

Determining the Feasibility of Evaluating the National Vaccine Injury Compensation Program

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I. Executive Summary

Overview

Vaccinations against once-common childhood illnesses such as diphtheria and polio have all but eradicated these and other diseases. Unfortunately, however, for a very small number of people, vaccinations themselves may cause adverse events. In the late 1980s, as litigation by injured parties mounted, many vaccine companies stopped manufacturing vaccines, leading to widespread shortages of key childhood immunizations. To curb the growing number of lawsuits while addressing the needs of injured patients and families, Congress established the National Vaccine Injury Compensation Program (VICP) in 1988. As a “no-fault” program, the VICP provides liability protections for vaccine companies and health care providers who administer vaccines. The VICP, recognizing that families come to the Program having suffered a devastating injury or loss, works to compensate families “quickly, easily, and with certainty and generosity.”

In September 2005, the Department of Health and Human Services, Division of Vaccine Injury Compensation (DVIC) contracted Altarum Institute (formerly Health Systems Research) to conduct an evaluation feasibility study of the VICP. Although specific components of the VICP had been evaluated, the entire program had not undergone a comprehensive, independent evaluation. Through this feasibility study, Altarum Institute (Altarum) recommended several possible evaluation approaches. Of these, DVIC opted to survey VICP petitioners to assess their satisfaction with access to the Program, with its claims process and determination of damages, and with the VICP overall.

To this end, Altarum developed a petitioner satisfaction survey to assess three key issues:

- Do petitioners feel capable of navigating the legal process?
- Do petitioners feel that the decision on their claim was reached in a timely manner?
- Do petitioners who receive financial awards feel that the amount is adequate?

The survey results point to several steps through which DVIC could improve the VICP process—from disseminating information to resolving claims—so that petitioners find an accessible program that responds to their needs and circumstances.

Evaluation Design and Methodology

Altarum researchers developed a 32-question survey to examine petitioners’ perceptions of four key issues: access to VICP information, Program implementation and processes, financial award decision, and overall satisfaction. One hundred and seven petitioners completed the survey, yielding a response rate of 23.88%. Evaluators used qualitative and quantitative data analyses to assess responses, using descriptive statistics for closed-ended questions and developing a coding scheme for open-ended questions.

Key Findings and Recommendations

The evaluation underscores the importance of refining the VICP to expand its reach and to better meet the needs of petitioners. In particular, the evaluation found that:

- Certain populations were underrepresented among VICP survey respondents, especially racial and ethnic minorities, low-income families, and individuals with lower educational levels; however, due to the low response rate, the population of survey respondents may not be representative of the population of VICP petitioners;
- Although petitioners were generally satisfied with the method through which the financial award was paid, most were dissatisfied with the lengthy claims process (an average of 3.5 years); and
- Petitioners who received a financial award responded more positively to the Program than did those who had not.

These findings point to several areas in which DVIC might work to improve the VICP process, making it more accessible and responsive to petitioners.

Continue to elicit VICP petitioner feedback on the claims process. Continued feedback from VICP petitioners can inform process improvements. Development of a mechanism to elicit routine VICP petitioner feedback on the claims process could accomplish two main goals: first, it may result in a higher response rate, thus allowing feedback to be reflective of and generalized to the entire population VICP petitioners; and second, feedback may be more accurate, because the length of time between the petitioners' experience with the claims process and receipt of feedback would be minimized.

Conduct future evaluations that elicit a diversity of perspectives. To obtain a more comprehensive view of the Program, DVIC might consider obtaining periodic feedback and input from a broad range of stakeholders, beyond petitioners. Key stakeholders who might have other perspectives about the Program include petitioners' attorneys; staff from DOJ, DVIC, and the Court; life care planners; and health care providers who administer vaccinations.

Continue outreach efforts to build awareness of the VICP. One component of the VICP's mission is to "raise awareness of the existence of the VICP."¹ The skewed demographic distribution of survey respondents suggests that the VICP should continue its outreach efforts, specifically targeting hard-to-reach populations, including racial and ethnic minorities and low-income individuals. Raising awareness requires carefully balancing messages that market the availability of the VICP to families who experience an adverse event with messages that encourage and promote childhood immunization.

Consider options to streamline the claims process. VICP stakeholders have recognized the need to streamline the claims process, which petitioners have also found to be a lengthy process. A Work Group comprised of stakeholders, including petitioners and attorneys, might be convened to prioritize streamlining efforts. It is important to acknowledge that the length and navigability of the process is

¹ Division of Vaccine Injury Compensation, Healthcare Systems Bureau, Health Resources and Services Administration, Department of Health and Human Services. (2006). *National Vaccine Injury Compensation Program Strategic Plan*. Retrieved March 26, 2009, from ftp://ftp.hrsa.gov/vaccinecompensation/strategic_Plan_20060411.pdf.

affected not only by the VICP, but is heavily influenced by the attorney-VICP and attorney-petitioner interfaces.

Although widespread immunization has been a mainstay of public health for more than 100 years, a very small percentage of individuals will suffer adverse events as a result of being immunized. For these individuals, the VICP is essential to addressing their financial needs and personal loss. At the same time, it offers a no-fault alternative to the traditional tort system, ensuring that vaccine companies can continue their research and development activities and health care providers can continue to administer vaccines. Although this study demonstrates that the VICP has performed its duties and responsibilities adequately, it also points to areas in which changes might improve the claims process. In particular, the VICP should continue to conduct outreach to racial and ethnic minorities and low-income families and streamline the claims process. With the VICP, the government demonstrates its commitment not only to public health, but to those individuals who, through tragic and unforeseen circumstances, suffer unintended consequences in efforts to protect against communicable diseases.

II. Introduction

The Vaccine Injury Compensation Program

In the early 1980s, news reports suggested that the DTP (diphtheria, tetanus, and pertussis) vaccine might cause serious side effects. As a result of these reports, vaccine companies and health care providers who administered vaccines faced a sharp increase in lawsuits filed on behalf of children who experienced adverse events, such as brain damage and death.² Consequently, a number of vaccine companies reduced or altogether ceased vaccine production. In fact, between 1984 and 1987, the number of companies licensed to make vaccines dropped from 15 to three.³ This resulted in DTP vaccine shortages, which, in 1984, led the Centers for Disease Control and Prevention (CDC) to recommend delaying booster shots for pertussis for children more than one year old. Concerns about an increased incidence of pertussis and other communicable diseases in unprotected children spurred government and public health officials to take action.⁴

To address the vaccine shortage, the growing uncertainty of new vaccine research and development, and the looming threat of disease outbreaks, a group of doctors, public health organizations, vaccine companies, and private citizens began to campaign for protective legislation for resolving vaccine injury claims. Their efforts encouraged Congress to enact the National Childhood Vaccine Injury Act of 1986 (the Act), which featured two key goals: (1) to compensate individuals injured by certain vaccines “quickly, easily, and with certainty and generosity;”⁵ and (2) to provide liability protection to vaccine companies and health care providers who administer vaccines. The Act established the National Vaccine Injury Compensation Program (VICP), which began on October 1, 1988. Legislators believed that once the Act was implemented, the vaccine market would stabilize.⁶

The new VICP legislation established a “no-fault” compensation program for individuals injured by certain vaccines and specified protections for vaccine companies and health care providers who administer vaccines. Under the legislation, an individual who believes that he or she was injured by a vaccine must go through the VICP before litigation can be initiated against a vaccine company or an administering health care provider. After completing the VICP proceedings, an individual may elect to reject the findings, regardless of whether a financial award is made. Only then may the injured individual file suit against a vaccine company or health care provider.

The Act also established a Vaccine Injury Table (the Table), which covers all vaccines recommended by the CDC for routine administration to children. Vaccines currently covered include: diphtheria, tetanus, pertussis (DTP, DTaP, Tdap, DT, TT or Td); measles, mumps, rubella (MMR or any component); polio (OPV or IPV); hepatitis A (HAV) and hepatitis B (HBV); Haemophilus influenzae type b (Hib); varicella (VZV); rotavirus (RV); pneumococcal conjugate (PCV); influenza [trivalent] (TIV, LAIV); meningococcal conjugate and polysaccharide (MCV4, MPSV4); and HPV (human papillomavirus). The Table lists compensable injuries or conditions and the timeframes within which onset must occur to be considered

² Levine, R. (December 16, 1984) Ideas & trends; risk forces out vaccine maker. *The New York Times*, A:7 Retrieved March 15, 2009.

³ Gailey, P. (October 20, 1986) Legislators head home after final flurry of bills. *The New York Times*, B:12 Retrieved March 15, 2009.

⁴ Engelberg, S. (December 19, 1984) Vaccine: Assessing risks and benefits. *The New York Times*, C:1 Retrieved March 15, 2009.

⁵ Pub. L. 99-660, title IV, Sec. 402, Nov. 14, 1986, 100 Stat. 3784.

⁶ Pub. L. 99-660, title IV, Sec. 402, Nov. 14, 1986, 100 Stat. 3784.

adverse vaccination events. The Table may be modified to include newly recommended childhood vaccinations; the addition or removal of injuries, or adjustment of the time period during which injuries may occur to qualify for compensation.

The Act also established guidelines to determine who may be compensated through the VICP. An individual who demonstrates an injury listed on the Table within the time period specified may be eligible to receive compensation. For non-Table injuries, or Table injuries falling outside the prescribed time intervals, compensation is possible by proving vaccine causation. Individuals also may receive compensation by proving that the vaccine significantly aggravated a pre-existing condition. However, proving vaccine causation or significant aggravation requires scientific evidence and/or expert medical testimony. Compensation may be paid to vaccine-injured parties for past and future non-reimbursable medical and rehabilitative care, lost earnings, and pain and suffering. For a death, the estate of the deceased individual may receive up to \$250,000. Additionally, attorneys' fees and costs may be awarded even if compensation is denied, as long as the U.S. Court of Federal Claims (the Court) determines that the petition was brought in good faith and that there was a reasonable basis for the claim.

In 1987, Congress established the Vaccine Injury Compensation Trust Fund (the Trust Fund) to compensate individuals injured by vaccines administered on or after October 1, 1988. The Trust Fund is funded by a \$0.75 excise tax on each dose of covered vaccine purchased.

The National Childhood Vaccine Injury Act of 1986 has been amended numerous times since its passage. Significant amendments and changes to the Act include:

- The creation of the VICP's funding mechanism (the Trust Fund);
- The naming of the Court to hear vaccine injury claims;
- Requirements to develop rules to make proceedings "less adversarial, expeditious, and informal";
- The authorization of special masters to make initial decisions on petitions;
- The direction of the Secretary of the Department of Health Human Services (HHS) to undertake "reasonable" efforts to inform the general public about the VICP; and
- Removal of the requirement that awards should be paid in four equal annual installments and the encouragement of the use of annuities for financial awards.

The Evaluation

In September 2005, HHS, Health Resources and Services Administration (HRSA), Healthcare Systems Bureau (HSB), Division of Vaccine Injury Compensation (DVIC) contracted Altarum Institute (formerly Health Systems Research, Inc) to conduct an evaluation feasibility study of the VICP.

DVIC solicited the feasibility assessment in response to the results of the Office of Management and Budget's (OMB) 2005 Program Assessment Rating Tool (PART). PART is intended to identify program strengths and weaknesses by examining factors relating to performance, including program purpose and design, performance measurement, evaluations, strategic planning, program management, and program

results. Although evaluation reports had been issued on specific components of the VICP (in 1992 and 1999), there had been no comprehensive, independent evaluation in the VICP's 18-year history.⁷

The feasibility assessment informed the design of a set of realistic and manageable evaluation options that responded to the needs of DVIC, the U.S. Department of Justice (DOJ), the Court, Congress, and other stakeholders. The evaluation options Altarum presented to DVIC included studies to:

- Assess petitioner satisfaction;
- Determine the effect of processes and stakeholder interactions on claims processing;
- Assess sufficiency of financial awards;
- Assess communication and outreach efforts;
- Assess scope and effectiveness of the Advisory Commission on Childhood Vaccines (ACCV) (which, among other activities, considers proposals for revisions to the Table and makes recommendations on Table revisions to the Secretary of HHS);
- Determine the effect of the Expert Witness Program (medical experts who testify at vaccine injury hearings on behalf of HHS) on claims preparation and presentation;
- Assess consistency of claims processing and award disbursement;
- Assess the effect of the DVIC Medicaid waiver/lien forgiveness negotiation; and
- Explore petitioner use of financial awards.

Based upon the scope of the evaluation and in consultation with ACCV, DVIC decided to pursue a petitioner satisfaction survey.

⁷ Office of Management and Budget. (2005). *Vaccine Injury Compensation Program Assessment* (No. 10003807). Retrieved March 14, 2009, from <http://www.whitehouse.gov/omb/expectmore/detail/10003807.2005.html>.

III. Evaluation Design

Purpose

This study aims to assess the extent to which petitioners are satisfied with the VICP. In particular, stakeholder groups raised the following questions:

- Do petitioners feel capable of navigating the legal process?
- Do petitioners feel that the decision on their claim was reached in a timely manner?
- Do petitioners who receive financial awards feel that the amount is adequate?

The evaluation surveyed VICP petitioners who had completed the claims process within the last five years to assess the extent to which the process functioned as intended and to measure petitioner satisfaction with the process and its outcomes. Survey results were analyzed and form the basis for recommendations to DVIC on ways to improve the VICP process to better serve petitioners.

Evaluation Domains and Questions

The evaluation questions focus on measuring petitioner satisfaction and address key aspects of Program implementation, including fidelity to Program design, satisfaction of the target population, and Program reach.⁸ Section B of the Appendix lists the evaluation questions and their operational definitions.

Evaluation questions include the following:

- Access to VICP Information
 - How did petitioners learn about the VICP?
 - To what extent are petitioners satisfied with the initial information they received from the VICP on filing a claim?
- Program Implementation and Processes
 - To what extent are petitioners satisfied with their interactions with life care planners?
 - To what extent are petitioners satisfied with the clarity, ease, and navigability of the process: (1) identifying an attorney, (2) filing a claim, (3) participating in the hearing process, and (4) determining the award amount (where applicable)?
 - To what extent are petitioners satisfied with the length of the process?
 - How do petitioners who do not receive a financial award proceed with the claims process?

⁸ Program reach is defined as the population who completed the VICP claims process.

- Financial Award Decision
 - To what extent are petitioners satisfied with the process regarding: (1) receipt of a financial award and (2) adequacy of that award?
 - To what extent are petitioners satisfied with the VICP’s negotiation with Medicaid to reduce and/or eliminate their lien (where applicable)?
- Overall Satisfaction
 - How are measures of satisfaction affected by: (1) whether or not the petitioner received an award and (2) the type of respondent?

In addition to probing these evaluation questions, this study also characterizes the population of petitioner respondents.

Evaluation Design

The evaluation featured a survey designed to obtain a comprehensive picture of petitioner satisfaction with the VICP, including petitioners’ perceptions of Program strengths and areas for improvement.

Data Source and Instrumentation

A consumer satisfaction survey was developed in coordination with DVIC to address the evaluation questions. Closed-ended survey questions captured quantifiable data or issues for which multiple-choice responses were appropriate. Open-ended survey questions were used to further clarify and capture nuances related to the closed-ended questions. For example, the survey includes a closed-ended question regarding the petitioner’s level of satisfaction with the adequacy of his or her financial award using a five-point Likert scale (not at all satisfied, somewhat satisfied, neutral, somewhat dissatisfied, and very dissatisfied) coupled with an open-ended question asking the petitioner to suggest changes in how the financial award is paid. See Section C.1 of the Appendix for the survey instrument.

