

***REQUEST FOR PROPOSAL***

**EMPOWER**

**Portal**

*“Pursuing a Cure for Pancreatic Disease”*

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# **1.0 BACKGROUND**

## **1.1 ABOUT THE NATIONAL PANCREAS FOUNDATION**

The National Pancreas Foundation (NPF) is a 501(c)(3) non-profit organization based out of Bethesda, MD. The NPF was founded in 1997 by Patter Birsic and Jane Holt as an organization committed to advancing patient education, treatment, and research regarding benign and malignant conditions of the pancreas. The NPF is the only foundation dedicated to patients who are suffering from all forms of pancreatic disease. The mission of the foundation is to help raise awareness for both benign and malignant pancreatic disorders, advocate for new and improved treatments, sponsor innovative clinical research, promote quality in patient care, and offer support and educational opportunities for adult patients, pediatric patients, their families and caregivers, and medical professionals. Since its inception, the NPF has successfully funded cutting-edge clinical research projects and has awarded grants to fund 115 ground-breaking research projects devoted to pancreatic diseases. Furthermore, NPF has supported initiatives that have led to millions of dollars of additional research funding by the National Institutes of Health (NIH) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), as well as other institutions.

## **1.2 ABOUT PANCREATIC DISEASE**

Acute pancreatitis, chronic pancreatitis, and pancreatic cancer contribute to the majority of disease burden in exocrine pancreatic conditions. Acute pancreatitis (AP) is one of the leading gastrointestinal-related causes for recurrent hospitalizations in the United States (U.S.) [1]. Comparatively, the incidence and prevalence rates of chronic pancreatitis (CP) is less than AP; however, CP significantly impacts the quality of life of affected patients. Recent evidence indicates that there exists a strong correlation between CP and the development of pancreatic cancer [2]. According to the National Cancer Institute’s Surveillance, Epidemiology, and End Results Program (SEER) [3], pancreatic cancer constitutes approximately 3% of all new cancer cases diagnosed annually in the U.S. Over the past 10 years, incidence rates for new cases of pancreatic cancer have increased an estimated average of 0.8% annually [3]. Unfortunately, there is a poor prognosis for pancreatic cancer, and there does not exist a standard diagnostic method for early detection. The five-year survival rate is approximately 7.2% [3].

While there have been advances in clinicopathogenesis, genetics, and therapeutic modalities in recent decades, there still remains a great deal of unanswered questions and challenges in the clinical management of pancreatic disease, including:

* the lack of early detection methodology
* a cost-effective approach to the diagnostic testing sequence
* the demand for targeted therapies
* the selection of surgical indications and procedures
* the clinical characteristics that are predictive of outcomes
* the preventative measures to reduce morbidity rates

# **2.0 PURPOSE**

The NPF is seeking proposals from experienced and qualified firms or individuals to assist with the development of a cross-platform application to function as a web-based patient portal and mobile-enabled solution, which will be referred to as the EMPOWER Portal.

The NPF has recognized the need for a national patient data repository to better understand the natural history and progression of pancreatic diseases, the effectiveness of current treatments, and the quality of life of patients affected by pancreatic conditions.

The NPF intends to enter into a partnership with an experienced, responsive, responsible and financially sound organization that is qualified to establish and maintain a registry of patient-reported health data.

# **3.0 OBJECTIVES**

## **3.1 PRIMARY OBJECTIVES**

1. To collect patient-reported health data and outcomes focused on the following domains:
	1. Symptomatology and management of chronic pain
	2. Nutrition
	3. Quality of life

## **3.2 SECONDARY OBJECTIVES**

1. To collect and maintain patient-reported data that can be used for future studies to:
	1. Evaluate measures of patient wellness and quality of life in patients with these pancreatic disorders
	2. Evaluate the quality of patient care and determine the level of influence per the following variables:
		1. Geographical regions
		2. Type of healthcare facility
		3. Type of healthcare providers
		4. Point of entry into a healthcare facility
		5. Socioeconomic factors
	3. Assess variations in patient satisfaction, adherence, and engagement activities
	4. Promote collaborative research among interested investigators by identifying a larger pool of potential research subjects that would be available to these investigators at their own institutions
2. To empower patient participants to become more proactive in their health to help improve the quality of their lives by providing the ability to:
	1. Journal their patient perspective of their personal disease experience by providing chronological/ longitudinal views of their personal health data to help discover correlations among diseases, symptoms, etc.
	2. Self-report and monitor their symptoms and outcomes to help identify trends over time
3. To establish a patient community resource for educational and awareness purposes that may enhance patients’ ability to manage their condition(s)

# **4.0 SCOPE OF WORK**

Although the complete scope of work will be dependent upon the contracted services/ software solution, the selected vendor will be responsible for all aspects of software development and implementation, including design, programming/ coding, testing, and configuration.

