



INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

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Patient and Family Leaders in Paid Positions 2011 Salary Survey Results

Overview

Health care systems are increasingly recognizing the importance of establishing paid positions for patient and family leaders, and there is growing evidence that more organizations are indeed bringing patients and families to the table in expanded roles. Whereas patient- and family-centered health care organizations rely on partnering with patients and families in many ways as volunteer advisors to improve operations and the experience of care, many of these volunteer advisors are now interested in serving their health care system in a greater capacity—in a paid position as patient or family leader—to enhance quality and safe health care.

The Institute for Patient- and Family-Centered Care frequently receives requests for information from patient and family leaders, as well as from organizations planning to budget for a position for a patient/family leader. In March 2010, the Institute launched its first *Patient and Family Leaders in Paid Positions* survey to respond to these requests. As a survey such as this had never been undertaken, this survey was designed to offer a baseline for data relating to patient and family leaders in paid positions within health care organizations (e.g., salary ranges, position titles, and roles and responsibilities). The survey generated much interest from patient and family members hoping to expand their volunteer roles into paid positions as well as from health care executives preparing to advance patient- and family-centered practice by hiring experienced and valued consumers.

The survey responses offer a snapshot of the trends for actively engaging patients and family leaders as paid employees. Survey results reflect the importance of expanding the value of these partnerships by bringing patients and families in as part of the health care team and to effectively use their experiences in day-to-day operations to represent the voices of patients and families.

In an effort to support patient and family leaders and organizations as they budget for creating new roles for patients and family leaders, the Institute expanded the scope of the 2011 survey by adding questions about:

- 1) The region to reflect the respondent's location of employment
- 2) Salary in regards to the title/region
- 3) Funding allocation

4) Position information of the paid patient/family leader.

Survey Structure

To learn more about patients and family members in paid positions, the Institute created an informal voluntary survey (SurveyMonkey™) and invited patient and family leaders who have been hired by their health care organization as employees to participate. Health care executives were invited to participate in the survey only if a paid patient/family leader position was vacant but would be filled. The survey was made available on the Institute's website as well as distributed to the PFAC listserv.

A committee of patient and family leaders representing a variety of health care organizations assisted in the development of the survey questions to ensure that the data collected would be beneficial to those seeking paid positions within a health care organization.

This 2011 survey featured 21 questions with several open-ended questions as well as 'select all that apply' choices. The survey yielded 185 responses over a three-week period in July 2011. However, only 140 responses met the criteria to be included in the analysis of the results.

The 2011 *Patient and Family Leaders in Paid Positions* survey results were highlighted at the *Hospitals and Communities Moving Forward with Patient- and Family-Centered Care* Intensive Training Seminar, Madison, WI, November 7-10, 2011, in the session, *Creating Paid Positions for Patient and Family Leaders: Key Considerations*.

Survey Summary

Of those responding to the survey, a little more than half (51.8%) of the participants had never worked in a hospital/health system before being hired in their current role as a patient/family leader. Of the 48.2% who had been employed previously in a health care setting before being hired in a paid patient/family role, their former titles represent a wide-range of positions from therapist to family support specialist to health literacy specialist. Comparatively, the 2010 survey reflected that 65% of respondents had not previously worked in a health care system before being hired in their current role as a patient/family leader.

Length of Time in Position

The majority of patient and family leaders completing the survey (33.3%) have been in their current paid patient/family leader position for 3 to 5 years, whereas 9.6% have been in this role more than 9 years. Those having been in their position for less than a year represent 21.9% of the survey respondents, and equally, 21.9% have been in this role for more than 1 to 2 years. Also, 13.2% have been in employed for 6-8 years. (See Figure 1. Q4-Length of Time in Paid Position)

Full/Part-time Status

More than half of the survey participants work full-time (55.3%) with 44.7% hired on a part-time basis. In the 2010 survey, 67% of respondents reported that they had full-time positions. This comparison does not necessarily indicate a shift in trends but may reflect the difference in survey respondents. (See Figure 2. Q11-FTE Status)

Educational Background

Paid patient and family leaders had a strong educational background with 90% of the respondents earning college degrees—47.4% earning a college degree and 43% obtaining a Masters degree. Only 6.1% received a high school diploma as their highest educational status. Those receiving their Doctorate represented 3.5% of respondents (*See Figure 3. Q5-Education Level*)

