

# Health Services Research

Advancing the Science of Patient Preferences  
and Social Support Navigation



# Health Services Research at PAF

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*For more than two decades, PAF has provided financial and insurance navigation, social services support, direct financial support and educational services for millions of primarily low-income patients and caregivers experiencing distressing financial, employment, insurance coverage or household material hardships because of their health conditions and associated treatment. Through this work we have created and curated an extensive catalogue of resources, experience and expertise in designing and implementing projects as well as analyzing data to support our growing research and evaluation portfolio to promote the delivery of person-centered care.*

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## Research Interests and Agenda

*While trying to solve access and affordability issues for patients battling life-threatening and chronic illness, it is our goal to improve the patient experience by studying the patient journey, unmet needs, and the impact that systems and social support interventions have on patient health and wellbeing. Our focus areas are outlined below.*

### Case Management: Strengthening the Science of Patient Navigation

Knowing a patient's priorities and financial stressors while coping with a severe chronic illness is not enough. We also must align the supports and resources necessary to assist them in mitigating their concerns and minimizing the costs. The concept of "patient navigation" has been recognized consistently as an important aspect of providing quality care. With the escalating costs of care and associated impact of medical debt and distressing material hardships experienced by patients and families in more recent years, financial-focused navigation has emerged as an area of heightened interest and need in providing comprehensive care.

### Costs of Care: Financial Toxicity and Transparency

The inability to afford healthcare has a widespread effect on patients with chronic, debilitating, and life-threatening illnesses, notably impacting treatment decisions and outcomes. Patients with severe chronic illness struggle to afford needed medical care alongside daily financial obligations due to rising healthcare costs. This may be more pronounced in under-resourced communities, as well as in those individuals with barriers to seeking assistance to mitigate their financial distress.

### Social Determinants of Health: Economic and Social Care Impacts

Emphasis on social determinants of health (SDOH) and their impact on patient access and outcomes has increased over the past decade. For organizations whose goals are to assist patients in navigating the healthcare system, good management will entail not only provider knowledge of insurance plans, utilization management tools and out-of-pocket costs, but also knowledge of the specific environmental and other SDOH constraints placed on patient capacity to adhere to recommended treatment—as well as the presence and/or lack of community resources to meet those needs. Addressing SDOH to increase access and improve clinical outcomes requires a standardized, measurable, and integrated strategy. With the development of ICD-10 codes that identify a variety of SDOH, social needs and barriers PAF has the ability to utilize our robust issue and resolution service data to map and document SDOH needs and to provide data illustrating how these patients needs once identified can be met.

### Patient Centricity: Advancing the Science of Patient Preferences, Outcomes and Engagement

Patient engagement takes many forms. It encompasses patients being able to define and share their care goals, gather information to make informed choices, engage in shared decision making with providers, navigate the health and insurance systems, be proactive in their health and care, and expand their advocacy to advise the wider system or community. Success in any (or all) of these activities requires skilled communication, confidence, self-efficacy, and self-advocacy skills. All of these can be learned or strengthened through training and practice. There is anecdotal evidence to support that many components of patient navigation facilitate the development of these patient engagement skills that we know to be crucial, yet the impact of patient navigation on these aspects of patient engagement has yet to be robustly measured.

### Health Equity: Understanding the impact of Social Determinants of Health

Emphasis on social determinants of health (SDH) and their impact on patient outcomes has increased over the past decade. Yet health systems often lack staff capacity, infrastructure and resources to identify and address SDH concerns that affect clinical outcomes. As a result, non-profit organizations have emerged as critical partners in confronting these challenges -- linking patients and caregivers to resources and services that help meet their needs. Addressing SDH through person-centered assessment and referral can influence patients' ability to attain their full treatment potential while minimizing preventable suffering, financial distress, and wasteful spending. Consistent use of appropriate Z-codes aligned with SDH needs provides a tangible link for health professionals and organizations to collaboratively strengthen community-clinical linkages and optimize equitable identification and resolution of these key patient concerns.

## Our Data Sources

### Patient Network

Our patient network is geographically, racially and economically diverse— comprised of tens of thousands of people from across the US who each year seek various forms of assistance from PAF and have agreed to participate in other initiatives to improve patient access and care. Many of these patients and caregivers come from marginalized populations based on race, disease type, disability, geography, and socioeconomic status. Our unique patient population covers more than 600 different diagnoses, with cancer, HIV/AIDS, Hepatitis, and pulmonary conditions as our largest response groups. Most have insurance and nearly all are actively receiving treatment with low socio-economic status as the most common characteristic across our patient population. We serve patients whose voices are rarely heard, and research often overlooks. Our Patient Network provides insight into cohorts of individuals who struggle to access, utilize and thrive in our current healthcare environment

### Provider Network

Providers are a key stakeholder in both the work we do and the care our patient's experience. To capture their experience and perspective we developed a Provider Network from healthcare professionals that utilize our services. Our Provider network consists primarily of social support, financial navigation, billing, administrative and pharmacy staff. These medical professionals routinely support patients in their search for financial help and barriers to care and they routinely reach out to PAF as a solution.

