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# A human centered design approach: utilizing family voice to drive practice transformation in Boston medical center's pediatric practice of the future

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BOSTON UNIVERSITY  
SCHOOL OF MEDICINE

Thesis

**A HUMAN CENTERED DESIGN APPROACH: UTILIZING FAMILY VOICE  
TO DRIVE PRACTICE TRANSFORMATION IN BOSTON MEDICAL  
CENTER'S PEDIATRIC PRACTICE OF THE FUTURE**

by

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B.S., Tufts University, 2018

Submitted in partial fulfillment of the  
requirements for the degree of  
Master of Science

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Financial Distress/Financial Well-Being  
Scale on page 48 as indicated

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## **DEDICATION**

I am dedicating this work to my patient husband, Jean St Hilaire, my wonderful family of first-generation Haitian immigrants, and my friends. A special feeling of gratitude to my supportive and loving parents, Jean Marie Fegens Lynce and Marie Andree Lynce for their constant encouragement and dedication to providing me with access to the best education they could growing up. To my sister Myrria-Tahisha Andrelle Lyncee for being one of my top supporters on this journey to become a physician and anything else I set my heart to. I am also dedicating this thesis to my supportive colleagues at the Center for Urban Health and Healthy Family located in the Pediatrics Department of Boston Medical Center.

## **ACKNOWLEDGMENTS**

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**MYRNA-NAHISHA A. LYNCEE**

**ABSTRACT**

Pediatric primary care is the first line of defense when it comes to the health and wellbeing of a child. During the first few years of life, outside of the patient's family, primary care is the most consistent provision of care and developmental screening for families. To address the current needs of patients, The Center for the Urban Child, and Healthy Family at Boston Medical Center (BMC) developed a new model of care using Human Centered Design methods to promote an equitable health system. The main objective of this study is to explore ways to optimize care provided at BMC by utilizing family feedback and implementing changes accordingly in the care design for the Practice of the Future (POF) clinic. This quality improvement research data was used to analyze the core drivers of family well-being: economic wellbeing, school readiness, health equity, and integrated care. Additionally, qualitative feedback was elicited from families through surveys regarding the care they receive from the POF clinic. The results indicated that parents were overall satisfied with the care they receive and have few concerns about their encounters with providers and staff regarding racial and health equity and care integration. Many of our POF families have a higher prevalence of financial distress and low financial well-being compared to the national sample on the IFDW scale. We found different results using the CFPB scale. The POF clinic is building

systems to present the results to the families in a way that ensures that their priorities are at the center of the model and that their comments are leading to improvements to model of care.

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## LIST OF ABBREVIATIONS

AIM.....	Advanced Integrated Models
BMC.....	Boston Medical Center
BU.....	Boston University
CDC .....	Center for Disease Control
CFBP.....	Consumer Financial Protection Bureau
CHCS .....	Center for Health Care Strategies
HC.....	Haitian Creole
HCD.....	Human Centered Design
HRTL .....	Healthy and Ready to Learn
IFDFW .....	InCharge Financial Distress/Financial Well-Being Scale
JLA.....	Joslyn Levy & Associates
NSCH.....	National Survey of Children’s Health
PFW .....	Personal Finance Well-Being Scale
POF.....	Practice of the Future
SDOH.....	Social Determinants of Health
SES.....	Socioeconomic Status
SSDH .....	Social and Structural Determinants of Health
QI .....	Quality Improvement

## INTRODUCTION

Human Centered Design (HCD) is an interactive approach to healthcare that involves partnership between the medical team and the “end user” (the patient) (designkit.org). HCD design involves working alongside the end user to generate ideas, build prototypes, getting feedback from the user on the product/service provided and making the necessary changes. This approach’s goal is to make systems useful by shifting the focus on the user’s needs and requirements for the product or service provided. Using HCD methods, The Center for the Urban Child and Healthy Family at Boston Medical Center (BMC) Pediatrics worked alongside patient families to develop an innovative model of care. The new model of care, named the “Practice of the Future” (POF) clinic was co-designed with the end users, which in this case are the families who receive primary care at BMC Pediatrics, to create a comprehensive care system that put the needs of the families in the forefront of the delivery of care.

The POF model aims to promote an equitable health system by transforming the dynamic between family and care team based on holistic, family-driven, cumulative, intentional, and responsive care. After intensive research into patients and their families’ lives, understanding what they value as important to their own health and wellbeing, the pilot for the model of care was launched at BMC in January 2020. Social determinants of health (SDOH) are defined by the CDC as the conditions in which children are born, raised in, live, work attend school etc., “that affect a wide range of health and quality-of-life outcomes” (Chung, Siegel, Garg, Conroy, Gross, Long, Lewis, Osman, Messito, Wade, Yin, Cox and Fierman, 2016). SDOH includes but are not limited to family

structure, social and financial support, access to benefits and education, and access to food. To understand how families conceptualize and think about their own wellbeing, it is important that we look beyond physical wellbeing and consider social and cultural factors. Using HCD methods to understand BMC patient families' life, and their perspective on their own healthcare, we also found that priorities in health and wellbeing for some families included spiritual wellness. Understanding that "racism is a core social determinant of health that is a driver of health inequities" (Trent, Dooley, Douge, 2019), and hearing families bring concerns related to race and discrimination, the POF model also attempts to address these concerns. Given such significant differences in health outcomes related to racial inequalities and social factors, it is undeniably important to consider how this might affect the population of patients at BMC, more specifically the POF patient families.

The POF model was created to encompass the values of and provide families with a healthcare system that optimizes their wellbeing by integrating what they believe is important for their family's complex health and social needs. The guiding principles and drivers for this pilot is based on the HCD process and what we learned families believe their priorities are for their healthcare. From connecting with families through the HCD process, the POF clinic was developed with three key components including bi-generational well-being, support of parental self-efficacy and autonomy and to embed financial mobility into clinical practice. In addition to the principles of this model, the pilot focuses not only on physical and emotional health but also on how to meet needs of families related to the social determinants of health which include economic stability,

education, health, and wellbeing (Mallow et al 2015). Care in the POF clinic is organized into a delivery cycle that is created to optimize the relationship between the family and the care team and to put the family at the main drivers of their own care.

The goals of this thesis are to (1) assess family feedback on the POF clinic at BMC and the ways in which the clinic responds to the needs of patients according to their input in the design of the clinic model and (2) analyze quality improvement data and explore ways in which the data can be implemented into the practice. This thesis also explores the meaning of health and racial equity, social and structural determinants of health (SSDH), and the HCD methods used in designing the POF model of care.

### ***Socioeconomic Disparities effects on health outcomes***

Despite the detrimental effects that poor social environments, SES, and other factors can have on health, many clinics do not routinely address unmet SDOH and other psychological factors that impact patient's health systematically (Adler and Newman, 2002). Children living in poor conditions, abusive family dynamics, and living in poverty with lack of social and educational support are more susceptible to toxic stress and problems that will have a profound impact on their growth and development (Chung et. al, 2016). During the Human Centered Design research that was conducted with families before the launch of the POF clinic, families were asked about stressors and the obstacles in their life that keeps them from their idea of what it means to be healthy and many indicated housing, financial stress, lack of educational access and resources. Similarly, studies indicate that housing, neighborhood safety, socioeconomic and environmental factors, and access to healthcare impact physical health such as asthma, diabetes, obesity,

mental health and more (Walker, Williams, Egede. 2017). As a result of the HCD work we did to create the clinical program, the POF model addresses different factors of harmful stress that play into the health and wellbeing of patients and their families, through providing connections to resources for basic needs (e.g., food) and financial planning. We are also interested in evaluating the experience and health outcomes of the program because of implemented changes we are making.

### ***An Understanding of Healthy Equity and Education***

The effects of SDOH extend beyond health to education. It is also a well understood that early childhood education has a significant impact on adult outcomes in success (Walker, Williams, Egede, 2017). To measure the POF clinic's efforts in supporting families to prepare their school aged children for education, we administered the National Survey of Children's Health (NSCH) Healthy and Ready to Learn by Five Survey. Recognizing the importance of education as it relates to health, the goal of this survey is to assess whether the new model of care is having an overall positive effect on school-aged children regarding kindergarten readiness. As part of this thesis project, the clinic will assess the caregivers/parents' confidence in their child's social-emotional development, self-regulation, and early learning skills to assess how the clinic has supported them in their child's readiness for education.

## **THE PRESENT STUDY**

To ensure that the POF clinical model aligns with the HCD methods, which serves as the foundation of the model, it is imperative that evaluative measures are in place to gain feedback from the “end-users”, which in this case are the patient families. The data presented is part of a larger quality improvement (QI) project that Boston Medical Center (BMC) Pediatrics has undertaken in efforts to test whether this nuanced approach to healthcare is well-received by the Pediatric families. The primary objective of this study is to gain quantitative and qualitative information from parents to understand more about how they are receiving the care we provide in the POF clinic and how we can improve the delivery of care. The aim of this study is to assess the degree to which the POF model of care is aligns well with and is responsive to families’ stated goals and priorities, based on the HCD principles that have been used to design the model.

## METHODS

### *Patient Inclusion/Survey Procedure:*

Baseline for the Advancing Integrated Models (AIM) survey data collection was conducted last year though this thesis will focus on the year two data collection methods, data analysis and results. The first round of survey occurred December 2020-February 2021, were not used due to differences in measures used. For the second round of survey administration, which took place from February 2022-March 2022, in addition to having recruited more families in the clinic, since there was capacity to collect data from English, Spanish and Haitian Creole speaking families, more families were contacted to participate than the baseline. Research assistants used scripts for contacting families to ensure that all participants were provided with the same information upon enrollment. The original recruitment script used in 2021 has been translated to Haitian Creole (HC) and Spanish as well as modified to speak with families who have already completed the first round of the surveys. Altogether, there are 4 scripts that research assistants are using to contact families. Data collection was based on the quality improvement guidelines for survey administration and parents, or caregivers were informed of the survey content and purpose.