Position Titles/Departments

The survey reveals a variety of position titles of paid patient/family leaders with 114 different responses. The titles have been categorized and each title has been assigned to a category that most accurately represents the appropriate category. The categories are: Administration (Manager, Director, VP), Mentor, Patient- and Family-Centered Care Consultant, Patient- and Family-Centered Care Coordinator, Patient/Family Leader (Specialist, Advocate), Service-Line Oriented, and Other (*see Table 3. Q6-Titles*). The department that has supervisory responsibility for the paid position is also indicated (*see Table 4. Q7-Departments with Supervisory Responsibility for Paid Patient/Family Leaders*).

Table 3. Q6-Titles

Patient/Family Leader (Specialist, Advocate)	30%
PFCC Administrator (Manager, Director, Vice President)	30%
PFCC Coordinator	28%
Service-line Oriented	4%
PFCC Consultant	4%
Mentor	3%
Other	1%

Table 4. Q7-Departments with Supervisory Responsibility for Paid Patient/Family Leaders

Patient- and Family-Centered Care	29%
Administration	11%
Pediatrics	9%
NICU	9%
Quality	6%
Nursing	6%
Community Home Health	6%
Clinical Services	6%
Center for Families	4%

Region

New to the 2011 survey, respondents indicated their region of employment. Of those participating, 21.9% represented the Pacific region (Alaska, Washington, Oregon, California, Hawaii), followed by the South Atlantic region (Delaware, Maryland, District of Columbia, Virginia, West Virginia), and Mid-Atlantic region (New York, Pennsylvania, New Jersey) with 14% each. Canadian respondents represented 9.6% of the region and are categorized as “Outside the US.” To see other respondent regions, see *Figure 4. Q8-Region*.

Position Data

In their paid positions, only 34.9% of patient/family leaders supervise other employees and 65.1% do not supervise other employees.

Respondents indicated the primary populations they work with in their organization. They chose from multiple responses based on their areas of service and their supervisory roles. Not surprisingly, more than half (53.5%) work in pediatrics, 36.8% work with the NICU population, and 13.2% work in adult services. Several other population areas were identified. Almost equal, 43.9% of respondents reported primarily working in outpatient services while 40.4% worked in inpatient services, and 24.6% indicated that they worked in all areas. *(See Figure 5. Q9-Primary Populations)*

Paid patient and family leaders reported that 28.9% work with 1-2 others in their department, 27.2% have 3-5 colleagues working with them, and 7% have a team of 6-10 in their department. Accordingly, 22.8% of the respondent's work as the sole employee in their department. *(See Figure 6. Q10-Number of Employees in Department)*

Individuals working as paid patient/family leaders are accountable to a variety of supervisors according to the survey. The organizational hierarchy appears to determine the reporting structure based on the table below. *(Table 5a. Q14-Title of Supervisor)*

Table 5a. Q14-Title of Supervisor

Director of Patient- and Family-Centered Care	13.2%
Chief Nursing Officer	10.4%
Administrative Director (service line)	9.4%
Supervisor	8.5%
Nurse Manager	5.7%
Director, Volunteer Services, Child Life, Patient- and Family-Centered Care	5.7%
Chief Executive Officer	5.7%
Nursing Administrator	4.7%
Director of Family Services	4.7%
Department Chair	4.7%
Vice President of Office of Patient-Centeredness	3.8%
Hospital Administration	3.8%
Director of Patient Care	2.8%
Director of PFCC, Social Work, Child Life, Spiritual Care	2.8%
Director of Clinic Operations	2.8%
Director of Child and Family Support Services	2.8%
Coordinator of Patient- and Family-Centered Care	2.8%
Director of Social Services	1.9%
Senior Vice President	1.9%
Other	1.9%

The following other service areas are included in the same department as the paid patient/family leader: *(Table 5b. Q15-Services Areas in Department)*

Table 5b. Q15-Service Areas in Department

Department	
Social Work/Social Services	18.1%
Patient Experience	18.9%
Volunteer Services	16.5%
Pastoral Care	12.6%
Quality	12.6%
Multi-Department Areas	9.4%
Child Life	3.1%
Education	2.4%
Patient Relations/Services	2.4%
Clinical	1.6%
Patient Educators	1.6%
None of the Above	0.8%