## **4.1 GENERAL REQUIREMENTS**

Our approach incorporates a set of requirements that outline core functionality for success of our solution, based on feedback gathered from advisors and staff. To that end, our minimum viable product (MVP) must include the following characteristics. Where the proposed budget constrains the ability to deliver MVP features, please indicate this and provide an estimation of cost. :

1. Cloud-based platform and application (e.g., SaaS), tailored to meet the functional requirements for NPF
2. Scalable technology
3. Platform scalability associated with data management, user accessibility and application responsiveness to end users
4. Designed as a modular solution to which future enhancements or new components may be added. Specifically, we seek the ability to have access to a self-service form/survey builder tool. The intent of this tool is to create additional surveys as future needs arise, accessible for building by NPF administrators
5. Wide browser support (e.g., Google Chrome, Mozilla Firefox, Safari, Internet Explorer, etc.)
	1. While we acknowledge that support for browser versions aligns with the ongoing support by the developer, it is imperative that the proposed solution does not have dependencies on embedded tools or plug-ins, such as text editors. Our goal is to reduce/eliminate the risk of obsoletion of the proposed solution, as new browser software versions are brought to market.
6. Device compatibility (e.g., PC desktops, MacOS, smartphones, tablets and other mobile devices)
7. Adaptive, responsive layout / user interface
8. Mobile optimization
9. NPF will own / govern all data within the registry
10. User access controls
	1. User roles and permissions that provide different levels of access for different types of users
11. Secure user authentication (e.g., unique username and password, two-factor authentication)
12. Ability to provide an application timeout function for end users
13. User-friendly interface and intuitive UI design, for instance:
	1. Visual and functional consistency (e.g., typeface, color scheme, labels, etc.)
	2. Simple website navigation with standard components, such as tab bar, sidebars, hamburger menu, etc.
	3. Familiar interface elements, such as visual/ text objects that may resemble real word counterparts to make the functionality clear and obvious to the patient end user
	4. Predictive interactions (e.g., predictive caching)
	5. Visual cues, for example, subtle icons to serve as call to actions (CTA), hover effect over text to aid/help on relevant fields
14. Unique user identity and record verification (i.e., to prevent duplication of end users/ records)
15. “Opt-in” form(s) / window(s) (i.e., requires interaction from patient end user) to include:
	1. Informed consent form
		1. Time/date stamp
		2. Electronic signature (e.g., require the user to manually type their full name into respective textboxes OR digitally sign by touchscreen or mouse OR verify identity with a web token sent to user’s designated email address)
		3. Participation options (i.e., requires the user to make a declaration of their preferred participation, such as whether they wish to be contacted in the future about new clinical trials OR if they are willing to be contacted to provide clarification or additional information)
	2. Terms and Conditions
		1. Required user acknowledgement (e.g., user selects a checkbox OR types initials into a textbox AND system records user input and date/time stamp)
	3. Privacy Policy
		1. Required user acknowledgement (e.g., user selects a checkbox OR types initial into a textbox AND system records user input and date/time stamp)
16. Interactive form-based surveys designed to keep patient end user engaged by including features and functions such as the following:
	1. Progress indicator/ tracking (e.g., progress bar of survey completion)
	2. Dynamic data entry fields equipped with conditional logic that are dependent upon user input
	3. User help / assistance (e.g., tooltips, floating help text)
	4. Inline data validation
	5. Meaningful error messages
	6. Autosave (i.e., automatic save feature)
	7. *Refer to* ***Appendix B*** *for general data requirements of initial survey*
17. Print capability (i.e., for patient end users to print completed surveys, copy of informed consent form with electronic signature, etc.)
18. Reporting tools
	1. Ability to have dashboard views of data using data visualization, such as heat maps, summary reports, charts, tables of aggregate data, to illustrate visual trends associated with patient’s diagnosis, geographical area, data-driven content, etc.
		1. Dashboard views may vary based on user roles
		2. *Refer to* ***Appendix C*** *for concept examples of dashboards*
	2. Menu-based reports for end users which may be accessible using permission levels (i.e., preset report templates)
	3. Access to the data for ad hoc reporting by way of a query builder tool that allows for data field selection to complete parameters for reporting
	4. Ability to provide database level access for direct queries on the data.
19. Push notifications/ scheduled reminders (e.g., follow-up reminders to motivate user to finish survey OR to encourage user to return to update their information since their last entry)
20. Customizable survey creation (e.g., survey form builder tool)
	1. As noted above, we seek to understand if the solution offers the ability to create new surveys on an as needed basis.
21. Survey management, such as distribution automation, response tracking (e.g., indicate how many participants opened a survey)
	1. This component should include the ability to share additional survey questions based on end-user response to standard question sets.
22. Secure messaging, including end users (e.g., NPF Administrators, participants, caregivers) and third parties (e.g., clinical providers, research investigators, etc.)
	1. Ability to exchange secure messages from within the application (preferred) or a third-party app integration (if more cost effective)
23. Safeguards consistent with industry best practices
24. Platform data center hosting security in compliance with SSAE 16 rating SOC 1, 2 or 3
25. Application Security
26. User access security auditing ability
27. Privacy/ Confidentiality
28. HIPAA and HITECH Act compliance
29. Encryption of data at-rest and in-transit.
30. Uploader function with ability to store materials that may be accessible via download or viewer to patients (e.g., for NPF to share educational materials with patient end users)
31. Download ability to support the sharing of above-mentioned educational materials.