### Social Needs Navigation Network

Our Navigator Network is comprised of professional as well as trained community navigators. It includes dozens of PAF case managers who work one-on-one with patients to resolve critical medical and non-medical barriers to care. The average tenure of PAF's case management staff is approximately 5 years and covers individuals with backgrounds in nursing, clinical billing, insurance appeal, and customer support and service. In addition, we have a broader network of community navigators engrained in predominantly minority, rural and other geographically defined regions where disease morbidity and mortality are high, and resources are limited.

## Studying Case Management as an Intervention

Consistent throughout its 25-year history, the mission of PAF is to help one patient at a time by providing highly skilled case management service and/or financial aid to resolve problems related to their ability to access care and overcome financial hurdles during the most vulnerable times of illness.

To better understand the impact of social support navigation or financial assistance, PAF can evaluate a subset of patients before and after they receive services from PAF to test various tools for measuring the efficacy of these interventions. PAF can measure changes over time in financial distress, quality of life, patient activation, health literacy, health care access and utilization as a result of navigation or financial support.

## Research Skills and Partnerships

*In addition to our internally led research and evaluation initiatives, we often partner with others on various aspects of their research projects. These project partnerships often leverage our patient and provider networks, case management interventions and/or our internal expertise. Below are a few ways we can support our partners through research activities.*

### Patient Centered Research and Survey Design

Our expertise in patient-centered research project design, especially as it relates to low-income and marginalized patient populations, makes PAF a sought-after research partner. We can leverage our Patient and Provider networks for direct data collection and/or utilize our case management services as a navigation intervention. We will collaborate with your organization to develop a patient-centered strategy to answer critical research questions. Our team has experience in qualitative and mixed methodologies, survey design, grant writing, data analysis and data visualizations.

### Patient Engagement

Research teams often find it challenging to sufficiently gather or incorporate the patient perspective when designing, developing or implementing protocols. PAF has expertise in engagement methodology as well as the logistical and patient recruitment resources required to successfully execute a patient engagement strategy. PAF can help enhance patient engagement and maximize the people-centeredness of projects. We can support the development of engagement protocols, share internal methodological and engagement expertise, and connect to the appropriate patient community to ensure meaningful engagement of vulnerable populations. We hold focus groups, recruit patient partners, build advisory groups, or deploy surveys to gather the patient perspective. We also can target a specific patient group(s) by a variety of factors including disease/condition and demographics.

### Addressing SDOH and Health Equity

PAF works directly daily with a diverse group of low-income and marginalized patients to understand and navigate their needs related to social determinants of health. Research often overlook or underrepresent those who are under served – and their voice provides important insight into the experience of individuals who struggle to access, utilize and thrive in our current healthcare environment. We can help design and implement a project that will adequately address social determinants of health and execute the project with a sensitivity of language, culture and community.

### Issue Framing & Dissemination

We can work with external organizations to create in-depth analyses of survey results, create case studies, infographics and patient stories that reflect the current state of patient challenges to access and affordability.

Study results can be disseminated through white papers, peer reviewed journals, media and other external communication activities. In conjunction with the team at National Patient Advocate Foundation (NPAF) data can be translated into op-ed articles, patient perspective pieces, policy and advocacy positions and/or briefs. We can assist in identifying opportunities at the state and federal level to help shape the future of health care access and reimbursement.

### Data Collection

#### Programmatic Data

Structured and unstructured information is routinely collected during service delivery and curated into standard reports by the data department. This programmatic data can be analyzed on its own or in tandem with survey data.

Demographics, issues, resolutions, and condition specific data can be matched to independently collected survey and/or evaluation data.

## Retrospective and Prospective Survey Data

To ensure that informed decisions around research and evaluation projects reflect what matters most to our patients, we conduct survey projects targeting issues or concerns that are observed in our current programmatic quantitative and qualitative data from our patient population. Cross-sectional retrospective studies allow PAF staff to formulate hypotheses about possible associations between an outcome of interest and patient demographics allowing the team to investigate potential relationships after service delivery. To capture patient perspectives prior to service delivery, data collection fields can be embedded into online intake forms or patient portal workflow to facilitate rapid research and evaluation initiatives.

## Qualitative Data

In addition to our large format data collection activities, PAF can conduct qualitative data collection activities such as focus groups, key informant interviews and town hall discussions. This data can be used to integrate the patient voice in the design and execution of research projects, inform program design and improvement, understand the patient perspective as it related to treatment and care, or as a data collection activity for an established research protocol.

## Existing Datasets

An extensive amount of structured and unstructured data is collected during case management services. In addition, we conduct surveys targeting issues or concerns that are observed in the data collected from our direct patient services. These surveys are used to ensure that our interventions, research and policy work reflect what matters most to patients.

Deidentified patient data can be used for both prep-to-research and research projects. Current datasets and survey tools have questions that address the following topics: financial distress and toxicity, patient preferences and care goals, communication, shared decision making, transportation, patient values, health literacy, system and person-level trust, patient experience, and social determinants of health. A complete list of research projects, domains and measures can be found in Appendix B and C.

