



Dear Friend,

Did you see our campaign on October 12th?! We shared loud and proud that "Our Health Matters" on [Facebook](#), [Twitter](#), and [Instagram](#). You can still share this important message with your network. As the first long-term national health study of LGBTQ+ people today, we thought LGBTQ+ History month would be a great month to spread the word about the importance of adding LGBTQ+ stories to health research. Our health mattered then and our health matters now!

Speaking of adding LGBTQ+ stories to health research, our very own Ava Cecilia Snow, had been working for The PRIDE Study for a year before she realized she could join herself. "I had assumed that researchers were not allowed to contribute data to the study due to conflict of interest but when one of my mentors mentioned — he was a participant — I knew it was important for me to join." You can read more about her journey on [The PRIDE Study blog](#).

In other great news for health research, the *All of Us* program has more than 296,000 participants fully enrolled. Fully enrolled participants are those who have shared their health information with *All of Us*, including giving blood and urine or saliva samples. They are also opening in-person enrollment in some places. You can still join online at jonallotus.org/igtq.

I also want to share with you two publications that were published in the past two months. Anthony Pho published the first study where a large number of transgender and gender diverse (TGD) people were asked whether they had ever received the HPV shot. This was also the first time TGD people had been asked how easy it is for them to search the Internet for health information. The second study by Sachiko Ragosta is an analysis of words used by people of marginalized sexual orientations and/or gender identities to replace common sexual and reproductive health terms. These studies can help health professionals understand how *SGM* people are being reached and given information, and how to improve current practices.

We hope you enjoy the Fall Newsletter and join us for our [PRIDENet Cafe](#) on October 19 at 4pm PT. PRIDENet will be joined by ZAMI NOBLA (National Organization of Black Lesbians on Aging) for a cross-cutting conversation (held via Zoom) that centers the experiences of black sexual minority women who have survived breast cancer and discusses the advantages of building strong academic-community partnerships in cancer research.

Together in Pride,



Ana Rescate
Ana Rescate, MBA (she/her/ella)
Communications Specialist

You're Invited!
PRIDENet Cafe presents:

CLOSING THE GAP: A COMMUNITY CONVERSATION ON RACIAL DISPARITIES IN BREAST CANCER CARE

Tuesday, October 19, 2021
7:00pm EDT / 4:00pm PDT

October is Breast Cancer Awareness Month! Join PRIDENet and ZAMI NOBLA (National Organization of Black Lesbians on Aging) for a cross-cutting conversation that centers the experiences of black sexual minority women who have survived breast cancer and discusses the advantages of building strong academic-community partnerships in cancer research.

Register Online at: <https://bit.ly/3IGTMEa>

Speakers: Mary Anne Adams, MSW (ZAMI NOBLA Breast Cancer Educator), Lorraine T. Dean, PhD (Assistant Professor, Johns Hopkins University Public Health), Cynthia McKinney (Breast Cancer Educator), Karen Bailey (Breast Cancer Educator), and Mabel Bahall, MPH (Moderator, Community Engagement Specialist, PRIDENet).

Did you know that sexual minority women (eg. lesbian, gay, and bisexual women) have an elevated prevalence of breast cancer risk factors, yet are less likely to receive timely screening in comparison with heterosexual women? Additionally, although overall breast cancer mortality rates have declined, the death rate remains 40% higher in Black women than White women, and Black women younger than 50 years have a death rate twice that of White women. In observance of Breast Cancer Awareness Month, join PRIDENet and ZAMI NOBLA (National Organization of Black Lesbians on Aging) for a cross-cutting conversation (held via Zoom) that centers the experiences of black sexual minority women who have survived breast cancer and discusses the advantages of building strong academic-community partnerships in cancer research.

Register online at: <https://bit.ly/3IGTMEa>

New Blog!

The PRIDE Study from the Participant's Perspective



Ava Cecilia Snow

"Despite having worked with The PRIDE Study as an undergraduate research assistant for over a year, I had yet to join the study as a participant. I had assumed that researchers were not allowed to contribute data to the study due to conflict of interest but when one of my mentors mentioned — he was a participant — I knew it was important for me to join. Not only would it be a way to contribute more to LGBTQ+ health research but, going through the questionnaire as a participant would help me understand the data that we work with in The PRIDE Study from a fresh point of view."

[Read more](#)

New Publications!

The connection between using the Internet to search for health information and getting a shot to prevent human papillomavirus (HPV) infection among transgender and gender diverse (TGD) people



Anthony Pho, PhD, MPH, ANP-C

This was the first time a large number of TGD people were asked whether they had ever received the HPV shot. This was also the first time we asked TGD people how easy it is for them to search the Internet for health information.

[Read more: pridestudy.org/research](https://pridestudy.org/research)

From 'Shark-Week' to 'Mangina': An Analysis of Words Used by People of Marginalized Sexual Orientations and/or Gender Identities to Replace Common Sexual and Reproductive Health Terms



Sachiko Ragosta, Ibis Reproductive Health - Research Assistant

This was the first study, to our knowledge, to directly measure whether sexual and gender minority people use medical terms to talk about their sexual and reproductive health, and if not, what words they use.

