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Parent and Teen Engagement in Pediatric Health Services Research Training

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Background

There is increasing appreciation of the contribution patients and families can make in designing, conducting, analyzing, and interpreting clinical and health services research that is focused on optimizing care and outcomes.^{1,2} However, enduring culture change, such as that envisioned by the Patient Centered Outcomes Research Institute (PCORI),^{3–6} will require researchers who both understand the need for patient engagement and are trained in the methods for achieving it. Research training programs can play an important role in helping move the field toward authentic partnership among mentors, trainees, and patients.

The Harvard-wide Pediatric Health Services Research (HSR) Fellowship Program is a multidisciplinary program that has trained child health researchers for over 20 years. In 2013, we set out to engage patients and families in the redesign of our research training activities.

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The sponsors of this work have had no input into the design, analysis, or reporting of results.

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Educational Approach and Innovation

The HSR Fellowship Program is based at Boston Children's Hospital, with partner sites at MassGeneral Hospital for Children, The Department of Population Medicine of Harvard Pilgrim Health Care Institute, and the Institute for Healthcare Improvement. The NRSA-funded Fellowship is a 2-year program with 10–12 trainees. It includes: formal coursework; individualized mentorship; and, a weekly, 3-hour seminar series, including frequent “works-in-progress” (WIP) sessions.

Leaders of the Boston Children's Hospital Family Advisory Council and Teen Advisory Committee facilitated introductions to three parents and two teens, who volunteered to participate as Advisors to the program. The parents were two mothers and one father; the two teens, both female, were a High School student and a College Freshman. Participation as Advisors was voluntary and no criteria for inclusion were set. Each Advisor committed to attend program orientation, a minimum of 4 WIP seminars, graduation and social events. Participation in WIP seminars was the most natural venue for Advisors' input into trainees' research projects. We also invited Advisors to join our Program Advisory Board, comprising senior faculty and health system leaders. Finally, we asked Advisors to serve as mentors to fellows on individual research projects when appropriate. We provided a small annual honorarium in recognition of time and travel costs, and parking vouchers to support attendance.

We obtained qualitative feedback on the impact of this program change through: regular discussions with Advisors including formal mid- and end-of year “check-ins”; meetings between fellows and the program's Associate Director; questions on the annual fellows' survey; and, additional questions to fellows and Advisors by email and phone. All advisors contributed to the preparation of this manuscript and three are co-authors.

Results

Illustrative reflections of fellows and Advisors are presented in Table 1.

Some fellows admitted to early skepticism about the value of parent and patient participation in WIPs, which was overcome as the year progressed. The Advisors challenged fellows to consider assumptions underlying their research priorities. Advisors also helped fellows consider practical and emotional barriers for parents and families that could undermine their research. They constructively challenged fellows on their use of medical and research terminology, pushing them to clarify concepts in accessible language. Advisors' input also directly altered fellows' research design – for example, based on Advisors' suggestions, one fellow added qualitative data collection to her research project on end of life care for children with complex chronic conditions. Without exception, fellows reported that Advisors' input served as reminder of the importance of their work –to make a difference to the health of children and families –and to motivate them in their research careers.

All of the Advisors noted respect, openness, and collaboration as hallmarks of their interactions with fellows and faculty. The Program's attention to small but crucial practical details –providing parking, consulting them on timing of sessions –reinforced that their

contribution was valued. They welcomed learning more about the complexities of designing and conducting rigorous research studies. While all Advisors had welcomed the opportunity to contribute to research, some feared it might be a “token” rather than real partnership. Instead, they found that their feedback was actively sought and had a genuine impact on fellows’ research. Advisors reported increased understanding of research, and confidence to contribute to similar partnerships. Lastly, Advisors recognized that their contribution to developing skills and attitudes in a new generation of clinician researchers could impact child health research more broadly.

Discussion and Next Steps

The benefits from including parents and teens in our program exceeded our expectations. Patients and parents of children with chronic illness came to understand how research informs the care they receive. The fellows, in turn, received invaluable advice on the development, design, and presentation of their research. It powerfully underscored the connection of their research to the problems that patients and families experience, and modeled how patients and families can be respectfully engaged in research.