Ninety-seven families within the pilot were eligible for contact to complete the survey, which takes 20-30 minutes to complete, like the baseline survey. The protocol was to reach out to families three times before ceasing to contact and thereby excluding them from that year's survey collection. The primary survey components are detailed in Table 1. Families that participated in the baseline data collection were all given an

opportunity to participate in this second round (unless they unenrolled from the POF clinic). Participants were given the option to complete the surveys over the phone with a researcher or to fill it out on their own via a survey link generated using REDCap and were told that they were free to skip any questions they felt uncomfortable answering. All scripts used to enroll participants can be found in **Appendix 1**. Of the ninety-seven families that are eligible participants, 84 were contacted so far, demographics were collected for 37, and 36 families completed the survey. This research is ongoing; therefore, this thesis paper will cover results of the preliminary data for the 36 families that completed the survey in full.

Surveys were administered to POF families to capture their experience within the clinic. The QI data will be used to influence the quality of care in health systems so that it prioritizes the reduction of health disparities and moves towards a delivery of care that promotes health equity. The data collected will be analyzed, discussed, and eventually shared out to both the clinical staff and the families who are currently part of the POF clinic. All surveys were conducted according to the quality improvement guidelines for survey administration and demographic information was collected to ensure that all responses were correctly linked to corresponding participant data entry into REDCap database. The survey had 5 sections: Demographics (information on age, race, and ethnicity), Measures from the Center for Health Care Strategies (CHCS), the Consumer Financial Protection Bureau (CFPB) financial well-being scale, The Healthy and Ready to Learn by Five Survey (HRTL) from the National Survey of Children's Health (NSCH) and Personal Finance Well-Being Scale (PFW) also known as the InCharge Financial

Distress/Financial Well-Being Scale (IFDFW). Participating families were compensated \$25 for completing the survey.

***Measures:***

The CHCS works with state and federal agencies, health plans and providers to advance models of delivering health care services. The Advancing Integrating Models (AIM) Measures library was developed in partnership with CHCS, Joslyn Levy & Associates (JLA) and other experts to demonstrate how models are framed with the intention and impact of implementation through the perspective of patients and staff (Silverman et al. 2021). Measures from the CHCS measures library were used to assess caregivers' perspectives on the four construct areas : goals of and experience with care, health equity, well-being, and care integration. The survey includes eight questions regarding goals of and experience with care, five questions on racial and health equity, seven questions related to health and well-being, and six questions related to care integration. The measures were designed on a Likert Scale ranging from Strongly Disagree to Strongly Agree in addition to open-ended questions so that participants could further explain their thought about the POF clinic, including things they liked and issues they had. This questionnaire can be found in **Appendix 2**.

To measure whether the POF model of care addressed effectively financial wellbeing, previously mentioned as important to families, we utilized the Consumer Financial Protection Bureau (CFPB) Financial Well-being scale, which is a measure that investigates the relationship between financial knowledge and financial well-being (Lee Min, Lee, Tae Kim, 2020). Financial Well-being is defined as a state where someone (or

family) can meet current and ongoing financial obligations and feel secure in the future of their finances, which allows them to make choices that promotes enjoyment of life (Bureau of Consumer Financial Protection, n.d.). It is based on a consumer-driven definition of financial well-being that takes insights from consumers as well as financial practitioners. The CFPB was developed and tested to allow practitioners and researchers to quantify and observe the extent to which someone's financial situation and understanding of it provides them with feelings of security or distress (Bureau of Consumer Financial Protection, n.d.). We used the abbreviated 5-item version of the scale which was summarized according to validated CFBP scoring guidelines. We compared the findings from our baseline data as well as our most recent survey responses from our sample of adults ages 18-61 years to the scores for all adults ( $\geq 18$ ) in Massachusetts and the US for context. Survey and measures can be found in **Appendix 2**.

Parents and caregivers with children between ages of 3 and 5 years in the POF clinic were administered an additional survey to assess whether the new model of care has a positive effect on kindergarten readiness. The Healthy and Ready to Learn by 5 (HRTL) developed by the National Survey of Children's Health, is a nationally representative household survey that assesses the health and development of children between the ages of 3 to 5. The survey assesses four different domains in Self-Regulation, Social-Emotional Development, Early Learning Skills, and Physical Well-Being/Motor Development. Item responses were scored as "At-Risk" (0), "Needs Support" (1), and "On-Track" (2), considering the specific abilities amongst different ages between 3-5 years. This measure was included in the evaluation of the clinic as a

key outcome measure because of the POF clinic’s audacious goal to have all children served be healthy and ready to learn by 5.

The Healthy and Ready to Learn by Five measure includes questions that fall under the category of Early Learning Skills, Self-regulation, Social-Emotional Development, and Physical Well-Being and Motor Development. Our data on Physical Well-Being and Motor Development are not comparable to the HRTL measure due to differences in wording and are, therefore, not reported here. Since the original Healthy and Ready to Learn measure used in 2016, it has been updated to include an additional response in the category of “about half the time”, and due to our small sample size, we combined our results in that area with “about half the time” and “sometimes”, we were limited in ability to compare those result to national data. Survey and measures can be found in **Appendix 2**.

Table 1. Family Survey		
Variable Name	Source	Sample Item
<b>Goals of and Experience with Care</b>	CHCS Measures Library	“My care team and I regularly review my care plan, so it reflects my preferences and current circumstances.”
<b>Equity</b>	CHCS Measures Library	“I believe my care team feels comfortable around people who look like me and/or sound like me.”
<b>Health and Well-Being</b>	CHCS Measures Library	“The staff truly believe in me - that I can achieve my goals.”
<b>Care Integration</b>	CHCS Measures Library	“My care team considers other aspects of my life when helping me make health care decisions.”
<b>Open ended program specific questions</b>	Center Evaluation Team	“Is there anything else you would like us to know about your experience in the Star Program so far?”
<b>Economic Well-being</b>	CFPB Financial Well-Being Scale	“Because of my money situation, I feel like I will never have the things I want in my life.”
<b>Healthy and Ready to Learn</b>	NSCH	“How high can your child count?”
<b>InCharge Financial Distress and Financial Well-being Scale</b>	InCharge Education Foundation and E Thomas Garman	“How often do you worry about being able to meet normal monthly living expenses?”

**Table 1. Family Survey.** Sample Items from the Family Survey administered to patient families.

In addition to the CFBP financial well-being measure, we included the InCharge Financial Distress/Financial Well-Being Scale (IFDFW) in the second round of survey administration. The IFDFW Scale is an eight-item self-report subjective survey that measures the “latent construct of perceived financial distress” and wellbeing on a scale from 1 (“overwhelming financial distress/lowest financial well-being”) to 10 (“no financial distress/highest financial well-being”) (Thomas, 2020). The sum of individual scores is then divided by 8 to find the participant’s overall score. The distribution of possible scores ranges from 1.0-10.0; a chart of this breakdown can be found in **Appendix 3**. This measure not only evaluates for participant’s current financial situation and their perceptions of it, but it also assesses their reactions to their current economic situations, i.e., how overwhelmed they feel regarding their financial situation. We were able to compare our results to national data obtained in 2004 from a general population size of n=1,097. Survey and measures can be found in **Appendix 2**.

## RESULTS

The data in this section is from the second round of surveys administrated to Practice of the Future Families with results represented from the 37 families who participated in the survey between February 2022 to March 2022. Of the 37 families who participated, 36 completed the full survey. Approximately 82% of the parents who participated in the survey were Black or African American and 31% were Hispanic or Latinx and about 8% identified as White (**Table 2**).

Table 2: Patient Demographics (n=37)	
Race	(n) %
Black or African American	(31) 81.58
White	(3) 7.89
Other	(4) 10.53
Ethnicity	
Hispanic or Latino	(10) 31.25
Not Hispanic or Latino	(22) 68.75

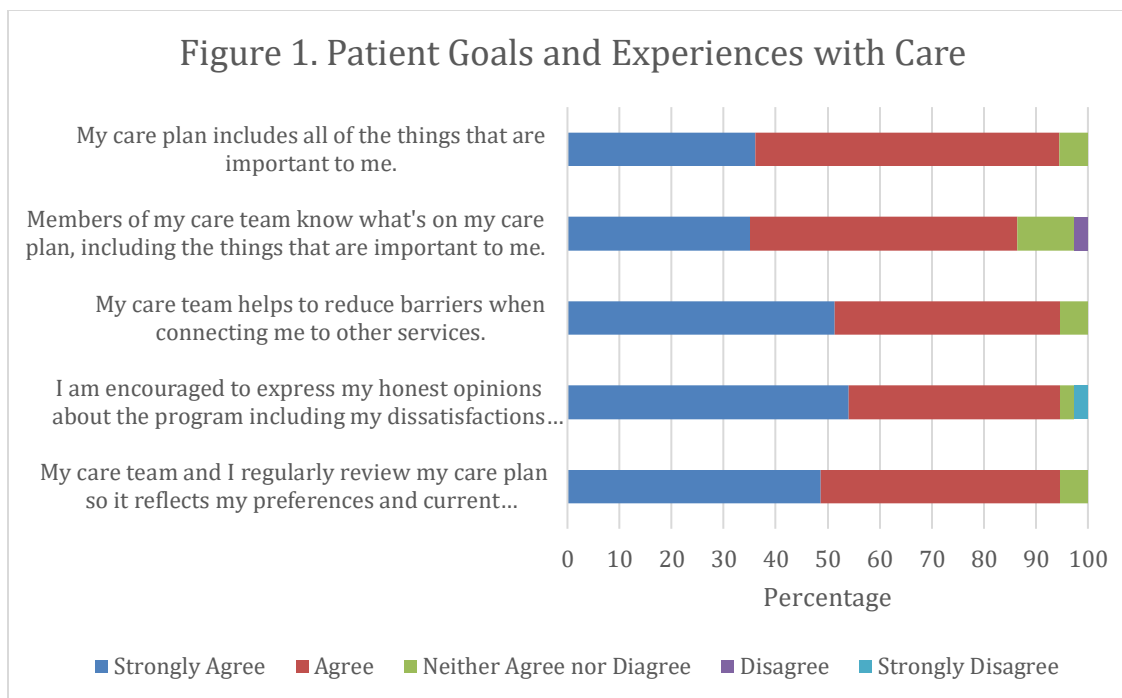
**Table 2. Patient Demographics.** Preliminary Family Demographics data from year 2 (February 2022-March 2022) Preliminary data on race, ethnicity and prevalence of school aged children collected for patient demographics.

