

Health Equity: Access to Care

Working Group Leader	BMS Champion	GRYT Health Leader
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Participants' Affiliate Organizations



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Key Insights that Inspired Session 1 Conversation

- Access to Care is a complex issue that involves many factors, and “access” can mean different things to different people.
- We are going to expand our definition to include “availability” since this is an important consideration.
- Geography/transportation, technology, lack of qualified/appropriate care for specific diseases, lack of accessibility services (like closed captioning services and ASL interpreters), age, and culture are among the largest challenges people face in accessing care.

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What are the powerful stories?

- Re: online healthcare/telehealth - many of the patients are 75+ years old and the move to this style of medicine created anxiety for those who are less comfortable with the technology; A highlight that has come out of this was that grandkids paved the way, by setting up their grandparents with tablets and tutorials to help manage this
- Traditionally, access can be determined by your zip code, but telehealth removed that challenge for some; For others, barriers like not having access to broadband brought new challenges; Access opened in a new way, but also created different challenges
- Cost is something we don't talk about enough. For example, the cost of insulin can directly impact access to the people who need it, particularly in the US - there has been no resolution and work needs to be done here; There has been probably an unfair narrative on both sides of this issue but this should be discussed a bit more openly. **GOAL for this group:** the ongoing narrative can be more nuanced and fair to everyone - it's a complex issue and we need to be open in discussing the various perspectives.

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Powerful stories, continued:

- My insurance is top notch due to my wife's job so I had great care for my lumpectomy - it's easy for me and not for everybody; there are people who don't have the same access that I had
- Re: insurance - someone needed a CT scan and it would be about \$700 to do this with insurance and \$7,000 without insurance - that cost is insane, especially for that one procedure for people who don't have insurance
- Personal health experience - had a full slate of help, including state insurance - state decided they wouldn't cover his cardiac imaging for surgery the next day; He was "too young" to need this, so it was considered "experimental" and not covered; \$10,000 for it - even with all of the privileges, he couldn't have the scan because he couldn't write that check the day
- Transportation can be a large barrier - some people need to take a 4-hour trip to get a basic test - this isn't possible for a lot of people who have jobs; those who rely on others for transportation to appointments are impacted by this as well; for some kinds of care, the gender of the provider can make a difference

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Powerful stories, continued:

- Mother was misdiagnosed by several doctors and for the final meeting for diagnosis, was only given 15 minutes, allowed 3 questions and told that the session couldn't be recorded or have a caregiver relative call in to listen; Patient went for another opinion where they received a different stage diagnosis and went on to become cancer-free, because they were persuaded not to take the initial doctor's word for it. "How dare you question the doctor?" was a common theme among older patients in our group discussion.
- **The doctor is deity.**
- Friend was diagnosed with stage 4 lung cancer as a young nonsmoker. Since she was "young and healthy" she was unable to get the screening necessary to have found it earlier. She also did not know to immediately ask for biomarker testing - she was on a number of treatments before realizing she had a particular mutation that would not respond to those...she passed away after less than a year and I always wonder if she could've had more time.

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Other concerns:

- Navigating the system can be so difficult. Even for covered care with great insurance, the obstacles to find the right provider and then have the “right” services covered can be overwhelming.
- Fear can play into self-advocacy. These stories highlight a lack of trust, and without trust, how do you develop care? **This connects with Sheila’s group: “I trust who I trust, even if they’re not the expert.”**
- Quality of life decisions are relegated to staff who don’t get the training or support; Social workers, nurses, etc. who don’t have the experience or time to handle things appropriately
- These are systemic issues that have existed for so long and are largely driven by benign neglect

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Our Working Group's Goal:

- We need to move from benign neglect to intentional wellness in thinking about those practices
- This is where we're trying to get. By documenting this, we can look for what those key points are and look for solutions. We are fortunate to have a lot of different organizations represented and can use this to find ideas, exert influence in areas like professional standards of care, who our organizational partners are and changing the way practice takes place.
- With CAE, we can't solve all of these things, but we can move the metrics on a few of them - develop accountability standards

Join Us for the Next Working Group Session

Thursday, March 11, 2021
12:00 - 1:30pm ET