

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

DATA USE AGREEMENT

For use with a De-identified Data Set Only

This Data Use Agreement (“Agreement”) is made and entered into as of this [_____] (the “Effective Date”), by the Pancreatic Cancer Action Network (“PanCAN”) with an address at 1500 Rosecrans Avenue, Suite 200, Manhattan Beach, CA 90266, and [_____] (hereafter “DATA RECIPIENT”), on behalf of its employee [_____] (where applicable), (hereafter “INVESTIGATOR”). PanCAN and DATA RECIPIENT, hereafter referred to individually as a (“Party”) or together as the (“Parties”).

RECITALS

WHEREAS PanCAN contemplates sending DATA RECIPIENT certain de-identified information (“De-identified Data Set”) for the purpose of conducting research.

WHEREAS it is the intent of both Parties to fully comply with the laws and regulations related to confidentiality and information security.

THEREFORE, in consideration of the foregoing recitals, the parties agree as follows:

A. SCOPE AND PURPOSE

1. This Agreement sets forth the terms and conditions pursuant to which PanCAN may disclose a De-identified Data Set to DATA RECIPIENT for the purpose of conducting the Project (“Project”) as described in Appendix A to this Agreement.
2. Except as otherwise described herein, DATA RECIPIENT shall not use or disclose the De-identified Data Set for any other purpose other than to perform the Project as described in Appendix A to this Agreement or as required by law.
3. Transferring the De-identified Data Set:
 - a) PanCAN shall transmit the De-identified Data Set to the DATA RECIPIENT electronically
 - b) Upon execution of this Agreement, PanCAN or DATA RECIPIENT shall provide any specific instructions necessary to complete the transfer of the De-identified Data Set.

B. RECIPIENT OBLIGATIONS

1. DATA RECIPIENT shall use the De-identified Data Set solely to conduct the Project by DATA RECIPIENT and other DATA RECIPIENT employees, independent contractors, agents, and professional advisors, collectively (“DATA RECIPIENT Representatives”) that have a need to use the De-identified Data Set in connection with the Project. DATA RECIPIENT shall ensure its Representatives' compliance with all applicable terms of this Agreement and shall be responsible for any breach or violation of the applicable terms of this Agreement caused by any of its Representatives. DATA RECIPIENT shall not use the De-identified Data Set for any other purpose, without the prior written approval of PanCAN.
2. RECIPIENT shall employ all reasonable and appropriate safeguards to prevent the use or disclosure of the De-identified Data Set other than those uses or disclosures authorized by this Agreement or as required by law.
3. DATA RECIPIENT agrees to retain control over the De-identified Data Set and shall not disclose, release, sell, rent, lease, loan, or otherwise grant access to the De-identified Data Set to any third party that is not a DATA RECIPIENT Representative, without the prior written consent of PanCAN. If approved, DATA RECIPIENT will ensure the third

party agrees to the same restrictions and conditions that apply through this Agreement to the DATA RECIPIENT with respect to such information.

4. DATA RECIPIENT shall promptly report to PanCAN any use or disclosure of the De-identified Data Set that is not allowed for under this Agreement of which it becomes aware.
5. Upon request, DATA RECIPIENT will provide PanCAN access to any resulting de-identified aggregate data set. PanCAN may use the de-identified aggregate data for research purposes.

C. PUBLICATIONS/PUBLICITY

1. The Parties agree to the dissemination of Project findings by publication or otherwise is a valuable objective of the Project. Joint publications are encouraged with authorship of such publications decided according to ICMJE publication standards. DATA RECIPIENT reserves the right to publish the result of any work completed under this Agreement. Prior to submission for publication or presentation, DATA RECIPIENT will provide PanCAN thirty (30) days for review of a manuscript. PanCAN's comments will be considered in good faith by the DATA RECIPIENT. PanCAN and DATA RECIPIENT will arrange expedited reviews for abstracts, poster presentations, or other materials. If requested in writing, DATA RECIPIENT will withhold such publication for up to an additional sixty (60) days to allow for the filing of a patent application. The DATA RECIPIENT agrees to cite PanCAN as the source of the De-Identified Data Set for any results in all presentations, publications, abstracts, or other public disclosures of the De-Identified Data Set.
2. DATA RECIPIENT shall provide PanCAN access to, either electronically or in paper form, a copy of every publication of material based on or developed under this Agreement.
3. Neither Party shall use the other Party's name, trademark, or other logos in any publicity, advertising, or news release without the prior written approval of an authorized representative of that Party.
4. The Parties agree that each Party may disclose factual information regarding the existence and purpose of the relationship that is the subject of this Agreement without written permission from the other Party provided that any such statement shall not in any manner imply endorsement by the other Party whose name is being used.

