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Health Care Engagement of Limited English Proficient Latino Families: Lessons Learned from Advisory Board Development

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Abstract

Background—Specific information on the development and evaluation of patient/family engagement in health care improvement for populations with limited English proficiency (LEP) is lacking.

Objectives—We sought to provide information for use by other health care organizations aiming to engage LEP populations through advisory groups.

Methods—Informed by community-based research principles, we formed a family advisory board of LEP Latino families and conducted a multimodal evaluation of initial implementation and partnership development.

Results—The board met process measures goals for sustained engagement of LEP families and for establishing a group structure and process. Board outcomes included contributions to clinic educational materials and initiation of a project to increase the child friendliness of the physical space. Mothers on the board reported satisfaction with their participation.

Conclusions—We successfully sustained engagement of LEP Latino families in health care improvement using an advisory board. To promote patient-centered care and address health care disparities, LEP populations should be included in patient engagement programs.

Keywords

Health disparities; community health partnerships; delivery of health care; ambulatory care facilities; parents

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Patient engagement is frequently cited as a key mechanism to health system redesign, and achieving the "triple aim" of improved health outcomes, better patient care experiences, and lower health care costs.[1,2] In general, patient engagement refers to collaborative partnerships between patients and their families to improve health and health care across various levels of the health system including individual health care, organizational design and governance, and policy making.[1,3–5] There is a particular need for information about strategies for engaging patients and families who have difficulty navigating and using the health care system, such as those with low-income, LEP, and/or limited health literacy.[1,4,6] Formation of patient/family advisory groups is a common mode of engaging health care users in a

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clinic or health care organization, but available resources on forming patient/family advisory groups lack specific information on advisory groups that incorporate populations who are more likely to experience health and health care disparities.[7–10] Failing to engage these patients and families may exacerbate health care disparities and reduce the potential of patient engagement to improve the health and health care of vulnerable populations.

Health care engagement of vulnerable populations may require particular attention to partnership development and establishing mutually respectful relationships that promote trust between the health care organization and participants in health care engagement activities. Formation of patient/family advisory groups should not occur in isolation from other health care organization efforts to engage in promotion of improved health and well-being of the community that it serves.[5] The development of relationships between health care organizations and vulnerable community members in the context of advisory groups must take account of and be responsive to other existing relationships between the health care organization and the community.

Our aim is to describe the process of establishing a family advisory board composed of LEP Latino families at a pediatric primary care clinic, with a focus on initial partnership development and the experiences of family members on the board. Latino children are the largest minority group among U.S. children, and experience disparities in health care access and quality.[11–17] Health care disparities for Latino children in the United States are especially prevalent among those with LEP parents, who often have co-occurring low income and limited health literacy.[18–24] Thus, health care engagement in the pediatric setting must extend to Latino families, and include Spanish-speaking LEP parents. We present findings that directly address the gap in current resources by providing information for use by other health care organizations aiming to engage LEP populations through advisory groups.

METHODS

Board Development

The Latino Family Advisory Board/*Consejo de Familias Latinas* (LFAB) was developed at an urban, academic general pediatric practice where the majority clinic population is native-born and immigrant low-income Latino children with immigrant parents. Clinic efforts to tailor services to the specific needs of low-income, immigrant Latino families have included employing Spanish-speaking clinical and support staff and providing additional family support services. Despite these efforts, clinic leaders felt that their health care access and quality were disparate compared with English-speaking families. Clinic providers felt the voices of families had intrinsic value in making needed clinic improvements and prioritized including Latino families in clinic improvement efforts. A review on engaging families in health care improvement prompted several providers, including the clinic medical director, to apply for, and subsequently secure, funding to start an advisory board for LEP Latino families (L.R.D., S.P., D.T.). In preliminary work to prepare funding applications, partnership development was often noted as a key step in advisory group implementation, but information on the process of partnership development was sparse.[7–10] Given the limited guidance on the process of partnership development, and the underlying concern by clinic