To test the data collection instrument and process, surveys were first distributed to petitioners represented by five attorneys who each represented more than ten petitioners. After testing, the survey instrument was revised to improve its clarity.⁹

Data Collection Methods

Participant Recruitment

Survey Population

Petitioners were included in the sample if (1) they had filed a claim that had been resolved (either compensated or dismissed and closed) within the last five fiscal years (FY2005-FY2008) and (2) were represented by an attorney. This sample does not include those petitioners who voluntarily dropped out

⁹ No edits were made to survey question content and only one substantive edit was made to response categories: in survey question 23, which asks the respondent’s relationship to the injured party, the category “Partner/Spouse of injured party” was added to the original two choices of “Injured party” and “Parent/Guardian of the injured party”.

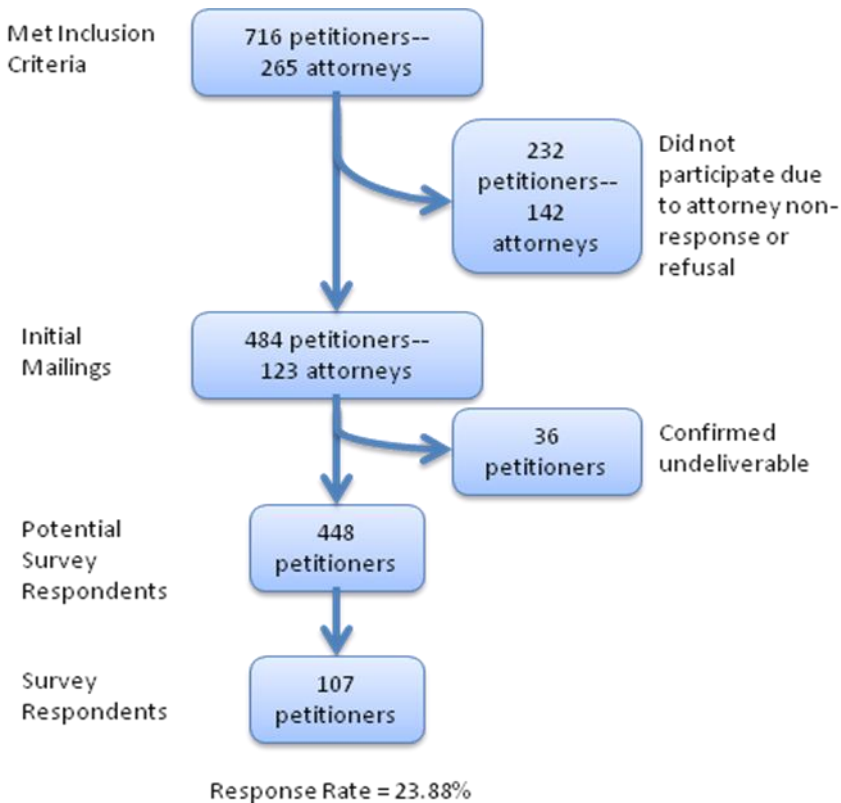
of the VICP process. Researchers identified the sample population by abstracting the following information from the DVIC database:

- Claim resolution date;
- Decision status (compensated or dismissed);
- Petitioner’s attorney’s name; and
- Petitioner’s attorney’s contact address.

Sample Size

Figure 1 illustrates the sampling process and sample size used for quantitative analysis.

Figure 1. Petitioner Sample



As depicted in Figure 1, 716 petitioners met the requirements for inclusion in the sample. The 142 attorneys who did not respond to inquiries or refused to participate represented 232 petitioners. Surveys were distributed via 123 petitioners’ attorneys in an effort to reach 484 petitioners. Of these surveys, 36 were confirmed undeliverable, either because the petitioner was incapacitated, could not be located, or had died. Therefore, satisfaction surveys could have reached a maximum of 448 petitioners.

Survey Administration

Both mail and Web-based surveys, in English and Spanish, were offered in an effort to increase response rate and reduce burden to the respondent. To ensure the confidentiality of petitioners' personal information, surveys were administered through the petitioners' attorneys instead of directly by Altarum. Once the survey population had been identified, Altarum staff contacted those petitioners' attorneys via phone call.

After testing the instrument via distribution through five "high-volume" attorneys (those representing more than 10 petitioners each) surveys were distributed to the remaining petitioners in the sample through their attorneys. Attorneys representing ten or fewer petitioners are subsequently referred to as "low-volume attorneys" (see Table 1).

Table 1. Attorney type

Attorney Type	Number of Attorneys	Number of Petitioners per Attorney	Total Number of Petitioners Meeting Inclusion Criteria
High-Volume	5	>10	328
Low-Volume	260	≤10	388
Total	265	N/A	716

Attorneys mailed surveys, along with instructions on their completion, and a stamped, return envelope addressed to Altarum, to petitioners. The mailing also included an informed consent statement. In addition, petitioners received, via their attorneys, two reminder letters at one-month intervals. All materials were provided in English and Spanish. Section C of the Appendix includes all communications sent to petitioners.

Informed Consent and Confidentiality

The petitioner survey was anonymous; petitioners were instructed not to write their names on the paper-based version. The Web-based survey did not capture or retain identifying personal computer information (such as an IP address).

Petitioners received an informed consent statement, which explained the purpose of the survey, its structure and content, any potential risks and benefits associated with taking it, and how the results would be analyzed and used. The informed consent statement also explicitly stated that participation in the survey was purely voluntary and anonymous, and it provided contact information for Altarum's Project Director.

Data Analysis

Quantitative Data Analysis

Quantitative data were stored and entered into a Microsoft Excel database for data cleaning and subsequently imported into STATA Version 9 software¹⁰ for statistical analysis. Descriptive statistics, such as frequencies and percentages, were calculated for all data. Due to the skewed distribution of age data, and to provide an accurate description of data obtained, continuous age data are described in

¹⁰ StataCorp. 2005. Statistical Software: Release 9.0. College Station, TX: Stata Corporation.

terms of the median, inter-quartile range (IQR),¹¹ and range, rather than the mean and standard deviation. Categorical data are described in terms of proportions.

Evaluation questions were generally assessed using descriptive statistics. Pearson's χ^2 test statistics were used to determine the extent to which receipt of an award was associated with satisfaction levels for various components of the VICP; the extent to which the type of survey respondent (e.g., injured party or parent of injured party) was associated with satisfaction with components of the VICP and/or receipt of award; and the extent to which census region was associated with ease of finding an attorney. In addition, Global Information System (GIS) analysis¹² was used to analyze Program reach. See Table 2 for a list of the analyses used in answering each evaluation question.

Missing Data

Missing data did not present a significant challenge. Section A of the Appendix lists the data elements and percentage of missing data. All of the data elements were missing less than 20% of data.

Response Rate

Altarum Institute received a total of 107 survey responses, 96 paper survey responses and 11 Web-based responses, giving a response rate of 23.88%. All of the survey respondents completed English surveys; none completed Spanish surveys.

Qualitative Data Analysis

Qualitative data captured from the open-ended survey questions were initially stored and cleaned in a Microsoft Excel database and subsequently imported into NVivo 7 software¹³ for content analysis. Coding schemes were devised for each of the following categories:

- Heightening the public's awareness about the VICP;
- Facilitating the process of finding an attorney;
- Improving the claim filing process;
- Improving the award payment process; and
- Satisfaction with life care planner interaction.

¹¹ IQR is the range between the 25th percentile and 75th percentile. It is a measure of spread used in describing non-parametric data.

¹² Environmental Research Systems Institute. 2008. ArcGIS, Desktop GIS: Release 9.3. Redlands, CA: ESRI.

¹³ NVivo qualitative data analysis software; QSR International Pty Ltd. Version 7, 2006.

Table 2. Analysis method for studying evaluation questions

Evaluation Question	Analysis Reported
1. How did petitioners learn about the VICP?	Descriptive statistics
2. To what extent are petitioners satisfied with the initial information they received from the VICP on filing a claim?	Descriptive statistics Qualitative analysis
3. To what extent are petitioners satisfied with the clarity, ease and navigability of the process: 1. Identifying an attorney, 2. filing a claim, 3. participating in the hearing process, 4. Determining the award amount (where applicable)?	Descriptive statistics Qualitative analysis Pearson's χ^2 test statistic
4. To what extent are petitioners satisfied with the length of the process?	Descriptive statistics
5. To what extent are petitioners satisfied with the process regarding: (1) receipt of a financial award and (2) adequacy of that award?	Descriptive statistics Qualitative analysis
6. To what extent are petitioners satisfied with the VICP's negotiation with Medicaid to reduce and/or eliminate their lien (where applicable)?	Descriptive statistics
7. To what extent are petitioners satisfied with their interactions with life care planners?	Descriptive statistics Qualitative analysis
8. How are measures of satisfaction affected by: (1) whether or not the petitioner received an award and (2) type of respondent?	Pearson's χ^2 test statistic
9. How do petitioners who do not receive an award proceed with the claims process?	Descriptive statistics

Limitations

Generalizability of Findings

Selection bias—specifically, non-response bias—limits the generalizability of the survey results. Given the low response rate, those petitioners who completed and returned the surveys may be different than those who did not. Consequently, the results of this study cannot be generalized to the population of all petitioners who completed the VICP process, and instead reflect only the group of VICP petitioners who responded to the survey.

Subgroup Analysis

The limited sample size coupled with few responses from racial and ethnic minorities, low-income individuals, and low-education level individuals precludes analysis of these subgroups. The number of individuals in each of these categories is not large enough to give adequate statistical power to analyses.

Recall Error

Given the retrospective nature of this study design, petitioners are asked to recall events and feelings surrounding a claims process that may have occurred years ago, likely resulting in some recall error. However, it is unknown whether or not recall *bias* would be an issue, as there is no reason to believe that those who received an award would have any better or worse recall than those who did not receive an award.

IV. Results

Program Reach

Key Findings:

- Racial and ethnic minorities, low-income families, and individuals with lower education levels are significantly underrepresented among survey respondents, of whom 89.42% self-identified as non-Hispanic white, 52.08% reported an annual income over \$60,000, and 56.19% possessed a college or graduate degree.
 - Among respondents, injuries occurred most frequently in infants, with one-quarter of reported injuries occurring in children six months of age or younger. The remaining injuries were relatively evenly distributed between ages five to 45 years with few injuries occurring in older adults.
-

This section describes the reach of the VICP in terms of the demographics of survey respondents. It is important to reiterate that the demographics of the survey respondents may differ from the demographics of all petitioners who completed the VICP claims process. Table 3, below, characterizes the population of survey respondents.

Table 3. Characteristics of VICP satisfaction survey respondents (N=107)

Characteristic	n
Age at injury, median (IQR), y	9 (0.50-33.00)
Age if not the injured party, No. (%)	
18-35 years	7 (11.11)
36-49 years	38 (60.32)
50 years and older	18 (28.57)
Relationship to injured party, No. (%)	
Self	43 (40.19)
Parent or Guardian	62 (57.94)
Partner or Spouse	2 (1.87)
Hispanic, No. (%)	7 (6.67)
Race, No. (%)	
African American	2 (1.90)
American Indian or Alaska Native	0 (0)
Asian	2 (1.90)
Native Hawaiian or Other Pacific Islander	1 (0.95)
White	100 (95.24)
Region, No. (%) ^{*14}	
Northeast	25 (26.04)
Midwest	20 (20.83)
South	36 (37.50)
West	15 (15.62)
Territories	0 (0)
Household yearly income, No. (%) [*]	
Less than \$20,000	8 (8.33)
\$20,000 – 39,999	11 (11.46)
\$40,000 – 59,999	27 (28.12)
\$60,000 – 79,999	13 (13.54)
\$80,000 or more	37 (38.54)
Household size, median (IQR), number of persons ^{**}	3.5 (2, 4)
Highest level of education completed, No. (%)	
Elementary school (grades 1 through 8)	0 (0)
Some high school (grades 9 through 11)	1 (0.95)
High school graduate or GED	8 (7.62)
Some college, or a technical or trade school	24 (22.86)
Associate degree (2-year)	13 (12.38)
College graduate (4-year) or graduate degree	59 (56.19)
Note: Variables without superscripts are missing less than 5% of data Percent missing: * 10.28%, ** 6.54%.	

¹⁴ States were grouped by Census Region.

Most VICP satisfaction survey respondents were highly educated, from middle- to upper-income households, and self-identified as non-Hispanic white (see Charts 1-3). The racial and ethnic demographics of respondents are particularly striking for their underrepresentation of minority populations.

Chart 1. Highest level of education completed (n=105)

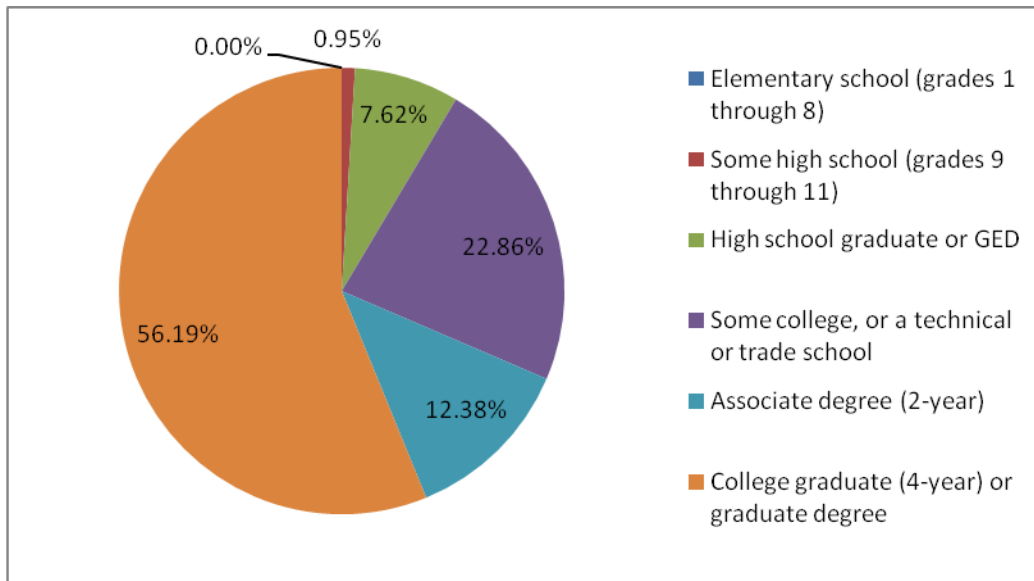


Chart 2. Annual household income (n=96)