## **4.2 OPTIONAL FUNCTIONS/ COMPONENTS**

The following describes desired functions of the software solution:

1. Data integration capabilities
	1. Data import/ migration/ conversion, such as a tool that offers administrative end users the ability to consume data from external information systems, which must be extracted and formatted into a pre-defined file structure that corresponds with the data elements of this registry system
	2. 3rd-party application integration with solutions, such as electronic health record systems (EHRs)

## **4.3 REQUESTED VENDOR SERVICES**

The following outlines the requested services/ functions:

1. Software development, programming, testing, and implementation/ deployment approach
2. End user documentation and training
3. Ongoing software maintenance and technical support. Please provide a description of any service level agreement and user support tiers and expectations.

## **4.4 WORKFLOW DESIGN CONCEPT**

1. Participant Eligibility/ Pre-screening/ Registration
	1. Review online consent form, as well as Terms of Service and Privacy policies
	2. Report minimum set of data as part of the participant registration process
		1. To confirm eligibility for participation (per conditional logic)
		2. To validate unique identification (per conditional logic)
		3. To identify/ eliminate duplicate submissions (per conditional logic)
	3. Submit electronically signed consent form to participate
2. Participant Onboarding
	1. A unique participant account is generated in the system after validating submission
	2. A unique username/ password is assigned to participant to access their personal account
3. Participant Activities
	1. Participants may log into their personal account to do the following:
		1. Complete surveys to self-report their personal disease history, symptoms, treatment and disease management, and quality of life
		2. Self-monitor/ track symptoms and quality of life variables over time through data visualization and/or reporting tools
		3. Explore and access patient resources available through the NPF website - https://pancreasfoundation.org (e.g., sidebar menu containing external links to NPF online resources)
			1. Patient education materials
				1. Animated Pancreas Patient, an interactive patient educational tool
				2. Nutritional advice & online recipes
			2. Patient support community (INSPIRE), an online support group and discussion community
			3. Newsletters
			4. NPF Centers directory
			5. Clinical trials directory
			6. NPF organization
				1. NPF State Chapters

In-person patient education sessions

In-person patient support group meetings

Volunteer opportunities at fundraising events

## **4.5 END USER ROLES**

1. NPF Administrators
	1. Full data access
	2. Maintains data and registry operations
	3. Conducts internal data analyses
2. Participants/ Caregivers
	1. Given access to self-reported data
	2. Given ability to generate a print summary of self-reported data (e.g., PDF format)
	3. Data visualization and/or reporting tools available for individual use, if desired
		1. To monitor self-reported data over time
		2. To compare individual data across aggregate population data
3. Interested Stakeholders (e.g., Clinical providers/ investigators, physicians, etc.)
	1. Limited data access per NPF approval (e.g., View-only)
		1. Potential access to summary reports of aggregated de-identified data (i.e., preset reports defined by NPF Administration)
		2. No direct access to patient-reported data

## **4.6 BUDGET REQUIREMENTS**

The NPF has allocated a project budget ranging between $50,000 - $75,000 for the software solution. In areas where the specified requirements cannot be met in the budget, it is important for the NPF to better understand the costs involved to accomplish, as well as the minimum viable product outlook.