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providers that lack of attention to partnership development could undermine current and future community-based efforts by the clinic and larger parent health care organization, partnership development emerged as a key step in operationalizing system-level health care engagement of LEP Latino families. The specific principles of partnership outlined by experts in the field of community-based participatory research (CBPR) promote sustained, effective partnerships that respect and value the perspectives of community members and the distinct assets they bring to partnerships. We used these principles to inform partnership development during advisory board implementation.[25]

Selection of Board Members

The LFAB consisted of both of clinic staff members and families who used the clinic as their child's medical home. Three pediatricians at the clinic, including the medical director (S.P.) and the clinic's lead social worker (F.G.) were staff representatives on the board. These staff members volunteered their time to serve on the board. Schedule and overtime work and compensation constraints precluded the involvement of other clinic staff (e.g., nursing, front-desk staff), although this was desired. Two clinic staff members were primarily responsible for facilitating meeting discussions, but the other staff members and mothers present also contributed to guiding discussions and small group work. The clinic's lead social worker (F.G.) was selected as a co-facilitator based on her interest and relevant experience. The other co-facilitator was a clinic physician responsible for board implementation and evaluation (L.R.D.). All staff members were bilingual or highly proficient in Spanish.

We selected families for LFAB membership based on recommendations from providers and staff. Providers and staff were specifically asked to think of families who both did and did not face challenges using the health care system, families who had generally well children and children with special health care needs, and families who were frequent or long-time users of the clinic as well as families who were infrequent or recent new clinic patients. We asked providers to tell patients that a group for Spanish-speaking parents to participate in clinic improvement was being formed, and that if interested the provider would share their name with the board coordinator.

Twenty-nine families were recommended to the LFAB coordinator, and 20 were successfully contacted by phone. Seventeen families agreed to come to the first meeting and 12 mothers attended. Reasons given for not participating included lack of time, work hour conflict, or disinterest. Although we invited all parents/guardians to LFAB meetings, only mothers attended. We invited all first meeting attendees to subsequent LFAB meetings during the initial year and all mothers who had attended at least two meetings in the initial year to the first meeting of the second year. To maintain attendance in the range of 8 to 10 mothers, we invited additional families to participate in the second year of the LFAB, using the same recommendation process. The LFAB coordinator received 14 recommendations, reached 10 by phone, 7 agreed to come to the initial second year meeting, and 4 attended.

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Board Meeting Logistics

The LFAB coordinator (M.C.), a bilingual Latina of Cuban descent, organized meetings, initiated and maintained contact with board members outside of meetings, and managed all data on members, board meetings, and projects. Included in funding requests for the board was support to cover the percent effort (approximately 5%) dedicated by the board coordinator. Throughout implementation clinic staff members on the board and the board coordinator met regularly to plan upcoming meetings and reflect on meetings that had occurred. LFAB meetings were held on Wednesday evenings every 6 to 8 weeks. At each meeting we provided free childcare and a meal, and LFAB members received $30 cash remuneration for time and travel.

Board Evaluation

In the initial year we conducted a comprehensive multimodal evaluation of board activities and participation. Evaluation activities included 1) structured meeting observation to record meeting activities and group processes, 2) periodic member check-ins to assess member satisfaction, logistics (food, timing, etc.), and topics discussed, 3) a group reflection session at the final meeting, and 4) semistructured individual qualitative interviews (2 per participant) during which sociodemographic information was collected. In the second year, we continued evaluation using structured meeting observation and periodic member check-ins. Ten mothers on the board completed initial individual qualitative interviews with the board coordinator in their homes between October 2011 and January 2012 after attending one to three board meetings. The same mothers completed qualitative interviews between June and July 2012 after the first year of the LFAB concluded. We did not have sufficient funding to complete qualitative interviews after the first year. Interviews were digitally recorded and transcribed into English and Spanish. Staff members on the board (L.R.D., S.P.) participated in the qualitative coding and analysis. Themes identified in interviews were discussed during board meetings during the second year to confirm the analytic findings. A summary of interview findings are presented here; the results of the in-depth qualitative analysis of these interviews will be reported elsewhere. All mothers on the board signed informed consent for their participation on the board after the consent form was orally read to them and their questions answered. Additionally, mothers completed the informed consent process for each interview and received $25 per interview for participation. LFAB implementation and evaluation activities were approved by the Johns Hopkins Medicine Institutional Review Board.