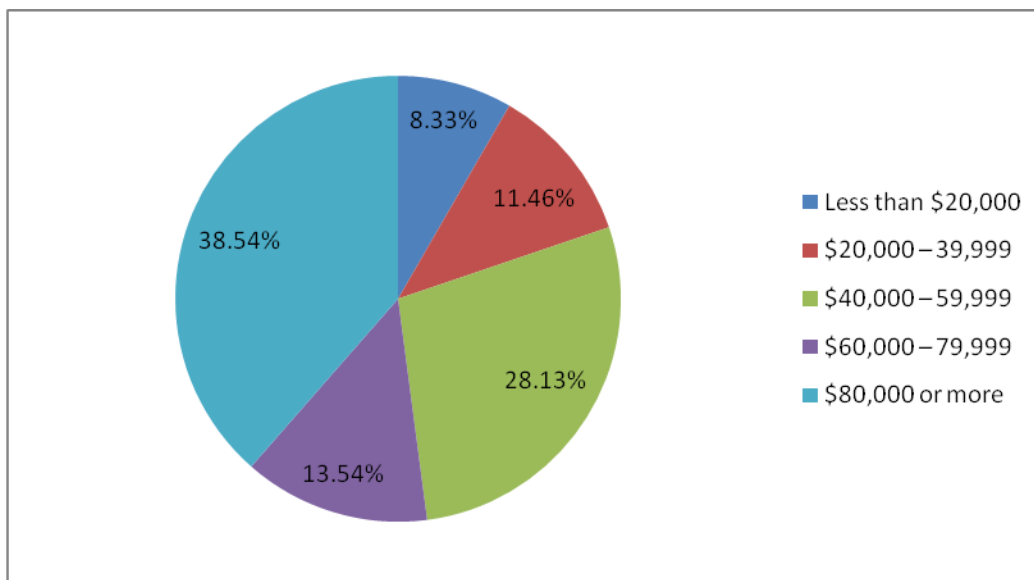
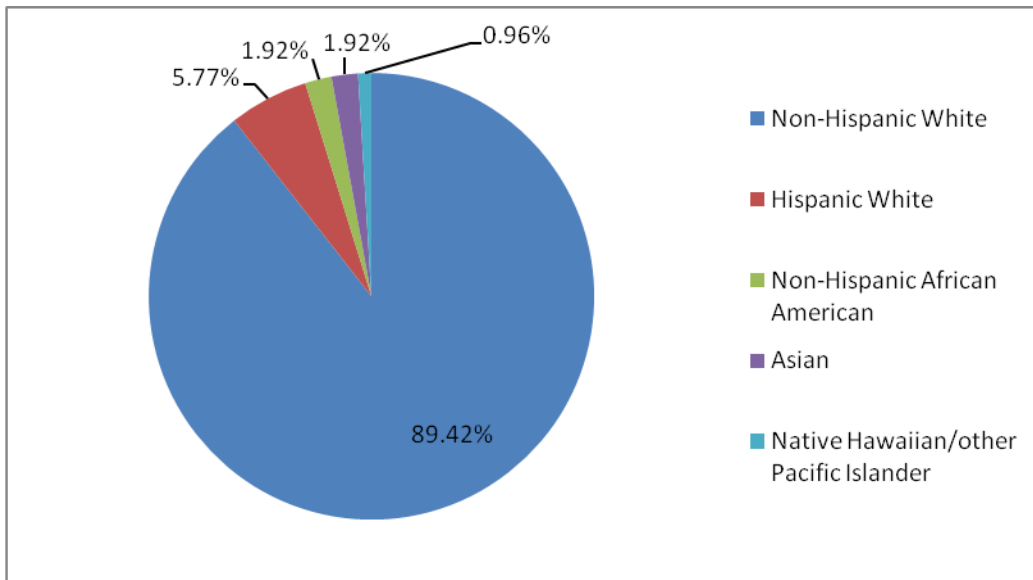


Chart 3. Petitioner self-identified race and ethnicity (n=104)



If not the injured party, the vast majority of respondents were the parents or guardians of the injured party (96.88%) and were 36 years of age or older (88.89%) (see Charts 4-5).

Chart 4. Type of respondent (n=107)

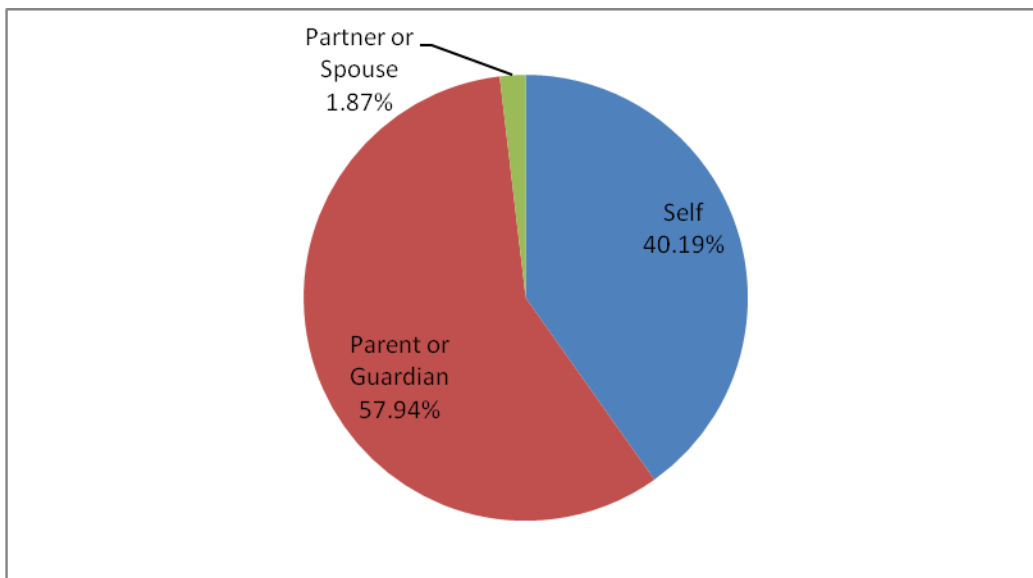
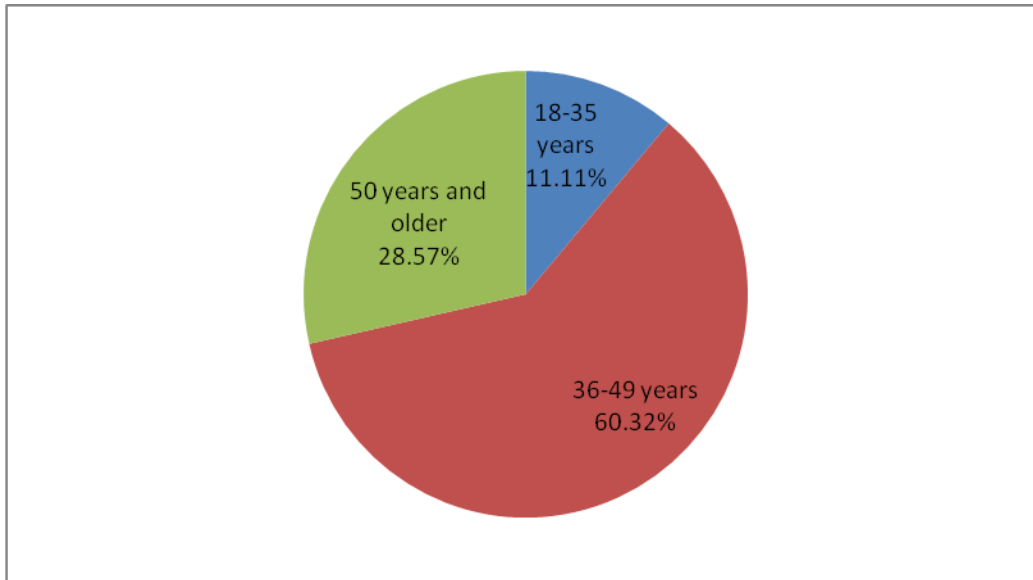


Chart 5. Age of survey respondent if not the injured party (n=63)



Injuries reportedly occurred most frequently in infants, with one-quarter of reported injuries occurring in children six months of age or younger. The remaining injuries were relatively evenly distributed between ages five to 45 years with few injuries occurring in older adults (see Charts 6a-b).

Chart 6a. Age at time of injury (n=107)

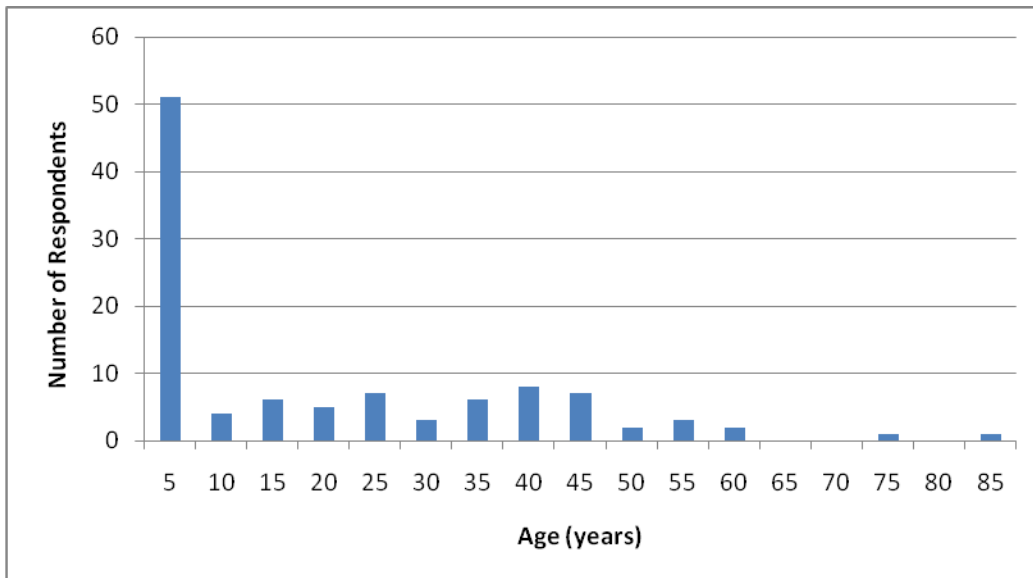
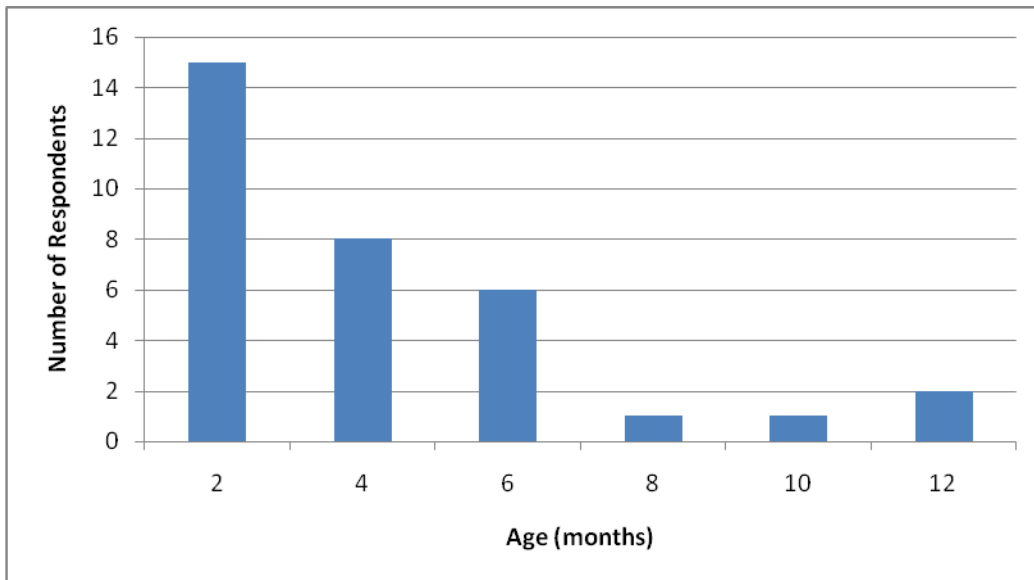
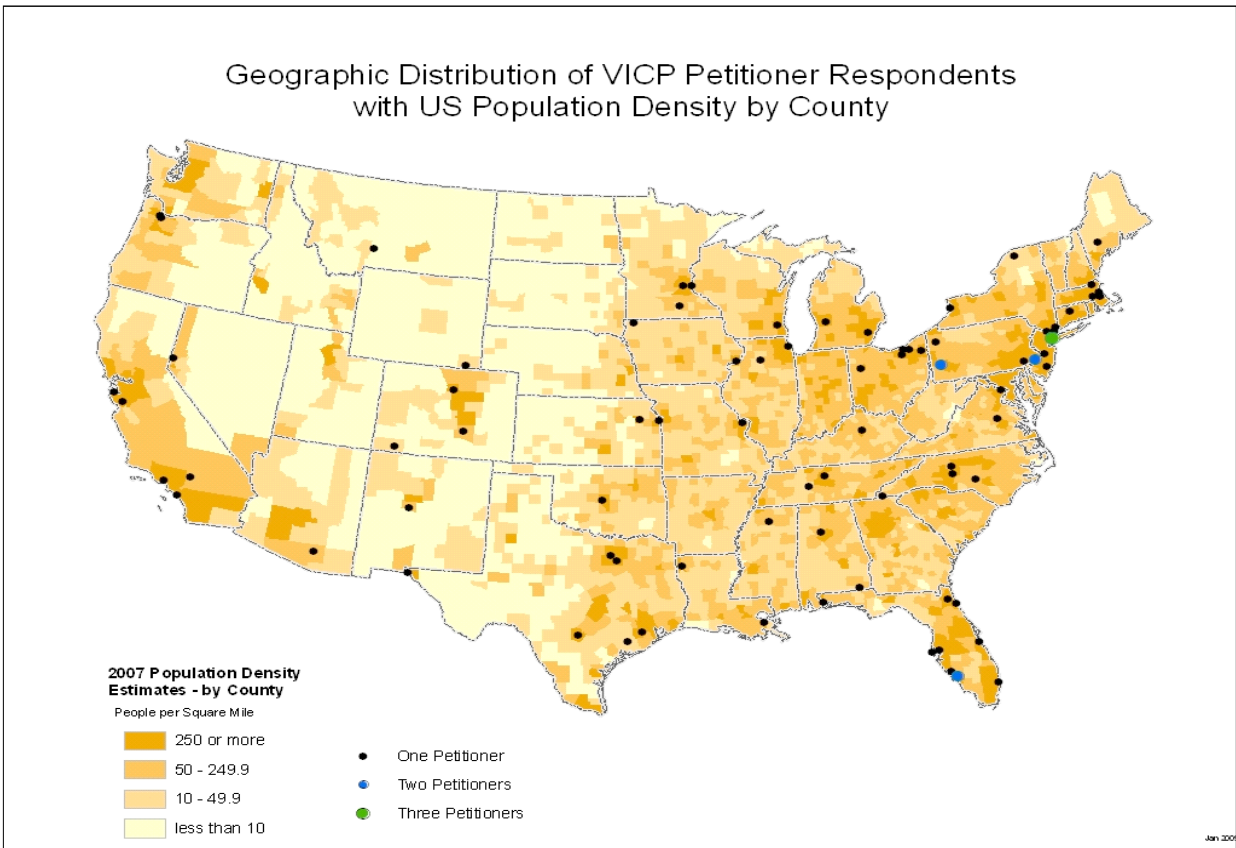


Chart 6b. Age at time of injury (n=33)



Survey respondents' geographic location appears to track with population density (Figure 2). However, the Pacific Northwest may be underrepresented among petitioner respondents.

