

**PANCREATIC CANCER ACTION NETWORK
HEALTH DATA SHARING AGREEMENT and ACCESS PROCESS**

**Please follow the steps below to request access to the SPARK platform.
Email SPARK@PANCAN.ORG with any questions.**

- 1**
Navigate to the SPARK homepage pancan.org/spark
- 2**
Click "Request Access" and complete the Data Sharing Agreement form
- 3**
Email the completed form to spark@pancan.org
- 4**
You will receive 2 emails from PanCAN
 1. Welcome email
 2. An email inviting you to create your SPARK account



PANCREATIC CANCER ACTION NETWORK

HEALTH DATA SHARING AGREEMENT

Data Sharing Request:

Section 1: To be completed by external collaborator.

When completed please save and email to SPARK@PANCAN.ORG

General Information			
Date	<i>[Date of request]</i>		
External Collaborator Name	<i>[External requestor's name]</i>	External Collaborator Title / Role	<i>[External requestor's title]</i>
External Collaborator Organization	<i>[External requestor's organization]</i>		
Data Requested			
Data source(s)	<i>[PanCAN data source(s) and/or program(s) where data originates]</i>		
Description of data elements being requested	<i>[List or description of types of data attributes being requested]</i>		
Estimated number of patient records being requested	<i>[Estimated number of individual patient records being requested]</i>		
Intended Use of Data			
Primary Objectives			
<i>[Brief description of study / analysis objectives and expected output – please include attachment as necessary]</i>			
Study Design / Methods Planned (As Applicable)			
<i>[Brief description of proposed study design including initial hypotheses, statistical design / methodology, and rationale – please include attachment as necessary]</i>			
Potential Value / Impact to Pancreatic Cancer Patients or Broader PanCAN Community			
<i>[Brief description of the potential benefits to pancreatic cancer patients and/pancreatic cancer community – please include attachment as necessary]</i>			

Intended Dissemination Plan (Internal / External)
<i>[Brief description of the expected timing and channel(s) for dissemination of any data, analyses, or insights resulting from the requested data sharing – please include attachment as necessary]</i>
Biosketch of External Collaborator(s)
<i>[Name and brief description of the education and/or experience of the external collaborating person or persons should be included for all personnel that will be working with PanCAN data. Alternatively, a separate CV or biosketch can be provided with this completed form – please include attachment or cv as necessary]</i>

Section 2: To be completed by PanCAN staff:

General Information			
PanCAN Staff Name / Title	<i>[PanCAN staff name]</i>		
Is the data sharing arrangement exclusive to the external organization above?	Exclusive <input type="checkbox"/>	Has the external organization above contributed financially to PanCAN within the past 5 fiscal years?	Yes <input type="checkbox"/>
	Non-exclusive <input type="checkbox"/>		No <input type="checkbox"/>
Data Requested			
Is personally identifiable information (PII) being requested (PII defined below)?	Yes <input type="checkbox"/>	Are patients consented for the use described below?	Yes <input type="checkbox"/>
	No <input type="checkbox"/>		No <input type="checkbox"/>
Intended Use of Data			
Alignment with PanCAN Mission and Strategic Theme(s)			
<i>[Brief description of how this data sharing request supports PanCAN's mission and listing of the PanCAN Strategic Theme(s) that are supported]</i>			

All PanCAN health data originates from collection within the United States. PanCAN is a U.S. organization but will attempt to work with external collaborators subject to laws outside the United States that impose additional obligations on external collaborators in the utilization of PanCAN health data for research and/or education purposes so that external collaborators may comply with such laws. External collaborators must identify to PanCAN any such laws to which external collaborators are subject.

Terms of Agreement:

PanCAN is committed to protecting the security of our patient health data and ensuring expeditious dissemination of findings resulting from the analysis of our health data. To gain access to PanCAN's health data, you hereby agree to the following provisions:

Security

I will not release, nor permit others to release, to any person except persons on my research team who agree to abide by all of the terms and conditions of this Agreement, the data I receive through PanCAN. All members of the research team who have access to this data have signed this agreement.

- I will take appropriate and reasonable safeguards to protect PanCAN provided data from unauthorized uses, disclosures or access and/or data breaches. I will promptly notify PanCAN if I discover there has been any unauthorized use, disclosure, access or a data breach.
- I will not use, or allow others to use, the data in any way other than for statistical analysis and reporting for research or educational purposes as described in the proposal above.
- I will not attempt to learn the identity of any patient who chooses to provide access to de-identified information only. If I inadvertently discover the identity of any patient, I will make no use of this knowledge, will inform PanCAN of the discovered identity, and will not otherwise disclose the identifiable information.
- I will not contact any patient without PanCAN's prior written consent.
- I will not publish or present data in which an individual patient can be identified without explicit written permission from the patient or legal representative, and with PanCAN's knowledge.

Data Analysis and Publication

- I will make the results of my research publicly available through one or more publications in a generally accepted scientific journal, abstract, or similar publication (which may include on-line).
- I will keep PanCAN updated on any results obtained from analysis of the data I receive. I will provide copies of any slides or abstracts to PanCAN 10 business days in advance of their public disclosure. I will provide a courtesy review of any publications in which I utilize data received from PanCAN, at least 30 business days in advance of submission.
- I will cite the 'Pancreatic Cancer Action Network (PanCAN)' as the source of data for my results in all presentations, publications, abstracts or other public disclosures of the data.

Debarment/Exclusion

The investigator and their institution/company must ensure that no one on the research team has been debarred or excluded, from any federal or state government program, or is the subject of an investigation that could lead to debarment or exclusion.

Indemnification

Each party will hold harmless the other party from any costs or consequences that arise out of negligent or willful misconduct, breach of this Agreement or breach of any applicable law, regulation or rule that applies to this Agreement.



Term and Termination

This Agreement will start on the date of the last signature to this Agreement (the “Effective Date”) and remain in effect for two years from the Effective Date. PanCAN reserves the right to terminate this Agreement at any time by giving written notice to the other party. Upon termination all data in use by the investigator will be destroyed. The *Security and Data Analysis and Publication* terms outlined above shall apply until all PanCAN-owned data is destroyed.

Signatures (add additional signatures as needed):

External Requestor(s)

Pancreatic Cancer Action Network (PanCAN)

Name: _____

Name: _____

Title: _____

Title: _____

Date: _____

Date: _____

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Definition of Personal Identifiable Information (PII):

Any information that permits the identity of an individual to whom the information applies, by direct or indirect means. PII is information: (i) that directly identifies an individual (e.g., name, address, social security number or other identifying number or code, telephone number, email address, etc.) or (ii) by which a recipient may identify specific individuals in conjunction with other data elements, i.e., indirect identification. Information permitting physical, electronic, or online contact of a specific individual also is PII.