RESULTS

Seven LFAB meetings were held during the initial year between September 2011 and June 2012. Thirteen mothers attended at least one LFAB meeting. Average meeting attendance was nine mothers (range, 6–12) accompanied by approximately 10 to 12 children. Of all first-year attendees, 10 mothers completed the qualitative interviews and sociodemographic surveys. Nine of these 10 women continued on as board members in the second year. The women who completed the qualitative interviews were immigrants from five different Latin American countries and were classified as having LEP as they all reported speaking English less than “very well” when responding to the U.S. Census Bureau question: “How well do

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you speak English?”[26,27] Most had less than a high school education and two or three children, the majority of whom were born in the United States. All of the mothers’ U.S.-born children were insured through Medicaid. Table 1 displays additional sociodemographic characteristics of these board members. We did not formally collect sociodemographic information on board members who did not participate in the qualitative interviews, but based on discussions during meetings they had similar sociodemographic profile, as did new board members in the second year.

First Year Activities Summary

Each board meeting followed the same format. For the first 30 minutes, attendees introduced themselves, ate dinner together, and heard announcements. Announcements focused on updates to clinic functioning, activities such as parenting classes or free legal aid sessions, and community events. The subsequent hour was devoted to focused work on clinic improvement. The first LFAB meeting consisted of a discussion of the positive and negative aspects of the clinic to identify future meeting topics. During that meeting a brief orientation was provided. This orientation covered the overall purpose of the board to improve clinic services to better meet the needs of immigrant Latino families and discussed the process of working as a group to develop expectations for membership and the conduct of meetings. The second meeting consisted of feedback on an oral health brochure designed for an existing clinic oral health promotion program in effort to create a tangible board product early on. Subsequent meeting topics were derived from the list of suggested areas for improvement generated at the first meeting based on mothers priorities for improvement. In general, board facilitators incorporated teaching for mothers into the clinic improvement activities. For example, when the board discussed recommendations for pharmacies to improve the experiences of LEP families obtaining prescription medication, part of the meeting was devoted to practicing dosing of liquid medications.

Board members discussed and decided on the board governance and structure and portions of some meetings were dedicated to discussion of these group processes, including establishing and then posting “group rules” at each meeting. Other practical applications of CBPR principles included having board members participate in meeting agenda creation, continuous evaluation of whether board structure, function, and future plans were consistent with families’ expectations, and establishing the goal of shared leadership of the board between clinic staff and board members. During periodic evaluation check-ins, LFAB members expressed satisfaction with participation and affirmed board logistics such as having food, childcare, and meeting timing. Although clinic staff on the board were concerned about lack of participation on the board by fathers, mothers on the board did not share this concern during check-ins and did not feel recruitment of male members should be pursued.

Second Year Activities Summary

Meetings maintained the same format as the first year. In addition to clinic improvement activities, selected guests attended LFAB meetings. LFAB activities involving these guests included 1) feedback on design of the new emergency department to hospital personnel directing that effort, 2) participation in the hospital community health assessment, and 3)

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feedback on a clinic-affiliated research project focused on improving neighborhood supports to decrease childhood overweight. Conducting the meetings in Spanish did not prohibit the participation of non–Spanish-speaking guests. For guests without Spanish proficiency, side interpretation was effective and did not disrupt meetings. Additionally, nonverbal communication and observation of group dynamics and personal expression were powerful adjuncts to interpretation for guests. During periodic check-ins, board members continued to be satisfied with their participation in the second year, and decided not to make changes to board logistics such as meeting times, although this was debated. Board members reported enjoying extending their reach beyond the clinic, although they stated that clinic improvement should remain the focus.

Board Evaluation

Process and Outcome Measures—Process and outcome measures used in in the evaluation of the first 2 years of LFAB implementation are displayed in Table 2. Clinic changes attributable to the board were improvements to the waiting room such as child-oriented decorations, a greater variety of magazines, and books for the children. The clinic also distributed new educational materials on oral health and implemented a new family support services brochure and intake checklist, all co-developed with the LFAB. Evaluation metrics were used in discussions with hospital leadership to obtain a commitment for continued LFAB funding.