Figure 2. Geographic location of respondents (n=87)



Access to VICP Information

Key Findings:

- Many respondents learned about the Program through unofficial sources, such as vaccine injury-related Web sites and other parents or adults.
 - Respondents expressed differing opinions on the ease of access to and perceived helpfulness of information provided by DVIC.
-

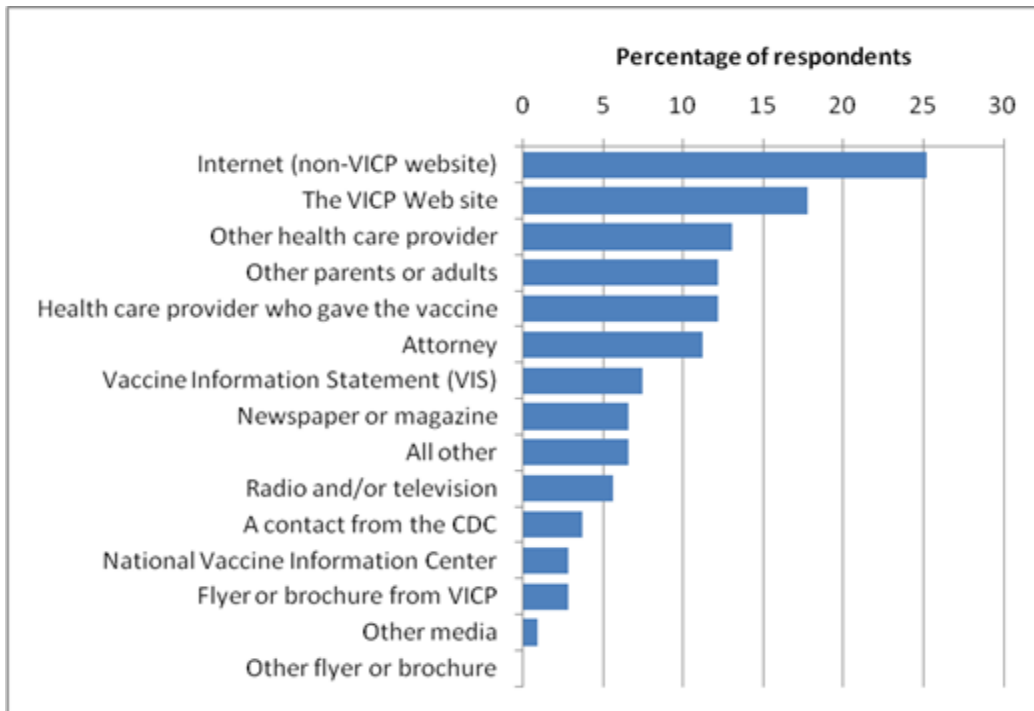
How Respondents Learned about the VICP

Many respondents learned about the Program through unofficial sources (see Chart 7). One-quarter of respondents (25.23%) learned about the Program from a Web site other than the one maintained by the VICP. However, the VICP Web site was the second most frequently reported source (17.76%).

Common health care-related sources of VICP information included the health care provider who gave the vaccine (12.15%), another health care provider (13.08%), and the Vaccine Information Statement (VIS) (7.48%) that is given to the patient or parent/ guardian with each vaccination. Relatively few respondents found out about the Program through advertising: 6.54% read about it in a newspaper or magazine, 5.61% heard about it on the radio or television, and 2.80% saw a flyer or brochure from the VICP. Four respondents (3.74%) found out about the VICP when they were contacted by the CDC.

Other sources of information included other parents or adults who had been involved with the VICP (12.15%), attorneys (11.22%), and the National Vaccine Information Center (2.80%), a private advocacy organization.

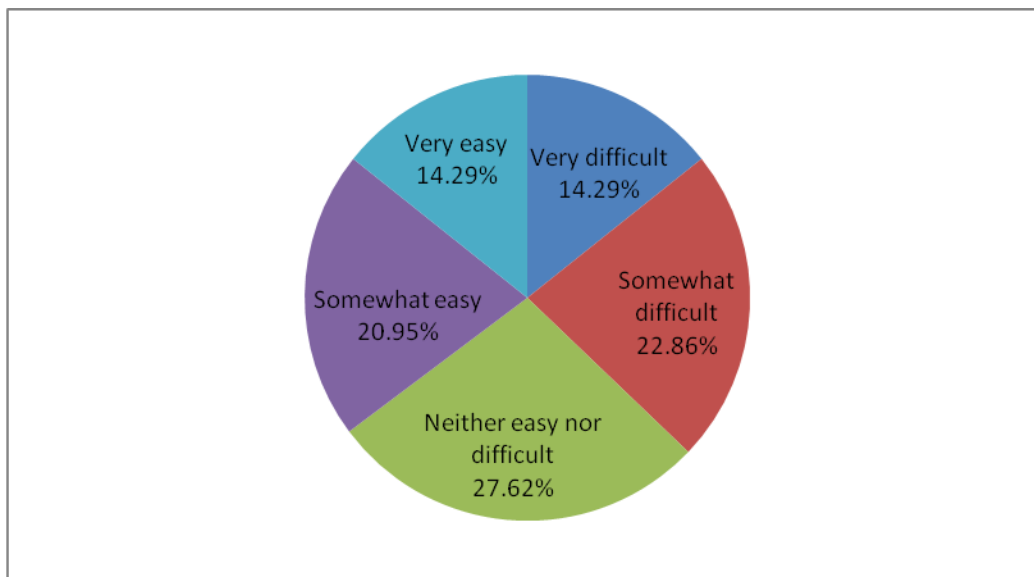
Chart 7. How respondents learned about the VICP (n=107)



Note: Survey responses were not mutually exclusive, and therefore the total percentage exceeds 100%.

Respondents had differing opinions on the perceived ease of obtaining information about the VICP (see Chart 8). Over one-third of respondents (35.24%) felt that the process was very or somewhat easy, and nearly the same proportion (37.15%) found the process very or somewhat difficult. The remaining respondents (27.62%) felt neutral about the ease of obtaining information about the VICP.

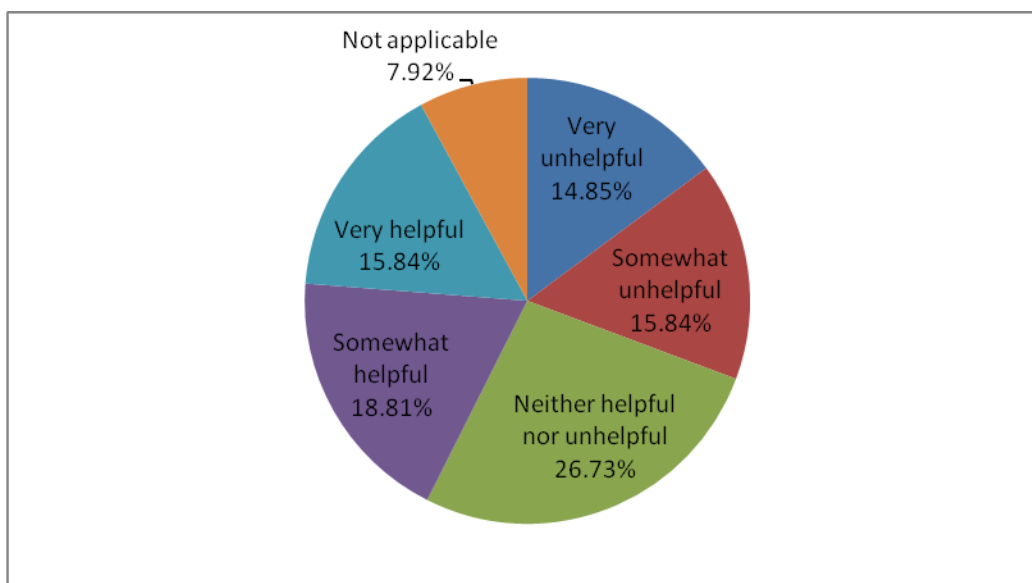
Chart 8. Ease of obtaining information about the VICP (n=105)



Respondent Satisfaction with Initial Information

Both the VICP and the Court maintain Web sites that explain the claims process and provide relevant contact information. The Court also provides claim filing forms. Respondents had differing opinions on the perceived helpfulness of the initial information provided by the VICP on filing a claim (see Chart 9). More than one-third of respondents (34.65%) found the information very or somewhat helpful, and slightly less than one-third (30.69%) found the information very or somewhat unhelpful.

Chart 9. Helpfulness of information provided when filing a claim (n=101)



Suggestions for improvement. Respondents most commonly suggested that health care providers should be made more aware of the VICP and be responsible for providing information about it to patients (n=17):

Ideally, all medical practitioners giving vaccines should be completely informed of the VICP and be able to direct their patients to the Program. Written information on how to communicate with the VICP should be available from these practitioners to the patient. Every medical practitioner who gives vaccines should be certified as knowing the benefits of each vaccine, possible adverse reactions...and how to connect patients to the CDC and VICP.

– VICP petitioner

Nine respondents felt that patients or parent/guardians should receive information at the time of the vaccination.

Fourteen respondents felt that the VICP should be more widely advertised. Their suggestions included distributing pamphlets, e.g., in doctor's offices; advertising on television and in magazines; and maintaining a telephone hotline. Respondents felt that VICP outreach materials should be easy to read and include Program contact information.

Program Implementation and Processes

Key Findings:

- Respondents reported difficulty locating an attorney and suggested that an up-to-date list of attorneys be maintained and easily accessible.¹⁵
 - Many respondents found the claims process unsatisfactory, giving particularly low ratings to the process of filing a claim, providing additional requested information after the claim was filed, and determination of damages. Respondents reacted most negatively to the length of the process, with which 64.08% were dissatisfied.
-

Satisfaction with Life Care Planners

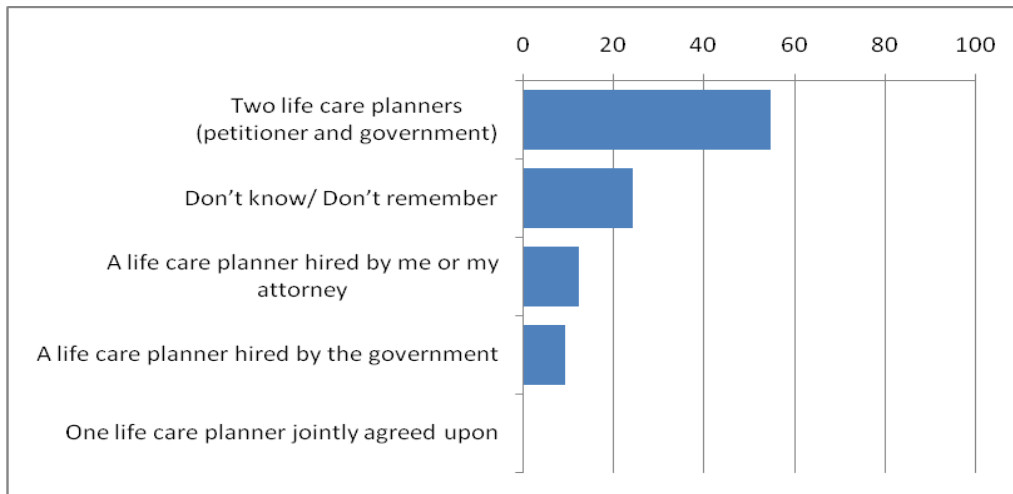
If a financial award is granted, life care planners help the petitioner to develop a plan for acquiring and funding services and any equipment required for the injured individual. Life care planners review medical records, collaborate with health care providers and experts, identify patient needs, and calculate costs of care. In general, the petitioner and HHS each retain a life care planner, but in some cases, a single life care planner is agreed upon.¹⁶

Among respondents who had a life care planner, the most common arrangement was to have two life care planners, one hired by the petitioner or the petitioner's attorney and one hired by HHS (54.54%) (see Chart 10). Few respondents had one life care planner, hired by the petitioner or petitioner's attorney (12.12%), or one life care planner hired by HHS (9.09%), and no respondents reported using a life care planner jointly agreed upon by the petitioner or petitioner's attorney and HHS. Almost one-quarter of respondents (24.24%) could not remember or did not know the nature of their life care planner arrangement.

¹⁵ The Court will provide a list of attorneys upon request.

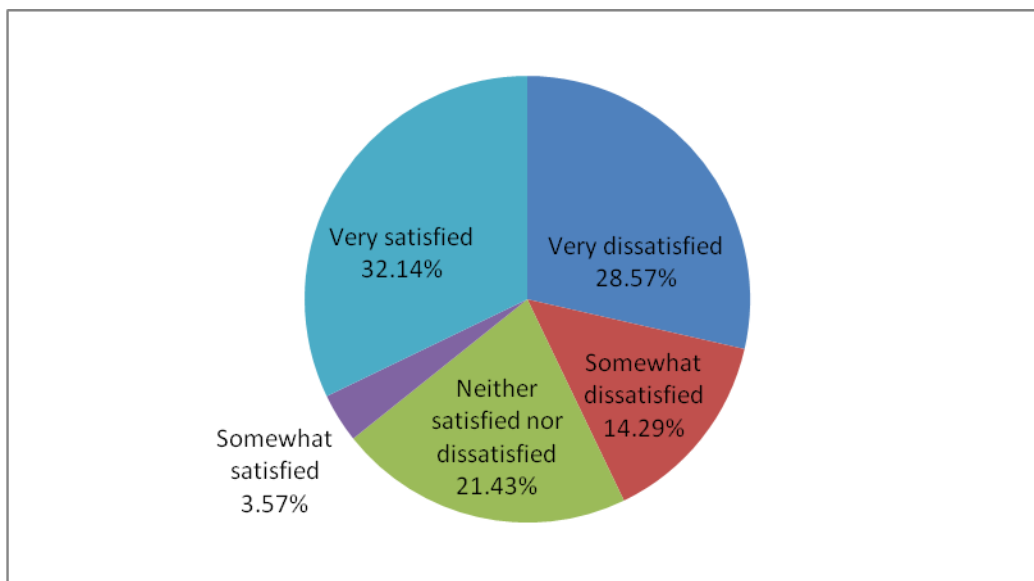
¹⁶ Holakiewicz, L. (2006). The life care plan and the Vaccine Injury Compensation Program. *Journal of Legal Nurse Consulting*, 17(2), 6-10.

Chart 10. Life care planner arrangements (n=33)



Respondents had differing, yet strongly-held opinions about their satisfaction with the role of the life care planners (see Chart 11). There were slightly more satisfactory responses than unsatisfactory ones, with almost one-third (32.14%) reporting being very satisfied with their life care planner(s) and 3.57% reporting being somewhat satisfied. Twenty-eight percent (28.57%) reported feeling very dissatisfied. This distribution must be interpreted with caution, however, given the small number of respondents to this survey item (n=28).

Chart 11. Satisfaction with role of the life care planners (n=28)



Suggestions for improvement. Respondents were not asked directly for suggestions for improving the role of the life care planner; instead, they were asked to explain the source of their satisfaction or dissatisfaction. Those who felt dissatisfied reported feeling that the life care planners were not realistic when accounting for current or future needs of the patient, such as lost earnings and the possibility of a

patient becoming increasingly sick over time (n=7). Another key reason for dissatisfaction was the perception that the life care planner(s) had an unprofessional attitude (n=4).

Respondents who were satisfied with the life care planner felt that the life care planner focused on the needs of the patient and paid personal attention to the claim (n=8). These respondents praised life care planners who met with the patient personally, made telephone calls, focused on the needs of the individual, and acted professionally.