[Read more: pridestudy.org/research](https://pridestudy.org/research)

In the News

Digital Strategies to Create Mutual Benefit for Researchers and Research Participants

"Another example of returning results is PRIDENet's longitudinal study of the physical, mental, and social health of LGBTQ+ adults called The PRIDE Study. To ensure that LGBTQ+ community members receive timely, accessible, and relevant information about research results, activities, and outputs, the team developed a suite of resources and tools including a set of dissemination standards and guidelines to which PRIDENet research teams must adhere. This content provides detailed instructions that ensure new research partners understand what is expected of them — such as providing community-facing descriptions of research. The standards and guidelines also describe what kind of support researchers can expect from the network — such as access to communications templates and guidance as well as the opportunity to receive feedback from the PRIDENet Participant Advisory Committee.

Notably, PRIDENet offers strict guidance related to communicating results back to participants. For example, the guidance states: "The most historically marginalized and underrepresented LGBTQ+ sub-communities receive tailored research results dissemination first [when feasible]." The network also requires research findings to be published in journals that are either 100 percent open access or offer an open access option. Finally, they also provide examples of how different types of audiences can expect to be engaged at each stage of the dissemination process.

PRIDENet's offerings provide value by ensuring research results are more accessible to the public, heightening visibility of LGBTQ+ communities' needs, priorities, and interests. Similar to ABOUT's work, these guidelines and requirements also create a robust and accessible feedback loop for the PRIDENet participant community. The public commitment to these standards also empowers participants and LGBTQ+ communities more broadly to hold PRIDENet accountable to its dissemination principles and guidelines."

[Read more](#)

(We've provided the entire section about PRIDENet above. To read the rest of the article, you may need to sign up with your email.)

Exhibit 1: Principles for returning value to research participants

	Participant-centered	Ensure the approaches will be valued from the perspective of the participants.
	Broadly Defined and Multi-focused	Value should be defined broadly, beyond the traditional approaches of financial incentives and provision of aggregate study findings. Because participants derive value differently, researchers should pursue multifaceted strategies that deliver value in multiple forms.
	Timely and Ongoing	Researchers should identify opportunities to deliver value close in time to the act of study participation and on an ongoing basis to maintain relationships with participants.
	Accessible	The method of value delivery should ensure all participants have access and can benefit.
	Effective	Researchers should seek to ensure that value delivered is, in fact, received by evaluating and measuring activities, outcomes, and impact.

Source: Analysis presented in conceptual framework.

All of Us by the Numbers

- More than 407,000 participants who have completed the consent process. **407,000+**
- More than 296,000 participants fully enrolled.* **296,000+**
- More than 650 research projects are using *All of Us* data. **650+**

*Fully enrolled participants are those who have shared their health information with *All of Us*, including giving blood and urine or saliva samples.

When the pandemic began, *All of Us* paused all in-person enrollment and other live events. We are just starting to open up again in places where it is safe. If your area hasn't started in-person enrollment yet, you can still sign up and participate online at jonallotus.org/igtq.



Community Partner Events



NAESM, Inc. is pleased to announce their 18th annual National African American MSM Leadership Conference on Health Disparities and Social Justice. The theme of the conference is "Our Lives Matter: Turning the Tide Together." They also have their call for abstracts open. Abstracts will be accepted as institutes, workshops, or poster presentations.

[Registration](#)

[Submit an abstract](#) by the November 30 deadline!

Fellowship opportunity!

[The C.F.I.B. Fellowship](#) begins each January at the National African American MSM Leadership Conference on Health Disparities and Social Justice where participants must attend specific workshops and institutes on leadership and professional development. Deadline: December 10th.

Meet a PRIDENet Ambassador



Rosaia Shepard grew up in Seattle's Colored District, where, as a student activist in the 1960s, she fought racism, sexism, sexual abuse, as well as sexual orientation discrimination. Over the decades, ableism and ageism were added to the list. Rosaia has held many management, advising, and consulting positions for various enterprises including the Internal Revenue Service, the University of Washington, and Deloitte. Recently retired in Metro Atlanta, she writes nonfiction and volunteers her time supporting Georgia political candidates who advance LGBTQ+ rights. Rosaia holds a B.A. in African American Studies and Literature from the University of Washington and an MBA from the University of Arizona.

Thank you Rosaia, for all your hard work and dedication!

OUR ONLINE COMMUNITY!

Become a part of our online community and learn about program updates, as well as what's happening in the community around the world.

Follow One, Follow All, Follow Today!

The PRIDE Study



All of Us LGBTQ+



In Case You Missed It - From our social media feed

- [Male' and 'female' labels should be left off birth certificates, says AMA in new recommendation](#)
- [Stanford researchers to improve LGBTQ+ health and representation](#)
- [When you join All of Us, you have the option to receive your #DNA results!](#)
- [Veterans dismissed under Don't Ask, Don't Tell can get free help changing their discharge status](#)



View more stories and images by joining our online community!

The PRIDE Study



All of Us LGBTQ+



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