Care research: The importance of philanthropy

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In this exclusive interview, Dr Benson from the Robert H. Lurie Comprehensive Cancer Center explores the importance of philanthropy and the power it has to drive innovation and collaboration, particularly in cancer research and patient care

Philanthropy driving innovation

Q: How does philanthropic funding specifically accelerate or enable early-stage research that might be considered too high-risk for traditional government or industry grants?

That is a good point because although there are some grants that support the study of very early, riskier types of research, more commonly a grant requires at least reasonably convincing preliminary data to support the next research step. This can be particularly challenging for early-career investigators because, in terms of risk, some grants want to ensure the investigator has a good chance of success. If you are a more senior investigator or have already successfully obtained grants and published completed projects, grant funding organisations might see you as a less risky investigator or research team to support.

This is where, for example, Northwestern has funds set aside, as do many institutions, to help support at least seed money for investigators. This is extremely important for early-career investigators and also for research that might be considered somewhat risky but is of interest to the institution. There are other organisations that can provide support; while they may not offer the full funding required for a project, they can provide seed money or supplementary funds to help get the research started and progress such that the research results will lead to successfully receiving subsequent grant support to expand upon initial findings for example. Often, individuals obtain this funding through their institution, or there may be foundations willing to offer this level of support.

Q: How can research institutions and philanthropic partners measure and communicate the impact that their donations have on patient outcomes and the public good?

I believe one thing we have learned, especially in the United Kingdom and the United States, with COVID and the current debates around vaccines and research in general, is the importance of trusting government organisations that are vital for public health, such as the Centers for Disease Control. These bodies conduct extensive monitoring, offer highly expert advice, and support research through grants. The key message is that the scientific community, including the medical profession, must find better ways to effectively communicate to the public to regain trust and confidence in public health and other scientific recommendations and reporting.

There has also been much discussion about science education that must be well integrated in our schools, starting with young children and continuing throughout children's progressive educational experience. We must reconsider how we teach and communicate to people about science because I believe there is significant scientific illiteracy worldwide, and certainly in the United States. This may be due to our education system, where, for example, children are not adequately exposed to the importance of science in our daily lives and what science has accomplished over the years, including the understanding of basic principles such as the scientific method. There should be a clear understanding that in science, you need to generate a hypothesis, develop a methodology, have a robust way to interpret results, and understand that many leads may be false, often with hypotheses being wrong or investigations generating data that will require additional research efforts to explain the findings. When results are not what might be expected, it is important to figure out why. Both in scientific education and public reporting, it is essential to explain scientific results or recommendations in language that conveys what question was asked, what the results showed, what the limitations were, and what can be done with the results, including next steps to try to answer additional questions.

I believe that with COVID, which was remarkable because all the prior years of research and technological development led to the rapid understanding of the virus and the creation of specific COVID vaccines, what emerged was that the public was not convinced, did not understand, and lost trust in the entire system. We must work to regain their trust. If we fail, it could impact philanthropy, as people may be hesitant to donate. Many individuals contribute relatively small amounts to organisations such as the American Red Cross and the American Cancer Society, but these sums accumulate and are significant. It is important that people feel confident to give even relatively small amounts of money in support of science.

Addressing funding disparities and collaboration

Q: Your research has examined the comparison of cancer burden and nonprofit organisation funding. Could you elaborate on the role philanthropy plays in addressing disparities in research funding across different cancer types and how this impacts patient populations with less prevalent malignancies?

This is another significant concern in the United States, where diversity, equity, and inclusion have become contentious topics. A key point here, especially in cancer medicine, is that we have learned from numerous publications that social drivers of health or social determinants of health can directly influence outcomes, including survivorship. One area of research that needs urgent acceleration, particularly in clinical research where we work with individuals and aim to discover and improve the efficacy of drugs, biologics, and various treatment combinations, is to start integrating these social drivers as components of collected data and analysis. If people lack transportation, have inadequate food, do not have strong support networks, or cannot afford their medications, it generally leads to poorer health outcomes for individuals. Moreover, in research settings, these factors can also directly impact the interpretation of results, including survival outcomes.