Clarity, Ease and Navigability of the Process

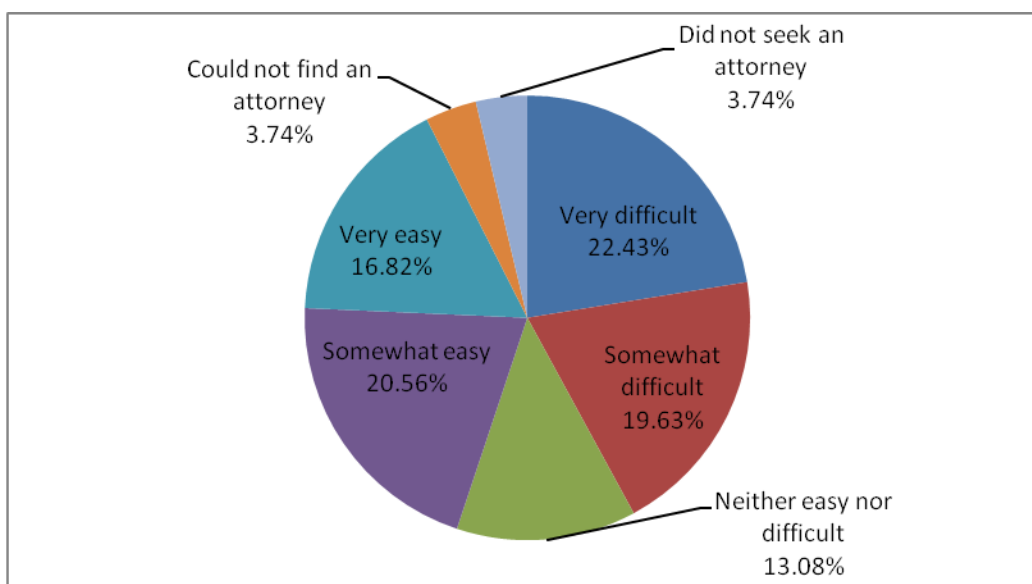
A claim must be filed by or on the behalf of the individual thought to be injured by a vaccine covered by the VICP. The process for filing a claim is as follows:

1. The petitioner or petitioner's lawyer sends one original and two copies of the claim along with the medical records, other appropriate documents, and a \$250 filing fee to the Court;
2. The petitioner or petitioner's lawyer sends one copy of the claim including the medical records and other appropriate documents to the Secretary of Health and Human Services, care of the Director of the Division of Vaccine Injury Compensation;
3. The Court sends one copy of the claim and medical records to the DOJ;
4. HHS reviews the medical information in the claim and this review is sent to the DOJ lawyer who represents the Secretary of Health and Human Services;
5. The DOJ lawyer reviews the legal aspects of the claim and writes a report;
6. The HHS and DOJ reviews are combined into one report that is sent to the Court and petitioner or petitioner's lawyer;
7. The DOJ and petitioner or petitioner's lawyer take legal action to resolve the claim;
8. A "special master" (a lawyer appointed by the judges of the Court) decides if the claim will be paid and how much will be paid for the claim;
9. If the special master decides to pay the claim, the petitioner must make a decision to accept or reject the special master's decision in writing; and
10. The special master's decision may be appealed to a judge of the Court by the petitioner or HHS, then to the U.S. Court of Appeals for the Federal Circuit, and finally, to the U.S. Supreme Court.

Finding and Hiring an Attorney

Many respondents reported difficulty in finding an attorney: nearly one-quarter (22.43%) replied that finding an attorney was very difficult, and another 19.63% felt that finding an attorney was somewhat difficult (see Chart 12).¹⁷ One-fifth of respondents (20.56%) felt that finding an attorney was somewhat easy, and 16.82% replied that the process was very easy. There was no statistically significant difference in the reported ease of finding an attorney among the four different census regions (Pearson's $\chi^2 = 5.89$, $p = 0.436$).

Chart 12. Ease of finding an attorney to pursue claim (n=107)



Suggestions for improvement. Respondents most commonly suggested (n=23) that an up-to-date list of attorneys who handle vaccine injury claims should be published and made easily accessible.¹⁸ A nationwide directory of attorneys “experienced in this area...compiled and easily accessible via the Internet” would be helpful to respondents. Respondents reported finding that many attorneys will not take vaccine injury claims (n=6), and finding an attorney who is geographically close is even more difficult (n=5). Five respondents suggested that health care provider offices should provide attorney contact information to patients at the time of the vaccination.

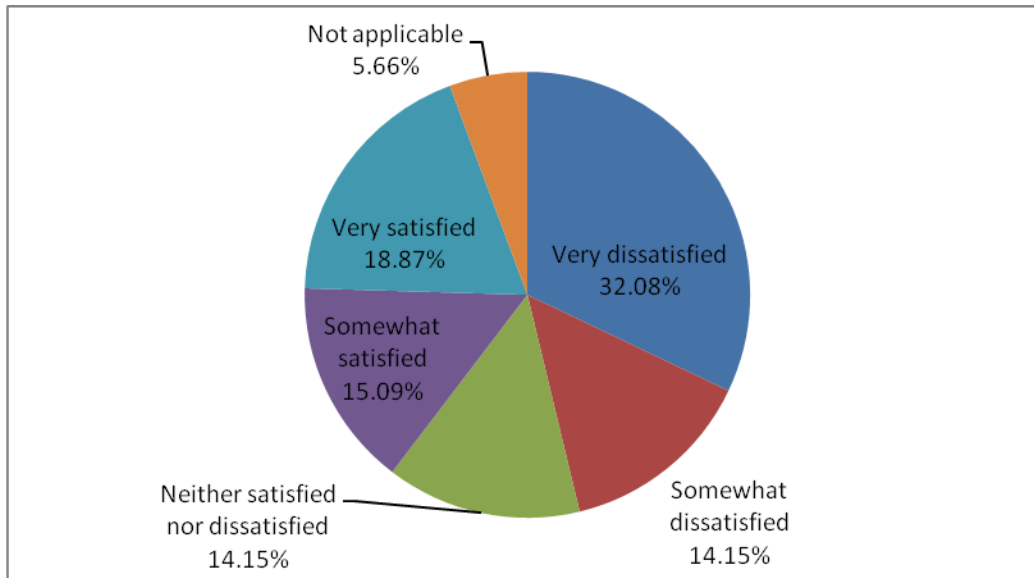
¹⁷ When asked about the ease of finding and hiring an attorney, 3.74% of respondents replied that they did not seek an attorney, and 3.74% replied that they could not find an attorney. It is unknown why a survey respondent would answer that he or she had not hired an attorney, as all surveys were sent through attorneys. Possible explanations include that the participant did not understand the question or did not recall hiring an attorney.

¹⁸ The Court of Federal Appeals will provide a list of attorneys upon request.

Filing a Claim

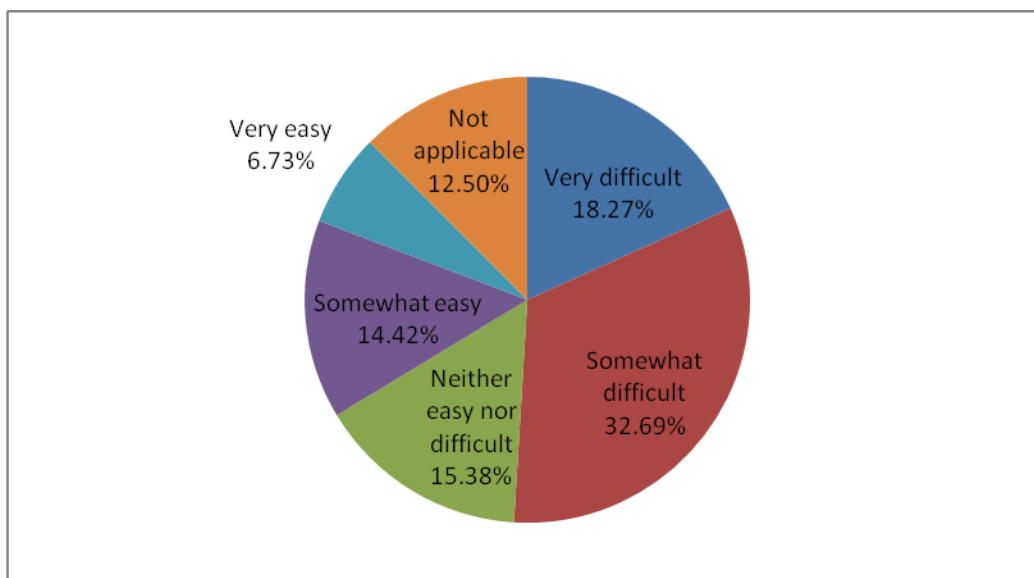
Respondents most frequently reported feeling “very dissatisfied” (32.08%) with the process of filing a claim with the VICP (see Chart 13). A further 14.15% were somewhat dissatisfied. In contrast, 15.09% were somewhat satisfied and 18.87% were very satisfied with the process.

Chart 13. Satisfaction with filing a claim (n=106)



If further information was requested after the claim had been filed, a plurality of respondents found it very difficult (18.27%) or somewhat difficult (32.69%) to do so (see Chart 14). In contrast, only one-fifth of respondents found it somewhat (14.42%) or very easy (6.73%) to provide additional requested information.

Chart 14. Ease of providing requested information after the claim was filed (n=104)

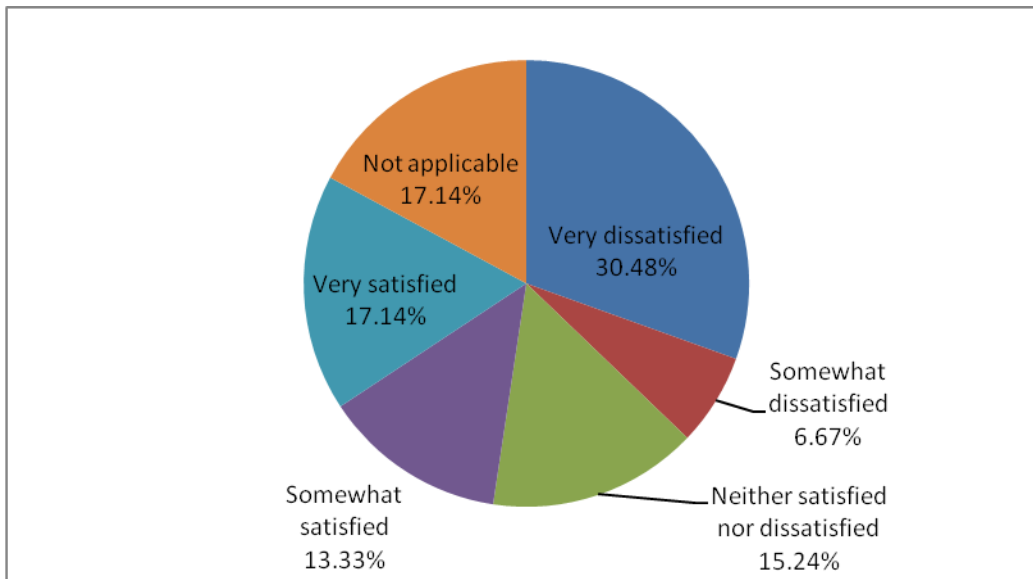


Suggestions for improvement. Respondents gave a variety of suggestions for improving the claim filing process. Respondents commonly reported that the current process places too great a burden on petitioners and family members. Fifteen respondents felt that the process should be shortened or otherwise streamlined, explaining that the process is “cumbersome” and characterized by “red tape”. One noted that some of the information requested is no longer applicable because of the passage of time. Thirteen respondents want the VICP to provide more personal contact, information, and help to petitioners.¹⁹ Outreach, presumably by DVIC or the Court, to health care providers to encourage cooperation with the data collection and the testimony process was suggested by 11 respondents who had reported difficulty working with health care providers.

Hearing Process

Almost one-third of respondents (30.48%) were very dissatisfied with the hearing process and an additional 6.67% were somewhat dissatisfied (see Chart 15). In contrast, only 17.14% were very satisfied and 13.33% were somewhat satisfied. The distribution for this factor was bimodal, with fewer respondents (15.24%) reporting a neutral opinion on the hearing process.

Chart 15. Satisfaction with the hearing process (n=105)

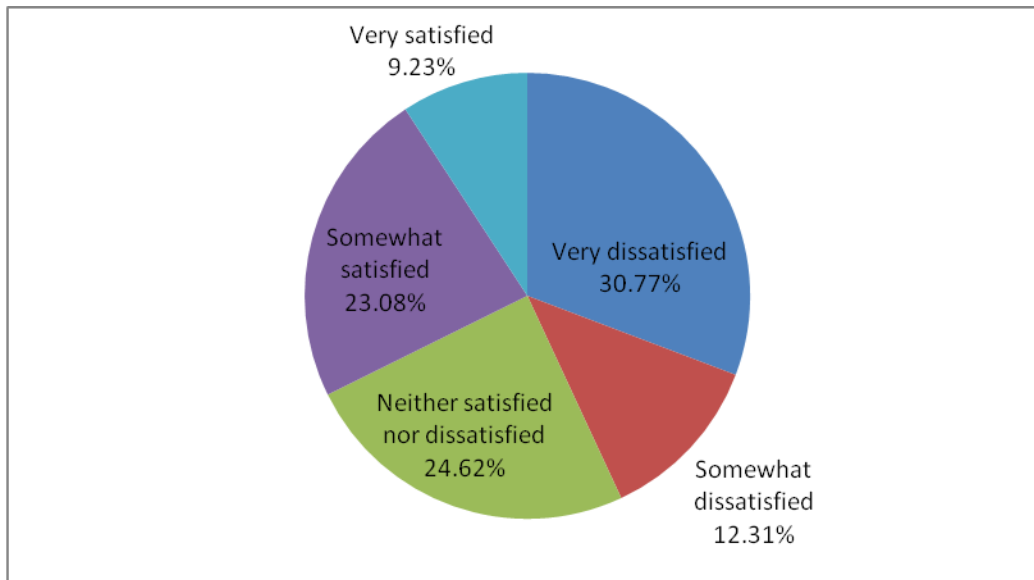


¹⁹ It is important to note that the VICP is restricted from having contact with petitioners once they have retained an attorney.

Determination of Damages

Respondents tended to be dissatisfied with the process for determining damages; nearly one-third (30.77%) were very dissatisfied and 12.31% were somewhat dissatisfied (see Chart 16). Only 9.23% were very satisfied and 23.08% were somewhat satisfied. Almost one-quarter of respondents (24.62%) were neither satisfied nor dissatisfied with the process.

