Engaging Patients to Support Prevention Efforts

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Projects meant to help patients that engage those patients as partners (advisors, developers, evaluators) is more relevant and useful.

PCORI (largest public research funder focused on comparative effectiveness research) requires the inclusion of patients throughout the research process → scientifically sound and grounded work.

The disability community reminds us that every policy that will affect a particular group of people should be created with the express participation/leadership of a member of that community.
The American Trauma Society

Educating... Advocating

The Trauma Survivors Network (TSN) is a program developed by the ATS that is designed to fill a critically important gap in the services now available to trauma patients and their families.
Mission: To support trauma survivors and their families through recovery by helping them connect and rebuild their lives after serious injury

**for Survivors**
- Connect with experts and other survivors
- Share experiences

**for Friends & Family**
- Learn what to expect throughout recovery
- Use resources for support

**for Trauma Centers**
- Partner with American Trauma Society as a TSN member
- Help patients through recovery
Patient Engagement at Inova

- **TSN (then “Rebuild”) 1995 - 2017**
  - Peer visiting, Community Education & Outreach

- **Research participation**
  - Community Advisory Board
  - Care team members on PTSD treatment research project

- **Resident training**
  - Practice patients & communication feedback
I’m a trauma survivor

• 24 Aug 2014 – riding on a bicycle path in Northern Virginia…
• I hit 2 trees … found unconscious by a good Samaritan
• EMT arrived taking control of the situation
  • Possible TBI on the scene when I became conscious
  • Transported to the Inova TICU
• Astute EMT who suspected TBI: calmed me and kept me focused
• Inova treated me for SDH, 2 brain bleeds, multiple contusions and broken bones
Recovery

- 5 month physical recovery; 2 year speech therapy and cognitive exercises
- PTSD: claustrophobia, audio sensitivity
- LCSW therapy for meditation and EMDR therapy
TSN engagement

- Cautiously evaluated TSN before becoming an active member
- Approached TSN as a way to help others in ICU; the benefits to me were unexpected

The ROI from this work:

- **Community Panel Presentations** - EMT/FD trainees, nursing/medical college student classes, medical adult education programs, aspiring students in high school magnate centers
- **Resident Communication Training** – role play patient-doctor discussions to improve patient communication skills for surgical residents
- **Peer Visitation** – meet bi weekly at Inova and visit patients at bedside to listen and share trauma experiences
- **Group Support Meetings** - to share life experiences with fellow TSN survivors
Engaging Survivors in Injury Prevention Work

- Current Examples
- Possible Options
- Getting Started