# **5.0 PROPOSAL GUIDELINES**

## **5.1 QUALIFICATIONS OF VENDOR**

The vendor must have experience in the following:

1. Cloud-based application development
2. Mobile application development
3. Software development/ implementation of healthcare-related applications
4. Use and management of large data sets in various formats (XML, CSV, etc.)
5. Development of and integration with 3rd party APIs and web services

## **5.2 SUBMISSION REQUIREMENTS**

To ensure proper consideration for this RFP, your proposal should include all of the following:

1. Executive Summary/ Vendor Profile [Page Limit: 2 pages]
	1. Primary contact information
	2. Company background
		1. Company history
		2. Mission of the company
		3. Business goals
		4. Keys to success
		5. Legal form of ownership
		6. Financial stability
		7. Track record
	3. Product(s) and service(s) (Page Limit: 3 pages)
	4. Project management team (Page Limit: 2 pages)
		1. Roles and responsibilities
		2. Experience should be documented in CVs or resumes of team members and accompany vendor’s proposal. Prior work in developing similar applications for non-profit organizations, medical associations, or healthcare facilities should be highlighted.
	5. Summary of recent and/or similar projects demonstrating relevant experience
2. Client References (minimum of 3) (Page Limit: 1 page)
3. Proposal (Page Limit: 12 pages)
	1. Detailed response to the requirements and design concept as described under “Scope of Work”
	2. Hardware and Configuration Specifications
	3. Development/ Testing/ Implementation Plan
		1. Project management
			1. Vendor’s project manager responsibilities
			2. Vendor/ Client responsibilities
			3. Change management process
		2. Methods and procedures (e.g., Method of Sprint Planning and Sprint procedures)
		3. Work breakdown structure of project
		4. Estimated timeline
	4. Training Plan
		1. Methodology
		2. Options and costs
		3. Requirements
	5. Ongoing Support/ Maintenance Plan
		1. Options
		2. Goals
		3. Procedures (e.g., problem escalation)
		4. System updates
	6. Cost Estimate
		1. Development and testing
		2. Training
		3. Implementation
		4. Ongoing support and maintenance
		5. Additional requirements or services
4. Responses to questions included in Appendix A
5. Vendor-based contract agreement templates
	1. Software License Agreement
	2. Service Level Agreement
	3. Business Associate Agreement

The cost estimate should include all expenses associated with providing and completing all work and services to support the project by the respective vendor, as described under “Scope of Work”. All projected expenses should be itemized to include an explanation of all fees and costs. Additionally, please provide a separate cost estimate to define additional pricing for the following:

1. Section 4.1 – In areas where the above requirements cannot be met within the specified budget, please define option pricing for customization.
2. Section 4.2 - ***OPTIONAL FUNCTIONS/ COMPONENTS***

If the prospective vendor submitting a proposal must outsource or contract any work to meet the requirements contained herein, this must be clearly stated in the proposal. Additionally, all costs included in proposals must be all-inclusive to include any outsourced or contracted work. Any proposals which call for out-sourcing or contracting work must include a name and description of the organizations (subcontractors) being contracted.

All contractual terms and conditions will be negotiated between both parties, and subject to review by NPF’s legal consultants.

## **5.3 RESPONSE FORMAT**

The response must follow the proposal content requirements in the order in which they appear in the proposal. Responses that do not conform to this format may not be considered for evaluation. Responses must be typewritten in a readily legible typeface that is easy to read. Each page must be clearly and consecutively numbered. All responses must be submitted in the name of the legal entity or authorized agency. Responses must be signed in ink by the officer or officers legally authorized to bind the company, partnership or corporation.

Responses must be submitted in PDF format and sent via electronic mail (e-mail) to the NPF Registry Manager. Please include "**RFP: Vendor Response**" in the subject line. Receipt will be acknowledged via e-mail.