Qualitative Interviews Summary—The qualitative interviews provided rich feedback on the board from the perspectives of non-staff participants. Mothers reported joining the board out of a desire to learn something, to contribute to improving the clinic, and because of a sense of maternal duty to participate in activities that may improve the services their children receive. Mothers valued learning opportunities resulting from LFAB membership. Importantly, mothers often expressed confidence about the validity and importance of their opinion in clinic improvement. One mother stated that the reason for the group was to solicit opinions from “the people who truly know what is going on in the clinic.” Board members also expressed that the group was respectful of the person speaking and of differences of opinion and reported positive relationships with staff members on the board, including lack of concern for adverse consequences if they expressed negative opinions about the clinic. No mothers expressed concerns about privacy; however, several stated that explicit expectations about maintaining confidentiality in the “group rules” were important to them.

When asked about the board’s accomplishments, members often discussed their contributions to an oral health brochure in use at the clinic and working with clinic staff on improvement. Mother’s expressed a high level of satisfaction with their LFAB participation in part owing to board accomplishments, but also owing to personal gains such as increased confidence in group settings, increased capacity to secure needed health care resources for their children, and increased interpersonal support owing to new relationships with other mothers in their community. In nearly all interviews, LFAB members mentioned how personal gains as a result of board participation countered marginalization and discrimination perceived and/or experienced in the community. Finally, mothers expressed optimism about the potential benefit of both patients at the clinic and Latino children in

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general in the community. Many members felt that forming the board itself was an achievement because before they had had “no voice or vote” and now a group had “taken account of Hispanics” and given them a “hope of a better service” for their children.

CONCLUSIONS

Establishing a family advisory group is one model for increasing patient engagement and patient-centeredness of the health care system, but reports of successful implementation of advisory groups inclusive of diverse populations are lacking in the literature.[2,4,7–10] Our experiences demonstrate that is it possible to sustain engagement of LEP families in a patient advisory group. Over 2 years, we maintained consistent attendance at advisory board meetings by a cohort of LEP Latina mothers. Although LFAB meetings were conducted in Spanish and members represented a patient population who in general are not included in advisory boards, LFAB accomplishments are similar to other reports of advisory boards. Achievements of ambulatory care advisory boards have included improvements to the clinic physical space and contributions to educational materials that were among the projects completed by the LFAB.[7,8]

During implementation, we used similar methods to other advisory boards to initiate and maintain engagement including direct provider invitation to the group rather than passive recruitment (i.e., waiting room flyers) to recruit a group reflective of the diversity in the larger clinic patient population, and tangible support for participation through the provision of a small stipend for participation, childcare, and a meal during evening meetings.[2,7–9] Board members stated that they would continue participation should compensation for attendance not be possible, but that it was valued. Advisory board evaluation data helped to sustain external financial support for the board and the ability to provide compensation for attendance. The approximately $3,500 annual operating costs could not be covered by the clinic because there was not sufficient extra clinical revenue. Other clinics serving primarily low-income, underserved populations may face similar lack of clinical revenue and so implementing remuneration, food, or childcare at meetings for advisory boards may not be feasible. We made funding concerns explicit with our group, to help them understand the process and the need for evaluation data to apply for funding. Prior experience with similar discussion during CBPR partnerships by staff on the board helped to facilitate discussions on this topic.

Although there are similarities between the LFAB and advisory boards in other clinical settings, our CBPR-informed approach seems to be distinct. We intentionally chose to use a CBPR-informed approach to partnership development given our experience with our local Latino community, members of which often face marginalization owing to their immigrant, LEP, and low-income status. Interviews with LFAB mothers consistently highlighted the unique opportunity available through the LFAB for their voice to be heard. A CBPR-informed approach assisted us in navigating feelings of marginalization and discrimination in a way that fostered partnership and trust with LFAB members. The social worker, who co-facilitated meetings and had more than 20 years of experience and relationships in the community, helped to serve as bridge between other staff members on the board who had less experience in the community. The explicit link between CBPR and successful patient

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engagement is nascent. However, information discussing frameworks for patient engagement reflect many concepts fundamental to CBPR.[1,3,8,9,28]