## Our Team

*To support the work required to advance our research agenda, PAF has assembled a team with diverse expertise, complementary skillsets, and the capacity for exceptional thought leadership.*

### ***Alan Balch, PhD – CEO Patient Advocate Foundation, National Patient Advocate Foundation***

Advancing the science of navigation and the incorporation of the patients voices into research and policy, Dr. Balch is trained in the areas of social inquiry techniques including survey development, data collections and analysis and statistical inferences. Dr. Balch has nearly fifteen years of executive leadership in the non-profit sector with an emphasis on consensus-building and collaboration. He became the CEO of both PAF and NPAF in 2013. From 2006 – 2013, he served as the Vice President of the Preventive Health Partnership — a national health promotion collaboration between the American Cancer Society, American Diabetes Association, and American Heart Association. Prior to his work with the Preventive Health Partnership, Dr. Balch was the Executive Director of Friends of Cancer Research.

### ***Rebekah Angove, PhD – VP Evaluation & Patient Experience***

Drawing from her expertise in patient engagement, Dr. Angove is responsible for the design and management of PAF's comprehensive evaluation and patient experience program. In her role she helps PAF to identify patient needs, translate those needs to direct services and policy recommendations, and evaluate the impact of these programs and services on patients and the patient community. Her work includes the development of a research infrastructure to deploy validated screening tools, quality measures and patient reported outcome measures.

### ***Shonta Chambers, MSW – EVP Health Equity Initiatives & Community Engagement***

Leading the development and execution of strategic initiatives to expand PAF's approach to achieving health equity through grass roots community and national level partnerships. Initiatives are designed to link limited income communities to resources to abate financial, logistical and social access to care barriers. She brings to this role over 20 years of non-profit and public sector middle and senior level experience that spans public health, women's health and behavioral health.

### ***Kathleen Gallagher, MPH – Senior Director Health Services Research***

Serving as the quantitative research lead for Patient Advocate Foundation she is responsible for the design, implementation and analysis of prospective and retrospective survey initiatives to support operational, advocacy and policy programs. Prior research endeavors have focused on traditional and non-traditional underserved patient populations and the links between health access, service utilization and barriers to care. Her current research focus at PAF centers around financial toxicity, healthcare barriers and identifying unmet needs in low income chronically ill patients.

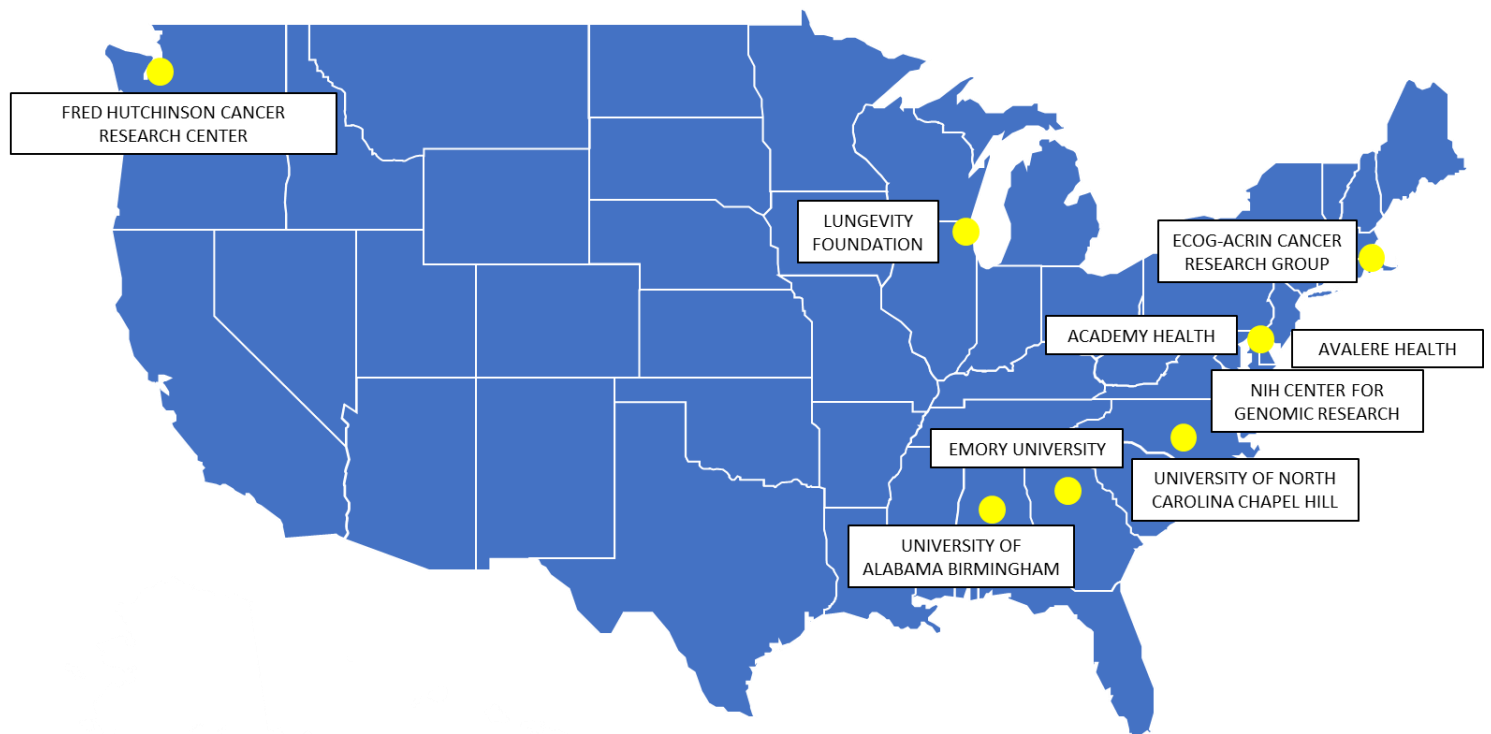
### ***Eric Anderson, BS – Director Research & Data Reporting***