Where philanthropy is relevant here is because even people with very good insurance often require services that are not covered or are inadequately supported. These can include essential interventions such as those from social workers, particularly for individuals who require significant assistance, whether it be transportation, organising home care, or seeking help for medications. These interventions often demand considerable effort and time from the health care team and may involve pharmacists, social workers, or nurses, whose time and effort are often not reimbursed. Yet, for comprehensive cancer care, these services are extremely important and should be appropriately recognized and compensated.

I was part of a group that published a survey conducted across centres in the United States. It was very clear that, regarding comprehensive cancer care, many essential services are inadequately provided and, quite often, not funded, with many centres relying on philanthropy to provide non- reimbursed services. Relying on philanthropy presents its own problems. At Northwestern, we have a team dedicated to raising funds to support philanthropy, which helps fund various programmes, including research and patient care. However, in rural areas, or at so-called safety net hospitals – by definition serving a large Medicaid population, often with multiple disadvantages – or at small clinics or hospitals, the ability to secure philanthropic funding is significantly lower. To do so requires a dedicated structure and personnel to raise funds. If you operate on a tight budget, it is highly unlikely you will have the capacity to organise fundraising efforts for these supportive services.

I believe we should carefully consider what should be covered by insurance. You might argue that many of these services are essential because they directly impact patient outcomes and, thus, should be reimbursed. Adequate reimbursement for comprehensive cancer care including social services is a way we can address disparities. Currently, we often rely on other organizations such as not-for-profits to provide assistance to patients. One example is the Patient Advocate Foundation. They distribute millions of dollars annually for copay relief and also offer case management, which can take hours of time to assist people in navigating the healthcare system, managing financial stress, and connecting them to available resources.

Q: Looking ahead, what innovative funding models or partnerships between philanthropy, government, and academic centres are needed to sustain a robust pipeline of cancer research and rapidly move new discoveries to the bedside?

We have been fortunate in the United States that significant partnerships do exist, particularly at academic centres that receive significant government funding. In addition, through the US government-supported National Cancer Institute National Clinical Trials Network (NCI-NCTN) and the NCI Community Oncology Research Program (NCORP), community clinicians can also participate in research programs. I should emphasise that there are three main pillars of research. There is laboratory-based research, there is clinical research, which is my area, and there is also what we broadly refer to as cancer control or population research, which is a very wide field and, for example, includes prevention, screening, symptom management, patient-reported outcomes, cancer care delivery and issues related to financial burden. Our research enterprise has long depended upon a funding structure that incorporates separate but also integrated collaborative funding from industry, government, foundations and other not-for -profit groups such as advocacy organizations.

In fact, the way I connected with your group was through your reading of the recent publication on Philanthropy, Improving Cancer Care, and Oncology Research. In this report, we used the example of the Harold E. Eisenberg Foundation, which is a wonderful story because what I love about the Eisenberg Foundation is that they have three levels of groups involved in their philanthropic efforts. They have the more traditional board, but they also have what they call their Associates Board, consisting of younger career professionals, and additionally, they have children who raise a substantial amount of money. It's fantastic. These children visit Northwestern, where we give them tours, show them the laboratories, and introduce them to our tumour bank area – highlighting what we actually do in providing patient care and conducting cancer research. It's a valuable part of their science education and also showcases the elements of cancer research and how the dollars they raise support the research. These children are learning about philanthropy, a skill set and philosophy which we hope will encourage a lifelong commitment to philanthropy.

One of our current concerns is whether the government will significantly reduce funding for cancer control research. Components of this research involve making sure diverse populations are included in research proposals, not only in the area of cancer control but also cancer therapeutic clinical trials (which often incorporate cancer control issues such as patient-reported outcomes as well as laboratory correlates such as tumor molecular profiles). These research proposals are also addressing issues such as existing disparities and their impact on overall health, as well as studies in the area of implementation science. Important research strategies not only attempt to identify variables that can significantly affect health outcomes across populations, but also, once variables are identified, what implementation strategies are needed to improve outcomes.