According to the survey results, 65.1% paid patient and family leaders do not supervise other employees, however, 50% of them do supervise a variety of volunteers. Of the 34.9% paid patient/family leaders who supervise other employees, individuals with positions in the following categories report to them: *(Table 5c. Q16-Titles Reporting to Paid Patient/Family Leader)*

Table 5c. Q16-Titles Reporting to Paid Patient/Family Leader

Patient/Family (Mentors, Advisors)	40%
Administrative Staff	29%
Service Staff	14%
Clinical Staff	11%
Patient/Family Consultants	6%

Funding Allocation

More than half of the budgeting for paid patient and family leader positions are funded through department budgets (52.6%) and 21.1% reflect funding from their organization's general operational budget. Other funding sources include grants (10.5%), Foundations (7%), and partnerships with other organizations (.9%) as well as multiple sources or blended funds. *(Figure 7. Q13-Funding Allocation)*

Scope of Activities for Patient/Family in Paid Position

As paid patient/family leaders, respondents highlighted services and projects that they are responsible for performing *(see Table 6. Q18-Scope of Activities):*

Table 6. Q18-Scope of Activities

Patient/Family Advisors	14%
Education/Orientation	14%
PFCC Programming	10%
Mentoring/Peer/Support	7%
System Committee Participation	7%
Communication	4%
Quality/Safety	4%
Medical Education	3%
PFCC Clinical Services	3%
PFCC Resources	3%
Systems Level Programs	3%
Patient Satisfaction	3%
Policy Development	3%
Process Improvement	2%
Service Excellence	2%
Patient Experience	2%
Bereavement/Palliative	1%
Facility Design	1%
Family Resource Center	1%
Performance Improvement	1%
PFCC Rounds	1%
Volunteer Programs	1%
Community Liaison	1%
Ethics	1%
Navigation Services	1%
PFCC Research	1%
Cultural Diverse Programs	1%
Medical Home	1%
PFCC Annual Awards	1%
Sibling Issues	1%
Transition	1%
Website	1%
Family Presence	1%

PFCC Consultant

	East North Central	East South Central	Mid-Atlantic	Mountain	New England	Pacific	South Atlantic	West North Central	West South Central	Canada
\$10,000 - \$25,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
\$26,000 - \$40,000	0%	100%	0%	0%	0%	0%	100%	100%	100%	0%
\$41,000 - \$55,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
\$56,000 - \$70,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
\$71,000 - \$85,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
\$86,000 - \$100,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Over \$100,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%

PFCC Coordinator

	East North Central	East South Central	Mid-Atlantic	Mountain	New England	Pacific	South Atlantic	West North Central	West South Central	Canada
\$10,000 - \$25,000	14%	0%	0%	50%	50%	0%	33%	29%	100%	50%
\$26,000 - \$40,000	29%	0%	0%	0%	0%	33%	33%	14%	0%	50%
\$41,000 - \$55,000	29%	0%	75%	50%	50%	0%	0%	29%	0%	0%
\$56,000 - \$70,000	14%	0%	25%	0%	0%	67%	0%	29%	0%	0%
\$71,000 - \$85,000	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%
\$86,000 - \$100,000	0%	0%	0%	0%	0%	0%	33%	0%	0%	0%
Over \$100,000	14%	0%	0%	0%	0%	0%	0%	0%	0%	0%

Patient/Family Leader (Specialist)

	East North Central	East South Central	Mid-Atlantic	Mountain	New England	Pacific	South Atlantic	West North Central	West South Central	Canada
\$10,000 - \$25,000	33%	100%	75%	0%	100%	18%	29%	0%	0%	33%
\$26,000 - \$40,000	33%	0%	0%	0%	0%	73%	29%	0%	50%	33%
\$41,000 - \$55,000	33%	0%	0%	0%	0%	9%	43%	0%	0%	0%
\$56,000 - \$70,000	0%	0%	0%	0%	0%	0%	0%	0%	50%	0%
\$71,000 - \$85,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
\$86,000 - \$100,000	0%	0%	25%	0%	0%	0%	0%	0%	0%	0%
Over \$100,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	33%