Providing statistical support and database management to research and evaluation projects. Mr. Anderson has expertise in MS Excel, SQL, Tableau, R as well as other programming/database languages.

### ***Beth Hoer – Grants Administrator***

Developing grant applications to public, private and government-based requests for proposals, Ms. Hoer has over 10 years of experience writing and administering grant projects for patient advocate foundation. In conjunction with research and development staff, Ms. Hoer has successfully assisted PAF in acquiring grant funded aid from the CDC, RWJF, private donors and public foundations.

## Examples of Partnerships with Academic and Non-profit Organizations



**University of Alabama at Birmingham:** Joint submission with the University of Alabama at Birmingham to The Breast Cancer Research Foundation of Alabama’s Collaborative Breast Cancer Research Award for our project “*Quantifying breast cancer patient preferences and their association with financial toxicity during treatment decision-making*”. This research project offers an innovative solution to address financial toxicity in breast cancer care by going beyond the evaluation of financial outcomes to look at additional health and social concerns through an online survey initiative.

**University of North Carolina – Chapel Hill (UNC-CH):** This National Institutes of Health R01 application poses a unique opportunity for PAF to partner with academic researchers to address patient needs in underserved rural areas of North Carolina to address the growing problem of financial toxicity in cancer care.

**Emory University:** With funding from NCI/ECOG ACRIN in year 1 we plan to conduct a second pilot project with Emory University “Oral chemotherapy non-adherence in brain cancer patients: a randomized controlled feasibility trial”. This pilot project offers a unique opportunity for us to partner with researchers at Emory University through our partnership under the ECOG-ACRIN grant to address this growing problem in cancer care.

**Avalere Health:** PAF disseminated a modified version of the Patient Survey on Attitudes and Perspectives Surrounding Cost of Care (RWJF-Avalere) in May 2018 to collect responses from over 1,000 PAF Case Management, CPR and FAF patients. We are currently working with the team at Avalere to co-author a journal article highlighting our results.

**National Institutes of Health:** The purpose of this mixed-methods qualitative study “*Evaluating Underserved Populations’ Access to Genomic Medicine and Clinical Trials*” is to explore the barriers to genomic medicine and clinical trial enrollment of underserved patient populations. This study also aims to understand the case manager role as a key component to the connection between patients and adequate medical care, and how their position shapes their outlook on the healthcare field.



**Fred Hutch:** With funding from NCCN, we will partner to conduct a randomized “*Pragmatic Trial of a Proactive Financial Navigation Intervention in Patients with Newly Diagnosed Gastric and Gastroesophageal Junction (GEJ) Adenocarcinoma*”. Despite the growing financial burdens on patients, oncology clinics often lack the resources and expertise to help families proactively deal with financial issues. To address this hypothesis, PAF will participate in a prospective randomized trial in which 128 gastric and GEJ cancer patient caregiver dyads at the Fred Hutch cancer center will receive either three months of proactive financial navigation (PAF) or usual care.

**Academy Health:** With funding from PCORI, PAF partnered with Academy Health to serve as the PCORnet Coordinating Center for Person Centered Engagement to increase the capacity of patients, care partners, and community members to participate and guide PCORnet activities, while also ensuring that non-patient stakeholders work respectfully and productively with researchers, patients care partners, and community members.

## Glossary: Organization Abbreviation Descriptions

**Eastern Cooperative Oncology Group (ECOG) - American College of Radiology Imaging Network (ACRIN):** is a multidisciplinary, membership-based scientific organization that designs and conducts biomarker-driven cancer research involving adults who have or are at risk of developing cancer. The Group is dedicated to its stated purpose, which is to achieve research advances in all aspects of cancer care and thereby reduce the burden of cancer and improve the quality of life and survival in patients with cancer.