D. MISCELLANEOUS

1. In the event of any conflict between the terms and conditions stated within this Agreement and those contained within any other agreement or understanding between the Parties, written, oral, or implied, the terms of this Agreement shall govern.
2. Except to the extent prohibited by law, the DATA RECIPIENT assumes all liability for damages, which may arise from its use, storage, disclosure, or disposal of the De-identified Data Set. PanCAN will not be liable to the DATA RECIPIENT for any loss, claim, or demand made by the DATA RECIPIENT, or made against the DATA RECIPIENT by any other party, due to or arising from the use of the De-identified Data Set by the DATA RECIPIENT, except to the extent permitted by law when caused by the gross negligence or willful misconduct of PanCAN. No indemnification for any loss, claim, damage, or liability is intended or provided by either Party under this Agreement.
3. Each Party acknowledges that they are subject to applicable export control laws and regulations (collectively, "Export Control Laws"), which include (without limitation) the International Traffic in Arms Regulations (ITAR), the Export Administration Regulations (EAR), and regulations and orders administered by the Treasury Department's Office of Foreign Assets Control ("OFAC Regulations"). Each Party agrees to comply with all Export Control Laws. Neither Party shall disclose any technology or technical data subject to Export Control Laws unless and until a plan for the transfer, use, dissemination, and control of the information has been approved by each Party's Export Control Officer. The Parties agree that DATA RECIPIENT has not requested the disclosure of, and PanCAN does not intend to disclose, any technology or technical data subject to Export Control Laws.

E. TERM and TERMINATION

1. The term of this Agreement shall commence beginning on the Effective Date as first written above and shall terminate on three (3) years from the Effective Date, or when the De-identified Data Set has been destroyed by DATA RECIPIENT and PanCAN has been notified, whichever occurs first. On termination or expiration, the DATA RECIPIENT will cease to use any De-Identified Data Set received under this Agreement.
2. Agreement to protect the De-identified Data Set shall survive termination of this Agreement.
3. In the event the DATA RECIPIENT breaches this Agreement, PanCAN, in its sole discretion, may: i.) terminate this Agreement upon written notice to DATA RECIPIENT; or ii.) request that DATA RECIPIENT, to the satisfaction of PanCAN, take appropriate steps to cure such breach. If the DATA RECIPIENT fails to cure such breach to PanCAN's satisfaction in the time prescribed by PanCAN, PanCAN may terminate this Agreement immediately, upon written notice to DATA RECIPIENT.

F. NOTICE

1. Any notice permitted or required by this Agreement shall be in writing and sent to the contact address noted below or as may be provided by either Party to the other in writing from time to time.

PanCAN:

Name: _____

Address: 1500 Rosecrans Avenue, Suite 200

City/State/Zip: Manhattan Beach, CA 90266

Email Address: _____

DATA RECIPIENT:

Name: _____

Address: _____

City/State/Zip: _____

Email Address: _____

COPY TO INVESTIGATOR:

Name: _____

Address: _____

City/State/Zip: _____

Email: _____

IN WITNESS WHEREOF, the parties have entered into this Agreement as of the Effective Date set forth above.

PanCAN

DATA RECIPIENT:

Signed: _____

Signed: _____

Name: _____

Name: _____

Title: _____

Title: _____

Date: _____

Date: _____

Investigator/ Acknowledgement

I have read and understand my obligations pursuant to the above agreement.

INVESTIGATOR Signature: _____ Date: _____

Printed Name: _____

Data Use Agreement

CONFIDENTIAL

Appendix A:

Data Sharing Request:

Section 1: To be completed by an external collaborator.

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

General Information			
Date			
External Collaborator Name		External Collaborator Title / Role	
External Collaborator Institution			
Data Requested			
Data source(s)			
Description of data elements beings requested			
Estimated number of patient records being requested			
Intended Use of Data			
Primary Objectives			
Study Design / Methods Planned (As Applicable)			
Potential Value / Impact to Pancreatic Cancer Patients or Broader PanCAN Community			

Intended Dissemination Plan (Internal / External)
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			
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)			