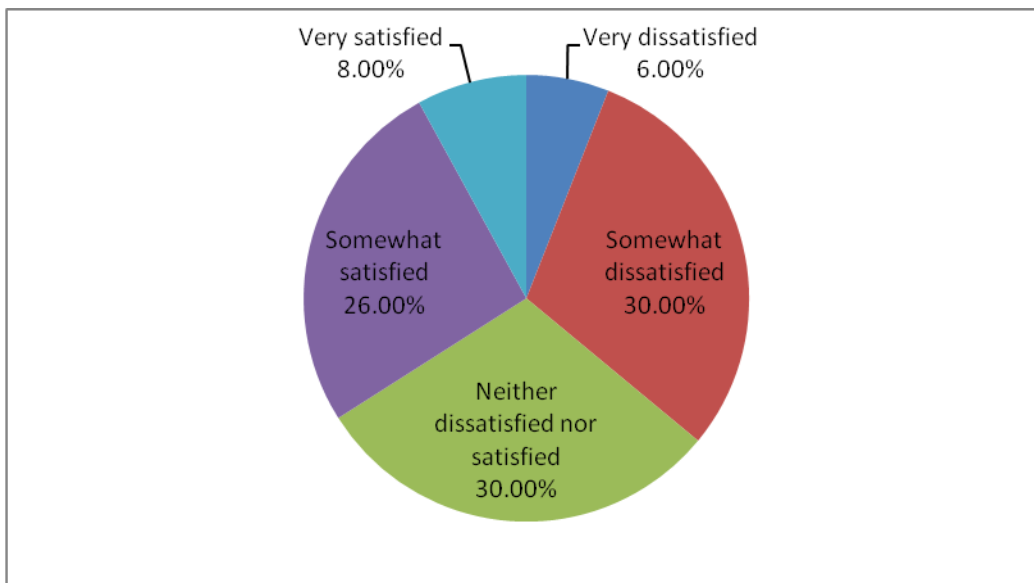
Chart 16. Satisfaction with the determination of damages (n=65)



Summary of Overall Satisfaction with the Legal Process

Scores for survey items about the process of filing a claim, providing additional requested information, the hearing process, and the determination of damages were averaged and reported as an overall index of satisfaction with the legal process. The ease of finding and hiring an attorney was excluded. Only respondents who provided a measure of satisfaction for all questions were included; consequently, data must be interpreted cautiously given the small number of respondents to this survey item (n=40). Opinion on the overall legal process followed a uniform distribution: 36.00% were very or somewhat dissatisfied, 34.00% were very or somewhat satisfied, and 30.00% of respondents felt neither dissatisfied nor satisfied (see Chart 17).

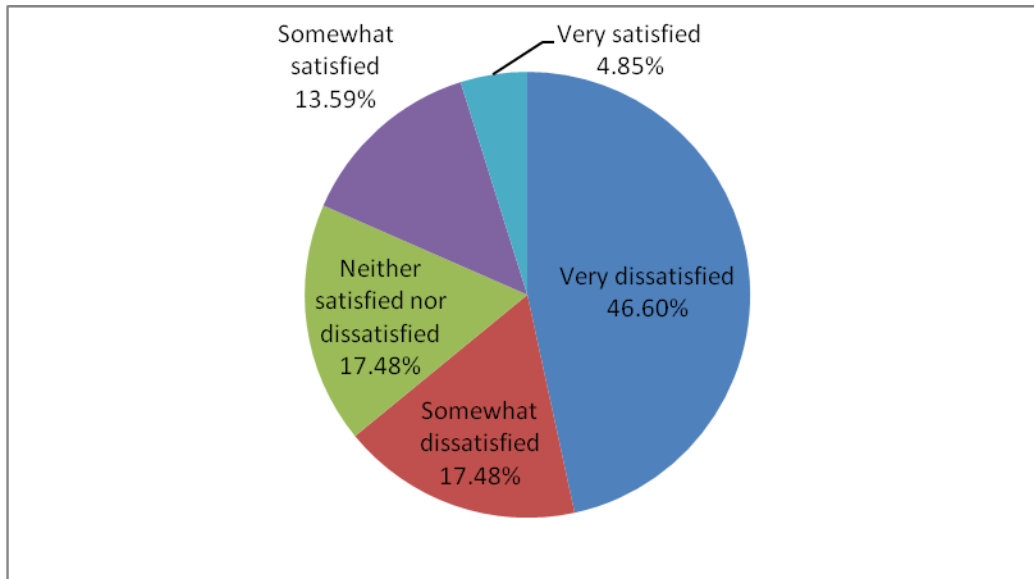
Chart 17. Overall satisfaction with the legal process (n=40)



Satisfaction with the Length of the Process

In 2007, the average claim processing time was 1,337 days, or nearly three and one-half years.²⁰ The majority of respondents were dissatisfied with the length of the claims process. Almost half of the respondents (46.60%) were very dissatisfied with the length of the process, and a further 17.48% were somewhat dissatisfied with it (see Chart 18). Less than 20% of the respondents were very or somewhat satisfied (4.85% and 13.59%, respectively).

Chart 18. Satisfaction with length of the process (n=103)

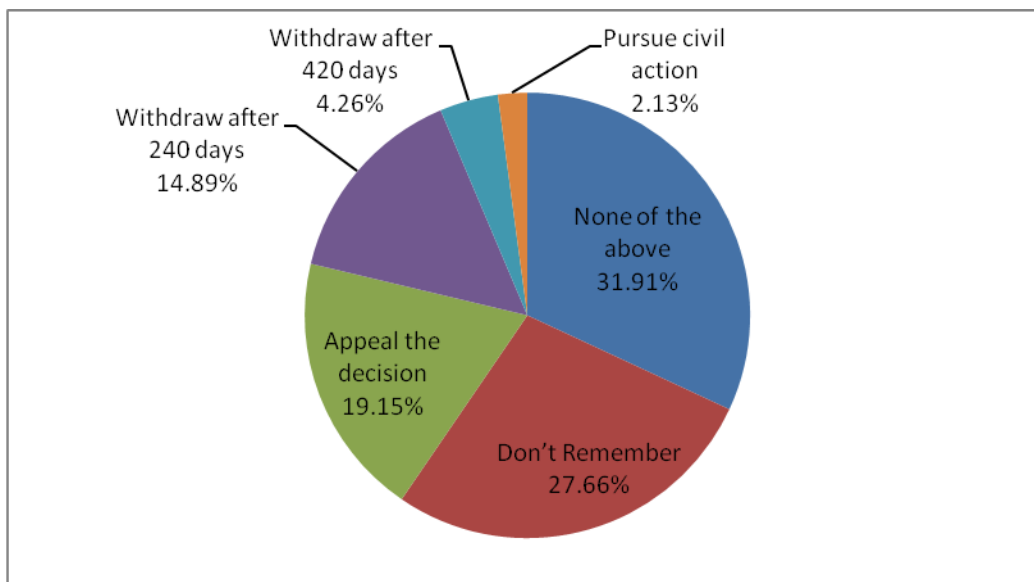


²⁰ Health Resources and Services Administration, U.S. Department of Health and Human Services. (2009). *Online performance appendix: Fiscal year 2009*. Retrieved March 26, 2009, from <http://www.hrsa.gov/about/budgetjustification09/performance/VaccineInjury.htm>.

How Petitioners who do not Receive an Award Proceed with the Claims Process

Petitioners may appeal an award decision, first by appealing to a judge of the Court, then to the U.S. Court of Appeals for the Federal Circuit, and finally, to the U.S. Supreme Court.²¹ Those who reject the award decision may file a civil lawsuit against the vaccine company or the health care provider who delivered the vaccine, but only after the completion of the VICP process.²² Most of the survey respondents (59.43%, n=106) did not receive an award in the claims process. Of these, 19.15% appealed the decision, 14.89% withdrew their petition after 240 days, 4.26% withdrew their petition after 420 days, and 2.13% pursued civil action (see Chart 19). Nearly one-third (31.91%) pursued an option not included in the survey, and more than one-quarter (27.66%) could not remember what action they had pursued.

Chart 19. Action taken by petitioners who did not receive an award (n=47)



²¹ Health Resources and Services Administration, U.S. Department of Health and Human Services. *National Vaccine Injury Compensation Program: Filing a claim with the VICP*. Retrieved March 26, 2009, from http://www.hrsa.gov/vaccinecompensation/filing_claim.htm#summary.

²² Health Resources and Services Administration, U.S. Department of Health and Human Services. *National Vaccine Injury Compensation Program: Filing a claim with the VICP*. Retrieved March 26, 2009, from http://www.hrsa.gov/vaccinecompensation/filing_claim.htm#summary.

Financial Award Decision

Key Findings:

- There is a statistically significant association between the type of respondent (e.g. parent/guardian vs. injured party) and receipt of an award.
 - Respondents were generally satisfied with how the awards are paid, but feel that the compensation is inadequate.
-

After the court proceedings, a special master decides if an award will be paid, and if so, the amount. For an injury, the petitioner may be paid for past and future non-reimbursable medical and custodial care, rehabilitation costs, up to \$250,000 for actual and projected pain and suffering, lost earnings, and reasonable legal costs. In the case of a death, the petitioner may be paid up to \$250,000 as a death benefit and for reasonable legal costs.

Compensation is paid through a lump sum and/or annuity. Attorneys' fees and costs are paid whether or not compensation is awarded if the claim was filed "on good faith and reasonable basis."²³

Financial Award Receipt

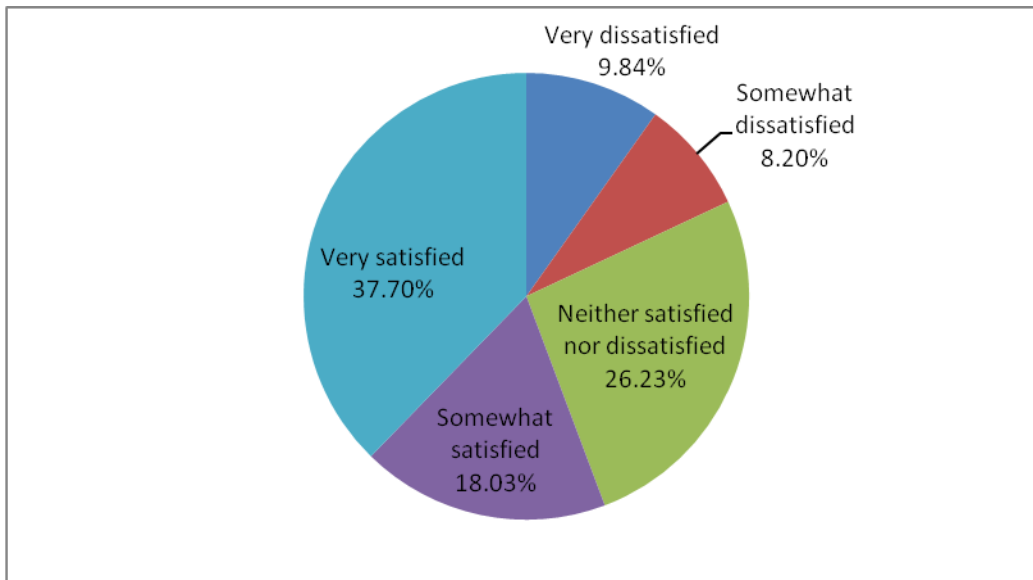
Two-fifths of respondents (40.57%) received compensation; 59.43% did not. More than half of the respondents (57.94%) who received compensation were the parent or guardian of the injured party, and 40.19% were the injured party. While there was a statistically significant association between the type of respondent (e.g. parent/ guardian vs. injured party) and receipt of a financial award (Pearson's $\chi^2 = 9.89$ $p = 0.002$), this was not further explored in the survey, so reasons for this association are unknown.

Satisfaction with Method of Award Payment

Respondents were asked about their satisfaction with the method of award payment. In general, they were satisfied with the method. More than half of the respondents were very satisfied (37.70%) or somewhat satisfied (18.03%), while less than one-fifth were very dissatisfied (9.84%) or somewhat dissatisfied (8.20%) (see Chart 20). About one-quarter of respondents (26.23%) were neither satisfied nor dissatisfied.

²³ Health Resources and Services Administration, U.S. Department of Health and Human Services. *National Vaccine Injury Compensation Program: Filing a claim with the VICP*. Retrieved March 26, 2009, from http://www.hrsa.gov/vaccinecompensation/filing_claim.htm#summary.

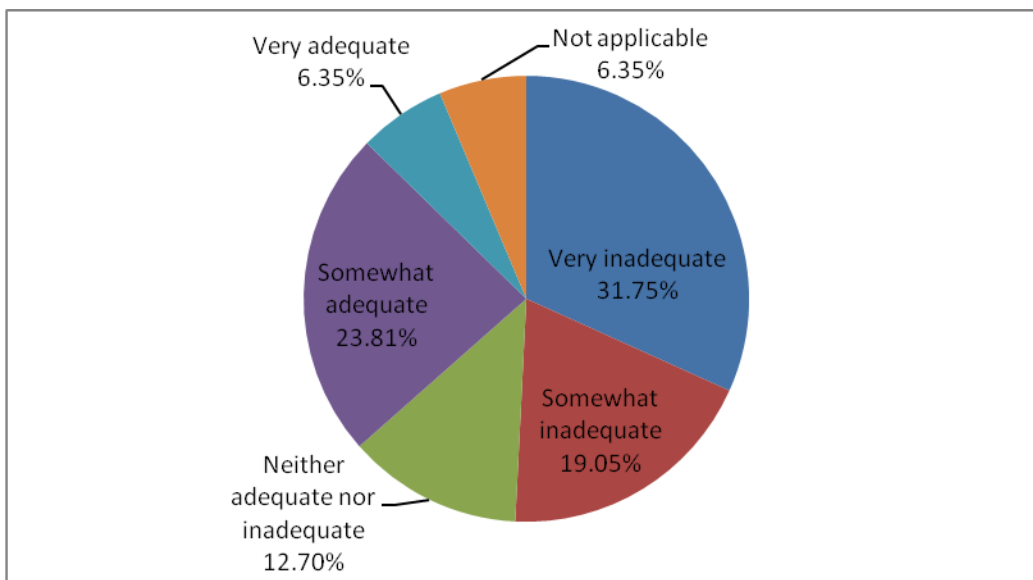
Chart 20. Satisfaction with the mode of payment award money (n=61)



Adequacy of Compensation

Respondents were asked whether the amount of the award was adequate to cover past and future medical care not reimbursed by other sources. In contrast to respondents' general satisfaction with the method of payment, most respondents felt that the award amount was inadequate. Nearly one-third felt that the award amount was very inadequate (31.75%) and 19.05% felt that it was somewhat inadequate. Only 6.35% of respondents felt that the award amount was very adequate and 23.81% felt it was somewhat adequate (see Chart 21).

Chart 21. Adequacy of award to cover past and future medical care (n=63)



Suggestions for improvement. Overall, respondents suggested that DVIC develop more timely and flexible payment mechanisms (n=14). This would include allowing for different family structures in determining who receives payments, allowing the payment to be disbursed as a yearly lump sum, and eliminating the payment agency. For example, some respondents with complex family structures found the financial award difficult to access. Respondents also suggested that the award amount should be more comprehensive in accounting for vaccine injury costs, including future disability and pain and suffering (n=6):

When receiving the monetary reward, you sign paperwork that states you know this payment is a one-time deal. I think patients should be reevaluated within a couple years of receiving settlement to make sure [the] patient's condition has not gotten worse, as in my case.