### *Overall Family Results*

Caregivers reported overall good experiences with the STAR Program team, their children's care plans, and the innovative program. This result included experience with the plans for care coordination, availability of providers, the knowledge that the care team has regarding their care and alignment of what is important to patient caregivers and their families. The caregivers also reported positive experiences regarding the effort that providers made to understand caregivers' motivation.

### *Goals of and Experience with Care*

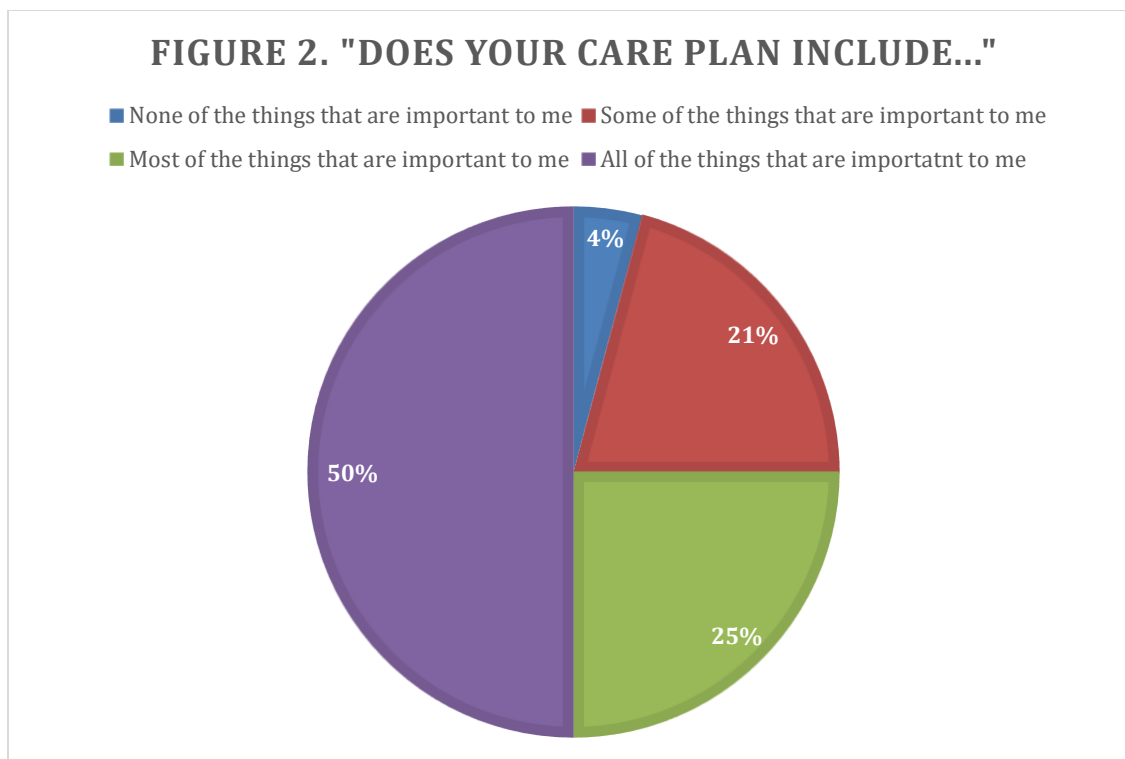
**Figure 1** shows that most caregivers strongly agree/agree with all questions related to whether their care plan reflects what matters to them and that their care team was knowledgeable about their plan. Nearly all parents agreed or strongly agreed that their care team regularly reviewed their care plan to make sure that it reflects their preferences (94%) and that they were encouraged to discuss their honest opinions about the program, including their dissatisfactions (94%). Most of the patient caregivers reported that the care team helps to reduce barriers when connecting them to outside services (about 51% strongly agree and 41% agree). According to **Figure 1** 84% of the caregivers responded either strongly agree or agree to the statement that “members of the care team know what’s on my care plan, including the things that are important me”. 43% of caregivers reported that every effort was made to listen to their needs and 46% reported that every effort was made help them understand their health situation (**Table 3**). According to **Figure 2**, 50% of the participants reported that their care plan includes *all* the things that are important to them, 25% believed that it includes *most* of the things that are important to them, 21% believe that it includes *some* of the things that are important to them and 4% believed that it includes *none* of the things that are important to them.



**Figure 1. Patient Goals and Experiences with Care.** Results are tabulated by count for each of the five different choice options and then divided by the total number of answers and multiplied by 100 to find the percentage (n=37).

Table 3. BMC Survey: Patient Goals of and Experience with Care					
Question	No effort was made, (n) %	Little effort was made, (n) %	Some effort was made, (n) %	A lot of effort was made, (n) %	Every effort was made, (n) %
“[Thinking about the care you received in the past 3 months] how much effort was made to listen to the things that matter most to you about your health issues? “	(4) 10.81	(3) 8.11	(3) 8.11	(11) 29.73	(16) 43.24
“[Thinking about the care you received in the past 3 months] how much effort was made to help you understand your health issues?”	(3) 8.11	(2) 5.41	(3) 8.11	(12) 32.43	(17) 45.95

**Table 3. Patient Goals of and Experiences with Care.** Results for questions addressing efforts made to listen to and help patient families with understanding their health issues (n=37).



**Figure 2. Does Your Care Plan Include...** Results for patient families regarding whether they felt that their child's care plan reflected the things that were important to them (n=24)

### ***Racial and Health Equity***

Most of the patient caregivers reported that they experienced equitable treatment in the STAR Program. As shown in **Table 4**, approximately 58% of participants strongly agreed with the statement that the care team felt comfortable around people who look, and sound like them and about 30% agreed to the same statement. 92% of patient caregivers either strongly agreed or agreed that they feel like they are cared about as a person at the POF clinic; and 83% reported either strongly agreeing or agreeing with the statement that the care team thinks about their values and traditions when they recommend treatments and services. However, 19% of the participants reporting that at

times they felt judged and criticized by the people who work in the POF clinic and 14% reported feeling like they were treated differently because of their race, ethnicity, or gender identity.

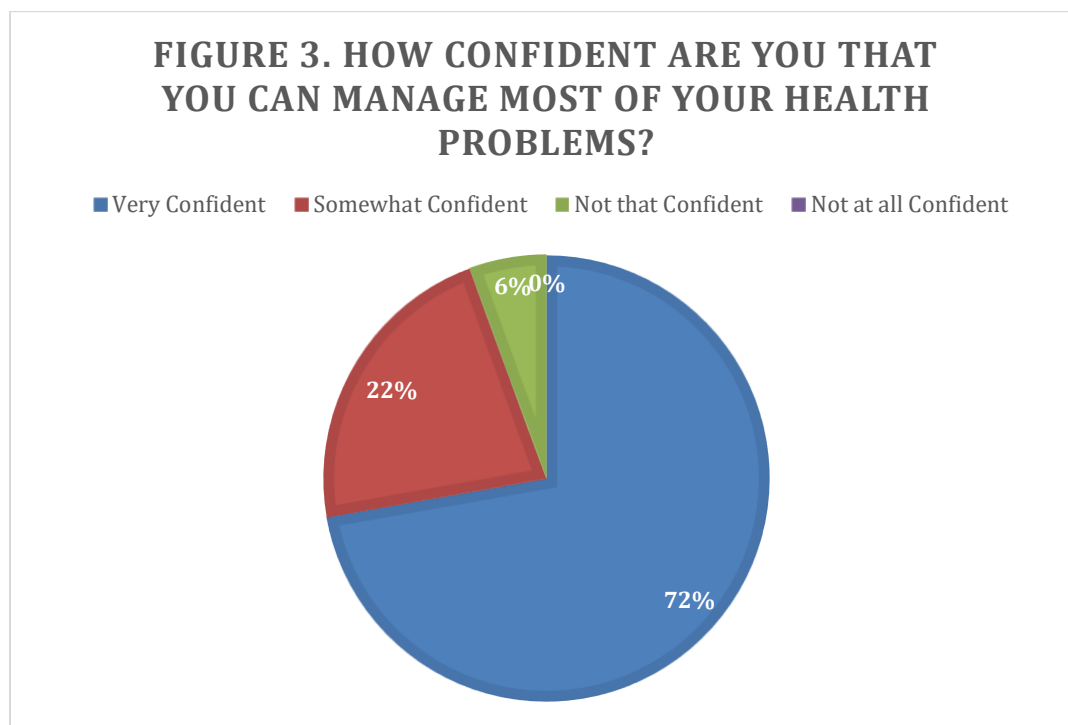
Table 4. BMC Survey: Patient Equity					
Question	Strongly Agree, (n) %	Agree, (n) %	Neither Agree nor Disagree, (n) %	Disagree, (n) %	Strongly Disagree, (n) %
“I believe my care team feels comfortable around people who look like me and/or sound like me.”	(21) 58.33	(11) 30.56	(2) 5.56	(1) 2.78	(1) 2.78
“At times I feel I am treated differently here based on my race, ethnicity and/or gender identity.”	(1) 2.78	(4) 11.11	(2) 5.56	(10) 27.78	(19) 52.78
“When I come here, I feel like they care about me as a person.”	(23) 63.89	(10) 27.78	(1) 2.78	(3) 8.33	(0) 0.00
“At times I feel judged and criticized by the people who work in this program.”	(4) 11.11	(3) 8.33	(3) 8.33	(5) 13.89	(21) 58.33
“My care team thinks about my values and my traditions when they recommend treatments and services to me.”	(15) 41.67	(15) 41.67	(3) 8.33	(2) 5.56	(1) 2.78

**Table 4. BMC Survey Patient Equity.** Results by count and percentage for patient survey regarding equity and treatment within the clinic based on race and identity (n =36).