## **5.4 PROPOSAL REVIEW CRITERIA**

NPF will evaluate all proposals based on the following criteria:

1. Vendor qualifications
2. Overall proposal suitability: proposed plans pertaining to project management and estimated cost must meet the scope and needs included herein and be presented in a clear and organized manner
3. Value and cost: evaluated based on the work to be performed in accordance with the scope of this project

# **6.0 TIMELINE(S)**

## **6.1 RFP SCHEDULE**

|  |  |
| --- | --- |
|  | ***Date*** |
| ***NPF will invite prospective vendors to submit proposals*** | ***06/13/2019*** |
| ***NPF will accept questions/ inquiries from prospective vendors*** | ***06/21/2019*** |
| ***Responses to this RFP due for NPF consideration*** | ***07/19/2019*** |
| ***NPF will review the proposal submissions*** | ***07/26/2019*** |
| ***NPF projects to respond to proposals*** | ***07/31/2019*** |

## **6.2 PROJECT MILESTONES**

1. RFP process
2. Vendor demonstration(s)
3. Selection of vendor
4. Contract review/ negotiations
5. Contract acceptance
6. Approval of project charter (i.e., outline design/ development/ implementation plans)
7. Application development (e.g., sprint phase development)
8. Beta testing (e.g., following each sprint)
9. Pilot testing
10. Implementation
	1. Go-Live initiation
	2. Go-Live completion

# **7.0 CONTACT INFORMATION**

Please reply to this RFP no later than **7/19/2019**at the following contact information:

|  |  |
| --- | --- |
| NPF Registry Manager: | Catie McGilvray |
|  |  |
| E-mail:  | cmcgilvray@pancreasfoundation.org |

## **7.1 QUESTIONS/ INQUIRIES**

All questions/ inquiries should be submitted via e-mail to the NPF Registry Manager per above RFP schedule. Please allow at least two business days for response.

If additional information or discussions are needed during this time frame, then NPF will notify the respective bidder/ vendor.

# **8.0 REFERENCES**

1. Raimondi, S., et al., *Pancreatic cancer in chronic pancreatitis, aetiology, incidence, and early detection*. Best Practice & Research Clinical Gastroenterology. 2010 June. 24(3): 349-358. doi: http://dx.doi.org/10.1016/j.bpg.2010.02.007.

2. Yadav, D. and Lowenfels, A.B., *The epidemiology of pancreatitis and pancreatic cancer.* Gastroenterology. 2013 June. 144(6): 1252–1261. doi:10.1053/j.gastro.2013.01.068.

3. Sherman, R.L., et al., *Annual report to the nation on the status of cancer, 1975-2011, featuring incidence of breast cancer, subtypes by race/ethnicity, poverty, and state*. JNCI Journal of the National Cancer Institute. 2015. 107 (6): djv048 doi:10.1093/jnci/djv048.

# **9.0 APPENDICES**

All appendices attached hereto and referred to herein are made part of this RFP.

## **APPENDIX A – PROSPECTIVE VENDOR WORKSHEET**

Please refer to *Appendix A – Prospective Vendor Worksheet* (attached separately as XLSX file).

## **APPENDIX B – GENERAL DATA REQUIREMENTS (EMPOWER PORTAL)**

Please refer to *Appendix B – EMPOWER Portal General Data Requirements – NPF RFP* (attached separately as XLSX file).

## **APPENDIX C – DASHBOARD CONCEPT EXAMPLES**

Although exact KPIs cannot be determined at this time, the following is intended to provide an overview of concepts.

EXAMPLE 1:

Title:

* Patient Management Dashboard

Objective(s):

* To monitor enrolled patient end users
* To guide patient engagement efforts

Target Audience:

* Power users (i.e., NPF Administrators)

Call to Action:

* Monitoring Patient end user activity to detect overall trends, such as types of enrolled patient end users, survey completion, login activity, etc.

Data Update/ Refresh Frequency: Daily

* Daily

How will the dashboard be accessed?

* Desktop

EXAMPLE 2:

Title:

* Patient Exploration Dashboard

Objective(s):

* To allow patient end users to monitor and track their progress based on data reported (e.g., symptoms, quality of life)
* To allow patient end users to view their self-reported data compared to all patient end users with the same diagnosis (aggregate data)
* To encourage patient end users to be proactive in their health

Target Audience:

* Patient end users

Call to Action:

* Monitoring self-reported data to detect overall trends in symptom recurrence, symptom progression, quality of life, etc.

Data Update/ Refresh Frequency: Daily

* Daily (Real time)

How will the dashboard be accessed?

* Mobile