**National Cancer Institute (NCI):** is the federal government's principal agency for cancer research and training. As the leader of the cancer research enterprise, collectively known as the National Cancer Program, and the largest funder of cancer research in the world, NCI manages a broad range of research, training, and information dissemination activities that reach across the entire country, meeting the needs of all demographics—rich and poor, urban and rural, and all racial/ethnic populations.

**National Comprehensive Cancer Network (NCCN):** is a not-for-profit alliance of 30 leading cancer centers devoted to patient care, research, and education. NCCN is dedicated to improving and facilitating quality, effective, efficient, and accessible cancer care so patients can live better lives.

**Patient-Centered Outcomes Research Institute (PCORI):** was established to fund research that can help patients and those who care for them make better-informed decisions about the healthcare choices they face every day, guided by those who will use that information.

**Robert Wood Johnson Foundation (RWJF):** is the nation’s largest philanthropy dedicated solely to health. Their goal is to help raise the health of everyone in the United States to the level that a great nation deserves, by placing well-being at the center of every aspect of life.

## Appendix A: PAF Patient Characteristics

**TABLE 1: Demographic Breakouts for Survey Participants<sup>1</sup>**

GENDER		
	<i>Female</i>	53-58%
	<i>Male</i>	42 – 47%
ETHNICITY		
	<i>Hispanic</i>	7-8%
	<i>Non-Hispanic</i>	91-93%
	<i>Unknown</i>	0-1%
RACE		
	<i>African American</i>	13-18%
	<i>Asian</i>	3-7%
	<i>Caucasian</i>	69-76%
	<i>Other</i>	3-7%
AGE GROUP		
	<i>19 to 35</i>	4-5%
	<i>36 to 55</i>	26-29%
	<i>56 to 75</i>	54-61%
	<i>Over 75</i>	8-14%
EDUCATION LEVEL		
	<i>8<sup>th</sup> grade or less</i>	0-1%
	<i>Some high school</i>	2-3%
	<i>High school graduate/GED</i>	18-19%
	<i>Some college/2-year degree</i>	35-38%
	<i>College degree (4-year)</i>	20-26%
	<i>Post-graduate/professional degree</i>	17-21%
HOUSEHOLD INCOME		
	<i>&lt; \$24,000</i>	36-43%
	<i>\$24,000-\$47,999</i>	34-41%
	<i>\$48,000-\$71,999</i>	14-15%
	<i>\$72,000-\$95,999</i>	4-6%
	<i>\$96,000-\$119,999</i>	1-2%
	<i>&gt;\$120,000</i>	1%
HOUSEHOLD SIZE		
	<i>1</i>	39-45%
	<i>2</i>	39-44%
	<i>3 or more</i>	16-17%
LOCATION		
	<i>Rural</i>	20-14%
	<i>Urban/Suburban</i>	66-72%

<sup>1</sup> Demographics are representative of the population of patients served by Patient Advocate Foundation and are not representative of the United States as a whole.

**TABLE 2: Top Diagnosis Breakouts for Survey Participants<sup>2</sup>**

DIAGNOSES		
	<i>Cancer</i>	42-62%
	<i>Hepatitis</i>	5-8%
	<i>HIV/AIDS</i>	20-26%
	<i>Pulmonary Conditions</i>	6-10%
	<i>Other Chronic Diseases</i>	19-27%
CANCER BREAKOUT		
	<i>Breast</i>	49-53%
	<i>Myeloma</i>	16-19%
	<i>Prostate</i>	7-9%

<sup>2</sup> Diagnoses served may vary year to year as program and partnerships with other organizations may increase or decrease the number of patients with a certain chronic conditions.

## Appendix B: Previous Research Projects

The following are listed in chronological order starting with most recent and organized by general categories. Unless stated otherwise, all were conducted online using email invitations. There is a small set of standard questions we ask in almost every survey related to financial hardships and travel burdens as these are the two most common issues patients are facing when they contact PAF for assistance. Survey response rates vary depending on cohort selected (range is 50 – 3,500; Average cohort size is around 1,000). Respondents are consistently low income and racially/ethnically diverse across the different survey activities.

