Community collaborations targeting breast cancer

Breast cancer affects millions of people around the world and innovative research is essential to end this disease. The state of California alone invests $15 million into various research projects each year, raising the important question — what is the best way to invest these precious resources? At the California Breast Cancer Research Program, this responsibility falls to its director – Dr Marion Kavanaugh-Lynch.

Dr Kavanaugh-Lynch and partners from Commonweal and the Orange County Asian and Pacific Islander Community Alliance are developing a programme to encourage members of the local community to engage in their own research projects. Approximately 70% of breast cancer cases could have an environmental cause and, with wide-ranging social disparities in outcomes, the more insight that communities can contribute, the better.

QUICKSTART
This innovative programme, known as QuickStart, delivers face-to-face, telephone-based, and online sessions for either established or newly formed partnerships. Throughout the programme, teams develop a research plan. This includes firstly, identifying the problem and formulating a research question; secondly, designing a research plan; and thirdly, developing a budget and writing a grant proposal.

All partnerships include a Community Co-Principal Investigator and an Academic Co-Principal Investigator. The Co-Principal Investigators share leadership on the research project and ensure an adequate representation of both community and academic perspectives. The Community Co-Principal Investigator represents a group within the community and should have the trust of their organisation, as well as the skills to communicate with all members of the research team and the broader community, who may be impacted by the research. The Academic Co-Principal Investigator must have allocated time for research. Their skill set and knowledge base should align as closely as possible to the research interests of the Community Co-Principal Investigator. The QuickStart programme allows for thorough development of the research question and helps partnerships discern where specific expertise is required.

Eligibility is largely unrestricted, provided participants are willing to commit to all aspects of the programme. The practicalities of taking part in the QuickStart programme are made evident to applicants in the brochures and application forms they receive. For those willing to undertake the commitment, including four days of face-to-face sessions, online weekly assignments, and telephone coaching, the benefits are huge. The three-month programme provides opportunities for both the academics and the community members involved. Academics can gain critical insights into the realities of breast cancer in specific communities, as well as improve their likelihood of receiving funding for a project, due to the demonstrably high level of stakeholder interest.

Likewise, community members can gain valuable research skills — improving the reputation of the organisation they represent and gathering data for their own campaigns. Both academics and communities increase their chance of creating actual long-term change to policy and practices.

COLLABORATIONS AND PARTNERSHIPS
The type of research created by partnerships in the QuickStart programme is community-based participatory research. The programme specifically focuses on the environmental causes of breast cancer and social disparities experienced by breast cancer sufferers.

It is hoped that successful completion and evaluation of this project will lead to an established method of delivering a curriculum of this nature to the public. Ultimately, it is expected that the partnerships that participated in the QuickStart
QuickStart has been described as “invaluable and career changing” and “an excellent combination of scientific content and team building exercises”.

In order to maximise the reach of the project, Dr Kavanaugh-Lynch has formed important partnerships with organisations to enable expansion of the opportunity to diverse cross sections of Californian communities. These partner organisations include Commonweal and the Orange County Asian and Pacific Islander Community Alliance (OCAPICA). Commonweal is a California-based non-profit health and environmental research institute which seeks to engage in activities to improve public health. Their activities span education, research and charitable work, with the impact of their programmes not only improving the health of individuals, but also enhancing the health of the global environment. OCAPICA works to benefit the health and wellbeing of Asian and Pacific Islanders living in Orange County, California. Their involvement in this project is testament to the importance of encouraging maximum diversity of groups benefitting from and contributing to the QuickStart programme. The project is supported by the National Cancer Institute of the National Institutes of Health. Previous programmes have resulted in successful research funding for more than half of their participants, and the range of topics studied has been diverse. Projects can be broad in their intended impact or can target a small and specific group of people. Examples of previous projects include an investigation into the effect of benzene exposure on air pollution, as well as a study encouraging teenage mothers to persist with breastfeeding to protect against future incidences of breast cancer. QuickStart has been described as “invaluable and career changing” and “an excellent combination of scientific content and team building exercises”.

Q&A
When developing the programme did you need to build in flexibility to accommodate the different cultures throughout California? Yes. We continually evaluate our progress and refine aspects of the programme so that community and academic organisations across California can participate. For example, we have shortened the schedule so that partnerships attend four days of in-person sessions (down from six). Also, we have revised our application process to provide technical support to organisations that are interested in participating but would like our support in finding a partner for the programme.

Research Objectives
QuickStart supports community-academic teams in conducting community based participatory research (CBPR) related to breast cancer. This is a rare opportunity to get technical assistance directly from a potential funder on a research proposal that the teams develop over the course of the programme. Participants build their partnerships and workshop a research idea through in-person and online sessions. QuickStart participants develop the expertise to collaboratively develop research questions, plans and grant proposals.

Collaborators
• Senaida Poole, PhD, Program Officer, Community Initiatives and Public Health Sciences, California Breast Cancer Research Program (CBCRP)
• Heather Sarantis, MS, Women’s Health Program Director, Commonweal
• Mary Anne Foo, MPH, Executive Director, Orange County Asian and Pacific Islander Community Alliance (OCAPICA)

Bio
Dr Kavanaugh-Lynch’s accomplishments include championing the role of advocates and survivors in the peer review process, developing a successful model for funding community-based participatory research and developing rigorous evaluations of the programme. In recent years, she led a national panel that developed research strategies to explore the role of environmental contaminants in breast cancer, breast cancer disparities, and prevention of breast cancer.

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What has the feedback from the academic Co-Principal Investigators been like? Have they had any surprises along the way? They have learned that forging productive partnerships and working collaboratively can be very time-consuming. But they have found that the rewards are profound. Their research theories come alive and transform lives.

Is there scope to tackle research questions about other diseases using a programme like QuickStart? This sort of research partnership can be used to tackle any disease that the community is concerned about.