Service-line Oriented

	East North Central	East South Central	Mid-Atlantic	Mountain	New England	Pacific	South Atlantic	West North Central	West South Central	Canada
\$10,000 - \$25,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
\$26,000 - \$40,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
\$41,000 - \$55,000	0%	0%	0%	0%	100%	0%	0%	0%	0%	0%
\$56,000 - \$70,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
\$71,000 - \$85,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
\$86,000 - \$100,000	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Over \$100,000	0%	0%	100%	0%	0%	100%	0%	0%	0%	0%

Goals for Paid Patient/Family Leaders

The top projects/goals that paid patient/family respondents plan to achieve this year include (listed in order of most selected): (*Table 7. Q19-Goals*)

Table 7. Q19-Goals

Patient and Family Advisory Councils (PFAC)/Advisors (Expand Existing)	Advisor Certification
Expand PFCC Programs	Culture Change
PFAC (Create)	Engage Staff
Patient Satisfaction	Education (Patient/Family)
Clinic PFCC Programming	PFCC Resources
Education (Staff)	Patient Satisfaction
Support/Mentoring/Peer	Facility Design
Culture Change	Increase PFCC Staffing
Expand Patient/Family Services	Medication Reconciliation
PFCC Outreach	PFAC Guidelines
Transition Programs	PFCC Resources
Budget/Finances	PFCC Rounds
Create Annual PFCC Conf	PFCC - Staff Evaluation
Education (Medical)	Process Improvement
PFAC/Advisors (Culturally Diverse)	Quality Improvement
"Dad" Involvement Program	Research/Evaluation
Achieve Organization's Goals	Title Change for Paid Leader
	Web Design

Accomplishments

Paid patient/family leaders reported their top accomplishments listed in the table below:

Table 8. Q20-Accomplishments

PFCC New Programs	15.2%
PFCC Training Series	14.1%
Expanded Patient and Family Advisory Council (PFAC)	13.1%
PFCC Visibility	9.1%
Expanded PFCC Programming	5.6%
Filled Paid Patient/Family Position	5.1%
Created PFAC	4.5%
24hr. Family Presence	4.0%
Established Peer to Peer/Mentor Program	2.5%
Expanded Education	2.5%
Cultural Programming	2.0%
Attended IPFCC Seminar	1.5%
Bedside Rounds	1.5%
Facility Design	1.5%
Patient/Family Engagement-Mission	1.5%

Top Challenges for Advancing the Practice of Patient- and Family-Centered Care
 Respondents chose the top three challenges they face in their paid roles. The top three challenges included: Changing the Culture (41.9%), Funding/Budget (35.5%), and Too Many Opportunities—Not Enough Time to Implement (33.3%). Other top challenges include: Moving to the Next Level of Patient- and Family-Centered Care (30.1%) and Resistance to Change from Nurses and Other Staff (28%). (See Table 9. Q21-Challenges)

Table 9. Q21-Challenges

Changing the culture within the entire organization	41.9%
Funding/budget	35.5%
Too many opportunities—not enough time to implement initiatives	33.3%
Moving to the next level of patient- and family-centered care	30.1%
Resistance to change from nurses and other staff	28%
Orientation/Ongoing staff education	23.7%
Leadership buy-in/support	18.3%
Getting physicians onboard	24.7%
Diversity of patient and family advisors	26.9%
Bureaucracy/organization politics	14.0%
Limited or no staff support	7.5%
Ensuring that legal obligations are met	1.1%
Other	11.8%

Conclusion

After the initial survey results were released in 2010, the Institute received responses from patient and family leaders stating that the information provided the impetus to move a volunteer position forward into a paid position or provided a means to increase their salary, or upgrade their title. This information was also used to support efforts of patient and family leaders as they proceeded to create new paid positions within their health care organizations. Likewise, health care executives reported that they utilized the survey results to more fully integrate patient- and family-centered care as they worked to create paid positions for patient and family leaders.

It is the hope of the authors of this survey that the 2011 results will continue to support the efforts of patient and family leaders in paid positions and encourage organizational commitment to advance the practice of patient- and family-centered care.

