Patient Advisors and PEOs – 1pm-2pm

Discussion topic – Pilot Awardees

- Big picture reactions – global responses
  - Exciting studies
  - Educational poster walk
  - Several seemed to be leading to guidelines which makes us wonder about dissemination and implementation with clinicians – these should also be provided to patients
  - Challenging protocols
  - Patient education and advocacy
  - All seemed concerned that they didn’t have the complete data needed for their studies to answer their questions – is the big data precise enough? Sufficiency and integrity
  - Different levels of thinking about engaging patients as things came out – how could patients be engaged after the study regarding interpreting results etc.
    - Many people seemed open to improving this, but their studies did not start with this and their methods did not seem to find this as important (was an afterthought)
    - Not enough patient engagement in any of them
  - Why aren’t we asking patients what they want them to research?
    - In what patients want to research, what do they want to know in these categories?
    - Patients need to know about the results of their particular participation results even if the doctors do not find it significant to share
      - This creates lack of trust
      - Isn’t this an ethics issue? Not everything detected is shared with patients
      - Patients are also not often informed about the causes of their medical issues, and this is very important information to them
  - There is an imbalance between system efficiency and patient burden
    - We can save money if we are efficient, but it could be a greater burden on the patient. This could drive dissatisfaction even though it is better from a systems perspective.
    - We need to think about protocols as they affect patients and caregivers?
    - All but one study did not mention compensation to patients for the imposed burdens, inconvenience and participation
  - At least one study seemed very open to accepting advice from patients on ways to increase their engagement even though they did not have much in their original plan
  - Life circumstances should be considered when determining patient care methods
    - Great burdens that can be eliminated should not be imposed if at all possible – example of a patient having to travel 6 hours total for a chemo treatment rather than taking it at home, but patients who can come in should be able to due to the significance of the treatment.
Some pilot awardees were very happy about the pilot program because it was open to researchers much less further along in their careers, and this is good too because we can open them up to the idea of lots of patient engagement right from the beginning.

- It did not appear that many surveys included questions developed by patients.

Some pilot awardees seemed to think surveys were the only way to engage patients, but after discussion with our group they were surprised to hear many other ways in which patients can be involved in the research process.

- Are there resources out there for researchers to learn patient engagement? The patient advisors and patient engagement officers have the duty of providing these resources and learning.
- One pilot awardee connected with the patients and engagement officers at their sites to get suggestions for leveraging engagement strategies in their projects – she received a lot of feedback which she implemented into her plan and poster.
- Other applicants formed entire plans and then asked about how to answer the engagement question on the application – this seemed to say that they did not plan to include patient engagement in the way that is preferable and productive. These individuals did not receive awards.
- Many researchers act like they do not have time to involve patient engagement.
  - This attitude is changing as many grants now require this to be a factor in grant applications – NIH is included in this category.

Some researchers believe that using patient data counts as patient engagement, but this is not the case.

- When we see this we need to offer that the researcher can meet with a group of patients to go over ideas for engagement.
- Information on increasing engagement is often positively received because a patient voice will add great value to results.

Many researchers did not even reach out to engagement groups for feedback on their projects, however there did not appear to be a lot of researchers who were aware of these groups on their campuses.

Researchers only see the scientific side of things, but meeting face to face with patients can lead to a great improvement in their consideration of the patient side of things too – data itself is not a good reflection of the entire experience.

- Many researchers also do not understand the information given to them by patients on ways to improve their engagement.

**Pilot Program Awardees – specific feedback**

- Neena Sharma
  - Prior use of opioid question stuck with her.
  - Did not originally before meeting with Kim and Cheryl understand why patients would be interested in participating in data studies – however, after this meeting she was eager to engage patients and was very open to feedback on methods to improve the engagement.
  - Also did not originally understand why patients would be interested in results, but had a much better understanding after this meeting.
Noted that there are no effective guidelines on when people should go home and thought this might be a good area to create best practices for these issues as it is a very important issues to patients.

She was very interested in how to use patient engagement in research to improve clinical care.

She is making great improvements in her understanding and incorporation of engagement – very exciting.

- Julie Panepinto
  - There is a chemotherapy drug that can be very effective for sickle cell anemia that many patients and clinicians are not aware of.
  - Many African Americans have not had positive experiences with healthcare and engagement from this population could provide great insight into how this can be improved – this is a vulnerable population.
  - Patients often feel like clinicians are annoyed with the amount of information they are provided with by the patient, and tend to lean towards believe that patients are drug seeking rather than having a legitimate need.
  - Still trying to figure out if we even have the data in the GPC she needs to answer her research question.
  - Sometimes generic prescriptions are not prescribed and patients are not aware of them, so they end up being prescribed medications that are unaffordable – addressing this could be a great improvement for care in sickle cell patients who are often prescribed very expensive medications.
  - Pharma pushing different medications causes a lot of distrust among patients.
  - Opioid treatments are often used by sickle cell patients due to the great pain.
  - Internal audits and understanding why their site isn’t the best performer could be very valuable.
  - Including pharmacists in these conversations could also be valuable.
  - Patients employed by institution and research team may not be the best choice for engagement in these studies.

- Mary Schroeder
  - There are 5 studies within this pilot on breast cancer – too ambitious.
  - Sometimes patients are offered therapy before any surgery
    - Is this offered to everyone or just to a specific subset?
    - Is this based on your diagnosis? Whether or not you want chemotherapy or surgery?
  - Concern was thinking that the majority of her search should be getting data sources to communicate with one another, and patient outcomes was secondary to getting data set put together.
  - Unclear where patients were being engaged – just the survey it sounded like, and surveys do not equal engagement, although it is better than nothing.
  - No jargon was used and things were explained well so this was a positive.

- Bradley Brimhall
  - Looking at clinical tests that shouldn’t be happening.
• Didn’t see much room for patient engagement and design did not include any – neither did he
• In the midst of discussion, he seemed to begin understanding the value of engagement more than he did previously
• Seemed to be just a way to determine how money can be saved
• Patients often have to do multiple tests that are identical for different doctors who all order the same thing, and this is fraudulent and is very redundant inconvenient for patients
  • We need to be looking at duplicity of test ordering – patients need to be aware of the frequency of this happening
  • Tests are often also ordered that are expensive and have no value when cheaper and more valuable methods are available
• We need to do more work with this researcher
• There is a disconnect between what physicians want and what is redundant according to insurance companies since the tests have already been done recently