Other advocacy groups play a critical role in providing resources for patients, fundraising, lobbying government agencies, supporting legislation to provide dollars for research, awarding research grants and supporting ongoing research. They are instrumental in providing both the patient and caregiver perspectives, which can influence both patient care and research strategies. They also train advocates to work within their communities to promote change, such as improving healthcare accessibility. Their focus is on systemic change in healthcare, which includes not only engaging with Parliament or the US Congress, but also developing white papers and collaborating with various organisations to ensure the patient voice is heard. Often, this voice is lacking and the advocacy groups intent is to fully involve patients as active partners in healthcare delivery as well as to support philanthropic efforts.

Translating science into policy and care

Q: As a major contributor to NCCN guidelines and a member of the NCCN Foundation Board, what is the connection between private philanthropic investment in research and the resulting evidence that informs national standards and improves the quality of clinical cancer care?

Well, research provides the evidence you need to best inform medical guidelines. As I previously mentioned, our research enterprise has long depended upon a funding structure that incorporates separate but also integrated collaborative funding from industry, government, foundations and other not-for -profit groups such as advocacy organizations. The results from this complex mix of research projects, which are presented at national/international meetings and published, provide the evidence reviewed by guideline groups to inform recommendations. One of the reasons guidelines are developed and adopted is to try to reduce variability in care, especially care that might be considered ineffective or even harmful to people. Guidelines can not only inform national standards but also worldwide patient care. For 30 years the National Comprehensive Cancer Network in the US (NCCN) has worked to establish the standard of cancer care worldwide with the goal to provide the best current evidence in real time to support treatment recommendations across all cancer types, reduce variability in cancer care and as a result, improve outcomes by defining and advancing quality, effective, equitable, and accessible cancer care and prevention so all people can live better lives. There have definitely been a number of articles examining concordance with guidelines and the improvement in overall care and outcomes strongly supporting the NCCN mission.

The operational structure of NCCN is designed to maintain independence from outside funding/influence by creating an absolute firewall around the development of the guidelines, which is entirely funded by the 33 member institutions' annual dues. This is crucial because, for example, the CMS, our Centre for Medicare and Medicaid Services, uses the NCCN compendium for reimbursement purposes, as do many insurers. There must be confidence that this is genuinely an independent effort, and it is. This effort is also voluntary. For instance, as a panel chair and NCCN board member, I am not paid; my participation is entirely voluntary. Each NCCN guideline (there are over 90 guidelines) is fully updated at least annually (and often with more frequent updates as needed), including annual review by each institution's other experts. These comments as well as all external comments that are sent to NCCN are viewed by the respective panel members during their panel annual review.

The NCCN Foundation does receive external funding from a variety of resources, including advocacy groups, industry, and other foundations that support the creation of patient treatment guidelines. Although the content is fully developed by NCCN and the panels, funding is needed for distribution. We believe this is an incredibly important effort so that laypeople can understand the treatment recommendations based on the best evidence and to help inform patient and family discussions with clinicians.

Philanthropy is important for the NCCN Foundation to support the Young Investigator Award programme, which helps young investigators finance their research efforts and who, as mentioned, often find it difficult to obtain grant funding as early-career investigators. There are other examples of opportunities for early career investigators such as the Winn Career Development Award designed to connect early-career, ethnically diverse young investigators with a mentor to develop their research agenda and secure funding. This serves as a great example of supporting young investigators by providing financial assistance, allowing them time to work on projects that they hope will eventually be successful and lead to further funding. It is important for institutions to provide protected time, especially for early career investigators, and these types of awards, as well as institutional commitment of resources and salary support, are essential for investigators to have the time over and above patient care responsibilities to conduct research, whether laboratory, clinical or health services research.
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