### *Health and Well-Being*

Seventy-two percent of the patient caregivers reported that they felt very confident in managing their healthcare related issues, compared to 6% who indicated that they were not that confident (**Figure 3**). Of the 36 patients who responded to this measure, 94% reported that they strongly agree or agree that the service they receive through POF has helped them live a better life. When asked about how they would rate their problems and symptoms now and their ability to deal with their daily problems now compared to 3 months ago, 75%, and 67% rated much better, respectively (**Table 5**). Approximately 89% strongly agreed/agreed that the staff truly believes in them and that

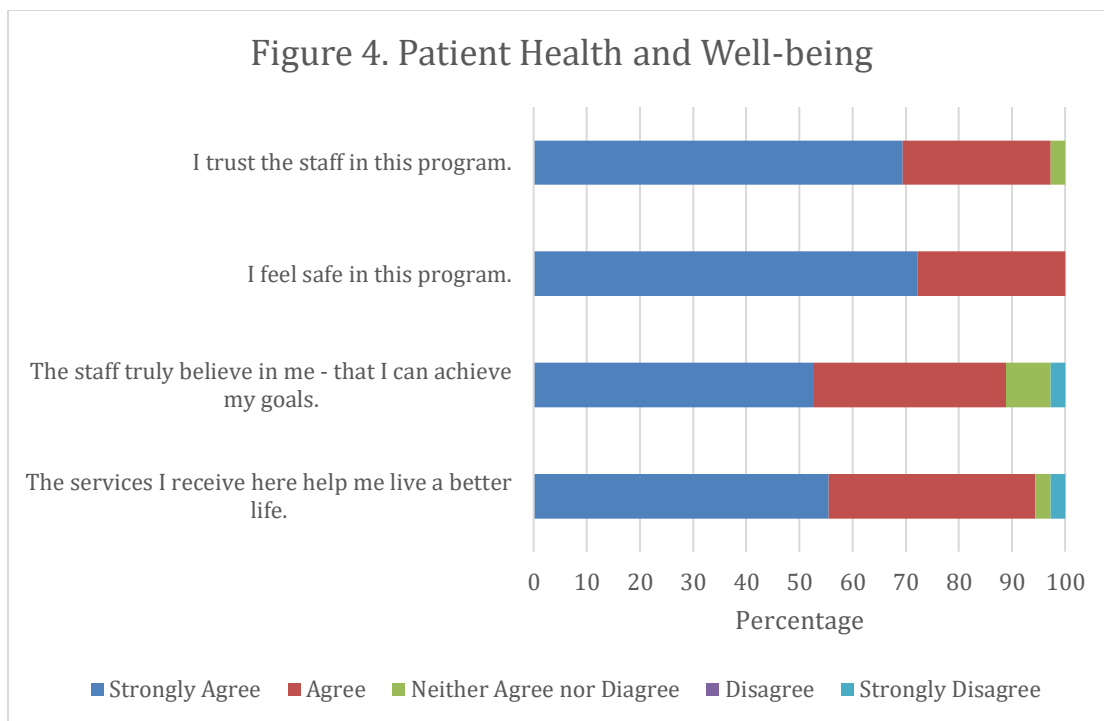
they can achieve their goals and more than half reported feeling sage in the program and that they trust the staff in the POF program (Figure 4).



**Figure 3. How Confident are You that You can Manage Most of Your Health Problems?** Results in percentage for how patients feel regarding the management of their current health issues (n = 36)

Table 5. BMC Survey: Patient Health and Well-Being (n=36)					
Question	Much Better, (n) %	A Little Better, (n) %	About the Same, (n) %	A Little Worse, (n) %	Much Worse, (n) %
“Compared to 3 months ago, how would you rate your problems or symptoms now?”	(27) 75.00	(5) 13.89	(4) 11.11	(0) 0.00	(0) 0.00
“Compared to 3 months ago, how would you rate your ability to deal with daily problems now?”	(24) 66.67	(9) 25.00	(3) 8.33	(0) 0.00	(0) 0.00

**Table 5. Patient Health and Well-Being.** Results in count and percentage for questions regarding current symptoms and problems faced by patient families (n=36).



**Figure 4. Patient Health and Well-Being.** Results in percentage values for questions related to patient health and well-being with a particular focus on the level of trust and safety that families feel within the clinic (n=36).

### *Care Integration*

**Table 6** indicates that most families report that the staff cares about aspects of their life that affect their healthcare (approximately 47% strongly agree) and that the care team advocates for them when it comes to the resources and services they need (nearly 53% strongly agree). More than half responded that the staff works together to coordinate their services, that their care team asks them about stressful situations they may experience in life that may harm their health, and that they are given information about how stress affects their overall health. Approximately 6% of the participants disagreed/strongly disagreed that the staff was helpful in getting them the resources they needed.

Table 6. BMC Survey: Patient Care Integration (n=36)					
Question	Strongly Agree, (n) %	Agree, (n) %	Neither Agree nor Disagree, (n) %	Disagree, (n) %	Strongly Disagree, (n) %
“My care team considers other aspects of my life when helping me make healthcare decisions.”	(17) 47.22	(15) 41.67	(4) 11.11	(0) 0.00	(0) 0.00
“The staff here try to help me with things I might need right away, like food, shelter, or clothing.”	(19) 52.78	(13) 36.11	(2) 5.56	(1) 2.78	(1) 2.78
“My care team helps coordinate all the services I receive.”	(20) 55.56	(14) 38.89	(2) 5.56	(0) 0.000	(0) 0.000
“The staff here work together and coordinate with my other service providers to come up with a plan that meets my needs.”	(15) 41.67	(18) 50.000	(3) 8.33	(0) 0.000	(0) 0.000
“I am asked about any stressful life experiences that may harm my health and emotional well-being.”	(15) 41.67	(14) 38.89	(5) 13.89	(1) 2.78	(1) 2.78
“I am given information about how my stressful life experiences may affect my overall health.”	(15) 41.67	(13) 36.11	(5) 13.89	(3) 8.33	(0) 0.000

**Table 6. Patient Care Integration.** Results for survey questions related to care integration within the clinic, tabulated by count and percentage (n =36).

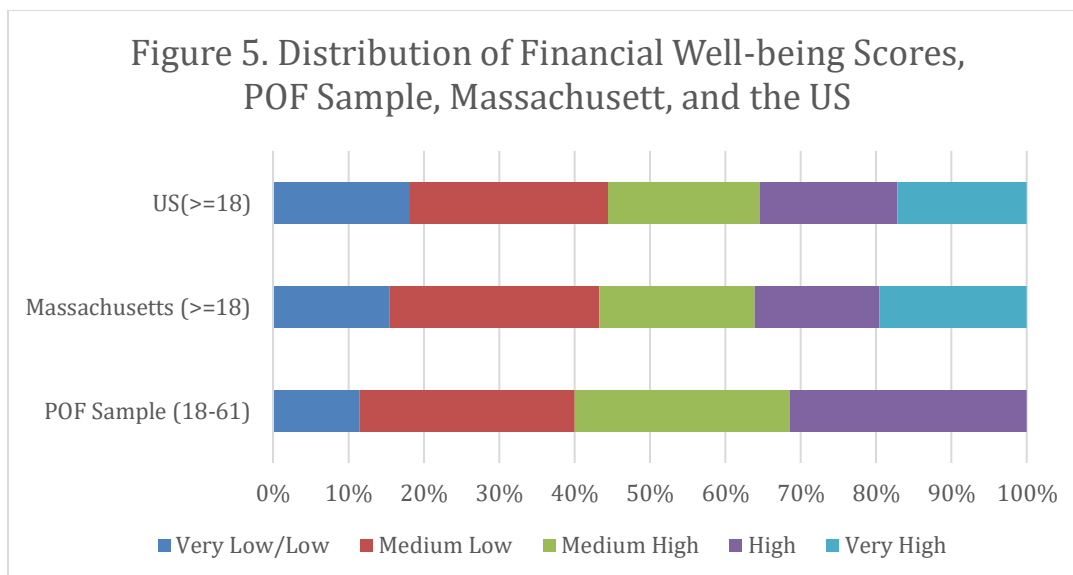
### ***CFBP Financial Well-being score***

According to **Table 7**, approximately 39% of the participants reported “somewhat” to feeling that they will never have the things they want in life because of money and 5% reported “completely” to the same statement. Approximately 39% reported that the statement “I am just getting by financially” applied to them completely or very well. About 36% reported that being concerned that the money they have won’t last applied completely or very well to them and the same percentage (36%) of the participants responded that the statement describes them very little or not at all. 44% of participants felt that they rarely or never have money left over at the end of the month and 39% reported that they always or often feel like their finances control their life.

