



August 9, 2021

Dear PHCC Sites,

We are excited to share some anticipated improvements in the PHAR. To put this in context, we would like to briefly review the value of the PHAR, to introduce our new ancillary study policy, and to provide an update on the PHAR's future direction.

Where We've Been

The PHAR began enrolling patients from a few initial PHCCs in 2015. Growth has been exponential, as we've now surpassed 1700 patients enrolled from 59 PHCCs, and the PHAR has become the largest active longitudinal PH registry in the United States. While its value as a quality improvement tool for sites and its role in replacing the patient roster during reaccreditation visits have been apparent from the start, many other benefits have emerged during the past few years. Not only have there been many publications utilizing the PHAR in the past year, but most have involved a trainee or junior faculty member as the first author (see below "PHAR Publications" table). The PHAR is succeeding as a tool that not only helps advance new science and discovery within the field of PH, but also allows the next generation of providers to get their start and solidify their career choice as PH providers – how wonderful that a fellow from one institution can receive mentorship from not only their 'on site mentor,' but also from many other site directors that serve as coauthors. The collaboration, connectivity, and community that has developed among PHAR providers cannot be undervalued. With over 30 active research proposals, the PHAR is being used in ways that will make our patients proud to participate. These unique features of the PHAR will continue to set us apart from other PH registries.

What's Brand New?

We have initiated the first ancillary study involving the PHAR, focusing on the impact of coping on patients outcomes under Kate Courtright's approved proposal. This ancillary study is scheduled to continue through 2021. As we anticipate further ancillary studies in the future, we have developed an ancillary study policy for the PHAR. This policy is included as an attachment on this e-mail. We want to ensure that we are transparent with this policy and provide it to all sites. If you have any questions about the policy, please don't hesitate to e-mail daniel.grinnan@vcuhealth.org.

What Lies Ahead?

Since the first patient was enrolled in the PHAR, we've been well aware that the PHAR has not provided financial support for data entry. As the PHAR has grown, we have been very aware of the potential burden that this can place on sites. We have always emphasized the need to minimize additions to the PHAR, as even small changes can increase this burden. We have also worked hard to develop the infrastructure needed, such as the attached ancillary study policy, to allow funding for PHAR participating PHCC sites. While we cannot share details at this time, we are excited to announce that a



pathway allowing some funding to sites is anticipated! While funding will be modest, and this change will take some time to implement, we are excited about this important step.

We are looking forward to continuing this journey with each of you, and your feedback is always valued.

Best Regards,

PHAR Committees

PHAR Publications

<u>First Author</u>	<u>Senior Author</u>	<u>Subject of Publication</u>	<u>Journal</u>
Jeff Min https://doi.org/10.1513/AnnalsATS.202006-612OC	Nadine Al-Namaani	Obesity in PH	Annals ATS
Jeff Min DOI: 10.1164/rccm.202010-3967LE	Nadine Al-Namaani	Predicting QOL & hospitalization	AJRCCM
Jacqueline DesJardin DOI: 10.1016/j.healun.2020.05.005	Teresa DeMarco	Age Differences in PH	JHLT
Marissa Borgese DOI: 10.1183/13993003.00414-2020	Roham Zamanian	Emphasis-10 in PH	ERJ
Shoaib Fakhri DOI: 10.1177/2045894020964342	David Badesch	Altitude in PH	Pulm Circ
Nicholas Kolaitis https://doi.org/10.1016/j.healun.2019.01.499	Teresa DeMarco	Meth PAH vs. iPAH	Annals ATS