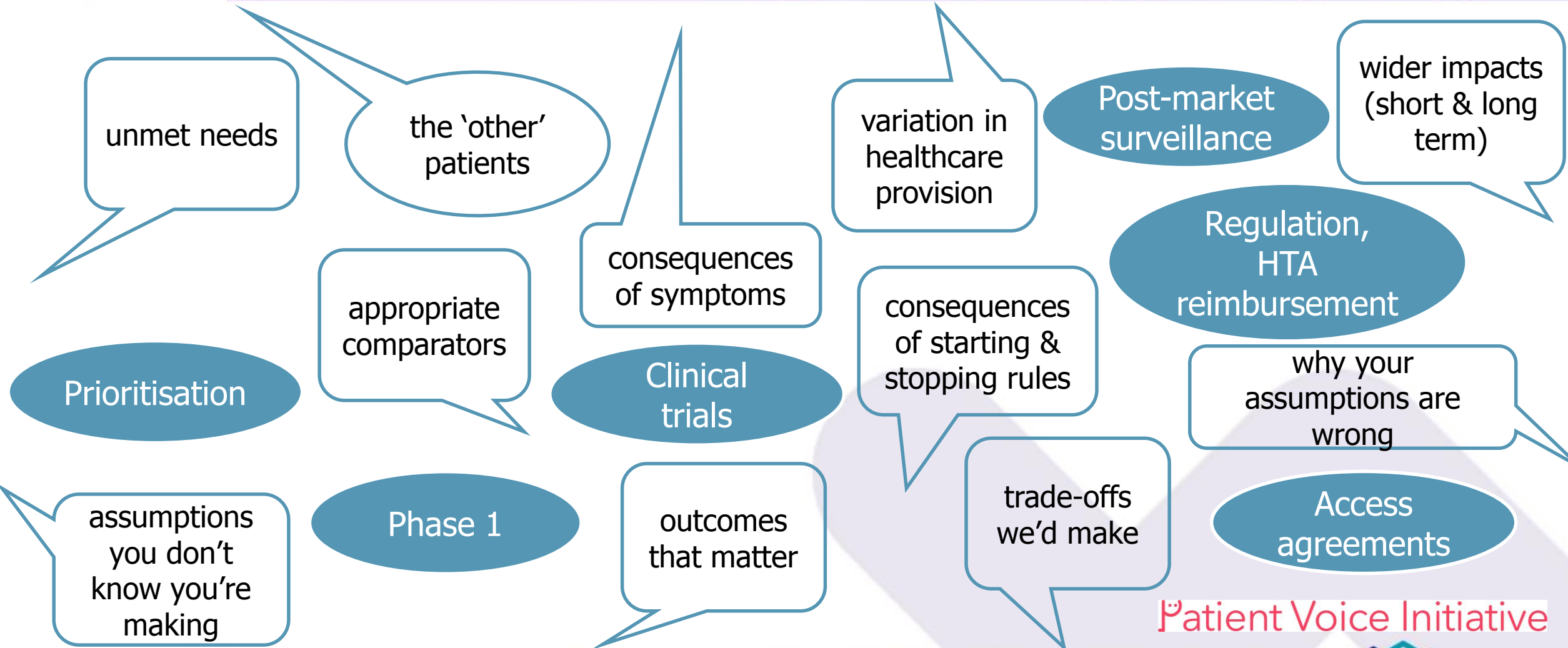
However patient input might demonstrate that impact of the medicine was actually this...

Without including patients in the conversation the complete picture may not be represented.



Before
treatment

After
treatment



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Building an engaged community takes time & a track record of success. Creating a dialogue that shares problems, identifies limitations & embraces innovative solutions is essential & requires courage.

Jonathan Q Tritter

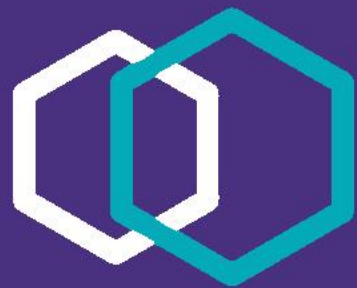
Revolution or evolution: The challenges of conceptualizing patient & public involvement in a consumerist world. *Health Expectations*, Sept 2009

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Presented by



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