Resources:

To see samples of position descriptions from health care organizations, go to:

<http://www.ipfcc.org/tools/position.html>

To read about patient and family leaders in paid positions, go to:

<http://www.ipfcc.org/advance/pafam.html>

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Appendix

Figure 1. Q4-Length of Time in Paid Position

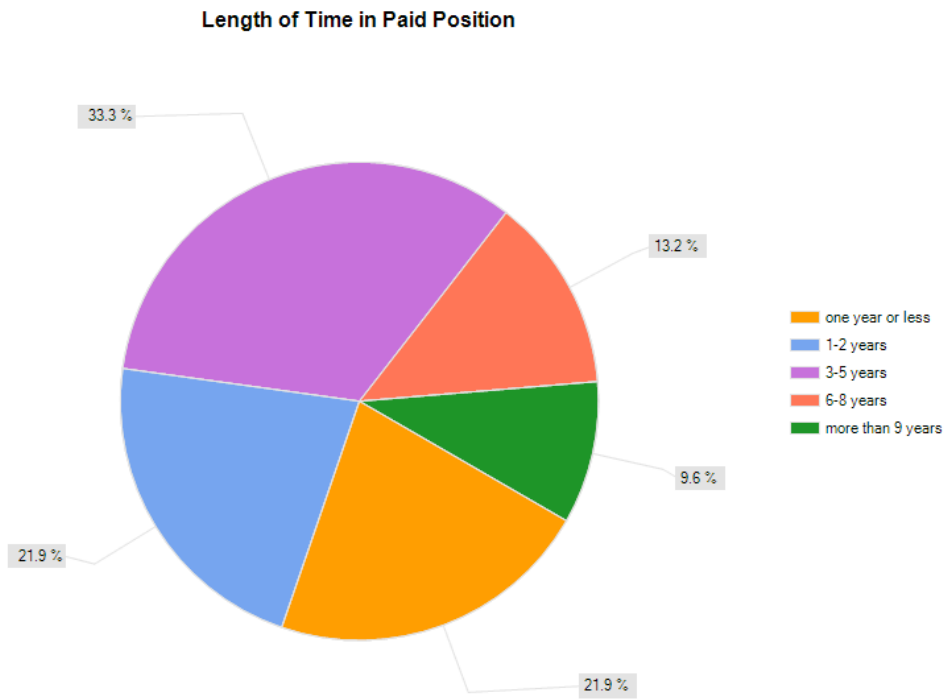


Figure 2. Q11-FTE Status

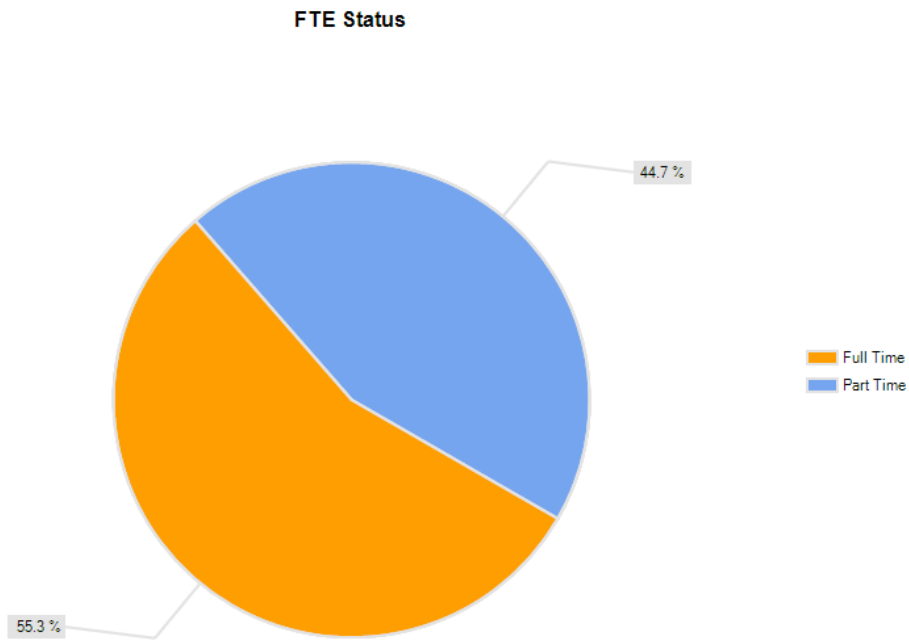


Figure 3. Q5-Education Level

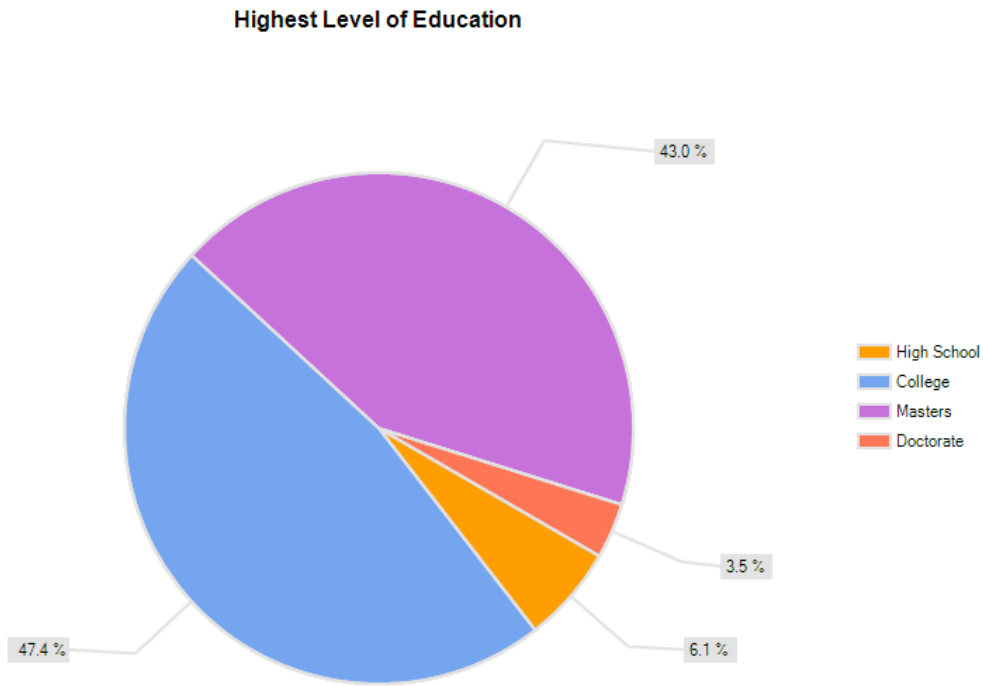