Table 7. CFPB Financial Well-Being Item Responses										
	<i>This statement describes me:</i>									
	Completely		Very Well		Somewhat		Very Little		Not at All	
	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%
“Because of my money situation, I feel like I will never have the things I want in life.”	(2)	5.56	(3)	8.33	(14)	38.89	(3)	8.33	(14)	38.89
“I am just getting by financially.”	(7)	19.44	(7)	19.44	(12)	33.33	(1)	2.78	(8)	22.22
“I am concerned that the money I have or will save won't last.”	(6)	16.67	(7)	19.44	(9)	25.00	(4)	11.11	(9)	25.00
	<i>This statement applies to me:</i>									
	Always		Often		Sometimes		Rarely		Never	
	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%
“I have money left over at the end of the month.”	(2)	5.56	(4)	11.11	(14)	38.89	(8)	22.22	(8)	22.22
	<i>This statement applies to me:</i>									
	Always		Often		Sometimes		Rarely		Never	
	(n)	%	(n)	%	(n)	%	(n)	%	(n)	%
“My finances control my life.”	(6)	16.67	(8)	22.22	(11)	30.56	(3)	8.33	(8)	22.22

**Table 7. CFPB Financial Well-Being Item Responses.** Results for questions regarding the CFPB national scale for financial wellbeing (n =36).

**Figure 5** compares the financial wellbeing of the POF sample to adults in the US (18 years or older) and Massachusetts (18 years or older). Item scores (**Table 7**) were summed and standardized using the CFPB guidance (Bureau of Consumer Financial Protection, 2020). Standard scores were categorized as very low/low, low, medium low, medium high, high, and very high (Bureau of Consumer Financial Protection, 2020). The Bureau found that very low and low scores indicate material hardships as well as frequent struggles with finances, whereas high and very high scores indicate a relative absence of both (Bureau of Consumer Financial Protection, n.d.). Approximately 11% of the POF Patient sample were categorized as having low or very scores, indicating frequent struggles with finances, compared to the 18% of the US samples size and 17% of the Massachusetts sample. None of the patients in the POF sample scored very high and approximately 31% scored high compared to the 35% in both US and Massachusetts.

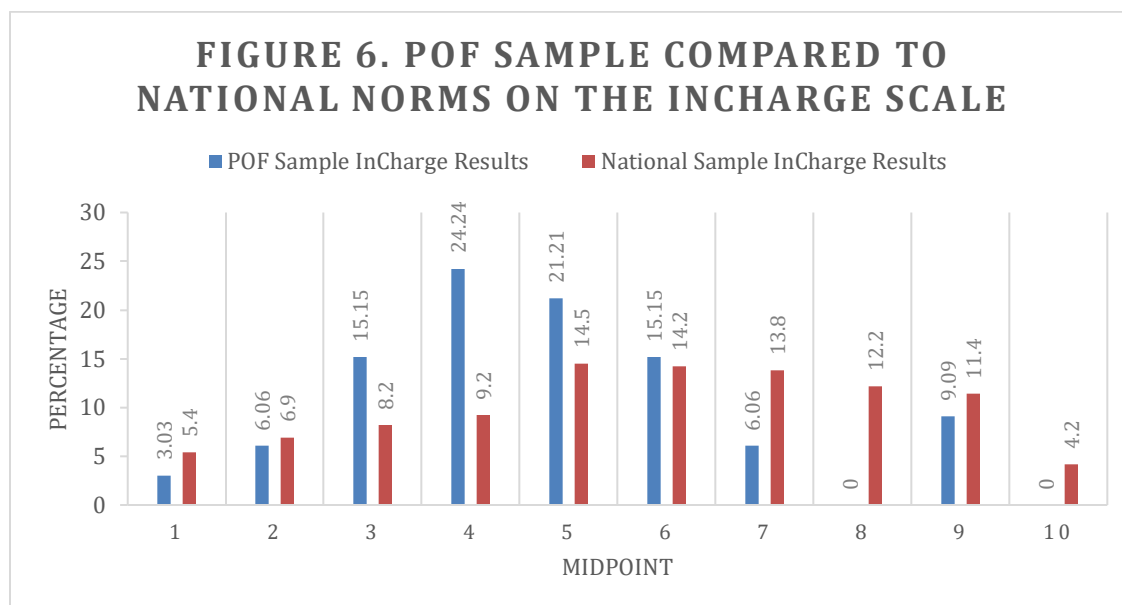


**Figure 5. Distribution of Financial Well-being Scores, POF Sample, Massachusetts, and the US.** Shows the percent of the US, POF Sample and Massachusetts’ adult population that falls inside the score range.

### *InCharge Financial Distress and Well-being scale*

Scores are scale on a continuum from 1 (“Overwhelming Financial Distress/Lowest Financial Well-Being”) to 10 (“No Financial Distress/Highest Financial Well-Being”). As shown in **Figure 6**, the mean score of 5.21 (SD = 2.00) for the POF sample was similar to the national data (5.7 (SD = 2.4)). In the POF sample, approximately 48% of respondents scored between 1 and 4 (inclusive), which indicates high financial distress/low financial well-being; approximately 15% scored between 7 and 10 (inclusive), indicating low financial distress and high financial well-being. Compared to the POF sample, about 30% of those who participated in the InCharge Education Foundation’s National survey collection scored between 1 and 4 (inclusive) and 42% scored between 7 and 10 (inclusive). None of the POF sample patients scored a

“10”, which represents no financial distress/highest financial well-being compared to 4.2% in the national sample.



**Figure 6. POF Sample Compared to National Norms for Financial Distress/Well-Being on the InCharge (IFDW) Scale.** This table includes Results from POF Sample families who completed the InCharge Survey and National Norms values were taken from the InCharge Education Foundation for general adult population.

### *Healthy and Ready to Learn by 5*

There may be some limitations about the items collected for the Healthy and Ready to Learn (HRTL) data that need to be taken into consideration in the ongoing research. One of the branching logics questions (other questions depend on a response for this question to populate) for the HRTL measure asks about the age of the patient, which was collected in years. Among the 37 families, there initially appeared to be about 13 children whose ages were reported to be between 3-5 but upon data cleaning, one respondent reported “2 and 4” to the question regarding age. To be considered for the HRTL survey, the patient had to be between ages 3-5 (therefore, this was not an

appropriate answer for this question type). More data cleaning revealed that four additional children were reported outside the HRTL age range (the children were reported to be under the age of 3), which also makes their caregivers ineligible for the questionnaire. Furthermore, some of the respondents answered what seems to be ages in months, but there is no way to verify that they were actual months and not the ages for older children. Therefore, unfortunately, there are only 5 responses that meet the age criteria and therefore can be used for analysis. Because of these limitations and concerns for accuracy, no data was analyzed for the HRTL survey at this time for these preliminary findings. Since survey distribution is ongoing, there will be opportunity to analyze information on HRTL data in the future. As data continues to be collected, research assistants may want to emphasize that the age is collected in numbers and should only apply to children who are age 3-5.

***Open Ended Question Responses:***

Participants were asked if “there was anything else [they] would like us to know about [their] experiences in the STAR Program so far” as a measure. Their responses fell into two main categories: things that were going well and things that can be improved moving forward. Some respondents from the POF clinic reported that the staff’s flexibility of care, communication, and ability to provide resources and supports was going well and provided convenience for their family, which was valuable to them:

*“I really like that Star Program helps coordinate care with both my kids and the resources you provide (like the food pantry) They overextend themselves. Flexibility with timing as well (even calls in the evening). Communication is really helpful and gas cards, detergents. When the care team refers me to check in with my mental health. Assistance with finding resources is very helpful. The STAR Program is really helpful and sensitive to my needs”*

*“I really like the program because it creates more convenience for reaching out to the hospital. I have point of contact to know about any problems I may have with appts. The doctor still takes us and the diapers they supply when the baby was younger [was helpful]. I like the convenience of knowing who to talk to especially when you need something urgently. They communicate and within shorter time I can get the information I need...I know where to go to ask questions and they can communicate with my doctors so when I get to the appointment my doctor already knows what’s going on.”*

Another area of things that were going well in the clinic was related to patient comfortability with the staff and knowing that their health was just as important as the health of the baby. Participants mentioned their experience with the clinical staff in terms of if they felt cared for and valued in the clinical space (touching on patient goals/experience with care and advocacy):

*“...The doctor also cares about me, not only my baby. They say if you are not healthy baby will not be better. She convinced me to care about my health too. When you go to appointments the visit is friendly and they care about my family. The doctor explains the developmental milestones for the baby, which helped me be aware of how baby is going to behave. I was able to ask questions and had great communication, which shows someone really cares about your baby.”*

There were also responses that indicated areas of improvement for the care team in the subject of cultural competence and understanding. One respondent mentioned that they want to see a difference in the considerations for different diets and lifestyle during doctor visits:

*“I notice that EPIC things are mentioned or considered. I feel like when I talk to the doctors, they don’t take it into considerations that our diet and lifestyles might be different. (They may not consider culture, lifestyle, such as not eating meat etc.)”*

Patient caregivers noted improvement needs regarding communication outreach to families to connect more with providers and improving racial and linguistic equity and cultural competence and understanding.

## DISCUSSION

The goal of this QI data collection was to evaluate data to improve the POF clinical staff in providing care to patients and their families. There are multiple key findings resulting from the analysis of the survey that show that the POF model is working well for end users. First, patient caregivers reported good experiences with the STAR Program team, their individualized care plans, and the overall efforts of the team and the program. Second, the data indicate that most families strongly agreed with all the questions that asked about their care plans or the staff's knowledge of their care plans. Third, most patient caregivers reported that their experience with the STAR Program reflected equitable treatment by the care team. Fourthly, our results indicate that families felt confident in managing their health problems and majority reported that the services they receive through the program will help them to live a greater life.