Year	Title: Description	Diagnosis	Response # (rate %)	Format	Partner
<b>RETROSPECTIVE SURVEY PROJECTS</b>					
2014	<p>Patient Satisfaction: <i>Designed by American Institute for Research (AIR) and Mayo with direct input from patients during the design process through focus groups, the Consumer-Based Cancer Care Value Index (CCCVI) is a validated survey that measures the importance patients place on the different aspects of their clinical care experience and also measures how often patients received care consistent with what the patient finds important. It also measures the utilization and availability for key support services. It was piloted and field tested in various clinical settings that included multiple cancer centers and thousands of patients. The survey has been fielded twice in the PAF population.</i></p>	Cancer	Wave 1: 293 (14.3%) Wave 2: 458 (17.6%)	Online	AIR and Mayo
2015	<p>Medical Expenses and their Impact on Health Care and Financial Health of Patients: <i>A comprehensive survey about treatment cost, financial toxicity, and how financial challenges impact patient care. Patients were selected for invitation to participate in the survey if they had received services from Patient Advocate Foundation's Case Management Division between January 1, 2014 and February 28, 2015 and had an email address in their case file.</i></p>	All diagnoses	Phase 1: 657 (9.4%) Phase 2: 223 (19.5%)	Online	Completed a sub-analysis as part of the ECOG-ACRIN NCORP grant
2015	<p>Transportation Needs Assessment Survey: <i>A data collection tool to gather targeted issue specific data on cancer patients facing the inability to travel to and from their medical treatment and compiled into a report titled: Transportation Needs Assessment and Financial Implications of the Cost to Travel to Care. The purpose of the needs assessment was to gather in-depth information about the means patients use for going to and from treatment, the barriers they experienced and reasons for transportation difficulties. The assessment was designed by the PAF Case Management Division in collaboration with the Data Management Division.</i></p>	Cancer	146 (48.6%)	Online	None
2015	<p>Copay Relief Patient Survey <i>Patient Advocate Foundation undertook an initiative to better understand the multiple factors that affect patients' needs for co-payment assistance. The survey collected targeted data on patient experiences with genomic testing and clinical trials, travel to and from care, health and well-being, cost of care, and medication access and adherence.</i></p>	All diagnoses	Wave 1: 463 (18%) Wave 2: 416 (13%)	Online	None

2016	Changes in Site of Cancer Care: <i>Designed in the wake of the proposed 340B demonstration project, the Site of Care Survey was administered to cancer patients with email addresses, who were served by PAF case management or approved by PAF Co-pay Relief between January 1, 2015 and June 20, 2016. The survey covered a range of topics dealing with diagnosis and treatment site selection, changes in site of care (both reasons for and impact of any changes) and patient perceptions on provider reimbursement in addition to general questions about travel and financial burdens associated with treatment.</i>	Cancer	1,349 (20.5%)	Online	None																
2016	Hepatitis C Patient Access and Cost Survey: <i>The survey collects data on current and recent treatment, access to care and utilization review, diagnosis and testing, current and previous treatment, cost of care, medication adherence, and travel to and from care, and stigma or discrimination experiences.</i>	Hepatitis C	159 (20.1%)	Online	None																
2016 and 2017	Value Survey Series: <i>Designed with emerging trends in precision medicine, person-centered care, and MACRA implementation in mind as well as the recent development of several prominent “value assessment” tools, this series is tied to our RWJF grant regarding consumer clarity in healthcare. It is a market research tool designed to provide insights into what patients self-reported experiences are and matters most to them regarding costs, benefits, and side effects as well as key decision-making processes. Each survey cohort received approximately 100 questions which contained universal themes (e.g. communication experience, financial impact) as well as target disease specific components (e.g. methods of treatment, medications).</i>	<table border="1"> <tr> <td>Multiple Myeloma</td> <td>196 (36.1%)</td> </tr> <tr> <td>HIV</td> <td>279 (29.1%)</td> </tr> <tr> <td>Hepatitis C</td> <td>225 (28.8%)</td> </tr> <tr> <td>Cardiovascular Disease</td> <td>42 (14%)</td> </tr> <tr> <td>Inflammatory Arthritis</td> <td>45 (16.9%)</td> </tr> <tr> <td>Breast Cancer</td> <td>510 (12%)</td> </tr> <tr> <td>Lung Cancer</td> <td>50 (7.4%)</td> </tr> <tr> <td>Prostate Cancer</td> <td>88 (14.3%)</td> </tr> </table>	Multiple Myeloma	196 (36.1%)	HIV	279 (29.1%)	Hepatitis C	225 (28.8%)	Cardiovascular Disease	42 (14%)	Inflammatory Arthritis	45 (16.9%)	Breast Cancer	510 (12%)	Lung Cancer	50 (7.4%)	Prostate Cancer	88 (14.3%)		Online	NPAF to support a white paper as part of a RWJF grant deliverable
Multiple Myeloma	196 (36.1%)																				
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2017	Consumer Clarity Patient Value Survey for Prostate Cancer: <i>Follow up to the value survey series, PAF partnered with five advocacy groups to refine the PAF value survey to create a shortened and modified version touching on many of the same themes.</i>	Prostate Cancer	946 (n/a)	Online, email, Facebook	Men’s Health Network, Prostate Conditions Education Council, Us Too International, Zero Prostate Cancer																
2017	Patient Priorities for Healthcare Coverage: <i>The purpose of this survey is to more fully understand and represent the patient’s experience with serious chronic illness and its related care, costs, and issues. In response to the renewed debate over health insurance coverage, this survey is intended to capture the experience and challenges of navigating the health insurance system so that PAF can express questions and concerns to decision-makers and the medical community.</i>	All diagnoses	1,328 (16.3%)	Online	NPAF																