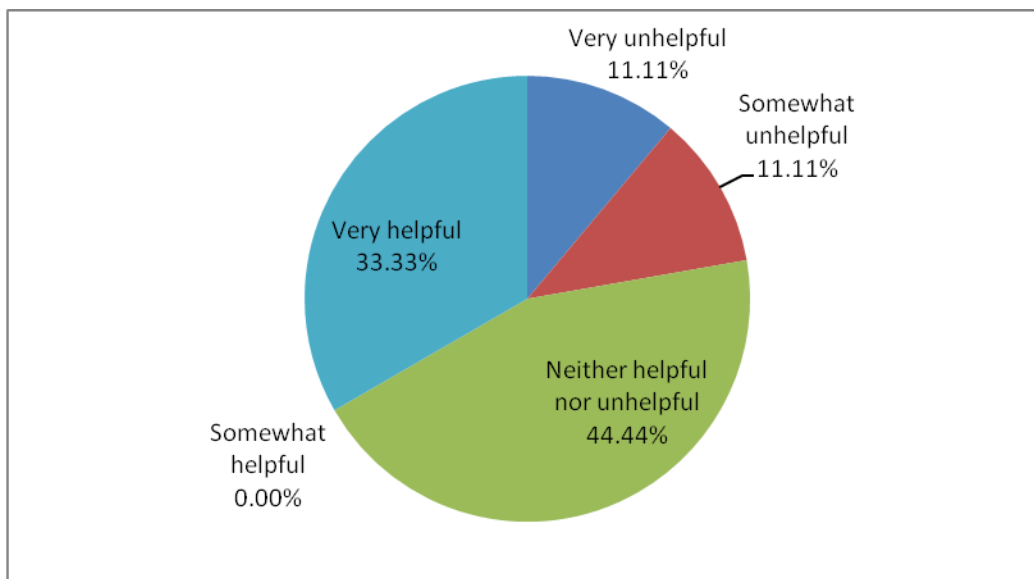
-VICP petitioner

Reducing the Medicaid Lien

Some States attempt to recoup past Medicaid payments by filing liens against the VICP financial award for those petitioners who were covered by Medicaid at any time after the vaccine-related injury.²⁴

The majority of respondents (84.76%) did not have a Medicaid lien; however, among those who did, a plurality felt that the VICP was neither helpful nor unhelpful (44.44%) in negotiating their lien, and 33.33% felt that the VICP was very helpful. Only one respondent replied that the VICP was very unhelpful and one felt it was somewhat unhelpful (see Chart 22). This distribution must be interpreted with caution, however, given the small number of respondents to this survey item (n=9).

Chart 22. Helpfulness of the VICP in reducing or eliminating a lien (n=9)



²⁴ U.S. Court of Federal Claims. (1997). *Damages order*. Retrieved March 26, 2009, from <http://www.uscfc.uscourts.gov/sites/default/files/Damages.pdf>.

Overall Satisfaction

Key Finding:

- Receipt of a financial award is associated with increased satisfaction with all relevant elements of the claims process addressed in the survey.
-

Statistical analysis was used to explore the extent to which receipt of an award was associated with satisfaction with elements of the VICP process. Receipt of a financial award through the VICP was associated with increased satisfaction with all elements of the claims process (see Table 4).

Table 4. Association between satisfaction and receipt of an award

Subject	Pearson's χ^2	P value
Satisfaction with claim filing process	11.69	0.003
Satisfaction with the hearing process	18.54	<0.001
Satisfaction with the length of process	6.21	0.045

Statistical analysis was also used to determine whether reported satisfaction levels differed between respondents who were parents or guardians and respondents who were the injured party. No statistically significant differences were found in satisfaction between these groups for any of the survey measures (results not shown).

V. Key Findings and Recommendations

This study provides valuable insight into the petitioners' experience with the VICP and points to ways to improve the Program, especially in terms of outreach and the claims process.

Key Findings:

- Certain population groups were not well represented among survey respondents, specifically, racial and ethnic minorities, families with low incomes, and people with low levels of education; 89.42% of respondents self-identified as non-Hispanic white, 56.19% possessed an undergraduate or graduate degree, and 52.08% reported an annual income of over \$60,000. However, due to the low response rate, the population of survey respondents may not be representative of the population of VICP petitioners.
 - Many respondents learned about the Program through unofficial sources, such as non-VICP Web sites and other parents or adults.
 - Respondents reported difficulty locating an attorney to assist them with the filing process and suggested that DVIC make an up-to-date list of attorneys easily accessible.
 - Respondents were generally satisfied with the method of award payment, although they perceived the amount of the award to be inadequate.
 - Respondents reacted most negatively to the length of the claims process (an average of 3.5 years in 2007). Nearly two-thirds (64.08%) were dissatisfied with the lengthy process.
 - Those petitioners who received an award answered more positively on questions of satisfaction than did those who did not receive an award.
-

The following recommendations are based on the study's key findings, and many support goals previously articulated in the VICP Strategic Plan.²⁵

Continue to elicit VICP petitioner feedback on the claims process. Feedback from petitioners is necessary to inform Program performance and support the VICP's ability to continue meeting its directive.²⁶ As discussed in the limitations section of this report, the low survey response rate (23.88%) limits the generalizability of this survey's findings. DVIC might mitigate selection bias and achieve a higher rate of survey response from VICP petitioners by developing a mechanism for eliciting routine petitioner feedback on the claims process²⁷. These options would help ensure a higher rate of response

²⁵ The VICP Strategic Plan was developed in 2006 to "address critical issues" facing the VICP over a five year span: 2005-2010. Division of Vaccine Injury Compensation, Healthcare Systems Bureau, Health Resources and Services Administration, Department of Health and Human Services. (2006). *National Vaccine Injury Compensation Program Strategic Plan*. Retrieved March 26, 2009, from ftp://ftp.hrsa.gov/vaccinecompensation/strategic_Plan_20060411.pdf.

²⁶ Aligned with Strategic Theme 3.2.

²⁷ Identified as a weakness in the Strategic Plan.

and help to control for selection bias and recall error by minimizing the length of time between the petitioners' experience with the claims process and receipt of feedback.

Conduct future evaluations that elicit a diversity of perspectives. To obtain a more comprehensive view of the implementation of the Program, DVIC might consider obtaining periodic feedback and input from a range of stakeholders, such as petitioners' attorneys, DOJ staff, DVIC staff, Court staff, life care planners, and health care providers involved with administering vaccinations. Ongoing feedback from petitioners will also be essential to this process.

Continue outreach efforts to build awareness of the VICP. According to the Strategic Plan, one component of the VICP's mission is to "raise awareness of the existence of the VICP."²⁸ The skewed demographic distribution of survey respondents suggests that the VICP should continue its outreach efforts, specifically targeting hard-to-reach populations, such as racial and ethnic minorities and low-income individuals, to provide information about the Program.²⁹ Raising awareness requires carefully balancing messages that market the availability of the VICP to families who experience an adverse event with messages that encourage and promote childhood immunization.

Consider options to streamline the VICP claims process. VICP stakeholders have recognized a need to streamline the claims process; petitioner respondents reinforced the need to do so.³⁰ This task is likely to be a challenging one, especially in regard to developing a standard for non-Table claims.³¹ To ensure that the views and perspectives of all stakeholders are taken into account, DVIC might convene a Work Group comprised of stakeholders, including petitioners and attorneys, to prioritize streamlining efforts. It is important to acknowledge that the navigability and length of the claims process is not solely affected by the VICP, but is heavily influenced by the attorney-VICP and attorney-petitioner interfaces.

The study findings indicate that although the VICP has accomplished its mandate, it would benefit from efforts to streamline the claims process, continue to conduct reasonable targeted outreach to racial and ethnic minorities and low-income families, and engage in future evaluations. Widespread immunization has been a mainstay of public health for more than 100 years. With the VICP, Congress achieved three keys goals: ensuring an adequate vaccine supply, stabilizing vaccine costs, and establishing and maintaining a forum in which individuals injured by certain vaccines could seek compensation. For the small number of people who experience an adverse event in reaction to a vaccination, the VICP is essential to addressing their financial needs and personal loss. At the same time, it offers a no-fault alternative to the traditional tort system, ensuring that vaccine companies can continue their research and development activities and health care providers can continue to administer vaccines.

²⁸ Division of Vaccine Injury Compensation, Healthcare Systems Bureau, Health Resources and Services Administration, Department of Health and Human Services. (2006). *National Vaccine Injury Compensation Program Strategic Plan*. Retrieved March 26, 2009, from ftp://ftp.hrsa.gov/vaccinecompensation/strategic_Plan_20060411.pdf.

²⁹ Aligned with Strategic Theme 4.

³⁰ Aligned with Strategic Theme 3.

³¹ U.S. House of Representatives, Committee on Government Reform, Subcommittee on Criminal Justice, Drug Policy and Human Resources. (2000). *The Vaccine Injury Compensation Program: Addressing needs and improving practices*. Washington, D.C.: U.S. Government Printing Office.

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A. Data Elements and Percent Missing Data

Data Element	n	Percent Missing Data
How did you first hear about the VICP?	107	0
How easy was it to get information about the VICP?	107	1.87
How helpful was the information provided when filing a claim with the Program?	107	5.61
Did you hire an attorney to pursue your claim with the Program?	107	0.93
How easy was it to find an attorney to pursue your claim with the Program?	107	0
How satisfied are you with the process of filing a claim with the VICP?	107	0.93
If you were asked to provide more information after you filed the claim, how easy was it to get this information?	107	2.80
How satisfied were you with the hearing process with the special master?	107	1.87
Did you receive a monetary award from the VICP?	107	0.93
If you did not receive an award, which of the following did you do?	43	2.08
What kind of life care planner(s), if any, helped decide the amount of your award?	63	1.59
How satisfied were you with the role of the life care planner(s) in this process?	23	4.35
How satisfied are you with the process used to decide the amount of your award?	63	1.59
How helpful was the Program in working with Medicaid to reduce or forgive your lien?	63	7.94
How adequate do you feel the award is to cover past and future medical care (that is not reimbursed by other sources) for the injured party?	63	3.17
How satisfied are you with the way you currently receive award payments?	63	6.35
How satisfied are you with the amount of time it took for you to complete the entire claim process?	107	3.74
Injured Party	107	0
Ethnicity of injured party	107	1.87
Race of injured party	107	1.87
Age of injured party at time of injury	107	0
If not injured party, respondent's age	107	4.67
City of residence	107	18.69
State of residence	107	10.28
Highest level of education respondent has completed	107	1.87
Including you, how many people live in your household?	107	5.61
Household's total yearly income, not including any award?	107	10.28

B. Evaluation Questions and Operational Definitions

Survey Domain	Evaluation Question	Survey Item	Operational Definition
Awareness about the VICP	1. How did petitioners learn about the VICP?	I.1	Modes of communication about the VICP are enumerated and participants will identify each mode of communication that they used to learn about the VICP. The frequency of each of these communication avenues will be reported.
		I.2	Petitioner's perception about ease of access of information of the VICP will be assessed with a 5-point Likert-style scale: 0=very difficult, 1=somewhat difficult, 2=neither easy nor difficult, 3=somewhat easy, 4=very easy. Summary statistics will be reported
Satisfaction with initial information from the VICP	2. To what extent are petitioners satisfied with the initial information they received from the VICP on filing a claim?	I.3	Petitioner's perception of utility of the VICP information on filing a claim will be assessed with a 5-point Likert-style scale: 0=very unhelpful, 1=somewhat unhelpful, 2=neutral, 3=somewhat helpful, 4=very helpful and 9=not applicable. Summary statistics will be reported.
		I.4	In addition, petitioners will also respond to the open-ended question of what information should be added. Common themes from the qualitative data analysis will be reported.

Survey Domain	Evaluation Question	Survey Item	Operational Definition
To what extent are the petitioners satisfied with the VICP process?	8. To what extent are petitioners satisfied with their interactions with life care planners?	III.14	<p>Respondents will be asked if they hired a life care planner, and if so, the type of life care planner. Responses will be coded as:</p> <p>0=hired by me or my attorney, 1=hired by the government, 2=one hired by me and/or my attorney and one hired by the government, 3=jointly agreed upon by me and/or my attorney and the government, 4=don't know/don't remember, 9=no life care planner involved</p>
		III.15a	<p>Respondents will then be asked their level of satisfaction with their life care planner. Responses will be coded on a 5-point Likert-style scale: 0=very dissatisfied, 1=somewhat dissatisfied, 2=neutral, 3=somewhat satisfied, 4=very satisfied.</p> <p>The number of people using life care planners will also be summarized for any life care planner as well as for specific types of life care planners. Odds ratios of dissatisfaction will be calculated to compare the types of life care planners.</p>
		III.15b	<p>Respondents will then be asked an open-ended question of why they were satisfied or dissatisfied with their life care planner.</p>
			<p>Summary statistics for each question will be reported. Common themes from the qualitative data analysis will be reported.</p>

Survey Domain	Evaluation Question	Survey Item	Operational Definition	
To what extent are the petitioners satisfied with the VICP process? (cont.)	4. To what extent are petitioners satisfied with the clarity, ease and navigability of the legal process: 1. identifying an attorney, 2. filing a claim, 3. participating in the hearing process, 4. determining the award amount (where applicable)?	I.5	Respondents will be asked if they hired an attorney. A “yes” response will be worth one point and a “no” response will be worth zero points.	
		I.6	Respondents will also be asked how easy it was to find their attorney. Responses will be coded on a 5-point Likert-style scale: 0=could not find an attorney, 1=very difficult, 2=somewhat difficult, 3=neither easy nor difficult, 4=somewhat easy, 5=very easy, or 9=not applicable/ did not seek an attorney. Summary statistics will be reported. Respondents will then be asked an open-ended question of how the process of finding an attorney could be made easier. Common themes from the qualitative data analysis will be reported.	
		I.7		
	5. To what extent are petitioners satisfied with the length of the process?	5. To what extent are petitioners satisfied with the length of the process?	II.8	Respondents will be asked how satisfied they are with the process of filing a claim through the VICP. Responses will be coded on a 5-point Likert-style scale: 0=very unsatisfied, 1=somewhat unsatisfied, 2=neutral, 3=somewhat satisfied, 4=very satisfied, 9=not applicable.
			II.9	Respondents will also be asked how easy it was to provide any additional information, if it was needed for the claims process. Responses will be coded on a 5-point Likert-style scale: 0=very difficult, 1=somewhat difficult, 2=neither easy nor difficult, 3=somewhat easy, 4=very easy, or 9=not applicable
			II.11	Respondents will also be asked to rate their satisfaction with the hearing process. Responses will be coded on a 5-point Likert-style scale: 0=very dissatisfied, 1=somewhat dissatisfied, 2=neutral, 3=somewhat satisfied, 4=very satisfied, 9=not applicable.
			III.16	Respondents will also be asked to their level of satisfaction with the process of deciding the award amount. Responses will be coded on a 5-point Likert-style scale: 0=very dissatisfied, 1=somewhat dissatisfied, 2=neutral, 3=somewhat satisfied, 4=very satisfied. Summary statistics for the above four questions (excluding responses of “9”) will be reported alone and averaged to give a composite score for satisfaction with the legal process. Respondents will then be asked an open-ended question of how the process of filing a claim could be made any easier
	II.10			
	IV.21	Respondents will be asked to rate their level of satisfaction with the length of time of the claims process. Responses will be coded on a 5-point Likert-style scale: 0=very dissatisfied, 1=somewhat dissatisfied, 2=neutral, 3=somewhat satisfied, 4=very satisfied. Summary statistics will be reported.		