Almost all parents reported that the POF staff considers other aspects of their life when it comes to helping them make healthcare decisions. When it came to measures on financial well-being and distress, this POF patient sample self-reported being more financially stable on average than other people in Massachusetts and the US. It is important to keep in mind that since this was a self-reported measure, some of these differences may be because of social desirability bias, differences in age group (this study compared US and MA samples which consisted of people >18 to the POF sample, which was 18-61). Another reason for these differences could be because of the varying perceptions of financial distress or well-being for different sub-populations, not mention that culture may also play a role in the interpretations of some of the measures. In

addition, an important consideration is that perceptions of financial well-being may not always correlate well with actual finances depending on some sub-populations perceptions of what it means to be financially distressed/overwhelmed versus what it means to have low financial stress. On the other hand, interpreting the scores on the InCharge scale, the POF sample results indicates higher financial distress and lower financial well-being when compared to the national scale.

These results certainly bring into question of how the patient samples are interpreting the InCharge financial distress/well-being questions differently from the questions in the CFPB scale. The InCharge results reflect more of our findings during the Human Centered Design work than that of the CFPB scale. During our initial HCD work before the POF clinic launched, we found that many of our patients indicated feelings of financial distress and feeling like their finances kept them from living their idea of a healthier life. Interpreting and understanding the relationship between financial distress and financial well-being is important to the work of the POF clinic because it is well-known that they have a huge impact on health and overall positive outcomes in life. There might be a benefit to doing a follow-up study with the POF patient population that includes the definition of financial distress and well-being as a survey instrument to gain a better understanding of how the patient population views financial security as it relates to quality of life and health outcomes. One of the goals of the POF clinic is to create purposeful interventions like financial planning and goal setting to help improve financial well-being in the patient population. Overtime, we hope to see a change in the financial

well-being of our patients because of the interventional programs and work with the POF family population.

Parents report being overall satisfied with the care they receive and only having a few concerns with their encounters with providers regarding the support they receive, quality of care, equity, and care integration. Since one of the major goals of this ongoing research is quality improvement for the clinic, moving forward, the clinic plans to ensure that the patient facing staff and clinicians continue to provide patient-centered care to each POF family. Moving forward the POF clinic will also be keeping family voice and priorities at the center of the model by meeting weekly to discuss care plans for the upcoming patients and to address concerns that families may bring up during clinic. The clinic will continue to identify and improve areas where the program can improve on to increase parent check-ins and coordinate care in response to the families' needs and concerns, particularly those highlighted in the open-ended section of the family surveys.

Aligned with our integrated HCD principles used in the development of the POF model, we plan to also bring the data results to our staff and families and continue to create spaces for discussion on whether the program addresses the needs and concerns of the patient population. An ongoing portion of this research is to develop a plan for presenting family with the results of the survey and fostering family engagement as well as creating concrete steps to integrate the suggested improvements following the family focus groups to ensure change that reflects family needs. I will continue to attend the clinical practice innovation meetings to gain insight on how the clinical team operates as well as organized family focus groups to effectively understand ways to implement

changes in the way we collect data in the second round and the clinic. My participation in the POF clinic meetings will allow me to observe the clinical staff and better understand the dynamic of the clinical team, their practice processes and experience with delivering care. As this research continues to progress, it is important that we keep family voices at the center of the conversation and development. Family feedback provides the research and the clinical team with context around how to refine the model in a way that is meaningful to families and aligns with their vision of health and wellbeing.

As the clinic continues to collect data from the families on their experience with the POF clinic, the goal is to use this information to better understand what being healthy means to families and understand how the Pediatrics department at BMC can more effectively support caregivers in reaching their individual goals for their families. As part of the HCD methods, an important part of the POF model is learning directly from families what they like and do not like about the care they receive at BMC and taking that information to continue to design and change the POF model and eventually scale to the standard of care for all of BMC Pediatrics.

## APPENDIX 1

### AIM Survey Phone Script (NEW PARTICIPANTS)

Hello, My name is XXX, I work at Boston Medical Center with the Star Program Team. *[ask about preferred language in case an alternative time needs to be arranged]*. As you know, we created the STAR Program to try new ways of delivering care to families based on your priorities, goals, and needs. The Star Program started about a year ago and we are reaching out to families now to learn a little bit more about your experience with the Star Program so far. We are doing this because we believe that an important part of what we are doing is learning directly from families what you do and do not like about the care you receive at BMC. Do you have about 20 minutes to respond to some questions? As a thank you, we would like to offer you a \$25 BMC ClinCard which we can mail to you after the interview is complete. Would you like to participate?

*If no, see if setting up an alternative day/time would be more convenient.*

*If still no, thank them for their time and record that they have declined.*

*If yes, proceed to below.*

First, we will ask you some questions about your overall experience with the Star Program. Our goal with these questions is to help the clinical team better understand how you feel about the care you receive and how it can be improved. We will reach out to you again in a couple of months to see if you would like to answer the survey again. It's helpful for us to receive multiple responses to this survey over time so that we can see if the changes we are making have benefited you or if there are new things we need to work on. To protect your privacy, all of your answers are anonymous and will not be shared with your care team. Responses to this survey will be combined and will be presented as a group, instead of as individual answers. Your care team will only see counts of how many participants responded in a certain way to different questions.

#### *If child is between 3-5 years old*

Because you have at least one child who is school aged, we also have a few additional questions at the end about how you think they are doing with learning. Part of the goal of the Star Program is to support families with young children to be school ready. These questions will help us understand how we are doing with that across families of children ages 3-5 years old.

Voice mail:

Hello, this is XXX from Boston Medical Center Pediatrics with the Star Program Team. As you know, we created the STAR Program to try new ways of delivering care to families based on your priorities, goals, and needs. The Star Program started about a year ago and we are reaching out to families now to learn a little bit more about your experience with the Star Program so far. We are doing this because we believe that an important part of what we are doing is learning directly from families what you do and do

not like about the care you receive at BMC. I am calling today to see if you are interested in taking a survey to let us know about your experience with the STAR Program, and as a thank you we would like to offer you a \$25 BMC ClinCard, which works just like a Visa Gift Card, that we will send to you after the survey is complete. The survey should only take 15 – 20 minutes. If you are interested in participating in this survey, please give me a call back at XXX-XXX-XXXX. Thank you so much for your time and I hope you have a great day.

### **AIM Survey Phone Script (RETURNING PARTICIPANTS)**

Hello,

My name is **XXX**, I work at Boston Medical Center with the Star Program Team. *[ask about preferred language in case an alternative time needs to be arranged]*

As you know, we created the STAR Program to try new ways of delivering care to families based on your priorities, goals, and needs. The Star Program started about a year ago and we are reaching out to families now to learn a little bit more about your experience with the Star Program so far. We are doing this because we believe that an important part of what we are doing is learning directly from families what you do and do not like about the care you receive at BMC.

I see in our records that you completed the survey last year. Do you have about 20 minutes to respond to some questions? As a thank you, we would like to offer you a \$25 BMC ClinCard which we can mail to you after the interview is complete. Would you like to participate again?

*If no, see if setting up an alternative day/time would be more convenient.  
If still no, thank them for their time and record that they have declined.*

*If yes, proceed to below.*

First, we will ask you some questions about your overall experience with the Star Program. Our goal with these questions is to help the clinical team better understand how you feel about the care you receive and how it can be improved. We have reached out to you again because it's helpful for us to receive multiple responses to this survey over time so that we can see if the changes we are making have benefited you or if there are new things we need to work on.

Just as before, to protect your privacy, all your answers are anonymous and will not be shared with your care team. Responses to this survey will be combined and will be presented as a group, instead of as individual answers. Your care team will only see counts of how many participants responded in a certain way to different questions.

*If child is between 3-5 years old*

Because you have at least one child who is school aged, we also have a few additional questions at the end about how you think they are doing with learning. Part of the goal of the Star Program is to support families with young children to be school ready. These questions will help us understand how we are doing with that across families of children ages 3-5 years old.

Voicemail:

Hello, this is **XXX** from Boston Medical Center Pediatrics with the Star Program Team. As you know, we created the STAR Program to try new ways of delivering care to families based on your priorities, goals, and needs. The Star Program started about a year ago and we are reaching out to families now to learn a little bit more about your experience with the Star Program so far. We are doing this because we believe that an important part of what we are doing is learning directly from families what you do and do not like about the care you receive at BMC. I see in our records that you completed the survey last year, and I am calling today to see if you are interested in taking it again to let us know about your experience with the STAR Program. As a thank you we would like to offer you a \$25 BMC ClinCard, which works just like a Visa Gift Card, that we will send to you after the survey is complete. The survey should only take 15 - 20 minutes. If you are interested in participating in this survey, please give me a call back at XXX-XXX-XXXX. Thank you so much for your time and I hope you have a great day.

## APPENDIX 2

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Page 1

### STAR Program Survey

The following survey is in regards to the care that you receive in the Boston Medical Center Pediatrics STAR Program.

To protect your privacy, all of your answers are anonymous and will not be shared with your care team. Responses to this survey will be combined and will be presented as a group, instead of as individual answers. Your care team will only see counts of how many participants responded in a certain way to different questions. Because of this, the care team will not reach out if you write feedback requesting certain changes or resources.

If you do have feedback that you specifically want someone from the team to get back to you about, such as if you want the frequency you receive calls from the team to change or if you want to ask about a new type of resource, please reach out to your Community Wellness Advocate (CWA).

Mitsouka: 617-352-0980

Lupita: 857-262-7243

If you have any questions about this survey, please reach out via email ([miriam.kamens@bmc.org](mailto:miriam.kamens@bmc.org)) or phone (617-414-3672).

Thank you!

#### Demographics

Date of survey \_\_\_\_\_

Which of the following best describes your race?