2017	Securing the Safety Net- Evaluation of Programs Used by Low Income Patients to Address Financial/Economic Burdens: <i>This survey is intended to capture the patient perspective and experience with certain safety net, charity or social service programs that exist to help patients and families cope with distressing financial or material hardships that may interfere with their well-being (such as food, energy or housing security and transportation). Through this survey, we hope to understand which of these programs or services are most important to patients and their caregivers so we can better connect people to these resources, as well as better explain the need to preserve, expand and enhance these programs.</i>	All diagnoses	1,378 (15.5%)	Online	University of Alabama at Birmingham
2017	Multiple Myeloma Access Research Project: <i>The survey collected data on current and recent treatment, access to care and utilization review, treatment switching and step therapy, cost of care, medication adherence, and travel to and from care.</i>	Multiple Myeloma	84 (21.1%)	Online	None
2018	Treatment Preferences of Lung Cancer Patients and Caregivers: <i>With the emergence of new treatment options, the complexity of treatment decisions for people living with lung cancer has increased. The aim of this study was to elicit the preferences of people diagnosed with lung cancer and their caregivers for different attributes of treatments using a discrete choice experiment (DCE).</i>	Lung Cancer	31 (6.5%)	Online	LUNGevity
2018	Patient Survey on Attitudes and Perspectives Surrounding Cost of Care: <i>As the healthcare system increasingly shifts cost to patients, there exists a fundamental lack of understanding of how to really deliver, measure, and pay for care in ways that are truly co-created with low income patients in ways the incorporate what truly matters to them. PAF disseminated a modified version of the survey in May 2018.</i>	All diagnoses	1,468 (14.2%)	Online	Avalere Health
2019	Retrospective Survey - Collecting Baseline Measures to Evaluate PAF Satisfaction and Impact: <i>This cross-sectional study collected survey data from patients receiving services from PAF in 2018. Respondents answered questions describing their financial distress, root causes of financial toxicity (COST Tool), care planning, PROMIS Measures, Patient Activation (ACE Measure), use of Palliative Care, Unmet needs and Patient Satisfaction.</i>	All diagnoses	2,883 (21.5%)	Online	None
2019	Impact of Disease Diagnosis on Employment & Patient-Provider Trust: <i>The purpose of this survey was to ask patients about the impact of diagnosis on their ability to work as well as questions surrounding patient and provider trust. Question sets included insurance status at diagnosis, employment changes, treatment decisions and physician communication, employer response to diagnosis, care goals and trust in the healthcare system.</i>	All diagnoses	3,352 (25.8%)	Online	None
<b>PROGRAMMATIC SURVEY ACTIVITIES</b>					
2013	Pre and Post Marketplace Exchange Enrollment: <i>We conducted a pre-marketplace enrollment survey via phone administered to roughly 900 patients who called seeking assistance with marketplace enrollment from 10/1/13 to 3/31/14 for patients assisted with Marketplace/Exchange related issues.</i>	All diagnoses	Pre: 866 Post: 247: p (28.5%)	Phone	None

2019	Pre/Post Patient Activation and Financial Distress Screening Study: <i>To better understand (and support) the work our case management teams perform, we launched a 8-month evaluation study capturing metrics from a subset of PAF CM patients: COST score, Distress levels (NCCN) and Patient Activation Measures (PAM) captured at the beginning of their experience with PAF(Pre Test) and will then be reevaluated after their issue/concern has been resolved (Post Test).</i>	All diagnoses	Pre: 1,235 Post: 589	Online	None
2019	CoPay Client Experiences: <i>Questions embedded in our patient portals collected data on our clients' experiences with general and financial distress, barriers to access and adherence, quality of life, and trust in health care systems and providers.</i>	All diagnoses	3,930	Online, patient portal	None
<b>PROGRAMMATIC DATA PARTNERSHIPS</b>					
2015 Thru 2017	Development of a Financial Navigation Program for Patients with Advanced Cancer: <i>The purpose of this pilot study is to assess the feasibility of implementing the Consumer Education and Training Services educational course along with other components of a financial navigator program through the clinic and Patient Advocate Foundation (PAF) in patients newly diagnosed with cancer, and measure the impact of this intervention on out-of-pocket costs and incidence of financial hardship.</i>	Cancer	34 (n/a)	Recruitment by Fred Hutch, CM services by PAF	Fred Hutch
2017 and 2018	Measuring Outcomes of fiNancial counseling in brain canCEr study (MONEY)- a pilot: <i>The primary goal of this study is to test the feasibility of delivering a financial navigation intervention administered by The Patient Advocate Foundation (PAF, see below) to a cohort of newly diagnosed primary malignant brain cancer survivors. Eligible patients or their caregivers (if patients cognitively do not have the capacity to participate) will be consented to participate in the study undergoing the financial navigation intervention and complete surveys at baseline, 3 months, 6 months and 9 months to assess their financial status (including employment and insurance status, measures of financial distress and quality of life</i>	Brain Cancer	13 (n/a)	Recruitment at Emory, CM services by PAF	ECOG-ACRIN – Emory University
2018 and 2019	A Pilot Feasibility Study of a Proactive Financial Navigation Intervention in Newly Diagnosed Cancer Patients and Caregivers: <i>We conducted a single-arm pilot study with the primary goal of assessing feasibility of delivering the intervention. The financial counseling and navigation services were provided directly by PAF and CENTS, who serve distinct but complementary roles.</i>	Cancer - Metastatic solid tumor diagnosis	29 (n/a)	Recruitment by Fred Hutch, CM services by PAF	Fred Hutch
2019	Evaluating Underserved Populations' Access to Genomic Medicine and Clinical Trials: <i>The purpose of this mixed-methods qualitative study was to explore the barriers to genomic medicine and clinical trial enrollment of underserved patient populations. This study also aimed to understand the case manager role as a key component to the connection between patients and adequate medical care, and how their position shapes their outlook on the healthcare field.</i>	Cancer	300 (n/a)	Programmatic data review	NIH