Application of CBPR principles to advisory board development is a useful, but not exact, match for the goals of patient engagement in health care. In patient engagement at the organizational level, the intended product is not a research project aimed to contribute to improved community health, but instead the goal is to improve a particular health care setting that may or may not be accessed by all community members. Health care improvements, however, may require application of research or quality improvement methods. Full integration of community members into the research process is often challenging for CBPR teams.[25] Similarly, our advisory board represents organizational-level engagement that has not yet reached the far end of the patient engagement continuum, in which patients/families are embedded within quality improvement projects and other clinical committees and have a voice that is valued equally with that of clinicians.[1] This kind of involvement might pose challenges for members of our advisory board owing to language, limited educational attainment by many group members, and lack of experience with any type of similar work setting. This should not preclude visioning this for the group.[3] In the initial years of the board, we have established a mutually respectful partnership with mothers who are actively involved in shaping the future of the group. The next step is to move onto shared leadership of the board, and then we can strategize about how best to fully integrate families into the clinical improvement process. As the field of patient engagement evolves, we expect that there will be more explicit discussions of the continuum of health care engagement. The lessons learned from CBPR likely will be increasingly relevant, especially among those health care systems seeking to engage vulnerable populations. The same communities that may be engaged through CBPR are patients in local health care systems and bring similar challenges of distrust and unequitable and negative interactions with “the system” to their health care experiences.

The value of advancing and enriching efforts at moving along the patient engagement continuum and devoting time and energy to partnership development depends, at least in part, on identifying outcomes that demonstrate the value of patient advisory groups. We did not focus on health care outcomes in our initial implementation. Other published reports of advisory groups, similarly lack evidence of health care impact.[2,4,7,8] When considering health care impact outcomes of advisory boards, several domains may be important to consider, including those at the advisory board participant level, individual-level clinical outcomes, and broader health system change. Other advisory boards have found patient advisory group members demonstrate improved individual-level health care engagement as a result of advisory board participation.[2] During qualitative interviews and board discussions, mothers reported participation improved their capacity to navigate the health care system and advocate for their child’s health needs. Another particularly relevant individual-level outcome in our population may be social support and an increase in board members’ social networks; immigrant Latinos often experience social isolation and limited social support.[29,30] Increased interpersonal support and expanded social networks were among the benefits of participation highlighted by mothers on the board.

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Among the possible individual-level clinical outcomes, improvements in the patient experience among all patients are commonly cited as a relevant outcome for advisory boards, although it is problematic to specifically attribute changes in patient experience solely to an advisory board.[2,8,9] As we work toward evaluating the health care impact of the group, we face barriers to adequately assessing the patient experience, without investing additional resources. Our clinic currently assesses the patient experience through a commercial service, but this has not resulted in meaningful feedback from LEP families. In 2012, our overall response rate was very low for Spanish-language surveys (2.14%). This challenge may not be unique to our setting. Data regarding success in achieving response rates that reduce non-response bias among LEP populations are not widely available. Other individual-level health care outcomes such as immunization rates or receipt of recommended screening could also be considered as potential areas of clinical outcome impact for an advisory board. The system-level impact of advisory boards could range from new clinic or community programs to changes in the health care organization strategic plan. How best to measure the contribution of the advisory group compared with other clinical or organizational processes to these outcomes is complex. Future research should explore measurement of the health care impact of advisory boards on individual-level clinical outcomes and across the health system more broadly.

Despite challenges in outcome measurement for advisory boards, there remains considerable promise for advisory groups to promote a more patient- and family-centered health system. Inclusion of vulnerable patients and families in patient engagement activities is critical to realizing the potential of patient- and family-centered care to generate much-needed improvements in health services delivery and reduce health care disparities. Our experiences with the LFAB demonstrate that, even among a traditionally hard-to-reach population, sustained engagement is possible and can generate positive change for primary care clinics and participating families. Policies that promote patient/family advisory groups should explicitly address how patient engagement opportunities will incorporate LEP patients and families and other vulnerable patient populations. Coincident with increasing health care engagement opportunities for vulnerable populations should be discussions of the distinct opportunities and challenges in engaging vulnerable populations along the continuum of engagement to achieve high-quality, safe, and equitable care for all patients.