While our initial experience was overwhelmingly positive, we also learned important lessons, including: the need for fellows to learn more about Advisors’ care experiences early on; and, the need to actively facilitate contact between fellows’ and Advisors on specific projects.

From this experience, we present the following recommendations for engaging patients and families in research training:

- Provide clear (written) expectations, with regular review and revision.
- Understand the desired personal outcomes for each participant helps to promote sustained engagement. Among our Advisors these included greater understanding of research methods; specific skill development; contributing to topics of interest.
- Make parent and teen Advisors integral to the life of the fellowship (including social events) to foster a feeling of partnership rather than of service.
- Recognize Advisors’ contribution, by providing stipends, reimbursement for costs and alternate ways to participate (web conference, phone etc.).
- Encourage Advisors to participate as mentors on particular projects. This requires additional commitment from both Advisors and trainees, but is a vital next step.

On the basis of this experience we view patient and family engagement in training as fundamental for building a cadre of researchers who have the will and expertise to partner with patients in research. The result will be patient-oriented research conducted over entire careers that family advisors during training will have helped to shape.

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What's New?

We successfully integrated parents and patients as collaborators in a pediatric health services research training program. Such approaches could be used by other training programs to help build national capacity for patient-engaged research.

Table

Qualitative observations of Fellows and Parent/Teen Advisors

Fellows
<p>Exceeded expectations:</p> <ul style="list-style-type: none"> I think I was skeptical at first, but it was soon clear that parents and teens offered great feedback. I don't think I fully bought into having all stakeholders involved in the development and initiation of research projects until I observed the insight of both the parents and teens. <p>Enhancing/altering the design and conduct of research:</p> <ul style="list-style-type: none"> For me, feedback received from the parent and teen advisory group ...shaped the research questions I was asking and in some cases altered the methods I was planning to use. They brought reality checks. For instance, telling me that I should not do my own interviews for my qualitative study because patients would always see me as an MD. <p>Changing presentation style:</p> <ul style="list-style-type: none"> Having families present when fellows gave scientific presentation helped us become more aware of presenting our research to families in a way that is understandable to them. This will be a useful consideration and skill as we embark on our research careers. <p>Increased motivation and awareness:</p> <ul style="list-style-type: none"> I feel very privileged that we had the opportunity to receive feedback from this group... They really had a way of recharging our efforts and motivating us to improve our research. The parent and teen advisory group ensures that our projects keep the patient and family center stage. As academics, we have a tendency to overthink our research. The parents and teens keep us focused on what is most important, the health of real children.
Parent and Teen Advisors
<p>Exceeded Expectations:</p> <ul style="list-style-type: none"> I thought I would be just sitting in on presentations and occasionally make comments that would be ignored or brushed off. It did not take long to realize I was wrong. I was quickly integrated into the group. The young researchers really want to hear what I have to say (parent). <p>Making a difference:</p> <ul style="list-style-type: none"> I suggested along with others that (a fellow's quantitative) project would be better as a qualitative research project. The next time she presented her project it was a qualitative project. It really showed the fellows take suggestions to heart (parent) I enjoyed giving feedback in WIPS. I think that being the patient gives you a different perspective on how patient care should be approached, so I felt my opinion on certain topics gave the fellows ideas of how to modify their research (teen) <p>Collaboration and respect:</p> <ul style="list-style-type: none"> The key component that, in my opinion, helped make this group so successful was the partnership between fellows/faculty and family advisors. As a parent, I was given all the information I needed to fully participate in the discussions, to provide input and to feel empowered to share ideas. Fellows and faculty were also encouraged to seek out our ideas and their WIP presentations were always thoughtful in considering family input (parent). <p>Personal learning:</p> <ul style="list-style-type: none"> I've learned a little about a lot of different research topics...I've also learned that I don't have to be a medical doctor or expert to influence research and progress in the medical world (parent). <p>Wider and long-term impacts:</p> <ul style="list-style-type: none"> I also gained a lot of confidence by being in an environment where I sometimes felt intimidated, but still felt welcomed, so I was encouraged to speak up (teen). It is so rewarding because we know that down the road, those doctors will translate their early experiences with parents/teens into more fruitful working experiences/relationships with their own patients/families. Ultimately, it's a way to positively impact future patients/families by promoting collaboration between clinicians and families NOW. That feels REALLY good! (parent)