## Appendix C: Dataset Domains and Measures

Standardized tools and measures<sup>3</sup>

<i>Domain</i>	<i>Tool/Measure</i>	<i>Data Available</i>
<i>Patient – Provider Trust</i>	Wake Forest Physician Trust Scale Physician CAPHS Health Plan Survey	N=2,913 N=2,865
<i>Patient Activation</i>	Altarum Consumer Engagement (ACE) Measure	N=4,001
<i>Health &amp; eHealth Literacy</i>	The eHealth Literacy Scale (eHEALS)	N=296
<i>Family Material Hardship</i>	PediCARE Survey Baseline tool modified for adult population	N=560
<i>Financial Toxicity</i>	COmprehensive Score for financial Toxicity (COST) tool	N=5,172
<i>General Distress</i>	NCCN Thermometer Problem List	N=7,396 N=937
<i>General Health/ Quality of Life</i>	PROMIS Scale v1.2- Mental PROMIS Scale v1.2- Physical	N=4,420 N=5,925
<i>Social Determinants of Health</i>	ICD-10 Z-codes Z55-Z65 mapped to PAF issue codes	n/a
<i>Work Impact from Diagnosis</i>	Work Productivity and Activity Impairment (WPAI) Questionnaire General Health V2.0	N=121

<sup>3</sup> Data counts/availability accurate as of 03/24/2020



## Appendix D: Select Conferences & Publications

### *Conference Presentations:*

1. B Barris, K Deehr, E Anderson, K Gallagher, S Chambers, A Balch. "Identifying financial toxicity and unmet needs in cancer patients receiving financial assistance: Exploring trends in under resourced populations to address healthcare barriers." Poster presented at ASCO Quality of Care Symposium. San Diego, CA. September 5-6, 2019.
2. K Gallagher, B Barris, E Anderson, K Deehr, S Chambers, C Williams, G Rocque, A Balch. "Navigating costs of care in women with breast cancer: Examining racial differences in non-treatment costs and financial toxicity in under-resourced populations struggling to afford medical care." Poster presented at ASCO Quality of Care Symposium. San Diego, CA. September 5-6, 2019.
3. K Gallagher, B Barris B, Chambers S, Angove R. "Establishing the Role of Nonprofit Organizations in Assisting Cancer Patients with Addressing Social Determinants of Health in an Era of Big Data" Poster presented at National Cancer Policy Forum. Washington DC. October 28, 2019.
4. K Gallagher, A Richardson, R Angove. "Identifying the Role of Nonprofit Patient Navigation Services in Assisting Nurses with Addressing Social Determinant of Health." Oral presentation at 32nd Annual Association of Nurses in AIDS Care (ANAC) Conference. Portland OR. November 5, 2019. [1 of 4 late breaking abstracts to be selected]
5. R Angove . "Effectively Engaging Patients in Quality Measurement" Facilitated workshop at the Physician Consortium for Performance Improvement (PCPI) Conference. Chicago, IL. November 2019.
6. R Angove. "Cost of Care and The Patient Experience" Keynote speaker at Next Generation Patient Experience (NGPX). Palm Springs, CA. December 2019
7. N Braccio, K Gallagher, P Jolley, D Ngo. "Advancing person-centered care: equipping pharmacists with knowledge to engage patients in cost of care conversations." Poster presented at American Society of Health Systems Pharmacy Midyear Clinical Meeting. Las Vegas, NV. December 13, 2019.

### *Publications:*

1. Shankaran V, Leahy T, Steelquist J, et al. Pilot Feasibility Study of an Oncology Financial Navigation Program. *J Oncol Pract.* 2018;14(2):e122-e129. doi:10.1200/JOP.2017.024927
2. Sadigh G, Gallagher K, Obenchain J, et al. Pilot Feasibility Study of an Oncology Financial Navigation Program in Brain Cancer Patients. *J Am Coll Radiol.* 2019;16(10):1420-1424. doi:10.1016/j.jacr.2019.07.014
3. Gallagher K, Richardson A, Angove R. Mitigating Financial Toxicity Through Cost of Care Conversations. *HIV Specialist*, March 2020.
4. Balch A. A Framework for Person-Centered Care Pathways in Oncology. *J Clin Pathways.* 2020;6(1):40-42. doi:10.25270/jcp.2020.2.00116