Figure 4. Q8-Region

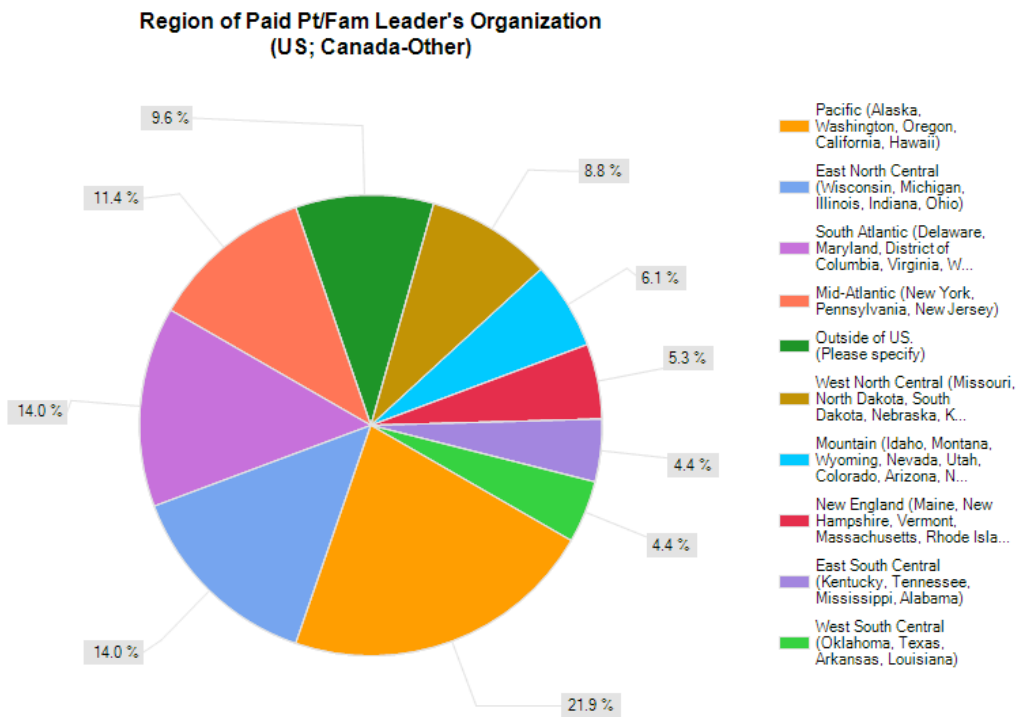


Figure 5. Q9-Primary Populations

Primary Work Areas Represented

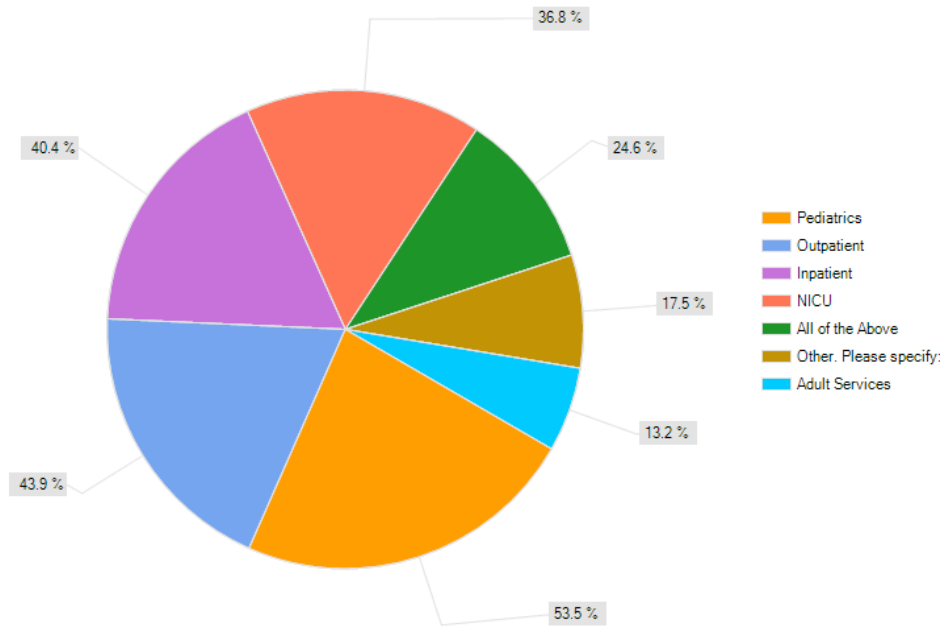


Figure 6. Q10-Number of Employees in Department

Number of Employees in Department