Survey Domain	Evaluation Question	Survey Item	Operational Definition
To what extent are the petitioners satisfied with their award?		III.12	Respondents will be asked if they received an award from the VICP. Responses will be coded as follows: 1=yes and 0=no. Odds will be reported.
	10. How do petitioners who do not receive an award proceed with the claims process?	III.13	Respondents will be asked what action they chose, if they were denied an award. Responses will be coded as follows: 0=appeal, 1=pursue civil action, 2=withdraw after 240 days, 3=withdraw after 420 days, 4=don't know/don't remember, 5= none of the above.
	6. To what extent are petitioners satisfied with the decision regarding: (1) receipt of a financial award and (2) adequacy of that award?	III.19	Respondents will be asked their level of satisfaction with the mode of payment of award money. Responses will be coded on a 5-point Likert-style scale: 0=very dissatisfied, 1=somewhat dissatisfied, 2=neutral, 3=somewhat satisfied, 4=very satisfied. Respondents will then be asked an open-ended question of how they would change how the award is paid.
		III.20	
		III.18	Respondents will be asked how adequate they believe the award is to cover related medical care. Responses will be coded on a 5-point Likert-style scale: 0=very inadequate, 1=somewhat inadequate, 2=neither inadequate nor adequate, 3=somewhat adequate, 4=very adequate.
	7. To what extent are petitioners satisfied with the VICP's negotiation with Medicaid to reduce and/or eliminate their lien (where applicable)?	III.17	Respondents will be asked how helpful they perceived the VICP to be in reducing or eliminating their lien. Responses will be coded on a 5-point Likert-style scale: 0=very unhelpful, 1=somewhat unhelpful, 2=neutral, 3=somewhat helpful, 4=very helpful and 9=not applicable.
			Summary statistics for each question will be reported. Common themes from the qualitative data analysis will be reported.
9. How are measures of satisfaction affected by: (1) whether or not the petitioner received an award and (2) type of respondent?		Odds ratios will be calculated to compare measures of satisfaction among those who received an award to those who did not and among respondents who were the injured party and parents/ guardians of the injured party. Statistical significance will be determined at the 95% confidence level.	

C. Data Collection Instruments

1. Petitioner Satisfaction Survey

The Division of Vaccine Injury Compensation (DVIC)³² wants to know more about your experiences with the National Vaccine Injury Compensation Program (VICP). Your response to this questionnaire and your recommendations will help improve the Program.

INSTRUCTIONS: Please read each question below. Then mark the answer or answers that best describe your experience. When you are finished answering all of the questions, please place your questionnaire in the addressed stamped envelope provided and return it to the evaluation contractor (Altarum Institute) by mail.

Please complete and return this questionnaire only once.

This questionnaire is anonymous. You will not be asked to provide personal identifying information, such as your name or address. Information from this survey will be reported only in aggregate.

Your feedback is important. Please answer each question honestly and thoughtfully. If you have any questions, please contact Dr. Namratha Swamy, the Altarum Institute Project Director, at 202-828-5100.

Section I – Before Filing the Claim

1. How did you first learn about the National Vaccine Injury Compensation Program? (check all that apply)

- Vaccine Information Statement (VIS)
 - Flyer or brochure from the National Vaccine Injury Compensation Program
 - The National Vaccine Injury Compensation Program Web site
 - Other flyer or brochure
 - Internet (other than the National Vaccine Injury Compensation Program Web site)
 - Other parents or adults who have been involved with the National Vaccine Injury Compensation Program
 - The health care provider who gave the vaccine
 - Other health care provider
 - The media
- Please specify:
- Radio and/or television
 - Newspaper or magazine
 - Other (please describe):

-
- A contact from the Centers for Disease Control and Prevention (CDC)
 - Other (please describe):
-

³² DVIC is a division of the Department of Health and Human Services, Health Resources and Services Administration, Healthcare Systems Bureau.

2. How easy was it to get information about the National Vaccine Injury Compensation Program? (circle your response)

Very difficult	Somewhat difficult	Neither easy nor difficult	Somewhat easy	Very easy
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3. How helpful was the information provided when filing a claim with the Program? (circle your response)

Very unhelpful	Somewhat unhelpful	Neutral	Somewhat helpful	Very helpful	Not applicable
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4. What other sources or kinds of information would make it easier to learn about the Program?

5. Did you hire an attorney to pursue your claim with the Program? (circle your response)

Yes	No
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6. How easy was it to find an attorney to pursue your claim with the Program? (circle your response)

I could not find an attorney	Very difficult	Somewhat difficult	Neither easy nor difficult	Somewhat easy	Very easy	I did not seek an attorney
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7. How do you think finding and hiring an attorney to pursue a claim with the Program could be made easier?

Section II – The Claims Process

8. How satisfied are you with the process of *filing a claim* with the National Vaccine Injury Compensation Program? (circle your response)

Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied	Not applicable
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9. If you were asked to provide more information after you filed the claim, how easy was it to get this information? (circle your response)

Very difficult	Somewhat difficult	Neither easy nor difficult	Somewhat easy	Very easy	Not applicable
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10. What changes would you make to the process of filing a claim and submitting any additional requested information?

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11. How satisfied were you with the hearing process with the special master? (circle your response)

Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied	Not applicable
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Section III –The Compensation Decision and Payment of the Award

12. Did you receive a monetary award from the National Vaccine Injury Compensation Program? (circle your response)

Yes	No
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If yes, then go to Question 14.

13. If you did not receive an award, which of the following did you do? (check all that apply)

- Appeal the decision
- Pursue civil action
- Withdraw after 240 days
- Withdraw after 420 days
- Don't know/Don't remember
- None of the above

IF YOU DID NOT RECEIVE A MONETARY AWARD, PLEASE SKIP TO SECTION IV.

14. What kind of life care planner(s), if any, helped decide the amount of your award? (check only one response)

- A life care planner hired by me or my attorney
- A life care planner hired by the government
- Two life care planners: one hired by me (and/or my attorney) and one hired by the government
- One life care planner jointly agreed upon by me (and/or my attorney) and the government
- Don't know/ Don't remember
- No life care planner was involved → *(Skip to question 16)*

15a. How satisfied were you with the role of the life care planner(s) in this process? (circle your response)

Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied
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15b. Why were you satisfied or dissatisfied with the role of the life care planner(s)?

16. How satisfied are you with the process used to decide the amount of your award? (circle your response)

Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied
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17. How helpful was the Program in working with Medicaid to reduce or forgive your lien? (circle your response)

Very unhelpful	Somewhat unhelpful	Neutral	Somewhat helpful	Very helpful	Not applicable
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18. How adequate do you feel the award is to cover past and future medical care (that is not reimbursed by other sources) for the injured party? (circle your response)

Very inadequate	Somewhat inadequate	Neither inadequate nor adequate	Somewhat adequate	Very adequate	Not applicable
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19. How satisfied are you with the way you currently receive award payments? (circle your response)

Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied
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20. What changes would improve the way the award is paid?

Section IV – Overall Process and Communications

21. How satisfied are you with the amount of time it took for you to complete the entire claim process? (circle your response)

Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied
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22. How helpful was each of the following agencies:

A. Division of Vaccine Injury Compensation? (circle your response)

Very unhelpful	Somewhat unhelpful	Neutral	Somewhat helpful	Very helpful	Not applicable	Do not know who they are/ what they did
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Based on your experiences, how could the Division of Vaccine Injury Compensation staff have been more helpful?

B. The Department of Justice? (circle your response)

Very unhelpful	Somewhat unhelpful	Neutral	Somewhat helpful	Very helpful	Not applicable	Do not know who they are/ what they did
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Based on your experiences, how could the Department of Justice staff have been more helpful?

C. The Court (the special master)? (circle your response)

Very unhelpful	Somewhat unhelpful	Neutral	Somewhat helpful	Very helpful	Not applicable	Do not know who they are/ what they did
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Based on your experiences, how could the Court staff have been more helpful?

Section V – Please Tell Us About Yourself

The questions below might feel more personal than the questions you already answered. Remember that you cannot be identified based on your answers.

Your answers will not affect any award you may have received from your vaccine injury compensation claim.

23. Are you the (check one response):

- Injured Party
- Parent/Guardian of the Injured Party
- Partner/Spouse of the Injured Party

24. What is the ethnicity of the injured party? (check one response)

- Hispanic/Latino
- Not Hispanic/Latino

25. What is the race of the injured party? (check all that apply)

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

26. How old was the injured party at the time of injury? _____

27. If you are not the injured party, how old are you? (check one response)

- 18-35
- 36-49
- 50 and up
- I am the injured party

28. Where do you live?

City _____ State _____

29. What is the highest level of education you completed? (check one response)

- Elementary school (grades 1 through 8)
- Some high school (grades 9 through 11)
- High school graduate or GED
- Some college, or a technical or trade school
- Associate degree (2-year)
- College graduate (4-year) or graduate degree

30. Including you, how many people live in your household?

31. What is your household's total yearly income, not including any Program award? (check one response)

- Less than \$20,000
- \$20,000 – 39,999
- \$40,000 – 59,999
- \$60,000 – 79,999
- \$80,000 or more

32. If you have any other suggestions for improving the National Vaccine Injury Compensation Program, please write them below.

2. Initial Mailing Materials

i. Introductory letter to attorney

Dear

We recently spoke about the petitioner satisfaction survey currently being conducted by the Division of Vaccine Injury Compensation (DVIC) within the Federal Department of Health and Human Services. As discussed, DVIC has asked our firm, Altarum Institute, to conduct the survey with petitioners who have gone through the Vaccine Injury Compensation Program (VICP). We discussed how we could work with you to distribute the survey to your client(s), and you graciously agreed to help by addressing our pre-prepared envelopes and sending them to your client(s). We greatly appreciate your willingness to help us distribute this survey and the follow-up letters.

Listed below are the last names of your clients to whom we would like the survey sent. These last names come from a DVIC-generated list of petitioners who have completed claims within the past 5 years. If you believe that you have additional clients who are part of this group, please let us know.

This package contains two sets of envelopes:

- (1) A flat envelope containing: the petitioner survey, introduction letter, informed consent document, and instructions on filling out the survey. All postage is affixed.
- (2) Two business-size envelopes, which are reminder letters to be mailed at one and two months after the initial survey. All postage is affixed.

Please let us know if you have any questions and if we can be of any assistance. Again, thank you very much for your help with this survey to improve the VICP claims process.

Regards,

Kara Rudolph, MPH

Policy Associate

Altarum Institute

1200 18th Street NW, Suite 700

Washington, DC 20036

202-828-5100

List of Petitioners:

ii. Introductory letter to petitioner

Dear Prior Petitioner to the National Vaccine Injury Compensation Program:

The Altarum Institute, a non-profit organization with a mission to improve health and health care in the United States, has been contracted by the National Vaccine Injury Compensation Program (VICP) to conduct a petitioners' survey to determine ways to improve how the Program operates. As a petitioner to the VICP who has completed the Program's claims process, we invite you to tell us about your experience and level of satisfaction or dissatisfaction with that process by completing the enclosed survey. Your feedback and recommendations will help to improve the Program for future participants.

We value your privacy and ask only that you provide as much information as you feel comfortable sharing. The survey is anonymous. You will not be asked to provide personal identifying information, such as your name or address. When you are finished filling out the survey, we ask that you please return your survey by mail in the enclosed pre-addressed, postage paid envelope directly to us at the Altarum Institute. We have sent this letter to you by way of your attorney because we do not have contact information for you. Please know that neither the VICP staff nor your attorney will ever see your responses.

Filling out this survey should take no more than 15 minutes. If you would prefer to complete this survey on the Internet, please go to <http://vicp.notlong.com>. We ask that you complete and return this survey only once.

Your honest and comprehensive feedback will make a difference in the ability of all of those involved with the VICP to better meet the needs of future petitioners. We greatly appreciate your help. If you have any questions about the survey please contact me, Namratha Swamy, the person at the Altarum Institute responsible for this project. My phone number is 202-828-5100. You may also send me an email at namratha.swamy@altarum.org.

Thank you in advance for your assistance.

Sincerely,

Namratha Swamy

Director, Evaluation and Research Methods Practice Area

Altarum Institute

1200 18th Street NW, Suite 700

Washington, DC 20036

iii. ***Informed consent statement to petitioner***

Participant Consent Form

Before taking part in this study, please read the information below. Only complete the enclosed survey if you understand the statements and freely consent to participate in the study.

You are invited to participate in a research study on the National Vaccine Injury Compensation Program (VICP) claims process. This study is being conducted by the Altarum Institute, a non-profit organization, on behalf of the Health Resources and Services Administration. The purpose of this study is to identify ways to improve the VICP and its claims process.

This study involves a paper- or Web-based satisfaction survey. As a recent VICP petitioner, you will be asked questions about how you feel about the claims process, like how easy it was to get information about the VICP and your level of satisfaction with the process of filing a claim. You will also be asked to describe how you feel the process could be improved. Lastly, you will be asked to supply some non-identifying, demographic information, like your age and geographic location. Filling out this survey should take approximately 15 minutes.

There are no foreseeable risks associated with participation. We acknowledge that minor emotional discomfort may occur when thinking about a past vaccine injury event. Potential benefits of participating include improving the claims process for future VICP petitioners.

Please understand that your participation is completely voluntary, and you have the right to refuse, withdraw your consent, or discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. Additionally, you have the right to not answer particular questions of the survey. We ask that you provide only as much information as you feel comfortable sharing.

If you agree, your individual privacy will be strictly maintained. The survey is anonymous – you will not be asked to provide any personal identifying information, such as your name and address. The survey responses that we receive will be analyzed and published in aggregate form only.

We will use your survey responses to identify specific parts of the VICP claims process that are in need of improvement and outline ways to make those improvements. Our goal is to make the claims process function better for future petitioners.

If you have any questions, concerns, or complaints about this study and its procedures, you may contact the Project Director, Dr. Namratha Swamy, at 202.828.5100.

Signature of Researcher

Date

iv. Online survey instructions to petitioner

If you choose to fill out a survey online please keep in mind the following:

- This is a brief survey that should take approximately 15 minutes to complete.
- The survey may be reached by typing the following link into your Web browser:
 - English version: vicp.notlong.com
 - The link is not case sensitive
- Once you have started the online survey, please click on the “Next” button at the bottom of each page to advance through all of the survey questions. You may click on the “Back” button to revisit previous survey questions.
- You must start and finish this survey during one computer session. That means that if you exit the survey before completing it, your responses will not be saved.
- Please take the survey only once.

Again, we greatly appreciate and value your participation!

3. Survey Follow-up Letter to Petitioner

Dear Prior National Vaccine Injury Compensation Program Petitioner:

You were recently contacted by the Altarum Institute to complete an anonymous survey about your experiences with the National Vaccine Injury Compensation Program (VICP) process. If you have completed and returned the survey, then thank you very much!

If you have not completed the survey we would very much appreciate your taking about 15 minutes to do so. Your responses and feedback will help improve the process for future petitioners.

If you have misplaced the survey, please contact me, Namratha Swamy, the Project Director, and I will send you another copy. My phone number is 202-828-5100 (mention VICP), and my email address is namratha.swamy@altarum.org. If you would prefer to take the survey online, please go to <http://vicp.notlong.com> for instructions and access.

Thank you for your past or future contributions to providing information to improve the VICP.

Sincerely,

Namratha Swamy

The Altarum Institute

Director, Evaluation and Research Methods Practice Area

1200 18th Street NW, Suite 700

Washington, DC 20036