- American Indian or Alaska Native  
 Asian  
 Black or African American  
 Native Hawaiian or other Pacific Islander  
 White  
 Other

If you said other, please explain. \_\_\_\_\_

Which of the following best describes your ethnicity?

- Hispanic or Latino  
 Not Hispanic or Latino

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Goals of and Experience with Care					
	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
My care team and I regularly review my care plan so it reflects my preferences and current circumstances.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am encouraged to express my honest opinions about the program including my dissatisfactions and disagreements.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My care team helps to reduce barriers when connecting me to other services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Members of my care team know what's on my care plan, including the things that are important to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My care plan includes all of the things that are important to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Does your care plan include...					
<input type="radio"/> None of the things that are important to you <input type="radio"/> Some of the things that are important to you <input type="radio"/> Most of the things that are important to you <input type="radio"/> All of the things that are important to you					
	No effort was made	A little effort was made	Some effort was made	A lot of effort was made	Every effort was made
[Thinking about the care you received in the past 3 months] how much effort was made to listen to the things that matter most to you about your health issues?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
[Thinking about the care you received in the past 3 months] how much effort was made to help you understand your health issues?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Equity					
	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I believe my care team feels comfortable around people who look like me and/or sound like me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
At times I feel I am treated differently here based on my race, ethnicity and/or gender identity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I come here, I feel like they care about me as a person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
At times I feel judged and criticized by the people who work in this program.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My care team thinks about my values and my traditions when they recommended treatments and services to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Health and Well-Being					
	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
The services I receive here help me live a better life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The staff truly believe in me - that I can achieve my goals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How confident are you that you can manage most of your health problems?					
			<input type="radio"/> Very confident		
			<input type="radio"/> Somewhat confident		
			<input type="radio"/> Not that confident		
			<input type="radio"/> Not at all confident		
Compared to 3 months ago, how would you rate your problems or symptoms now?					
	Much better	A little better	About the same	A little worse	Much worse
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Compared to 3 months ago, how would you rate your ability to deal with daily problems now?					
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel safe in this program.					
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I trust the staff in this program.					
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Care Integration	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
My care team considers other aspects of my life when helping me make health care decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The staff here try to help me with things I might need right away, like food, shelter, or clothing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My care team helps coordinate all the services I receive.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The staff here work together and coordinate with my other service providers to come up with a plan that meets my needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am asked about any stressful life experiences that may harm my health and emotional well-being.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am given information about how my stressful life experiences may affect my overall health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is there anything else you would like us to know about your experience in the Star Program so far?					
_____					
Do you have any other feedback for us about your experience with the Star Program so far?					
_____					

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How well does this statement describe you or your situation?	Completely	Very Well	Somewhat	Very little	Not at all
Because of my money situation, I feel like I will never have the things I want in my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am just getting by financially.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am concerned that the money I have or will save won't last.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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How often does this statement apply to you?					
	Always	Often	Sometimes	Rarely	Never
I have money left over at the end of the month.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My finances control my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How old are you (years)?		<input type="radio"/> 18-61 <input type="radio"/> 62+			
Based on our records, you have 1 child in the STAR Program who is between the age of 3-5 years old. Below are questions about that child.					
Based on our records, you have 2 children in the STAR Program who are between the ages of 3-5 years old. Below are questions about those 2 children.					
Based on our records, you have 3 children in the STAR Program who are between the ages of 3-5 years old. Below are questions about those 3 children.					
What is the age (in years) of your child between the ages of 3-5 years?		_____			
What is the age (in years) of your youngest child between the ages of 3-5 years?		_____			
Below are questions about your child, whose age you listed above					
Are you concerned about how this child is learning to do things for him or herself?		<input type="radio"/> Yes, somewhat concerned <input type="radio"/> Yes, very concerned <input type="radio"/> No <input type="radio"/> No answer			
How often can this child recognize the beginning sound of a word? For example, can this child tell you that the word "ball" starts with the "buh" sound?		<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer			
About how many letters of the alphabet can this child recognize?		<input type="radio"/> All of them <input type="radio"/> Most of them <input type="radio"/> About half of them <input type="radio"/> Some of them <input type="radio"/> None of them <input type="radio"/> No answer			
How often can this child explain things he or she has seen or done so that you get a very good idea what happened?		<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer			

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How high can this child count?	<input type="radio"/> This child cannot count <input type="radio"/> Up to five <input type="radio"/> Up to ten <input type="radio"/> Up to 20 <input type="radio"/> Up to 50 <input type="radio"/> Up to 100 or more <input type="radio"/> No answer
How often can this child identify basic shapes such as a triangle, circle, or square?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
Can this child identify the colors red, yellow, blue and green by name?	<input type="radio"/> Yes, all of them <input type="radio"/> Yes, some of them <input type="radio"/> No, none of them <input type="radio"/> No answer
How often does this child keep working at something until he or she is finished?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
When this child is paying attention, how often can he or she follow instructions to complete a simple task?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
How often does this child show concern when others are hurt or unhappy?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
When excited or all wound up, how often can this child calm down quickly?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
How often does this child bounce back quickly when things do not go his or her way?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer

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During the past 12 months, how often have this child's health conditions or problems affected his or her ability to do things other children his or her age do?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
To what extent do this child's health conditions or problems affect his or her ability to do things?	<input type="radio"/> No difficulty <input type="radio"/> A little difficulty <input type="radio"/> A lot of difficulty <input type="radio"/> No answer
Is this child affectionate and tender with you?	<input type="radio"/> Always <input type="radio"/> Often <input type="radio"/> Sometimes <input type="radio"/> Rarely <input type="radio"/> Never
Does this child smile and laugh?	<input type="radio"/> Always <input type="radio"/> Often <input type="radio"/> Sometimes <input type="radio"/> Rarely <input type="radio"/> Never
How often does this child play well with others?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
How often is this child easily distracted?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
In general, how would you describe this child's health?	<input type="radio"/> Healthy <input type="radio"/> Moderately Healthy <input type="radio"/> Not Healthy <input type="radio"/> No Answer
Compared to other children his or her age, how much difficulty does this child have making or keeping friends?	<input type="radio"/> No difficulty <input type="radio"/> A little difficulty <input type="radio"/> A lot of difficulty <input type="radio"/> No answer
Compared to other children his or her age, how often is this child able to sit still?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
How would you describe the condition of this child's teeth?	<input type="radio"/> Healthy <input type="radio"/> Moderately Healthy <input type="radio"/> Not Healthy <input type="radio"/> No Answer

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What is the age (in years) of your second youngest child between the ages of 3-5 years? \_\_\_\_\_

---

Below are questions about your child, whose age you listed above

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Are you concerned about how this child is learning to do things for him or herself?

Yes, somewhat concerned  
 Yes, very concerned  
 No  
 No answer

---

How often can this child recognize the beginning sound of a word? For example, can this child tell you that the word "ball" starts with the "bah" sound?

Always  
 Most of the time  
 About half the time  
 Sometimes  
 Never  
 No answer

---

About how many letters of the alphabet can this child recognize?

All of them  
 Most of them  
 About half of them  
 Some of them  
 None of them  
 No answer

---

How often can this child explain things he or she has seen or done so that you get a very good idea what happened?

Always  
 Most of the time  
 About half the time  
 Sometimes  
 Never  
 No answer

---

How high can this child count?

This child cannot count  
 Up to five  
 Up to ten  
 Up to 20  
 Up to 50  
 Up to 100 or more  
 No answer

---

How often can this child identify basic shapes such as a triangle, circle, or square?

Always  
 Most of the time  
 About half the time  
 Sometimes  
 Never  
 No answer

---

Can this child identify the colors red, yellow, blue and green by name?

Yes, all of them  
 Yes, some of them  
 No, none of them  
 No answer

---

How often does this child keep working at something until he or she is finished?

Always  
 Most of the time  
 About half the time  
 Sometimes  
 Never  
 No answer

---

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When this child is paying attention, how often can he or she follow instructions to complete a simple task?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
How often does this child show concern when others are hurt or unhappy?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
When excited or all wound up, how often can this child calm down quickly?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
How often does this child bounce back quickly when things do not go his or her way?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
During the past 12 months, how often have this child's health conditions or problems affected his or her ability to do things other children his or her age do?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
To what extent do this child's health conditions or problems affect his or her ability to do things?	<input type="radio"/> No difficulty <input type="radio"/> A little difficulty <input type="radio"/> A lot of difficulty <input type="radio"/> No answer
Is this child affectionate and tender with you?	<input type="radio"/> Always <input type="radio"/> Often <input type="radio"/> Sometimes <input type="radio"/> Rarely <input type="radio"/> Never
Does this child smile and laugh?	<input type="radio"/> Always <input type="radio"/> Often <input type="radio"/> Sometimes <input type="radio"/> Rarely <input type="radio"/> Never
How often does this child play well with others?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer

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How often is this child easily distracted?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
In general, how would you describe this child's health?	<input type="radio"/> Healthy <input type="radio"/> Moderately Healthy <input type="radio"/> Not Healthy <input type="radio"/> No Answer
Compared to other children his or her age, how much difficulty does this child have making or keeping friends?	<input type="radio"/> No difficulty <input type="radio"/> A little difficulty <input type="radio"/> A lot of difficulty <input type="radio"/> No answer
Compared to other children his or her age, how often is this child able to sit still?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
How would you describe the condition of this child's teeth?	<input type="radio"/> Healthy <input type="radio"/> Moderately Healthy <input type="radio"/> Not Healthy <input type="radio"/> No Answer
What is the age (in years) of your third youngest child between the ages of 3-5 years?	_____
Below are questions about your child, whose age you listed above	
Are you concerned about how this child is learning to do things for him or herself?	<input type="radio"/> Yes, somewhat concerned <input type="radio"/> Yes, very concerned <input type="radio"/> No <input type="radio"/> No answer
How often can this child recognize the beginning sound of a word? For example, can this child tell you that the word "ball" starts with the "buh" sound?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
About how many letters of the alphabet can this child recognize?	<input type="radio"/> All of them <input type="radio"/> Most of them <input type="radio"/> About half of them <input type="radio"/> Some of them <input type="radio"/> None of them <input type="radio"/> No answer
How often can this child explain things he or she has seen or done so that you get a very good idea what happened?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer

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How high can this child count?