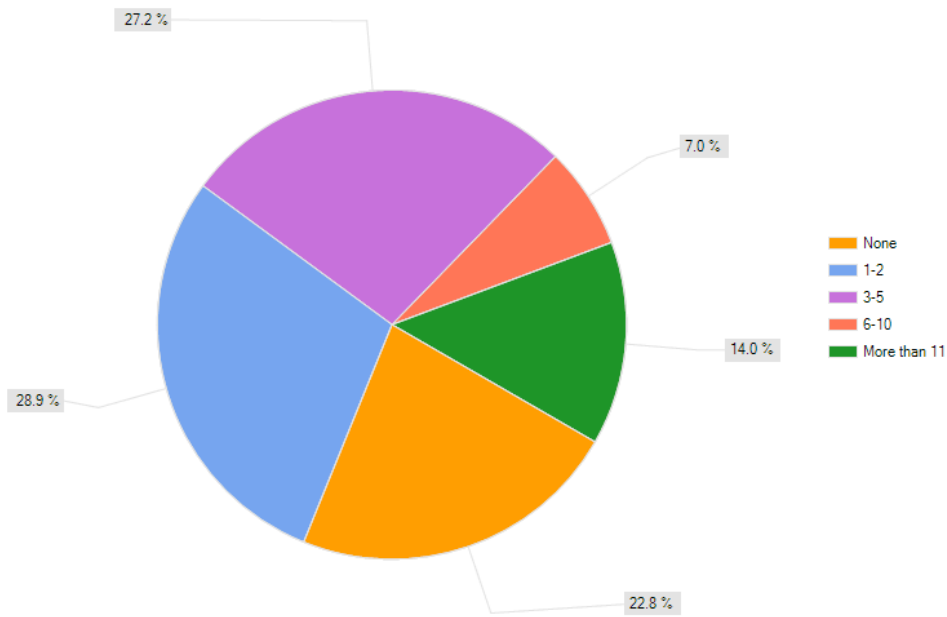


Figure 7. Q13-Funding Allocation

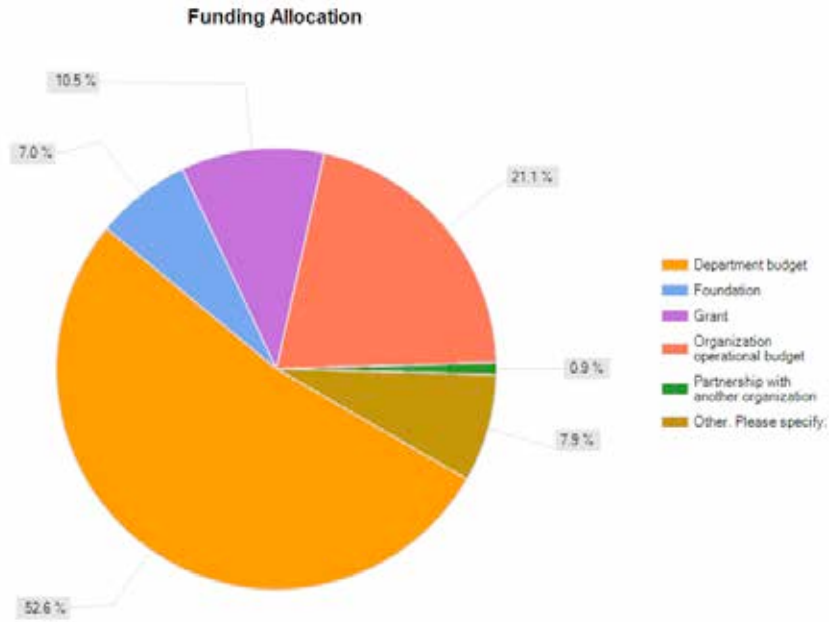


Figure 8a. Q12-Salary Ranges

A. Full-time

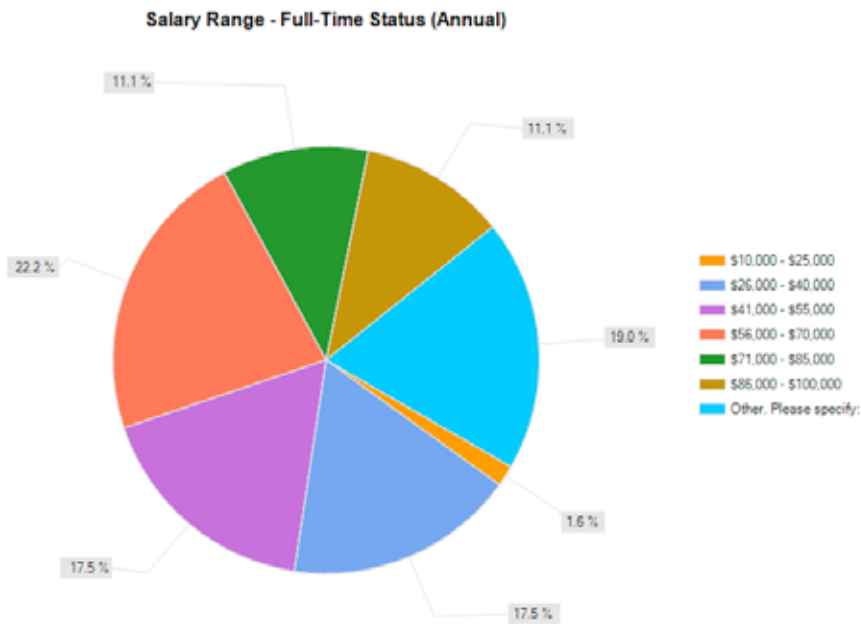


Figure 8b. Q12-Salary Ranges
B. Part-time