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Table 1

Characteristics of LFAB Mothers Who Participated in Interviews (*n* = 10) and Their Children

Characteristic	**Value**
Maternal age (y), mean (range)	34 (22–42)
Maternal country of origin	
Mexico	5
Honduras	2
El Salvador	1
Argentina	1
Dominican Republic	1
Length of stay in United States (y), mean (range)	10 (3–21)
Maternal education (%)	
≤6th grade	40
Some high school	30
High school or more	30
Annual household income (%)	
< $20,000	80
Mother lives with husband/partner (%)	70
Mother's health status fair/poor (%)	20
Mean number of children (range)	2.6 (2–5)
Age of children (y), mean (median)	7.4 (4.9)
US-born children (%)	81
Children's health insurance status (%)	
Medicaid	81
Uninsured	19
Children's health status fair/poor (%)	7.7

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Table 2

Latino Family Advisory Board Evaluation Metrics and Findings

	Measure	Year 1	Year 2
Process Measures	No. of meetings held	7	6
	Board member retention	Average meeting attendance: 9 mothers Attended at least one meeting: 13 mothers (10 of these mothers completed qualitative interviews) 9 mothers attended 5 of the 7 meetings (All participated in qualitative interviews)	Retained 9 mothers who attended 5 of the 7 meetings in the first year (all had participated in qualitative interviews) Average meeting attendance: 9 mothers Four new mothers attended at least one meeting, 1 attended all meetings in year 2
	Clinic staff participation	Facilitators: social worker, pediatrician Meeting attendance by clinic director and additional pediatrician	Facilitators: social worker, pediatrician Meeting attendance by clinic director
	Hospital staff participation (attendance at 1 meeting each)	Hospital executive vice president Health leads supervisor for clinic desk	Community relations staff Research team member (study on childhood overweight) Emergency department team representatives (2) working on new building construction
	Generation of board charter and structure	Mothers decided to maintain clinic facilitators without other governance structure Mothers did not want to be involved in extra board planning meetings Generated “group rules” Mothers decided there would be no term limits or attendance requirements	Continued facilitator structure, although some interest in a mother taking on a leadership role Recommended that one mother work with board administrator outside of meetings to plan (implemented midway through year 2) Display of “group rules” poster during meetings Upheld no term limits, but some now desiring term limits to increase opportunity for others to participate
	Recommendations provided to clinic	Presented at monthly clinic provider meetings (both years)	
	Recommendations provided to hospital	Presented during biannual feedback sessions between hospital leadership, clinic director, and co-facilitator (both years)	
	Creation of a work plan for future projects	Contribute more to hospital access projects for Spanish speakers, improving child friendliness of waiting room	Contribute to orienting new families to clinic and clinic community bulletin boards, and improving access/use of patient portal
	Group dynamics	Structured observation notes positive group processes and ratings for specific items consistently 2 or 3/3 Mothers positively assess group dynamics in interviews	Structured observation findings consistent with first year

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	Measure	Year 1	Year 2
Outcome Measures	Clinic changes in response to recommendations	Prioritized increasing sick care access including working to improve phone triage system	Implementation of waiting room improvements Implemented use of new family support services brochure and intake form
		Modified process to access social work and other family support services	Meeting planned to discuss board member feedback with local Medicaid managed care organization insuring most clinic patients
		Implemented Spanish-language brochure in oral health promotion program	Will display Spanish-language brochure in clinic detailing use of web-based secure patient portal
		Applied for internal grant to improve child-friendliness of waiting room	Revision of types of physical activity toys to be given out at well visits
	Hospital changes in response to recommendations	Improving signage for non–English-speaking populations	Amended ED plans reflect some board recommendations
		More formal assessment of Latino patient needs and inclusion in patient engagement programs	Latino health a priority topic for community benefit work Board contributed to justification for institutional formation of Center for Latino Heath
	Dissemination products	News story on internal website	Presentation at regional/national academic meetings (n = 4) In-print hospital news story Featured in national website news story
	Board member satisfaction	Check-ins, qualitative interviews, and group reflection session all revealed a high level of satisfaction	Continued high-level of satisfaction identified during check-ins