- This child cannot count  
 Up to five  
 Up to ten  
 Up to 20  
 Up to 50  
 Up to 100 or more  
 No answer

---

How often can this child identify basic shapes such as a triangle, circle, or square?

- Always  
 Most of the time  
 About half the time  
 Sometimes  
 Never  
 No answer

---

Can this child identify the colors red, yellow, blue and green by name?

- Yes, all of them  
 Yes, some of them  
 No, none of them  
 No answer

---

How often does this child keep working at something until he or she is finished?

- Always  
 Most of the time  
 About half the time  
 Sometimes  
 Never  
 No answer

---

When this child is paying attention, how often can he or she follow instructions to complete a simple task?

- Always  
 Most of the time  
 About half the time  
 Sometimes  
 Never  
 No answer

---

How often does this child show concern when others are hurt or unhappy?

- Always  
 Most of the time  
 About half the time  
 Sometimes  
 Never  
 No answer

---

When excited or all wound up, how often can this child calm down quickly?

- Always  
 Most of the time  
 About half the time  
 Sometimes  
 Never  
 No answer

---

How often does this child bounce back quickly when things do not go his or her way?

- Always  
 Most of the time  
 About half the time  
 Sometimes  
 Never  
 No answer

*Confidential*

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During the past 12 months, how often have this child's health conditions or problems affected his or her ability to do things other children his or her age do?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
To what extent do this child's health conditions or problems affect his or her ability to do things?	<input type="radio"/> No difficulty <input type="radio"/> A little difficulty <input type="radio"/> A lot of difficulty <input type="radio"/> No answer
Is this child affectionate and tender with you?	<input type="radio"/> Always <input type="radio"/> Often <input type="radio"/> Sometimes <input type="radio"/> Rarely <input type="radio"/> Never
Does this child smile and laugh?	<input type="radio"/> Always <input type="radio"/> Often <input type="radio"/> Sometimes <input type="radio"/> Rarely <input type="radio"/> Never
How often does this child play well with others?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
How often is this child easily distracted?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
In general, how would you describe this child's health?	<input type="radio"/> Healthy <input type="radio"/> Moderately Healthy <input type="radio"/> Not Healthy <input type="radio"/> No Answer
Compared to other children his or her age, how much difficulty does this child have making or keeping friends?	<input type="radio"/> No difficulty <input type="radio"/> A little difficulty <input type="radio"/> A lot of difficulty <input type="radio"/> No answer
Compared to other children his or her age, how often is this child able to sit still?	<input type="radio"/> Always <input type="radio"/> Most of the time <input type="radio"/> About half the time <input type="radio"/> Sometimes <input type="radio"/> Never <input type="radio"/> No answer
How would you describe the condition of this child's teeth?	<input type="radio"/> Healthy <input type="radio"/> Moderately Healthy <input type="radio"/> Not Healthy <input type="radio"/> No Answer

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**ClinCard Compensation**

Thank you for completing the STAR survey! We will be mailing you your clincard and loading your payment of \$25 onto it. We will follow-up in 2 weeks to confirm you have received your card. If you have any questions regarding this survey or your payment, please contact research staff here:

Email: miriam.kamens@bmc.org

Phone: 617-414-3672

Thank you for completing the STAR survey! We will be loading your payment of \$25 onto your existing Boston Medical Center clincard. If you have any questions regarding this survey or your payment, please contact research staff here:

Email: miriam.kamens@bmc.org

Phone: 617-414-3672

You will be compensated for this survey using the Boston Medical Center Clincard Program. Clincards are reloadable cash cards, and they look and function like debit cards. In the email that you received this survey link, there is an attached document that is called "Clincard Cardholder FAQ" which has information about how to use your clincard.

If you already have a clincard from a previous research study at Boston Medical Center, we can reload your current card with your payment. If you do not already have a clincard, we will mail you a new card and load your payment onto that card. If you do have a card from a previous study, but you lost it, do not know where it is, or it has expired, we can mail you a new one.

If you do already have an active clincard, but we are unable to find it in our system for some reason, we will mail you a new one. We will reach out before doing so to let you know that we were unable to reload money onto your current clincard.

We will load \$25 onto your clincard as compensation for this survey.

We have attached a form to the email that this survey link was sent in. Please fill out the information on this form so that we can either create a clincard account for you or update your current account. If it is easier for you, you can just write the requested information in an email response instead of on the form itself.

The boxes you should fill out on this form are:

- Name
- Address
- Preferred phone number (either home or cell)
- Date of birth

If you check either of these boxes, you will receive a notification when we add your payment to your card.

Please fill out this form (or enter the information into an email response) even if you already have a clincard.

If you have any questions about this form, your clincard, or anything related to your survey compensation, you may contact the research team here:

Email: miriam.kamens@bmc.org

Phone: 617-414-3672

Do you already have a Boston Medical Center Clincard that has not yet expired?  Yes  No

What are the last 4 digits of your card? \_\_\_\_\_

## InCharge Financial Distress/Financial Well-Being Scale

**Directions:** Circle or check the responses that are **most appropriate** for your situation.

1. What do you feel is the **level** of your **financial stress today**?

1	2	3	4	5	6	7	8	9	10
Overwhelming Stress		High Stress			Low Stress		No Stress at All		

2. On the stair steps below, mark (with a circle) how **satisfied** you are with your **present financial situation**. The “1” at the bottom of the steps represents complete dissatisfaction. The “10” at the top of the stair steps represents complete satisfaction. The more dissatisfied you are, the lower the number you should circle. The more satisfied you are, the higher the number you should circle.

Satisfied

Dissatisfied

3. How do you feel about your **current financial situation**?

1	2	3	4	5	6	7	8	9	10
Feel Overwhelmed		Sometimes Feel Worried			Not Worried		Feel Comfortable		

4. How often do you worry about being **able to meet** normal monthly living expenses?

1	2	3	4	5	6	7	8	9	10
Worry All the Time		Sometimes Worry			Rarely Worry		Never Worry		

5. How confident are you that you could find the money to pay for a **financial emergency** that costs about **\$1,000**?

1	2	3	4	5	6	7	8	9	10
No Confidence		Little Confidence			Some Confidence		High Confidence		

6. How often does this happen to you? You want to go out to eat, go to a movie or do something else and **don't go because you can't afford to**?

1	2	3	4	5	6	7	8	9	10
All the time		Sometimes			Rarely		Never		

7. How frequently do you find yourself just getting by financially and living **paycheck to paycheck**?

1	2	3	4	5	6	7	8	9	10
All the time		Sometimes			Rarely		Never		

8. How **stressed** do you feel about your personal finances **in general**?

1	2	3	4	5	6	7	8	9	10
Overwhelming Stress		High Stress			Low Stress		No Stress at All		

## APPENDIX 3

<b>Appendix 3. Healthy and Ready to Learn Measure Domains and Items</b>			
<b>Early Learning Skills</b>	<b>Social-Emotional</b>	<b>Self-Regulation</b>	<b>Physical Well-Being</b>
How often can this child recognize the beginning sound of a word? For example, can this child tell you that the word “ball” starts with the “buh” sound?	How often does this child play well with others?	How often is this child easily distracted?	In general, how would you describe this child's health?
About how many letters of the alphabet can this child recognize?	Compared to other children his or her age, how much difficulty does this child have making or keeping friends?	Compared to other children his or her age, how often is this child able to sit still?	How would you describe the condition of this child's teeth?
How often can this child explain things he or she has seen or done so that you get a very good idea what happened?	How often does this child bounce back quickly when things do not go his or her way?	How often does this child keep working at something until he or she is finished?	During the past 12 months, how often have this child's health conditions or problems affected his or her ability to do things other children his or her age do? (combined with) To what extent do this child's health conditions...
How high can this child count?	How often does this child show concern when others are hurt or unhappy?	When this child is paying attention, how often can he or she follow instructions to complete a simple task?	
How often can this child identify basic shapes such as a triangle, circle, or square?	Does this child smile and laugh?	When excited or all wound up, how often can this child calm down quickly?	
Can this child identify the colors red, yellow, blue, and green by name?	Is this child affectionate and tender with you?	Are you concerned about how this child is learning to do things for him or herself?	

APPENDIX 3. Normative Descriptive Terminology for Interpreting IFDFW Scores	
Score	Descriptive Terminology
1.0	“Overwhelming financial distress/lowest financial well-being”
2.0	“Extremely high financial distress/extremely low financial well-being”
3.0	“Very high financial distress/very poor financial well-being”
4.0	“High financial distress/poor financial well-being”
5.0	“Average financial distress/average financial well-being”
6.0	“Moderate financial distress/moderate financial well-being”
7.0	“Low financial distress/good financial well-being”
8.0	“Very low financial distress/very good financial well-being”
9.0	“Extremely low financial distress/extremely high financial well-being”
10.00	“No financial distress/highest financial well-being”

*Note.* From InCharge Education Foundation, “Normative Descriptive Terminology for Interpreting IFDFW scores”. 1 = “Overwhelming Financial Distress/Lowest Financial Well-Being”; 10 = “No Financial Distress/Highest Financial Well-Being” ©Copyright by InCharge Education Foundation and E. Thomas Garman, 2004-2006. All rights reserved.

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**CURRICULUM VITAE**

